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Getting them ready: The descriptive nature of parental beliefs, values, and behaviors around supporting the development of health-related skills in adolescents with cystic fibrosis

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Getting them ready: The descriptive nature of parental beliefs, values, and behaviors around supporting the development of health-related skills in adolescents with cystic fibrosis

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Education

by
Jessica Rose Oviatt

Dissertation committee members:
Distinguished Professor Jacquelynne Eccles, Chair
Professor Sandra Simpkins
Assistant Professor Rachel Goldberg

2020

DEDICATION

To my husband and children in recognition of the sacrifices made and for the endless support.

To the families that shared their stories with me so I that could share them with the world.

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VITA

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ABSTRACT OF THE DISSERTATION

Getting them ready: The descriptive nature of parental beliefs, values, and behaviors around supporting the development of health-related skills in adolescents with cystic fibrosis
by
Jessica Rose Oviatt
Doctor of Philosophy in Education
University of California, Irvine, 2020
Distinguished Professor Jacquelynne Eccles, Chair

Background: Advances in medical care and treatment options have extended the life expectancy of millions of youth with chronic conditions. This change in prognosis has led a majority of these youth to eventually transition from pediatric to adult medical care. This transition can be difficult as evidenced by declines in adherence after transitioning as well as reported struggles between parents and youth. Less is known about how specifically parents and youth prepare for adulthood or about the beliefs they have around becoming an adult with a chronic condition. What are parents thinking about for their children as they teach them to manage their condition?

Method: This mix-method study used survey and interview data from families receiving care at a pediatric cystic fibrosis clinic. All eligible primary caregivers completed an online survey during a routine clinic visit. The full sample consisted of 38 parents while a sub-sample of 9 parents were randomly selected and took part in a phone interview.

Results: Parents reported a variety of important skills such as medication and treatment related skills as well as their worries with compliance being the most commonly discussed parental worry. Parents are doing a variety of things to address their skills and worries, with talking and teaching being the most prevalent reported behaviors. They reported on their child’s ability at specific tasks and the value they had for each task. Parents also discussed many factors that influence what they are doing around self-management and what successful management meant to them.

Conclusions: Understanding the beliefs, worries, and behaviors of parents has major implications for thinking about transitioning such as the role parents play as teachers/supporters. Healthcare professionals now have a more nuanced way to think about what families are doing in order to provide more effective resources and support to families.

CHAPTER 1

Introduction

Advances in medical care and treatment options have extended the life expectancy of millions of children and adolescents with chronic conditions (Compas, Jaser, Dunn & Rodriguez, 2012). This change in prognosis has led a majority of these youth to eventually transition from pediatric care to adult medical care once they reach a certain age. This transition can be difficult on both the youth and parents as evidenced by declines in adherence to medication after transitioning (Crowley, Wolfe, & McKee, 2011; Pai & Ostendorf, 2011) as well as reported struggles between parents and youth as the division of responsibility of care shifts from parent to youth (Iles & Lowton, 2010). Previous research has primarily examined the transition process with a focus on medical compliance during and after transition (Pai & Ostendorf, 2011), changes in parental and youth roles during and after transition (Iles & Lowton, 2010; Tuchman, Slap, & Britto, 2008), and the evaluation of effective transition programs (Gravelle, Paone, Davidson, & Chilvers, 2015; Schwartz et al., 2013).

Less is known about how specifically parents and youth prepare for adulthood or about the beliefs they have around becoming an adult living with a chronic condition. What do parents think is important for their children to know and what are they doing to teach their children to manage their condition? Parents and youth may have specific beliefs and values around self-management skills and they may engage in a variety of behaviors around learning to self-manage. These beliefs and behaviors may promote positive health outcomes. Bucks and colleagues (2009) found that youths' beliefs about treatment predicted their engagement in health behaviors. However, more work is needed on the role these specific health beliefs play in influencing how parents and youth prepare for becoming an adult with a chronic condition. The positive link between self-efficacy and treatment adherence is evidenced by research (Iannotti et al., 2006; Skelly, Marshall, Haughey, Davis, & Dunford, 1995), and further supports the importance of understanding the relationship of ability beliefs to engaging in certain health behaviors. To date, there is little research examining the beliefs and values parents have regarding the self-management skills of their child and the ways those beliefs influence how parents engage in teaching those skills to their children with a chronic condition. Given that parents play an important role in preparing their children to become adults (Kuczynski, Parkin, & Pitman, 2015), knowing more about the beliefs and values they have related to the skills necessary to successfully transition to adult care will help practitioners working with these families to improve their overall transition processes as well as the experiences of the families and youth they serve. To understand more about the role parents' play in preparing their youth with a chronic condition for adulthood, it is important to first focus on what chronic conditions are and then in how families think about transitioning.

Cystic fibrosis

Similar to many researchers, Compas and colleagues (2012) define chronic conditions as any condition that requires regular care from healthcare professionals and disrupts youths' abilities to partake in age-related activities. Cystic fibrosis (CF) is a genetic chronic condition where thick mucus impairs lung and pancreas functioning often resulting in complex treatment regimens, persistent infections, and premature death. To manage CF, most youth must take inhaled medicines and undergo airway clearance treatments that help thin and loosen mucus in their lungs twice a day, take additional medications and enzymes to help with digestion at every snack or meal, and take antibiotics or other medications to help with infection and inflammation (American Lung Association, 2017). These youth are also followed closely by their pulmonologists requiring multiple appointments and routine tests. Advances in treatment options and research have significantly prolonged the average life expectancies for most youth with CF to an average of 40 years of age (American Lung Association, 2017); thus, many will live into adulthood and need to transition from pediatric care to adult care centers. In the current work, I focused on this specific population of youth with CF and their caregivers given the chronic nature and unique treatment demands of this condition. I investigated what parents of these youth think about in terms of getting their children ready to be adults with CF and eventually move to adult health care.

Transitioning

What does 'transitioning' mean in this particular experience? For the purposes of this study, it encompassed families with a youth who has a chronic health condition having to move from the pediatric health care system to the adult health care system. When this move is necessary is often determined by either the facility or most often, the legal age of the youth (i.e., 18 years of age or 21 years of age). Additionally, many health care facilities offer some sort of program geared towards assisting with the move. Transitioning as a construct has been studied in a variety of ways.

Many researchers have examined the transition process in terms of effectiveness of existing programs or evaluations of new programs from families' perspectives(Schwartz et al., 2013). Additionally, families are often asked to report on how they think the transition process went for their child and themselves (Iles & Lowton, 2010; Tuchman et al., 2008) and the transition process is often studied as a distinct event in time. Thinking about transitioning as a developmental process was an interesting idea that resulted from discussions with parents (Reiss, Gibson, & Walker, 2005). Previous research with participants in focus groups with youth, families, and medical providers discussed the developmental nature of the transition process (Reiss et al., 2005). According to participants, the transition process was divided into 3 stages: “envisioning the future”, “age of responsibility”, and “age of transition” (p115). Initially, youth and families had to come to terms with the diagnosis and its implications for the future of the youth. The following stage was then seen as the time when families actively taught youth the skills necessary to function independently in the future and begun to shift responsibilities. Finally, youth reached the legal age of transitioning from pediatric to adult care.

As with any developmental process, progression through can be influenced by multiple factors such as delays in other areas of development or type of chronic condition (Reiss et al., 2005). Given that the actual transition event is a short period in time and I am interested in the development of health-related skills, this work was situated more in the period leading up to transitioning and not on the transition process itself. In the current work, I examined what parents and youth believed about and were doing during this extended preparation phase in terms of getting ready to be an adult with a chronic condition.

In addition to parents viewing the transition process as developmental, research with these families supported the conclusion that youth and parents generally feel that the shift in responsibility should begin before youth entered adolescence (Foster et al., 2001; Reiss et al., 2005). Across numerous studies, increasing age was related to taking on more responsibilities for self-care for a chronic condition (McQuaid et al., 2001; Psihogios & Holmbeck, 2013; Walders, Drotar, & Kercsmar, 2000). Additionally, longitudinal work found that children took on more responsibility over time as reported by both parents and youth (McQuaid et al., 2001). These developmental trends can appear as gradual shifts in who was claiming responsibility for completing the tasks or as shifts in parental roles (e.g., manager to assistant role) (Iles & Lowton, 2010). Perhaps for parents, transitioning is a much slower process that begins early and continues after the move to adult health care. To parents transitioning may be defined more in terms of how well they think their child has mastered the necessary self-management skills needed to survive in adulthood. It is not hard to imagine that when the shift is dictated by a legal age as opposed to mastery of skills, problematic health outcomes arise.

When considering the transition process, evidence supported poorer disease management and adherence during and after transitioning to adult care (Pai & Ostendorf, 2011). One hypothesis as to why declines were seen after transitioning was that youth were not prepared for the new adult environment as well as they needed to be. From a socialization viewpoint, perhaps there is something missing from how youth with chronic conditions are being prepared to be adults. One factor influencing this socialization process might be the general and child specific beliefs parents have and how those beliefs are impacting their preparation behaviors. If for example, a parent believes that their child is good at taking their medications already, they may not reinforce taking medication behaviors and so when it is time for the young adult to do it on their own, they may not have a repertoire of skills to draw upon in times of difficulty. Further discussion on parent’s beliefs, goals, and expectations for this unique aspect of preparing for adulthood is warranted so that we may understand adherence, self-management, and health-related outcomes better. While each chapter provides a review of the work relevant to that particular section, I felt it necessary to first discuss the overarching theories that supported the current work at a foundational level.

Theoretical frameworks

Two main theories provided foundational support to the current work: The Family Management Style Framework and the Expectancy Value Theory of Achievement Related

Behavioral Choices. One provided a broad way of thinking about families and how they might incorporate a chronic condition into their daily life. The other provided a more individual level way of thinking about the unique beliefs of parents and how those beliefs influence behaviors. Both a broad level view and an individual level view were necessary to think about parenting a child with a chronic condition especially as it relates to getting them ready to manage their health as an adult.

General theory on managing conditions

The Family Management Style Framework (FMSF) was introduced as a way to think about how families responded to health-related challenges and how they incorporated these challenges into their everyday lives (Grey, Knafl, & McCorkle, 2006; Knafl, Deatrick, & Havill, 2012). It is important to understand the ways in which families manage a child's condition as research supported that how well families adjusted was associated with how well a child adjusted to illness (Grey, Knafl, & McCorkle, 2006). According to the FMSF, there were three components that described the overall management process: 1) Defining the situation, 2) Management behaviors, and 3) Perceived consequences (Knafl, Deatrick, & Havill, 2012). These components all work together to describe why and how families managed to integrate a child's condition into their daily lives. Cystic fibrosis is a chronic condition that must be managed throughout the entire life of the child. Due to its unique treatment demands and chronic nature, families with a child with cystic fibrosis must often enact some form of family management strategies.

Defining the situation has multiple sub-components including a) child identity, or parental views of the child in terms of abilities versus weaknesses with focus on the condition or focus on the child, b) views of the illness, or the beliefs parents have regarding the condition itself and associated outcomes, c) management mindset, or how efficacious parents feel about managing the condition, and d) parent mutuality, or the beliefs parents have in relation to their partner's beliefs about managing the condition (Knafl, Deatrick, & Havill, 2012). Families can come to terms with the condition and define it in different ways and thus manage it differently. Parents can vary on the sub-components within individual families as well as across families. For example, both parents might feel competent at doing the daily treatment regimen (i.e., positive management mindset) and view their child as having more abilities but if one parent fixates on the condition and not the child (i.e., child identity), different management outcomes could result.

The second component, management behaviors, has two parts: a) parenting philosophy, or the goals, expectations, and beliefs that guide parents' approach to managing a chronic condition, and b) management approach, or parent's thoughts about how well they have initiated a routine and the other strategies they have for incorporating the condition into family life. Finally, the third component of perceived consequences is comprised of a) family focus, or the evaluation of how well the condition has been integrated into the family, and b) future expectations, or the parent's assessment of the condition and its influence on their child's and the family's future (Knafl, Deatrick, & Havill, 2012). Similar to how a family defines a condition, there are implications for how a family engages in management behaviors and the futures they see for their families as to how they enact family management strategies.

Interview data analyses supported the presence of the components of the FMSF across different ages and a variety of conditions (Obrecht, Gallo, & Knafl, 1992; Rempel, Blythe, Rogers, & Ravindran, 2012; Wollenhaupt, Rodgers, & Sawin, 2012). A family management scale was also constructed based on qualitative work and both interview and scale data supported that unique patterns existed in how families managed their child’s condition (Knafl, Breitmayer, Gallo, & Zoeller, 1996; Knafl et al., 2013). These patterns (e.g., thriving or floundering and family focused or condition focused) were associated with family and child functioning and child adaptation (Knafl et al., 2013) as well as social competence and life satisfaction (Deatrick et al., 2006). When a family used management behaviors that were more family focused and had more confidence in their abilities to manage, they were more satisfied with life and had overall better family functioning. Additional work applying the FMSF to study parental behavior supported that parents’ perceptions of their ability to manage and the amount of effort it took to manage the illness influenced rates of hospitalizations and school absenteeism (Gibson-Young, Turner-Henson, Gerald, Vance, & Lozano, 2014). For example, parents that felt confident that they could manage their child’s condition had youth with lower missed school days and hospitalizations.

In summary, this framework attempts to address multiple factors within the family that influence management of a condition, with primary attention focused on parental beliefs and behaviors. Many of the sub-components of this model focus on parental beliefs in some capacity lending support for the importance of those beliefs to how families initiate and maintain the management of a chronic condition in their everyday lives. The parental beliefs stressed in the FMSF were hypothesized to operate at a more general level and be influenced by broad contextual factors (e.g., religion or society’s view of chronic illness) (Knafl, Deatrick, & Havill, 2012). Also, the FMSF management behaviors were more situated in broad views of parents’ overall approach to managing a condition (Deatrick et al., 2006), with less focus on those management behaviors at the level of every day or the individual. Riekert and Drotar (2000), argued that global measures of adherence often do not capture all the patterns of adherence. For example, if a person is fully adherent to taking medication but is not at all adherent on diet and exercise, when you aggregate all those aspects to give a global adherent score, you lose vital information that could help increase adherence to particular tasks. This issue of global measures also applies to the FMSF. Although it is useful for understanding, in general, how families manage and what patterns they exhibit; it is also important to understand family management from a task specific level if we want to intervene with families that are struggling. I drew upon one other theoretical framework for this more nuisance level of description (i.e., the level of specific tasks or behaviors).

Skill specific theory for making behavioral choices

The Eccles et al., Expectancy Value Theory of Achievement Related Behavioral Choices (EV theory) is a model of motivation that focuses on how well children believe they will do on a specific task in the future and the value the child places on the task (Eccles, Wigfield, Harold, & Blumenfeld, 1993b). The two components, expectancy and value, are represented by self-concept of ability or a child's beliefs about their abilities on a given task and subjective task value or the value a child places on a specific task (e.g., attainment and utility value) (Eccles et al., 1993b). Additionally, the E-V theory has components meant to describe the influence of important socializers on youth's motivational beliefs and behaviors (Simpkins, Fredricks, & Eccles, 2015b). This influence was hypothesized to occur through parent's general beliefs, parent's child specific beliefs, and parental behaviors (i.e., activity specific behaviors and role-modeling) (Eccles et al., 1993b). While this theory has been mainly examined for academic domains (e.g., math), it may be relevant to a variety of health-related skills that prepare a youth to become successful adults living with a chronic condition.

It has been primarily used with academic domains however, less is known about the application of this theoretical framework to health-related behavioral choices. One might argue that learning and then mastering self-management skills could be a unique achievement context for youth with CF, especially if achievement is conceptualized as gains in knowledge and successful completion of specific skills. If youth with CF and their parents view mastery of these self-management skills as a form of achievement, it would support the use of the E-V theory constructs in the study of parental beliefs and behaviors with child beliefs around transitioning to adult care. Also, one could imagine that parents might hold different beliefs about their child's abilities for different medical tasks as well as view certain medical tasks as more important or useful for their child's future. Additionally, youth may have differential views of abilities and values for given medical tasks.

Parental beliefs, both general and child specific, regarding a particular domain have been shown to influence their behavioral engagement in activities around that domain (Simpkins, Fredricks, & Eccles, 2012). Parental behaviors (i.e., encouragement and co-activity) then further predict child beliefs about those domains. For example, it has been shown that parental encouragement of physical activity predicted to not only the child's actual levels of physical activity but their intentions to be physically active as well (Biddle & Goudas, 1996). Additionally, parental beliefs about their child's abilities on a task influenced their child's own ability and value beliefs as well as actual task participation by the child (Simpkins et al., 2012; Simpkins, Fredricks, & Eccles, 2015a). Finally, research supported that a child's self-concept of ability beliefs and subjective task values predicted to future achievement (Eccles et al., 1993b). This suggests that parental ability and value beliefs serve as powerful predictors of parental behaviors as well as youth beliefs and behaviors. In the current work, I aimed to learn more about the ways in which parental beliefs and values influenced how they engaged in health-related behaviors meant to prepare youth to become adults with CF.

Summary

As youth with chronic illness continue to survive into adulthood, the need for a better understanding of how they are prepared for that phase is vital. It is important to think about the manner in which a family addresses a chronic illness as well as parental beliefs and behaviors as they related to that chronic illness. Knowing more about the parenting process of this unique aspect of some adolescents can inform many professionals who work with youth with a chronic illness and their families. How can we improve the self-management teaching process for these families so that young adulthoods with conditions thrive in adulthood? What can we learn from parent's beliefs and behaviors that might aid in this goal?

In the following chapters, I will explore the findings of a study and discuss the ways parents are thinking about and behaving towards the concept of preparing their youth to self-manage their health. I start by providing a description of the study itself. Next, I will move to parent self-reported goals and worries. Followed by an exploration of parental health beliefs, both general and child specific, and then parental behaviors as they relate to teaching their youth self-management skills.

CHAPTER 2

The study

In this chapter, I outline the study in detail and discuss the construction of the survey, interview guide, and study participants. Before exploring the participants across a variety of descriptive statistics, I will spend some time describing how the study came to be, the study procedures, and survey construction.

The research partnership

I reached out to a multi-disciplinary medical team at a local children's hospital to collaborate on this research. The team consisted of a pulmonary doctor, a CF trained psychologist, a CF nurse manager, a CF nurse coordinator and me, as the researcher. The team regularly met and were responsible for input on questionnaire and study details. The purpose of the study was twofold, I as a researcher was interested in learning more about what parents were doing to help teach their children the necessary skills to manage their health as adults and the medical team was interested in improving the transition services they provided to youth and families. Our collaboration afforded both our interests to be explored and informed. The medical team was primarily involved in study formation and data collection. They helped generate a list of necessary skills youth needed to master to successfully manage their own health and then helped reduce the list to a select important few skills for the study.

While the research team members had input on the entire questionnaire, their feedback and attention were focused primarily on creating the health-related skills to be studied and the behaviors associated with those skills. To ensure that the questionnaire was valid and sound in terms of research standards, I sought out feedback throughout its creation from academicians and research scientists. Their feedback was extremely valuable in creating a survey that would not only address the concepts of interest but that was also as clear and understandable as possible. I performed content validity checks, item reliability checks, participant survey fatigue and burden, and overall survey organization. The resulting survey took over a year to create and revise. The survey is discussed in further detail below in the order it was presented to participants.

Survey

General health beliefs. Parents were first asked 19 broad general health belief items. I wanted to acknowledge that once I asked a parent to think about their child with a chronic condition, it might be difficult for them to think more generally. With this in mind, the general health beliefs were asked first.

Health control beliefs. Overall attitudes towards health and managing health were represented with three items "How much control do people have in managing their health?" (1= *No control;* 5= *Full control*), "How well can medicine, if prescribed, manage health?" (1= *Not well;* 5= *Very well*), and "How important is doing what the doctor says to staying healthy?" (1= *Not important;* 5= *Very important*). These items were created for this study and informed by previous work on perceived control and health (Furnham and Forey, 1994; Moss-Morris et al., 2002). Researchers interested in perceived control and health behaviors have typically measured participants views of self-control or personal control, treatment control, and provider control over health (Furnham and Forey, 1994; Moss-Morris et al., 2002). My items were generated to address each of these three areas of health control (e.g., treatment control is represented with the item "How well can medicine, if prescribed, manage health?").

Self-efficacy and outcome expectancy. Health-related self-efficacy and outcome expectancies were assessed with 6 items on general illnesses (e.g., cold and flu). The items for outcome expectancies were "If a person is sick, how much will going to the doctor help them get better?” (1= *Not much;* 5= *A lot*), “If a person does everything the doctor recommends for treating an illness, how much will their health improve?” (1= *Not much;* 5= *A lot*), and “If a person takes the medicines as prescribed, how much will their symptoms improve?” (1= *Not much;* 5= *A lot*). Heath-related self-efficacy beliefs were “Please choose the response that best shows how confident you are that you can… a. Tell when you are getting sick, b. go to the doctor when illness symptoms get worse, c. do all the things the doctor tells you to do as part of treatment.” (1= *Not at all confident;* 10= *Very confident*). Although, these six items were also newly created for this study, they were informed by previous work on measuring self-efficacy (Bandura, 2006). Bandura (2006) offered researchers guidance in creating self-efficacy scales, discussed content validity and response scales, and provided numerous examples of scales in the appendices. This paper was referenced to construct the self-efficacy scale used in this study and I followed many of the suggestions when creating these items.

Family management. Ten items from the condition management ability scale of the larger family management measure (Knafl et al., 2009) were included in the survey to examine how families view their ability to manage their child’s condition. All items have a 5-point response scale (1= *Strongly disagree* to 5 = *Strongly agree*). The items were “In the future we expect our child to take care of the condition.”, “We have some definite ideas about how to help our child live with the condition.”, “It’s often difficult to know if we need to be more protective of our child.”, “We have not been able to develop a routine for taking care of our child’s condition.”, “When something unexpected happens with our child’s condition, we usually know how to handle it.", “We feel we are doing a good job taking care of our child’s condition.”, “It is difficult to know when our child’s condition must come first in our family.”, “We often feel unsure about what to do to take care of our child’s condition.”, “Despite the condition, we expect our child to live away from home in the future.", and "We have goals in mind to help us manage our child's condition". This scale has been psychometrically tested numerous times and found to be reliable and valid (Knafl et al., 2009).

Parental values and worries. Next, parents were asked a series of open-ended response items about things they viewed as valuable to learn and their worries for their child in terms of becoming an adult with CF. The value items were "What are some important health-related skills/things you feel your child should know/or be able to do as they become an adult with CF?" and "What are some things you are doing to help your child improve at these skills/things?" The worry items included "What are some things you are worried about with getting your child ready to be an adult with CF?" and "What are some things you are doing to prevent these worries from happening to your child?" These questions were asked before parents were introduced to the skills that the team felt were important in the attempt to get unbiased reports of values and worries from parents. Parents were given the option of putting up to three responses for each item.

The skills. Five transition-related CF self-management skills were chosen based on previous work and collaboration within the research team. I initially created a list of CF-related self-management skills derived from the CF R.I.S.E Milestones document (Nelson, 2016) which was then trimmed down by the team into three sub-skill domains with 4 skills per domain (i.e., medicine, doctor, and lifestyle). However, once the questionnaire was created with all items, the team decided to remove some skills to reduce participant burden. The reduction resulted in two sub-skill domains (i.e., medicine and doctor) with a total of 5 skills.

The final set of skills were: 1. doing airway clearance treatments on their own, 2. taking enzymes on their own, 3. tracking medication refills on their own, 4. tracking symptoms to share at appointments on their own, and 5. answering questions asked by the doctor during appointments on their own. ‘On their own’ was defined and presented to participants as without help or a reminder from an adult. For study purposes in understanding what parents are doing with their youth at home to teach health self-management, I wanted to distinguish between those parents who were actively working on the skills and parents who have youth who had already mastered it. This was done because I assumed that for parents with youth already doing the skill on their own there might be significant recall bias especially if the length of time between when they taught their youth the skill and the survey was years.

To this end, each skill had a beginning question meant to divide responders for that question into two groups: 1. Those youth doing the skill independently and 2. Those youth who not doing the skill on their own. For example, “Does your child … [do their airway clearance treatments/take enzymes /track medication refills/track symptoms to share at appointments/answer questions asked by the doctor during appointments] 90-100% of the time on their own?” (1 = *Yes* ; 0 = *No*). If a parent replied yes, their child does the skill on their own, they were only asked the self-concept of ability, attainment, and utility items. If a parent selected ‘no’ their child is not doing it on their own, they were asked child-specific ability, value, and cost items as well as questions on their own abilities and behaviors around teaching the skills as parents.

Child-specific beliefs. For this research, child-specific beliefs were conceptualized based on the self-concept of ability (SCA) and subjective task value (STV) beliefs found in Eccles’ expectancy - value theoretical framework. Work using the E-V theory in academic and non-academic domains has supported the relationship between ability and task value beliefs and behaviors (e.g., Simpkins et al., 2015b). The self-concept of ability and task value scales have shown high reliability in multiple studies (e.g. Archambault, Eccles & Vida, 2010). With this in mind, one of the underling goals of this work was to think about how health-related ability beliefs and task values might influence health behaviors. Because one goal of this study was to examine the application of a theoretical framework not typically used in studying health domains, I wanted to keep the modified items as close to the original items as possible. As seen in Table 1, the E-V theory measures were modified by replacing the academic domain with a transition-related skill (e.g., "doing airway clearance treatments on their own" replaced "math"). The modified E-V items were reviewed by a group of researchers currently using the E-V theory in their work and underwent multiple revisions based on their feedback.

The final questionnaire had one SCA item and four STV items asked for each health-related skill. Self-concept of ability was measured with "How good (will) is your child (be) at … [doing their airway clearance treatments/taking enzymes /tracking medication refills/tracking symptoms to share at appointments/answering questions asked by the doctor during appointments] on their own?" (1= *not good*; 5= *very good*). The 'will your child be' ability question was presented only if their child had never tried to do the skill on their own. The four subjective task value components were measured with Likert scale items (i.e., attainment, utility, and cost). Subjective task value items for utility and attainment were prefaced with "For the following questions please think about getting your child ready to be an adult with CF:" then "How useful is … [doing their airway clearance treatments/taking enzymes /tracking medication refills/tracking symptoms to share at appointments/answering questions asked by the doctor during appointments] on their own to your child?" (1= *not useful*; 5= *very useful*") and "How important do you think being good at … [doing their airway clearance treatments/taking enzymes /tracking medication refills/tracking symptoms to share at appointments/answering questions asked by the doctor during appointments] on their own is for your child?" (1= *not important*; 5= *very important*").

The cost items were only asked to parents who had children that had not started learning the skill yet or if they selected 'not good' or 'a little good' on the self-concept of ability item. It was decided that the cost items were most appropriate for parents who had not started teaching or were in the active stage of teaching their child the self-management skills. Cost items were "How much effort will it take you to help your child learn to … [do their airway clearance treatments/take enzymes /track medication refills/track symptoms to share at appointments/answer questions asked by the doctor during appointments] on their own?" (1 = *no effort*; 5 = *a lot of effort*) and "How much time will it take you to help your child learn to … [do their airway clearance treatments/take enzymes /track medication refills/track symptoms to share at appointments/answer questions asked by the doctor during appointments] on their own?" (1 = *no time at all* ; 5 = *a lot of time*).

Table 1

Original and Modified Expectancy-Value Theory Items

	Self-Concept of ability	Scale	Subjective task value	Scale
Modified item	How good is your child at (transition-related skill)?	1= not at all good; 5=very good	How important do you think being good at (transition-related skill) on their own is for your child?	1= not at all important; 5=very important
	--	--	How useful is (transition-related skill) on their own to your child?	1= not at all useful; 5=very useful
	--	--	How much time will it take you to help your child learn to (transition-related skill)?	1= No time at all; 5= A lot of time
	--	--	How much effort will it take you to help your child learn to (transition-related skill)?	1= No effort; 5=A lot of effort
Original item	How good is this child at (sports/music/math/reading)?	1= not at all good; 7=very good	How important is it to you that this child do well in (sports/music/math/reading)?	1= not at all important; 7=very important
	--	--	How useful do you think each of these activities (sports/music/math/reading) will be to this child in the future?	1= not at all useful; 7=very useful
	--	--	How much does the amount of time you spend on math keep you from doing other things you would like to do?	1= not at all; 7= very much

Parental behavioral engagement. What are parents doing to help their child learn to master health-related skills? Are there specific behaviors they are engaging in as they teach? Parents were asked a series of skill-specific predetermined behaviors and how often they engaged in those behaviors with their child. For example, “For their airway clearance treatments please indicate how often in the last week you encouraged your child: a. to get everything ready to begin on their own, b. to do their full treatment on their own, c. to clean their equipment after on their own.” (1 = *Never* ; 5 = *Every time*). In addition to the three choices listed above parents were given an option to write in a behavior of their own if they wanted and the frequency with which they engaged with that behavior. Finally, I wanted to explore how parents might be working collaboratively with their child in the process given what is known about shared responsibility in health management being optimal (Duncan et al., 2013). Parents were asked “How often do you and your child … [do their airway clearance treatments/take enzymes /track medication refills/track symptoms to share at appointments/answer questions asked by the doctor during appointments] together as a team so they can learn to do it on their own?” (1 = *Never* ; 5 = *Every time*).

Each skill had three behaviors asked of participants that were unique to the skill and were created to be as concrete and specific as possible. The goal was to have general behaviors that most families would be doing while also having very clear concrete behaviors to help with participant understanding and response. These behavioral items were presented to the team and based on their feedback were modified until approved by all members. For example, the team decided that the best way to divide up doing airway clearance treatments was to first get the material ready, then to do the actual treatment, and finally clean up the equipment after. Please see Appendix A for a list of all the pre-determined behaviors.

Background information. The concluding portion of the survey included obtaining background information on the parent and then the child. The descriptive parent items were gender, occupation, ethnicity, age, current marital status, highest level of education, and averagely yearly household income. Next parents were asked a series of questions specific to their child with CF. Those questions included child age, gender, their relationship to the child, responsibility for child's health care, child ethnicity, and grade in school. At the very end of the survey parents were given the opportunity to share any additional information if they would like.

The study

Participants and procedure. Participants were recruited from a local pediatric cystic fibrosis clinic within a larger children's hospital network. All youth between 10 and 21 years of age with a diagnosis of CF and their primary caregivers were eligible to participate. This age range was selected after discussion by the team on when parents might start teaching self-management skills, when the team starts actively involving youth more at clinic, and the mandatory age they must transition from this pediatric clinic to adult care. Recruitment occurred at scheduled routine well check visits and not during a sick visit or follow up visit. This was decided as an attempt to reduce bias in the responses as the focus of interest was in the average daily routine of families versus sick care routines. Thirty-eight parent and youth dyads participated in this study. The study was approved by the hospital's IRB and followed all safety and confidentiality procedures.

The surveys were completed online during the clinic visit on a tablet connected to REDCap, a secure HIPAA compliant online database. All eligible families were approached about participating and from those that agreed, a smaller subsample of parents were recruited for interviews. Interview participants were randomly selected from a list of all interested parents who opted in to be entered into the interview recruitment pool. Selected participants were emailed to confirm participation and to schedule the interview. A total of 9 interviews were conducted over the phone. The majority of interviews lasted between an hour to an hour and a half. All interviews were audio recorded and transcribed for analysis. The interviews were semi-structured using a set of questions that was continually revised (please see Appendix A for full interview guide). The focus of the interviews was to not only give parent's the opportunity to speak on parenting a child with CF and transitioning to adult medical care but also allowed myself, as researcher, to delve deeper into the behaviors of parents and the reasons behind those behaviors. Finally, a medical chart review was completed on all youth participants to collect health information that was used to determine illness severity (e.g., pulmonary lung function test results) as well as to describe the youth participants.

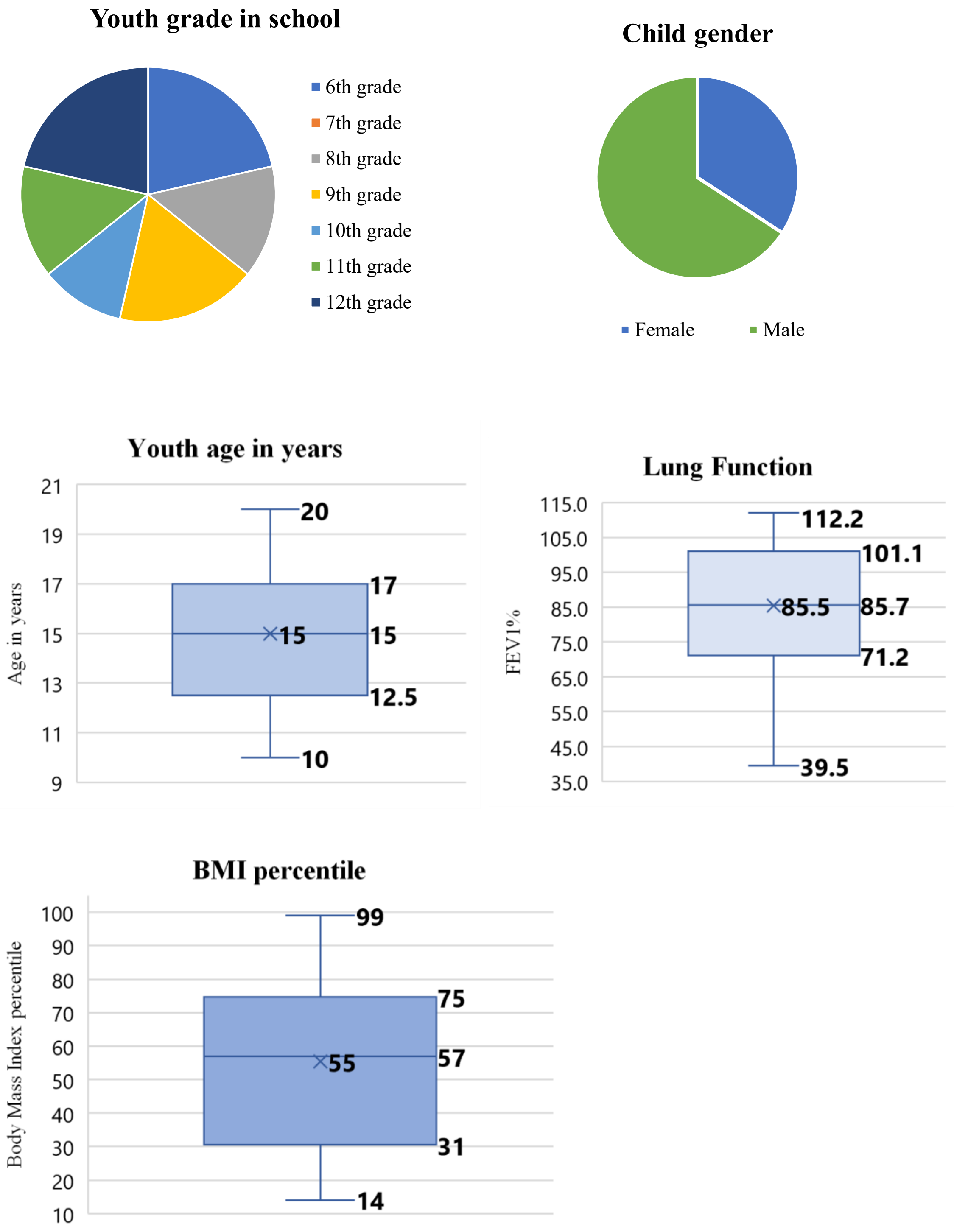
Descriptive statistics. The study participants were fairly diverse on a number of variables considering the size of the sample (n=38 dyads). In terms of general youth characteristics, the child participants were 66% male and ranged in age from 10 years of age to 20 years of age with an average of 15 years. The study also had a fairly even distribution across grade in school from 6th grade to out of high school. As for cystic fibrosis characteristics, the sample was primarily pancreatic insufficient (meaning they have to take enzyme pills with all meals), an average of 55th percentile for body mass index (BMI), and an average lung function of 85.5. Please see Figure 1 for youth population descriptive statistics.

For the parents, mothers were the primary responders however, the study did have 21% of the fathers participate. Cystic fibrosis is a genetic condition that predominately occurs in the Caucasian population so a majority of the study population classified themselves as Caucasian or White. The other main ethnicity within the sample was Hispanic and three people classified themselves as either Asian or Native American (refer to Figure 2). The majority of the parents were at least high school graduates but 50% had college or advanced degrees. Finally, 51% of the parents reported an average yearly income of $90,000 or more. The smaller sub-sample of 9 interviewed parents were mothers, all but 1 classified themselves as White, 63% reported making over $90,000 yearly, and 78% had at least a college degree or above.

It is important to note that there might be significant differences in terms of responses from parents who agreed to be interviewed compared to those who did not. However, given the descriptive nature of the study, I felt the information obtained was still useful. Further interview studies that focus on more underrepresented parents are needed to fully understand what parents of a child with cystic fibrosis are doing at home. I also felt confident in the findings as the survey study had almost 100% response rate for eligible families making that data somewhat representative. Additionally, the interview sample and full sample were similar on child demographic variables suggesting that the interview data was somewhat representative of the larger full sample (please see Table 2 for a comparison of the interview and full samples).

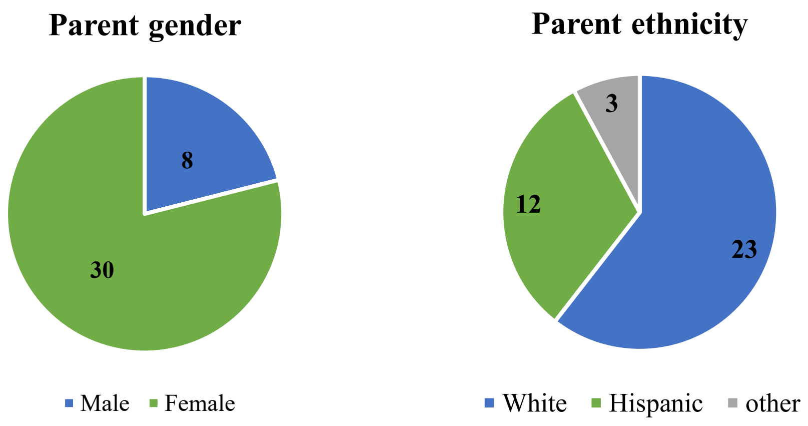
Figure 1

Descriptive statistics of study population



Note. Descriptive statistics of the youth study population. Forced Expiratory Volume in the first second (FEV1) is a measure of lung function and 80% to 120% is considered in the normal range. Body Max Index (BMI) percentile is a measure used for children under the age of 18 and is a calculated using height and weight.

Figure 2
Gender and Ethnicity for the Parent Study Population



Note. Bolded numbers indicate the sample size for each group. The other ethnicity group included Asian and Native American responses.

Table 2.
Comparison of Interview Sample to Full Sample

Variable	Full sample	Interview sample
Parent age	44.8 years	44.9 years
Parent ethnicity	62% White	89% White
Parent income level	67% above the median	86% above the median
Parent education level	50% college or above	78% college or above
Youth age	15 years	15.3 years
Youth gender	66% male	56% male
Youth BMI	54% above 50th percentile	33% above 50th percentile
Youth lung function	26% improved function	33% improved function

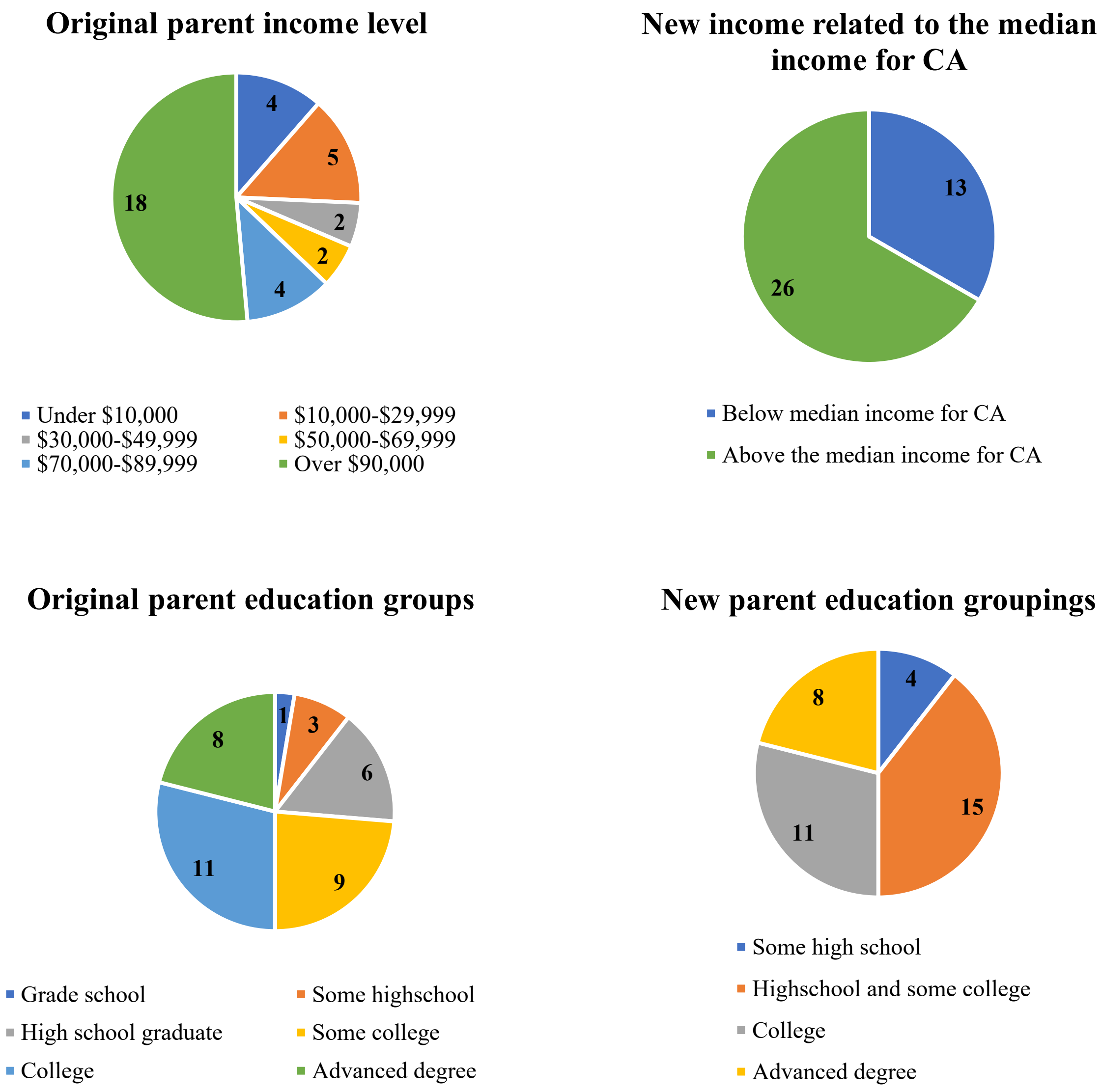
Group differences. To explore meaningful group differences, I looked for any significant differences for the variables of interests across these groups: child gender, child age, child BMI, child lung function, parent income, and parent education level. To ensure group size maintained a threshold of at least 5 participants for statistical tests, I had to create some new groups using the background variables collected in the survey and medical chart review. Previous research has supported that parents differentiate their beliefs and behaviors based on the gender of their child across a variety of domains including health (Raley & Bianchi, 2006; Williams, 2018). Therefore, one of the group differences tested was child gender. The sample had 13 daughters and 25 sons.

Additionally, it was believed that parents varied in their health beliefs and behaviors across different income groupings (Ejebe, Jacobs, & Wisk, 2015; Vijayaraghavan, Jacobs, Seligman, & Fernandez, 2011). The income survey item resulted in 6 initial groups ranging from ‘Under $10,000’ to ‘Over $90,000’ however, some of the groups had less than five participants so a new income variable was created. I used the 2017 median income for the state of California (U.S. Census Bureau, 2017) to create a cutoff point that differentiated all participants in to one of two groups: above the median or below the median income for the state (see Figure 3).

Next, I hypothesized that parent education level might have an influence on health beliefs and behaviors due to work with education level and health literacy. Existing work suggested that people with lower education levels often have lower health literacy (Shah, West, Bremmeyr, & Savoy-Moore, 2010). Furthermore, decreased health literacy has been linked to lower or more negative health beliefs such as views of illness (Shone, Conn, Sanders, & Halterman, 2009). Similar to income, the parent education variable resulted in 6 groups ranging from grade school to advance degree with some groups having below the recommended 5 participant minimum. I further condensed groups by creating the cut off points of high school graduate, college degree, and advanced degree (see Figure 3).

Figure 3

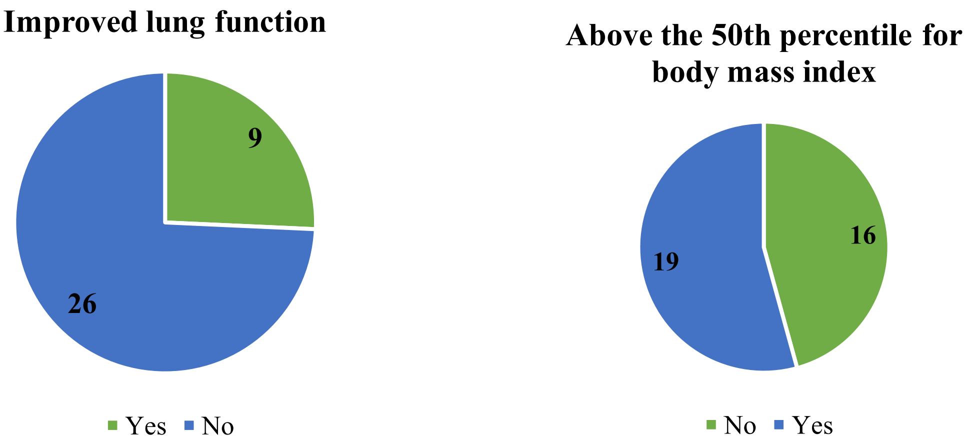
Parent Income and Education Variables



Note. The bolded numbers indicate the sample size for each group. The new income variable used in the study was created from the parent yearly income variable. The new parent education variable for this study was created from the parent highest level of education.

Finally, I wanted to explore some different youth health-related group differences. Research suggested that a BMI over the 50th percentile often resulted in better lung function outcomes (Stallings, Stark, Robinson, Feranchak & Quinton, 2008), therefore, I created a new variable with a cutoff point of being above or below the 50th percentile in BMI. Additionally, I wanted to have some measurement of overall CF health status and lung function tests are usually used as an indicator of disease progression. From the medical chart, I collected their most recent lung function results as well as the results from approximately one year prior. However, lung function is not typically compared across people and there is not always an optimal number to aim for but instead a focus of avoiding further declines in function. Considering this, I decided to look at whether a youth's lung function improved or went up versus their lung function declining or going down over the course of a year. To that end, I created a variable that divided people into two groups: 1. Youth with improvement in or no change in lung function over the course of a year and 2. Youth with decreased lung function from a year ago. The hypothesis was that parental beliefs and behaviors would vary depending on the lung function of their child. It is not hard to imagine that parents of youth with declines in lung function may not belief their child is very good at managing their own health or that parent involvement in care might be different based on lung function.

Figure 4
Cystic Fibrosis Youth Health Variables



Note. Bolded numbers indicate sample size for each group. Youth with a BMI percentile above 50% were denoted with a Yes and those 49% or below were denoted with a No. Youth whose FEV1 increased or stayed the same over a one-year period were given Yes while youth whose FEV1 decreased were given a No.

Summary

In a collaborative effort, this study was born out of a desire to understand more about what parents of youth with a chronic condition were doing to prepare their children for adulthood and the eventual transition to adult care. Time was taken to construct a survey and interview guide that would explore concepts related to the preparation of youth for self-management. The survey was constructed to examine parent's general health beliefs, the specific ability beliefs they have about their child, and the behaviors they are engaging in to teach self-management. The interview semi-structured guide focused in more depth on what successful management looked like for parents, their daily routines, and the reasons behind some of their behaviors. The teams effort resulted in a study with a high participation rate on the survey (n=38 dyads) and a small but fairly representative sample for interviews (n=9). In future chapters, I explore in more detail the findings of both survey and interview data as they relate to beliefs and behaviors around self-management. Also, I explore the differences across the groups discussed above to more fully understand parenting and youth self-management.

CHAPTER 3

Parental reported values and worries

Raising a child is a complex process that can be influenced by many factors that operate on the belief's parents have and the behaviors they engage in with their children. To begin to think about what parents of youth with a chronic condition are doing to prepare their youth for adulthood, it is important to first look at parenting more generally through a discussion of parenting in terms of socialization and then parental cognitions. This review of the literature on parenting will help establish a foundation of the kinds of things that influence parental beliefs and how they relate to the different behaviors of parents.

Socialization

Parenting has historically been studied from a variety of perspectives. One way to explore how people raise children is through the examination of socialization processes. Socialization is a term used to describe "the processes whereby individuals are taught the skills, behaviors patterns, values, and motivations needed for competent functioning in the culture in which the child is growing up." (Maccoby, 2015, p3). Some researchers view the primary role of parents to be the socializers of their children, preparing them to be functioning adults within the broader society (Kuczynski et al., 2015). Socialization research has primarily focused on teaching children such things as social skills, impulse control, self-regulation, and other larger societal or cultural standards (Maccoby, 2015) rather than on how parents might socialize their youth to handle a chronic medical condition. Now that life expectancy rates are improving, it is necessary to think about the ways in which parents of youth with a chronic condition are socializing their children to manage that condition and preparing them to interact independently in the adult medical environment.

It has been suggested that socialization is occurring across the entire lifespan in the presence of new social situations (Kuczynski et al., 2015; Maccoby, 2015). One new social setting that might necessitate the need to learn new skills and behaviors, as well as how to function within a unique social environment, is the medical environment. As children with chronic conditions age, their parents and medical professionals not only have to teach them the skills they will need to successfully self-manage their condition, but also how to transition to and navigate within the adult medical environment. Knowing more about what parents believe about and are doing to help teach their children these necessary skills can inform hospital policy and transition preparation programs.

Parental cognitions

Parents have unique ideas or attitudes about parenting, expectations and goals for their children, perceptions of their children and their abilities, and beliefs that have sometimes been aggregated together under a broad 'parental cognitions' term (Okagaki & Bingham, 2005). Researchers often study only a few aspects of parental cognition (e.g., parental beliefs and perceptions) at a time but many agree that the terms are interrelated (Okagaki & Bingham, 2005). Beliefs and perceptions are often studied together as they may be associated more strongly than other components of parental cognitions. Also, in general parental goals and expectations may serve as a major driver of the actions that parents take to meet their goals and thus often are studied along with behaviors. In the following section I address beliefs and perceptions followed by parental goals and their influence on parental behavior and youth beliefs and behavior.

Beliefs and perceptions. Parental beliefs have been shown to influence subsequent parental behaviors in a variety of domains (e.g., language and math) while parental perceptions of their child’s abilities have been shown to change parenting strategies used with the child (Okagaki & Bingham, 2005). Also, general parental beliefs (e.g., gender roles) can influence their perceptions of their child’s abilities and their subsequent behaviors (Simpkins, Fredricks, & Eccles, 2015a). For example, research on achievement supported that parental beliefs in terms of an academic domain (e.g., the importance of math) influenced how a parent engaged with their child regarding math (e.g., doing math homework together) as well as influenced how a child and parent perceived the child’s math abilities (Simpkins et al., 2015a). Although parental beliefs influence behaviors, they may not be the only driving force behind parent’s behavioral engagement. The goals a parent sets for their child may also be influencing how they engage with their child.

Goals. Parental goals are another area of parenting that has implications for parental behavior. When thinking about parental goals, Goodnow and Collins (1990) suggested that parents may be setting goals based on where the goal falls on what they conceptualized as a hierarchy of needs. A basic goal for parents was the survival and health of their child, followed by other goals that resulted in their child having economic stability in adulthood, and finally goals that addressed cultural values (Goodnow & Collins, 1990). Others suggested that parental goals were driven more by what society expects of adults (Okagaki & Bingham, 2005). No matter what is driving the goals parents have for their children, these goals can have lasting influences on parental behaviors.

Parents often employed a variety of strategies to promote the goals they had for their children such as verbal encouragement or participating in shared activities (Furstenberg, Cook, Eccles, Elder, & Sameroff, 1999). For example, if a parent has a goal that their child will be reading independently by the end of first grade; they may engage in more behaviors around reading with their child. Also, if it is assumed that parents of children with chronic conditions all have the goal of survival for their child, they will engage in behaviors that promote survival (e.g., following treatment regimens). It is important to learn more about some of the driving forces behind parents of children with a chronic condition and the ways those forces relate to the health-related behaviors they do with their child, if we are to understand how parents go about raising children who are ready to take on managing their own medical condition in adulthood. When thinking about how a parent might go about getting their child ready to manage their condition as an adult or the goals they might set, it is also important to recognize the role the child plays in the process.

The reciprocal nature. Once thought to be a unidirectional path from parent to child, many researchers now view the influence of parents on children as a reciprocal process with parents influencing children and children influencing parents (Kuczynski et al.,2015). Child characteristics (e.g., gender or temperament) influenced parents' beliefs and then behaviors (Karraker & Coleman, 2005). Traditionally, the child characteristics studied have been gender, temperament, age, physical attractiveness, and activity level (Karraker & Coleman, 2005). However, it could be argued that the presence of a chronic condition is a child characteristic that could potentially influence the beliefs, goals, and expectations a parent has about their child.

Some chronic conditions have physical limitations, cognitive limitations, or complex treatment regimens that could influence parental beliefs and behaviors. For example, children with Williams syndrome have difficulty with spatial awareness and when engaged in a puzzle task with their parents, their parents helped and reinforced their child more than the comparison parent-child dyads without the syndrome (Hodapp & Ly, 2005). It is less clear what parental beliefs were driving this helping behavior as another study with parents of children with

Williams syndrome showed that parents knew about the affective characteristics of their child's condition (i.e., fears and anxieties) but had less awareness of the condition's characteristic weak visuospatial skills or strong linguistic abilities (Hodapp & Ly, 2005). Additional work on what beliefs parents have specific to their child's chronic condition is important to further our understanding of how parents engage in behaviors with their child around teaching health-related skills. What beliefs are driving the parent as they socialize their children to be adults with a chronic condition and for the adult medical environment?

In general, parents have individual ideas or attitudes about parenting, expectations and goals for their children, perceptions of their children and their abilities, and beliefs that can influence their behaviors. Parents have beliefs about their child's ability that may influence the goals they set for their children and then the behaviors they enact to meet those goals. To understand parenting a youth with a chronic condition, it was first important to discuss how general parental beliefs and goals associate with behaviors and now it is important to recognize that these parents may have unique beliefs and goals related to the condition itself.

Current study

Considering the roles parents play as socializer for their children, it is important to think about the skills and goals parents are setting themselves, their personal worries, and how they are thinking about self-management if we hope to plan interventions that support both parents and children. Before focusing on the beliefs and behaviors of parents on a set of pre-determined health-related skills in future chapters, I wanted to give parents an opportunity to think about and discuss self-management in their own terms. In this chapter, I first aimed to understand more about what parents were thinking about as it relates to what they think is important for their child to know how to do. Next, I asked them to think about what worries they had for their child. Finally, I explored what they thought successful management looked like for their child.

The current study used a mixed methods approach drawing data from both survey responses and interviews. The data for this chapter came from the open-ended survey responses and interviews. I used both quantitative and qualitative methods to analyze the data. To understand more about the goals and worries parents of youth with CF have in terms of preparing their youth for adulthood, I analyzed the open-ended responses on the parent surveys using inductive analytic techniques (Corbin & Strauss, 1990; Saldaña, 2009) to further categorize the responses into themes. In the initial round of coding, I used descriptive coding to summarize the basic topic of the unit of analysis (i.e., the individual response) and then I performed a secondary round of coding using pattern coding to further collapse codes and identify themes (Saldaña, 2009).

In the initial coding phase, all responses were examined separately and grouped together based on similarity. Then comparisons of these smaller groups of similar responses were made to see connections or patterns. For example, five smaller groups all had a common theme of being directly related to CF, though the specific aspects of CF addressed (e.g., medication, treatment, diet and exercise) were somewhat distinct. Because all related directly to CF, they were collapsed together under one major category. Additionally, analysis of the responses within each small group led to sub-category formation in some cases. For example, all response involving medication were examined further and it became clear that several distinctions could be made between taking medicine, ordering medicine, managing medicine, and having knowledge about the medication. The different rounds of analysis resulted in three major categories for skills and five categories for worries. For the complete codebook, please refer to Appendix B.

Finally, I conducted an inter-rater reliability check on both category placement within major categories as well as the individual coded responses. Independent reviewers were asked to place sub-categories under which major category they felt it fit best and then to code 10 randomly selected responses for each item (i.e., 10 skills and 10 worries) based on the codebook. Percent agreements were averaged across code and coders. In general, percent agreement was good across individual responses for skills and worries (mean = .95; range = .87-1.00) and category placement (mean = .94; range = .70-1.00).

The codebook created for the open-ended survey responses was then used as the basis for coding all of the interview data. Additional codes that arose from individual interviews were added to the complete codebook (please refer to Appendix B for complete codebook). The initial round of coding for the interview data involved reviewing verbatim transcripts of interviews for discussion of important or useful skills, what successful management meant to the parent, and mentions of worries. This was followed by a second round which collapsed codes based first on the codebook created from survey data and then additional category formation with codes unique to the interviews.

Findings

Skills

What are the skills parents think are important for their child to know to successfully become an adult with CF? Responses to the question "What are some important health-related skills/things you feel your child should know/or be able to do as they become an adult with CF?" were analyzed qualitatively as described above. Parents reported three major types of skills that were important for their children to master to successfully manage their own health: 1. youth characteristics or more stable attributes that persist over time and are embodied by the youth, 2. health protocol skills or skills that deal with aspects unique to cystic fibrosis care, and 3. administrative or managerial type skills or skills that represent the more administrative side of managing health. Within each major category there were several categories and sub-categories that supported and further defined the category as a whole. In terms of any group differences across the reported skill categories, there were no significant differences suggesting that what parent's think was important to successfully manage health in adulthood was similar across child gender, child age, income level, and parental education level (refer to Appendix B for a description of quantifying the qualitative responses).

Youth characteristics. From the survey data, 25% of all responses were categorized as a youth characteristic skills. These skills were then sub-divided into organization, time management, communication, independence, accountability/responsibility, staying informed, and other. In general, parents reported the importance of their child being organized, independent, responsible, with good communication skills, and able to manage their time well. Additionally, they wanted their child to be able to balance the demands of their health with life in general. See Table 3 for example youth characteristic codes.

Table 3.

Examples for youth characteristic skills from survey data.

Category	Example response	N
Organization	"Organization"	3
Time Management	"Time management"; "plan ahead"	3
Communication	"Talk with doctors, team, self-advocate"	2
Independence	"Be independent"	4
Responsibility	"Hold himself accountable for working with his medical team to care for his condition"	2
Stay Informed	"Stay informed"	2
Other	"Achieve your goals"; "To learn how to have a good and better lifestyle"	6

Furthermore, in the interviews, parents talked about the importance of balancing life with the demands of cystic fibrosis (e.g., "balancing that life of medical necessity and just real life"). Also, one parent discussed the importance of happiness and mental health as a skill that promotes successful management:

> First and foremost, I always want to make sure he is not feeling like CF is drowning him emotionally mentally, like he can enjoy other parts of his life besides needing to constantly worrying about is he doing all of his care and everything. So, happiness is huge for me.

Mental health was a topic that arose in the interviews and parents want their children to be able to balance CF and other aspects of their lives. Perhaps to parents the ability to balance equally important areas of life is a youth characteristic that they hope their youth possesses. Communication was also a valuable skill that parents wanted their child to have in their arsenal.

While some parents listed general communication as an important skill, the idea that youth needed to be confident at asking questions when they were confused or unsure was unique to the interview data. Parents spoke about wanting their children to not only ask questions and seek out more explanations when necessary but to understand that this practice was appropriate. For example:

> Yeah, I think sometimes people especially get intimidated by doctors and they say…we have always been told to get a second opinion on some things, and maybe with CF I don't know if that applies as much but, maybe its learning that you can be an empowered person. That it is ok to ask for more information, ask for more explanation on some things. So maybe I am getting at letting the patient know that they can……its ok to question, or ask for more information, or wonder about say a treatment or medicine or that sort of thing.

Parents want their children to be empowered to know that it is ok to ask for clarification and that it is appropriate to speak up when talking with medical personnel. Additionally, parents wanted to not only encourage question asking behaviors in times of confusion but also when its ok to push back or question a particular course of care or treatment. Some parents framed the idea of appropriate pushing back against doctors as being assertive as seen by this mother:

> Yeah and I think some of that is I know my husband and I both stood up to the doctors a little bit more and said that and put them on the spot sometimes too like 'why are you doing this' but that is also because we have been dealing with this hassle since he was a lot younger and we are adults. We've learned how to stand up for ourselves and be more assertive about these things. And ask the right questions. I guess that is something that could be a struggle, while we may have been talking to our child about that stuff as well, that is still going to be a learned thing and he is going to have to learn that and I could see how… I mean even adults they are not as assertive when it comes to an authority figure like a doctor.

Some parents wanted their children to ask questions but also recognized that being comfortable or confident at doing that was a learned skill. They recognized the tension that even some adults struggle with speaking up at doctor's appointments and that it is not always an easily obtainable skill to master. Exploring how parents overcame this tension to teach their children to be more outspoken with their health could provide useful insight for professionals working with these families. Also, parents may view one of their roles as socializer to be that of teaching assertiveness. Future work examining this idea of assertiveness as a socialized skill could inform professionals as to how best to support parents. Being assertive was primarily a youth characteristic yet could have further reaching implications in terms of health protocol-related skills. For example, parents may wish for their youth to be assertive in understanding why they need to take medication so that they comply with it more.

Health protocol-related skills. These skills comprised the bulk of survey responses by parents with 65% of responses for this question being categorized under the health protocol-related umbrella. Health protocol-related skills were responses that dealt with some aspect of daily CF care and consisted of five categories (please refer to Table 4 for code examples for this major category). The category with the most responses was medication-related skills that consisted of sub-categories taking medication, ordering medication, managing medication, and knowledge of medication (41%). Next, treatment-related skills were reported frequently and further separated into the sub-categories of doing treatments, managing treatments, and cleaning or sterilizing related to treatments (27%). The other categories included diet and exercise as they relate to cystic fibrosis care (16%), self-care (10%), and hygiene/germ control (6%). It seems for parents that medication-related and treatment-related skills were the most salient and as such then deemed as important for managing health.

One interesting finding related to medications was the distinction parents made around taking medication as prescribed. The idea of adhering to the prescribed treatment plan or medication was seen in both survey and interview responses suggesting that parents do make a distinction between simply taking medication and taking medication in the intended way. All 9 interviewed parents spoke about the importance of taking medication and doing treatments as part of successful management. Additionally, 4 of the 9 parents went beyond just referencing taking medication or doing treatments to incorporate the additional layer of doing those things as prescribed or per treatment plan. One parent stated:

> Well, thinking about her… number one would be making sure she takes her medication every day as she is supposed to and not thinking that it's ok to skip and just take it whenever she thinks about it or thinks she needs it. Understanding the importance of, especially when something is prescribed, you take it every time and not skip any.

While another parents said:

> So obviously, taking all his medicine when he needs to, doing all his breathing treatments, day in and day out that is prescribed, taking the time to properly care for and sanitize all of his equipment when it comes to his cups, his nebulizer cups.

Furthermore, some survey responses added the additional layer of 'as prescribed' as well suggesting that exploration of this distinction is warranted especially in how it associates with the kinds of teaching behaviors parents engage in to make that distinction clear to their children.

For example, would one find different parental behaviors around teaching medication compliance depending on whether they think just taking medication is important versus taking it in the way it was prescribed by a healthcare professional?

Table 4
Examples for Health-Protocol Related Skills from Survey Data.

Category	Example response	N
Medication		
a. Taking meds	"Take meds"; "Medication done correctly as RX"	6
b. Ordering meds	"Order his medication"	9
c. Manage meds	"Have all medication available as needed; Have more control of your medications"	7
d. Know meds	"Know medications"	3
Treatments		
a. Doing treatments	"Set up and do her treatments"	7
b. Manage Treatments	"Manage treatment times"	4
c. Clean/Sterilize	"Sanitize her nebulizer parts"; "Clean supplies correctly"	5
Diet and Exercise	"How to Access exercise and healthy eating options"	6
Self-care		
a. Self-care	"Take care of yourself"	2
b. Symptoms	"Know when they feel sick"	2
Hygiene/Germ control	"Keep clean"	3

Administrative/Managerial Skills. Finally, 19% of responses fell into the last major category of administrative or managerial skills. This category consisted of three sub-categories: 1. Appointments, 2. Insurance, and 3. Bills. Refer to Table 5 for example survey responses. Although this category was the smallest for survey responses, almost all the interviewed parents discussed some aspect of administrative skills, primarily insurance related or making/keeping doctor's appointments as being important for their child to master. One mother stated:

> Also, understanding, I guess, how insurance works and how to you know talk to the doctors, who to talk to if he needs to refill something or something is quite not right. So that's communication with his care facility and the insurance company that he is under.

An additional parent said:

> Number two would be making sure she follows up and keeps with her regular doctor appointments, especially if she is doing really well, that she doesn't, you know, postpone it, skip, or delay.

While parents reported that these administrative skills were important, few parents interviewed had started teaching these types of skills or expressed confidence in their child's ability to currently master them. For example:

> I would say probably her dad and I will be taking care of the bill part of it for longer, I am guessing. So, I am not expecting in two or three years that she will be paying all her medical bills or even have her insurance under her own name.

For some parents, the expectation was to maintain control of these more administrative skills until sometime in the future. One reason they may hesitate to relinquish control is the stress that is associated. Some parents recognized that these types of skills are necessary, but they can elicit a lot of stress which might be a reason for the delay in giving their child full autonomy on them. One mother described her stress:

> Yeah, I feel like it's a huge unknown what is going to happen with her right now. To be honest its really stressful, for me, and since it's in her hands, she is procrastinating like crazy. She hasn't made the last appointment at [name of medical provider redacted] and she has not made the new appointment at the new center.

Parents spoke about the associated stress of giving control up to their child and the worry it caused them. Previous research supported the association of parental stress with parental responsibility for health management as well as with child self-management behaviors (Cousino & Hazen, 2013). Parents that reported greater stress were more likely to be more responsible for condition management or have children doing less self-management behaviors. Future work that explores this association is needed to understand if the stress is leading parents to hesitate in giving up control or not giving up control leads to more stress.

In general, these findings suggest that parents have specific skills they think are important for their youth to master before they can successfully manage their health on their own. Also, as seen in the quote above, these skills although thought of as important, might be coupled with stress and worry which can have implications on the teaching of these skills to their child.

Worries

What are some worries parents have for their children as they prepare their youth to become adults with a chronic condition? To this end, parents were asked "What are some things you are worried about with getting your child ready to be an adult with CF?" and their responses were coded as described above. Parents reported several different types of worries related to getting their child ready to be an adult and manage their own health. Analysis of these responses created five major categories: 1. Compliance (40%), 2. youth characteristics (19%), 3. Administrative (13%), 4. Adulthood (21%), and 5. disease progression (7%).

Table 5.
Examples for Administrative Skills from Survey Data.

Category	Example response	N
Appointments	"Make apptments"	6
Insurance	"Deal with insurance company"	4
Bills	"Managing bills"	1
Pharmacy	"Manage dealing with pharmacies"	1

Compliance. The majority of responses fell under the major category of compliance defined as encompassing the concept of compliance and adherence to treatment regimens/protocols with 28 responses. Further distinctions under compliance were made with five categories and 6 sub-categories. Complying with treatments made up the largest proportion of responses related to compliance at 32% and was sub-divided into treatment compliance and skipping/not doing treatments. Twenty-five percent of compliance worries were related to medication and skipping or not taking medications. The last few categories of worries were general compliance (18%), ‘other’ compliance worries (e.g., germ control; 14%) and diet and exercise worries (11%). Please refer to Table 6 for examples of each of the categories and sub-categories of the major category of compliance or Appendix B for full codebook.

In terms of group differences across reported worries, age of the child influenced the types of worries that were reported by parents especially in relation to compliance worries. Compliance worries were one of the only worries that were found to differ significantly across child age groups. Parents of high schoolers reported more worries related to compliance (X_2=11.87; p=.001) compared to parents of middle school youth who reported less compliance worries than expected. These findings speak to the developmental nature of learning to manage health and that as youth get older or closer to adulthood, parents may start worrying more about compliance. In the interviews, parents frequently spoke to their worries of their children being compliant especially when they move away from home. One mother agreed:

Table 6.

Examples of Compliance Category from Survey Data.

Category	Example	N
Treatment		
a. Treatment compliance	“Importance of treatments”; “Regular on treatments”	3
b. Skipping/no doing	“Won't do treatments”; “Skipping breathing treatments”	6
Medication		
a. Medication compliance	“Importance of taking meds regularly”	2
b. Skipping/no taking	“Not taking medications”; “Skipping pills”	5
General	“Compliance without my supervision”	5
Other		
a. Cleaning	“Germ control”	3
b. Missing doctors	“Missing doctors”	1
Diet and Exercise	“He might not continue exercising; Eat correctly”	3

> Yes, I anticipate another spike in stress because I worry that when she is away from me, away from being reminded by me to do things, that she will forget. I have to silently lecture myself that is important for her to be away from me and say, ‘oh shoot, I forgot my Flovent and my asthma is kicking up that is a learning experience because I have been forgetting my Flovent and my mom isn’t hear to remind me’. So yeah, I anticipate that I will have a spike in stress when she goes away to college.

Parents recognized that compliance will most likely drop when their child goes to college or leaves home as well as the role they played as the reminder. Work that looked at the changes to parental roles in young adulthood supported that parental roles shift from hands on doer to manager to supervisor (Iles & Lowton, 2010; Tuchman, Slap, & Britto, 2008). This shifting in roles can be stressful for both youth and parent as each have to adjust to new roles. Parents worried about their child forgetting when they weren’t around to be reminded. Forgetfulness to be complaint as a worry was also found in the youth characteristic category.

Youth characteristics. In terms of the other major categories, parents reported concern about a variety of things from being organized to insurance to going to college. Similar to skills, worries related to more stable youth characteristics were also found and also included their child being organized and responsible (see Table 7). Additionally, the worry associated with forgetfulness arose in the interviews as seen in the parent quote above. Parents often predicted increases in stress due to their child’s forgetfulness. Parents also worried about their child being responsible enough to manage their own health in the same way that parents did. For example:

> I do believe my child is extremely competent and intelligent and responsible and could to do could manage his care and all the pieces that come with it very successfully. I just think that because there are a lot of other competing priorities in his life right now that he wouldn’t prioritize this one as much as I think you know he should. And that is why things would fall through the cracks.

For parents, they thought their child may be responsible but that time management and prioritizing would result in sub-optimal management according to the parent’s standards.

Parents also reported prioritizing concerns as they related to the more administrative like tasks. There were no significant group differences for this category of worries.

Table 7.
Examples for Youth Characteristic Worries from Survey Data.

Category	Example response	N
Organization/Time management	"Organization"; "Time pressure to skip meds"	4
Responsibility	"Be more responsible and independent"; "A sense of ownership and desire to do everything it takes to manage CF"	4
Other		
a. Advocate	"Ability to self advocate"	1
b. Manage health	"Ability to manage health"	1
c. Knowledge	"Know their medications and their times"	1
Mental health	"Anxiety and depression"	2

Administrative. Also similar to skills, there was a major category of administrative worries that encompassed worries related to insurance, cost, and access. Parents expressed concern that their child wouldn't want to take time to sit on long phone calls with insurance or deal with ordering medications (see Table 8). Worries related to insurance were further explored in the interviews. Parents discussed their worries related to their child being able to obtain insurance and how much control they can even expect in the process. One parent had this to say about insurance:

> Insurance is huge, you know she is only on our insurance until she is 26. Then at that point she either has to be married to someone who can provide the insurance or she has to have a job good enough to provide her own. And so that is enormous. That's enormous right there and that is a huge pressure and that I am afraid of. I am personal not sure that I can control any of that.

Access to insurance was a major concern from some parents. Additionally, the stress of the unknown and confusion around insurance was a major stressor for most parents. Some parents also mentioned the hesitance that their children can have to taking over control of this particular component of care. One mother talked about her daughter:

> She is kind of afraid of it, I mean because she sees me struggling with the insurance companies, she sees me trying to schedule all these appointments and she is like 'I don't want, I don't even understand insurance and I don't really want to have to handle that'. So, whenever the issue of you know maybe you should be calling the hospital and making your own appointments, she is afraid of it.

Perhaps parents think about insurance as being the last thing to pass along to their children because it is the one most out of their control and their child's control. Nevertheless, parents were aware of the importance of and frustrations with these administrative skills, especially insurance, as they related to successfully managing health. Often these skills posed a challenge to teaching or a significant worry for parents when they thought about their child as an adult managing their chronic condition. Perhaps the administrative-related worries for parents feel less controllable much like the worry of disease progression. There were no significant group differences for this category of worries.

Table 8.
Examples for Administrative Worries from Survey Data.

Category	Example response	N
Insurance	"She will need good insurance"	4
Cost	"She doesn't get a job with good benefits"	3
Access	"Continued access to clinic"	2

Adulthood and disease progression. Finally, survey responses related to adulthood and disease progression were unique to worries. Parents report being worried about their child as it related to adulthood in starting a family, college-related worries, and living away from home. Also related to adulthood, parents expressed concern over their child being able to live up to their potential and getting discouraged. Parents worried about the nature of some lessons about living with CF being only learned through experience while others discussed the uncertain of adulthood and the worry associated with it (see Table 9).

Table 9.
Examples for Adulthood Worries from Survey Data.

Category	Example response	N
Family	"Beginning his own family"	2
College		
a. Managing health	"Going to college or work when sick"	4
b. Dorm germs	"College life / dorm germs"	2
Living away	"Living on her own when sick"	2
Other		
a. Greatness	"That the disease may keep him from realizing his destiny for greatness"	1
b. Depressed	"That he will get discouraged or depressed"	1
Job	"Keeping a job"	3

In terms of learning and growing as a person, one parent interviewed expressed worry over some difficult lessons related to the illness and the necessity of experiencing those firsthand. For example:

> I think he will be ok with it; I am just worried that I won't be able to teach him that without a lot of him having life experiences to teach … I mean I don't want it to have to be that he has to learn that the hard way and that's what I worry about.

Firsthand experience is often considered a useful way for children to learn yet in the case of health and self-management it may have more consequences (e.g., poorer health). This risk for CF-related consequences could increase parental worry as well as decrease autonomy-granting behaviors. Additionally, in general parents may base their expectations for the future and their role as socializer for their child on feedback from the environment and advice offered by experts in the field. This feedback helps parents set realistic goals and decide on important areas to focus on in terms of socializing their child. However, uncertainty about what the future may hold for their child or their child's illness can increase worry in parents of a child with a chronic condition. Parents expressed the stress for their children and themselves at not being prepared for the task of socializing. One parent stated:

> I think that their whole life they are told that they have this limit on their life span especially his generation. I think they are doing a better job now and I think with the new corrector medications it is different for the younger kids but for (child name redacted)'s generation you know when he was diagnosed, we were told all the things he wouldn't do and we were told these milestones he wouldn't hit, and then when they hit them, they don't know what to do because they weren't prepared for the next stage of life because they were told they wouldn't make it.

Parents and youth felt unprepared for adulthood especially if the expectation was that they would not reach it. They struggled with knowing what to teach and how to teach something that wasn't on their radar and having to switch gears. The worry may switch from one of a shortened life span to one of playing catch up to get their youth ready for adulthood. In general, these findings supported the idea that parents have specific worries related to illness and health which may be influencing the ways they engage with their children as they address these worries. The skills they think are important and the worries they have may also play a role in how they define successful management for their children.

Successful management

Success and being successful is defined by the person and has individualized meaning which may differ across people. Professionals working with families in the healthcare system with the goal of successful health management would benefit from understanding more about how individual families define success. What to parents think about when they imagine their child as an adult successfully managing their health? To answer this question, in interviews parents were asked to think about their child as an adult in the future and that they were managing their health well. Then parents were asked to describe what successful management of CF looked like for them.

In general, parents rarely hesitated in answering this question and were able to list a variety of things they thought were important for their child to master to signal successful adult management. To these parents, success was often defined by multiple aspects of life and care that mirror the open-ended categories listed above. One parent had a lot to say about successful management:

> She is ordering her own refills of all her prescriptions in a timely manner from the mail order pharmacies. She is sort of tracking that in a timely, responsible way instead of letting it get away from her and finding she is out of things which is what is happening in our home now while I am transitioning her. You know she is forgetting, so if she is successful as an adult on her own, she will have conquered that and been organized about that. She is keeping herself on her own treatment regimen, morning, noon, and night depending on if she is also doing her sick plan. She is knowing that when she is sick, she has to back off of her other responsibilities and put her health first and make adjustments in her life schedule to accommodate that and those four times a day treatments and getting more rest and all of that. She is following the hand sanitization and 6-feet apart rule whether she's at work, giving friends a ride home, she is not giving a ride home to folks that are sick and in the car with her. Sort of managing her whole germ control thing within reason…in all her environments, with her housemates if she has them, with her schoolmates, or her work mates.

Parents wanted their young adult with cystic fibrosis to follow treatment protocols, stay organized, watch their physical health, and navigate medication ordering and insurance with efficiency and understanding. While some parents conceptualized successful management in terms of mastery of different skills, others thought about it in terms of physical daily health care and 'other things' as evidenced by this parent's response:

> I think CF from our standpoint we have learned there is a lot of not just the daily things you have to take care of like doing your vest treatments and your nebulizer treatments and also taking your pills, but there are the other things that are part of it which are maybe not necessarily health care but stuff you still have to follow up and do which is taking care of getting your medications ordered, depending on how your insurance has that set up and dealing with phone calls and stuff like that and monitoring how much medication you have and staying on top of that. And then also there are a lot of phone

> calls with insurance, a lot of times dealing with making sure that that stuff has being meet that things are being taken care of from that side of it as well. So, I guess…there is a lot of…it's not just your own physical things you think about of you need to manage your care. There is a lot other things that can go into it as well which is the insurance and the phone calls to different people to order stuff.

No matter how they are conceptualized, these skills were similar to the categories of what parents reported in response to open-ended survey questions. Youth characteristics like time management and communication, health-related protocol skills such as taking medications and doing treatments, and administrative skills such as ordering medication and handling insurance were all supported in interview responses on successful management. All this suggests that parents do actively think about their child being successful in adulthood and what that might look like for them.

Summary

In general, parents have an idea of what successful management of cystic fibrosis means to them as supported by parents' willingness to engage in lengthy discussions in response to interview questions around success. Furthermore, the majority of surveyed participants put at least one skill they felt was important to learn for management in adulthood. Although future chapters will discuss the more specific ability beliefs related to management skills, this chapter shed light on the variety and diversity of what parents thought was important to master as a sign of success. In this study, parents reported a variety of skills and worries but there were a few that seem more salient than others as a majority of parents mentioned them. The frequent mentioning of compliance, medication or treatment protocols, and insurance suggested that parents do think about what goals they have for their children as they relate to managing cystic fibrosis.

As discussed in the introduction to this chapter, parents set a variety of goals for their children that can range from basic needs (i.e., survival) to economically stability (Goodnow & Collins, 1990). Compliance is a major factor echoed in both discussion of skills as well as worries. One might argue that compliance for these parents is a basic need as it will lead to better health and ultimately longer life spans for their children. One mother expressed her frustration:

> It gets a little frustrating and so there are times like 'alright fine, this is your body, this is your life, this is you having to take care of you. If you know what the consequences are, you are old enough. If you don't want to do a breathing treatment, I am not going to sit here and force you to do it. This is your…you have to live with it, not me. You have to take care of yourself'. And I do get to a point where I tell him 'if you don't want to do a breathing treatment than don't. Don't do it.' And then I just kind of walk away and he will sit there and think about it for a second. He will be like 'ok, you are right mom, I need to do it' and he will go sit down.

Some parents recognized the importance of treatments for survival and made conscious efforts to get their children to value it as well. Also, the notion of 'as prescribed' indicated that parents recognized that taking medication or doing breathing treatments was important in so far as the youth was following the protocols established for each medication or treatment. For some parents, it is not enough to simply take the medication or do the breathing treatments but that doing them as they were intended, and in the manner, they were meant to be taken, was what was important. However, some parents took a different approach and focused more on getting the treatments done when possible as opposed to not doing them at all. For example, one mother said:

> I hate watching her miss her treatment but I will remind her 'you know you really do need to do this' or 'at least if you can't get this before we leave you have to do it when we get home, I mean don't forget to do this…this is why you are healthy, you got to keep doing it'.

This suggested that parents' decisions on how to teach compliance might be more complex or have multiple components and be driven by different goals. Even with these differing views of the role compliance plays in managing health, it was consistently viewed as a measure of success by parents and therefore something to be considered by and factored in when working with these families.

Additionally, even though families acknowledged the importance of compliance, they also admitted the difficulties of complete compliance. For example:

> You know she is working to and so everything is getting bumped around and because she can't…she hasn't quite figured out how to manage her own schedule, her compliance has drops way down. Because sometimes she just gets home and she is so tired, she is like 'I've been in class until 9 o'clock tonight I just can't sit here and do meds, I am going to bed'. And honestly, at that point I don't know if I want to make her do it because she is tired you know she is easily tired out. I don't know as a parent I'm not sure how far to push that. At this point I see that she is dropping in her compliance because her schedule is gone crazy.

There may be many factors influencing the compliance of a youth and/or family, so those working with these families might find it beneficial to factor those influences in or acknowledge those influences when assisting families on compliance. Parents also appreciated the opportunity to be able to explain why compliance might not be ideal at the moment. The same mother from above said:

> The fact that you are asking the questions is a really positive thing to me because it gives me a chance to say you know what we really are trying and even though it might not look like it when we go to the clinic because you ask us about compliance. Well compliance is not that great right now but the reason the compliance is not that great is because we are trying to move her into this next phase of maturity. It's nice to be able to say that to somebody and have go on some record somewhere like you know what 'this is what we are doing and we are trying are best'.

These findings supported that being able to comply with a treatment regimen or medical protocol was salient to parents. Parents reported it as important but also discuss the inherent difficulties that arose when they try to make the appropriate accommodations to their everyday lives. The insights gained from these interviews and survey responses can inform the topics and resources professionals provide these families as they relate to preparing youth to manage their own health. For example, compliance was a commonly mentioned skill or worry so professionals might want a range of resources to provide families that address compliance.

While insurance was recognized as important to successful management of health by parents, it was also discussed frequently in terms of stress or worries, suggesting that it might be viewed as a necessary evil by some parents. Parents voiced having little control over insurance issues and frustration at the difficulty in teaching this skill to their children. Finally, thinking about parents of children with a chronic condition as having extra responsibilities in terms of socializing their children to the medical environment was a very real thing for some parents.

They understood that their role was to help their children learn these skills but they struggled with being in uncharted territory or with knowing when to start teaching their children more self-management. One mother suggested:

> I definitely think there needs to be conversations with the parents where they are starting to talk about the goal of transition, where we want him to get, here are some milestones we want him to get. Even like what should my kid be able to do by themselves, when should they start doing these things, when should they start doing these things, when should they start doing these things, we get those things from pediatricians when are kids are growing up but when it comes to CF, I don't know, this is my only kid with CF and he is my first kid, so I have no idea when he is supposed to be doing certain things. As parents we're caretakers and advocates for them and sometimes it is harder to let some of those things go and if people aren't telling us what we should be doing, then we are just going to keep reins on it because that is what we have been doing since they were little.

Parents with children with chronic conditions acknowledged that eventually children should be responsible for their own care but it's the timing that was less clear. They may hold on to doing particular tasks because they don't know when to let go. Professionals working with these caregivers could provide resources that inform parents of when to start or how to start transitioning skills over to their child. It is important to not simply think parents want to maintain control but be mindful that some parents just lack the knowledge of how to implement the necessary changes. Professionals working with these families are in a unique place to provide assistance to these families as they navigate the medical environment and balance parenting and socializing their youth to manage their own health.

CHAPTER 4

Parental health beliefs

Parents can behave in a variety of ways related to dealing with their child's chronic condition; there can be many factors that drive those behaviors. The beliefs that parents have about their child with a chronic condition not only influence adherence but can have implications for their behavior as well as how they parent their child. To understand parental health-related management behaviors it is important to discuss unique parental beliefs related to chronic conditions (i.e., vulnerability beliefs and worry or concern beliefs) and then how those beliefs related to self-management.

Vulnerability beliefs

Parents' views about their child's vulnerability can have consequences for a variety of health outcomes. Parents of a child with a more severe chronic condition were likely to hold views of greater child vulnerability than parents of child with either a less severe condition (Anthony, Gil, & Schanberg, 2003; Carpentier, Mullins, Wolfe-Christensen, & Chaney, 2008) or no medical condition (Houtzager, Moller, Maurice-Stam, Last, & Grootenhuis, 2015). Across different chronic conditions, increased parental views of the child vulnerability were associated with increased youth social anxiety (Anthony et al., 2003), depressive symptoms (Mullins et al., 2004), and views of uncertainty (Mullins et al., 2007) as well as decreased emotional adjustment (Colletti et al., 2008). However, child vulnerability was often measured too broadly with items that may not represent the ways parents of youth with a chronic condition think about vulnerability (e.g., "I get concerned about circles under my child's eyes"; Mullins et al., 2007). For instance, lack of sleep may be less salient for a parent with a youth with a respiratory condition. Furthermore, parental stress predicted increased child vulnerability beliefs (Driscoll et al., 2018) and so understanding more about what things parents of youth with a chronic condition worry about may help inform future work on vulnerability.

Worry and concern beliefs

Parents of children with a chronic condition often reported high levels of worry related to their child (Foster et al., 2001; Noll, McKellop, Vannatta, & Kalinyak, 1998; Nuttall & Nicholes, 1992). Additionally, in interviews, parents discussed the idea of a sense of helplessness, “It’s the feeling of being helpless and watching him and trying to pretend that everything is fine.”(Nuttall & Nicholes, 1992, p206). The constant worrying and feelings of being helpless may influence the ways in which parents engage with their child especially when teaching them how to be an adult living with a chronic condition. Shorer and colleagues (2011) found that increased feelings of helplessness in parents was related to decreases in adherence and control of their child’s diabetes. Parental vulnerability beliefs, worry beliefs, and feelings of helplessness may all play a role in how parents think about and teach health-related self-management to their children. With this in mind, next it is important to examine the previous work on self-management in more detail.

Self-Management

To better understand disease management, a clear definition of adherence was needed; however, scholars struggled with how best to conceptualize and operationalize the concept of adherence (Riekert & Drotar, 2000). Some argued that adherence and compliance were terms that did not fully encompass the complex process of managing a chronic condition and thus preferred terms such as self-management that included a focus on patient and families’ active participation and decision-making along with adhering to a treatment regimen (Drotar et al., 2000). Given the focus on youth and families, I conceptualized self-management as discussed above with adherence to treatment regimens combined with recognizing the contributions and participation by youth and families. There were many factors that influenced self-management behaviors and adherence to treatment regimens. Research suggested that self-efficacy as well as youth and parental health-related beliefs influenced self-management and adherence.

Self-efficacy for self-management. Self-efficacy, or how much a person perceives they are capable of completing a task, was a predictor of self-management and adherence behaviors (Clark & Dodge, 1999; O'Leary, 1985). Bandura (2004) suggested that self-efficacy was a direct and indirect predictor of behavior, in that current self-efficacy beliefs would influence later behavior directly and indirectly through outcome expectations and goal setting. Numerous studies of self-efficacy and health behaviors have supported this causal direction (Bandura, 2004; Clark & Dodge, 1999; O'Leary, 1985). As self-efficacy increased, so did reported self-management behaviors (Bartholomew, Parcel, Swank, & Czyzewski, 1993), better disease control (Johnston-Brooks, Lewis, & Garg, 2002), and adherence (Ott et al., 2000) in young adults and youth with chronic conditions. Additionally, general self-efficacy was associated with higher reports of health status and quality of life in adults with cystic fibrosis (Wahl, Rustøen, Hanestad, Gjengedal, & Moum, 2005) and youth with chronic conditions (Cramm, Strating, Roebroeck, & Nieboer, 2013). Feeling able to complete a given medical task is an important component to self-management and understanding more about the ability beliefs both parents and youth have related to managing a chronic condition can inform medical professionals and the transition process.

Health-related beliefs and self-management. Self-efficacy is one belief that influences self-management yet there are other youth and parental beliefs that may play a role in self-management and adherence behaviors. These additional beliefs include treatment beliefs, medication beliefs, and vulnerability beliefs.

Treatment beliefs on self-management. Treatment beliefs were one example studied and shown to influence adherence rates (Bucks et al., 2009). Bucks and colleagues (2009) showed that treatment beliefs held by youth predicted to the health behaviors they engaged in and treatment beliefs explained around half of the difference in adherence behaviors. Necessity beliefs about treatment and medication were one example of a treatment belief. Increases in necessity beliefs held by youth were associated with better adherence (Bucks et al., 2009; Hilliard, Eakin, Borrelli, Green, & Riekert, 2015). Additionally, parental beliefs about the necessity of treatment predicted adherence (Conn, Halterman, Lynch, & Cabana, 2007). However, parental necessity beliefs were influenced by concerns about medication. For example, in parents with increased concerns about a medicine, adherence decreased but if necessity beliefs were higher than the concern beliefs, adherence increased (Conn et al., 2007). Finally, parents who had more negative beliefs about the need for and importance of vaccines were more likely to oppose mandatory vaccinations and had reported intent to forego vaccinations for their children (Kennedy, Brown, & Gust, 2005). Another belief in youth that influenced adherence was medication beliefs.

Medication beliefs on self-management. Parents and youth can have different beliefs about medication, its need, and importance of it to managing their health. Parents can have medication beliefs that influence adherence, more specifically, concerns regarding medications. Parents often reported believing medication was necessary for optimal health (Hansen & Hansen 2006; Zelikovsky, Dobson, & Norman, 2011) and higher necessity beliefs were associated with more medication use (Klok, Kaptein, Duiverman, & Brand, 2012; McQuaid et al., 2009).

However, if a parent's concerns about a medication were higher than their necessity beliefs, their adherence to asthma medication for their child was lower (Conn et al., 2005). Additionally, medication beliefs may also impact how other factors influence adherence. Hillard and colleagues (2015) found an indirect effect of depression on adherence through medication beliefs with less positive medication beliefs leading to lower adherence in the presence of more symptoms of depression. Given that medication beliefs have been shown to influence adherence, it is important to understand more about how parents value different health-related tasks associated with medicine and whether those values associate with their behaviors around teaching their child those tasks. In this study, I asked them how important and useful the skills were to their child as well as what behaviors they were engaging in around those skills.

Vulnerability beliefs on self-management. Finally, parental views of the child as vulnerable to their illness influenced adherence. As discussed above, parental views of child vulnerability were positively associated with chronic condition severity (Anthony et al., 2003; Carpentier et al., 2008). Parental beliefs that their child was more vulnerable to an asthma attack or that their child's asthma was in general more severe, positively predicted to better adherence (Becker et al., 1978). Also, parental views of their child's vulnerability were positively associated with medication use and health care utilization (Connelly, Anthony, & Schanberg, 2012; Spurrier et al., 2000). Perhaps when a parent thinks their child is more vulnerable in terms of their illness, they are more actively involved in treatment adherence. Yet, as discussed above, higher vulnerability beliefs were associated with more negative outcomes such as anxiety and depression. Are the behaviors parents engage in because of these vulnerability beliefs one explanation for why this discrepancy exists (e.g., high levels of involvement and less agency granted to youth)? More information is needed to understand how parents' child-specific beliefs associate with their health-related behavioral engagement with their child.

In general, given that the literature supported that treatment, medication, and vulnerability beliefs youth and parents have influenced rates of adherence in youth with a chronic condition, it is important to examine these beliefs in more nuanced ways. For example, do beliefs about the importance of treatment or the usefulness of medication have the same influence that concern beliefs have on self-management and adherence behaviors? The current work aimed to examine parental beliefs and values, such as usefulness, with behaviors in more depth as it relates to preparing their child with a chronic condition to be an adult. Parental beliefs were discussed in this chapter while behaviors will be explored in the following chapter.

Current study

The aims for chapter 4 were to examine the various health beliefs of parents. To better understand the child specific beliefs parents held and the behaviors they engaged in with their child, it was first important to investigate parents' beliefs more generally. These general beliefs were important as they may influence future specific beliefs and behaviors (Eccles, 1993a). Next, understanding more about the ability and value beliefs parents had for the health-related skills can offer useful insight into how to best support children and families as they prepare for adulthood. Knowing more about the utility and importance they placed on certain skills can aid practitioners in individualizing transition programs to have optimal outcomes. What do parents' think about health generally and their abilities to manage health? What are parents' perceptions of their child's ability to complete health-related skills? Finally, what are parents' perceptions of the value of completing health-related skills?

The current study used a mixed methods approach drawing data from both survey responses and interviews. The data for this chapter came primarily from survey responses yet interview data was used to support or explain some of the quantitative findings as well as inform the reliability and validity tests of some of the measures. The survey items covered general health beliefs and child condition specific belief items which will be described in further detail below. I ran the descriptive statistics of all scales that were formed and included those with the individual item level statistics to gain a better understanding of the ability and value beliefs of parents. What skills do parents perceive as the most useful and important for their child? In what skills do most parents perceive higher abilities for their child? Basic comparison tests (i.e., correlations, chi-squared, and t-tests) were performed to see if parental beliefs differ across groups as well. The comparison groups were 1. child gender, 2. child in middle school or high school, 3. parental education level, 4. income, 5. child body mass index, and 5. child lung function. For example, do parents of girls tend to perceive their daughters as being better at doing the health-related skills than parents of boys? The findings are discussed in further detailed in the following section.

Findings

General health beliefs

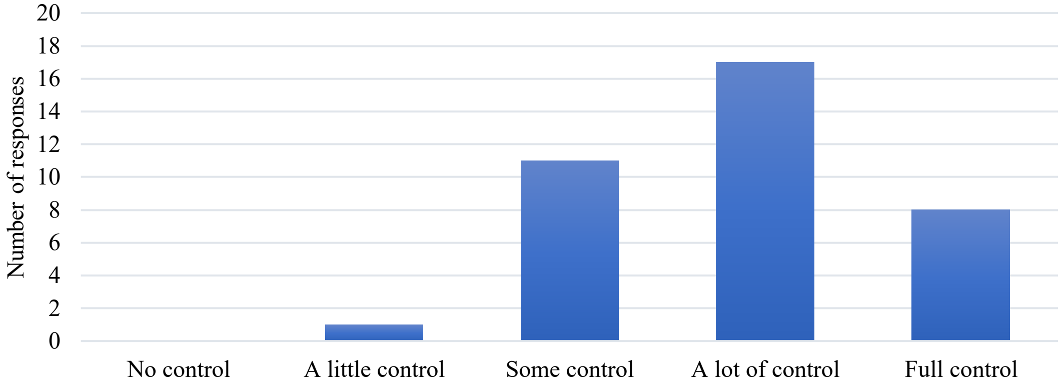
How do parents think about the management of health generally? Do they feel like they have control, that medicine is useful, and that listening to doctors will result in positive health outcomes? To best answer these questions, I used three items "How much control do people have in managing their health?" (1= *No control;* 5= *Full control*), "How well can medicine, if prescribed, manage health?" (1= *Not well;* 5= *Very well*), and "How important is doing what the doctor says to staying healthy?" (1= *Not important;* 5= *Very important*). Based on reliability and validity tests (please see Appendix C for a more detailed explanation of tests), these three items were examined as separate beliefs.

It seems that for the parents in this study, an individual has some control to a lot of control in the management of their health. Effective health management can also be done by taking medicine, when prescribed, and following the doctor's orders. As seen in Figure 5, parents tended to believe that health was manageable to a degree and that medicine and doctors helped in that management. These findings supported previous work on medication beliefs that suggested that optimal health was associated with the belief that medication was necessary (Hansen & Hansen 2006; Zelikovsky, Dobson, & Norman, 2011) and thus associated with the use of medication (Klok, Kaptein, Duiverman, & Brand, 2012; McQuaid et al., 2009).

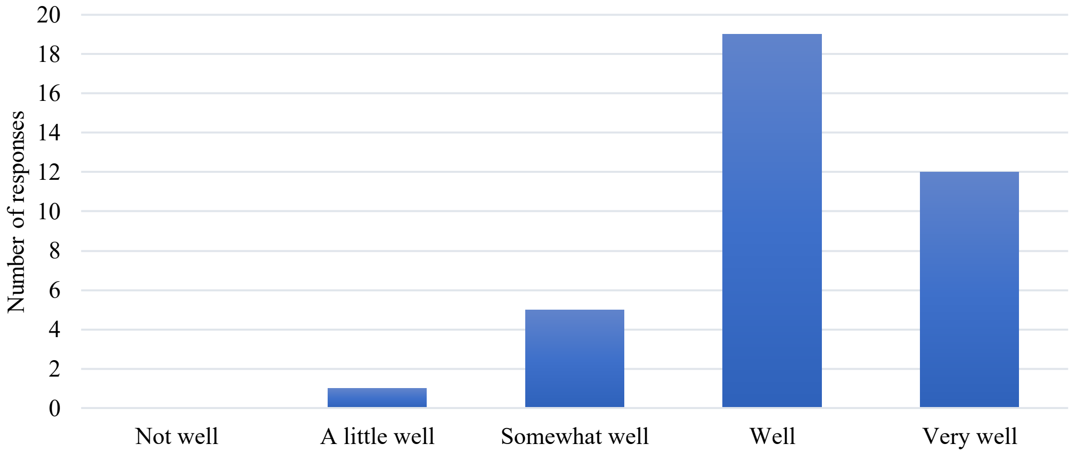
Figure 5

Parent General Health Beliefs

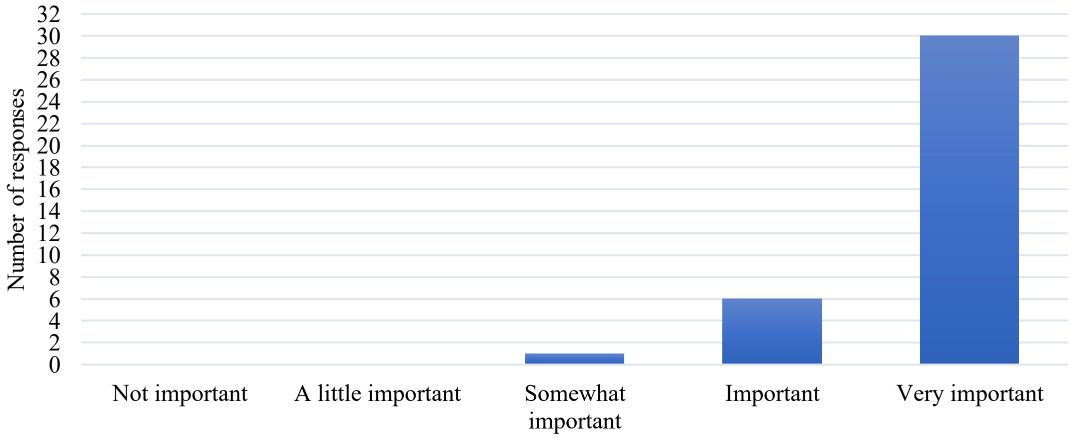
How much control do people have in managing their health?



How well can medicine, if prescribe, manage health?



How important is doing what the doctor says to staying healthy?



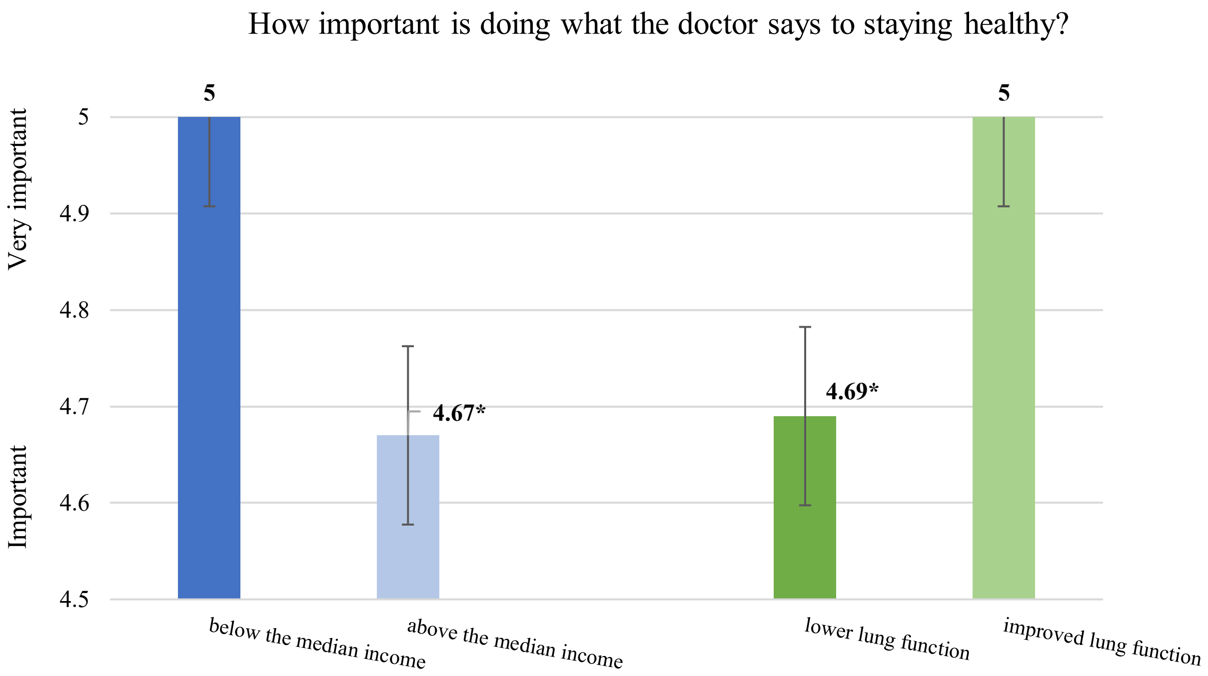
Note. Parents were asked to respond on three general health belief questions using a 5-point scale with no as 1 and very as 5.

In terms of group differences across these general health beliefs, I found only a few significant differences. Parents below the median income for California thought it was more important to do as the doctor said to stay healthy than parents with above the median reported income (see Figure 6). Additionally, doing what the doctor says was more important to parents of youth who had improved lung function over a one-year period than parents of youth with declines in lung function. The literature on income and patient-physician trust was mixed with some finding that lower income patients have less trust of doctors (Richardson, Allen, Xiao, & Vallone, 2012) while others found higher ratings of doctors (Coats, Downey, Sharma, Curtis, & Engelberg, 2018). The findings here supported the latter work and suggested that lower income families placed a lot of importance on following doctor instructions.

Further work is needed to explore whether the association of trust and income could be influenced by condition type or years receiving care by a particular physician. Perhaps, families that have been seeing the same medical team since birth for a condition are more likely to have developed a strong sense of trust. This developed trust relationship might also help explain the finding that families with a youth whose lung function improved thought following doctors' plans were important. It is not hard to imagine that if a family trusts their doctor, they may be more likely to follow the treatment plan without fail. Following the treatment plan consistently then may improve lung function. Further work on this idea is needed as there are many factors that can influence lung function.

Figure 6

Significant Group Differences for General Health Beliefs

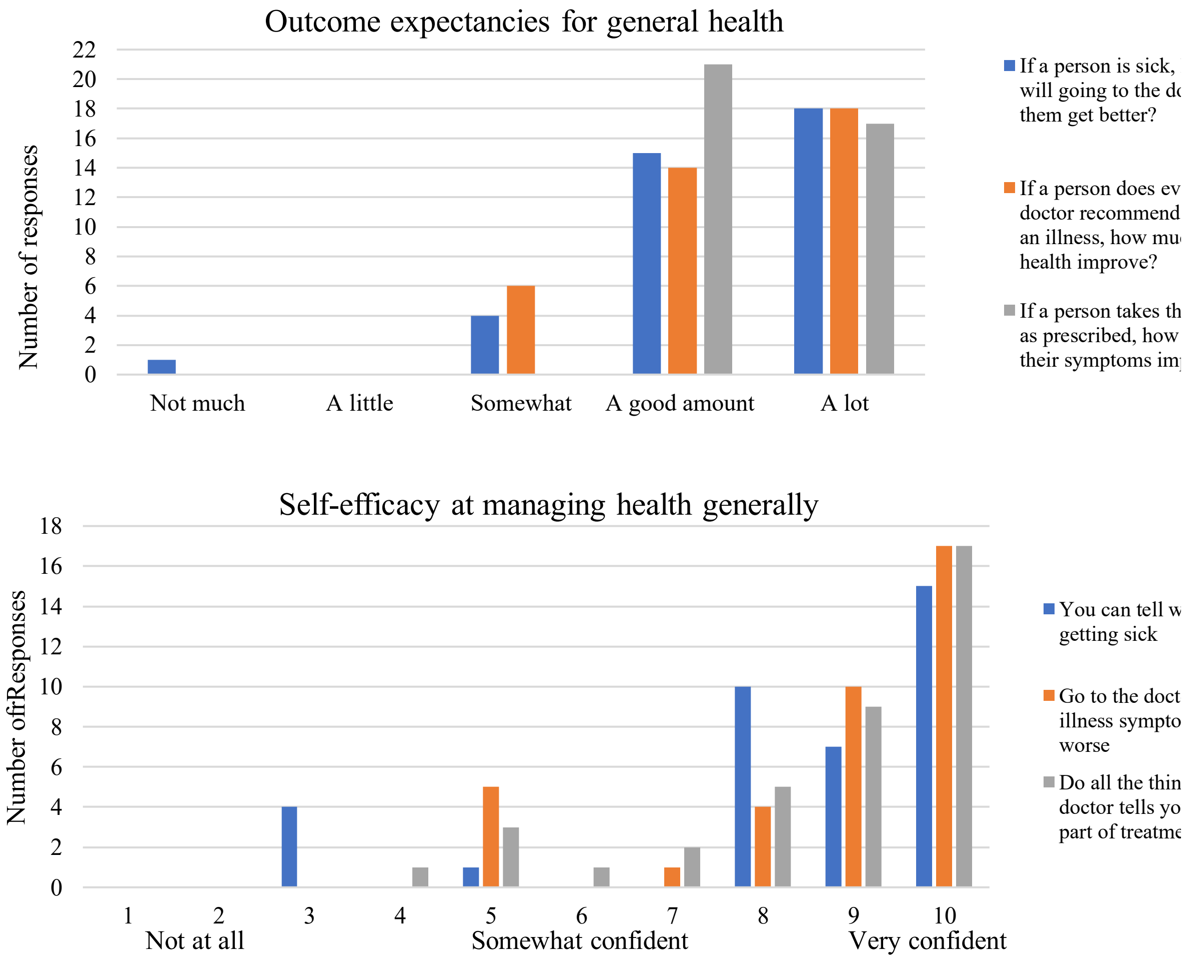


Note. Bolded values are averages for each group. All items had a 5-point scale with 1 being not important to 5 being very important.
*$p < .05$.

Self-efficacy and outcome expectancies. Another way parents can think about health in general terms that may have implications for how they interact with and manage their child's health are the beliefs they possess about their own abilities to manage health and whether or not they think certain actions will result in positive health outcomes. Health-related self-efficacy and outcome expectancies were represented by 6 items and included outcome expectancies related to general illness (e.g., If a person is sick, how much will going to the doctor help them get better?, 1= *Not much;* 5= *A lot*) and general health-related self-efficacy beliefs (Please choose the response that best shows how confident you are that you can… a. Tell when you are getting sick, 1= *Not at all confident;* 10= *Very confident*). Reliability and validity tests supported the formation of a self-efficacy scale averaging all three items (α=.77) as well as an outcome expectancy scale averaging the three expectancy items (α =.70; please see Appendix C for more detail).

In this study, parents tended to have positive views of their behaviors resulting in improved health. On average, they reported that doing a particular behavior would lead to ‘a good amount’ of health improvement. Also, they reported that for general health management, they felt confident in their own abilities (refer to Figure 7).

Figure 7
Parent Outcome Expectancies and Self-Efficacy Beliefs



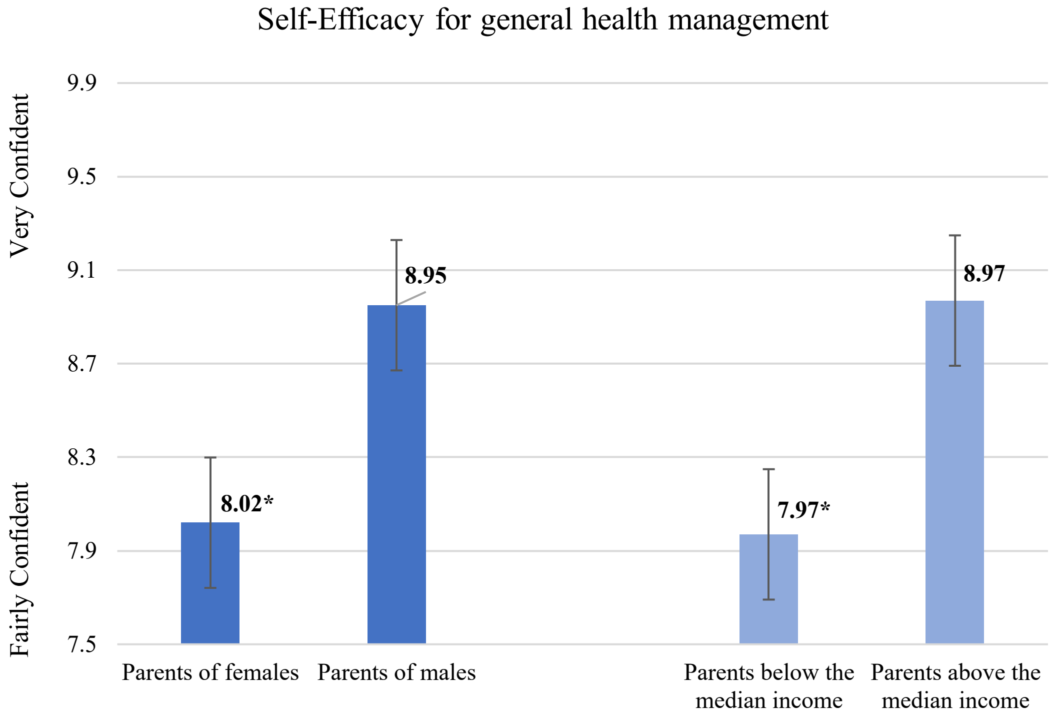
Note. Outcome expectancy beliefs were on a 5-point scale with 1 being not much and 5 being a lot. Self-efficacy beliefs were on a 10-point scale with 1 being not at all confident to 10 being very confident.

As for significant group differences in outcome expectancy or self-efficacy beliefs, only self-efficacy varied across some groups of parents. Parents of girls reported being less confident in their own general abilities to manage health compared to parents of boys (see Figure 8). Parent's own health management was not the focus of this study and so it was not studied in enough detail to fully explore it. This finding suggests that further research needs to be done to better understand parent's own health management with child's gender as a potential mediating factor.

Additionally, parents above the median income felt more confident in general health management than parents below the median. The finding supported that of previous work which suggested that there was a positive association between income and health-related self-efficacy (Ejebe, Jacobs, & Wisk, 2015; Vijayaraghavan, Jacobs, Seligman, & Fernandez, 2011). Additionally, previous work with low income parents found that insurance coverage, access, and medical costs were the three most common barriers to healthcare (DeVoe, Baez, Angier, Krois, Edlund, & Carney, 2007). It is not hard to imagine that lower income parents might feel less confident in their abilities to manage health given obstacles such as access to resources, lack of insurance, or rising healthcare costs.

Figure 8

Significant Group Differences Across Self-Efficacy for General Health Management



Note. Bolded numbers are the average value for each item. Parents were asked to select a yearly average income range from a list. If parents reported an average income of $69,999 or less were designated as below the median income for CA in 2017. Parents reporting $70,000 or above were designated as above the median income level. *$p < .05$.

Family management measure. Finally, it was important to explore the beliefs parents have about health management and more specifically their child's condition, to get a descriptive picture of parental health beliefs. Do parents tend to view conditions as manageable? How do parents think about their own abilities at doing what is necessary to manage their child's health? The condition management ability scale (Knafl et al., 2009) was used to assess how families viewed their ability to manage their child's condition with 10 items. Example items included "In the future we expect our child to take care of the condition." and "When something unexpected happens with our child's condition, we usually know how to handle it." (1= *Strongly disagree*; 5 = *Strongly agree*). A few items were reverse coded and then an average score was calculated across the items with higher scores representing views that the condition was more manageable (α =.60). This measure has been psychometrically tested and shown to have good reliability and validity (Knafl et al., 2009).

In this study, the average summative score on the condition management ability scale was 39.90 out of a total of 50 suggesting that parents felt their child's conditions were fairly manageable and that they felt pretty capable of managing it. More specifically, 87% of parents agreed or strongly agreed that they had been able to develop a health care routine and that they knew when to make health a family priority. Also, 97% of parents agreed or strongly agreed that they felt pretty good about the job they were currently doing in managing their child's condition. Additionally, 92% of parents agreed that their future expectations involved their child taking over care (see Figure 9 for more details about individual items). It seems that the parents, for the most part, have developed ways of handling their child's condition that they are comfortable with and feel confident about maintaining those routines.

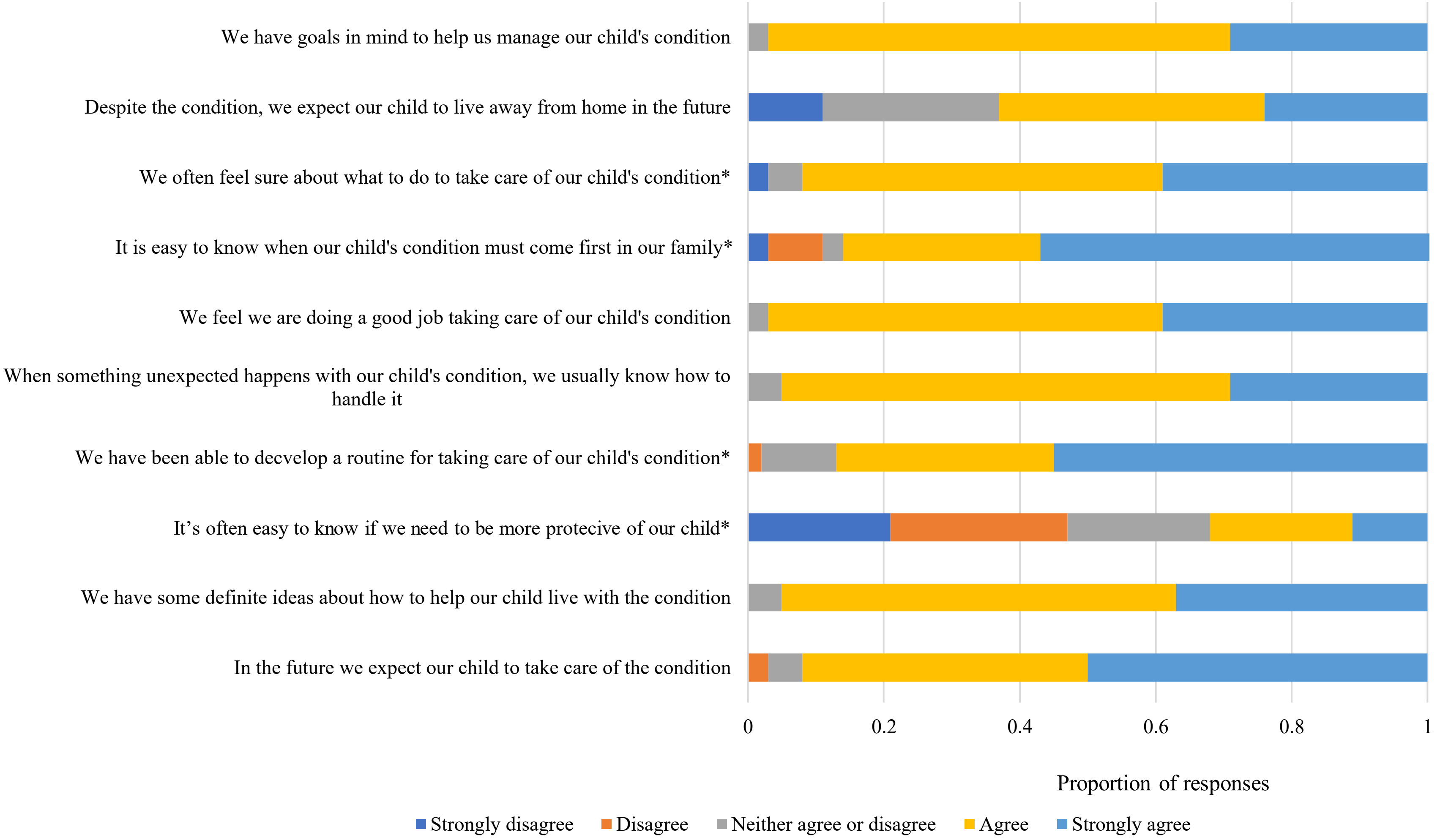
One finding to make note of however, is that some parents struggled with knowing how protective to be of their child and some uncertainty about whether their child would be able to live away from home in the future. In response to a statement of the ease of knowing how protective to be, 46% of parents reported disagree or strongly disagree. Almost half of the parents in this sample acknowledged that it was not often easy to know when to be protective and when not to be protective. Parental protectiveness has historically been found when studying parenting a child with a chronic condition (Carpentier et al., 2008; Holmbeck et al., 2002) and has been linked to increases in depression and externalizing problems as well as decreases in parents' willingness to give independence to their adolescents (Holmbeck et al., 2002) and providing opportunities to learn self-care (Gray, Schaefer, Resmini-Rawlinson, &

Wagoner, 2017). However, one could argue that the researchers' conceptualization and measurement of parental protection is not accurately applied to parents of youth with a chronic condition. These previous studies used a parental protection scale that measured general protective behaviors such as immediately comforting a distressed child, granting the child decision making opportunities, and disciplining behaviors (Carpentier et al., 2008; Holmbeck et al., 2002). However, general protective behavioral measures do not get at the unique forces that drive the beliefs and behaviors of parents of youth with a chronic health condition.

For example, allowing a child the opportunity to decide their bedtime has very different implications than letting a child decide to take their daily medications. These general measures of parental protective behaviors may label a parent of a youth with a chronic condition as over-protective when in fact it is the appropriate level of protection given the unique circumstances (Colletti et al., 2008; Pinquart, 2013). A similar point has been made with low income minority parents and more authoritarian like behaviors. Although they seem more controlling, given their unique physical environments (e.g., poor urban areas with high violence), these authoritarian behaviors may be more beneficial and not as detrimental to development (Furstenberg, Cook, Eccles, Elder & Sameroff, 1999; Steinberg, Blatt-Eigengart & Cauffman, 2006). Given that I used a measure that is more health condition specific and the finding that some parents reported a struggle with knowing how protective to be, suggests more work in this area is warranted. How do parents of a child with a chronic condition define protectiveness? What kinds of things are they doing that they perceive as protective in nature?

Figure 9

Individual Family Management-Condition Management Scale Items



Note. * indicates that the item was reverse coded. The condition management scale is a sub scale of the larger Family Management Measure.

There were two significant group differences on this management ability measure: child gender and parent education level (refer to Figure 10). Parents of boys viewed themselves as more capable of managing the condition than parents of girls. Previous work on parenting a child with a chronic condition found that mothers of boys were often more involved in routine health care, interjected more often, and closely supervised their child more than mothers of girls. In contrast, girls with chronic conditions were often granted more autonomy and responsibility in managing their own health compared to boys with the same conditions (Hill & Zimmerman, 1995; Williams, 2018). Also, Williams (2018) found that mothers of daughters with a chronic condition reported pleasure at their daughter's autonomy yet increased worry because of a lack of control in regard to their daughter's self-management:

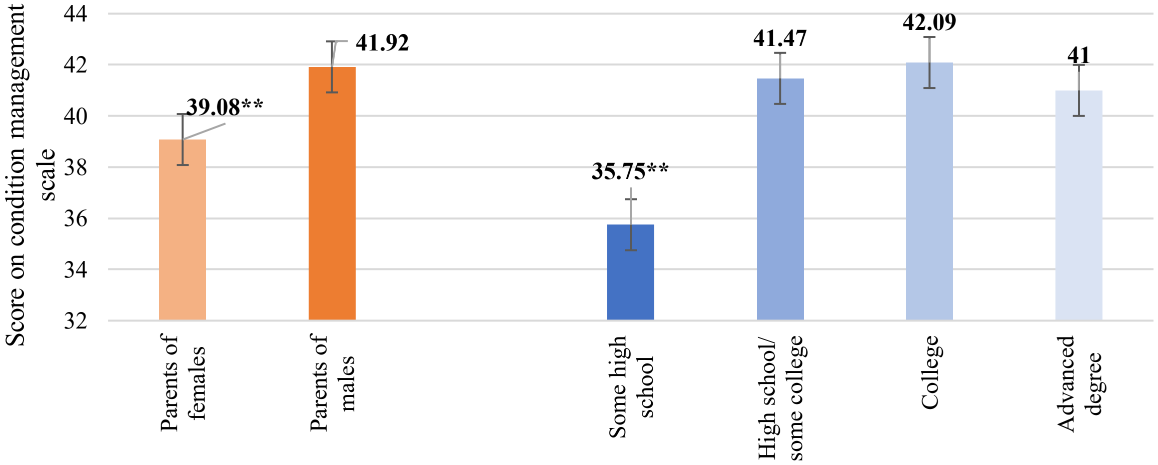
> Whereas developmental activity was often under the control of the mothers of boys, the mothers of girls often had little, if any, control over the situation. As girls took their own steps towards autonomy in self-management, mothers were forced along at a pace which they considered was too fast for their daughters, leading to many anxieties (p46).

One such anxiety for parents could be a lack of confidence in their own abilities to manage their child's condition. It is not hard to imagine that if daughters are taking on more of the health care responsibilities and sooner than sons, their parents may feel less involved in the daily management process. This lowered involvement could then lead to feeling less capable over time as well as feeling out of control of the situation. Finally, the lack control and participation in their daughter's self-management practices could in turn negatively impact how confident they feel at doing self-management practices. I will explore how the gendered beliefs mentioned above may influence parental behavior in the next chapter. Do parents of girls do more autonomy granting behaviors than parents of boys? Do parents of boys monitor their sons more because they feel their sons are in need of more support and protection?

Finally, parents who did not complete high school viewed themselves as less capable of managing the condition compared to parents in all other education groups. One explanation for this group difference was that of the association of health literacy, educational level, and self-efficacy. There was a positive association of formal education and health literacy with more formal education predicting to higher health literacy scores (Shah, West, Bremmeyr, & Savoy-Moore, 2010). Additionally, Wood and colleagues (2010) found that a parent's level of health literacy was positively associated with their perception of how much efficacy they had for dealing with their child's asthma. Also, it has been shown that lower parental health literacy was linked with the view of their child's condition as a burden and lower quality of life (Shone, Conn, Sanders, & Halterman, 2009). Overall, this previous research supported the finding of a group difference for ability to manage a chronic condition across education level. If a parent has only some high school level education and thus lower health literacy coupled with views of the health condition as a burden, they may not feel as confident in their abilities to manage their child's health.

Figure 10

Significant Group Differences on Condition Management Measure



Note. Bolded values are the average summed score for each group. Higher scores on the condition management scale indicate seeing the condition as more manageable.
**$p < .01$.

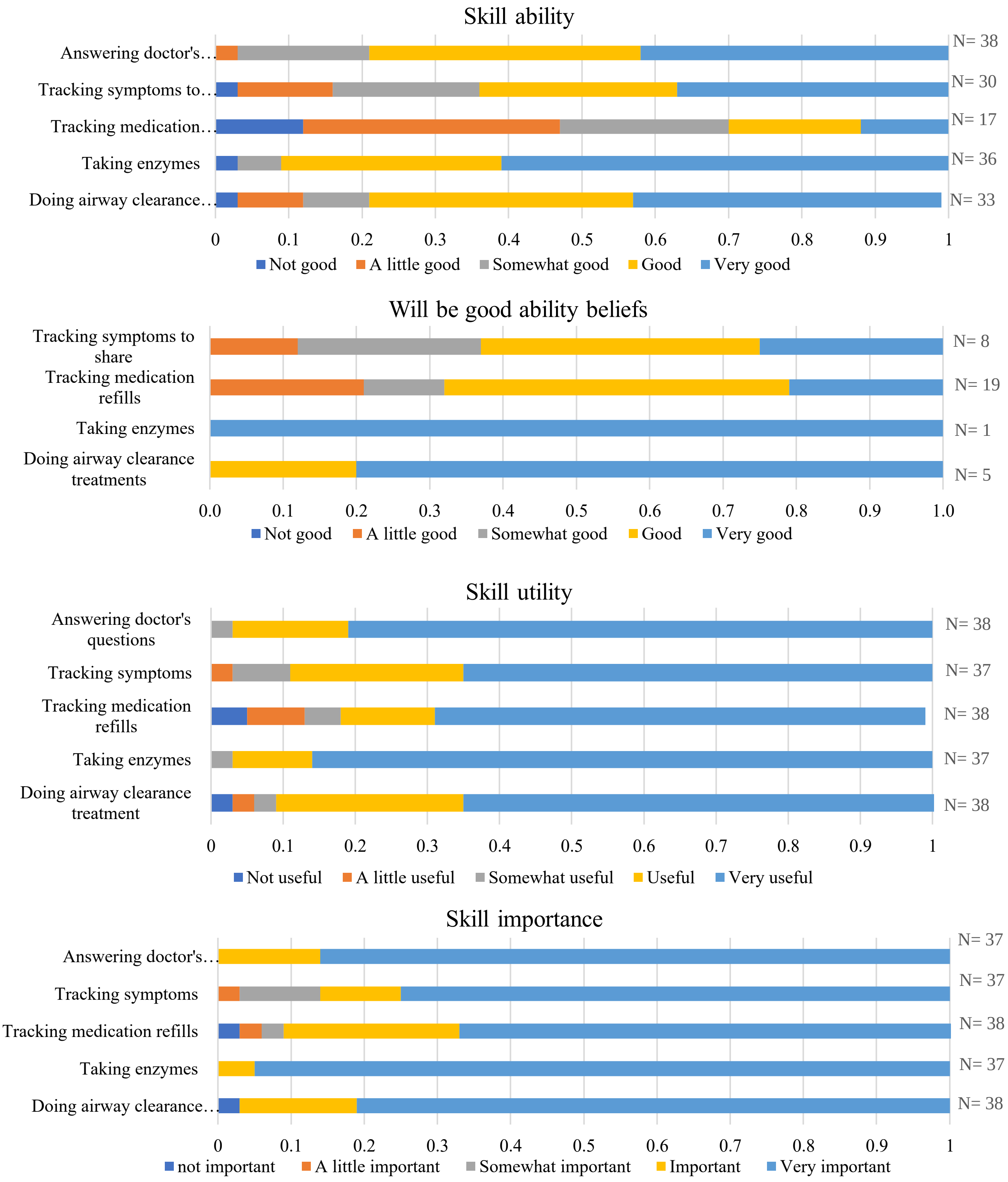
Child Specific Beliefs

Previous work using the expectancy-value theory suggested that parents had specific beliefs about their children's abilities at various tasks; the current study further supported this understanding of child specific parental beliefs. As proposed by the expectancy-value theory, parents can think about how good their child is at doing a task and also the importance and utility of the task. Both beliefs have implications for parental behavior and child beliefs and behaviors. Validity and reliability were assessed for the SCA and STV items. The tests supported that the modified expectancy-value items did subdivide into the typically featured two components of self-concept of ability (SCA) and subjective task value (STV) that have been supported by previous work on the E-V theory (Eccles et al., 1993b) (please refer to Appendix C for a more detailed description).

In general, the findings of this study showed that parents did have differing views of how good they thought their child was at particular skills. However, they tended to think the skills were equally important and useful (please refer to Figure 11). As can be seen in Figure 11, the self-concept of ability items had higher proportions of the low values compared to the subjective task value items. The expectancy-value scales will be discussed in more detail below (please see Appendix C for detailed information about the individual items).

Figure 11

Expectancy-Value Theory Individual Items



Note. The x-axis for all figures is the proportion of each type of response. There were no responses for ‘will be’ good for answering doctor’s questions.

Self-concept of ability. Do I think my child is good at doing their airway clearance treatments on their own? How good is my child at answering questions asked by the doctor at appointments? Parents can have a range of ability beliefs for their children as they relate to cystic fibrosis management. Self-concept of ability was measured with one item for each skill "How good (will) is your child (be) at … [doing their airway clearance treatments/taking enzymes /tracking medication refills/tracking symptoms to share at appointments/answering questions asked by the doctor during appointments] on their own?" (1= *not good*; 5= *very good*). Originally, I hypothesized that the five skills would subdivide into two distinct constructs: medication-related and doctor-related skills. The reliability and validity tests, however, supported that, although there were two distinct groups of skills in terms of ability, they differed from the hypothesized groupings. The five skills subdivided into treatment-related abilities and administrative abilities (please refer to Appendix C for full details). The qualitative data supported this configuration and further informed the skill groupings.

In the open-ended responses, an administrative skill theme arose from the responses as well as a treatment protocol theme suggesting that parents think about managing health in different ways. Furthermore, in the interviews parents often spoke about these skills as being on different levels:

> I look at it from multi-dimensions because that's the reality. The most important dimension is that my child will be taking the medications and conducting the treatments as prescribed. … Third level would be that he has figured out a system to simplify, automate, and just streamline the whole insurance, medication ordering, reimbursements, you name it … And there is always changes so I would say those three-fundamental sort of ways to think about him being successful as an adult managing this condition.

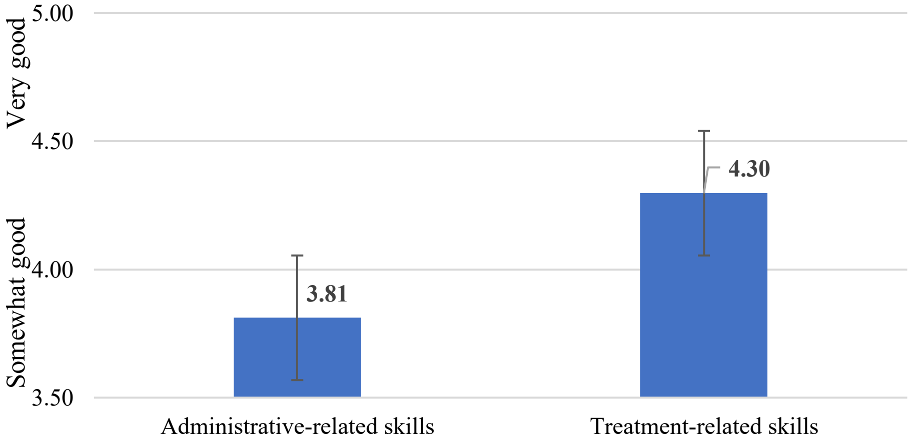
While another parent responded:

> There is a lot of…it's not just your own physical things you think about of you need to manage your care. There is a lot other things that can go into it as well which is the insurance and the phone calls to different people to order stuff.

For parents, there was the skill of directly managing of the condition through treatments and taking medications. Also, a separate but equally important skill of managing the logistical, behind the scenes aspects of the condition. With this in mind, the self-concept of ability items were combined into two average scores: treatment related SCA (i.e., airway clearance treatments and taking enzymes; α=.62) and administrative SCA (i.e., tracking medication refills, tracking symptoms, and answering doctor questions; α=.69).

In general, parents had moderate to high ability beliefs for the children related to cystic fibrosis management. More specifically, the two groupings of skills: treatment-related and administrative-related had parents reporting their children as good on both. However, treatment-related skill abilities were higher than administrative-related skills suggesting that parents may have higher beliefs about that particular aspect of CF care. Parents reported on average that their child was good to very good at the treatment-related skills and somewhat good to good on administrative-related skills (please see Figure 12).

Figure 12
Self-Concept of Ability Beliefs Across Both Skill Types



Note. Bolded values are the average for each item. Administrative skills include ordering medication refills, tracking symptoms to share with doctor, and answering doctor questions. Treatment-related skills include doing airway clearance treatments and taking enzymes. Self-concept of ability was a 5-point scale with 1 being not good and 5 being very good.

This difference in the level of good was further supported by interview data that showed parents worried more about the administrative aspects of care. Perhaps this worry stems from a lower belief in their child's ability to handle the different components of the administrative aspects. One mother discussed her view of how difficult it might be:

> So, I think that kind of thing handing that over to them, the really difficult insurance, trying to get certain drugs that need those pre-authorizations and have to be signed for or just take a long to order, I think that would be hard for a kid.

Furthermore, some of the parents interviewed discussed that teaching administrative skills like ordering medications was often a last step. Parents might hesitate in teaching their children the skills they feel are more arduous:

> We've talked about…actually since our last check up, we did discuss that and I asked them about her being able to do the order, going over the order on the phone for her refills. I think that is the next step, she is going to start becoming more involved in that…that is kind of the last thing, is her helping to order refills.

Parents often thought these administrative skills were more difficult to master and sometimes hesitated in giving their children independence at these skills. Thus, it was not surprising to hear parents speak of their lowered expectations in regard to their children taking over control of the more administrative tasks associated with CF care.

Both interview and survey data supported that parents rated their children's abilities differently across the two skill types and that administrative skills may be the more difficult of the skill groups to teach and master. This was further supported by previous work with children with epilepsy that showed parents reported the primary responsibility for administrative health care task (e.g., lab work and clinic appointments) compared to more shared responsibility of taking medication tasks (Holbein, Smith, Peugh & Modi, 2019). Less is known about the reasons why parents might hold on control of these more administrative tasks and future work examining this could be useful. A potential reason could be that parents don't always know when or how to hand over the more administrative tasks. In the interviews, parents spoke often of the difficult of dealing with insurance, the long phone calls, and not knowing the logistics about literally passing on the responsibility:

> Would I really like to start passing that one to him but then I guess that is what we are going to have to figure out in the way how he can take that stuff on and at what point we're separated completely from it and he is solely in charge of ordering his medications and everything even though he might still be on our insurance. So, we will be figuring out what parts were allowed to I guess one from the legal aspects figuring out the right forms to help him with some of these things until he completely takes control even though he is legally an adult but technically still on our insurance and everything is falling under our stuff too.

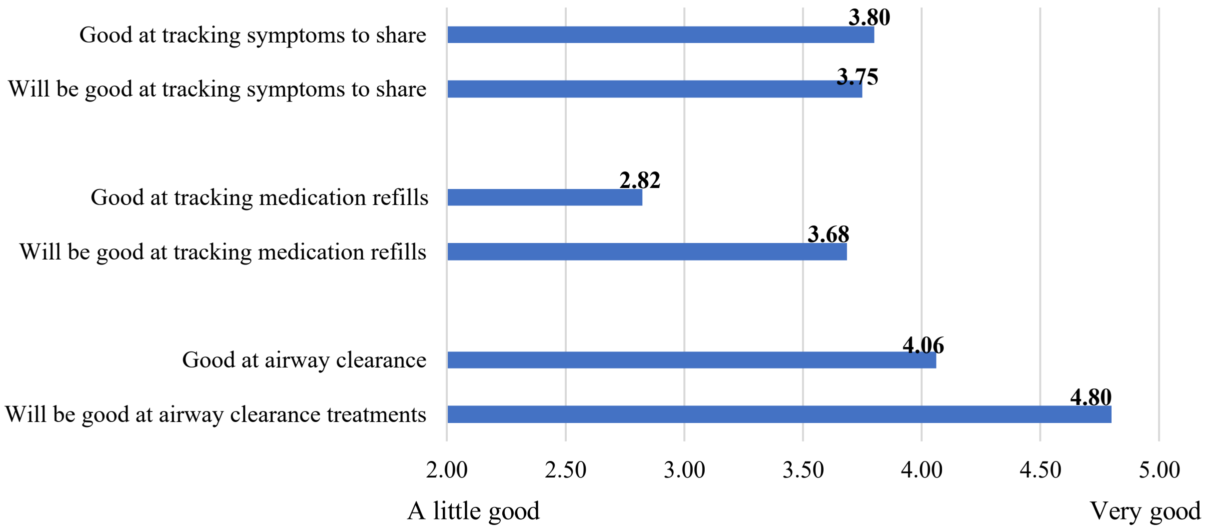
Parents understand that dealing with insurance was a skill that had to be mastered by their children in order for them to successfully manage their own health yet they also acknowledged the challenge it brought. The steps they must take or the legal ramifications of those steps were less clear to parents.

Finally, when a parent reported that their child was not doing a skill independently and had not started trying yet, they were asked to project how good they thought their child would be at it in the future. Values on the 'will be good' items tended to be higher than the 'good' items suggesting that parents of course hold optimistic ability hopes for their children (please see Figure 13). Previous research supported parents having more optimistic beliefs, especially as they related to health outcomes for their child with a chronic illness (Mack et al., 2007). Additionally, optimistic beliefs have been shown to promote psychological adjustment in parents of youth with disabilities (Bretherton & McLean, 2014). Therefore, perhaps parents of younger teenagers with CF who haven't started managing their own health, hold optimistic beliefs about their children's potential abilities as a coping mechanism for the unknown. As their children begin to take over more responsibilities, they have opportunities to evaluate their child's abilities and adjust their beliefs.

Finally, there were no group differences at the aggregate level for the ability belief scales. This suggested that parents in this population often thought about and rated their child's abilities in similar ways as it related to differences in child gender, child age, parental education level, income, or health status of child.

Figure 13

Self-concept of Ability 'good' versus 'will be good' items

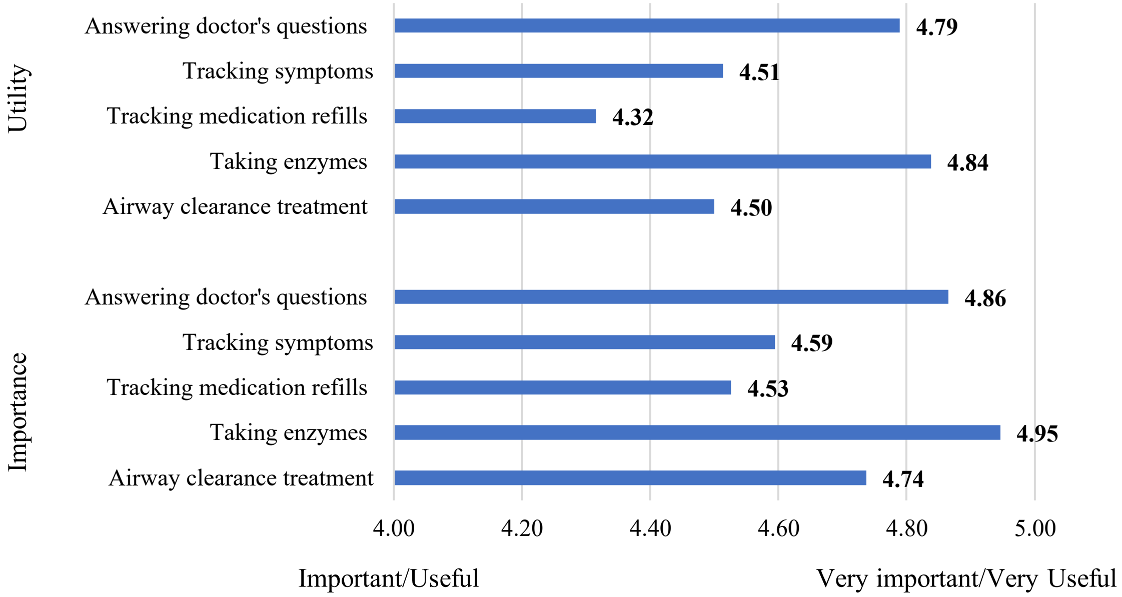


Note. Bolded numbers are averages or the item. Only three of the five skills had responses on this item due to the skip pattern. Items had a 5-point scale with 1 being not good to 5 being very good. The average for each item is displayed at the end of each bar.

Subjective task value. Another component in the expectancy-value theory relates to the value a person places on a particular task or skill. Is the task useful to my child? Is the task important? Subjective task value components of attainment and utility were measured with two Likert scale items. Subjective task value items were "How useful is … [doing their airway clearance treatments/taking enzymes /tracking medication refills/tracking symptoms to share at appointments/answering questions asked by the doctor during appointments] on their own to your child?" (1= *not useful*; 5= *very useful*") and "How important do you think being good at … [doing their airway clearance treatments/taking enzymes /tracking medication refills/tracking symptoms to share at appointments/answering questions asked by the doctor during appointments] on their own is for your child?" (1= *not important*; 5= *very important*"). In terms of the hypothesized medication-related and doctor-related skill constructs, all the subjective task value items formed one large construct and for future analyses were combined into a transition-related skill score (α=.81; refer to Appendix C).

In the current study, I found that parents viewed these beliefs as one construct with little variation in responses. Most parents reported that the skills were important and useful to their children to manage their health in adulthood. Reliability and validity tests supported this as well. There were no significant group differences for the combined transition-related scale suggesting that like ability beliefs, parents in the sample didn't differ greatly on their value beliefs across child gender, age, parental education level, income, or child health status. As an aggregated scale, the average importance and utility of the five skills was important and useful to very important and very useful. In general, parents found all the skills to be useful and important to their child (please see Figure 14).

Figure 14
Subjective Task Value Average Scores



Note. Bolded values are the average for each item. A 5-point scale was used for both utility and importance with a 1 being not important/not useful and 5 being very important/very useful.

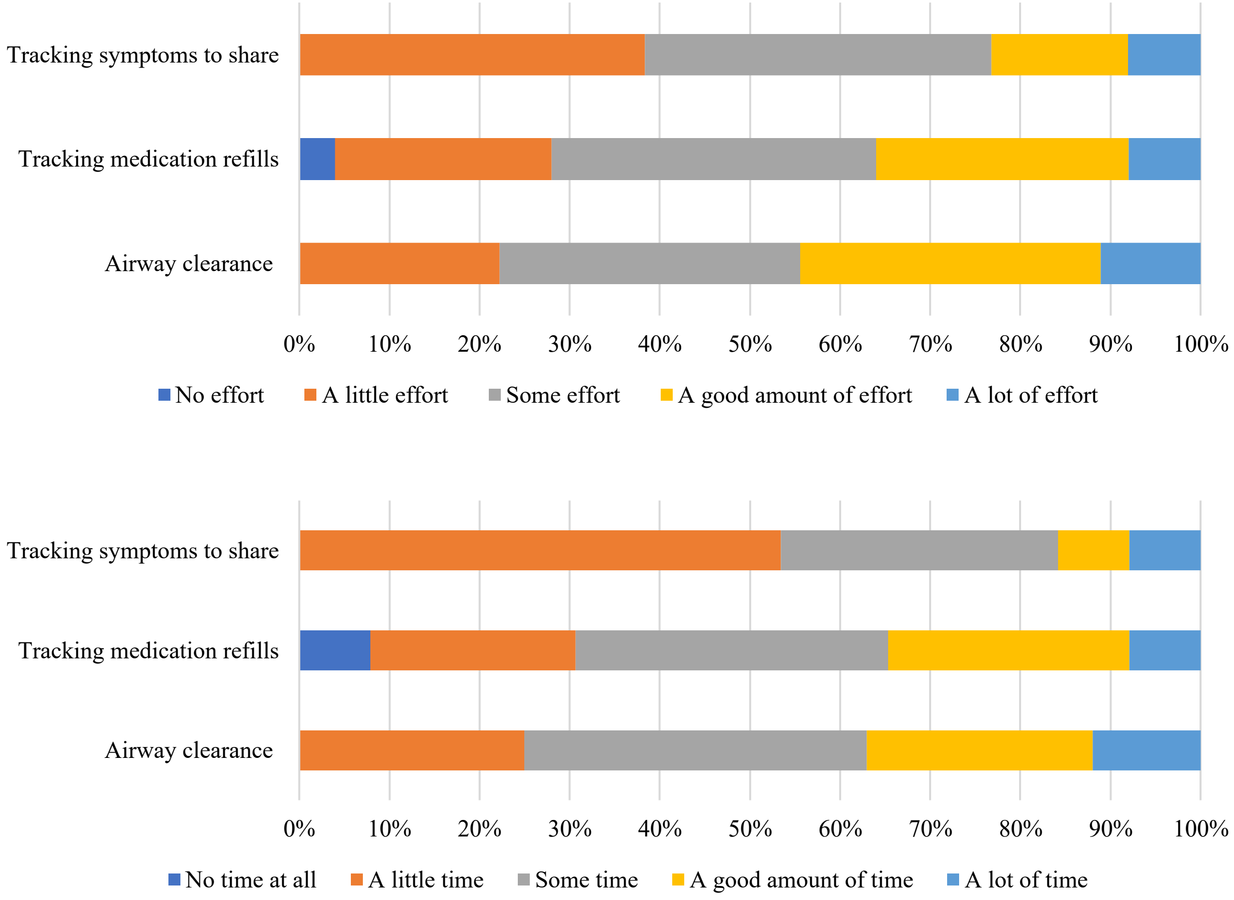
Cost. An additional construct within subjective task value that is often included in studies using expectancy-value theory is cost. In thinking about their values related to particular health tasks, some parent might question what are the associated costs of doing the task? Will teaching my child this skill take a considerable amount of time or effort on my part? In this study, cost items were only asked to parents who reported that their child was not doing the skill on their own and then not good at doing the skill and thus this skip pattern resulted in a different and small sample size per skill. In most cases less than 15 people reported on cost items. Due to this issue, cost items were excluded from the subjective task value analyses and will be discussed as an independent belief. The cost items were "How much effort will it take you to help your child learn to … [do their airway clearance treatments/take enzymes /track medication refills/track symptoms to share at appointments/answer questions asked by the doctor during appointments] on their own?" (1 = *no effort*; 5 = *a lot of effort*) and "How much time will it take you to help your child learn to … [do their airway clearance treatments/take enzymes /track medication refills/track symptoms to share at appointments/answer questions asked by the doctor during appointments] on their own?" (1 = *no time at all*; 5 = *a lot of time*).

Three of the five skills had parent responses on the cost items with 23% of parents for airway clearance treatments, 64% for tracking medication refills, and 33% for tracking symptoms to share at appointments. Across each skill, effort and time were highly correlated suggesting that parents thought helping their child learn the skill would take approximately the same amount of time and effort (airway clearance r =.79; tracking medication r = .82; and tracking symptoms r = .80). Parents reported that the effort and time to help their child learn to do their airway clearance treatments independently as well as track medication refills would take about the same amount as evidenced by very similar graphs (refer to Figure 15). Additionally, parents reported that on average, it would take 'some time' and 'some effort' to help their children with these two particular skills. Of note was that approximately 50% of parents reported some effort or time to no effort or time which suggests parents don't necessarily see teaching airway clearance treatments or tracking medication refills as much of a cost. As mentioned above, optimistic beliefs are not uncommon for parents of youth with chronic conditions and so the parents in this sample may see the cost as less because they think it will be easier to accomplish.

Additionally, of interest was that parents thought it would take 'some effort' yet less time to help their child learn to track their symptoms to share at doctor appointments. Perhaps parents feel that teaching their child how to monitor their symptoms and their health is more difficult yet once they start, it will come more naturally with the child taking over more quickly. Another explanation may be that for parents tracking symptoms was the skill that they had the least amount of control over and so it would require more effort to get their child to actually do it. For example, with airway clearance treatments and tracking medication refills, the parent may be heavily involved yet knowing what your symptoms are is primarily a child directed skill. There may be less opportunities for them to intervene on that skill, raising the parental effort component of cost to teaching the skill.

Figure 15

Subjective Task Value Cost Items

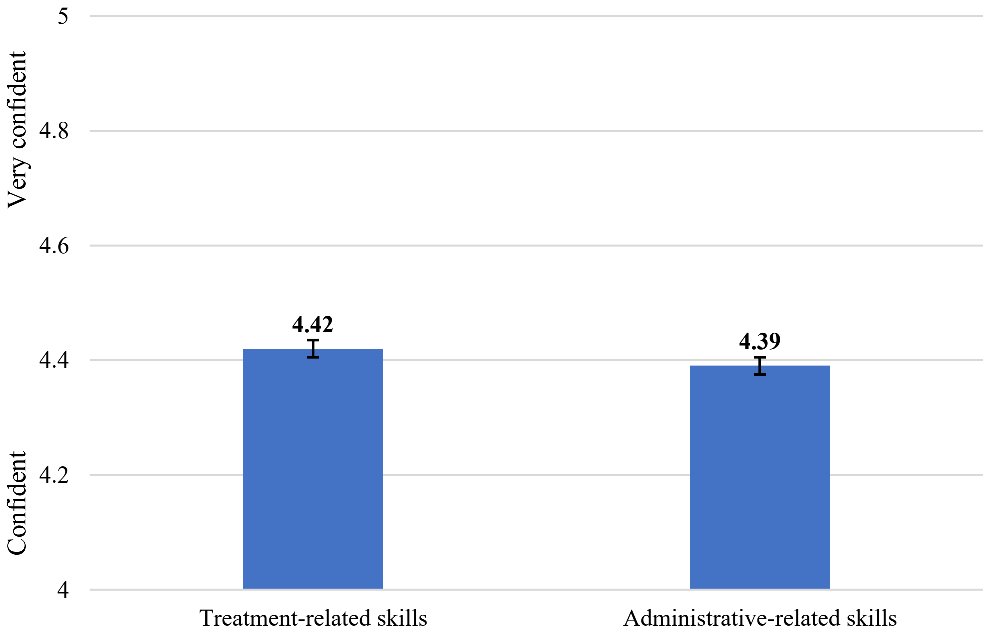


Note. The first graph is effort it will take to teach and the second table is time it will take to teach their child to do the skill. The x-axis refers to the percentage of responses for each item.

Confidence. One last child specific belief examined was parent's reported self-confidence in helping their child learn to do the skill on their own. This item was asked for each skill but only to parents who responded that their child was not already doing the skill independently. The survey items for this construct were "How confident do you feel you can help your child learn to [do their airway clearance treatments/take enzymes /track medication refills/track symptoms to share at appointments/answer questions asked by the doctor during appointments] on their own?" (1 = *not confident*; 5 = *very confident*). Given that these items were asked for each skill, I aggregated them into average scores based on the skill groupings discussed above: treatment-related and administrative-related. In general, parents report that they felt confident at doing both types of skills (see Figure 16)

Figure 16

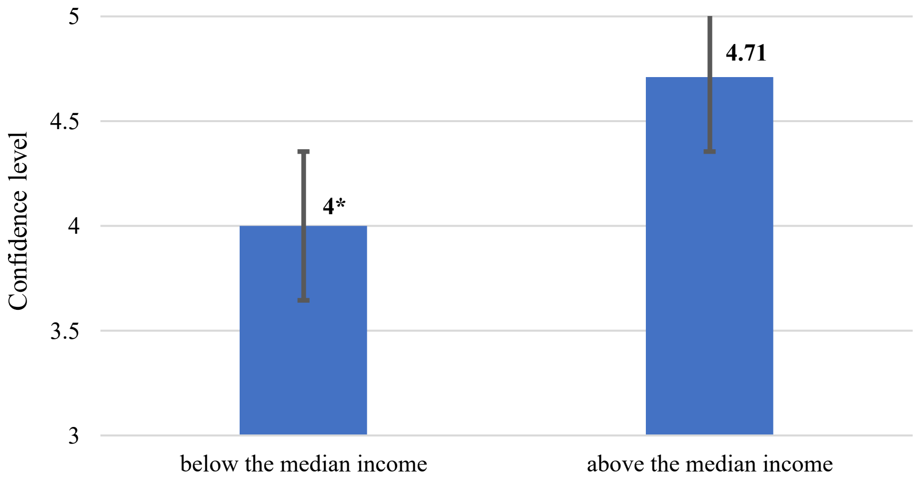
Parent Self-Confidence Beliefs Across Health-Related Skills



Note. Bolded values are averages for each item. Treatment-related skills included doing airway clearance treatments and taking enzymes while administrative-related skills included tracking medication refills, tracking symptoms to share, and answering questions asked by the doctor.

In terms of group differences in level of confidence, there was only one group difference. Parents below the median income level reported on average less confidence in their abilities to help their child learn to do treatment-related skills. As discussed above, lower income parents often had lower health-related self-efficacy (Ejebe et al., 2015; Vijayaraghavan et al., 2011) as well as reported insurance, access, and medical costs as burdens or hurtles in their seeking of healthcare (DeVoe et al., 2007). Lower income parents in this sample may feel less confident that they can help their child learn how to take medication or do airway clearance treatments because they may lack resources or access as well as they may not be able to fully pay the higher costs of some of the CF specific medications. Further work that focuses on lower income parents and the reasons they may feel less confident is warranted so that professionals working with these families can assist them in addressing the individual hurtles they may face.

Figure 17
Significant Income Group Difference on Parent Self-Confidence



Note. Bolded numbers are averages for each group. Confidence items were a 5-point scale with 1 being not confident to 5 being very confident.
**p* < .05.

Summary and Implications

The findings of the current chapter suggest that parents can think about health in general ways as well as ways that relate specifically to their child with a chronic condition. Although most parents reported the value of all CF health-related skills as being important and useful, they did vary on the ratings of their child's abilities on the same skills. Additionally, there were only a few group differences as they related to child gender, child age, child health status, parental income and education level. This suggests that the parents of youth with a chronic condition in the sample think about successful self-management in similar ways. However, differences across income was one very interesting group difference that came up more than once.

The findings supported that parents below the median income level for California felt less confident in their abilities to manage health generally and help their child learn to manage their own health specifically in terms of the treatment-related aspects of CF care. An in-depth examination of the factors that might be influencing lower income parents and their confidence was out of the scope of this work but would prove beneficial in the future. One parent during an interview spoke to the uniqueness of the CF journey and the need for more information on how diversity and socio-economic status plays a role in that experience:

> The one thing I would just encourage you to think about is everyone's journey and experience can be very different. And I hope that … some other project will also look at very different socio-economic demographics. Because I can…again I feel very blessed to have the resources and be so proactive about finding them when they are not in front of me but I can understand that for other people who might be in a different place in life, who might not speak English, who might not have the support, who might not have the access, I can just imagine how different this might feel for them and how overwhelming and so this process and this journey is so different for everyone and it would be very important to look at the diversity and understand what this could look like for someone in a very different place. And how one can support them as well.

The more we know about what makes the journey unique, the more personalized assistance we can provide to lead to optimal health outcomes. From a practical standpoint, understanding in a more nuanced way how parents think about their own health-related self-efficacy and the health-related skills has great benefit for practitioners working with these families.

In terms of how parents thought about health-related skills, one additional interesting finding occurred at the construct level. As a team, we hypothesized a particular grouping of skills and these were different than how parents thought about or grouped the skills. This finding supports that those professionals working with these families might benefit from talking with families directly about self-management and the beliefs they have around managing a chronic health condition. By collaborating with families, we can improve the services and resources we provide them. For example, I found that insurance was a big concern and challenge for families raising children with chronic conditions especially as it relates to wanting and needing more information and support with navigating insurance. Some examples of potential interventions include resources on how to understand insurance policies, the legal ins and outs of having a young adult on a family plan, and tips on how and when to transition a youth to being in charge of their own insurance needs. In understanding more about how parents naturally group the various components of CF care, we can inform practice and services to better meet the family needs as they navigate their CF journey.

CHAPTER 5

Parental health-related behaviors

In the previous chapter, I discussed the unique beliefs parents of a child with cystic fibrosis have as they relate to their child's abilities at doing and the associated value of particular health-related skills. Given that parental beliefs can influence adherence it is not hard to imagine the implications of beliefs for other health-related behaviors as well as how they parent their child. Now that I have explored the general health and child specific beliefs of parents, I shift our focus to understanding parental health-related management behaviors. I start by reviewing previous research in parenting styles as they relate to parenting a child with a chronic illness and then the division of responsibility literature.

Parenting styles

Research suggested that the two dimensions of parenting styles, responsiveness/warmth and demand/control, suggested by Baumrind, were present in families of a child with a chronic condition (Goethals et al., 2017; Luyckx, Goossens, Missotten, & Moons, 2011; Monaghan, Horn, Alvarez, Cogen, & Streisand, 2012; Young, Lord, Patel, Gruhn, & Jaser, 2014). Higher levels of warmth and responsiveness were positively associated with adherence while higher levels of control were negatively related to adherence (Davis et al., 2001; Goethals et al., 2017). Also, studies specifically focused on the authoritative parenting style within the chronic condition literature suggested that authoritative parents had youth with better adherence and disease management (Monaghan et al., 2012; Shorer et al., 2011; Young et al., 2014) compared to youth with more permissive parents who had lower adherence and control (Shorer et al., 2011). In terms of the control dimension, the findings were mixed.

Some findings supported that increases in parental control were positively associated with youth self-care behaviors and lower depressive symptoms (Helgeson et al., 2014) while other findings suggested that increases in control predicted to lower youth adherence (Goethals et al., 2017) and self-efficacy (Young et al., 2014). One explanation for the mixed findings relates to how the control dimension was operationalized. For example, psychological control that was overly critical and negative had worst implications for adherence and disease management (Lewin et al., 2005; Young et al., 2014), then control that was perceived as more parental involvement in disease care (Helgeson et al., 2014). Parental involvement versus parental control may be a harder distinction to make in families and youth with chronic conditions given the nature of disease management and what age a child can physically and cognitively take on the health-related tasks.

Considering the difference between involvement and control, youth's perceptions of how involved their parents are may be more informative to health outcomes such as adherence than level of control generally exhibited by the parent. For youth with a chronic condition, parental involvement in their health care may be routine and more normative, thus youth may perceive involvement more positively then parental control. Ott and colleagues (2000) found that youth who had better adherence reported that their parents did more supportive behaviors and fewer unsupportive behaviors related to their illness management. Also, it was the unsupportive behaviors that had a greater impact on adherence (Ott, Greening, Palardy, Holderby, & DeBell, 2000), suggesting that youth's perceptions of their parents' behaviors as either supportive or unsupportive was critical in terms of rates of adherence.

However, more work is needed that examines what exactly parents are doing in terms of illness management as there was a discrepancy between adolescent and parent reports of supportive and unsupportive behaviors (Ott et al., 2000). Although, parents reported doing more supportive behaviors and fewer unsupportive behaviors, their youth did not report the same levels of each type of parental behavior. This discrepancy in reported behaviors may have implications for interventions that aim to modify parental behaviors and supports getting insight from both youth and parents about parental behaviors. For example, if a parent perceives themselves as very supportive even though the youth does not share this view, then attempting to modify parental behaviors may not be very effective. In the current research, I asked parents to report on more specific skill-related behaviors to understand more about what parents are doing around the different health-related skills. One-way parents might be engaging with their child is dividing up the CF care responsibilities.

Division of responsibility

Caretakers and youth divide responsibility of health-care tasks in many ways with research primarily focused on either parental responsibility or shared responsibility. When parents reported being primarily responsible for self-care tasks, adherence to treatment regimens were highest (Pai & Ostendorf, 2011; Psihogios & Holmbeck, 2013; Vesco et al., 2010). However, division of responsibility was typically measured on only a three-point scale with child responsible at one end, parent responsible at the other end, and shared in the middle. Treatment regimens can be complex multi-step processes that may not be explained by a simple all or nothing viewpoint and may take years to fully master independently. Additionally, unless clearly defined, the idea of sharing responsibility could look very different across families and conditions.

For example, how should a parent respond if they only have to remind their child to do their breathing treatment everyday but then the youth does it independently? It is not hard to imagine that parents and youth might struggle with how to respond to who is responsible for certain health skills if clear definitions are not given and a more appropriate scale is not provided that reflects the unique nature of the skill. Although, parental responsibility suggested better outcomes for youth in terms of medical adherence and control of the condition (Pai & Ostendorf, 2011); youth often reported wanting a more cooperative treatment experience with parents as well as annoyance at being treated like children (Bregnballe, Schiotz, & Lomborg, 2011). One could argue that only shared responsibility fosters independence, agency, and support for management of a condition into adulthood.

There was support for positive outcomes when responsibilities were shared. Intervention based studies including a component of cooperation and teamwork between parents and youth showed better adherence to treatments and less parent-child conflicts (Duncan et al., 2013), as well as increases in parental teaching behaviors (Clark et al., 1986). Additional research supported that sharing responsibility for diabetes self-care tasks resulted in lower risk for deviations from normal blood sugar levels and less overall fluctuations in glycemic control (Marker, Noser, Clements, & Patton, 2017). In their interview work with adolescents with cystic fibrosis, Bregnballe and colleagues (2011) discussed the negative outcomes that can occur when parents do not involve children in any medical decision making. One such outcome was youth potentially not feeling responsible for, or any concern over, their own health.

This was further supported by work with youth with diabetes that showed that there was an increased risk for blood glucose levels to fall outside the acceptable range and to greatly fluctuate overtime if parents were the sole managers of self-care (Marker et al., 2017). These findings suggested that youth with parents who are mainly responsible for diabetes care, do not manage their diabetes well when on their own (e.g., at school or with friends). This is problematic as youth will spend more and more time away from parents as they age and need to be able to manage their care in a variety of situations. It is important that they value and feel responsible for their own health so that they can eventually take full control of it.

Discrepancies in responsibility. Another problematic issue that arises in the division of responsibility literature was the discrepancy between parent and youth reports of who is responsible. Discrepancies can occur between how much responsibility a youth reported compared to what a parent reported for given health tasks. Adolescent youth often reported having more responsibility in medical self-care tasks than their parents reported the youth having (i.e., parental underestimation) (McQuaid et al., 2001; Ott et al., 2000; Psihogios & Holmbeck, 2013). Additionally, parents can overestimate their child responsibilities for a given task (i.e., when a parent reports their child having more responsibility than the child perceives). These two types of discrepancies were problematic because the degree of difference between parent and youth reports can negatively influence health outcomes (Pai & Ostendorf, 2011). Researchers have found that larger differences in reports can lead to poorer adherence (Pai & Ostendorf, 2011) and overestimating by parents can predict to non-adherence in youth (Walders et al., 2000). For instance, if a parent thinks their child is fully responsible for a given task but the youth does not perceive themselves as responsible for that task, it is highly likely poor or non-adherence will occur because they each think the other is responsible. Also, if a parent underestimates how much responsibility their child has for a given task, yet the youth perceives themselves as responsible for it, the parent may be more involved with doing the skill leading to conflict between parent and youth.

In summary, research supported the conclusion that parental involvement was related to better adherence especially when the responsibility was shared between parents and youth, but in addition, however, many youths would like more opportunities for responsibility. Also, reported discrepancies between who was primarily responsible were both common and associated with lower adherence rates. Given that this discrepancy exists and can have negative implications for adherence, more work is needed that examines the reasons behind those discrepancies. Perhaps parents do not relinquish as much responsibility to youth because they do not think their child is good at the skill or they feel their child is not ready to assume responsibility. Parents may also think the cost of sharing the responsibility is too high or too time consuming. The previous chapter examined the parent's child specific ability beliefs regarding specific transition-related skills and found that parents do have a range of ability beliefs across skills for their child. This chapter will further explore the ways parents report behaving as they teach their child self-management.

Current study

The aims of chapter 5 are to examine what parents are doing with their child in terms of preparing them to manage their chronic condition in adulthood. Having this understanding of what parents are doing to teach these skills can suggest ways for practitioners to cater their interventions towards particular behaviors and hopefully improve transition-related outcomes. In what ways are parents engaging with their child around health-related skills? How often are parents engaging in health-related behaviors with their child? And finally, are there any group differences across behaviors reported?

The work discussed below used a mixed methods approach drawing data from both survey responses and interviews. The data for this chapter came primarily from survey responses; interview data were used to support or explain some of the quantitative findings. The survey items were scale items that covered specific behaviors for each health-related skill and open-ended responses about what parents were doing to address their own specific worries and goals. Each skill had three predetermined behaviors presented to parents allowing them to report how often they did these behaviors in a given timeframe. Individual items are described in further detail below. I ran descriptive statistics of all items to understand better the behaviors of parents. What kinds of behaviors are parents reporting more often? Basic comparison tests (i.e., correlations, chi-squared, and t-tests) were performed to see if parental behaviors differ across groups. As done in chapter 4, the comparison groups were 1. child gender, 2. child in middle school versus high school, 3. parental education level, 4. income, 5. child body mass index, and 5. child lung function. For example, do parents of girls tend to do less health-related behaviors with their daughters than parents of boys?

Findings

In what ways do parents engage with their children when they have specific health goals or health worries in mind? What are parents doing as they navigate the process of teaching self-management to their youth? In the following sections I discuss what parents are doing around health-related self-management skills by first exploring behaviors that are meant to address their specific goals or worries. Next, I discuss the ways parents engage with a set of pre-determined skill related behaviors and the group differences across those behaviors. Finally, I examine the concept of teamwork and how parents engage in collaborative behaviors with their child.

Open-ended parent reported behaviors

Before introducing parents to a list of predetermined behaviors around each skill, they were asked to report on some ways they were addressing their own particular goals and worries. As discussed in further detail in chapter 3, parents were first asked to report on up to three health-related skills they felt their child should be able to do as an adult and up to three worries they have about getting their child ready for adulthood. Parents were then asked, "What are some things you are doing to help your child improve at these skills/things?" and "What are some things you are doing to help prevent these worries from happening to your child?".

I analyzed the open-ended responses on these items using inductive analytic techniques (Corbin & Strauss, 1990; Saldaña, 2009) to further group the responses into themes. In the initial round of coding, I used descriptive coding to summarize the basic ideas in the response and then I performed a secondary round of coding using pattern coding to further collapse codes and identify larger patterns (Saldaña, 2009). For a more detailed description of methods used for this data, please refer to chapter 3.

Behaviors. Although asked what specifically they were doing to address their particular skills and worries separately, very similar patterns emerged for the types of behaviors parents engaged in to meet those needs. Both skill-related behaviors and worry-related behaviors fell under the same three major categories suggesting that although parents have unique goals and worries, they were addressing them in similar ways. The three categories include: 1. Parent-child interactions, 2. Parent-driven interactions, and 3. Structuring the environment. Each group is discussed in further detail below.

Parent-child interactions. Parent-child interactions were conceptualized as encompassing interactions between a parent and child; they most often included verbal exchanges ranging in the level of additional involvement. For example, the category of talk was considered to be the least involved in terms of effort by both parties while the category of teach was considered to include talking but also an additional element to the interaction such as modeling. Finally, co-activity was considered the most involved parent-child interaction because it implied talking or teaching but also a direct mention of doing it together. Please see Appendix B for the full codebook and Table 10 for example codes.

Across both skills and worries the interactions included both talk and teach categories with a relatively equal amount of both behaviors. Parents reported talking about medication, general health topics, and the future with their children while teaching behaviors were more goal driven or CF care related in nature. Furthermore, in the interviews parents often spoke about having conversations with their child around different aspects of CF care and self-management:

> But there is a lot of discussing and conversations about everything so we talk a lot about everything, responsibility, what's important…so I definitely think for a lot of those things there was discussions on being…it wasn't a structured discussion where I had a note pad and go down a list and say 'this was the thing', it was more approaching it as life brings it type of … that is kind of how we do it. But there was a lot of discussion about responsibility that she would take on in the future. That is always a kind of an on-going conversation that we have here and there with her dad and myself or just myself and her.

In addition to conversations about self-management, an interesting caveat to talking and teaching that came out of the interview data was the idea that often these teachable conversations arose in the moment. Parents also discussed the additional steps they take when a teachable moment arises and how they use the moment to begin conversations or establish habits that they hope will take hold in the future:

> I mean we have been trying to teach him, I guess some of the stuff ordering, we have been trying to teach is as well is … we've have had to talk with him about like he will come to me and say I need this and what we've actually been teaching him is instead of just coming…because what that is precipitated by is that he has realized 'oh I had to go take this particular medicine and I just grabbed the last bottle and now he comes and tells you that he is almost done. But I have actually been sending him back in those moments to go and review all his medications because what I have found is usually, he comes to me and tells me 'oh I need this' and then three days later he comes back 'oh I need this'. I was like 'I am not calling the same people or ordering this stuff like this all the time. You need to sit down and review everything and come to me once you've done that with all the medications. I am trying to help him and I think, I know he doesn't realize why that is important now but once he is on the other end of it, I think he will realize that too.

As parents were engaging in daily routines and care, they found themselves using those experiences as teachable moments to pass along information to their child. In addition to using the moment to moment experiences to educate their children, parents also reported behaviors that were collaborative in nature and involved both the parent and child actively participating.

As seen in both survey responses and interview data, these co-activity behaviors ranged from having the child present with them when doing the behavior to more elaborate discussion and planning sessions. For example, from the survey data, one parent said “Finding a balance between illness management and living a fulfilled life” was an important skill her child needed to know how to do to manage health as an adult. Her efforts to address this goal were “When my child gets home from school, I ask him about his homework assignments, then we review the commitments and activities for the day, then discuss how to schedule homework, breathing treatments, meals, and activities”. To some parents’ co-activity started as a way to teach their child a skill but then changed to wanting to help their child with the burden of lengthy treatments. One mother spoke about the process:

> Well she’s kind of aware of because we have done it together here and there but I definitely the first time we went and I did it and talked through what I was doing and just went over the important parts of why and how it’s important to make sure everything stays clean. … I did it first and then walked her through and then I think the first few times she did it, I kind of monitored. I was with her to make sure she was doing it properly for sterilization. And yeah now she pretty much does it, sometimes I will help her wash the nebs if she is busy and needs help washing them but then she will load the basket. So, we still kind of share because of her school schedule sometimes it’s so busy but she has definitely still taken over most of that.

It was not uncommon for parents to mention in interviews that they wanted their child to learn the skills necessary to manage their own health but also wanted to help their child to save time and energy. Finally, the category of co-activity was unique to skill responses suggesting parents may not address their worries together with their children. Work on parental information sharing and children with genetic conditions suggested that some parents selectively shared information and made a conscious choice to not disclose information they felt was worrisome such as shortened lifespans (Gallo, Angst, Knafl, Hadley, & Smith, 2005). Perhaps parents in the study choose to handle their worries without the child as a way to avoid adding undue stress and worry on to their child. Future work would benefit from exploring collaborative behaviors and addressing worries. Are there particular worries that parents might address with their child in a collaborative manner and others that they handle without the child? By definition the parent-child interaction behaviors were more collaborative in nature then the other parent behaviors so perhaps parents utilize other more parent driven behaviors to address worries.

Table 10
Parent-child Interaction Examples from the Codebook

Category	Example	N
SKILLS		
Talk		
a. Medication	"Talk to him about it, have him fill his own meds each week, talk through decisions"	4
b. Future	"Discuss the importance of being at appts and following doctors' orders for when he is in charge of this when he gets older."	2
c. Other	"I ask them to investigate and read more about their illness so that they can get an idea of what to be"	4
Teach		
a. Medication	"Teaching how to order all medications to be on hand"	5
b. Treatments	"Putting on his vest and hoses, knowing when to huff cough, and how to stop and restart treatments."	4
c. Other	"Know what to look for when his weight goes down. Make certain that he will not allow it to get too far out of hand"	3
Co-activity	"Have him listen while I order"; "Watch's how I do it "	4
WORRY		
Talk		
a. General	"Talking to him about resilience and our unconditional support"	6
b. CF-related	"Talking to him about how doing his treatment plan impacts his wellbeing"	4
Teach		
a. Goal driven	"Showing how long it takes for your treatment and what you have to do"; "Teaching him weekly, monthly planning techniques"	6
b. General	"I try to make my child aware of logical consequences (if you don't take enzymes, you will get stomach pain)."	2

Parent-driven interactions. Parent-driven interactions encompassed parental behaviors that were driven primarily by the parent such as granting autonomy or monitoring. Please refer to Table 11 for a full list of parent-driven interaction categories with examples. These interactions were thought to originate from and be driven primarily by the parent. Similar themes were found across both skills and worries in terms of offering support, granting autonomy, and monitoring. For skills, autonomy granting behaviors were the most prevalent, followed by monitoring behaviors, and then support. For worries, support behaviors were mentioned most often, then monitoring, and autonomy granting.

These overall themes were mirrored in the interviews. Parents regularly acknowledged the need for, yet inherent struggle with, granting autonomy to their child as well as monitoring being a significant part of how they helped their child remember self-care. Giving responsibilities over to their children, for some parents, was seen as a natural evolution of CF care and similar in a lot of ways to other adolescent responsibilities. One mother elaborated on this idea:

> I think it was just a natural kind of progression just like you give any kid independence on anything. So, when they learn how to drive, at first you are like 'well only on surface streets to and from school' or whatever your rules are, 'not after dark'. So, there were certain things like now 'you have to clean your cups just like you have to do your laundry' or whatever. It is just little like incremental, 'now this is your responsibility. I have been doing this for a long time but now you are going to do it. You are perfectly capable.'

While multiple parents talked about knowing that autonomy and responsibility were important and necessary to their child learning to manage their own health, many also discussed the struggles that were a natural part of the process. One such struggle was knowing when to give over control of certain aspects of CF care as described by one parent:

> but when it comes to CF, I don't know, this is my only kid with CF and he is my first kid, so I have no idea when he is supposed to be doing certain things. As parents we're

> caretakers and advocates for them and sometimes it is harder to let some of those things go and if people aren't telling us what we should be doing, then we are just going to keep reins on it because that is what we have been doing since they were little.

Perhaps for parents maintaining the status quo was easier than implementing a plan for their child to take over more of the care. The time and effort it would take to fully pass control and responsibility for a given task to their child was an additional struggle that influenced when and how parents grant autonomy and control. This parent talked about the struggle:

> I mean really need to start doing this'. That is what truly got me thinking of it, otherwise it would probably just be more like keep doing what we are doing to get through the day because honestly it takes a lot of extra effort to try to train somebody else to do it when I know I can as a mom, you know what I mean? I can do this but to train you is going to be like two months.

Parents admitted knowing that a large part of self-management will come from them relinquishing control over to their child but timing and effort played factors in the process. One last factor that was discussed by parents was one of being psychologically reading to pass the skills along:

> Well there is two components to me being ready. One of them is psychologically and the other one is cognitively and physically, procedurally right? I mean procedurally I am ready. Psychologically I am not, I don't have the confidence that that things will continue to be managed in a way that is in his best interest, you know because he will forget.

Knowing how to pass along the information and responsibility, for some, was the easier part while actually doing it was a challenge. Parents acknowledged the importance of letting their child try skills on their own yet recognized that it could be difficult letting go of the control or finding the time and effort to teach. One way they may deal with this difficulty was to still monitor their child doing the task to ensure it is done correctly, or at all. A parent said:

> He has been responsible for a while now keeping track of that and I think we will go and double check still kind of behind him sometimes."

While another parent explained:

> For me… the one thing that I do know that she could work on and I am still constantly reminding her on is when she is doing her vest to stop for the huff cough. She has gotten kind of lazy on doing the huff cough and I am still prompting her for that a lot of times.

Reminding and double checking were common monitoring behaviors mentioned by parents in both the interview and open-ended data. Perhaps parents used monitoring as a way to slow the transition of care tasks down enough so that their child had time to try while still having parental support. This mother described the process as she saw it:

> I am always trying to get her to step up, you know where we approach things like ordering meds and when it doesn't get done in a timely manner we just 'you are out of meds, now what are you going to do?' It's kind of like guided collapsing if you know what I mean. I watch her make the mistakes and then I go back and I correct her and we do it again. It's just trial and error at this point. I am just watching, giving her the responsibility, watching her fail at it and then we are picking up the pieces and moving on and trying to do it again in a better way.

Parental support was found for both skills and worries reported in the survey as well as in the interviews. As evidenced above in the quote, parents wanted to help support their children when they failed in the hopes that through supported failure, they would eventually learn and succeed. Also, the same parent later discussed "We want nothing but the best for her and at this point the best for her means letting her fail, even in her treatments, so that she can learn and move on to doing it herself."

There was one unique theme under worry-related parent-driven interactions, avoidance, suggesting that parents were more likely to report avoiding a worry than a skill. The literature on distress tolerance offered an interesting explanation for why parents might avoid addressing their worries as opposed to their goals. Distress tolerance refers to a person's ability to tolerate distressing emotions and thoughts in the face of stressful events (Brown, Lejuez, Kahler, & Strong, 2002) and has been linked to avoidance behaviors (McHugh, Reynolds, Leyro, & Otto, 2012). For these parents, their worries may cause them more stress and negative emotions then they feel they can handle, so they choose to avoid particularly stressful worries. Exploring parental distress tolerance and its role in avoidance of addressing self-management related worries could help to explain this finding in more detail.

Table 11
Parent Driven Interaction Examples from the Codebook

Category	Example	N
SKILL		
Autonomy granting		
a. General	"Letting him make choices, decisions, step back, allow him to be independent"	2
b. Treatment	"Letting him manage his treatments more by himself."	3
c. Medications	"Letting him start to place some of the refill orders"	5
d. Other	"We are letting her learn to pay bills"	2
Support		
a. General	"I try to support him in that predominantly"	5
b. Medication	"Help with medicine"	2
Monitor		
a. Reminders	"Reminders and guidance"	3
b. Ensuring it gets done	"Make sure he does/remind him" ; "Observing that all this well with his medicines"	5
WORRY		
Autonomy	"Make him accountable now."	3
Support	"Help him when he needs it"	5
Remind	"Reminders"	4
Avoidance	"I do not talk about that with him"	2

Structuring the environment. Structuring the environment were attempts or efforts made by the parents to provide an environment that would foster desired behaviors or avoid undesirable ones. These types of behaviors, for both skills and worries, fell under one of two categories: 1. provision of resources and 2. establishing routines or habits. Provision of resources were responses describing parental efforts to provide tangible items geared towards helping with the skill or opportunities for access to resources for the youth. In the interviews, parents mentioned a variety of motivations for needing resources and ways they provided things to their child in the hopes of streamlining or encouraging self-management:

> We did have to start introducing trying to get him to manage that stuff better with how you are taking it because he was just having the bottle sitting there and grabbing the pills and then go take them but then once he started getting more and more pills … We realized we were forgetting a lot of it. Right now we finally got him on, we got him a pill case that is a weekly pill case that he is supposed to be putting all his pills in there and that way he can easily see which pills he needs to take morning, noon, and night and not sitting there figuring out which ones…

Providing resources was only one-way parents attempted to structure the environment for their child. Another way was to establish routines which entailed responses that related to creating general and CF specific routines or habits. Over half (56%) of the structuring environment responses were establishing routines/habits suggesting that parents utilized this behavior frequently as a way to teach self-management skills to their child. This parent described how they started at a young age:

> We don't have to really tell him to get on his treatments in the morning. He wakes up in the morning and gets ready for school and the first thing he does is get on his treatments, we've been doing that we built that in a long time ago so I think it was just there, it was never, it's was a habit that developed and it was never any question. That was just the first thing that he had to do.

As seen in the data, parents relayed on a variety of resources as well as on creating routines and good habits during youth to support skill development and to deal with some of their worries. Please refer to Table 12 for more examples of structuring the environment. In terms of family management, perhaps parents structure the environment to help manage the daily care of their child. This structure may reduce worries because families feel more confident at managing the condition when they have routines and good habits established.

Table 12
Structuring the Environment Examples from the Codebook

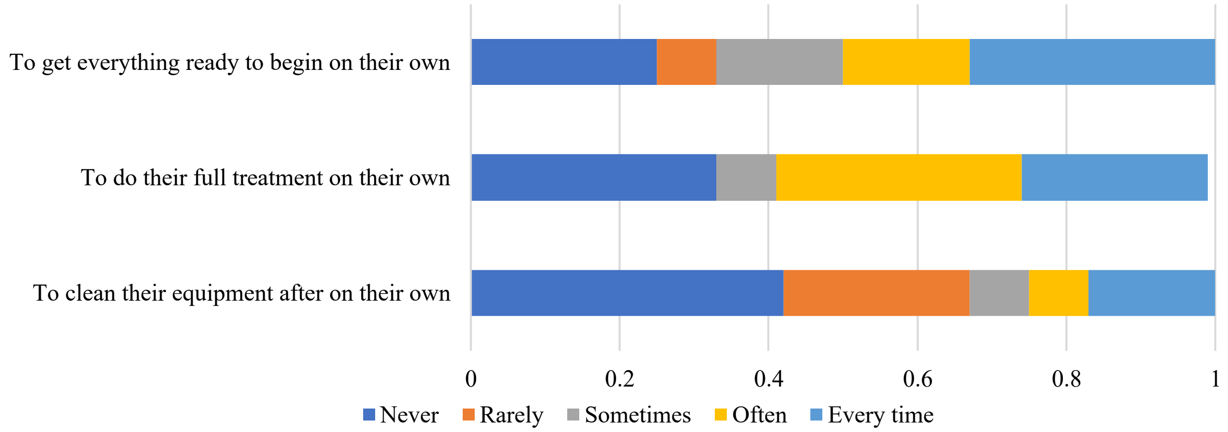
Category	Example	N
SKILL		
Provision of resources		
a. Diet and exercise	"Cooking different foods at home"; "We provide workout equipment and options to play sports and cook at home."	6
b. Organization	"We gave him his own medical counter in which he organizes and keeps clean"	3
c. Other	"Take her to her appointments"	2
Establishing routines		
a. General	"Stay on schedule and give rewards schedule is posted"; "Daily chores and good shower practice"	6
b. CF-Specific	"Have her leave space in her schedule to do meds"; "Getting him to understand that they need to be sterilized every time."	4
WORRY		
Provision of resources		
a. CF-specific	"Giving him a timer and having him switch neb cups after one is finished."	3
b. Living arrangements	"Not moving and making sure insurance covers it even if switching carriers is necessary."	2
c. Other	"He sees a therapist"	1
Establishing habits		
a. General routine	"By not letting him miss and keeping a routine daily"; "Keep their room and their person clean"	6
b. CF-specific	"Staying on a schedule and not missing treatments. Letting him know how important each med is."	6

Skill-related behaviors

At the beginning of each pre-determined skill, parents were asked if their youth was doing that particular skill independently yet. Only parents who reported 'no' were asked further items related to behaviors around teaching the skill. Of the five skills only three had parent reports on behaviors, suggesting that taking enzymes and answering doctor's questions were skills that youth had predominately taken over responsibility for while doing airway clearance treatments, tracking medication refills, and tracking symptoms to share with the doctor were still being mastered. The three skills will be discussed in further detail below.

Airway clearance treatments. Youth with cystic fibrosis must do numerous airway clearance treatments a day as part of condition management. In this study, airway clearance treatment related behaviors dealt with setting up, doing full treatment, and cleaning equipment after treatments. Thirty two percent of parents reported on these behaviors. As seen in Figure 18, parents were more likely to report ‘sometimes’ to ‘every time’ having their child set up and do the full treatment than to have their child clean the equipment after. Almost half of parents with kids not doing this skill independently reported never encouraging their child to clean the equipment after completing the treatments.

Figure 18
Airway Clearance Treatment Behaviors

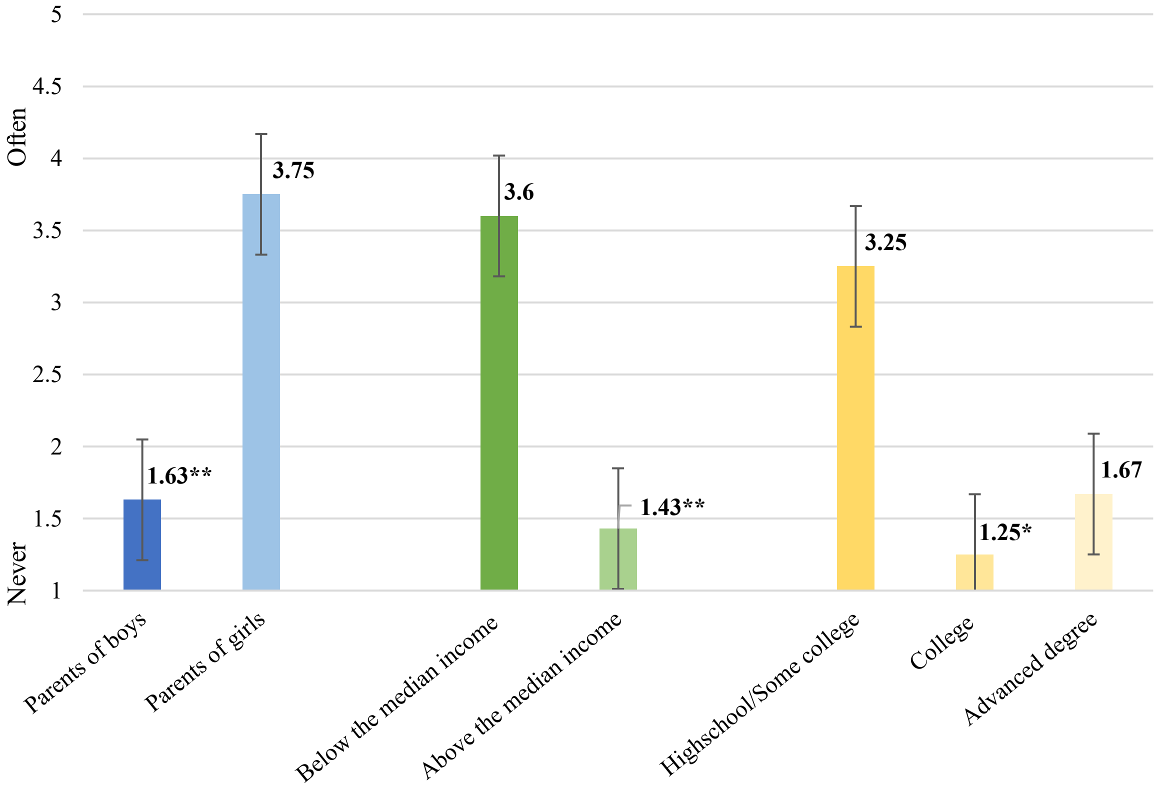


Note. Values are proportions.

Additionally, one of the two major group difference findings was on this particular item across multiple groups. Whether a parent encouraged their child to clean their airway clearance treatment equipment after finishing was significantly different across three of the groups. Parents of girls often encouraged their daughters to clean equipment compared to parents of boys who rarely do. Parents below the median income often encouraged their child to clean equipment compared to higher income parents. And finally, the higher the parent’s education level, the less often they encouraged cleaning behaviors (refer to Figure 19). As mentioned in earlier chapters regarding group differences, previous work supported that mothers of girls often gave their daughters more responsibilities for healthcare task compared to mothers and sons (Williams, 2018). Also, education level and income level were associated with health literacy which in turn was associated with health management beliefs (Shah et al., 2010; Wood et al., 2010). It is not hard to imagine that if a person has lower health literacy, they may not understand the importance of properly cleaning equipment.

Figure 19

Significant Group Differences for Airway Clearance Treatment Cleaning Parent Behaviors



Note. Bolded values are averages for each group. The question asked was how often in the last week you encouraged your child to clean their equipment after on their own? The scale was 1 being never to 5 being every time.
**p* < .05. ***p* < .01.

Exploration of the interview data provided some insight into this unique behavior and its many nuisances. One hypothesis for the group differences was that sterilizing equipment is a complex process that can have significant health risks if done improperly (e.g. bacteria growth). The more knowledge about bacteria, the more they may feel that sterilizing is too risky of a skill to pass on to their child. Also, there are often multiple steps that required precision that parents may have felt more confident to handle. This mother explained the precision needed for her son's special treatment:

> We have a sterilizer called the Waby, that we use for his regular treatments. But this one is like special. It has to have distilled water, has to boil before and after, that parts certain parts can't be touch because of the coil, the medication is in a special vial that is really difficult to open and it has sharp edges.

Given the complexity and severe repercussions of improper sterilization, it is not hard to imagine why parents hesitated in passing along full control of cleaning equipment. Also, in the interviews, parents spoke about the lingering doubts they had about the proper way to sterilize equipment and the frustrations that arose when discussing this particular task with health care professionals. For example:

> …but for some reason they don't really go over sanitizing and cleaning maybe it's just with me. But we went for a really really long time not sanitizing our cups properly and even though it says on the cup how to do it, for some reason I was given indication that it was ok to sanitize your cup in the microwave, in like a bottled sanitizer instead the microwave. Then we use the same cup in the morning, we use it again at night and we did that for like years, like a long time. And then just recently when he grew pseudomonas, um it I kind of brought it up 'like ok I just want to make sure' or maybe they asked me how are you sanitizing your cups and then all of a sudden it was like red flag. 'No the microwave doesn't clean it well enough and also you need to use a new cup, you need to use a new cup every time' …and so that kind of information was never given to me I guess.

Another reason for hesitating could be that parents themselves may not feel fully confident at doing the cleaning process. Finally, some parents discussed a lack of trust in their child to complete the task properly as a reason for still managing this aspect of care:

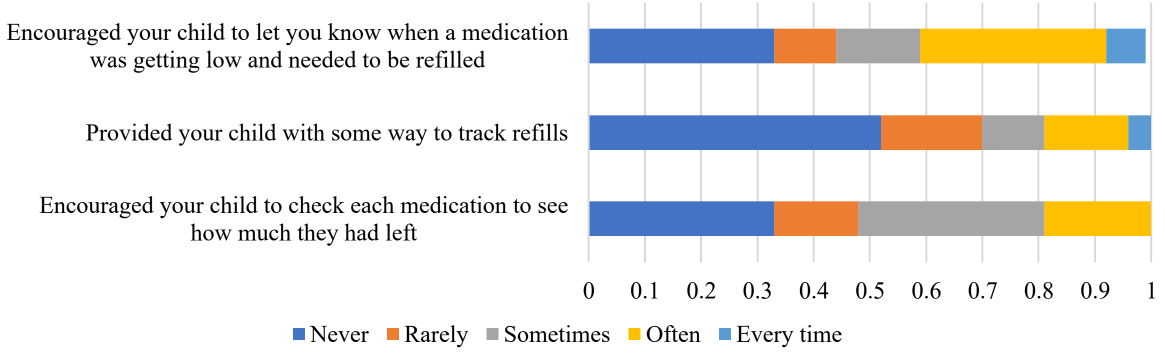
> I did find out, belatedly, that she was doing the teenage thing and trying to take short cuts. (*Laughs*) So, in the evening sometimes the parts which need to be sanitized now at the end of the day they need to go into the sanitizer and we have the kind that you have to go back and push the second button to dry them in…it's like a heat dry. She wasn't even bothering, 'that was like too much work, I'm busying texting with friends. So, she would wash the parts but she still not always going back and sanitizing them.

Whether because of the complex nature, a lack of procedural knowledge, or not trusting their child to complete it the correct way, parents in this study were still primarily responsible for the cleaning of equipment in daily CF care. Future work is necessary in this particular area so that professionals working with these youth and families can focus on the best ways to transition the skill of equipment sterilization from parent to youth.

Tracking medication refills. Of the pre-determined skills asked of parents, tracking medication refills was the skill with the greatest number of children not doing it independently. Seventy one percent of parents reported on tracking medication refill related behaviors. Parents sometimes encouraged their child to check medication amounts but rarely provided their child with some way to track refills (refer to Figure 20). Further investigation into what exactly parents are doing to teach their children to track medication refills is needed as survey data conflicted with the qualitative data on provision of some resource for tracking.

Figure 20

Tracking Medication Refill Parent Behaviors



Note. Values are proportions.

The survey data suggested that parents were rarely to never giving their child something to use to track medication refills while open-ended and interview themes supported that parents do in fact provide resources to their child. One family discussed what they had provided:

> Well we did buy…before I would just get everything ready and put it all in a little cup and then we, about I guess at least six months ago, we bought a daily pill dispenser and she started filling them all up for each day with her medications. That kind of inspired her to visually see them each day and have it out on the table so she can see it and that helped her remember to take all the other things besides just her Creon enzymes.

Perhaps parents think about medication refills in two different ways: 1. Tracking refills from an insurance/ordering point of view and 2. Tracking medication taken on a daily basis. Parents in the interviews talked about each kind of medication tracking at different times and thus future work needs to explore the intricate ways tracking medications might be different for parents. Additionally, parents also had the opportunity to write in a behavior they did with their child for each skill and for tracking medication refills, these written in responses were of both kinds of tracking medications listed above (refer to Table 13). Future work can build in this area by unpacking how parents might be differentiating between tracking medication refills for pharmacy and insurance purposes versus tracking every day medication taking behaviors.

Table 13

Parental Tracking Medication Refill Behaviors Written in the 'Other' Option

Keep excel sheet with reminder dates
Gave her a notepad for tracking meds
Pill organizer
Asking him what he needs

Note. Parents were given the option for each skill to write in a behavior not listed that they were doing with their child.

Tracking symptoms to share with doctors. Finally, 34% of parents reported on tracking symptom related behaviors. Parents in this group sometimes talked with their child about their symptoms but never to rarely had them write down the symptoms (refer to Figure 21). Talking to their child was a common behavior parents engaged in to teach their children self-management skills as supported by open-ended and interview data. One parent described how they talked with their child:

> So, we are trying to talk through it. ... So, know I am trying to back off a little bit and says let's talk this through, let's take a step back, let's try to tease out if its side effects from the inhaled Tobi. So, what she is doing is testing her glucose too often, too frequently, because the symptoms of too much Tobi or the symptoms of getting a cold or all these other things can feel like low blood sugar. So, we are talking about that, about how to really recognize the differences if you can and tease them out and maybe not test for glucose quite as often.

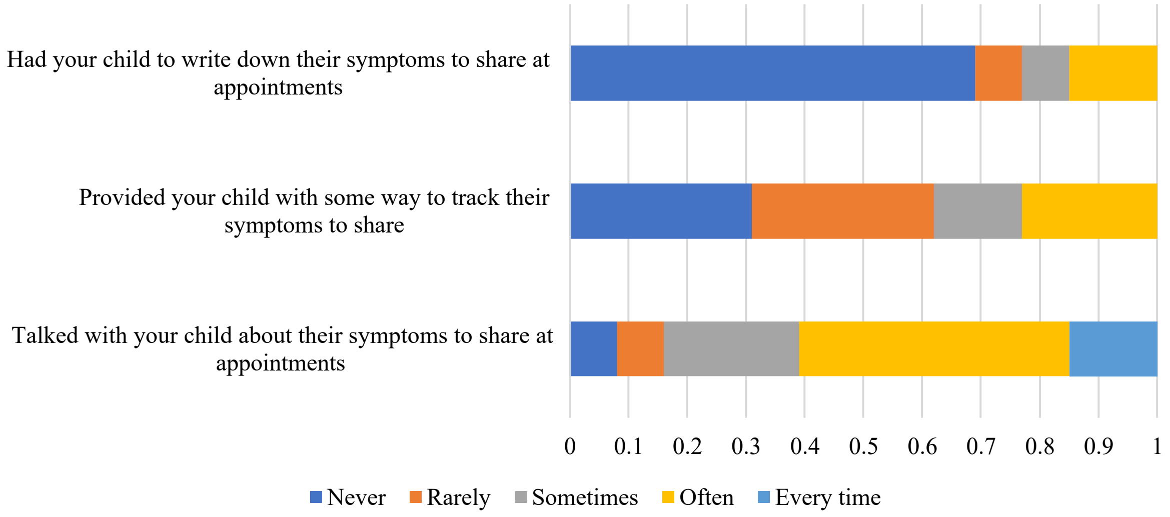
These parent-child symptom conversations seemed to begin as discussions on how to recognize symptoms but further work is needed to explore the conversations parents have around getting their kids to actually track their symptoms. One interesting finding for this particular skill was discussed in the interviews. Parents talked about wanting some technology related phone application that would allow their child to track symptoms in real time. This desire for a more technology-based tracking method might explain why most parents were not encouraging their child to write symptoms down but instead they were encouraging them to record it electronically. One parent suggested:

> Yeah to be honest, I think that if there was some way that you…so I don't know this is really abstract but I am just thinking on reflection, in the moment when they are scared or having the issue, I think it would be important for them to record it then. Like I might write something down and the date and time something happened but she wouldn't necessarily do that. And so, if there could be some way…if we could encourage them, you know you just need a video or make a memo right now 'this happened to me, I had this pain or I had this whatever it is' and then when you went back when you were at the doctors you could say 'oh yeah that did happen'. I don't know I just feel like if you had this objective way, instead of you subjectively analyzing maybe it wasn't that bad, you would have the evidence in your hand, you know?

Parents discussed wanting a more objective way to record symptoms as they occur, so that they could be easily and accurately recalled at appointments. Reviews of mobile phone health interventions supported their use in increasing health-promotive behaviors as well as positive reactions to and feasibility with mobile phone health-related applications/interventions (Klasnja & Pratt, 2012). Pursuing this avenue in future work could help youth become better at tracking and then reporting their symptoms at appointments.

Figure 21

Tracking Symptoms to Share at Appointment Parent Behaviors

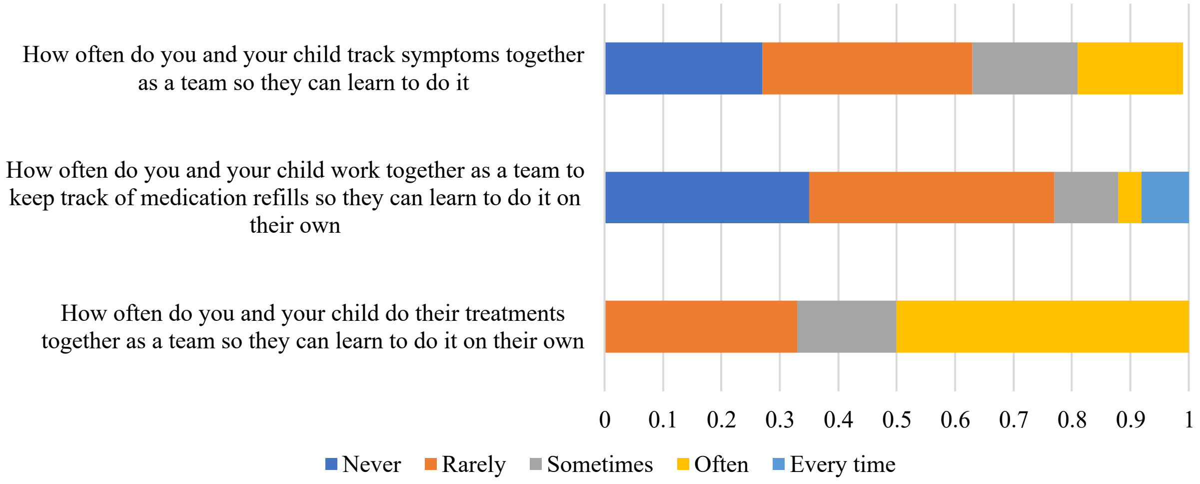


Note. Values are proportions.

Teamwork and collaborative behaviors. Do parents and youth engage in teamwork as they teach and learn to self-manage cystic fibrosis? After being asked to report on skill specific behaviors, parents were then asked how often they engaged together as a team with their child so their child could learn to do the skill on their own. Fifty percent of parents often engaged in teamwork with their child for airway clearance treatments. Parents may feel that this is one skill in particular that they can help to relieve some of the care burden from their child by working together to complete it. One parent mentioned slowly changing from doing all of the treatment process to sharing responsibility with her child, "I have gotten to the point because I used to put the vest on him and hook everything up so now I just say 'go put your vest on, go hook the tubes up and I will go get the cups'". However, only around 12-18% of parents often engage in teamwork for tracking medication refills or symptoms to share.

The themes discussed in chapter 4 that parents think about tracking medication refills as an administrative skill and struggle with giving their child full control in this area help explained this finding. Given this, it is not surprising that they report never and rarely any teamwork for it. Additionally, in chapter 4, I spoke about how tracking symptoms may be a more child-directed, less parentally controlled skill and thus maybe parents felt that tracking symptoms to share was not an inherent teamwork related skill.

Figure 22
Parent-Child Skill-Related Teamwork Behaviors



Note. Value are proportions

Developmental process

When the skill related behaviors were examined for group differences, an interesting pattern emerged. The majority of group differences were found between parents of middle school students and parents of high school students. Two thirds of behaviors were found to be significantly different between parents of middle schoolers and high schoolers. Parents of high schoolers reported encouraging their child to set up and do their full airway clearance treatment, check medication amounts, write down symptoms to share, and providing some way to track symptoms more than parents of middle schoolers. Please see Figure 23 for all group differences across middle school and high school parents.

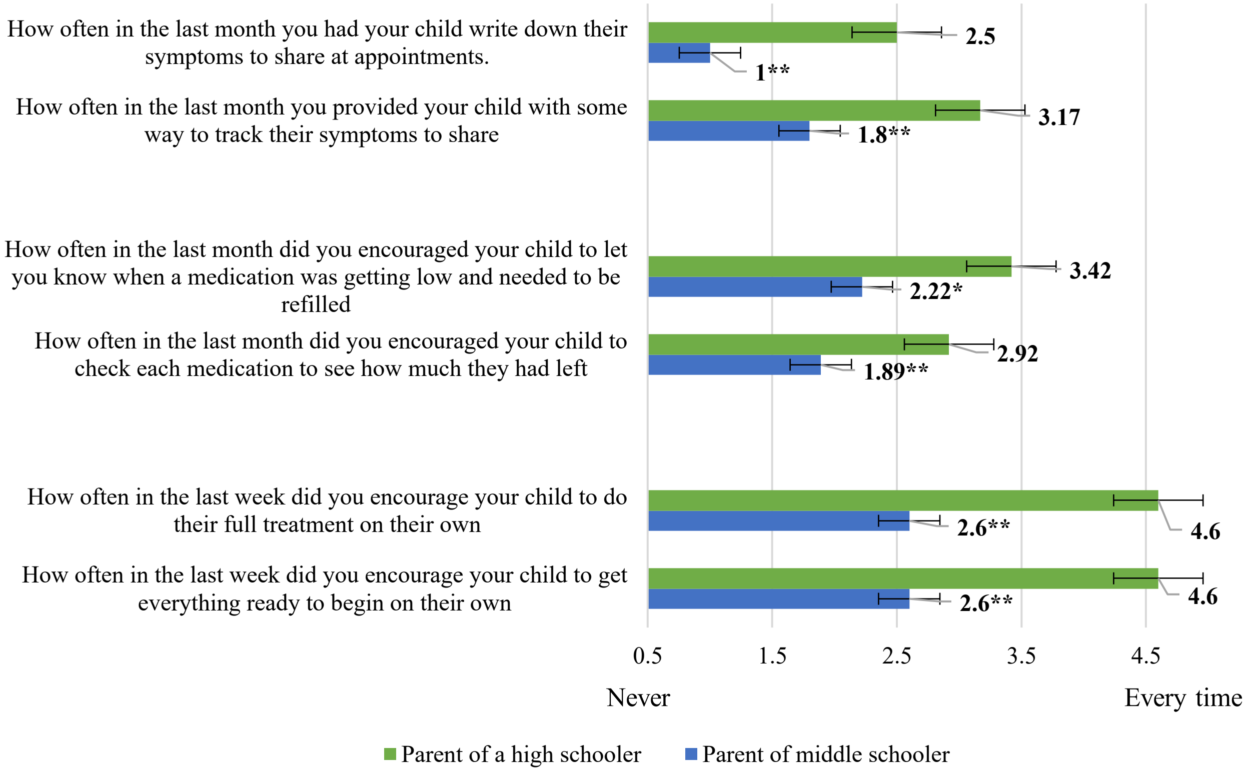


Figure 23

Significant Group Differences between Parents of Middle School and High School Youth

Note. Bolded numbers are averages for each group. Response scale for items was 1= Never to 5= every time. *$p < .05$. **$p < .01$.

While age differences were expected given what is known about adolescent development and transitioning to adulthood, it was interesting that a majority of the age differences were found for behaviors but not beliefs. This suggested that parents of different aged children had similar beliefs in terms of ability and value yet behaved in different ways as the child aged. Interview data further supported this difference across groups as parents spoke about high school being a natural indicator that their child should be taking on more responsibility:

> Well I definitely think high school is a natural transition because as an educator, when they become 9th graders, we stop talking to the parents, we talk to the students. It is a pretty easy transition education wise where in middle school it goes to the parents and in 9th grade it starts going through the student. We want them to self-advocate, we want the first communications to be from them and not the parent so I think that is an easy transition just societally where and I think some of that starts with the demeanor and the attitude of the providers, where they are treating them as adults or almost adults and not like little kids. They are really bringing them in on the decisions like 'what do you think? How do you feel? What do you think would best, like we want to hear what your input is'?

As youth took on more responsibility in other areas of their lives such as school, it often signaled parents to start increasing responsibility of health care and self-management as well. While parents recognized the importance of giving responsibility over to their child, they also acknowledged that adolescence, in general, could already be a difficult time management period for their child. One mother described her son's busy schedule as a reason for her hesitance in releasing some responsibility:

> He is very active in school, he gets great grades, he is a boy scout, he does a bunch of stuff with boy scouts, he is about to become an eagle scout, he works, he drives, he is in robotics, he is traveling with robotics, he is living life. and oh yeah, I have to do this thing to called treatment and CF.

Believing that there were increases in time-constraints and responsibilities for their youth during adolescence lead some parents to do more for their child in terms of self-management. While parents recognized that transitioning over skills was important and inevitable, they based their decisions on a variety of factors including current time commitments and ‘average’ teenage activities.

Previous work with families supported the finding of the developmental nature that parental behaviors take as children with cystic fibrosis age. From talking with families, Reiss and colleagues (2005) found that parents of youth with chronic health conditions often thought about the transition process as being stage-like or developmental. The group differences across the parents of middle schoolers and parents of high schoolers in terms of behaviors further supported the idea that teaching self-management occurs in stages as children aged and took on more responsibility.

Summary and implications

The findings suggested that while parents have different goals and worries for their child, they are doing similar behaviors to address them. Primarily parents were engaging in parent-child interactions such as talking and teaching, parent-driven activities such as monitoring, and activities that structure the environment in ways that promote self-management. Interestingly, as opposed to other work examining mothers and children with asthma or diabetes that found gendered differences in parental behaviors (Williams, 2018), I only found a significant gender difference for one behavior, cleaning airway clearance treatment equipment. The previous work suggested that girls were given more responsibility related to self-management than boys (Williams, 2018). Findings here provided further support for this view as the parents of girls had their daughters take on more cleaning responsibility compared to parents of boys.

The major group differences I found were related to age and parental behaviors such that parents of high schoolers were doing more behaviors that promote self-management than parents of middle schoolers. Understanding how parents are viewing the process can inform professionals working with these families.

Interventions aimed at helping families transition responsibility to their child would benefit from including talking points that can facilitate discussions as well as guidance on how to effectively monitor their child's self-management attempts. Additionally, providing this support at the end of middle school or beginning of high school would be optimal given the age differences found. In interviews, parents discussed naturally using high school as a signifier that they start the process:

> I have been saying for a while that this summer you are going to do that so I kind of prepped her for that and then I've been saying 'as you get older you know in high school, I am not going to be doing all these for you', so she has known that that was coming. That she is going to have to eventually start taking care of all her things in regard to her health.

Parents of youth with cystic fibrosis knew that eventually their child would have to take responsibility for their own health and they often used the transition to high school as an indicator to focus their attention on shifting responsibilities. These parents also recognized that once they started focusing on shifting the care over to their child, they would benefit from assistance provided by health care providers. One parent suggested:

> I definitely think there needs to be conversations with the parents where they are starting to talk about the goal of transition, where we want him to get, here are some milestones we want him to get. Even like what should my kid be able to do by themselves, when should they start doing these things, when should they start doing these things, we get those things from pediatricians when are kids are growing up but when it comes to CF, I don't know … So, I think the conversation needs to come from the providers of like here are some ways we can help them advocate and transition and then we are going to start trying to have conversations with them.

Parents want more focused guidance on not just that they should be giving more responsibility to their child but also on how to actually shift the responsibility of managing health. Parents are not arguing that the process has to happen but struggle more with enacting the plan.

CHAPTER 6
Wrapping it up

As discussed throughout the previous chapters, parents of children with a chronic condition have unique health-related beliefs and are engaging in purposeful ways as they prepare their child for managing health in adulthood. Although each chapter discussed findings and implications in depth, here I wanted to spend some time focusing on the major themes from this work. Chapter 5 discussed the significant group differences that were found across the two groups: parents of middle school age children and parents of high school aged children. In light of this support for a developmental process, I will use a case study comparison to discuss the main findings of this work in the following pages.

This case study comparison drew from 4 interviews that represented children of different ages across the full sample and included interviews with a parent of an eleven-year-old male (parent A), fourteen-year-old female (parent B), seventeen-year-old male (parent C), and a twenty-year-old female (parent D). As I found fewer significant differences across gender compared to age, I chose to use both male and females in the case study. First, I explore how parents conceptualized the health-related skills. Next, I discuss the consistency of parental behaviors as they relate to parent reported important skills and worries. Finally, I touch on what successful health management means to parents.

Parents' conceptualization of the health-related skills

One major finding of this study was that parents did not conceptualize the health-related skills in the same way that researchers did. The research team originally grouped the five health-related skills into two groups: 1. Medicine-related and 2. Doctor-related. However, interview data as well as survey open-ended responses and scale reliability and validity data suggested that parents actually think about health-related skills as either treatment-related or administrative related. To parents managing the daily treatment tasks of doing airway clearance treatments and taking enzymes were separate from the overall health management of tracking medication refills and doctor's appointments. Additionally, some parents spoke to the difficulty of transitioning skills such as handling insurance or ordering medication over to their children (refer to chapter 3 and 4).

Across the four interviews, parents spoke about a variety of skills involved in the CF care of their child. Although often listed together as skills that needed to be mastered for successful management in adulthood, treatment-related and administrative related skills were different for parents. Two of the four parents discussed the difficulty at transitioning administrative-related skills they expected, compared to little mention of any difficulty with treatment-related skills:

> yeah so the one priority right now for us is just helping him understand the connection between adhering to treatment and quality of care quality of life. … and so right now that's the one we are focused on and imagine if I tried to bring in by the way sit here with me and let's start this filing system to start to figure out medications and insurance and by the way there is this foundation and that foundation that you should know about. You can always apply to it that would just totally overwhelm him and it would go in one ear and out the other because I just know that right now, he is not at a stage in his life where he is going to listen or even pay attention.
>
> Parent C of a 17-year-old

> I think that [passing on bills and insurance] is going to be one of the biggest issues. I think about it all the time… I think of just ordering their drugs, so I always order the drugs. …. It takes me 45 minutes…She would not, if she had to do that every month, she would not do it. Flat out, that would not be happening. So, I just do it…
>
> Parent D of a 20-year-old

Parent C and Parent D expressed the difficulty they anticipated from transitioning over skills like ordering medication and handling insurance to their youth. These same difficulties were not mentioned in interviews with the parents of the eleven-year-old or fourteen-year-old, suggesting that these administrative skills are not on the horizon for parents of younger children.

However, Parent B with a fourteen-year-old did acknowledge that her child still needed to master ordering medications, it was not seen as a difficulty yet. Perhaps as youth get older and parents start to think more seriously about transitioning over control of ordering medication to their child, they start to encounter more hurdles and difficulties in the process.

In general, parents thought about the health-related skills presented in this study as two different types of necessary skills. Their children need to master treatment related skills such as doing airway clearance treatments and also master administrative skills such as ordering medications. Additionally, parents thought about how capable their child was at doing these types of skills and how important and useful each skill was to their child. Thinking back to the theoretical frameworks discussed in the introduction, we see that individual task beliefs and task values do play a role in when parents start teaching their children particular skills. For example, skills viewed as harder for their children to master or more costly in terms of health outcomes were often transitioned later. Additionally, parents have adopted a management mindset that divides the skills into groups that make the most sense to them and their daily lives. For parents it seemed that teaching treatment related skills were not as much a concern as teaching the more managerial skills that come with CF care.

Consistency in parental behaviors

How are parents teaching self-management to their children? Do they behave in different ways as they address teaching what they think is important compared to what they are worried about? In this study, I found that while parents did have unique skills that they thought were important and distinct worries, they reported doing similar behaviors to address these skills and worries. Parents were doing a lot of talking, teaching, monitoring, and structuring the environment to help get their children ready for health management in adulthood. They were also engaging in those same behaviors to address the worries they had for their youth. Additionally, some parents talked about what they did when they encountered setbacks or resistance to their teaching efforts:

> I tried it a year ago when she was 15. I tried getting her to start being with me when I'm ordering her or reordering her prescriptions, all her meds. … What I found a year ago when she was 15 was, she was pretty overwhelmed. I couldn't add on 'ok great now you can order all your own, on your own'. Nope she wasn't ready. … She was getting frustrated with that so I backed off a little … And now that she is 16, she is still overwhelmed about ordering them on her own but I am having her flag me when she is getting low on certain meds. … So, kind of like a baby step to transition her towards doing the entire reordering herself.

When some parents experienced obstacles to their teaching, they stepped back and reevaluated. They shifted their behaviors or changed their goals in the face of these obstacles. However, more work is needed to explore how parents behave if they experience issues in teaching self-management to their child if we are to fully understand and anticipate ways to help these parents.

In terms of how parental behaviors compared across the case study interviews, the findings showed a change in division of responsibility as age increased. The division of responsibility literature supports that responsibility changes as children age. Initially, parents were primarily responsible for health care tasks, followed by a shared responsibility, and ending with the youth responsible (Iles & Lowton, 2010; McQuaid et al., 2001). What was interesting in the current work was that across the four interviews I saw more distinction in the shared responsibility phase.

In terms of sharing responsibility, I noticed a shift in not all aspects of care but that as youth got older, they were more likely to be doing their treatments independently but still not managing the administrative aspects yet. Two of the case study parents spoke to this:

> She is definitely these pass six months or so there has been a big shift I've noticed in her remembering pretty much everything that she needs. She has her own refrigerator for her medication, a mini fridge, she goes and gets everything out in the morning. So yeah I don't have any concern with her not doing it at this point and she is doing most of it all on her own.
>
> Parent B with a 14-year-old

> Because of his age personally I don't get very involved in managing his care other than asking him 'have you done your treatment'. 'Did you pour this medication into your shake?' So, it's more reminders. Then for me on the back end, the administrative is more 'is it time to refill or I need to return the phone call from the pharmacy that just left me a message or a new medication came in let me take the receipts and figure out what I am going to do with those next. It's more of that that's my end of the maintenance but day to day treatment he handles 100%.
>
> Parent C with a 17-year-old

The two parents of teenagers both had children who were responsible for their daily treatments and medications but they, as parents, still maintained control of and responsibility for the administrative tasks. Additionally, these administrative skills were still not completely transitioned over even at 20 years of age as supported by Parent D:

> All the ones that are just through Walgreens or something, they take care of all that. And they are fine with that, it's really just the high-end drugs that are hard, take a long time to get and you have to have all those copay cards. That is the other thing, like I do take care of their copay cards because those will expire and then once again you have to go and have all the information, all the different numbers and stuff so that takes a little while. I do that for them too."
>
> Parent D with a 20-year-old

Even though we see a slow transition from parent being mainly responsible to youth being mostly responsible (refer to Table 14), the findings suggested that further work is needed to explore at what ages various youth take on full responsibility of health care including all administrative tasks and why these ages might vary. Programs that are designed to transition youth at the age of 18 or 21 (depending on condition and location) need to consider if youth are prepared to handle administrative tasks as parents are still mainly responsible for medication ordering and insurance issues at this age. How can we partner with families to support them in transitioning administrative tasks over to youth and youth as they accept more responsibility?

In general, parents in the current study have established routines and engaged in similar behaviors to address all aspects of CF care from teaching skills to handling worries. Furthermore, I found that there were some skills that were viewed as more difficult to transition and thus still not being done by young adults. Reflecting on the E-V theory introduced in chapter 1, there are likely many reasons for this delay in transitioning some skills. Perhaps parents think that the costs associated with transitioning particular skills over are too high or parents may not think their child is good at particular skills and so they hesitate. Future work needs to explore what it is about these specific tasks that cause parents to delay transitioning them over to youth. Also, additional work looking at the cost of these skills for parents and how their views of cost influence their decisions and actions is needed.

Table 14. *Case Study Responsibility Continuum Examples*

Parent responsible	**Youth responsible for treatments only**		**Youth mostly responsible**
"I pretty much remind him of most everything at this point."	"We have gotten to the point now in her life where she is pretty much self-sufficient on remembering to take everything [ok]. I still give reminders, sometimes she gets annoyed with me reminding her…"	"He is the best at preparing his medication and then sitting down and doing the treatments. He is been doing that independently for years."	"But she does go to her appointments and now she can go to her appointments on her own. … I used to have to go with her to every appointment but probably in the last year for sure she does it on her own."
Parent A with an 11-year-old male	Parent B with a 14 -year-old female	Parent C with a 17-year-old male	Parent D with a 20-year-old female

What does successful management mean to parents?

In general, across all interviews, but specifically across the four used in the case study, parents viewed successful management in adulthood in similar ways. All four parents mentioned that their child would be doing their treatments and taking their medications. Furthermore, all parents discussed compliance to treatments and/or medications in some form during their interview as a measure of success for their child. Three of the four parents discussed the importance of going to doctor's appointments and handling medication refills and insurance. Finally, two of the four brought up quality of life and mental health as well as being an empowered person as important for successful management in adulthood. Interestingly, the case study comparison uncovered the theme of parent's accepting a lack of control in the process that followed a developmental process. First, I explore compliance across the four interviews, followed by youth empowerment. Finally, I will discuss the idea of accepting a lack of control across the four interviews.

Compliance. Similar to division of responsibility, across the four case interviews I noticed a shift in compliance as children aged. Previous work suggested that compliance decreased as youth got older (Pai & Ostendorf, 2011). As seen in Table 15, the findings here supported previous work that suggested that as youth age, parents reported changes in compliance.

Table 15. *Case Study Compliance Continuum Examples*

Compliant	**Mainly compliant**		**Not compliant**
"I think just the fact that he is so compliant even though he doesn't remember to do something on his own, he never fights me on it, ever!"	"I would say getting a treatment going right away when we come home for school is more of a challenge because there is a lot of you know 'I want to relax; I want to eat' and then this and that. … But nothing super challenging. She's easy overall, just getting it all done. She is not very resistant to anything so that is good. Not overly resistant."	"It's like did you do your treatments like the doctor said you should, did you take all the medications. Usually the answer is yes but the reality is no not really. And there is a gazillion reasons why cause at this stage in his life he is super busy, he's got other things that he thinks he needs to be doing."	She is not super diligent about doing her treatments or taking her drugs but she does…actually she is pretty good about taking her drugs. She is not really good about doing treatments.
Parent A with an 11-year-old male	Parent B with a 14 -ear-old female	Parent C with a 17-year-old male	Parent D with a 20-year-old female

There are likely many reasons for this change in compliance. I argue, based on the findings from the current work and the case study comparison, that youth may not be as compliant as they were when they were younger but that many factors influence this compliance rate. Such factors include busy school schedules, part-time jobs, and afterschool commitments. These influences need to be considered before labeling a youth or family as non-compliant. Two parents discussed their children's busy schedules:

> Which you know sometimes I say well am I making the decision for him but I am just basing it on the fact that he has a ton of homework, he has AP courses, he works, he is you know managing care, he's doing all these other things I mean I… It makes perfect sense not to dump this big ole ball of wax on him right now.
>
> Parent C with a 17-year-old

> She is way busy. I mean the girl goes to school full time, she is a musical theater BFA in a program so she is in plays all the time, plus she wants to work all the time. Any time anyone offers her paid chance to perform, you know when you are a performer that is amazing especially when you are young, so just sucks that up. Basically, she just works herself way too hard and so she doesn't have time.
>
> Parent D with a 20-year-old

Time management was definitely a skill that was required of youth as they grew up and took on part time jobs, divided their time between family and friends, and received progressively harder schoolwork. Being an average teenager juggling these new time constraints may be difficult, so it is not hard to imagine that adding on a complex treatment regimen that is extremely time consuming often overwhelms youth with chronic conditions. Professionals working with these older youth might start with helping youth develop time management skills in generally and then shift the focus to helping these youth incorporate their treatments and daily management into their already busy lives.

Youth empowerment. In chapter 3, the idea of empowering youth to be more assertive in their own care was introduced and explored. However, during the case study comparison, a pattern emerged around empowering youth that suggested that parents of younger children may think more about teaching their child to be assertive than parents of older youth:

> I worry that like teaching him to I mean he is a little … speak up for himself and say 'I need this' you know or like it's hard because sometimes he is very good at that and then sometimes he is a little, I don't want to say a pleaser, like he doesn't want to upset anyone so he doesn't want to rock the boat. And so, I worry that teaching him to speak up even if it's not the right time … like I shouldn't be doing this or whatever. I just worry about that I hope that he will be strong enough and I hope that I will be able to teach him to be strong enough have the confidence to say, 'no this isn't working for me I need to figure out something else'.
>
> Parent A of an 11-year-old

> I think as they get older too that she can have some choice on some things. That she doesn't have to always take everything that…like you have to do this, this, and this…some things you can… What I am getting at is that she does have a say in her own body and her care and her life and that she doesn't have to take everything that is told to her and is coming at her as the only way. That it is there for her benefit and for her to analyze and consent to. That she has to give consent for everything that happens to her.
>
> Parent B of a 14-year-old

As seen above, the idea of youth empowerment shifted from being a worry for Parent A with their eleven-year-old to something that came with age as believed by Parent B with their fourteen-year-old. Parent A and Parent B both discussed their desire for their child to be empowered to speak up for themselves that was largely absent from Parent C and Parent D interviews. It seems that by older adolescence, youth have begun to be more involved in their own care and in decision making that their parents don't think about it to the same extent. Another explanation for the lack of discussion on empowerment for parents of older youth stems from their acceptance of the level of control they have compared to their youth in the management of care. Perhaps older youth have already become empowered and their parents have accepted the reduction in control as a result.

***Acceptance of a lack of control*.** An interesting idea emerged as I analyzed the case study interviews that was a reflection of how parents might be preparing themselves for their children to take over health management. Thinking about what successful management means to parents themselves and not for their youth, I saw a shift in a more ‘accepting of a lack of control’ attitude for parents of youth who were older compared to parents of younger youth. The parents of older youth often spoke about having to come to terms with not having the level of control and involvement they wanted and having to accept it:

> I could control things a little bit more and as soon as they became teenagers I couldn’t as much anymore. Because I just couldn’t. You try getting a teenager to do what you tell them to do, it just doesn’t work. It just doesn’t work the way it used to when they were smaller. So that’s where the psychological adjustment came in for me. It’s like ok how do I prepare myself and work with my child…young adult…differently so that I can maintain a positive relationship and encourage them to do what I and the team the doctors believe is in his or her best interest. And still allow room for the young adult to be who they are and need to be and sometimes the pieces don’t always align. And that’s where the preparation has come in for me, like how can I be ok with what is. Sometimes what is can be very imperfect.
>
> Parent C with a 17-year-old

Over time parents may have developed coping mechanisms to deal with the continual worry and stress that was associated with the condition itself as well as transitioning over health management. Perhaps for them, success on their part was when they were able to come to terms with what they could control and what they could not. Parent D explained how she came to terms with it:

> So, if they were sick and they didn’t do a treatment or something, it took me a long time to get to the place where I could be like ‘that’s ok, they are not going to drop dead’. I need to not burden them with my fear or…and I think that is part of the biggest trauma that I handed to them. Probably the most traumatizing thing is handed to them is that I was super fearful and so I gave them so fear, you know? I would think if a parent could do anything it would be just take a step back and look at the big picture and don’t freak out. If a kid misses a treatment, they are not going to die and so you putting that on them because you are scared it makes their life unhappy and they feel burdened and so it’s just really important to have a perspective. It’s a terrible disease and they probably will get sick even if you do everything perfectly, that’s the frustrating part about it. So, you just have to have a mindset that you are not going to dwell on that part of it, freak out and think that you are going to control it. Because you can do a lot but you are not going to make it go away.
>
> Parent D with a 20-year-old

This idea of having come to terms with the reality of the condition and their child's eventual control of it, was found in both Parent C and Parent D with older youth. In contrast, Parent A with an eleven-year-old acknowledged their struggle with letting go of some of the control and their worries associated with relinquishing it:

> I am not very looking forward to many parts of it but you know like I worry that he is not going to be as compliant when he is 14 because he will have some attitude and he will realize 'oh this is something I can control' and I hope I hope he does not do that.
>
> I mean mostly because I am terrified because he has never gone anywhere without me and so its part on me. … I am a totally 'smother' (laughs) and so I am always … I'm trying to work on that but (laughs). … its absolutely like I know what I have to do … it's just I have to do it (laughs).
>
> I may be that mom calling him when he is at college and saying, 'did you remember to take the…you know and so that will be on me not to do that.
>
> Parent A with an 11-year-old

While using humor as a coping mechanism for what they felt was an issue on their part, it was clear that they understood that transitioning control of health management to their child was necessary but they were still working on accepting it within themselves. Parent B whose child was slightly older at fourteen spoke to their own personal challenge of wanting what's best in terms of CF care for their child but also wanting to trust and allow for mistakes to be made by their child:

> For myself otherwise, my biggest challenges is learning to back off and let her do things without reminding her or being involved in letting her…there has always been a thing with … you know normally with a kid sometimes you let them make mistakes. But it's harder with CF because you don't want them to miss taking enzymes or miss doing their treatment. I think for me it's just trusting that she can do it on her own and backing off but still being a parent and still making sure she is doing what she needs to.
>
> Parent B with a 14-year-old

This parent had begun to think about stepping back and what that might mean for their child compared to Parent A who didn't seem to have started the process yet and who was still struggling with envisioning a future where they were not heavily involved in care. This case study comparison suggested that as children got older, their parents started to move from acknowledging the need for, to attempting to, and finally to fully accepting the uncertainty for what it was, their child in full control of their own condition.

Returning to the theoretical frameworks introduced in chapter 1, it is clear that parents do enact management mindsets and those mindsets can be influenced by a range of beliefs parents might hold. Some parents may shift their mindsets as children age from one of being in charge to one of accepting that control has been given to their child. Others may take the management mindset of helping their child to reduce the burden for as long as they can. In general, future work exploring these ideas in more depth and with more cases is needed so that we may understand more fully how parent's management mindsets change over time and also, how parents' think about success in terms of themselves and whether they have successfully transitioned control for health care to their child. Do parent's think about their own success at these things or is their success dependent on the success of their child?

Summary

As seen throughout this book, parents had unique beliefs about condition management and their child's ability to self-manage in adulthood. They also engaged in a variety of behaviors to address preparing their children for self-management in adulthood. Additionally, many of these behaviors were developmental in nature and changed as youth get older. It would prove beneficial if professionals working with families that have a youth with a chronic condition made efforts to recognize the importance that parental beliefs and behaviors had on the success of transitioning over self-management. Parents reported skills and worries as well as what they were doing to specifically address those things. They rated their child's ability on a variety of health-related skills and assigned task values to those skills as well. They took time to report in what ways they were engaging with their children around health management tasks. Some even talked in depth about what factors were driving their decisions and actions. Furthermore, interviewed parents shared their experiences and feelings related to preparing their children to be adults. They offered suggestions and acknowledged the importance of getting their children ready. All this suggests that parents are willing to talk (and collaborate) if professionals are willing to listen.

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Appendix A

A.1 List of all pre-determined behaviors used on the survey

Now please think about what you are doing to help your child learn this skill.

For airway clearance treatments please indicate how often in the LAST WEEK you encouraged your child:

- to get everything ready to begin on their own.
- to do their full treatment on their own.
- to clean their equipment after on their own.

For taking their enzymes please indicate how often in the LAST WEEK you encouraged your child:

- to set out their enzymes for the day on their own.
- by reminding them to take their enzymes.
- by letting them be responsible for it on their own.

For tracking medication refills, please indicate how often in the LAST MONTH you:

- encouraged your child to check each medication to see how much they had left.
- provided your child with some way to track refills (e.g., a calendar).
- encouraged your child to let you know when a medication was getting low and needed to be refilled.

For tracking symptoms to share at appointments, please indicate how often in the LAST MONTH you:

- talked with your child about their symptoms to share at appointments.
- provided your child some wat to track their symptoms to share (e.g., a journal).
- had your child write down their symptom to share at appointments.

For answering questions asked by the doctor, please indicate how often at their LAST APPOINTMENT you:

- waited a minute for your child to answer the questions asked by the doctor before chiming in.
- prompted your child to answer the questions asked by the doctor.
- made your child answer the questions asked by the doctor on their own.

A.2 Semi-structured interview guide

Thank you again for taking the time to talk with me today. We would like to understand more about how families are teaching self-management skills and getting ready to move to adult care, so your help is greatly appreciated. *Pause*

Now I would like to start by asking you to please think about *your child* as an adult with CF. If they are successfully managing their CF, what kinds of things are they doing? **What does successful management look like to you?** *Pause and give time for them to respond*

> *If they need prompting or request more clarification…* For example, what things would they be doing to manage their health? What things are important for them to be doing? Would they be going to the doctor frequently, would they be journaling their symptoms, etc.?

Great, thank you for talking about that with me. Now I would like to ask you to please think about if there are any skills that they are not doing well at on their own.

> What are some of the things they are not very good at doing? *Pause and allow them to talk.*
>
> For what reason do you think they are not doing well at this?
>
> Have they shown any interest in learning this? *Pause…* in what ways are you helping them to do these things?
>
> Have you given any thought to how you might teach them to do this now or in the future?
>
> Can you describe in what ways it might be difficult for them to be successful at these skills?
>
> Can you talk a little bit about the ways it might be difficult for you to teach them the skill?

If you could choose one thing related to CF care that they are the best at doing on their own, what would it be and why are they the best at it?

How did you go about teaching them this skill when they were learning it?

Thank you. That was very helpful. Now I would like to ask you to please think about how you and your child manage their CF on a daily basis.

> What is a typical day like for you and/or your child in terms of CF care?
>
> Are there any parts of the day that you struggle with the most? *Pause and allow them to talk…* any parts your child struggles with the most?

Can you please describe the kinds of social support and/or resources you use to help you and your child with their CF care?

If you could pick one area where you would like additional support from the medical team in terms of getting your child ready to take care of their own health as an adult, what would it be? *Pause and allow them to talk...* Can you describe the kinds of assistance that would be most helpful to you?

When did you start thinking about transitioning (doing more conscious efforts to teach)? What age was your child? What encouraged you to start thinking about it at that time?

Great, thanks for sharing those thoughts. Of the things you mentioned above, are they doing any of those things on their own already?

*If yes, let them talk first then prompt them with…*what age did they start doing this? what kinds of things did you do with her/him to help her/him learn to do this?

If no, let them talk first then prompt them with... has she/he shown any interest in learning some of the things you mentioned above? *Pause and allow them to talk.* What skills/tasks have they shown in interest in learning? *Pause and allow them to talk.* How have you been helping them with the things they have shown an interest in?

Health literacy?

Do you feel confident that you understand things when you read health information that is given to you by the team or that you find online?

Do you think that your confidence has grown over time?

Thank you for sharing that information with me. Finally, I would like to ask you some questions that relate to the survey you filled out a little while ago.

On the survey we asked families to think about tracking medication refills. What do you think of when we say tracking mediation refills on their own? *Pause and allow them to talk...*

Do you do something in particular to track medication refills?

If yes, what do you do?

Thank you so much for taking the time to speak with me today. That is all the questions I have for you but is there anything else you would like to share with me? Anything you think is important to know?

Appendix B

Complete codebook for open-ended responses and interview data

Major Category (A-D)	Category (1-9)	Sub-Category (a.-d.)	Definition	Example responses
Skills				
A. Youth Characteristics			Major category encompassing characteristics of youth that are more stable over time or are embodied by the youth. More general in nature.	
	1. Organization		Organization or being able to organize.	Organization
	2. Time Management		Mention of time management or abilities to plan.	Time management; plan ahead
	3. Communication		Communication or communication skills.	Talk with doctors, team, self-advocate
	4. Independence		Mention of independence or being independent.	Be independent
	5. Responsibility		Responses including responsibility or accountability.	Hold himself accountable for working with his medical team to care for his condition
	6. Stay Informed		Responses that relate to staying educating.	Stay informed
	7. Other		Responses that mention having a better lifestyle or achieving goals.	
B. CF-related health			Major category encompassing skills that deal with some aspect of cystic fibrosis care.	
	1. Treatments		Category including reference to treatments or treatment protocols.	
		a. Doing treatments	Specific to doing treatments or setting up treatments.	Set up and do her treatments
		b. Manage treatments	Specific to managing treatments.	Manage treatment times
		c. Clean / Sanitize treatments	Specific to cleaning treatment supplies.	Sanitize her nebulizer parts; Clean supplies correctly
	2. Diet and Exercise		Responses that reference diet and/or exercise.	How to Access exercise and healthy eating options

	3. Self-care			
		a Self-care	Responses that are geared toward self-care and taking care of oneself.	Take care of yourself
		b. Symptoms	More specific to self-care as it relates to symptoms.	Know when they feel sick
	4. Hygiene/Germ control		Responses that are about staying clean or managing germ control.	Keep clean
	5. Medication		Responses encompassing medication related to CF care.	
		a. Taking meds	Specific to taking medication.	Take meds; Medication done correctly as RX
		b. Order meds	Specific to ordering medication or refills.	Order his medication
		c. Manage meds	Specific to the management of medication or use of something to manage.	Have all medication available as needed; Have more control of your medications
		d. Know meds	Specific to having knowledge about what medications do.	Know medications
C. Administrative/ Managerial			Major category encompassing the more administrative skills that are meant to manage health or illness.	
	1. Appointments		Responses that deal with making or attending appointments.	Make apptments
	2. Insurance		Responses that deal with handling insurance	Deal with insurance company
	3. Bills		Responses about bills.	Managing bills
	4. Pharmacy		Responses dealing with pharmacies	Manage dealing with pharmacies
Worries				
A. Compliance			Major category encompassing the concept of compliance and adherence to treatment regimens/protocols.	
	1. General		General references to compliance	Compliance without my supervision
	2. Treatment		Responses related to treatments and treatment protocols more specifically.	
		a. Treatment compliance	Specific to remaining compliant with treatments or being regular with treatments.	Importance of treatments; Regular on treatments
		b. Skipping/not doing treatments	Mention of skipping treatments or not complying with protocols.	Won't do treatments; Skipping breathing treatments
	3. Medication		Compliance references relating to medication.	

		a. Medicine compliance	Specific to taking medication.	Importance of taking meds regularly
		b. Skipping/not taking medications	Specific to not taking medication.	Not taking medications; Skipping pills
	4. Diet and Exercise		Compliance as it relates to diet and exercise.	He might not continue exercising; Eat correctly
	5. Other			
		a. Cleaning	Compliance regarding cleaning and germ control.	Germ control
		b. Missing doctors	Compliance with attending doctor's appointments.	Missing doctors
B. Youth Characteristics			Major category encompassing characteristics of youth that are more stable over time or are embodied by the youth.	
	1. Organization/ Time management		Mention of organization or time management skills.	Organization; Time pressure to skip meds
	2. Responsibility		Responses about being responsible or taking ownership.	Be more responsible and independent; A sense of ownership and desire to do everything it takes to manage CF
	3. Other			
		a. Advocate	Being able to self-advocate.	Ability to self-advocate
		b. Manage health	Being able to manage health.	Ability to manage health
		c. Knowledge	Being knowledgeable about care.	Know their medications and their times
	4. Mental Health		Responses that include mention of mental health related things such as anxiety and depression.	Anxiety and depression
C. Administrative worries			Major category encompassing more managerial level aspects of care.	
	1. Insurance		Specific to insurance.	She will need good insurance
	2. Cost		Specific to the cost of care.	She doesn't get a job with good benefits
	3. Access		Specific to access to healthcare.	Continued access to clinic
D. Adulthood			Major category encompassing worries related to adulthood or the youth's future.	
	1. Family		Specific to starting a family.	Beginning his own family

2. College		Specific to college.	
	a. Managing health	Managing health while at college.	Going to college or work when sick
	b. Dorm germs	Germ control related to college lifestyle.	College life / dorm germs
3. Living away		Specific to living away from home.	Living on her own when sick
4. Other			
	a. Greatness	Mention of destiny and recognizing greatness.	That the disease may keep him from realizing his destiny for greatness
	b. Depressed	Specific to youth mental health.	That he will get discouraged or depressed
5. Job		Specific to future jobs, finding jobs, and working with illness	Keeping a job
E. Disease Worries			
1. Disease Progression		Major category including mention of disease progression or staying healthy over time.	Declining health and ability to stay healthy
SKILL BEHAVIOR			
A. Parent-Child Interactions		Major category encompassing parent-child interactions, most often verbal exchanges ranging in involvement.	
1. Talk		Responses that mention talk or talking but that lack other forms of involvement.	
	a. Medication	Specific to talking about medications.	Talk to him about it, have him fill his own meds each week, talk through decisions
	b. Future	Specific to talking about the future or getting older.	Discuss the importance of being at appts and following doctor's orders for when he is in charge of this when he gets older.
	c. Other	General responses about talking.	I ask them to investigate and read more about their illness so that they can get an idea of what to be
2. Teach		Responses that mention teach or teaching or imply more to the interaction then just talking. Talk with the potential for modeling or more involved interactions between parent and child.	
	a. Medication	Specific to teaching about medications.	Teaching how to order all medications to be on hand

	b. Treatments	Specific to teaching about treatments or treatment protocols.	Putting on his vest and hoses, knowing when to huff cough, and how to stop and restart treatments.
	c. Other	General responses about teaching.	
3. Co-activity		Responses that imply talking or teaching but that directly mention doing it together.	Have him listen while I order; Watch's how I do it
B. Parent Driven Interactions		Major category that includes parental behaviors that are driven primarily by the parent.	
1. Autonomy Granting		Responses that are a direct mention of parent allowing or letting the youth perform certain things or suggest parent giving the youth some responsibility to do on their own.	
	a. General	General responses about giving autonomy	Letting him make choices, decisions, step back, allow him to be independent
	b. Treatments	Autonomy for doing treatments or treatment protocols.	Letting him manage his treatments more by himself.; Preparing chambers on his own before treatments
	c. Medications	Autonomy for medications or ordering medications.	Letting him start to place some of the refill orders
	d. Other	Autonomy for doing other health related skills.	We are letting her learn to pay bills
2. Support		Responses that mention parent providing help or support.	
	a. General	Generalized support or help.	Help him when he needs it
	b. Medication	Support or help with medication.	Help with medicine
	c. Goals	Support for setting and meeting goals	Acknowledging challenges Focusing on Goals, planning
3. Monitor		Responses that suggest parental monitoring of youth behavior or reminding the youth to do a certain thing.	
	a. Reminders	Mention of reminders or reminding the youth.	Reminders and guidance
	b. Ensuring it gets done	Mention of "make sure" or that suggest that the parent is ensuring that it gets done.	Make sure he showers and washes his hands; Observing that all this well with his medicines
	c. Other	Mention of general monitoring behaviors	Starting to leave taking meds up to him, but monitoring
C. Structuring the Environment		Major category that encompasses parents’ efforts to provide an environment that will foster the behavior.	

	1. Provision of Resources		Responses entailing parental efforts to provide resources or influence resources available to youth.	
		a. Diet and Exercise	Providing food or opportunities for exercise.	Cooking different foods at home; We provide workout equipment and options to play sports and cook at home.
		b. Organization	Providing a means to stay organized.	We gave him his own medical counter in which he organizes and keeps clean
		c. Other	Providing access to resources such as taking to appointments.	Take her to her appointments
	2. Establishing routines/habits			
		a. General	Responses that relate to establishing a routine or habit but that are general in nature.	Stay on schedule and give rewards schedule is posted; Daily chores and good shower practice
		b. CF-Specific	Responses that are about establishing a routine or habit but that directly relate to cystic fibrosis (e.g., treatments).	Have her leave space in her schedule to do meds; Getting him to understand that they need to be sterilized every time.
D. Nothing				
	1. Nothing		Major category for responses that indicate that parent is currently doing nothing to address the skill.	Nothing at the moment
WORRY BEHAVIOR				
A. Parent-Child Interactions			Major category encompassing parent-child interactions, most often verbal exchanges ranging in involvement.	
	1. Talk		Responses that mention talk or talking but that lack other forms of involvement.	
		a. General	General talk or talking	Talking to him about resilience and our unconditional support
		b. CF-related	Talking that is related to some aspect of cystic fibrosis care.	Talking to him about how doing his treatment plan impacts his wellbeing
	2. Teach		Responses that mention teach or teaching or imply more to the interaction then just talking. Talk with the potential for modeling or more involved interactions between parent and child.	
		a. Goal driven	Teaching behaviors that are addressing a specific goal behavior.	Showing how long it takes for your treatment and what you have to do;

				Teaching him weekly, monthly planning techniques
		b. General	General teaching	I try to make my child aware of logical consequences … I also try to instill a desire for optimal health and wellness.
B. Parent Driven Interactions			Major category that includes parental behaviors that are driven primarily by the parent.	
	1. Support		Responses that mention parent providing help or support.	Helping him, counseling; Practicing it, counseling
	2. Remind		Responses indicating parental efforts to monitor youth behavior and remind when necessary	Always reminding him how important it is to do it and what the consequences could be
	3. Autonomy		Responses that include making the youth accountable or engaging in behaviors that support the youth's participation.	Make accountable now.
	4. Avoidance		Responses about avoiding the topic with the child or hiding feelings from child.	I do not talk about that with him
C. Structuring of the Environment			Major category that encompasses parents’ efforts to provide an environment that will foster the behavior.	
	1. Establishing habits			
		a. General routine	Responses that relate to establishing a routine or habit but that are general in nature.	By not letting him miss and keeping a routine daily; Keep their room and their person clean
		b. CF-specific	Responses that are about establishing a routine or habit but that directly relate to cystic fibrosis (e.g., treatments).	Staying on a schedule and not missing treatments. Letting him know how important each med is.
	2. Provision of Resources		Responses entailing parental efforts to provide resources or influence resources available to youth.	
		a. CF specific	References to resources that are provided that are specific to CF and CF care.	Giving him a timer and having him switch neb cups after one is finished.
		b. Living arrangements	Reference to living arrangements or behaviors that deal with living arrangement.	Not moving and making sure insurance covers it even if switching carriers is necessary.
D. Nothing			Major category for responses that indicate that parent is currently doing nothing to address the skill.	
	1. Nothing		Not doing anything or engaging in any behaviors to address it.	I am doing nothing, that's why I'm worried

Quantifying the qualitative responses

In order to test group differences on the open-ended responses I first needed to quantify the responses. To start, I created a spreadsheet that took the qualitative code categories and indicated whether a particular code was mentioned by a participant or not. For example, if a participant had said compliance was a worried they had, they were given a 1 for the category of compliance. If the code category was not mentioned by a participant, they received a 0. Please see Table 1 for an example.

Table 1.
Example of Quantifying Process

Participant ID	Youth Characteristic skill	CF-related health skill	Admin/Manage skill
8	1	1	0
9	1	1	1
10	0	1	0
11	0	1	1
13	1	0	0
14	1	1	0

Next, I examined the averages for each category to make sure I had an appropriate amount of variability. If there was not enough variability for a given major category, then the sub-categories were explored. For example, if a category had an average of .8 or .1 that meant that there was not much variability for that code by participants. Averages for each major category can be found in Table 2. Based on the averages for the skills, I decided to keep the major skill categories of Youth Characteristics and Administrative skills. However, the major category of CF-related health skills had a high average and therefore I broke it down further for the group comparisons. The sub-categories of CF-related skills included: 1. Treatment skills, 2. Medication skills, and 3. CF-related other. All the major categories for worries had acceptable variability and so were left at the higher level.

Table 2.
Averages across the major categories

Major Category	Average
Youth Characteristic skills	0.342
Admin/Manage skills	0.297
CF-related health skills	0.868
Treatment skills	.368
Medication skills	.605
CF-related other skills	.368
Compliance worry	0.5
Youth Characteristic worry	0.211
Administrative worry	0.184
Adulthood worry/Disease Progression	.368

Finally, chi-squared analyses were run on each skill and worry category across the groups child gender, income, parent education level, middle schooler, BMI, and lung function. Results of these analyses were discussed in the main text.

Appendix C

Reliability and validity tests for health belief items

Univariate descriptive statistics of all parental belief items as well as correlational analyses were performed. I also evaluated the distributions of the data to address any non-normality, ceiling effects, and potential outliers for each item. Once I had examined the individual items, I assessed the best ways to aggregate items into scales. The family management scale has been extensively, psychometrically studied and the creators suggest calculating an average score across at least 9 of the ten items. For all other scales, I conducted reliability and validity tests.

General health beliefs.

The three general health belief items were selected to represent three different types of control beliefs informed from previous work: 1. participants views of self-control or personal control, 2. treatment control, and 3. provider control over health (Furnham and Forey, 1994; Moss-Morris et al., 2002). The three items were not highly correlated with each other ($r = -.08$ to $.24$) and the Cronbach alpha was low ($\alpha = .27$). So, for further analyses, these three items were treated as separate beliefs.

Outcome expectancy and self-efficacy beliefs.

The individual outcome expectancy and self-efficacy items were tested as an outcome score for general illness and a self-efficacy score for general illness. Higher averages represented more confidence in their abilities to manage health generally and represented beliefs that certain health behaviors resulted in general health outcomes. The three outcome expectancy items were moderately correlated with each other ($r = .38$ to $.55$) and had a good Cronbach alpha ($\alpha=.70$). The three self-efficacy items were also moderately correlated with each other ($r = .41$

to .66) and had a good Cronbach alpha (α=.77). Therefore, I created an outcome expectancy score and a self-efficacy score by averaging across the three items, respectively. These new scores were used for future analyses.

Child specific beliefs.

Reliability and Validity. A review of the literature on transition readiness skills as well as an expert panel review was performed to address content validity of the modified measure. We conceptualized the 5 transition-related skills developed from the literature and expert team review into two distinct skill sub-groups: medicine-related skills and doctor-related skills that were theoretically different from each other. In addition to content validity, convergent and discriminant validity was assessed on the modified measures. I conducted multi-trait analyses by examining the correlations of the individual items across the two skill type groups to assess the convergent and discriminant validity of the measures. The medicine-related skill items should, hypothetically, be more correlated to each other than the doctor-related skills. Additionally, the self-concept of ability items should hypothetically be more correlated to each other than the subjective task value items. Given my small sample size these multi-trait analyses were better suited for smaller samples (Hays, Anderson, & Revicki, 1993; Alpern, Gardner, Kogan, Sandberg, & Quittner, 2017).

First, I conducted these analyses on the items to see if they subdivided into self-concept of ability and subjective task value groups. Convergent validity was supported for the expectancy-value modified items. Individual SCA items were more correlated with each other and less correlated with the STV items and vice versa (discriminant validity). Please see Table 1 for correlations. This suggested that the ability and task value items of the modified scales split into the typically assembled two components of self-concept of ability (SCA) and subjective task value (STV) that have been supported by previous work on the E-V theory (Eccles et al., 1993b). In future work, it would be beneficial to test the modified items with a larger sample size as well as more skills to further support that ability and task value beliefs can be found in other domains.

Next, I conducted analyses to test whether the five skills grouped together in the hypothesized way. Interestingly, the convergent validity of the skill groupings was not supported. Originally, it was hypothesized that the five skills would be grouped into two separate groups for both SCA and STV: medication-related and doctor-related skills. After conducting reliability and validity tests, it was determined that parents think about these skills in different ways than hypothesized. These differences will be discussed in the following section.

Subjective task value. Across the five skills, it appeared that parents viewed the importance of a skill and the utility of a skill as one large group instead of the hypothesized two groups: medication-related and doctor-related. Correlations and alphas supported that all the subjective task value items could be aggregated into one transition-related skill group (please see Table 1 for correlations and Table 2 for alphas). The majority of importance and utility items were moderately to highly correlated with each other. Additionally, the averages for the individual importance and utility items were relatively high with little variation suggesting that most parents reported that all the skills were important to very important and useful to very useful (refer to Table 3 for descriptive statistics). For all further analyses, the subjective task value items were averaged into one score.

Self-concept of ability. Ability beliefs also differed from the hypothesized groupings. Originally, medication-related skills were hypothesized to include airway clearance treatments, taking enzymes, and tracking medication refills while doctor-related skills included tracking symptoms to share at an appointment and answering questions asked by the doctor at appointments. However, reliability and validity tests supported that airway clearance treatments and taking enzymes were thought of as one construct and tracking medication refills, tracking symptoms, and answering questions another construct. The correlations for airway clearance treatments and taking enzymes were moderate with each other yet were lower with tracking medication refills and the two doctor themed skills. However, tracking medication refills was moderately correlated with tracking symptoms to share and answering questions asked by the doctor (please refer to Table 1 for correlations and Table 2 for alphas). The qualitative data supported this configuration and further informed the skill groupings as well but was discussed in the main text. To summarize the qualitative data from the main text, open-ended and interview data revealed patterns that reflect that parents think about the skills their children need to learn as either related to the direct treatment of CF or skills that were behind the scenes management of health. An administrative skill pattern emerged in the open-ended responses that appeared to suggest that tracking medication and doctor-related items were grouped together in parents' minds and that more daily treatment specific management skills formed another group.

Given the qualitative data, correlations, and alphas I created new skill groupings for self-concept of ability analyses. The new skill groups were 1. treatment-related skills including doing airway clearance treatments and taking enzymes and 2. Administrative-related skills including tracking medication refills, tracking symptoms to share with doctor, and answering questions asked by the doctor at appointments.

Table 1.

Correlation Table for Expectancy Value Items using Pairwise

		Self-concept of Ability					*Subjective Task Value*									
		AC	TE	MR	TS	AQ	IMP AC	USE AC	IMP TE	USE TE	IMP MR	USE MR	IMP TS	USE TS	IMP AQ	USE AQ
Self-concept of Ability	AC	1														
	TE	0.44	1.00													
	MR	0.13	0.10	1.00												
	TS	0.28	0.17	0.45	1.00											
	AQ	0.43	0.03	0.32	0.51	1.00										
Subjective Task Value	IMP AC	0.10	-0.17	0.15	0.18	0.17	1.00									
	USE AC	0.52	-0.03	0.40	0.16	0.27	0.67	1.00								
	IMP TE	-0.10	-0.16	-0.25	-0.02	-0.08	0.09	0.00	1.00							
	USE TE	0.15	0.29	0.04	0.11	0.10	0.13	0.13	0.46	1.00						
	IMP MR	0.03	-0.09	0.27	-0.21	0.01	0.14	0.41	0.14	-0.06	1.00					
	USE MR	0.16	-0.21	0.12	0.08	0.13	0.53	0.65	-0.04	-0.01	0.64	1.00				
	IMP TS	0.12	0.33	0.00	0.12	0.23	0.24	0.17	0.18	0.52	0.35	0.30	1.00			
	USE TS	0.20	-0.12	0.14	0.36	0.43	0.20	0.39	0.00	0.08	0.55	0.60	0.53	1.00		
	IMP AQ	-0.08	0.13	-0.05	0.16	0.27	0.51	0.39	0.25	0.58	0.05	0.23	0.60	0.26	1.00	
	USE AQ	0.34	0.33	-0.05	0.19	0.44	0.31	0.38	0.14	0.62	-0.05	0.12	0.56	0.31	0.82	1

Note. IMP = importance items; USE = Useful items. The skills are doing airway clearance treatments (AC), taking enzymes (TE), tracking medication refills (MR), tracking symptoms to share at doctor appointments (TS), and answering questions asked by the doctor at appointments (AQ).

Table 2.
Alphas for the Expectancy-Value Items and Skill Groupings

		α
Self-concept of Ability	**Medication related skills***	0.49
	Airway clearance treatments	
	Taking enzymes	
	Tracking medication refills	
	Doctor related skills*	0.67
	Tracking symptoms to share	
	Answering doctor questions	
	Treatment related skills^	*0.62*
	Airway clearance treatments	
	Taking enzymes	
	Administrative skills^	*0.69*
	Tracking medication refills	
	Tracking symptoms to share	
	Answering doctor questions	
Subjective Task Value	**Medication related skills***	0.72
	Airway clearance treatments	
	Taking enzymes	
	Tracking medication refills	
	Doctor related skills*	0.76
	Tracking symptoms to share	
	Answering doctor questions	
	Transition related skills^	*0.81*
	All utility and importance items	

Note. The alphas in *italics* are the combinations that were used in further analyses. * indicated the hypothesized groupings while ^ signifies the groupings supported by tests and qualitative data.

Table 3.

Descriptive Statistics of Expectancy-Value Individual Items and Aggregate Variables

		Obs	Mean	Std. Dev.	Min	Max
Self-concept of Ability	Airway clearance treatments	33	4.06	1.09	1	5
	Taking enzymes	36	4.47	0.84	1	5
	*Treatment related skills**	*37*	*4.30*	*0.81*	*1*	*5*
	Tracking medication refills	17^	2.82	1.24	1	5
	Tracking symptoms to share	30	3.80	1.19	1	5
	Answering doctor questions	38	4.18	0.83	2	5
	*Administrative related skills**	*38*	*3.81*	*0.88*	*2*	*5*
Subjective Task Value	Importance of airway clearance treatments	38	4.74	0.72	1	5
	Utility of airway clearance treatments	38	4.50	0.89	1	5
	Importance of taking enzymes	37	4.95	0.23	4	5
	Utility of taking enzymes	37	4.84	0.44	3	5
	Importance of tracking medication refills	38	4.53	0.89	1	5
	Utility of tracking medication refills	38	4.32	1.21	1	5
	Importance of tracking symptoms to share	37	4.59	0.80	2	5
	Utility of tracking symptoms to share	37	4.51	0.77	2	5
	Importance of answering doctor questions	37	4.86	0.35	4	5
	Utility of answering doctor questions	38	4.79	0.47	3	5
	*Transition related skill**	38	4.66	0.44	3.3	5

Note. The aggregated scale variables are in *italics* and indicated with an *. ^tracking medication refills has a smaller number of observations because if a parent indicated that their child never tried the skill, they were asked how good do you think they will be. As ‘will be good’ is different than ‘good’, the ‘will be good’ items were not aggregated with the ability items.