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## Parent-Child Collaborative Decision Making for the Management of Chronic Illness: A Qualitative Analysis

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### Abstract

Parent-child collaborative decision making (CDM) is a potentially important precursor to full decision making independence and may be particularly significant for the management of childhood chronic illnesses. The primary aim of this qualitative study was to explore the concept of CDM from the perspective of children and parents. Children (ages 8-19 years) with asthma, type 1 diabetes, or cystic fibrosis and parents of children with these illnesses participated in focus groups and individual interviews. Participants described various ways they collaborate with one another (e.g., asking for the other's opinion; providing information). Participants viewed collaboration as beneficial, regardless of who ultimately makes the decision. Several factors emerged as potential predictors of CDM, including parent/family factors (e.g., parental time; parent-child conflict), child factors (e.g., maturity; emotional/behavioral functioning), and decision/situation factors (e.g., seriousness of the decision; extent to which the child is experiencing symptoms). These data suggest ways to enhance collaborative decision making interactions between children with a chronic illness and their parents, as well as several areas for future quantitative research.

### Keywords

childhood chronic illness; collaboration; decision making; parent-child interactions; qualitative

### Introduction

The notion of collaborative decision making, or shared decision making, between clinicians and adult patients has garnered widespread approval as a model of decision making in medical settings (Charles, Gafni, & Whelan, 1999). Prior research suggests that collaborative decision making promotes patient health, patient-physician relationship quality, and patient satisfaction (Greenfield, Kaplan, & Ware, 1985; Kaplan, Greenfield, & Ware, 1989; Martin, DiMatteo, & Lepper, 2001; Shields, Franks, Fiscella, Meldrum, & Epstein, 2005).

Less attention has been paid to collaborative decision making between clinicians and children and between parents and children. Parent-child collaborative decision making (CDM) is particularly important, because it may facilitate the transition to greater decision making

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independence during childhood and adolescence. For the purpose of the present study, CDM is defined as the way in which parents and children/adolescents engage each other in decision making and problem solving about chronic illness management. This definition goes beyond a reflection of who makes decisions and, instead, captures a range of potential child and parent behaviors that might occur when a decision needs to be made (e.g., child asks the parent for advice; child and parent negotiate; parent asks for the child's opinion). This approach reflects the view that children can be meaningfully involved in decision making in multiple ways, without necessarily having shared decisional authority, and that parents typically retain a critical role as sources of support and advice, even as children and adolescents assume increasing levels of decision making independence (Fuligni & Eccles, 1993). CDM can be differentiated from the constructs of parent social support and parent involvement because of its focus on decision making and *both* parent and child behaviors. Thus, mutual engagement is considered a key feature of CDM (Beveridge & Berg, 2007).

The aim of the present qualitative study was to explore parent-child CDM for chronic illness management, in a sample of children with asthma, cystic fibrosis, or type 1 diabetes and parents of children with these illnesses. This research has significant implications for the health and well-being of children and adolescents with chronic illness, by seeking to understand how they learn to manage their health independently and effectively. Furthermore, the transition to greater independence may provide the foundation for effective illness management during adulthood, making it a critical area of investigation.

### Decision Making and Childhood Chronic Illness

The ability to make decisions effectively has far reaching consequences for many life contexts. One of the most salient of these is related to the management of childhood chronic illnesses, which affect between 7% and 18% of children (see Schmidt, Petersen, & Bullinger, 2003). The treatment regimen for a chronic illness typically involves requirements to manage diet, activity, medications, symptom monitoring, and response to acute symptoms. For example, the treatment regimen for cystic fibrosis can include chest physiotherapy, aerosol breathing treatments, prophylactic antibiotics, pancreatic enzyme replacement, and increased caloric intake. Challenges can arise when these treatment tasks conflict with other individual or family activities and responsibilities (e.g., what to do when the child is invited to a sleepover).

While parents often retain some responsibility for monitoring, decision making, and assuring adherence to the treatment regimen, these tasks may become challenging as children begin to strive for more decision making independence. This transition can be difficult for families, due to parental anxiety about potential disease complications, as well as the child's resistance to lifestyle changes imposed by the treatment regimen (Wysocki, White, Bubb, Harris, & Greco, 1995) or the child's perception that parental attempts to monitor the treatment regimen limit the child's independence unnecessarily. Prior research with children and adolescents with type 1 diabetes suggests that the transfer of responsibility for diabetes management is often associated with poor diabetes outcomes (Wysocki et al., 1996). Increased decision making independence, without the requisite skills for making decisions effectively, may contribute to the decreases in adherence that are typically seen when children with a chronic illness, including type 1 diabetes, cystic fibrosis, and asthma, reach adolescence (Bender, Milgrom, Rand, & Ackerson, 1998; Miller & Drotar, 2007; Ricker, Delamater, & Hsu, 1998). The way in which families manage the child's transition to greater decision making independence may influence effective self-management for illness-related tasks.

It has been hypothesized that CDM provides an opportunity for children to learn what family members take into account when making decisions, the consequences of different decisions, and the communication skills that are necessary to negotiate and influence decisions (Wills, Blechman, & McNamara, 1996). When independent decision making emerges out of a

collaborative process between parents and children, children may be better prepared to make decisions effectively on their own. CDM has also been addressed in prior discussions of decision making in pediatric settings (Joffe, 2003). For example, some commentators have described ways that children can participate in decision making about treatment or health-related research without having actual decision making authority, such as being provided with information about the decision or expressing an opinion about the decision to be made (Joffe, 2003; McCabe, 1996; Weithorn, 1983). CDM may facilitate open communication among clinicians, parents, and children, increase satisfaction with medical care and cooperation with treatment, and promote the ability to cope with illness (McCabe, 1996).

Parent-child CDM for chronic illness management has received little empirical attention. Related research suggests that children often seek their parents' input or involvement for decisions having to do with treatment or research participation (Broome & Richards, 2003; Dunsmore & Quine, 1995; Geller, Tambor, Bernhardt, Fraser, & Wissow, 2003; Miller, Reynolds, & Nelson, 2008). In addition, Scherer and colleagues (1991) utilized an experimental manipulation to measure the effects of parental influence on children's, adolescents' and young adults' responses to hypothetical treatment dilemmas and concluded that decisions continue to be influenced by parents into young adulthood. These studies suggest that both children and adolescents desire parental input about health-related decisions and are frequently influenced by such input. Prior research also suggests that constructs related to CDM are associated with important outcomes. For example, an intervention designed to increase parent-child teamwork around diabetes tasks prevented the worsening of metabolic control that was seen in the control group after one year (Laffel et al., 2003). In addition, children's perceptions of greater maternal collaboration in coping with diabetes stress was associated with better adherence and metabolic control (Wiebe et al., 2005). Although not focused on CDM per se, these prior studies suggest that the way in which parents and children/adolescents interact around decision making about chronic illness management is an important component of the transition to greater independence. Data related to CDM will help researchers and clinicians to facilitate the appropriate involvement of children and adolescents in health-related decision making and to identify families that may benefit from interventions to improve decision making interactions.

A review of the literature yielded no measures that assess specific ways children and parents engage in CDM about chronic illness management. Existing measures focus on joint decision making by assessing who makes the decision about a variety of daily issues, such as chores and homework (Dornbusch et al., 1985), or disease-specific issues (e.g., when to inject insulin) (Miller & Drotar, 2003). In other words, these questionnaires focus on decisional authority (e.g., child makes the decision alone, parent makes the decision alone, or child and parent make the decision jointly). As such, they do not provide information about *how* responsibility is shared or *how* children and parents interact around decision making about chronic illness management. The aim of this study was to explore the concept of CDM from the perspective of children with a chronic illness (cystic fibrosis, type 1 diabetes, or asthma) and parents of children with these illnesses and to generate items for a new parent- and child- report measure of CDM.

## Methods

### Child Participants

Eighteen children and adolescents with cystic fibrosis ( $n=6$ ), asthma ( $n=3$ ), or type 1 diabetes ( $n=9$ ) participated in the present study. They ranged in age from 8 to 19 years ( $M=12.6$ ,  $SD=3.6$ ) and were predominantly Caucasian ( $n=17$ , 94%). The duration of their diagnosis ranged from 1 to 14 years ( $M=9.2$ ,  $SD=4.9$ ), and 56% ( $n=10$ ) were female. Ten of the child participants had a parent or parents who also participated in the study, while eight did not have a corresponding parent participant.

## Parent Participants

Sixteen parents of children with cystic fibrosis ( $n=6$ ), asthma ( $n=5$ ), or type 1 diabetes ( $n=5$ ) also participated. Parents' ages ranged from 33 to 59 years ( $M=42.1$ ,  $SD \pm 7.7$ ), while their children's ages ranged from 8 to 17 years ( $M=11.1$ ,  $SD \pm 2.4$ ). The majority of parent participants were Caucasian ( $n=14$ , 88%) and mothers ( $n=14$ , 88%). The duration of diagnosis for their children ranged from 1 to 17 years ( $M=8.2$ ,  $SD \pm 3.8$ ). Eleven parent participants had a child who also participated in the study, while five parent participants did not. There were two couples in the parent sample.

## Focus Groups and Individual Interviews

Participants were interviewed by the author in focus groups or individual interviews. Focus groups were chosen as the primary means of data collection, because they allow participants to discuss similarities and differences in their experiences, resulting in a richer discussion. The drawback of focus groups is that comments cannot be attributed to specific individuals, making it impossible to explore if factors such as illness group or age are related to perceptions of collaborative decision making. Because exploring the influence of such factors was not a goal of the study, the use of focus groups was considered the optimal approach for generating a diversity of themes and perspectives. However, individual interviews were used for children with cystic fibrosis because of the need for infection control; they were also used when other members of the scheduled focus group canceled or did not show up for the group. For child participants there were three focus groups ( $n=11$ ) and seven individual interviews. For parent participants there were five focus groups ( $n=15$ ) and one individual interview.

Prior to the first group, an interview template addressing themes related to CDM was developed. The word "collaboration" was not used early in the interviews, to avoid biasing the participants and to encourage conversation about the various ways parents and children interact around decision making. The interview template addressed the following questions: 1) What decisions come up in the management of the illness? 2) To what extent do parents and children involve each other in decisions about treatment? 3) What gets in the way of involving each other in decision making? What makes it easier? 4) Does the child's or parent's involvement change over time? If so, why? 5) What are the benefits and drawbacks of involving each other in decision making? 6) Are decision making interactions different for decisions not related to chronic illness, such as chores, curfew, and activities? If so, why? 7) If someone used the words "collaborative decision making" to describe the behaviors we've been talking about, would you agree with that? Why or why not? Follow-up probes were used as necessary to explore participants' responses more carefully.

The interviewer used the interview template to guide the discussion but asked the questions in an open-ended and nonstandardized manner. This allowed the participants to develop the thematic foci, relate them to their own personal experience, and talk about what was most important to them, increasing the validity of the experiential data (Briggs, 1986; Clandinin & Connelly, 1994). Although probing of specific responses was used frequently, the interviewer avoided interruption, because the thoughts and associations that reflect participants' thinking would be lost in rigid, directive questioning.

## Procedure

The study was approved by the institutional review board. Participants were identified and recruited in one of two ways, between July 2007 and March 2008. Children with diabetes and their parents were recruited from a local diabetes camp and a diabetes family retreat. Children with asthma or cystic fibrosis and their parents were recruited from the Division of Pulmonary Medicine at a Northeast children's hospital. The author contacted potential participants to explain the study and solicit their participation. Those who agreed to participate were scheduled

to complete either a focus group or individual interview. Focus groups for children with diabetes and their parents were conducted at the diabetes camp or during the retreat. Focus groups and individual interviews for children with asthma or cystic fibrosis and their parents were conducted at the hospital. Verbal informed consent was obtained for parent participants, and both verbal parental permission and child assent were obtained for child participants. Focus groups and interviews lasted from one to two hours and were audiotaped. Participants were each given \$20 as a thank you for their time and effort. Immediately following each focus group or interview, the author wrote a memo summarizing the major themes and documenting initial interpretive thoughts.

After being transcribed and anonymized, transcripts of the focus groups and interviews were imported into the qualitative data management program NVivo (Richards, 1999). Memos were also imported into the program. Interviews were conducted until preliminary content analyses suggested that no new themes were emerging from the interviews (i.e., thematic saturation). This strategy ensures that all relevant themes are represented in the data; that is, if another sample were drawn from the same population, the same themes would emerge.

### **Coding and Data Analysis**

The analysis utilized an inductive approach and involved close readings of the text to identify preliminary themes and generate potential items for a measure of CDM. An initial set of codes was developed by the author and created in NVivo, which were refined as additional transcripts were added to the database. The final coding scheme was applied to the remainder of transcripts, and earlier transcripts were recoded to reflect the final coding scheme.

Consistent with standards of qualitative research, the reliability of the data was addressed by the parallel concept of dependability (Erlandson, Harris, Skipper, & Allen, 1993; Lincoln & Guba, 1985). First, a collaborative approach was used in the application of codes to the transcripts and resolution of differences. There was a second coder for a subset ( $n=8$ , 50%) of the transcripts, using the coding structure developed by the author. After the second coder coded each transcript, the author reviewed the double-coding and identified discrepancies in the application of codes. We then met to review, discuss, and resolve the discrepancies. The primary aim of these discussions was to promote better understanding and a shared interpretation of the data (Armstrong, Gosling, Weinman, & Martaeu, 1997). By discussing discrepancies, we identified potentially important theoretical issues relevant to the construct of CDM. Unlike quantitative analysis, which is concerned with the reliable measurement of a construct, qualitative analysis is focused on the identification of themes and the generation of hypotheses. In this context, different researchers are expected to have different accounts of the data. A second way to ensure the dependability of the data was the use of memos to document how codes were determined, how text was interpreted throughout the process, and the interpretations and questions that arose when discussing discrepancies in the application of codes. An audit trail, which includes recorded materials, interview guides and transcripts, notes about research procedures, and memos, was used to document how data were generated and analyzed and how key decisions about coding were made (Lincoln & Guba, 1985).

### **Results**

This section begins with a discussion of the types of decisions parents and children have to make about illness management, followed by the ways in which parents and children engage each other in decision making, how participants viewed the meaning of CDM, the factors that make CDM more or less likely, and the outcomes of CDM. The final section describes the decision making skills that appear to emerge out of a collaborative process between parents and children. Quotes are incorporated to illustrate key themes.

## What Types of Decisions Do Parents and Children Have to Make?

Parents and children described a variety of decisions they face regarding chronic illness management. These include the timing of treatments (i.e., when and how to “fit it in”), determining treatments based on symptoms or other information (e.g., frequency of chest PT; whether to take rescue inhaler; how much insulin to bolus), estimating calories or carbohydrates and using this information to shape treatment (e.g., how much insulin to bolus; how many enzymes to take), weighing the benefits and long-term complications of certain medications (e.g., steroids; antibiotics), determining activities based on current symptoms or potential health consequences, and sharing information about one's illness (e.g., what to share and with whom). Participants' comments suggest that these decisions often were related to specific aspects of the child or family's lifestyle and social functioning, such as peer activities, school and camp attendance, outings with other families, and family vacations. Balancing aspects of the treatment regimen with these activities appears to be an important and frequent task for families.

**Child Participant** We play a game called “Capture” in our neighborhood, and we have, like, 32 kids there ... I can't play that too much in a row, or I really don't feel good the next day.

**Parent Participant** ... for me it's about how I'm going to fit it in, when I'm going to fit it in around school, dance class, Brownies, all the other things that she does, and you don't want to take away those things, just to get your treatments done, but you've got to get the treatments done.

## How Do Parents and Children Engage Each Other in Decision Making?

Parents and children engage each other in decision making about chronic illness management in a variety of ways. For parents, this includes asking the child for his/her opinion or ideas about what to do, asking the child for information (e.g., Are you wheezing? How many carbs did you have?), giving the child options to choose from, suggesting ideas, sharing his/her opinion, sharing information with the child, giving feedback about a decision that was made, explaining his/her reasoning for a particular decision, explaining the pros and cons of different options, and checking for the child's understanding. The behaviors for children are similar and include asking the parent for advice or information, asking questions about a decision, expressing an opinion, suggesting ideas, sharing information with the parent, identifying a barrier or problem related to treatment, and notifying the parent after making a decision. Parents and children also reported that they interact around decision making by negotiating, compromising, and brainstorming together about what to do.

Parents and children also described behaviors that reflect a lack of mutual engagement in decision making. For example, children and parents both reported that children sometimes fail to notify the parent about symptoms. The intent of this failure to notify varies and includes avoiding treatment or activity restrictions, preventing the parent from worrying, and wanting to be strong.

**Interviewer** Why do you try to hide it?

**Child Participant** Because I know they'll try to keep me in more and not let me play as much because they know something is going on, and they want me to rest so it really doesn't get serious.

**Parent Participant** When it's her stomach, she tells me. When it's her lungs, she's not so interested in telling me. And I think part of it could even be because she knows that if she tells me that, she knows what it means when ... her lungs are getting sick. She knows that that means extra treatments and she knows that ... we'll probably end up being sent down here.

Additional behaviors reflecting a lack of mutual engagement include leaving the decision to the other person without discussion, making the decision oneself without discussion, and withdrawing from the decision making interaction. Children also noted that their attempts to engage parents in decision making sometimes result in parental overreaction or unwanted advice.

Participants also described parent behaviors that appear to engage the child in decision making but which both parents and children recognize as empty gestures (i.e., tokenism; Simovska, 2004). For example, both children and parents noted that parents may ask the child what he/she wants to do about a decision, even if the outcome is already decided or the child's input will not influence the decision that is made.

**Child Participant** When we first got the port, my mom was like, “Well, do you want to get this?” Of course, she didn't really mean that, because, you know, she was going to force me to get that anyway.

**Parent Participant** I think ... if I say, “[Child's name], what do you think,” if I ask him, he's happy that I'm including him in making the decision instead of, “[Child's name], go give yourself the albuterol because you know it's time for it” ... of course, we know it's time for a treatment, but asking him, “How do you feel?” ... So trying to make him feel that he's part of that decision, I think he's more willing to go ahead and do it.

As the previous quote suggests, these behaviors on the part of parents are often meant to increase compliance with parental decisions. Parents also shape the information they provide to children so that one option appears unattractive, making the “correct” choice quite obvious.

**Interviewer** Do you ever try to steer them towards a certain choice? And, how do you do that?

**Parent Participant #1** Well, you can make one seem so unattractive. [LAUGHTER]

**Parent Participant #2** Well, for instance, “Okay, it has to happen now or you know what? We've got a hospital admission looming.” That's always ... when you really have to steer.

**Parent Participant #1** “But it's your choice. If you want to go inpatient, okay.”

**Parent Participant #2** But sometimes when it's a big, huge thing and they're really flipping out on you, sometimes it's like, “You know what? These are our choices. I know you're getting extra treatments. I know you don't like it. I'm sorry. I don't really like doing it so much extra myself, either. However, these are the things we need to do, unless, of course, you'd rather go stay in the hospital for a week and get a PIC line.”

### How do Parents and Children Define Collaborative Decision Making?

When asked what they thought about the phrase “collaborative decision making,” parents and children had a variety of responses. Children see collaboration as working together, listening to each other and expressing an opinion, or negotiating/compromising. One teenager noted that collaboration is a “fantasy,” because he and his mother are both stubborn. Parents view collaboration similarly in that they said it meant making decisions together, listening to and respecting each other, and taking the child's opinion into account. They also used the words “team,” “partnership,” and “dance” to describe collaboration.

**Parent Participant** I'd say it's a dance. Sometimes I'm leading, sometimes he's leading a little bit, so it's a collaboration. It's not necessarily even, and it shifts with where he is in terms of his severity.

**Parent Participant** You have the final decision, obviously, because you're the grown-up, so in that sense, it's not collaborative. But the interaction might be. You're always allowed to voice your opinion.

### What Factors Influence CDM?

Children and parents described a variety of factors that influence whether they attempt to engage each other in decision making. For example, parents and children noted that a lack of time decreases the likelihood of parents engaging children in decision making. When there is less time, parents are more likely to be either “dictatorial” (i.e., telling the child what to do) or permissive (i.e., “giving up” and letting the child decide).

**Parent Participant** And, so, sometimes, just for the sake of time, you have to be dictatorial.

**Interviewer** Do your parents ever just kind of say, “Okay, well, it's up to you?”

**Multiple Child Participants** Yeah.

**Child Participant** Yeah, my mom does a lot.

**Interviewer** Yeah? When does that normally come up?

**Child Participant** Anything. Because ... she'll just give up. My mom works a lot, so she's tired a lot ... so my mom will just give up and then I'll feel like, “Okay, well, I didn't really get to discuss this. I don't know.”

Both parents and children noted that they are more likely to engage one another in decision making as the child acquires greater understanding and decision making skill. For children, this is because with greater knowledge and skill, they are less likely to ignore their symptoms and more likely to recognize when they need help with decision making. Similarly, parents recognize that children's increasing knowledge and skills justify a more prominent role in decision making.

Parents and children mentioned a number of other factors that influence the extent to which they engage one another in decision making. Children's comments suggest that they are *more* likely to engage parents in decision making when the parent is open and trusting, the marital relationship is strong, the child desires information, the decision is “bigger,” the child's symptoms are more severe, and the decision situation deviates from what is typical.

**Interviewer** And then what do you do? If you start to feel like you can't fit all the air in? Do you kind of keep that to yourself for a little bit, or do you tell your mom or your dad?

**Child Participant** I'll keep that to myself a little bit. Then when it starts to get, like, severe, then I'll tell my mom.

Parents' comments indicate that they are *more* likely to engage children in decision making when the child is well-behaved and when there are acceptable alternatives involved in the decision.

**Parent Participant** These are the things that the doctors have studied and know that are going to work and I'm definitely doing those things, but when we come to the more elective things that can crop up, then I'm more apt to give her more control over it because I figure if she controls that kind of stuff now, she's going to learn about controlling the other stuff as she goes along, hopefully.



Children's comments suggest that they are *less* likely to engage their parents in decision making when the parent is in a bad mood or tends to worry, there is more parent-child conflict in general, the child wants to avoid treatments or activity restrictions, the child does not want responsibility for chronic illness management, the child tries to be strong, and the child is stressed, anxious, or depressed.

**Child Participant** If I don't feel like thinking about things, I just let them do it.

**Interviewer** You let them decide?

**Child Participant** Yeah.

Parents' comments suggest that they are *less* likely to engage children in decision making when the parent is tired, there are other children in the home, there is more parent-child conflict in general, the child is inattentive, the child is not well-behaved, the child has a learning disorder, the decision is serious, the child is sick or experiencing symptoms, and immediately following a hospitalization.

**Parent Participant** It's not appropriate for her to decide that she's not going to the hospital, when her lungs sound like junk ... and she's been terribly sick, it's not appropriate. That's when it's not appropriate for her to be involved in that decision.

**Interviewer** So it's the type of decision, really.

**Parent Participant** It depends on the decision ... I mean the consequence of her not going in when she really needs to go far outweighs the fact of her not being able to make that decision.

**Parent Participant** I mean, when you're acting out and you're showing me things that are red flags for me to think that you're getting sick, then you know what? Certain decisions I'm not going to give you. Certain ones, I might.

The interviewer also asked if decision making interactions differed for illness-related versus other types of issues. Some parents and children viewed these issues as similar.

**Child Participant** I think it's just another decision to make. I don't think it has any difference from anything else.

**Parent Participant** We manage asthma the way we manage everything else.

Some parents commented that illness-related decisions were just like other decisions but that all decisions vary in terms of their seriousness (i.e., potential negative consequences). Parents noted that their own opinion would have more weight for issues that are more serious, whether these decisions had to do with the illness or not.

**Parent Participant #1** I'd say it's similar to anything that's like really, really important. Like, personal safety, that's really, really important to us, like wearing a helmet, when they do sports or bicycling. It's just like those are just as important as CF treatment.

**Parent Participant #2** Exactly.

**Parent Participant #1** But there's some things I'll be a little more flexible about.

Children also commented that they had more "say" in normative decisions compared to illness-related decisions because they are less serious.

**Child Participant** I don't have to ask them if I'm allowed to be friends with someone, or if I want to start doing something after school ... So, I can make more of the different decisions by myself.

**Interviewer** You can? What makes those different?

**Child Participant** ... the asthma, it's sort of more like a major decision ... I mean, it's not like I'm going to have to go to the hospital because I decided to join some club in school.

### What Are the Outcomes of CDM?

Parents and children noted that there are a variety of positive outcomes associated with collaborative decision making. For children, these benefits include that everyone is happier, that you become closer as a family, that everyone knows what's going on, that there is value simply in being heard, and that it decreases the burden of illness management on the child.

**Child Participant** I think the good things would be everybody knows what's going on then, whereas if my parents just made this decision, I would have no idea. Or if I just made a decision, then my parents wouldn't know.

**Interviewer** Are there good things about collaborative decision making?

**Child Participant** Yeah. When we get together, everybody gets to express their feelings and tell what they're thinking, and everybody puts their ideas in.

For parents, the benefits of collaboration include that it helps the child to become independent by increasing knowledge and decision making skills, that the child is happy to be included, that it increases the child's sense of control, and that it increases compliance.

**Parent Participant** But I think, too, all this negotiation in a way is also helping them become more independent because you're involving them in making choices and knowing what they need to do, why they need to do it, and why certain times are not negotiable.

**Parent Participant** Just making her feel like she's not completely out of control. This thing controls her life, but that she can have a little bit of control in how we handle it, I think, is really good and really important.

Parents also said that engaging children in decision making about chronic illness management is important in and of itself, independent of any positive outcomes. This is because the decisions directly impact the child.

**Parent Participant** I feel it's her life, you know? It's her life. It's not mine. I'm not going through it. I mean, I'm going through it, but, you know, it's [child's name] that's basically going through it.

Similarly, children felt it was important to be involved in decision making because of the impact the decisions have on them.

**Interviewer** When did it become your decision versus their decision?

**Child Participant** It was always kind of my decision because I'm the one who would have to sit through it.

Parents also noted that children have a need for freedom and that they are more likely to involve children in decision making and give them choices as a result.

**Parent Participant** You try as hard as you can, whenever it's possible, for him to play a role in decision making or make the whole decision himself, to let him do it. I think more so than for other kids, we try and make sure we do that. Because there's so many things that he can't decide for himself.

### What Child Decision Making Skills Are Related to CDM?

A number of important decision making skills were discussed by participants, and these skills seemed to emerge out of a collaborative process between children and parents. Children frequently talked about knowing their bodies well, and that this should give more weight to their role in decision making.

**Child Participant** And if there's something wrong with my asthma, then, you know, I know that, and she doesn't usually, and I kind of know when to do something, when to take medicine ...

**Child Participant** It is annoying when they're like, it's like they know. Like, "Oh, well, I can tell that you're ..." You're not inside me. I know how I feel.

Children related their knowledge and experience of symptoms to the ability to communicate with parents and health care practitioners.

**Child Participant** I think probably I can communicate better how I'm actually feeling, like how bad it actually is. They don't have to guess so much, so as I get older, I feel I think about it better ... I know how to describe it better. Like, before, they would have to be like, "Does it feel tight? Does it feel like squeezing? Does it feel like choking?" And now I can just be like, "It feels like whatever." And also I've been through more or whatever, so if it feels a certain way, I can be like, "I think it's probably an infection" or "It will pass."

Even though some children stated that they know their body better than anyone, parents described a lack of awareness on the part of children and noted that they often try to help their children to identify symptoms and link these symptoms to specific aspects of the treatment regimen.

**Parent Participant** It partly for me means making him more aware of how he feels, because his oxygen will be 93, and he's blowing a 55, and you'll say, "How are you feeling today?" And he'll go, "Good. I feel good" [MAKING A WHEEZING SOUND]. And so, it's like, "Huh, there's a little disconnect here." And then, other times, when he's feeling really good, I'll try to point out and say, "Do you remember how you felt last week? Do you feel any different now? Do you feel better?" "No, I still feel good." And it's like, "Hello. There must be something that you feel that's different here." And so, sometimes I'm trying just to get him to connect more, just what's going on with himself and how he feels and can get some feeling within himself of, "I'm not feeling as well."

Children's comments also suggested that children are aware of the consequences of different choices and understand that such consequences should impact the decisions they make about chronic illness management.

**Child Participant** If they're going to the park or to the mall, when I got out of the hospital, I would think, "Well, that's a lot of walking, and that's just going to tire me out, and I'm just not up for it yet." So it's stuff like that that I have to think about ... I'll have a sore throat for the next three days, so I just have to take into consideration what's going to be going on.

However, children were also aware that although they might recognize the consequences of a specific decision, they don't always act on this knowledge in the moment.

**Child Participant** In middle school, I didn't really understand the consequences until after the fact, but then in high school, when I started getting sick more often, I started to think about the consequences before, and I would realize what that consequence was, but sometimes I would just go through with my plans anyway and be like, "Oh, you know, forget it. I'm just going to go out with my friends."

Children and parents also described how parents explain the consequences of different choices.

**Parent Participant** "We just need to keep your lungs healthy. These things will keep your lungs healthy," and [child's name] will say, "Well, if I don't keep my lungs healthy, will I have to go in the hospital?" "Well, yeah, if you don't keep them healthy, you're going to go in the hospital." But I try and talk to her about, "Well, the more you have to go in the hospital, it means the more problems your lungs are having, and that's not good for you."

Children appeared to be aware of their own weaknesses in decision making and to recognize that seeking help from parents or letting parents make the decision is sometimes necessary.

**Child Participant** But my mom thinks things through and thinks of what would happen, so I always ask her for her opinion because she'll think about it more than I will.

**Child Participant** So that's another reason why I get other opinions. Because I know I'm not always right.

Children indicated that they might need additional help when the decision is "bigger," when they are experiencing more serious symptoms, and when the situation deviates from what is typical for the child. Children reported that they feel frustrated when they don't get the advice they need from their parents, such as when the parent insists that the decision is up to the child.

**Child Participant** Sometimes, I'll be like, "I understand it's my opinion, but there's a reason why I'm coming to you. Because I need your answer and your help with it."

**Child Participant** It's kind of like they're almost making it too much your choice when you really do want their opinion –

## Discussion

Parents and children reported a range of decisions they face regarding chronic illness management, most of which occurred on a frequent or daily basis. The decisions they described typically involved some level of uncertainty as to what the best choice or plan of action should be. Such decisions provide frequent opportunities for parents and children to interact around chronic illness management. Parents and children described multiple ways of collaborating, such as sharing information, asking for the other's opinion, and expressing one's point of view. In general, the views of parents and children with respect to decision making interactions were remarkably similar. This data sheds light on what it looks like when responsibility for chronic illness management is "joint" or "shared" between parents and children.

The intent and tone (e.g., warm, hostile; Berg, Johnson, Meegan, & Strough, 2003) of specific behaviors are likely to influence how parents and children respond to one another during a decision making interaction. For example, some children were aware when parental efforts to involve them in decision making were merely empty gestures, and parents also admitted to soliciting the child's choice even though they did not necessarily plan to honor that choice (i.e., "tokenism"). The impact of such strategies cannot be determined from the present study. However, such strategies may make children feel that they don't have a meaningful voice, discourage active involvement in future decisions, or decrease the child's sense of control or

ownership over illness management. It is also possible for a child to have inaccurate perceptions of the parent's intentions or to underestimate the extent to which the parent is willing to consider the child's opinion or change his/her mind based on the child's feedback.

Participants' comments suggest that parents' and children's behaviors influence one another, highlighting the role of reciprocal influence in parent-child decision making interactions (Beveridge & Berg, 2007). For example, when a child shares information about his/her symptoms or treatment with the parent, and the parent responds with anxiety or unwanted advice, the child may be less likely to disclose to the parent or seek the parent's advice in the future. For parents, responding effectively to the child's efforts to interact around decision making may be challenging, especially because of the complexity and emotional weight of illness management. Child behaviors are also likely to influence decision making interactions over time. For example, when children ignore their parents' efforts to engage them in decision making or fail to respond with meaningful input, parents may be less likely to attempt to engage them when additional decisions need to be made.

Parents and children identified several benefits of CDM. One benefit is that there is value simply in being heard, regardless of whether one actually makes the decision. This is particularly salient for children, who typically don't have the final say for many decisions having to do with them. Parents also noted that collaboration is important so that children can experience a sense of freedom, especially because of the burden and multiple demands of having a chronic illness. However, parents described the importance of balancing the child's need for freedom with their responsibility as parents to maintain the child's health. This balance is likely to become more difficult when children begin to strive for increased autonomy during adolescence (Steinberg & Silverberg, 1986). Parents and children also noted that CDM ensures that both the parent and the child have relevant and up-to-date information (i.e., being "on the same page"), which probably contributes to more effective and efficient illness management. However, both children and parents reported controlling or shaping the information they shared with each other in order to produce a more desirable outcome for him- or her- self. Indeed, the control of information may be one way that children try to exert autonomy over decision making.

Parents also reported that CDM provides an opportunity for children to gain knowledge and decision making skills with respect to chronic illness management. Children's comments suggest that they recognize that parents have more knowledge and decision making skill and often seek advice from parents or ask parents to make decisions for them. Specific decision making skills identified as important by parents and/or children included linking symptoms to one's treatment regimen, communicating about one's symptoms to parents and the health care team, being aware of the consequences of different choices and acting on that knowledge, and knowing one's own weaknesses and seeking help when necessary. These skills have been described as components of effective decision making (Byrnes, 2002; Creer, 2000) and are likely to be important in the transition to independent management of chronic illness. Parents described teaching children the consequences of different decisions about chronic illness management and explaining the relationship between symptoms and treatment strategies. Thus, CDM provides an opportunity for parents to model effective decision making and teach specific knowledge or skills, and for children to practice decision making and receive feedback from parents. The provision of choice to children, in the absence of parental advice or support, may be unhelpful in some circumstances and have a negative impact on the decisions children make about their health. Indeed, children reported feeling frustrated when this occurs. This pattern may be consistent with a permissive parenting style and may deprive children of the opportunity to learn effective illness management and decision making skills. This hypothesis is consistent with Byrnes' (2005) summary of prior research related to the development of effective decision

making: “education and scaffolded input from knowledgeable mentors may be more likely to improve decision making than personal experience or vicarious learning” (pg. 34).

### Clinical Implications

The findings from this qualitative research have implications for professionals who work with children and parents in health care settings. For example, symptom recognition and notification of these symptoms to parents emerged as important skills for chronic illness management and often served as a catalyst for parent-child decision making interactions. Children may benefit from guidance from clinicians related to symptom recognition and when and how to notify parents about symptoms. Regular office visits provide an opportunity for clinicians to ask about how the child handled recent symptom flares, identify potential barriers to parental notification, and problem-solve with the child about ways to overcome these barriers (e.g., What did you do when you started to wheeze? What would have happened if you told your Dad? What else might you have done?). Similarly, parents may need support and feedback about the most effective ways to respond to children's notifications and requests for help. For example, children sometimes perceived parents as overreacting or providing unwanted advice. Clinicians can engage parents in conversations about the ways in which their responses may impact the child and strategies that will enhance parent-child collaboration (e.g., How do you typically respond when your child tells you she has been coughing more? Then what happens? What would she say if you asked her for her opinion about what to do?). In addition, it may be helpful for clinicians to teach parents about how they can involve their children meaningfully in decision making, while still retaining decision making authority. The data presented here suggest that parents can do this by asking for the child's opinion, listening to what the child has to say, or providing information about the decision to be made. Indeed, children's comments suggest that it is important for them to be involved in these ways. Parents may also benefit from talking with one another about strategies for enhancing collaborative interactions with their children (e.g., support groups; clinician-facilitated education sessions). For example, in the focus groups some parent participants noted that other parents had helpful ideas; the parent-to-parent exchange of ideas may have increased the likelihood of collaborative decision making at home. Future research is needed to develop and test specific intervention strategies related to enhancing parent-child collaborative decision making.

### Limitations

This study has several limitations. First, the sample was primarily Caucasian, and it is impossible to say if perceptions of CDM would be similar in non-Caucasian ethnic groups. Furthermore, families who consent to participate in research may approach decision making and illness management differently from those who do not consent to participate. Second, the sample size was small, so the findings are not necessarily representative of all parents and children with CF, asthma, and type 1 diabetes. However, the purpose of qualitative research is to explore themes, not to make statistical inferences about the broader population from which the sample was drawn. Third, the sample included a broad age range of children with three different chronic conditions, representing a spectrum of disease duration, severity, and prognosis. While this diversity strengthened the analysis by allowing for a comprehensive picture of the variety of children's and parents' perspectives, it does not allow for the testing of differences between subgroups of children. Both illness experience and illness severity may influence perceptions of CDM and illness management. In addition, the use of focus groups does not allow for the attribution of comments to particular individuals. Therefore, it was impossible to explore if factors such as illness, age, or family structure impacted perceptions of collaborative decision making.

## Directions for Future Research

The present findings suggest four areas for future research: 1) examination of predictors and outcomes of CDM in quantitative research, 2) determination of benefits of CDM at different ages, 3) examination of how CDM varies by decision and situation variables, and 4) development of an instrument to measure CDM. First, potential predictors and outcomes of CDM should be explored in a quantitative study. An examination of predictors will shed light on why families vary with respect to CDM and identify those who might benefit from education or support related to parent-child decision making interactions. An exploration of the outcomes of CDM will increase our understanding of the impact of CDM on adherence, decision making skills, and health-related outcomes such as hospitalizations, ER visits, lung functioning, and metabolic control. Second, it will be useful to determine the specific aspects of CDM that are most helpful across different development stages. This developmental perspective is important for understanding how children become more independent with respect to decision making and necessitates longitudinal research. Such longitudinal research can also be used to examine how parent and child decision making behaviors influence one another over time and how the benefits of CDM vary based on multiple child, parent, or family characteristics. For example, a collaborative decision making process may be less effective when either the parent or child is anxious or when the parent lacks effective decision making skills. This needs to be tested in future research, so that interventions tailored to subgroups of patients/families can be developed. Third, future research should explore how CDM varies by decision and situation characteristics. Daily illness management decisions may be handled differently by families compared to less frequent decisions. For example, decisions about participation in clinical research may not be familiar to parents and children. Future research should examine the extent to which parents and children collaborate around research decisions and other less frequent decisions (e.g., medication changes; elective surgery). Such data will help researchers and clinicians facilitate appropriate involvement of children in a range of decisions that may occur in relation to chronic illness management.

Fourth, in order to undertake such quantitative research described above, a measure of parent-child CDM is needed. A study to develop a parent- and child-report questionnaire of CDM is currently underway. Items were derived from both a literature review and the qualitative data described here. The experimental form of the questionnaire, as well as additional measures of child-, parent-, and family-level variables, are being administered to children with asthma, CF, or type 1 diabetes and their parents. The final instrument will be used in future longitudinal research to examine how CDM changes over time, identify the developmental mechanisms that underlie such changes, and examine various predictors and outcomes of CDM. Such data will be clinically useful to professionals who interact with children and parents around health-related decisions in various contexts. For example, data utilizing the new measure of CDM will lead to the development of intervention strategies to enhance parent-child decision making interactions about chronic illness management at different ages.

## Summary

In sum, this study adds to the literature related to chronic illness self-management, by exploring parent and child perceptions of how they interact around illness-related decision making. Parents and children identified multiple ways of collaborating, and they viewed collaboration as important and beneficial. In particular, CDM between parents and children may facilitate skill acquisition and treatment adherence. A variety of factors emerged as potential predictors of CDM, suggesting that there is significant variability both within and between families with regards to CDM. These findings suggest that families may benefit from guidance from clinicians regarding symptom recognition and notification, effective ways of responding to each other's decision making behaviors, and strategies for enhancing children's meaningful involvement in health-related decision making. Future quantitative research is needed to

determine predictors and outcomes of CDM, to develop intervention strategies to improve parent-child decision making interactions, and to facilitate the appropriate involvement of children in health-related decision making at different ages.

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