CHILDREN'S PARTICIPATION IN CHRONIC ILLNESS
DECISION-MAKING: AN INTERPRETIVE DESCRIPTION

by

GLADYS IRENE MCPHERSON

B.Sc.N., University of Alberta, 1981
M.S.N., University of British Columbia, 1999

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ABSTRACT

Participation in decision-making and inclusion in the important matters of one's life are upheld as measures of equality and indicators of the moral status of individuals in liberal democratic societies. To some extent, the status of children in western societies is a contested question, and hence, the nature of children's contributions to decisions is a matter of debate. Evidence suggests that in spite of an apparent societal commitment to children's participation in the important matters of their lives, children tend to be excluded from decisions in which they might reasonably be involved. This project investigated the participation of one group of children—chronically ill school-age children— in decisions related to their health care. Adopting interpretive description as methodology, data were collected and analyzed through interviews and participant observation with 31 chronically ill children (ages 7 to 12 years) and their parents, as well as through interviews with health care providers.

In this study, children's participation in health care decisions emerged as a complex activity, deeply embedded in relationship and history. Participation varied within two key domains: children's opportunities and abilities to formulate and make known their intentions and desires in decisional contexts (the *resonance* of children's voices); and the standing achieved by children's views within decisional processes (the *relevance* of children's voices). The interplay of adult authority and children's agency at the nexus of the resonance and relevance of children's voices created certain *participatory spaces*, depicted as moral and social realms variously characterized by children's silence, children's tangible expression, adult imposed authority, or adult assumed responsibility.

The findings of this study demonstrate a need to re-think our concept of children's participation, and point to the importance of developing a more relational and contextual understanding of how chronically ill children may contribute to important matters in their lives.

The findings also support a view that nurses and other health care providers hold certain responsibilities to critically question the relationships and structures that comprise children's health care encounters, toward a goal of creating conditions where possibilities for children's participation are optimized.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

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> *This being human is a guest house.*
> *Every morning a new arrival.*
>
> Rumi

CHAPTER ONE

INTRODUCTION TO THE STUDY

The last 20 years have been characterized by significant efforts on the part of academics, professionals, policy makers and others as they grapple with implications of the principle embodied in Article 12 of the United Nations (UN) Convention on the Rights of the Child (United Nations Children's Fund, 1989): that children have a right to a say in all matters that affect their lives. Children's participation in governance structures, as well as in the immediate and more private affairs of their lives, is deemed ethically important, and academics, professionals, and policy makers are asked to pay attention to the ways that children are represented in all matters of their lives (Government of Canada, 2004; United Nations Children's Fund, 2002). Amidst these calls for increased attention to children's participatory rights, and amidst admonitions that we are failing our children on this front (Franklin & Sloper, 2005), the rhetoric of children's participation has proliferated; we debate their rights and their interests, and we endeavour to determine children's capacities for participation in various matters. Within health care practice and policy, children's rights to participation have been difficult to reconcile with concerns about their interests, and a growing body of research and theory has addressed the question of how we might best ensure children's rights are met. In this context, where the language of children's participation has become increasingly prevalent and where considerable efforts have been directed toward enhancing children's participation in various domains, our understandings of what constitutes children's participation, how particular life experiences influence that participation, and how participation is shaped by the relational and contextual aspects of children lives, remain matters of debate.

In this project, I enter into these debates, raising questions about what constitutes children's participation in health care decisions when children live with chronic illness.[1] Among the questions I consider, the following are of primary concern: How do perspectives on children and childhood influence health care practice with children and shape the contexts of decision-making with or for them? Who are children in relation to their parents and health professionals, and what status ought they to have in processes of health care decision-making? As a paediatric nurse and paediatric nurse educator, and having worked with children and their families for many years, I am aware of some of the complexities inherent in eliciting children's views and in incorporating their views in decisions related to their care. I have been influenced by scholars in various disciplines, particularly those writing from feminist and critical perspectives who have challenged some of the embedded assumptions about children and their abilities, and questioned certain entrenched views of children's position within our social order.

There is little doubt that adult perspectives on children and their interests profoundly shape children's lives. Research has shown us that in spite of a societal commitment to the inclusion of children in decisions that influence them, and a recognition of the benefits of such involvement, children tend to be excluded from many decisions in which they might reasonably be involved (Hart, 1997; Lansdown, 2001; Shemmings, 2000; Shier, 2001). As has been substantially shown by several researchers in recent years, however, adult perspectives on children are not the sole determinants of children's opportunities and capacities to engage actively in the matters of their lives; children are active participants in the affairs of their own lives (e.g., Archard & Macleod, 2002; Bluebond-Langner, 1978; Prout, 2002). That children are

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[1]   In this study, I define *chronic illness* as a child's embodied experience of a long-term disturbance in the structure and function of a bodily organ or system, and of the constructed meanings of that condition within the relational contexts of his or her life (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993, p. 345). Throughout this work, I use the term *chronic health condition* interchangeably with the term *chronic illness*.

not merely passive recipients of adult attention, but are active agents in their own lives, has been an important theme in both empirical and theoretical literature in the disciplines of education, anthropology, geography, and sociology. However, in spite of this attention to children's agency, considerable evidence demonstrates that children's opportunities to participate in the important matters of their lives continue to be constrained. *This place of intersection between the opportunities and constraints created by adults for children, and chronically ill children's agency within the contexts of their lives, is this focus of this project.* Ensuring chronically ill children's position as fully human beings, as important members of families and communities, while ensuring their best interests are protected, is the central concern underpinning this research project.

In one sense, the debate I bring to attention here can be understood as the agency–structure debate that has been the subject of much discussion in the field of philosophy and its sub-discipline, ethics. While this debate remains salient and interesting, what is ethically and practically important in this study is that these issues manifest in real ways in the lives of real children. This study brings this tension into focus, particularly as it is embodied in the lives of a particular group of children: school-age children who live with chronic health conditions.

Focus of the Study

Decisions as Sites of Analysis

At the outset of this study*, decisions* were understood as sites in children's lives where multiple interests intersect and, hence, where ethically important dimensions of children's experience might become visible. Decisions, defined by the *New Oxford Dictionary of English* (Pearsall, 1998) as "conclusion[s] or resolution[s] reached after consideration," along with the corresponding processes of decision-making, can be understood as analytic sites for the

investigation of ethical dimensions of child-adult relationships. In this study, decisions in the health care of chronically ill children were seen as locations where adult views of children and their interests, children's own intentions and desires,[2] and other contextual dimensions come into focus.

As I have suggested, concerns related to the inclusion of chronically ill children in decisions regarding their own health care are largely rooted in beliefs about children's rights, including our societal commitment to ensure that children (like all people) have a say in matters that affect their lives. In keeping with Article 12 of the UN Convention on the Rights of the Child (United Nations Children's Fund, 1989), professional guidelines and provincial legislation have focused attention on the inclusion of children in decisions about their health care (Government of British Columbia, 1996; Registered Nurses Association of British Columbia, 2000). While encouraging inclusion of children in decisions, these guidelines also oblige the various carers of children (including health care professionals and parents) to ensure that wise decisions are made, that children's "best interests" are upheld. It is at this juncture that the tensions among children's intentions and desires, their capacities and opportunities to express their views, and adults' perspective on what constitutes children's best interests in particular situations become visible. Seen this way, the participation of children in decisions that influence their health care becomes an important ethical concern.

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[2]   Throughout this thesis I use the phrase *intentions and desires* to capture what children have in mind or hope to bring about in specific instances. Searle (1983) distinguishes intentions and desires from other states of mind such as beliefs, hopes, and fears. Specifically, intentions and desires are identifiable by a mind-to-world direction of causation; they provide the starting point toward particular action. In this analytic philosophic approach, the term *desires* is considered weaker than the term *intentions*. Bratman (1987) suggests that intentions have a stronger motivational force and hence imply a greater commitment to action than desires. Secondly, intentions are more settled than desires; there is little space for deliberation between pros and cons when an intention is formulated. The distinctions between these two terms, however, are less important than the construct that the phrase is intended to capture as I use it throughout this thesis. Stated simply, intentions and desires refer to the scope of children's thoughts and feelings about what matters to them and what they want in relation to those matters.

Childhood Chronic Illness, Decisions and Children's Participation

Children with chronic illness are a particularly important group when we consider issues of participation and decision-making. First, this is a group for whom the experience of chronic illness and the decisions related to the health care management of the condition are often portrayed to significantly shape their life experiences. Secondly, these children and their families tend to have ongoing contact with the health care system and the care providers within that system; the consequences of these interactions can have a profound effect on child and family health and well-being. Given the complexity of the lives of children with chronic illness, and the extent to which their voices might be suppressed, arguments have been made that these children not only have a right to be heard, but are deserving of special measures to ensure their views are taken into account in matters that are important in their lives (Alderson & Montgomery, 1996; Brennan, 2002; Franklin & Sloper, 2007).

While I was primarily drawn to this topic because of an interest in the ethical dimensions of chronically ill children's status in relationships with adults and within our health care systems, I was also interested in the relevance of children's inclusion in the matters of their lives for its influence on certain outcomes related to children's health and development. The importance of fostering children's participation in health care decision-making becomes evident when we consider that experiences in early life have lifelong-term effects within a wide range of health outcomes, including the ability to manage life events competently and to cope with life stressors (Keating & Hertzman, 1999; Lerner, Fisher, & Weinberg, 2000). Recent work by Keating and Hertzman provides substantial evidence of a relationship between stressors and the events of early life (including how these are managed) and individuals' abilities to modulate and control responses to stressors in later life. Thus, we might surmise that supporting children to develop the skills and abilities they need to make decisions about their health care may well have

implications for health throughout their lifespans. On a broader scale, it could be argued that knowledge that augments chronically ill children's abilities to manage the events of their lives may enhance health care effectiveness and efficiency (Bricher, 1999; de Winter, Caerveldt, & Koolstra, 1999).[3]

While chronically ill children's participation in decisions about their lives (including their health care) is important, it is also problematic. It is important because, as I have briefly outlined above, as a society we have agreed that children have a right to be heard in decisions; because, to varying extents, current policy requires that children's thoughts and wishes be solicited and taken into account in matters that significantly influence their lives; and because children's participation in decisions may have implications for long-term health outcomes. It is problematic because what constitutes children's participation is a matter of debate, because children's rights to voice their opinions may clash with adults' responsibilities to ensure children's well-being and attend to their interests, and because determination of children's interests is often a complicated endeavour. Recognition of the importance of this issue for chronically ill children's health and well-being has resulted in calls for research into children's participation in health care decision-making that may inform the practice of health care professionals as they work with children (Jenson & Stroick, 1999; Mitchell, 2000; Priestley, 1998; Tipper & Avard, 1999). Additional knowledge about patterns of children's participation in health care decision-making, and the conditions that support or hinder that participation, may assist us in our commitment to upholding the rights of children and to meeting our goal of creating conditions that foster improved health outcomes throughout children's lifespans.

Many decisions are made with and for children with chronic health conditions: discrete, formal decisions such as those about treatment and care, but also less formal decisions regarding

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[3]   This remains a speculative claim, as there is little empirical research addressing this topic.

the more day-to-day dimensions of their existence. As I have stated, at the outset of this study decisions related to children's health care were held to be sites where children's intentions and desires would intersect with multiple other interests, and where adult perspectives on children would become visible. In chapter four, I portray how this view of decisions as discrete sites available for analysis was challenged, and how, as the project progressed, my understanding of decisions shifted.

The Research Problem and Questions

The principle focus of this study was the formal and day-to-day decisions made in the health care of chronically ill children: the conversations in which children took part; the discussions and consultations between parents, health care providers, educators, and others, discussions to which the children may or may not have been privy; and the day-to-day negotiations of family or institutional life in which health care decisions were formed and enacted. Of primary concern were the children at the centre of these activities, their expressions of wishes and desires and the extent to which their voices were heard. The problem I sought to address had to do with the existing confusion around children's participation, and an insufficiency in existing knowledge addressing complexities of decision-making in the health care of chronically ill children, specifically the issue of children's participation in those decisions.

Several factors have shaped how I approached this problem. First, because research into decision-making with and for children with chronic illness is sparse, part of the project was to describe this complexity, including a depiction of the qualities children's contributions to decisions. Secondly, while we have a growing body of research investigating children's experiences of chronic illness from children's points of view (e.g., Beresford & Sloper, 2003; Schmidt, Petersen, & Bullinger, 2003; Steele, 2000), little of that research specifically addresses

the question of children's participation in health care decision-making. In relation to any investigation of children's participation in decisions, it seems self-evident that children's own voices ought to be included. Because of the extensive descriptive component of this project, and because of the necessity of listening to children and others in order to comprehend the complexities of children's participation in decision-making, a qualitative approach to inquiry was logical. I selected interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004) as a methodology for this project because of its support of detailed description of clinical problems such as children's contribution to decision-making, and its sustained focus on interpreting clinical problems in light of the practical concerns of health care practitioners. I detail my use of this methodology in chapter three.

The following questions shaped the design and guided initial data collection in this project:

1. What do children think and feel about the formal and day-to-day decisions regarding their health care?
2. How do children's expressions of intentions and desires related to specific decisions influence adult understandings of children's interests?
3. How do adult understandings of children's interests in particular situations influence the opportunities for chronically ill children to participate in decision-making related to their health care?
4. How do the social, economic, and political contexts in which decisions are made shape adult understandings of children's interests and influence children's participation in decision-making?

As I describe in chapter three, this project has both longitudinal and cross-sectional components. This design was selected because of the anticipated complexity of decision-making in the lives of chronically ill children, including the temporal and processural nature of decision-making, and the fact that children's thoughts, feelings, and abilities might shift over time. The design was

intended to generate interactions with a small number of individual children and their family members over a longer period of time, as well as creating opportunities to investigate the views of a larger number of children and their parents through briefer interactions. My goal in planning the inquiry was to develop a rich description of children's experiences of participation, and to interpret what I learned about children's participation in light of existing health care practice and policy.

Structure of the Thesis

This thesis is comprised of seven chapters. In chapter two, I summarize existing theory and research related to children's participation in health care decision-making, and I articulate the philosophical position of the study. This location provides, to some extent, the rationale for many of the methodological choices made in the design of this study. I describe the methodology in chapter three, depicting how the research process unfolded, including details of the sample, activities of data collection, characteristics of the data set, and the analytic processes.

The main findings of the research are presented in chapters four and five. Chapter four provides a detailed description of interpretations of chronically ill children's participation in decision-making. I follow that description with a more conceptual analysis in chapter five, in which I begin to imagine how we might simultaneously attend to the complex dimensions of decision-making and participation, in ways that make visible morally relevant dimensions of these activities.

Chapter six is devoted to a discussion of the findings in light of existing knowledge in the field, including accepted practices and current structures that constitute health care for chronically ill children and their families. In chapter seven, I consider the implications of the findings for our work with chronically ill children and their families and outline what I believe to

be future directions for work in this field. In as much as decision-making with and for children is a complex and multifaceted process, so too are the implications of the findings for adult-child interactions, including how practitioners practice with these children and families and the guidelines and policies that guide their practice. In this descriptive and interpretive process, I attempt to delineate the limits of our knowledge and to highlight areas where additional research might be warranted.

Summary

This thesis is my account of a project investigating chronically ill children's participation in health care decision-making. The topic has its origins in practical and moral questions, primarily the problem of what it means to foster chronically ill children's participation in the many decisions that comprise much of their lives, or more broadly, the ethical problem of chronically ill children's standing as persons within our health care policies and practices. A wide range of literature and theory informed my thinking as I entered this project, and shaped my approach to research. In chapter two, I present a synthesis of this literature along with the philosophical underpinnings of the study as a foundation for the methodology discussion that follows in chapter three.

PHILOSOPHICAL, THEORETICAL, AND EMPIRICAL LOCATIONS OF THE PROJECT

Introduction

The problem of chronically ill children's participation in health care can be situated within various theoretical domains; it stretches across the fields ranging from the philosophical perspectives on children and childhood to very practical topics of health care communication with children and families. As such, the research problem led me to explore a range of literature from a range of disciplines, including nursing, medicine, social work, sociology, geography, and anthropology. In this chapter I review selected empirical and theoretical literature in order to provide an overview of what is known about the experience of childhood chronic illness, about health care relationships in childhood chronic illness, and about theoretical approaches to children's participation. Having described the theoretical location of the project, I conclude this chapter with a discussion of the philosophic approach to knowledge and knowledge development that I have assumed in this project, and I begin to depict the influence of that approach on methodological decisions.

Chronic Illness and Children

Substantial evidence suggests that the prevalence of chronic illness among children is significant and rising. Although there is no data for school-age children, data from the Canadian National Population Health Survey (1996-1997) indicates that 35% of older children (aged 12 to 14) reported having some chronic health condition (Statistics Canada, 1999, p. 439). International data indicates that between 15% and 20% of all children and adolescents live with a chronic condition of some sort, whether physical, developmental, behavioural, or emotional (Newacheck et al., 1998). Precise numbers are not available, and those that exist are limited in their applicability by the different inclusion criteria they rely upon. Influencing the numbers of

children with chronic illness is the fact that the long-term survival of many groups of children

with chronic conditions has greatly improved in recent years; consequently, children who might

not have survived through childhood now live to adulthood. Hence, a substantial, and likely

growing, number of children live with chronic health conditions in British Columbia.

Defining Chronic Illness

One of the challenges in conducting research into the experiences of chronically ill

children has to do with the variability in how the term *chronic illness* is defined. Other terms

address related and often overlapping concepts, including the terms *chronicity*, *disability*, *special

needs*, and *developmental delay*. While it is not so important that chronic illness be narrowly

defined in this study, the more general orientation toward what is important about chronic illness

is very important, and some of this can be gleaned through various efforts to define the concept.

Early attempts to define and categorize childhood chronic illness tended to be based on

certain medically distinguishable features of disease condition, such variables as the duration of

the illness, time since diagnosis, and the severity of effect on body systems. Mattson's (1972)

definition, for example, defined chronic illness as "a disorder with a protracted course which can

be progressive and fatal, or associated with a relatively normal life course" (p. 801) – a definition

that relies on symptom duration as the key feature of chronic illness. In an effort to move beyond

the restrictions inherent in a purely medical definition of chronic illness, Stein and colleagues

(1993) advocated a noncategorical approach to defining chronic illness. They added criteria of

individual functioning to the definition of chronic illness, which they defined as any health

condition that (a) has a biological basis; (b) has lasted or is virtually certain to last for at least one

year; (c) results in limitation of function, activities, or social role; (d) depends on medications,

special diet, medical technology, assistive devices, or personal assistance to compensate for or

minimize limitation of function, activities, or social role; and (e) creates a need for medical care,

psychological services, or educational services over and above the usual for the child's age, or requires special ongoing treatments, interventions, or accommodations at home or in school.

Cassell (1991) and Kleinman (1988) expanded this view of chronic illness to suggest that what is important about chronic illness becomes visible through the experience of the individual. According to Cassell, chronic illnesses "are the set of disordered function, body sensations, and feelings by which persons know themselves to be unwell" (p. 49). Others have illustrated that chronic illness experience is largely constructed within the social context of health care (Thorne, 1993), and that experiences of chronic illness may have as much to do with opportunity and constraint within relationships and structures as with the medical dimension of various health conditions themselves.

Drawing from these various perspectives on chronic illness, in this project I viewed children's chronic illness as *a child's embodied experience of a long-term disturbance in the structure and function of a bodily organ or system, and of the constructed meanings of that condition within the relational contexts of the his or her life.* In one sense, this definition of chronic illness leads into many bodies of literature that may contain topics relevant to considerations of children's contributions to decisions. Among these might be topics of how the meaning of chronic illness shapes children's intentions, what family coping and adaptation means for health care decision-making, how stigma decreases options available to children, and how power dynamics within children's relationships with parents and health care providers may shape their chronic illness experience.

The body of research and theory in these areas is vast, especially if we consider that some of the research and theory addressing adult chronic illness may also have relevance for children. Not only is this body of literature large and diverse, but, because of the diversity, it is difficult to

analyze and summarize how it might be relevant in inquiry into decision-making in childhood chronic illness. As an example of this challenge, in a metastudy of qualitative studies addressing various aspects of living with chronic illness, Thorne and colleagues (2002) were unable to derive core knowledge about the chronic illness experience. In their words, efforts to analysis existing qualitative studies

> was somewhat akin to staring through one of those mirrored kaleidoscopes that uses glimpses of the real world to create an infinite set of new pictorial images in an endless constellation of new configurations. (p. 439)

Although my look across the literature addressing childhood chronic illness was far less systematic and thorough than Thorne and colleagues' metastudy, I was equally boggled by the array of theoretical and conceptual perspectives that confronted me in this body of literature. So, as I gaze through the kaleidoscope of theory and research addressing children's chronic illness experiences, I have select two areas of research that I believe might have relevance in this inquiry into children's participation. The first is literature about stress, coping, and adaptation, and I delve into these in order to make these concepts accessible within this inquiry. Secondly, I summarize key research and theory addressing the relationships between health care providers and children and families.

Decision-Making, Coping and Adaptation in Childhood Chronic Illness

A large and important body of literature addresses children and families' experiences of chronic illness from a stress and coping perspective. Research with chronically ill children has tended to focus on attributes and factors related to the child, the illness, or the social situation that shape the child's capacity to manage his or her illness. Concepts including social competence (Breitmayer, Gallo, Knafl, & Zoeller, 1992), social support (Ellerton, Stewart, Ritchie, & Hirth, 1996), and cognitive appraisal of stressful events (Theis & Walsh, 1999) have been described as specific determinants of children's experience of chronic illness, particularly

their ability to cope with or adapt to the condition (Stewart, 2003). In general, children are better able to manage their health conditions when they have extensive family support; when their social competence is adequate; and, like adults, when they are able to assign positive meaning to the difficult and stressful events of their lives.

Family coping has also been a matter of intense interest (Hayes, 1997). Family attributes that shape child and family adaptation, including the meaning of the illness to family members, social support, family style, financial resources, family coping strategies, knowledge of the child's condition, and the burden of care, have been identified as important influences on child and family adaptation (Canam, 1993; Gallo, 1991; Gravelle, 1997; Knafl, Breitmayer, Gallo, & Zoeller, 1996).

Eiser (1993) problematized the deficit approach that tends to characterize research into children's and families' experiences of childhood chronic illness, suggesting that research and theory have "focused on the negative consequences of chronic disease, and individuals are often given little opportunity to describe their strengths and coping resources" (p. 8). This concern is echoed in Hayes's (1997) call for research with children and families that attends to much more than the deficits associated with the condition, and that focuses on considering families "in all their diversity, contextualization and health" (p. 281). So, while support systems, patterns of coping, and available resources may well be important in this inquiry into participation in chronic illness decision-making—and family dynamics are no doubt a vital consideration— notions of diversity, relationship, context, and health deserve equal attention, and may prove to be important analytic lenses when child and family management of chronic health conditions comes into focus.

Health Care Relationships and Decision-Making in Childhood Chronic Illness

Health care relationships constitute important relational contexts for decision-making in children's health care, and are often understood as sites where children's participation may be supported or constrained. A wide range of concepts attend to dimensions of health care relationships, among which are theoretical topics variously framed as communication and collaboration (O'Connor, Morgenstern, Gibson, & Nakashian, 2005), partnership (Alderson, Sutcliffe, & Curtis, 2006), or parental participation in care (Johnson & Lindschau, 1996). Most influential, however, is the predominant and often overriding discourse in children health care: that of *family-centred care*. At the heart of the family-centred movement is the notion that families must be supported in their position at the centre of health care for their children; family members are not only the constants within the children's life, parents also become experts in the care of their children (Chernoff, Ireys, DeVet, & Kim, 2002; Institute for Family Centered Care, 2006).

Family-centred care emerged in the consumer and family support movements of the 1960s, largely in response to the disjuncture between practices and policies within health care for children and families' experiences, expertise, and needs. The gulf between these perspectives had resulted in the exclusion of family members from much of children's health care, and manifested in policies such as restricted visiting hours and other paternalistic practices within health care relationships. As the movement gained momentum through subsequent decades, several conceptual models of family-centred care emerged (Casey, 1993; Gabe, Olumide, & Bury, 2004), the most influential of which continues to be that originally published in 1987 by the Association for the Care of Children's Health (Shelton, Jeppson, & Johnson, 1987; Wertlieb,

2003).[4] The widely accepted principles of family-centred care promoted by this group gradually gained a place in the policies and standards that shaped health care for chronically ill children today (Johnson, 2000). Currently, in several health care jurisdictions, family-centred care has been declared a standard in paediatric health care (American Academy of Pediatrics Committee on Hospital Care, 2003). It is generally viewed as an essential philosophy across health care settings, finding its way into hospital mission and vision statements and into standards and guidelines for practice with children (e.g., Capital Health, 2006; SickKids, 2006).

The bulk of the literature related to family-centred care when children have chronic illness has focused on the experience of parents, with emphasis on the extent to which parents are involved in the care of their children. In an influential review of research and theory addressing family-centred care, Dunst and Trivette (1996) concluded that family-centred care practices can be deemed effective when characterized by "positive relational features"—a view of children and parents "as having existing capabilities as well as the capacity to become more competent"—and when parents are "actively and meaningfully" involved in care practices (p. 336). Many studies draw attention to the challenges inherent in enacting parental participation in children's care: issues of role stress, difficulties in negotiating across difference, power struggles,[5] and policy limitations (MacKean, Thurston, & Scott, 2005). Letourneau and Elliott's (1996) research with professionals portrays an interesting problem in the enactment of family-centred care principles: that although most nurses in their sample claimed to value family-

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[4]   The core principles of family-centred care evolve from the belief that the family has the greatest influence over an individual's health and well-being, and that, because of this influence, families must be supported in their roles as caregivers. While the principles vary slightly between approaches to the philosophy, principles of dignity and respect for all human beings, positive communication strategies in interactions with children and families, and a focus on individuals' and families' capacities rather than deficits are prevalent in all definitions (Ahmann, 1994).

[5]   In research with parents of children with chronic illness, Knafl and colleagues (1992) found these power struggles manifest in patterns of communication that undermined parents' confidence. A parent's perception of a lack of respect or compassion on the part of the health care provider was particularly damaging to the health care relationship.

centred care, a significant discrepancy existed between those espoused principles and actual

practice with children and parents. However, as Franck and Callery (2004) articulated, family-

centred care has been theoretically developed in the literature and a substantial number of studies

have added to our understanding of specific dimensions of practices of family-centred care. In

spite of this rather large body of theory and research, family-centred care as a comprehensive

model of care is principally descriptive, and few studies have tested the theory or care delivery

models.

Although it would seem that the enactment of family-centred principles within health

care interactions would bode well for children's participation, how children contribute to health

care matters is not often addressed in this literature. Differences between the perspectives and

interests of children and their families create an interesting tension not well addressed in the

family-centred care literature. Recently, researchers who have noted that attention to children's

own views is largely absent from this discussion about health care relationships in general, and

family-centred care in particular, have begun investigation into what it might mean for children

to be partners with adults in their care (Alderson et al., 2006). It is at this juncture that family-

centred care research and theory intersects with research and theory addressing children's

participation.

Children and Children's Participation

What constitutes children's participation and what are the conditions in which that

participation is facilitated or constrained? This question has been the subject of theoretical and

empirical inquiry across several disciplines and, in the philosophical domain, has been developed

as an important topic of ethical inquiry. As the discourse of children's participation has become

more prominent, two separate yet related literatures have emerged. The first has to do with

children's participation in democratic processes: that is, their participation in the organization

and operation of the institutions that affect their lives. The second is more closely related to this inquiry, and addresses children's contributions in the more private matters of their lives. Many of the models and theories of children's participation transcend this distinction, and in this review of the literature, I include both as theoretical views within each have relevance to this project.

Theories and Models of Children's Participation

Developmental perspectives on participation

The earliest, and arguably still the most influential, theories related to children's capacities to participate in decisions come from within fields of developmental science, particularly the works of Piaget (1969), Erikson (1963), and Kolberg (1968). Based on their research with children, these theorists described how children's capacities to contribute reasonably to decisions are shaped by their cognitive, emotional, social, and moral development. Simply stated, school-age children's thinking is characterized by concrete rather than abstract thinking.[6] Further, they tend to judge the rightness or wrongness of an action by its direct consequences to themselves rather than by evaluating behaviour in relation to societal views and expectations.[7] These important beginnings from developmental science have had a profound influence on our conceptual view of children's ability to engage in decisional processes. From

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[6] Piaget (1969) was a developmental biologist whose work has been particularly influential. The stages of intellectual development he proposed were, he believed, closely related to major developments in brain growth throughout childhood. As they enter the school-age years, children are just completing the "preoperational period" of intellectual development. During that period, children gradually become less egocentric in their view of the world, and develop basic concepts for thinking (although these remain elementary and crude). Throughout the school-age years, Piaget claimed that, as children proceed through the period of "concrete operations," their thinking becomes more organized and logical. They develop the ability to perform more complex intellectual activities, such as logical sequencing and multiple classification. Toward the end of the school-age years (beginning about age eleven), children start moving into the period of "formal operations"— a time when thought becomes more abstract, and children have the capacity to begin to incorporate the principles of formal logic.

[7] This question of moral development was addressed by Kohlberg (1968). Within Kohlberg's theory, school-age children are expected to be in a pre-conventional level of moral reasonableness. In making decisions about actions, school-age children are likely to focus on the direct consequences their actions will have for themselves and to define right behaviour in accordance with what the child perceives to be in his or her own best interests.

this developmentalist perspective, school-age children are seen as in the process of becoming independent, autonomous beings capable of rational choice, not yet fully capable of consistently sound judgement.[8]

Following the direction of these theorists, early research in developmental psychology continued to investigate the cognitive, moral, and social competencies of children (e.g., Ferguson, 1978; Grisso & Vierling, 1978). Consensus exists among these theorists that children need a certain level of reasoning ability and emotional maturity to demonstrate the kind of competence necessary to make reasonable decisions. Grisso and Vierling added four characteristics that are prerequisites to competent decision-making. The individual must be able to demonstrate:

> (a) the capacity to sustain one's attention to the task, (b) [the] ability to delay response in the process of deliberation, (c) [the] ability to think in a sufficiently differentiated manner to weigh more than one treatment alternative and set of risks simultaneously, and (d) [the] ability to employ inductive and deductive forms of reasoning (p. 418).

In this way, as the field of developmental psychology became more sophisticated, a more complex normative understanding of children's capacities became available to professionals.

Limits of developmental theories as guides to children's participation in health care decision-making, however, became apparent in the early 1980s with the work of Weithorn and Campbell (1982). Other important critiques of developmental approaches to children's moral and cognitive capacities came from the work of feminist researchers and writers, particularly Gilligan (1982) and Belenky, Clinchy, Goldberger, and Tarule (1986). These authors were particularly

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8   Erikson saw the development of a sense of autonomy as a key task of childhood growth and development, a task that is first evident in "stubbornness" of toddlerhood and continues and is seen in the self-actualization effort of adults (1963). In Erikson's view, autonomy (as the marker of successful development) stands in opposition to shame and self-doubt.

concerned about the gender bias within existing developmental theories, and the consequent silencing of the voices of girls and women.

Subsequent research has clarified that experience, rather than development, may represent the critical determinant of competency in decision-making. Research with adults with chronic health conditions has shown that individuals' abilities to make sound decisions gradually develop with time and experience (Ellison & Rayman, 1998; Paterson & Thorne, 2000; Price, 1993). There are suggestions that this development of expertise over time may well hold true for children in a similar way. Several investigations of children with chronic health conditions have shown that children's capacities to make reasonable decisions are influenced as much by factors such as emotional state and previous experience as by chronological age or stage of cognitive maturity (Alderson, 1993; Dorn, Susman, & Fletcher, 1995).

Contextual perspectives on participation

Within this context of a critique of developmental perspectives of children's capacities, researchers in various fields began to take a different direction, shifting the focus from individual children's competence toward an understanding of children's capacity and opportunities in particular social and relational contexts. Hart (1992, 1997) was concerned with the absence of children in the development of community programs and policies. Adapting Arnstein's (1969) ladder of participation[9] to the case of children, he proposed a model of a ladder with eight rungs to represent degrees of children's participation in democratic processes: each rung represented a level of children's increased agency, from no agency at the lowest rung of manipulation, to full

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[9] Arnstein's (1969) ladder of participation is an important, now classic, work in the field of human rights and democratic citizenship. He generated a typology of citizen participation—a ladder where each rung corresponds to the extent of individuals' power in influencing decisions. The lowest rung is labelled *manipulation*, a token solicitation of views without intent to incorporate those views within the decisional process. The highest rung is *citizen control,* where individuals assume control and governance.

agency at the highest rung, characterized by child-initiated, shared decisions with adults. In promoting children's participation, Hart is very clear that he is not advocating that children should always operate at the highest rung of the ladder, but rather that they be offered the opportunity and choice to participate at the highest level of their abilities.

Research by Thomas and O'Kane (O'Kane, 2000; Thomas, 2000; Thomas & O'Kane, 1999) and others (Munro, 2001; Murray & Hallett, 2000) has demonstrated that children's participation in decisions is not only a product of the child's state of development, but is influenced by the context in which particular decisions are made. These authors' research with children "in care" brought attention to relationships between institutional structures and children's abilities and opportunities to participate in decision-making, as well as the multiple ways in which decisions are negotiated and decided in relationships with caregivers and professionals. Also prevalent in the findings from these studies are the multiple ways in which children's opportunities to contribute to decisions vary according to age, gender, background, and personal characteristics. In this work, Thomas and O'Kane extended and adapted Hart's (1997) ladder of participation. They found that patterns of children's participation are complex, they are less linear and more multidimensional than is captured in the ladder metaphor. Implicit in a model that ranks levels of participation (such as Hart's) is the assumption that one person's participation can be ranked unequivocally as more or less significant or substantial than another's. In his research, Thomas shifted the focus from degrees of individual agency toward a model that takes into account many individual, relational, and contextual factors. Among these factors were considerations of how well the child understands the issues at stake, the reasons why certain decisions have already been made, how much choice the child has in who he or she speaks to, where conversations take place, the child's options to choose to participate in the process or not, the child's understanding of the context wherein decision-making is located, and

whether the child knows how to challenge the decisions that have been made or opinions that are being expressed. In an effort to incorporate these complexities into a model of children's participation useful to social work practitioners, Thomas proposed a new typology of participation. This typology is not rank-ordered and acknowledges that any child's involvement may be strong in some aspects and weaker in others. Thomas's model includes six key domains of children's participation:

1. the *choice* the child has over his or her participation
2. the *information* he or she has about the situation and his or her rights
3. the *control* he or she has over the decision-making process
4. the *voice* he or she has in any discussion
5. the *support* he or she has in speaking up
6. the *degree of autonomy* he or she has to make decision independently

Thomas's work marks a movement toward a more contextual and relational approach to children's participation. This perspective not only acknowledges the influence of child development and emphasizes the centrality of children's agency, but also draws attention to dimensions of particular decisions and their contexts that may have important implications for participation.

Children's Participation from an Ethical Perspective

At what age are children competent to consent to treatment? Who rightfully makes decisions on behalf of children? How do we determine what constitutes children's best interests? These are questions of an ethical nature, questions that have been addressed in a number of ways within the existing literature. Here I explore three interrelated topics, each of which casts a somewhat different light on inquiry into children's participation in decisions: children's moral status, children's autonomy, and children's interests.

Do children hold moral status?

The ethical term *moral status* has been used by some theorists to explore the political and social position of individuals and groups of individuals in relation to others. This concept is useful in drawing attention to the complexities of children's opportunities in our society, making explicit some of our society's commitments to children and drawing attention to how these commitments might be differently understood and interpreted in different contexts (Arneil, 2002; Brennan & Noggle, 1997; Schrag, 1977). In her conceptual analysis, Warren (1997) illustrates clear linkages between how we think about a group of individuals and how we understand our moral responsibilities toward that group: "To have moral status is to be morally considerable, or to have moral standing. It is to be an entity toward which moral agents have, or can have, moral obligations." She goes on to describe how moral status granted to any individual shapes others' orientation toward that individual, linking moral status to what might be understood as personhood or fully human status: "If an entity has moral status, then we may not treat it in just any way we please; we are morally obligated to give weight in our deliberations to its needs, interests, or well-being" (p. 3).

Theorists from diverse disciplines have concerned themselves with questions about children's positions in our societies: considering the capacities and opportunities of children; critiquing how children's lives may be constrained by the political, social, and physical environments in which they live; and grappling with the moral dimensions of adult-child relationships. Literature from various disciplines, including philosophy, political science, sociology, and psychology, examine these questions from different perspectives. Within and across these perspectives, an interesting and challenging paradox becomes apparent. On one hand, children are understood to have very strong moral status, and adults carry a correspondingly weighty responsibility to provide for children's needs, to protect them, and to

support their development. Alternatively, others claim that the way children are generally treated is evidence of children's weak moral status (Alderson & Montgomery, 1996; Lansdown, 2000). For example, in relation to children's participation in decision-making, adults are not compelled to attend to children's perspectives or foster their participation in matters that affect their lives, and consequently (some claim) rarely do so. Writing about the problem of children within the American health care system, particularly the legal issues that arise, Mohr and Kennedy (2001) summarize this problem, suggesting that "children occupy an indeterminate position between property and constitutionally protected citizen" (p. 196). While the legal position of children in Canada is somewhat different, many of the social and cultural factors that influence children's moral status are similar. In considering matters of children's participation, notions of moral status lead to questions of how different groups of children are assigned different degrees of worth, and a critique of how the status of children varies according to ability, diagnosis, gender, race, age, appearance, and socioeconomic status—important questions in the analysis of this project.

To what extent are children autonomous beings?

Questions of children's participation are sometimes interpreted as questions of children's autonomy—a much-contested topic—and contrasting views of the concept of autonomy populate the literature. Predominant in the literature is a conventional view on autonomy, summarized by Sherwin (1998) as the individual's capacity to: (a) be "sufficiently competent" to decide, (b) choose reasonably from the available options, (c) obtain adequate information and demonstrate understanding of the information related to the options available, and (d) not be coerced by others. Conventional developmental theories, as described earlier, have provided the theoretical foundation of this view of autonomy. Erikson (1963) and Kohlberg (1968), through their stage-like approaches to children's moral and social capacities, cast autonomy as the ideal toward

which much of children's development is directed. From dependence to autonomy, from irrationality to independent rational moral agents, school-age children find themselves granted some sort of incomplete agency.

An alternate view of autonomy, advanced by Sherwin and others (Mackenzie & Stoljar, 2000; Sherwin, 1998), is a *relational* approach to understanding autonomy, a move away from a strongly individualistic view of what it means to be a competent human being. These challenges to conventional perspectives on autonomy represent, in part, a reaction to the dominance of Kantian individualism and the perceived link between this view of human existence and claims of invariant developmental sequencing in child development (Gilligan, 1993; Sherwin, 1998). From a standpoint that autonomy is relational, personhood is understood as at least partially constructed within particular human relationships; autonomy is "a capacity or skill that is developed and constrained by social circumstances" (Sherwin, p. 36). Research in this area has shown that children's capacity to participate in decision-making may be linked to the nature and style of their relationships with parents, professionals, and other adults (Brown & Gilligan, 1992; Munro, 2001; Woodgate, 1998b), suggesting, for example, that autonomy and competence are related as much to context as to the cognitive and social maturity of the individual child. For these reasons, these theorists advocate a more relationally composed understanding of autonomy. The now classic work of Gilligan (1993), whose research addressed the development of girls and women, has been in the forefront of this thinking. Gilligan suggests that individual cognitive and moral autonomy (particularly as represented by Kohlberg [1968] and Erikson [1963]) ought not to be seen as universal goals of development, and that, in fact, this ideal has lead to the systematic oppression of girls and women in western cultures.

Although Sherwin's (1998) critique of individualistic perspectives on autonomy is less scathing than the critique advanced by Gilligan (1993), she draws our attention to the need for a

broader understanding of what this concept might mean in health care decision-making, introducing a concept that she labels "relational autonomy." From this standpoint, Sherwin defines autonomy as "a capacity or skill that is developed (and constrained) by social circumstances. It is exercised within relationships and social structures that jointly help to shape the individual while also affecting others' responses to her efforts at autonomy" (p. 36). A relational understanding of autonomy forces us to reconsider a view of children's capacities for autonomy as purely individually determined, and prompts consideration of how a child's autonomy and voice intersect with, and are at least partially determined by, relationships with important others, as well as by the physical, social, and political contexts within which decisions are made. This adds an important dimension to thinking about children's capacities for participation in decision-making. From a relational perspective, legitimate decisions are not only those made in isolation, but include decisions made in association with significant others.

What constitutes children's best interests?

Conventional wisdom about children's autonomy and rights closely links these to notions of children's interests. Our society's shared statement of children's rights as depicted in Article 12 of the UN Convention on the Rights of the Children (United Nations Children's Fund, 1989) makes explicit "that States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." While advocating children's participation, the Convention also frames children's rights to protection and care in the declaration that in all decisions, "the best interests of the child shall be a primary consideration." In decision-making related to children's health care, professionals (with children's parents and guardians) have responsibilities to foster children's participation while ensuring that the decisions attend to children's best interests. This tension between participation

and protection deserves attention in any inquiry addressing decision-making with or for children.

Children's interests are generally understood to be that which is judged to profit a child, a group of children, or children in general the most. Judgements of best interests are sometimes measured according to an objective "reasonable person standard," wherein a view of best interests is detached from the particular individual's intentions and desires (Beauchamp & Childress, 1994; Kluge, 1992). Beauchamp and Childress describe limitations to this approach to judging best interests. The difficulty of determining, in many instances, what a reasonable person would want, is linked to questions of who holds the authority to make that judgement.

Recognizing the centrality of parents in children's health care decision-making and the limitations of a best interests standard in determining children's care, Ross (1997, 1998) endeavours to create an approach to decision-making with or for children that does not hold parents simply to the best interests standard. She calls for a standard that allows parents more flexibility, that recognizes that privileging what might be understood by some as the ill child's so-called best interests may not be the most reasonable decision for the child as a person, as a family member, or as a member of a community. She advocates an approach of "constrained parental autonomy": parents are positioned in a sort of surrogate decision-maker position, wherein matters of importance are not reduced to interests and needs, and the child's interests, while a vital component of decisional processes, are not privileged over all other considerations.

Elsewhere, my colleagues and I (McPherson et al., 2004) have advocated a broader understanding of children's interests than that traditionally depicted in the biomedical ethics literature, a perspective that synthesizes considerations of children's rights, needs, and relationships. Notions of children's interests have importance in this project when concepts of

autonomy, competence, and consent arise. In making judgements about children's interests, adults are asked to take into account children's own wishes and desires while ensuring wise judgements are made, to respect children's rights while protecting them from harm. Given these often competing obligations, it is not surprising that how and when children ought to contribute to decisions is a matter of interpretation, emphasis, and debate.

Children's Contributions to Health Care Decisions

In recent years, several authors have engaged in research regarding the inclusion of children in health care matters and the relative outcomes of such endeavours. In these works, various perspectives exist on the construct of children's involvement in health care matters. What children contribute to their health care has been cast variously as children's participation in health care (Franklin & Sloper, 2004), consultation with children (Coyne, 2006), involvement in health care decisions (Angst & Deatrick, 1996), and participation in decision-making processes (Runeson, Hallström, Elander, & Hermerén, 2002). In this section, I explore theory and research within this construct of children's involvement in health care matters, focusing on existing knowledge on the topic of consent to treatment, as well as on the less formal and often less discrete decisions that characterize day-to-day care for many children with chronic health conditions.

Children's consent to treatment

Of the gamut of decisions that are made in children's health care, those that receive most attention in theory and research tend to be the more formal decisions about treatments and procedures for which informed consent is generally required: for example, decisions to provide or stop treatment, or to conduct invasive procedures or surgery (Alderson, 1993; Angst & Deatrick, 1996; Dorn et al., 1995). Children's consent to treatment and care has been the subject of extensive debate among theorists and practitioners, and discussion related to these decisions

tends to centre on legal, political, and professional obligations of parents and professionals in the context of the care of particular children. When issues of children's contributions to these decisions arise, discussion tends to focus on whether the children should participate or not, and how that participation will be determined. In this area, the majority of literature has been developed theoretically; empirical research is sparse.

Questions of children's competency in decisions are foundational to debate about children's consent. The topic of patient expertise has been addressed in various ways in the chronic illness literature. This topic is important in this inquiry into children's participation in heath care decision-making because it speaks to the critical issue of children and parents' competence in decisional matters. Research by Thorne, Patterson, and Russell (2003) revealed that people living with chronic illness tend to develop a very practical and specialized knowledge over time, knowledge developed through experience rather than through exposure to standardized theory and procedure.

There is reason to believe that children and their parents develop knowledge in similar ways, and such knowledge about the development of expertise has important implications for children's participation in health care decision-making. Investigations into the experiences of children with specific diseases such as cancer (Woodgate, 1998b), diabetes (Grey & Sullivan-Bolyai, 1999), asthma (Yoos & McMullen, 1996), and rheumatoid arthritis (Berry, Hayford, Ross, Pachman, & Lavigne, 1993) suggest that children and their parents may in fact develop this kind of expertise over time, although none of these studies addresses how the characteristics of specific illness experiences shape children's participation in decision-making. Although such specific dimensions of decisional processes were not the prime focus of the study in its early stages, exploring dimensions related to children and parents' expertise—including how children's contributions to decision-making varied over time, how the social legitimacy of the

disease influenced perceptions of children's knowledge, the impact of the illness on day-to-day life, and the nature of the treatment regimen—became important analytic filters as this project proceeded.

A particularly important work in this area is Alderson's 1993 publication, "Children's Consent to Surgery." Through interviews with 120 children ages 8 to 15 years of age, Alderson explored children's abilities to arrive at informed, wise decisions about surgery.[10] Her results showed that children's ability and desire to be involved in decisions about surgery varied, and that respecting children meant supporting them to participate to the extent they desired, preventing children's undesired over-involvement, but at the same time avoiding exclusion. She found that many children were inclined to accept their physicians' or parents' decisions; others wanted to be fully involved in decisional processes; yet others expressed a wish to be the main decision-maker regarding their surgery. Summarizing her findings about children's competence, Alderson writes:

> Competence to consent is not a fact, and it does not appear to develop evenly and gradually. Competence has more to do with qualities, experiences, and perceptions. It is affected by the child's inner qualities (abilities, memories, and confidence) and by outer influences (the nature and circumstances of the decision, its salience to the child's concerns, the adults' expectations and information, their support and respect for the child). (p.193)

This multifocal view of children's competence is not reflected in the majority of literature influencing policy and practice with children. In British Columbia, the standard for eliciting children's views and evaluation their competence is embedded in the Infant Act, passed by the BC government in 1996 (Government of British Columbia, 1996). This act states that children of any age may consent to treatment and care, and, in instances where children's consent is valid,

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[10] The health conditions for which children in Alderson's study underwent surgery were generally orthopaedic in nature and included scoliosis, short stature, hip dislocation, and malformation secondary to muscular dystrophy and cerebral palsy.

consent from the parent or guardian is unnecessary. The conditions of validity for this consent

reflect the double bind described earlier. In Section 17, the act states that:

> A request for consent, agreement or acquiescence to health care by an infant does
> not constitute consent to the health care … unless the health care provider
> providing the health care
>
>> a. has explained to the infant and has been satisfied that the infant understands
>> the nature and consequences and the reasonably foreseeable benefits and risks
>> of the health care, and
>> b. has made reasonable efforts to determine and has concluded that the health
>> care is in the infant's best interests.

The tension between protection and participation is unresolved in this act and in the various

endeavours to translate it into policy. The stalemate created when this tension manifests in

practice is also largely unresolved, and children's consent to treatment and care remains

primarily in the hands of adults.

Day-to-day decisions in children's health care

Another (often overlooked) group of decisions made in the health care of children are the

day-to-day decisions that are generally not considered in discussions of informed consent. These

are the less-formal decisions that constitute much of the management of many health conditions.

Decisions such as those addressing nutrition, activities of daily life, and pain management, tend

to be of this sort. An example of an effort to make some of these day-to-day decisions more

visible can be found in research by Collins (1999), who investigated the practice of restraining

children for painful procedures. Within health care settings, restraining a child generally does not

require the specific consent of the child or the parent(s), and is considered to be a discretionary

decision on the part of the health care practitioner. Whether or not restraining a child ought to

require consent, or if, because the child is obviously not consenting, we should take the view that

restraint is a violation of a child's autonomy and dignity (and consequently a threat to their

integrity), is a matter of debate. What Collins's research accomplishes is to bring these less-

formal decisions—everyday experiences for many children with chronic illness, for their parents,

and for the health care providers who work with them—into the arena of discussion of children's

participation in decision-making. To date, where these discussions about children's participation

in either formal or day-to-day decisions take place, children's participation continues to be

viewed as a dichotomy; either they are to be allowed to consent to care, or not.

Descriptive research by Angst and Deatrick (1996) into the involvement of children in

decisions about their health care showed that children's involvement varies based on the type of

the decision (children tended to be included in discussions about surgery, but excluded from

more day-to-day decisions). Recent qualitative studies with children in hospitals have

endeavoured to capture some of the nuances of participation in decisions not usually considered

in discussion of informed consent. In an observational study of 24 hospitalized children (ages 5

months to 18 years), Runeson and colleagues (2002) found that children are not always allowed

to participate in instances where their participation seems reasonable.[11] Through non-participant

observation, situations related to children's participation were identified and grouped according

to levels of participation, ranging from a failure to listen to the child's wishes to full

implementation of the child's wishes and desires.[12] This is important work, as it begins the

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[11] In this study, analysis is based on 186 situations in which the researchers deemed children might
      reasonably be involved. Judgements of children's participation were based on action or inaction
      within the immediate decisional context.

[12] The instrument, developed by Hermerén (as cited in Runeson, 2002), grades situations into 5 levels of
      participation in decision-making:

   1) A (A=member of the staff) does not listen to B's (B=child) opinions, wishes, and valuations.
   2) A listens but refuses to discuss the opinions of B with B; no consultation, no two-way
      communication takes place.
   3) A communicates with B but does not care about B's answer; B's opinions, wishes, and
      valuations do not influence the actions of A.
   4) A cares about what B says but acts only partially in accordance with B's opinions, wishes,
      and valuations.
   5) A acts in accordance with B's opinions, wishes, and valuations. (p. 589)

project of investigating children's contributions to everyday sorts of health care decisions, and points to a degree of exclusion of children in these situations. An assumption embedded in this study—one that had important implications for the conduct of my investigation into children's participation in chronic illness decision-making—was related to the researcher's judgements about children's participation. The researchers assumed that what is seen in the moment of observation, what researchers can learn from listening and watching, provides sufficient evidence to judge children's participation. While much might be visible in these moments of observation, I am left to question how the nature and extent of children's participation might have been differently interpreted if the complex relational and contextual dimensions had been more fully understood. As I explain in chapter three, the methodology for this study included interaction with children and parents and observation of health care encounters in an effort to begin to understand something about the relational and contextual nature of children's decision-making.

A Pragmatic Approach to Knowledge Development

Given the breadth and scope of knowledge development related to children's participation in chronic illness decision-making, and given the practical origins of the questions that I am asking, I realized that inquiry in this area could follow several paths. In considering knowledge and its relationship to health care practice with children and their families, I have been enticed by the works of pragmatic philosophers—particularly Bernstein (1983, 1992), but also Rorty (1999), and Dewey (1927, 1931).[13] In part, this attraction is linked to pragmatism's emphasis on the practice origins and the action orientation of knowledge—its perspective that knowledge is not merely abstract and theoretical but is always practically and morally manifest

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[13]   Although I write in general terms about pragmatism, I recognize that within that tradition, great diversity exists. Perhaps the starkest distinction is between the traditional pragmatism and neo-pragmatism. I discuss this distinction below.

in the lives of human beings. From a pragmatic standpoint, "what works" in the resolution of particular human problems becomes the standard for truth and justice (Bernstein, 1983, 1992; Rorty, 1999). "Truth" about chronically ill children and decision-making, is measured by the extent to which the knowledge claims are derived from the human problem of children's contribution to decisions and by the extent to which the knowledge generated usefully informs our thinking about children's participation. In this way, as Doane and Varcoe (2005) articulate, "Pragmatism does not stand for any special results. It is only a process" (p. 82).

This focus on the practical contributions of knowledge and theory is taken up differently by different philosophers within the pragmatist tradition. In this discussion, I am drawing mainly on the so-called neo-pragmatists, specifically Bernstein and Rorty. The work of these philosophers built on classical pragmatism (including the works of Dewey, Peirce, and James), and in the case of Bernstein, analytic hermeneutics (particularly the work of Gadamer). Neo-pragmatism brings to traditional pragmatism considerations of power, inequality, and oppression (Musolf, 2001), topics Rorty and Bernstein believed were gaps is earlier pragmatist works. These pragmatic philosophical approaches influenced the development and conduct of this project within four domains. In the sections that follow, I illustrate how pragmatism (a) draws attention to the moral dimensions of children's participation, (b) supports sustained attention to human activities related to decision-making, (c) demands an accounting of the ways in which knowledge

is viewed as contingent and contextual, and (d) calls for sustained attention to the complexity of the phenomena of study.[14]

Attending to the Moral Dimensions of Children's Participation

Vokey (2001) writes about our "moral point of view," those "sets of beliefs, attitudes, interests, norms, and priorities that condition (but do not determine) practical and moral judgement" (p. 3). At the heart of this project are the moral points of view that shape particular judgements within interactions with children, and in the development and manifestation of the many policies and structures that constitute children's contexts. Who are chronically ill children in the contexts of decision-making? What are the priorities that shape our judgements about their health care?

Moral concerns are practical concerns and practical concerns are moral in nature. This is a fundamental position of pragmatism—that moral problems are important, as they manifest in the everyday lives of human beings. Hence, as Rorty (1999) writes, the purpose of inquiry is to "achieve agreement among human beings about what to do, to bring about consensus on the ends to be achieved and the means to be used to achieve those ends" (p. xxv). Understanding more about what we hold as a shared moral point of view and how that point of view is translated into the structures and practices that shape children's lives is where the practical meets the ethical. Learning about predominant moral points of view is facilitated by looking at the problem of

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[14]   While pragmatism provides this project with useful structures for thinking, it provides less guidance about the goals of inquiry. Rorty (1999) suggests that what is important in human inquiry is "devising ways of diminishing human suffering and increasing human equality, increasing the ability of all human children to start life with an equal chance of happiness" (p. xxix). What constitutes suffering and what counts as equality remain undefined, and are themselves left open to redefinition and reinterpretation. This has been identified as one of the main limits of pragmatism—that temporary and contingent understandings of social goods[14] create a political space wherein the consensus of the majority renders the suffering of a few invisible, that when asking "what works?" we neglect the question of "for whom?" (Mouffe, 1996).

children's participation from several philosophical angles; the traditions of critical social theory, post-structuralism, and pragmatism contribute to inquiry in this area.

Sustaining Attention to Practices of Participation[15]

At first, the pragmatic requirement to sustain attention to the very human problem underpinning the project and the human practices related to that problem seemed straight-forward. Given that decisions in children's health care constitute the human practices around which the project revolved, it was evident that children's and adults' perceptions and activities relating to these decisions would be the focus of this inquiry. Decisions would be sites of human practice, where experience and action related to participation would become evident.

As the project proceeded, however, data from children and their parents challenged my conceptions of the foundational concepts of decisions, decision-making, and participation. Pragmatism's challenge led me to question how thinking about these concepts in particular ways was shaping the research process. Because what is important about any concept or theory lies in what it leads us to assume, to expect, to attend to, and to do (Doane & Varcoe, 2005), it became necessary to examine and critique these concepts in light of what I was hearing and observing. In this way, as I will present in chapter four, my perspective on the problem itself shifted; my notions of what the concepts of decisions and participation represented became more nuanced and complex. "What works," then, as a criterium for knowledge and truth, serves also as an analytic device in this research project.

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[15] The notion of practice is at the heart of pragmatic traditions. The term *pragmatism* is derived from the Greek word *pragma*, which means "that which has been done, an act, a deed, a factaction" (Pearsall, 1998). Schatzki (2001) sees practice as "embodied, materially mediated arrays of human activity centrally organized around shared practical understanding" (p. 2). In this study, activities related to decisions (including children's participatory activities) are embodied and materially mediated. The work of the research was to learn about the embodied activities, and the patterns of material mediation, and to ask the question, "What shared practical understanding exists about children's participation in health care decision-making?"

This focus on the practices of decision-making and the activities within them had

consequences for the collection, description, and analysis of the data that I describe in detail in

chapter three. Importantly, this focus demanded efforts to get as close to phenomena of decision-

making as possible and to learn about practices and actions through a variety of sources and

methods; it required that, while placing great value on what the participants thought about

decisions and decision-making, I also asked questions about what people actually did, and who

they were in the world (Doane & Varcoe, 2005; Musolf, 2001).

Accepting the Contingent Nature of Knowledge

> We realize that although we must begin any inquiry with prejudgements and can
> never call everything into question at once, nevertheless, *there is no belief or
> thesis—no matter how fundamental—that is not open to further interpretation and
> criticism.* (Bernstein, 1983, p.327, emphasis added)

At the heart of pragmatic traditions is the rejection of the notion that human knowledge

rests on fixed foundations and an acceptance that human knowledge is both contingent and

contextual, that all our beliefs are open to interpretation and criticism. Bernstein (1992) portrays

pragmatism as a process of "engaged fallibilistic pluralism" (p. 336). This orientation toward

knowledge and interpretation is, I believe, one of the great strengths of a pragmatic approach to

inquiry. Any quest for overarching truths is relinquished, and inquiry becomes a project of

generating wisdom and understanding about human practices and activities, an orientation to

learning that emphasizes the contingent nature of our knowledge and invites challenges to

existing interpretations.

Claims about the contingent nature of knowledge give rise to basic questions of

epistemology and ontology. If knowledge is contingent, then there are no foundations, and, if

there are no foundations, can we know anything at all? Bernstein (1983) contends that questions

of realism versus idealism and foundationalism versus anti-foundationalism represent a sort of

misplaced anxiety brought to us by the Enlightenment (particularly through works of philosophers such as Descartes and Kant). He holds that the important concerns regarding human knowing and being are not those of epistemology or ontology; rather, he suggest that when we cannot "relate some pre-given determinate universal to a particular situation" (Bernstein, 1982, p. 830), the only kind of knowledge we can develop is a sort of *practical wisdom*. The key to developing useful knowledge is through deliberation and judgement regarding the moral and practical dimensions of shared human activities.

At this point, I likely do not need to explain that this project was not a quest for stable truths about chronically ill children's participation in health care decision-making; rather, I was looking to create useful knowledge that might inform health care practice with children and their families. Relinquishing the quest for certainty meant repeatedly holding up to scrutiny preformulated beliefs and subsequent interpretations about children and children's participation. Viewing knowledge about children's participation in decision-making as contingent had important implications throughout the project. In chapter three, this influence is made evident in the descriptions of data collection and analysis. Likewise, my expectations of the final product of this project were shaped by this understanding of knowledge as contingent. Rather than a lasting sort of explanatory truth, my findings represent a historically located explanation of the phenomena of children's participation, an interpretation that reflects the human phenomena as they became manifest in a particular research project. The end product of this project can be understood, then, as a historically located, partial and temporary interpretation of the phenomena of children's contribution to decisions. It may have, however, practical significance.

Embracing Complexity

Complexity abounds in any field of study related to human existence, and this study is no exception. A pragmatic viewpoint lends itself to resisting the temptation to ignore variation or to

simplify complex phenomena. Here I will show how pragmatism's concern with dualistic thinking plays out in this project. From a different perspective, I will show that deconstructive approaches have something to bring to pragmatic thinking when it comes to embracing the complexity of children's participation in health care decision-making.

Pragmatic thinkers suggest that human tendencies toward dualistic thinking often result in simplistic understandings of complex human problems, practices, and activities.[16] This study harboured several important phenomena that might tend to binary thinking (e.g., participation versus isolation, voice versus silence, decision versus indecision, and child versus family). Looking back, I can see that, to some extent, these phenomena existed as binaries in the initial conception of this work. Attending to the complexity of these phenomena resulted in moving further from dualistic thinking, toward interpretations that capture some of the diversity and commonality of the human experiences these concepts represent.

In part, the consequence of rejecting binary thinking in the analysis of the data resulted in a product that James would have described as "a turbid, muddled, gothic sort of affair without a sweeping outline and with little pictoral nobility" (cited in Bernstein, 1992, p. 329). Without a doubt, attending to the complexity within the data set of this project created what was, for me, a daunting challenge. I was confronted with the question of what useful claims could be made

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[16] The fundamental dualisms against which pragmatists (and others) rebel (subject versus object, mind versus body) are closely associated with the division between rationalism and empiricism. The pragmatist tendency to balance dualisms can be seen as structuring a whole complex and interrelated field of similar dichotomies. Strauss (1993) sums this up:

In the writings of the Pragmatists we can see a constant battle against the separating, dichotomizing, or opposition of what Pragmatists argued should be joined together: knowledge and practice, environment and actor, biology and culture, means and ends, body and mind, matter and mind, object and subject, logic and inquiry, lay thought and scientific thought, necessity and chance, cognitive and noncognitive, art and science, values and action. (p. 45)

when so much diversity exists in the experience of children and their families. This is one of the creative challenges of inquiry in a pragmatic tradition.

Here I want to say a little about the contribution of post-structural perspectives to my thinking throughout this project.[17] Post-structuralism and the deconstructive activities it supports, by their very nature, magnify the complexity of human practices and activities. Like pragmatism, post-structural perspectives reject the project of creating grand narratives of human existence. Post-structuralism's project is to draw attention to the pervasive nature of power and discourse and to demonstrate how these operate to shape human relations and human existence (Mouffe, 1996). From a deconstructivist position, the influence of power is everywhere—from the highest level of political organization to the routines of daily life.[18] Discourse can be understood as one medium through which power relations are maintained and reproduced. It is within these relations of power that human experiences are constituted and defined (McCormick & Roussy, 1997). From this stance, children's participation in health care decision-making is perceived as mainly a political activity, focusing attention on how children, parents, and others might be subjugated in the context of decision-making. In this research endeavour, deconstructionist approaches draw attention to the structural manifestations of power within the life experiences of individual children and in that way assist in making sense of the practical realities of children's

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[17]   Pragmatism and post-structuralism can be understood as incommensurable perspectives on the creation of knowledge about human phenomena. While both deconstruction and the pragmatic perspectives of Bernstein, Rorty, and others reject any link between knowledge and universalism, some would suggest that although deconstruction has efficacy in the analysis of power, it has little to contribute to the practical concerns of human existence (Mouffe, 1996). One prominent critique of post-structuralism is that, while providing the tools to understand how power and discourse operate in society, it fails to offer any means by which to practically attend to oppression and inequality (Misgeld, 1992). Another critique has to do with how power is conceptualized within post-structural views, as a social force capable of subjugating human beings. This view of power excludes notions of human agency (Layder, 1997).

[18]   In outlining his perspective on power, Foucault writes that power is everywhere, comes from everywhere, and cannot be "possessed, held, acquired, seized or shared, but only exercised" (Foucault, 1990, p. 92).

lives. Critical perspectives supported attention to the various and complex ways power dominated and shaped the experiences of the children as they lived their lives, the realities of families as they participated in the decision-making processes with or for their children, and the practices of health care professionals as they worked with children and families (Crotty, 1998; Kincheloe & McLaren, 2000). Specifically, critical perspectives call into question many of the patterns and practices that shape human existence; they form a critique of those values, norms, and beliefs that have been thematized in human interaction and in health care policy and practice.

In addition to a critique of structures and ideologies, critical social theoretical perspectives call for an analysis of competing power interests and a description of how these power interests play out in the lives of children with chronic illness (Kincheloe & McLaren, 2000). This supports specific attention to manifestations of power within human interactions and communications which, in the case of health care decision-making for children, leads to questions such as who has a say in decision-making and why, who speaks to (and for) whom, and how children's expressions of wishes and desires are taken into account.

Summary

Recognising the need for an increase in knowledge that informs professionals in their practice with children and families, several researchers have begun projects investigating a variety of topics related to children's participation in decision-making. Once again, research from several disciplines informs our thinking about this issue. Specifically, an important backdrop for this proposed project is provided by research investigating three related topics: the nature of children's contribution to decisions, children's competence, and contextual influences on decision-making.

Also relevant to this project is research that assists us in understanding children's expressions of intentions and desires: the ways in which they express themselves in decision-making contexts. Facing these challenges is particularly important for chronically ill children, given the pervasiveness of health care decision-making in their lives. Little research has directly addressed how children perceive their involvement in the decisions that are made. The proposed project begins to address this gap, seeking to elicit children's opinions of the decisions that are made in their lives, and the extent to which their own views influence those decisions.

In this chapter, I have mapped the complex terrain of existing knowledge in the field of children's participation in chronic illness decision-making. This field is characterized by expanding knowledge regarding the experience of children's chronic illness and uncertainty about the nature and qualities of children's participation in health care decisions. Within the domain of ethics and ethical inquiry, the topic of children's capacities and competence, and how we enact our understandings of these, remains unsettled. These complexities characterize the launching point for this project. Pragmatism, combined with elements of post-structuralism and critical social theory, provides guidance for knowledge development when the problems we seek to address are complex and yet have important, real-world consequences. I have delineated the key avenues through which these philosophical approaches guided my thinking as I decided on methods and as I conducted the study. Building on the theoretical and philosophical location of the study I have articulated here, in chapter three I detail both the decisions that guided my approach to knowledge development in this process, and the specifics of the research design that shaped sampling, data collection, and data analysis.

Introduction

In chapter two, I outlined the theoretical location of this project, situating the research problem and questions within the broader theoretical and empirical terrain. My project in this chapter is to depict my approach to researching chronically ill children's participation in health care decision-making, making explicit how the research project was planned and how it actually unfolded. I begin this chapter with a brief history of the project, and then proceed to detail the methodology that guided the inquiry. In the sections that follow, I describe the specifics of design and method, and suggest that (at least in part), the data generated in this project was created in the space where various philosophical and methodological commitments intersect with the practical everyday realities of the children and parents who participated in this study.

History of the Project

The original proposal for this project was defended in December of 2002. The project was approved by the university ethics committee in March of 2003 (see Appendix A), and data collection and analysis commenced in May of 2003. At that time, the project was designed as a relatively small, qualitative project, wherein my intent was to collect data with seven or eight chronically ill children and their parents, following each family group for the period of approximately one year. Believing that a larger sample size and expanded project would provide more substantial insight into the nuances and complexities of chronically ill children's participation in decision-making, applications for operating grants were made to two health research funding organizations. Both applications were eventually successful, and in October of 2003, the project was granted operating funds from the Canadian Institutes of Health Research

(CIHR).[19] At that time, this project was expanded: the sample size was significantly increased, and plans for dissemination of findings became more ambitious.

The data collection and analysis that began in May of 2003 continued until June of 2005. At that point, the research process was interrupted for a period of ten months.[20] Beginning in April of 2006, I undertook the final analysis and the writing of this dissertation. The timeline for the project is depicted below.
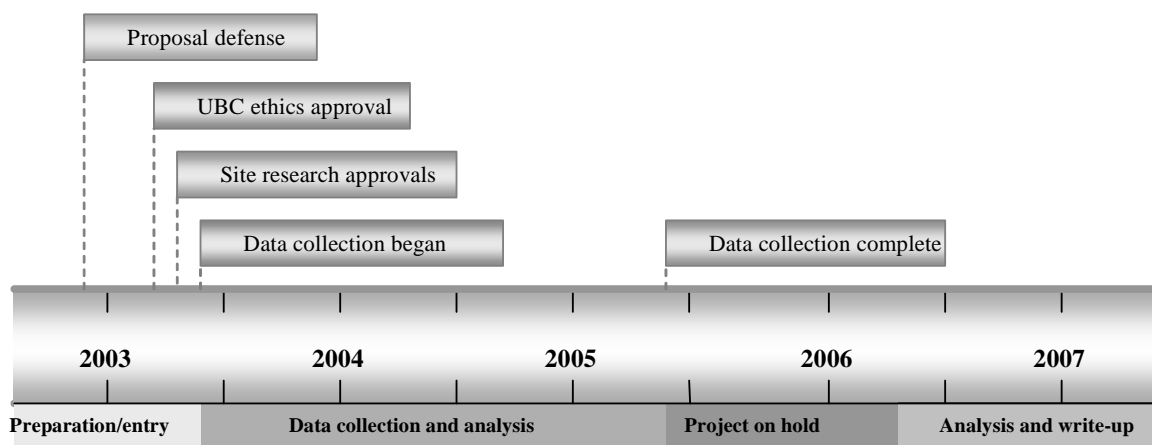
Figure 1. Timeline depicting the history of the research project.

Because this project unfolded over an extended period of time, certain questions arose. The primary question has to do with the extent to which data collected over a period of time, and analysed later, is an accurate representation of the current experience of children, parents, and health care providers. This is an important concern, one worthy of attention when the implications of the findings are scrutinized. I do believe, however, that certain aspects of this

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[19] Project title: Children's Participation in Chronic Illness Decision-Making. Principal investigator: Dr. Sally Thorne. Co-Investigator: Gladys McPherson. A condensed version of the CIHR research proposal is included in Appendix B.

[20] An interruption in the research process of several months was neither anticipated nor welcomed. Ideally, of course, data collection, analysis, and dissemination would have flown seamlessly one into the other. Sometimes life can get in the way, and in this project, for health reasons, the final analysis and write up had to be delayed by several months.

phenomenon, i.e. children's participation in health care decision-making, are not particularly time sensitive. That said, evidence exists in the data suggesting that changes to the health care system do shape some of children's and families' experiences. And in a world where health care structure and practice is rapidly changing, this is an important consideration--one that I will address again in the final chapters of this dissertation.

Interpretive Description as Methodology

Depending on one's beliefs about the nature of the problem and the orientation to knowledge development assumed, the project of investigating chronically ill children's participation in decision-making could reasonably be addressed from a variety of methodological positions. As I detailed in chapter two, I was most interested in the complexities of children's participation, including the many individual, relational, and contextual influences that shaped children's contributions to decisions. I was less interested in the generation of generalizable knowledge that would cross health conditions, age, and other variables than I was in learning about certain nuances, paradoxes, and contradictions that make this phenomenon a particularly challenging one for nurses and other health care professionals. Because qualitative approaches to knowledge development tend, in different ways and from different standpoints, to render visible some of these complexities of human experience, I decided in this project to take a qualitative approach to knowledge development.

Interpretive description might be understood to be a second-generation approach to qualitative health research. Over the past decades, as qualitative work has gained credibility, and as knowledge generated though these approaches has flourished, researchers in a variety of fields have grappled with some of the limitations inherent in the traditional methodologies, methodologies originally developed to meet the knowledge agendas of particular disciplines. Correspondingly, throughout the past decade, various health researchers have begun tailoring

qualitative approaches to research in ways that attend more specifically to the health and illness experience of human beings, and that focus on the kinds of clinical knowledge practitioners seek (Sandelowski, 1995a, 2000). *Interpretive description* is one such approach (Thorne et al., 1997).[21]

First described in 1997 by Thorne and colleagues, interpretive description is grounded in a notion that human health and illness experiences are comprised of complex interactions between individuals as biological, social, and emotional beings, and that these interactions unfold within complex and shifting physical, social, and political worlds. Nurses and other health care professionals are interested in generating knowledge about these experiences and interactions for one primary purpose: to improve clinical practice.

As a methodology, interpretive description has strong links to grounded theory, naturalistic inquiry, and ethnography, drawing on methods refined within those traditions. Interpretive description, however, departs from these approaches in its clear and sustained emphasis on the practice origins of the research problem and questions and its persistent attention to the practical implications of the research findings. It pushes researchers toward a comprehension of problems from clinical or practice perspectives, and toward research designs that will lead to the development of some theoretically defensible conceptualization of the characteristics, patterns, and variations that might constitute and shape particular clinical phenomena. The hallmark of a good interpretive description, then, is the generation or extension of knowledge about the clinical phenomena in a way that guides practitioners, or, more specifically, provides "a mental heuristic … that would be consistent with the reasoning of

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[21] I think it is worth mentioning the work of Kincheloe (2001; 2005), and his view of research as constructed activity, and methodology as an effort to draw on all the epistemological tools that we have available to us to create complex understanding s of human phenomena. "We actively construct or research methods from the tools at hand rather than from passively receiving the 'correct,' universally applicable methodologies" (p. 324). In his work, Kincheloe is calling for knowledge generation across disciplinary boundaries, and the development of tools that will assist us to look at human phenomena from a number of different perspectives.

expert practitioners for whom a similar understanding had been acquired through extensive

pattern recognition and reflective practice observations" (Thorne et al., 2004, p. 8).

 Certain principles of interpretive description manifest in the design decisions of this

study. I have summarized several of these principles in Table 1. The first of the principles listed

has to do with the generation of an analytic framework; a synthesis of the state of existing

knowledge related to the research topic that "orients the inquiry, provides a rationale for its

anticipated boundaries, and makes explicit the theoretical assumptions, biases and

preconceptions" (Thorne et al., 1997, p. 173).[22] The analytic framework for this project is made

explicit in the philosophical, theoretical, and empirical locations of the project that I detailed in

chapter two.

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[22]   Layder uses the term "theoretical scaffold" (1997, p. 146) to describe a similar sort of framework. Layder, however, understands this framework as providing structure for both data collection and data analysis, holding that analysis is the active questioning the theoretical positions inherent in the framework. The "analytic framework" of this project is somewhat less directive, intended more as a vehicle that makes explicit the values and beliefs underpinning the design and conduct of the project.

Table 1

Principles Guiding Design Decisions in Interpretive Description

Design Component	Guiding Principles
Analytic framework	1. Locate the inquiry within the field of knowledge development 2. Make explicit the theoretical assumptions, biases and preconceptions that underpin design decisions
Sample selection	1. Sample theoretically and purposefully 2. Seek maximal variation on emerging themes 3. Foster a strong database to enhance credibility of claims
Data sources	1. Determine who experiences the phenomena of interest and who among them may be best able to convey that experience and variations in that experience 2. Scrutinize the relationship between data sources and the findings that derive from them 3. Actively seek a range of data sources
Data analysis	1. Analyze inductively rather than deductively 2. Sustain a comprehensive perspective of the data, avoid fracturing the data into small, decontextualized segments 3. Emphasize synthesis, theorizing, and recontextualization

Note. These principles are drawn from Thorne and colleagues (1997) and Thorne and colleagues (2004).

The analytic framework influenced the design of this study in multiple ways, many of which will become apparent in the description of the project that follows. For instance, given that previous research has shown that children are often excluded from decisions, it was vital to look for decisions children might be unaware of, and to attend to how and when children were invited into decisional processes. Likewise, to be consistent with a pragmatic approach to knowledge development, it was essential that the process of inquiry support multiple perspectives on the phenomena of children's participation in decision-making; fostering sustained attention to the experiences of children, their parents, and health care providers; supporting reflection on the data

and emerging interpretations from a variety of philosophical perspectives; and ensuring critical questioning of pre-existing beliefs and emerging interpretations.

The analytic framework I provided in chapter two, and the methodological commitments inherent in interpretive description, led to particular goals that influenced the design of this project. These goals can be summarized in the following statements:

- To learn from school-age children who vary according to the health conditions that they experience, and who vary in age and sex[23]

- To seek multiple perspectives on children's participation, especially those of parents and health care professionals

- To interrogate contextual influences on children's participation, particularly as manifest in the organization of health care, in media depictions of chronically ill children, and in policy documents

- To begin data analysis early by considering the bigger picture of the data, and on the basis of early impressions, to tailor ongoing theoretical sampling.

The data that eventually comprised the data set included demographic information about the participants; audio files from interviews; transcriptions from interviews with children, parents, and health care providers; written fieldnotes; photographs taken during encounters with children; drawings by children; newspaper clippings; and policy documents. In the following sections, I detail how and where these data were collected.

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[23]   Deciding on what ages of children to include in this study was the subject of much deliberation. On one hand, we know that there tends to be a developmental component to what children understand about their illnesses and the decisions related to their care. On the other hand, as I mentioned in chapter two, there is substantial evidence that children's capacities to participate in decisions may be as much influenced by life experience as by developmental stage. In the end, the age range of the children recruited into this study is fairly wide: that group of children commonly identified as school age (ages seven to twelve).

Data Collection with Children and Parents

Data collection with children and their parents was at the heart of this project. Data was collected regarding thirty-one children with a variety of health conditions; for each of these children, data was also collected regarding at least one of their parents. The children I sought to include in this study met the following criteria:

- The child would be between the ages and seven and twelve years of age at the time recruitment.

- The child and his or her parents were able to converse in English.

- The child and his or her parents would be available for data collection in the Lower Mainland of British Columbia.

- The child was at least three months post-diagnosis of his or her primary chronic health conditions.

- The child lived with at least one of his or her natural or adoptive parents.[24]

- The child expressed willingness to participate in the study.

- The child's parents consented to the child's and their own participation.

In this project, I did not set out to collect data with siblings, step-parents, grandparents, or children's friends although in certain instances, these people were present during periods of data collection. While data collection with these important people may have resulted in useful insights, I decided not to include them as primary participants, in order to sustain attention on the children themselves, and on the primary relationships in their lives – their relationships with their parents.

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[24] Children who do not live with their natural or adoptive parents are another important group worthy of study. A disproportionately large number of children living in care have chronic health conditions, and decision-making related to their health care may be, at least along certain dimensions, more complex than decision-making among the population included in this study. This may be an interesting area for future inquiry.

The process of data collection with children who met the above criteria and their parents required a great deal of thought, reflection, and conversation. Issues related to negotiating entry to the study sites, access to children and their parents, and the practicalities and ethics of recruitment and sampling were vital to ensuring the integrity of the project.

Negotiating Entry and Access

As many authors have described, the process of negotiation and renegotiation that characterizes access and recruitment of participants in qualitative projects can be an arduous task (Glaser & Strauss, 1967; Lincoln & Guba, 1985). For many reasons, accessing chronically ill children and negotiating entry to their lives was challenging and complicated. The complexity of the lives of these children and families, the tendency of some health care professionals to protect chronically ill children from excessive demands on their time and energy, the many layers of formal or informal approval required in certain settings, and my own concerns about intrusion and coercion of children and families were some of the influences that limited access to certain potential participants in this study.

In order to create a strong and diverse data set, I set out to gain access to children of varying ages, with varying health conditions. To do this, I embarked on a process of connecting with nurses and physicians in several different clinical practice areas served by two health centres in the Lower Mainland of British Columbia. Although formal research approval was readily obtained at each of these sites, access to the children and parents themselves was not always so simple. As has been the experience of other researchers, certain practice areas were welcoming of this research project while others were less so. In certain practice areas, informal rules held that access to children and families must be approved by the physicians responsible for the children's care. In many areas, nurses and physicians who would, under other circumstances, assist with recruitment, were hesitant to do so because of workload or workplace stress. When

approached with the request to assist with recruitment of children, several nurses expressed unwillingness to add one yet one more responsibility into a work situation in which they already felt overwhelmed. In the end, entry to certain areas, and hence access to certain groups of children, was not possible. In contrast, in other settings the research was welcomed; nurses and physicians facilitated recruitment supported data collection in their practice sites.

The first site for recruitment and data collection was a tertiary care pediatric hospital where children received health care for a variety of chronic health conditions (hereafter referred to as Site A). Because health care in that organization was largely organized according to medical specialty, access to children with different conditions meant negotiating with many different health care providers. As such, much of my time in the early stages of this project was devoted to meeting with nurses and physicians, explaining the project, and requesting access to the children and families in their domains. Importantly, in Site A, I gained access to two hospital units that provide care to a substantial number of children with a variety of health conditions, and it was from these units that a large number of children were recruited.

The second setting was a large urban hospital that had a substantial pediatric health care program and a pediatric inpatient unit (hereafter referred to as Site B). This centre served as more of a community health centre, although some specialized services were offered. A smaller number of children were recruited from this centre.

Recruitment of Children and Families

In both settings, nurses and physicians were enlisted to assist with recruitment of children and parents who met the inclusion criteria for this study. The initial recruitment plan held that a health practitioner would introduce the study to the child and family, provide them with written information (see recruitment pamphlet, Appendix C), and invite them to contact me if they were

interested in participation in the study. This approach was largely unsuccessful. In their busy work lives, health care practitioners rarely remembered to mention to study to potential participants; when they did, even when parents and children expressed interest, parents rarely contacted me. In the end, changes were made to recruitment processes.[25] Enlisted nurses and physicians remained the initial contact with children and parents; however, either a research assistant or I sustained presence in the clinical areas, being available to talk to parents and children when they expressed interest in being part of the study. Depending on the nature of that encounter, arrangements were made for data collection, with opportunity provided for parents and children to rescind their agreement to participate. This approach was resulted in the recruitment of the majority of the child and parent participants in this study.

Certain children and parents were recruited into this study through other means. Five of the families approached me having heard of the study from my colleagues or other participating children and families. One family approached me having learned of the study through posters in the clinical area. A significant number of the children in this study were recruited from two hospital units where children received treatments that required several hours per day, often for several consecutive days or several times a week, but were not inpatients.

Recruitment of children and parents into this study took far longer and was much more difficult that I had anticipated. Looking back, I would say that recruitment was difficult for two main reasons. The first was that I endeavoured to access children through a number of sites and programs and hence though layers of formal or informal gatekeepers. In doing so, I encountered an impressive array of orientations toward this kind of research with chronically ill children. The second factor that made recruitment difficult was the undeniable fact that school-age children living with chronic health conditions are very busy people, as are their parents. For most, there is

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[25]   University ethics approval and institute approval were obtained for this change in recruitment plans.

no ready-made space in their lives into which a researcher can easily enter. Time and energy to participate in this research project were by necessity drawn from other activities and occupations in their lives. That said, as I will describe below, many children and parents gave willingly and enthusiastically of their time and energy to speak of their experiences with chronic illness and of the decisions in their lives.

Sample

The final sample in this project consisted of 31 school-age children and 37 of their parents. The sample included three pediatric nurses, interviewed early in the study as part of the initial process of entering the field and clarifying the current professional context within which children's decision-making might be understood. While sample size remains a contested question in the field of qualitative health research, I believe Sandelowski's suggestion that sample size should be small enough to "permit a deep analysis and large enough to give a new and richly textured understanding of the experience" (1995b, p. 182) provides important direction. In my efforts to generate a rich data base, initial decisions about the projected sample size relied, in part on the experiences of other researchers who have conducted related or similar research. In a grounded theoretical project with school-age children in care, Thomas (2000) found a sample size of 47 was sufficient to create an interpretation of these children's participation in decisions such as where they would live. In an ethnographic study of the children's coping with chronic illness, Clark (2003) collected data with 46 school-age children, inquiring about their experiences living with asthma or diabetes. Other qualitative projects with children have, with sample sizes less than 12, also provided rich descriptions of the experiences of particular groups of chronically ill children (Woodgate, 1998a, 1998b).

In interpretive description, purposeful and theoretical sampling are foundational principles. This means that the selection of individuals and instances for data collection are

initially guided by existing understandings of commonalities and variations in the phenomena of interest, and subsequently shaped by evolving interpretations of the data. , Principles of purposeful and theoretical sampling are intended to guide researchers toward identifying shared realities among the people who experience the phenomena of interests, in this case children and families, while at the same time seeking variation on the themes and concepts that become prominent as the analysis proceeds (Sandelowski, 2000; Thorne, 1997). The goal in this project, then, was to obtain a sample that had sufficient heterogeneity to produce an in-depth and comprehensive representation of variations in children's participation in health care decision-making, while at the same time gathering sufficient substance to formulate some account of the patterns of participation that were shared across cases.

I began sampling by seeking variation along certain *demographic parameters* (see Appendix D). For children, this included type of health conditions, time since diagnosis, age, family composition, and sex. .In addition to these usual sorts of demographic variables, I collected information about children's medications and diets, the nature of their treatment regimes, and their use of health various health services. Additional demographic information collected about the children's parents included sex, age, ethnicity, education, employment status and socio-economic status. At the same time, I sampled according to what I understood as certain *phenomenal variations* (Sandelowski, 1995b), i.e. children who lived with day-to-day types of decisions, children for whom health care decisions tended to be more formal and discrete, and children for whom decisions have varying degrees of influence on their lives. As analysis proceeded, theoretical sampling became more a matter of "sampling" for variation on emerging themes, and less about seeking demographic and phenomenal differences that might distinguish children in certain ways. For example, as the project proceeded, I was less focused on finding new and different 'kinds' of children and decisions, and became more interested in certain details about children's expressions, the important matters of their lives, and their

relationships. Sampling then became more about an inquiry into children's and parents'

experiences along these lines, and less about accessing more and different children.

The age range of the children at the time of recruitment was seven years to 12 years with

a mean age 10.0 years. More than twice as many boys as girls participated in the project (see

Table 2). This difference is not readily explained by incidence of the various health conditions,

or by any obvious selection bias. And, while I endeavoured to include more girls in the study, in

the process of recruitment, this effort was only partially successful, and the sample is

consequently significantly uneven along this parameter.

Table 2

Sample Composition by Age and Sex

Age at recruitment	Girls	Boys	Total
7 years	1	2	3
8 years	2	3	5
9 years	-	5	5
10 years	2	-	2
11 years	3	6	9
12 years	1	6	7
n	9	22	31
M	9.8	10.1	10.0

Of the parents, eight were men, 29 were women. The most obvious explanation for this

difference was that children and parents were recruited in health care settings, places where an

adult accompanied the child as the child received health care. In most instances this adult was the

child's mother. Five of the fathers contributed to this research during research encounters in their

homes. Data was collected with three of the fathers during clinic their child's clinic visits. There

are no instances in this sample where data was collect from the child's father but not the child's

mother. There are instances where a father was present or available to engage in the research process, but did not choose to do so.

Of the 29 families, 19 were two parent families, and 10 were families with one parent (in every case a woman). Several of the two parent families were blended families. In regard to siblings, the children in this study had from 0 to 5 brothers or sisters (if step-siblings are included). With the exception of one adopted boy, all children lived with at least one of their biological parents.

All of the children in this study spoke fluent English. English was a second language for several of the parents: within the sample were men and women who first languages were Mandarin, Portuguese, Spanish, Punjabi, and Polish. The families varied according to their identified ethnicity. The majority (20) of the parents identified their families as Caucasian, two as First Nations, three as South Asian, and three as from other backgrounds. Five of the families were first generation immigrants from other countries, specifically Guatemala., Portugal, Poland, India, and Taiwan.

Of the 29 families (two of the families had two children with chronic health conditions that were included in the study, reducing the number of families from 31 to 29), 21 families lived in the Lower Mainland region of British Columbia, four were from various regions of Vancouver Island, three were from the interior of British Columbia, and one family was from the North. Research encounters with children and parents whose homes were outside the Lower Mainland of British Columbia took place in the Greater Vancouver region where the children received treatment for their chronic health conditions. Income levels, although not always reported, varied widely. These descriptors of family structure however, do not fully capture the diversity apparent

within the sample children and families – they varied according to interactional styles, interests, religious and spiritual commitments, and along other such parameters that I did not measure.

Table 3 lists the range of primary diagnoses ascribed to these children. Although helpful, this list does not capture the range of influences these conditions had on the children's lives. For some children, i.e. children with severe allergies or seizure disorders, managing their health conditions was largely a matter of vigilance, of avoiding dangerous situations and being prepared to respond to crisis events. For other children, it appeared that their illnesses defined, to a large extent, the structure and substance of their daily lives. Children with renal failure spent up to 15 hours per week undergoing hemodialysis. Children with diabetes endeavoured to adhere to a rather strict regimen of blood testing, insulin administration, dietary restrictions, and exercise requirements.

Table 3

Primary Medical Diagnoses of Child Participants

Primary Medical Diagnosis	Participants (n=31)
Asthma	2
Congenital heart disease	2
Diabetes	4
Seizure disorders	4
Osteogenesis imperfecta	4
Progressive neuromuscular conditions	1
Rare metabolic and genetic disorders	5
Renal disease	5
Rheumatoid conditions	2
Severe allergies	2

Note. Many of the children in this study had more than one diagnosis. The diagnoses listed here represent those that were considered to be the children's primary diagnosis.

School was another important feature in the lives of the children in this study. All the children in the study attended school and, among these, twelve of the children had support from educational assistants within regular classrooms. According to parents' accounts, at school several of the children in this study lagged behind their peers in academic achievement. Various reasons were sited for this: slight cognitive delay, missed school, the side effects of medication, and effects of seizures or other physiologic events.

Another element of theoretical sampling shaped the data set and influenced analysis in this project. This had to do with those children and instances that are known to exist within this

population but to whom or which I couldn't or didn't have access. For example, it is plausible that certain children with chronic health conditions might, for reasons of shame or embarrassment, make apparently unwise decisions, or that certain families might grant nearly full autonomy to their children in matters of decision-making. These "theoretical outliers" (McPherson & Thorne, 2006) represent children and families whose experience might differ from the experiences of children in the sample population--those instances that practitioners in the field could describe as challenges to emerging analyses. Reference to these theoretical outliers appears in the findings presented in chapters four and five.

Research Encounters with Children and Parents

> In five, four, three, two, one. Fantasy Star is a place. Earth 1 has exploded. And now there's Earth 2 Ragor. We have been searching for a Red Wing Rico. He has been caught by a diabolical alien and then we try to get Ogoflow but our men didn't make it. And then Ogoflow was healed from me, the one and only me. [Makes chugging noise] And then we have been searching for DNA tests from Ragor's animals like Rag Rapis, Boomers, Gigaboomers and humongous boomers. A place 2000 and X, the future is here and then this will be the end.
>
> (Lucas, eleven-years-old)

Lucas[26] borrowed my recorder to tape this audio. It is an imitation of something he knew a great deal about—a particular video game. As I came to appreciate that video games provided important entertainment for him during the hours he spent undergoing dialysis, and as I began to understand that video games were one of the few activities that he could engage in with his friends, I came to understand this apparent gibberish in the transcript data as an key symbol of what really mattered to Lucas. I start my description of research encounters with children and parents with this excerpt in order to illustrate an important point that shaped this project: that while children's agendas were often unsynchronized with mine, their forthright honesty and integrity would yield clues to what mattered to them about decisions in their health care. As I hope will become clear, understanding and appreciating the significance of this difference

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[26]   All children and some of the parents in this study were assigned pseudonyms. None of the names used in the recording of findings are the child's real name.

became a central focal point for theoretical sampling and for the ongoing process of analysis. To get to that point, however, I need to explain the many details of my interactions with children and their families.[27]

From interviews and observation to research encounters

My original proposal for this project suggested that data collection with the children and parents would take the form of semi-structured interviews in conjunction with periods of participant observation. My intent was to engage in one or two semi-structured interviews with each of the children and their parents,[28] and, for a select subset of the sample, to conduct multiple semi-structured interviews and engage in repeated periods of participant observation over an extended period of time. While some of the data collection instances with children resembled what are generally understood as semi-structured interviews or periods of participant observation, more often, what constituted the encounters with children was some combination of the two, and the boundaries between them are not entirely distinguishable. Interviews with parents tended to follow a more conventional, semi-structured interview format, but when children and parents were present together in the same interaction, there was an ebb and flow between an interview-like encounter and periods of engagement in more participatory activities and observation. For this reason, I came to label instances of data collection with children and their parents as "'research encounters," a term I use to express the variation within research activities that comprised data collection with children and their parents in this study.

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[27] I am writing here as if I personally conducted all the interviews, and that is not the case. Some of the research encounters with children and parents were conducted by research assistants in the project. For clarity, I am using the personal pronoun to refer to my position in this project. Where research assistants have been involved in data collection, I endeavor to make this explicit in my account of research encounters.

[28] See Appendix E for the list of questions originally developed to guide the initial semi-structured interviews with children and their parents.

Research encounters then, took many forms. I met with children and their parents in their homes, usually on weekday evenings. This seemed to be the time that fit best into family life. Other times, I joined children and parents when they went to clinic visits, and sat with them as they talked with health care providers. At yet other times, I spent time with children as they spent hours in clinic, receiving treatment – usually medication infusions or hemodialysis. As such, the data set is comprised of a range of types of research encounters: some with children, others only with a parent, yet others in which parents and children participated together. Originally, I had hoped to have the opportunity to interact with children alone, and I had many such opportunities. Where both parents and children were present, in more structured sorts of encounters, children were given a choice of whether they wanted to be interviewed alone, or whether they wished to have their parents present. In most instances, children chose to have their parents present. In several instances, when children and parents were together in the same interview-type encounter, parents would excuse themselves for a period time to allow the child some time with alone with me. Figure 2 illustrates the proportional amount of research encounter time spent with children only, parents only, and where children and parents jointly participated.
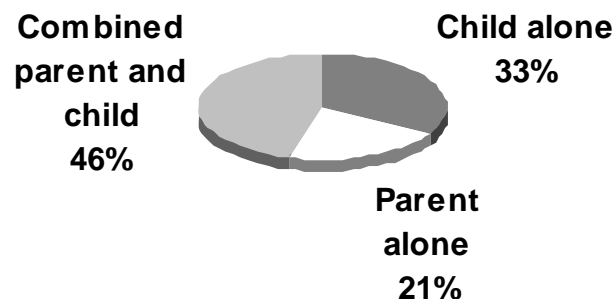
Figure 2. Participant composition of research encounters with chronically ill children and their parents.

The number of research encounters with family units ranged from a single encounter in the cases of five of the children and their parents to, in the case of one child and his parent, ten research encounters spanning a period of eleven months. Research encounters with children and parents took place in a variety of settings, including family homes, outpatient clinic settings, and hospital inpatient units.

Engaging with children

In general, the goal of the encounters with each child was to learn about the child, the child's daily life, and where possible to hear about the kinds of decisions that were made in the child's life. Strategies for data collection with children were based on theory and research underpinning clinical practice guidelines for communication with children and practices outlined in existing literature about research with children (Docherty & Sandelowski, 1999; Irwin & Johnson, 2005; Nespor, 1998; O'Kane, 2000; Thomas & O'Kane, 1999, 2000). Certain understandings, including the following, were important in planning and conducting encounters with children:

- school-aged children sometimes endeavour to please adults and may tailor their behaviour or answers to achieve that goal

- children's responses to open requests such as "what happened?" tend to be richer than their responses to more specific questions (Goodman & Schwartz-Kenny, 1992)

- children tend to be more responsive when they are engaged in participatory activities than when expected to engage in dialogue with adults (Wesson & Salmon, 2001)

- children are more likely to participate fully if they contribute to the agenda of the interview (Alderson, 1993; Mauthner, 1997; Thomas, 2000)

- children, like adults, will shape their behaviour and responses in relation to perceptions of privacy and vulnerability within the relational context, and in relation to other priorities in their lives (Docherty & Sandelowski, 1999; Nespor, 1998)

In order to engage children as fully as possible, a number of participatory strategies were developed. These activities had two purposes. The first purpose was to create a vehicle that facilitated connection with the children, fostering connection and establishing some common ground. The second purpose was more directly related to the research goals: that is, to foster conversation about the children's experiences of health and illness, including their views of health care decisions. The first of these participatory activities to be developed was an adaptation of a decision-making grid originally designed by Thomas (2000) and O'Kane (2000). This was a chart where the axes represent *decisions* in the child's life and the *people* involved in those decisions (see Appendix F). On this grid, children indicated their perceptions of how much say each person had in each decision, degrees of "say" represented by "traffic light" stickers: red for "no say," yellow for "some say," green for "a lot of say."

Several children in this study completed this decision-making grid, and the process of engaging in this activity often fostered interesting conversation. What was particularly useful about the conversations generated through this activity was the evidence that the concepts of "decisions," "decision-making," and "choices" were not a particularly good fit for many of the children in their descriptions of their everyday lives. This was particularly true for the younger children, but seemed to hold to be generally true for the older children as well. The conceptual work of identifying decisions fell to the researcher as the children talked about their everyday experiences of home, school, friends, and family.

In addition to the decision-making grid, a variety of other activities were used throughout the study to foster engagement with children, and many of these appear in the findings presented in chapters four and five. Activities included drawing, crafts, and games. One other activity, developed midway through data collection, was "conversation cards." These were a series of laminated cards with pictures and words that could be used to spark conversation with children

(see Appendix G for examples). These were developed in response to early analysis revealing that what mattered most to children could best be understood by paying close attention to their everyday lives. Hence, the cards depicted topics and activities such as "the clothes that I wear," "my parents," "parties," and "rules."

Not surprisingly, children varied in their capacity or desire to verbalize their thoughts and feelings about what was important to them, including their beliefs about their health conditions and the decisions related to those conditions. About certain topics, some children were very clear: "So one of these things I don't really like is having needles. That was mostly the hardest thing." About other topics, some children were less clear, sometimes uncertain, sometimes apparently uninterested. A small number of the children seemed to grasp something of the nature of this inquiry readily and with ease. Two of the 12-year-old boys, and one 11-year-old boy provided accounts of their experience of chronic illness and their understanding of some of the decisions they face with little assistance from me or their parents. These children were able to cast their experiences of chronic illness in a way that seemed different from the other children, and in that way provided a different kind of data in the analysis of this study.

Engaging with parents

As mentioned, I planned to conduct at least one semi-structured interview with one or both parents of each child recruited into this study. And, as I have described, many interviews were conducted with the parents alone, but many were also conducted with children present. When possible, these interviews centred on the parents' experiences of managing their children's chronic health condition, the decisions that were made regarding the child's care, and the factors that shaped those decisions. Parents conveyed much about their children and provided and a view of the children and their desires that, in many instances, articulating the children's own apparently deeply held intentions and desires, understandings that might not have been available

to me in my own encounters with the children. In many instances, parents' accounts resounded with the kind of intimate knowledge that parents gain as they live with their children and manage their children's health conditions. While most of the data elicited from parents was gained through direct encounters, some of what I learned from them was conveyed in telephone conversations or electronic mail.

Capturing the data from research encounters with children and parents

Where possible, encounters with children and their parents were recorded and transcribed verbatim. Where drawings, photographs, or other artefacts were collected, these were linked to the participant's code and the appropriate transcript, and included in the data set. Fieldnotes were written after each research encounter, including telephone conversations. Electronic communications were saved and entered into the data set. All this data was entered into qualitative research software (QSR NVivo™) for tracking, organizing, and eventual coding.

Other Sources of Data

Three interviews with nurses were conducted early in the study. These interviews with experienced pediatric nurses focused on the nurses' experiences with and beliefs about children's abilities and opportunities to participate in health care decisions. These interviews varied in length from 40 to 65 minutes. Each was recorded, transcribed, and entered into the data set.

In addition to the semi-structured interviews with nurses described above, health care professionals, primarily nurses and physicians, became part of the data set as they appeared in research encounters with the children and parents of the study. In every instance where the words and actions of specific health care providers were recorded, the health care provider was informed of my presence and role and the purposes of the study. In most instances, these health

care providers had been exposed to various efforts to publicize the purpose and process of the study, and so were familiar with me and the study.

In addition to data collected through research encounters with the children and their parents, and through interviews with health care providers, other sources of data were collected and entered into the data set as they became relevant. These included media accounts depicting the experiences of three of the children in the study, newspaper and magazine articles documenting cases where children or parents questioned or refuse medical treatment or where health care professionals raised concerns about the ethical care of children, and newspaper accounts of issues of access to health care for particular groups of children with chronic health conditions. Other documents that became relevant included institutional policies about informed consent and families' access to information. Finally, publications produced by certain interest groups proved relevant to the analysis in this study. These included groups that advocated for children with specific health conditions and groups that championed movements such as family-centred care in the institutional settings.

Data Analysis

The Analytic Process

Data analysis proceeded concurrently with data collection, with early data analysis guiding, at least to some extent, the ongoing process of theoretical sampling. Broadly speaking, analysis took a constant comparative approach, a process through which early data was compared to the understandings implicit in the analytic framework and where later data was compared to emerging conceptual accounts of decision-making in children's health care (Layder, 1998; Thorne, 2000). Analysis was facilitated by repeated immersion in the data, asking questions of the data that addressed the key question of "what is really going on?" Where

transcripts or fieldnotes seemed rather devoid of relevant data, I was prompted to ask questions about what it was that I was not noticing; why it was that I couldn't see what I thought I was looking for. The purpose of this constant comparative analytic process was to support openness to a wide variety of ideas and concepts (Lincoln & Guba, 1985; Sandelowski, 1995a) and to call into question pre-existing assumptions and conceptual positions.

Questions (drawn from the theoretical underpinnings of the analytic framework) that guided initial interrogation of the data included:

- What kinds of decisions were being made? What characterizes these decisions?

- Where is the child in the decisional process? Who is the child in the decisional process?

- How did the child express (or recount expressing) her or his wishes and desires in regard to particular decisions that were made?

- How was the child's participation shaped by the nature of the health condition and its treatments?

- What social and political influences shaped the process of decision-making?

After spending time considering and interrogating the data, I began the process of assigning tentative labels in an effort to classify segments of the data. In some ways, this was the beginning of the conceptualization of the findings that I present in chapters four and five. This process of beginning to assign labels also assisted me in viewing new data through an emerging conceptual lens, a process that revealed certain nuances, contradictions, and paradoxes that characterize the phenomena of children's participation in chronic illness decision-making. The overall goal of this process was to target the theoretical importance of segments of data in order to begin to make sense of the large volume of data produced in this study. Codes and conceptual views that were established remained provisional; they were modified and abandoned, or

confirmed and retained, as required by the unfolding of new data and shifting theoretical understandings.

Specific Analytic Challenges

As I engaged in the diverse activities that comprised data collection for this project, and as I began analysis of decisions in the health care of chronically ill children, I found myself exploring intricate and complex places of human interaction: sites where it seemed that children's perspectives were created and expressed in diverse and interesting ways, and where, for what appeared to be complex reasons, they could be heard or dismissed. My initial analytic efforts were geared toward the identification of decisions within these spaces, and these efforts were followed by activities intended to make some sense of children's participation and adult views in relation to each decision. Inadequacies in this formula soon become apparent, as did problems with the original concepts of decisions, participation, and interests.

Two challenges arose related the concepts of decision and decision-making when I considered these ideas in light of the origins of the study and the purposes of the project. The first challenge related to the difficulties involved in judging exactly what constituted a decision. A related and more serious challenge was that the concepts of decisions and decision-making tended to exclude what intuitively seemed to be important dimensions of children's experience when we consider their positions as fully human beings in negotiations of matters that influence their lives. Evidence of the children's status in the matters of their matters of their lives, and particularly their contribution to those matters, stretched my understanding of the notions of decision and decision-making.

Isolating decisions and decision-making processes

At the beginning of this study, moments of decision-making were anticipated to be windows into dimensions of children's lives that have moral and practical significance. The term

"decision" was defined as "a conclusion or resolution about how to proceed in a health care matter when more than one option exists." Broadly understood, decisions were taken to be distinct sites of analysis where important dimensions of child-adult interactions were made visible, where evidence of adult perspectives on children's interests would be manifest, where the nature and extent of chronically ill children's contributions to the affairs of their lives could be seen. In this view, for a decision to be present, a problem or issue must be identifiable, and the resolution of that problem or issue must include some sort of deliberation. So, strictly speaking, to make a claim that a decision was present, three elements must exist: a problem, alternative solutions, and a process of deliberation.

Adhering to these criteria, certain decisions could be discerned in the data, such as deliberations about the timing of transplants, about whether hemodialysis of peritoneal dialysis would be most appropriate for a child, and about whether a child could go to summer camp. Children engaged in decision-making processes with their parents around topics like how and when they would engage in social or athletic activities, about the particulars of day-to-day activities such as what to eat, and in some instances, discussions of treatment options.

More often however, as children talked about matters of importance to them, concepts of choice, participation and decisions were rarely articulated. They spoke about what mattered to them, what they thought about those matters, but only rarely of what choices were offered to them and the nature of their contributions related to those choices. As a researcher, I was aware of the potential harm that could occur if children were pushed down pathways of thinking that are incompatible with how they understand their lives. Hence, throughout the study I was very cautious to avoid leading children into interaction regarding issues about which they have little input; rather, I waited for their lead. As a result, what exists in the data are a large number of descriptions by children of issues that are important to them. Within these are many instances of

decisions: a few where clearly the child and/or the parent engage in active deliberation about an issue or problem, but more often where there are some discernable dimensions of what constitutes decisional processes.

Adding to the analytic challenges of isolating decisions and decisional processes within the data is one further problem: distinguishing health care decisions from the other decisions in the children's lives. Particularly for children, the experience of their chronic health condition is deeply enmeshed in their experience of the many other dimensions of their lives: school, sports, play, and family. I depict these phenomena in more detail in chapter four, presenting them as important findings in making sense of decisions in the lives of chronically ill children.

Participation as a partial view of children's agency

At the commencement of this study, participation was conceptualized as the nature and extent of children's contributions to decisions that are made, including their opportunity and freedom to engage in decision-making processes. As I will demonstrate in the findings, several aspects of the children's involvement in decision-making processes didn't fit within the original view of participation; consequently, those views were called into question in the analytic process. The nature of participation—what we are looking for and how we know we have found it— was a challenging questioning that arose in the analytic process. If participation was understood as a sort of indicator of children's autonomy and agency in decisional processes, then how do I make sense of those instances where children appear uninterested in certain decisions, or when they seek their parents' assistance in formulating and expressing their views? The answer demands a richer description of the nature of children's participation, a task that I engage with in chapter four.

Ethical Dimensions of the Project

As a vulnerable group, children warrant particular attention in regards to ethical considerations in research design and implementation, particularly with issues of consent, voluntariness, confidentiality, and privacy (Graue & Walsh, 1998; Holmes, 1998; Medical Research Council of Canada, Natural Science & Engineering Research Council, & Social Sciences and Humanities Research Council of Canada, 1998). Extensive theorizing and debate has surrounded the issue of research with or for children. At the heart of all these debates is the question of how children can be protected from harm by research processes, yet included in ways that they might reasonably participate. Often these concerns are framed in terms of the issues of informed consent, and issues of privacy and confidentiality.

Consent and Assent

Ensuring that the participation of children, their parents, and health care providers was voluntary and without coercion was an essential ethical consideration in the planning and conduct of this study. Many efforts were made to ensure that children and their parents understood the nature and purpose of the study, and that they comprehended that their participation in the study must be fully voluntary. On a formal level, written consent to participate in the study was directly obtained from participating parents and health care providers (see consent form in Appendices H and I). In the case of children, as the legal representatives of minor children, parents were asked to sign a consent authorizing their children's participation in the study.

The issue of ensuring children's agreement to participate in research projects is a topic of ongoing debate. Recently, in her review of guidelines for ethical research with children, Neill (2005) claims that consent should be obtained from children, except in instances where children

are unable to comprehend the nature of involvement and the consequences of involvement in research. In contrast, Cocks (2006) suggests that a requirement to obtain informed consent from children may have the inadvertent effect of excluding particular groups of children from the research agenda to which they need to contribute.

While, after much deliberation, I did not ask children to sign formal consents for participation, their assent to participation was a fundamental ongoing principle guiding all aspects of this project. Recognizing that children may be in a particularly vulnerable position when it comes to being fully informed and free of coercion, the following practice guidelines were established to ensure that the encounters with children met ethical standards. In every interaction with children, I endeavoured to:

- explain the project to the child and illustrate the child's freedom to refuse to answer questions or to ask to stop the research process;

- be sensitive to verbal or non-verbal cues that might indicate that a child is reluctant to participate in any portion of the study, and to respond to those cues in a ways that creates opportunities for the child to withdraw from the process; and

- encourage children to contribute to the agendas of research encounters interviews, inviting children to talk about what was important to them, and to discuss what they thought were the significant events of their days. (Morrow & Richards, 1996; Thomas & O'Kane, 1998).

In their research into chronically ill children's consent to research participation, Broome and Richards (2003) found that children's relationships with powerful adults in their lives strongly influenced their beliefs about participation, and that children's consent to participation tended to be highly relational in nature: that relationships with parents and health care professionals were important components of children's assent or consent. In many instances, this

seemed to be the case in this study. Children frequently, but not always, looked to the parents for support in making a decision about whether to participate in the study or not.

The ongoing and relational dimensions of children's assent to research were evident throughout the study. In one instance, immediately following an explanation about the purposes of the research and the nature of data collection, when asked why she thought that the researcher was present, 11-year-old Jenna responded, "I have no idea they didn't tell me anything." In a second research encounter with 7-year-old Emma and her parents, I had just completed reminding her about the project and emphasizing the voluntary nature of her participation when the following exchange took place:

Interviewer: What do you think, Emma, is there anything in there that's causing you any concern?

Emma: No.

Interviewer: Any questions you might have about what we are up to here?

Emma: I was thinking … I had one [question] when you came here.

A little later, after describing what she understood about the research project ("diabetes…and asthma"), Emma remembered her question and asked me, "How much people's houses you've been to?" In this instance and others, while I was most concerned with ensuring that children understood something about the study and that they appreciated that their contributions must be entirely voluntary, these issues often seemed less important to the children themselves. For this reason, part of my work in this study was to assist children in understanding in some way what we mean by research, and what it might mean to agree or not to agree to be part of projects like this.

Confidentiality

As it is in all qualitative research projects, confidentiality is an important ethical consideration. Throughout this project, many efforts were made to ensure that the data collected with children, their parents, and health care providers were protected throughout the research process and in the reporting of the results. Research practices designed to optimize confidentiality included assigning pseudonyms to all the children in the study, assigning code numbers rather than children's and parents' names to the data files, and changing identifying details in the reporting of case examples from the data. While confidentiality guarantees for children are limited by constraints related to the child protection responsibilities of researchers and health care professionals, no such instances arose in my encounters with the children in this study.[29]

Rigour in Interpretive Description

My goal in this project was to represent the voices of the children and their parents honestly, openly and respectfully. My goal was also to interpret what I heard and learned in order to render children's experiences of participation more visible and to locate those experiences in the broader field of health care practice and policy. As a researcher I was in a privileged position where children and parents trusted me, and where they shared their experiences with me and allowed me access to a portion of their lives. I was determined that this research would represent these children's contributions to decisions in a manner true to their experiences, and in a manner that would be informative to those who work with them. For these interpretations to be believable and justifiable, I needed to articulate an approach to scientific rigour that would guide this study.

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[29]   Had concerns related to child protection arisen, I would have followed the established protocols for reporting such incidents. In most cases, this would have been a direct reporting to the Ministry of Children and Family Development.

In 1985, Lincoln and Guba set out four criteria that they believed to be measures of trustworthiness in qualitative inquiry: credibility, transferability, dependability, and confirmability. Since then, the criteria by which qualitative research ought to be judged have been the subject of extensive debate (e.g., Hall & Stevens, 1991; Lather, 1991; Lincoln & Guba, 1985; Sandelowski, 1986, 1993; Thorne, 2002). These debates have variously grappled with topics such as differences between quantitative and qualitative inquiry and the consequent translation into measures of quality, and whether strict adherence to specified research traditions (and the adoption of the corresponding epistemological and ontological commitments) is essential to the development of credible and trustworthy knowledge.

In addition to these more general debates about rigour in qualitative projects, quality within so-called "generic" approaches to qualitative research have been the subject of additional scrutiny (Caelli, Ray, & Mill, 2003; Sparkes, 2001). The term *generic* has been used to describe research methodologies such as interpretive description that cross research disciplines, and that may draw on a variety of methodological tools to create research approaches tailored to specific knowledge generation projects. Caelli, Ray and Mill emphasize the importance of clear and well articulated decisions in generic projects, including for example, a careful depiction of the relationship of methodology to method.

It was within this array of perspectives on quality in qualitative research that I needed to critically consider the integrity of this project. Specifically, I needed to understand what theoretical and practical problems might threaten the validity of the project, and what techniques might enhance its credibility and relevance. In one sense, I have come to understand rigour as the processes through which the scientific process is shown to be consistent with the researcher's claims about knowledge and knowledge development. In chapter 2, I made the following claims about inquiry in this project: (a) that analysis from several philosophical or theoretical

viewpoints would be essential if useful and practical insights were to be generated; (b) that sustained attention to the very human problem of children's position in contexts of health care decision-making would be vital; (c) that all interpretations would necessarily be viewed as contingent and partial; and (d) that the complexities of children's and parents experiences of decision-making would not be reduced or dismissed. In the end, my efforts to ensure scientific integrity in this project involved many activities that attended to these claims and spanned all aspects of the study, beginning in the early stages with the formulation of the research questions, continuing through the implementation phases of the project, and into the writing of this dissertation. Throughout the findings chapters of this dissertation and within the discussion chapter that follows, I endeavour to make my analytic processes explicit. To do so, in some instances I provide alternate interpretations of some events, or qualify the interpretations I provide.

Credibility

Credibility in the project demanded an awareness of, and attention to, the effects of myself as researcher—in all my humanness, my power, and my vulnerabilities—across all aspects of the research project. I came to this project with certain beliefs and assumptions that shaped the project and that influenced what I was looking for, what I could see, and where I looked as endeavoured to learn about children's participation in health care decision-making. For example, I held certain beliefs about children's positioning in this world. I believed that children were often dismissed or ignored in matters that were important to them, and assumed this might be the case with children who are chronically ill. My perspectives on this were grounded in my experiences as a pediatric nurse, as a mother, and as having been a child once myself. Reflection on these beliefs was paramount in the earliest stages of the project, particularly as I worked to establish the research questions and as I decided what theoretical approaches held relevance in

this inquiry. Reflective journaling became a means through which I made sense of who I was in this research project and how that shaped the research process and product.

The credibility of my findings must also be judged by the quality of the data I was able to gather. I think that the quality of the data in this project was intricately related to the relationships that developed between the children and their parents and me as researcher. There is no doubt that the quality of those relationships varied widely. For example, single encounters with children, particular in busy clinic settings were generally not conducive to the collection rich and descriptive data collection, at least not as might be manifest in audio recordings and transcripts. In these single encounter interviews, connecting with the children could be challenging. I sometimes felt awkward in my endeavours to steer them toward conversation, and grappled with sense that I may be imposing on them something that they really didn't understand. Constraints of time, with insufficient time to establish rapport with children, did, in some instances detract from the quality of the data collected. In contrast, other encounters with the children and their parents produced data that was full and rich. Often these were with the children and parents who I came to know over a period of several encounters, but not always.

There were times in this study where I questioned the overall quality of the data and even despaired of the paucity of rich and detailed stories from children. I had plenty of detailed and descriptive data from my encounters with parents, but much of what the children said or did seemed unrelated to what I was searching for in the data. As will become evident in the interpretations I present in chapters four and five, what I could see in the data shifted, and I came to understand the kinds of stories or fragments of stories that children told me in quite different ways. So the quality of data was influenced not only by the nature of my relationship to the children and their parents, but was also related to what I recorded, what appeared interesting to me, and what I could see.

Finally, for the findings of this study to be credible, the interpretations must be justifiable. As I depict the interpretations I propose as the findings of this study in chapters four and five, I endeavour to depict the logic trail that lead me to those interpretations. In many instances, the interpretations are fairly clearly linked to the analytic framework I presented in chapter two. As I move on into chapter five, I start to draw on a wider range of theoretical perspectives, particularly geographical concepts of space and place. At the beginning of chapter five, I summarize the influence of those perspectives on my analysis, and endeavour to depict the logic that follows throughout the remainder of the chapter. The credibility of the findings rests on the extent to which the interpretation I present is convincing, defensible in the data, and rings true for those who hear it.

Relevance

In addition to the establishing credibility, rigour in interpretive description demands attention to the relevance of the project and the findings to those whose lives are affected by the phenomena under investigation. In particular, in this project my interpretive activities and interpretations must be scrutinized for their meaning for nurses as they work with chronically ill children and for policy makers as they grapple with decisions that affect these children's lives. In one effort to address this aspect of ensuring integrity, as my interpretations evolved, I sought feedback in various places—from expert nurses in the field, and from nurses at one specialty focused conference, and through two presentations at academic conferences. Nurses in clinical practice confirmed that the emerging interpretations provided a useful mental heuristic for this complicated project of including children in health care decisions. In every instance, the nurses raised new examples that challenged or confirmed my interpretations or asked questions that assisted me in the clarification of my concepts. Feedback from peers at the conferences prompted

further reflection on assumptions that underpin the concept of participation, and caused me to reflect on and grapple further with the intricacies of the persistent agency-structure issue.

Table 4 summarizes the main principles that guided my efforts to ensure scientific integrity in this project, and lists the corresponding techniques and activities I engaged in to build credibility and relevance in this project.

Summary

As I listened to children and parents, as I spoke with health care professionals, and as I engaged in critical questioning of the assumptions that underpinned the study, my understanding of what it might mean for chronically ill children to participate in health care decisions, and what is important about that participation, began to shift. The data set generated in this study created challenges that caused me to rethink concepts of participation and decision-making, to begin to understand that what children were saying was important to them in new ways, and to begin to comprehend what might stand in the way of children's full contribution to decisions related to their health care. In chapters four and five, I describe what I have come to understand as the constituents of children's voices when it comes to health care decision-making and my endeavours to link these notions of participation and decision-making to the positioning of children within relationships and within institutions

Table 4

Summary of Principles and Techniques Employed to Ensure Scientific Integrity

Criterion	Principles	Techniques Employed
Credibility	Explicitly account for the presence of the researcher in the research process, particularly in the analytic process	Articulate the interrogation of embedded assumptions in reports of the analytic process and in the interpretations of the data
	Ensure a rich data base with maximum variation on themes related to children's participation	Maximize sample size, with extended exposure to several participants
		Theoretically sample according to demographic and phenomenal variables
		Draw on multiple data sources: children's accounts, parents' accounts, observation, policy documents, media reports
		Seek out children and parents who may be able to articulate their experiences of participation in health care decision-making
	Account for analytic decisions, and the incorporation of multiple perspectives	Provide adequate justification of interpretations, account for variations in the data set
Relevance	Locate the problem and questions in the theoretical and applied traditions of nursing	Explicitly describe the practice foundations of the research problem and questions
		Sustain attention to the clinical origins of the problem throughout data analysis and into the reporting of the findings

CHAPTER 4

CHILDREN'S VOICES IN CHRONIC ILLNESS DECISION-MAKING

Introduction

What I have learned about children's participation in health care decision-making has been learned in and through my many encounters with the children and parents in this study, through reflection on the contexts in which decisions were made, and in conversation with health care providers. In this chapter and in chapter five, I present my interpretations of what I saw and heard; what I came to understand as I reflected on questions of what constituted the children's participation, and as I thought about the contexts where decisions unfolded.

My analytic process was guided by a curiosity regarding exactly what we can know about what children want, and how those intentions and desires are taken up in actual moments of decision-making. In addition, my thinking was continually challenged by the question of how particular interpretations might assist us, as health care professionals, to develop more sensitive means of fostering children's participation.[30] So, while what I heard and saw in my encounters with children and their parents could be understood in many different ways, what I offer in these chapters is an interpretation that reflects my concern about children's position in matters related to their health care, and my curiosity about what health care professionals might be able to do to ensure that children are cared for in an ethically sound manner.

Questions regarding what constituted children's intentions and desires, as well as the question of what might count as the expression of those views, persisted from the earliest days of

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[30]   In the interpretation of the data and the presentation of these findings, I have repeatedly returned to the very practical question that prompted this inquiry in the first place: How might health care practitioners safely and ethically foster chronically ill children's participation in health care decisions? This privileging of the clinical origins and practice consequences of knowledge is a fundamental principle of interpretive description (Thorne et al., 1997; Thorne et al., 2004).

analysis in this project. I begin my presentation of the findings of this study at this point, portraying the intricacies of what I came to understand as the children's voices. I illustrate how the children's voices varied in their *resonance*, that is, the extent to which children formulated intentions and desires in regard to certain decisions, and in addition, delivered those views into the contexts of decision-making. The second part of this chapter addresses the more specific issue of children's standing in places of decision-making, asking the questions: to what extent are children's voices heard in these contexts of decision-making? And, to what extent do those voices achieve *relevance* among other voices in decisional processes?

Discerning Children's Voices

Not surprisingly, perhaps because of the diversity of the children in this study, wide variation existed in the nature of decisions made in the children's health care, in what the children wanted in relation to those decisions, and in the patterns of expression of the children's intentions and desires.[31] Hints of what children wanted could be found in many places, including in what children explicitly articulated, and in their parents' accounts, as well as within less obvious places, such as in children's patterns of engagement and disengagement. Discerning children's voices—those expressions of what they wanted in relation to particular issues regarding their health care—required attention to the many and diverse means through which who they were and what they intended were manifest.

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[31] At various times as the analysis of the data proceeded, I endeavoured to distinguish between what children wanted (i.e. their intentions and desires) and the means by which these intentions or desires were expressed. In some instances, this distinction seemed possible. For example, when a child clearly wanted specific food to eat, or did or did not want a certain medical procedure, the content of the expression seemed obvious and the means of expression could be isolated from it. As I demonstrate in this chapter and chapter 5, however, my efforts to isolate children's intentions from the means of expression created two problems. The first was that such a process presumed that the children's intentions pre-existed their action (or expression). The second problem was closely related to the first: that in requiring a distinction between intention and expression, much of what children contributed to decisions in this study would be rendered irrelevant.

The Many Expressions of Children's Intentions

Consider these three brief excerpts from transcripts and observation data. Each is, in a more or less precise fashion, an expression depicting some dimension of what a child thought or wanted:

"Does that mean I have to have a needle?" (Alexandra, age 10) [32]

As Dr. K. listens to Jessica's (age 8) chest, she stands upright, both hands obscuring the stoma of her gastrostomy.

"Do you know, even when he was in the hospital, what gets him happier? His little friends." (Lucas's mom)

Words, silences, gestures, singing, drawings: these are a few of the means through which hints of the children's intentions and desires were manifest. I noticed many ways that these views were made known: by the children themselves, by their parents, and on occasion, by health care providers. I came to understand that rarely, if ever, could a single expression be held as a true and final representation of a child's intentions. Importantly, what the children wanted and how they expressed those desires were reflections of who they were as persons, of what had gone before, and, in many instances, illustrations of some of the contradictions that characterized their experiences of everyday life.

Children's own representations

As the examples above illustrate, the children in this study presented their own views about what mattered to them in various ways, most obviously though what they said, but also in how they acted and, in some ways, through their silences. Speaking, acting, and silence were all vehicles through which the children represented their own intentions.

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[32] In an effort to sustain confidentiality, all the children and parents in this study have been assigned pseudonyms. In addition, in several instances where details of a child's experience might identify the child, those details have been changed.

Speaking

"So one of these things I don't really like is having needles. That was mostly the hardest thing." Like several of the other children, 10-year-old Alexandra was unequivocal about one thing, her fear of needles. Although Alexandra was very clear about her intentions and desires when it came to injections, not all apparent intentions were so strongly and persistently held. It seemed that the children varied widely in their willingness and capacity to convey verbally what was important to them. As one might expect, the older children tended to provide the most detailed verbal accounts of what mattered to them, while the accounts of younger children tended to be less detailed and moved quickly from topic to topic. Regardless, within the data are several instances of children's verbal expressions of their intentions in actual moments of decision-making, children of all ages verbally express certain intentions and desires. These verbal expressions reflected more than the language and cognitive abilities of the children. I had a clear sense that what children said was shaped to fit the relational dynamics of the decisional context.

During a routine clinic visit, a decision about 7-year-old Charlie's diabetic diet was being revisited. The following is a fieldnote excerpt describing the decisional process.

> Catherine [Charlie's mom] mentions that Charlie has complained that his morning snacks at school are too large—that at recess he feels full and has to make himself eat what his mother has sent. Catherine explains to the clinic nurse that she understands that changing the carbohydrate content of any snack or meal has implications for insulin dosage and for food portions at other meals. Catherine looks at Charlie and asks, "What do you think about your recess snack at school?" Glancing toward his mom, Charlie responds, "It is too much at school. It is ok on weekends."

What Charlie wanted in this instance was made at least partially clear by his words: his snacks are too large at school; he wants to have less to eat. As was often the case in such instances, explanations of why he thinks this, and the nuances of his feelings and reasoning, were not made explicit, at least in the immediate context of the clinic visit.

In this instance, I was conscious that Charlie's words were generated and presented in the presence of six adults: his mother, father, and grandfather; the clinic nurse; a medical student; and me. Often in this kind of decision-making, where a decision about children's care was being made in a conference-like setting, children tended to say little. What was clear to me here was that the words Charlie spoke represented conversations that had gone on over time within the context of his day-to-day life. There was much that I did not know about what was important to Charlie in this instance, or about the meaning the particular dietary requirements had in his everyday life. Charlie's words reveal something about his intentions and desires, but clearly are only a partial representation of what matters to him.

Often, because of the nature of the data, I learned about many of the children's spoken representations of intentions and desires through second-hand accounts: either children's own descriptions of what they had said in specific past instances, or in their parents' accounts of what they had heard their children say. Among the most articulate of the children in this study was 12-year-old Anthony. Anthony had a moderate form of osteogenesis imperfecta (OI). He described his efforts to explain what he needed to one of his physical education (PE) teachers at school:[33]

> Well, [in] PE I had a few times last year that I actually had to get a little wise, like a smart-aleck towards the—towards one of the PE teacher last year. He just wouldn't back down… He wouldn't do it, so I had to raise my voice and then I got in trouble for that.

In this instance, there are hints of Anthony's concerns about his safety at school. There are also echoes of a sense of injustice, a certain frustration for not been taken seriously in his efforts to advocate for himself.

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[33] I recognize the limitations of making claims based on children's accounts of what they said or did in particular instances. As I proceed in this analysis, I build an argument that children's voices are not comprised of any one expression, and that none are irrelevant. So, in Anthony's story, the important issue is not whether or not this is an authentic representation of what really happened; rather, it is important as a depiction of who he was and what mattered to him.

In one instance, a child's language expressions were conveyed electronically. Twelve-year-old Nick said barely a word to me when I met with him and his mother in the clinic. Six weeks later, an e-mail message arrived with these words:

> Hey its nick and u wonted me to be a part of somtin well yeah thats kool so u can email me any time u ahve time alrighty... talk to u soon [sic].[34]

Asked about decisions in his life, he responded:

> i made decisions to not do drinking and drugz and also jobs. i didnt really have any dicison on what medications i was on. I think kids should be able to decied what do and not want [sic].

Nick's words, while few, point to important themes that would become central to my understanding of children's expressions of intentions: that the important choices in children's lives had to do with their everyday experiences, and that children may sometimes not be included in decisions where they believe that they should have a say.

As reflected here, the children all had their own means of expression, their own language for conveying what it was that they thought and wanted. Perhaps most importantly, what children said reflected more than the content of what they wanted in regards to specific decisions. Their words seemed shaped by the context in which they were delivered. In upcoming sections, I will address this issue more fully.

Acting

At the beginning of this section, I included the segment from observation notes where I described 8-year-old Jessica obscuring her gastrostomy as the doctor examined her. Her message in that instance was clear. Without a single word exchanged, her physician perceived her specific

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[34] Translation: "Hey, it's Nick. You wanted me to be a part of something. Well, yes, that's cool. So you can e-mail me any time you have time alrighty? Talk to you soon." This conversation with Nick continued over the course of two additional e-mail messages, after which I didn't hear from him again.

wish that he not touch her stoma. In that decisional moment, Jessica did not have to put words to what she wanted; her message was clearly conveyed through her action and expressions.

In many instances, the intentions embedded within actions were not so easy to decipher. Ethan closed his eyes as the physician approached his stretcher. Leanne grimaced and guarded her arm each time she had to have her blood pressure taken. Without hesitation and with ease, Emma showed me how she tests her own blood glucose levels. Alexandra peered from another room as I entered her home. Children's actions and mannerisms reflected dimensions of who they were and revealed something of what they wanted. As I worked with these children I came to understand that, if children's intentions are broadly defined, evidence of children's intentions could be found in all expressions, whether through words, action, or silence.

Silence

To this point, I have been mainly concentrating on children's verbal and behavioural expressions as representations of their intentions and desires. What the children *didn't* say also deserves specific attention. The children's silences also provided important indications of their intentions and desires. For reasons I often could not know, silence (as the absence of direct expressions about a particular topic) occurred when children changed topics of conversations, demonstrated disinterest, or ignored questions or prompts about topics I thought might be important to them.

Eight-year-old Derek's hesitance to speak about his health condition illustrated the potential contribution of silence to an understanding of a child's intentions and desires. As Derek and I coloured a paper airplane we had constructed (Figure 3), I made a direct effort to elicit his views about his debilitating condition. I asked, "So, while you are doing that, Derek, can you tell

me about [your condition]? Do you mind talking a bit about that?" He responded, "Umm, no." I

persisted.

> **Interviewer**: No, you don't want to?
>
> **Derek**: It's complicated.
>
> **Interviewer**: Complicated? Can you tell me one thing about it?
>
> **Derek**: No… I won a Nintendo game.

Our conversation continued with discussion of the event of winning a video game and the

specifics of the game itself. In this instance, I don't know why Derek didn't want to talk further

about his health condition. I suspect that he was far more interested at the moment in doing

something he enjoyed more than talking about his health condition: colouring and making things.

It is also conceivable that he did not want to talk about his chronic health condition. Whatever

the interpretation, such silences provided important glimpses, however non-specific and

imprecise they might be, into the worlds of particular children.

Figure 3. Derek displayed his paper airplane. He enthusiastically participated in activities and
conversation but was reluctant to speak about his health condition.

Twelve-year-old Sanha's account of his day-to-day life post-renal transplant was strikingly similar. After several years of hemodialysis, one year ago Sanha had a renal transplant. Since that time, his parents and health care providers have been concerned that his renal failure might recur, and that his new kidney might be at risk. His life now included a regimen of anti-rejection drugs along with some diet and activity restrictions. When asked how having a transplanted kidney affected his life, Sanha looked puzzled. After hesitating for a few moments and looking toward his mother (possibly for assistance in answering a difficult question), he responded simply by explaining that one thing he really wanted to do was to take karate lessons. Because of the need to protect his kidney, he couldn't. Other than that, Sanha had nothing to say about the consequences of having a chronic health condition—no mention of doctor's visits, diet, or medications.

That Sanha didn't describe the details of his health condition, and that he seemed at a loss to articulate any ways in which his life was shaped by therapies and lifestyle restrictions intended to protect his kidney, could be interpreted several ways. Again, it is possible that Sanha didn't feel comfortable discussing this with me. It might be that his health condition was not in the foreground of his thinking at present. It might be he did not distinguish the activities related to his health condition from activities of the remainder of his life in any meaningful way. While I don't know precisely what Sanha's situation was, with him as with many other children, I sensed that questions posed about his chronic health condition, including my efforts to isolate choices related to his health condition, seemed incongruent with how he understood his own life.

Parents representing children's intentions

In this study, parents spoke passionately about what their children needed, wanted, and desired, and presented these understandings into the contexts of decision-making in a variety of ways. In these instances, children's voices could be understood to be represented by their

parents, an interpretation that raises many difficult and important questions. In one striking example, 9-year-old Scott's mother believed that her son Scott was enduring severe pain, and tried to communicate this understanding to the nurses and physicians who made decisions about pain medication. This mother recounted how she pleaded with nursing staff, "Please give him medication, give him stronger medication. He is in pain and we're not relaxing his heart." In this instance, the mother presented her interpretation of her child's experience of pain, endeavouring to make heard what she thought he would intend or desire, an interpretation no doubt grounded in her knowledge of her child, and located within her experience as a particular child's mother within a complex health care system.

As in the above example, within the data are many accounts of instances in which parents interpreted and represented their children's intentions and desires. Ryan's story provides an example of the complexity of these representations. Because of airway problems, Ryan had a tracheostomy inserted soon after birth. When I met Ryan and his parents, Ryan was 9 years old. Living with a tracheostomy had far-reaching consequences in his life, resulting in limitations to activity, difficulties in speaking, the necessity of intermittent suctioning and cleaning of the tracheostomy, and the requirement of constant surveillance by a nurse or parent. At the time of data collection, Ryan, his parents, and his health care providers were deliberating about a specific decision: whether or not Ryan's tracheostomy should be removed. Early in our discussion, Ryan's parents explained that Ryan deeply desired to have the tracheostomy taken out, and that over the past months he had repeatedly articulated this desire. They explained that Ryan wanted the tube removed for two very specific reasons: he wanted to swim, and he wanted to be able to go to sleepovers at friends' homes without being accompanied by a parent or nurse.

As they met with the health care team, Ryan's mother, Heather, represented what she understood as Ryan's intentions. Twice, Ryan was present in the room as she endeavoured to

articulate what he wanted. In those instances, she provided opportunity for Ryan to confirm or expand upon what she was saying. In each instance, he merely nodded.

In many such instances, parents of the children in this study made explicit what they believed to be their children's intentions and desires in regard to specific health care decisions. In both Scott's and Ryan's mother's stories, representations of their sons' intentions during a specific periods of decision-making reflected their embodied knowledge of their children, attention to their children's expressed wishes, as well as, I believe, a certain knowledge of the health care system wherein these decision-making processes were enacted.

As in Ryan's story, to varying degrees the parents in this study accepted a responsibility to speak for their children—to represent them in challenging decisional processes— whether the children were physically present or not. This role is illustrated in 10-year-old Alexandra's mother's account of her work to smooth the path for her child's next surgery. Alexandra had a well-established and intense fear of needles, a fear that was foremost for Alexandra and her parents in decision-making about various treatments and procedures. Alexandra's mother, Jill, presented this fact when decisions were made about surgery, immunization, and dental work. In the following excerpt, Jill described her efforts to ensure that injections were minimized prior to a surgery that Alexandra was about to have, by requesting inhaled rather than intravenous medication for the induction of anaesthetic.

> Alexandra is so needle-phobic that one of the things I like is a gas induction. So I always ask for that up front. And I always get the same party line, "This is where you have to ask the anaesthetist." And I always say, "Yes." …. They'll say, "Well, we can give her EMLA cream[35]." I say, "Don't go there because as soon as you come in with the EMLA cream, she knows that means you're preparing her

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[35]   EMLA© Cream is a topical analgesia that reduces pain associated with needle insertions. Typically, the cream is placed on the needle insertion site 20 to 30 minutes prior to the anticipated procedure time.

for a needle and that gets her started. You don't want to see that." We've done
this before. I know.

In many instances, parents' knowledge of their children's unique wishes and intentions coalesced
with their understanding of responsibility to advocate for their child, and resulted in specific and
explicit positions in matters of health care decision-making.

In this study, I didn't set out to look at differences in mothers' and fathers' relationships
with their children; although the majority of my conversations with parents were with mothers,
fathers also contributed to this work. The parents each knew their children in different ways;
individual parents' relationships, and their knowledge of their children, were unique. The
following comment by 12-year-old Anthony illustrates how his mother and father differ, and the
consequences that has for decisions related to his health care:

> Yeah, my dad doesn't spend as much time with me, he's at work from 8 till 5.
> Since I was young, my mom has had me from 8 till 5 without dad. My dad
> doesn't know my limitations; he completely freaks out whenever something
> happens to me. And I'm like, "Dad, I broke my fingers." He's like, "Oh my God,
> we're going to die." My mom says like, "Okay, Anthony, sit down, I'm getting
> the ice"… my mom's calm and my dad's running around in circles.

In keeping with Anthony's comments, it seemed to me that the parents in this study were as
different from one another as the children were. Differences according to parenting role,
including such family positions as step-parents and grandparents, might be an interesting site for
future analysis of this data.

I believe there is sufficient evidence in the data of this study to suggest that, in many
instances, the children wanted their parents to speak for them or to represent them within
decisional contexts. The children often relied on their parents' knowledge of their illness and
also their parents' knowledge of their unique personalities, likes and dislikes, and expected them
represent these within decisional contexts. I believe Ryan's story above provides some evidence

of this, in that Ryan relied on his mother and father in this important context, trusting that his mother would accurately and passionately present what it was that he needed and wanted within the decisional context. I am not claiming that children always wanted their parents to represent them, or that they always believed their parents' representations were always accurate or fair. My claim is, rather, that parents' representations are vital considerations when we think about children's voices in health care decision-making.

In this section, I have begun to relate some of the complexities in children's expressed intentions, considering some of the variance in forms of expression and in the delivery of those intentions. I have suggested that discerning the children's voices in decisional contexts was more complex than simply noting what children wanted and listening to how those views were expressed or not expressed. In the next section, I illustrate more fully how the children's intentions related to health care matters, including the expressions of those intentions were intertwined with the matters of their everyday lives and embedded in the relationships and histories that constituted the places of decision-making.

The Embeddedness of Children's Intentions

Discerning children's intentions[36] was particularly complicated: (a) when children seem unconcerned about or disinterested in the specific issue under deliberation, (b) when children's perspectives didn't hold steady, but rather developed or evolved as decisional processes unfolded, and (c) when children expressed multiple or conflicting intentions in relation to a single issue. In these instances, judgements about what constituted children's intentions were far from straightforward.

Expressions of children's intentions and desires related to health care decisions could rarely, if ever, be extricated from the complexities of children's current circumstances and their lives as a whole. As such, what might be understood as children's intentions varied in the extent to which the intention specifically addressed a particular health care issue, in the preciseness with which the intention could be isolated, and in the apparent consistency of one intention with other intentions a child might express. While sometimes what children wanted was simple and straightforward, often children's expressed intentions co-existed with other apparently incompatible and sometimes contradictory wishes. In this section, I focus on these complexities, illustrating how a view of children's intentions as embedded in everyday life, history, and

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[36] A tension persists throughout this analysis of the children's participation in decisions. This is the tension between the tendency to depict children's expressions as authentic representations of their true desires and the recognition that all human expressions are, to some extent, products of the contexts in which they are created and expressed. This tension exists in the murky space where children's individual subjectivities meet with contextual opportunities and constraints. My intention is neither to polarize children's subjectivities and the contexts of those subjectivities nor to suggest that subjectivity is solely constructed by social and historical factors. Thinking about children's participation from both angles—that of children's subjectivity (and their agency as related to that subjectivity), and that of the contextual determinants of children's expressions of intentions— provides a complex view of these activities. In this analysis, I don't endeavour to judge the extent to which children's subjectivities are reflections of human agency or products of context (or as Foucault [1984] might suggest, power relations). I do, however, believe that this agency–structure debate opens up important questions about the positioning of children within the worlds we construct for them. As I proceed in the next sections to describe various representations of children's intentions and desires, I do so knowing that judgements of authenticity are complicated, and that no particular representation of children's intentions—whether expressed by the child or the parent—can be understood outside the history and place where the child's intentions were formulated and expressed.

relationship provided a foundation for a more complex understanding of the children's participation in decision-making processes.

Precision, specificity, and consistency in representations of children's intentions

"I don't care. Just so it doesn't hurt." This was 11-year-old Kyle's response as a research assistant sought his consent to involvement in a different research project. As in this instance, children's intentions were sometimes clearly formulated and obviously linked to specific decisions; children's intentions appeared pre-formulated, ready to be offered into places of decision-making. In many instances of decision-making, however, what a child wanted was not particularly clear, and vagueness and ambiguity characterized the child's expressed views. The question that confronted me in these instances was what, if anything, could reasonably be concluded to be the child's expressed intention? Even in instances such as Kyle's expression above, where what the child wanted seemed clear and unambiguous, certain questions arose. These questions had to do with what it was that the expressed intention actually represented, and the extent to which the expression actually addressed the problem at hand. Striking variation existed in the degree of specificity and precision of children's expressed intentions. And, regardless of the specificity and precision ascribed to the expressed intention, questions of consistency with the child's true intentions persisted.

Earlier, I described 10-year-old Alexandra's fear of needles. When decisions related to surgery, dental appointments or flu shots were made; her position (already formulated long before any particular decision became a relevant concern) tended to be clearly presented. She did not want dental work, and she did not want flu shots; where a needle was involved, her intentions were clear and unambiguous. What she wanted was precise and specific: no needles of any kind. However, while Alexandra came to decisions where injections were involved with clear intentions, on a broader look across the data, this apparent clarity tended to be the exception

rather than the rule. And, in Alexandra's story, as I will show later, her unwavering protest against needles was met at times with other apparently contradictory expressions.

Some of the most imprecise expressions of children's intentions became apparent in the children's spontaneous behaviours. In the following excerpt, 11-year-old Lucas' mother described events that occurred as he arrived home after his regular hemodialysis appointment.

> Lucas knew that he needed to begin his gastrostomy feed as soon as he arrived home from the dialysis unit. This involved having his gastrostomy tube connected to a feeding bag and pump, limiting his mobility. When he arrived home, he raced out of the house, jumped on his bicycle and raced down the street.

What is the decision in this instance? Perhaps it could be understood as whether and when to start Lucas's gastrostomy feeding. What was his intention? His intentions in this instance could be interpreted in several ways: perhaps he wanted freedom, privacy, exercise, or entertainment. Lucas's mother did not provide her interpretation of his intentions. In her words, "I just let him ride his bike for half an hour or something." In many instances such as this the children's intentions were not entirely clear, and hence subject to diverse interpretations.

The children's expressions of intentions sometimes manifest as anger, rage, and rebellion, and although at times, the meanings embedded in these expressions seemed obvious; more often, they were imprecise and non-specific. Because of his worsening seizures, 11-year-old Sean was no longer allowed to go out on his bicycle alone, and definitely not without a helmet. Other things were going on in his life at the same time: his parents were sorting out a difficult separation and divorce, and he was struggling academically and socially at school. In the words of his mother,

> he was mad at his brother about something and maybe with me a bit … I'm wondering how much is because there is our separation going on. And then there is that he seems to be hit with his early adolescence coming on real strong too. Everything going on.

Sean's intentions and desires could be understood as embedded in his actions, words, and silence, and culminated in a particularly difficult episode for Sean and his mother:

> He's standing on the roof and he's got two bricks in his—oh, he's got something he's pretending is a sword and he raced into the kitchen and peeking out the door. I just closed all the drapes and ignored him. So then he climbs back up and then I look one more time and he's got two bricks and he's going to thrown them down.

As in this instance, expressions of anger or rage seemed non-specific, not explicitly related to any particular event or decision. Yet when Sean's mother comments on "everything going on," she is speaking to the many pressures and complexities in Sean's life. These complexities, and Sean's seemingly dissociated reaction, point to the likelihood that isolating distinct kinds of decisions, and Sean's response in relation to each, is likely not possible. Yet expressions of anger such as these provided, I believe, important glimpses into the children's embodied subjective experiences of their lives, and the meaning of the events and decisions that unfolded in their everyday lives.[37]

Histories and relationships within children's intentions

Interviewer: So, Juan, if I asked you to tell me about your illness, could you—what would you tell me?

Juan: Nothing.

Interviewer: Nothing?

Juan: I don't really pay attention to my disease…. I only pay attention to my life.

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[37] This lack of precision and specificity of children's intentions might be interpreted as a function of the nature of the data—that many of the decisions available for analysis are based on the reports of children and parents rather than direct real-time observations. I don't believe, however, that this entirely explains this observation; rather, substantial patterns within the data set suggest that the children's intentions, however vague or imprecise they might be, were rooted in children's embodied subjectivities.

In this excerpt, Juan articulated an important and recurrent theme that I began to illustrate in the previous section: that the meanings of children's experiences of chronic illness and health care were dimensions of children's embodied and situated subjectivity, and that children's intentions were deeply embedded in this subjectivity. As such, discerning children's intentions—what they wanted in particular instances—became a search for clues regarding who each child was and how the child as a person was represented in decisional processes.

Thinking about children's relationships and histories—dimensions of the children's lives to which I had variable access—provided key clues to who the children were. In the following paragraphs, I endeavour to portray the children's wants and desires as located in their relationships and embedded in their histories,[38] illustrating how this interpretation of children's expressions might provide a more complex approach to the discernment of children's voices. Although there is much to be said about how the decisions themselves were shaped by history and within particular contexts, here I restrict my attention to how children's histories and their relationships shaped what the children wanted.

"What matters" as created in relation with others

What mattered to the children in regard to particular issues in their lives was often intertwined with, and sometimes indistinguishable from, the intentions of others, most often their parents, siblings, or friends. In describing what they wanted or what they were thinking, the children at times used the term *we* to indicate "me and my parent": "*We* changed to a different school," or "*we* wanted the afternoon class." Seven-year-old Emma demonstrated this relational dimension of formulating intentions when, in response to a question, she glanced toward her

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[38] I am using the term *history* here similarly to a definition provided by the *New Oxford Dictionary of English* (Pearsall, 1998): "the whole series of past events connected with someone or something." Events in the child's life, the life of the family, as well as community affairs, may combine to comprise historical location of a child's expressed intention.

mother and commented, "I'm lookin' at my mom's answer." Similarly, when asked about school, 9-year-old Rhys looked at his mom and said, "She knows everything." In these instance and others, the children looked to their parents as resources for knowledge about themselves and even perhaps for confirmation and clarity about what they themselves might want in certain instances. When this happened, children's authentic intentions were not easily disentangled from what their parents believed and wanted. While the precise synchrony between parents and children in these instances is not self-evident, what is important is the existence of at least some degree of shared meaning, and that such meaning was constituted and shared in a relational form.

In contrast, the relational nature of children's intentions was not always manifest in a product of shared intentions: children did not always agree with their parents and others; at times, the children held views very different from those of their parents. Children disagreed with their parents; parents set rules for children; children and parents negotiated when topics of diet, exercise, friends, activities, and routines emerged. Yet even in instances of disagreement, the relational nature of children's knowledge was evident.

The history of "what matters"

Features of children's experiences such as the pain, fear, and loss sometimes associated with long-term health conditions constituted, for many children, an important aspect of their histories that became manifest in intentions and desires. The example of Lucas illustrates this point. Eleven-year-old Lucas was a candidate for a second renal transplant. He had a clearly expressed intention: he did not want a transplant, did not want to go on "the list,"[39] at least not at the present time. Without attending to the dimensions of history and anticipated future events, making sense of Lucas's position was difficult. Obvious explanations such as fear of pain or

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[39] Going on the transplant list means being prepared to go to the hospital at any time a kidney becomes available. "The list" refers the names and details of individuals approved for and awaiting organ transplants.

surgery seemed inadequate. At first glance, the likely benefits of a successful transplant seemed indisputable. Lucas would no longer need dialysis three times a week, his dietary restrictions would be eased, and his attendance at school could be more regular.

Explanation for why transplant was not what Lucas wanted could be located in part in his chronic illness history of renal failure, kidney transplant, and the rejection of his first transplant. His intention could also be located in other meaningful dimensions of his life: his friends, school, and activities. At the time he expressed these views about transplant, the end of the school year was approaching, and he was looking forward to his summer. Lucas wanted, for once, to enjoy his summer. To him, enjoying his summer meant having the energy to immerse in friendships and the events of day-to-day life—trips to the dialysis unit and all. It meant not being ill as the result of surgery.

Important to understanding the meaning of this decision, and Lucas's intentions in that regard, is the fact that surgery to remove the previously transplanted kidney had taken place just a few months prior to my interview with him. At that time, Lucas was very ill. The experience was characterized by additional surgery, a long stay in the intensive care unit, and concerns about whether he would survive at all. Now, after several months, in the words of Lucas's mother, Lucas finally felt stable:

> For the first time in Lucas's life, I find he's doing—he's healthier now than he was even when he was transplanted. He's doing better now. He's growing. He's never had a growth spurt like this before … his numbers[40] have never been this high before. So it was his decision. A month-and-a-half ago, he said, "Can we postpone it till September, the fall? Because I want to enjoy the summer?" And I didn't know…

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[40] For children with renal failure, their "numbers" are the serum electrolyte and renal function values that demonstrate the effectiveness of renal function. For children on dialysis, these numbers are also a reflection of their adherence to their prescribed diet and fluid restrictions.

Beyond understanding the meaning of surgery—potential serious debilitation—the location of Lucas's intention was also characterized by his experiences of hemodialysis throughout the previous few years. To Lucas, spending endless hours in the dialysis unit was not the problem others might see it to be. It was evident that there were many aspects of his visits to the dialysis unit that he enjoyed, valued, and that held meaning for him. In particular, over time he has developed strong relationships with the nurses in the unit, the hospital teacher, and with his physician. These people were clearly important to Lucas. So while a successful transplant would mean freedom from hemodialysis, it may also hold meaning of some separation from people who presently inhabited important places in his life. Lucas's intentions related to kidney transplant illustrate the historical locations of his embodied subjectivity: that the meanings of dialysis, transplants, play, and summer have roots in past experience and anticipated events.

Past events and experiences that shaped the children's intentions were not restricted to those that took place in the child's immediate context, or even within the child's own lifetime. This is a juncture at which relational dimensions of children's intentions intersected with the historical locations of those intentions. The broader histories that shape families and communities could be manifest in the children's intentions. A particularly striking example existed in 11-year-old Leanne's position regarding inclusion in physical education (PE) class at school. Leanne had osteogenesis imperfecta, as did her mother. Leanne had strong views about inclusion in PE class, believing that although modifications must be made, she wanted to attend PE classes.

Although a desire to be included in PE class seemed like a reasonable intention for any school-age child, it was apparent that Leanne's mother's childhood experiences of exclusion contributed to the meanings of inclusion for Leanne and her mother. Recounting her own

childhood of growing up with osteogenesis imperfecta, and how her experiences of exclusion shaped her view of her daughter's life, Leanne's mother explained,

> [My job is] making sure that she still has what she needs and doesn't feel really left out. Whereas with me, in PE when they did basketball, I had to write a report. You know, so I almost felt like I was being punished… I think in ways it's a good thing because I have been through it so I know what she's going through.

In this and other instances, events of the past had important influence on the meanings that underpinned children's intentions in health care and other decisions; history and relationships both manifest in the creation and expression of children's intentions.

Complex meanings within children's expressed intentions

As I have already mentioned, for the children in this study, decisions related to health care were often indistinguishable from decisions related to the other dimensions of their lives. And, within the multi-faceted and complex lives of the children and their families, the meanings of decisions could also be complex. Decisions and the possible alternatives could hold multiple, sometimes conflicting, meanings for children.

Embedded in the everyday

Much (or perhaps most) of what was important for children in relation to what particular health care decisions had to do with their everyday lives. Concerns about health, illness, treatment, and procedures were intertwined with concerns about sleepovers, birthday parties, sports, school, and siblings. For these children, chronic illness experiences tended to be embedded in their experiences of everyday life. Consequently, what mattered most to children in health care decisions did not always concern chronic illness itself or its symptoms and treatment. As I listened to the everydayness of children's embodied and situated experiences of chronic illness, I became increasingly aware that the meanings within expressed intentions related to health care decisions were often the same intentions children held in relation to other aspects of

their lives. Similarly, the meanings embedded in intentions related to decisions about school, family life, and friends were not distinguishable from what mattered regarding their illness and health care. Sean's story provided a detailed glimpse into this embeddedness of chronic illness experience in the everyday experience of children.

It was my second visit to the home of 11-year-old Sean. Sean had epilepsy, and recently the seizures had worsened significantly, influencing his school attendance and performance, his independence, and his social relationships. In the course of this visit I wanted to learn how Sean and his mother were managing the seizures, to discover what Sean thought about what was happening to him, and to gain some insight into the nature and extent of Sean's contributions to the decisions that were necessarily part of this change in his condition. Sean's expressions of his experience and what mattered to him took a variety of forms. The majority of what I learned about his health care was not expressed as explicit and direct intentions; rather, I came to understand something of what he wanted by being with him and through listening to his accounts of his life.

Sean experienced his seizures in a deeply embodied manner. With words and though gestures, Sean described his seizures:

> It starts in the toe and they feel all bruised… And it went up on both arms like that, close to the body and including the arms…. So once it would get to here [indicating his lower torso], it would start my hands too and on to my arms and once it got to the heart, the heart would start pounding like that, very hard. And after it's pounded hard enough, it would start going up again once it reached the… disorder. Once it reached the disorder, the epilepsy in the head, I go from this to like—fall down [falling on the floor] and have a seizure.

Sean's seizures were indisputably a very physical experience for him. Shortly after Sean's very physical and intense description of his seizures, our discussion shifted to what had happened during and after recent seizures. Sean mentioned difficult events: the pain of needles at the

hospital, the embarrassment of seizuring in his classroom at school, and his worries about potential injury during grand mal seizures. In contrast to his earlier enthusiastic and animated demeanour, Sean now sat far from me, looking out the window, answering in short sentences. At one point, listing the last four seizures, Sean said simply, "There was an order.... classroom, classroom, gravel, medical room."

The contrast between the two patterns of expression was made more vivid in light of an earlier conversation I had with him at very outset of this encounter. For the first half hour, Sean actively engaged in discussion about something of passionate interest to him: the intricate Lego™ warships he has constructed (Figure 4). Sean took control of that discussion, and my intermittent efforts to steer the conversation in the direction of his health and health care were completely ignored. Again, toward the end of that encounter with Sean, he returned to talking about topics of great interest to him: guns and space ships, Lego™, and army men. I was impressed by Sean's willingness to discuss the difficult matter of seizures for a short time, and wondered if his ability to talk about something so much out of his control as his seizures was bolstered by the opportunity to engage in discussion about something he is very much in control of and that demonstrated his competence and expertise.[41]

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[41] I offer this as a tentative and partial interpretation of what might have been going on in this encounter with Sean. In this, as in other encounters, I only have partial glimpses into what the children are experiencing and what they think about the matters of their health care.
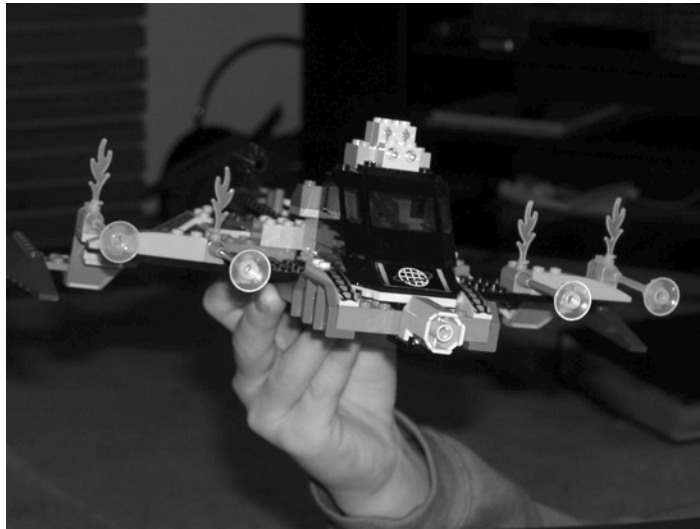
Figure 4.   In great detail, Sean explained the construction and function of this Lego^TM airship to me.

So what does any of this have to do with Sean's intentions, in relation to specific decisions in his health care? His embodied experience of seizures, his reluctance to talk about certain aspects of his health care, his difficulties sustaining focus and attention at school, and his passion for building and creating, all provided glimpses into Sean as an individual and clues to some of the struggles in his life. Seizures and decisions about his epilepsy held many different meanings and were intertwined with the other dimensions of his life. So later, when Sean's mother talked about Sean's clear intention related to school attendance—that he didn't want to go and wanted to change schools—I understood better some of the many meanings of this intention; these meanings had to do with many aspects of his life, including his health and health care. In this way, Sean's intentions related to school were also intentions about his health and health care.

The encounter described above occurred at a time when Sean's health condition figured prominently in his day-to-day life. In many instances, however, this distinction between the matters related to chronic illness and experiences of everyday life was even less obvious.

Illustrating this barely visible distinction between everyday life and the management of severe and life-threatening allergies, 12-year-old Nathan commented, "Usually, I j... I just totally forget about it." Such lack of prominence ascribed to the health condition was echoed in the words of several children in this study. Explaining what forgetting about his allergies means, Nathan went on to say

> Some days I just hang out with my friends and usually at a party ... I check[42] and it's usually just on a subconscious level. [Then he added] But of course, I, I don't just totally forget about it.

It is evident to me that Nathan was not saying that his health condition was of no consequence to him, nor was he saying that matters related to his severe allergies didn't have important meaning for him; rather, I interpret this pattern of minimizing the impact of the health condition as a reflection of the everydayness of the experience of living with chronic illness: that symptoms of health conditions and activities related to the monitoring and treatment of those chronic health conditions were deeply embedded in the routines and events of everyday life. For these children, intentions related to their health care, and expressions of those intentions, were deeply enmeshed in the whole of their lives.

Obscure meanings in children's expressions

In some instances, what was most important to children—what worried or embarrassed them most—was not immediately evident in their expressed intentions. Seven-year-old Charlie had well formulated intentions in relation to the rotation of sites for his twice-daily insulin injections. This intention was expressed during a clinic visit where Charlie, his mother, his father, the clinic nurse, and his endocrinologist discussed the details of his diabetes management.

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[42] Nathan is alluding to his practice of checking labels or using other means to ensure that what he eats is safe and allergen free.

The following excerpt from my fieldnotes depicts an interaction toward the end of the family's appointment with the physician:

> Dr. H asks Charlie if there is anything else he would like to talk about. Charlie looks at Dr. H and then begins playing with the handle of his lunch box. "The bum hurts me too much." Dr. H's response indicates that he understands what Charlie means, asking, "Does it hurt more or is it just too weird?"

As the conversation proceeded, several actual or possible interrelated meanings of injections in the buttocks emerged. This site for injection was painful. Because Charlie was a small, wiry child, and because there is so very little fat on his buttocks (or on his abdomen or legs for that matter), injections at that site could be more painful than injections in his arms. Pain and the meaning of this pain were embedded in Charlie's statement of intention.

Dr. H. made explicit another possible meaning regarding injections in the buttocks for Charlie in his question, "or is it just too weird?" His question implies that he would believe that Charlie could reasonably be embarrassed or in some way feel awkward about exposing this site. Whether or not this was true for Charlie as part of his experience in diabetes management was impossible to confirm by the data available to me. In addition to the pain of these injections, Charlie's sense of his body may have contributed to the meaning of injections in the buttocks.

As was the case with Charlie's desire never to have injections in his buttocks, many examples of children's intentions were reflections of multiple, sometimes complex meanings. In Kyle's story, for example, the multiple meanings of assistance in his classroom at school became evident over various interactions. In early conversations, Kyle had mentioned how he likes the CEA (certified educational assistant) who works with him at school. He mentioned that she gives him gifts, and that she helps him with his writing. Another time, however, he mentioned that he hates having a CEA at school. When I ask why he simple says, "I don't know." His mother, sitting nearby, encouraged him saying, "You can be honest with her." I asked Kyle if his dislike

of the CEA had something to do with having someone else present all the time. "Yeh," he said, without elaborating.

Often, as was the case in Charlie's and Kyle's stories, I could not be confident that I understood the precise meanings of the children's expressed intentions. What seemed evident, however, was that multiple meanings of certain events or activities could co-exist, that children's sometimes-simple expressions of desires or intentions might be only partial representations of the complex meanings expressed by particular activities and decisions.

Complexities and contradictions in children's expressed intentions

"I want to play soccer": Shauna provided another illustration that the meanings within children's intentions were sometimes complex and multifaceted, and that those intentions were part of a child's situated and embodied subjectivity. Although, as she expressed, 11-year-old Shauna desired to play soccer, because of her chronic condition she was not allowed to do so. In this statement and at other times, Shauna was explicit and direct about what she wanted, depicting a clear and specific desire, one that her parents claimed she had held for several years.

Taken alone, Shauna's unambiguous expression of intention is hardly surprising and can be easily understood to echo what many of the children seemed to want: to be part of the activities of the school and community, and to have an able and strong body. I suspect that Shauna was no different, and that these reasons for wanting to play soccer seem fitting intentions for an 11-year-old girl. However, in addition to these rather obvious interpretations of Shauna's expressed desire, unique elements in her story support an expanded view of what wanting to play soccer might mean to her.

The sport of soccer has deep roots in the lives of Shauna and her family. Through my encounters with Shauna and her parents, I learned that her parents had immigrated to Canada

from Italy several years ago. In Italy, her father had been an avid, semi-professional soccer player. Shauna's younger siblings play soccer, and her father coaches her brother's team. While she didn't mention it to me at the time she declared her desire to play soccer, Shauna's siblings and father would soon leave for Italy and would be devoting much of that holiday to watching important soccer games in that country. Because of her treatments, Shauna, the oldest of five siblings, would have to stay home. These events in the history of Shauna's family shifted how I now interpreted Shauna's statement, "I want to play soccer," and led me to ask new questions, questions about the substance and gravity of the embodied experience linked to that expression.

As Shauna's story begins to illustrate, knowledge of the children and families—what was important to them, the events and people that define their lives, their experiences of the child's chronic illness and treatment—widens the spectrum of possible interpretations of a child's intentions and desires. In the case of some of the children, I had access to only small portions of their stories. Other times, as with Shauna and her family, through repeated encounters I came to understand some of the story of the child and family and began to appreciate some of the situated and embodied dimensions of their expressed intentions.

Shifting meanings of everyday decisions

According to her own account and that of her parents, 11-year-old Jenna adhered closely to her prescribed diet for diabetes; however, in certain instances, such as parties, restrictions on carbohydrate intake had more significance than in her usual day-to-day life. At those times, Jenna really wanted to have some of the cake and candy. This was particularly difficult, as these holidays and other occasions were to a large extent defined (at least for many children) by the candy and sweet food linked to them. Jenna's mother described her child's reaction to being restricted at these important times as manifested in anger:

It is a lot of rage at Easter and Halloween and all those occasions when she just can't eat all the stuff at her friend's birthday parties. She gets a little piece of cake and everybody else gets a big piece of cake. And marshmallows around the camp fire and all the other kids get unlimited and she gets three marshmallows … lots of rage and all.

As this project proceeded, I came to understand some of the complexities involved in discerning what it was that children wanted in relation to particular decisions, and to appreciate the embodied and relational nature of their intentions. In my inquiry about children's participation in decision-making, I came to appreciate that mistakes might be made by assuming that one expression is an accurate and full representation of what matters to children. While it is vital that children's perspectives be elicited if participation is to occur, a complex view of these voices is necessary.

My efforts to this point have been directed toward describing the intricacies of children's voices, addressing some of the many ways that the children's intentions and desires were presented and represented in places of decision-making. I have depicted how those intentions are best understood when considered in light of the relationships and contexts wherein they are expressed. As important as it is that children's own views be expressed, for children's voices to be heard, those voices must have achieved some standing in the places of decision-making. This is the focus of the remainder of this chapter.

Children's Standing in Places of Decision-making

"Sometimes… [laughing] … sometimes I don't want to hear you." These words, spoken in jest by 12-year-old Jason's mother, attest to the possibility that the children's voices could be ignored or suppressed, and suggest that certain people may have the authority to influence the standing of children's expressed views. From the outset of the study, I have held that the dynamics of participation are twofold; not only must children (or their representatives) have the

ability and opportunity to express intentions and desires, but those intentions and desires must been taken seriously in decisional contexts. As is made explicit in the questions that guided the study, I suspected that, when presented in the contexts of decision-making, the children's views would be subjected to various evaluations, evaluations that would shape or even determine the weight granted to the children's intentions and desires. In this way, I was looking at the data through a critical eye, paying attention to manifestations of power and authority and their influence on children's voices within decisional contexts.

It was evident that there was great variation in the standing granted to or achieved by the children's perspectives in matters related to their health care. At various times and in various decisional processes, children were invited to express their views; other times, children apparently assumed that their views were irrelevant; while at yet other times, children actively insisted that their views be heard. In some instances, representations of children's intentions appeared to be, without question, taken seriously, while at other times it seemed their views were rather summarily dismissed. The children's views in decisional contexts relied on much more than mere presentation or representation of children's intentions within processes of decision-making, and it is the influences on this standing that is my focus in this section.

In the following pages, I illustrate how the standing achieved by children in matters of decision-making is determined, in part, by certain qualities ascribed to the child and the child's views. In this way, the authority structure of decision contexts becomes clear; adults were the gate keepers to participation in decisional processes. I illustrate how this dynamic was manifest in processes of decision-making and show how, for the children in this study, attainment of standing in contexts of decision-making relied on adult beliefs that the child was capable of reasonable thought—that the expressed intentions or desires could be judges to be sound and rational within the decisional context. In order to achieve some sort of standing in matters of

decision-making, the children's expressed intentions, however reasonable they might be deemed, also needed to be deemed significant in relation to the particular decision. Taken together, the deemed reasonableness and significance of the child's intentions and desires shaped the standing of those views within decisional contexts.[43]

Meeting a Standard of Reasonableness

Whether presented directly by the child, or represented in the context of decision-making by a parent or health care professional, for what was understood as a child's intentions in relation to a particular issue to be taken seriously, it must first be deemed reasonable. Generally, for the children's views to be considered reasonable, they were measured against some standard of maturity and good judgement.

Not surprisingly, children's views tended to be readily accepted as rational and reasonable when they were synchronous with the views of those holding authority. Likewise, standards of rationality posed little problem and were easily met in the instances where children appeared to be the sole decision-makers. It was in instances where children's intentions diverged from intentions of the other contributors in decisional processes that judgements of reasonableness were particularly salient, and various criteria existed against which children's sensibilities were measured. In the following sections, I describe two of these criteria: beliefs about children's best interests, and understandings of children's levels of maturity.

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[43] Given what I have already claimed about the complexity of children's expressions, it is reasonable here to suggest that although a particular child's expressed view may be excluded from the decisional process, other (re)presentations of a child's wishes and desires may have influence. This is another dimension of the complexity of participation, and further evidence that participation is far from an "all or none" phenomena.

Perceptions of best interests

"You can't play with your health": this statement by one of the mothers of a child with diabetes reflects her strong and sustained views about what constituted her child's best interests. In this case and others, parents and health care professionals held clear and apparently unequivocal beliefs about what constituted the child's best interests in particular decisional contexts.[44] Other depictions of children's interests were more subtle, yet notions of what benefited children permeated conversations about the children and their care. These notions of children's best interests seemed to constitute powerful standards against which representations of the children's expressed intentions were judged.

I came to understand perceptions of children's interests as reflections of three persistent tensions at play in decisional contexts. The first was the tension between efforts to optimize children's physical health and ensuring that children have some sort of "normal" life. The second had to do with the tension between perspectives on what might benefit the child in the here and now and what the future child might need or want. The third tension manifested in perspectives of benefit based on what is good for all children versus what might be good for a particular and unique child.

Maximizing physical health versus creating and sustaining a normal life

Because all the children in this study had chronic physical health conditions, considerations of their physical health were prominent themes in the data. It is therefore not surprising that beliefs about what might maximize children's health constituted an issue of vital

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[44]   In this section, I am rather bluntly portraying various perspectives on children's interests as singular criteria against which particular expressed intentions were measured; however, the process was often much more subtle. In several instances, parents and health care providers grappled with various views of a child's interests, and reflected on their own beliefs and judgements about what constituted a particular child's best interests. In this section, for the purpose of explanation, I present various understandings of children's interests without detailed attention to some of the more complex dynamics of decisional processes. I draw attention to these complexities in chapter 5, where I explore the dimensions of participatory spaces in more detail.

interest that resonated in many descriptions of decisional processes. Maximizing children's physical health appeared to be, in some instances, the primary criteria of reasonableness against which children's expressed intentions were measured.

Jenna's mother explained it this way: "There's safety and there's good control, and good control isn't a choice." For this mother, her child's physical health seemed to be held as the absolute priority. Where her child's intentions and desires might lead to compromise in physical health, these expressed intentions were likely to be dismissed. Hence, Jenna did not go to camp, she missed a school trip, and she was not allowed to have sleepovers, in spite of her expressed desires to participate in all these activities. As Jenna's mother described her processes of decision-making, it seemed apparent that the potential for physical harm outweighed any arguments for the contribution of these activities to Jenna's overall well-being. As such, Jenna's expressed intentions to participate in these activities were deemed unreasonable.

Other parents seemed less convinced that physical health should always be held as the top-priority concern for the child, and described how they grappled with how to position health in relation to their child's overall well-being. At one point, 7-year-old Emma's mother made the comment, "There is only so much cucumber dip one person can eat." She was illustrating her belief that, in specific instances, enforcing adherence to dietary regimens may have physical benefits in the short term, but forcing a child to eat or not eat has other consequences and that those consequences are important. The broader context of her comment was as follow,

> It's hard when Emma's high yet she's hungry,[45] so then it's giving her these
> snacks that are low in carbohydrates and trying to do that. Then that's fine and
> she'll accept that, like cucumber dip. But *there's only so much cucumber dip one*

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[45] Here, Emma's mother was describing a recurrent point of decision-making in families of children with diabetes. Emma is "high"—her blood glucose levels are above what they ought to be—yet Emma's body is telling her to eat.

person can eat. I don't make it a battle because in the long run it will backfire. So it is very fine line –

This idea that children's best interests may extend beyond ensuring what might be optimal treatment at the moment was evident in many examples provided by children and parents. Time with friends, unstructured time, experimentation with different foods, and play, were some of the elements of life understood to benefit children that found a place in judgements of the reasonableness of children's intentions and desires.

Notions that the child's best interests could only be understood by considering the child as a whole were evident in many of the statements by the parents in this study. This perspective was very evident in the story of Lucas described earlier, in which the decision about the timing of transplantation was influenced by the Lucas's wish to have a summer free of surgery and recovery. Perhaps the most dramatic example of the tension between optimal physical health and ensuring a normal life was illustrated in the account of one mother who, frustrated with having to wait for months for a decision about surgery for her child, debated whether to give up on the surgery and let her son "just be a kid":

> I said to the doctor, if this surgery doesn't happen real quick, I'm going to buy him a brand new bike and I'm going to let him play, because he hasn't been able to ride a bike, so I'm going to buy him a brand new bike and do whatever he wants to do for the rest of his life.

She summarized this tension as she went on: "I said [to the doctor], you have put my kid in a bubble for five months; he's 11 years old, looking out the window and wishing he could play." This perspective on her child's overall well-being manifests in other examples, where she allowed her child to participate in sports or to push his own limits, going well beyond what might be considered reasonable by the standards of others.

I noticed that even within the same transcript, parents move back and forth between a commitment to optimizing children's health and a belief that a normal life is an essential part of a child's life, as they relate the rules, routines, and decisions that constitute their lives with their children. I have a sense that this is a persistent tension that parents grapple with as they juggle multiple, sometimes conflicting perspectives in making judgements about their children's expressed intentions.

Today's child versus the future person

As they listened to what children might want and made judgements about children's intentions and desires in decisional contexts, parents accounts reflected the juxtaposition of what held that the child might need or want in the present against some notion of a future child/person and the best interests of that person. Often the perceptions of future were based in worries and concerns about the adolescent years. Looking beyond adolescence, in some instances as well, parents and health care providers' perceptions of the child's interests reflected beliefs about the adult future of the child and what the best interests of that adult might be.

"The adolescent thing is nearby already." The imminence of the adolescent years was a foremost concern for many parents, including the mother of 11-year-old Sean. A certain sort of foreboding about the upcoming developmental stage seemed to characterize many of the parents' accounts. Even 8-year-old Jarrod's mother worried about this: "sometimes I think, oh god, when he's a teenager I can just see it, I can just see it, it's like the writing on the wall, I think he'll kind of rebel a bit." Shifts in body image and changes in behaviour, along with the anticipation of diminishing parental control, were reflected in parents' understandings of a future child. How these beliefs were manifest in particular perceptions of children's interests varied. In some instances, beliefs about the adolescent's potential (or probable) risk-taking behaviours and the loss of parental control in those years meant that it was in the child's interests centred on

establishing good health practices in these early years. As one mother noted, "I'm hoping she maintains her same concerns for her [health condition] when she's a teenager out with her friends as she does now." While variation from routine and occasional slips in adherence to health routines and rules seemed accepted in some families, these slips had a different meaning in other families.

Not all parents believed that the challenges of adolescence meant that children should learn responsibility early. In one instance, a mother outlined her belief that taxing her child with too many decisions or too much responsibility in early years might result in problems in the teenage years:

> She's still a child. And I don't want her a couple of years down the road after making all these decisions... to do that all the time by herself, I think is going to lead to burnout which often has been proved to be the case. Teenagers at a time when they really need to have good control are just burnt out and refuse to do anything about it.

When this child wanted to take on the management of her diabetes diet and monitoring, her mother refused to relinquish control. The child's expressed intentions and desires were measured against a standard that included the perceived interests of the future adolescent.

Concerns for some future child extended into concern over as-yet-unknown complications of treatments and therapies. Here, a father's worry about what his daughter might feel in the future about a treatment decision in the present was explained this way:

> And he said, "You know it's going to be a lot easier for me to explain to my daughter why I didn't give her growth hormone when she comes back to me and says, "Dad, why didn't you give me growth hormone, I'm so short," than it would be if something went wrong and she said to me, "Dad, why did you give me growth hormone and now I'm dealing with this complication."

These concerns about the future child and understandings of interests associated with that child created another perspective on the reasonableness of certain children's intentions in regard to particular decisions.

Any child versus this child

In some instances, perceptions of best interests were very specifically linked to the knowledge that the parents or health professionals held of a particular child. These instances were most obvious at times when what was understood as a child's best interests strayed from what would generally be considered to benefit children the most. Eleven-year-old Kyle's mother's beliefs about the administration of growth hormone to her son provided one example of this.

Kyle lived with a serious rare serious genetic condition. He was short for his age, and administration of growth hormone may have helped him grow to a more usual height.[46]Because of complications related to his condition, Kyle was also somewhat cognitively delayed, a fact that was an important consideration in determining his best interests in regard to the administration of growth hormone. Without consulting Kyle, his parents eventually made the decision against growth hormone for him. While he was not directly consulted, an understanding of who Kyle was and what he would want were represented in his parents' understanding of his interests in this instance. In addition to considering the problem of daily needles for Kyle, his

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[46]   For many children with a variety of conditions, decisions about the administration of growth hormone are particularly complex. None of the children in this study are candidates for growth hormone because of some endocrine deficiency. Rather, for each of these children, growth hormone has been recommended because of the child's short stature arising from other causes. Decisions about growth hormone are rendered particularly complex when a) data about the efficacy in relation to the child's particular conditions does not provide clear guidance, b) when families must pay for the medication and equipment, c) when children are very adverse to injections, and d) when support groups and health care professionals place pressure on children and families in either direction regarding this decision.

parents believed that, as a shorter person, others would expect less of Kyle and, hence, his cognitive delay would create fewer problems for him.

In this instance, the representation of Kyle's intentions and desires merges with some view of how the world will react to him. In contrast to the this example where beliefs about an child's interests were generated through consideration of particulars of the child's story, in other instances more general notions of children's interests constituted standards against which children's expressed intentions and desires were measured. These situations tended to reflect discourses of optimal health care for particular health conditions, some of which I described above.

I have endeavoured to illustrate how notions of the children's best interests were important standards against which children's expressed intentions were measured. Thinking about these views of children's interests provided useful insights into the standing granted to children's voices in situations of decision-making. What is interesting, of course, is that in all the examples I have provided here, adults decided what constitutes children's interests. Children did not appear to be invited into these conversations.

Beliefs about children's rationality

Determinations of the reasonableness of children's intentions and desires were not only based on the notions of children's interests held by the various participants in decisional processes, they were also grounded in beliefs about children's capacity to formulate rational perspectives, understandings of the extent to which children's stage of development and their life experiences might have shaped their capacity to formulate logical and morally sound views.[47]

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[47]   Concepts of children's interests and children's rationality can be understood to overlap when we consider evaluations of children's expressed intentions. My goal here is not to present these as mutually exclusive categories, but rather as somewhat different points of view, varying ways of thinking about what children's expressed intention encounter in places of decision-making.

Many of the attitudes and opinions parents and health care providers appealed to in judging children's reasonableness were grounded in notions of growth and development. However, as I will show later, some parents and health care providers noticed and articulated a sense that children with chronic health conditions, for whatever reason, can develop a wisdom or maturity that is not so easily explained.

Developmental maturity

"And he's able to handle a lot of situations." As in this statement, parents articulated their belief in their children, a view that at least certain children were capable of acting in reasonable ways. There were several examples such as this, where parents expressed a general confidence in the abilities of their children to make sound judgements.

Similarly, parents described their growing confidence in their children's abilities to make judgements in regard to specific aspects of the child's health care, their belief that, at times of decision-making, their children were capable of formulating reasonable intentions and desires. In the excerpt below, parents described how their children had come to understand the nature of risks to their health and the potential consequences of various behaviours. Here, the mother of 10-year-old Natasha speaks about her somewhat shaky, but growing confidence in her child's ability to assess the safety of food and to protect herself against exposure to life-threatening allergens:

> We've always talked to her about the risks to her health—not saying that she could die from it but just saying that it's certainly important that she not eat anything with nuts in it. And I think a lot of what she's learned has been role modelled by us because we read everything that we give her. So now she knows that's what she has to do.

In contrast to such a confidence in their children's abilities, other parents and health care providers explicitly described how children's lack of maturity was a vital consideration when the

reasonableness of children's intentions and desires was determined. One parent made this statement depicting her beliefs about the lack of maturity of her child and the consequences of that immaturity on the child's ability to contribute to decisions:

> My attitude is that Jenna is a child and I'm an adult. I am responsible for her diabetes care until she is mature enough to take on the responsibility. So even though Jenna can have some say in things I feel that she has to listen to what I want her to.

Explicit in this comment is a belief that there is some threshold below which children are not capable of making reasonable choices, at least in regard to certain matters. While most parents and health care providers were less direct in expressing their standards for evaluation, the notion that adults had a certain responsibility in this regard was a consistent theme throughout the study.

Descriptions of specific instances of decision-making provided a more nuanced view of the responsibilities parents felt as they judged their child's wishes against some notion of the child's best interests. Depending on the risk and potential consequences of misjudgement, these situations evolved differently. For some parents, such as those whose children had diabetes, these situations were a daily occurrence. These parents were constantly aware of their children's diet and conscious of the many opportunities their children had to make mistakes. Seven-year-old Emma's father articulated this process of deliberation in the following way:

> It is probably bit of a burden, a little bit of a negative, but you become the resident expert, so that every time your child goes to a party or goes over to a friend's house for an afternoon, [you think] … it depends. Does the visit span dinner or lunch? Can she do a sleep-over or not? And you freak when you hear she had a drink of pop or juice. She knows not to, Emma's very good that way. But kids slip.

Kids slip; they make mistakes. And often these lapses in judgement were understood as a function of their stage of development and moral, cognitive, or social immaturity.[48]

In certain instances, beliefs about the child's maturity had to do with more than the child's chronological age. A feature of the health condition of some children was the tendency to be less emotionally or cognitively mature than other children their own age. For three of the children in this study, complications connected to their health condition meant gradual but progressive deterioration in the child's cognitive or emotional capacities. This was a particularly difficult situation for parents and health care providers. Parents of these children described the very complicated judgements they made about their children's capacities to formulate reasonable intentions. What they had once understood as the child's capacity for reasonable judgement shifted, and previously held perspectives on the child's best interests were called into question.

A certain wisdom

In certain instances, parents and other adults conceded that children might be better positioned to make wise judgements than they themselves were. One parent reflected on her own limitations in knowing what was best for her daughter in many decisions, and her belief that her child had "a certain wisdom":

> The other thing I really feel about this child is that there have been times when I've pushed something with her and then she has resisted ... And I've realized later that she had some wisdom. It was like unknowing wisdom, and she was actually making the right call for her.

In conversation with this mother, the notion of the child's "unknowing wisdom" arose in discussion of her child's desire to be part of a dance group at school. As this mother recounted the decision-making process, she described her sense that an important interest for her child was

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[48]   A detailed analysis of parents' perspectives on the roots of children's lapses in judgement would be an interesting additional analysis of this data. Variously, these lapses were portrayed as being founded in cognitive, moral, or social immaturities.

the preservation of her child's self esteem. Because of her daughter's lack of skill in this area, she worried about the possibility of embarrassment and humiliation and the consequences of that for her child: "I don't want to give more fodder for teasing." Yet in the end, this mother decided not to intervene and to encourage her child in her expressed desire, "to trust the wisdom of the child and go with it."

The sense that children with chronic conditions might have a kind of knowledge that other children don't have was echoed in the perspectives of certain other parents. In the words of 11-year-old Shauna's mother, "There is something different about them in their way of thinking." What is particularly interesting is that notions that these children had a certain knowledge that other children do not have did not supplant coexisting perspectives on the child's immaturity and maturity. In both of the examples cited here, the mothers recounted a sense that their child had a wisdom that other children may not have access to, while maintaining their concern that their children's intentions and desires might at times be reflections of immature thinking.

Not only did some parents hold a view that their children might have a unique wisdom of some sort, some children also held this belief. Anthony analytically portrayed his own unique wisdom as a function of what he had to do: "I think it's because I've always had to be so careful of not, like, falling or I think I've developed like a sixth sense almost of everything around me and everything." In Anthony's stories, it is evident that he draws on this understanding as he argues his stance in places where he might otherwise be dismissed.

In contexts of decision-making, for children's expressed intentions and desires to be considered relevant, they must first meet some standard of reasonableness. This standard of reasonableness was often shaped by notions of children's best interests and beliefs about

children's rationality. In this section, I have described some of the complexities embedded in these judgements and hinted at the important issue of authority in moments of decision-making. It is this issue of authority in contexts of decision-making that I address in more detail in the next section, as I portray a second important dimension of the standing of children's views: the significance that their voices attain within the relational contexts of decisions.

Achieving Significance

As I have already suggested and will demonstrate in more detail here, meeting some standard of rationality did not necessarily ensure that children's intentions achieved standing in decision-making processes. Although children's views, whether represented by the children themselves or by others, might be deemed to reflect important interests and demonstrate some sort of rational thinking, this alone did not ensure that the children's voices achieved standing in places of decision-making. The children's intentions and desires must first be deemed significant within authority structures of decisional processes. For children's views to matter in decisional contexts, they needed to be in some way important to those who could influence whose voices are heard and which perspectives were privileged. I suggest that, in the decisional processes into which the children in this study entered, the significance of children's expressed views was largely determined by the multiple meanings that co-existed about decisions themselves, and by the many other voices with which children's own voices sometimes had to compete.

The many meanings within decisions

Earlier in this chapter, I highlighted the multiple and complex meanings that seemed evident within many of the children's expressed intentions and desires. When I consider the various inhabitants of decisional contexts, it is evident that, in many instances, multiple meanings of particular decisions were at play as the decisional process unfolded. As the children sought to be heard in decisional contexts, in many instances, the meanings of decisions differed

for the various participants. These differences in meaning, combined with the relative power and authority of those who held the different meanings, had important implications for the standing granted to children's expressed perspectives.

One family had to make a decision about the timing of a ten-hour infusion that the child would need every day. Most children receiving this medication timed the infusion so that it would take place while the child slept at night, yet in this case, neither the child nor the mother wanted the infusion to happen during the night hours. For the child, an intravenous infusion at night meant limitations on his movement during sleep. His mother was concerned about infection at the insertion site, worrying that her child's tendency to bedwetting might jeopardize the integrity of that site. In this case, the intentions were the same, while the motivations and meaning were different. While in this instance intentions merged, more often, when the decision held different meanings for the various participants in the process, perspectives on what should be done also varied. It was in these contexts that the child's perspectives may or may not be considered relevant within processes of deliberation.

Meanings of particular decisions differed along various parameters, and it was within these parameters that expressions of children's intentions found or failed to find relevance. Notions of risk associated with various alternatives, perspectives on the health condition itself held by the various participants in the decisional process, and the beliefs held by parents and health care providers about the children themselves, coloured decisional processes.

Perceptions of risk

The risks associated with particular decisions were often understood differently by different persons within decisional processes. This was perhaps most obvious in those instances where children wanted to participate in certain activities and were prevented from doing so. In

these instances, the divergences in meaning regarding decisions were particularly evident. Parents might understand their child's perspective as reasonable or not reasonable, but regardless of that evaluation, could hold some notion of risk as a more pressing consideration. These kinds of decisions became even more complicated when the circle of participants in decisional processes expanded to include health care providers, teachers, siblings, step-parents, grandparents and others. Describing one decision in which a grandparent perceived a different level of risk to the child than she did, Lucas's mother explained

> Even yesterday my mom bought brownies. And [Lucas] wanted them so bad and, there on the label, last thing, [was the phrase] "may contain trace amounts of peanuts and/or nuts." Sorry, you can't have them.

While I don't know the grandmother's motivations in offering her grandson this food, I suspect that it would be fair to say that her sense of risk in relation to Lucas's diet differed from that of her daughter, and that what was most important to her (what this decision meant to her) was somewhat different from that of both Lucas and his mother. Lucas's mother here held final authority and her beliefs about risk rendered Lucas's grandmother's desire to provide brownies to her grandson, and Lucas's desire to eat them, irrelevant.

In some instances, parents and children were prepared to accept certain risks.[49] There are many examples of instances where parents accepted a certain amount of risk of physical injury in order to allow their child to participate in certain sports or social activities. In these instances and others, perceptions of risk seemed to be tempered by the meanings ascribed to the decision,

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[49] This concept of risk would be an interesting site for secondary analysis and/or future research. An analysis of the concept of risk including variation of the meaning of risk for parents, children, teachers, and health care providers might provide useful insight into the dynamics of decisional processes and the relative positioning of children in those processes. Interesting work by sociologists Kelley, Mayall, and Hood (1997), as well as by nurses Lindberg and Swanberg (2006), has begun in this area.

perhaps a weighing interests associated with ensuring physical health against interests associated with wanting the child to have some sort of normal life.

Perceptions of ability

Perhaps one the most difficult tasks the parents in this study faced was that of defending and justifying the legitimacy of children's intentions to teachers, other parents, and health care providers. This task seemed to be less complicated when the child had a relatively common condition such as diabetes or renal failure. The task appeared to be more daunting when the child had a more obscure condition, and especially if that condition had few visible manifestations.

At first glance, 11-year-old Kyle appeared healthy, and it was not immediately apparent that he had a life-threatening and chronic health condition. In our conversation, Kyle's mother described many instances where she has had to justify requests for accommodations or the use of resources intended for children and families with serious health conditions. She has had to defend their right to stay at Ronald McDonald House[50] to other parents of ill children, responding to sceptical questions such as, "Is that kid really sick?" At school, she has had to argue for Kyle's special status in physical activities, and his need for CEA support at school. So when it came to advocating for Kyle in his expressed desire to participate in sports, she found herself in some instances defending his need to have modifications while at other times arguing for inclusion. In various contexts, Kyle's condition was not considered a meaningful consideration, and his mother was faced with ensuring that it became a significant consideration in contexts of decision-making.

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[50] Ronald McDonald Charities supports Ronald McDonald Houses in several cities in Canada. These houses are intended to be a home-away-from-home for families of seriously ill children being treated in a nearby hospital.

Variously, it appeared children's experiences with chronic illness could either enhance their standing in places of decision-making or hinder their efforts to be heard. In some instances, it was evident that the children were granted some authority in decisional processes because of their knowledge and experience with their health conditions. At other times, they were seen as less capable and competent, a person in need of protection rather than a person whose voice must be heard. These important distinctions may be as much a reflection of various views of children as they are of views of chronic illness.[51]

Perceptions of children

While views of risk and of children's health conditions among contributors to decisional processes were important determinants of the relevance granted to children's intentions and desires, perhaps even more influential were the views about children in general. Perspectives on children were embedded in the comments that parents and health providers made as they described the specific children or explained the possibilities they imagined for children. Perspectives on children could also be discerned in children's own accounts of being in decisional places and their experiences of relevance or dismissal. Correspondingly, the conceptualizations of children implicit in this space tended to reflect view of the child either as innocent and in need of protection or as out of control and at risk for causing harm.[52]

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[51] Another direction for further analysis might be a consideration of the relative positioning of various health conditions. I have a sense that different health conditions, for example, diabetes, epilepsy, and osteogenesis imperfecta, held quite different meanings for adults when it came to matters of decision-making. I am curious about how, if true, this manifests in contexts such as school and organized sports.

[52] In an important contribution to our knowledge of children's moral status in various contexts, Valentine (1996) provides a historical account of how what it means to be a child has varied over space and time. Vacillation between imaginings of children as "angels" and children as "devils" has characterized modern Western history, she claims, and is manifest in the lives of contemporary children .

For most of the children in this study, I had only brief glimpses into how they were perceived and positioned by adults. In one example, Anthony described his experience of being considered lazy or manipulative when he requested exemption from a particular activity in PE class. He described the orientation of his teachers to him in the following way:

> They say, you do it or you flunk, that type of thing. [They tell me to] do some activity that I can't do or—like I've been this close to actually just sitting down and [saying] you call my mom and I'm not getting up until you call my mom.

In contrast, he described other instances where teachers apparently considered what he had to say as meaningful and granted standing to his intentions in those contexts of decision-making.

The many voices in places of decision-making

"And so in terms of the decision, it's honouring her—what she's telling us. And it's hard sometimes because there's a lot of pressure." In many places of decision-making, the significance of children's expressed intentions diminished in the presence of other, often very influential, voices.[53] As this mother suggests, children's expressed views could be countered by pressures from other sources, voices against which the child's voice must compete for relevance.

The intentions of 11-year-old Lucas in regard to using his newly established arteriovenous fistula as an access site for hemodialysis were clear: no thanks.[54] His mother

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[53] In order to illustrate the tensions between children's expressed intentions and other influential voices in decisional processes, and the implications of these relationships in shaping the significance of children's expressions, I am depicting these as competitional dynamics. Portraying the relationships thusly could be seen to detract from my earlier argument that the children's intentions reflected relationship and context; however, here I am illustrating particular dynamics that shaped processes of deliberation and suggest that the relative privileging of certain voices had important implications for the possibilities within decisional places.

[54] For long-term hemodialysis, an arteriovenous fistula is created. Generally this fistula consists of a surgically created connection between the main artery and vein in the forearm. At the commencement of each dialysis session, needles are inserted into the fistula, and this becomes the site of blood exchange between the patient and the dialysis machine. Prior to the establishment of the fistula, Lucas had a central line, a surgically implanted semi-permanent access to the major vein near the heart. Accessing this line for dialysis does not require needle, and the access site is well hidden. Because of potential complications, however, central lines are not intended for long-term dialysis.

respected the meaning accessing that fistula had for her son. For Lucas, the risks associated with use of a central venous line did not offset the pain associated with the insertion of a needle into his fistula. His mother understood that he was unhappy with the changes to his body that resulted from the creation of the fistula, and she fully appreciated that these meanings were manifest in her son's refusal to allow his fistula to be used for hemodialysis. In this way, Lucas's mother acknowledged that his views regarding dialysis could be understood as reasonable. Yet, in a decisional place dominated by voices of "best medical practice" and '"standards of care," little significance was granted to Lucas's expressed intentions. Standards of treatment for children undergoing hemodialysis, statistics of infection risk associated with each, and established routines and patterns of practice in the location where hemodialysis took place, represent voices that held more authority Lucas's concerns about pain, and his own sense of his body.

In some instances, the intentions of other family members or the family overall could be understood to compete with the child's own views. The tensions parents experienced as they attended to the differing needs of various members of their families were echoed in many of their accounts of decision-making with and for their chronically ill children. Depicting this tension as she judged what weight to grant to her child's expressed wish to participate in a particular activity that would require a great deal of her time and energy, the mother of 9-year-old Rhys commented,

> If it was just Rhys then, like I said, it wouldn't be too bad… I could just focus all my time and energy and not worry about too much. Whereas, you know, I have a completely opposite child… he's into every sport that possibly could be out there… and he's always wanting my attention, more so now than ever.

Rhys's expressed intentions and desires entered a place of decision-making where the voice of his brother and the concerns of the entire family constituted other important interests.[55]

The voices within places of decision-making could be linked to the embodied subjectivities of the inhabitants of those places; to the histories, relationships, and locations that compose decisional places; and to the influences from outside those places that are manifest in the decisional dynamics as they unfold. Varying forms of discourse found expression in the decisional processes. Among these were expressions reflecting prevailing beliefs about optimal health care and what that might be in the lives of particular children. Describing the impact of accepted views regarding the appropriateness of providing a particular medication for her child's condition into the decision *not* to require her child to take that medication, Jill commented, "And so when you talk to other parents, they're like, what do you mean she's not on [the specific medication]? And they think it's awful…" While parents varied in the extent to which prevailing views of the right thing to do affected their decisions, awareness of these larger discourses also permeated their decision-making. In similar ways, discourses of what constitutes good parenting, and matters of safety, found voice in particular places of decision-making. These voices influenced, in varying ways and to differing degrees, the standing of children's expressed intentions. In these places where multiple voices converge, adults inhabiting the space of deliberation demonstrated varying degrees of uncertainty about what it was that the child might want, need or desire, or varying degrees of certainty about what the best course of action might be.

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[55] An important distinction must be made here between the status of children themselves in decisional places and the standing granted to specific expressed intentions. These are, of course, interrelated. Here I am not suggesting that Rhys's status as a person in this decisional place has been diminished. Rather, I am illustrating that the standing of his expressed intention was influenced by other important voices in that decisional context.

Summary

My intent in this chapter was to depict some of the complexities inherent in efforts to discern chronically ill children's voices in matters of decision-making and to highlight aspects of decisional contexts that shaped the standing of the children's voices in places of health care decision-making. The children's voices assumed many forms, and the task of judging what constituted a particular child's voice in specific instances was often difficult. What I have come to understand from my encounters with the children and their families in this study is that children's intentions and desires have a location in the children's histories and in the relationships wherein those views are expressed. Furthermore, children's intentions can be complex in their meanings. Children, like adults, juggle multiple and competing desires and intentions, some of which may at time appear conflicting or contradictory.

The standing achieved by children as their intentions are presented into decisional contexts is another complex matter. In this chapter, I have depicted dimensions of the standing of the children by suggesting that for children to achieve standing, their views must meet some standard of reasonableness and be considered relevant in the contexts of decision-making.

In chapter five, I continue describing the findings of this project, casting children's participation as a relational dynamic that was shaped in particular contexts, contexts that were determined, at least in part, by the resonance and relevance of the children's voices. Specifically, I describe how the resonance of children's voices could be understood to intersect with the deemed relevance of children's voices within moral or social spaces and suggest that it was in these spaces of human experience where possibilities for children's contributions to decisions were created or dissolved.

PARTICIPATORY SPACE AS A REALM OF VOICE AND STANDING

Introduction

As this project proceeded, and as the complexities within the data multiplied, I became increasingly aware that neither what constituted the children's voices in places of decision-making nor what might be judged as children's participation in those decisions could be reasonably comprehended without careful consideration of the social realms wherein those decisions unfolded. The children's expressed views and the standing of those views intertwined with the relationships, histories, and structures that constituted the places of decision-making. Depicting some of these complexities was the project of chapter four. In that chapter, I proposed that the nature and quality of children's expressed intentions (i.e., the resonance of children's voices) and the standing achieved by those voices in places of decision-making (i.e., the achieved relevance of their views) were vital determinants of children's participation in health care decision-making.

In this chapter, I take up these notions of children's voices and attend more carefully to the social or moral spaces where decisions unfolded and where children's agency was enacted. In this chapter, I look into these *participatory spaces*;[56] I describe how possibilities for and constraints upon children's contribution to health care decisions both shaped and were shaped within these realms, where agency and structure intermingle. My concern in this analysis has to do with the intricacies of these participatory spaces: what created opportunities for the children and their parents; what suppressed their voices; what gave structure to these spaces; and, most

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[56] I am using the term participatory spaces to describe the moral and social realms wherein children's contributions to decisions unfold. The concept of participatory space is one lens through which to interpret these complex locations of decision-making.

importantly, what shaped possibilities for the children's contributions to the important matters of their lives.

A View of Children's Participation

Before I proceed to depict children's participation as located in certain social or moral spaces, I will summarize what I have come to understand about the children's participation in decision-making. To begin, what the children intended and desired was sometimes obvious, other times more obscure. Importantly, their intentions in regard to health care matters were generally not easily distinguished from their concerns about their everyday lives: their experiences of health and health care were embedded in their every day existences. Further, while the children's intentions varied in the specificity with which a particular expression might address the decision at hand, in the degree of precision as to exactly what it was that a specific child wanted, and in consistency over time and across situations, these intentions were nonetheless deeply embedded in the children's relationships and their histories. Children's participation was the process whereby children's relationally formulated intentions and desires were made accessible to, and achieved standing within, decisional processes.

Given this perspective on children's participation, I use the terms *resonance* and *relevance* in the following ways (see Table 5). *Resonance* refers to the child's abilities and opportunities to formulate intentions, and to make those intentions available to and accessible within decisional processes. In one sense, resonance emanates from the child; it is some reflection of the child's embodied subjectivity. *Relevance* has more to do with features external to the child. It refers to the extent to which children's intentions and desires gain standing, the extent to which their views are deemed both reasonable and important by those in authority within decisional contexts. Power and authority are central considerations in this notion of

relevance, where questions such as "Who gets to speak?" "Whose voice counts?" and "Who gets to decide?" gain importance.

Table 5

Dimensions of Children's Participation and Key Influences on Each

Dimension of Children's Participation	Key Influences
Resonance of children's voices	Children's own abilities to formulate and express views
	The nature and quality of the relational context
	Availability of representatives
Relevance of children's voices	Adult claims to authority (beliefs about children's interests, protection and maturity)
	Children's capacities to advocate for themselves
	Adult orientations toward children
	Existence and strength of competing voices

Spaces of Children's Participation

Participation then, can be understood as an activity deeply embedded in relationship and history, and having to do with children's opportunities and abilities as well as with constraints imposed upon them; my task in this project was not just to describe those complexities but also to interpret them in a way that might assist health care providers as they encounter chronically ill children in their practices. Given these premises, I found it necessary to think further about how the contexts of decision-making might differ from situation to situation, what variations in the resonance and relevance of children's voices might manifest in particular situations, and what features of the decisional contexts are fixed and what might be alterable.

Although some existing theoretical approaches to children's participation in decision-making attend to aspects of both agency and structure (Hart, 1992; Thomas, 2000), none that I

encountered seemed to fully address some of the more complex questions this analysis was uncovering. For example, as I considered the resonance and relevance of children's voices in various decisional processes, it was not at all clear to me how one might discern what a child's optimal participation would be. How much resonance is a good thing? Should parents and health care providers always seek to foster children's involvement in decisions? How can we reasonably think about representations of children's intentions by others? How these questions are answered has important implications for the lives of chronically ill children, yet doing so demands simultaneous attention to structure and agency or, as I am suggesting, to the resonance and the relevance of children's voices.

The work of scholars in the field of critical human geography (e.g., Aitken, 2001; Gallager, 2006; Valentine, 1999; Valentine, Butler, & Skelton, 2001) have provided some guidance to my analysis in this project, particularly through analyses of children's social and moral spaces. Most of these authors draw, in one way or another, on the works of Lefebvre and Foucault to describe the complexities and dynamics of spaces of human existence. As a construct, 'space' becomes much more than some sort of void to be filled; it is shaped by power and human activity, and hence it is neither solely a product of structure nor a consequence of human agency. In his classic work, *The Production of Space* (1991), Lefebvre depicts social space as something more than a vast emptiness waiting for events to unfold:

> (Social) space is not a thing among other things, nor a product among other products: rather, it subsumes things produced, and encompasses their interrelationships in their coexistence and simultaneity—their (relative) order and/or (relative) disorder. It is the outcome of a sequence and set of operations, and thus cannot be reduced to the rank of a simple object. At the same time there is nothing imagined, unreal or "ideal" about it. (p. 73, parentheses in original)

In his philosophical analysis of social space, Lefebvre suggests that, at its most basic level, space must exist for an individual or group to be seen and recognized. He asserts that "groups, classes

or fractions of classes cannot constitute themselves, or recognize one another, as "subjects" unless they generate a space" (p. 416). While Lefebvre suggests that individuals can and do produce space, Foucault's writing (1973, 1977) suggests a different view: that space produces certain sorts of subjects. This is a tension that I try to keep alive in my depiction of participatory spaces; thus, both these views are helpful in my analysis of children's participation in decision-making.

Other authors have also built on the concept of social space, addressing ethical and moral dimensions within these realms of human existence. In their exploration of the links between ethics and world politics, Campbell and Shapiro (1999) approach moral spaces as "the bounded locations whose inhabitants acquire the privileges deriving from practices of ethical inclusion" (p. ix). Walker (2003) depicts moral spaces as sites of reflection and action, openings in which ethical concerns can be seen and named, and where dialogue about these concerns can be initiated and sustained.

In this analysis, I am peering into the moral spaces of children's existences toward the goal of understanding some of the complexities of their participation in important matters of their lives. I begin to use the term *participatory space* in terms of the social relations that shape possibility and opportunity for children's contributions. In one sense, space is an abstract field "in which are mapped trajectories of history, political economy, technology, and social relations in on-going dynamics" (Kelly, 2003, p. 2280). The concept of space, when understood as constructed from the multiplicity of social relations and the interplay of them, creates a way of thinking in terms of "the ever-shifting geometry of social/power relations" (Massey, 1994 quoted in Kelly, 2003, p. 2280). In this analysis, then, participatory space can be understood as a dynamic field of power on which are mapped elements of health, health care, policy, children's bodies, and adult-child relations. Participatory is space is the dynamic field of power where

children seek to make their voices heard, and where those voices sometimes struggle for relevance.

In one sense, I am peering though the layers of human dynamics and social relations: through the broad social and moral world of children's and parent's everyday existence, into the spaces where decisions of various sorts unfold, and then, into the more narrow field of social relations that might be understood as the location of children's participation. In the analysis that follows, I begin to look at the participatory spaces in decisions with and for school-age, chronically ill children. In order to accomplish this, the following lines of inquiry informed my analysis of the data:

- What characterizes adult-child relations in this instance? Who owns the space of decision-making?

- What does the child want? How is that view expressed? What does or would constitute participation?

- What is the nature of the child's own social action?

- How do the structures expand or limit children's alternatives? Who controls the spaces where decisions unfold?

The answers to these questions speak to, in part, the resonance of children's voices and the relevance of those voices in decisional contexts.

Participatory Spaces in Chronic Illness Decision-Making

As I attended to variations in the resonance of the children's voices and what I perceived as the achieved relevance of those voices, certain patterns characterizing the social dynamics of decisional processes became evident. Broadly speaking, the moral spaces where decisional processes unfolded and where children's participation was enacted could be understood to be characterized by one of four dominant features: children's silence, children's tangible

contribution, adult imposed authority, or adult assumed responsibility. Figure 5 depicts these

variations within the moral spaces where decisional processes unfolded and where participation

was enacted.

Children's voices
resonate

Children's
views
irrelevant

Adult imposed
authority

Children's
tangible
contributions

Children's
silence

Adult assumed
responsibility

Children's
views
relevant

Children's voices muted
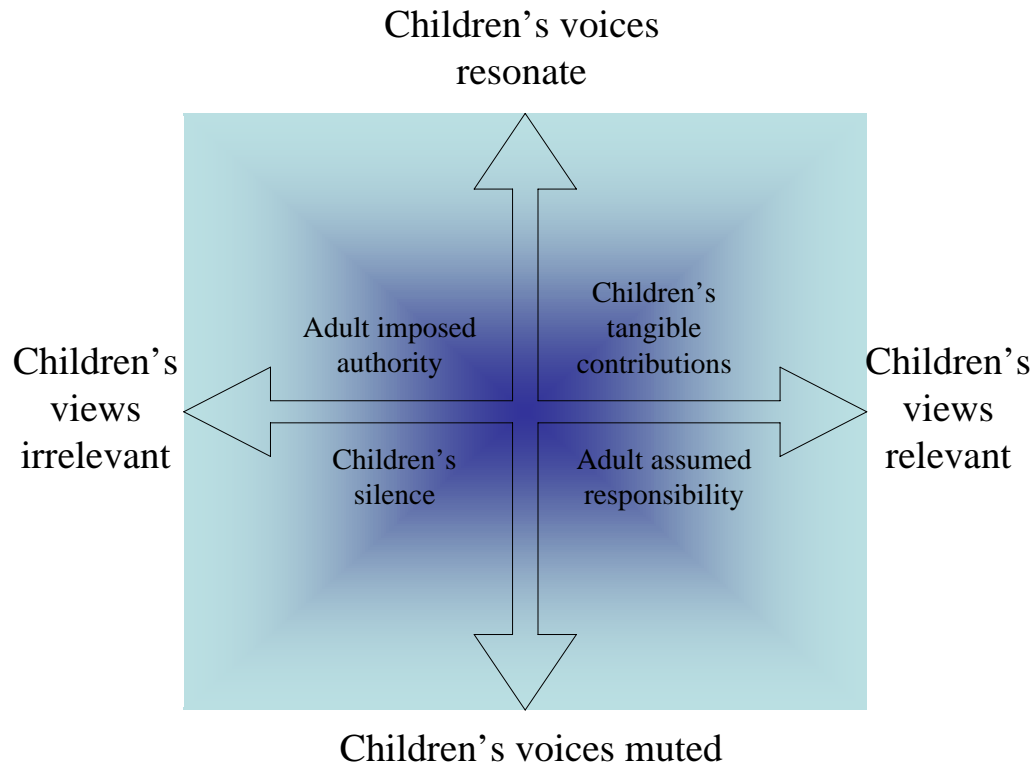
Figure 5.   Participatory spaces in relation to the resonance and the relevance of children's voices

The resonance of children's voices, represented on the vertical axis, is a continuum depicting the

extent to which the children's intentions and desires were available and accessible in decisional

processes: made available through representations of the children's intentions, and accessible to

other inhabiting that space (usually adults: parents, teachers, or health care providers). As I

described in chapter four, what might be judged as children's expressed views varied along

several parameters, including the manner of representation, the precision of the child's

expression, and the specificity with which expressions were linked to the problem under

consideration.

The horizontal axis in Figure 5 represents the extent to which the children's views were taken into account within in the power dynamics of the decisional process: the relevance that children's expressed wishes and desires achieved within decisional contexts. As I portrayed in chapter four, the standing achieved by the children's expressed views in contexts of decision-making constituted a vital dimension of children's participation, influenced by adult authority and children's agency in places of decision-making.

Although I am portraying the resonance and relevance of children's voices as separate axes, they are not independent concepts. It is the differences that I am pulling apart in these axes: emphasizing, on one hand, the clarity and authenticity of children's expressions as the resonance of children's voices, and, on the other hand, the standing of those views as the relevance of children's voices. Of course, I don't have to go far down any analytical path to realize that dimensions of power are manifest in what can be expressed (by whom in what context), and what is heard (by whom and in what context), and are intricately intertwined with any understanding of both the resonance and relevance of children's voices.

Before I go on, I want to qualify the interpretation I present in the following sections in two ways. First, while my efforts in this chapter are devoted to depicting some of the variations in the participatory spaces, I want to emphasize that my goal in doing so is not to propose a comprehensive explanation of children's participation in chronic illness decision-making, but rather to provide a framework, a model, that might assist practitioners in making sense of this complex domain of human activity. My intent is to support sustained attention to patterns and variations in decisional processes and children's participation, rendering visible some of the morally relevant aspects of activities related to decisions in children's health care.

Secondly, in order to depict patterns and variations within the spaces of children's participation convincingly, it is essential that I make some judgements about the degree of resonance of children's voices and the extent to which their voices achieve relevance in decisional processes. For reasons outlined in chapter four, these kinds of judgements must be undertaken with caution. I therefore reiterate that all my interpretations are partial, that they must be understood to be grounded within what was available to me as a researcher-observer in certain instances. I hold my interpretations not as the "truth" of children's participation in these cases, but rather as illustrations of the kinds of contexts and dynamics that could reasonably be believed to unfold in certain moments of decision-making.

A Space of Children's Silence

Instances of decision-making exist in the data where little or nothing could be heard of particular children's intentions and desires, and where the voices of individual children were seemingly irrelevant in decisional contexts—at least in the view of the adults holding authority. These instances existed in social or moral spaces characterized by children's silence.[57] Silence characterized spaces of decision-making when something or someone within the context or the relationships rendered the individual child invisible—the child's voice was not heard; his or her intentions and desires were unavailable, unsolicited, or unnoticed. In these places, children might try to speak, but they went unnoticed. Alternatively, silence characterized the space because a child or the child's representative was absent from the decisional process, or for some reason incapacitated in their ability to formulate and express intentions and desires.

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[57] I debated whether to use the term "children's silence" or "children's absence" to describe this space of decision-making or participation. I am using the term silence here in a very different way than when I used the word in chapter four to depict silence as a means of expression. The paradox between these two usages of the word is not unnoticed, but I believe the word is, for now, the best available term to describe instances where children's voices are muted and their status questionable.

Two categories of decisional processes became evident when I considered the conditions under which certain children were silent within the decisional processes that shaped their lives. First were those instances where children were physically present as decisions unfolded but were somehow rendered invisible. The second were a group of decisions that had profound affect on the children's lives, in which children often had little input. These are decisions about the structure and organization of services to school-age children, including health care, education, and social services. These two categories of decisions are not mutually exclusive, but I address them separately here.

Present but invisible: The paradox within a space of children's silence

The fieldnote excerpt I have included here is longer than usual; I include it in order to reveal some of the complexities of an encounter I observed and to illustrate certain dimensions of authority and agency that might manifest in a space characterized by children's silence. This excerpt picks up at a point where 12-year-old Ethan was lying in bed, receiving an infusion that would be ongoing for the next several hours. He watched television in the darkened room as his mother and father sat side-by-side in chairs at his bedside. A physician from a specialty service was about to enter Ethan's room. Although this family was aware of and had had previous contact with other physicians in the specialty service, this particular physician was new to them.

> A doctor enters the room and stands at the foot of the bed, speaking across Ethan to his parents. She does not greet or speak to Ethan. Ethan does not look at her. For fifteen minutes the physician asks a continual stream of questions about diet, weight and height, psycho educational testing, marks at school, blood results, history of fractures over the past months, and medications. The physician writes notes as Ethan's mother and father endeavour to answer the questions posed. Ethan's mother speaks clearly and eloquently, obviously understanding what the physician is asking and providing the answers to the questions. Occasionally she consults her notebook for details. Throughout, the physician does not acknowledge Ethan. Ethan neither looks at nor speaks to the physician. He keeps his eyes on the TV.

Questioning complete, the physician proceeds to examine Ethan. Ethan places his right arm across his eyes. The physician squeezes his ankles and arms, lifts his shirt, palpates his abdomen and percusses his liver. While being examined, Ethan lies motionless, saying nothing.

A nurse in the room has been monitoring Ethan's IV and prepares to take Ethan's blood pressure. Ethan's mother takes Ethan's arm away from his face and straightens it so that the blood pressure monitor will function properly. So, Ethan's blood pressure is taken as Ethan stares at the TV, his mother holding his arm straight, and the physician palpating his abdomen. No one says anything directly to Ethan.

Examination complete and blood pressure taken, the physician asks Ethan's mother and father if they have any questions. Ethan's mother asks if she can have a copy of this physician's report. The physician comments that they should be receiving a small piece of paper each time after Ethan's admission. Ethan's mother comments that occasionally they get a piece of paper with numbers, but it is difficult to understand what the numbers mean, and the numbers don't address conversations about how Ethan is doing or future plans for his care. Mom points out that they need something to refer to as they try to understand the changes in Ethan's condition, and to use as a basis for reporting to other physicians in their home community. She repeats her request for a copy of the records. The physician once again mentions that the lab results should be mailed to them after each admission. Again, Mom reiterates that they generally receive those records, and emphasizes that those records do not provided a comprehensive account of what every physician has said. Dad mentions that it would be helpful for them to be able to see the records and to understand how things change from admission to admission for Ethan. Again the physician mentions that the numbers should be available to them. Mom comments that they need more than the numbers.

"What kind of report do you want?" the physician asks. Mom provides an example. "Today I saw [name] for [reason] and these are my impressions." The physician is clearly reluctant to commit to providing a full report to this family. At one point she says, "I don't know what we usually do about giving this information to families." Once again, Ethan's mother and father repeat why this information is so important to them and why they need it.

After the physician leaves the room, Ethan's father and mother looked at me and his mother comments, "This is what we always have to deal with."

To some extent, Ethan is both present and absent within this story. Information was being

gathered that would provide the foundation for decisions about aspects of his health care,

including medication dosages, diet recommendations, and long-term plans for care. The process of decision-making was somewhat vague: the problems were never named, alternatives never made explicit, and the parents were unclear about who it was that would make these decisions and how the decisions would be made. I think it is reasonable to surmise that, in this instance, Ethan's voice was largely muted, and that, while Ethan's parents were struggling to represent him, they did so without particular success. Based on the physician's actions and words in this encounter with Ethan and his parents, it seemed apparent that, at least in part, Ethan was no particular child in the sights of this physician.[58]

Authority in this instance rested largely in the domain of the physician. I surmise that the physician, as the expert in one aspect of the care of this child with complex and chronic illness, understood her responsibility to be that of collecting necessary information and, on the basis of her expertise, contributing to judgements about the best approach to care for Ethan. What the physician wanted to know in this instance appeared guided by some framework in the physician's mind. This framework seemed to render invisible the particular intentions and desires of Ethan or his family.

While Ethan's parents struggled to be heard—to claim some authority based on their position in relation to Ethan and their responsibilities for his care—this authority was neither readily granted nor easily achieved. As his parents struggled for voice, and as Ethan remained silent, Ethan's voice was muted and his standing in the place of decision-making compromised.

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[58] I am making this claim knowing that this is but one interpretation of what happened here. In chapter 4, I emphasized the historical and relational dimensions of participation, and the suggested that it is possible to make errors in judgement when we base our assumptions regarding children's participation on the basis of a single encounter. What I take from this illustration, however, is the possibility of children's silence, an absence within a decisional process. For example, while I have interpreted Ethan's behaviour as indifference or acquiescence, he may have been conveying a sort of passive resistance, a possibility I might have been able to discern more clearly if I had known Ethan better and if I understood more of his patterns of communication and relationship.

It seems evident that the gatekeeper to more active engagement was the physician. This space appeared controlled by adults, and Ethan had little place in it.

In some ways, this story of Ethan is an exception in the data set. Very few of the encounters between adults and children could be interpreted appeared to render children's voices silent. [59] Even in the story of Ethan, my suggestion that he was largely silent in the space of decision-making is based on an analysis of a relatively brief interaction and partial knowledge of what was going on in this particular encounter. I presented this story, however, as an illustration of the possibility that children could be absent from decisional processes, even while physically present, and even as their parents endeavoured to represent them.

What is important about Ethan's story is that the struggle for voice by children and their parents can be very real. In this instance, as the parents' voices became more muted and their efforts to represent their child's intentions and desires were dismissed, the opportunity for their child's participation diminished correspondingly. Many parents recalled instances when they believed that, in their efforts to represent their child's voice, they were also silenced. One mother articulated her frustration in not being heard by health care providers, and her beliefs about what that meant for her son, as follows:

> And a lot of times you find that they don't listen to what you have to say and I
> think that moms or dads that have kids that have chronic illnesses, like we've
> dealt with that since day one so we know really what's best for that child. I mean
> maybe I haven't got a big degree behind my name or anything but you know for

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[59] Again, participation in this study raised the awareness amongst children, parents, and health care professionals of the issue of children's voice. And, because of the nature of the study, potential participants who had reservations about the inclusion of children in decisional processes did not likely participate, while those who did participate may have been sensitized to what it might mean to listen to children. That said, a less-plausible but possible explanation of the composition of the participants of this study would hold that some parents who don't believe in including children might volunteer so that their views be heard and, similarly, that some of those who already try to maximize children's input may not feel the need to be heard. While my sense is that the former is the better explanation, I acknowledge that the second explanation remains possible.

that particular child and maybe not for the next child that has [this particular chronic illness].

In my master's thesis project investigating moral dimensions of the nursing care of critically ill children (McPherson, 1999), I found that critically ill children could be rendered invisible by nurses, even when the nurses actively attempted to sustain a perspective of children as fully human beings. When there were few reminders of who the child was, when parents were absent, and when there were multiple, competing pressures in the work of the health care providers,[60] perceptions of children as fully human beings could become threatened. In Ethan's case, I suspect that a number of factors muted his voice and rendered his views irrelevant: factors that might be related to the physician's perspective on the child; to the physician's understanding of her responsibilities to Ethan, his parents, and the health care team; or to the socio-cultural positioning of Ethan and his family and their corresponding credibility in the eyes of the physician.

"Generic" children in policy and practice

Policy decisions at various levels had important implications in the health care of all of the children in this study, yet, because of the levels and kinds of decisions, individual children tended to have little or no influence on these decisions. Diverse policies such as those shaping access to health care, availability and cost of certain medications or treatments, and inclusion at school, profoundly influenced the children's lives. For the children in this study, policy manifested in the children's everyday lives in often subtle ways, shaping diverse structural aspects of their lives: matters such as how far children and families had to travel to access services, what was important when it came to children's assent or consent to treatment and

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[60]   In that study, I described tendencies toward the objectification of children when they were very ill, and highlighted the dominant discourses of attention to the physical body and of ensuring efficient function of the critical care unit as important competing interests.

surgery, what constituted accepted practices in relation to pain management, and how children and parents accessed information about children's treatment and care.

The relevance of these structural features of decision-making to this analysis of children's participation in health care decision-making may not be self-evident. What I want to illustrate here is that the policies that created and shaped the structures and practices that were enacted in the children's lives tended to be generated with some objectified notion of children in mind. Hence, in many instances, the resulting practices and structures created conditions where the needs, intentions, and desires of particular children were neither elicited nor heard. Here I draw attention to two groups of these political sorts of decisions: decisions determining the costs of treatment for certain children, and decisions about children's access to resources at school.

The availability and cost of treatment

The availability and cost of various medications or treatments for the children and their families in this study raised questions for me about why it was that certain families were able to access resources more readily than others, and why some health conditions seemed to warrant more resources than others. It was strikingly apparent that, for the families in this study, the financial cost of a child's chronic illness could be substantial;—in some instances it was devastating. Often these financial concerns were directly related to policies about the distribution of resources at the federal, provincial, or health authority level.

Describing the cost of her son's treatment—both the direct costs of treatment and the less visible cost created by her inability to work—9-year-old Rhys's mother said:

> I don't care if I live in a cardboard box. My main focus is on [Rhys] and that's all I have time to care about right now—and my other son. I threw a fit when they wouldn't give us medical coverage and we weren't able to afford his prescriptions. There was nothing we could do.

Rhys was a candidate for a new medication that might help control his seizures, a medication that would cost the family approximately $900.00 per month. Having moved from their home to an area where housing was less expensive, now living apart from her husband because his place of employment was located 270 kilometres away in their original community, and having given up her own job to care for her child, Rhys's mother summed up the financial challenges by saying, "Come on. How do you eat, how do you pay your bills and any mortgage and buy $900.00 worth of medication a month? ... I'm going to have to get some sort of a part-time job to be able to afford to have the medication."

In this instance and others, decisions about whether to provide certain medications to children were based, at least in part, on the family's ability to pay, shaping the opportunities that might exist in the moral spaces of decision-making. The relevance of Rhys's intentions diminished as another very poignant competing voice came into play: cost.[61] As they were for Rhys, prescription medications constituted an important aspect of therapy for most of the children in this study. Where treatment took place in hospital settings, medications were generally funded by the provincial Medical Services Plan (MSP). Outside of the hospital, however, parents were almost always responsible for the cost of their children's medications, whether purchased out of the family budget or subsidized, as was the case for many, through

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[61]   For chronically ill children in British Columbia, the funding for medications and treatment is somewhat convoluted. The provincial Medical Services Plan (MSP) provides basic health care (which does not cover medications) to all residents. British Columbia's MSP is available to all residents of BC who meet eligibility requirements. Monthly premiums are $108.00 CDN for a family of three or more (Government of British Columbia Ministry of Health, 2006a). For many of the families in this study, the premiums were paid by a parent's employer. Because they were residents of British Columbia, the children in this study were entitled to access to physicians, medical specialists, and, when available through a hospital-based program, other services including psychology, physiotherapy, and speech therapy. Outside of hospital programs, services such as physiotherapy, speech therapy, occupational therapy, and counselling were generally not funded by MSP; the cost of these services tended to be borne by the families. The exceptions to this were those children who qualified for these therapies through programs jointly funded by local school districts and the BC Ministry of Children and Family Development.

extended health benefits provided by a parent's employer. [62] Rhys's family was not alone in facing daunting medication or equipment costs. The parents of another child in this study, for example, described spending $600.00 per month on insulin supplies. [63] Another mother, describing the decision about whether or not to provide a certain medication for her son, made this statement:

> So it's licensed to be used in Canada, but the B.C. government and many provinces in Canada don't pay for it. And [the medication] costs, when you start off, a small dose, maybe 15 grand a year, and it goes up to 30 grand once you get cooking with the full dose. We have no extended healthcare, so that cost would be borne by our family.

Interestingly, medications for certain children were reimbursed through specific plans, and most were at least partially covered once a certain deductible had been met. For example, medications for children with chronic renal failure were fully covered through a provincial organ transplant program. As well, children who qualified for the "At Home" program, a provincial program for parents of children with severe disabilities, had all approved medications fully reimbursed through the provincial Pharmacare program. [64] So, while some families faced devastating medication costs, for other children, medications were provided for little or no cost. Children with certain chronic health conditions, such as children with diabetes and those with organ transplants, had their medication funded through provincially mandated programs. As I

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[62]   In 2003, the British Columbia government introduced Fair Pharmacare Coverage to assist families with lower incomes (Government of British Columbia Ministry of Health, 2006b). With this plan, families have a certain deductible to meet (0-3% of net income) before Pharmacare begins to pay a significant portion (70%) of drug costs. Once a family maximum is reached (2-4% of net income), 100% of prescription drug costs are covered. Rhys's family met the criteria for Fair Pharmacare support; however, the medication that Rhys needed, while approved for use in Canada, was not considered an eligible benefit within the Pharmacare program.

[63]   While the cost of insulin was covered through a provincial program, certain equipment such as syringes and blood glucose testing supplies were not.

[64]   The "At Home" program is administered by the British Columbia Ministry of Children and Family Development, and is intended to assist families with the extraordinary costs of caring for severely disabled children at home. The benefits provided include respite benefits, and a range of medical benefits (Ministry of Children and Family Development, 2006). Three of the children in this study qualified for this program.

recorded earlier, as a result of the cost of their children's medications, some families had to make difficult choices. When we consider the spaces of children's participation, these economic and social influences become important. Quite outside any particularly decisional context, opportunities for children and their parents (as well as siblings and sometimes grandparents) were sometimes greatly influenced by decisions into which they had no input. Costs of medication, which medications and therapies are included in various programs, the availability of services: these elements all shaped where participation might even exist.

It is worth noting here that a large number of the children in this study had rare health conditions. Because of the low incidence of many of these conditions, the relative paucity of research into effective treatment for these children, and, possibility, because of the relative invisibility of these children in the grand scheme of health care research and funding, these children and families could find themselves without effective treatment or without the necessary funding to access potentially effective treatment. In the words of Dr. Joe Clarke, a national specialist in the field of rare genetic disease in children, "if you happen to be born with a rare disease, you do not have the same access to new, groundbreaking treatments as people who have more common diseases. And in fact, you may not be treated at all, ever "(Eaves, 2005, p. A36).

Chronic illness at school

For the children in this study, school policies, including how chronic health conditions were managed in children's classrooms, provided other examples of decision-making in spaces where children's voices could be muted and their perspectives rendered irrelevant. Schools in British Columbia tend to produce mission statements that espouse philosophies addressing the topic of difference at school, highlighting principles of equity and justice. The philosophy of one district, for example, states:

Since students vary widely in their backgrounds, needs and abilities, and since there is no single approach to learning, schools should adapt their educational programs and services to the needs of each student insofar as an equitable application of resources will allow (School District No. 38 Richmond, 2006).

While this statement illustrates a philosophical commitment to the needs of each student, the data of my study demonstrate that the needs of individual children did not always drive decisions about resource allocation at school, decisions that had profound influences on the lives of the children and their parents. Several children and parents expressed views that that the distribution of resources at school were unfair, that fiscal concerns triumphed over individual children's needs, and that services for children with "special needs" were terminated first when school districts experienced financial pressures.

One mother described this experience as she compared how her son was treated differently in two different school districts; while the support was officially the same across districts, the enactment of that support varied. Describing the work of certified education assistants in the school, this mother linked the practical availability of this support to the extent to which children with disabilities were valued differently in the two systems. Whereas in their previous school the assistants stayed in the classroom and worked with her child and other children with chronic illness or disability, in the current district, the assistants were unavailable. Her scepticism about the roots of this difference was reflected in her comment: "I don't know if it's the school, because I've heard they don't even like kids with disabilities of any kind, and now they're telling [us that] they don't have the funding for that."[65]

Policy at the school district level as well as more localized decisions about how that policy was implemented for children with chronic health conditions—decisions that I suspect

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[65] According to district guidelines, this same boy officially qualified for home schooling, which was also rendered unavailable. In the mother's words, "So I phoned his school and they said, oh, no, we haven't done that in two, three years now. There's no funding for that."

relied on some generic image of chronically ill children—had enormous influence on the lives of both the children and their parents. While policies and their enactment came to life in the lives of the children, authority in the decisional processes tended to rest far from the individual children and families.

Because authority sat at a distance from particular children and their representatives, it is reasonable to surmise that those who shaped decisions about medication funding for particular illnesses or resource allocation for children at school did so with some vision of children's place in the world and some notion of chronically ill children's interests. However, not all policy work took place at such a distance from the children. In upcoming sections, particularly as I describe participatory spaces characterized by children's tangible contributions and adults' assumed responsibility, I will show how certain children and parents penetrated the policy world in ways that enabled children voices, when heard, to achieve a certain standing in structural and policy decisions.

To summarize, in a space characterized by children's silence—those places where children's voices were muted and their views were rendered irrelevant—authority sat politically or geographically at some distance from the child. Whether because the child was somehow rendered invisible in the relational context, or whether the child was represented by some general or generic understanding of children and children's interests, in these places, children were silenced: children and their representatives were largely unable to penetrate the authority structures that dominated decisional processes.

A Space of Children's Tangible Contribution

In contrast to a space characterized by children's silence, certain decisional processes unfolded in spaces where children's contribution was evident and tangible. In chapter four, I

described the decision made by 10-year-old Lucas and his mother regarding whether and when he should go on the renal transplant list. Lucas actively participated in that decision; what he wanted was clearly expressed, and his intentions gained standing in the deliberative process. Spaces of children's tangible contribution existed in sites like this, where children's voices resonated and where those voices achieved relevance in the processes of deliberation. Children's standing within the authority structures, whether they struggled to attain standing or whether that standing was granted to them, is a vital consideration in this space of children's tangible contributions.

A defining feature of this space had to do with the distribution of power. In instances where children's voices were heard and where those voices achieved standing, the children held at least some authority within decisional processes. The sources of this authority and its manifestations of power varied across children and across situations. In some cases, children's authority appeared to be located in the knowledge or wisdom they possessed or were perceived to possess. In other instances, when portrayed as holders of certain rights, children's authority was based on some sense of their entitlement to have a say in particular matters that influenced their lives. In yet other instances, children's authority seemed rooted in a notion of the child's standing as a fully human being, the standing of children's intentions and desires linked to values of human dignity and respect. The interplay of authority and agency was particularly interesting in spaces where children were substantial contributors within decisional processes.

Authority and agency: Forces at play in a space of children's tangible contributions

In spaces of children's tangible contributions, diverse patterns of children's participation unfolded. At times, children appeared to act outside the reach of adult authority, making decisions largely uninfluenced by parents, health care providers, or teachers. Other times, adults

and children engaged in some sort of collaborative process: processes that might be characterized as either negotiation or resistance.

Where children claim authority

In certain instances, children's decisions and actions appeared to mirror their intentions and desires, and the influence of parents, teachers, or health care providers appeared minimal. Adults may have been physically present or they might have been absent. In this place, children's enactment of authority ranged from apparently unpremeditated responses within particular situations, to carefully considered approaches to concerns they held about certain matters in their lives.

Many instances of children's unpremeditated responses within the everyday events of their lives could be understood as a particular form of embodied responsiveness. This embodied responsiveness was evident in the account of 7-year-old Emma as she described a time when, contrary to what would be generally accepted as a good choice in diabetes management, she chose to fully participate in a school class party—eating a banana split along with her classmates:

> The last day I had a feast. I had chicken, rice, corn, gravy and water and a banana split. And there was, I think, four workers doing it. Johnny, Pietra, Riley, Brianna, and they had to cook the food … We got to make the banana splits…And then we ate.

So Emma ate a banana split, a move that (at least on some level) she would have known would raise her blood glucose above acceptable levels. In as much as she presented a matter-of-act account of her choice to eat the banana split, she was equally straightforward about the consequences of that choice:

Mom: So, what happened after you had your banana split?

Emma: I was 14.3.[66] I had to do 12 laps around the gravel field.

Emma: The gravel field. Okay. ... The gravel field is this big [gesturing with her hands]. You run like this and you stop there, and you run and you run and you run and you run, and you run and you run and run and run and run and run and run.

Like Emma, other children regularly made seemingly independent decisions, decisions with implications for their day-to-day well-being and health. The extent to which Emma's choice was more a conscious decision or an embodied response is difficult to discern from the data, but, in this analysis of children's participation, I'm not sure that distinction matters. What is significant here is that Emma had both the capacity and opportunity to act in accordance with what she wanted to do, and that her action was largely unimpeded by external authority.

I have included this brief story from Emma's account in order to illustrate that within spaces characterized by children's tangible contribution, children acted in accordance with their own wishes, often relatively uninhibited by impositions of adult authority. Obviously, this rather thin analysis does not take into account certain manifestations of adult authority and influences on Emma's agency that are unavailable in the story I heard. It could reasonably be argued that, in instances like this, children are never free from adult authority, that whether adults are present or not, their influence enters into children's thinking and acting. Interpreted this way, Emma's behaviour could be understood to take on tones of resistance. Nevertheless, at least to some extent, in the decision about whether or not to eat the banana split Emma acted in accordance with her own intentions and desires; her agency was substantial. It seems plausible that she was willing to trade off indulging in this treat with her friends, fully appreciating that she would need to "run and run and run and run" to take care of herself.

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[66]   Emma was referring to her blood glucose level, which was 14.3 mmol/L. For school-age children, normal values for blood glucose are approximately 4-10 mmol/L. A blood glucose reading of 14.3 mmol/L is high, and Emma describes the exercise she engaged in to try and bring her levels down.

Children's claims to authority sometime manifest in more subtle ways. I noticed this particularly in instances where a certain sort of resistance could be discerned. Ten-year-old Natasha had a life-threatening allergy, but rarely wore her allergy alert bracelet, although Natasha's father and mother were quite insistent that she should wear it. As is evident in the following excerpt, Natasha appeared to acquiesce to her parents' wishes, yet, while reluctantly agree to follow their instructions, she enacts a kind of authority through quiet resistance:

Dad: [Speaking to interviewer.] We got Natasha a MedicAlert™ bracelet and she doesn't wear it. We buy this thing, and they're not cheap—which is not the issue anyhow. But I mean it's important for her to have it. If something happens when she's walking the street, then somebody should know what's happening. And she doesn't—although she's very cautious about eating foods that anybody offers her—she doesn't take the same concern with wearing this MedicAlert™, and that's something I think she should.

Interviewer: [To Natasha] Why don't you wear your bracelet?

Natasha: I don't know.

Dad: She finds it uncomfortable. It's like wearing a watch. If you don't wear a watch for six months and then … you put it on it feels weird. But after a while you don't notice it at all, right?

Natasha: Yeah.

Dad: [Looking at Natasha.] It's something you should really work on doing, Natasha, because one day when you're found laying on a street—but if you're found laying there and you're not breathing, somebody may think you've had a heart attack instead of not being able to breathe.

The conversation continued in this tone for several minutes, Natasha's parents continuing to explain the importance of the bracelet to Natasha and the interviewer, while expressing their frustration that Natasha would not wear it:

Dad: And we've got her a nice bracelet now. Like, it's actually not a bracelet. We tried three different bracelets from MedicAlert™ and

	they kept getting busted … And we got her a nice one with a nice sports strap, Velcro, very easy to handle. It is copper, isn't it?
Natasha:	It snapped.
Mom:	It sort of—snapped.
Dad:	Oh, okay. Where is it?
Mom:	It gets put on in the morning and then she comes home with it off, at school somewhere along the line.
Interviewer:	Is it just because it's not comfortable that you don't like wearing it?
Natasha:	That's one of the reasons. I wouldn't bring it. I wear it to school, and sometimes it gets worn back.

In this interaction, Natasha's parents' claims to authority were at least threefold. They appealed to concerns for Natasha's safety and hinted at the problem of expense of buying unused bracelets. A related, perhaps more subtle, claim to authority was an undercurrent in their conversation, some notion that Natasha did not or could not fully comprehend the relationship between wearing a bracelet and her safety. In this conversation, Natasha's nominal efforts to describe to why she didn't wear her bracelet were largely dismissed; her view that her bracelet was uncomfortable did not achieve much status in the deliberations.

Natasha:	It's uncomfortable. Like when you're writing or something, that's what—before I never used—like, I never wore it. Well, I still don't. But when I was writing and it just really pushed, and then after I'd get marks all the way around my hands because—
Dad:	But would you try wearing it more?
Natasha:	Yeah.
Dad:	Get used to wearing it all the time, so it will become second—it would become—you could wear it all day long, you could wear it at night and it wouldn't be an issue at all after a while.

Natasha: Okay.

I think this rather lengthy example illustrates an important point: that children's resistance, however passive it might seem, is in some way an enactment of their agency. I don't pretend to fully comprehend the complex dynamics that underpinned this interaction between Natasha and her parents; history and relationship had roles in this story. On one hand, Natasha's participation in this dialogue is minimal, even stifled, yet her contribution to decisions about whether or not she wears her bracelet is significant.

In both the examples I have provided here, children acted largely in accordance with their own intentions and desires, in spite of (or perhaps, in the case of Natasha, because of) adult claims to authority. In each instance, children assumed a certain degree of authority. In an extreme manifestation of what might unfold in a space characterized by children's tangible contribution, it is conceivable that children's views could be uncritically accepted and that these voices might achieve full authority. If children were seen to possess full rights to autonomy, or if their wisdom was deemed absolute, the centre of authority would shift ever closer to the child. There may be hints of this possibility in certain expressed perspectives, such that of the mother of a 10-year-old child: "I think there's a wisdom there—she doesn't want it, I can't override it." However, there were no examples in the data that I could confidently interpret as instances in which adults relinquished all authority and children were, in that way, fully autonomous. This possibility exists as a theoretical outlier,[67] an extreme manifestation of children's voices resonating and achieving full standing in decisional matters. From my own experience and as confirmed in conversations with parents and expert clinicians, the possibility exists; there are instances where adults concede to children and are prepared to accept the consequences of

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[67]   Theoretical outliers are those plausible variations in patterns of children's participation that likely exist but that are not captured within this particular data set (McPherson & Thorne, 2006).

whatever the child decides. This theoretical possibility deserves inclusion if the purpose of this project is to develop knowledge that is reflective of a wide range of participatory possibilities.

Questioning existing authority

In the vast majority of children's accounts of their lives, structure and policy appear to be taken for granted, creating or constraining possibilities for the children to act in accordance with their intentions and desires. In rare instances, however, I noticed children's questioning of certain existing policies and structures. Unlike the earlier examples describing children's silence in policy decisions, these children contributed, albeit often in small ways, to the shaping of the structures that constituted their lives.

In one notable example, 11-year-old Nathan challenged the school practice of segregating children with peanut allergies from other children during lunch time. This practice was soon changed, and the eventual result was a shift in policy toward a "peanut-free" school. To be honest, I am unsure of how much of this effort was Nathan's alone and how much was a combined effort by Nathan and his parents. In instances like this, the relational nature of children's voices becomes evident, and what might be understood on first reading as a child acting on his or her own behalf, after further consideration is better understood in light of the relationships and history that shape children's intentions and capacities. Nathan's agency did not appear compromised by his parents' involvement; rather, his ability to speak on his own behalf was support by and through the work undertaken by his parents.

Sharing authority in space of children's tangible contributions

Two relational patterns characterized the space of children's tangible contributions; implicit in these patterns are particular notions about who children are and who they can be. More specifically, in this space of children's tangible contribution, the children's views had to be

in some way valued, and their standing in decisional contexts at least partially negotiable. As a

consequence, the sharing of authority was possible.

Valuing children's contributions

The sharing of authority that characterized this space was manifest in adults' orientation

toward children, often echoing a certain stance of openness to the children's capacities and a

curiosity about what children might think and want. Parents, in many instances, clearly

articulated the perspective that their children ought to have at least some say and that the

children's thoughts were important when it came to decisions that influenced their lives. One

mother, although convinced that her son should not always have full or final say, held a view that

hearing what he had to say was important:

> We have discussed everything with him now because he is 12 and he should know
> the final decision. If I feel that this is what's going to happen, this is what's going
> to happen. But he does have his say and I think it is important. I think he has to
> take responsibility or a hold of his own life.

Shades of the tension between adult responsibility and children's agency are evident in this

quotation; parents weighed their responsibilities to ensure the health and safety of their children,

while simultaneously holding in mind a commitment to foster their children's independence and

to respect their freedom.[68] On one hand, the mother making the statement above is claiming that

she has the final say. On the other hand, she holds a perspective on the importance of her son's

contributions, an awareness that her son must have the opportunity to take up his own interests.

In this way, negotiation in a place of children's tangible contribution was often messy, fraught

with contradiction and tension.

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[68] There was an undeniable hint of fear in this mother's voice; the weighing of responsibilities, and
commitments to ensure children have a voice were never fully separate from the worries about their
children's current state of health, and future well-being.

Assuming a stance of uncertainty

Adults assumed knowledge of what was best for children tended to limit the space available for children's contribution to decisions; a stance of uncertainty did the opposite. Parents not knowing what was best, grappling with various interpretations of the problems, entertaining various alternatives, created openings for the children's participation. In these places, adults inhabiting the space of deliberation demonstrated a degree of uncertainty about what it was that the child might want, need, or desire, or some uncertainty about what the best course of action might be. Other times, a sharing of authority was visible in the expressions of deep and abiding concern for the child. This position of uncertainty could be a place of tension for adults; in such cases, uncertainty was expressed as conflict between some understanding of their responsibilities as adults and a sincere respect for the child's views.

Ten-year-old Alexandra's mother recounted her struggle as she debated how to address her daughter's likely unrealistic intention to participate in a talent show:

> Like last year she wanted to be in the talent show—she's wanted to be in the talent show ever since kindergarten. And I thought, what is she going to do? She doesn't have polished skills. When I talked to the teacher about that she said, "Well, she's forming this little dance group and they're creating a dance at school." So then I thought, well maybe I should hire a dance teacher from the community centre and the girls could practice at my place on Saturdays and they could get a routine and it would look half decent, she wouldn't embarrass herself.

As events unfolded, Alexandra's mother did not intervene and supported her daughter's efforts. She went on to describe the outcome:

> Anyway, Alexandra just kind of carried on with her plans with her friends, and they pulled it off, they actually did it, and I was sitting in the audience just hoping that she wasn't going to embarrass herself. She did it and she didn't do any worse than a lot of kids and there…and she was so happy.

What I find interesting in this story is that while I would say that this is an instance of decision-making that might be within a space of children's tangible contribution, there is little

evidence of active negotiation between the parent and child. The child's views were clear and unambiguous, expressed through her action and words. The mother's deliberation took place away from the child, yet Alexandra had some agency, was granted standing in the decisional process. Alexandra actively contributed to the decision about whether or not she would be encouraged to participate in this talent show. The negotiation was characterized by a stance of some parental uncertainty and by a perception of the child as a person deserving of consideration and respect.

Children did not always get what they wanted, even when the space was evidently characterized by children's tangible contributions. The following story is important, because it illustrates the nuanced conversations that took place at certain times between children and parents, and the many and competing concerns that could find a place in difficult decisions. Eleven-year-old Kyle's mother was describing her heartfelt desire that her son be able to participate as fully as possible in physical activities and at the same time be protected from the consequences of overexertion. In her words, "Kyle is like a typical boy; he puts his all into everything. He wants to win too."

The decision Kyle and his parents faced was whether or not he would be allowed to continue participating in the track and field events of the ongoing Special Olympics. He desperately wanted to continue, but was experiencing pain and shortness of breath after each competition.

> And so every night after he would come home and go to bed and then he'd have a problem in the middle of the night. Every single time. Pain in chest, he has a headache or he can't breathe. My husband said, "I don't think he should be doing this." And then it was me going, "Well, you know, he really likes it. I don't want to take it away from him." Then him saying, "But, look at what happens during the night."

So we're back and forth, too, in thinking whether we should and then who's going to break that little kid's heart. Is it gonna be you or is it gonna be me?

And so I tried to sit down and reason with him and say, "You know what's happening at night." I said, "I really know you love doing this but how do you feel about it?" He just looked at me and said "I really don't like having the pain at night." So, I mean he kind of made that decision himself even though, I mean, it affects the whole family anyway because he's awake at night then everybody's awake.

Unfortunately, he loved it and so he was really disappointed. So that was difficult for him.

In the story that Kyle's mother told, manifestations of authority were somewhat difficult to distinguish. What is evident is the substantial consideration that Kyle's expressed intentions achieved. In a more complex reading of this story, Kyle's intentions appeared to be complex and competing: he wanted to be part of the Special Olympics, but he did not like the pain that he suffered as a consequence. The intentions of his parents seem remarkably similar: they wanted their son to participate in this activity and they wanted to support him to do so.; however, his suffering was difficult to witness, and the consequences for the family were significant.

A Space of Adults' Imposed Authority

In an incident first described in the previous chapter, Kyle wanted a brownie, but no matter how he protested and begged, no possibility existed that he would get what he wanted. In instances such as this, while children's intentions and desires were clear and discernable, those voices had little status. These spaces were characterized by adult imposed authority: adults held the balance of power, and their authority undermined the relevance of children's expressed views.

There are few instances in the data where, with confidence, I can declare that particular decisional processes were characterized by an absolute imposition of adult authority. This may

not be surprising, given the self-selection inherent in volunteering to participate, or the illustrative examples that parents chose to share with me. Perhaps the following example provides a glimpse at what such a case that might look like. This excerpt is taken from a segment in which a mother was describing her struggle to decide whether or not her daughter would receive growth hormone therapy. She was articulating her belief that, if she decided to proceed with growth hormone therapy, she would have no choice but to impose that decision upon her daughter through manipulation or force:[69]

> So if I was going to get those injections, that growth hormone into her … I think it would be really going against her bodily consent. And some parents do that. Some of them sneak up on them while the children are asleep at night and they give it to them.

The image of sneaking up on children and injecting them in the night is likely an extreme and particularly graphic example of what might be understood as adults' imposed authority. Based on this example, one might be tempted to assume that decision-making in spaces of adults' imposed authority is harsh and brutal (however rare these examples might be). Throughout the data, however, there were more subtle examples from which shades of adult imposed authority could be discerned. In these instances, parents' and health care providers' strongly held views rendered children's intentions and desires largely irrelevant.

Rules, routines, and tests: Components of a space of adults' imposed authority

In a space of adults' imposed authority, the standing of children's expressed intentions and desires was diminished, generally for the reasons that I detailed in chapter four: children's expressed intentions and desires might be deemed unreasonable, their ability to make considered judgements questioned, the risks embedded in various alternatives understood to be too great, or

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[69]   Of course, the very fact that this mother is holding in mind what she knows her child would want moves this decisional process outward from a the realm characterized by adult's imposed authority and more toward a realm characterized by children's tangible contribution.

their intentions subjugated to more pressing concerns. Whatever it was that undermined the relevance of the children's voices, in a space of imposed authority, firm boundaries partitioned existing authority and children's expressed views. Children's views, however expressed or represented, did not penetrate the adult-held authority structures that constituted the places of deliberation.

"So, as I say, I made some rules." These were the words of one mother as she described how she ensured her daughter's adherence to her diabetes management regime. Rules, routines, and tests at home and school were places where the partition between adult authority and children's expressed views were made visible. In the following excerpt, 11-year-old Jenna's mother described their process of decision-making as she and Jenna's father determined whether or not they would allow Jenna to go on a trip to another province. Jenna had expressed a clear and unambiguous desire to go on this trip, to attend a summer camp in province part way across the country. In this instance, the boundaries of adult authority were made explicit, formalized in a sort of test:

> When she shows her independence and her proficiency, she can go for week-long camps. There was a choice. She could go to [the province] by herself this summer, but she had to be able to prove that she could do everything independently. *She didn't pass the test.*

Jenna didn't pass the test. In this instance, Jenna wanted to go to camp; that intention had been made clear. In this place of decision-making, Jenna's intention could achieve relevance only if she passed the test—if she met some pre-established criteria against which her behaviour was judged. The perceived risks associated with poor diabetes control outweighed any argument that Jenna might make to defend her stance that she should go on the trip. Expressing her thoughts about this standard, Jenna said, "That's not fair," to which her father responded, "You can take it on Jenna. You can take it on any time you want. You can just do it and succeed."

As in Jenna's case, failing to respect the bottom line could result in certain imposed sanctions. Nine-year-old Scott's activity was severely restricted as he awaited surgery for his heart condition. One day, contrary to the rules that had been established, Scott was found outside by his brother, running and playing. In response to this situation, his mother commented:

> I had to ground him one day where I said, "look, you're disobeying Mom, you're disobeying the doctors, we're trying to keep you alive here before you have surgery and you go off and do this. That's it. You're in the house the rest of the day."

As in the cases of Jenna and Scott, there are many, many examples in the data of boundaries set by adults: expectations set in regard to how children ought to behave in particular circumstances, and conditions created where children's options were limited. For example, for most children with severe food allergies, scrutiny of ingredients before the child was allowed to consume any food was non-negotiable. And for children with diabetes, such as Emma, there were rules about what to do with high or low blood glucose readings:

> **Mom**: So what do you do when you're 2.7?[70]
>
> **Emma**: Take these little candies, all pure sugar. You have six if they're little and three if they're big. And you test in 15 minutes—wash your hands and test in 15 minutes and see what you are. If you're still low, you do the same thing … And then you wash your hands and if you're up, you eat lunch.

Is there really any decision when it comes to Emma's behaviour in response to blood glucose readings? Does Emma have any choice? Maybe, maybe not. But it is in these everyday accounts of entrenched rules and routines that limits set by the adults in children's lives are manifest. Although there is a bottom line that underpins most rules and routines, in many instances these rules provide important structure in the lives of the children. For Emma, what she would do when her blood glucose was low seemed rather taken for granted, or at least a part of a well-

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[70]   Emma's mother was referring to a blood glucose level of 2.7 mmol/L, which is dangerously low.

accepted routine. She didn't have a say in the parameters that surrounded this part of her life, and if she failed to follow the rules, or if routines were broken, certain sanctions might follow.

Children's positioning in a space of adults' imposed authority

Policies and practices in a space of adults' imposed authority tended to reflect some belief that children and/or their parents were incapable of reasonable judgement, or that the children were at risk of some harm that they or their parents might not comprehend. As the medical authority based in perceptions of wisdom moved further away from the child, the resonance of relevance of the child's and parents' voices tended to diminish and opportunities for participation diminished.

A view that kids don't understand

"But she's a kid. She doesn't care." These were the words of one mother as she described her daughter's sensibilities when it came to the vital issue of fluid intake. Eleven-year-old Shauna had renal failure; for that reason, her fluid intake was restricted, requiring careful monitoring. As she described her daughter's pleas to be allowed to drink extra fluids, this mother summarized her position: "They don't get it. They're just kids." In cases like this, even though children's views were accepted as reasonable in some way, the wisdom of those intentions could be understood to be limited by children's immaturity and inexperience. Whether implicitly or explicitly expressed, perceptions of children as immature and incapable of sound judgement could culminate in decisional processes in which children's expressed views achieved little or no standing, and where the boundaries separating adult authority and children's agency were firm.

Often, the authority granted to health care professionals created boundaries that reduced the potential for children's voices to achieve any relevance in certain decisional contexts. One

mother described her struggle in the early days following her child's diagnosis with osteogenesis imperfecta:

> [My son said] "Oh! My God I don't want this." But you kind of just go along with what everybody tells you … "Okay this is what you should do, that is what you should do." Sometimes it is not that the decisions are wrong but sometimes you don't feel that you are making them.

This mother described how, as she gained experience and expertise in managing her child's care and in working with health care providers, she became more able to hear her son and to attend to his views. In this way, under some conditions, authority could shift outward from the child and family and could come to rest in the expertise and positioning of the health care professionals. As authority moved outward, the relevance of the child's voice tended to diminish. In this case, as the mother gained confidence in her own knowledge and the knowledge of her child, authority once again moved inward.

Deciding whether or when to insert their authority was, for several of the parents in this study, clearly a matter of reflection and debate, and sometimes led to soul-searching about their beliefs about children and their role in relation to their children. In the following excerpt, 7-year-old Emma's father is describing his responses when a friend arrived at the house asking his diabetic daughter to buy some of the kool-aid she was selling:

> She knocked on the door and asked for Emma. So, I'm standing in the garage and listening to the conversation and she's trying to sell this kool-aid to Emma. So of course my immediate reaction is Emma can't drink that because she has diabetes, so I've labelled my kid, "the diabetic." And I'll walk away from the situation after the other child's gone, and I think, maybe I shouldn't interfere on behalf of my child. So it's hard to know when you should intervene and how much you do intervene.

I think that this is an important point, that the imposition of authority was sometimes the product of a parent's or health care professional's conscious deliberation as they weighed what they

understood as their responsibilities to protect and nurture the child against the consequences of an actual or potential choice the child might make.

The privileging of other voices

The following is another example of the triadic relationship between health care providers, parents, and children, and the consequences of the relative distribution of power within the relationship. In this segment from an interview with 11-year-old Leanne and her mother, the ascription of wisdom to medical authority undermined the child's standing. Leanne had osteogenesis imperfecta and, as a consequence, her bones were brittle and prone to fracture. Leanne wanted independence and resisted the stigma associated with taking the "special" bus to school. She had already expressed this sentiment and, as the conversation moved toward Leanne's experiences at school, her mother implied that Leanne should appreciate the generosity of the school in providing this service to her:

Mom: [to Leanne] And what else does the school do for you? What comes to pick you up every single morning?

Leanne: I don't like that part.

Mom: Yeah, but …but instead of you having to walk, right?

Leanne: But I'd rather walk.

Mom: Yeah, but Dr. S. says it would be too hard on your bones.

The privileging of an external authority, in this case the physician's view of what was best for Leanne, made the issue of transportation to school largely non-negotiable. Throughout my conversations with this mother and child, I noticed a similar tendency to privilege unquestioningly the advice of health care practitioners, and I wondered how that tendency limited the extent to which both mother and child were able to contribute to certain decisions.

In a space of adult's imposed authority, children's voices could be heard, but because those voices were deemed to be unreasonable or insignificant, children could not achieve status in decisional processes. Children's voices diminished in status when the children's capacity to make reasonable judgements was called into question, and when voices somewhat external to the decisional process were granted authority.

A Space of Adults' Assumed Responsibility

A space characterized by adults' assumed responsibility appeared to resemble, at least on the surface, a space of adults' imposed authority. In both, adults were the primary decision-makers, and in both, individual children's views were not well accounted for in decisional processes. Key differences, however, existed. In a space of adults' assumed responsibility, although children *appeared* to hold standing as unique and respected human beings in decisional processes, for various reasons, children's voices were muted. Perhaps the most obvious examples of decisions within this space existed where children were too ill to formulate and express intentions and desires, or where, because of cognitive or emotional immaturity, they were deemed unable to comprehend the nature of certain decisions. In a space of adults' assumed responsibility, children's interests are represented by adults (usually parents) as they endeavoured to make decisions on behalf of the children.

Representations of children in a space of adults' assumed responsibility

In a space of adults' assumed responsibility, children's participation was restricted. Children were not invited or were unable to enter into decisional processes. They depended on parents, teachers, and health care providers to represent their interests in places of decision-making. Parents often advocated for their children. Many times the children were unaware of the issue or debate in which they were being represented; sometimes children were aware of the

issue, but uninvolved in the discussions. In these places, all the complexities of parents'
representations of children's intentions that I detailed in chapter four become visible.

The work of certain parents and health care providers to represent children in the fight for
resources provided vivid examples of adults' assumed responsibility. Parents advocated for their
children to ensure that their children held standing at school, in the clinic, and in health care
policy decisions. One mother devoted endless hours to accessing a medication that her child
needed, a medication not yet approved by Health Canada, and not funded by any source. This
medication was accepted in other parts of the world as an effective treatment for her son's
condition, reducing the progression of symptoms, potentially prolonging children's lives. At the
time of data collection, her son, 8-year-old Jarod, had been accepted into a clinical trial
conducted by the drug company, who thus covered the cost of the medication. Within 6 months,
that trial would be complete, and the prohibitive cost of $300,000 per year would fall on the
shoulders of the family. The work of this mother and the child's physician to access the drug was
extensive. In spaces of adult assumed responsibility, adults in children's lives took on, for
various reasons, the work of decision-making, and children were not invited to directly
participate in decisional processes.

Protection and nurturance in a space of adults' assumed responsibility

In the data, there were several examples of times where parents or health care providers
believed that children could not or should not contribute to certain health decisions, however
respected those children might be. There were instances where children were too ill to
comprehend what was going on, and there were times when the children seemed to be limited in
their capacities to comprehend certain problems. Importantly, within the accounts by parents
there was a subtle suggestion that there was something morally questionable about drawing
children into decisions where their ability to comprehend was limited and where, because of that,

their input would not likely be taken into account. While these children inhabited an important position in decisional processes, their voices were muted.

Deciding for the child

In the following excerpt, 10-year-old Alexandra's mother is describing a difficult decision regarding whether or not Alexandra should commence speech therapy. This mother did not include Alexandra in the decisional process, because she believed that her daughter could not adequately comprehend the nature of the problem. Alexandra's mother believed that, for that reason, Alexandra's view (which would likely be against the commencement of therapy) could not be reasonably incorporated into the decisional process:

> She doesn't hear that her speech is [sometimes incomprehensible] and that's part of her problem. What she's hearing … it all makes sense to her. It's not like she's not producing the sounds that she thinks she hears. To me, that decision definitely falls into my realm.

In this instance, Alexandra's voice is (literally), at best, faint. While she was not consulted, it could be reasonably argued that she held significant standing in the decisional process.

Somewhat similar to the previous example were those instances in which children were shielded from certain decisions, where adults endeavoured to protect children from perceived harms. Whatever the foundation of beliefs about the need to protect children, in these instances, the consequence was that children were neither aware of the problems and the decisions, nor were their opinions elicited. In the following example, a mother described her decision-making process regarding adjustments in 11-year-old Jenna's insulin dosage through her insulin pump.[71] This mother was very clear that these decisions ought not to fall on the Jenna's shoulders; it was a responsibility that she, as a mother, assumed:

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[71] Insulin pump therapy uses a battery-operated, external pump, which is about the size of a pager. The pump continuously delivers fast-acting insulin under the skin through a catheter, inserted using a small needle, which may be removed, leaving only the catheter or tubing under the skin.

And you know I'm the one who makes the decision to boost the basal rate if she's going through a growth spurt or she's sick or something. So I make the adjustments to the basal rates. Jenna is not involved with that at all.

Although this mother seemed quite confident in her decision that she should control her daughter's insulin dosages, other parents expressed more ambivalence about how and when to assume responsibility for decisions in their child's health care.

Deciding whether or not to involve the child

Another, more subtle category of decisional processes that might fall in a space characterized by adult's assumed responsibility involved those decisions where adults struggle with how they would approach decision-making with or for their child. Parents' accounts were full of these kinds of quandaries: descriptions of their struggles to craft an approach to their children that would be congruent with their beliefs about parenting, chronic illness, and their child. By the very nature of many of these decisions, children could not be directly involved. Parents grappled with decisions such as whether or not to encourage their children to participate in certain activities, or whether or when to inform their children about certain diagnoses or risks.

In the next excerpt, 11-year-old Kyle's mother was describing a new treatment in Kyle's care, one that would have a significant impact on his daily life and that would involve daily needles. This mother and her husband had to decide how and when to inform Kyle of this treatment. In a sense, they grappled with the moral problem of how to respect Kyle as a unique human being, to include him in a decision that will greatly affect his life, and yet protect him from undue fear and anxiety. These were her words:

> We're kind of toying with how we are going to [tell Kyle] and how to make it easier for him to understand that. And I think a lot of times he gets nervous because he doesn't really understand, so helping him understand —that is always a concern for us because we don't want him to panic. He has tendency to get anxiety. We've seen that before and so it's not worth it for us to panic him.

I don't think there could be any doubt that these parents' orientation toward Kyle positioned him as an important contributor within the decisional process. The decision the parents faced was how and when to inform him about this difficult treatment.

As in the above story, protecting children from worry, sadness, or pain underpinned many of the parents' decisions. Eleven-year-old Lucas's mother described her struggle to decide how and when to inform Lucas about the very recent death of another child that Lucas knew well, a child who had a condition similar to Lucas:

> [He has often asked] am I going to die, am I going to die? He always asks me that now. I try to reassure him. I've never said anything negative to him. I'm always thinking maybe [he will die]. I haven't mentioned to Lucas. You know, I don't know if you've heard [that the other boy died]. I wouldn't know what to tell him yet. I don't want him to worry.

In instances like this, parents faced decisions that only they could make, decisions that, by their very nature, could not include consultation with the child and yet necessarily incorporated the parents' understandings of their child and the child's capacities.

In this space of adults' assumed responsibility, while children's wishes and desires may have been considered highly relevant and important, and children held certain status in the place of decision-making, what the children wanted in relation to particular decisions was largely unavailable within decisional processes. Children's voices were sometimes muted by illness or perceived immaturity, but many times by the nature of the decision itself. In these places, children relied on representation by others who knew them well.

Summary

Throughout chapters four and five, I have illustrated how, for the children in this study, participation in health care decision-making was, first and foremost, a complex and multifaceted activity. Narrow interpretations of participation failed to do justice to the complexities of health

care decision-making in the lives of the children and their families, tending to extract children from the temporal and relational contexts wherein their intentions were formulated and though which those intentions were expressed. In this analysis, I have proposed a more robust conceptualization of participation, one that takes into account the physical, familial, political and social influences that shaped and constrained the children's opportunities and capacities to participate in decisions.

In this chapter, I have begun the project of portraying children's participation as shaping and being shaped within moral or social spaces. Voice and standing interplay, resulting in spaces variously characterized by children's silence, children's tangible contributions, adult imposed authority, or adult assumed responsibility. This view of children's participation, however blunt it might be in its depiction of children's and parents' experiences, makes visible certain sites wherein health care providers may hold responsibility. Difficult questions arise: What is morally relevant about the structure of and dynamics within existing spaces of decision making? What responsibility do health care providers and policy makers hold as architects of participatory spaces? These are questions I take up in chapter six.

CHAPTER 6

CHILDREN, PARTICIPATION, AND HEALTH CARE DECISION-MAKING

Given that I entered this project explicitly interested in the moral status of chronically ill children, it is hardly surprising that much of the findings presented in chapters four and five centre on my interpretations of the positions of children in decisions and decision-making, and depict dimensions of those processes that are constitutive of children's standing. In this analysis addressing school-age children's contributions to health care decisions, however, significant shifts occurred, resulting in a re-evaluation of what I understood as children's participation; a rethinking of what constituted decisions and decision-making in children's health care; and perhaps most importantly, a re-conceptualization of what it was about concepts of participation and decision-making that may be important in the ethical analysis of children's participation. In this chapter, I explore some of the implications of these shifts in thinking.

Before I go on, I want to clarify where I am locating the findings of this project within the broader field of knowledge and knowledge development for health care policy and practice. The findings from an interpretive descriptive project become knowledge when those interpretations are explored in light of existing health care practices or policy and as they are tested for their utility in informing those practices or policies.[72] To some extent this process began in the research process itself, as early interpretations of the data were tested against subsequent data; interpretations were then evaluated by expert nurses who, in thoughtful responses to the interpretations I was developing, judged the "fit" of the findings. My project in this chapter, then, is to continue my examination into how the interpretations I presented in

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[72] This perspective on knowledge generation is rooted not only in how I have come to understand interpretive description as methodology, but also in the pragmatist foundations of the research question itself. Pragmatism demands that, in our knowledge development efforts, that we not lose sight of the problem that brought us to the project in the first place. Holding the problem in mind was vital in this project, particularly as the data (and my analysis of it) challenged the adequacy of the foundational concepts of participation, decisions and decision-making.

chapters four and five might contribute to the knowledge that nurses and other health care providers draw on as they endeavour to deliver ethically sound health care to children with chronic health conditions. To achieve this, I concentrate on aspects of the two foundational themes within the findings: (a) the question of participation—what it is and why it matters what we believe it is; and (b) the features of the moral spaces of participation, and how attending to these might lead us to imagine and shape health care policy and practice with and for chronically ill children.

I began this project believing that (a) children ought to be full members of our human community, and their voice in matters that are important to them matter; (b) for many reasons, children are a vulnerable group, their voices may be easily dismissed and suppressed; (c) because of their illnesses and the treatments associated with those illnesses, children with chronic health conditions may be a particularly vulnerable group, and; (d) in regard to all these matters, adults have certain moral responsibilities. This perspective stands, but through this project my thinking about these matters has consolidated, and I have come to understand participation itself in a very different way.

Toward a Moral Understanding of Children's Participation

At the outset of the study, I understood children's participation in health care decision-making as a marker of children's status, a site where adults' beliefs about children's autonomy and agency, their rights and interests, would be made evident, and where the influence of these beliefs on children's opportunities and capacities would be revealed. The research questions reflected my curiosity about the multiple influences on children's participation, including those arising from adult perspectives on children and their interests, and those that might rest in the social, economic, and political contexts where decisions unfold. As I proceeded, I encountered

some very challenging questions, questions that at times seemed to undermine the very foundations of the project.

As the project progressed, I began to more fully appreciate that all health care practice with or for children can be understood to be linked to values underpinning notions of participation. In this process of inquiry, my thinking has been challenged and guided by conversations with scholars who have grappled with ethical questions of human subjectivity and health care practice,[73] and by certain authors within the disciplines of nursing (Liaschenko, 1997; 1999), human geography (Aitken, 2001; Crooks, 2006; Smith, 2000; Valentine, 1996) and education (Masschelein & Quaghebeur, 2005). In addition to these, the work of Walker (1993, 1998, 2003), as she inquires into the nature of moral life, and as she carefully critiques notions of vulnerability and responsibility within the moral spaces of human existence, has been enormously helpful.

Why We Should Care about Children's Participation

Morality is about mutual understanding and habitable ways of life.
Margaret Urban Walker (1998, p. 6)

Repeatedly in our literatures, where theoretical or empirical arguments for children's participation are advanced, certain phrases paraphrasing Article 12 of the UN Convention on the Rights of the Child (United Nations Children's Fund, 1989) appear. "Children have the right to be consulted," "children have the right to have their views taken into account" or variations on this theme anchor and justify arguments for children's inclusion in various domains; whether health care, school, or family life. Although participation is generally held as a unquestionable good, I think the findings of this study support a critique of our assumptions about why is that we

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[73] I want to acknowledge my dissertation supervisor and committee members here, who in different ways and at different times, posed questions or thoughtful alternate understandings, challenging my thinking and unsettling my existing analytic frames.

are concerned about children's participation, and what it is that we hope to achieve in our efforts to enhance the inclusion of children in matters of importance in their lives.

This question of what it is that we are hoping for in our moral deliberations has fuelled many recent debates in the field of ethics, deliberations about what it is that we think our empirical and theoretical projects can provide. When I think about what kind of moral thinking will enhance practice with chronically ill children, I realize that underpinning my answer to this question is a belief that what is right and good cannot be understood outside of knowing something about the contexts where practice takes place, and an acceptance that there is no "compact, propositionally codifiable, impersonally action-guiding code" (Walker, 1998, p. 7) by which to judge adequate moral behaviour. Rather, morality sits in the places where humans engage in the matters of their lives; where they exist in relation with other humans and with their environments; and where individual intentions, abilities, and capacities encounter possibilities and constraints. Our concern, then, is how we can understand the complexities of these places, creating and shaping them in ways that enable human beings to live a good existence, however defined. So when it comes to chronically ill children, moral deliberation is not only about whether they have a say in matters that affect their life, but also about the more complex issue of how children gain entry into the spaces of decision-making they have a right to co-construct.

Positioned this way, my inquiry into chronically ill children's participation in health care decision-making becomes an inquiry about the *habitability*[74] of those places of decision-making. What is important about participation rests in an understanding of what is good for children and their parents, and the corresponding responsibilities that health care providers and policy makers might hold? Depicting participation in this way deflects the emphasis away from some of the

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[74]   By *habitability*, I am referring quite broadly to the extent to which those places of decision-making are fit and good to exist within.

traditionally held moral concerns—judgements of competency, discernment of interests—and

toward a more relational and contextual view of children's contribution to decisions and

decision-making. It shifts our gaze from the qualities a child might or might not possess and

toward the moral and social realms where authority and agency are enacted.

Of course, what creates a morally habitable place of decision-making can be understood

in very different ways. Questions of the good in participation, and how contribution to decisions

benefits children, can be answered quite differently from diverse standpoints. The diversity of

perspectives is captured by Sinclair (2000) in her analysis of the range of theoretical and

empirical projects addressing children's participation. Justifications for children's participation

include the following intents:

- to uphold children's rights: children are citizens and service users and share the same fundamental rights to participate as other

- to fulfill legal responsibilities: the right of children to be consulted is included in the UN Convention on the Rights of the Child

- to improve services: consulting with children enables services to be improved and adapted to meet changing needs, which children can help define; participation gives them a level of influence and an element of choice about the provision offered and can help them understand their own wants and needs

- to improve decision-making: participation leads to more accurate, relevant decisions, which are better informed and more likely to be implemented

- to promote children's protection: participation is an important aid to protection

- to enhance children's skills: participation helps in developing skills useful for debate, communication, negotiation, prioritization, and decision-making

- to empower and enhance self-esteem: effective participation can provide a sense of self-efficacy and raise self-esteem (p. 1-2)

This list clearly echoes much of what I heard from parents and health care practitioners in this study. All are arguably laudable reasons to be concerned about children's participation, and may provide sufficient justification for fostering children's participation in many instances. What is evident to me, however, is that children's participation is being asked to serve many purposes, yet sometimes these purposes are incompatible with one another; certain discourses of participation deflect attention toward other priorities, such as children's growth and development or adults' legal obligation, obscuring attention to the moral contexts of children's lives and the habitability of their everyday existence.

For these reasons, I believe that attention to how we orient our efforts to foster children's participation is vital, and that we need to be clear about our motivations. Failure to do so may serve to reproduce and entrench certain notions of children and childhood and generate corresponding views of adult responsibility that undermine children's existence as embodied beings, persons with standing in a complex world.

Why a Limited Concept of Participation Might Cause Harm

Several authors have argued that many existing theoretical perspectives on children's participation in general (Arneil, 2002; Masschelein & Quaghebeur, 2005; Vandenbroeck & Bie, 2006), and children's participation in health care decision-making in particular (Alderson, 1994; Carnevale, 2004), have their roots the values of liberal individualism; they see these origins as having fundamentally shaped prevailing views of what constitutes participation, including justifications for why children's participation might be a good thing. With its roots in notions of rights, and with the autonomous individual firmly entrenched as an ideal, the word "participation" seems to have become some sort of proxy for evidence of an ideal human existence: a free-thinking, rational being who is capable of formulating independent intentions, expressing those intentions, and who has the capacity to, on the basis of such rational thought,

influence decisions and generate change. This view of participation draws attention to concepts such as children's competence, autonomy, and moral development, but, as I articulated in the findings, renders irrelevant many of the complexities of decision-making with or for chronically ill children.

This privileging of the rational, autonomous being of liberal individualism has been attacked within various philosophical projects, most obviously perhaps, from within feminist camps (Alcoff, 1991; Gilligan, 1993), but also by philosophers from poststructural (Foucault, 1970) and pragmatist (Bernstein, 1992; Rorty, 1999) traditions. These thinkers have called the adequacy of the individualist view of the ideals of human existence into question, and have articulated various harms that result from the dominance of this view. Because of their lack of autonomy, and their not-yet-rational status, children occupy a very limited and restricted place in liberal theory. Arneil (2002) summarizes the position as that of "citizens in waiting."

> The role children play in … liberal theory is one of citizens in waiting, human beings who do not yet possess the necessary attributes of citizenship, namely reason, autonomy, and the capacity for having authority over oneself, but will possess them in the future … Children are not ends in themselves but rather creatures in the process of development. (p. 70)

Other analyses suggest that the obsession with growth and development of children that has developed during the past 75 years has direct links to the idealization of this rational autonomous being, rendering childhood a time for education and training to create these kinds of people. In a compelling analysis of policy in Norway, Kjorholt (2002) argues that the UN Convention on the Rights of the Child and the resultant theory and research addressing children's participation are firmly grounded in these ideals of the rational autonomous, and that these values are manifest in discourses of "normal" childhood and "normal" development (p. 70).

This project was not intended as critique of various views of the subjectivities of children and the implications of these views for children's opportunities and capacities to contribute to the matters of their lives. These notions of children and childhood, however, have clear implications in analyses of the social and political dimensions of the space wherein decisions unfold. As I entered this study, I held a notion that children's participation may well be relationally shaped. At that time, I drew on the work of Sherwin (1998), who depicts human autonomy as developed and shaped within relationships, and influenced by social structures. From this vantage point, I was, from the outset, interested in complex renderings of the concept of participation, in questioning certain assumptions about the limitations of children's autonomy. My finding that the children's voices were manifest in their own expressions but sometimes also through the expressions of others, that children spoke through silences as they did through words and actions, and that, in many instances, making sense of children's participation required attention to the relational context including the history of their relationship with parents and health care providers, supports a relational and contextual understanding of children's participation.

Conceptual challenges in enacting a vision of participation

Throughout recent years, academics and children's advocates from many sectors have claimed that, in spite of our supposed commitments children's rights (of which participation is one), we have progressed little in our efforts to foster children's opportunities to contribute to matters of their lives, either at the individual level or at the level of service development. For example, when it comes to school-age children with chronic health conditions in our province of British Columbia, children's participation appears largely absent from the agendas of the three governmental departments that seem to have the most influence in the lives of these children with chronic health conditions: the Ministries of Health, Family and Child Development, and

Education.[75] Similarly, there is little evidence that children's participation is a priority for formal workings of the professional bodies for nursing or medicine. Even in response to governmental commitments to the enhancement of children's rights, including the participation of children in decisions that affect their lives (Government of Canada, 2001, 2004), policy and practice guidelines that might promote participation are few, and those that exist are largely underdeveloped.

This relative silence at a governmental and service delivery level on the topic of children's participation is important, and I suspect that it is grounded in something more than a lack of commitment or resources. It may be that the standstill on this issue reflects persistent tensions embedded in conventional views of participation, some of the same tensions that manifest in the analysis of this study. I find it interesting that our experience in British Columbia, while similar to most other North American jurisdictions, stands in apparent contrast to efforts underway in Europe, specifically in the United Kingdom (UK), where the federal government has taken up the "children's agenda," establishing a framework of core principles for children's involvement across all government departments (Children and Young People's Unit, 2001).[76] In the UK, all government departments are required to document their efforts to create conditions for children's participation and to account for children's inclusion in these policies and practices (for the implementation of these principles in the UK Department of Health, see Department of Health, 2002, 2003).

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[75]   In British Columbia, our commitment to children's participation has progressed little beyond the key guidelines of the Convention on the Rights of the Child (United Nations Children's Fund, 1989). Although these guidelines are echoed in the Infants Act (Government of British Columbia, 1996), these principles have been given little attention in the development of policies for health care delivery or in guidelines for work with children and families.

[76]   The core principles established to guide policy makers include that departments must (a) show that "a visible commitment is made to involving children and young people, underpinned by appropriate resources to build a capacity to implement policies of participation" (p. 10), (b) demonstrate that children's participation is a value and priority, and (c) develop approaches where children have equal opportunity for involvement (Children and Young People's Unit, 2001).

The corresponding body of empirical and theoretical research emerging from the UK experience provides evidence of the many tensions that challenge enactment of the children's participation agenda. While there are documented examples of substantial and effective work to enhance children's participation in various domains, this movement remains subject to the critique that efforts to foster children's participation have been only selectively and partially successful (Franklin & Sloper, 2005). Researchers, policy makers, and practitioners continue to grapple with persistent questions of what exactly they mean by children's participation, whose interests are being served when participation is held as an unequivocal good, and, of course, how to proceed in fostering disabled[77] children's participation in decision-making (Franklin & Sloper, 2005, 2007; Mayall, 2006b; McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006).

While there is much that we can learn from the UK experience, what I have come to understand in the current study leads me to wonder if the views of decision-making and participation embedded in much of the existing theory and research may be restricting possibilities, constraining rather than enhancing children's agency in certain circumstances. I am concerned that the discourses of participation and inclusion have become weak proxies for the larger, more morally significant issue of the standing of children in society, health care, and everyday encounters, thus uncritically reproducing conditions that limit children's and families' possibilities, constraining children's agency. This raises once again the question of what it is that we are looking for when we look for children's voices, when we advocate children's participation, and when we idealize participation as a marker of a civil society. From a moral perspective, I think there are many questions that we have left unasked about how children's participation is related to the habitability of their lives.

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[77] I used the term *disabled* here because, in much of the literature from the UK, this term is used as an umbrella term for children with a variety of conditions, including chronic health conditions.

Challenging the perception of participation as an unequivocal good

A limited view of participation, particularly one uncritically grounded in an idealization of the autonomous rational individual, may be an insufficient foundation for moral work designed to ensure children's standing within decisions and the important matters of their lives. If our moral responsibilities include, as I believe they do, ensuring that children's voices are heard and that they occupy and important and substantial place in the matters of their lives, then notions of participation may find a place in deliberations about what is right and good in our practice with children and their families. However, I think that there is substantial evidence that participation, particularly when understood as certain kinds of action or as an identifiable end point, ought not to be uncritically held as an unequivocal good in and of itself. The problem lies largely in two domains. The first is that the language and rhetoric of children's participation can be used to serve many purposes, not all of which are morally defensible. The second is that, in holding a limited notion of participation as the measure of ethical practice with children, we risk being blinded to other manifestations of uninhabitibility of the places of decision-making with children.

As I have already said, much hinges on the view of children and childhood that underpins beliefs about and concepts of participation. Embedded within any conversation about children's participation is some notion of what or who children are and, correspondingly, their place in the world. The findings of this study suggest a view of children as embodied beings, persons who hold intentions and experience certain desires, the formulation and expression of which unfold in complex relational contexts. These relational contexts are characterized by enactments of authority, and in almost all cases, adults are the gatekeepers into places of participation. Failing to account for these complex contexts restricts what can be seen and what might be considered relevant or important in analyses of children's contributions to decisions.

Existing research exploring chronically ill children contributions to health care decision-making varies in the concept of participation adopted, and in the notion of children that underpins those projects. Much of the research appears to adopt rather uncritically views of children's participation as an unequivocal good, a view that serves as a launching ground for a search for the evidence that participation does or does not exist. Generally, these studies have tended to measure participation on the basis of observable behaviours, or accounts of parents regarding the existence of such behaviours. For example, in their program of research with hospitalized children and their families, Runeson, Hallström, Elander, Hermerén, and Kristensson-Hallström (e.g., Hallström & Elander, 2004; Runeson, Elander, Hermerén, & Kristensson-Hallström, 2000; Runeson et al., 2002) rely on "observed events, behaviors, words and sentences" (Hallström & Elander, p. 369) to make judgements about children's participation or non-participation. Through observation only, these researchers judged children's contributions to decisions on the bases of the nature of dialogue observed, the extent to which health care providers apparently cared about children's concerns, and the degree to which the health care providers acted in accordance with children's wishes (Runeson et al., 2002). These kinds of observations are unquestionably important in assessing children's contributions to decision-making, but clearly rely on a notion that participation can be objectively observed outside of an appreciation of the relational contexts where it unfolds.

In a recent inquiry into children's participation in care within hospital settings, Coyne (2006) collected and documented instances where children were present during discussions about their health care but evidently were not included. On the basis of those examples, she makes a claim that a particular behaviour—discussing children in their presence—is a violation of children's rights: "The discussion of children in their presence, often with only minimal effort to involve them, clearly demonstrates who is in control and whose decisions matter" (p. 66). Few

would dispute that discussing children in their presence may reveal an imposition of adult authority and provide evidence of a disrespect for the personhood of children, undermining their subjectivity; however, I think we make a mistake when we suggest that such behaviours are always misguided. As I documented in chapter four, in my encounters with and observations of children in this study, significant evidence existed that the children contributed to decisions without saying a word. Sometimes adults engaged in conversation and discussion about important matters where the child was not involved, but where I would suggest there was no evidence of disrespect or dismissal of the child. The complexity of such interactions must be taken into account and, I believe, our analyses must be directed toward the questions of moral significance that might reveal motivations, assumptions, and constraints within decisional contexts rather than interpretations limited to observed behaviours of children, parents, and health care providers. In the example of instances where adults might have a conversation about a child when the child is present, the crucial questions might be "What is the standing of the child in this place?" "How is the child being represented, and by whom?" and "Who controlled access to participation in the decisional process?" Behaviours and actions on the part of children and adults will be clues to children's voice and standing, but reveal only a piece of the larger picture of children's participation.

What is at stake is that in narrowing our targets of interest through limited conceptions of participation, or through assumption that children's participation is revealed in a set of observable behaviours or actions, we might (a) mistakenly assume that we understand what is important about a particular decision to a child or parents, (b) rely on limited or faulty interpretations of children's expressions in judgements about what children want, or (c) misjudge the nature and extent of a child's contribution, failing to account for the broader relational contexts that shape the participation space in any given instance. A further danger lurks in

uncritical assessments of children's participation, where misguided notions of the concept may become entrenched practice guidelines or policy measures. Such an approach would stand in opposition to the findings of this study, which highlight the historical and relational dimensions of children's contributions to decisions. The findings remind us that, as health care providers, we will only ever have limited and partial access to children's and families' experiences; nonetheless, in spite of incomplete knowledge, our practices may shape the moral spaces of participation in significant ways.

Herein lies an important choice that we face: a choice that has implications for how we enact such basic principles as children's participation in matters of health care decision-making. The choices are about who we believe children are in this world, what standing we believe they ought to hold in decisional processes, and how, as nurses we understand our moral responsibilities to children who live with chronic illness. A view of children that holds childhood as time of becoming fully autonomous individuals, and children as separate beings whose rights, interests, and needs can be understood in a disembodied and decontextualized way, will take us down a very different path than a view of children as co-citizens in a complex world, as embodied beings whose existences are embedded within relationships, culture, and history.

What We Need in a Concept of Participation

My early analytic efforts to isolate decisions and locate evidence of participation within those decisions rendered most of what children had to say, and many of their activities within the research encounters, irrelevant. And yet children were talking about what was important to them, and illustrating much about their place in matters that they cared about.[78] In order to come to

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[78] There is, no doubt, a separate design and methods issue here. In these arguments, I am focusing on how conceptual views influenced what could be seen: the question of what was available to analysis could also be asked. I began to tackle this question in chapter three, but it remains an important issue for further reflection and analysis.

understand this problem as more of an analytic challenge than a data collection problem, I found it necessary to scrutinize my assumptions about decisions, decision-making, and participation.

Key to advancing the project of including children's participation in chronic illness decision-making is the critical question of what fostering participation is supposed to accomplish. If children's participation is but one of many manifestations of children's moral status in our communities, then I believe that this is an important conversation that must also take place.[79] On the basis of what I have learned in the conduct of this study, I believe we need a concept of participation that begins with inquiry into what it means to accept children as fully human beings, as people who live in and experience the world through their bodies, and whose expressions and intentions are deeply embedded in the relational contexts, histories, politics, and economics that constitute their lives. Given this orientation toward children and their place in the world, the notion of what is morally relevant about children's participation shifts, and the kinds of questions we are led to ask about instances of chronic illness decision-making change.

The morally relevant questions, then, have less to do with the particular actions and the specific language used when we observe encounters between children and their parents, or children and health care providers, than with the extent to which the child's intentions and desires might be represented in the place of decision-making and the standing that the child holds in the decisional process. We might look for participation in manifestations of representation and standing, rather than in the specifics of language and action. The question is not "What did the child say that he or she wants?" but rather, questions such as "What representation of the child's intentions and desires was manifest in the decisional process?" or "On what basis do we believe

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[79]   In a way, questions of children's moral status are the fodder of basic philosophy, embedded in questions that have perplexed thinkers throughout our history, and about which we are not likely to reach consensus, yet motivations for fostering participation, including how we understand what counts as participation, rely on some notion of who children are and what position we believe they do or should occupy in our societies, and therefore become central questions.

that the presentation or representation of the child's intentions is an authentic indicator of what

the child might want?" These kinds of questions and the analyses they prompt may provide

important guidance for understandings of health care policy and practice, and assist in

determining what the concept of participatory space might offer. We need a perspective on

participation that attends to the capacities of individual children, to their unique circumstances

(including their illness and its treatment), while simultaneously acknowledging that such

participation and its activities do not reside in particular people or their capacities, nor in

particular structures and institutions. Rather, participation might be understood as unfolding in

relational contexts, shaping and shaped by the physical, social, and political realms where

decisions unfold. Activities intended to foster children's participation, then, are moral practices,

or, in Walker's (1998) words, "practices of responsibility" (p. 16).

Health Care Practice and Policy within Participatory Space

As I explained in chapter five, the interpretive concept of participatory space is an

analytic device intended to support simultaneous attention to the multiple influences that shape

children's contributions to health care decision-making, and that highlight the contextual and

relational nature of children's contributions to decisions. It reflects an effort to minimize the

dichotomization of the notions of children's voices and their standing, children's agency and the

structures of their lives, and to create a means for attending to key elements of both these notions

in particular instances where decisions unfold in chronically ill children's lives. This concept is

my interpretive response to the observations that, for the children in this study, participation was

a far more nuanced and complex activity than is generally understood; that expressions of

children's intentions and desires, and the standing achieved by those expressed views, transpired

within the influence of the physical, social, and political realms wherein they unfold; and that

making sense of those realms was vitally important in understanding children's opportunities and the constraints on their agency.

The moral spaces of participation, then, are not static locations nor, for that matter, locations at all in the conventional sense of the word. These are realms within human existence that shape the habitability of chronically ill children's lives. Everyday choices in the lives of chronically ill children can be understood to unfold in this space: a space structured and shaped by a multitude of factors, some particular to individual children, others more systematic in their influence, and always imbued with power. For the children in this study, their physical abilities, their previous experience, school policies on inclusion, the availability of certain therapies, the patterns of communication with the family, and the economic resources of families are among the diverse influences in this space. There are, then, many architects of this space: children themselves, parents, siblings, nurses, physicians, therapists, teachers, policy makers of all sorts, and others.

The central questions that arise have to do with how children enter into the participatory spaces, how the conditions that exist in those places may invite or exclude certain children. What do children have to do to gain access to and sustain standing within these spaces? The starting point is, I believe, an understanding that children's participation is deeply embedded in relationships, shaped within the dynamic contexts of their lives. Analysis of children's contributions to decisions through this perspective of participatory space has implications for how we come to understand the circumstances of particular children and their families, and, correspondingly, what we might see as our responsibilities toward them. A view through participatory space may inform our theoretical projects, including the influential discourses of informed consent and family-centred care, and provide certain guidance for our uptake of knowledge in these areas into our policy and practice with children and families.

<center>**Practices of Responsibility**</center>

Walker (1998) locates morality "in *practices of responsibility* that implement commonly shared understandings about who gets to do what to whom and who is supposed to do what for whom" (p. 16). These practices of responsibility reveal what is valued in human encounters, and make evident the standing of individuals within the social order. Understanding the work of nurses and other health care providers as practices of responsibility invites reflection on a range of issues related to children's participation, opening up rather than narrowing the scope of relevant contextual details.

Shaping participatory spaces

In the data of this study, features of participatory space varied widely when it came to the contributions of school-age children to the matters that are important in their lives. To capture some of this variation, I depicted four variations in participatory spaces: a space characterized by children's tangible contribution, a space of children's silence, a space of adult imposed authority, and a space of adult assumed responsibility. Although many important nuances may be lost in labelling possible "kinds" of participatory space in this way, this method of thinking about children's participation lends itself to certain questions about what sorts of participatory spaces may exist in certain instances and, correspondingly, what sorts of participatory spaces ought to exist. Participation is not all or none, nor it is uniquely located only in the child or only in the context. From a theoretical view of participatory space, any analysis of particular children's participation must attend to both voice and standing: to the resonance and the deemed relevance of children's voices.

A conceptual view of children's participation through a lens of participatory space supports thoughtful consideration of what constitutes optimal participation in any given circumstance. Such a view may challenge certain assumptions that underpin some existing work

addressing children's participation, assumptions such as the conviction that more participation is better, and the idea that we will know children are participating when we hear what they want and when we pay attention to their wants.

At the outset of this study, I drew on the work of Thomas (2000), including the typology of participation developed through his research with school-aged children "cared for" by the state. He found participation to be multidimensional and dynamic, a view supported by my analysis in this study. He depicted variance in participation across six specific domains: the child's choice to participate or not, the information the child had about the situation, the control the child had over the decisional process, the voice the child had in the discussion, the support provided to the child in the expression of his or her views, and the degree of autonomy the child held to make independent decisions. In many ways, these domains can be understood to shape and be shaped by certain participatory spaces and raise questions similar to those that my analysis generates. What I believe the concept of participatory space brings to this discussion is a means of attending to the complex dynamics that shape the domains Thomas has identified, dynamics such as the enactment of adult authority, the diverse representations of children's intentions and desires, and the discourses of parenting and health care that influence what children can say and alter the standing that might be achieved by certain views.

So what are the responsibilities of nurses and other health care professionals within participatory space? Claims such as that made by Coyne (2006), that "nurses, as children's advocates, must play a key role in ensuring that all children are encouraged and facilitated to be active partners in decisions about their health and care" (p. 69),[80] begin to capture some of the practical and moral responsibilities of health care providers, but fall short of addressing some of

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[80]   Coyne (2006) qualifies this claim by saying that children should not be forced to develop skills in complex decision-making before they are ready or able to do so.

the more subtle dimensions of children's participation. In our work with chronically ill children and their families, we need to start with the question "Who is this child in this place?" The answer to this question will lead to other related areas of inquiry, prompting such further questions as:

- What does this child want? Where are we looking when we seek evidence of this child's intentions and desires?

- What are the prominent features of the relational context of decision-making? What is the child's place in that context?

- What ought this child to know about the problem the decision is intended to address? What are the child's vulnerabilities in this place? What are the child's capacities?

Beyond where these questions lead, we might inquire further by reflecting on assumptions about children, chronic illness, family, and decision-making as we make judgements about what kind of participatory space exists and, perhaps, how that space might be created or shaped in efforts to support children's participation.

Listening to children

When we consider that children's intentions and desires, and the expression of their views, is foundational to a notion of children's participation, then responsibilities of looking and listening for children's voices become a matter of both ethical and practical significance. A great deal has been written about what listening to children entails, and what it might look like. What the findings of this study bring to this conversation are particular questions about what constitutes a child's voice, how we know that what we hear are authentic representations of children's voices, and where it is that children's voices might be found. Most importantly, adult orientations toward children were an essential foundation to listening to children. An orientation of uncertainty and inquiry made hearing children possible, and allowed adults in positions of some authority to appreciate the complexities of some of children's intentions and desires.

The findings of this study reveal a spectrum of issues that might be taken into consideration in our efforts to hear children's voices. To begin, children's expressions take many forms—including speech, action, and silence—and any expression may be only a partial or temporary representation of the child's intentions. Secondly, expressions of intentions, while varying in specificity, precision, and consistency, all may hold some clue to child's subjectivity, including what is important to that child and the specifics of what the child wants. Thirdly, children's intentions have roots in histories, and may be formulated within relationships with parents, teachers, and health care providers. Children's authentic expressions of intentions are often entwined in their relations with parents and health care providers. Finally, what matters about particular issues may be different for children than for others within decisional processes, and sometimes these differences are subtle and difficult to discern.

What children want in regard to their health and health care is generally intermingled with their concerns about their everyday life; this observation has important implications for nurses and others. In her research with hospitalized children, many of whom were chronically ill, Coyne (2006) similarly identified the everyday issues of everyday life as matters that children cared about, and about which they wanted to have a say. The hospitalized children in her study were concerned about bed allocation, food preferences, hygiene needs, timing of procedures, waking time, sleeping time, and discharge time (p. 66). Coyne found that failure to hear children's views on these matters resulted in children's feelings of insignificance and depersonalization, clearly matters of moral concern. This seems true of the children in the current study as well, that separating matters of concern related to health and health care from the other dimensions of their lives not only rendered much of what was important to the children rather insignificant, but served to undermine their standing and muted their voices.

When we consider, then, what it might mean to hear children's voices, we need to look beyond the obvious and the immediate. Eliciting children's views becomes more than a matter of good communication practices and skilful judgement of children's competency and rationality. Of particular importance is the suggestion that we can rarely, if ever, confidently claim that we have full knowledge of what is important to a child in relation to an important matter in his or her life, or that we know with certainty what a child wants in a given situation.

That said, there is often a great deal we *can* know, and the findings of this study point to many places we can look as we seek to hear children's voices. What we need to take from this, however, is that a degree of uncertainty must characterize our inquiry into what children want, recognizing that what is visible or audible is generally only part of the story. This uncertainty leads us to ask certain questions about particular children's contributions to the matters of their lives. What matters to this child? How do we know? What does the child want in regard to these matters? What kind of standing does the child have in the decisional process?

Keeping participatory space open

It is tempting, in a way, to skim across this discussion of participatory space with only brief mention of very difficult issues that arise in the real moments of health care practice with chronically ill children, the very issues that prompted this inquiry in the first place. In participatory spaces, as nurses and other health care professionals engage with children whose lives include a chronic illness and with parents who grapple with the complexities of that illness amidst other pressing concerns, differences in values and priorities and differences in views of children and their interests emerge. Doane and Varcoe (2006) depict these as the "hard spots" of nursing practice:

> [Hard spots arise] when particular families and particular nurses in particular
> contexts experience differences between them … Difference implies more than

one perspective and thus draws attention to the place *in between* different perspectives. (p. 291)

As nurses and others engage with children within what might be understood as a participatory space, differences will arise: differences in perceptions of interests, difference in beliefs about what children want, differences in perspectives about the standing that ought to be granted to children. Understanding that these differences exist in a complex physical, social, and political domain, rather than residing within particular people, is key to navigating these moments of practice.

As I write this, a debate is being waged about certain decisions in the care of disabled 9-year-old girl in Washington State. Nine-year-old "Ashley" has severe brain damage, and has, since birth, been completely reliant on her parents. Recently, Ashley underwent growth attenuation therapy, a combination of surgical and medical interventions intended to halt her growth and stave off puberty. In the media, this case has been cast as an instance in which the interests of the parents compete with those of the child. Variously, the decision to proceed with these interventions has been cast as yet another example of the systemic abuse of people with disabilities (Picard, 2007), an instance of parents seeking treatment for selfish reasons; alternatively, it has also been cast as an effort to enhance Ashley's quality of life through making her care more possible, and protecting her from possible abuse (Gunther & Diekema, 2006; Vallis, 2007).

While Ashley's story differs in important ways from those of the children in this study, some of the issues raised by this controversy illustrate the complexities of decision-making with children and the "hard spots" we encounter as we engage in our work with chronically ill children and their parents. The responsibilities of nurses and other health care providers do not lie on either side of the controversy. The work lies somewhere in-between, in the space where

the representations of the child's intentions meet with the standing the child achieves in that place. This view does not answer the question of how we navigate through difficult places of difference, but it provides a starting point for addressing what are ethically important and challenging questions.

In this study, I documented a few striking examples of what I interpreted as skilled practice, where nurses or physicians clearly held a child in a position of respect, listened for and heard a child's views, and responded to the parent or child in a way that reflected a sense of the child as a person, the expressed views as significant, and the matter in question as important. I think of the example of Dr. H's interaction with Charlie, when Charlie mentioned that he really didn't want to have insulin injections in his "bum." I think of the example of the nurse as she inserted the needle into Lucas's fistula—not speaking, but listening to his body and his expressions. And I think of the times that parents were encouraged and supported as they represented their children and their children's wishes in ways that they understood to be true to their child and to their experience as a family. These examples illustrate how children's voices may be heard, and the kinds of diverse practices that might reflect an orientation toward children that would create the conditions to make that possible.

Critiquing the Theoretical Terrain

The topic of children's participation reaches into many diverse theoretical fields, some well developed and obviously relevant, others more obscure. Here I want to touch on two important topics, both of which have been substantially developed within the field of paediatric health care. The first has to do with the nature of health care relationships with families, variously labelled in the language as *partnership* and *family-centred care*. The second topic, *informed consent*, has very obvious links to the topic of children's participation and has, at times, been the focus of the majority of debate in the field.

Partnership and family-centred care

In research and theory about health care relationships with children and families, philosophies of family-centred care have figured prominently. Conversations focusing more specifically on children, including principles of child-centred care, children's rights, and children's participation in decision-making, have been largely separate from and secondary to these more prominent discourses of family-centred care. If we hope to provide ethically sound care to chronically ill children, I believe we need to find theory and language that synthesizes this body of knowledge regarding family-centred care with the emerging conversations about children's rights, their interests, and, as has been the focus of this study, children's participation. In some ways, practices of family-centred care and the attention to parents' position in health care can be understood as sitting in apparent tension with notions of children's participation (when grounded primarily in notions of children's rights). Yet, as the findings of this study suggest, children's participation is embedded in that vital relationship with family.

Attention to the complexities of children's participation in decision-making may have a great deal to offer in the development of principles and practices of family-centred care. To begin, if children's rights as manifest in their expressions of intentions are important, and if children's participation is dependent upon our abilities to hear and understand those intentions, then, as health care providers, we have certain obligations to recognize this pivotal role of listening to and hearing children, a role where parents figure prominently. Considering this, new areas of inquiry emerge. For example, there is evidence in the findings of this study that the nature and extent of children's participation can be partially dependant on the parents' learning trajectory and on the concurrent pressures experienced by parents. This finding is congruent with existing studies exploring the development of expertise when adults live with chronic illness and the implications of that expertise for decision-making abilities (Montori, Gafni, & Charles, 2006;

Paterson & Thorne, 2000; Thorne, Patterson, & Russell, 2003). In the way that adults' capacities to make decisions develop as they gain experience and confidence, it may also be true that parents' abilities to make decisions for and with their children are, in part, a function of the same sort of experience and confidence (Coyne, 2006). Likewise, because most health care decisions for chronically ill children tend to take place at home and at school, not in the health care settings, the feasibility of options and the consequences of decisions are linked to the knowledge and experience of both parents and children. We need to know more about these kinds of experiences of parents and children, so that we can expand our understanding of the linkage between relationships with children and parents and the opportunities and capacities of children to participate health care decision-making.

According to many researchers, children with chronic health conditions may be excluded from decisions where they likely ought to be involved (e.g., Alderson, 1993; Coyne, 2006; Runeson et al., 2002; & Sloper and Lightfoot, 2003). If this is the case, then there is much we need to know if we assume we hold moral responsibility for enacting health care relationships with children and families in a way that enhances children's contributions to decisions about their health and health care.

Informed consent and children

To this point I have largely avoided the tricky topic of informed consent. Yet, because it is a formalization of much of what we, as a society, hold to be central when we consider children's participation in health care decision-making, informed consent is a very important issue. Reflection on the concept of informed consent reminds us that there are important differences between children and adults when it comes to experience and maturity. Emphasis on this difference has resulted in the issue of informed consent becoming the fulcrum in the debate that pits children's capacities in against adult responsibilities to ensure that children's best

interests are met. One of the difficult features in debates about informed consent it that they centre on judgements about the child's competence to make a rational, independent choice. When the debate about whether or not to involve a child in decision-making is reduced to whether or not the child is competent to consent, the participatory space shrinks, and the child's opportunities diminish.

I think, however, that research and theorizing must continue in this area as we refine what it means to hold certain understandings in the practical application of this concept, and to ensure that our practices and policies of informed consent are congruent with a view of children's participation as embedded and embodied, and our relationships with children and families as important dimensions of participation. We might want to consider our policies of informed consent: to examine how those policies and practices serve to ensure that children's voices are heard, or hinder our ability to hear what is important to children. In some parts of the world, this work has begun. In the UK, the Department of Health has developed guidelines for health professionals as they seek to ensure children's contribution to health care decisions (Department of Health, 2001). Evident in this work are clear efforts to scrutinize concepts such as *autonomy* and *competence* and to move toward a more relational understanding of what these might mean. Competence, for example, "is not a simple attribute that a child either possesses or does not possess; much will depend on the relationship and trust between you and your colleagues, and the child and their family" (Department of Health, 2001).

While informed consent is a formalized process intended to ensure the ethical treatment of children, it must be understood as an adjunct to rather than the whole of children's contribution to health care decisions. Informed consent, rather than an end in itself, ought to be but one component of the processes that unfold in participatory spaces.

Asking the Difficult Questions

Many questions remain. Among these are questions of equity: Why it is that certain children have less opportunity than others? How it is that for some children, participatory space holds more possibility than it does for others? In the findings and in this discussion, I have mentioned the existence of some evidence that participatory space varies along certain parameters, implying that certain children have different opportunities than others. These parameters include such diverse factors as the kinds of services developed for particular illnesses, the prevalence of the various health conditions, the geographic location of the children's homes, the stigma linked to certain illnesses, and families' socioeconomic conditions. For example, in regard to families of children with chronic health conditions, we know that, like all populations, the health of this group is likely linked to their socioeconomic position. In a recent report, the BC Progress Board (Banting, 2006) depicted this link between economic status and health as an important priority:

> All children, irrespective of their social background, should have an equal chance to succeed in the province, and there is compelling evidence that children from low-income families are at greater risk … The fact that one in ten British Columbians lives on the economic margins for extended periods stands as a pressing policy challenge. (p. 1)

At the same time, a growing body of evidence suggests that a disproportionate number of families of disabled children live in poverty.[81] What has yet to be researched and theorized is how these features of the lives of children and families fit within our moral commitments to them, and in particular, have relevance for our understanding of concepts such as participatory space.

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[81] This claim is based on data from the UK (Gordon, Loughran, & Heslop, 2000; Patricia Sloper & Bryony, 2006). I suspect the situation in Canada is similar.

Prout (2000) has raised another important question that will deserve some attention in future research and theorizing about the participation of children in health care matters. His concern has to do with the possibility that our notions of children's participation, however well developed and articulated, run up against another increasingly influential discourse. Whichever notions of human flourishing, self- realization, or even autonomy are embodied within a concept of participation, these values coexist with a persuasive discourse about the control of children (and hence, their families). Prout convincingly argues that our efforts to establish children's position as fully human beings in this world are systematically undermined by manifestations of a view of children as in need of protection from themselves:

> On the one hand, there is an increasing tendency to see children as individuals
> with a capacity for self-realization and, within the limits of social
> interdependency, autonomous action; and on the other, there are practices directed
> at a greater surveillance, control and regulation of children. The tension between
> control and self-realisation … influences the capacity for retaining or opening up
> space for the representation and participation of children. (pp. 304-305)

There were hints of this tension in my interpretation of the findings of this study. In the analysis of the influences shaping the relevance of children's expressed intentions and desires in places of decision-making, I mentioned two distinct discourses: that of good parenting and that of best medical practices. How these influence different chronically ill children in different ways and how certain devices of control shape participatory space is likely an important area for future inquiry.

Perhaps the most persistent question that we need to continue to ask is the question of who children are with our human order, and what the consequences of that view of subjectivity are for how we understand children's participation as we attempt to establish our ethical responsibilities. In an inquiry into what it means to authentically listen to children, Carnevale (2004) concluded that the activity of hearing children's voices hinges on a recognition of the

moral worth of children, and requires that efforts be undertaken to hear what children want and to attend to those expressed views. Furthermore, he suggests that the relational aspect of children's experience must not be overlooked, and that ethical practice with children requires

> (1) identifying the persons who matter (morally) in each child-patients' life, (2) seeking to understand how these persons matter, and (3) striving to find ways to help preserve the continuity of such relationships with in the context of clinical care. (p. 407)

I agree with Carnevale on this matter; his view captures many of the themes within the findings of this study. This brings me full circle, to a realization that what prompted this study in the first place, a concern for the moral status of chronically ill children, re-emerges in the end as a question that can't entirely be answered by research. What we can learn from research, however, may inform our theorizing so that we can address the practicalities within our encounters with children and families, consider our critique of our policies and practices, and refine our imaginings of the world we want to create for ourselves and our children.

Summary

How we understand participation, and what we believe to be important about the concept, have much to do with how we proceed in the project of fostering chronically ill children's participation in health care decision-making. Among the key findings from this study is the notion that, at the very least, we need to be clear about what we understand participation to represent: what we hope to achieve, and why we believe it is important. Striving toward increasing clarity, we might better position our effort to foster children's participation within our broader commitments to children, and we might further our understandings of the implications of their relationships to the important people in their lives. How we proceed, then, to engage with children who live with chronic illness, can be guided by some vision of participatory space and

what we believe is important in that space: specifically, notions of what it means to listen to children, and to ensure their standing in the important matters of their lives.

CHAPTER 7

IMPLICATIONS AND FUTURE DIRECTIONS

My intent in this project was to contribute to the knowledge that nurses and other health care providers might draw upon in endeavouring to provide ethically sound health care to chronically ill children. I entered the study believing that a more detailed and comprehensive understanding of children's participation in health care decision-making—an understanding that incorporated children's own views about the nature and extent of their involvement—might in some way inform the practice of nurses and other health care providers and guide policy decisions. In this chapter, I consolidate what I believe can be reasonably concluded from this study; depict my understanding of the implications of these findings for health care practice, education, and policy; and outline what I see as directions for further inquiry in this field of study.

Children's Participation in Health Care Decision-Making

Through this project, I have come to understand the participation of children with chronic health conditions in health care decision-making as complex and multidimensional: a reflection of children's voice and standing in particular moments of decision-making. I believe that the findings of this study support the following conclusions:

1. Discourses of children's participation in health care decision-making are powerfully influenced by an idealization of the rational, autonomous being: notions that manifest in perspectives of children's subjectivities, in adult-child interactions of all kinds, and in the organization and delivery of health care to children with chronic health conditions. This idealization of the rational, autonomous being, when embodied in concepts and practices of participation, may render children's views irrelevant.

2. What is morally important about children's participation transcends what can be readily translated into the existing bioethical concepts of rights, interests, and obligations. These concepts tend to underemphasize the interdependence of children and their families, obscure the particularities of children's subjectivities, and discount much of the moral work of children, parents, nurses, physicians, and other influential people in children's lives.

3. Children with chronic health conditions are a heterogeneous group, and hence efforts to foster children's participation necessitate access to a range of theoretical approaches and practical tools.

4. Chronically ill children's intentions related to health and health care may not be readily discernable from those related to the decisions and events of their everyday lives. School-age children's experiences of health and health care tend to be deeply embedded in the relationships, events, and structures of their lives, and in their embodied experiences of illness, treatment, routine, play, school, sport, friendship, and family.

5. Children's intentions are often complex in substance, and expressions of intentions may be characterized by apparent contradictions or paradoxes. Similarly, children's intentions and desires regarding important matters of their lives are revealed in multiple, diverse locations: in what children say or fail to say, in their actions and their silence, and in the representations made on their behalf by others. This complexity is magnified by the variance in precision and specificity that may characterize children's expressed views.

6. Participation unfolds in sites where the authority and agency of children and adults (including parents, health care providers, and others) manifest in complex and dynamic ways. Children endeavour to make their voices heard in a largely adult constructed world. Hence, fostering children's participation demands attention to power dynamics within the spaces of participation.

7. Health care practices that effectively nurture children's participation are not rooted solely in specific guidelines, regulations, or rules; they are grounded in understandings of the moral spaces where participation unfolds and beliefs about adult responsibilities therein. For this reason, meaningful practice intended to foster children's participation must be understood as an integral part of health care relationships with children and their parents.

8. Participatory opportunities are not equitable for all children. Although universal and unchangeable features related to children's maturity and specific health conditions likely exist, children's participation may be significantly undermined by embedded assumptions about age, gender, race, family, and social position that manifest in health care practice with children and families, and in the policies that shape health care, education, and social support for these children and their families.

Moving Forward

The conclusions I outlined above traverse a broad field of theoretical, ethical, and practical considerations, and have varying implications for health care practice with chronically ill children and their families, for the development and enactment of policies that influence their lives, and for the education of health care providers. Here I delineate what I understand to be some of the most pressing ramifications of the findings of this study.

Underpinning the recommendations from this study is a perspective that participation is not an end in and of itself, that it is a dynamic process that unfolds in complex physical and social environments. Fostering children's participatory activity might have as much to do with shaping the conditions wherein these activities take place as with actual work with children and their parents. As Sinclair (2004) has carefully articulated, for practice and policy guiding children's participation to be "meaningful, effective and sustainable," the values and understandings that lie beneath these efforts must be embedded in the structures that shape children's lives, and held as an integral element of our relationships with children and their parents (p. 106). I believe that, if this is to happen, we need to critique the perspectives on participation that form the foundation of our practices and policies, and we must develop the kinds of conceptual and practical tools we need to create contexts and practices that will enhance children's participatory opportunities.

Shifting our Discourses

One of the most striking interpretations in this study was the way that certain taken-for-granted assumptions underpinned the very notion of participation, and that these assumptions were manifested in important ways in the lives of children and parents. Assumptions about the purposes of participation, the nature of children's expressions, and the relevance of children's views operated, often simultaneously, to shape children's experiences and determine their opportunities. It seems clear, then, that ethical practice with chronically ill children requires careful attention to the conceptual views of children and participation that are embedded in our guidelines, practices, and policies. Here I offer my thoughts about where we might begin in our efforts to shift these perspectives, looking particularly at how concept of participation manifest in projects intended to ensure children's rights, and in the expansive and diverse field of theory and research addressing health care relationships with children and families.

Children's rights

In 2004, following the UN General Assembly Special Session on Children, the Canadian Government reaffirmed its commitment to children's participation:

> Children who are capable of forming their own views have the right to express those views freely in all matters affecting them, their views being given due weight in accordance with their age and maturity. The active involvement of children in decision-making expands the diversity of perspectives reflected in the process, and contributes to more relevant and equitable policies and programming including more sustainable outcomes. Meaningful child participation increases children's capacity for responsible citizenship and their respect for democratic principles. (Government of Canada, p. 40)

In essence, this is a reiteration of statements articulated in 1989, in the declaration from the UN Convention on the Rights of the Child. Underdeveloped within this and other declarations is specificity of purpose about why children's participation is important, and any clarity about the ends that participation is intended to serve. In the excerpt above, participation is apparently valued because it enhances policy, and because it assists children to develop needed skills. Both are important, no doubt, but I believe that as we move forward with a participation agenda, we desperately need to locate calls for children's participation within a conversation about children's place in the world, with particular attention to certain complex dynamics of their lives. That children are often viewed as "human becomings" rather than "human beings" might be an overused slogan, but the concerns the phrase illuminates remain relevant. Ethical analysis of the important directions and policies for children's participation that emerge from influential international bodies such as UNICEF and UNESCO, federally from the Government of Canada, and provincially from the Ministry of Health, the Ministry of Education, and the Ministry of Children and Family Development, may provide substantial direction and may, in fact, facilitate efforts to move this agenda forward. At this governmental level, we need to include ethical analyses in policy development; analyses that critique embedded orientations toward children, and that ask whether the voices of children were heard in the development of the policies and

guidelines that structure their lives. Inclusion of this step in our policy processes would begin to create the groundwork for the kinds of structures needed for a meaningful and systematic approach to children's participation.

In addition to ethical analyses of governmental policy, local policies might be scrutinized in a similar way. Standards and guidelines shaping health care practice with chronically ill children and their families might be similarly critiqued according notions of children and childhood that underpin them, and the corresponding understanding of the responsibilities of health care professionals that emanate from those beliefs. Where policies and guidelines specifically address children's participation, ethical analysis might also include an inquiry into assumptions about the goals of participation, including a critique of notions of the good regarding children's involvement that are embedded in those policies.

I think a reasonable place to begin this critique would be an ethical analysis of our policies and practices of consent and assent with or for children, beginning with the Infants Act (Government of British Columbia, 1996), and proceeding to institutional policies and professional practice guidelines. At institutional levels, I believe that simultaneously analyzing policies and practices of family-centred care, while attending to how these intersect with practices and policies of informed consent, might generate useful insights and spawn further critique and progress.

When we consider the complexities of children's contributions to the important matters of their lives, ethical analysis of policies and guidelines does not end with inquiry into beliefs about children, childhood, their participation, and the corresponding adult responsibilities. We know very little about how the possibilities for different children are influenced by the important variables of age, class, race, ability, and gender. At the very least, ethical analysis of our policies

and guidelines affecting the lives of children must begin to ask these questions, and explore linkages between the conversations about children's participation and issues of equity in health and health care.

Health care relationships with children and parents

A wide range of theories and practice guidelines about what is good in health care relationships with children and their parents, all intended to support particular goals relevant to the care of chronically ill children, is available and accessible to health care providers in this province. Consider, for example, the extensive literature addressing the clearly relevant topics of advocacy (Deirdre, 2002; Hewitt, 2002), family-centred care (Corlett & Twycross, 2006; Sheilds, Pratt, & Hunter, 2006), effective communication with children (Shin & White-Traut, 2005; Wassmer et al., 2004; Young, Dixon-Woods, Windridge, & Heney, 2003), and effective communication with parents (Hummelinck & Pollock, 2006); as well as more specific topics, including patient compliance (Baumann, 2000; Drotar, 2000; Fielding & Duff, 1999; LeBlanc, Goldsmith, & Patel, 2003) and informed consent (Foreman, 1999; Miller, Drotar, & Kodish, 2004). All these fields of study potentially contribute to our understanding of the spaces in which children's participation takes place and may, in various ways, help us determine our moral responsibilities within those spaces. Other, less obvious bodies of theory and research are likely equally important, however, and may provide knowledge that informs practice. These include perspectives from fields such as disability studies (McConachie et al., 2006) and human geography (Crooks, 2006; Eriksson & Granlund, 2004; Vanderbeck & Dunkley, 2004). I list these only to suggest the vast array of knowledge available to inform this project and to make evident that it is unlikely that nurses or other health care providers would ever be able to see everything at once in the real moments of work with chronically ill children and parents.

However, given that health care relationships are unquestionably important in considerations of children's participation, and that at least some of our responsibilities to children and families lie in these relational places, I think we may benefit from the construction of a model for thinking about our work with children and families that transcends specific concepts such as participation, family-centred care, advocacy, and even partnership, a framework that enables thoughtful integration of a wide range of moral and practical concerns. My depiction of the moral spaces of participation might be understood as one such effort, a frame for deliberation that amalgamates a spectrum of theoretical and practical considerations.

Wherever we choose to begin, I believe that our discourses surrounding care provision to chronically ill children must in some way be synthesized. Our conversations are never only about participation, or family-centred care, or informed consent; rather, even as we focus on these topics, we hold in mind the values that underpin our projects, and understand something of the complex spaces wherein our relationships with children and families unfold.

Shifting our discourses in nursing education

This positioning of conversations about our responsibilities to children and families within the moral spaces of practice is vitally important for how we approach the education of practitioners in nursing and other health disciplines. Taken this way, ethics is far from a discrete topic of study, and hence is better perceived as a thread across nursing curricula. Topics such as children's moral development remain vitally important, but are most usefully situated within broader considerations of health care relationships with children and with their parents, and the moral responsibilities embedded in those relationships. The tools that such specific knowledges provide are essential, yet their application is tempered through a scrutiny of how they support (or fail to support) productive relationships with children and their families. In nursing education then, students would benefit from opportunities to reflect upon their beliefs about children, to

examine the structures and institutions that shape chronically ill children's lives, and to consider how these manifest in nurse-child and nurse-parent relationships.

Scrutinizing Policy and Practice

So where do we go in our practice with chronically ill children, their parents, and the important others in children's lives? If health care practice is influential in shaping participatory space—in determining the extent to which children's views are made known, and in shaping that status granted those views—then there is no doubt that certain ways of being with children and parents will be more effective than others. If we accept that children's intentions are formulated in relation with others, and that those relationships shape the expression of their views, then the responsibilities of nurses and other health care providers are not restricted to questions about what the child wants and efforts to ensure that the child's voice is heard. Our responsibilities also include the following activities:

- Recognizing parents as potentially powerful representatives of their child's intentions and desires. This role needs recognition in our conversations about practical topics such as parental presence during intrusive procedures, parental presence during rounds, and visiting policies.

- Searching for children's voices in many places: accepting that multiple voices exist, that they may appear to be contradictory or inconsistent, and being reluctant to dismiss children's expressed views on the basis of irrelevance or unreasonableness.[82]

- Carefully attending to power dynamics and enactments of authority in our all our encounters with chronically-ill children and their parents.

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[82] I am aware that I have not begun to address the important and difficult issue of those instances when family relationships may be more destructive than constructive, where family life might be anything but the safe and loving place that is idealized in contemporary western society. I do think, however, that values giving rise to notions of participation remain important in those circumstances, and that practices of listening, attending to authority, and recognition of the relational dimensions of children's intentions and the expression of those intentions, may well hold in those instances.

That said, I have concerns about the ethics of scrutinizing family relationships. When it comes to the specific issue of children's participation in health care decision-making, I believe we must be cautious about our judgements of the familial dynamics shaping children's participation in decisional processes. I am concerned that, in privileging participation, we add a layer of surveillance into the already scrutinized lives of chronically ill children and their parents, and that, by the imposition of certain values, we may cause further harm. I think Darbyshire and Jackson (2004) articulate this concern well when they pose the question, "Where is the balance between privacy and state scrutiny, between a family's rights to live according to their values and choices and any greater societal good, between parents' child-rearing styles and children's wellbeing, and countless other tensions?" (p. viii).

Directions for Research

In the findings of this study, I proposed a construct of participatory space as way to simultaneously attend to the multiple moral and practical features that shape and constrain children's participation in specific moments of decision-making. While I have suggested that this space shapes children's participation in health care decision-making and simultaneously is shaped by the efforts of children and others to ensure that children's voices are heard, further investigation into the usefulness and fit of this construct in policy and practice is warranted.

To start, I believe that there is more to be learned from the data set for this study, and further analyses are possible. I have begun an analysis of various perspectives on children's interests, building on the interpretation presented in the findings suggesting that perceptions of children's best interests serve as powerful criteria against which the reasonableness of children's expressed views are often measured. As I analyze this further, I am endeavouring to isolate various perspectives on what benefits children, drawing on the views of children themselves, the perspectives of parents, the views of health care providers, and what can be discerned from the

actions of the various participants in this study. Likewise, I am looking at notions of children's interests embedded in the documents guiding family-centred care and informed consent in the practice areas where the children received care. A more detailed understanding of the nuances of various perspectives on interests, including how these overlap or conflict with each other, may shed further light on why some perspectives achieve standing in decisional processes, while others do not. This kind of analysis may assist us in our efforts to integrate the substantial body of existing theory about children's interests into a relational and contextual view of children's participation.

In a project like this one, as alternate paths for thinking about complex phenomena are proposed, and as parameters that constitute or define certain constructs are articulated, initial ways of thinking and seeing the phenomena of interest are inevitably displaced. The construct of participatory space requires scrutiny on this front; further theoretical and empirical inquiry is needed into what is obscured when we begin to think about children's participation along these lines. In particular, because an important premise of this interpretation of participatory space is that children's contributions to the important matters of their lives ought not to be isolated from other dimensions of their lives, the notion of participatory space must be interrogated for the extent to which it serves this purpose, with particular attention to how it might serve to narrow conversations about participation and obscure important moral and practical considerations. For example, further inquiry is warranted along lines of children's autonomy and agency, asking whether or not a view of children as active agents can be sustained in the face of questions of authority and hegemonic views of children's location in society.[83] More exploration in needed of

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[83] I highlight this debate about children as social actors or active agents because it is a contentious topic, with certain camps advocating that, because children are generally portrayed as passive beings in our research projects, we must rectify this problem through rigorous attention to the ways that children actively, and often deliberately, contribute to and shape the contexts and events of their lives (e.g., Barker & Susie, 2003; Prout, 2002).

participatory spaces in families that are experiencing serious challenges: including poverty, violence, and abuse.

In the face of these kinds of questions, I think a productive next step in this inquiry into what constitutes and shapes children's participation might be a participatory research project with children and the significant others in their lives, investigating how, in the important matters of their lives, their voices are heard or not heard, and learning about the various factors that determine the extent to which children's views achieve any standing as decisional processes unfold. Research with children whose opportunities for contribution within the important matters of their lives may be shaped by embedded assumptions about gender, race, family, ability, or social position may assist us to refine our understanding of the moral and practical dimensions of participatory space, and to comprehend more fully the responsibilities of health care providers and other professional groups toward these children. I can imagine this project proceeding down any number of paths, with chronically ill children living in poverty, with children living with substance abuse in their homes, or possibility with First Nations children with chronic illness. Whatever the group of children and parents selected, it is the particularities of children's lives that will be important, the multiple influences shaping voice, authority, agency, and standing that—from the perspective of the children themselves, their parents, and others—are the important issues in their lives.

As an aside, and as a consideration for future research, I want to mention that throughout this study I have been perplexed by what to about understanding children's bodies—that is, what place their physical beings ought to hold in an analysis of their participation in health care decision-making. As I have explained, conventional views of participation tend to separate children's intentions and desires and the expression of those intentions from their bodily experience of being-in-the-world. Butler (1999) advocates a view of the body as "an active and

reactive entity which is not just part of us, but is who we are" (p. 239).[84] The findings of this

study raise, but do not answer, the question of what it might mean for children to engage in

decisional processes as embodied beings, and what it means for health care providers to perceive

children as embodied beings. This area of inquiry is underdeveloped, and needs further

theoretical and empirical work.

Summary

In conclusion, this study has explored the participation of school-age children in chronic

illness decision-making. The findings illuminate the complex and multidimensional nature of

participation, and demonstrate multiple influences within the physical, social, economic, and

political contexts of children's lives that mediate and profoundly shape children's opportunities

and abilities to contribute to the important matters of their lives. The findings of this study

indicate a need to re-think the ways that participation is understood and to explore how certain

assumptions influence, and often dominate, efforts to foster children's participation in decision-

making. Such awareness will pave the way toward a clearer understanding of children's

participation in health care decision-making and provide a more solid foundation for articulating

the responsibilities of health care providers toward children and their parents within the moral

spaces of participation and informing related policy and research.

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[84]   James, Jenks, and Prout (1998) caution against what they perceive as "the dangers of a foundationalist
      view of the body" (p. 149). They are concerned about the mistakes we make when we limit our
      understandings to current biological and medical views of the body, failing to consider how children's
      bodies are related to the social relations and cultures of childhood within which their experiences are
      embedded.

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APPENDIX A

UBC BEHAVIORAL ETHICS BOARD APPROVAL

The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

PRINCIPAL INVESTIGATOR	DEPARTMENT	NUMBER
Thorne, S.E.	Nursing	**B03-0054**

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
Children's & Women's Health Ctr , Surrey Memorial Hospital,

CO-INVESTIGATORS:
McPherson, Gladys, Nursing

SPONSORING AGENCIES
Canadian Institutes of Health Research

TITLE:
Toward an Understanding of the Participation of Children with Chronic Health Conditions in Decisions Regarding their Health Care

APPROVAL DATE	TERM (YEARS)	DOCUMENTS INCLUDED IN THIS APPROVAL:
MAR 2 7 2003	1	Jan. 26, 2003, Contact letter / Consent forms / Questionnaires

CERTIFICATION:

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

_____

Approval of the Behavioural Research Ethics Board by one of the following:
Dr. James Frankish, Chair,
Dr. Cay Holbrook, Associate Chair,
Dr. Joe Belanger, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures

CIHR Operating Grant Research Proposal

CHILDREN'S PARTICIPATION IN CHRONIC ILLNESS DECISION-MAKING (CONDENSED)

The objective of this research is to increase our knowledge about chronically ill children's participation in health care decision-making by focusing on children's own perceptions of these processes. We will attend to what children say regarding decisions in their health care, while holding in mind the multiple contextual factors that influence both the processes and products of decision-making. To facilitate this approach, our research project will be guided by the following questions: (1) What do chronically ill children perceive to be the nature and extent of their participation in decisions about their health care? (2) What factors do chronically ill children believe influence the nature and extent of their participation in health care decision-making? (3) What relationships exist between children's views and the views of their parents related to decisions made in their health care?

Given the exploratory nature of this project and its descriptive goals, a qualitative approach to knowledge development is employed. In order to generate a rich and detailed description of children's views of their participation in health care decision-making, and to develop an interpretation of patterns and variations in children's participation, we utilise the methodology of interpretive description (Thorne et al., 1997).

In keeping with interpretive description, the methods selected for this study are based on our understanding of the clinical problem underlying the research questions. Specifically, given that we want to determine children's perceptions, we need direct access to chronically ill children as well as methods of data collection that will enable us to develop a rich and detailed understanding of patterns and themes apparent in their perceptions. Because we know that

children's views are often significantly influenced by and intertwined with those of their parents, hearing what parents believe about the decisions in their child's life will add an important dimension to our findings.

Methods

This is a two-year project. Data collection will consist of interviews with children (n=50) and their parents (n=˜75). Interviews with 5 of the child and parent groupings will be completed as pilots during April to July 2003. This proposal addresses data collection with the remaining 45 child and parent groupings. In accordance with principles of theoretical sampling (Lincoln & Guva, 1985; Thorne et al., 1997), exact numbers of participants may shift as new variables become important during testing of working hypotheses.

Sample

Theoretical sampling will be used throughout. This will guarantee a sample that has sufficient heterogeneity to produce an in-depth and comprehensive description of variations in children's participation in health care decision-making, as well as providing a foundation for an account of the patterns of participation that are shared across cases (Sandelowski, 2000; Thorne, 1997). Recognizing that children's experiences and their perceptions of those experiences may differ according to various factors (such as age, time since diagnosis, the types of decisions to be made, and the context in which decisions are made), we intend to recruit children with a variety of health conditions. We will theoretically sample within the age bracket of 7 to 12 years.

Beyond the inclusion criteria outlined above, the recruitment of children in the sample for this study will require that each child is able to speak and understand English, has at least one parent able to speak and understand English, lives with at least one of his/her natural or adoptive parents, and, according to the nominator, has no known cognitive deficit. Children will also be recruited to this study on the basis of an expressed willingness to take part, and the consent of the

parents to the child's and their own participation. If a child is recruited to this study and is unable to participate in the complete data collection process, the data collected will be included in the analysis unless otherwise requested by the child or parents.

Initial contact with children and families will be through nominators in various clinics and inpatient settings where chronically ill children receive health care. The nominators will be health centre professional staff and will not be otherwise involved in the research project. Upon identifying a child and family as potential participants in this study, the nominator will provide them with a package containing descriptions of the research project and an invitation to participate. Parents will contact the investigators if they are interested in participating. Upon contacting the investigators, parents of children who volunteer, and the children themselves, will be provided with additional information about the study and initial interviews with the child and parents will be scheduled.

Data Collection

Data will be collected using qualitative and descriptive techniques: interviews with children, interviews with parents. Data collection will consist of two semi-structured interviews with the children and an interview with at least one of each child's parents. Interviews will be conducted by the co-investigator or a research assistant. Research assistants hired to assist with interviews will have previous experience working in professional roles with children and will be trained by the investigators in the methods and ethics of qualitative interviewing and data collection with this population.

Demographic data. Demographic and background information will be obtained from each child and parent during the first meeting. Included in this information will be details about the child's history of chronic illness as well as demographic particulars. Through this process we will obtain information about the child's chronic health condition, including the length of time

since diagnosis, limitations of function, activities, or social activities; the use of medications, special diets, medical technologies, assistive devices, personal assistance; patterns of usage of medical care or related services; and special ongoing treatments, interventions, or accommodations at home or in school. Demographic information about each parent, including education and socio-economic status, will also be obtained.

Interviews with children. Two semi-structured interviews will be conducted with each child (n=50) recruited to this study. Initial interviews will take place within two weeks of initial contact with the researcher and the subsequent interview will take place 2 to 4 weeks later. Ideally, the child will be interviewed alone with the researcher. We will work to develop sufficient rapport with each child and family accomplish this goal. However, each child will have the option of someone else being present (a friend, sibling, or another adult). While the type of data generated will differ depending on who is present, this issue will necessarily be negotiated in the context of working with each child and family. Fortunately, in a study of this nature, the absolute equivalence of each data collection instance is less relevant than the interpretations that are made of the variations that differences might create.

The goal of interviews with children will be to obtain rich and detailed descriptions of decisions made in children's health care, and of the children's perceptions of their involvement in these decisions. In order to maximise the quality of data collected from children, interviewer behaviour and demeanour are important considerations in each interview. Taking this into consideration, we have developed an interview guide that draws on the principles of

developmentally sensitive interviewing (Poole & Lamb, 1998)[85] and incorporates participatory techniques (O'Kane, 2000).

Developmentally sensitive interviewing draws attention to practices of questioning (the use of open-ended prompts, and steering away from direct questioning), and the format of vocabulary and syntax (the use of concrete, basic words, and drawing on the child's own vocabulary).

Participatory techniques are defined activities in which the child engages actively, and which tend to foster conversation and dialogue. One participatory activity that will be used in the initial interviews with children is the decision-making grid (adapted from Thomas, 2000; Thomas & O'Kane, 1999). To facilitate conversation and to expand the scope of the data accessible, a variety of other activities appropriate to the child's interests and abilities may be used. Where drawings or other creative objects are produced, these will be considered the property of the child, and used as research data only with permission of the child and the child's parents.

The second interview will focus on what it is like to live with a chronic health condition, what it is like to manage that condition on a daily basis, and the processes by which various decisions are made. The selection of questions and activities will be informed by information from previous interviews, as well as by any issues and questions that child brings to the session.

All interviews will be audiotaped and transcribed verbatim for use in the analytic process. Interviewers will also document their observations in extensive fieldnotes that will contribute to

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[85] These principles were developed to guide practitioners as they seek information from children who have been abused. While the kinds of information we are attempting to obtain in this study is very different; these principles reflect attention to children's level of development, the integrity of their narratives, and sensitivity to the subject matter.

the analytic process. Where drawings, photographs, or other artefacts are collected, these will be included in the data set.

Interviews with parents. We will conduct semi-structured interviews with one or both parents of each child recruited to this study. These interviews will take place separate from the child. These interviews will centre on the parents' experience of managing the child's chronic health condition, the decisions that are made in the child's care, and the factors that shape those decisions. Emphasis will be on specific decisions that have recently been made in the child's health care. The goal will be to elicit the parent's or caregiver's perspectives of the factors that shape each decision, including their understanding of the child's perspective on the specific issue and their beliefs about the child's capacity to contribute to the decision-making process.

Secondary sources. Other strategies for data collection will include examination of documents as they become available to the researchers. Relevant media accounts of current events may be included as data in this study, particularly articles documenting cases where children or parents question or refuse medical treatment or where health care professionals raise concerns about the ethical care of children.

Data Analysis

Data analysis will proceed concurrently with data collection, with ongoing data analysis informing the process of theoretical sampling. Analysis will take a constant comparative approach, a process through which early data is compared within and between cases and against the theoretical underpinnings of this study. As the process proceeds, new data will be used to test emerging understandings of how children perceive their participation in health care decision-making (Layder, 1998; Thorne, 2000). Questions that will guide initial provisional coding, drawn from the theoretical underpinnings of the study, may include: What kinds of decisions are being

made? How do children see their involvement in each decision? How does the child's participation relate to the nature of the health condition and its treatment? How are children's perspectives about their participation in decision-making similar to or different from the perspectives of their parents? The overall outcome of the analytic process will be the production of an explanatory model, informed by the perspectives of children, that depicts children's participation in chronic illness health care decision-making.

Claims and Limitations

Because of the exploratory nature of this project, the findings of the study will be largely descriptive. The findings will interpret how children in this study understand their participation in decision-making, and how children's and parents' views interrelate. These findings, combined with the findings of the previous study, will provide an important foundation for further research, including an exploration of how the practices of health care professionals with children influence children's participation, and how current health care policy facilitates or hinders children' abilities and opportunities to contribute to health care decisions.

Certain factors limit the claims that can be made based on the findings of this study. Importantly, this is not a representative sample of all chronically ill children or their families. Parent and child perceptions of decision-making in health care will likely influence the sample selection for this study. Specifically, we acknowledge that parents who are most likely to feel comfortable participating in the study will be those that are most comfortable with involving their child in decisions. We will account for the effect of this bias in our invitations to participate by emphasising to potential participants that decision-making is a multifactorial process, not solely dependant on the qualities of individual persons or their relationships. The sample is also limited by the exclusion of children who do not live with at least one of their natural or adoptive parents. These children would have important perspectives on participation in decision-making,

both in relation to health care and in regard to living arrangements, and we believe that the

perspectives of this group of children warrants separate investigation in a subsequent study.

Children whose health conditions do not have a biological basis are also excluded from this

study. Again, this is an important group of children that warrants study in subsequent

investigations. We recognise, therefore, that the study represents an attempt to "drill deep" in

relation to the phenomenon of interest within a specific subset of the theoretical population.

Ethical Considerations

As a vulnerable group, children warrant particular attention in ethical considerations

related to research design and implementation, particularly regarding issues of consent,

voluntariness, confidentiality, and privacy (Graue & Walsh, 1998; Mahon, Glendinning, Clarke,

& Craig, 1996; Medical Research Council of Canada Natural Sciences and Engineering Research

Council of Canada & Social Sciences and Humanities Research Council of Canada, 1998). In

this study, formal consent for the child's participation will be obtained from the parents. Consent

for the parent's participation and the child's participation in the study will be obtained prior to

commencement of data collection. As the child's authorised representative(s), the parents will

provide legal consent to participation in this research project. To minimise risk of coercion or

violation of children's psychological integrity, the following special procedures will be

implemented: (1) interviewers and investigators will ensure the child's assent by reviewing the

purposes of the research with each child, and emphasising the voluntary nature of participation

during each session; (2) interviewers will respond to any verbal or non-verbal cues indicating

that the child may be reluctant to participate in any portion of the study; (3) children's artwork,

photographs and other artefacts will be considered to be the property of the child and will be

used for analysis and reporting only with the permission of the child; (4) children will be

encouraged to contribute to the agendas of the interviews (Morrow & Richards, 1996; Thomas &

O'Kane, 1998). Every effort will be made to sustain children's confidentiality within the legal and ethical constraints governing the practice of researchers and health care professionals. Because of constraints related to child protection, children cannot be guaranteed absolute confidentiality. When safety issues are divulged, the child and/or family will be referred to the appropriate consultant from the British Columbia Ministry of Children and Families.

Summary

This proposed project is intended to address an important issue in health care delivery to chronically ill children. It will draw attention to children's views of their involvement in health care decision-making, and will provide a detailed description of how involvement in decision-making varies according to the nature of the decision being made and other factors as they emerge in the data analysis. The findings of this study will augment the understanding developed from earlier findings, and will contribute to the knowledge that health care professionals and policy makers employ as they seek to create the conditions in which optimal health care for chronically ill children may be delivered.

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Children's Participation in Chronic Illness Decision-Making
A UBC Research Study

This pamphlet provides information for children and parents about this study being conducted by nursing researchers from the University of British Columbia.

Study purpose: To learn about decisions children and families make related to the child's health care, including how those decisions are made. This information will assist nurses and other health care professionals to provide quality care to children with chronic health conditions.*

Principal Investigator: Sally Thorne, RN, PhD
Co-Investigator: Gladys McPherson, RN, PhD(c)
Research Assistants:

Funded by: The Canadian Institutes of Health Research

School of Nursing
UNIVERSITY OF BRITISH COLUMBIA

* *This study is part of Gladys McPherson's doctoral studies in the School of Nursing at UBC. Committee: Dr. Sally Thorne (chair), Paddy Rodney, Hillel Goelman and Angela Henderson.*

What is this research study about?

The researchers in this study are working with school age children and their parents. We want to understand what it is like to live with a long term health condition. We especially want to hear about how children and families manage the day-to-day decisions that need to be made.

Who is participating in this study?

Children with a variety of health conditions and their parents are invited to participate in this study. To date children with conditions including diabetes, seizure disorders, renal conditions, severe allergies and asthma have joined the study.

To participate in the study, children need to be between 7 and 12 years of age, be able to speak English, and have lived with their health condition for at least 3 months. If your child has a long term health condition, we would be very interested in talking to you and your child.

You may also see us spending time in clinics and other health settings observing the delivery of health care children and families. When we do this we will take notes about what we observe. Before any notes are taken about you or your child, we will talk to you about the study and ask for your consent.

What does participating in the study involve?

The nature of participation depends on you and your child and what would work best for you. We would like to talk to you and your child about your daily lives, including what it is like to live with the health condition. These conversations can take place in the clinic, in your home, or in a place more convenient for you. If possible, we would like to talk with you more than once over the next several weeks.

How will my privacy and the privacy of my child be protected?

Maintaining your privacy is an essential part of the study. While we will keep records of conversations, names will not be included. Any information that has identifying information will be kept by the researchers in a secure location. Information that has no identifying information will be used to write interim and final reports, will be used for future presentations and publications, and may be used for secondary analysis in other related research.

How will the information we provide be used?

What we learn from you and others in this study will be presented to nurses and other health care professionals through written articles and presentations. Where appropriate, we will use what we learn to advocate for change to policies and practices that influence the lives of children with chronic health conditions and their families. In addition, we plan to write a summary of what we find for children and families.

Please contact us if you have questions and/or are interested in participating in this study.

(xxx) xxx-xxxx

We'd love to hear from you!

DEMOGRAPHIC FORM

Children's Participation in Chronic Illness Decision-making

**Demographic and Background Information:
Child and Parent Participants (Ref. # 203)**

Date information collected _____

Interviewer _____

Child's name _____

Parent(s)' name(s) _____

_____

Address (for purposes of notification of study results only)

_____

_____

_____

Child information and demographics

ID _____

1. **Age**: ____years ____ months

2. **Gender**: ☐ female

☐ male

3. **Family members (relationship to child and age):**
   _____
   _____
   _____
   _____
   _____

4. **Grade in school:** _____

5. **First language:** _____

Primary health condition: _____

Date of diagnosis: _____

6.   **Other health conditions:**

7.   **Effects of health conditions on activities (school, sports, etc):**

8.   **Medications (name of medication, route of dosage and frequency):**

9.   **Special diet (if any):**

10.   **Assistive devices and/or medical technologies**

11.   **Personal assistance at home or school**

12.   **Medical care and related services used**

    ❑   Family physician

    ❑   Specialist physicians (Specify specialties)

            _____

            _____

            _____

            _____

            _____

    ❑   Nurse specialist or clinician

    ❑   Physiotherapist

    ❑   Occupational therapist

    ❑   Psychologist

    ❑   Nutritionist

    ❑   Child development specialist

    ❑   Other (Specify)

            _____

            _____

Parent demographics

ID _____

Gender: ❑ female

               ❑ male

Age: _____

Ethnicity: _____

Education

❑   Less than high school

❑   High school diploma

❑   Diploma

❑   Baccalaureate

❑   Masters

❑   PhD

❑   Technical certificate

❑   Other: _____

Employment status

❑   Unemployed

❑   Unemployed, receiving income assistance

❑   Self-employed

❑   Employed full-time

❑   Employed part-time

❑   Other: _____

Status of residence

❑   Share residence with child

❑   Live in a separate residence than the child

❑   Live in the same residence as the child part of the time

Average household income per year (optional)

❑   Less than $10,000

❑ $10,000 to $20,000

❑ $20,000 to $30,000

❑ $30,000 to $40,000

❑ $40,000 to $50,000

❑ $50,000 to $60,000

❑ $60,000 to $70,000

❑   greater than $70,000

INTERVIEW GUIDES

Questions for Children

(These are trigger questions to be posed to the child in an individualized, developmentally appropriate manner.)

1. Tell me what you usually do everyday.

2. In what ways does having (health condition) affect your life?

3. What kinds of things have to be done every day related to (health condition)? What usually happens when (this health care routine/practices) takes practice?

4. What choices have to be made about (aspect of treatment or health management)?

5. How much say do you have in that decision?

6. Who else is involved in that decision?

7. How much does that decision matter to you?

8. Tell me about your experience with doctors, nurses, and (other health care professionals).

Questions for Parents

1. Tell me about (child). What does managing his/her health condition involve?

2. Tell me about decisions that need to be made related to (child)'s health care. Can you give me an example(s)?

3. What decisions are most important? What makes these decisions important?

4. Who is responsible to make decisions about (child's) health care?

5. Does (child) ever express thoughts or feelings about the decision that are made? Can you give me an example of a time when he/she agreed with the decision that was made? A time when he/she disagreed with the decision that was made?

Choices about my life

By _____

What people?

What choices?

How much say each person has about each choice …

◯ = A lot of say

◯ = Some say

◯ = No say

APPENDIX G

CONVERSATION CARDS

My room

What I eat

Needles

My hair

Privacy

Sleepovers

APPENDIX **H**

CONSENT FORM – PARENTS

THE UNIVERSITY OF BRITISH COLUMBIA

School of Nursing
T201- 2211 Wesbrook Mall
Vancouver, B.C. Canada
V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

Consent Form (Ref # 101v.2)

Children's Participation in Chronic Illness decision-making

Principal Investigator: Dr. Sally Thorne
Director, School of Nursing
University of British Columbia
Telephone (XXX) XXX-XXXX

Co-Investigator: Gladys McPherson
Doctoral Student, School of Nursing
University of British Columbia
Telephone ((XXX) XXX-XXXX

You and your son/daughter are being invited to participate in a research study. We are investigating how decisions are made in the health care of children with chronic health conditions. This project is part of the co-investigator's (Gladys McPherson's) doctoral studies. It is funded by the Canadian Institutes of Health Research.

Purpose:
The purpose of this study is to get to know more about decisions that are made when children have chronic health conditions. We are particularly interested in children's contributions to health care decision-making—including what they think and feel about their health care and about the decisions that are made. This knowledge will assist nurses, physicians and other health care professionals to understand some of the important issues children and parents face.

You are being invited to participate in this research project because we are interested in learning about your experiences and the experiences of your child. We would like to hear what it is like for you and for your child to make decisions related to your child's health care.

Study Procedures:
We are asking you and with your child to talk with us (in informal interviews) so that we can learn about decision-making in your child's health care. We would like to conduct two interviews with your child (with about two to four weeks between the interviews), and one interview with you and/or your child's other parent. The interview with you and/or the child's other parent will take place separately from the interviews with your child.

During informal interviews with your child, we will ask your child about his/her daily life and about the decisions that are made in relation to his or her chronic health condition. We may use drawing, play or other activities to assist your child to express what he or she thinks and feels. We expect that the interviews with your child take between 30 and 45 minutes each.

In our interview with you, you will be asked to tell us about your experience with your child's chronic health condition. We would like to hear about the decisions that have been made in the course of the illness, the resources you draw on, and the challenges you face in managing your child's health condition.

All interviews will take place at a time and in a place that is convenient for you and your child. The total time required for participation in this study is approximately 1 and 1/2 hours of your child's time, and 1 and 1/2 hours of your time. All interviews will be audio taped and transcribed. These transcripts will be used in the process of data analysis.

Throughout your participation in this project, you are free to refuse to answer any question. You can request that any taped information be erased or notes be destroyed. In addition, you may ask that sensitive information not be divulged. In our interviews with your child, we will ensure that your child knows that his/her participation is voluntary and that he/she is does not need to talk about anything that he/she does not wish to discuss.

When this part of the study if finished, you may be asked if you are interested in continuing in another segment of this study. Additional information about the second part of the study will be provided at that time, and you may chose to participate or not participate.

Confidentiality:
Your names will not be used in the transcripts of the tapes. Only a code number assigned to you and your child will identify your tapes and interviews. The tapes and transcriptions will be stored in a locked filing cabinet to which only the

research team has access. The tapes and transcripts will be destroyed five years after the completion of the study. The findings of the research may be published but your name will not be associated with the study. The researchers may use the data as part of another related study. In that case, confidentiality will be maintained as described in this consent.

Excerpts from your child's interviews may be used in presentations of findings. In this case, identifying features of the excerpts will be edited from the audio recording.

Risks and Potential Benefits:
There are no known risks to this project. If you agree to participate you will contribute information that may benefit other children with chronic health conditions and their families. When we are finished this project, you will receive a written summary of the results. There will be no monetary compensation for participation.

Contact for information about the study:
If you have any questions or if you would like information about this study, contact Gladys McPherson at (604) 948-1299.

Contact information about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598.

Consent

Your participation and the participation or your child in this study is entirely voluntary and you may refuse to participate or may withdraw from the study at any time without jeopardy to your child's health care. Your signature below indicates that:

a) You freely consent to your own and your child's participation in the study.
b) You give permission for the information that you provide and that your child provide to be used for presentations, publication in research articles/journal/books and teaching materials.
c) You understand that neither you nor your child waive any of your legal rights by signing this consent.
d) You have received a copy of this consent form.

Authorization for child's participation:

I, _____, have read the above information, have had opportunity to ask questions, and I consent/I do not consent to have my child, _____, participate in this study.

Name of person consenting (Please print): _____

Relationship to child: _____

Signature:_____ Date: _____

Consent to participation:

I, _____, have read the above information, have had

opportunity to ask questions, and I have decided to participate in this study.

Name of person consenting (Please print): _____

Signature: _____

Date: _____

Name of witness (Please Print): _____

CONSENT FORM – HEALTH CARE PROVIDERS

THE UNIVERSITY OF BRITISH COLUMBIA

School of Nursing
T201- 2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

Consent Form (Ref# 103)

Children's Participation in Chronic Illness Decision-Making

Principal Investigator: Dr. Sally Thorne
Director, School of Nursing
University of British Columbia
Telephone (XXX) XXX-XXXX

Co-Investigator: Gladys McPherson
Doctoral Student, School of Nursing
University of British Columbia
Telephone (XXX) XXX-XXXX
E-mail

You are being invited to participate in a research study in which we are investigating how decisions are made in the health care of children with chronic health conditions. This project is part of the co-investigator's (Gladys McPherson's) doctoral studies. It is funded, in part, by the Canadian Institutes of Health Research.

Purpose:
The purpose of this study is to get to know more about decision-making related to the health care of chronically ill children. We are particularly interested in children's contributions to health care decision-making—including what they think and feel about their health care and about the decisions that are made. We are also interested in how health care professionals endeavour to incorporate children's perspectives into decision-making processes.

You are being invited to participate in this research project because of your experience in providing health care to chronically ill children. We would like to hear what you

believe about decision-making with this group and your accounts of efforts to involve children in decision-making processes.

Study Procedures:
We are interviewing chronically ill children and their parents, listening to their perspectives on decision-making related to health care issues. These interviews and periods of participant observation are ongoing. We recognize the importance of health care professional perspectives on this issue and would like to like you to talk to you.

During the interview, you are free to refuse to answer any question. You can request that any taped information not be transcribed or notes be destroyed. In addition, you may ask that sensitive information not be divulged.

Confidentiality:

The interview will be tape-recorded and transcribed. To protect your anonymity and confidentiality, code names will be assigned to each group and pseudonyms (false names) will be substituted for your name and the names of anyone else mentioned in the discussion. All tapes, transcripts and consent forms will be kept in a locked filing cabinet in the project office. All tapes and transcripts will be destroyed after 5 years. The information gained from this research will be written up in publications and/or reports and these will be shared with university colleagues, members of the health provider and lay community. You may also read our report and request a summary of the results of the study.

We may want to use the data for secondary analysis in another study. If that happens, we will contact you for permission to use the information you gave us for that purpose.

Risks and Potential Benefits:
There are no known risks to this project. There will be no monetary compensation for participation.

Contact for information about the study:
If you have any questions or if you would like information about this study, contact Gladys McPherson at (XXX) XXX-XXXX.

Contact information about the rights of research subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (XXX) XXX-XXXX.

Consent

Your participation in this study is entirely voluntary and you may refuse to participate or may withdraw from the study at any time without jeopardy to your employment or practice. Your signature below indicates that:

- You freely consent to participate in the study.

- You give permission for the information that you provide in the focus group to used for publication in research articles/journal/books and teaching materials.
- You understand that do not waive any of your legal rights by signing this consent.
- You have received a copy of this consent form.

Consent to participate:

I, _____, have read the above information, have had

opportunity to ask questions, and I have decided to participate in this study.

Name of person consenting (Please print): _____

Signature: _____Date: _____

Name of witness (Please Print): _____

Signature (witness): _____ Date: _____

United Nations Children's Fund. (1989). Convention on the rights of the child.   Retrieved Oct.
    30, 2006, from http://www.unicef.org/crc/crc.htm