

PARENT-CHILD COLLABORATION IN HEALTH CARE DECISION MAKING:
PERSPECTIVES OF YOUNG PEOPLE WITH CHRONIC ILLNESS

by

Elana Jackson

Bachelor of Applied Science, Major in Child Youth and Family

University of Guelph, 2012

A Major Research Paper

presented to Ryerson University

in partial fulfillment of the

requirements for the degree of

Master of Arts

in the Program of

Early Childhood Studies

Toronto, Ontario, Canada, 2013

© Elana Jackson 2013

Author's Declaration

I hereby declare that I am the sole author of this major research paper. This is a true copy of the major research paper, including any required final revisions, as accepted by my examiners.

I authorize Ryerson University to lend this major research paper to other institutions or individuals for the purpose of scholarly research.

I further authorize Ryerson University to reproduce this major research paper by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

I understand that my major research paper may be made electronically available to the public.

Parent-child collaboration in health care decision making:
Perspectives of young people with chronic illness

© Elana Jackson 2013

Master of Arts
Early Childhood Studies
Ryerson University

Abstract

This study explores the perspectives of young people with chronic illness on their participation in health care discussions and decision making, with a specific focus on the role of parents in facilitating participation. Semi-structured interviews were conducted with 26 participants between the ages of 5 and 18. Participants were recruited from inpatient units at a pediatric hospital. A range of chronic illnesses were represented among members of the sample, including kidney failure, Crohn's disease, organ transplant, and sickle cell anemia. Following data collection, a focused analysis was conducted of participants' statements related to parent involvement in the health care decision making process. Salient themes that emerged from analysis of the data reveal a complex and bidirectional process in which young people and parents negotiate children's participation in making decisions related to their health care. Based on the findings, a collaborative-contextual model of decision making is proposed.

Keywords: Participation, children's rights, decision making, parent-child relationships, children, adolescents, chronic illness

Acknowledgements

Thank you to Dr. Donna Koller, who supervised this project, and Dr. Rachel Berman and Dr. Mehrunissa Ali for their insightful suggestions.

I gratefully acknowledge the support of the Social Sciences and Humanities Research Council and Ryerson University in funding my graduate work.

The original study described in this paper was funded by a grant from the Canadian Institutes of Health Research. To Donna Koller, David Nicholas, Katherine Covell, and Allan Coates, and the rest of the research team, thank you for generously granting me permission to analyze data from your original study.

Parts of this paper are adapted from previous work I completed as part of the MA program in Early Childhood Studies at Ryerson University.

Table of Contents

Introduction.....	1
Research Questions	4
Theoretical Framework.....	6
New Sociology of Childhood.....	6
Child Development	7
Bilateral Model of Parent-Child Relations	9
Literature Review.....	11
Scope of Literature Review	13
Benefits and Potential Drawbacks of Children’s Health Care Participation	15
Benefits.	15
Potential drawbacks.	17
Stakeholders’ Perspectives on Children’s Health Care Participation	19
Children’s perspectives on health care participation.	20
Parents’ attitudes toward children’s health care participation.	24
Health care providers’ attitudes toward children’s health care participation.	27
Methodology	31
Research Paradigm.....	31
Sample and Recruitment	32
Sample demographics.	32
Recruitment.....	33
Consent and assent to participate.....	33
Data Collection	34
Setting.	34
Interview protocol.....	34

Data Analysis	37
Data saturation.	40
Findings.....	41
Parent Takes the Lead	41
Minimal discussion of illness.....	42
Wanting to feel normal.	43
Child/Adolescent Takes the Lead	44
Ownership of health care needs	44
Recognition of evolving responsibility	45
Working Together	47
Partnership	47
Different perspectives	48
Determining the level of participation	49
Discussion	53
The collaborative-contextual model of pediatric decision making	53
Description of model.....	53
Findings in support of the collaborative-contextual model.	57
Implications for Practice	61
The role of the health care provider in facilitating participation.	61
Collaborative decision making as integral to ethical care.	64
Strengths and Limitations	66
Strengths	66
Limitations	67
Areas for Future Research	68
Conclusion	70

References	72
------------------	----

Introduction

The prevalence of childhood chronic illness in North America has increased dramatically in the last half century. While rates of childhood acute illness have declined with improved health care and medical technology, the same improvements have resulted in the survival of children with chronic conditions caused by congenital disorders, prematurity, and cancer (Halfon & Newacheck, 2010). As these children¹ progress through the health care system, they and their families confront complex and serious medical decisions in collaboration with their health care providers. When they reach adulthood, children with chronic illnesses become responsible for their own medical choices, and should have the skill and expertise to competently navigate their care. It is therefore critical that families and health care professionals provide opportunities for young people to develop health literacy and decision making skills during childhood and adolescence, to prepare them for future health care responsibilities.

In addition to this practical imperative, involving young people in medical decision-making acknowledges their right to voice their opinion on matters affecting them. This right is recognized by Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) (1989), which mandates that signatory countries “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.” Scholars and professionals in the health care field have interpreted this provision as conferring on children the right to be involved in making decisions about their health and well-being (Moore & Kirk, 2010).

¹ In this paper, the terms “children” and “young people” refer to individuals between the ages of 0 and 18.

The ethical and practical obligation to involve young people in medical decision making is constrained by the political dynamic surrounding children's citizenship rights in North America. James, Curtis, and Birch (2008) explain that within this dynamic, children are constructed as requiring 'protection' due to their (presumed) inherent vulnerability. Policy directives give parents and other adults responsibility for children's care, allowing them to make decisions on their children's behalf. In contrast to this discourse of 'protection' is an approach relating to children's 'participation.' Child sociologists and theorists such as Qvortrup, Alanen, Corsaro, and James (see Qvortrup, Corsaro, & Honing, 2009) argue that children are not inherently vulnerable and naïve. Rather, they are competent individuals who should be valued and respected as full human beings, allowed to make choices, take risks, and actively participate in matters affecting them.

This conflict pervades the hospital context, where parents and health care providers, following a discourse of protection, may restrict children's participation in receiving medical information and making medical decisions (James, Curtis, & Birch, 2008). Alternately, there are parents and health care providers who recognize children's agency and are open to children's participation. Yet, they may struggle to provide opportunities to involve children in their medical care in ways that respect their preferences and abilities (Coyne, 2006; Coyne & Harder, 2011; Runeson et al., 2001). Further complicating this debate is the position of the young person with a chronic illness, who may or may not have a desire to participate in making medical decisions.

As the discourses of protection and participation collide around families and health care providers, parents and health care practitioners are left feeling conflicted as to how they can include children in health care decision making in a way that best addresses children's rights, abilities, and desires (James, Curtis, & Birch, 2008). An examination of how young people with

chronic illness experience and perceive their participation in medical decision making is a potent starting point for addressing the issues outlined above. This research can inform health care policy and practice by identifying how the discourses of protection and participation may be balanced in a way that respects children's rights and abilities. This research can also inform guidelines to assist parents and health care providers in facilitating children's health care participation.

Research Questions

The purpose of this study is to examine the perspectives of young people with chronic illness with regard to their health care participation. This involves activities such as communicating with health care providers, making health care decisions, and discussing their illness with family members. Of particular interest are participants' experiences negotiating aspects of health care participation with their parents and family members. This study is part of a larger research project funded by the Canadian Institutes of Health Research led by Donna Koller, David Nicholas, Katherine Covell, and Allan Coates, which was completed in 2011 at a large pediatric hospital in Toronto, Canada. The purpose of the original research project was threefold:

1. To examine the extent of children's participation in medical decision making and health care discussions, from their perspectives.
2. To determine if children feel they receive adequate medical information from parents and health care providers.
3. To investigate issues experienced by children as they participate in self-care activities and communicate with health care providers

For the purpose of this Major Research Paper, a secondary analysis of the original data set was undertaken. Given my research interests and prior research experience, I chose to focus on the parent-child relationship and examine how children with chronic illness negotiate decision making within their families. I conducted a thematic analysis (Braun & Clarke, 2006) of all interview transcripts, exploring the ways in which children described their experiences of negotiating, and discussing, health care participation with parents and family members. The specific research questions for this secondary analysis were as follows:

1. How do young people with chronic illnesses perceive the role of their parents in enabling and/or constraining their health care participation?
2. Do young people with chronic illnesses feel that their parents enable their health care participation to the degree children desire?
3. How do young people with chronic illnesses describe negotiating or discussing their health care participation with parents?
4. What factors influence young people's preferences for participation, and the quality of participation they experience?

Theoretical Framework

The key theoretical framework informing this study is the ‘new’ sociology of childhood, an interdisciplinary field of research that emerged in the 1980s as researchers began to examine childhood as a social construct (Honig, 2009). The new sociology of childhood, a field which views knowledge as socially constructed, stands in contrast to the field of child development, which follows a positivist tradition (Corsaro, 2011). The field of child development views children as immature humans who develop along a linear and predictable path of development toward adulthood (Penn, 2008). Given the prominence of these two frameworks in the research literature on pediatric experiences, both were considered in the design and analysis of this study. Additionally, the bilateral model of parent-child relations (Kuczynski, 2003) was chosen to provide a theoretical framework for examining parent-child relationships. The bilateral model considers how parents and children mutually influence the beliefs and behaviours of the other, within the context of an intimate, long-term relationship.

New Sociology of Childhood

At different times in history, children have been perceived as passive, innocent, delinquent, or vulnerable (Hendrick, 1990). Scholars in the ‘new’ sociology see children as social actors. Though they share an unequal balance of power with adults in their lives, children are nonetheless capable of agency and social influence (Matthews, 2007). Researchers working in the field of the new sociology recognize children and childhood as important subjects of study in their own right. Prout (2000) thus argues that “there is merit in understanding children’s lives because their present being matters as much as their future becoming as the next generation of adults” (xi). In addition to being worthy subjects of study, children are also understood to be experts on their own lives, and should be consulted directly in research studies. Researchers working from this paradigm therefore strive to conduct research “with” children, rather than “on”

children, by using participatory research techniques (Punch, 2002). Participatory techniques not only allow children to be more actively involved in data generation, but enhance their engagement, sense of control, and ability to express their ideas as participants in research studies (Carter & Ford, 2013). Researchers aligned with this framework further recognize children's agency by requiring their informed consent to participate in research (Punch, 2002).

The framework of the new sociology of childhood has been drawn on extensively in research examining children's experiences of illness and hospitalization (Kirk, 2007). This emerging body of research positions children as key informants and stakeholders in the study of pediatric health. It is motivated by both the new sociology of childhood and the mandate of the United Nations Convention on the Rights of the Child (Coyne, 2008). Through this lens, researchers have examined children's feelings about hospital life (Coyne & Kirwan, 2012); their hospital-related fears (Salmela et al., 2011); their perceived involvement in communication with hospital staff (Lambert et al., 2008); and their preferences for participation in medical self-care (Newbould et al., 2008). Together, findings from these studies support the assertion that young people have thoughtful opinions on their lived experiences and have a desire to express those opinions and have them heard. Child-centred health research respects children's participation rights and rightfully acknowledges them as "present and future health care consumers" (Coyne, 2008, p. 1683).

Child Development

Theories of child development attempt to explain the universal and linear ways in which children develop their cognitive, socio-emotional, and physical abilities. The work of Piaget focuses on children's cognitive development through sequential stages and has been a particularly influential theory of child development (Rathus, 2008). Piaget posited that children

advance through four stages of cognitive development: sensorimotor, preoperational, concrete operational, and formal operations. Through his work, he connected each stage of development to an age range, and hypothesized that children's cognitive abilities become more complex as they gain experience manipulating objects in their environment and thereby construct a sense of their natural world (Rathus, 2008). According to Piaget, children only became capable of abstract thought when they reach the formal operational stage of cognitive development, which begins around age 11. This stage is characterized by a capacity for more complex thinking, such as hypothetical thinking, understanding metaphors and abstract concepts, and more sophisticated problem solving (Arnett, 2007).

Piaget's theory of cognitive development is problematic when applied to children's participation in personal decision making because it generally underestimates young children's cognitive and empathetic abilities. Piaget's work has been criticized for overlooking individual differences in the attainment of cognitive development and for largely ignoring cultural variation in how children from diverse backgrounds acquire knowledge and develop problem solving skills (Arnett, 2007). Despite these criticisms, his work is cited in research on children's participation in medical decision making as a framework for determining children's competence to make decisions (Hunfeld & Passchier, 2011).

There *is* evidence in the research literature to support a positive correlation between age and ability to make competent medical decisions (Mårtenson & Fägerskiöld, 2008). However, researchers have been unable to tie an exact age or age range to children's competence, due to diverse factors such as child's previous medical experience, knowledge of illness, prior opportunities for participation, individual variation in cognitive abilities, and nature of the decision (Moore & Kirk, 2010). In support of child development theories, there appears to be a

correlation between cognitive ability and capacity to make competent medical decisions. Conversely, situational factors and individual variance must also be carefully examined to determine a child's actual abilities in a given medical situation. Despite the controversies surrounding Piaget's theory of cognitive development, it remains a useful framework from which to examine children's participation in health care decision making.

Bilateral Model of Parent-Child Relations

Kuczynski's (2003) bilateral model of parent-child relations provides a micro-level analysis of the ways in which culture and power interact to determine how children develop and gain agency within parent-child relationships. The bilateral model assumes that parents and children are equally active agents within a long-term, enduring, close relational context. They mutually influence one another as they react to and respond to changing characteristics and actions of the other. While each party has the capacity to express agency through action, this model recognizes that power within the relationship is asymmetrical, with parents typically holding the majority of power.

Kuczynski (2003) claims that parents and children make use of three types of resources to gain power in their relationship: individual resources (such as physical strength, expertise, and cognitive abilities), relational resources (including the ability to proffer love and intimacy), and cultural resources (the constraints and rights available to parents and children that are legitimated through law or cultural custom). Within parent-child relationships, both parents and children continuously work within, and push against, the boundaries imposed by culture and policy. Together, they construct meaning and determine power in their relationship based on their past relational history as well as the resources each member brings to the relationship. In terms of children's participation in medical decision making and communication, Kuczynski's model

offers a valuable perspective from which to examine the contributions of both parents and children to the decision making process.

Literature Review

Introduction

This literature review will examine research on the participation of children and adolescents in health care discussions and decision making. Historically, patients in the health care system – adult patients and children alike - were excluded from health care discussions (Kon, 2010). Until the twentieth century, paternalism was the prevailing approach to patient decision making in the health care system (Kon, 2010). The health care provider was understood to be the ‘caretaker’ of the patient’s interests, and held the right to make decisions on the patient’s behalf (Sandman & Munthe, 2010). Over the course of the last century, two approaches to patient decision making have emerged which grant patients considerably more involvement in making decisions. The autonomous model of decision making stands opposite to the paternalistic model. Also known as “patient-driven” or the “consumer model,” this approach provides the patient with the ultimate authority in making decisions about his or her care (Kon 2010; Sandman & Munthe, 2010). The third model occupies a place in the middle of the paternalistic-autonomous continuum. According to the shared decision making model (SDM), the final decision for health care treatment is mutually agreed upon by the health care provider and patient. As well, both the patient and the health care provider actively participate in the decision making process (Sandman & Munthe, 2010). SDM aligns well with the ideology of patient-centred care that has been embraced by the health care sector (Sandman & Munthe, 2010). This model has also been popularized due to research suggesting it leads to better physical and psychological health outcomes for patients (Hack et al., 2006; Joosten et al., 2008).

The three models of health care decision making have typically been applied to and researched with adult populations. However, researchers have recently begun to consider how models of decision making can be examined with pediatric populations, with the goal of

identifying models that lead to positive health outcomes and increased patient satisfaction. Specifically, scholars studying pediatric experiences have begun to advocate for the shared decision making model to be used more widely in pediatric health care (Coyne et al., 2013; Curtis-Tyler, 2011; Miller, 2009). Coyne and colleagues (2013) trace this growing support for children's involvement in decision making to policy documents like the UNCRC and research findings that point to the positive effect of participation on children's self-esteem, preparedness, and decision-making abilities.

A gap of this research is that the shared decision making model applies differently to adult and pediatric populations. When a health care decision is being considered for a child, a parent or guardian is necessarily involved. In pediatrics, the decision making dyad of doctor and patient becomes a triad. The decision making process becomes potentially more complicated as the concerns and preferences of a third stakeholder are added. Clemente (2009) refers to this dynamic as “a dance of three partners” (p. 873), with each partner perceiving the decision making environment differently depending on their own perspective and agenda. Yet when analyzing this process, researchers typically focus on interactions between the physician and child or physician and parent (Clemente, 2009). Clemente proposes that the parent-child relationship is worthy of further study, particularly because parents can assist children to participate more fully in pediatric encounters.

In addition to the obvious consequences of involving a third stakeholder in health care decision making, the involvement of pediatric clients is complicated by political tensions related to the participation of children in decision making processes. Lee (2001) traces the historical roots of the modern-day model of decision making between parents and children to seventeenth-century Europe. With the rise of the ‘modern’ state, children came to be seen as investments and

resources to serve the state's economic and military goals. Adult authority over children became legitimated, with parents in particular being deigned responsible for much of children's socialization, or 'proper' development (Lee, 2001). This construction of children as dependent on adults continues to influence parent-child relationships and decision making processes (James, Curtis, and Birch, 2008). Yet, with increasing popular support for children's rights and greater recognition of the importance of children's health care participation, this construction has encountered some dissidence. Today, parents, children, and health care providers hold varying perspectives on the appropriateness of children's participation in health care discussions and decision making. They are influenced by the historical constructions of children's dependence, as well as their own lived experiences and personal encounters with illness (Mårtenson & Fägerskiöld, 2008). Canada is a signatory to the United Nations Convention on the Rights of the Child (1989), but adherence to the Convention is difficult to enforce and has been unevenly adopted by Canadian social systems, including health care, child welfare, and education (Canadian Coalition for the Rights of Children, 2011; Garbarino, 2011). Within this historical and political account, this literature review will examine the perspectives of children, parents, and health care providers with regard to children's health care participation.

Scope of Literature Review

This literature review will explore the perspectives of children, parents, and health care providers on children's health care participation. Of particular interest are the positive and negative outcomes of children's health care participation according to the perspectives of health care providers, parents, and children themselves. As well, the facilitators and barriers to children's participation will be examined with regard to each of these three stakeholder groups. This literature review will focus on children's participation in health care discussions and

decision making, although broader aspects of patient participation will also be considered.

Schmidt, Petersen, and Bullinger (2003) define *patient participation* as:

a patient's active role in the diagnostic and therapeutic process not only as concerns the more passive concept of compliance but also as concerns the more active concept of exerting control, taking part in the choice of treatment options, [and] engaging in self-management strategies with regard to desired health outcomes. (p. 71)

The majority of studies considered in this review were conducted in the United Kingdom, Scandinavian countries and the Netherlands. Few studies on children's participation in health care discussions and decision making have been conducted in North America (see Moore & Kirk, 2010). Of the studies conducted on this topic, most follow cross-sectional, qualitative research designs. In systematic literature reviews on this topic conducted by Moore and Kirk (2010) and Mårtenson & Fägerskiöld (2008), 20 out of 25 studies, and 11 out of 15 studies, respectively, used qualitative designs. The present literature review reflects a similar pattern.

The following electronic databases were searched: Academic Search Premier, Proquest Research Library, PsycINFO, Scholars Portal Journals, and Medline. Search terms used included: children, adolescents, parents, doctors, physicians, nurses, health care providers, chronic illness, chronic health condition, pediatrics, paediatrics, hospital, decision making, communication, self-management, self-care, involvement, participation, medical, and health care. Reference lists of select articles were reviewed for additional studies. Approximately 50 peer-reviewed articles were selected for inclusion in this literature review. Selected studies were published between 2000 and 2013 (with the exception of one article from 1996).

Benefits and Potential Drawbacks of Children's Health Care Participation

Benefits.

Findings from research with adults. To my knowledge, no experimental or quasi-experimental studies have been conducted that specifically examine the outcomes of children's participation in health care discussions and decision making. In comparison, outcomes associated with adult health care participation have been researched more extensively. Though it is unclear whether the same mediators and outcomes can be associated with children's participation, this research indicates potential benefits of participation and important areas for future research. Research with adult patients has linked participatory doctor-patient interactions to better patient emotional health, functional status, and pain control (Roter, 2000). Adult patients who perceive effective communication from health care providers are more satisfied with their medical care, are more likely to adhere to prescribed treatment, and experience less psychological distress (Ha & Longnecker, 2010; Roter et al., 1995). Similar benefits have been found with regard to adult participation in health care decision making. For instance, active participation in health care decision making has been correlated with improved patient physical functioning, increased self-confidence, feelings of empowerment, and better adjustment to the medical situation (Hack et al., 2006; Jagosh et al., 2011, Sahlsten et al., 2008).

Confidence and self-esteem. A review of the research on outcomes of children's health care participation indicates that much of the research is descriptive, from parents' perspectives, and focuses primarily on the psychosocial benefits of health care participation for children (Moore & Kirk, 2010). For instance, Coyne (2006) found that parents associated children's participation in making medical decisions with enhanced self-esteem and self-regard. Parents in Miller's (2009) study also described psychosocial benefits of participation for children, such as

increased sense of autonomy and control. As well, these parents perceived children's participation as providing psychosocial benefits to all family members. Parents who collaborated in making health care decisions with their children reported feeling closer as a family and 'happier' when everyone knew what was going on.

Children's involvement in health care discussions may boost feelings of self-esteem and self-regard by allowing them to feel respected by health care providers. Youth participants in several qualitative studies have reported that participation in health care discussions and decision making made them feel valued and recognized by hospital staff (Coyne, 2006; Van Staa, Jedeloo, & van der Stege, 2011; Zwaanswijk et al., 2007). Children interviewed for these three studies were between the ages of 8 and 19, and with the exception of participants in Coyne's (2006) study, were hospitalized with a chronic illness or cancer. Related to the previous finding is children's desire for relationship-building interactions with health care providers. Participants in these studies indicated that they appreciated health care providers' efforts to talk about hobbies and interests, facilitate discussion around concerns, and make fun with patients. These types of interactions allowed children to feel more comfortable approaching their health care providers, in turn enhancing their involvement in health care discussions and their confidence in disclosing health-related information.

Enhanced knowledge. In addition to identifying the psychosocial benefits of children's health care participation, parents emphasized the health-related knowledge and skills children gain as an important outcome of their health care participation. In Miller's (2009) study, parents listed increased knowledge and decision-making skills as important benefits of collaborative decision making with children. Children reported similar outcomes, explaining that as a

consequence of being included in health care discussions, they felt better equipped with the knowledge and vocabulary needed to communicate with health care providers.

Enhanced knowledge through health care participation may ease children's feelings of anxiety relating to their illness and treatment. For instance, participants in Kelsey and colleagues' (2007) study indicated that involvement in decision making reduced their feelings of anxiety and fear. Participants, who were adolescent inpatients on an acute pediatric ward in a British hospital, reported that they felt better when they were able to ask questions and discuss their treatment and care. In contrast, children who were excluded or minimally addressed during health care discussions reported feeling confused, upset, and angry over the lack of shared information (Coyne, 2006).

Preparation for adulthood. Coyne and Harder (2011) draw attention to children's health care participation as integral to the development of decision making competency. They argue that "children need opportunities to learn how to participate in decision making over a period of time and in various situations" (p. 316). Reflecting this assertion, adolescent participants in Viklund and Wikblad's (2009) study reported that opportunities to learn about their illness, make mistakes, and practice self-care tasks were essential to the development of their ability to manage type 1 diabetes. Indeed, both parents and children with chronic health conditions have indicated that slowly increasing self-care and decision making responsibilities over time eases young people's transition to adult health care (Giarelli et al., 2008; Meah et al., 2009; Schilling et al., 2006).

Potential drawbacks.

Anxiety. The drawbacks of children's health care participation have also received little attention in the research literature (Moore & Kirk, 2010). Despite the limited research in this

area, it is important to provide a critical review concerning both the positive and negative outcomes of children's health care participation. Again, most of the findings on negative outcomes relate to children's psychosocial functioning. For instance, some children have reported that participating in health care decision making renders them anxious and scared, and that they would rather leave the "serious" decisions to their parents and doctors (Coyne & Gallagher, 2011). Children may also feel pressured to participate in decision making or be afraid to express their true views due to skepticism over patient confidentiality (Terry & Campbell, 2001). For example, a participant in Kelsey and colleagues' (2007) study expressed concern that his parents would feel "shut out" if he were to take greater ownership of decision making and communication with doctors.

Conflict with parents. Children's participation in health care discussions and decision making poses a potential threat for conflict when parents and children disagree on a course of treatment or division of responsibilities. Indeed, several studies involving adolescents with chronic health conditions have described discussions around self-care and decision making responsibilities as sources of conflict between adolescents and parents (Dashiff, 2003; Sawyer & Aroni, 2005; Williams, 2000). Lindsay and colleagues (2011) explain that such conflict may arise when parents and children differ in their understanding of priorities and division of responsibilities for self-care management. Elsewhere, researchers have reported that parents may limit children's participation in health care discussions and decision making specifically to prevent further parent-child conflict (Dashiff et al., 2009). Preliminary findings from recent studies suggest that parent-child conflict around chronic health issues may act as a moderator of other negative health outcomes. For instance, research with adolescents with diabetes has linked diabetes-specific family conflict to poor diabetes management (Hood, Odell, & Sander, 2010).

Feeling ignored and devalued. From the available research, psychosocial outcomes of decision making can be dependent on the climate of support surrounding the child in enabling their participation. In other words, the research seems to indicate that children are more comfortable participating in decision making when their involvement is encouraged and genuinely accepted by parents and health professionals (Moore & Kirk, 2010). When children's participation is discouraged, or their opinions are solicited but then effectively ignored, children feel devalued, disrespected, and upset (Moore & Kirk, 2010). Miller (2009) examined how parents and children (ages 8-19) with chronic illnesses negotiate decision making. She found that though parents are open to children's participation, they often ask for children's opinions even when they don't intend to honour them or take them seriously. Miller reasons that such behaviour discourages children's active involvement in future discussions and decreases their sense of control over their illness.

Stakeholders' Perspectives on Children's Health Care Participation

Researchers have examined the perspectives of children, parents, and health care practitioners on children's participation in medical decision making and communication. Studies have reported on the extent of children's participation and facilitators and barriers toward greater involvement. Most of the research relating to *children's* perspectives on children's health care decision making and communication has used qualitative methodologies. In particular, much of the data has been collected through semi-structured interviews and non-participant observation (Moore & Kirk, 2010). Qualitative studies conducted with children have employed a variety of child-centred techniques, including drawing (Lambert, Glacken, & McCarron, 2008), sentence completion (Coyne & Kirwan, 2012), photography, and play-based discussions (Curtis-Tyler, 2012). There appears to be a clear tendency toward qualitative, participatory research methods in

the literature on children's health care participation. Carter and Ford (2013) explain that many researchers examining this topic adhere to an "emancipatory, rights-based, empowering, ethical and participatory paradigm" (p. 96); a paradigm which aligns well with the use of qualitative, participatory techniques.

Though the majority of research in this area has employed qualitative approaches, a few studies have examined children's participation in medical decision making and communication using quantitative methods. Scales such as the Decision-Making Involvement Scale (DMIS) have been used to evaluate the involvement of children with chronic illness in medical decision making, according to the perceptions of children and parents (Miller & Harris, 2012). Several researchers have employed quantitative video analysis to examine communication patterns between parents, physicians, and children during clinic and hospital visits (Stivers, 2012; Van Dulmen, 2004; Cahill & Papageorgiou, 2007). Questionnaires have been used to assess the perspectives and attitudes of parents, children, and health care providers towards children's participation in pediatric environments (Vaknin & Zisk-Rony, 2011; Van Staa, 2011; André et al., 2005; Devine et al., 2010). Findings from these studies will be reported in the following sections.

Children's perspectives on health care participation.

Children's preferences. Research on children's perspectives on health care decision making and communication has explored their preferences for participation and their perceptions of the barriers and facilitators towards involvement. In their meta-analysis of the literature on children's participation in health care decision making, Moore and Kirk (2010) found that across studies, most children wanted to be involved in health care discussions and decision making with family and health care providers. Shared decision making involving parents and health

professionals was preferred by the majority of children, in comparison to the few who desired no involvement or independent involvement. Interestingly, the authors identified very few studies that directly asked children if they would *like* to be involved in making medical decisions. Rather, most of the studies described in their review looked more generally at children's experiences communicating with health practitioners and family regarding health care issues and concerns.

Like Moore and Kirk, Jedeloo and colleagues (2009) propose that there is no "one size fits all" approach to establishing young people's preferences for health care participation. In their study of adolescents with chronic health conditions, Jedeloo et al. identified four general profiles representing participants' preferences for health care involvement. These profiles included the "conscious and compliant" adolescent, who prefers active involvement with parents and health care providers in disease management; the "backseat patient" who is minimally involved in their own health care management and defers responsibility to parents; the "self-confident and autonomous" patient who has a strong desire to be autonomous in decision making; and the "worried and insecure" adolescent who is reticent in their health care management and wants to avoid thinking about the future and the transition to adult care (p. 598). The authors did not report on the distribution of profiles among participants in the study. However, a consistent finding among participants was the desire to have a say in important treatment-related issues.

Children's perceptions of the parental role in facilitating health care participation.

Children identify the parent-child relationship as an important factor in their ability to participate in health care discussions and decision making. According to Miller (2009), children with chronic illnesses have described consciously avoiding health-related discussions with parents when they see parents are in a bad mood or they perceive a possibility of parent-child conflict.

Conversely, children reported being more likely to engage parents in decision making when parents have a strong marital relationship and the child perceives the parent to be open and trusting (Miller, 2009). A strong parent-child relationship has also been correlated with children's participation in diabetes self-care (Hanna et al., 2003; Wiebe et al., 2005), children's adherence to treatment regimes (DiMatteo, 2004), and adolescents' medical decision-making competence (Viklund & Wikblad, 2009).

Children are keenly aware of their parents' role in enabling their participation in health care discussions and decision making. School-age and adolescent participants in Young and colleagues' (2003) study characterized their parents as assuming five roles in helping them navigate encounters with health care professionals. Participants, who were inpatients on a pediatric oncology unit, described parents as "envoys" who relayed questions to health care providers; "buffers" who sheltered them from burdensome questions; "databases" who shared medical information, "facilitators" of communication between health care providers and themselves, and "brokers" who clarified or repeated information stated by health care providers (p. 2). Despite appreciating the efforts of parents to explain medical information, participants in the study differed in satisfaction regarding their level of participation in decision making and communication. Some endorsed their parents' efforts to limit their exposure to medical information, while others expressed concern that parents were withholding information children felt they had a right to know. Taken together, this research reflects the many nuances reported in the literature regarding children's diverse perspectives on health care participation.

Children's perceptions of the health care provider role in facilitating their health care participation. In addition to their perceptions of parents' roles, researchers have examined the views of children regarding how health care providers facilitate their involvement in health care

discussions. Lambert, Glacken, and McCarron (2008) examined the communication preferences of 49 children ages 6 to 16 on a general pediatric ward in Ireland. When physicians and nurses communicated directly with children, actively listened, and relayed information clearly, participants reported feeling respected and were observed to participate more actively in discussions with health care providers. A similar study by Kelsey, Abelson-Mitchell, and Skirton (2007) explored the hospital experiences of ten children ages 13 to 16 in the UK. Participants shared a preference for being included in discussions where health care providers and parents were both present, and indicated a desire for information to be shared at a level they could understand.

The interpersonal qualities of health care providers influence how comfortable young people feel communicating with them. In a quantitative study of the communication preferences of parents and their adolescent children with chronic illnesses, adolescent participants rated the importance of various qualities in a health care provider. Honesty, confidentiality, having good medical knowledge, and possessing good listening skills were rated as the most desired qualities (Farrant & Watson, 2004). Participants were 45 parents and 53 adolescents, between the ages of 13 and 18, who attended pediatric outpatient clinics in New Zealand. In a qualitative study, similar findings were shared by Beresford and Sloper (2003) where adolescents with chronic illnesses reported feeling more comfortable communicating with health care providers who have good communication skills, respect their need for privacy, and avoid coming across as intimidating or condescending. For these participants, the presence of a parent during doctor visits was alternately seen as supportive or inhibitive, particularly when parents dominated the conversation. The sample consisted of 63 chronically ill adolescent outpatients ages 11 to 16 in the United Kingdom.

Parents' attitudes toward children's health care participation.

Parents' role perception. Parents' experiences in pediatric decision making and communication can be examined two ways: how parents perceive their role in making decisions for their child, and how parents perceive their role in facilitating their *child's* involvement in decision making and communication. Lipstein and colleagues (2011) suggest that parents perceive themselves as taking on an active role in making decisions for their child with a chronic illness. This may be due to the finding, reported by Merenstein and colleagues (2005), that parents feel more satisfied with active involvement in decision making, compared to passive involvement. In their literature review on pediatric decision making, Lipstein and colleagues found that across studies, parents prefer to be actively involved in discussions with health care providers, and favour shared decision making models over autonomous or paternalistic approaches. However, parents' preferences for involvement in decision making do vary depending on the clinical decision, their relationship with the health care provider, and influence from their social network (i.e. opinions of other parents, school staff, or advocacy groups) (Lipstein et al., 2011).

Similarly, when facilitating their child's involvement, role perceptions across groups of parents show greater variability. Parents of pediatric cancer patients have described themselves as "executive" managers for their children's care, determining when and what medical information is relayed to them (Young et al., 2003). Elsewhere, parents have discussed being more open to sharing information, stating their desire to involve children in decision making and management of their chronic illness (Coyne, 2006; Miller, 2009; Palmer et al., 2004). Nonetheless, it is important to note that parents within these studies varied greatly in the amount of information they chose to share with children, the types of decisions they encouraged children

to participate in, and how they perceived their role in facilitating communication between their child and health care providers.

Factors affecting parental support for children's participation. A child's age may affect how parents perceive their role in supporting the child's involvement in health care communication and decision making. For instance, parents of preadolescent children with diabetes perceive their role to be that of a "dominant" manager (Schilling, Knafl, & Grey, 2006), while mothers of adolescents with diabetes report high role ambiguity as their child transitions to adult services (Allen et al., 2011). However, parents in Coyne's study (2006) stated that because their children often behave younger or older than their chronological age, parents relied on their relational knowledge of their child, rather than their age, to determine how to involve them in health care discussions and decision making. Similarly, Kieckhefer and colleagues' (2009) suggest that a child's age is not a strong indicator of parental willingness to involve children in medical communication and illness management. In their study, complexity of the child's chronic illness was a stronger predictor than age of shared management with parents. A more severe medical condition, having a developmental or behavioural condition in addition to the chronic illness, and having at least three emergency room admissions in the previous six months were all factors associated with less child involvement.

Further examination of parents' motivations for including children in medical communication and decision making reveals a complex process mediated by parents' fears, hopes for their child, and needs for control. For instance, Palmer and colleagues (2004) reported that mothers' primary reason for transferring diabetes responsibility to their children was to promote the child's maturity and health management skills. Parents in Miller's study (2009) revealed that they sometimes involve children in decision making to increase their compliance

with a decision. For instance, parents stated that they might speak negatively about certain options to make their preferred choice appear more attractive to the child. Coyne (2006) described how some parents constrained their hospitalized child's involvement in health care discussions and decision making, out of concern that involvement would provoke feelings of anxiety in their child.

Practical concerns also influence parental support for children's health care participation. For example, parents in Miller's (2009) study indicated that they were less likely to engage children in health care discussions when a decision needed to be made quickly. In those instances, parents either made decisions unilaterally, or, for minor decisions, 'gave in' and allowed the child to decide. Another practical factor described by parents relates to the child's intimate knowledge of their illness. Parents in Coyne's (2006) study said that involving their child in health care discussions was necessary simply because their child was best acquainted with how to do certain procedures, and was solely capable of describing their own symptoms.

Researchers have investigated the factors associated with diminished parental support for child involvement in health care discussions and decision making. Video analyses of parent-child-physician interactions indicate that parental needs for control may impact how parents facilitate children's involvement in medical visits. During consultations with doctors, parents have been observed frequently interrupting their children and answering physicians' questions directed at children (Cahill & Papageorgiou, 2007; Tates & Meeuwesen, 2000). These studies were conducted in the United Kingdom and The Netherlands, respectively. Parents may attempt to take control of their child's medical visit to ensure that physicians receive the information they feel is necessary for adequate diagnosis or treatment (Tates & Meeuwesen). Cahill and Papageorgiou posit that when parents are able to voice their concerns early on in the

consultation, they feel secure in their role and are thus more agreeable to children interacting with and responding to the physician.

Concerns around confidentiality are a related factor affecting parental support for children's participation in health care discussions. Parents of adolescent hospital outpatients reported that they are not always comfortable with their children speaking to health care providers independently, and worry that information will be withheld from them (Byczkowski et al., 2010). However, parents of chronically ill children and adolescents have also spoken of a need to nurture children's independence and prepare them for taking greater responsibility for their health (Giarelli et al., 2008).

A review of the literature highlights additional factors related to parental support of child participation in medical decision making. These include: length and severity of child's illness; parenting style and cultural beliefs surrounding children's involvement in decision making; and parents' own desires for gaining information and being involved in their child's health care (Coyne, 2008). According to Angst and Deatruck (1996), the type of decision will also influence parental views on child involvement. They identify three factors that influenced perspectives on involvement for parents of children with cystic fibrosis. These factors are: whether multiple options are available; whether consequences of making the wrong decision are serious, and whether parents had previous positive experiences involving their child in medical decision making.

Health care providers' attitudes toward children's health care participation.

Researchers have examined how practitioners involve children in making decisions, whether they believe that children should be making medical decisions, and what criteria should be used to determine if a child is capable of making competent medical decisions (Coad & Shaw,

2008). Findings demonstrate mixed support for children's participation. McPherson and Redsell (2009), in their study of children's involvement in asthma consultations with doctors and nurses, found that practitioners varied widely in their approaches to child involvement. While many of the practitioners spoke about involving pediatric patients in the consultation, offering choice and opportunities to voice opinion, other practitioners reported seeking less involvement, particularly with younger patients. Given the preliminary nature of their study, McPherson and Redsell suggest that more research is needed to understand why some practitioners are more supportive than others of children's involvement in health care discussions.

Factors affecting health care provider support for children's health care participation.

McPherson and Redsell (2009) reported that a child's age and cognitive ability were the two most important factors identified by respondents in terms of influencing the practitioner to involve children in the medical consultation. Several other studies have confirmed that health care providers perceive the child's age and cognitive ability as influential determinants of participation (Coyne, 2006; Vaknin & Zisk-Rony, 2011; Runeson et al., 2001). Qualitative and quantitative studies have revealed other criteria health care providers use to determine a child's ability to participate in health care discussions and decision making, including: child's attitude, severity and length of illness, type of medical intervention, and presence of chronic illness (Coyne, 2006; Vaknin & Zisk-Rony, 2011). Video analyses of patient-health care provider interactions have shown that health care providers interact more frequently with older children (Tates & Meeuwesen, 2000; Van Dulmen, 1998) and children of university educated parents (Cox et al., 2009). Cox and colleagues (2007) found that girls interacted more frequently with physicians during pediatric visits compared to boys, while Van Dulmen (1998) reported that boys communicated more actively with physicians during pediatric visits, compared to girls.

Parents also play a role in influencing health care providers' attitudes towards children's health care participation. Health care providers have reported that fears around creating conflict with parents constrain their ability to involve child and adolescent patients in consultations. In one study, physicians, nurses, and social workers described being wary of interfering in parent-child relationships, and were hesitant to see adolescent patients independently lest parents complain (Van Staa, 2011). Coyne's (2006) examination of nurses' perspectives on children's participation in healthcare settings yielded similar results. Nurses explained that whether they felt compelled to actively involve children was highly dependent on whether parents supported or disapproved of children being involved in making medical decisions. Similar to the findings reported by Van Staa, nurses in Coyne's study explained that they might avoid involving children in consultations and care if it would become a source of conflict between nursing staff and parents.

Summary

Taken together, this review of the literature suggests that children's, parents' and health care providers' attitudes towards children's health care participation are dependent on a myriad of factors. Cultural beliefs around parent authority and children's competence likely influence stakeholders' attitudes towards children's health care participation, yet there is little discussion in the research literature related to the role of culture in facilitating or constraining children's participation in health care discussions and decision making. However, it is clear that situational factors influence the extent of children's health care participation, with parents and health care providers playing an important role in creating opportunities for children's involvement. The limited research available suggests that promoting children's participation in health care discussions and decision making can lead to positive psychosocial outcomes for children,

facilitate the development of children's decision making skills, and increase their health-related knowledge. Few studies have examined this topic from the perspectives of young people themselves, and more research is needed to understand how children negotiate their health care involvement with parents.

Methodology

Research Paradigm

The social constructivist worldview is the research paradigm guiding the design of this study (Creswell, 2009). This paradigm posits that individuals make meaning of their experiences through social interactions with others. Individuals are also influenced by the cultural and historical norms that organize their social lives and the social contexts in which they are situated. Given the variation in norms and practices across time and culture, making meaning of one's lived experience becomes a highly subjective and individual experience. Researchers who seek to gain understanding about the lives of others must account for such diversity of experience by considering the complex social and historical influences that contribute to an individual's interpretation of his or her experiences (Creswell, 2009, p. 8). Social constructivist researchers typically use qualitative research approaches. Qualitative approaches offer researchers detailed insight into participants' unique perspectives on their world. Through qualitative methods, researchers and participants can explore how their experiences and beliefs are shaped by the social world around them (Creswell, 2009).

The social constructivist paradigm aligns well with the theoretical framework for this study. The new sociology of childhood and the bilateral model of parent-child relations perceive children as social and independent actors who are subject to power differentials in their relationships with adults (Kuczynski, 2003; Matthews, 2007). The social constructivist paradigm is compatible with the view that children are social actors and that children's research involvement is valuable. Qualitative approaches provide adaptive methods from which to examine the experiences of participants who represent a wide range of ages and experiences. The open-ended nature of qualitative data approaches enables the participation of children with a range of cognitive and verbal abilities. In summary, both the theoretical framework for this

study and the qualitative research methods described above are well supported within a social constructivist paradigm.

Sample and Recruitment

Sample demographics. Using a purposive sampling method, 26 participants (11 male, 15 female) were recruited from a pediatric hospital in Toronto, Canada. As potential participants were approached, all agreed to participate and complete the study. Bearing in mind possible developmental issues, the cross-sectional sample was stratified by age, with 6 participants between the ages of 5 to 8 (“younger children”), 6 participants between the ages of 9 and 12 (“older children”), and 14 participants between the ages of 13 and 18 (“adolescents”). The UNCRC (1989) defines “children” as individuals under the age of 18. In keeping with this guideline, young people up to the age of 18 were selected for participation in the study. An age of five was selected as the lower age limit for participation as children younger than age five are less likely to have the verbal skills required to effectively participate in an individual interview session (Mauthner, 1997).

Age stratification was based on Piaget’s stages of cognitive development (preoperational, concrete operational, and formal operational), which are used widely in child development research (Rathus, 2008). The sample was stratified into three age groups for the purposes of data collection and analysis. Participants had a range of chronic illnesses, including kidney failure, cystic fibrosis, and Crohn’s Disease. The sample was racially and culturally diverse, reflecting the demographics of the urban setting in which the study took place. Participants from varying socioeconomic levels were included. As well, a diversity of family forms were represented in the sample, including participants from single parent families and participants cared for by extended family members. A summary of demographic information is presented in Table 1.

Table 1

Demographic Summary

Groups of Participants	Number and Gender	Nationality, Cultural and Religious Background	Languages Spoken
Younger Children (Ages 5-8)	6 (2 male, 4 female)	Participants represented several nationalities, cultures and religions, including: Canadian, Italian, Jamaican, Jewish, Pakistani, Polish, Filipino, and Sikh	English, Polish, Punjabi, Tagalog, Tamil, Ukrainian, and Urdu
Older Children (Ages 9-12)	6 (2 male, 4 female)		
Adolescents (Ages 13-18)	14 (7 male, 7 female)		
Total:	N = 26 (11 male, 15 female)		

Recruitment. Participants were recruited from inpatient units at a pediatric hospital.

Child life specialists from several hospital units were chosen as research collaborators to assist with recruitment. Based on inclusion criteria, child life specialists from each unit reviewed daily inpatient lists for potential participants, and then approached a family member to assess a potential participant's interest in the study and ability to consent. Subsequently, a research assistant followed up with more information on the study and obtained consent to participate.

Inclusion criteria were as follows:

1. Participant had been diagnosed with a chronic condition for at least one year.
2. Participant had experienced at least one hospitalization and was in hospital at the time of study participation.
3. Participant was able to speak and understand English.

Consent and assent to participate. Parents provided informed consent for younger children to participate, while older children and adolescents provided their own consent.

Younger children received assent procedures, where a research assistant provided verbal and

visual information on the study prior to beginning the interview. This discussion included developmentally appropriate language, and children were asked to repeat areas to ensure they understood the study objectives. Families were informed that participation was voluntary. Participants received a gift certificate as a token of appreciation for their participation in the study. Parents were reimbursed for related travel expenses.

Data Collection

Setting. Interviews took place in patient rooms, and in some cases, a youth lounge in the hospital. In all instances, a quiet space was secured in order to conduct the interview. Parents were also encouraged to take a break while interviews were conducted and were given a coffee gift card. It was explained to parents that in order to conduct a research interview, it was best to have the child feel free to express themselves. In most cases, parents agreed to leave the room during the interview. Parents who remained in the room were asked to remain quiet and uninvolved. All participants were interviewed during an inpatient admission. Interviews lasted between thirty minutes for younger children and up to an hour and a half for older participants. Due to the interruptions experienced during hospitalizations, some patients required small breaks between discussions to attend to medical tasks. For example, children and adolescents in the dialysis unit required more time to complete interviews.

Interview protocol. The primary source of data were collected through semi-structured interviews with participants. McCracken's (1988) guide to the long interview method was used to inform the interview process. Prior to beginning the interview, the research assistant (RA) collected demographic information from parents and participants, including age, gender, grade level, diagnosis, number of previous hospitalizations, parents' occupations, family composition, languages spoken in the home, identified cultures, and country of origin. Interviews were

conducted by child life specialists, who have a background in child development and extensive experience discussing medical issues with young people. Child life specialists frequently use play-based techniques, including the use of dolls and medical equipment, to explain medical information to children (Koller, 2008).

Two interview protocols were developed to address differences in cognitive and verbal abilities of younger and older participants. In both protocols, the interview commenced with general questions about the participants' diagnosis, their understanding of their illness, and reason for past and present hospitalizations. Additional interview topics addressed participants' experiences in health care discussions with staff, involvement in personal care and decision making, knowledge of children's rights, and sources of emotional support. Topics and interview questions emerged from focus groups with hospitalized youth conducted by the research team as part of a previous pilot study. Interview topics were further developed in consultation with the Children's Council at the pediatric hospital.

Interviews with younger children. Research with young children is often challenged by children's limited verbal abilities. A 'mosaic' or multi-method approach to research can be useful as it allows children to share their perspectives through a variety of means (Clark, 2004). The present study employed pictures, dolls, art supplies, pretend medical equipment, and semi-structured interview questions to elicit young children's perspectives on health care decision making and communication.

Interviews began with a question regarding the reasons for the participant's current hospitalization. Irwin and Johnson (2005) have found that when interviewing children, beginning with direct, rather than open-ended questions, is most effective. Direct questions place less emphasis on a child's verbal abilities and allow children to develop a sense of comfort and

confidence with answering questions before moving on to more abstract questions as part of the interview. Next, the interviewer introduced pictures of children receiving a medical treatment or checkup. In each interview, the child depicted in the picture corresponded roughly to the age of the participant being interviewed. The interviewer asked the participant to describe what he or she thought was happening in the picture, and followed up with probes such as, “What is the child doing?,” “What is the doctor doing?,” and “Can you tell me what happens to you when the doctor or nurse comes in to your room?” Previous research with child participants indicates that pictures can be an effective tool to assess young people’s knowledge of health behaviours, prompt discussion of hospital experiences, and act as cues for memory retrieval (Wiley & Hendricks, 1998; Wilson et al., 2010; Salmela, Aronen, & Salanterä, 2011).

Art supplies, dolls, and pretend medical equipment were presented to participants throughout the interview sessions to prompt discussion and provide alternate ways for children to express their ideas. Activities used in interviews with children help researchers build rapport and can provide participants with a greater sense of control and choice in how they express themselves (Fargas-Malet et al., 2010). Props and play equipment used in interviews may also enhance children’s interest and improve their comfort in the research process (Irwin and Johnson, 2005)

Interviews with older children and adolescents. The phrasing and number of questions asked of older children and adolescents were adapted to suit their cognitive and verbal abilities. Semi-structured interviews included questions such as, “Tell me about the things that you do to take care of your health?” and “What is it like coming to the hospital?” As in the interviews with younger children, pictures were used to prompt discussion and assess participants’ knowledge of hospital procedures and environments. Props and art supplies were used during interviews with

some older participants when they expressed interest, or as deemed appropriate by the Research Assistant.

Data Analysis

In the original study, interviews were recorded using a digital audio recorder. Two types of data were gathered: demographic data and qualitative data. Demographic information collected from participants was organized in an Excel spreadsheet. Interviews were transcribed verbatim into Word documents and then imported into NVivo 10 software for further data analysis.

A secondary analysis of the original qualitative data set was conducted. Drawing on the definition by Hinds and colleagues (1997), this approach involved “reanalyz[ing] all or part of a data set by focusing on a concept that seemed to be present but was not specifically addressed in the primary analysis” (p. 410). Data analysis followed the six-stage thematic analysis method described by Braun and Clarke (2006). Braun and Clarke define thematic analysis as “a method for identifying, analysing and reporting patterns (themes) within data” (p. 79). Following the method set out by Braun and Clarke, I first reviewed the entire data set and engaged in preliminary raw coding of the data. During this stage, I read and re-read interview transcripts, actively searching for possible patterns and meanings in the text. Concurrently, I sought to understand some of the major themes of the data set, which led me to identify salient issues to examine as part of a secondary analysis. I had a research interest in parent-child relationships prior to beginning the analysis and this interest led me to examine how parent-child interactions were represented in the data.

During the second stage of coding, I began to gather an initial list of ideas about the data and organized these ideas into meaningful groups, or codes. All transcripts from the original data

set were included in this analysis, though coding was focused on statements relating to parental involvement. I met with my advisor on several occasions to discuss the meaning of codes in the context of this research. We refined various codes, re-labeled them, and engaged in a process of clearly defining them within the scope of the project. The research questions were used to guide further data analysis and to elicit data reduction. Some issues that emerged during this stage related to understanding the complexity of interactions between participants, their parents, and health care providers, as well as accounting for the specific context in which the study took place. Accordingly, codes and major themes changed over time as I explored the connections between codes and examined differences in the statements made by participants across stratified age groups.

Codes defined through thematic analysis may be semantic (data-driven) or latent (theory-driven: the researcher approaches analysis with specific theories or questions in mind) (Braun & Clark, 2006). The present study predominantly used a semantic approach, coding the explicit, or surface-level, meanings of the text. However, some codes, particularly those relating to developmental themes and the evolution of health care responsibility, were theory-driven. Other codes were elicited spontaneously in the data. Initial coding of data for the focused analysis yielded 52 codes.

In the third stage of thematic analysis, Braun and Clark (2006) direct the researcher to determine how initial codes can be organized into overarching themes. After the initial list of codes was constructed, I reviewed the list of codes and began to identify codes relating to parent-child dynamics that appeared to be associated with children's health care participation. Briefly, these codes referred to participants' experiences with decision making, health care discussions, and self-care management in which parents were involved. Reading into the subtext underlying

these codes revealed varying ways participants experienced health care participation within their families - for instance, by avoidance, active participation, or conflict with parents. As part of the fourth stage of analysis, I recoded the data by further refining and collapsing ‘candidate’ codes. This process involved reviewing themes and determining whether the collected extracts for that theme represented a coherent pattern. Some new themes emerged at this stage as I reviewed and refined codes. In some cases, this led to a renaming of the code and subthemes to adequately represent the meaning of the data.

According to Braun and Clark (2006), the fifth stage of analysis involves further refining and defining themes by identifying the scope and content of each theme. The final sixth stage consists of producing the written report. At this point, I reorganized some themes and subthemes as I recognized areas of overlap or identified further nuances in the data that I wanted to explore. A final set of ten codes was then organized into three major themes and seven subthemes. These themes are presented in Table 2. This final set of codes reflects a coherent narrative of the ways participants in the study described talking about, negotiating, and coping with health care decision making and communication in their families.

Table 2

Themes and subthemes

Theme	Subthemes
Parent takes the lead	Minimal discussion of illness
	Wanting to feel normal
Child/adolescent takes the lead	Ownership of health care needs
	Recognition of evolving responsibility
Working together	Partnership
	Different perspectives
	Determining the level of responsibility

Data saturation. Given that this project was focused on a particular aspect of the data (the parent-child relationship), saturation of data was experienced early. Theoretical saturation is a concept associated with grounded theory, a method of qualitative analysis closely related to thematic analysis. According to Bloor and Wood's (2006) definition, theoretical saturation involves the continuation of data collection and analysis "until no new conceptual insights are generated" (p. 165). Repeated themes that appeared early on related to ways participants described being involved in their care, descriptions of their preferences for participation, and descriptions of ways parents supported their health care participation. Common patterns and responses also appeared early when data within stratified age groups were analyzed, sometimes within four interviews. Nevertheless, due to the richness of experiences cited by adolescents, additional interviews with adolescents were analyzed in order to include a wide range of experiences and perspectives.

Findings

This paper presents a focused analysis of relevant data on how children and adolescents perceive parental involvement in their health care discussions and decision making. The core finding was that young people have diverse preferences for parental involvement and for their own level of participation in health care decision making. This variability in preference was represented in the data by the divergent yet overlapping ways participants described their interactions with parents when navigating their involvement in health care participation. Variability in preference and experiences also existed within and across stratified age groups. Data analysis yielded three major themes or profiles that reflect the ways participants' families approached children's involvement in health care decision making, discussions, and learning about their illness. These themes included: 1) parent takes the lead, 2) child/adolescent takes the lead, and 3) working together. Themes reflect the actual health care decision making process between parents and children. Additional subthemes elucidate the complexities and nuances associated with health care participation in pediatrics. Subthemes are presented in Table 2.

Parent Takes the Lead

Both younger and older participants indicated a preference for having their parents make decisions and speak to health care providers on their behalf. However, the desire to defer to parents was predominantly expressed by a majority of the youngest participants (ages five to eight). A smaller proportion of older children and adolescents wanted their parents to be mainly responsible for health care decision making and communication with the health care team.

Younger and older participants differed in their explanations for why they preferred parents to take the lead in health care discussions and decision making. Many younger participants characterized health care decision making as an adult responsibility and a topic not appropriate for young kids. They stated that health care decisions should be "up to mom"

(female, age 6) and believed that health care providers should talk “to grownups like moms or dads” and “grownup kids” (female, age 6). The younger participants all gave similar reasons as to why they preferred for parents to take the lead in making decisions and talking to medical staff. One explained that “the kids don’t really know what you do, like, sometimes what it means” (female, age 6). A five-year-old participant felt that “kids don’t know what to say” and therefore she preferred doctors to talk only to her parents (female, age 5). Another said that when doctors come into her room, “it’s more of a grown-up talk” and that she feels “scared” when she thinks about making medical decisions (female, age 6).

Older participants referred to aspects of their personality when explaining why they chose parents to take the lead in making health care decisions and speaking to health care providers. A self-described shy or anxious personality appeared to be associated with this preference. A 17-year-old male participant explained that he prefers for his doctors to “talk to mom” because “probably I am more afraid and stuff.” A 13-year-old male said that when he needs to communicate something to doctors, “I tell my mom and my mom asks,” because, “I’m too shy when it comes to this.” Unlike the younger children, older participants indicated that even when they preferred for parents to take the lead in health care discussions, they expected parents to share information with them. For instance, a 16-year-old male participant shared that “They [doctors] talked to my mom and dad first, and they [mom and dad] told me.”

Minimal discussion of illness. Two older children and three adolescents stated that there was minimal discussion of their illness within their family. These participants either stated that they preferred not to talk about their illness or medical choices with parents; that parents preferred not to discuss it with them; or that, in general, family members were not open to discussing the topic. For example, a 13-year-old male stated that *he* prefers not to talk about his

illness with his parents. Reflecting on a time his parents tried to initiate a conversation about his diagnosis, he stated, “They tried once and I got really mad. So they’ve held that away from me because I don’t really like talking about it.” A 17-year-old female participant also disliked talking about her illness, although she feels that her parents are as hesitant as she is to address the topic. Instead, she turns to others for support, explaining, “Usually I complain to my friends and my sister. But other than that I don’t really talk about it to anyone else other than the doctors and my health care people.”

While some children appeared comfortable with the minimal amount of communication in their families, others differed in their satisfaction with family communication. One participant experienced a low level of communication in her family, leading her to hear about a potential surgery from someone else:

“There was a time last year they asked me if I wanted to do surgery or not for my sickle cell, I think it’s called the bone marrow transplant. My friend told me and [I said] ‘How do you know, cause my mom has never told me yet?’ She said she overheard it from my mom talking” (female, age 11).

The same participant described struggling to receive desired health information from her family. She relayed her experiences asking her mom to clarify information shared during medical appointments, disclosing, “Sometimes they [doctors] use words that I don’t know, sometimes I would ask my mom and she would say ‘Well I don’t really know, but I know what it means’ but *I* still don’t understand.” She often turned to other sources for information, including the internet, books, and members of her health care team.

Wanting to feel normal. Some participants explained that they preferred for parents to manage personal care and decision making so that they could live their lives as “normal” kids.

One 11-year-old boy explained that while his parents do talk to him about his illness, they limit the amount of discussion, “because mom doesn’t want to get me worried and stuff...she knows I’m a normal kid living a normal life.” A 17-year-old girl explained her family’s limited discussion of her illness in a similar way, saying “They don’t really talk about it much to me and I don’t really talk much about it with them cause I don’t want to feel like I’m a sick kid, I want to feel like a normal person like my sister.” She prefers for her parents to make decisions so that she can “enjoy my childhood,” but, “once I turn 20 or 21 then I have to take the responsibility.”

Child/Adolescent Takes the Lead

This theme emerged predominantly from statements made by three adolescent participants as they discussed their involvement in making medical decisions and negotiating involvement with their family members. While many participants in the sample spoke of being involved in making medical decisions, the three adolescents discussed in this theme described a much higher level of independence and responsibility in their health care relative to the rest of the participants. These participants spoke of taking responsibility for making health care decisions, communicating independently with health care providers, and managing their personal health care (e.g. taking medication). For at least one participant, family dynamics precluded the involvement of his parents in making decisions. This adolescent participant, who was in the care of extended family members, found that he was ultimately responsible for making personal health decisions as his guardians had little involvement or knowledge of his health care needs. Though this theme reflects the experiences of a small portion of the sample, it highlights another way in which young people navigate life with a chronic illness.

Ownership of health care needs. Participants provided several reasons as to why they wanted to take a leading role in health care discussions and decision making. One adolescent

explained that, “It’s really important to know what’s happening to me and what’s going on with my body” (male, age 17). An important priority for these adolescents was feeling that they had control over their medical decisions and knowledge of their prognosis and treatment options. For these participants, knowledge and responsibility was empowering, and the absence of it, as one explained, “could bring on some fear” (female, age 16). Another also felt it was important that she communicate directly with the doctors, “because it’s exactly how I feel – it’s more like you can hear the expression in my voice, rather than if I tell someone and they tell the doctor. It’s coming right from me” (female, age 16).

However, despite their desire to take responsibility for their medical care, they acknowledge that they still require - and desire - support from health care providers and family members to make medical decisions and manage the complexity of their illnesses. For instance, a 16-year-old participant values her mother’s perspective when she is trying to decide among treatment options. She explains:

“I ask her opinion and I ask her what she thinks I should do, if she were in my position. It does help to hear from somebody else’s point of view who is standing on the sideline and looking at the situation as someone who isn’t biased by the illness or who isn’t biased as a doctor.”

Though these participants stress their desire to take responsibility for decision making and communication with health care providers, they recognize that support from their families and health care teams remains essential for their success in such an endeavour.

Recognition of evolving responsibility. Another reason participants described wanting to take a greater leadership role in their health care was to prepare them for future adult responsibilities. These participants felt that by slowly taking on more responsibility for their

health care over time, they would be better prepared to cope with their illness as adults. As one explained, “When you get much older, you are going to need to talk to doctors all by yourself. There’s going to be no mom, no dad anymore” (female, age 16).

Among participants who spoke of taking responsibility for their health care, all described an evolving process in which they took on more involvement in their health care as they matured and learned more about their illness. For a 16-year old participant, her ability to assume more responsibility for managing her illness has been facilitated by her family and health care providers, who have made an effort to provide her with more information and opportunities for decision making as she became more comfortable and knowledgeable of her illness. She endorses this approach, explaining that “it’s important to have it [responsibility] because I’ve been having it slowly added on and it’s not like one moment I don’t have any responsibility and then the next I have a ton.”

Connected to their recognition of evolving responsibility was participants’ acknowledgement that they were at an age when it was appropriate for them to take responsibility for their own health. As one stated, “I’m at an age that it’s my own responsibility to take my meds and I need to choose to eat right... You know it’s not at the point that my mom has to chase me around now, force the food down my throat or anything” (female, age 16). Similarly, when another participant described an incident where she had a disagreement with her doctors, she explained that she wanted to speak to them independently, “because I am an adult and this is something that had to do with me and I really wanted to speak up for myself” (female, age 16).

Working Together

In contrast to participants who preferred parents take the lead, or take the lead themselves, about half of participants described working together with parents to make health care decisions. This theme appeared predominantly in interviews with adolescent participants, although a few school-age participants also spoke about working together with parents. The youngest participants did not state an explicit preference for sharing decision making and communication responsibilities with parents. In interviews where children's statements reflected the idea of working together, children spoke about their parents' openness to discussing illness and talking about concerns and challenges. In these families, children and parents respected each other's perspectives and valued one another's input. For example, a 12-year-old participant spoke about her experience with making the decision to have surgery. When asked about her involvement in making the decision, she explains, "I was asked if I wanted to do it and I was a little bit optimistic about it at first but I wanted to do it." However, she also notes that it was a decision that "everybody" made: "my doctors, my nana, my mom, and my grandpa thought it was time for it to come out, that's one big one [decision] that we all decided, not just a couple of people but most of my family."

Partnership. Statements reflecting the subtheme of partnership were often made in response to questions about the participant's involvement in making medical decisions. For instance, when asked "Do you make decisions with your mom or do you make them just by yourself or does she help you make them?" one participant responded "We always make it together, for medical stuff" (female, age 16). Participants who saw themselves as partners with parents also described their decision making experiences using an inclusive "we." One participant described her family's struggle to negotiate treatment with her health care team.

While telling her story, she framed her medical experience as one faced by the whole family, explaining, “I just feel like they [doctors] just try to push things on us that we don’t need. We push things on them that they should do like last year where I had 4 or 5 UTIs [urinary tract infections] and they were like, they didn’t do anything at all” (female, age 16).

Some participants felt excluded or overwhelmed during discussions with their health care team. They described asking parents to facilitate their involvement in discussions or relay their preferences. For instance, one 13-year-old girl talked about feeling disregarded by doctors, explaining, “Sometimes I’ll be like ‘That’s a good idea, how about this’ and like [the health care provider] sort of ignores it.” However, she partners with her parents to identify concerns and issues, and in turn, her parents present her ideas to the health care team:

“Last week I went to the doctors and I’d been having these weird headaches, so the doctor said ‘What do you think we can do about it?’ and I said maybe we can get an x-ray to see, maybe something is wrong. And so they [parents] took that advice and my mom and my dad talked to the doctor and said ‘I think that she should get an x-ray.’”

Different perspectives. Sharing decisions with parents can also lead to conflict between children and their parents. The majority of participants who described having different views from their parents were adolescents (with the exception of one 11-year-old participant who described a conflict with parents). Statements from this subtheme were often characterized by the child or parent perceiving a situation to be more or less serious than the other. For example, a 16-year-old female participant stated:

“My mom would be like, ‘Don’t be silly, it’s just like a blood test.’ It would be easier if she said like, ‘No you can be worried but like if you want to be worried that’s okay, as

long as you don't get sick from it.' I think I should be allowed to be worried about things and I worry about a lot of things."

In contrast, another participant complained that her mother tended to overreact to medical situations:

"I mean this isn't against mom or anything but I think if she finds a situation really, I don't want to say important – because it is important – but like she took diabetes more seriously than I did. Like, I took it seriously but she was a lot more worried than I was, and I was like, 'Okay, we can deal with it, whatever.' So I think she might exaggerate a little bit" (female, age 13).

Other participants shared examples of disagreements over the course of treatment. One participant explained that when she communicates her choices to her mom, her mother sometimes responds by saying "We can try my way first and then we'll go your way" (female, age 11). Another told her parents she did not want to have a kidney transplant, leading to an argument with her family. She states:

"I was like '[I'd rather] be on dialysis forever!' And they're like, 'You'll die soon' and I was like, 'I don't care' and they are like, 'We want you to live and enjoy your life and everything, and if you get a transplant you can swim and everything.' But I'm just like 'I'm not ready.' But if I have to do it, then I have to do it" (female, age 17).

Determining the level of participation. This theme refers to some of the situational variables that participants identified as affecting their abilities and preferences for participation in health care. Some participants distinguished between minor and significant decisions, recognizing that there were some decisions they thought were important to contribute to, while other decisions should be left to parents or physicians. School-age and adolescent participants

were more likely than the youngest children to talk about a desire to balance their involvement in decision making, communication with health care providers, and personal care.

Most of the participants who identified with the subtheme of determining the level of participation explained that they vary their involvement in making medical decisions depending on the seriousness of the decision. For example, a 13-year-old girl said:

“If it’s little things like when I want to take my medicine or like what I like to take it with or things like that, I think it is pretty easy choice to decide that but like when it comes to big things like things that involve operation, I think that I’m not that involved and I think that I don’t want to be involved in that because really I don’t know what is best for me.”

Similarly, a 12-year old female participant distinguishes between minor and significant medical communication, explaining that she does not feel a need to be involved in every aspect of her treatment:

“I don’t need to know every single thing, like if there’s an appointment or something and somebody told my mom and not me, I’ll just ask my mom so I don’t need to ask every single thing, but I do need to know what’s going to happen on certain days, when things are going to happen, I like to know what my levels are.”

With regard to participation in making health care decisions, this participant states that she chooses to be involved in some decisions but not others, stating that decisions “that involve medication, I think she [mom] should be the one that I think should decide on, if she feels comfortable or not. And then there’s ones like I don’t want my mom to have all the say and [for me to] not have a single word in it.”

Being seriously ill was another reason participants provided for why they would choose to balance their involvement in decision making and communication with health care

professionals. One of the adolescent participants typically likes to be very involved in making medical decisions. However, during an acute period of illness, she knew she had to rely on her parents to make certain decisions, saying, “Back then I wasn’t really coherent, but I respected the fact that my mom thought it [chemo treatment] wasn’t good for me” (female, age 16). Another adolescent participant described a similar experience. Though he also likes to be very involved in making decisions, he says, “At the beginning, no [choices] because I was so sick. But as things progressed they asked me if I wanted to do the other type of dialysis and I said no” (male, age 17).

Summary of Findings

These findings reflect a range of issues associated with children’s health care participation. For this reason, issues surrounding children’s participation in health care decision-making are complex. Though participants in this study typically preferred one of three broad levels of participation, some participants identified with more than one level of participation, or vacillated between them. Key to understanding this finding is recognizing that children’s preferences for participation, and their abilities to participate, are influenced by situational and relational factors.

Factors discussed by participants include contextual factors such as the seriousness of the decision, the degree of the child’s acute illness, or the attitude of the health care provider towards a child’s health care participation. Participants, regardless of their preferences for participation, also described personal factors influencing the extent of their desired participation. These factors included prior experiences, their personality (in particular, being shy or anxious), their ability to understand medical information, and their perception of the decision as minor or significant. Finally, all participants recognized the influence of parents and family members in facilitating their health care participation. In particular, the quality of the child’s relationship with their

parent, the parent's skill in facilitating the child's involvement, and the child's perception of parents' parenting style, influenced participants' preferences for participation.

Discussion

Participants in this study, who varied in age and had a range of chronic health conditions, described salient experiences related to learning about their diagnosis, coping with medical treatments, and making health care decisions alongside parents and health care providers. Based on the findings of this study, a model of decision making will be presented and discussed. In contrast to previous models, such as the shared decision making (SDM) model, this model accounts for the many factors impacting children's and adolescents' preferences for participation and recognizes their rights and competence to share their views on medical issues. An examination of the strengths and limitations of the present study will be offered. This section will conclude with associated implications for clinical practice and suggestions for future research.

The collaborative-contextual model of pediatric decision making

Description of model.

Experiences shared by participants in the study reflected three broad types of participation: 1) parents who took the lead in health care discussions and decision making, 2) children who took the lead, and 3) parents and children who worked in partnership with health care providers to make medical decisions. Health care providers were involved in the decision making process through their role in providing the family with information, proposing treatment options, and making recommendations. Though most of the data could be classified according to each of the three profiles, there was also an overlapping of profiles within interviews. This typically occurred in instances where children indicated that their level of involvement varied depending on contextual factors, such as the seriousness of the decision or their degree of acute illness at the time of decision making.

What emerges from these findings is a portrait of pediatric decision making as a somewhat convoluted, fluid, and emotionally-charged process. While recounting their

experiences, participants described instances of conflict with parents and health care providers. Some children spoke about their fears and concerns relating to the provision of information, while others described anxiety stemming from information being withheld. Several participants, particularly the younger ones, reported that they were most comfortable with having parents direct their health care by making decisions and communicating with health care providers on their behalf. At the same time, there were older participants who were adamant that they should be the one to speak to health care providers, and preferred to be highly involved in making health care decisions.

It is clear that regardless of age, children's and adolescents' preferences for health care participation do not necessarily reflect a logical or defined path. For instance, some older adolescents who participated in the study were much less involved in their care than other younger children, thereby discrediting the age-related expectations held prior to conducting the study. This research indicates that parents and health care providers cannot make assumptions about children's preferences to participate in health care discussions and decision making, as their preferences are affected by a myriad of changing factors. Accordingly, parents and health care providers who seek to facilitate children's involvement in health care must be aware that changing factors influence children's preferences and abilities for participation. Coyne and Harder (2011) refer to this as taking a 'situational' perspective in pediatric decision making. They write:

Parents and professionals should view children as individuals with needs that vary according to each situation. The need for protection and/or participation is situational, rather than temporally bounded. The situational position recognises children's right to have a say, without necessarily having full control over decision-making. (p. 316)

Building on this notion of a ‘situational’ perspective, I suggest a collaborative-contextual model of pediatric decision making that accounts for environmental factors, children’s participation rights, and children’s developmental needs and abilities. This model extends the shared decision making model (SDM) used in the health care field to describe partnership between patient and health care provider (Kon, 2010). In this proposed model of collaborative-contextual decision making, both the patient and the health care provider actively participate in making health care decisions. Where this model differs from SDM is in its emphasis on parents and children as stakeholders in the decision making process, and in its recognition of the many factors influencing children’s abilities and preferences for participation. While both parent and child are necessarily involved, this model posits that at times, the parent or child may take on a greater leadership role in directing discussion around the health care decision, while still involving the other in the process. This choice will be determined by factors relating to the given context of the decision, the parent-child relationship, child factors such as prior decision making experiences, and the philosophy of care practiced by the institution and health care provider.

Figuratively, this model perceives pediatric decision making as a process involving bidirectional interactions between the parent and child. The bidirectionality of the parent-child relationship assumes that both parent and child have relatively equal influence in the relationship, even if the parent holds more ‘legitimate’ or overt power. The health care provider is involved in this process in the role of consultant, advisor, and facilitator. In other words, the health care provider provides medical information and treatment recommendations to the parent and child, who then participate in a collaborative process with each other, and the health care provider, to arrive at a decision regarding course of treatment or a related aspect of the child’s care. In addition to providing information, the health care provider can also be an important

influence on the decision making process. For example, the health care provider may advocate for the child's right to know details of their diagnosis, or promote the child's inclusion in health care discussions. Developing a trusting relationship with the family is key to the success of the health care provider in fulfilling this important role.

In some cases, the process of making a decision will be more child-led, while in other instances, parents will assume greater leadership in facilitating the making of a decision. Parents and children may also engage equally as partners in the decision making process. The health care provider supports this process by providing information, recommendations, and advocacy. Together, the child, family, and health care team must determine the type of involvement appropriate for each stakeholder in the specified decision. Yet, regardless of whether a particular decision is more parent-led, child-led, or partnered, a spirit of collaboration infuses the process so that parents and children are continuously involved, to the degree appropriate for the given situation. Figure 1 provides a visual representation of the collaborative-contextual model of pediatric decision making.

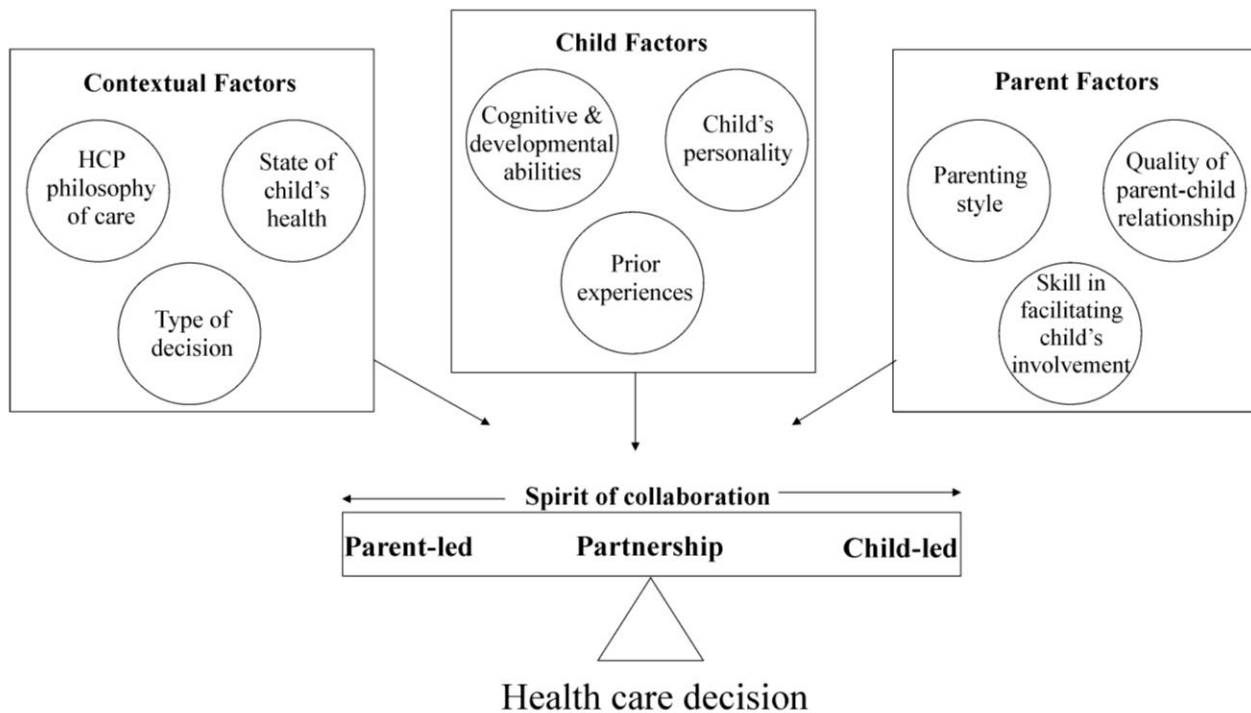


Figure 1: The collaborative-contextual model of pediatric decision making

Findings in support of the collaborative-contextual model.

Relationship between age and preferences for decision making. The collaborative-contextual model depicts a continuum of involvement that vacillates between child-led, parent-led, and partnered decision making. In the present study, the majority of children described experiences where they made health care decisions in concert with parents. However, a small number of adolescent participants described a preference for taking the lead in making health care decisions. Similarly, several of the youngest participants, and a few adolescent participants, stated that they preferred that their parents take the lead on decision making. The collaborative-contextual model thus reflects children's preferences by emphasizing that participation can exist along a spectrum of involvement. Participation is not an either/or proposition. Rather, children, parents, and health care providers should recognize that children should have opportunities for varying levels of participation in decision making, depending on contextual factors relating to the

decision, and the child's preferences for participation. Essential to this process is the need for parents and health care providers to continually check in with the young person to ensure their participation is being facilitated to the extent they desire.

Along the continuum of involvement, a spirit of collaboration permeates all interactions, so that whether a decision is more child-led or parent-led, the family works with the health care team to arrive at a decision together. This process ensures that the voices of all stakeholders are acknowledged and validated. When a health care interaction is parent-led, a child's role is not negated, but reduced according to the preferences and needs of the child, for that decision, in that moment. Similarly, when the young person takes greater ownership over making the decision, the perspectives of parents are still considered and valued. The health care provider can play an important role in facilitating a discussion with the family around preferences for participation in various types of health care decisions.

Relationship between contextual factors and preferences for decision making. Findings from this study lend support for a model of decision making that acknowledges children's preferences for participation are constantly shifting, and evolve over time. Such a model would need to consider contextual factors as well as the child's prior health care experiences. Previous research on children's perspectives on health care decision making indicates that children generally prefer shared decision making with parents over autonomous (child-led) or paternalistic (parent-led) models (Coyne, 2006; Moore & Kirk, 2010). The present study replicates these findings and extends them by drawing attention to the importance of the child's relationship to parents and health care providers in establishing a climate that promotes their participation. Like Coyne and Harder's (2011) 'situational' perspective, the proposed collaborative-contextual model of parent-child decision making emphasizes the many factors that

must be considered when determining the appropriate level for children's health care participation. Parents, children, and health care providers should be involved in a discussion of these factors when determining the extent of a child's participation in a given decision or health care discussion.

The visual representation of the collaborative-contextual model depicts some of the factors influencing the child's abilities and preferences to participate in health care decision making. Factors identified by participants in this study both influence their desire to participate in health care decision making (e.g. personality, prior experiences making health care decisions), and impact their ability to participate effectively (e.g. parent's skill in facilitating their involvement, health care provider's attitudes toward children's health care participation). Many of these factors have been identified in previous studies (see Coyne, 2006; Coyne & Gallagher, 2011; Jedeloo et al, 2010; Miller, 2009). Although the model is limited to the factors described by the participants in the study, other factors described elsewhere in the literature should be noted. These factors include child's age, coping style, health care provider's personality, and parents' cultural beliefs and parenting style (Beresford & Sloper, 2003; Coyne, 2006; Coyne, 2008; McPherson & Redsell, 2009; Miller, 2009; Runeson et al., 2001; Young et al., 2003).

Influence of parent-child relationship. Parents' involvement in pediatric decision making is customary and expected. In interviews, participants described the many ways parents supported them through their illness, whether by teaching them about their diagnosis, providing emotional support, giving reminders to take medication, or facilitating their involvement in discussions with health care providers. Parent-child interactions that were described by participants in this study reflect the bilateral model of parent-child relations (Kuczynski, 2003) described previously in the theoretical framework. The bilateral model perceives children and

parents as active agents in an intimate, long-term relationship. Though both parents and children have power in the relationship, parents hold proportionally more power, as their authority is legitimated by cultural practices and attitudes. At the same time, children can draw on their relational knowledge of parents to influence their beliefs and actions. Participants in this study validated this construction of parent-child relationships. On the one hand, parents had the final say in many matters (“If the doctors tell me and my mom tells me then I have to listen,” female, age 7). Yet participants also described instances where they influenced parents’ behaviours (“They tried once [to talk about my diagnosis] and I got really mad. So they’ve held that away from me because I don’t really like talking about it,” male, age 13). Accordingly, the collaborative-contextual model of pediatric decision making operates on the premise that parents and children are both responsible for the quality of their interactions. It recognizes that children hold power in decision making processes, but are constrained by the parental authority legitimated by social custom and law (Lee, 2001). Pediatric decision making, however, can become contentious when power and preferences of parents and children clash. A model that emphasizes collaboration and the need for both parents, children, and the health care provider to be involved in decision making can be a promising start to addressing the potential for conflict.

Children’s evolving participation reflected in the model. Health care decisions vary in seriousness and scope. For example, in the present study, choosing which arm to receive an IV was identified by participants as a health care decision alongside the decision to have a surgery. Of significance is participants’ discussion of how making small health care decisions allowed them to develop confidence and competence in making larger, more significant decisions as they matured and gained experience with managing a chronic illness. This assertion is supported both by participants’ statements, and current discourse, which emphasizes the need for children to

have opportunities making increasingly bigger decisions as part of developing decision making competence (Coyne and Harder, 2011).

Findings from this study, along with findings reported elsewhere (Coyne, 2006; Moore & Kirk, 2010) suggest that while children generally prefer shared decision making with parents, there are instances where they want parents to take the lead, and other times when they desire to make decisions autonomously. All children should have the option to make some decisions independently. Previous research indicates that even making small decisions affords children a level of control over their illness or hospitalization, and provides opportunity for practice in making decisions (Coyne, 2006; Miller, 2009). When very young children are confronted by serious, life-or-death choices, a parent-led decision is likely to be more appropriate. Young children in this study reported that discussing serious medical decisions sometimes made them feel scared and that they felt more comfortable leaving decision making to parents. Therefore, while the proposed model presents collaboration as an ideal, it also acknowledges that child-led and parent-led decision making processes can be appropriate in certain situations.

Implications for Practice

The role of the health care provider in facilitating participation. This study is informed by the new sociology of childhood and psychological theories of child development. These two frameworks are often viewed as contradictory constructions of childhood. The former characterizes children as competent social actors while the latter understands children's competence as tied to age-related behaviours and abilities (Matthews, 2007). Theories of child development continue to permeate the construction of children in the health care field, and influence how we view their abilities for participation (Alderson, Sutcliffe, & Curtis, 2006). Indeed, several studies report that health care providers associate a child's competence to

participate in health care decision making with chronological age and cognitive ability (McPherson & Redsell, 2009; Runeson et al., 2001; Vaknin & Zisk-Rony, 2011). It appears that rarely do health care providers' perceive children (regardless of age) as competent beings who have a right to voice their opinions on health care matters. In contrast, participants in this study generally indicated that their health care providers were caring, respectful, and encouraging of their participation. Many participants described highly positive relationships with health care providers, where they felt validated and heard. For instance, a 17-year-old female participant said:

“They [health care team] understand me which is a good thing and they know how I feel and sometimes they do understand and why I’m like this. And sometimes they let me be myself and like let me do the things that I want to do and sometimes they don’t.”

One participant described contrasting experiences as an inpatient at the pediatric hospital and a general hospital:

“Here [pediatric hospital] they make an effort to speak to the patients even to the point that they sometimes ignore my mom. But they put a lot of emphasis on making sure that the child knows everything about their own care. Whereas sometimes when I went to [general] hospital for blood work one time, where they treat me like you are a child, you’re young, you’re immature, you’re 15, you don’t know much, you’re not that knowledgeable. It’s kind of irritating because it’s like I know what I’m going through.”

The experiences of the participants in this study suggest that they value being treated as a ‘real’ person, one who is involved in health care discussions and treated respectfully by health care providers.

The insights shared by participants offer important implications for health care practices. Young people do not want to be ignored or treated as invisible when receiving health care interventions or attending medical appointments. Though some children wanted to avoid hearing ‘scary’ medical information, most wanted to be informed about their medical care and included in discussions with health care providers. What varied among participants was the extent to which they desired involvement in these discussions. Some participants wanted to lead discussions with doctors and nurses, while others were more comfortable observing discussions and having parents communicate concerns to the health care team on their behalf.

The challenge for health care providers is to assess each child’s situation and preferences, and determine the optimal extent to which a child should be involved. An ongoing process of checking in with the young person and their family is essential to ensuring that all stakeholders feel that they are receiving adequate information and are able to participate in the decision making process to the extent they desire. Accordingly, health care providers must be able to quickly assess a family’s communication style and facilitate discussions informed by an understanding of parents’ cultural beliefs, parenting style, and the child’s personality, abilities, and preferences for participation. Health care providers can play a crucial leadership role by modeling for parents and other hospital staff effective ways to engage children in health care discussions and decision making.

The importance of interpersonal interactions when working with children cannot be understated. Training for pediatric health care providers should emphasize effective communication skills with children, as well as facilitation skills for helping families navigate health care discussions. Finally, health care providers should be educated around their role in teaching children health literacy through encouraging their participation in health care decision

making. Findings from this study, as well as those reported elsewhere (Coyne & Harder, 2011), show that children develop decision making abilities by gradually gaining responsibility in care and decision making over time. Health care providers can facilitate this process by establishing a climate of participation that encourages children's involvement and respects their needs for information and support.

Collaborative decision making as integral to ethical care. Ethical considerations are fundamental to any discussion of health care decision making. The collaborative-contextual model of decision making holds potential for addressing these issues while supporting the preferences and best interests of young people. From an ethical perspective, there is the question of how children's participation in health care decision making can encompass the four principles of medical ethics: respect for autonomy, beneficence, non-maleficence, and justice (Baines, 2008). These principles dictate that patients should be free to make autonomous medical decisions, that medical decisions should be made in a patient's best interests, medical care should not produce further harm, and that medical care should be distributed fairly. Baines writes that in the case of children's participation, there is debate as to whether children are competent to make autonomous decisions and concerns regarding the ethical acceptability of parental authority in making medical decisions for children.

The proposed collaborative-contextual model of decision making speaks to many of the challenges stemming from the application of these principles to children's participation in health care decision making. By presenting pediatric decision making as a collaborative process, children's autonomy as patients is acknowledged and addressed. Though the collaborative-contextual model does not advocate for young people to have sole discretion in all decisions, the model advocates for their right to voice their opinions and for that voice to be heard and

respected. It should be noted that the model may be limited in its ability to address situations where parents and children hold truly conflicting views surrounding a health care decision.

The collaborative-contextual model of pediatric decision making is consistent with the Canadian Paediatric Society (CPS) position statement on treatment decisions regarding infants, children and adolescents (2004). The CPS calls for decision making that is “interdisciplinary and collaborative, and actively involve[s] the family and, when appropriate, the child or adolescent” (p. 99). Consistent with the findings reported in the present study, the CPS advises that children should be given opportunities to participate in health care decision making “to an increasing degree as they develop” (p. 99). Most importantly, the position statement affirms young people’s participation rights, stating:

While some practitioners believe that children either do not want or are incapable to participate in treatment decisions, to deny decision-making to mature adolescents may be interpreted as a violation of their fundamental rights. (p. 100)

Of note is the language used in this affirmation. While the CPS recognizes the human right of ‘mature’ adolescents to participate in decision making, the same provision is not extended to younger children. The abilities of young children are afforded little value in the position statement, which includes the following assertion: “Preschool children have no significant skills to participate in decision-making in any meaningful way” (p. 101). It should be noted, however, that the Ontario Health Care Consent Act (1996) does not specify a minimum age for consenting to medical treatment. Furthermore, as stated in Article 12 of the United Nations Convention on the Rights of the Child, all young people have a right to express their opinion on personal matters and to have the opinion be heard. Expanding children’s participation in health care decision

making is integral to providing ethical care, yet there is a lack of recognition in the Canadian health care field of the extent to which children can and should be involved.

Strengths and Limitations

Strengths. This study contributes to our understanding of the intricacies and variables associated with children's health care participation. It also provides a uniquely North American perspective given the limited amount of research conducted in the United States and Canada. Recognition of children's participation in health care decision making is also lacking in the Canadian public policy arena. For instance, a 2012 status report on children's rights and child and youth health published by the Canadian Paediatric Society makes no mention of children's health care participation rights. A report on the implementation of the UNCRC in Canada, published by the Canadian Coalition for the Rights of Children (2011) reported that three quarters of young people in Canada do not know what their participation rights are or how to exercise them. It is hoped that the work presented as part of the present study can elicit further research and discourse regarding children's health care participation rights, and indeed, extend the discussion to other aspects of social life.

A unique contribution of this study is its application of the bilateral model of parent-child relations to assist in analyzing parent-child dynamics within the context of pediatric decision making. While previous studies have examined how parents influence children's preferences and abilities relating to health care participation, no theoretical framework has been applied to this area of research. The bilateral model offers a practical yet nuanced framework for understanding children's participation in health care decision making as a bidirectional process. This theory calls attention to children's influence and power in parent-child relationships; a concept which

may be of use to health care providers as they facilitate collaborative decision making and try to address the needs and preferences of parents and children.

Limitations. This study was conducted at a large urban pediatric hospital committed to family-centred care. Participants in the study described their experience at the hospital very favourably, and noted in particular the sensitivity and friendliness of staff as contributing to the positive nature of their hospital visits. Accordingly, findings from this study must be understood within this particular context. It is possible that participants' views could vary significantly had the study been conducted with children treated on a pediatric ward at a general hospital, in another country, or at a hospital in a more rural location. Given that the study was conducted in a large urban centre with a diverse patient population, health care providers at this hospital likely possess a high level of sensitivity in providing culturally-sensitive family-centred care, a skill that may be performed differently in a rural hospital serving a more homogenous population.

Another contextual factor that should be understood as a limitation of this study is the participant inclusion criteria. All participants in this study had been diagnosed with a chronic illness and had experienced at least one hospitalization. Most of these young people had considerable experience with the health care system and extensive knowledge of their illness and medical procedures. The perspectives of children hospitalized with an acute illness might vary significantly from those with numerous health care experiences.

As data analysis for this study was informed by the bilateral model of parent-child relations, analysis focused on dyadic interactions between participants and their parents. However, it should be noted that many participants in the study described siblings and extended family members as playing a role in their health care management and decision making. The use of a more macro-level theoretical framework may have drawn greater attention to the

involvement of other family members in influencing the quality of children's health care participation. For instance, using family systems theory as a lens through which to understand children's participation in health care decision making would have emphasized the dynamic ways family members interact when considering a health care decision (see Smith et al., 2009). Consequently, a caveat of this study is its focus on the parent-child relationship, and its limited consideration of the role of extended family members in facilitating children's health care participation.

Finally, as a secondary analysis, this study examined the perspectives of children on health care participation, excluding the views of parents or health care providers. Together, children, parents, and health care providers play an integrated role in pediatric decision making, yet this study presents the views of just one stakeholder group. Interviews with parents and health care providers would have provided a more comprehensive understanding of these complex processes and associated controversies. Inclusion of these participants would have offered further possibilities for analysis, by providing the ability to analyze parents', children's, and health care providers' statements for discrepancies and contrasting views.

Areas for Future Research

Future research should examine the perspectives of young people confronted with health care decisions during an acute hospitalization for illness or injury. Such research may shed light on how children participate in decision making differently, depending on the acuity, stage, and severity of illness. As well, present findings demonstrate that young people with chronic illness gain responsibility and practice in health care decision making over time (see also Giarelli et al., 2008; Meah et al., 2009; Schilling et al., 2006). How do young people facing an acute health

situation cope with decision making when lacking prior experience or significant knowledge of the health care system?

Though a limitation of this study was its singular focus on children's perspectives, other research has examined the attitudes of parents and health care providers toward children's health care participation. More research is needed to understand commonalities and discrepancies across children's, parents', and health care providers' attitudes toward participation. A comparison of stakeholders' views would enhance understanding of how differences in perspective contribute to challenges in facilitating children's health care participation. As well, future research should examine whether experienced and novice health care providers differ in their attitudes towards children's health care participation. This research would inform training modules for new health care providers and identify health care disciplines that can take a leadership role in facilitating children's health care participation rights.

Finally, it has been noted that much of the research on children's perspectives in health care decision making has been conducted in the UK and Scandinavian countries. That these countries support a research agenda that furthers children's rights likely indicates underlying cultural values that recognize children as competent social 'beings.' More cross-cultural research is necessary to understand the role of culture in influencing attitudes towards children's health care participation rights. Both exploratory and descriptive research is necessary to examine the extent of children's health care participation worldwide, as well as children's varying preferences for participation in different cultures.

Conclusion

This study demonstrates the ability of young people to discuss complex matters with candidness, depth, and insight. The perspectives shared by participants lend support for a model of decision making that promotes collaborative participation between young people, parents, and health care providers. Participants both recognized and desired the critical support provided by parents and health care providers as they managed the daily challenges of chronic illness. With regard to decision making, participants varied in their preferences for involvement, but collectively acknowledged a desire to be informed about their illness and treatment.

At the same time, findings indicate that parents can constrain or enable a child's health care participation. A young person's preference and ability for participation must therefore be understood in the context of the parent-child relationship, as well as in relation to other contextual factors in the decision making environment. This finding highlights a significant clinical practice issue relating to the ability of parents and health care providers to facilitate children's health care participation in a way that respects their rights, abilities, and preferences. Adults supporting children with chronic illnesses must establish an atmosphere of open communication even around topics that may be difficult or emotional to discuss. As well, they must be able to assess a child's desire for information and involvement and adjust their support to ensure the child's comfort in health care participation.

This study carries important implications for health care policy and practice, in elucidating young people's preferences for health care participation, and indeed, in revealing their ability to participate with confidence and competence. Though children and adolescents with chronic medical conditions have the ability and desire to participate in decision making, they live in a society that often minimizes their abilities and overlooks their rights. To begin with, children, parents and health care providers must recognize the complexities inherent to

child-parent relationships and the challenges of making decisions in the context of childhood chronic illness. It is hoped that continued work in this area will draw ongoing attention to the participation rights of young people and illuminate new ways to achieve greater ethical practice for children and their families.

References

- Alderson, P., Sutcliffe, K., & Curtis, K. (2006). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 91(4), 300–303. doi:10.1136/adc.2005.079442
- Allen, D., Channon, S., Lowes, L., Atwell, C., & Lane, C. (2011). Behind the scenes: The changing roles of parents in the transition from child to adult diabetes service. *Diabetic Medicine*, 28(8), 994–1000.
- André, N., Gaudart, J., Bernard, J.-L., & Chabrol, B. (2005). How paediatric residents involve children during medical decision-making. *Archives de Pédiatrie*, 12(7), 1068–1074.
- Angst, D., & Deatrick, J. (1996). Involvement in health care decisions: Parents and children with chronic illness. *Journal of Family Nursing*, 2(2), 174–194.
- Arnett, J. J. (2007). *Adolescence and emerging adulthood* (3rd ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Baines, P. (2008). Medical ethics for children: Applying the four principles to paediatrics. *Journal of Medical Ethics*, 34, 141-145.
- Beresford, B. A., & Sloper, P. (2003). Chronically ill adolescents' experiences of communicating with doctors: A qualitative study. *Journal of Adolescent Health*, 33(3), 172–179.
- Bloor, M. & Wood, F. (2006). *Keywords in qualitative methods*. Thousand Oaks, CA: Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Byczkowski, T. L., Kollar, L. M., & Britto, M. T. (2010). Family experiences with outpatient care: Do adolescents and parents have the same perceptions? *Journal of Adolescent Health*, 47(1), 92–98.
- Cahill, P., & Papageorgiou, A. (2007). Video analysis of communication in paediatric consultations in primary care. *British Journal of General Practice*, 57, 866-871.

- Canadian Coalition for the Rights of Children. (2011). Right in principle, right in practice: Implementation of the Convention on the Rights of the Child in Canada. Retrieved from <http://rightsofchildren.ca/wp-content/uploads/CCRC-report-on-rights-of-children-in-Canada.pdf>.
- Canadian Paediatric Society. (2004). Treatment decisions regarding infants, children and adolescents. *Paediatrics & Child Health*, 9(2), 99-103.
- Canadian Paediatric Society. (2012). Are we doing enough? A status report on Canadian public policy and child and youth health. Retrieved from <http://www.cps.ca/advocacy/StatusReport2012.pdf>.
- Carter, B., & Ford, K. (2013). Researching children's health experiences: The place for participatory, child-centered, arts-based approaches. *Research in Nursing & Health*, 36(1), 95–107.
- Clark, Alison (2004). The mosaic approach and research with young children. In V. Lewis, M. Kellett, C. Robinson, S. Fraser, & S. Ding (Eds.), *The reality of research with children and young people* (pp. 142-1161). London, UK: Sage.
- Clemente, I. (2009). Progressivity and participation: Children's management of parental assistance in paediatric chronic pain encounters. *Sociology of Health & Illness*, 31(6), 872–888.
- Coad, J. E., & Shaw, K. L. (2008). Is children's choice in health care rhetoric or reality? A scoping review. *Journal of Advanced Nursing*, 64(4), 318–327.
- Corsaro, W. A. (2011). *The sociology of childhood*. Los Angeles: Sage/Pine Forge Press.

- Cox, E. D., Smith, M. A., Brown, R. L., & Fitzpatrick, M. A. (2007). Effect of gender and visit length on participation in pediatric visits. *Patient Education and Counseling*, 65(3), 320–328.
- Cox, E. D., Smith, M. A., Brown, R. L., & Fitzpatrick, M. A. (2009). Learning to participate: Effect of child age and parental education on participation in pediatric visits. *Health Communication*, 24(3), 249–258.
- Coyne, I. (2006). Consultation with children in hospital: Children, parents' and nurses' perspectives. *Journal of Clinical Nursing*, 15(1), 61–71.
- Coyne, I. (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies*, 45(11), 1682–1689.
- Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: Children and young people's experiences in a hospital setting. *Journal of Clinical Nursing*, 20(15-16), 2334–2343.
- Coyne, I., & Harder, M. (2011). Children's participation in decision-making: Balancing protection with shared decision-making using a situational perspective. *Journal of Child Health Care*, 15(4), 312–319.
- Coyne, I., & Kirwan, L. (2012). Ascertaining children's wishes and feelings about hospital life. *Journal of Child Health Care*, 16(3), 293–304.
- Coyne, I., O'Mathúna, D. P., Gibson, F., Shields, L., & Sheaf, G. (2013). Interventions for promoting participation in shared decision-making for children with cancer. *Cochrane Database of Systematic Reviews*. Chichester, UK: John Wiley & Sons.

- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed Methods approaches*. Thousand Oaks: Sage.
- Curtis-Tyler, K. (2011). Levers and barriers to patient-centred care with children: Findings from a synthesis of studies of the experiences of children living with type 1 diabetes or asthma. *Child: Care, Health and Development*, 37(4), 540–550.
- Curtis-Tyler, K. (2012). Facilitating children's contributions in clinic? Findings from an in-depth qualitative study with children with type 1 diabetes. *Diabetic Medicine*, 29(10), 1303–1310.
- Dashiff, C. J. (2003). Self-and dependent-care responsibility of adolescents with IDDM and their parents. *Journal of Family Nursing*, 9(2), 166-183.
- Dashiff, C., Vance, D., Abdullatif, H., & Wallander, J. (2009). Parenting, autonomy and self-care of adolescents with type 1 diabetes. *Child: Care, Health and Development*, 35(1), 79–88.
- Devine, K. A., Wasserman, R. M., Gershenson, L. S., Holmbeck, G. N., & Essner, B. S. (2010). Mother-adolescent agreement regarding decision-making autonomy: A longitudinal comparison of families of adolescents with and without spina bifida. *Journal of Pediatric Psychology*, 36(3), 277–288.
- DiMatteo, M. R. (2004). The role of effective communication with children and their families in fostering adherence to pediatric regimens. *Patient Education and Counseling*, 55(3), 339-344.
- Fargas-Malet, M., McSherry, D., Larkin, E., & Robinson, C. (2010). Research with children: Methodological issues and innovative techniques. *Journal of Early Childhood Research*, 8(2), 175-192.

- Farrant, B., & Watson, P. D. (2004). Health care delivery: Perspectives of young people with chronic illness and their parents. *Journal of Paediatrics and Child Health*, 40(4), 175–179.
- Garbarino, J. (2011). Commentary: An approach to assessing “accountability” in implementing the UN Convention on the Rights of the Child. *Child Abuse and Neglect*, 35, 990-992.
- Giarelli, E., Bernhardt, B. A., Mack, R., & Pyeritz, R. E. (2008). Adolescents’ transition to self-management of a chronic genetic disorder. *Qualitative Health Research*, 18(4), 441–457.
- Ha, J. F., & Longnecker, N. (2010). Doctor-patient communication: A review. *The Ochsner Journal*, 10(1), 38-43.
- Hack, T. F., Degner, L. F., Watson, P., & Sinha, L. (2006). Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psycho-Oncology*, 15(1), 9-19.
- Halfon, N., Newacheck, P.W. (2010). Evolving notions of childhood chronic illness. *Journal of the American Medical Association*, 303(7), 665-666.
- Hanna, K., Juarez, B., Lennox, S.S., & Guthrie, D. (2003). Parent-adolescent communication and support for diabetes management as reported by adolescents with type 1 diabetes. *Pediatric Nursing*, 26, 145–158.
- Health Care Consent Act S. O. (1996). Retrieved from http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm
- Hendrick, H. (1990). Constructions and reconstructions of British childhood: An interpretive survey, 1800 to the present. In A. James & A. Prout (Eds.), *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*, (35-59). Basingstoke: Falmer Press.

- Hinds, P. S., Vogel, R. J., & Clarke-Steffen, L. (1997). The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research*, 7(3), 408-424.
- Honig, M. S. (2009). How is the child constituted in childhood studies? In J. Qvortrup, W. A. Corsaro, & M.S. Honig (Eds.), *The Palgrave Handbook of Childhood Studies* (62-77). Basingstoke: Palgrave MacMillan.
- Hood, K. K., Odell, S., & Sander, E. P. (2010). Diabetes-specific family conflict and blood glucose monitoring in adolescents with type 1 diabetes: Mediation role of diabetes self-efficacy. *Diabetes Spectrum*, 23, 89-94.
- Hunfeld, J. A. M., & Passchier, J. (2011). Participation in medical research: A systematic review of the understanding and experience of children and adolescents. *Patient Education and Counseling*.
- Irwin, L. G., & Johnson, J. (2005). Interviewing young children: Explicating our practices and dilemmas. *Qualitative Health Research*, 15(6), 821-831.
- Jagosh, J., Boudreau, J. D, Steinert, Y., MacDonald, M. E., & Ingram, L. (2011). The importance of physician listening from the patients' perspective: Enhancing diagnosis, healing, and the doctor-patient relationship. *Patient Education and Counseling*, 85(3), 369-374.
- James, A., Curtis, P., & Birch, J. (2008). Care and control in the construction of children's citizenship. In J. Williams & A. Invernizzi (Eds.), *Children and Citizenship* (85-97). London: Sage.
- Jedeloo, S., van Staa, A., Latour, J. M., & van Exel, N. J. A. (2010). Preferences for health care and self-management among Dutch adolescents with chronic conditions: A Q-methodological investigation. *International Journal of Nursing Studies*, 47(5), 593-603.

- Joosten, E. A. G., DeFuentes-Merillas, L., De Weert, G. H., Sensky, T., Van Der Staak, C. P. F., & de Jong, C. A. (2008). Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychotherapy and Psychosomatics*, 77(4), 219-226.
- Kelsey, J., Abelson-Mitchell, N., & Skirton, H. (2007). Perceptions of young people about decision making in the acute healthcare environment. *Paediatric Nursing*, 19(6), 14–8.
- Kieckhefer, G. M., Churchill, S. S., Trahms, C. M., & Simpson, J. N. (2009). Measuring parent-child shared management of chronic illness. *Pediatric Nursing*, 35(2), 101-108.
- Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies*, 44(7), 1250–1260.
- Koller, D. (2008). *Therapeutic play in pediatric health care: The essence of child life practice*. Child Life Council evidence-based practice statement. Retrieved from <http://childlife.org/files/EBPPlayStatement-Complete.pdf>
- Kon, A. A. (2010). The shared decision-making continuum. *Journal of the American Medical Association*, 304(8), 903-904.
- Kuczynski, L. (2003). Beyond bidirectionality: Bilateral conceptual frameworks for understanding dynamics in parent-child relations. In L. Kuczynski (Ed.), *Handbook of dynamics in parent-child relations* (pp. 3-24). Thousand Oaks, CA: Sage Publications.
- Lambert, V., Glacken, M., & McCarron, M. (2008). ‘Visible-ness’: The nature of communication for children admitted to a specialist children’s hospital in the Republic of Ireland. *Journal of Clinical Nursing*, 17(23), 3092–3102.

- Lee, N. (2001). *Childhood and society: Growing up in an age of uncertainty*. Buckingham: Open University Press.
- Lindsay, S., Kingsnorth, S., & Hamdani, Y. (2011). Barriers and facilitators of chronic illness self-management among adolescents: A review and future directions. *Journal of Nursing and Healthcare of Chronic Illness*, 3(3), 186–208.
- Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2011). What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, 32(2), 246–258.
- Mårtenson, E. K., & Fägerskiöld, A. M. (2008). A review of children's decision-making competence in health care. *Journal of Clinical Nursing*, 17(23), 3131–3141.
- Matthews, S. H. (2007). A window on the 'new' sociology of childhood. *Sociology Compass*, 1, 322-334.
- Mauthner, M. (1997). Methodological aspects of collecting data from children: Lessons from three research projects. *Children & Society*, 11(1), 16–28.
- McCracken, G. (1988). *The long interview*. Newbury Park, CA: Sage Publications.
- McPherson, A. C. & Redsell, S.A. (2009). Factors affecting children's involvement in asthma consultations: A questionnaire survey of general practitioners and primary care asthma nurses. *Primary Care Respiratory Journal*, 18 (1), 15-20.
- Meah, A., Callery, P., Milnes, L., & Rogers, S. (2009). Thinking 'taller': Sharing responsibility in the everyday lives of children with asthma. *Journal of Clinical Nursing*, 19(13-14), 1952–1959.

- Merenstein, D., Diener-West, M., Krist, A., Pinneger, M., & Cooper, L. A. (2005). An assessment of the shared-decision model in parents of children with acute otitis media. *Pediatrics*, 116(6), 1267-1275.
- Miller, V. A. (2009). Parent–child collaborative decision making for the management of chronic illness: A qualitative analysis. *Families, Systems, & Health*, 27(3), 249–266.
- Miller, V. A., & Harris, D. (2012). Measuring children’s decision-making involvement regarding chronic illness management. *Journal of Pediatric Psychology*, 37(3), 292–306.
- Moore, L., & Kirk, S. (2010). A literature review of children’s and young people’s participation in decisions relating to health care. *Journal of Clinical Nursing*, 19(15-16), 2215–2225.
- Newbould, J., Smith, F., & Francis, S. A. (2008). ‘I’m fine doing it on my own’: Partnerships between young people and their parents in the management of medication for asthma and diabetes. *Journal of Child Health Care*, 12(2), 116–128.
- Palmer, D. L., Berg, C. A., Wiebe, D. J, Beveridge, R. M., Korbel, C. D., Upchurch, R.,... Donaldson, D. L. (2004). The role of autonomy and pubertal status in understanding age differences in maternal involvement in diabetes responsibility across adolescence. *Journal of Pediatric Psychology*, 29(1), 35–46.
- Penn, H. (2008). *Understanding early childhood: Issues and controversies* (2nd ed.). Berkshire, England: Open University Press.
- Prout, A. (2000). Foreword. In P. Chirstensen & A. James (Eds.), *Research with Children: Perspectives and Practices* (xi-xii). London: Falmer Press.
- Punch, S. (2002). Research with children: The same or different from research with adults? *Childhood*, 9(3), 321-341.

- Qvortrup, J., Corsaro, W. A., & Honig, M. S. (2009). *The Palgrave handbook of childhood studies*. Basingstoke: Palgrave Macmillan.
- Rathus, S. A. (2008). *Childhood: Voyages in development* (Third ed.). Belmont, CA: Thomson Wadsworth.
- Roter, D. (2000). The enduring and evolving nature of the patient-physician relationship. *Patient Education and Counseling*, 39, 5-15.
- Roter, D. L., Hall, J. A., Kern, D. E., Barker, L. R., Cole, K. A., & Roca, R. P. (1995). Improving physicians' interviewing skills and reducing patients' emotional distress: a randomized clinical trial. *Archives of Internal Medicine*, 155(17), 1877.
- Runeson, I., Enskär, K., Elander, G., & Hermerén, G. (2001). Professionals' perceptions of children's participation in decision making in healthcare. *Journal of Clinical Nursing*, 10(1), 70–78.
- Sahlsten, M. J., Larsson, I. E., Sjöström, B., & Plos, K. A. (2008). An analysis of the concept of patient participation. *Nursing Forum*, 43(1), 2-11.
- Salmela, M., Aronen, E. T., & Salanterä, S. (2011). The experience of hospital-related fears of 4- to 6-year-old children. *Child: Care, Health and Development*, 37(5), 719–726.
- Sandman, L., & Munthe, C. (2009). Shared decision making, paternalism and patient choice. *Health Care Analysis*, 18(1), 60–84.
- Sawyer, S., & Aroni, R. (2005). Self-management in adolescents with chronic illness. *Medical Journal of Australia*, 183, 405–409.
- Schilling, L. S., Knafl, K. A., & Grey, M. (2006). Changing patterns of self-management in youth with type I diabetes. *Journal of Pediatric Nursing*, 21(6), 412–424.

- Schmidt, S., Petersen, C., & Bullinger, M. (2003). Coping with chronic disease from the perspective of children and adolescents—a conceptual framework and its implications for participation. *Child: Care, Health and Development*, 29(1), 63–75.
- Smith, S.R., Hamon, R.R., Ingoldsby, B.B., & Miller, J.E. (2009). *Exploring family theories* (2nd ed). New York: Oxford UP.
- Stivers, T. (2012). Physician–child interaction: When children answer physicians’ questions in routine medical encounters. *Patient Education and Counseling*, 87(1), 3–9.
- Tates, K., & Meeuwesen, L. (2000). ‘Let Mum have her say’: Turntaking in doctor–parent–child communication. *Patient Education and Counseling*, 40(2), 151–162.
- Terry, L., & Campbell, A. (2001). Are we listening to children’s views about their treatment? *British Journal of Nursing*, 10(6), 384.
- United Nations (1989). *Convention on the Rights of the Child*. Retrieved from <http://www2.ohchr.org/english/law/crc.htm>.
- Vaknin, O., & Zisk-Rony, R. Y. (2011). Including children in medical decisions and treatments: Perceptions and practices of healthcare providers. *Child: Care, Health and Development*, 37(4), 533–539.
- Van Dulmen, A. M. (1998). Children’s contributions to pediatric outpatient encounters. *Pediatrics*, 102(3), 563–568.
- Van Dulmen, S. (2004). Pediatrician–parent–child communication: Problem-related or not? *Patient Education and Counseling*, 52(1), 61–68.
- Van Staa, A. (2011). Unraveling triadic communication in hospital consultations with adolescents with chronic conditions: The added value of mixed methods research. *Patient Education and Counseling*, 82(3), 455–464.

- Van Staa, A., Jedeloo, S., & van der Stege, H. (2011). 'What we want': Chronically ill adolescents' preferences and priorities for improving health care. *Patient Preference and Adherence*, 5, 291.
- Viklund, G., & Wikblad, K. (2009). Teenagers' perceptions of factors affecting decision-making competence in the management of type 1 diabetes. *Journal of Clinical Nursing*, 18(23), 3262–3270.
- Wiebe, D. J., Berg, C. A., Korbel, C., Palmer, D. L., Beveridge, R. M., Upchurch, R., & Donaldson, D. L. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology*, 30(2), 167-178.
- Wiley, D. C., & Hendricks, C. M. (1998). Using picture identification for research with preschool children. *Journal of School Health*, 68(6), 227–230.
- Williams, C. (2000) Alert assistants in managing chronic illness: the case of mothers and teenage sons. *Sociology of Health & Illness*, 22, 254–272.
- Wilson, M. E., Megel, M. E., Enenbach, L., & Carlson, K. L. (2010). The voices of children: Stories about hospitalization. *Journal of Pediatric Health Care*, 24(2), 95–102.
- Young, B., Dixon-Woods, M., Windridge, K. C., & Heney, D. (2003). Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *British Medical Journal*, 326(7384), 1-5.
- Zwaanswijk, M., Tates, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., & Bensing, J. M. (2007). Young patients', parents', and survivors' communication preferences in paediatric oncology: Results of online focus groups. *BMC Pediatrics*, 7(1), 35.