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Adapting the Family Management Styles Framework to Include Children

Barbara L. Beacham, PhD, RN [a,*], Janet A. Deatrick, PhD, RN, FAAN [b]

[a] University of Minnesota, Minneapolis, MN, United States of America
[b] University of Pennsylvania, Philadelphia, PA, United States of America

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ABSTRACT

Empirical study purpose: Propose an adapted Family Management Style Framework that includes the perspectives of children with chronic health conditions.
Design and methods: Building on the current Family Management Style Framework, the authors used recent empirical studies with children to further develop the framework. Definitions of each dimension and component of the framework were reviewed and revised to reflect the perspectives of the child, based on the child data and prior work.
Results: The Family Management Style Framework was adapted to reflect children's perspectives of themselves and their family. Based upon our understanding of the components of the framework, we expanded the components and revised the definitions of the dimensions to reflect the child perspectives.
Conclusions: Incorporating the perspectives of children allows us to consider the transactions that occur during condition management between parents, children and families. Additional research is needed to explore this interaction and the implications it has on the outcomes.
Practice implications: Children experience the way their family manages their chronic health condition and incorporate those experiences as part of their developing understanding of themselves and their condition. Practitioners should encourage children to express their understanding of their condition and its management to model and encourage them to dialogue about management with their families.

Child adapted Family Management Styles Framework

Families create the universe that is the young child's world. The world of children with chronic health conditions includes experiences with how the family cares for them and their condition as well as how they learn to care for themselves. We know much about the perspectives of parents regarding how they care for children with chronic conditions, but much less about children's perspectives about how their families care for them and how they learn to care for themselves. A recent review of family studies found that of the 144 studies focused on child condition management, 82 included the child voice in studies that included parent(s) and the child, and six studies looked at the child only, leaving over 1/3 of the studies without child data (Beacham, Martin, & McKechnie, n.d.).

Incorporating the child's voice into discussions of family management will help us understand more about the interplay between the parents and child, and between family management and the development of self-care. According to the emerging theoretical framework of Life Course Health Development (Halfon & Forrest, 2018), an individual has both internal and external environments that support their unique health development trajectory. Across the lifespan, changes to both environments influence health development. Family is one of the external environments identified as an important environment to the developing child in which care ideally transitions from being more reliant on the family to being more reliant on the self. That is, while school aged children are typically still reliant on their family, they also are beginning to have increased exposure to the outside world. Attending school, participating in extracurricular activities such as sports, dance, and music provides them with more opportunities to see the world without the parents' oversite. They may be exposed to children with similar conditions whose family manages things differently and begin to make comparisons between themselves and others as well as between their family and other families.

The Family Management Style Framework (FMSF) identifies the ways families organize, integrate, and accomplish the work related to condition management of children's chronic health conditions (CHC) (Knafl, Deatrick, & Havill, 2012; Hutton, Munt, Aylmer, & Deatrick, 2012). This framework (see Table 1, Column 1) includes the child and has been used to study parents' perspectives about family management of their children with CHC across multiple conditions and cultural settings (Knafl et al., 2012; Hutton et al., 2012). In this body of research, except for one study using the FMSF to examine the perspectives of adolescents with spina bifida (Wollenhaupt et al., 2012) and our study

* Corresponding author at: University of Minnesota School of Nursing, 6-140 Weaver-Densford Hall, 308 Harvard Street SE, Minneapolis, MN 55455, United States
E-mail address: bbeacham@umn.edu (B.L. Beacham).

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Table 1
Parent perspective FMSF and child adapted FMSF definitions of components and dimensions with exemplars.

	Definitions within the parent perspective FMSF (Knafl et al., 2012; Hutton et al., 2012)	Examples of child's view of condition management (Beacham & Deatrick, 2015)	Exemplars of child's view of family member management	Definitions from the child adapted FMSF
Component 1 Definition of Situation	The subjective meaning family members attribute to important elements of their situation			
Dimension: Child identity[a]	Parents' view of the child and the extent to which those views focus on the condition or normalcy and capabilities or vulnerabilities	**They (parents and providers) want us to be like regular kids** "…you have to be able to push it aside…. 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" (11-year-old, Type 1 Diabetes) (p.29)	**Capability** "… I started growing up, …then my mom asked me if I wanted to try to start doing [the injections] and I said I would try…she showed me how stuff would work…I felt like I knew a lot more about myself" (11-year-old with type 1 diabetes). **Vulnerability** "…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" (12-year-old with cystic fibrosis)	Child identity is interplay between how the child and their family believes the child is similar to his/her peers as normal and capable or vulnerable and is similar to the parents' view of the child.
Dimension: View of condition	Parental beliefs about the cause, seriousness, predictability, and course of the condition	**Sometimes I get scared** "…she wasn't worried about it at that time cause I wasn't like…older yet" (9-year-old, Type 1 Diabetes) (p. 29) "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" (13-year-old, Asthma) (p. 29) "Mine's just really weak…. The asthma's weak. I don't even think I need the medication" (11-year old, Asthma). (p. 29) "That kind of scares me. That pretty much convinces me to get my blood sugar down all the time" (11-year-old, Type 1 Diabetes). (p. 29) **And then we're good** "I have my own emergency cell phone…. I always have it … call [mother's] cell, I'm like, 'oh, I'm here,' or 'hi, I'm low' or whatever. Then I'll go to sleep…I keep my phone right beside me… Test, tell [mother] my blood sugar, and then we're good" (11-year-old, Type 1 Diabetes). (p. 29)	**Cause** "…just my Dad and my Grandmother have it…he passed it down to me. I think they found it once I was born; the doctors tested me. I don't know really how, they just found it." (11-year-old with hereditary spherocytosis) **Seriousness** "…she [mother] wasn't worried about it at that time cause I wasn't like…older yet" (9-year-old with type 1 diabetes) "…I think Mom worries about I might not, what if I get sick one day and I get real sick and I might die." (10-year-old with asthma) "…my Mom told me if I continue, like if my sugar is gonna be high, when I get older my kidneys will be bad and I'll have to be on dialysis." (10-year-old with type 1 diabetes) **Predictability/course** "I asked my mom why my asthma has gotten better, she said when you're my age it gets better and then if you get older it starts to get like it was when you were little. I don't really care because it's just the way it is." (11-year-old with asthma)	Children's view of the condition encompasses the interplay between how the child and their family views what caused the condition, what has changed, what may change in the future, and the their worry or concern.
Dimension: Management mindset	Parental views of the ease or difficulty of carrying out the treatment regimen and their ability to manage effectively	**It's pretty easy for us to handle/it's hard for us cause it's not normal** "I don't have bad allergies…no, just like I'm anaphylactic…so if I touch it, I get a hive. If I eat it, then that's when I'll need an Epipen" (8-year-old, Cystic Fibrosis, Allergies). (p. 29) "I didn't really want it. It's not good. I don't like it and I want to get rid of it" (9-year-old with Cystic Fibrosis) (p. 29)	[a]No exemplars of ease or difficulty family experiences from the child's perspective	Management mindset is the interplay between how the child and their family views the ease or difficulty of their carrying out treatments and incorporating condition management into family life.
Dimension: **Family mutuality**[a]	Parents' beliefs about the extent to which they have shared or discrepant views of the child, the illness, their parenting philosophy, and their	**Mom and dad agree/disagree** "…mom just doesn't want me to do it, but I don't know why. She thought	**Parent mutuality** "I'm not really sure if they (parents) disagree with anything. My parents, they always (say) 'don't do that'…..or	Family Mutuality reflects the interplay between the child's satisfaction and the satisfaction of their family with the how they work

(continued on next page)

Table 1 (*continued*)

	Definitions within the parent perspective FMSF (Knafl et al., 2012; Hutton et al., 2012)	Examples of child's view of condition management (Beacham & Deatrick, 2015)	Exemplars of child's view of family member management	Definitions from the child adapted FMSF
	approach to condition management (named Parent Mutuality)	that I did it the wrong way … My dad, he does think I can do it, but I think no" (9-year-old, Type 1 Diabetes) (p. 30)	'Hey, you shouldn't do the vest today' or something. They always like to keep me on track for my cystic fibrosis." (11-year-old with cystic fibrosis) **Family mutuality** "Me and my parents kind of share drawing insulin and doing all that. I usually give my own shots. I try to remember but usually my mom does it….my mom and dad do it for me." (11-year-old with type 1 diabetes)	together to manage the child's condition and the degree to which they receive support from each other and share views on the management of the child's condition.
Component 2 Management Behaviors	The efforts directed toward caring for the illness and adapting family life to illness-related demands			
Dimension: **Family philosophy**[a]	Parent's goals, priorities, values, and beliefs that guide the overall approach and specific strategies for condition management	**They do it for my health and stuff** "…he [Dad] [looked up Olympians with diabetes] said he looked them up, 'Just to let you know your dreams will never be crushed because of this.' That helped" (12-year-old, Type 1 Diabetes). (p. 30)	**Priority** "…they always concentrate on what I do, like as for my health and stuff." (11-year-old with cystic fibrosis) "…they were just like 'Okay, what do we do now?'" (11-year-old with type 1 diabetes) **Value** "There's a biker and there's a swimmer just like you…Just to let you know your dreams will never be crushed because of this." (12-year-old, Type 1 Diabetes).	Parenting philosophy refers to the interplay between how the child and their family views the parents' goals, priorities, values, and beliefs that guide the overall approach and specific strategies for condition management
Dimension: Management approach	Parents' assessment of the extent to which they and their child have developed a routine and related strategies for management of the condition and incorporating it into everyday life	**I do it**, **they do it**, **and we do it** Children used "I" statements to explain management activities they did on their own (e.g., I check my blood sugar, I take my treatment, and I do it myself). Children used "they" statements to identify management activities outside of their control. Finally, children used "we" statements, talking about management as a joint venture between them and their parents. (p. 30) **It's just kind of my schedule** When I run, I only run like two laps. 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 breathe 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 (10-year-old, Asthma). (p. 30) **To tell or not to tell** "If I'm acting like upset or angry all the time, they'll just be like 'Okay, are you alright? Do you need to do your thing or whatever?' I'm like 'Yeah, I'll go test' and they're usually right" (11-year-old, Type 1 Diabetes). (p. 31) **If they weren't hounding me**, **I wouldn't be this free**	**Strategy** A doctor we know, his son has diabetes and he switched to this insulin and said that it was a lot better. We, me and my mom, talked about it for a few months…we just kind of researched it and talked about it with my dad. …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 …(11-year-old with type 1 diabetes)	Management Approach is the extent to which the child and their family has developed routines and strategies to incorporate the condition into everyday life and the interplay between the child and parent in terms of control of those routines and strategies (parent-led vs child-led).
Component 3 Perceived Consequences	Actual or expected family, child and illness perceived outcomes that shape management behaviors and			

Table 1 (*continued*)

	Definitions within the parent perspective FMSF (Knafl et al., 2012; Hutton et al., 2012)	Examples of child's view of condition management (Beacham & Deatrick, 2015)	Exemplars of child's view of family member management	Definitions from the child adapted FMSF
	affect the subsequent definition of the situation			
Dimension: Family focus	Parent's assessment of and satisfaction with how condition management has been incorporated into family life	Children in this study did not directly refer to their view of the family's focus as included in this publication.	"We did this one night and it turned out really good…We just kind of recap what you should do the next week and just keep trying to figure out what helps and what doesn't and just talk and see." (11-year-old with type 1 diabetes) "As long as she [mother] gets the neb started…it's fine with me. I just don't want to wait. Sometimes my brothers ask her for stuff and then I wait for the neb to come…I always wait like 10 min." (12-year-old with cystic fibrosis) "I think that it's [that] more responsibility has been put on our backs, but we have been able to take [on] more challenges." (11-year-old with type 1 diabetes) He had no stability over it [blood sugar] whatsoever and it [instability] was probably from his parents because they probably never helped him out. He's probably like 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. (12-year-old with type 1 diabetes)	Family focus is the interplay between how the child and family assess the how the condition has been incorporated into family life in terms of being well incorporated or disruptive,
Dimension: Future expectation	Parents' assessment of the implications of the condition for their child's and their family's future	**I might have a totally different life when I'm older** "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 (11 year-old, type 1 diabetes)" (p. 31) "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 (8-year-old, hemophilia)" (p. 32)	"I'll have to get up in the night and give it myself, my injections, when I'm still getting shots." (9-year-old with type 1 diabetes)	Future expectations is the interplay between the awareness of the child and family about the implications the condition has on their future and the extent to which this awareness is specific and condition focused or very general and globally expressed

Bold type highlights the components and bold italics identified the dimensions changed in the adapted framework.

[a] Wollenhaupt, Rodgers, and Sawin (2012) proposed dimension be called self-identity, mutuality of family members and family philosophy. We kept child identify, but concurred with mutuality, changing parental mutuality to family mutuality, and philosophy to family philosophy.

that described family management from the perspectives of school-aged children with a variety of CHC (Beacham & Deatrick, 2015), children's perspectives about their chronic condition management using the FMSF have been largely overlooked. In order to provide the next step for including children's voices about family management in future research, this manuscript uses the current FMSF, perspectives of adolescents with spina bifida (Wollenhaupt et al., 2012), and the results of our recent empirical study (Beacham & Deatrick, 2015), to propose an adapted FMSF from the child's perspective in order to further advance the FMSF (Barakat, 2012).

Description of the parent focused FMSF

Based on the principles of symbolic interactionism (Blumer, 1994), the FMSF was first conceptualized by Knafl & Deatrick (1990) in a concept analysis review of the literature. The current FMSF situates the family within a social ecological perspective in terms of multiple, reciprocal, positive and negative influences on child and family development (Barakat, 2012) and functioning. The framework considers Contextual Influences, Major Components, the Family, Management Patterns, and both family and family member outcomes. The three Major Components are definition of the situation, management behaviors, and perceived consequences. These three components and their eight corresponding dimensions were refined over time based on research of parent perspectives and relevant literature reviews (Knafl & Deatrick, 2003; Knafl et al., 2012; Hutton et al., 2012; Knafl, Breitmayer, Gallo, & Zoeller, 1996). Component 1, Definition of the Situation includes four dimensions: child identity, view of condition, management mindset, and parental mutuality. Component 2, Management Behaviors includes two dimensions: parenting philosophy and

management approach, and Component 3, Perceived Consequences includes two dimensions: family focus and future expectations (Knafl et al., 2012; Hutton et al., 2012). (See Table 1, Column 2 for definitions of components and dimensions). Although children were included in the initial study, subsequent research has not included the perspectives of children about their family's management.

The Family Management Measure (FaMM), based on the FMSF, again is from parents' perspective. The FaMM is a psychometrically sound instrument (Knafl et al., 2011) that measures specific ways families respond to chronic conditions during childhood. The FaMM has been translated into other languages and used to research the concept of family management in other cultures (Knafl et al., 2012; Hutton et al., 2012; Ichikawa et al., 2014; Kim & Im, 2013; Zhang, Wei, Han, Zhang, & Shen, 2013).

The FMSF and the FaMM, have guided research on family management of children with chronic physical conditions of childhood such as Type 1 Diabetes Mellitus, Asthma, and Cystic Fibrosis (Gallo, 1990; Gibson-Young, Turner-Henson, Gerald, Vance, & Lozano, 2014; McCarthy & Gallo, 1992; Rearick, Sullivan-Bolyai, Bova, & Knafl, 2011) as well as families of children with an intellectual disability (Van Riper, Knafl, Roscigno, & Knafl, 2018). It has also been used in studies where the sample represents more than one chronic health condition (Beacham & Deatrick, 2015; Gallo & Knafl, 1998; Knafl, Darney, Gallo, & Angst, 2010; Knafl & Zoeller, 2000; Zhang, Wei, Zhang, & Shen, 2013). Additionally, research using the FMSF has expanded its use beyond families of children with chronic conditions to include adolescents. Wollenhaupt et al. (2012) proposed an adolescent-focused family management framework based on the perspectives of adolescents with spina bifida. Major changes were made in the descriptions of each of the dimensions to reflect the adolescent's perspectives about themselves, their management, and their family's management. Minor changes were made in the names of three dimensions: self-identity (child identity); mutuality of family members (parental mutuality); and, family philosophy (philosophy).

Researchers have examined families of adults with conditions such as Alzheimer's, Dementia, and Huntington's disease (Beeber & Zimmerman, 2012; Perry & Olshansky, 1996; Van Riper, 2005) and in situations where the family was dealing with an unexpected, life threatening event and decisions around withdrawal of life-sustaining therapies (Wiegand, Deatrick, & Knafl, 2008; Wiegand, 2012). Each found the framework to be a useful guide for examining these families of adults. Most recently, quantitative patterns of FM were identified for children with chronic conditions (Knafl et al., 2010) and with adolescent and young adult survivors of childhood brain tumors (Deatrick et al., 2018); the patterns build on the patterns previously identified from work with the qualitative interviews (1996). These studies found families who maintained a family-focused pattern had better outcomes, while families who maintained a condition-focused pattern were linked to poorer child, maternal and family outcomes (Knafl et al., 2013; Deatrick et al., 2018). The only data from children, adolescents or young adults used in these analyses were quantitative validation measures from the adolescent and young adult survivors of pediatric brain tumors (Deatrick et al., 2018).

The FMSF from the child's perspective

In our first paper on children's perspectives of family management (Beacham & Deatrick, 2015), the aims were to describe the unique perspectives of children with CHC have regarding condition management, and, using the FMSF to guide the interview and analysis, identify child perspectives of condition management that corresponded to the components of the FMSF. An institutional review board charged with the protection of human subjects approved the study Qualitative content analysis, using a conventional approach (Hsieh & Shannon, 2005), of transcribed interview data was used to describe the children's perspectives of their condition management ($N = 32$). There children, 8–13 years old, were identified by nine unique recruitment diagnosis (Type 1 Diabetes Mellitus and Asthma, being most frequent), and together had more than 20 health conditions identified across the sample (Beacham & Deatrick, 2015). Families represented a diverse sample across parent education, household income, and race/ethnicity. (For more information, see Beacham & Deatrick, 2015).

Findings supported use of the FMSF with children and found that children viewed condition management in ways that were like the parents (see Table 1). A gap remained, however, regarding how the framework itself could be adapted to support inclusion of the child. During the initial analysis of the child interviews, it became apparent that children not only understood ways that they managed their own condition but were also beginning to realize their parents' perspective of the condition and its management. Children discussed their own perspectives about the management of their condition, and some were also able to talk about the management of families, parents, siblings and/or friends to varying degrees (Beacham & Deatrick, 2015). This dual perspective was somewhat surprising in school-aged children because of their typical self-centeredness (Dambrun & Ricard, 2011). We wanted to capture how children spoke specifically about their perspectives on their family's management of the chronic health condition. In the analysis on which this manuscript is based, we revisited these data to inductively develop an adapted FMSF that incorporated children's perspective of their own and their family's management of the chronic condition, and to discuss suggested adaptations considering the current literature. The focus remains on family management, that is, how they individually manage their condition and incorporates children's views of their family's collective management of their condition. These impressions are distinct from how the children understand the outcomes of those efforts (e.g. psychosocial correlates; self-care). We believe those distinctions are important for future descriptive, model testing, and intervention research that is developmentally appropriate for school-aged children.

Approach

For the present analyses, we used the data (interviews) from the prior study to adapt the FMSF to include the perspectives of children with chronic health conditions. The intent of the directed content analysis was to translate and broaden the existing FMSF by incorporating the child's perspective of family management. Revisions to the definitions of each of the dimensions of the FMSF were made to include the perspective of the child and more closely reflect the child's voice. Based on the results of the child's perspective from the interviews, the primary author developed initial definitions (translated from the original FMSF) to guide the analysis. Each interview was read line by line and coded for fit in the framework dimensions and components. Subsequently, quotes supporting the various dimensions of the FMSF were included and definitions revised to assure integration of the child perspective of their family's management of their chronic health condition. Two senior researchers, one with extensive knowledge and one with more limited knowledge of the FMSF, performed a review of the analysis to ensure consistency and clarity of the analysis and definitions. Final concurrence on the definitions resulted from revisions and discussion between the author and senior researchers.

Table 1 provides an overview of the adapted framework by noting 1) the definitions of each component and dimension based upon the original framework (Knafl et al., 2012; Hutton et al., 2012; 2) exemplars of the dimensions based upon the perspectives of the school-aged child with a CHC (Beacham & Deatrick, 2015); 3) exemplars of the dimensions based upon the school-aged child's perspectives of family condition management; and 4) the proposed definitions of the components based upon the child perspectives. Contributions supported by Wollenhaupt et al. (2012) are acknowledged in the footnotes.

Updating the Family Management Style Framework

The modified FMSF is depicted in Fig. 1 in terms of the contextual influences, major components, and outcomes. Below we present our revised framework reflecting changes based upon Wollenhaupt et al. (2012), Beacham and Deatrick (2015), and our current analysis. First, we present the contextual influences on family management. Second, we review the major components showing the continuing relevance of both the components and dimensions when updating the framework to include the child's voice.

Contextual influences

The sociocultural influences identified by Knafl et al., 2012 and Hutton et al., 2012 apply to our updated framework, however, some areas noted to be important to the family can be expanded to emphasize how they may be important to children. For instance, family structure, presence of other family members with a chronic condition, and number of family members living in the home are concrete features of a family and may influence the perceptions of the developing child with a chronic health condition.

In addition, children are dependent on adults in their communities for their stewardship of resources so that resources can be accessed for management of their condition. For example, the family's overall financial strain from the perspective of children must be understood as contextual to their overall sense of how the family is managing their condition. In fact, we know now that such contextual influences are complex, multi-level determinants of health that are more important than biological mechanisms for preventing and treating disease (Knafl et al., 2013; Deatrick, 2017).

Furthermore, children depend upon their friends, teachers, school nurse and other adults when they are outside the purview of the family. Friends can influence how they see themselves and the acceptability of management routines that may or may not be obvious or known to them. Teachers, school nurses, coaches, as well as other adults are sought to support management when parents are not present. Although parents may view healthcare and school professional as sometimes unhelpful and non-supportive (Knafl et al., 2012; Hutton et al., 2012), children rely on them for support and assistance for the daily management of their condition.

Major components/updates

The proposed framework is presented in Fig. 1 with the revisions depicted in bold italic font (Hutton et al., 2012; Beacham & Deatrick, 2015; Wollenhaupt et al., 2012). More details about the development of the proposed adaptations are provided in Table 1: the 1st column lists the major FMSF components; the 2nd column lists definitions consistent with the parent perspective FMSF (Knafl et al., 2012; Hutton et al., 2012); the 3rd and 4th columns lists empirical examples from the child's perspective of both condition management and family member management; and the 5th column lists our updated conceptual FMSF definitions that are further explicated below and are an integration of data from the prior 4 columns.

Overall, the FMSF (Knafl et al., 2012; Hutton et al., 2012) was supported. We do, however, propose four modifications to the FMSF that incorporates the child's perspective. First, the data reflected school-aged children's developing sense of their own personal view of the condition and their own management in addition to a perspective on family management of their condition. Therefore, Mutuality and Philosophy are beyond that of parents and becomes family constructs (Wollenhaupt et al., 2012). Second, it incorporates a description of the child with the condition as an individual participant within the family. Third, language pertaining to Family Management Patterns was updated (Knafl et al., 2013; Deatrick et al., 2018). Fourth, the Individual Child Outcomes will include not only child functioning but also measures of condition control (e.g., HbA1C for children with diabetes) and Caregiver Outcomes have been identified as a separate outcome (Deatrick et al., 2018). An explanation of each component follows that includes these proposed modifications detailed in Table 1.

Component 1: definition of the situation

The first FSMF component, *Definition of the Situation*, includes four interactive dimensions: Child Identity, View of the Condition, Management Mindset, and Parent Mutuality (Knafl et al., 2012; Hutton et al., 2012).

Child identity

Child identity is an interplay between how the child with the condition and other family members believes the child is similar to his/her

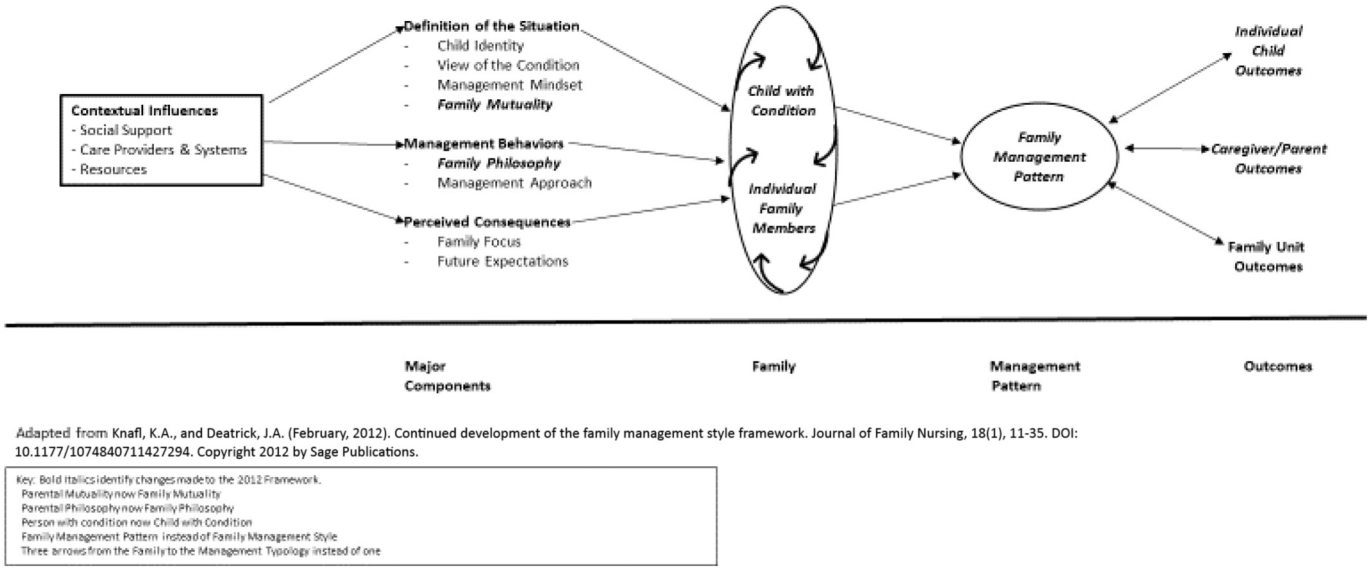

Fig. 1. Child Adapted Family Management Style Framework.

peers (as normal and capable or vulnerable) and is similar to the parents' view of the child. School-aged children have a sense of how they and their families see them within the context of their illness as to whether their family emphasizes their capabilities despite the condition or their condition-related vulnerabilities.

Based on this analysis, children may emphasize their vulnerability when others in their environment treat them as different (Beacham & Deatrick, 2015). That is, children may be aware of the consequences of their differences in terms of family life. They may be embarrassed when their families' everyday activities need to be altered to accommodate the chronic condition management needs when parents call attention to their differences and point out why these accomodations are needed. For instance, families may change mealtimes and eating patterns for the entire family to accommodate their child's condition so that everyone can eat together and eat the same foods. Or, a family may alter plans and make accommodations when traveling in order to manage the condition.

In contrast, generally children feel more capable and self-sufficient when their family views them as essentially normal and condition management is folded into ongoing family life. In addition, children will likely feel more capable when they believe their family has confidence in them and their abilities. Children talk of their parents' trust in them and their parents' confidence in their ability to handle situations concerning their condition. For these children, adjustments or accommodations to the condition were viewed as expected and routine, not burdensome, and not significant to them or their families.

View of the condition

The view of the condition encompasses the interplay between how the child and their family views what caused the condition, what has changed, what may change in the future, and their worries or concerns. School-aged children tend to focus on the seriousness and predictability of their condition, with less insight into its cause or course.

When children focus on the seriousness of their condition and are aware of times when the condition causes their parents to worry about them, they tend to fall back on any vivid memories they may have about the condition such as when they were diagnosed and they observed their parents' reactions to the potentially serious nature of their condition. They also focus on triggers that make their condition worse or better (e.g. what might cause an exacerbation or a period of relative wellness) but may not have the autonomy to intervene in these instances.

The course of the disease is still a rather abstract idea for most children. Their knowledge is based upon what members of the family have told them. That is, while the cause of many conditions is unknown, they may have heard but not understood discussions of issues such as the genetic origin of their condition or an incident believed by family members to have triggered the condition.

Finally, school-aged children do not typically have a view of the future course of the condition, however, they most likely recognize change across time, especially since diagnosis. They may cite issues such as worsening/improving symptoms, their understanding of the condition, and, their parents' expectations for them being more active in management.

Management mindset

Management mindset is the interplay between how the child and their family view the ease or difficulty of their carrying out treatments and incorporating condition management into family life. Children are aware situations and activities that make management easier or more difficult for themselves and the family. Thus, school-aged children may be sensitive to the expertise of their primary caregiver (e.g. parent[s]) in managing their condition and how their primary caregiver involves them in treatment regimens and planning for family outings and activities.

Family mutuality

The final FSMF dimension of the adapted framework that is explored in *Definition of the Situation* is family mutuality. Family mutuality incorporates not only congruence between parents, but also congruence between the children, their parents, and other family members. As a result, this component was renamed Family Mutuality by Wollenhaupt and colleagues (Wollenhaupt et al., 2012). Family Mutuality reflects the interplay between the satisfaction of the child and their family with the how they work together to manage the child's condition; the degree to which they receive support from each other; and if they share similar views on the management of the child's condition. Children may express concern, for example, with their sibling's view of their condition or if one parent criticizes the other parents' management.

Component II: management behaviors

The two dimensions of *Management Behaviors* are Family Philosophy (Wollenhaupt et al., 2012) and Management Approach (Knafl et al., 2012; Hutton et al., 2012). These two dimensions focus on efforts that are directed toward both caring for the condition and incorporating the condition into family life.

Family philosophy

Family philosophy refers to the interplay between how the child and their family view the goals, priorities, values, and beliefs that guide the overall approach and specific strategies for condition management. School-aged children typically have limited insight regarding their parents' goals for condition management. They can use their keen observational skills at concretely making conclusions about their parents' philosophy of management, but can be poor interpreters without information and dialogue. That is, if they indirectly glean their interpretations from their parents they are not privy to their parents' rationale or management goals. For example, the child may see their parent monitoring treatments and deduce that their parents do not trust them to complete their treatments. Alternatively, with parents using both observation and dialogue, the child can better understand the parent's goals of keeping them safe and healthy.

Management approach

Management Approach is the extent to which the child and their family has developed routines and strategies to incorporate the condition into everyday life; and the interplay between the child and parent in terms of control of those routines and strategies (parent-led vs child-led). Caregiver/parental assistance regarding consistency, monitoring, and problem solving is often needed to help the school aged child adhere to treatment. School-aged children will typically make statements referring to “I do it…they do it…and we do it” which are very important because they are the evidence of that interplay (or not) between the child and their family. In doing so, children are describing the processes that occur within the family in order to manage their condition and recognize varying degrees of control over management. Some children have very little control beyond following instructions given by their health care provider or parent or passively watching the parents perform the management activities. Other issues include the child's accounts of any routines and rules for maintaining treatment and medication schedules.

Component III: perceived consequences

The third component of the FMSF, *Perceived Consequences*, refers to the family focus and future expectations as they pertain to the child's condition (Knafl et al., 2012; Hutton et al., 2012). Perceived Consequences focuses on actual or expected family, child and illness outcomes that shape how the family defines their situation.

Family focus

Family focus is how the condition and its management has been incorporated into family life in terms of being well incorporated or disruptive. School–aged children may/may not describe family activities in terms of how condition management was/was not incorporated successfully and the activity itself could/couldn't take center stage and the condition a back seat. Children may also have preferences as to how often their condition needs to be addressed, for example, less frequent rather than more frequent check-ins that may dominate family life. They may or may not understand that the condition may have to dominate family life during symptom exacerbations when previously the condition was in the background. Thus, children during the school-aged developmental period may be adherent with treatment but not understand the context and integration of that treatment in their lives or the lives of the family as they are keen observers but can be poor interpreters of their world (Coyne et al., 2016). Complexity is added, of course, for the parents when they are helping with treatments and siblings are vying for the parents' attention. Finally, children will inevitably compare themselves to others and how their parents manage.

Future expectations

Future expectations is the interplay between the awareness of the child and family about the implications for their condition in the future. This awareness may be specific and condition focused or very general and globally expressed. School-aged children may not be aware of or mention future consequences of their condition within the family context in regular conversation. They may not be aware of their parents' future expectations. Children might imagine a future where their parents are not readily assisting with their care, possibly related to living on their own or general fears about the same. As the child matures, it may be important for them to be aware of the parents expectations, especially as the anticipated transitions from more family-centered management to child self-care progresses.

Outcomes

As represented in Fig. 1, there are three separate outcomes that are supported by the family studies to date. Child outcomes examine both issues such as the functional and socio-psychological status of the child as well as the condition specific measures that need to be monitored. These child and condition specific outcomes help assess the overall health and wellbeing of the child with the condition. Doing so will allow for the evaluation of potential interventions for the child and condition management. Family outcomes remain as identified in the previous model; examining the functioning of the family specific to the family process of concern. Parent/Caregiver outcomes may be considered when the focus of the research and/or intervention is more specifically focused on or includes the caregiver/parent in addition to or as opposed to the family unit.

Discussion

The data from our prior study provided the school-age children's reports that were largely congruent with the FMSF and incorporated the children's perspectives about themselves (Beacham & Deatrick, 2015) and also about their families. Developmentally appropriate definitions incorporate both the child's perspectives on the FMSF component, both from how they manage (personal view) and how the family manages their condition (family view).

Although the ability to differentiate between the personal and family view is not well developed in school-age children with CHCs, our results indicate school-age children are beginning to differentiate their personal views from those of the family (Beacham & Deatrick, 2015). These beginning impressions form the foundation for the development of condition management/self-care, (i.e. how the child organizes, integrates, and accomplishes the work related to condition management) over time as the child with a CHC grows and matures (Rolland, 1987).

This revision of the FMSF integrates the child's view of family management and extends use of the FMSF to include the voice of children with CHC. The revised framework expands the understanding of all three components (Definition of the Situation, Management Behaviors, and Perceived Consequences). Comparing the *definition of the situation*, children speak of their chronic health condition in terms of what the conditions means to their family, how the family views them, the difference the condition makes to the family, and if the family's views of the situation are congruent with their own. These perspectives of having a chronic health condition are similar to findings in studies of family management from the parent perspective (Knafl et al., 2012; Hutton et al., 2012).

The parents' perspective of the child's identity seems to revolve around the activities and behaviors the child is able or unable to perform (Deatrick, Mullaney, & Mooney-Doyle, 2009; Herrenkohl, Hill, Hawkins, Chung, & Nagin, 2006; Kendall & Shelton, 2003; Rattanagreethakul, Lapvongwatana, Thiangtham, Sunsern, & McMullen, 2010; Roche & Leventhal, 2009). This view of the child's identity is often demonstrated by the family making comparisons between what the child could do before the diagnosis and after diagnosis. Parental views of the condition itself often are based upon their knowledge of the condition (Wiegand et al., 2008; Lin et al., 2000; Rattanagreethakul et al., 2010). In several studies, parental knowledge was key in the parents' ability to manage the condition and treatment regimen (Wiegand et al., 2008; McQuaid et al., 2008; McQuaid, Walders, Kopel, Fritz, & Klinnert, 2005; Rattanagreethakul et al., 2010). In addition to their knowledge, child identity is central to a parents capacity to manage the condition demands with a family context (Rempel, Blythe, Rogers, & Ravindran, 2012). The roles and views parents have about condition management can either be complementary or a source of conflict (Wiegand et al., 2008; Deatrick et al., 2009).

Children with CHC are beginning to form their own opinions of what the condition and its management means to them (Beacham & Deatrick, 2015). Children get their ideas about health from living life, and through observing, listening and experiencing (Michaelson, Mckerron, & Davison, 2015). They also take into account their beliefs about how the family views them and the condition, as well as the ease or difficulty the family has in caring for the condition. This finding is similar to that found in a study of adolescents with Spina Bifida (Wollenhaupt et al., 2012). Wollenhaupt et al. (2012) recognized that the adolescents in their analysis were aware of differences between parent views (parental mutuality) and the differences between the parents views and their own. Although the school-aged children in our study did not recognize conflict between their parents regarding management, they were becoming aware of differences between themselves and the family approach. Additionally, children were beginning to become aware of when they are at odds with their parents' views, indicating that Family Mutuality plays an important role in the child's perspective of family management (Beacham & Deatrick, 2015; Wollenhaupt et al., 2012).

Comparing *Management Behaviors*, the efforts directed toward caring for the illness and adapting family life to illness-related demands (Knafl & Deatrick, 2003) from the parent and child perspective provides insights into how family management may influence the child's development of self-management. From the parent perspective, *management behaviors* are often related to a specific condition or targeted behaviors. From the child perspective they were the most frequently mentioned FMSF dimension (Beacham & Deatrick, 2015).

Families often work together to help and encourage children to be successful with intervention strategies or independence (Deatrick et al., 2009; Rattanagreethakul et al., 2010). Additionally, management behaviors are evident in the priority parents give the condition and its management. Family interaction and communication are a valued management behavior (McQuaid et al., 2008; Tobler, Komro, & Maldonado-

Molina, 2009), as is the individuality of each family member (Wiegand et al., 2008). Parents stress the importance of family members' abilities and willingness to talk with each other and keep one another informed. Children are aware of these conversations; some talked of overhearing conversations, while others spoke of being included in these conversations. This is congruent with the findings of Michaelson et al. (2015) who found that observing others and listening to conversations is a way adolescents learned about health.

Management behaviors are also seen in family routines, often centered on meals, homework, and bedtime (Roche & Leventhal, 2009; Taylor & Lopez, 2005; Tobler et al., 2009). Routines may really be rituals; the difference often being how a disruption to the routine affects the family (Spagnola & Fiese, 2007). Rituals, when disrupted, threaten family cohesion, whereas a disruption in routines is seen as more of an inconvenience (Spagnola & Fiese, 2007). Children in the study often discussed the routine of their daily activities. While routines may help avoid disruptions in condition management, if these routines are seen as rituals by either the child or the family, then changes in family routines could be viewed as a threat to family cohesion and by extension, condition management. If changes in condition management create more than an inconvenience the family's ability to accommodate to the changing needs of school-age children with CHC may be challenged.

Comparing *Perceived Consequences*, the "actual or expected family, child, and condition perceived outcomes that shape management behaviors and affect the subsequent definition of the situation" (Knafl & Deatrick, 2003, p.239) are similar in the present consequences. Parents assess the balance between condition management and other aspects of family life (Rattanagreethakul et al., 2010). Similarly, children may be very aware of times when the family needed to incorporate their input about condition management into the activity. For example, a family may alter plans for a vacation, and the child may interpret the change as a results of their condition.

Alternatively *Perceived Consequences* highlighted the implications of the condition on the child's and family's future (Deatrick et al., 2009). Families understand the significance of a long-term condition and think about the future. Children, however, may not have well-developed insights about the future implications of their condition, but are aware of how things have changed over time since their diagnosis and imagine they will change in the future within the context of other life events. We can help children and families capitalize on this future-oriented perspective, in future research. For example, having the child look forward to a timem when they can manage their condition more independently, in a positive manner, can be seen as a developmental milestone to be accomplished rather than an unknown.

Research is needed to understand whether the child's perspective regarding Family Mutuality influences the child's ability to manage his/her own condition in the future. If the parents are unwilling to support and change as the child matures and wants to assume more responsibility and gain independence, conflicts may occur to the detriment of child and family outcomes (Coyne et al., 2016). Alternately, the growing child may not have insight into his/her functional limitations which may cause conflicts with parents. Additionally, if sibling conflict causes dissonance regarding the condition, all family members and the family itself may have poorer outcomes (O'Brien, Duffy, & Nicholl, 2009). Siblings were not directly addressed in this study nor was functional ability of the children, therefore, additional research would add insight into these issues.

Our results indicate that additional research is needed to be done to incorporate the perspectives of children into the FMSF and to test this proposed framework. The transactions between parents and children advance our knowledge of family management and child development within the context of condition management. Studies comparing child and parent perspectives regarding family phenomena such as family functioning demonstrate how two perspectives may be different and may generate family conflict and limit child outcomes (Popp, Robinson, Britner, & Blank, 2014). Studies that compare the child and parent perspectives are needed to address questions regarding the impact of similar, complementary, or disparate perspectives and the influence they may have on outcomes.

Limitations

Although this proposed framework is data based, its development was limited by the number of resources available exploring family management from the child's perspective. The data on which the adaptations to the FMSF were limited to a geographical area in the northeast and midwest; the children had at one time or another used the services of large children's hospitals. This homogeneity of child and family experience may have limited the breadth and depth of the experiences recounted. Diversity across conditions did exist, however, children with other conditions may experience other family or condition dynamics. Additionally, the parents were not interviewed, so the perspective of the children could not be contextualized or corroborated.

Data about both school-aged (8–13 years) and adolescents (12–21 years) allowed for a look at their perspectives; questions remain regarding the perspectives of younger children regarding management of their chronic condition. Some of these perspectives may be developmentally inappropriate for the school-aged child but appropriate for adolescents and vice versa. While research with other populations and age groups was helpful, a limited empirical literature exists on which to corroborate the children's perspectives.

Conclusion

The Family Management Styles Framework supports not only the views of parents of children with CHC, but also the perspective of children with CHC. Adapting the framework and definitions to support the child's perspectives is the first step in systematically creating a model that explains the relationship between family management and the individual condition management of the child with a CHC. Overall, the addition of the child's perspective supports the FMSF (Knafl et al., 2012; Hutton et al., 2012). We recognize, however, modifications in the FMSF that allows incorporation of the child's perspective. First, the data reflected these children's developing sense of their own personal view of the condition and their own management in addition to a perspective on family management of their condition. Therefore, Mutuality and Philosophy are family constructs, not just parental concepts. Second, it also considers the child with the condition as an individual participant within the family and looks at Family Management Patterns as the management typology of interest. Third, the Individual Child Outcomes will include not only child functioning but also condition specific management measures (i.e. HbA1C for children with diabetes). Likewise, caregiver/parent outcomes are identified separately for situations where the individual is the primary focus of the intervention. Research examining the child and parent perspectives is needed to better understand the congruence and dissonance these children and families are experiencing. Additionally, larger samples with more diversity both across condition, geography, and age will allow for increased generalizability of findings and model testing. Larger samples will contribute knowledge necessary for development of specific family and child interventions to address both family and child concerns. These interventions can help children with CHCs as they enter adolescence and increase their condition management responsibilities, and they can help parents as they become a family of a teenager and work on launching the young adult.

CRediT authorship contribution statement

Barbara L. Beacham: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing - original draft, Visualization, Supervision. **Janet A. Deatrick:** Methodology, Validation, Writing - review & editing, Supervision.

CRediT authorship contribution statement

Barbara L. Beacham: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing - original draft, Visualization, Supervision. **Janet A. Deatrick:** Methodology, Validation, Writing - review & editing, Supervision.

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