



“I have a Ph.D. in my daughter”: Mother and Child Experiences of Living with Childhood Chronic Illness

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Abstract

Children in the United States are increasingly living with chronic illnesses. Existing literature has focused on adolescent children’s experiences. The current study involved interviews with 10 families: children (ages 6–11) diagnosed with chronic illnesses and their mothers to better understand the experience of living with chronic illness. Using grounded theory, participants’ responses fell into several themes: impact on family dynamics, parental advocacy, initial difficulty followed by resilience, unique stressors, and areas of social support. Overall, both mothers and children reported unique challenges related to living with childhood chronic illness, especially in terms of family dynamics, sibling relationships, and the mother-child relationship. However, almost all families also emphasized their ability to be resilient. The results have implications for medical practitioners and teachers who work with school-age children with chronic illnesses. Mothers need to feel supported and understood by professionals. Families need support to cope with stressors and strengthen couple, sibling, and parent-child relationships.

Keywords Child chronic illness · Family dynamics · Qualitative interview · Parent-child relationship · Resilience

Highlights

- Children (ages 6–11) diagnosed with chronic illnesses and their mothers participated in semi-structured interviews.
- Both mothers and children reported unique challenges related to living with childhood chronic illness.
- Most families also emphasized their ability to be resilient in the face of childhood chronic illness.
- Children and mothers value support from medical professionals, family members, and friends to cope with childhood chronic illness.

The number of children in the United States (US) diagnosed with special health care needs (CSHCN) is on the rise (HRSA, 2022). According to the National Survey of Children’s Health, nearly 1 in 5 children in the US have a special health care need. CSHCN are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions who also require

health related services. Chronic illnesses, or medical conditions with debilitating symptoms lasting for three or more months, account for much of these health care needs. Chronic illnesses include illnesses such as asthma, type 1 diabetes, cystic fibrosis, celiac disease, and epilepsy, among others. Environmental influences such as malnutrition and rising poverty rates have increased the prevalence of certain illnesses (Judson, 2004), and SARS-CoV-2 infection may also increase risk of certain chronic illnesses, including diabetes (Barrett et al., 2022). Advances in medical technology have allowed for the management of many conditions at home rather than in hospital settings. These factors have increased the demands placed on families as they attempt to adjust to their children’s diagnoses.

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Experiences of Living with Child Chronic Illness

Childhood is a period of rapid development, and chronic illnesses have the potential to impact all domains of development. Children who are born with a chronic illness or diagnosed shortly after birth may experience unique struggles as they do not know a life without an illness, and at the same time they may be better able to build a life around the illness (Venning et al., 2007). Children who are diagnosed during childhood may experience a range of physical and cognitive adjustments following a diagnosis including appearance changes, frequent school absenteeism, and long-term dietary changes (Gannoni & Shute, 2010).

Children's Perspectives

Previous research into children's perspectives following a diagnosis of a chronic illness is limited. The limited research that is available often focuses on the perspectives of older school-age children or adolescents (Alderfer et al., 2001; Gannoni & Shute, 2010; Sartain et al., 2000; Wollenhaupt et al., 2012). Existing literature mostly focuses on the educational experience of children with chronic illnesses (e.g., Sisk, 2016), and limited studies examine psychological or socioemotional outcomes (Emerson et al., 2016). Immediately following a diagnosis, children often experience negative psychological health outcomes and report feelings of loneliness and alienation (Sartain et al., 2000). However, they also seek to be active participants in the diagnosis process and can form opinions about their experiences.

Existing literature has focused on the immediate adjustment of older school-age children and adolescents and their experiences with chronic illnesses. Younger children are also faced with understanding and incorporating a diagnosis of a chronic illness into their lives. This current study aims to understand the experiences of young school-age children as they navigate family, school, and personal changes that accompany a chronic illness diagnosis.

Parents' Perspectives

Existing research specific to parents' perspectives of chronic illness diagnoses highlights the ways in which child chronic illness impacts parenting and the family unit as well as important aspects of accepting, adjusting, and coping with chronic illness diagnosis. Parents must adjust to long-term stressors which accompany management of a childhood chronic illness (Pinquart, 2018), including financial demands (Foster et al., 2021; Gannoni & Shute, 2010; Romley et al., 2017), attending to children's daily medical needs (Hafetz & Miller, 2010), and regularly managing

unpredictable and uncertain situations (Nygård & Clancy, 2018). Parents report feeling a tremendous burden of ensuring their CSHCN are receiving the best possible care at home, school, and in healthcare settings. They also report feelings of guilt around the child's diagnosis and wellbeing and worries about the child's healthy siblings. In turn, parents report physical and mental health challenges resulting from caring for CSHCN. High stress levels in parents may, in turn, make it challenging to parent and contribute to child behavior problems (Hilliard et al., 2011). To cope with the stress and emotions associated with raising CSHCN, parents tend to rely on social support (Nygård & Clancy, 2018). However, family support networks are not always available, and when they are, parents express frustration that their family does not always understand the severity or chronicity of the diagnosis (Gannoni & Shute, 2010). Similarly, many parents report negative experiences with healthcare professionals (Nygård & Clancy, 2018).

Existing literature highlights the short-term experiences, unique stressors, and support systems for parents of children with a chronic illness. However, parents' long-term adjustments and impacts of child chronic illness on the parent-child relationship and family dynamics are still understudied.

Impact on Families

Consistent with the Social Ecological Model (Bronfenbrenner, 1977) and the Family Resilience Process model (Walsh, 2003), and across a myriad of family health research, it is clear that one family member's health issues have the potential to impact the whole family's emotional climate and health outcomes (e.g., Van Schoors et al., 2017; Woods et al., 2020). Following the diagnosis of a chronic illness, families are challenged to incorporate the diagnosis into their daily lives, redefine family roles, and attempt to cope with the demands placed on all family members (e.g., Gannoni & Shute, 2010; Knafel & Deatrck, 2002; Nabors et al., 2019).

The changes in daily routine, additional stressors, and emotional adjustment that accompany a diagnosis of a chronic illness can immediately impact sibling, parent, and overall family functioning (Lummer-Aikey & Goldstein, 2021; Nabors et al., 2019; Rosenthal et al., 2021). Healthy siblings of CSHCN are at risk for poorer school engagement (Rosenthal et al., 2021), behavioral and mental health issues (Lummer-Aikey & Goldstein, 2021), and lower self-esteem (Havermans et al., 2015). When siblings receive inadequate information or feel isolated from their parents, they are at higher risk of negative outcomes (Lummer-Aikey & Goldstein, 2021). Siblings also express feeling treated inequitably by their parents, receiving less attention and parental time and taking on

more responsibilities and independence. In turn, the sibling relationship may also be impaired (Batte et al., 2006). Birth order seems to contribute to siblings' experiences such that older siblings tend to take on more caretaking responsibilities for their ill younger sibling, whereas, younger siblings are more likely to experience more restrictions in typical activities like playing with friends (Waite-Jones & Madill, 2008). Yet, many siblings are resilient and engage in positive coping behaviors despite the challenges (Lummer-Aikey & Goldstein, 2021). Key protective factors include social-emotional support from family members, peers, and teachers.

Although a diagnosis of a chronic illness influences relationships among all family members, the parent-child relationship must especially adapt to the changing dynamics. Past research has focused on adolescents' perspectives of the changing parent-child relationship following a diagnosis (Gannoni & Shute, 2010; Hafetz & Miller, 2010; Miller, 2009), and indicates shared decision-making contributes to more positive relationships (Miller, 2009). When parents fail to accept a child's diagnosis they are at risk of more family conflict and less family cohesion and expressiveness (Popp et al., 2014). Although studies have focused on family functioning and relationships involving adolescents, it is unclear how these processes unfold among young children and their parents.

Study Aims

The current study aimed to better understand school-age children's and their mothers' perspectives of adjusting to life with a chronic illness. Previous literature has often neglected children's perspectives, and when children are included, most studies rely on the experiences of older school-age children or adolescents (e.g., Miller, 2009). By including younger children's perspectives in this study, it was possible to gain a more complete understanding of how diagnoses shape parent-child relationship dynamics. Further, because relationships are complex and require explanation beyond what a quantitative study can provide, we used a qualitative interview method to understand in-depth experiences of mothers and their children. Many studies about child chronic illness have focused on the immediate experiences following a diagnosis (e.g., Nabors et al., 2019). It is also important to consider how relationships evolve in a dynamic and transactional manner. As such, we examined experiences of mothers and their children at least six months out from diagnosis, to better understand the long-term changes in families of CSHCN.

Method

Author Positionality

Two authors contributed to the current study. K. B. identifies as White and is unmarried, without children. She holds a master's degree in Family and Child Life and is certified as a Child Life Specialist, working with children facing medical challenges in a hospital environment. A. C. identifies as White, is married, and has two young children who demonstrate typical development without special healthcare needs. She holds a doctoral degree in Marriage and Family Therapy and is a licensed clinician. Her primary role is as a teacher-scholar, although she provides parenting support to community members.

Participants

The study included 10 families, consisting of 10 mothers and 8 children, as 2 children opted out of the study. To be included, children must have been school-age (6–11 years old) and diagnosed with a chronic illness. Due to the prevalence of studies in the existing literature that have focused on asthma and cancer, children with those chronic illnesses were excluded from this study. Children with only behavioral (e.g., Autism Spectrum Disorder) or mental health disorders (e.g., depression) were also excluded, however, participants may have had existing comorbidities involving both a chronic illness and a behavioral diagnosis. Children must have also been at least six months post-diagnosis. The primary, residential caregiver to the child was interviewed, and in all 10 families, the caregiver was the child's biological mother.

Children in the 10 families all had different diagnoses (see Table 1). Children ranged in age from 6 to 11 years old ($M = 8.50$, $SD = 1.84$). Between 7 months to 10 years had passed since the child had been diagnosed ($M = 4.45$ years, $SD = 3.70$). The majority of families identified as White ($n = 7$, 70%). In only 2 (20%) families was the target child an only child. The majority of mothers were employed ($n = 7$, 70%). Most also had completed some higher education ($n = 9$, 90%). Additional demographic characteristics are presented in Table 1.

Measures

We conducted semi-structured interviews with the goal of promoting a conversational dynamic during interviews. Mothers and their children were asked demographic questions together, including the name of the diagnosis, time since diagnosis, age of child, grade in school, race/ethnicity, who lived in the residence, maternal education, and maternal employment status. Children were asked three

Table 1 Participant demographic characteristics

Pseudonym(s) Mother/Child	Chronic Illness Diagnosis	Comorbidities	Child's Age	Child's Grade ^a	Child's Race/Ethnicity	Time Since Diagnosis	Number of Children in Household	Parent Education
Nina	Kidney Disease	Deny's-Drash Syndrome	6	K	White	5 years	3	Master's degree
Karen Jenna	Type 1 Diabetes	–	6	K	White	1 year	3	Bachelor's degree
Susan James	Growth Hormone Deficiency	Tree Nut Allergy	7	1 st	African American, Korean, White	3.5 years	3	Associate degree
Nicole Zach	Lyme Disease	–	8	2 nd	White	1 year	3	Some college
Kelsey	Eosinophilic Esophagitis	Asthma, life threatening allergies	8	3 rd	Prefer not to say	8 years	1	Master's degree
Sara John	Heterotaxy Syndrome	Hypoplastic Left Heart Syndrome	9	2 nd	White	10 years	8	Some college and trade school
Mary Ben	Uveitis	Autism Spectrum Disorder	9	3 rd	White	1.5 years	1	Bachelor's degree
Cathy Ryan	Septo-Optic Dysplasia	Autism Spectrum Disorder	10	4 th	White, Hispanic	10 years	3	High school diploma
Linda Alexa	ALPS	Trisomy 21	11	6 th	Hispanic	4 years	5	Some college
Carrie Jim	Celiac Disease	–	11	6 th	White	7 months	3	Associate degree

Table is organized by target child's age, from youngest to oldest. All presented diagnoses, comorbidities, race/ethnicity, and parent education are based on mothers' reports and not a standardized set of response options. ^aK = Kindergarten

broad, open-ended questions regarding their diagnosis, parent-child relationship, and family dynamics (e.g., “Tell me how you get along with your mother.”). Mothers were asked four broad questions regarding their child's illness, their relationship with the child, family dynamics, and family resiliency (e.g., “How would you describe your relationship with your child?”). We asked follow-up questions to solicit more information, as appropriate.

Procedures

Following institutional review board approval (CWU #2020-062), we posted a recruitment flier on various social media pages, primarily Facebook. We mostly posted on support group pages for parents of children with chronic illnesses. Interested families contacted the researchers to schedule an interview. We conducted all interviews via Zoom between April – June 2020.

At the time of the interview, we first completed an informed consent process with mothers, which involved an option for participating in member checking. Then we conducted an assent process with the target child. Interviews began with the demographic questions and then mothers and children were given the option of who wanted to complete the interview first. Mothers were encouraged to allow their children to participate in the interview independently without parental interference. Similarly, children were encouraged to exit the room during the parent portion of the interview. Interviews with children lasted approximately 15–30 min and mothers' interviews ranged from 30 to 60 min. We audio recorded and transcribed verbatim all interviews.

Data Analysis

One researcher transcribed all interviews verbatim and another verified them for accuracy. Following transcription, we deleted the audio recordings to protect participants' confidentiality. We analyzed the transcripts using a grounded theory approach, which allowed themes to emerge from the data as we attempted to review the interviews without prior assumptions (Strauss & Corbin, 1997). We first each read the transcripts multiple times to immerse ourselves in the data and gain a sense of the whole (Tesch, 1990). Then, we used an open, axial, and selective coding process (Strauss & Corbin, 1997). In open coding, we both openly coded the first two transcripts independently and then met to discuss our codes and a plan for the remaining coding process. We decided to divide the remaining transcripts and code them independently because we seemed to be coding similarly, and we had both read all of the transcripts. We used descriptive and in-vivo codes to capture each point discussed in the interviews. After open coding, we met to

conduct axial coding where we reviewed all open codes and then developed categories among codes and identified patterns and relationships among and between transcripts. Finally, we grouped axial codes into overarching themes in a selective coding process. We present the results here in terms of overall themes which emerged from the data. We emailed a summary of the final themes to participants who opted into the member checking process ($n = 8$, 80%) to allow for validity checking of the data. Only one mother responded, indicating the themes accurately represented her experience.

Results

We identified five core themes through analysis of interviews: impact on family dynamics, parental advocacy, initial difficulty followed by resilience, unique stressors, and areas of social support. Each main theme also included subthemes. The themes and subthemes are discussed in detail below.

“It’s affected pretty much every aspect of our life:” Impact on Family Dynamics

Participants described a variety of impacts of the diagnosis of a chronic illness on family dynamics. Participants described resiliency and parentification of healthy siblings, varied parental couple dynamics, increased sacrifices made by mothers, and a highly involved but challenged mother-child relationship.

Resiliency and parentification of healthy siblings

In families with multiple children, almost all mothers discussed an increase in responsibility placed on healthy siblings. In some families, the older siblings took on parental roles. Linda talked about her oldest daughter taking care of her youngest son while she was at the hospital with the target child, “for the longest time he actually thought [she] was his mother because that’s who would take care of him all the time.” In other families, younger children assisted in therapies and daily care of the child with a chronic illness. For example, Sara said of her youngest daughter, “...during physical therapy, [she] would run off with the ball...[John] was slower and couldn’t quite do it but it really made him progress a lot. Because he had her.” Regardless of birth order, healthy siblings were given greater responsibility within the family.

Mothers also described differences in parenting their CSHCN and their healthy children. Siblings often received less attention from parents and were held to higher expectations. Linda said of her youngest son, “he really has a hard time because this, uh, kind of, he’s kind of left out in the

whole scenario.” However, participants felt siblings displayed greater resilience due to their experiences living with a chronically ill sibling. Sara remembered when her target child was not expected to live and how the experience shaped how her older sons handle hardships. She said, “it’s interesting to hear my oldest boys, when they go through something hard, they’re like ‘well, we have been through hard stuff before’... so it’s given them an added measure of confidence in facing hard things.” While most mothers indicated healthy siblings were given less attention, they also felt siblings were more resilient because they had a sibling with a chronic illness.

Mothers’ and children’s perspectives on how the chronic illness influenced sibling relationships seemed to differ such that mothers reported a negative impact on healthy siblings whereas children tended to view their relationship with their siblings as unaffected by the diagnosis. Mothers often perceived the diagnosis as adding strain and challenge to sibling relationships. Sara said her oldest son, “gets super annoyed by [John] all the time and it doesn’t help that [John] is like developmentally a little young... he just finally, over the past year, has been fed up with that, and it’s, it’s tough.” However, most of the children reported their relationships with their siblings were not affected by the chronic illness. Many of the children reported not discussing their diagnosis with siblings and instead described developmentally-appropriate sibling relationships. For example, Jim said about his siblings, “I don’t really talk to them that much [about my diagnosis]. It doesn’t really affect them, it only affects me.” Overall, mothers reported more challenges in sibling relationships than children.

Varied Parental Couple Dynamics

Many mothers discussed how parental couple dynamics were influenced by the chronic illness diagnosis, but there was not one consistent way in which couple dynamics were described. Instead, couples’ dynamics tended to fall into one of three categories. The first dynamic involved both partners sharing in responsibilities and agreeing on treatment decisions. For example, Nina said, “my husband and I, um, try to share you know, care taking responsibilities... so there’s a lot of communication there.” The second dynamic was defined by conflict resulting from partners’ disagreement about medical treatment, parenting, or diagnosis. Carrie said, “it’s really hard when [my husband] does see the cost of something...and he just doesn’t, you know, he doesn’t get it...it’s obviously a medical issue but my husband doesn’t get that.” The final dynamic was one in which the child’s father was uninvolved in treatment and decision making. Kelsey mentioned, “it’s basically made it so my husband is not involved much, because he doesn’t um want to face the, he wants to treat her like a regular kid and

ignore everything...he's here but he's not like involved." The level of father involvement in decision making and degree to which parents agreed on medical care seemed to define the couple dynamic.

Increased sacrifices made by mothers

Mothers described having to make various sacrifices following the diagnosis of their child's chronic illness. A few mothers mentioned the diagnosis completely changing their daily routines. For example, Kelsey said, "it's affected pretty much every aspect of our life." Some mothers were forced to make employment changes. Linda said, "I can't go to work certain times when her immune system is down...it impacts my work a lot." Other mothers felt the diagnosis left less time to spend with their partner. For example, Karen expressed that the diagnosis, "makes it virtually impossible to go on a date because there's nobody that can truly take care of her." Many mothers shared their struggle with lack of sleep due to monitoring and treatment throughout the night. Karen said, "lack of sleep is probably the hardest thing, I mean sleep deprivation is no joke. It is unbelievable...even if you got one night of rest it's just not going to help you recover from the chronic sleep deprivation." Mothers also mentioned the need for constant planning, which resulted in less spontaneity as a family. For instance, Susan said, "there's traveling with needles, and the pens and the alcohol swabs. Um, and then where are you going to store it when you are traveling?" Similarly, Kelsey felt her daughter's diagnosis had completely prevented any family outings or time for personal care, "she's almost basically home bound...I feel like I can't do things that I used to enjoy doing because I am stuck at home." Multiple dimensions of mothers' lives were impacted by the chronic illness diagnosis.

Highly involved but challenged mother-child relationship

Many mothers discussed the difficulty in parenting a child with a chronic illness. Difficulties centered on mothers needing to be highly involved with their child in order to manage the illness and struggling to set boundaries with the child. Some mothers reported the drawbacks of this parenting style, such as feeling guilty about the inability to set boundaries and wanting the child to be more independent. Linda said, "I think sometimes, um, I make her really dependent.... I'm her enabler I guess is what it is." Kelsey also shared, "there's just too many things, you know, that we need to do together which we shouldn't. You know, she should be more independent at this point." Others also discussed the benefits of being highly involved after fearing their child would die. For instance, Cathy said,

I think, um, going through what we've been through with them, like as far as surgeries and hospitalizations

and you know, emergency stuff, it just really makes me appreciate, probably more than normal, normal parents who have healthy kids. I don't think they can understand the relationship I have with my kids. I really try to just appreciate every minute of every day.

Mothers felt this had created a very close relationship with their children with chronic illnesses. Children also expressed feeling as if they had a close relationship with their mothers. John said, "[she's] an actual human shield." The feeling of a close and involved relationship was reciprocated in both mother and child interviews.

During the interviews, many mothers illustrated the highly involved parenting dynamic they discussed as almost all mothers prompted children's answers and repeated questions to the children. For example, when Zach responded with not knowing the hardest aspect of his illness, his mother Nicole prompted an answer for him, "maybe not eating what you like...and having to remember your pills." Zach then agreed with his mother, "yeah, probably trying to remember...all my pills." At the same time, mothers paid attention to what they disclosed in front of their children. Though most mother interviews began with both the child and mother present, many mothers moved to a separate room away from their child at some point during the interview to answer questions. For instance, when asked about how her relationship with the target child differed from her other children, Sara said, "I think I'm going to go into another room for this one." Despite the high involvement of mothers in their children's lives, they also demonstrated an ability to set boundaries and were conscious of what they discussed in front of their child during their own interviews.

Disagreements between mothers and children often centered on the diagnosis, particularly management of treatments. Mothers expressed feeling guilty for forcing their child to comply with treatments in which the child was refusing. Sara reflected on having to force her child to comply with blood draws,

To me it is very traumatic what he has to go through...just this last time we had to have a lab draw he was like, 'no, no, it's my body'...and I'm like, that would be abuse in any other situation when someone was saying, 'it's my body, stop.'...and yet here I am having to take him repeatedly into this situation.

Children expressed feeling angry and upset when their mothers restricted access to food and activities due to their diagnosis. James said he disagrees with his mom about eating "candy" and he can "get a little mad" when he cannot have it because of his blood sugar levels. Ben mentioned, "mom wants me to have Fluorescein. And I don't. Because

Fluorescein is one of those shots I don't like." Mothers and children both felt this tension to force treatments and restrict activities was a difficult aspect of their relationship.

Mothers often involved children in decision making surrounding chronic illness treatment, although the degree of involvement varied. Some mothers explained treatments to children and ensured they understood the purpose of treatment. For example, Cathy shared, "we are really open with [Ryan], um we tell him every time we have to go to the doctor if he's going to get poked or if it's going to hurt." Linda also said, "we talk to her and we explain to her that this has to happen and um why it has to happen." Other mothers similarly discussed treatment with their children, however, they acknowledged that their child had refused certain aspects of treatment. For instance, Susan said "we've just made [decisions] as parents... other than basically [James] did put his foot down that he wasn't going to have shots in certain parts of his body so I will say he kind of made that decision." Most mothers tried to give the child as many choices as possible during treatment when appropriate. Karen said, "we felt very strongly from the beginning that she needed to have choices... [Jenna] can decide whether to watch or not and she can decide whether we count or just go for it." Similarly, Nina said, "when appropriate we do give [him] options, um, you know like 'would you rather take your meds now or in ten minutes?'" While children had varying degrees of participation in decision making, most mothers explained treatments and provided choices when possible to children.

"You're a doctor, you have a Ph.D., but I have a Ph.D. in [my daughter]": Parental Advocacy

Mothers discussed the need to advocate for their child to multiple people in their lives. Many mothers focused on the need to repeatedly advocate with doctors for appropriate diagnoses and treatments. Linda described having to explain her child's diagnosis various times to doctors and finally said, "you're a doctor, you have a Ph.D, but I have a Ph.D in Alexa." Karen also had to take her child to multiple doctors, saying "we knew that she was sick... I had taken her to the doctor three times before her diagnosis because I, I, my spidey sense knew something was going on." Other mothers described how they had to educate teachers and nurses on daily care and emergency procedures. Nina said, "going into school was a new challenge. We had to make sure, you know, his teacher knew he needed to be drinking, we were in contact with the nurse." Cathy mentioned she created a presentation to share with teachers. A few mothers also expressed the importance of extended family members having a clear understanding of the diagnosis and treatments. For instance, Carrie discussed the struggle of educating her extended family on appropriate food for her child, "it's more training other

people about it that's been the hardest part with the family...it's just training his grandparents." Although areas of advocacy varied, most mothers mentioned an increased need to speak out and educate people who were involved with their child and the challenge this added to their experience of parenting a child with a chronic illness diagnosis.

"I cried for like a good two months and had a pity party...now I've kind of put my big girl panties on": Initial Difficulty Followed by Resilience

Many mothers described the initial transition following their child's diagnosis as extremely difficult and stressful. However, most families had created a new normal and felt their child's diagnosis was now manageable. Initially, most mothers discussed feeling angry and discouraged. Karen said, "I cried for like a good two months and had a pity party." Cathy said of her experience initially, "the first couple of years, they were pretty rough...we weren't sure, it was kind of a day by day." Most mothers discussed eventually accepting the diagnosis and incorporating it into their life. Karen continued about her experience, "now I've kind of put my big girl panties on and I'm back to just digging my heels in." Sara felt, "I don't feel like it's a lot anymore. Especially compared to what it was before." Nina said, "since then, he has been very stable and living a fairly normal life. As normal as can be for a trans, transplant patient." For the minority of mothers who reported the diagnosis was unmanageable, they tended to express a sense of not accepting the diagnosis and a hopefulness that their child would get better. For instance, Kelsey said,

I'm not really looking at her life as normal. I'm constantly trying to find a solution to make it more normal. So I, you know, there are therapies coming out...so she'll feel better...it's not happened so far but um, that's why I kind of have a lot of hope, despite everything.

While most mothers mentioned feeling like their child's diagnosis was manageable now, they described a very difficult transition in the beginning.

Children also described adjusting to their diagnosis. For example, Jim said of the beginning, "it was kind of annoying...but I kind of got over it and I realize that almost everything has a gluten free option." James agreed that in the beginning, getting daily shots was difficult but now he can give them to himself. Ben also has adjusted to getting shots, "I have it every week, enough, that would be enough to get used to it." Although Jenna reported she does not like her treatment, she acknowledged, "I don't get sick anymore. I don't like to get sick 'cause I don't get to go to school." Ryan shared a similar reaction to his shots, saying the shots

make him feel, “a little bit happy so that I don’t get sick.” Children initially struggled with daily treatments, however, seemed to have mostly accepted the necessity of treatments, and in turn, expressed a feeling of appreciation for feeling better following treatment.

“It felt kind of powerless”: Unique Stressors

Mothers described experiencing multiple unique stressors in relation to having a child with a chronic illness. These stressors centered on the unknown, possibility of child dying, increased responsibility to manage illness, and financial burdens. Children also discussed unique stressors related to managing a chronic illness.

The unknown

Many mothers discussed how one of the biggest stressors for their family was the unknown. This sense of not knowing was a factor in various aspects of their lives. The initial stress of not knowing how to help their child prior to diagnosis was mentioned by a few mothers. For example, Linda expressed “I think the hardest thing is um, seeing her struggle and not being able to really do anything about it.” Some mothers also described the difficulty of not knowing the right treatment for their child. Mary said, “it’s very abstract, knowing what is working, what wasn’t. It felt kind of powerless, you know, not being able to have like, a tangible idea of what we could do.” For a few mothers, there was the unknown of whether the diagnosis was genetic and would impact their other children. Susan shared her fears, “it might be hereditary or not. We do see some other trends in some of our other, um, boys, so we don’t know, yet know if it’s hereditary or not.” Karen shared similar fears for her daughters, “we’re also trying to keep an eye on her sisters to make sure we don’t miss any signs or symptoms if they do develop it as well.” Many mothers also experienced stress related to the possibility of flare ups occurring at any time. For example, Nina said, “he, um, will eventually need another kidney transplant. And so like every month when he has his labs...there’s that little bit of anxiety that’s like, ‘is, is this now, are we going to see a decline?’” Nicole similarly discussed her fears of flare ups, “once every, uh, 4-5 weeks he has a flare up...he’ll have temperatures of 105.8 for like 3–6 days and so we’re always trying to keep it down.” The unknowns of managing life with a child with a chronic illness contributed to the greatest stress for many of the mothers.

Possibility of child dying

Beyond the unknowns, the added stress from the possibility of their child dying was mentioned by many mothers. Some

mothers said this thought was always in the back of their mind. For example, Sara discussed how “it’s always that pit of your stomach, like this could be it.” Other mothers acknowledged how grateful they were to have their child, recognizing the possibility of death. Linda shared her thoughts, “I just gotta be grateful and thankful for the years that I got her because I don’t know how much longer.” Other mothers were told at some point that their child would not survive and indicated they are constantly aware of the possibility. Sara said, “they told us that he was going to die and we just had like a miracle that he survived...we thought we were really going to lose him.” This experience of almost losing their child in the past or the possibility of their child dying in the future was a major stressor described by mothers.

Increased responsibility to manage illness

Multiple mothers described the pressure of the full responsibility to manage medications and treatments. For example, Mary felt “it’s harder, ‘cause I have a lot of responsibility to be the decision maker of treatment things, you know, kind of unilaterally.” Most mothers discussed the inability to leave their child because of the need for constant monitoring. Cathy said, “I can’t leave him with just anybody. He has to go to certain people who are aware of how serious his illness is...so um, we don’t leave him.” A few mothers mentioned the need to take medications to manage their own personal mental health. Nina shared, “I myself do take anti-anxiety meds” and Kelsey said, “I have become very anxious and um, developed insomnia.” The pressure and responsibility to manage treatments was discussed as an additional stressor for many mothers.

Financial burdens

A majority of mothers talked about the added financial strain on their family due to hospitalization, medications, and changed dietary needs. For children who required regular treatments, mothers emphasized the extreme financial burden of hospitalization. Linda described the stress of staying at the hospital with her child,

It’s like having two households...I don’t get free nothing. You know, for everything that we, that I get there at the hospital, um, it has to come out of pocket...I’m having to be really conscious of you know, um, do I get food or do I leave it so the kids can get food at home?

The price of medications also add stress for mothers. For example, Nicole said, “it’s like almost \$1000 a month. Um, when you’re already living like month to month it’s hard to do... we have maxed out lots of credit cards trying to pay

for it.” Some mothers reported having to completely change their family diet due to the diagnosis, which also added financial pressures. For example, Carrie has to use gluten free foods and said, “it is a lot more expensive in my life... the noodles are twice the cost.” The financial stress of raising a child with a chronic illness was discussed as a major stressor in many families.

Children’s experiences of managing a chronic illness

Children offered their own perspective of the unique stressors in their life related to their diagnosis. Some children expressed the stress of hospitalizations. John said the hardest part was “going to the hospital every once in a while.” Other children mentioned the stress of procedures. For example, Ryan said, “I sometimes need to get a big ol’ shot. Bigger than the shot I take every night.” A few children discussed the stress of side effects of some of the medications. Ben shared about one of the shots he is required to get, “it makes my pee yellow, which is kind of embarrassing.” Jenna expressed similar feelings that, “sometimes it’s embarrassing.” Children also mentioned the stress of the added responsibility to remember medications and to follow a treatment plan. Zach said, “probably trying to remember...all my pills” was the hardest aspect and Jim said “resisting food that have gluten in them” was really hard. Many of the stressors children mentioned seemed to focus on the difficulty of managing their chronic illness.

“There’s a difference between a doctor that listens and a doctor that doesn’t”: Areas of Social Support

Many mothers discussed the importance of having social support to cope with the stressors associated with having a child with a chronic illness. Mothers emphasized the importance of having a supportive and available doctor. For example, Mary said “honestly the one thing I need is a clinician who is going to be transparent with me.” Susan also reflected on her experience with doctors, “I’ve just now realized that there is a difference between a doctor that listens and a doctor that doesn’t.” A majority of mothers expressed feeling supported by extended family members. For instance, Cathy said “my mom literally lives next door...and she’s there, um for [Ryan] and us whenever we need her.” Nina also described the support from her mother and her in-laws, “if I need assistance with something, I can call any four of them and, and they’re around and available.” Mothers who did not feel supported from extended family members expressed the lack of support as a challenge. Kelsey said, “we don’t have a lot of extended family...and I have noticed that people I know with, who have extended family, um, around do better.” Some mothers mentioned they typically have support from extended

family but due to the pandemic that was persisting during the study, they felt they lacked the ability to access this support. For instance, Karen said, “my mom is... super supportive...and of course with the quarantine, my mom hasn’t been out here.” Support from extended family and understanding doctors played a role in how a family managed their child’s chronic illness.

Discussion

The purpose of this study was to examine mothers’ and school-age children’s perceptions of the impact of childhood chronic illness on family dynamics. Qualitative interviews revealed multiple ways in which the child’s chronic illness impacted their family dynamics, including changes in sibling relationships, parental couple relationships, and mother-child relationships. Mothers expressed an increased need to advocate for their child and experienced a variety of unique stressors. Families described feeling overwhelmed initially with a chronic illness diagnosis, however, most reported adapting overtime and forming a “new normal.” Social support from extended family and doctors contributed to the ability to overcome stressors associated with a chronic illness diagnosis.

Several findings were consistent with previous literature including parenting differences between healthy siblings and CSHCN (Lummer-Aikey & Goldstein, 2021). Mothers reported giving more attention to their chronically ill child than their other children and placing more responsibility on healthy children. In this study, children and mothers had differing perspectives about sibling relationships which is also consistent with prior research indicating parents’ reports of sibling dynamics tend to be significantly more negative than children’s reports (Sharpe & Rossiter, 2002). This may be due to parents being overprotective of their CSHCN and being sensitive to any negative experiences between siblings. Parents also may have socialized expectations for how a sibling relationship should function and therefore compare their own children’s relationships to a norm, whereas children do not have this comparison and see their sibling relationship as typical.

Also consistent with previous literature (e.g., Nygård & Clancy, 2018; Rafferty & Sullivan, 2017), mothers reported needing to advocate for their chronically ill children across multiple contexts. As medical advances allow more children with chronic illnesses to return to school and daily life, parents are required to advocate for their child in multiple environments. Most mothers felt this need for advocacy was an additional stressor and reported how emotionally taxing it felt to constantly negotiate with doctors and to educate teachers and school staff. Since school-age children often are assigned a new teacher every year, it is important for schools to assist

parents in ensuring teachers are prepared to support students with chronic illnesses.

Mothers' intense caretaking responsibilities seemed related to the unique stressors they reported. Existing research highlights high levels of parenting stress among parents of children with chronic illnesses (Pinquart, 2018). Consistent with previous literature, mothers reported facing financial concerns, increased management of medications, and being forced to make numerous sacrifices due to the intense care required for their children (Nygård & Clancy, 2018). In this study, some mothers reported that financial strains resulted in the need to make difficult decisions such as sacrificing eating while their child was in the hospital to ensure their family had enough money and maxing out credit cards to pay for medications. Hospital programs that assist and alleviate financial stress should be made available to families of CSHCN to reduce the financial burdens these families face.

Consistent with previous literature, mothers also reported taking on additional responsibilities related to management of children's daily medical needs. For example, mothers reported the difficulty of remembering all the necessary medications and ensuring medications were given at appropriate times throughout the day. As parents manage medication regimes at home, it is also helpful for healthcare teams to provide adequate and available information for parents regarding treatment plans (Mitchell & Sloper, 2002). Despite these stressors and sacrifices, both mothers and children discussed the ability to incorporate children's diagnoses into daily routines and establish a new normal for their family. Mothers' reports of their emotional experience following diagnosis tended to reflect the stages of grief (Kübler-Ross & Kessler, 2009). Initially, mothers expressed feelings of anger and denial as they grieved for the life they expected their child to live. However, most mothers discussed how they had created a new normal for their family over time, and at the time of the interview reported their child's diagnosis was manageable. Mothers who felt they had created a new normal expressed acceptance of their child's diagnosis, a stage of grief that allowed for the creation of a new reality. Moving toward this stage is important for families as acceptance and normalization of a diagnosis play a role in overall family functioning (Popp et al., 2014). For the few mothers who did not feel they had created a new normal, they expressed feelings of hopefulness that their child would eventually get better. This difference may be due to the time that had passed since diagnosis, as these families had experienced their child's diagnosis most recently.

As highlighted in existing literature, social support was important for families with CSHCN in terms of coping (Nygård & Clancy, 2018). The mothers who reported acceptance and normalization of their child's illness tended to report a strong social network. Mothers reported relying on extended family and supportive doctors to cope with the

stressors related to their children's diagnosis. This finding is consistent with previous literature indicating availability of social support can help foster resiliency in families (Rehm & Bradley, 2005). For families who may not have available extended family, programs should be offered to connect them with other areas of support that can assist in creating and scaffolding resiliency.

The findings related to family relationship dynamics expand the literature. Most mothers described feeling highly involved with their child but struggling to set boundaries for various reasons. Parental over-involvement in families of CSHCN has been documented in other studies among parents of adolescents (Hafetz & Miller, 2010; Pinquart, 2013). Our findings highlight the importance of balancing parental involvement and child independence in school-age children as well. Although intensive parental involvement may be useful in the initial time following a diagnosis, the continuation of intensive parenting over time may create dependency in children. Difficulty in boundary setting by mothers in this study is inconsistent with previous quantitative research that found parents of children with a chronic illness tend to demonstrate high demandingness (Pinquart, 2013). Mothers in this study tended to describe highly controlled parenting but a lack of demandingness in setting rules. These differences may be due to mothers' hyperawareness of their parenting practices. Since mothers are so involved with their child, they have more opportunities to set boundaries and may be critical of their ability to do so. During interviews, many mothers demonstrated their ability to set boundaries by exiting the room to discuss certain topics apart from children. Hyperawareness and over-involvement may contribute to mothers' perception of boundary difficulties. These findings add depth and complexity to the current understanding of parenting practices in families with CSHCN.

Children and mothers both reported engaging in collaborative decision-making regarding treatment. Some mothers described a more passive decision-making process, explaining treatment and care to children and ensuring children understood the purpose of certain treatments, whereas others actively engaged children by providing choices and allowing for input (Knopf et al., 2008). Both processes are useful in improved general health in adolescents, and family cohesion, expressiveness, and support is associated with better child adjustment outcomes (Van Schoors et al., 2017). Although school-age children in this study expressed discontent when parents forced treatments, they also acknowledged and appreciated that treatments helped their body feel better. These findings highlight the ability of young school-age children to participate in the decision-making process and the importance of ensuring children understand the benefits of treatment to increase compliance.

The study findings related to parental couple dynamics also add to existing literature. Mothers who did not feel

their partner was involved or who did not agree with their partner on treatment decisions reported the most conflict. Existing literature highlights mutual involvement and supportive coparenting around illness-specific decisions tends to be related to more consistent compliance and treatment adherence in children with Type 1 Diabetes (Barzel & Reid, 2011). This study expands on those findings by emphasizing the importance of open communication and mutual involvement from both partners in treatment decision-making processes in families with CSHCN.

Limitations

Despite the contributions of this study, it was also limited in several ways. Participants self-selected into the study which likely biases the results. It is possible that families who were experiencing less stress may have been more interested or available to share their stories. Future studies should attempt to recruit using a probability sampling technique to avoid self-selection bias. Relatedly, although all parents were invited to participate in this study, we ended up only talking to mothers. The experiences and perspectives of mothers and fathers likely differ. We also did not include siblings, who likely have a unique perspective. Future researchers should attempt to incorporate additional family members to more fully understand family dynamics. All children in this study had different diagnoses and while this indicates the identified themes may be important across child diagnoses, it hinders in-depth understanding of experiences of specific diagnoses. Further research into experiences of specific diagnoses is needed. Additionally, because this study took place during the early stages of the COVID-19 pandemic, we completed all interviews virtually. This prevented us from conducting interviews with parents and children independently, which may have limited the openness of some participant responses. It is also possible families were under abnormally high stress, with less access to support networks at the time of the interview, perhaps influencing their responses. Additionally, each family structure was different and the time since diagnosis varied greatly. Parenting styles, acceptance of a diagnosis, and sibling relationships seemed to differ between families of children diagnosed at birth and those diagnosed later in life and should be further studied.

Conclusion

The findings of this study reveal the unique experiences of school-age children diagnosed with chronic illnesses and their mothers. Both mothers and children discussed unique hardships and difficulties associated with adjusting to life with a chronic illness, however, most all also emphasized their families' resilience and ability to adapt to a new

normal. School-age children demonstrated the ability and desire to actively participate in their treatment and should be given opportunities for independence when possible. Although mothers described difficulty in parenting children following the diagnosis, it is imperative to validate the strength of parents and children to adapt to a new reality. To further reinforce resiliency and reduce stress in families, support from extended family members and school staff should be promoted. Available and understanding primary physicians along with specialty practitioners who are willing to listen and build trust with families can also assist in navigating the complexities of life with a chronic illness. Support must be provided for all members of the family, including healthy siblings and couples, as childhood chronic illnesses influence the entire family system.

Compliance with Ethical Standards

Conflict of Interest The authors declare no competing interests.

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