



# HHS Public Access

Author manuscript

*Pediatr Crit Care Med.* Author manuscript; available in PMC 2019 July 01.

Published in final edited form as:

*Pediatr Crit Care Med.* 2018 July ; 19(7): 626–634. doi:10.1097/PCC.0000000000001528.

## Mothers and fathers experience stress of congenital heart disease differently: Recommendations for pediatric critical care

Erica Sood, PhD<sup>1,2,3</sup>, Allison Karpyn, PhD<sup>4</sup>, Abigail C. Demianczyk, PhD<sup>2</sup>, Jennie Ryan, MS APN<sup>1</sup>, Emily A. Delaplaine, LSW<sup>5</sup>, Trent Neely, MEd<sup>6</sup>, Aisha H. Frazier, MD, MPH<sup>1,3</sup>, and Anne E. Kazak, PhD, ABPP<sup>7</sup>

<sup>1</sup>Nemours Cardiac Center, Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE

<sup>2</sup>Division of Behavioral Health, Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE

<sup>3</sup>Department of Pediatrics, Sidney Kimmel Medical College, Thomas Jefferson University, Philadelphia, PA

<sup>4</sup>Center for Research in Education and Social Policy, Department of Human Development and Family Sciences, University of Delaware, Newark, DE

<sup>5</sup>Department of Patient and Family Services, Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE

<sup>6</sup>Sisters by Heart/Brothers by Heart, El Segundo, CA

<sup>7</sup>Center for Healthcare Delivery Science, Nemours Children's Health System, Wilmington, DE

### Abstract

**Objective**—To inform pediatric critical care practice by examining how mothers and fathers experience the stress of caring for a young child with congenital heart disease (CHD) and utilize hospital and community supports.

**Design**—Qualitative study of mothers and fathers of young children with CHD.

**Setting**—Tertiary care pediatric hospital in the Mid-Atlantic region of the United States.

**Subjects**—Thirty-four parents (20 mothers, 14 fathers) from diverse backgrounds whose child previously underwent cardiac surgery during infancy.

**Interventions**—Subjects participated in semi-structured, individual interviews about their experiences and psychosocial needs at the time of CHD diagnosis, surgical admission, and discharge to home after surgery. Qualitative interview data were coded, and consistent themes related to emotional states, stressors, and supports were identified.

**Measurements and Main Results**—Fathers experience and respond to the stressors and demands of CHD in unique ways. Fathers often described stress from not being able to protect

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Corresponding Author: Erica Sood, PhD, Nemours Cardiac Center, Alfred I. duPont Hospital for Children, 1600 Rockland Road, Wilmington, DE 19803. Phone: 302-651-6304. Fax: 302-651-5345. Erica.Sood@nemours.org.

No reprints will be ordered.

**Copyright form disclosure:** The remaining authors have disclosed that they do not have any potential conflicts of interest.

their child from CHD and the associated surgeries/pain and from difficulties balancing employment with support for their partner and care of their CHD child in the hospital. Fathers were more likely than mothers to discuss support from the work environment (co-workers/managers, flexible scheduling, helpful distraction) and were less likely to describe the use of hospital-based resources or CHD peer-to-peer supports.

**Conclusions**—This study highlights the importance of understanding the paternal experience and tailoring interventions to the unique needs of both mothers and fathers. Opportunities for critical care practice change to promote the mental health of mothers and fathers following a diagnosis of CHD are discussed.

### Keywords

congenital heart disease; pediatric cardiac intensive care; parenting; fathers; adjustment; psychological; psychosocial support systems

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### Introduction

Congenital heart disease (CHD) is the most common birth defect, affecting 9 per 1,000 live births worldwide (1). Children requiring early surgical intervention for CHD are at high risk for developmental and behavioral problems, which can impact school performance, social functioning, quality of life, and future employability (2). While clinical risk factors for neurodevelopmental impairment in this patient population have been identified, including prolonged hospitalization and history of mechanical circulatory support (2,3), most are medically necessary and not easily modified.

Mental health problems in mothers and fathers during the postnatal and early childhood period have been shown to impact the emotional, behavioral, and developmental outcomes of healthy children (4–6). For mothers and fathers adapting to CHD, difficulties coping with the immense demands of this diagnosis result in rates of parental anxiety, depression and traumatic stress as high as 25–50% (7–11), further impacting the developmental and behavioral trajectories of these vulnerable children (12–14). Parent mental health problems are modifiable risk factors for poor CHD outcomes that can be improved through psychological intervention, practice changes, and community supports as long as stressors and supports are identified and interventions are tailored to the unique needs of this population (15–18).

Prior studies evaluating parental stressors and supports following diagnosis of CHD have enrolled only mothers or a very small number of fathers. Lisanti and colleagues found an association between mothers' perceptions of altered parental role in the cardiac intensive care unit (CICU) and maternal anxiety (19). A recent literature review of common stressors during the transition from hospital to home for parents of children with CHD found that feeding problems, difficulties bonding, and a lack of confidence in one's own ability to care for a medically complex child were critical challenges (20). No prior studies have comprehensively examined the experiences of mothers and fathers of young children with CHD from diverse backgrounds from the time of CHD diagnosis through discharge to home after cardiac surgery.

This qualitative study aimed to understand the emotional states, stressors, and supports of parents caring for a young child with CHD, with a focus on similarities and differences between mothers and fathers. Study results may inform psychological intervention, practice changes, and community supports to improve the mental health of mothers and fathers raising a young child with CHD.

## Materials and Methods

### Participants

Participants were 20 mothers and 14 fathers from 21 families whose child underwent cardiac surgery with cardiopulmonary bypass for CHD at less than 6 months of age at Nemours/Alfred I. duPont Hospital for Children between 2012 – 2014. To be eligible for this study, their child had to be living, transplant-free, and between one to three years old at the time of the interview. In order to achieve a diverse sample, an independent consultant (AK) reviewed a list of de-identified information from 156 eligible families extracted from the Nemours Society of Thoracic Surgeons database and selected a cohort of 25 families intended to represent diversity on four clinical (gestational age at birth, CHD diagnosis, timing of diagnosis, genetic syndrome) and four demographic (race, ethnicity, insurance type, distance from hospital) characteristics. Families from minority racial/ethnic and cultural backgrounds were oversampled in order to understand the range of experiences. Four of the 25 selected families declined due to lack of interest (84% family participation rate). A mother from one family did not participate due to military deployment, and fathers from seven families did not participate due to inflexible or unpredictable work schedules where participation would have placed a financial burden on the family (n=3), limited to no involvement with the child/family within the context of a single parent family structure (n=3), and incarceration (n=1).

### Procedures and Instruments

Parents participated in a one-hour, semi-structured, individual interview about their experiences and psychosocial needs at the time of CHD diagnosis, surgical admission(s), and discharge to home after surgery. Interviews were guided by a traumatic stress framework (21) (script available upon request) and conducted in a private room by a pediatric psychologist (ES) or psychology fellow (AD). A phone interpreter service was utilized for three Spanish-speaking participants. Evening and weekend participation was offered to parents who were unable to participate on a weekday due to work or family obligations. Interviews were audio-recorded and transcribed, and de-identified transcripts were uploaded into Dedoose Version 7.5.16 (SocioCultural Research Consultants, LLC; Los Angeles, CA, USA). Participants also completed a demographic questionnaire, and child clinical characteristics were extracted from the electronic medical record. Participants received a \$25 debit card. This study was approved by the Nemours Institutional Review Board and written informed consent was obtained prior to any study procedures.

### Data Analysis

Qualitative interview data were analyzed using an inductive thematic approach. Thematic analysis focuses on the subjective human experience and emphasizes participants' perceptions, feelings and experiences (22). Code development was an iterative process by an

interdisciplinary team (psychologists, advance practice nurse, qualitative research expert). The first seven consecutive interview transcripts were each coded independently by 2–3 team members. Discrepancies and novel issues were discussed and the code book was iteratively refined. The next seven consecutive interview transcripts were each coded independently by two primary raters with inter-coder reliability of 0.85 (pooled Cohen’s kappa coefficient), after which disagreements regarding codes were resolved through reflection and discussion. The remaining 20 transcripts were divided between the two primary raters. Consistent themes and representative quotes related to emotional states (as described or labeled by the parent), stressors (aspects of the family’s experience that increased stress), and supports (aspects of the family’s experience that reduced stress) were identified from coded data. Themes related to methods of coping and long-term impact of CHD on the family were also identified, but are outside the scope of this paper. Thematic saturation was reached by the twenty-third interview, but all 34 interviews were completed to ensure that the sample was sufficiently diverse in sociodemographic and clinical characteristics.

## Results

### Sample characteristics

Sociodemographic and clinical characteristics of participants are displayed in Table 1. The study sample was diverse with regard to parent gender (41% male), parent race/ethnicity (62% minority), family SES and child clinical characteristics. Five participating mothers were single parents, whereas all participating fathers were married/partnered to the mother of their CHD child. Participants lived in four states in the mid-Atlantic region of the US. Thirty-eight percent of children received a prenatal diagnosis of CHD and tended to have more critical heart defects than those diagnosed after birth, consistent with national trends (23).

### Qualitative Themes

**Emotional States**—When reflecting on the time period from CHD diagnosis through discharge to home after cardiac surgery, both mothers and fathers described feelings of stress, fear, overwhelmedness, frustration and guilt (e.g., prioritizing CHD child over the needs of others, survivor’s guilt) (See Supplemental Digital Content 1 for themes and representative quotes regarding emotional states). Mothers were more likely to report feelings of anger, sadness, loneliness, helplessness, numbness and confusion. Fathers, and in particular those receiving a postnatal diagnosis, were more likely to report feelings of shock, such as when first learning about the diagnosis, treatment plan or unexpected complications. Positive feelings, including relief, gratitude, hopefulness, and calmness, were reported by mothers and fathers. Many parents described mixed emotions or a “rollercoaster” of emotions throughout this experience.

**Stressors**—Parents reported numerous stressors related to child illness, hospital/provider practices, social/relationship challenges, and daily living demands, as represented by the 13 broad themes described below and in Table 2.

**Illness/Hospital Stressors:** Insufficient preparation and knowledge was a dominant sentiment of mothers and fathers. Parents reported feeling unprepared for virtually every aspect of their experience, from confusion about the meaning of an unfamiliar CHD diagnosis, to their child's appearance after heart surgery, to the complexities of caring for their child at home. Both mothers and fathers described holding unrealistic or unrealized expectations regarding their child's health, medical course, and developmental milestones. A few mothers also noted feeling unprepared and holding unrealistic expectations for the emotional impact of CHD on the parent and family.

Mothers were more likely than fathers to describe stress from communication with healthcare providers, such as feeling that they were not given adequate information about the care plan or that needed information was not communicated effectively between providers/hospitals. Fathers were somewhat more likely than mothers to describe mistrust of healthcare providers, including concern that a mistake could have been made by the medical team.

The *potential* for a negative outcome, such as death or disability, was described by both mothers and fathers. Several parents noted that they feared their actions (e.g., touching or holding the child after surgery, performing daily care) could harm the child. Mothers and fathers also reported that *actual* medical and developmental complications increased stress due to perceived lack of preparation and heightened fear of death or disability.

Over three-quarters of parents reported stress associated with alterations to the parental role and feeling that they were not able to help their child, particularly within the hospital setting. Mothers more often described not being able to feed, comfort or hold their child, whereas fathers more often described not being able to protect their child (e.g., from CHD, surgery, pain). Mothers and fathers also commonly reported that the appearance of their child in the CICU and the medical equipment contributed to stress.

**Social/Relationship Stressors:** Inadequate support networks often resulted in stress for both mothers and fathers. Insufficient support/help, lack of follow through with promised help, unhelpful 'help' and criticism of decisions were common causes of stress. Some mothers noted that interactions with select family members or acquaintances intensified thoughts of self-blame as they perceived others were holding them responsible for the cause of CHD. Mothers were more likely than fathers to discuss problems related specifically to their spouse/partner (e.g., communication challenges, limited emotional support, insufficient help with childcare).

**Stressors Related to Finances and Daily Living:** Financial stressors affecting both partnered and single mothers included concerns for daily expenses (i.e., gas to/from hospital, food at hospital, medications, supplies) and longer term challenges such as attaining educational goals and maintaining a job or adequate transportation. Some single mothers described challenges getting to the hospital on a consistent basis due to lack of transportation or gas money, thereby spending less time with their child overall.

Mothers and fathers described daily challenges associated with parenting a child with CHD, including protecting the child from germs, attending frequent medical appointments, managing medical/feeding equipment, and navigating healthcare and insurance systems. Both mothers and fathers also frequently reported difficulties balancing other responsibilities with the care of their child with CHD. Mothers were more likely to discuss difficulty balancing care of other children in the family, whereas fathers were more likely to discuss difficulty balancing work responsibilities (including commuting to and from the hospital) and care of/support for the mother, who tended to be at the hospital alone while the father worked. Few mothers described a perceived need to care for or support the father during this time.

**Supports**—Parents reported many supports related to child illness and recovery, hospital/provider practices, social/relationship factors, and finances/resources, as represented by the 13 broad themes described below and in Table 3.

**Illness/Hospital Supports:** Support from, and confidence in, doctors and nurses were described by many mothers and fathers. Mothers more often discussed the provision of emotional support and encouragement for parent participation in infant care by doctors and nurses, whereas informational support was discussed frequently by both mothers and fathers. Mothers were more likely than fathers to discuss support from hospital resources beyond the core medical team (e.g., social work, developmental supports, pastoral care, lactation).

Mothers in particular also discussed the importance of their own expectations regarding hospital course and prognosis (e.g., realistic expectations, preparing for a worse outcome) in helping to prevent greater distress. Many mothers and fathers reported that child recovery and the passing of time helped to mitigate stress.

**Social/Relationship Supports:** The vast majority of mothers and fathers described support from friends, extended family and the community (e.g. emotional support, assistance with finances/child care). Social relationships providing informational support (e.g., physicians or nurses in their social network) were more often described by parents with higher education levels. Mothers were more likely than fathers to discuss support from their partner/spouse, often in the form of emotional support or help with childcare, and were also more likely to describe emotional support from other CHD parents within the hospital setting, in the community, or online. When fathers did report peer-to-peer support, it was more often in the context of educating themselves about CHD and what to expect or feeling reassured that their child could have a positive outcome. Some mothers and fathers also noted spiritual/religious support such as prayers and visits from spiritual leaders.

**Supports Related to Finances, Employment and Community Resources:** Mothers and fathers experiencing financial stability noted how helpful this was in relieving stress (e.g., ability to afford unpaid family medical leave, allowing for paid help with housework or childcare). Community public health and welfare programs (such as Medicaid, SSI, welfare, early intervention) were noted to be a strong source of support by all single mothers and many partnered mothers, though less often by fathers. Fathers were somewhat more likely than mothers to discuss support from co-workers/managers, the ability to work on a flexible

schedule, and the return to a work routine as being helpful, although it should be noted that many mothers did not return or delayed their return to work to care for the child with CHD.

## Discussion

Maternal and paternal mental health are important for the developmental and behavioral outcomes of children with CHD (4–6, 12–14). However, to date, much of the prior research on parental stressors and supports following a diagnosis of CHD has focused on the maternal experience (15,16,18,19). This study highlights the importance of understanding the unique paternal experience and the need for interventions developed for and tested with fathers.

Stress associated with disruptions to the maternal role in the neonatal intensive care unit (NICU) and CICU has been previously described (19,24), consistent with results of this study. A pilot study conducted by O'Brien and colleagues in the NICU found that maternal stress decreased when mothers were supported to be active partners in their child's care (25). Critical care providers should help to facilitate mothers' participation in care, including holding and feeding when possible. The traditional paternal role includes providing for and protecting one's child and family, yet fathers of infants with CHD are unable to protect their child from illness and painful procedures or perform the life-saving interventions that their baby requires. A father's ability to care for and protect their partner from physical and emotional stress at the hospital is also often limited by work and home demands. The development of tools to assess stress associated with parental role alteration should include fathers at every stage, from item generation to validation, in order to fully consider the ways in which a father's role is altered following diagnosis of CHD. Critical care providers must support and empower parents, including fathers, by providing them with the information needed to make decisions about their child's care and advocate for their child's wellbeing and should be mindful to direct information and questions to both parents, even if the mother is more often at the bedside or more vocal during rounds. An interaction style that is not inclusive of the father may intensify paternal role alteration and feelings of helplessness.

Consistent with prior research (26), the results of this study highlight the need for clear healthcare communication about the big picture and long-term implications of CHD. Critical care providers should promote parent preparedness by providing information on what to expect across a variety of domains, including medical, developmental, and psychosocial, such as how CHD can impact the whole family. Structured family meetings that are inclusive of developmental and psychosocial providers during both the prenatal and postnatal periods can assist with family preparedness and may also be an opportunity for care providers to learn about parental beliefs and concerns as well as each family's unique stressors and supports. Prior research in the NICU indicates that formalized peer-to-peer support can promote parent preparedness and reduce feelings of isolation (27). Based on the current findings, it is important that those introducing peer-to-peer support emphasize not only the emotional support aspect that may be more appealing to mothers, but also the informational support that is likely to appeal to both mothers and fathers.

Fathers often discussed having to balance work with their child's inpatient care, and one father described fending for himself while his baby and partner received supports within the

hospital setting. Indeed, results of this study suggest that mothers are focused on supporting the baby, and fathers and care providers are focused on supporting the mother and baby. Importantly, this appears to leave no group focused on supporting the father. It is crucial that critical care teams consider how to increase access to hospital-based supports for fathers, even when they are not physically at the hospital and their distress may not be visible to care providers. Fathers should be contacted directly to assess paternal support needs rather than relying on the available parent (more often the mother) to report all family needs. Scheduling family support and informational meetings around the father's schedule and utilizing technology to include fathers virtually are important ways to increase access to hospital and clinic-based supports. Linkages and referrals made by a hospital social worker can also help with family financial challenges, potentially affording fathers more time with the child and family by defraying the burden of gas money or time off from work.

Through its diverse sample of participants, this study touches upon the disparate access to supports based on family socioeconomic status. While family medical leave and paid help with housework or childcare are likely to mitigate stress for those with financial resources, many families are unable to afford these supports. Even spending time at the hospital with one's child every day is a privilege that many parents cannot afford due to transportation costs and financial demands. The ability to obtain informational support from medical professionals within one's social network is a form of social capital not often available to those of lower education levels. Social determinants of physical and mental health are well described in the literature (28,29), and supports to mitigate these disparities must be integrated into the care team and community. Critical care teams should include a psychosocial specialist (often a social worker) whose role is to identify social risk factors through standardized screening and assessment and to connect families with supports through foundations, community organizations and public health programs.

Military deployment, incarceration, and inflexible or unpredictable work schedules prevented some parents from participating who may have experienced unique stressors. Future research is needed to better understand stressors and supports unique to parents with language barriers and other cultural backgrounds and family structures (e.g., same-sex parents). This was a single-center study in the Mid-Atlantic region of the United States and stressors and supports may differ based on region and center-specific resources. While parents of children both pre- and postnatally diagnosed were included, prenatal diagnosis tended to be associated with more critical forms of CHD, precluding analysis of stressors and supports related specifically to timing of diagnosis. Lastly, parent disclosure during qualitative interviews could have been impacted by cultural/gender norms. For example, mothers may be more comfortable than fathers sharing certain information with a female interviewer, thereby impacting results.

## Conclusions

Ample opportunities exist for practice changes and psychosocial intervention strategies to mitigate maternal and paternal mental health problems following a diagnosis of CHD. Community-engaged research and quality improvement efforts can determine when and how these can be delivered, such that they are acceptable, feasible, and effective to parents and



providers. Formal standards for the psychosocial care of families impacted by CHD, as have been developed for other pediatric patient populations (30,31), may stimulate widespread changes in how families are prepared and supported following a diagnosis of CHD.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

The authors thank the mothers and fathers who participated in this study and shared their personal experiences with the goal of helping other families facing a diagnosis of congenital heart disease.

Source of Funding: This study was supported by grants from the Mend a Heart Foundation and the National Institute of General Medical Sciences of the National Institutes of Health (U54-GM104941 [PI: Binder-Macleod]).

The work was performed at Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE.

Dr. Sood's institution received funding from Mend A Heart Foundation (10% of her FTE to cover time spent on this project). Drs. Sood and Kazak received support for article research from the National Institutes of Health. Dr. Demianczyk's institution received funding from the Mend a Heart Foundation.

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**Table 1****Sociodemographic and Clinical Characteristics**

	<i>Frequency (%)</i>
<b>Parent Sociodemographic Characteristics (N = 34)</b>	
Single Parent (All Female)	5 (15%)
<b>Parent Race/Ethnicity</b>	
Non-Hispanic White <sup>a</sup>	13 (38%)
Black or African-American	8 (24%)
Hispanic/Latino <sup>b</sup>	10 (29%)
Asian	3 (9%)
Born Outside USA	8 (24%)
<b>Parent Education Level</b>	
Middle School/Partial High School	8 (24%)
High School Degree	10 (29%)
Partial College	6 (18%)
College Degree or Higher	10 (29%)
<b>Annual Household Income</b>	
<\$30,000	13 (38%)
\$30,000 – \$60,000	9 (26%)
>\$60,000	12 (35%)
<b>Child Clinical Characteristics (N = 21)</b>	
Prenatal CHD Diagnosis	8 (38%)
Preterm Birth (<37 weeks)	4 (19%)
Down Syndrome	3 (9%)
<b>Age at First Cardiac Surgery</b>	
<1 week	9 (43%)
1 week – 1 month	5 (24%)
2–4 months	7 (33%)
Norwood Procedure	5 (24%)
Multiple Cardiac Surgeries (>1)	8 (38%)
Discharged with Feeding Tube	6 (29%)
<b>Age at Time of Interview</b>	
12–23 months	8 (38%)
24–35 months	7 (33%)
36–47 months	6 (29%)

*Note.*

<sup>a</sup>Four non-Hispanic white participants identified as Amish.

<sup>b</sup>Three Hispanic/Latino participants spoke only Spanish.

Table 2

## Stressors

Themes (% Mo, % Fa) <sup>a</sup>	Representative Quotes
Insufficient preparation/Knowledge (75%, 79%)	<ul style="list-style-type: none"> <li>When they checked us out [of hospital], we knew like how to carry him in the car seat. I knew physically what to do. But I didn't know emotionally how I would be different. Mo 7</li> <li>Neither of our families have ever really dealt with something like this. So it was all just so new, you know? Like she has a very serious condition...that was very difficult to process or understand...And just being so far [from home], just out of our element. Fa 20</li> </ul>
Unrealized expectations (55%, 50%)	<ul style="list-style-type: none"> <li>I went in wanting to know if it was a boy or girl. I didn't want to find out there was anything wrong...It wasn't normal for me to have a baby that had something wrong...I took all of my babies home within 2 days, not hooked to monitors, not having feeding tubes, not having oxygen. Mo 14</li> <li>The 3 pediatricians that saw him in the hospital, saying he was A-okay, completely healthy... one week later he's in a helicopter to the hospital. Fa 10</li> </ul>
Self-blame/Questioning why (40%, 43%)	<ul style="list-style-type: none"> <li>I was blaming myself for a lot of things... What did I do wrong for him to be this way? Like I just feel like what did I do that my son's so sick? Mo 11</li> <li>I asked the Lord, I said, God, did I offend you in any kind of way? Did I do anything? If I offended you in any kind of way, not him, let it be me. Fa 13</li> </ul>
Potential for negative outcomes (70%, 50%)	<ul style="list-style-type: none"> <li>After [child]'s surgery, I was scared to touch her because I didn't know if I was gonna hurt her or what, because I knew they sewed her up and stuff, but I didn't know if like patting her was gonna hurt...I don't want to break her. Mo 21</li> <li>Fear of the worst. You know, we could be leaving this hospital without a child. I think that was like the most overpowering of all, just that fear of the unknown. Fa 7</li> </ul>
Medical/developmental complications (40%, 50%)	<ul style="list-style-type: none"> <li>It was stressful 'cause he wouldn't talk, he wouldn't look at you...and I'm his mom. He should be able to look at me. It was very difficult for like the first year...I'd say [child] and he'd rock back and forth. Mo 13</li> <li>We were about to be let go [to home], and then they said that we couldn't go because...they found out that he had an infection, and then they had to take him back to intensive care...we were not prepared for that. Fa 10</li> </ul>
Alterations to parental role (80%, 86%)	<ul style="list-style-type: none"> <li>Not being able to hold [child] for like a month after he was born. I was there day in and day out...I stood there and watched him crash right in front of me. I just had to step away from the bed and let the doctors just rush to him, because there's nothing I can do. Mo 2</li> <li>Seeing him in the ICU. That was the most difficult time because he's just so little and, you know, your job is to protect him and...just feeling that you can't help him. Fa 7</li> </ul>
Appearance of infant/equipment (40%, 36%)	<ul style="list-style-type: none"> <li>They were packing all of the equipment and I was just looking at them like you need all of that? He's going to be fine. You need oxygen and the CPR stuff? Um... I think that was the worst. Mo 14</li> <li>We go into the recovery room...that was devastating. You go in and see your child, you know, hooked up to all kinds of stuff and it's just...I was as prepared as I could be, but nothing really prepares you for that. Fa 19</li> </ul>
Healthcare provider communication issues (45%, 21%)	<ul style="list-style-type: none"> <li>Some of the nurses didn't talk much and so we didn't know everything about what was going on unless we asked a lot of questions. It was better for us if the nurse told us everything like what she's doing and what is going on. Mo 16.</li> <li>I kept going out there. I'm like something is wrong with [child]...and they're like, no, it's just normal, you know, blah, blah...[His lungs] got infected and they ended</li> </ul>

Themes (% Mo, % Fa) <sup>a</sup>	Representative Quotes
	<i>up having to put a drain tube in. We would have went through so much less if they would have just listened. Fa 2</i>
Mistrust of healthcare providers (30%, 50%)	<ul style="list-style-type: none"> <li>• <i>When he first came home, he had an episode... he was like foaming from the mouth and he could hardly breathe. I rushed him to [local hospital]...I had his chart explaining everything but they freaked out. They were just trying to poke all over him... I just finally picked him up and was like don't touch him. Mo 4</i></li> <li>• <i>I thought it's a mistake or something...like it should be fixed in one surgery only... But why she's needing a second surgery?Fa 5</i></li> </ul>
Problems with support network (75%, 50%)	<ul style="list-style-type: none"> <li>• <i>Because [partner] is overwhelmed about something or whatnot, he'll leave and then I'm just by myself. So I feel sometimes that I'm the only caretaker for my children. Mo 11</i></li> <li>• <i>A couple of work colleagues...were trying to be helpful, but in doing so they were prying and a lot of the stuff we didn't feel comfortable discussing with them. So while they had good intentions...by asking questions they were actually creating a more stressful situation. Fa 15</i></li> </ul>
Insufficient finances/resources (90%, 50%)	<ul style="list-style-type: none"> <li>• <i>Buying the stuff for him to drink, to thicken it. And then his clothes, I mean I was always having to cut a hole in something because of his feeding tube. Different toys, like different things for him to be in because he had to learn how to walk three different times because of the surgery from being in a bed for so long. Mo 4</i></li> <li>• <i>Not having [spouse] income put everything on me...hospital food is really not that cheap...I didn't really think about how with [child] being born that all of the bills would come down to me. Fa 2</i></li> </ul>
Parenting burden (90%, 64%)	<ul style="list-style-type: none"> <li>• <i>Any little thing would make her sick, we would be in the hospital for a week or two. If she got the little sniffles, we would be right back in the hospital. Mo 12</i></li> <li>• <i>The medical insurance was a whole other stress...sometimes the insurance would not take some of the billing from the hospital...it was kind of confusing when you got these bills, and you're like, what's going on? Aren't we supposed to be covered? It was a huge mess. I mean it took a lot to try to clear all that. Fa 10</i></li> </ul>
Balancing responsibilities (60%, 64%)	<ul style="list-style-type: none"> <li>• <i>Being a single mom, with one in the hospital and one at home, and trying to do what you have to do as a mother...at nighttime sometimes I would leave [hospital] and come back in the morning or I would leave after he takes his first nap and then come back in the evening. So I had a full schedule. Mo 4</i></li> <li>• <i>While mom was here and baby was here they got support and they got help, but I was pretty much fending for myself. Fa 15</i></li> </ul>

Note. Mo = mother; Fa = father.

<sup>a</sup>Indicates the percentage of interviews from which a particular theme was identified for mothers and fathers.

Table 3

## Supports

Themes (% Mo, % Fa) <sup>a</sup>	Representative Quotes
Child recovery/Time (75%, 57%)	<ul style="list-style-type: none"> <li>• <i>Before he went in, he was charcoal...But after surgery, everything was just so pink. His hands blew up and his feet was a rosy red. Once I seen that, it's like everything was relieved. It was good, you know? Mo 13</i></li> <li>• <i>Once we got home...he wanted to play, he was laughing, his eyes lit up...before he was diagnosed, you could tell that his eyes were just dark...when he came home, his eyes were just bright again...it just felt good. Fa 7</i></li> </ul>
Relevant prior experiences (20%, 21%)	<ul style="list-style-type: none"> <li>• <i>[Older sibling] paved the way in a way that he has no idea...I don't even know how I would have coped with it being the first time around. It definitely helped that I knew the belly button was going to fall off, that's fine...the one thing I didn't have to worry about is the belly button. Mo 15</i></li> <li>• <i>Because I was in the military...I was prepared for...the lack of sleep, the lack of being able to control time... the time that you spend on yourself. Fa 10</i></li> </ul>
Preparation/Realistic expectations (35%, 7%)	<ul style="list-style-type: none"> <li>• <i>Everybody thought we would have to take her straight from [hospital] to [surgical center] and it didn't happen like that. So everybody was happy that we were able to just bring her home and spend time with her, just home straight. Mo 8</i></li> <li>• <i>(On prenatal diagnosis) We were prepared. So just like when my son first came to [hospital] and we had to get here and everything, we knew what was going to happen. Fa 13</i></li> </ul>
Support from doctors/nurses (90%, 79%)	<ul style="list-style-type: none"> <li>• <i>[Nurse] really kept us involved, we really liked that...she helped us through that time and let us know what was going on. It was better for us if the nurse told us everything...Mo 16</i></li> <li>• <i>When [physician] told us...I know that people often have a perception of doctors and surgeons as not having time...I felt like he didn't have anything else to do that day. I felt like he would have stayed with us as long as we really needed. Fa 20</i></li> </ul>
Confidence in doctors/nurses (40%, 50%)	<ul style="list-style-type: none"> <li>• <i>I get the feeling from the hospital staff that my daughter is in good hands and that everything is going to turn out fine. Mo 3</i></li> <li>• <i>Once we went through the first surgery and then the second, we were comfortable with...what was going on in the hospital. We were confident in what the doctors were doing. Fa 10</i></li> </ul>
Resources in hospital and surrounding community (55%, 29%)	<ul style="list-style-type: none"> <li>• <i>(On cardiac developmental follow-up) When I got through that report...I felt so much comfortable, she's like a normal kid now...and I know where to concentrate on, you know, some of the areas she's lacking. Mo 5</i></li> <li>• <i>The social worker...helped us get in touch with resources and the Ronald McDonald House... With us not having any other help that made a world of difference. Just having somebody to talk to that we could ask questions and they could point us in the right direction. Fa 15</i></li> </ul>
Support from family/friends/ Neighbors (95%, 100%)	<ul style="list-style-type: none"> <li>• <i>One day we came home and our front porch was completely decorated for the holidays, I just started bawling my eyes out because that would not have happened. It felt like a Christmas miracle, you know?...I will never forget that. Never. It was one of the most wonderful things that anyone has ever done for me. Mo 20</i></li> <li>• <i>Financial support from the church for paying the hospital bill...I was thankful for it. What could we do? We couldn't turn it down because we needed it. Fa 16</i></li> </ul>
Support from partner (55%, 14%)	<ul style="list-style-type: none"> <li>• <i>I went in the room and me and his dad was talking and then we just both started crying... he said, yeah, I know it's hard but we're going to make it. We got each other so it's okay. So that really helped me out. Mo 9</i></li> <li>• <i>[Partner] just stood by my side. We walked, talked and stuff like that but...she just was there pretty much. 'Cause I couldn't have did it by myself. Fa 8</i></li> </ul>

Themes (% Mo, % Fa) <sup>a</sup>	Representative Quotes
Peer-to-peer support/education (40%, 21%)	<ul style="list-style-type: none"> <li>• <i>I found talking to people who were in a significantly worse situation than I was helpful to the extent that they are still there and going through it and believing in the process and working through...sometimes strangers can be more of a resource in that they have already gone through this. Mo 15</i></li> <li>• <i>We spoke to other people that had something to this nature happen. You know, we just wanted to educate ourselves, that way we kind of knew what was going on. Fa 7</i></li> </ul>
Spiritual/religious support (20%, 29%)	<ul style="list-style-type: none"> <li>• <i>It is very very affirming that the fathers from our parish came to see [child]. It was very special to us...comforting to us to have the chaplains come in. Mo 15</i></li> <li>• <i>There's so many people that we don't know that had [child] on a prayer list...there's a lot of people praying and keeping [child] in their thoughts. Fa 2</i></li> </ul>
Financial resources (25%, 21%)	<ul style="list-style-type: none"> <li>• <i>(On paid help) Cooking, cleaning, 'cause we could afford... we'd have frequently cleaners coming and going...the daily routine things like household...or daily routine cooking. Mo 5</i></li> <li>• <i>I had great insurance.... I really didn't see any kind of financial burden...together, we're financially capable of absorbing these types of issues. Fa 7</i></li> </ul>
Public health/welfare programs (60%, 14%)	<ul style="list-style-type: none"> <li>• <i>I was able to get SSI for her. And then the state helped, too... I was in the Medicaid promise program where you get a gift if you complete the program, like you go to all of your doctors' appointments...I almost had a year's worth of diapers and wipes. Mo 1</i></li> </ul>
Return to/Support from work (20%, 36%)	<ul style="list-style-type: none"> <li>• <i>My co-workers respected my need to not talk about it...to just come in and be the provider and the one caring for people...there was a tremendous amount of support there, but support the way I wanted it to be. Mo 19</i></li> <li>• <i>The first six months of [child]'s life we were in and out of the hospital for most of that time...so [employers] were really supportive as far as continuing to pay me and then just kind of letting me do what I could during that time...I wasn't stressed out at all about my job. Fa 20</i></li> </ul>

Note. Mo = mother; Fa = father.

<sup>a</sup>Indicates the percentage of interviews from which a particular theme was identified for mothers and fathers.