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# Perspectives of Family Management from School-Aged Children with Chronic Health Conditions: Through the Eyes of the Children

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# Perspectives of Family Management from School-Aged Children with Chronic Health Conditions: Through the Eyes of the Children

## **Abstract**

Families play a significant role in condition management processes. They influence how children interpret their Chronic Health Conditions (CHC) and interact with others at home and in social settings as well as how others interact with them. A gap currently exists in understanding children's perspectives about family management of their CHCs. It is, therefore, important to elicit children's perspectives and use them to inform future family management models. A qualitative, descriptive study was conducted among 8 to 13 year old children who had a variety of CHCs. They were asked to (a) describe family management of their CHCs within the home; (b) describe family management of their CHCs in social settings (i.e., at school, at extracurricular events, in health care settings, and within peer and adult social networks); (c) describe their own roles, responsibilities, and decision-making processes in a condition management context. Content analysis of their responses (N=32) to semi-structured interviews deepened the current understanding of children's perspectives regarding what family management means to them, how it impacts their daily lives, and how roles and responsibilities are distributed among parents and children during middle childhood. The school-aged children discussed condition management from a family perspective as well as from their own individual perspectives. The findings complement the Family Management Style Framework and broaden our understanding of condition management by adding the perspectives of the children about themselves and their families. Recommendations for future modifications of the framework include reconsideration of child identity and parent mutuality dimensions. Improvements in condition management among families and children have the potential to decrease both acute exacerbations and the use of health care resources while improving quality of life for children and their families. This research provides a foundation for future studies to identify related measures, interventions and policy changes related to school-aged children with CHCs and their families.

## **Degree Type**

Dissertation

## **Degree Name**

Doctor of Philosophy (PhD)

## **Graduate Group**

Nursing

## **First Advisor**

Janet A. Deatrick

## **Keywords**

Chronic Health Conditions, Chronic Illness, Family Management, School-aged Children

## **Subject Categories**

Nursing

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PERSPECTIVES OF FAMILY MANAGEMENT FROM SCHOOL-AGED CHILDREN  
WITH CHRONIC HEALTH CONDITIONS: THROUGH THE EYES OF THE CHILDREN

Barbara L. Beacham

A DISSERTATION

in

Nursing

Presented to the Faculties of the University of Pennsylvania

in

Partial Fulfillment of the Requirements for the

Degree of Doctor of Philosophy

2013

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PERSPECTIVES OF FAMILY MANAGEMENT FROM SCHOOL-AGED CHILDREN  
WITH CHRONIC HEALTH CONDITIONS: THROUGH THE EYES OF THE CHILDREN

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## Dedication

To the families and children who were gracious enough to allow me a brief look into their lives, to improve our understanding of condition management from the child's perspective. May you all have rich and full lives.

## ACKNOWLEDGMENT

This dissertation would not have been possible without the help and support from mentors, colleagues, family and friends. A special thank you goes to my advisor and dissertation chair, Dr. Janet Deatrick for her assistance and professional guidance through the process. I would also like to express my deep appreciation to my committee members, Dr. Lamia Barakat and Dr. Terri Lipman, for giving of their time and expertise to guide me in this work.

In addition, I am grateful to Dr. Marilyn S. Sommers for her encouragement, support and mentorship throughout my doctoral education. I would also like to thank the health care providers, clinicians, faculty, and support staff at The Children's Hospital of Philadelphia for the expertise they shared with me as I recruited and enrolled patients from their clinic populations. This work would not have been possible without their cooperation.

I had to good fortune to be associated with the Center for Health Equity Research and benefited greatly from having this academic home. Being a member of the center challenged my thinking in ways I had not imagined. I value our weekly discussions, the growth I've experienced as a member of the Center, and will miss you all deeply.

I would like to thank my Philadelphia family and friends. Your love and support gave me a home away from home, a place to study and unwind. Who knew I'd grow to call Philly home and you all my extended family. Thank you to my New Jersey family, especially Jud and Elva Beacham. Throughout my life you have encouraged me in all aspects of my educational endeavors and gave me the confidence to move forward with each new step. Finally, I would like to thank my partner Erika, for being there through the laughter and the tears. It was easier to complete this work because you were by my side.

## FUNDING ACKNOWLEDGEMENT

This research was primarily supported by a Ruth L. Kirschstein NRSA Individual Predoctoral Fellowship (1F31NR011524, PI: Beacham). Additionally, my training and scholarly inquiry were supported by a Ruth L. Kirschstein NRSA Predoctoral Fellowship Training Grant (T32NR007100, PI: J.A. Deatrck), as well as two research grants, "Injury in Latina Women After Sexual Assault: Moving Toward Health Care Equity" (R01NR011589, PI: M.S. Sommers) and "Mothers as Caregivers for Survivors of Brain Tumors" (R01NR009651 PI: J.A. Deatrck). Both of these training grants, along with the research grants were funded by the National Institute of Nursing Research and administered by the University of Pennsylvania School of Nursing. The content is solely my responsibility as the author and does not necessarily represent the official views of the National Institute of Nursing Research or the National Institutes of Health.

This research was also supported by a grant from Sigma Theta Tau International, XI Chapter at the University of Pennsylvania School of Nursing.



## ABSTRACT

### PERSPECTIVES OF FAMILY MANAGEMENT FROM SCHOOL-AGED CHILDREN WITH CHRONIC HEALTH CONDITIONS: THROUGH THE EYES OF THE CHILDREN

Barbara L. Beacham

Janet A. Deatrick

Families play a significant role in condition management processes. They influence how children interpret their Chronic Health Conditions (CHC) and interact with others at home and in social settings as well as how others interact with them. A gap currently exists in understanding children's perspectives about family management of their CHCs. It is, therefore, important to elicit children's perspectives and use them to inform future family management models. A qualitative, descriptive study was conducted among 8- to 13-year old children who had a variety of CHCs. They were asked to (a) describe family management of their CHCs within the home; (b) describe family management of their CHCs in social settings (i.e., at school, at extracurricular events, in health care settings, and within peer and adult social networks); (c) describe their own roles, responsibilities, and decision-making processes in a condition management context. Content analysis of their responses (N=32) to semi-structured interviews deepened the current understanding of children's perspectives regarding what family management means to them, how it impacts their daily lives, and how roles and responsibilities are distributed among parents and children during middle childhood. The school-aged children discussed condition management from a family perspective as well as from their own individual perspectives. The findings complement the Family Management Style Framework and broaden our understanding of condition management by adding the perspectives of the children about themselves and their families. Recommendations for future modifications of the framework include reconsideration of child identity and parent mutuality dimensions. Improvements in condition management among families and children have the potential to decrease both acute exacerbations and the use of

health care resources while improving quality of life for children and their families. This research provides a foundation for future studies to identify related measures, interventions and policy changes related to school-aged children with CHCs and their families.

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## CHAPTER 1

### Through the Eyes of the Child: Family Management of Chronic Health Conditions

The prevalence of children with chronic health conditions is rising (Perrin, Bloom, & Gortmaker, 2007). Although it is difficult to determine an absolute number due to varying definitions and lack of a national database, the Federal Interagency Forum on Child and Family Statistics identified 9% of U.S. children between 5 and 17 who have a chronic health condition that limits their daily activity (Statistics, 2012), while an earlier publication found 1-in-5 U.S. households containing a child with a chronic health condition (CHC) (Hagan, Shaw, & Duncan, 2008). Some of the issues and challenges that must be met in the daily life of both those children and their families include (a) dealing with symptoms related to the condition; (b) managing physical, cognitive, and emotional differences; (c) organizing complex therapeutic and medication regimens; (d) adjusting their lifestyles; and, (e) obtaining medical care. These are in addition to the typical activities of work, school and the delicate balance of scheduling that children and their families address daily in family life. Additionally, children with CHCs experience more school absences, use more medical services, and report having activity-related limitations more frequently than children without CHCs (Cadman, Boyle, Szatmari, & Offord, 1987; Suris, Michaud, & Viner, 2004).

Looking across conditions to identify the underlying principles incorporated in family management provides a basis for applying this knowledge to a variety of conditions. Studies on specific conditions tend to focus on tasks related to the condition. Recognizing the underpinnings of management allows for the application of a consistent approach across conditions, while allowing for the specific condition management activities to be understood within the context of family management. For example, daily management of diabetes may be very different than daily management of hemophilia, but the work of managing the condition takes into account the parents view of management, behaviors, and perceived consequences; what varies is how it is enacted within each family and for each condition.



CHCs have been defined in many ways for epidemiological and research purposes. A systematic review of definitions and measurement found the most common concepts were chronic illness, chronic health conditions and children with special health care needs, while the definitions of the concepts varied regarding inclusion criteria for meeting the category (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). For the purpose of this study, a chronic health condition is a diagnosed medical condition that is anticipated to require care to maintain the health status or manage the symptoms of the condition for more than six months.

Family management refers to the cognitive and behavioral response of the family to childhood CHCs – how they actively organize, integrate, and accomplish the work related to those conditions (Knafl & Deatrick, 1990). Family management differs from other family concepts, such as family functioning or family environment, in that it is specifically concerned with identifying the domains of condition management rather than more general family phenomena or individual tasks that are associated with specific condition interventions. Studies examining unique conditions like asthma and diabetes have been informative for those diagnoses and tasks, but they do not necessarily incorporate family perspectives and may not be relevant to other conditions (Alderfer et al., 2008; McQuaid, Walders, Kopel, Fritz, & Klinnert, 2005). By identifying global management domains, the family management perspective examines issues related to management across medical diagnoses. As such, it provides a model for family management that can be applied both to specific conditions and across different conditions by recognizing the similarities and differences that exist for children with CHCs and their family members.

Family management of various CHCs has been studied from the parent perspective. Knafl and Deatrick have spent more than 20 years investigating family management, beginning with the original conceptual article and followed with the first empirical study that consisted of open ended qualitative interviews conducted with families of children with CHCs (Deatrick & Knafl, 1990; Knafl, Breitmayer, Gallo, & Zoeller, 1996; Knafl & Deatrick, 1990). The analysis of those interviews led to the development of the Family Management Style Framework (FMSF) (Knafl & Deatrick, 2003) and subsequently, the creation of the Family Management Measure

(FaMM) ( Knafl et al., 2011). Researchers have used the FMSF and FaMM in a variety of settings to study various populations in the U.S. and worldwide (Alderfer, 2006; Beeber & Zimmerman, 2012; Bouso, Misko, Mendes-Castillo, & Rossato, 2012; Deatrick et al., 2006; Ogle, 2006; Wiegand, 2012; Wiegand, Deatrick, & Knafl, 2008; Wollenhaupt, Rodgers, & Sawin, 2012; Zhang, Wei, Han, Zhang, & Shen, 2013) while work continues on refining both the FMSF and FaMM (Knafl et al., 2011; Knafl, Deatrick, & Havill, 2012; Knafl et al., 2013).

While an understanding has been reached about parents' perspectives regarding family management of the child's CHCs, children have rarely been included as informants in such studies (Beacham, 2011). Using a broad definition of family management which included both health- and non-health-related life span issues, a recent review of family management literature found that children's voices were often elicited in certain types of studies (Beacham, 2011). Those involving academic performance or the desire to delay the onset of risky behaviors – such as drinking, using illegal drugs, or initiating a sexual debut – included their voices, but their voices are largely absent in health care literature (Beacham, 2011). Therefore, little is known of children's perceptions of family management of their CHCs, especially during middle childhood.

The developmental stage of middle childhood, which includes the years preceding adolescence, was absent from much of the health care literature, although many studies examined the adolescent period. Although, during this period, the children's main sources of information and guidance are their families, Coll and Szalacha (Coll & Szalacha, 2004) asserted that children in middle childhood are increasingly exposed to institutions and individuals outside of their family environments and may begin to incorporate ideas and guidance from outside sources. For children with CHCs, middle childhood transitions which may be difficult to navigate include (a) encountering new situations at school; (b) determining if and whom to tell about their conditions; (c) relying on adults other than their parents for guidance and support (Hagan et al., 2008).

## Purpose and Specific Aims

This dissertation sheds light on the perspectives of children with CHCs who are between the ages of 8- and 13-years old by addressing three specific aims:

- (1) describe Family Management of their CHCs within the home;
- (2) describe Family Management of their CHCs in social settings (i.e., at school, at extracurricular events, in health care settings, and within peer and adult social networks);
- (3) describe the roles, responsibilities, and decision-making processes in a condition management context.

Eliciting their responses is an important step in developing a better understanding of family management and the frameworks, models, and interventions that are needed to systematically include those children's perspectives in future research. Prepared in a three-manuscript format, Chapter 1 contains a study overview and examines the (a) background and significance of family management of CHCs; (b) development which occurs in 8- to 13-year-old children; (c) relationship between family management and child development during this stage; (d) theoretical underpinnings of this study; and, (e) methods used to conduct this study.

The **Chapter 2** manuscript is prepared for submission to the *Journal of Family Nursing*, "Children's Perspectives Regarding Daily Family Condition Management," reports the study findings based on children's perspectives of family management within the home environment, and highlights children's perspectives of family management in social settings outside of their homes. Guided by the Family Management Styles Framework, this analysis highlights the congruence and dissonance between the child perspectives and the framework developed from parental perspectives. This manuscript addresses Specific Aims 1 and 2. The **Chapter 3** manuscript, "Roles, Responsibilities, and Decision-making of School-Aged Children with Chronic Health Conditions" examines children's perspectives on the roles and responsibilities which revolve around condition management as they relate to children and their family members. Chapter 3 addresses Specific Aim 3 and is prepared for submission to *Child: Care, Health and Development*. **Chapter 4** addresses the clinical significance of family management and the

development of health care autonomy and self-care in children with CHCs. Theoretical in nature; it is based upon current literature, findings from this study, and the candidate's vision of how the components are related. Recently published in *Nursing Clinics of North America*, "Health Care Autonomy in Children with Chronic Conditions: Implications for Self-Care and Family Management" provides an overview of the three concepts with clinical examples of how the intersection of the concepts needs to be recognized (Beacham & Deatrick, 2013). **Chapter 5** is a synthesized discussion of the findings and identification of future research priorities.

### **Background and Significance**

A review of research focused on the family system response to a member with a chronic illness identified two major clusters of inquiry: those that described the family response to illness and those that explained the family response to chronic illness (Knafl & Gilliss, 2002). Studies described behaviors that are essential to family health and highlighted the development of routines necessary for disease management (Fiese & Everhart, 2006; Fiese, Wamboldt, & Anbar, 2005). Lewin et al. (Lewin et al., 2006) identified family functioning and adherence as two family factors that helped explain condition control. This dissertation assumes that family management (FM) represents the parents' view of condition management and family condition management (FCM) represents the children's view and thus will be used to identify the child's perspective. This subtle distinction helps to highlight the focus on the child's perspective of family condition management that can inform research that may improve the quality of care and quality of life for children and their family members.

### **Family Management of CHC**

Within the context of this study, the term family management is closely aligned with Schilling, Grey and Knafl's (2002) definition which identifies it as the active, daily process by which youth, their parent(s)/guardian(s), and other family members share responsibility and decision-making tasks to achieve disease control, health, and well-being through a wide range of illness-related activities (Schilling, Grey, & Knafl, 2002). Knafl and colleagues (2013) most recently describe it as "the efforts that family members make to incorporate the demands of the

treatment regimen and their child's special needs into everyday family life strategies into their daily life and the effects those strategies have on those families" (p. 2) . FCM, by contrast, encompasses the child's perceptions of family members (i.e., children, their parents, other family members) view of the child, efforts at managing their condition and their perception of the consequences.

Studies examining families of children with CHCs have found that the connections which exist between families and children can have great impact – with positive family relationships leading to better health outcomes (Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004; DeLambo, Ievers-Landis, Drotar, & Quittner, 2004; Fiese et al., 2005) and negative family relationships leading to declines in children's health (Fiese & Everhart, 2006; Lewin et al., 2006). For instance, these studies found that positive family relationships led to better adherence while negative family relationships led to poor levels of adherence. Thus, the ability of family members to anticipate and recognize changes in children's health and engage with one another helps create environments that support successful condition management. Furthermore, Zashikhina and Hagglof (2009) found that perceived disease severity and long disease durations were factors that contributed to family dysfunction (Zashikhina & Hagglof, 2009). While these studies have increased overall knowledge about condition management and adherence to medical regimens, adherence is only a single consequence or outcome of condition management. A broader view of family management which more clearly conceptualizes family processes specific to condition management from children's perspectives, FCM would allow for clearer identification of each component of that process and more accurate assessment of each one's relationship to health-related outcomes among children with CHCs.

### **Measurement**

Several reliable and valid instruments have been developed which are currently used to measure various basic family processes. Some, such as the McMaster Family Assessment Device (Bishop et al., 1983) and the Family Environment Scale (Moos & Moos, 1994), were not specifically developed with children with CHCs in mind. Yet, they are regularly used to assess the

families of children with CHCs and, as Alderfer et al. (2008) have pointed out, the psychometrics within those pediatric studies often go unpublished or are lower than those reported among the general population (Alderfer et al., 2008). In a critical review assessing evidenced-based family measures, Alderfer et al. (2008) identified three instruments which help assess the impact children's CHCs have on their families or parents. They are the Impact on Family Scale (IOF) (Stein & Jessop, 2003), the Parents of Children with Disabilities Inventory (PCDI) (Noojin & Wallander, 1996), and the Pediatric Inventory for Parents (PIP) (Streisand, Braniecki, Tercyak, & Kazak, 2001). Alderfer found that all three well-established scales relied on parents as respondents, were problem-oriented and failed to recognize potential family strengths and/or positive outcomes.

Disease-specific instruments have been created which examine basic family processes as they related to conditions such as diabetes, asthma, and ADHD (Kendall & Shelton, 2003; McQuaid et al., 2005; Song, Deatrick, Feetham, & Levin, 2011). A review of diabetes literature identified no fewer than eight instruments that measure family-related diabetes concepts (Song et al., 2011); the instruments are tailored to both the diabetes population and tasks associated with the disease, but they do not address concepts which would be applicable within the larger scope of chronic illness across conditions.

Non-disease specific inquiries concerning family management have explored the domains or categories common across disease entities with findings which are potentially applicable to a wide range of health conditions. These domains are not problem-oriented; they are global domains that allow for the reporting of positive and negative experiences that result from caring for children with CHCs. Knafl et al. (2012) have provided the FMSF for examining the families of children with CHCs that assumes a common foundation for condition management regardless of the disease entity, adding to our understanding of condition management provided by disease-specific models. The FMSF was the basis for development of the FaMM (Knafl et al., 2011), an instrument that measures various dimensions of family life in the context of childhood chronic conditions. Recently, the FaMM was used to identify patterns of family responses to

childhood chronic conditions and demonstrated that patterns were significantly associated with child and family functioning (Knafel et al., 2013). That is, family-focused patterns, those indicating that family incorporates the illness work into family life, rather than condition-focused patterns, are correlated with significantly better child and family functioning. The framework and instrument are supported by decades of work with the parents of children with CHCs, but it does not include children's perspectives regarding FCM. Adding children's perspectives would make the model more holistic, may lead to a child version of the instrument and may help inform interventions directed at both the child and the family.

### **Middle Childhood Development**

Children's understanding of their CHCs varies according to their everyday experiences and their level of cognitive sophistication (Crisp, Ungerer, & Goodnow, 1996; McMenamy & Perrin, 2008). The period of middle childhood, from 6- to 13-years of age, is an especially important period of development. The process of cognitive development outlined by Jean Piaget identifies the years of middle childhood as concrete operational; it is during this period that children are able to perform operations directly related to objects but have yet to take on verbal expression of hypotheses (Piaget, 1964).

Vygotsky (Vygotsky, [1967],2004) has further asserted that the brain is capable of two functions: providing a place to store previous experiences, as memories, and a place to produce creative activity; that creative activity enables us to imagine what the future will be like, be innovative and inventive, and combine what we know to reveal something new. During middle childhood, children lay down experiences, or memories, with which they can combine, imagine, and create new hypotheses that they can then share with others, often through oral or written language (Vygotsky, [1967],2004). Vygotsky ([1967], 2004) has stressed that it is the ability to express those thoughts and engage in literary creativity that is indicative of cognitive development during this period. For children with CHCs, their families are frequently their main source of information, guidance, and care within the context of condition management. The interactions between parents and children, therefore, represent experiences that create memories those

children use to create their own hypotheses regarding condition management. At birth, babies are totally dependent upon the caregivers within their families, yet the developmental process anticipates that as they gain cognitive, physical, and psychosocial abilities and experiences related to managing their conditions, the roles and responsibilities within their families grow and change. Especially when considering health-related issues, guidance provided by family members may continue until children with CHCs reach their late teen years. As a consequence, parents may continue to make the majority of health-care decisions, but children's perspectives about their parents and their own management may not be well understood (Smetana, Campione-Barr, & Daddis, 2004).

A better understanding of middle childhood is of particular importance for children with CHCs since, at this stage, children begin to mature and develop their own thoughts and ideas about condition management (Crisp et al., 1996); they build patterns that are certain to influence their future management patterns and outcomes. They work at separating from their parents and developing autonomy, making more independent decisions as they spend more time outside of the home either in school or socializing with peers. As Erikson (1968) has noted, the major psychosocial challenge for school-aged children is one of industry versus inferiority (Erikson, 1968). As they adjust to being away from their parents or caregivers and their level of social interaction with peers increase, they must simultaneously learn to navigate through a day at school. Children may compare themselves to their peers regarding performance in school, sports, and other activities. Children who successfully cope with the stress of these comparisons emerge with a sense of confidence and industry. Children begin to develop a truer sense of self, as compared to their ideal self that possesses characteristics or qualities that may not be attainable. Children who do not feel supported find themselves unprotected and may emerge with a sense of inferiority. Therefore, if there is a discrepancy between a child's true sense of self and the importance they place on particular characteristics, the child may develop a negative self-evaluation and lower self-esteem (Cook & Cook, 2007). Having a CHC can affect children's perceptions about themselves when compared to others and these comparisons can influence



their sense of self and affect their future development.

As a developmental process, autonomy in children gradually increases across middle childhood and into adolescence before rising sharply in late adolescence (Wray-Lake, Crouter, & McHale, 2010). One 10-year, longitudinal study found that joint decision making related to things like appearance, social life, schoolwork, curfew, and activities began in middle childhood and matured between the ages of 17 and 20, when the decisions involved money, health, and chores (Wray-Lake et al., 2010). Children with CHCs may be much more involved with health practices on a daily basis and see health care practitioners more often than their counterparts with CHCs. Medication and treatment regimens are incorporated into their daily schedules. Therefore, school-aged children with CHCs learn the tasks associated with condition management but may not be truly autonomous. Parents and providers should be aware that although these children may be proficient in accomplishing the tasks of management, they are not necessarily ready for the roles, responsibilities, and decision-making associated with condition management. Those processes may not develop until later in adolescence or young adulthood; and how these processes are transitioned from parent to child is not well understood. Additionally, children without CHCs see a health care provider once a year unless they are ill; children with CHCs may have multiple appointments with multiple providers over the course of a year, require medication management beyond taking the pills, and need to develop an understanding of all components of their health care management. Learning to address these issues does not occur overnight, but by gaining a better understanding of this process from the perspective of children with CHCs, we can begin to develop interventions to help guide the children and their families through this developmental challenge.

### **Significance**

Once children are diagnosed with CHCs, the goal of their families and health care providers should be to develop a plan that supports maximization of their health and encourages them to take control of condition management tasks. Like teaching young children to brush their teeth, those transitions are not instantaneous; they are part of a developmental process which

needs to be consciously supported with gradual changes in decision-making focus from parent to parent-child and, ultimately, to the child. If, as Wray-Lake et al. (2010) have found, responsibility for health-care decisions typically transfers to adolescents at 17- through 20-years of age, how involved should school-aged children with CHCs be in managing their own conditions? While individual children may excel at handling condition management tasks and following established rules regarding condition management, their developmental stage may not support independent decision making regarding health care issues. Conversely, for children with CHCs, the capacity to make health care decisions may develop earlier as they have more exposure to the health care system over the course of their childhood. Examining family management of CHCs, during the middle childhood, from the perspective of such children within both the family and developmental contexts can provide a means for exploring this issue.

### **Theoretical Approach**

The examination of condition management within the context of family management requires an understanding of two theoretical approaches that guided the study. The FMSF (Knafl et al., 2012) is the primary framework that guides this study and provides a framework for analyses of Specific Aims 1 and 2. The FMSF emerged out of research and theory development that spans 20 years and defines Family Management, from a health care perspective, as the way in which families respond to childhood CHCs – how they actively organize, integrate, and accomplish work related to the condition (Knafl & Deatrck, 1990). It was developed and later refined by Knafl and Deatrck (2012) with help from parents of children with CHCs (see Figure 1).

The FMSF includes conceptual themes based on symbolic interactionism that form three major components of the framework (Knafl & Deatrck, 2003; Knafl et al., 2012). The first, Defining the Situation, examines the subjective meaning family members attribute to important elements of their situation – with the conceptual sub-themes of Child Identity, Illness View, Management Mindset and Parental Mutuality used to define that situation. The second major component of the FMSF is Management Behaviors, which has been defined as the efforts directed toward caring for the illness and adapting family life to illness-related demands; this

component encompasses the Parenting Philosophy and Management Approach. The third major component, Perceived Consequences, examines the Family Focus on the condition and Future Expectations for the family and the child. As a whole, the FMSF also recognizes the perceived influences sociocultural contexts have on Family Management and identifies two outcomes – the functioning of the family, as a unit, and the functioning of the individual child (see Figure 1). Knowing how these components may, or may not, differ from those which are important from children’s perspectives will enhance our understanding of children with CHCs, as individuals, and their family units.

To identify if school-aged children have perspectives of family management similar to that of their parents, the definitions of the components of family management were adapted from the parent definitions to reflect the potential child perspectives. Acknowledging the potential for two child perspectives, that of family member and that of recipient of care, led to two potential definitions for each dimension of family management (see Chapter 2, Table 4).

### Family Management Style Framework

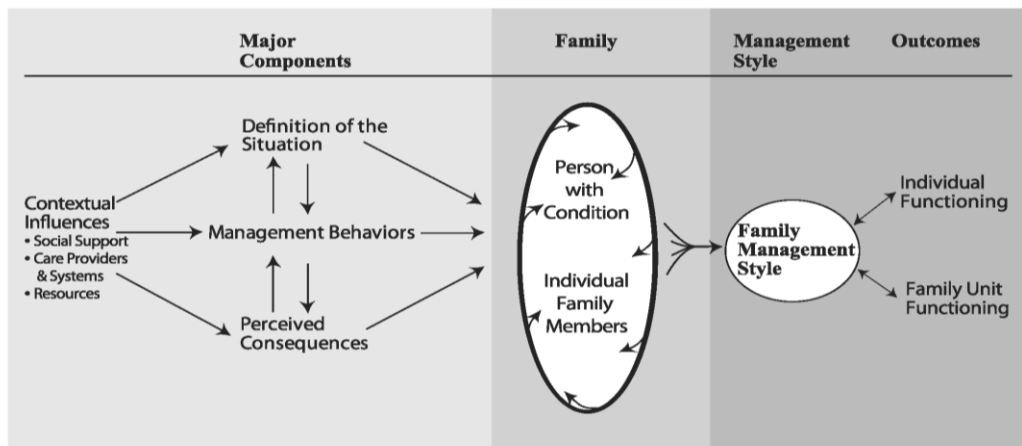


Figure 1. Current Model of the Family Management Style Framework. Reprinted from “Knafl, K., & Deatrick, J. (February 2012). Continued development of the family management style framework. *Journal of Family Nursing*.18 (1), 11-35. DOI: 10.1177/1074840711430665. Copyright 2012 by Sage Publications.

Noom's Autonomy Framework (Noom, Dekovic, & Meeus, 2001) guides the analysis of Specific Aim 3, exploring how the development of autonomy influences family condition management. It was selected for its ability to integrate psychodynamic, cognitive, and eclectic approaches to autonomy and identification of three unique dimensions of autonomy – attitudinal, emotional, and functional (see Table 1).

Attitudinal autonomy is cognitively based and is defined as “the ability to specify several options, to make a decision and to define a goal” (Noom, Dekovic and Meeus, 2001, p. 578). As such, this dimension deals with the perceptions individuals have about what they should do with their lives. Emotional autonomy is emotionally based and applies to either an affective or a relational situation. Defined as “a feeling of confidence in one’s own choices and goals”, emotional autonomy involves the perception of independence from both parents and peers and confidence in self-identified goals (p. 581). Functional autonomy is identified as the regulatory dimension that instills competence in identifying various strategies to meet personal goals and the perception of control, as it relates to choosing strategies and achieving success. Defined as “the ability to develop a strategy to achieve one’s goal”, functional autonomy motivates individuals to accept responsibility for their own behavior and the decisions they have made (p. 581). The dimensions of autonomy provide a lens for examining how autonomous children in the study may be within the context of their chronic condition. Are children able to see options, make decisions and define a goal around treatments; are they aware they exist? Do children have a feeling of confidence in their choices and goals? Are they able to develop a strategy to achieve the goal? All three components are essential to consider from a developmental perspective when considering family condition management for children with CHCs.

**Table 1.**  
*Approaches to Autonomy Used in Noom's Analysis (via the "Autonomy Framework")*

Approach	Definition	Theoretical Framework	Attitudinal	Emotional	Functional
Psycho-dynamic	Stresses the relational changes between parents and adolescents	Autonomy (Douvan & Gold, 1966)	X	X	X
		Psychosocial maturity (Greenberger, 1984)	X		X
		Psychological separation (Hoffman, 1984)	X	X	X
		Individuation (Grotevant & Cooper, 1985)	X	X	
		Autonomy (Steinberg & Silverberg, 1986)		X	
		Autonomy and relatedness (Frank et al., 1988)	X	X	
Cognitive	Stresses the importance of making a decision and the perception of control	Autonomy and relatedness (Allen et al., 1994)	X	X	
		Self-efficacy theory (Bandura, 1977)	X	X	X
		Perceived control (Skinner et al., 1988)			X
		Self-regulation (Markus & Wurf, 1987)	X		X
Eclectic	Integrates the relational and cognitive, and often connect them with a 3 <sup>rd</sup> or 4 <sup>th</sup> element	Autonomy (Dworkin, 1988)	X		
		Self-determination (Deci, 1980; Deci & Ryan, 1987)	X	X	X
		Self-regulation (Flammer, 1991)		X	X
		Autonomy (Koestner & Losier, 1996)	X	X	X

*Approaches to Autonomy in Noom's Analysis.* Adapted from Noom, M. J., Dekovic, M., & Meeus, W. (2001). Conceptual analysis and measurement of adolescent autonomy. *Journal of Youth and Adolescence*, 30(5), 577-595.

### Study Overview

The purpose of this study is to examine family management of chronic conditions from the viewpoint of children with CHCs in order to understand their perspectives as related to the FMSF. Children with a CHC participated in one-on-one interviews and provided their perspectives related to family condition management (FCM). Explanations of how FCM influenced their activity in school, participation in social and extracurricular activities, and development of social networks were explored. Existing division of roles and responsibilities related to FCM were also elicited from the participants. Finally, the clinical significance of family management and the development of health care autonomy and self-care in children with chronic health conditions were explored theoretically.

The lack of presuppositions and assumptions inherent in qualitative methodologies allowed informants to provide their own viewpoints on the phenomena of interest and provide

their impressions of the world around them. In fact, qualitative research methods are highly appropriate for a study of this nature, especially at the early stages of inquiry. Each child participated in a one-on-one interview; the interviewer followed a semi-structured interview guide (see Appendix A), and qualitative-descriptive directed content analysis methods were followed during analysis. This method follows a naturalistic-inquiry approach which preserves data during the analysis process (Sandelowski, 2000). Ultimately, a qualitative descriptive study such as this one has the potential to extend the Family Management framework and enhance future research by successfully incorporating children's perspectives. Demographic data (see Appendix B) was collected from the parent.

Defining and enhancing rigor or validity in qualitative research has been an evolving discussion. A recent synthesis of several traditions for ensuring rigor and validity led to a reconceptualization of validity in qualitative research (Whittemore, Chase, & Mandle, 2001). Whittemore, Chase and Mandle (2001) reviewed 10 approaches to validity criteria; their analysis led to the identification of four primary criteria to demonstrate validity. Primary criteria are necessary in all qualitative inquiries and include credibility, authenticity, criticality, and integrity. Credibility was demonstrated by providing evidence that supports the authors' interpretations; authenticity was maintained through journaling and memoing in order to discern the voices of all participants; criticality was demonstrated through the use of audit trails to track decisions during data collection and analysis. Expert checks were also used to demonstrate critical appraisal of the data. Integrity of the data was maintained through reflexive journaling and the acknowledgement of the researchers' perspective and bias throughout the research process. A qualitative method expert (JD) oversaw the process and met with the author periodically to discuss findings and ensure validity of the findings.

### **Participant Safety**

This study was conducted in full accordance with all applicable Children's Hospital of Philadelphia (CHOP) Research Policies and Procedures, as well as all applicable federal and state laws and regulations including 45 CFR 46 and the HIPAA Privacy Rule. Investigators (a)

carried out this study in accordance with Institutional Review Board protocol #11-007998; and, (b) obtained consent and assent from one parent and the child with the CHC. No episodes of noncompliance or unexpected problems occurred during the implementation of the research. The collection, recording, and reporting of data was accurate, and the privacy, health, and welfare of research subjects during and after the study period was maintained. Each child chose a pseudonym that was used during the interview, and all names were changed for reporting purposes.

The methods section reflects the protocols and procedures outlined in the current Institutional Review Board (IRB) protocol #11-007998. Approval was granted on 3/29/2011 by CHOP IRB (see Appendix C) and maintained through annual continuing reviews and is valid for the execution of the dissertation study by the candidate via the signed Penn-CHOP Determination Form (see Appendix D).

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## CHAPTER 2

Perspectives of Daily Family Condition Management:  
Through the Eyes of School-Aged Children with Chronic Conditions

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## **Abstract**

A gap exists in understanding the perspectives of school-aged children with chronic health conditions (CHCs) regarding how their families manage their condition. While a longstanding program of research has identified how the family integrates condition management into the family (Family Management Style Framework [FMSF]), most studies have investigated the parent or the adolescent perspective. The purpose of this qualitative descriptive study was to elicit descriptions of family management by school-aged children with chronic health conditions. Semi-structured interviews were conducted with 32 school-aged children, aged 8 to 13 who had chronic health conditions, to discern children's perspective of family management. The children spoke about family management of the condition and also discussed how they managed the condition. The findings complement the current FMSF, identifying the ability of these school-aged children to speak as both a member of the family and as the recipient of care and provide insight into their perspectives regarding the meaning, management and consequences of their conditions. Although children within this age identified concerns and issues with current management, they did not provide much insight into the cause of the condition or future issues and concerns for them or their families. The data from this study verifies that the FMSF can be expanded to include school-aged children with a variety of health conditions. Future research is needed to understand how the children's perspectives of family management could be integrated into the science of self-care.

## Introduction

One in every five families in the United States includes a child with a chronic health condition (CHC) (Hagan et al., 2008). For this study, a child with a CHC is one who was diagnosed with a health condition for at least six months and requires care in order to maintain their health status and/or manage the symptoms of those conditions. The families of children with CHCs have the added responsibility of incorporating condition management into family life. For families with a healthy school-aged child, middle childhood can be a time of change for both parents and children. While routines and illness management may have been well explored within the home, it is during this period that children begin having encounters with various institutions and individuals while learning to navigate in social structures outside of their immediate families (Coll & Szalacha, 2004). These changes bring new questions and uncover new concerns for parents of children who have CHCs. Parents are not only concerned about their children's conditions, but are also concerned with how those conditions are managed when their children are away from home. Parental management may have worked well with younger children in the home; however, those approaches may not be helpful for growing children who are navigating their schools. For instance, parents may reject teachers who are trying to encourage developmentally appropriate behavior (Thomasgard & Metz, 1999) or use health care resources immediately for acute exacerbations of symptoms without first using standardized treatments, for example during an asthma flare-up (Schraeder, Heverly, O'Brien, & McEvoy-Shields, 1992; Spurrier et al., 2000).

The ways families organize, integrate, and accomplish the work related to condition management have been elucidated in the Family Management Style Framework (FMSF) (Knafl et al., 2012). The framework, using the parental or adult view of family life, was developed with various populations and in various settings in the United States and worldwide to increase our understanding of family management. The voices of the children with CHCs have been largely overlooked (Wollenhaupt et al., 2012). By describing children's perspectives about their conditions and how they and their families individually and collectively manage those conditions, the FMSF can be modified appropriately and used in future descriptive, model testing, and



intervention research. The purpose of this study was to elicit descriptions of family management by school-aged children with chronic health conditions.

The period of middle childhood, from 6 to 12 years of age, is an especially important period of development for children with chronic conditions and for their families. During this period, children transition from childlike, concrete ways of thinking to cognitive thought processes that are more complex and intellectual ( Vygotsky, [1967], 2004). Children's understanding also varies according to everyday experiences, and for children with CHCs, the everyday experience of living with the CHC provides additional opportunities for experiential learning (Crisp et al., 1996; McMenamy & Perrin, 2008). Although the family remains the main source of information and guidance for the school-aged child, sustained encounters outside the home and family environment provide opportunities for expanded experiences (Coll & Szalacha, 2004). Thus, school-aged children with CHCs begin to learn how to navigate life and their conditions outside the home.

For children with CHCs, encountering new situations outside the home can be challenging. Meeting new adults and children, deciding whether to tell new friends about the condition, and relying on other adults for condition management when the parents are not present requires trusting others with the knowledge of the chronic health condition. These experiences are of particular importance since at this age children are beginning to develop their own thoughts and ideas regarding condition management (Crisp et al., 1996) and building patterns of condition management that will certainly influence management and outcomes in the future. For the families of children with CHC, the challenge of incorporating condition management is expanded from the home to include the school and the community as the children are away from home and relying more on adults outside the family structure (Emiliani, Bertocchi, Poti, & Palareti, 2011).

The major psychosocial challenge for this developmental stage is one of industry versus inferiority (Erikson, 1968). At a time when children with chronic conditions are working on separating more from the parents and spending more time outside the home in school and socializing with peers, they are also making and/or participating in more decisions about their conditions. As such, they are learning how to navigate through a day at school while integrating

any treatments or special precautions secondary to their condition. In addition, they are compared to their peers regarding performance in school, sports and other activities which can be especially difficult for children with chronic conditions (Cook & Cook, 2007). When these challenges are successfully met, children can emerge with a sense of relative confidence and industry; otherwise a sense of inferiority develops. Children are also developing a truer sense of self, as compared to their ideal self (characteristics or qualities they would like to have). If there is a discrepancy between the two, the child may develop a negative self-evaluation and low self-esteem (Cook & Cook, 2007). Thus, parents and other family members are challenged to support these developmental changes, e.g. maintaining family life, when helping them manage the work of their chronic condition.

Children are developing autonomy during the school-aged period, which is important to consider as it is complementary to the development of self-care. Autonomy can be understood as having three dimensions: attitudinal, emotional and functional (Noom et al., 2001). These three dimensions provide an understanding of autonomy that encompasses an ability to “specify several options, to make a decision and to define a goal (attitudinal)” (p. 578); have a “feeling of confidence in one’s own choices and goals (emotional)” (p. 581) and to have “the ability to develop a strategy to achieve one’s goal (functional)” (p. 581). Within the realm of health care and condition management, we can see that children can begin this process of development of autonomy around condition management with the help and support of their family.

The interactions between children with CHCs and their family about condition management are of value and have been shown to have an impact on both child and family outcomes. Family rituals, whether infrequent (e.g. birthday celebrations, holidays) or daily (mealtimes, games or reading) provide a more positive family environment and better health-related quality of life (Santos, Crespo, Silva, & Canavarro, 2012). For families and children with CHCs, recognizing the importance of rituals and routines and integrating illness care within family life and not focusing on the illness itself has a positive influence on both family and child outcomes (Knafl et al., 2013).

Prior studies examining the families of children with CHCs have found positive correlations between family processes related to condition management and child outcomes. That is, positive family relationships led to better levels of adherence (Cohen et al., 2004; DeLambo et al., 2004; Fiese et al., 2005), while negative family relationships led to poor levels of adherence and declines in child health (Fiese & Everhart, 2006; Lewin et al., 2006). The ability of families to anticipate and recognize changes in condition and engage with one another creates an environment that supports condition management. Although those studies provided important knowledge regarding condition management and adherence to medical regimens, adherence is only one perspective to consider. A broader view, which more clearly conceptualizes the family processes specific to condition management from children's perspectives, can better identify the components of those processes and demonstrate their relationship to children's health outcomes.

### **Measurement**

Family studies have typically examined either disease-specific management or taken a non-disease-specific approach. Both approaches provide valuable information. Disease-specific management approaches provide a focused view of a particular condition and the tasks and intricacies of its management, leading to specific findings and recommendations towards managing that specific condition. Non-disease specific approaches are able to identify universal findings across conditions, making the findings applicable to a broader range of conditions. These findings can be used by researchers and providers who apply the findings to their specific condition of interest.

Disease-specific instruments that have examined basic family processes within the context of conditions such as diabetes, asthma, and ADHD have been developed (Kendall & Shelton, 2003; McQuaid et al., 2005; Song et al., 2011). In a review of diabetes literature, Song et al. (2011) identified fewer than eight instruments measuring family-related diabetes concepts. Those instruments were tailored to the diabetes population and the tasks associated with the disease, but they did not address the concepts or family processes that would be applicable within the larger scope of chronic illness across conditions.

Basic family processes have also been measured via instruments such as the McMaster Family Assessment Device (Epstein, Baldwin, & Bishop, 1983) and the Family Environment Scale (Moos & Moos, 1994). Although those instruments have generally been considered reliable and valid, it was also noted that they were used regularly to assess aspects of family functioning (though not specifically regarding children with CHCs) even though the psychometrics within related pediatric studies have often gone unpublished or were found to be lower than those for the general population (Alderfer et al., 2008). Alderfer et al. (2008) further identified three instruments which specifically examined the impact of children's CHCs on their families or parents: The Impact on Family Scale (IOF) (Stein & Jessop, 2003), Parents of Children with Disabilities Inventory (PCDI) (Noojin & Wallander, 1996), and Pediatric Inventory for Parents (PIP) (Streisand et al., 2001). Yet, none of those instruments included children as respondents and they focused on problems and weaknesses rather than family strengths and positive outcomes.

Family management domains have also been explored in a non-disease-specific manner, identifying the domains or categories that are common across disease entities, with findings applicable to a wide range of health conditions. The domains identified were not problem-oriented; instead, they were global domains that allowed for positive and negative experiences resulting from providing care for children with CHCs. Work led by Knafel has provided a framework for examining the families of children with CHCs that assumes a common foundation for condition management regardless of the disease entity (Knafel, Deatrick, & Gallo, 2008; Knafel et al., 2012). That framework is supported by decades of work with parents of children with CHCs, but it does not include the perspectives of children with CHCs. In fact, a recent literature review of studies regarding Family Management has shown that parents are the informants 80% of the time (Knafel et al., 2012). By adding the perspectives of children, more holistic models can be created which may be used to inform interventions and guide instrument development.

The FMSF, which was developed using the concept of symbolic interactionism, is the primary framework that sensitized and guided this study. The framework, as outlined by Knafel and Deatrick (2012), defines the process of family management and includes three major

components, Defining the Situation, Management Behaviors, and Perceived Consequences. The first, Defining the Situation, examines the subjective meaning family members attribute to important elements of their situation; the conceptual themes which contribute to an understanding of the situation include Child Identity, View of Condition, Management Mindset, and Parental Mutuality (Knafl & Deatrick, 2003; Knafl et al., 2012). The second, Management Behaviors, has been defined as efforts directed toward caring for the illness and adapting family life to illness-related demands; it encompasses Parenting Philosophy and Management Approach (Knafl & Deatrick, 2003; Knafl et al., 2012). The third, Perceived Consequences, examines the Family Focus on the condition and Future Expectations for the family and the child (Knafl & Deatrick, 2003; Knafl et al., 2012). The FMSF model acknowledges the socio-cultural context of Family Management and the outcomes of both children, as individuals, and their families, as a whole. The three major components of the FMSF were used in conjunction with the developmental and empirical literature to develop both an interview guide and preliminary analysis of the initial interviews that informed this study.

A recent study examined family management from the perspective of adolescents with Spina Bifida (Wollenhaupt et al., 2012), how they discussed condition management and their consistency with the FMSF. The adolescents' perspectives about their families own concerns regarding condition management were not included. The findings, as acknowledged by the authors, were constrained by the secondary analysis nature of the study as well as a single condition sample. The authors proposed expanded definitions for the components and dimensions to be more inclusive and noted areas for future research and integration into clinical practice. For purposes of this study, the definitions were expanded further, to allow for the perspectives of school-aged children as a member of the family and as a recipient of care. Examining the perspectives of the school-aged child with a variety of chronic health conditions, this study looks to further expand our understanding of the utility of the FMSF by including this population as well.

## **Method**

### **Design**

This qualitative, descriptive study involved interviewing children who had been diagnosed with a CHC for at least six months and were between 8 and 13 years of age. A six-month lag from diagnosis ensured that the child and family had time to take in the diagnosis and develop an approach to condition management. Participation required that informed consent was provided by parents/guardians and then assent provided by each child participant.

Recruitment was conducted in three ambulatory clinics (Endocrine, Hematology, and Pulmonary) in a pediatric hospital located in the northeastern U.S. Three recruitment strategies were employed, based on the preferences of each clinic. On-site flyers allowed interested families to either call the researcher on a dedicated study phone line or approach clinic staff for more information. Mailing lists of clinic patients aged 8 to 13 who had been seen for more than six months' time were provided to the study team; their families were sent information packets with forms to mail back in a stamped, return-addressed envelope, if they were interested in participating (pulmonary, hematology). Additionally, four families heard about the study through word of mouth and called the research study line to inquire about the study. Both the hospital and the university granted IRB approval for the study prior to any recruitment activities. Thirty-two interviews were conducted between June 2012 and January 2013. Most of the interviews (n=30) were held at participant-family homes, although two families preferred to meet at an alternative setting; one at the local YMCA and the other at the University.

### **Participants**

Data were collected from 32 families. In each family, one child with chronic health condition and one parent provided the data. The participating parents provided the demographic data that is presented in Table 2. One primary chronic health condition was identified for each child even though over half of the sample had more than one chronic health condition.

Every effort was made to ensure diversity across and within conditions via recruitment strategies. As outlined by Rolland, (a) the onset of the conditions might range from acute to gradual; (b) the course of a particular CHC might be progressive, constant, or relapsing; (c) the

outcome of the condition might be nonfatal, might result in a shortened lifespan, or might be fatal; and, (d) the incapacitation might range from none to severe (Rolland, 1994). Table 3 depicts the primary health condition reported by children and parents along with the parents' assessment of two of the condition characteristics. Parents were asked to describe the condition characteristics regarding onset (acute or gradual), course (progressive, constant, relapsing) and, additionally were asked if the condition caused stigmatization for their child (did they feel the child was treated differently because of the condition). The parent perspective was used as a basis for reporting the condition characteristics. Although some characteristics were better represented than others, the sample represented a variety of condition characteristics both within and across conditions. These characteristics allow for the selection of information-rich cases whose study illuminated the questions being considered across a range of CHCs and condition characteristics (Patton, 2002).

The primary author conducted in-depth, semi-structured interviews that were based on a semi-structured interview guide. At the beginning of each interview, the child was asked to choose a pseudonym for use during the interview process and names were changed for reporting purposes here. Open-ended questions focused on children's descriptions of their families, what it was like to be diagnosed with a CHC, what typical school and weekend days were like, and how they perceived their futures. Probes were used to elicit additional information around the children's perceptions of their conditions; management behaviors and decision-making processes used by them; their parents, other family members, and those in the community; and, the consequences of living with their conditions. Examples from prior participants were used, as applicable, to illicit rich descriptions from participants. All interviews were digitally recorded and transcribed verbatim by a transcription service. As the children participated in their interviews, their parents or guardians provided demographic information about the children and their families. A trained research assistant was available to help parents with the reading and filling out of forms, as needed. When she was not available, the primary data collector spent time with the parents at the conclusion of the child interview to answer any questions. Data collection stopped when saturation on major themes was reached and no new information emerged from the child interview (Patton, 2002). Interviewers wrote field notes shortly after leaving the family

homes/interview to document impressions and reflections so as to improve the accuracy and thoroughness of the descriptions.

The three major components of the FMSF and developmental concepts provided the guiding framework for the study, the interview guide, and the analyses. For purposes of the findings addressed in this paper, analyses of the children's responses were conducted using directed, or deductive, content analysis methods (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). This allowed for the identification of categories related to children's perspectives of family management of their CHCs, which remained close to their own words and meanings while using our current knowledge regarding the FMSF to guide or sensitize the inquiry (Hsieh & Shannon, 2005). The lead author documented the decision process throughout the study, using audit trails. Coding of the interviews began with receipt of the first verified transcript. Each subsequent transcript was read and coded for descriptions of that child's condition, management behaviors and consequences. Constant comparison was used for subsequent interviews, allowing for analysis both with the individual data and across cases (O'Connor, Netting, & Thomas, 2008). Atlas-ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany), a qualitative data management software program, was used to maintain and sort the interviews and related data.

Several other techniques were employed to enhance the validity of the qualitative inquiry (Whittemore, Chase, & Mandle, 2001). A detailed audit trail was maintained and used to keep track of decisions that were made during sampling, data collection, and data analysis. Such information allows others to follow the decisions made during the research process and understand how findings were developed. In order to ensure that the researcher did not impose her thoughts and/or biases onto the voices of participants, reflexive journaling and memos were undertaken which provided transparency regarding the researcher's perspectives about the process and the interviews. Verbatim transcription was used to allow the thoughts and responses of participants to be directly represented. This, in conjunction with the audit trail, journal, and memos, allowed experts in the field to audit the process, analysis, and findings. Additionally, thick descriptions (which provided evidence supporting the interpretations) were examined and have been provided in the results section of this manuscript in support of the findings. An experienced



qualitative researcher (JD) listened to interviews and conducted an audit of the analyses of the data, using the audit trails as a guide. In addition, the researcher participated in a weekly qualitative collective - a group of scholars interested in qualitative methodologies - and provided feedback and confirmation of analysis process throughout the study.

## **Results**

The results of the directed content analysis were consistent with the FMSF and provided evidence that the FMSF is relevant to how school-aged children with CHCs view the family management of their condition. Additionally, some children within this age group were able to view management through two distinct lenses, the lens of family member and the lens of a care recipient. The results presented here follow the divisions of the FMSF's three dimensions and eight components. Table 4 contains the FMSF components with the definitions of each dimension from the framework from the latest Knafl review (Knafl et al., 2012) along with proposed definitions from a study of adolescents (Wollenhaupt et al., 2012) and this study of school-aged children. Observations about developmental implications are contained in the discussion.

### **Component I: Definition of the Situation**

The FMSF identifies four dimensions of Definition of the Situation: Child Identity, View of Condition, Management Mindset and Parent Mutuality, which form the family's Definition of the Situation.

**Child Identity.** The first dimension of the Definition of the Situation is child identity. The school-aged children in this study had a sense of *how the family saw them* as well as a sense of *their own personal view of themselves*. That is, child identity encompasses how the family sees the child and whether that view is focused on the condition or normalcy, and capabilities or vulnerabilities.

Some children recognized that the family viewed them as vulnerable and concentrated on managing their condition, e.g. the family perceived that they needed help and would try to help them. This wasn't seen as just a parental responsibility but also one in which siblings could participate, the whole family was sometimes involved. These parents recognized the children's vulnerability in home and also in school where parents would step in to trouble-shoot or problem-

solve situations and also accompany them on field trips to prevent problems. Some children were aware when families didn't do things "normally" and changed the way they accomplished everyday activities to accommodate their needs for condition management. For instance, families may have changed the mealtime or eating patterns for the entire family and so everyone still ate together and everyone ate the same thing. Other children noted that the family needed a large car when traveling in order to take along all of the equipment. As one child stated,

...cause CF, I can get sick and stuff and it can get in your way and treatments can get annoying because if you want to go somewhere you have to get a big enough car because you have to carry your treatments everywhere. If you want to go on vacation or something it gets annoying (Mariah, 12 year old Cystic Fibrosis).

Other children were treated as essentially normal and the family treated them as self-sufficient and capable, e.g. the family had confidence in them and their abilities and would provide assistance in such a way as to incorporate it into usual family life. Some spoke of how they were doing more management activities on their own because the parent believed they could do so. Other children also spoke of their parents trusting them to know what to do and how to handle situations now that they were a little older. As one participant reflected,

I was young. I did not know anything about it and um... I had no clue what to do. Like all of this stuff was there and it was kind of high tech for me, 'cause I was used to using kind of old-fashioned stuff. Like I was used to playing with like blocks, stuff like that. But then after that I started... after I started growing up a little bit, I started realizing how it started to work and then um... my mom, she asked me if I wanted to try to start doing it and I said I would try. And then after she showed me how stuff would work I was... I felt like I knew a lot more about myself (Clay, 11 year old, Type 1 Diabetes).

Along with the child's perception of their identity from the family's perspective, the children in this study also were able to provide insight into their *own personal view of themselves as a child with a CHC* which differed regarding their relative focus on condition and vulnerabilities

or normalcy. When asked to describe themselves, few children included the CHC condition in their brief introductions. Instead they spoke of age and grade, what activities they enjoyed, with many children prompted to begin to tell their condition stories. This was also true when the child was discussing their daily routines, sometimes overlooking the trips to the nurses' office and management activities before and after school. Children discussed the way they and their friends deal with the condition, and the support the friends provide, especially friends who have the same condition. For some children the condition was no problem, no big deal, something they recognized made them unique and they were proud of that. Two participants stated this acceptance or normalization rather eloquently. One, when discussing his allergies said, "I don't have bad allergies.....no, just like I'm anaphylactic, so if I eat....if I touch it, I get like a hive. If I eat it, then that's when I'll need an EpiPen" (Sylvester, 8 year old, Cystic Fibrosis) while the other explained how he deals with his diabetes:

...you have to be able to push it aside....Like you can't go "oh, I can't go with my friends cause my diabetes is messed up." You kind of don't have to think about it all the time. That's how you pretty much do it (Agent 99, 11 year old, Type 1 Diabetes).

Other participants had more difficulty incorporating the condition into everyday life and would state it was hard and that people don't really understand what it's like. As one girl said "I didn't really want it. It's not good. I don't like it and I want to get rid of it." (Brooke, 9 year old, Cystic Fibrosis). Another spoke of trying to get what she needed while at school and the frustration of not being heard,

I did (speak up) once because I could have had something but they just gave me salad. There was like noodles or something and I was like, "I could have them," and they're like, "No, you can't we checked twice" but I had them yesterday and they were having them today again and I was like "I CAN have them" and they were like "No you can't, we checked twice." I was like "Oh, okay." I went home and told my mom everything. I was UPSET (Mariah, 12 year old, Cystic Fibrosis).

School-aged children articulated perspectives regarding both how the family sees them and how they see themselves within the context of their condition. All participants recognized the vulnerabilities of the condition, but interpreted them differently as some saw themselves as “normal” within the constraints of the condition while others concentrated more on the constraints or vulnerabilities.

**View of Condition.** The second dimension of Definition of the Situation in the FMSF is the View of the Condition. This dimension examines the cause, seriousness, predictability and course of the condition and each of these areas will be examined separately. The school-aged children in this study viewed the condition in terms of *how the family viewed* the condition, cause, seriousness, predictability and course of the condition to varying degrees. Responses within this dimension were focused on seriousness and predictability of the condition, with fewer responses concerning cause or course.

**Cause.** Only one child spoke of the cause of the condition in either the context of the family’s view or their own. One child with a genetically transmitted condition spoke of the cause saying, “...just my Dad and my Grandmother (have it).....he passed it down to me. I think they found it once I was born like the doctors like they tested me. I don’t know really how, they just like found it.” (Rob, 11 year old, hereditary spherocytosis). No other children in the study spoke about what caused the condition.

**Seriousness.** Within the family context, the school-aged children in the study identified whether the parents worried about them, particularly within the context of remembering the reaction at diagnosis. Statements such as “...she wasn’t worried about it at that time cause I wasn’t like...older yet” (Manny, 9 year old, Type 1 Diabetes), showed an awareness of the potentially serious nature of the diagnosis and the likelihood that it would change in the future. Another child also mentioned the concern of her family and future consequences,

...sometimes my Mom told me like if I can continue like if my sugar is gonna be high like when I get older my kidney’s will be bad and I’ll have to be on dialysis....I think Mom worries about I might not, what if I get sick one day and I get real sick and I might die (Micky, 10 year old, Asthma).

In terms of the child's view of the seriousness of the condition, as one child with asthma stated "Basically when I'm swimming, sometimes I get scared and I'm like "Oh, no, what's going to happen?" I get scared that I won't be able to breathe." There are also children on the other side of the spectrum who don't think the condition is very serious. One boy with asthma stated, "Mine's just really weak.... The asthma's weak. I don't even think I need the medication." Some children recognized the seriousness of their condition but downplayed it at times,

I tell them I have diabetes; it's where my pancreas stops working. I need to do this, I need to do that, and that's pretty much it. I make it a lot simpler than in my opinion it is, but I just want them to know that I have something, that I have diabetes (Donald Duck, 11 year old, Type 1 Diabetes).

**Predictability.** Predictability of the condition was discussed in terms of some symptoms and symptom management. The children talked about doing things to decrease symptoms and managing the condition and the plans that were in place should something happen. For example children explained that they used cell phones to deal with possible unpredictable situations, as one participant with diabetes explained,

I have my own emergency cell phone that I, if I'm going biking or anything I will take with me. If I go to my grandparent's house, I don't really need it, 'cause they're always watching me; but if I go to a friend's sleepover, I always have it with me and then, I well, I always have it with me and then my mom will say oh, call. Like I'll call her cell, I'm like, "oh, I'm here, or hi, I'm low or whatever, I'm eating, and here's the carbs", and then she'll tell me like, "oh call back at nine o'clock" and then I'll call back and she'll be like, "okay, what's your number?" and she's like, "okay, ...I'm going to call, I'll call you up in the morning, okay?" and then I'll go to sleep and then I'll keep my phone right beside me and then when it starts ringing, I'll answer it. Test, tell her my blood sugar, and then we're good...and then from there I'll call her again and say 'now we're going to have breakfast or whatever (Clay, 11 year old, Type 1 Diabetes).

**Course.** When the children talked about the course of the disease it was not necessarily about toward the future; rather, it was about changes over time since they were first diagnosed or from when they were younger. Some spoke about the condition being easier to handle because they are older and understood more about the condition while others spoke about how the condition may have gotten better or worse over time. Only one participant specifically talked about the course saying,

I asked my mom why my asthma has gotten better and she said when you're my age it gets better and then if you get older then it starts to get like it was when you were little. I don't really care because it's just the way it is (Stephie, 11 year old, Asthma).

**Management Mindset.** Management Mindset, the third dimension of Definition of the Situation in the FMSF, examines the ease or difficulty of carrying out the treatments and the ability to manage effectively. The school-aged children in this study viewed management mindset in terms of how easy or difficult it was *for the family and* how difficult or easy it was *for the child*.

The participants in the study spoke of management mindset both within the home and during family activities. *Children who described their families' relative ease of management* also spoke of having the family showing support and understanding, telling how the family let them be in control relative to their treatment regimen when possible, including planning for outings and activities. At school, children who described relative ease of management had understanding teachers and nurses, an ability to integrate care into the everyday routine (e.g. keeping your inhaler in your desk, permission to have extra snacks) and a flexible schedule that allowed the student to do what needed to be done and still participate in the important classroom activities. For those children reporting more difficulty carrying out management within the home, perceived ability played a major role for the beginner or someone newly diagnosed. The children said it was difficult for them to perform the treatment correctly and there was no one to remind them or help them problem solve. These children had trouble remembering treatments and medications. These kinds of incidents threw off the day and the children found it difficult to get back on track. At school what made it more difficult were teachers or staff who didn't understand their condition and

prevented them from getting the treatment they need. Although this group is a minority, they spoke of the frustration of not being listened to when they believed they needed to do something.

**Mutuality.** Mutuality is the final dimension of The Definition of the Situation in the FMSF. Within the FMSF it is called *parent mutuality* and refers to the shared or discrepant beliefs and view of the child, the condition, philosophy and approach to condition management between the adult caregivers. As was done in the adolescent study by Wollenhaupt et. al. (2012), this dimension was expanded to include the mutuality between parents and children in addition to the child's observation of parent to parent mutuality. Mutuality, therefore, examines the perspectives of the children regarding the how the family attempted (or not) to establish mutuality; thus mutuality became *the children's view of the parents'* similar or disparate view of the child, condition, parenting philosophy and approach to condition management. The children in this study also view mutuality between their parents and themselves. This family mutuality acknowledges the personal view of the children within the family management dynamic.

**Parent mutuality.** The majority of children within the study identified no areas where their parents didn't agree. Only one participant in the study identified an area where his parents did not agree on a management activity. This disagreement revolved around the child's inability to give his own insulin injections. In recalling the situation he said,

My dad gives them (insulin injections) to me but I did it one time. I was just like "No; I don't want to do this ever again!" Because my mom and dad... Well my mom just doesn't want me to do it but I don't know why. She thought that I did it the wrong way so I was like ok, I'll not do it next time. My dad, he does think I can do it but I think no (Sid, 9 year old, Type 1 Diabetes).

The remainder of the children identified mutuality between the parents with regards to management and identified either a primary point person or shared responsibilities between parents. An example of the primary point person was exemplified by one participant "Mom does most of it. Sometimes my dad does it if he's....my mom isn't at home" (Spiderman, 11 year old, Cystic Fibrosis) or the child who explained,

If my mom can't, if we're going out of town or something and my dad is coming home or something and my dad is near CVS then my dad can pick up my medicine when my mom can't cause we're leaving or something (Mariah, 12 year old, Cystic Fibrosis).

Other children talk about the shared parental model as explained by one participant,

My mom makes sure I'm taking my treatment every two and four hours when it's needed and she makes sure I take my medicine. My dad tells me the things that trigger my asthma and makes sure like the TV stand isn't dusty and stuff (Andy, 11 year old, Asthma).

**Family Mutuality.** The participants also recognized the mutuality that occurs between them and their parents which reflects their own personal view of themselves. Here the child is concerned with the family's view of them, not just the parents. That is, *family mutuality is the extent to which the child and other family members have shared or disparate views of the child, the condition, family roles and approach to condition management.* The main concern of the children was if parents or family members agreed or disagreed with issues around condition management. Often their comments reflected that their parents agreed (or not) on a parenting philosophy or on an approach to condition management. For instance, this child shared his views on the roles and responsibilities of condition management,

Me and my parent's kind of share drawing insulin and doing all of that. I usually give my own shots. Usually I try and remember to do this but usually my mom does it....my mom and my dad do it for me (Donald Duck, 11 year old, Type 1 diabetes).

Another participant expressed it this way,

I'm not really sure if they disagree with anything. Like my parents, like they always, they're always like, don't do that or like they'll...like they don't say "Hey, you shouldn't do the vest today" or something. They always like to keep me on track for my Cystic Fibrosis (Spiderman, 11 year old, Cystic Fibrosis).

## **Component II: Management Behaviors**



The second component of the FMSF has two dimensions, Parenting Philosophy and Management Approach. These two dimensions examine the efforts that are directed toward caring for the condition and incorporating the condition into family life.

**Parenting Philosophy.** Parenting philosophy, for this study was adapted to examine the *child's view of the parent's* goals, priorities, values, and beliefs that guide the overall approach and specific strategies for condition management.

As might be expected given the developmental stage of the participants, the children in this study were not very insightful regarding the parenting philosophy used for condition management. A couple of children did acknowledge, "...like they (parents) always concentrate on what I do, like as for my health and stuff," citing activities such as checking in to make sure treatments were done, reminding participants about their schedules, and actively getting treatments and medications ready. One participant told of how surprised her parents were when she was diagnosed but quickly got into action mode, "...they got in it and they were just like 'Okay, what do we do now?'" (Donald Duck, 11 year old, Type 1 Diabetes) This problem solving philosophy reflected beliefs about being proactive and was also seen in another family where the father, upon hearing his daughter's diagnosis, took action,

I remember the first thing he did was go on the computer and look up Olympians that had Type 1 Diabetes and he's like "There's a biker and there's a swimmer just like you." I'm like "why are you looking up this stuff?" He said, "Just to let you know your dreams will never be crushed because of this." That helped (Minnie Mouse, 12 year old, Type 1 Diabetes).

From the *personal views of the children* in the study, children often talked about the goals they had playing games or sports, but were less likely to talk about them in terms of condition management. One child however, clearly identified one of the goals remembering, "Because I grew up with these pills, the first time I swallowed one my Dad was standing right there forcing me and I almost choked" but now talks of taking his pill "Every morning, that's my goal, every morning" (KC, 8 year old, hemophilia). Children also have treatment preferences based upon their priorities. One child with diabetes talked about changing insulin so she could have more

control and worry less about if she could eat something. A couple of children with Cystic Fibrosis talked about the time it takes for treatments and giving priority to a method that does the job and may take less time,

‘cause I cough better. Like the vest, I just like do breathing and breathe in medicine and I don’t really cough that much. And the acapella I cough a lot and I’ve been getting mucus out of my lungs. I’ve been coughing that up with the acapella. With my vest I don’t really cough that much (Brooke, 9 year old, Cystic Fibrosis).

**Management Approach.** Management Approach is the second dimension of Management Behaviors in the FMSF and was mentioned frequently by the children in terms of *their view of the family’s management approach*, that is, they discussed the extent to which the parent and their child have developed a routine and related strategies for management of the condition and incorporated the management into everyday life. From the participants perspective the management approach seemed to be child driven, parent driven or that of a shared collaboration. Child driven management displayed knowledge of more routine aspects of care and displayed little insight into the rationale for the care. Participants talked about management using statements such as, I check my blood sugar, I take my treatment, and I do it myself. The parent driven approach includes an overseer or monitor, either as the one who is responsible for them (e.g. take their medication) or is a “knower” (e.g. looks up to mother, advice is credible). One child remarked that his mother, “know how much carbs there are in that food” (Manny, 9 year old, Type 1 Diabetes). Another stated, “Mom will tell them (the school) about it (the new procedure) and see what they want me to do about it” (Donald Duck, 11 year old, Type 1 Diabetes). Finally, the shared approach is one where the participant recognizes that they can or want to work with the parents to come up with an agreeable solution. This is exemplified by the following story:

Because our doctor, not Jerry but our doctor, his son has diabetes and he switched to this insulin and he said that it was a lot better. We, me and my mom, talked about it for a few months maybe just to kind of... We just kind of researched it and just kind of said... We just kind of talked about it with my dad

just because we felt like we didn't have enough control over the levels and at times we thought that we were kind of guessing a lot, like when I could eat. I thought I was and I just felt like I couldn't really eat what I wanted because I felt like when I went over to my friend's house or something or when I went to a birthday party, I felt like it was kind of hard if I wasn't with my mom or something. Like at school if someone brought in birthday cake or something, I felt like it was kind of hard to try and figure it out myself. So I felt like I was trying to call my mom a lot and trying to figure out what to do, and I had to do a lot just to eat something. So I think that's the reason we did switch, just to have more control and for me to be able to manage it without having to try and call my parents and have to worry about can I eat this, can I not eat this, all of that. So I think that's the main reason why we did switch insulins, just to get more control and just so that if I wanted to eat something I wouldn't have to do a lot of really complicated...and go through a lot of trouble just to eat something. So I think that's why we kind of switched (Donald Duck, 11 year old, Type 1 Diabetes).

In terms of their *own personal view of themselves*, they also described how they developed their own routines and related strategies for management of the condition and incorporated them into everyday life. One child with asthma explains her strategy for participating in sports but keeping her asthma under control,

When I run, I only run like two laps. [Laughing] I run out of breath, I walk, then I run again, I run out of breath, then I walk for another couple of laps, then I jog while I'm breathing really heavy, and after, we stretch a little bit and there's this one stretch called the goalie stretch where you just lay down and you stretch your whole body. That kind of relaxes me. That's what I usually do (Brianna, 10 year old, Asthma).

Participants in the study talked about their view of condition management around the school day; what they do before school, during school and after. School seemed to ground condition management and talk centered around getting ready for school, management while at

school, and what they do after school. Treatments are tied to events, not clock time. Medications or treatment were done before lunch, during the second recess, or before taking the bus home. This also carried over to after school where treatments are tied to going to practice, dance or instrument lessons, and before going to bed. The children in the study looked at their daily routines as a series of events. As one child, a 12 year old with Cystic Fibrosis, explained when telling me about her treatment regimen “It’s just kind of my schedule, so I just kind of do that every single morning” (Mariah, 12 year old, Cystic Fibrosis). Over the weekend or on non-school days, the major differences were stated in terms of the school day. As one child said, “I can sleep in, so it happens later and I can take my time.” Children also spoke of the effort they needed to take to care for the condition and how it was incorporated into the school day or disrupted school. The participants spoke of having to leave class early to go to the nurses office for treatments, blood glucose testing, or other medications at certain prescribed times during the day.

Children also identified non-daily routines or schedules. These occasional activities also had identifiable routines and children talked about what has to happen on vacations or trips where planning must occur to ensure that the proper medications and technology is along with them. They also spoke of what needs to happen in order to sleep over a friend’s house or at the grandparents. Some children were also aware of the routine that was connected to provider appointments, talking about the need to go every three months for a HbA1C check, or once a year for pulmonary function tests. The student athlete reported that he often had to make concessions before, during, and after practices or games, including blood glucose checks at half time, inhalation treatments before the game, and rescue inhalers on the sideline. Parents were frequently at the games obtaining the assurance that medical needs could be handled. As one child said,

With the sports, usually my dad will test me at halftime. But if I feel... or if he sees me like out of ordinary playing sports, he’ll pull me aside and then he’ll test me. But he usually just tests me at halftime and I’m usually good. (Clay, 11 year old, Type 1 Diabetes).

The participants also spoke of the role telling others played in the management strategies

Some were very clear that others needed to know in order to maintain their health status. This was true across conditions as the children spoke of participating in activities outside of the home and recognized the risk of others not knowing in case they needed help. A couple of children stated that it was a group effort and one said his friends would actually ask him if he was okay sometimes,

Like my best friend, I've known him since kindergarten since I've moved here, I mean he's always, he knows everything. My friends like, my friend that comes down here, like any of my friends that like are really in touch with me or, like we're always with each other, they always know. So if I'm oh, like they'll know the symptoms. Like if I'm acting like upset or like angry all the time, they'll just be like, "Okay, are you alright?" And then I'm like "Oh, yeah." And they're like "You know, do you need to do your thing or whatever?" I'm like, "Yeah, I'll go test." And then they're usually right. So they also know, my brothers, my friends, my sister, my family, they all know (Clay, 11 year old, Type 1 Diabetes).

Others are more protective of the information, saying no one really needs to know. One girl said people knowing might hurt your chances of getting a job you really need. Another said she was teased by a friend who said, "she's a dumb diabetic and I hope she dies," so now her response is to not tell friends, "That's why I don't like to tell people, because the kids are cruel" (Micky, 10 year old, Type 1 Diabetes).

The participants in the study were able to describe the process that occurs within the family in order to maintain condition management and allow varying control over managing the condition. Certainly some of the participants had very little control beyond following the instruction they were given for condition management by the health care provider or the caregiver or passively watching the caregiver.

### **Component III: Perceived Consequences**

The third component of the FMSF, Perceived Consequences, consists of the final two dimensions: Family Focus and Future Expectations.

**Family Focus.** Family focus, the first dimension of Perceived Consequences, examines the child's assessment of how satisfied the parents are with condition management and how it is incorporated into family life. The children in the study spoke of their *view of family life* and also of their parents and their own satisfaction with the focus.

Many children spoke of the family's focus outside the realm of condition management, citing activities the family did together. Whether playing golf, watching the Three Stooges, or traveling, children recognized if their family was focusing on family life or was focused too much on their condition. As a family successfully maintained a focus on family life, it would be expected families did not ignore the condition, but successfully incorporated it into family life so that other activities were able to take center stage. One child suggested that families have check-in to recap the week in order to identify what worked well and what may need to change. This may be the child's recognition that occasionally the family focus needs to come back to the condition for a brief period of time in order to evaluate the process,

Yeah, just like every weekend or so just kind of recap "We did this one night and it turned out really good. We should do that differently. We shouldn't eat that before bed." We just kind of recap over what you should do the next week and just kind of keep trying to figure out what helps and what doesn't and just talk and see. "I don't really like this regiment, we should switch." Or "I feel like I'm testing not enough" or something like that, just so that you don't need to...or so that you can sit down and just focus on that (Donald Duck, 11 year old, Type 1 diabetes).

A couple of children recognized that the focus was on the condition when parents were doing or assisting with treatments. Complexity was added for the caregiver when they were helping with treatments and siblings were vying for the parents' attention. In both cases the children felt like they were the priority or should be the priority during that time as one of them said,

Oh, well my... the middle brother, Curt, he always wants stuff and he... like my mom gets really mad at him, 'cause he constantly keeps asking for stuff and like she's trying to help me with... like she's always back and forth. Like she's trying

to help me with my treatments and stuff and she's always like yelling at Curt to stop asking her and it's kind of like back and forth....Well as long as she gets like the neb started and like all of my medicine, it's fine with me. I just don't want to wait. Like sometimes my brothers constantly ask her and then after the vest, if I... well after the vest I still wait for the neb to come so I can like do the neb and I always wait like ten minutes (Mariah, 12 year old, Cystic Fibrosis).

Some children spoke of the attention or focus that was on the condition as a necessary part of family life; it was accepted. One child spoke of the family's adjustment to her condition this way, "I think that they... it's more um... more responsibility has been like put on our backs, but we have been able to take more challenges" (Clay, 11 year old, Type 1 Diabetes). Another child explained her perspective when she contrasted her family's focus to that of another child she knew saying,

There's this kid in my school, I don't know his name, but I know he had diabetes and he had like no stability over it like what so ever and it probably came from his parents because they probably never helped him out and he's probably like a lone duck, I mean a lone wolf all by himself trying to figure it out, but you need your parents to be there for you because you are never going to figure it out without them because they have more knowledge and wisdom than you. You just need to be there.... That's like my parents, but I appreciate it very much because I know I couldn't be where I am now without them and in the beginning they were all over me, hounding me, hounding me, but if they weren't hounding me, I wouldn't be like this free and just by myself now, so I am actually thankful (Minnie Mouse, 12 year old, Type 1 Diabetes).

Other children told about the family diet that changed for everyone, not just the child with the chronic condition, in conjunction with their diagnosis and diet restrictions. One child shared:

And then Easter came and my Mom had no idea what to do with us, so it was pretty interesting. I got a bunny with the carb labels on the side and she kept the Hershey Kiss bag with all the Hershey Kisses in there and stuff like that. In the

eggs we got little quarters instead of candy (Minnie Mouse, 12 year old, Type 1 Diabetes).

**Future Expectations.** Future Expectations is the second dimension of Perceived Consequences and the final dimension of the FMSF. From the adult perspective Future Expectations are the parents' assessment of the implications of the condition for the future of the child and family. Children defined their *view of their parent's* expectations for the future as well as how they viewed the future for themselves and the family.

The future is not something many of this group of school-aged children spoke of readily and even less so from the perspective of the parents or family. Many children spoke of having more responsibilities or being more responsible in the future, although what those responsibilities were and what being more responsible meant was largely left unsaid. Coupled with the expectation that responsibilities will increase is potentially the understanding that the parental responsibilities will decrease. One child did express that when he got older,

I think it's a little bit harder 'cause you have all the responsibilities, like your parents don't help you out with everything like when you're my age. I don't think it's that different. I just think you have more responsibility than you did (Donald Duck, 11 year old, Type 1 Diabetes).

In terms of the *children's own personal* future expectations, the children spoke about the implications of the condition for the future and the family's future. Expectations centered on changes in treatment and changes in expectations for self and the family. Some of the school-aged children in the study had a magical or "techie" look at the future imagining time machines so they could look ahead and see. One child imagined tech pads that would test your blood sugar similar to the "...heart thing that Ironman has," (Sid, 9 year old, Type 1 Diabetes), while another child seemed to be well versed in potential technological developments that may be on the horizon,

I know the automatic pancreas is going to come out, they said in about five years, I'm guessing around ten you know because FDA they take a little bit to approve. So I know that might come and stuff like that, but I am not sure I would



really want to get that. I would want to wait until like I am hearing all these things about like these patches that they are making in England this guy and I'm hearing like all these other things and I'd be like you know what I'd much rather keep my pump that I have now or something like that or get surgery actually because I know there are pros and cons to that, but I feel I am doing fine just the way I am right now and I would just want to wait and see (Minnie Mouse, 12 year old, Type 1 Diabetes).

Children saw change as one expectation of the future, although they did not explain how the change would take form. Children expressed uncertainty concerning the future in terms of medication and treatment requirements, as one child said "Maybe I won't have to take my pill as often... or I might have to take it even more", (Rob, 11 year old, Spherocytosis). Other children imagined a future where their parents would not be readily assisting with their care, possibly related to living on their own. One child expressed this thought saying, "I'll have to get up in the night and give it myself, my injections when I'm still getting shots" (Manny, 9 year old, Type 1 Diabetes). Several children talked about future changes related to the need to be employed and two children talked of having their own family one day. The non-specific nature of the future expectations within this sample of school-aged children is summed up by one child saying, "I might have a totally different life when I'm older. Maybe I would get a house, maybe I would get a job, and maybe I would get a life" (KC, 8 year old, hemophilia).

### **Discussion**

This analysis highlights the perspectives of school-aged children with CHCs regarding family management of their condition. The school-aged children in the study readily spoke of experiences throughout their day explaining how they and their families managed to maintain the treatments they needed within their schedules and activities. The children in the study were able to provide a snapshot of how they believe their parent and/or family as well as their peers see them within the context of daily life, at school and at home. The analysis used the FMSF to give structure to the findings and to identify the feasibility of expanding the FMSF model to include school-aged children. School-aged children, in telling their condition management stories,

encompassed all dimensions and components of the FMSF. They discussed the meaning the condition has for their life, the management efforts required, and the consequences of the condition and management needs. Not all areas were discussed with the same depth and description. The school-aged children in the study provided richer descriptions of the meaning and management components, while consequences of the condition and future considerations were less robust.

The child's voice has not been incorporated into the discussion of the FMSF, with the exception of a recent publication representing the voice of adolescents with spina bifida (Wollenhaupt et al., 2012). In that study, a secondary analysis was performed on an existing data set to identify the perspective of the adolescent with spina bifida as it relates to the FMSF. The results added to the knowledge of FMSF by adding the adolescents' unique perspectives that were most focused on themselves as a family member, not about the family itself. The author suggested expanding the labels and definitions of the FMSF based upon the adolescent perspective. The current study reported here addresses a recognized gap in knowledge (Barakat, 2012) by adding the school-age children's perspective of the family and themselves within the context of condition management to the discussion using data collected specifically for examination with the FMSF.

The typical development of the school-aged child must be taken into account when considering these results. The data presented here represent children across the across the range of participants. Younger (8 – 10 year olds) and older (11-13 year olds) responded to the work of family management in some different ways. The younger group tended to be more concrete and said less regarding certain areas. This is consistent other studies where older children demonstrated stronger language skills and higher levels of cognitive functioning (Coyle, Russell, Shields & Tanaka, 2007). Additionally, the younger group had less insight into several of the dimensions when compared to the older group. While these findings are typical within the developmental expectations, of importance is the degree of insight and perspective the older group does have. For example, the younger children in the study did not voice any conflict with

the parent led activities, while children in the older group discussed joint efforts in management and decision making and on occasion a conflict around management strategies.

The difference between the younger and older children was also evident in the parenting philosophy and family focus, where younger children were very concrete and task oriented. The older children, however, were broader in their understanding of condition management and were able to see how their condition management affected various family members. The future expectation dimension was not well defined by either group of children. Younger children in the study were more apt to reply “I don’t know” to questions about condition and condition management in the future, while the older group tended to respond with a more nebulous “I’ll be more responsible” without any real description of what that would mean. Both groups also talked about having a cure or outgrowing it, as one possibility. Therefore, the dimensions as defined in Table 4 identify the developmental work of children throughout the school-aged period but are not necessarily obtained by all children, even at the upper end of the range. There are certainly other variables both external (family situations, social determinants of health) and child specific (development, health condition) that influence these dimensions. Findings are important for practitioners, researchers and families to consider as we work to prepare children with chronic health condition to become adolescents assuming more of their health care management on a daily basis.

### **Practice Implications**

In a report published by the World Health Organization, Michaud, Suris and Viner (2007) acknowledged, “In clinical interactions with younger children, management decisions are made ‘adult to adult’ by health professionals in consultation with parents, and day-to-day disease management is generally undertaken directly by parents.” (p. 8). The findings here support the need for health care professionals to include children at a much younger age. The American Academy of Pediatrics supports that approach, recommending children be included in visits as early as age four in order to become comfortable speaking with the health care provider and recognize that children as young as 9 or 10 may have concerns or questions about their health that they want to discuss with the provider alone (while others this age may not be ready yet)

(Hagan et al., 2008). The school-aged children in the study were able to verbalize many issues regarding condition management, both from a family and an individual standpoint and are beginning to care for their condition when outside of the home. Including the school-aged child in discussions can help the child better understand and plan condition management when away from the parents and help the family create ways to support the child in this developmental endeavor (Kirk, Beatty, Callery, et al., 2012). One can imagine that a plan to develop the necessary tool box with the child and family will help support and ease transitions from family focused management to self-care in the young adult.

Concern is high regarding the transition of pediatric patients to adult care (Schwartz et al., in press); the goal is to have the transfer done in a timely and safe manner. This is especially true of specialty pediatric practices that see children and families with a variety of chronic health conditions. The evidence in this study focuses on the issues that concern school aged children. Most emphasis was placed by them on child identity, view of the condition, and management approach. Less emphasis was placed on family focus, future expectations, and on the course of the condition. Therefore, issues were not often mentioned about future responsibilities and expectations, ways to resolve conflict concerning condition management, and decision making within the health care context. Efforts need to be placed on building upon a developmentally appropriate awareness of future management goals to accomplish preparation for transition. For instance, children were able to accomplish the tasks of care, but were not aware of anticipated changes that may occur as puberty occurs, as they enter middle school, or as a general course of the condition. Helping to prepare the children for the changes that are anticipated and providing skills can help children manage these changes.

While I am not advocating for children as the decision maker, school-aged children with chronic health conditions are aware of many limitations, implications and useful strategies for management of their condition. If they are not included in discussions of goal setting, and creating strategies to meet the goals and evaluating the outcomes reflectively, how do we expect them to learn to make decisions for themselves in the future? If they are not able to see the consequences of decisions, how can we help them understand that condition management

requires planning and may sometimes involve trial and error? And how can we expect them or their family to be comfortable with transitions when we have held them in the comfort of pediatric care for so long? Health care providers usually have years, starting at diagnosis, to help children with CHCs and their families focus on those issues key to condition management and prepare for the transition to adult care, and that preparation can never begin too early.

### **Limitations**

There are several limitations to this study that must be acknowledged. Although an attempt was made to recruit a diverse sample of school-aged children, the participants all were treated at the same large children's hospital that may lend to some homogeneity with treatment experience, especially within clinics. Additionally, these children were typical for age related to cognitive development, and children with cognitive developmental issues would present differently. Although the characteristics of the various conditions are diverse, the nature of the conditions were predominantly physical. Considering some of the most prevalent CHCs among children are asthma, obesity and mental health conditions including ADHD (Perrin, Gnanasekaran, & Delahaye, 2012), only asthma was a primary diagnosis in this sample and ADHD was a comorbidity in four children. Future studies would look to increase sample diversity to include emotional and developmental conditions as well. The diversity across race was also limited and future studies would look to broaden the cultural experiences of the participants. The study only examined the perspective of the child, and future work should incorporate parent perspectives in order to gain insight into the dyadic nature of family management issues. The small sample size did not allow for comparison within and among subgroups marked by age, race, socio-economic status or other important variables. The characteristics of the sample, however, are described in Table 2.

### **Future Research**

The FMSF provides a way to examine the way families integrate the work of condition management into their daily lives. It has been used to explore management in a variety of populations around the world (Barakat, 2012). It has the potential to be used to guide clinical practice, policy, and future research. The recently developed patterns of family management are

an exciting addition to this body of work as they identify a relationship between family management pattern and family and child functioning (Knafl et al., 2013). The current study creates a starting point for expansion of the FMSF to include school-aged children. Future studies incorporating the child and family perspectives can account for varying perspectives of family management and begin to highlight optimal points and conditions for interventions. For example, over time, as the children develop and mature, they are able to assume more of the work of condition management. Family management, from the perspective of the children, may need to allow more strategies to support the development of self-care in these children. Studies are needed to examine the interaction between families and children in the context of condition management. Exploration of the family mutuality dimension can help us understand how the child and family interact and what influence mutuality may have on family and child outcomes. Additionally, studies may incorporate providers in order to develop interventions for family management, develop self-care and create a supportive practice environment during this time of development.

### **Conclusion**

School-aged children with chronic health conditions are able to discuss family management of the condition in a way that is congruent with the FMSF. They also look at management from their own viewpoint and this seems to increase as the child develops through the school-aged period. Management occurs within the course of their daily living, and routines and schedules are an important management strategy. Although many of the children are adept at taking their medications, management decisions are frequently in the parent realm. Parents, health care providers and researchers can take this information and incorporate it into their interactions with school-aged children as we all strive to improve the health and well-being of these children and their families.

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**Table 2.** Characteristics of study population

<b>Characteristic</b>	<b>N (%) or mean (range)</b>
Parent	32
Mother Informant	30 (94%)
Age in years	41 (32 to 51)
Household Income (US dollars)	11 (3%) less than \$30,000/year 3 (9%) \$30,000 - \$59,000/year 4 (13%) \$60,000 - \$99,000/year 13 (41%) over \$100,000/year 1 (3%) Not reported
Educational Level	24 (75%) graduated college
Race/Ethnicity	10 (31%) Black 1 (3%) Hispanic 21 (66%) White
Child	32
Age in years	10.4 (8 to 13)
Male	18 (56%)
Primary Diagnosis	
Asthma	13 (41%)
Diabetes	8 (25%)
Cystic Fibrosis	4 (13%)
Hemophilia	2 (6%)
Hereditary Spherocytosis	1 (3%)
Phenylketonuria	1 (3%)
Sickle Cell Disease	1 (3%)
Eosinophilic Gastrointestinal Disease	1 (3%)
Chronic Sinusitis	1 (3%)
Interview Location	
Home	30 (94%)
Local YMCA	1 (3%)
School of Nursing	1 (3%)

Table 3. Diversity Across Conditions							
Condition (n)	Onset		Course			Stigma	
	Acute	Gradual	Progressive	Constant	Relapsing	Yes – Stigma	No – Stigma
Asthma (13)	5	8	1	4	8	3	10
Diabetes (8)	5	3	2	2	4	5	3
Cystic Fibrosis (5)	2	3	1	3	1	4	1
Hemophilia (2)	2	0	0	2	0	1	1
Other (4)	1	1	0	3	1	2	2
<b>TOTALS (32)</b>							
2 diagnosed at birth; no symptoms/no onset	15	15	4	14	14	15	17
Total by Category	30 <sup>a</sup>		32			32	
Genetic	5	3	1	8	1	6	4
Developed	10	12	3	6	13	9	13

<sup>a</sup> Two children had conditions requiring management at birth and began treatment that pre-empted symptoms, therefore the parent did not identify with onset as acute or gradual.

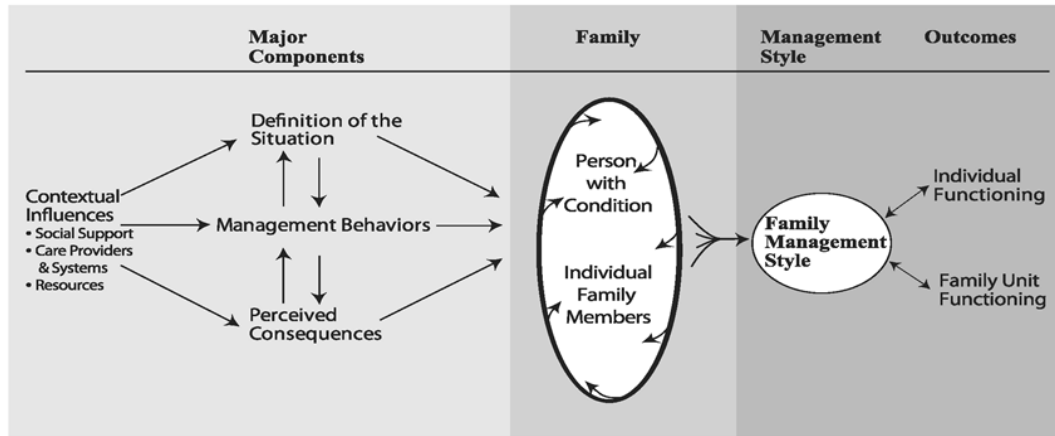
Table 4. Comparison of Definitions of FMSF 8 Dimensions

Define	Current FMSF definitions ( Knafl et al., 2012)	Proposed definitions with adolescent consideration ( Wollenhaupt et al., 2012)	Child's view of family management	Child's self-view of condition management
<b>DEFINITION OF SITUATION</b>				
CHILD IDENTITY	Parents' view of the child and the extent to which those views focus on the <i>condition</i> or normalcy and capabilities or vulnerabilities	(Self-identity) adolescent's view of self and the extent to which those views focus on the chronic health condition (CHC), or normalcy and capabilities or vulnerabilities.	Child's view of how the family sees them, the extent to which the view focus is on the condition or normalcy and capabilities or vulnerabilities	Child's view of self – degree focus is on condition and vulnerabilities or normalcy and capabilities
VIEW OF CONDITION	Parental beliefs about the cause, seriousness, predictability, and course of the <i>condition</i>	Adolescent's beliefs about the cause, seriousness, predictability and course of the condition	Child's view of how the family (parents) sees the condition, the cause, seriousness, predictability, and course.	Child's beliefs about the cause, seriousness, predictability, and course of the condition
MANAGEMENT MINDSET	Parental views of the ease or difficulty of carrying out the treatment regimen and their ability to manage effectively	Adolescent's views of the ease or difficulty of carrying out the treatment regimen and their ability to manage effectively independently or with the help of family	Child's view of how easy or difficult it is for the family to carry out the treatment regimen and the ability of the family to manage effectively	Child's views of the ease or difficulty of carrying out the treatment regimen and the child's ability to manage effectively
PARENT MUTUALITY	<i>Parent's</i> beliefs about the extent to which they have shared or discrepant views of the child, the illness, their parenting philosophy, and their approach to <i>condition</i> management	<b>Mutuality of family members)</b> Adolescent's beliefs about the extent to which family members have shared or discrepant views of the child, the condition, their beliefs about the roles of family members and their approach to CHC management	<b>Mutuality: Parents</b> Child's view of parent's similar or disparate view of the child, condition, parenting philosophy and approach to condition management	<b>Mutuality: Family</b> Child's view of the extent to which the child and other family members have shared or disparate views of the child, the condition, family roles and approach to condition management
<b>MANAGEMENT BEHAVIORS</b>				
PARENTING PHILOSOPHY	Parent's goals, priorities, values, and <i>beliefs</i> that guide the overall approach and	(Family Philosophy) Goals, priorities, and values shared by the	Child's view of the parent's goals, priorities, values, and beliefs that guide the	Child's goals, priorities, and values that guide the child's approach to

	specific strategies for <i>condition</i> management	parent and adolescent that guide the overall approach and specific strategies for condition management. Both adolescent and parent may have unique goals, priorities, and values that will shape family philosophy	overall approach and specific strategies for condition management	condition management
<b>MANAGEMENT APPROACH</b>	Parent's assessment of the extent to which <i>they and their child</i> have developed a routine and related strategies for management of the condition and incorporating it into <i>everyday</i> life	Adolescent's assessment of the extent to which she or he has developed a routine and related strategies for managing the condition and incorporating it into family life	Child's view of the extent to which they and the parents have developed a routine for managing the condition and incorporating it into everyday life	Child's view of how they have developed a routine and related strategies for management of the condition and incorporating it into everyday life
<b>PERCEIVED CONSEQUENCES</b>				
<b>FAMILY FOCUS</b>	Parent's assessment of and satisfaction with how <i>condition management has been incorporated into</i> family life	Adolescent's assessment of the balance between condition management and other aspects of family life	Child's assessment of how satisfied the parents are with condition management and how it is incorporated into family life	Child's assessment of how focused the family is on the condition and the child's satisfaction with that focus
<b>FUTURE EXPECTATION</b>	Parent's assessment of the implications of the <i>condition</i> for their child's and their family's future	Adolescent's assessment of the implications of the condition for their personal future and the future of their family of origin	Child's assessment of how the parents think about them and the condition looking into the future	Child's assessment of the implications of the condition for the future and the family's future

Figure 2. Current Model of the Family Management Style Framework.

### Family Management Style Framework



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## CHAPTER 3

### Roles, Responsibilities, and Decision-making of School-Aged Children with Chronic Health Conditions

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## **Abstract**

*Background* Family management of chronic health conditions in children has been well studied from the perspective of the parents or adults. Less is known about how the child, especially the school-aged child, views this phenomenon.

*Objective* To broaden our understanding of the structure and function of families of children with chronic health conditions, the child's perspective was elicited regarding the roles, responsibilities, and decision making processes that occur within these families with respect to condition management.

*Methods* Thirty-two children with a variety of chronic health conditions participated in one semi-structured interview. Directed content analysis was used to identify the child's perspectives of roles, responsibilities and decision-making involved in the daily management of the condition.

*Results* School-aged children acknowledge several roles throughout the day. They also identify the role their parents and others play in condition management. A range of responsibilities exist that show increasing responsibilities across this age range. Decision-making within the families was also varied, with some children not involved in decision-making, while others spoke of being closely involved in a collaborative process.

*Conclusions* School-aged children with chronic health conditions are able to articulate the roles, responsibilities, and decision-making processes at work within their family and the changes in their roles and responsibilities based upon their chronic health condition. Families and health care providers need to work with children in this age group to help them understand the processes that occur during condition management in order to prepare them for different roles, increased responsibility and decision-making. Additional research is needed to identify the child and family variables open to interventions.

## Introduction

Having a chronic health condition (CHCs) during childhood mean incorporating the condition into daily life, and eventually learning how to care for the condition independently. The family, and especially the parent-child dyad, is important as it supports the children's development in condition management. The current understanding of family dynamics, as they relate to condition management, is limited; the distinct and shared roles in management and daily decision-making responsibilities and processes are not well documented (Brown, Gallagher, Fowler, & Wales, 2010). As children mature they need to develop an appropriate level of autonomy, understand and discuss their health history, risks, and needs, and have disease management skills in order to be ready to assume their own condition management (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). These abilities do not occur overnight but develop in conjunction with typical childhood development.

Childhood is a time of growth and change for children and their families. At birth, children are totally dependent on others to see that daily needs are met. As children grow and develop, they become able to voice their needs and become a more active participate in the daily activities of care. Children with CHCs and their parents often recognize the need to develop the children's roles and responsibilities regarding self-management and looking back may feel that they started their efforts too late (van Staa, Jedeloo, van Meeteren, & Latour, 2011); when and how to begin this process is not well documented.

The school-aged period is considered a transitional stage where children are building on prior learning in preparation for adolescence, roles are expanding, and responsibilities are increasing. Families have the opportunity to help children manage these changes by recognizing the need for communication skills, positive peer relationships, self-esteem and independence (Hagan et al., 2008). The American Academy of Pediatrics recognizes that children as young as 7 or 8 need to begin to interact with the health care provider and that during this period children are solidifying health practices concerning nutrition, physical activity, and safety (Hagan et al., 2008). By early adolescence (age 11 – 14), children should be meeting with health care providers without parents for a period of time, and children should be active participants in health

maintenance, taking on new responsibilities and developing strong decision-making skills (Hagan et al., 2008).

Children's decision-making process regarding health care issues is not well documented. Studies outside of the healthcare arena have been conducted with emphasis on understanding decision-making and autonomy development in children. The decision-making process between children and parents, as it is related to homework and family leisure activities, has been observed with the goal of identifying the extent to which parents allow their children to actively participate in the decision-making process and exercise autonomy (Holmbeck et al., 2002; Kuhar, 2010; Milnitsky-Sapiro, Turiel, & Nucci, 2006; Ng, Kenney-Benson, & Pomerantz, 2004). Such studies have shown correlations between children's behavioral and academic outcomes and have added to our understanding of parent-child interactions. Maintaining a positive parent-child relationship is also important during the school-aged period as positive relationships improve outcomes for both children and their families (Bao & Lam, 2008; Kuperminc, Allen, & Arthur, 1996).

Condition management decisions, in a study with children (8-19 year) with asthma, Type 1 diabetes or Cystic Fibrosis and their parents, included timing of treatments, when treatments are required based upon symptoms, determining dose required, assessing risks and benefits of certain medications, and deciding who to tell about the condition (Miller, 2009). Collaborative or shared decision making processes were preferred by both children and parents alike (Kennedy, 2012; Miller, 2009; Miller, Reynolds, & Nelson, 2008).

Structural-functionalism provides a relevant way to investigate roles and responsibilities from the perspective of individual family members (Denham, 2003). The purpose here is not to better understand the family, but to gain an understanding of how school-aged children with CHCs are managing the work of condition management, within a family context. Delineating the roles of the children and their parents within daily condition management begins to broaden our understanding of the work of condition management and who is doing what. The results reported in this manuscript aim to describe the roles, responsibilities, and decision-making with regards to condition management from the perspective of 8 – 13 year old children with a variety of chronic

health condition. Future work can incorporate the perspectives of the children with CHCs into family studies.

### **Methods**

The results described in this paper are part of a larger study examining the perspectives of school-aged children regarding management of their chronic health condition. The study used a qualitative descriptive design, allowing for the voices of the children to be salient throughout the analysis (Sandelowski, 2010). Directed content analysis (Hsieh & Shannon, 2005) was used to determine the child's perspectives of the roles, responsibilities, and decision-making within the context of condition management.

### **Participants**

A purposeful sample (Patton, 2002) of 8 – 13 year old children with a chronic health condition were recruited from three specialty clinics (endocrine, pulmonary, hematology) within a children's hospital located in a major city in the northeastern United States. Families of children were invited to participate in the study if the child/family met the inclusion criteria: child was diagnosed with a chronic health condition for at least 6 months; both participating parent and child were able to read and write in English; child was within one year of age-appropriate grade; families had a telephone; and, both child and parent agreed to participate in the study. The child was the primary informant; the parent provided the demographic information.

The children participated in face to face, semi-structured interviews that lasted from 15 minutes to just under 75 minutes. The children ranged in age from 8 -13 years old with a mean age of just under 10.4 years. There were 18 boys and 14 girls in the study representing nine primary chronic health conditions. Asthma (n=13) was the most common condition, followed by Diabetes (n=8), Cystic Fibrosis (n=4) and Hemophilia (n=2). The remainder of the primary conditions; Heredity Spherocytosis, Phenylketonuria, Sickle Cell Disease, Eosinophilia Gastroenteritis and Chronic Sinusitis were found in one participant each. Four participants also had Attention Deficit Hyperactivity Disorder, and over 20 conditions were represented in the sample of 32 children with approximately half of the children having more than one condition.

Parents provided information regarding condition characteristics to ensure a diverse representation across and within conditions (Rolland, 1994). Onset of condition was rated as acute (15) or gradual (15). Two parents did not answer this question explaining that their children were diagnosed prior to experiencing symptoms and treatment has prevented symptoms; therefore they did not relate to the onset question. Course of condition was rated as progressive (4), constant (14) or relapsing (14). Additionally, the parent identified if they felt their child was treated differently because of the condition with 15 parent respondent's affirming some stigmatization of the child related to the health condition.

The 32 families who participated in the study came from New York, New Jersey and Pennsylvania. Thirty of the adult informants were mothers, while two fathers participated as informants. The adults provided the demographic data for the study. Three-quarters of the parents were college graduates and forty-two percent of those had graduate or professional degrees. Thirty-four percent of the families reported earning less than \$30,000/year while forty-one percent reported earning over \$100,000. The parent's self-identified race was Black (31%), Hispanic (3%), and White (66%).

### **Procedure**

IRB approval was obtained from the children's hospital. Recruitment occurred through flyers in the specialty clinics, provider identification, word of mouth, and/or mass mailing to potential families identified by the eligibility criteria. Verbal consent, screening, and scheduling interviews occurred via telephone when the parent called into the study telephone line. Interviews were conducted in person, with the majority of the interviews held in the participants' home (30 of 32). Before conducting the interview, the study was again explained to the parent and the child. After any questions were answered to their satisfaction, written consent was obtained from one parent and written assent from the child. At the beginning of the interview, the child was asked to identify a fictitious name for use during the interview; the names used in results have also been changed, while age and condition were maintained.

### **Data collection and analysis**

The first author conducted the interviews with the children following a semi-structured interview guide (see Table 5). The topics and prompts in the interview guide were sensitized by family management literature and were developed to aid the children in talking about themselves and their families within the context of their conditions. Interviews began by having the children tell the interviewer a little about themselves. Through the course of the interview, each child was asked to describe condition management from their perspective, with prompts used to elicit more detail when needed. The interviews were conducted in English and ranged in length from 15 to 74 minutes, averaging 45 minutes. Each interview was digitally recorded, transcribed and validated to ensure accuracy. Identifiable information was removed to ensure the confidentiality of the participants.

**Table 5. Interview guide**

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Sample Questions

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Tell me a little about yourself

Draw a picture of your family, tell me about it

Tell me when you found out you had (name of condition)

Take me through a typical school day

Describe a typical weekend day and its difference to weekdays

What will it be like when you're older? What will change?

Tell me your advice for another boy or girl who just found out they also have (name of condition)? Your family? Your friends?

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A directed approach to content analysis (Hsieh & Shannon, 2005) was used to identify the child's perspective of the roles, responsibilities, and decision-making process surrounding condition management. Analysis began by identifying passages that fit the definitions of these categories. Once the data had been identified, coding identified the child's description of the category, developing codes to identify the child's understanding of the roles, responsibilities and decision-making process that occur. A constant comparative method (O'Connor et al., 2008) was used when coding to examine both within and across case analysis to ensure a broad understanding of the perspective. The data was managed using Atlas-ti 7 Qualitative Data Analysis (Atlas.ti, 2012).

Attention was given to ensure the credibility, authenticity, criticality, and integrity of the study (Whittemore et al., 2001). Reflexive journaling throughout data collection and analysis,

along with memoing and maintaining a decision trail, provided credibility, authenticity, criticality, and integrity throughout the process. Additionally, raw data, analytic grids, and findings were reviewed with an expert in qualitative methods to add to the rigor. Finally, participation in a qualitative collection provided an opportunity to have coding reviewed and challenged by a group of colleagues well versed in qualitative analysis.

## **Results**

Between June 2012 and January 2013, 32 children were interviewed for the study. Thirty-four families were enrolled but two subsequently withdrew, one stating lack of time, and the second was not home for the scheduled interview and did not respond to follow up phone calls.

### **Roles and Responsibilities**

**The Child.** The primary role identified by the children in the study was that of student with a chronic health condition. The children's stories about their school day explained how the condition limited them in some way, or how they used accommodations to navigate throughout the day. The major responsibility identified was taking medication or treatments. Within the context of their chronic health condition, their stories included having to leave class early in order to "take a treatment", check blood sugars, or take other medications at a prearranged time during the school day. This role also took form as they had to "stay away from anyone who might be sick" or negotiate the cafeteria lunch offerings to ensure dietary restrictions were maintained. As one child with diabetes related,

Sometimes like if I feel really shaky I'll take one of my best friends and we'll walk down to the nurse together. I remember in elementary school when I was first diagnosed I felt so bad and I felt dizzy, it was actually like blurring my vision and everything was like tilting and that happened sometimes; but I remember my friend holding my hand and I like fell to the ground and then I got back up again. It was crazy, but we got there, it's all good (Minnie Mouse, 12 year old, Type 1 Diabetes).

The athlete with a chronic health condition was the second role many children assumed, with responsibilities similar to the student, managing medications and treatments. As the athlete,



these children participated in both formal and informal activities, close to home or further away. While playing with friends, they often had to limit their activities or cut short a game due to limitations in physical ability or a need to address a treatment requirement.

If I was running around and I get tired, cause I know for a fact when I'm, especially me, when I'm running around a lot and I stop, my friends keep running. I'm sitting like "Wait up, and I'm tired. I'm tired. Let's take a break for a few minutes." And I come home and it's; like when I run around like we used to do last year when I was in sixth grade. Me and my friends would go to the back of the school and have little races just to see who was faster. Then we'd touch the gate and we'd come back and I'd come back and it's really hard for me to catch my breath (Troy, 12 year old, Asthma).

Formal athletic activities also had special management considerations related to the condition, whether it was treatments or checks before practice or events, or the need to do something special at half-time. Whatever the regimen, children felt the responsibility of taking the pills or taking their treatment was theirs, although many relied on parents to remind them and put the medication out for them. For instance, checking their blood sugar was a common responsibility for the children with Type 1 Diabetes. Recognizing symptoms and reporting them to someone was another. One example of this was a child with asthma who reflected that she knows when she doesn't feel well and says "I think I need a treatment, 'cause after I took the treatment, I stopped coughing" (Brianna, 10 year old, Asthma).

Children shared how they decided who they would or would not tell about their condition in the role of informant. There was a range of what they were willing to disclose to others. Some children were very active in the process and others more passive, leaving it seemingly to chance. Some children shared information regarding the condition with anyone who asked. One child had given a presentation to his school while another went back to her old school to help children cope with CHCs. Others were more guarded and spoke of not telling people because it wasn't any of their business. Friendship was a reason to tell, while future job requirements and experience

being teased were reasons not to tell. One child, explaining why she told some friends but not others, put it this way:

I: Have you told any new friends?

R: No because usually I wait until they're like old friends because sometimes I don't want them to know right away.

I: How come?

R: 'Cause sometimes I get embarrassed and I feel like they're gonna laugh at me (Brooke, 9 year old, Cystic Fibrosis),

Another boy said "sometimes I explain it to them. If it's like a short time and I don't have that much time, I just say it's... you'll learn it when you're older (Manny, 9 year old, Type 1 Diabetes).

This leads to the final role the child identifies and that is as a child with a chronic health condition. Children realized this made them different, and some embraced the role while others ignored it or wished they didn't have it. One child who embraced the role said "I'm kind of proud I have it, it makes be different from the other kids, kind of stronger cause I know I can handle stuff and they don't know what it's like", (Jessica, 12 year old, Sickle Cell Disease) as opposed to another who stated "I didn't really want it...It's not good. I don't like it and I want to get rid of it...When Bea goes outside to play I have to stay inside usually and get my treatments" (Brooke, 9 year old, Cystic Fibrosis). The limitations the condition places on the child's activities and the social meaning of having a chronic health condition are readily seen in these examples.

**My Parents.** The role of the parent within the context of condition management was two-fold. First and foremost the parent was seen as the caregiver, the individual ultimately responsible for overseeing the administration of medications and treatments. The degree of interaction within the role varied. "Mom does it all" was at one end of the spectrum, with the parent telling the child what to do each step of the way. These children were not very involved in managing the condition; rather their condition was managed by the parent. Prompting (e.g. "Mom will say 'check your sugar'") was next. Here, the children were more involved in management activities but the activities would be triggered by the parent. Monitoring (e.g. "They are always checking on me")

was at the other end of the spectrum. The children saw the parent as a partner in management, either reporting activities or being asked but in a manner that involved working together, between the parent and child to manage the condition. As another child told me, "Every morning when I'm heading downstairs, they'll call out 'make sure you start your vest' " (Spiderman, 11 year old, Cystic Fibrosis).

The parent within the caregiving role was also seen as an active monitor in some cases. Several parents worked in the school their children attended. One girl with diabetes said her mom will walk by her lunch table after she's done with lunch and casually ask her what her blood sugar is and continue walking making a casual but active check to monitor the child's blood sugar daily. Another child reported that her mother will often say, it's time to start your nebulizer treatment, after monitoring the child's breathing and wheezing.

The second parent role the children in the study identified was expert (e.g. knowledge and skills). Some parents were designated as "knower of all things." These parents knew when to start medications, when to stop them, how much to take, or the nutritional content of certain foods. When the parent was designated to this role, the children didn't think too much about the condition, but saw the parent as having all the answers. No parents were otherwise classified, however; although they were not necessarily labeled as experts, children in the study continued to look to them as the primary authority figure for condition management.

The parent, in their role as expert, acts as informant to the health care team, whether at school or at the doctor's office. The parent is responsible for talking to the school nurse about the management that needs to occur while the child is at school. The parent is also responsible for notifying others in the school what they may need to know, such as the cafeteria staff regarding dietary practices and restrictions. The parent is also the primary communicator to the health care staff during doctor visits. Very few children viewed themselves as included in the doctor visits, saying the doctors mostly talked to their parents.

**Others.** The children in this study did identify other individuals who had roles within the context of condition management. Teachers and/or the school nurse were often seen as surrogate caregivers while the children are at school:

I tell the teacher that it's an emergency and that I feel lightheaded or my chest is hurting or I'm wheezing and she sends me down to the nurse. The nurse gives me my inhaler and if I'm not good in the next few minutes then she calls my mom and my mom either takes me to the clinic or the emergency room (Andy, 11 year old, Asthma).

Teachers remind them when it's time to go to the school nurse. In doing so, they monitor situations and sometimes act as a gatekeeper and deny access if they don't feel it's warranted. The teacher filled the role of monitor for these children, and when the situation warranted, the teacher or school nurse would call the children's parent for answers or suggested interventions. Children with diabetes mentioned that school nurses had the responsibility for ensuring that treatments are done, blood sugar checked, and insulin taken. The nurse also communicates issues between children and parents, calling to notify the parent when things are outside what they considered normal. It seemed clear that although the surrogate monitor was fine, the expert in charge, the one who knew what to do, was still the parent.

Children also spoke about the roles and responsibilities of other members of the family. As one child explained, even though the family member acknowledged how his diabetes made him different, "they wanted me to be like a normal kid" (Clay, 11 year old, Type 1 Diabetes). This ability to evaluate the reason help is provided is one example of how the children are interpreting the actions of those around them. In this case, Clay is assessing whether help is being given because he is not able to do it, or because it makes him more like a normal kid. Other children talked about the role they had as a child/sibling with a CHC and how those roles were important especially during exacerbations or crises in that they could depend on their parents, extended family and siblings for support. As one boy explained when he's having an asthma flare,

My uncles, they give me an inhaler or if I'm wheezing and I wanna get up, they'll tell me to stay down so I don't make it worse. They'll bring me the nebulizer or the inhaler...(my brothers) they keep me distracted (Chad, 12 year old, Asthma).

Family members are responsible for reminding the children to take pills, check blood sugar, and do the treatments. Family members are also responsible for assisting during a crisis, for example,

If I'm really low and I can't really like concentrate or get up, I'll call and I'll get my mom or usually my brother... sometimes he'll sleep with me, so then I'll um... call him. Like my brother and my sister all know the maneuvers, like go getting my tester, or glucose shot, or anything. Um... and then before I eat anything, I always test, dinner, breakfast, lunch, or anything (Clay, 11 year old, Type 1 Diabetes).

The final group of children identified as having a role in condition management was friends. Friends needed to know about the condition in case something happened while they were together. Some children told only a few close friends while others were more open; some felt there was a need for others to know while others felt no one else needed to know. One girl who appreciated her friends for support said, "I know my friend Robin whenever I'm like I go to the nurse she'll be like, "are you okay?" and I'm like, "yep, I'm fine" she's like, "good" and we'll talk about something else (Minnie Mouse, 12 year old, Type 1 Diabetes).

### **Decision Making**

Decision-making within the context of condition management may be a daily occurrence around management activities such as using a rescue inhaler, deciding whether to take extra enzymes with the snack you're about to eat, or if insulin should be taken and if so, how much? These types of decisions center around understanding the condition, identifying symptoms as they occur, knowing the treatment regimen and having the ability to "do the math" in figuring out dosing and timing of treatments. Other decisions are less routine, for example, what is the best method for blood glucose control for the child with diabetes? What's the best method to clear the lung of mucus in the child with Cystic Fibrosis? How does the child with hemophilia make decisions regarding safety versus risk while at play? The children that are asking these questions and looking for answers have come to understand that there are options in treatments and

decisions are being made. Children with CHCs are conscious of these decisions and articulate who is making the decisions for or with them and if they feel they have any say in the end.

From the child's perspective, parents make many decisions regarding condition management. Basically, the parents were the authority figures who made the decisions and these school aged children said they complied with what they asked. One child summed it up by saying, "if I need it that badly, I'll do it on my own, but if I start wheezing, I don't notice then my Mom tells me to do it" (Allen, 11 year old, Asthma),

What school-aged children do with regard to condition management also is closely tied to their schedule or daily routines, and therefore tied in closely with the school day. Condition management is easily framed around what is done before school, during school, after school and before bed. These routines seem to take decision making out of condition management. What was not clear from the children's accounts were how they handled unpredictable events that interfered with the routines; although one can imagine that surrogates or cell phones may fill that void. Further exploration to determine how children handle non-routine events is warranted.

Although most decision-making was discussed as occurring within the family, one child spoke of a time when a decision she felt she could make was overruled by school staff. Her food allergies were known to the cafeteria staff and when she went to take a food item, she was told she couldn't have it. After stating her case to the staff and continuing to be rebuffed, she acquiesced and took whatever they were offering her instead. Once at home she complained to her mother who called the school the next day. Things were better for about a week, and then reverted back to the more restrictive food offerings for the child.

Teachers and coaches also are recognized as participating in some decision making with the child's condition management. Teachers may observe a child having trouble breathing in the class and approach the child, recommending they go to the nurse. The coach may take a child struggling with asthma out of the game for a while so they can use an inhaler and recover before being put back into the game. School-aged children who are athletes rely on the coach's judgment and follow the coach's decision.

Some children recognized the doctor as the decision maker or authority for condition

management. One child said “They told me I gotta take thirty-five in the morning and fifteen at night” (Diane, 12 year old, Type 1 Diabetes). Others spoke of wanting to change the treatment regimen they were on but needed the doctors okay;

Well we have to talk to Dr. Smith about that, see if he’s alright with that because... And Stephen, which is someone who is my vest teacher thing...and if I tell him that I’m not really doing it (the vest) he might be mad at me and my parents... I don’t really do my vest anymore so it’s up to Dr. Smith to say that (Brooke, 9 year old Cystic Fibrosis).

A couple of children recognized a more sophisticated decision-making process. They identified a problem or desire for change, researched the topic, and discussed it within the family. They also discussed it with the health care provider, and helped to decide to implement the change. As one of these children noted:

We, me and my mom, talked about it for a few months maybe just to kind of... We just kind of researched it and just kind of said...We just kind of talked about it with my dad just because we felt like we didn’t have enough control over the levels and at times we thought that we were kind of guessing a lot, like when I could eat. I thought I was and I just felt like I couldn’t really eat what I wanted because I felt like when I went over to my friend’s house or something or when I went to a birthday party, I felt like it was kind of hard if I wasn’t with my mom or something. Like at school if someone brought in birthday cake or something, I felt like it was kind of hard to try and figure it out myself. So I felt like I was trying to call my mom a lot and trying to figure out what to do, and I had to do a lot just to eat something. So I think that’s the reason we did switch, just to have more control and for me to be able to manage it without having to try and call my parents and have to worry about can I eat this, can I not eat this, all of that. So I think that’s the main reason why we did switch insulins, just to get more control and just so that if I wanted to eat something I wouldn’t have to do a lot of really

complicated...and go through a lot of trouble just to eat something. So I think that's why we kind of switched (Clay, 11 year old, Type 1 Diabetes).

Decision making, relative to condition management, was varied across this group of school-aged children. Some children were very removed from the process while others felt like they were an integral player in process. Although the participation varied, no child expressed great distress at the decisions that were being made in the home. Without someone to put on one of the parent surrogate roles, the children were sometimes more frustrated when they were at school or organized activities and did not feel they were being heard.

### **Discussion**

This qualitative research is based upon interviews with school-aged children between the ages of 8 and 13 years who described the roles and responsibilities they and their family members had within the context of managing their chronic health condition. In doing so they made implications about decision making regarding their condition. The children who participated in the study were easily engaged and spoke readily about their experiences. Of note is that whether the children-identified responsibility was large or small, the children saw themselves as active participants in the process. The children might have to be reminded, but in the end that responsibility was theirs.

While structural-functionalism has been widely criticized because it may not acknowledge the complex interplay of factors operating in a family, in the case of this study, it provided a meaningful framework that is consistent with the developmental understandings of school aged children. The framework provided relevant ways to investigate roles and responsibilities from the perspective of individual family members (Denham, 2003).

It is acknowledged that parents play the primary role in managing the day-to-day work involved with management of chronic health conditions during childhood. Parents must have knowledge regarding the condition and treatments, understand how to monitor symptoms and respond to changes in the condition, and provide instruction for other caregivers when children are not at home (Brown et al., 2010; Emiliani et al., 2011; van Staa et al., 2011). This study, however, identified the many roles that parents and their surrogates take on for the management



of childhood chronic conditions. The children in the study identified the parent as expert and the one who was ultimately responsible for overseeing the treatments. This perspective is similar to that documented previously in the literature by parents of school-aged children with chronic health conditions (Brown et al., 2010; Raymond, Fiese, Winter, Knestel, & Everhart, 2012). Attention to the responsibilities inherent in those roles through daily management practices seems to improve adherence to the treatment plans (Fiese & Everhart, 2006) and lead to better outcomes for these children and their families (Graves, Roberts, Rapoff and Boyer, 2010).

Although the parent was seen as the expert, the children in the study recognized the important role teachers, coaches, and the school nurse play in assisting and overseeing condition management. When parents are not available, children with CHCs depend on these adults to help monitor and manage their condition. Adding the voice of these children to research and discussions regarding the need for school nurses, as well as training for teachers and coaches around condition management is recommended.

The social implications around informing others are significant to the children in this study, with the sense of self evolving within a social context (Hagan et. al., 2008). The perspectives regarding their CHC ranged from no big deal to something that changed their ability to keep up with peers, and ultimately could cost them a job. With these insights, it is important to consider the way the CHC is viewed by both children and their families. If the CHC is seen as something that needs to be hidden, it places a stigma on the condition that can influence the development of self-identity (Goffman, 1974). Fifteen parents believed that their child was treated differently than others because of the condition, and this is reflected in the perspectives of the children as well. Social exclusion during adolescence has been predictive of higher levels of depressive symptoms 1 year later (Masten et al., 2011) and similar changes were found in a study examining social exclusion that included children as young as seven (Booling et al, 2011). Therefore, understanding the perspective toward the condition within the context of social interactions with peers may be an area where intervention to support social skills would be beneficial.

The interactional nature of condition management among parents, children, and providers requires the study of related interactions as well as the decisions. Children in the study were aware of decisions being made but there was a variation in amount and type of their involvement. Research regarding decision making involvement acknowledges this variation, examining the ways that children contribute to the decision-making process, regardless of where the final decision lies (Miller & Harris, 2012). The Decision-Making Involvement Scale (DMIS) was recently developed and tested with children (8 – 19 years) and their parents (Miller & Harris, 2012). Measuring five factors (Child seek, Parent express, Joint/options, Child express and Parent seek) the DMIS will be useful in determining the child's involvement in condition relevant decisions. The findings of this study support the DMIS factors, with the child responses consistent with the factors. Although a new instrument, the DMIS may be useful in subsequent studies of family management and decision making within the context of condition management. The dyadic nature of the instrument provides potential for comparison of child and parent perspectives with the context of family management and the ability to identify changes that occur in the dyad as the child matures.

Decision-making involvement throughout the settings that families navigate may also be useful when examining the goals for children with CHCs. While most children mentioned the school nurse when asked about decision making in school, several children mentioned someone other than the school nurse intervening when they had a health related issue at school. For example, while at school the nurse could oversee blood sugar checks; but results that needed extra insulin warranted a call to the parent. The same went for children with asthma; if the inhaler didn't help, then the parent was called to make a treatment decision. The children easily identified this process. Districts have decreased the number of nurses in school, and the responsibility is left to teachers who are often too busy or ill-prepared to deal with the situation (Hill & Hollis, 2012). Having a school nurse available to oversee the health care needs of all students and especially those with chronic health conditions is imperative to the health and safety of these children. Additionally, knowing children can express their needs and opinions may help when they need assistance. Future research is needed to examine the association between school nurses

and health outcomes for children in schools, and especially condition management during school for children with CHCs.

Encouraging parents to use a more collaborative approach, involving their children in decision making while maintaining decision making authority, may lead children to make better condition management decisions for themselves later in life (Miller, 2009; Orrell-Valente & Cabana, 2008). Additionally, it is theorized that if parents are influential in socialization of their children, then the parent management may have a direct effect on the child's approach as they get older and gain more independence (Orrell-Valente & Cabana, 2008). Although providers or parents typically would not expect these individuals to make independent decisions, families should be counseled to expose children to the decision making that occurs with condition management in order to better prepare them for the decisions they will need to make as adolescents and young adults.

There are several limitations to this study. First, because the families were recruited from one medical facility in the northeast, they may have management approaches reflecting the culture of the facility. Second, limited types of households and families are represented. There is limited diversity in the sample. Although the representation of blacks and whites reflects the greater metropolitan area of the sample, Hispanics/Latinos/Latinas and Asians are not represented at all. Therefore, the results may not represent the beliefs and understanding of children from other cultures. Although nine primary conditions were identified and over 20 existed within the sample of 32 children, many other conditions exist.

### **Conclusions**

In summary, school-aged children are aware of the roles and responsibilities they and others assume regarding condition management. The children and parents are the primary players, while friends and school staff provide key support and coverage when the parents are not available. The parents were seen as being in the following roles: caregivers and expert. Children saw the parent/caregiver as responsible for condition management through direct care, prompting or monitoring. The parent/expert was the person who answered all questions regarding management and primary authority. The child saw themselves as student, athlete, informant, and

child with a chronic health condition. Although the latter role did impinge on the former ones, it was not a dominant role within this group. As student, athletes, and informants, the children had responsibility carrying out the treatments they agreed were theirs. As informant, the children controlled the information regarding their health condition and would identify who could know about it.

Decision making was conducted predominantly between parents and children. Parent strategies around decision-making ranged from parent directed, where the parents decided and the children did as they were instructed, to extremely collaborative decisions where children were very involved in the process. Future longitudinal studies to explore change over time in the roles and responsibilities and decision-making (DMIS) would enhance our understanding of family management and self-care.

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## CHAPTER 4

### Health Care Autonomy in Children with Chronic Conditions: Implications for Self Care and Family Management

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Statement of Authorship: Barbara L. Beacham was the lead author on this manuscript ( Beacham & Deatrck, 2013), performed the review of the literature and developed the conceptualization of Health Care Autonomy as a developmental attribute, important to the interplay between family management and self-care in children. Janet Deatrck, PhD, RN from the University of Pennsylvania School of Nursing, Philadelphia, PA, United States was co-author of this manuscript.( Beacham, B, & Deatrck, J. (2013) Health care autonomy in children with chronic conditions: Implications for self-care and family management. *Nursing Clinics of North America*, 48, 305-317. PMID: 23659815)

## **Synopsis**

Health care autonomy typically occurs during late adolescence but health care providers and families often expect children with chronic health conditions to master self-care earlier. Few studies have examined the development of health care autonomy as it pertains to self-care and family management. This review will link the three concepts and discuss implications for families and health care providers. Case studies are provided as exemplars to highlight areas where intervention and research is needed.

## **Health Care Autonomy in Children with Chronic Conditions: Implications for Self Care and Family Management**

More than half of all Americans have at least one chronic health condition, ("Chronic Diseases: The Power to Prevent, The Call to Control," 2009) and 1-in 5 households contain a child who has a chronic health condition (Hagan et al., 2008). Because the majority of these children now survive into adulthood, (Gortmaker & Sappenfield, 1984) their transition to self-care and eventually to adult health care is on the clinical, research, and policy agendas for many professional, advocacy, and governmental groups. (American Academy of Pediatrics & American College of Physicians, 2011; Cohen et al., 2011; Newacheck et al., 1996). While common sense links child development, family issues, and the acquisition of self-care, a gap exists regarding how the components can be integrated into a model to guide nursing practice.

Health care autonomy is a developmental key that links family management and self-care. Autonomy is the ability to evaluate options, make a decision and define a goal, feel confident about those decisions, and develop strategies to meet the goal. (Noom et al., 2001) Health care autonomy, then, refers to the ability to evaluate options, make decisions and define health related goals, the confidence to stand by those decisions and to develop strategies to meet those health related goals. Autonomy in health care situations for children usually is one of the last contexts in which autonomy will be expressed, typically in late adolescence (Smetana et al., 2004; Wray-Lake et al., 2010).

The general importance of autonomy is highlighted along with other factors, including family management and skills for self-management, within a social-ecological model of readiness to transition (SMART) to adult health care for children with chronic conditions proposed by Schwartz and colleagues (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). They explicitly indicate the importance of autonomy (developmental maturity), family management styles, and self-management to the transition process. The developmentally appropriate level of autonomy for the child is mentioned as a facilitator of the transition process. For all concerned (including the child and the family), family management goals that facilitate the child's autonomy and successful transition to adult care are necessary. More specifically, the family members and the family as a

unit need to believe that the child is capable (i.e. child identity) and that the child will be able to care for themselves in the future (i.e. future expectations) (Knafl et al., 2012). In addition, Schwartz points out that children who successfully transition must have disease self-management skills and parents need to be effective at supporting such skills.

The purposes of this paper are (1) to describe a developmental and family based model of health care autonomy that incorporates self-care and family management and (2) to apply the model to two case studies in order to highlight how it can be applied to nursing practice and possibility to nursing research.

### **Development of Health Care Autonomy**

The development of autonomy is integral to the development of self-care in children with chronic health conditions. As the model in the Figure depicts, health care autonomy, family management, and self-care provide the foundation for child health and well-being. Examining these concepts will provide a basis for understanding the challenges of incorporating management of a chronic condition into transitioning to young adulthood and how nursing care can best support this process.

The left hand side of the model depicts the key components required for development of autonomy. Autonomy readiness is assessed both by the parent and by the child, separately and based upon the feedback they get from one another. It is these individual assessments along with the interactions between the child and parent that provide the foundation for family management of the chronic health condition and the development of self-care within the child. The optimal outcomes of the process are health and wellbeing of the child and increasing health care autonomy.

Chronic health conditions can lead to decreased well-being for the child in terms of missed school days and opportunities for social interactions and activities, as well as lost productivity, poor health, lost wages, and increased medical expenses for parents (Cadman et al., 1987; Suris et al., 2004). Families of children with chronic health conditions face the challenge of managing all facets of the condition early in the child's life and then transitioning the management responsibility to the child. Therefore, by understanding the process of developing health care

autonomy, and the key components for both the child and the parent, health care providers can help to maximize child health outcomes.

### **Health Care Autonomy**

Autonomy is a complex developmental construct which is instrumental in the transition from childhood to adulthood. Successful autonomy can be assessed by examining decision-making, relationships, influence upon others, and perception of competence, control, and responsibility (Noom et al., 2001). It is often thought to be synonymous with independence and self-reliance.

Smetana et al, (2004) identifies four different domains of autonomy: prudential , conventional, multifaceted and personal in a study of decision-making autonomy (Smetana et al., 2004). Each domain reflects a different context for autonomy development, with prudential (decisions regarding health and safety, e.g., when/if to smoke cigarettes, drink alcohol) and personal (decisions regarding the state of one's body, and privacy) being especially relevant to the child with a chronic health condition. Each domain deals with different issues and therefore autonomy develops in each domain over time but at different times and rates. The study also found that mothers and children had different perceptions about when the child should or did have increased autonomy in each area.

Children with chronic health conditions need to develop autonomy within these domains specifically related to the management of their chronic health condition. As was stated earlier, autonomy over health related issues (prudential) typically occurs late in adolescence (Smetana et al., 2004; Wray-Lake et al., 2010), but we often expect children with chronic health conditions to master these tasks earlier. Helping children master all the components of self-care requires a well-constructed plan over many years and requires the support and buy in of the child and family (American Academy of Pediatrics & American College of Physicians, 2011).

### **Family Management for Children with Chronic Conditions**

Family management, how families actively organize, integrate, and accomplish tasks related to the chronic health condition in the child (Knafl et al., 2012), supports the health and well-being of the child. The 3 components and 8 dimensions of family management identified by

Knafl and colleagues (Knafl et al., 2012) highlight the areas and issues that families and practitioners need to consider. In the first component, definition of the situation, there are 4 dimensions. The family view of the child with a chronic health condition (child identity) and the view of the condition itself (view of condition) are the first 2 dimensions and are the foundation of family management. The next two dimensions develop from this understanding as the parents also assess the ease or difficulty they have in carrying out the recommended treatments (management mindset) and the extent to which they have shared views of the child, condition and approach to condition management (parental mutuality). The second conceptual component, management behaviors, identifies 2 dimensions, the parenting philosophy regarding condition management (parenting philosophy) and the ability of the parents and child to have a routine and strategies for condition management (management approach) (Knafl et al., 2012). The third component, perceived consequences, is comprised of 2 dimensions, the parents' assessment and satisfaction with how condition management has been incorporated into family life (family focus) and the parents assessment of the future for both the child and the family (future expectation).

Family management changes over the course of a child's life as the child develops the skills, cognitive ability and social confidence to manage their own health care activities. The authors of the model, developed primarily from the parents' perspective, have encouraged researchers to expand its use to other populations. A study of adolescents with spina bifida demonstrated the value of adolescents' perceptions of how they management their condition with their family (Wollenhaupt, Rodgers, & Sawin, 2012). The adolescents' description of condition management performed by themselves or their families was consistent with the dimensions and components within the family management model. In addition, self-management as well as the shared responsibility of care between the adolescent and the parent, was highlighted.

Moving the science forward will also require research regarding the children's perceptions about how their families manage within the context of their own self-care, as the child is both a recipient of family management and a participant with the family as they manage. Only then can we begin to examine the interplay of the family and child, recognizing that some of the

components or dimensions of family management may remain stagnant and may not support the development of the child. Optimal family management would transition most of the condition management to the child as they grow and develop, while maintaining health outcomes.

### **Self-care for children with chronic conditions**

Riegel, Jaarsma & Stromberg's, (2012) middle-range theory of self-care was created from experience with adults who have heart failure. The theory defines self-care as “a process of maintaining health through health promoting practices and managing illness” (Riegel, Jaarsma, & Stromberg, 2012)<sup>(p195)</sup>. The three components of the theory, self-care maintenance, self-care monitoring, and self-care management, delineate self-care and identify areas to consider when we are teaching children and their families.

Self-care maintenance are the behaviors used by patients with chronic conditions in order to maintain physical and emotional stability (Riegel et al., 2012). For children, the family, and health care provider, determining when the child is developmentally able to perform these behaviors is important when considering transitioning from an emphasis on parental agency in family management to child agency and self-care.

Self-care monitoring, the second component, is the process of observation or self-reflection in order to identify changes in signs and symptoms (Riegel et al., 2012). Again, the ability to attend to this process hinges on the child's developmental ability and self-awareness. As we will see, this component is most overlooked when considering a child's ability to perform self-care and may be a reason for a decline in outcomes during adolescence.

The third component of the model, self-care management, is defined as a response to the signs and symptoms when they occur (Riegel et al., 2012). Taking appropriate action requires knowledge of the options available, availability of the treatments required, and the physical ability and the psycho-social maturity to act. The child may have the knowledge, but not the maturity to act when faced with having to “show weakness” in front of friends or classmates. Both components of management are crucial when preparing the child for self-care activities.

This conceptualization of self-care provides a novel way to examine all the components of self-care that may be applicable for children with chronic health conditions and their families as

they navigate the process of maintaining the health of the child. Table 6 demonstrates the way the original framework may be adapted to include children and families. This adapted model will be used as a template to examine care components families provide and transition to children over time.

Self-care for children with chronic health conditions is a joint effort between the family/parents and the child. Learning self-care practices begin as a parent/caregiver driven effort when the child is young, with the goal of transitioning to a child driven effort, as the child becomes a young adult. The process of transitioning can be seen in everyday self-care activities, such as oral care. When a child is born and throughout infancy, the parent/caregiver is responsible for maintaining the oral care. As the child develops the ability to handle a toothbrush, they are given a toothbrush; which they basically chew on. The parent perseveres and handles the actual tooth brushing while the child is learning about brushing his/her own teeth. The child observes and experiences the parents' tooth brushing and alters their own actions with each attempt. Once the child is able to brush his/her own teeth, the parent still follows up to ensure they are doing a good job. Over time the child proves they are able to brush her/his own teeth. Tooth brushing become a child driven self-care activity, although the parent may still handle making appointments and acute situations. Although physical ability is one component that drives the transfer of care from the parent to child, another is the child's ability to act autonomously.

The level of self-care a child is capable of depends on several factors. Knowledge of the disease and treatment regime, which is part of self-care maintenance, along with age of the child has been attributed to skill mastery (Weissberg-Benchell, Goodman, Lomaglio, & Zebracki, 2007). But skill mastery is only one part of self-care. A study of children with asthma found that symptom recognition, the ability to identify changes early and intervene appropriately, is described by older children but not younger ones (Pradel, Hartzema, & Bush, 2001). This study also found that older children with asthma were more adept at self-care management and were able to manage an asthma attack independently while younger children required assistance and all children lacked knowledge required to avoid asthma triggers and prevent an attack (Pradel et



al., 2001). This finding is not surprising as symptom recognition is inherent in self-care monitoring and is a more sophisticated skill.

As children get older, studies have found that there is a decrease in self-care (medical adherence) for children with chronic conditions during adolescence resulting in decrease in well-being (Fiese & Everhart, 2006). For example, a 4-year longitudinal study of children with diabetes found that age was related to a decline in metabolic control (Helgeson & Novak, 2007). Additionally, self-care behaviors (maintenance) also declined over this period. Peer relationships were a risk factor for poor control. The authors posited that some of the deterioration may have been related to decreased parental monitoring, supervision and overall involvement in the diabetes management. In addition, parents may have decreased monitoring and direct involvement based on the observation that their school-aged children appeared to be autonomous as they were adherent with self-care maintenance. Attempting to reestablish monitoring and parental agency or control with an adolescent often fails. What may not have been so obvious when the parent decreased monitoring is that the adolescent did not have requisite skills regarding health care autonomy that are involved in self-care monitoring and management. This exemplifies the dilemma faced by families during transition of responsibilities. Without adequate training, development and oversight, the child is not being prepared for success in all areas necessary for successful condition management. If parents totally abdicate and withdraw support and monitoring, trying to regain parental control may not be successful and outcomes may suffer. Therefore, the school-age period is an extremely important but delicate time of preparation and transition.

### **Self-care, Family Management, and Health Care Autonomy**

Thus, the ability to practice self-care is dependent upon the child's developmental stage. Just as the child needed the dexterity to hold a tooth brush and understanding not to swallow the toothpaste, children need the cognitive, physical, and psychosocial abilities to be autonomous with condition management. When children are too young (not developmentally able) to successfully handle all the demands of self-care, the family shoulders the condition management responsibilities. The family most optimally includes the child as an active participant and also

allow them to observe the process used to make decisions. By actively participating in a developmentally appropriate manner, the child learns the thought processes, and can begin to understand the decision-making processes that are behind the skills and medical regimes they may already be doing.

In order for autonomy to develop, both the child and the parent need to be prepared. For the child, readiness to assume more autonomy for health related matters is dependent upon cognitive ability, physical maturation, feelings of competence or self-reliance and the perception of the parent/child relationship (Beacham, 2011). Somewhat independently, the parent is assessing the child's readiness to assume more autonomy, their own willingness to support autonomy development and relinquish management responsibility and their perception of the relationship with the child (see Figure).

The parent-child interaction determines the management activities and how those activities and decisions will be handled. Not surprising, the relationship between the child and parent, along with the family are important components in both the development of autonomy and self-care. Parental supports for the development of autonomy are those behaviors that provide autonomy support, that is, praise and encouragement, (Coatsworth & Conroy, 2009) as opposed to behaviors aimed at controlling the child or adolescent (Eccles, Early, Frasier, Belansky, & McCarthy, 1997; Vansteenkiste, Simons, Lens, Soenens, & Matos, 2005). Maternal separation anxiety decreases as the child grows older, and this allows cognitive autonomy to increase (Dashiff & Weaver, 2008).

Although the child and parent relationship may be harmonious, the perception of autonomy is not always congruent between parents and their children. Butner et al found that adolescents rated their functional autonomy higher than their parents (Butner et al., 2009). Although parents had less confidence in the adolescents' ability to act autonomously, they were willing to allow increased autonomy, even though outcomes declined.

Age also plays a role in the development of autonomy. In a study of children with diabetes, age of diagnosis was positively associated with child only responsibility and negatively associated with parent only responsibility (Weissberg-Benchell et al., 2007). Similar findings were

made in an asthma study where older children showed more autonomous behaviors than younger ones, with parents being the primary decision makers for the younger child (Pradel et al., 2001). Setting may also be important for school-aged children, because regardless of the age, most of them informed an adult when they experienced an asthma attack in a social setting.

Years of experience with a medication or treatment may also influence autonomy. Children who had been using a pump for delivering their insulin were more knowledgeable regarding diabetes management and the less parents were responsible for pump operations (Weissberg-Benchell et al., 2007). This study also reported a relationship between age of diagnosis and increased likelihood of independent responsibility for care of the insulin pump by these children.

Children mentioned behaviors that were autonomous included taking medications or telling someone when they were sick or having an asthma attack (Pradel et al., 2001). Taking medication is a multistep task and understanding what it means to the child is important to understanding the degree of autonomy they have. A child may say they take their medication on their own, but the parent provides the medication or reminds them to take it. It is also important to remember that it is the parent who most likely is still scheduling the doctor appointment and ordering the medication so it is available for the child to take. The larger task of obtaining the medication and ensuring it is available when and where the child needs it, is typically left up to the parent far beyond the school age years.

A closer look at what we know about the development of autonomy and its' relation to self-care, we can see that there are a couple of assumptions that need to be stated. For children, condition management involves interplay between health care autonomy, family management, and self-care. This relationship depends upon the child's development (physical, cognitive, psychological and social) as well as parent and child's assessment of readiness for assuming more responsibility and independence regarding condition management. If the child is to assume more responsibility, the parent must be ready to relinquish some of the control to the child.

Relinquishing control, however, does not mean that the parents withdraw entirely from the process. The child needs to be supported in their attempts at autonomously assuming

responsibility for self-care, coached through the trials of non-optimal condition management, encouraged to make good decisions, and appropriately monitored by their parents (Weinger, O'Donnell, & Ritholz, 2001; Wiebe et al., 2005). Family management optimally recognizes that the child needs to develop self-care in all three areas, maintenance, monitoring and management. Exploring the development of self-care in light of emerging autonomy and family management, we can see the areas where guidance, oversight, and monitoring may need to continue, even as the child assumes more and more responsibility and autonomy. That is, developing self-care does not mean that there is not still assistance, advice and support from the family or others. Successful self-care is not a solitary endeavor and needs to be supported.

Table 7 represents the intersection of health care autonomy, self-care, and family management. Identifying the important factors across autonomy development that can influence the development of self-care can help us to guide parents and children under our care to ease the transitions and minimize changes in outcomes. Understanding how and where family management guides this process for the child identifies areas where support and interventions may be required. The case studies and discussion that follows were developed systematically from Table 7. They are meant to highlight some of the areas where families may need guidance and children support in light of the knowledge we have regarding autonomy, self-care and family management.

## **Case Studies**

### **Case study 1**

*Michael, a 12 year old boy, lives in a large, 4 bedroom house with his mother, father, younger brother, and pet dog. The father works outside the home and the mother maintain the home and coordinates all family activities. She believes the family has enough money to live comfortably and that the health insurance through her husband's job covers most of the medical expenses for the family. Michael does well in school; his favorite subjects are math and science. He has friends that he spends time with after school and on weekends. He's involved in sports, plays baseball and basketball and participates in scouts. He was diagnosed with diabetes when he was 6 years old and feels it's no big deal. Sometimes he gets frustrated when he has to stop doing something*

*and check his blood sugar, but mostly it's okay cause, "Mom takes care of everything". She handles the daily dispensing of medications, draws up the insulin and gives Michael his injections. Michael says he tried to draw up his own insulin and give himself the injection when he was 9, but Mom said he didn't do it right so she has done it ever since. He thinks that when he's 15 he might be old enough to draw up the insulin and give himself the injections. He does prick his finger and use the glucometer, but reports the results to mom, who takes over from there. A chart on the refrigerator shows how much insulin is required for the glucose levels, but Michael isn't interested in checking it out, "Mom and dad tell me what to do and I just do it. It's easier that way".*

### **Case Study 2**

*Sam is a 12 year old girl with cystic fibrosis and asthma, and lactose intolerance. She does well in school, like to play with friends; takes dance lessons, and play the piano. She and her mother, father, older brother and sister live in a modest three bedroom row home in the city. She shares a bedroom with her sister and has her half of the room decorated in pink and has pictures of current pop musicians on the walls. Sam is able to identify the medication she takes and knows why she takes them. She is responsible for filling her weekly pill box on Sunday night and then her mom or dad checks it for accuracy. She has a small purse that she carries with her when she goes to a friend's home and brings along her enzymes and inhaler. She easily identifies when she needs to take extra enzymes when having a snack and when she has used her emergency inhaler. She usually doesn't ask or tell anyone about the enzymes, but if she needs to use her inhaler she usually informs her mom or other adult because, "sometimes it doesn't work and I need something else". She explains how she had chest PT when she was younger, which she liked and misses because it felt good, but now uses a vest twice a day. She was involved in discussions with the doctor and her mom regarding sleepovers and said she now uses the acapella® (Smiths Medical, St. Paul, MN), "it's easier to take with me and do at a sleepover". She gets frustrated at school when the people in the cafeteria won't let her have a certain food because they think I can't have it. She tells her mom when she gets home and the mother calls the school. It works for about a week and then they go back to the old way. She doesn't see a time when it will be different at school. She is learning to hook herself up to her nightly feeding*

*tube and at first thought it was fun, learning something new. But now it's kind of boring and she prefers when her parents do it as it interrupts her playing before bed.*

Although both Michael and Sam are 12 years old, their families treat them very differently. Both children know about their condition, but Sam is a much more active participant in her daily care. She has assumed some responsibility in preparing her daily medications but Mom or Dad monitor the activity. She is fairly independent in taking her enzymes prior to meals and snacks and has autonomy over the activity when visiting with friends. She is being supported to learn new self-care skills, such as attaching herself to the feeding pump for overnight feeds, with the support and direction of her parents. Michael, on the other hand, has not progressed much from his initial task of checking his blood sugar. He is not responsible for recording the results or figuring out how much insulin he requires. He lacked support when he attempted to draw up his own insulin and self-inject, feeling that he wasn't old enough to do it and estimates he'll be having mom draw up and inject for another three years.

While Sam is involved in decisions regarding treatment options, Michael has not been involved and cannot explain his recent change in insulin. He has to be reminded to check his blood sugar before eating a snack at home, and required additional reminding to tell mom what his blood sugar was so she could get the insulin prepared.

Both parents admit to worrying about the children, but Sam's mother says that Sam's is going to grow up and have to take care of herself, and although they will always be there for her, she will have to take care of herself someday. They are working toward that day in slow easy steps. Michael's mom also sees that Michael will need to take care of himself someday, but says that he will have to do it when he's older, while I'm here and I can do it for him, it allows him to be more like a regular kid. "I take care of his diabetes so he doesn't have to think about it".

Although there are no absolutes, Michael's parents are not providing him with the skills and understanding he needs as he grows up with diabetes. Without supporting his development, increasing his knowledge and teaching him the skills and decision making he will need to successfully manage his diabetes, Michael will one day be on his own and his health may suffer.

He may be more dependent on his parents for guidance and direction regarding basic care issues he could have developed for himself over time.

Sam has been exposed to increasing responsibility for self-care. She has also been involved in making decisions regarding treatment options and has seen firsthand how her parents and the physicians, and her mom and the cafeteria staff work to resolve things. Although she may feel powerless with the cafeteria staff right now, Sam has been given a voice to express her needs regarding her treatment and with the continued support and guidance from her parents, will develop the self-care maintenance, monitoring and management required for optimal outcomes.

### **Conclusion**

In order for self-care to be successful, all three components, self-care maintenance, self-care monitoring, and self-care management must be developed with increasing capacity for health care autonomy. Children with chronic health conditions may learn basic maintenance skills, and look very competent, but unless attention is paid to teaching them monitoring and management, as they mature and the expectations are placed upon them, they will not be successful. Paying attention to the components of self-care, as well as the family management style and the developmental abilities of the child will help nurses assess the care status and help to create a plan to assist the child and family with the care transitions.

Further research is needed regarding incorporating health care autonomy, self-care and family management. Studies aimed at testing interventions to improve child health outcomes throughout adolescence and into young adulthood may prove to assist children and families as they progress through this challenging transition.

### **Key Points**

- Autonomy in health care situations usually is one of the last contexts in which autonomy will be expressed, typically in late adolescence
- Self-care for children with chronic conditions incorporates self-care maintenance, self-care monitoring, and self-care management.

- Current care guidelines stipulate that health care providers and family caregivers need to ensure that children with chronic conditions master developmentally appropriate knowledge and skills regarding their disease.
- School-aged children between the ages of 8 and 13, with chronic conditions are becoming more knowledgeable about their disease and acquiring more skills to support their management activities.
- The development of health care autonomy requires appropriate family management as self-care develops from parent-focused care, to joint/cooperative/shared care, to child determined care.
- Supporting the development of health care autonomy in school-aged children with chronic health conditions also supports the development of self-care and more optimal outcomes throughout adolescence.
- During adolescence children with chronic health condition may experience a decline in management outcomes

#### **Recommendations for the family**

- When communicating with partner and other family members remember the importance of helping the child become able to take care of himself/herself overtime and a plan to do so.
- When communicating with the child remember to support self-reliance/self-competence. Increased use of guidance and monitoring as opposed to authoritative style of parenting.
  - Retain appropriate parental agency throughout school-aged years into adolescence that allows for the development of health care autonomy but enables safety and adherence for the child.
  - Develop skills in parental monitoring to encourage adherence and safety, especially during self-care transitions; that is, continue monitoring and involvement throughout school-aged years into adolescence even when the child appears able to perform basic skills independently as re-involvement during adolescence will be difficult.



**Recommendations for the Provider:**

Interventions to develop self-care need to consider

- assessing child readiness for self-care including developmental stage, self-reliance, physical, cognitive and psycho-social ability and the parent-child relationship;
- assessing agency: who is driving the condition management (parents, shared, or child) and determination as to appropriateness based on child's development;
- teaching skills for parental monitoring that are developmentally appropriate; and
- assisting the family and child with culturally appropriate interventions to transition to self-care, including responsibilities for self-care maintenance (behaviors), self-care monitoring (body listening), and self-care management (evaluation).

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**Table 6.** Adaption of Self-Care Model

<b>Self-care</b>	<b>Definition<sup>a</sup></b>	<b>Adaptation for Child/Family</b>	<b>Examples of Self-care in Action</b>
		Family management to maintain health promoting practices and	
Self-care	Process of maintaining health through health promoting practices and managing illness	managing illness; believes that the child will be or is capable and expects the child to care for self in the future	Transition from parental agency and family management to child agency and self-care
	Behaviors performed to improve well-being, preserve health, or to maintain physical and emotional stability	Behaviors performed by the child and/or family to improve well-being, preserve health, or to maintain physical and emotional stability	Daily flossing and brushing teeth. Reduced sugar intake. Biannual checkups
Self-care monitoring	Process of routine, vigilant body monitoring, surveillance, or “body listening”	Process of routine, vigilant body monitoring, surveillance, or “body listening” by the child and family	Awareness of tooth and gum status, sensitivity to hot/cold, bleeding, pain, need to brush teeth after eating and food sticks to your teeth or between
Self-care management	Involves evaluation of changes in physical and emotional signs and symptoms to determine if action is needed	The evaluation of changes in physical and emotional signs and symptoms by the child and/or family to determine if action is needed	Evaluation of tooth/gum pain and deciding to call the dentist, brush or floss as needed in addition to twice a day

<sup>a</sup> Definitions from Riegel et al (Riegel et al., 2012)<sup>(pp 195-196)</sup>

**Table 7.** Intersection of Autonomy, Self-Care and Family Management

<b>Autonomy</b>			<b>Self-Care</b>	<b>Family Management<sup>b</sup></b>
<b>Requirements</b>	<b>Self-Care Maintenance<sup>a</sup></b>	<b>Self-Care Monitoring<sup>a</sup></b>	<b>Management<sup>a</sup></b>	<b>Component</b>
				Child Identity
Developmental Stage	Consider all developmental areas, especially cognitive and psycho-social, Maslow's hierarchy of Needs.			Parenting Philosophy Family Focus
				Child identity
Self-Reliance	Is the child confident he/she can do the tasks at hand?	Is the child able to identify sign and symptom of condition change and communicate as needed?	Is the child able to decide on the intervention required and take the necessary steps?	View of the condition Parenting Philosophy Management Mindset Management Approach Future Expectation
Physical Ability	Does the child have the strength, dexterity, physical attributes necessary to perform the task?	Is the child self-aware of her/his own body to recognize the signs and symptoms of condition change?	Does the child have the strength, dexterity, physical attributes necessary to perform the task?	Child Identity
Cognitive Ability	Does the child have the cognitive ability required to perform the tasks?	Does the child have the cognitive ability to recognize the change in signs and	Can the child make decision regarding condition management?	Management Mindset

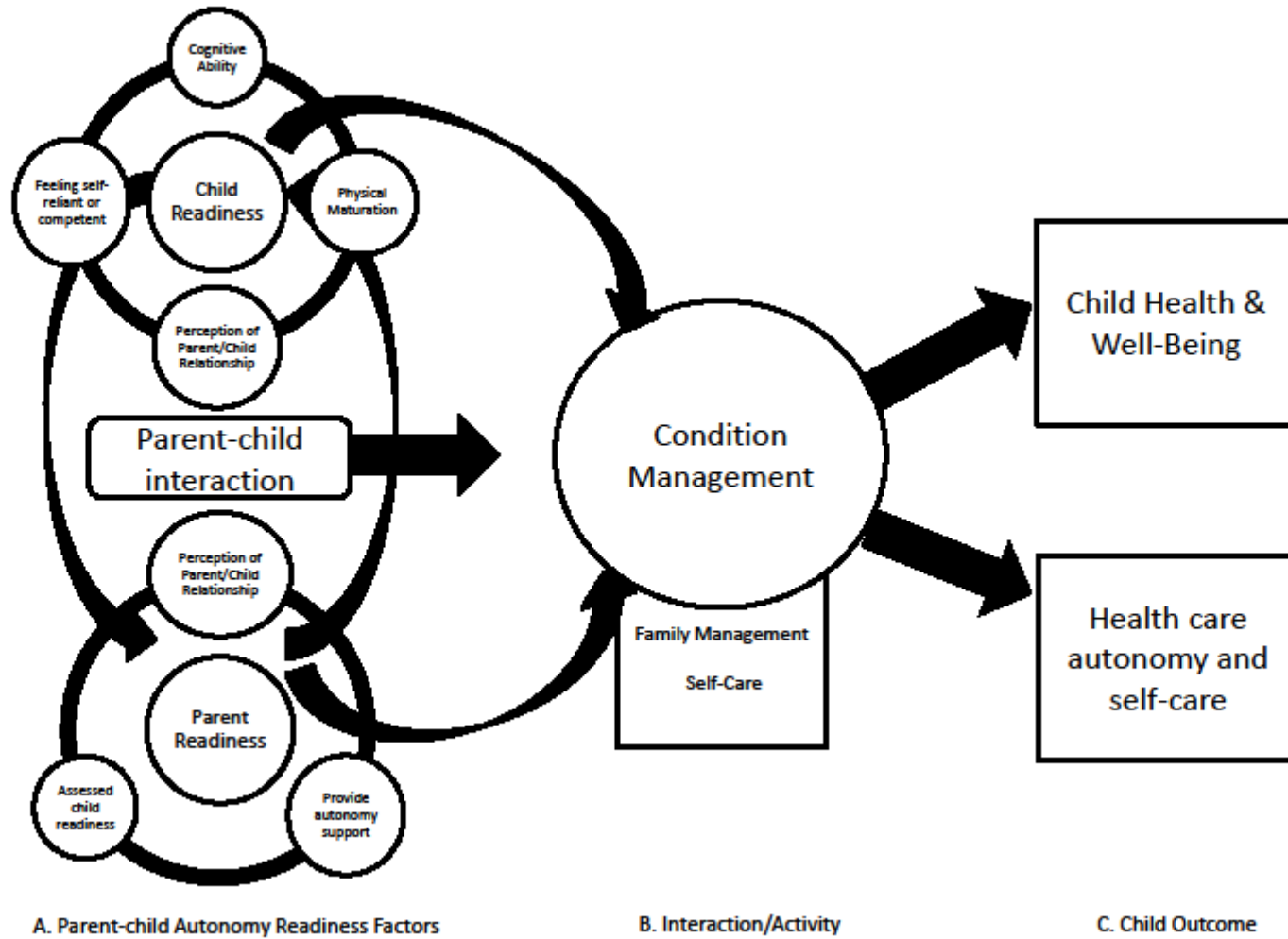
<b>Autonomy</b>			<b>Self-Care</b>	<b>Family Management<sup>b</sup></b>
<b>Requirements</b>	<b>Self-Care Maintenance<sup>a</sup></b>	<b>Self-Care Monitoring<sup>a</sup></b>	<b>Management<sup>a</sup></b>	<b>Component</b>
		symptoms?		
				Child identity
				View of condition
	Does the child have the support systems in place and the emotional maturity to maintain			Parental mutuality
Psycho-social Ability		self-care?		Parenting Philosophy
		Is the child listened to when		Child Identity
	Does the child feel supported	they perceive a change in	Is the child supported	View of Condition
	and trusted by the parent	condition that requires	during management	Management Approach
Perception of	while they transition and	intervention of some sort and	attempts and allowed to	Family focus
Parent/Child	assume more maintenance	are they supported in	reflect on different	Future Expectations
Relationship	responsibility?	decision making?	possible courses?	

<sup>a</sup> Adapted from Self-Care model, Riegel et al (Riegel et al., 2012)

<sup>b</sup> Adapted from Family Management Styles Framework, Knafl et al (K. A. Knafl et al., 2012)

**Figure 3**

Figure. Development of Health Care Autonomy





## Chapter 5

In this dissertation, I listened to school-aged children with a variety of chronic health conditions (CHCs) describe a typical day in their life, paying special attention to family management of their chronic health condition. Of particular interest was whether the children would view condition management in ways that previously have been described by their parents and elucidated in the Family Management Styles Framework (FMSF) (Knafl et al., 2012). The results that emerged from the analyses show many similarities between the parent-based framework and the children's perspectives. There were also a few new aspects identified. Where the original framework holds a single parent/family view, the children with CHCs in this study begin to assess and articulate their perspective of the family's view of them as well as their view of themselves and the family. This new perspective allows us to take a step toward exploring the developmental changes that occur during the school aged period.

The primary aim of this study was to describe the school-aged children's perspective of family management, both inside and outside of the home, to gain a deeper understanding of the FMSF and its applicability with school-aged children. The focus of the study was on their perspectives of condition management within the context of their family. A secondary objective was to identify the roles, responsibilities and decision-making regarding condition management as described by the children in the study in order to better understand the structure and function of condition management for this age group. To achieve these aims, I conducted face to face interviews with 32 children who had a variety of CHCs and elicited their perspectives of daily condition management; what it was like at home; at school; weekdays versus weekends and who did what for condition management. Findings support the feasibility of using the FMSF to examine condition management of school-aged children using complementary definitions that support the perspectives of these children. This expands the potential for using the framework for multiple family members. Additionally, I integrated my interest in family management, self-care and autonomy, creating a theoretical model explaining the relationship between autonomy and condition management. The goal of this theoretical exploration was to develop a model for further

studies of the relationship between these phenomenons with implications for condition management with and by the children with CHCs.

Findings from this study fill a gap in our knowledge regarding the FMSF. The FMSF was developed eliciting mainly the perspectives of the parents, few studies have explored its' applicability to younger populations. The study findings not only support the utility of the FMSF with this aged group but support the possibility of further development of a child measure to complement the FaMM. The FaMM is an instrument developed for parent informants, to better understand the family management of childhood chronic health conditions. The FaMM correlates to the dimensions of the FMSF, thus, exploring the feasibility of a child measure would add to our ability to assess the perspectives of these children (Knafl et al., 2011).

In this chapter, I will summarize the study findings and explore the integration of these findings into the model developed in Chapter 4. Discussion of the implications of the findings for children with chronic health conditions and their families will follow. I will close with a discussion of future research questions, overall clinical and policy implications developed from this study that may inform future work.

### **Summary of Study Findings**

Findings from this study describe the perspective of school-aged children with CHCs regarding family condition management. Adding the perspective of the children allows for a broader understanding of family management, especially as seen through the recipient of the care. A structural-functional approach to the children's perspective of the roles, responsibilities and decision-making around condition management adds to our understanding of the way these children view condition management by themselves and others. Decision making involvement may promote further investigation in the area of condition management. In **Chapter 2** I examined the components and dimensions of the FMSF from the voices of school-aged children. The children's recollection of daily routines, interactions with family, teachers, friends, and stories describing what the condition meant to them were analyzed for congruence or dissonance with the FMSF. Overall, the FMSF was supported by the school-aged children in the study and

provides a complementary view of family management that has the potential to lead to further research questions. The dimensions as defined in this study are seen as the developmental work of children during school-age but not necessarily obtained by all children even by the end of middle childhood depending on their health care conditions, family situation, and development,

Children were able to see two views of family management for many of the components, of particular note are the addition of a family identity and expansion of parent mutuality to include both parent and family mutuality. This finding is consistent with and supported by symbolic interactionism in that the perceived view of the parent (for each dimension) was mirrored in the children's views of themselves (their self-view) (for each dimension) and therefore are products of social interaction (child with family and family/others with child) (Mead, 1934). The children were much better at describing the concrete issues (name the dimensions) involved in personal meaning of self-care/management and not as verbose about recounting the other's perspective (family view) about parenting philosophy. That is, goals, priorities, values, and beliefs are abstract constructs that older school-aged children may just be grasping, so it would not be expected that school-aged children would be able to express their view of the parents' philosophy readily. They were, however, able to talk about the child and family identity as an important mirror to their own identity, again as in symbolic interactionism's *looking-glass self* (Cooley, 1902). While the size of this sample did not allow analyses according to condition or ethnic identity, there was one question that did elicit easily recognizable specific responses. Children with genetic conditions or those who developed the condition as an infant or toddler did not have a diagnosis story. They only knew life as a child with a chronic health condition as opposed to the children in the study who were diagnosed when they were older. This group also had more difficulty talking about the perceived consequences of the condition, that is, how the condition changed family life, because they haven't seen that transformation.

In **Chapter 3**, I examined the roles, responsibilities and decision making as described by the school- aged children with CHCs. Understanding that children within the school-aged period are developing more abstract ways of thinking, but remain fairly concrete, I took a functional-

structural approach to the analysis. Children identified the major individuals involved in condition management as the parents, others (teachers, school nurse, coach), and friends in the roles they assumed in assisting (or hampering) condition management. They also identified their own role in condition management and subsequently identified the responsibilities everyone took.

Children spoke with a level of comfort about the assistance they received from others regarding their care, but also were frustrated when they felt they weren't a priority or weren't being heard. The ability of children with CHCs to begin to speak up for them and be heard is an important skill for them as they grow and develop. As they spend more time outside the home and may require assistance with health issues, being able to express health related needs and concerns is a safety issue (Hagan et al, 2008; Scholes, Mendleco, Roper, Dearing, Dyches & Freeborn, 2013, Kennedy, 2011).

Decision-making involvement was varied in the group. Although none of the children had total decision making control, there was a range from very little involvement to very involved. Decision-making regarding condition management issues was seen as a family responsibility, with the parents either make most of the decisions or sharing the responsibility with the children to varying degrees. Daily management issues seemed more within the purview of the children, with more global, indirect decision handled by the parents. For example, children were very involved with taking medications and doing treatments, and spoke of how these activities were incorporated into their daily routines. For many to the children it was as if they were on autopilot, the condition management activities were so seamlessly interwoven into their day. Conversely, children were less involved with the larger, less frequent decisions, such as deciding on treatment options or scheduling doctor appointments. Some children never spoke of these types of decisions, while others related detailed decision making steps that occurred during a treatment change. These findings, similar to those in other highlight the understanding of condition management decisions from the perspective of school-aged children (Miller, 2009; Wray-Lake et al., 2010). The recently developed Decision Making Involvement Scale (DMIS) provides a way to measure decision making involvement from both the parent and child perspective (Miller & Harris,

2012) and will be useful in longitudinal studies to help clarify the transition of decision making from parent/family to child.

In **Chapter 4**, I presented a Development of Health Care Autonomy Model (HCAM) (Figure 2) and case studies based on the literature explaining the development of health care autonomy in children with chronic conditions. The HCAM identifies readiness factors influencing the development of health care autonomy and their relationship to family management and self-care. It is not age specific, but considers the components that children and parents move through as they provide increase autonomy within the health care realm. The process often begins when children start school and become more responsible for condition management as the parents are not readily available. It concludes at some point when children assume adult-like condition management behaviors; self-care. The HCAM asserts that children assess their own cognitive ability, physical maturation, feelings of self-reliance or competence as well as the parent-child relationship when evaluating their own readiness for autonomy. In addition, the parent also assesses the child's readiness, their own willingness to provide autonomy support and their perception of the parent child relationship.

The interaction between the individual assessments is important; those assessments result in the child and parent both independently and jointly determining how condition management is supported within the family. One can imagine potential situations where the child wants increased management responsibilities without the parent while the parent may be hesitant to switch from a more hands on approach to a supportive one, or one where the parent willingly provides the child with increased autonomy but fails to provide autonomy support. Both would create difficulties with condition management and outcomes.

The HCAM recognizes condition management as the interplay between family management and self-care. Throughout childhood the work of managing the condition transitions from more family driven to more child driven. Using the eight dimensions from the FMSF (Knafl et al., 2012) along with my adaptation of a self-care model (Riegel et al., 2012), I identified areas where dimensions of family management, the components of self-care and the autonomy

readiness factors coincide. This interaction is constantly changing as children grow and develop new skills and understanding of their condition. In the most optimal situation, the transfer of responsibilities regarding condition management would be informed by the outcomes of the parent-child readiness assessment and regarding the children's readiness to accept new responsibilities regarding condition management. This in turn allows for the development of confidence in their abilities and is able to support the development of autonomy in their children. Identifying where self-care (maintenance, monitoring and management), is being done by the child and understanding the family management dimensions at work (child identity, view of condition, management mindset, parent mutuality, parenting philosophy, management approach, family focus, and future expectations), provides a novel way to examine the interaction between these two concepts. Identifying the specific variables that support the development of self-care in children would support the development of model testing and interventions aimed at improving the transition from family management to self-care as it may be possible for these children and their families.

Several outcomes are identified in the model; child health and wellbeing, health care autonomy and self-care. Two case studies were provided to illuminate the model and suggest its applicability for providers caring for children with CHCs and their families. The non-categorical nature of the model increases its potential usefulness for providers caring specifically for the chronic condition and for primary care providers as well.

In summary, findings from this dissertation describe the perspective of family management as seen by children with CHCs. Their voices broaden our understanding of family management from the perspective of the care recipient, identifying the dual nature of this perspective. It exemplifies the interactional nature of condition management and reminds us that children develop their sense of self through social interactions. These interactions help children with CHCs understand their conditions and build the foundation for their ability to assume additional condition management responsibilities and decision making involvement as they mature.

## **Implications for Children with CHC and their Families**

Findings from this study have implications for children with CHCs and their families. While school-aged children with chronic health conditions are at school, they have varying experiences with condition management. Children rely on surrogates (teachers, coaches, school nurses) to assist them with management and decision making. Parents and the surrogates need to have plans in place that children, parents and surrogates understand to ensure condition management that keeps the child safe and healthy. Parents can work with children to prepare them to know the treatment regimen and verbalize acute needs as they arise. Parents also need to be aware that the school-aged children are forming their own management strategies; parents can be proactive in supporting this endeavor and assist with this process. For children who remember their diagnosis, the process of incorporating management and illness perspectives began at that moment. Parents can keep this in mind and help the child develop strategies and perspectives that support positive outcomes.

### **Implications: Clinical Practice and Policy**

Bright Futures Guidelines (Hagan et al., 2008) recommends that school-aged children should be actively involved in every encounter with their health care professionals to the extent they are able. Pediatric practitioners can reinforce this practice, thereby encouraging children and their caregivers/parents to discuss health practices and condition management. Encouraging condition management discussions in children with CHCs and their families can demonstrate the developmentally appropriate expectations and help guide the family through condition management challenges. The development of self-care practices has started in school-aged children with CHCs.

The components and dimensions within the family management are well documented for parents. This study identifies that they also need to be considered from the perspective of children with chronic health conditions. Based upon the findings, providers may want to incorporate questions regarding family management when talking to children with CHC. Although there are many potential questions, here are several examples:

- Child identity (condition or normalcy): how have things changed with condition management since first diagnosed, since changing schools, moving?
- View of Condition (cause, seriousness, predictability, and course of the condition): when do you (your parents) get worried about your condition? How did you get the condition?
- Management Mindset (ease or difficulty): what's the easiest thing about having the condition, what's the hardest?
- Mutuality (similar or disparate views): what things do you want to do that you're not allowed?
- Parenting Philosophy (goals, priorities, values, and beliefs): what is most important about having the condition?
- Management Approach (routines and strategies): explain how you get your medication, treatment. How does it work?
- Family Focus (satisfaction with condition focus): what does your family do together?
- Future Expectations (future for child and condition): tell me one thing that will change with your condition as you get older?

In the clinical report by several medical leadership groups, recommendations were made to guide medical practices in supporting children and their families through transition and transfer to adult medical homes. (Pediat, Phys, Phys, & Author, 2011). Although the recommendations begin when the children are 12 years old, it's noted that conversations and planning within the context of the family and community needs to begin much earlier. Identifying the changing roles within the family as the children assume additional responsibilities, and preparing these children for the condition management decisions that they will encounter can ease transition issues. The results of this research highlight the importance of planning and anticipating the developmental changes children experience and the ramifications it has for children with CHCs. Just as there are anticipatory guidance recommendations for developmental milestones across childhood, evidence based anticipatory guidance for children with CHCs and their families are needed in order to support these families and provide guidance around development of condition management.



In terms of the school, probably the most important policy implications for school aged children are Individualized Education Plans (IEPs) and 504 Plans. School administrations need to support these efforts thereby ensuring that the medical practitioners, the family and the school identify the transition needs and address them at developmentally appropriate times. Coordinating and supporting transition expectation between the IEP, the family and the medical home can provide the children and families with the support they need to develop the abilities that children need to successfully transition to adult care.

Family management, autonomy, and self-management skills are incorporated into Schwartz's Social-ecological model of readiness for transition to adult-oriented care (Schwartz et al., 2011). Identifying the variables required for adolescents and young adults to transition to adult providers, the model may help to identify developmentally appropriate goals for pre-adolescents with CHCs. Future studies are needed to examine the utility of this model for school-aged children with CHCs.

#### **Future Research Questions/Next Steps**

- The voices of the children in the study have broadened our understanding of family management, and how the school-aged child understands their condition, its' management and consequences. It provides a basis for comparing the parent perspective with the child perspective to answer the question: What is the relationship between the parent and child perspectives of family management? During data collection I requested the parents complete the FaMM ( Knafl et al., 2011; Knafl et al., 2013), the Family Assessment Device (FAD) (Epstein et al., 1983), the Eyberg Child Behavior Inventory (ECBI) (Eyberg & Pincus, 1999), and the Functional Status Measure II (FMS-II) (Stein & Jessop, 1990). A mixed methods study during my post-doctoral training, using the data from the interviews with the children along with the quantitative measures from the parents, is proposed.
- Recognizing that the FMSF is suitable when considering the perspective of children with CHCs, a next step is to determine the feasibility of developing a child measure to

complement the FaMM. A proposed child measure might be drafted by revising the FaMM based upon these findings and conducting cognitive interviews (Knafl et al., 2007) with children to determine their understanding of the questions.

- Culture, race/ethnicity and social determinants of health are important considerations when examining family and health conditions (Naranjo, Hessler, Deol, & Chesla, 2012; Zuijdwijk, Cuerden, & Mahmud, 2013). The small size of the sample and the research focus of eliciting the responses of school-aged children with chronic health condition limited our ability to explore cultural differences or underlying social determinants of health and the influence these important variables may have on family management and children's perceptions. Future studies to examine these concepts within family management will help to explain variations in the perceptions of the children.
- Little is known about the development of self-care practices or about the transfer of condition responsibility from family management to self-care. A follow-up study with this cohort to begin to understand the developmental processes that occur with self-care would be feasible and begin to describe this process. All but one of the families involved in this study agreed to be contacted in the future should a follow-up study be funded. Additionally, exploring the variable from the Social-ecological model of AYA readiness for transition (Schwartz et al., 2011) will improve our understanding of the process of transition readiness throughout childhood.
- Consider the role collaborative decision making might have within the Development of Health Care Autonomy Model and revise as appropriate. Begin to operationalize the variables in order to test the model and identify areas for interventions. Does time of diagnosis/type of condition (early in life/genetic disorder, during school-aged period) make a difference to the children? The latter group acknowledges how the family changed related to the diagnosis and management requirement; the former has not known anything different. Examine results from current study in light of these two groups to determine if actual differences in the perspectives of the children exist.

In summary, this dissertation presents a novel view of family management from the perspective of school-aged children with CHCs. Recognition that school-aged children are able to discuss family management as well as the roles and responsibilities within condition management has broadened our understanding of family management from the perspective of the care recipient. School-aged children with CHCs are often silent, letting the voice of their parents speak for them. This study identifies the insight they can provide regarding condition management and is a starting point for continuing to have them more fully engaged in the process.

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APPENDIX A  
Demographic Collection Sheets

ID \_\_\_\_\_

Date- \_\_\_\_\_

**What is your relationship to the child with the chronic health condition?**

- Mother
- Father
- Grandparent
- Aunt/Uncle
- Other: \_\_\_\_\_

**What is your age and date of birth? \_\_\_\_\_**

**What is your current relationship status?**

- Married
- Widowed
- Separated
- Never married
- Divorced
- Common law partner
- Remarried
- Partnered Relationship

**Are you currently employed?**

- Not employed
- No, retired
- Other \_\_\_\_\_
- Yes, part-time
- Homemaker
- Yes, full-time
- Student

**What is the highest grade of school you have completed?**

- Grade School
- College
- Some high school
- Some graduate school
- High school
- Graduate or professional degree
- Vocational school
- Other \_\_\_\_\_
- Some college



Considering all income for everyone in your household, check the box which best describes your total household income before taxes:

Less than \$20,000	\$20,000 to \$29,999	\$30,000 to \$39,999	\$40,000 to \$49,999	\$50,000 to \$59,999	\$60,000 to \$74,999	\$75,000 to \$99,999	\$100,000 to \$149,999	\$150,000 or more	Not reported
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Family structure: Think about the individuals you consider as part of your family. What is their relationship to you and your child (i.e. aunt, uncle, mother, father; friend, partner)

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Number of adults in the household \_\_\_\_\_

Do any of these adults play a role in caring for the child? \_\_\_\_\_ If yes, please list:

Relationship to the child?

---



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Siblings: Please list the children in your family in birth order, including your child with the chronic health condition. Place a check mark next to the child with a chronic health condition.

Child (circle son or daughter)	Age	Grade in School	Live: at home or away from home	Health Issues and/or accommodations
Daughter/Son 1				
Daughter/Son 2				
Daughter/Son 3				
Daughter/Son 4				
Daughter/Son 5				



Draw your family tree going back to the child's great-grandparents and indicate any individuals who had a chronic condition and the condition they had. Do not name the individual, but identify them following their relationship to the child. For example:

C1, C2, C3 = Child 1, Child 2 , Child 3 in the family

M = Mother, F = Father, MGM = Maternal Grandmother, PGM = Paternal Grandfather

Place a check mark next to the child with a chronic health condition

**Demographic Data Collection Sheet – Child**

ID \_\_\_\_\_

Age and Date of Birth of Child \_\_\_\_\_

Gender      **1 Male 2 Female**

What is your child's Race?

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- More than one Race
- Unknown/Not Reported

What is your child's Ethnicity:

- Hispanic or Latino
- Not Hispanic or Latino
- Unknown

**In general, how would you rate the health of your child's health at the present time?**

- Excellent    Good    Fair    Poor    Don't know

**Disease(s)/Condition(s) your child has and date of diagnosis:**

---

Conditions	Date of Diagnosis
1.	
2.	
3.	
4.	
5.	
6.	

**Does your child have any other health conditions? Yes No**

**If yes, what are they?**

---

---

**What medications does your child take? Why is your child prescribed this medication? Does your child know why they take this medicine?**

	Medication name	Why my child takes this medicine	Child aware Yes/No
1			
2			
3			
4			
5			
6			

**Other comments about your child's health:**

---

---

**Last hospitalization and reason for hospitalization:** \_\_\_\_\_

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**Last routine appointment:** \_\_\_\_\_

**Health care providers your child sees and for what condition:**

	Health Care Provider	Condition treated
1		
2		
3		
4		
5		
6		

**Have you changed health care providers in the past 2 years?** \_\_\_\_\_ If yes, why?

---

**Is your child covered by health insurance?**

Private \_\_\_\_\_ Public \_\_\_\_\_ Both \_\_\_\_\_ None \_\_\_\_\_

**Does your child attend:**

Public School     Private School     Home Schooled

What grade is your child in school \_\_\_\_\_

Has your child repeated a grade in school?  Yes  No

If yes, what grade(s) \_\_\_\_\_

B. Does your child have learning problems?  Yes  No

If yes, please list

---

C. What educational services does your child receive?

- Regular education
  - Gifted education
  - Part-time resource room
  - Full-time resource room
  - Tutor
  - Homebound instruction
  - Other; Please explain
- 
- 

Thank you for your time and for the information you have provided.

## APPENDIX B

### Interview Guide

Hi (Child's Name),

I want to thank you for agreeing to participate in this interview. To begin, let's start with introductions. My name is Barbara. I'm a student at the University of Pennsylvania and I'm a nurse. (Share a little more personal information and then...) Now it's your turn, tell me a little about yourself (Prompts and probes re: the child identity and how the child thinks others see them, identification of the condition, management tasks, friends, what they do around the house)

My research project is aimed at learning about what life is like for kids with chronic health conditions (like CCX). I'm really interested in talking to people your age with all sorts of chronic health conditions to find out what it's like to have the condition in all kinds of situations – at school, at home, with your family, friends, when no one's around, who or what makes it easier, or harder.....and who better to learn from than the experts, you and others your age who really know what it's like. So again, thanks for giving me this time and remember, what you share with me is just between you and me. Your name will not be connected with any of your answers and for the interview I'll call you (celebrity name), the name you chose earlier.

1. Remember I said I am interested in learning about you and your family. Could you draw a picture of your family? I'm going to give you about 5 minutes to complete the picture and while you're doing that I'm going to see how your Mom is coming along with the paperwork. (Leave and check on mom, return after about 4 minutes)  
That's great. Can you tell me about the picture? Who is included in your family picture? (Prompts and probes re: child identification, any sign of the CHC, management activities, roles and responsibilities, family relationships, who's responsible and who decides)
2. Wonderful! I am interested in learning more about what's it's like to have CCX. I'd like you to think back to the first time you knew you had CCX. What do you remember? (Prompts and probes re: Child impressions of condition, reaction of others, information shared with child, with other family members, with people outside the family, age when first told, description of treatments, who did what)
3. Now moving forward in time, what is a typical school day like for you now? Tell me about it; walk me through a day, what happens first, and then what, what next? (Prompts and probes re: Typical day likes and dislikes, is the condition part of a typical day, if not what happens with onset of attack, management tasks and strategies, consequences if meds/treatments aren't taken, do friends know, who told them, school visits by family, family activities, parents agree/disagree on management strategies )

4. Are weekends different? Tell me about a typical weekend day, a Saturday or Sunday.  
(Prompts and probes re: different about child, about schedule, better or worse, easier or harder, how are treatments different, who does the child spend time with, how are family interactions different on weekends, )
5. Looking ahead, what do you think things will be like when you're older? What will be different? What will be the same? (Prompts and probes re: will the condition change, how, will responsibilities change re: condition management, how old will you be when that happens, what's it like to have CCX as an adult, friend/social activities when you're older, will your family be different when you're older )
6. We're just about done and I really want to thank you for your help. Is there anything else we haven't talked about that I should know? Anything you think parents, brothers and sisters, friends should know. Do you have any advice for a person who has just been diagnosed with CCX? (Prompts and probes re: about the child, about what it's like to have CCX, things you would like to do, wish you didn't have to do )
7. Do you have any questions for me before I leave?

Ok, I have some paperwork to process when I get back to the office, and then you will be sent your gift cards. It should take about 2 weeks. Thanks again for all your help. (Leave the home)

These questions will allow the children to tell their story and include family. The prompts will be used to elicit additional details and explore their perceptions regarding:

The child's identity  
Their condition  
Management behaviors  
Perceived consequences  
Socio-cultural interactions  
Family interactions  
Emerging autonomy

## APPENDIX C

### IRB Approval Notification

**Date:** Mon Apr 4 16:48:04 EDT 2011

**To:** Terri Lipman

**CC:** , Barbara Beacham

**From:** Mark Schreiner, M.D., Chair, Committees for the Protection of Human Subjects

**Re: IRB#** [IRB 11-007998](#) , **Protocol Title:** Children with Chronic Health Conditions: Perceptions of Family Condition Management

**Sponsor:** National Institutes of Health (NIH) , NR011524

#### **IRB SUBMISSION: NOTICE OF IRB APPROVAL**

**Approval Date:** 4/4/2011

**Expiration Date:** 4/3/2012

**Approved Document(s):**

- Please refer to this protocol workspace in eIRB to identify the materials reviewed by the IRB. The IRB considered all of the submitted documents when the research was approved, including the protocol (version date 3/29/2011).
- Please note: the final formats of any recruitment materials (that subjects will see and/or hear) must be approved by the IRB prior to use. The approved, date-stamped recruitment materials are available in the eIRB study workspace to print out.
- Approval includes the CHOP/PENN Cooperative agreement where CHOP is the IRB of record for UPenn under scenario 1.c.i.a., where the primary grantee is at Penn but most or all of the human subjects research activity will take place at CHOP. The signed determination form is available in eIRB

#### **Performance Sites:**

- CHOP and affiliated sites
- University of Pennsylvania and affiliated sites

#### **Number of Approved Subjects:**

- CHOP Sites: 100 (50 children and 50 parents)
- Total Enrollment: 100 (50 children and 50 parents)

Thank you for submitting the above-named study. A member of the CHOP IRB reviewed and approved the study via expedited review with the following determinations:

- Expedited Category: 45 CFR 46.110, Categories 5, 6 and 7.
- Subpart D Determination: 45 CFR 46.404 / 21 CFR 50.51.

Please note the following conditions for conducting this study:



1. **REPORTABLE EVENTS:** On-site reportable events such as serious adverse events, Protocol Deviations/Violations, or any unanticipated problem involving risk to subjects or others, or non-compliance that occurs in relation to this study must be reported to the IRB in a timely manner, as outlined in the CHOP investigator instructions.
2. **RENEWAL (Continuing Review/Progress Reports):** Approval is valid until the expiration date for your protocol shown above. The IRB must review and approve all human subject research studies at intervals appropriate to the degree of risk, but not less than once per year, as required by 45 CFR 46 / 21 CFR 50, 56. To avoid lapses in study approval and suspension of study procedures, please submit the application for continuing review at least 45 days before the expiration date for your protocol. This will provide the IRB will sufficient time to review your study. As a courtesy, the IRB will send you a reminder; however, it is your responsibility to ensure that you submit the continuing review application on time.
3. **WAIVER OF ASSENT:** A waiver of assent has been approved per CFR 46.116(d) / 21 CFR 50.55(d) for the telephone screening as children will most likely not be present when the phone call is made.

**WAIVER OF DOCUMENTATION OF CONSENT**

**AND PARTIAL WAIVER OF HIPAA AUTHORIZATION:** A waiver of documentation of consent has been approved per 45 CFR 46.117(c)(2) / 21 CFR 56.109(c)(1) for verbal consent and verbal HIPAA authorization to do the telephone screening. The approved, date-stamped scripts are available in the eIRB study workspace to print out. Written consent, assent and HIPAA Authorization will be obtained at the beginning of the in-person meeting using the consent form (below).

**CONSENT FORM:** The approved, date-stamped informed consent document is available in the eIRB study workspace to print out.

4. **CHANGES/AMENDMENTS/MODIFICATIONS/REVISIONS:** You must obtain IRB review and approval under 45 CFR 46 / 21 CFR 50, 56 if you change any aspect of this study, including but not limited to study procedures, consent form(s), co-investigator, study staff, advertisements, protocol document or procedures, investigator drug brochure or accrual goals. Implementation of these changes cannot occur until you receive the IRB Approval notice.
5. **COMPLETION OF STUDY:** Notify the IRB when your study is completed. Neither study closure by the sponsor nor the investigator removes your obligation for submitting a timely continuing review or a final report.
6. **INVESTIGATOR RESPONSIBILITIES:** Please refer to the attached Investigator Responsibilities Sheet for information and guidance on the responsibilities of investigators who conduct human subjects research at CHOP.

Thank you for your cooperation in protecting human research subjects.

**DHHS Federal Wide Assurance Identifier: FWA0000459**

*\*\*\*\* This memorandum constitutes official CHOP IRB correspondence. \*\*\*\**

APPENDIX D

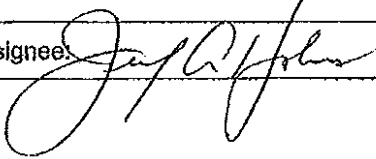
IRB Cooperative Agreement between CHOP & Penn  
Determination Form

813 434

Protocol Title: Children with Chronic Health Conditions: Perceptions of Family Condition Management	
Penn PI: Terri Lipman, PhD	CHOP PI: Terri Lipman, PhD
Penn IRB #:	CHOP IRB #: 11-007998
Please submit this form to the institution you are requesting to be the IRB of Record. Please note that IRB specific submission requirements still apply. If necessary, contact the respective IRB office for more information.	
This form is only needed when both CHOP and PENN are engaged in the research. Please reference OHRP's Guidance on "Engagement of Institutions in Research" at <a href="http://www.hhs.gov/ohrp/humansubjects/assurance/engage.htm">http://www.hhs.gov/ohrp/humansubjects/assurance/engage.htm</a> to determine if both CHOP and PENN are engaged in the research.	
CHOP IRB of Record	PENN IRB of Record
<b>Scenario 1a</b> <input type="checkbox"/> Where both institutions are engaged in the research, all research activities take place at CHOP, and the only involvement of Penn is the participation of a Penn faculty member involved in the research as a sub-investigator; in this circumstance CHOP will be the IRB of record.	<b>Scenario 1b</b> <input type="checkbox"/> Where both institutions are engaged in the research, all research activities take place at Penn, and the only involvement of CHOP is the participation of a CHOP-based faculty member involved in the research as a sub-investigator; in this circumstance, Penn will be the IRB of record.
<b>Scenario 1c: Other scenarios agreed upon on a case-by-case basis</b>	
<input checked="" type="checkbox"/> i.a. When the primary grantee is at Penn but most or all of the human subjects research activity will take place at CHOP.	<input type="checkbox"/> i.b. When the primary grantee is at CHOP but most or all of the human subjects research activity will take place at Penn.
<input type="checkbox"/> ii. Collaborative research involving neonates and taking place at CHOP and either Penn or the Pennsylvania Hospital or both - request to designate CHOP as the IRB of record;	<input type="checkbox"/> iii. When greater than minimal risk study procedures involving adults subjects take place at Penn and research activities at CHOP are limited to those considered not greater than minimal risk - request to designate Penn as the IRB of record.
<input type="checkbox"/> iv.a. When research involves both children and adult subjects, the IRBs at Penn -- request to designate CHOP as IRB of record.	<input type="checkbox"/> iv.b. When research involves both children and adult subjects -- request to designate Penn as the IRB of record.
<input type="checkbox"/> v.a. Other (explain below)	<input type="checkbox"/> v.b. Other (explain below)
<b>Summary for Scenario Selection</b> (include study purpose/procedure & participating personnel and if Scenario 1c is proposed, the rationale for designating either Penn or CHOP as the IRB of record) The study will describe family management of childhood chronic health conditions from the perspective of the child. Subject identification and recruitment will take place at CHOP, the main focus of the research is the child's perspective, therefore, we are requesting CHOP be the IRB of record.	
Signature of PI from institution serving as IRB of record:	Date: 1/21/11
Signature CHOP IRB Chair or designee: J. Boyle	Date: 2/14/11

Version: July 21, 2009

IRB Cooperative Agreement between CHOP & Penn  
Determination Form

Signature Penn IRB Chair or designee: 	Date: J-29-11
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