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Fathers of Children with Congenital Heart Disease: Sources of Stress and Opportunities for Intervention

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Abstract

Objective: To examine sources of stress for fathers of children with congenital heart disease (CHD) and opportunities for intervention to prevent or reduce paternal mental health problems.

Design: Qualitative study using online crowdsourcing, an innovative research methodology to create an online community to serve as a research sample.

Setting: Yammer, an online social networking site.

Subjects: Geographically diverse sample of 70 parents (25 fathers and 45 mothers) of young children with CHD.

Interventions: Participants joined a private group on Yammer and responded to 37 open-ended study questions over a six-month period. Qualitative data were coded and analyzed using an

iterative process, and themes regarding sources of stress for fathers of children with CHD and opportunities for intervention were identified.

Measurements and Main Results: Four broad themes regarding sources of stress for fathers of children with CHD emerged from the qualitative data from both mothers and fathers: Societal expectations for fatherhood and standards of masculinity, balancing work and family responsibilities, feeling overlooked as a partner in care, and lack of father supports. To begin to address these sources of stress, participants recommended that care teams acknowledge and normalize the impact of CHD on fathers, provide support for balancing work and family responsibilities, recognize and promote father knowledge and engagement, and provide formal and informal supports for CHD fathers.

Conclusions: Fathers of children with CHD experience unique sources of stress in the absence of targeted interventions to meet their needs. Care teams play an important role in acknowledging the experiences of fathers and including and engaging fathers in care.

Keywords

Congenital Heart Disease; Pediatric Cardiac Intensive Care; Fathers; Parenting; Adjustment; Psychological; Psychosocial Support Systems

Introduction

Parents of children with congenital heart disease (CHD) experience multiple stressful and traumatic events associated with their child's critical illness that can disrupt parent mental health (1). A recent systematic review of mental health symptoms in mothers and fathers of children with CHD found that over 80% exhibit post-traumatic stress symptoms, 30–80% experience severe psychological distress, and 25–50% have depression and/or anxiety (2). Preventing mental health problems in parents of children with CHD is critically important, as parent mental health can exert a significant influence on family and child well-being (3–5).

Prior studies described the experiences and needs of mothers raising a child with CHD, with the goal of identifying strategies to prevent and intervene upon maternal mental health challenges (1,6). Research has also begun to examine the collective parental experience, including a recent study by Sood et al. (7). Results identified a host of common parental stressors (e.g., insufficient preparation for the impact of CHD, inadequate support networks), yet brought to light some differences in the ways mothers and fathers experience the stress of raising a child with CHD. For example, fathers were more likely than were mothers to describe stress from not being able to protect their child from CHD and from difficulties balancing employment with the care of their family. In response, the present study used online crowdsourcing, an innovative methodology that engages an online community to generate ideas and solve problems, to specifically examine sources of stress for fathers of children with CHD and opportunities for intervention to prevent or reduce paternal mental health problems.

Materials and Methods

The current report is from a larger qualitative study of 108 parents of children with CHD using crowdsourcing methodology. Inclusion criteria were having a child born with CHD one to seven years prior who underwent open-heart surgery during infancy, being able to read and write in English, and access to the internet on a computer, tablet, or mobile device. An announcement about the larger study along with the direct link to a brief REDCap survey (8, 9) was posted to the social media pages of several CHD-specific non-profit organizations within the United States (e.g., Pediatric Congenital Heart Association, Mended *Little* Hearts). The REDCap survey collected basic demographic and clinical information (parent gender, race, ethnicity, and education level; United States region and community characteristics; child age and CHD type) along with an email address from parents interested in participating in the study. Two hundred and forty nine parents completed the survey over a one-week period. Using an algorithm that considered the frequencies of each demographic and clinical characteristic among those who completed the survey along with the demographics of the United States population, a subset of parents (N = 179) who represented the greatest diversity in backgrounds and experiences were then invited to review the electronic consent form for the larger study through REDCap and enroll in the study. Of these, 108 parents participated in the larger study, and 70 parents who submitted responses specifically regarding sources of stress and opportunities for intervention for fathers of children with CHD were included in the present analyses. This study was reviewed and approved by the Nemours Institutional Review Board prior to initiating study procedures, with a waiver of written documentation of informed consent to allow for an electronic consent process.

A stakeholder advisory council consisting of four CHD parents (three mothers, one father) and six medical and mental health providers convened twice per month by phone throughout the duration of the study to identify domains important for family-based psychosocial care for CHD (e.g., support for fathers), advise decisions regarding study methodology, and refine study questions. Two additional CHD fathers were added to the advisory council after the completion of data collection to assist with qualitative analyses related to sources of stress and opportunities for intervention for fathers of children with CHD.

Participants

Participants were 70 parents (25 fathers, 45 mothers) of young children with CHD who submitted responses regarding sources of stress and opportunities for intervention for fathers of children with CHD as part of the larger study. All mothers in this sample were married/partnered to the father of their CHD child at the time of the child's diagnosis and first cardiac surgery, which enabled them to contribute their perspectives on the father's experiences and needs during this time.

Collection of Crowdsourced Data

Qualitative data were collected using online crowdsourcing methodology via Yammer, an online social networking site. Crowdsourcing is the process of generating ideas and solving problems by soliciting contributions from large online communities (10). Although

crowdsourcing has been used extensively in business, information technology, and more recently public health (11–13), the application of crowdsourcing to qualitative research related to pediatric health is innovative. Three prior published papers of which we are aware have described the use of online crowdsourcing methodology to conduct qualitative research aimed at understanding the lived experiences of families impacted by pediatric illness (14–16).

Participants were invited to set up a deidentified account on Yammer and to join a private online group. Thirty-seven open-ended study questions were drafted by the study team, reviewed and revised by the stakeholder advisory council, and then posted to the online group over a six-month period. Three study questions specifically targeted fathers' experiences and needs and were worded differently for fathers versus mothers (e.g., for fathers: "What specific challenges have you faced as a 'heart dad?' How do you think your experience has been different from the experience of your wife/partner, if applicable?" and for mothers: "What specific challenges have you watched your husband/partner face as a 'heart dad,' if applicable? In your opinion, what are some ways that his experience has differed from yours?"). All other study questions were designed to be relevant to both genders (e.g., "What losses have you experienced, if any, and how have they impacted you and your family?").

Parents responded to study questions through the Yammer app on their tablet/mobile device, by logging on to the website or by replying to an automated email corresponding with each post. Questions had a suggested deadline of one week, although responses were accepted for all questions throughout the six-month period of data collection. Parents could view each other's deidentified responses and "like" or comment on others' responses, and all such dialogue were included as qualitative data. Parents were paid for their participation at the end of each month via reloadable study debit card (\$3 per question response; up to \$24 per month).

Data Analysis

Qualitative data were analyzed using an inductive thematic approach, focused on subjective perceptions, feelings, and experiences (17). Parent responses to open-ended questions and dialogue between participants were extracted from Yammer and uploaded into Dedoose Version 8 (SocioCultural Research Consultants, LLC, Los Angeles, CA). The analytical process was conducted in two stages. First, all data from the larger study were coded as part of an iterative process led by a four-person coding team, with input from the stakeholder advisory council. In order to establish inter-coder reliability, the team independently coded four participants' complete responses (0.81–0.90 pooled Cohen's kappa coefficient), after which disagreements regarding codes were resolved through reflection and discussion. Responses from the remaining participants were then divided among the coders for independent coding. Next, using only the content from the *fathers* code, an analytical team consisting of two psychologists and three CHD fathers with lived experience, using a methodology similar to Locock et al (18), collectively reviewed the responses of all 70 participants to identify common themes regarding sources of stress for fathers of children with CHD and opportunities for intervention to prevent or reduce paternal mental health

problems. Themes were shared with parent participants via Yammer to check for accuracy and resonance with their experiences, and feedback was incorporated into qualitative analyses.

Results

Participants (N = 70) were diverse with regard to U.S. region, education level, and household income (Table 1). The majority identified as Non-Hispanic White (87.1%). Over half lived in suburban communities, with 25% and 15% from rural and urban communities, respectively. Participants' children with CHD tended to be medically complex, with the majority having undergone multiple cardiac surgeries (75.7%). Five (7.1%) children died prior to their parent's participation in this study. Participants' children received care across 37 US pediatric hospitals in 26 U.S. states plus the District of Columbia.

Four broad themes regarding sources of stress for fathers of children with CHD (Table 2) and opportunities for intervention to address these sources of stress (Table 3) emerged from the qualitative data from both mothers and fathers.

Societal Expectations for Fatherhood and Standards of Masculinity

Societal expectations of fatherhood and standards of masculinity within the context of parenting a child with CHD were described as sources of stress for fathers. Participants often noted that the fathers' prescribed role was to "stay strong" for their family and to limit their emotional expression of fear, sadness, and grief. This made it more challenging for fathers to ask for help and to admit that they were struggling to cope with their child's diagnosis. Many participants also described the father's traditionally prescribed role as the protector of the family, which resulted in fathers feeling powerless when they were not able to protect their CHD child. Some fathers noted that they were not interested in additional supports, as they believed that obtaining support for themselves could take needed attention away from their child or the child's mother. Multiple participants perceived a widespread belief among the care team that mothers need more support than fathers, which resulted in less outreach to fathers and made fathers feel excluded by the care team. For example, many participants reported that care providers discussed the impact of CHD on mothers without acknowledging fathers, even when fathers were present. Some fathers also described comments by care providers about their role being to support the mother and/or support the family financially, which contributed to fathers' perceptions that their experiences were not understood by the care team.

Opportunity for Intervention: Acknowledge and Normalize the Impact of CHD on Fathers—

To begin to address these sources of stress, participants recommended that care providers make a concerted effort to speak to the impact of CHD on both caregivers and recognize common gender differences without making assumptions of an individual's need based on gender. Participants also suggested normalizing the impact of CHD on fathers in a noninvasive manner by providing written information specific to the father experience within the hospital setting (e.g., informational handouts). Participants noted that doing so may raise awareness regarding the impact of CHD on fathers, provide education without fathers having to request it, and foster an environment in which it is okay to ask for help.

Balancing Work and Family Responsibilities

Intertwined with societal expectations for fatherhood, participants reported that fathers often managed the majority of family responsibilities outside of the hospital, especially income generation. Most fathers worked throughout the hospitalization to support the family, while also managing other essential activities (e.g., managing finances, caring for siblings). These responsibilities limited their ability to be present at the hospital and led to feelings of guilt and disconnectedness from their child's care. When fathers were at the hospital, many reported feeling less engaged, as they perceived that the child's mother had stronger relationships with the care team. Similar challenges were reported in outpatient settings, as fathers frequently missed appointments due to work, thereby receiving information second hand from the mother.

Opportunity for Intervention: Provide Support for Balancing Work/Family Responsibilities—Participants suggested that hospitals provide accommodations enabling parents to work remotely, such as designated work spaces or increased access to Wi-Fi. Participants also noted that creating opportunities for fathers to meet and discuss how they have supported their families (e.g., managing time off and/or caring for other siblings during hospital stays) may decrease feelings of powerlessness. Participants recommended the creation of new means for communication between care providers and fathers, such as posting medical information online/through a secure app, utilizing video chat with fathers at work during bedside rounds, providing medical updates to fathers even when information has already been shared with the mothers, and hosting educational meetings that may be of interest to fathers. Participants also suggested the formation of financial assistance programs that would enable fathers to take time off from work without incurring additional financial burden.

Feeling Overlooked as a Partner in Care

Another prominent theme for fathers was feeling overlooked as a partner in their child's care. Many participants described feeling as though the father's input was not valued at the same level as the mother's. Several fathers discussed needing to demonstrate engagement and earn the level of respect from the care team that mothers are naturally afforded. Participants often discussed how fathers were treated as less knowledgeable than mothers, and that even when the father was present in the room, all information was directed towards the mother. Feeling overlooked as a partner also extended to hospital accommodations that inadvertently excluded fathers. For example, one father described their child's room as only having bedding for one parent, which meant that he had to stay elsewhere. Another discussed limited support in caring for siblings, which meant that the father often left the room with siblings while important information was communicated to the mother.

Opportunity for Intervention: Recognize and Promote Father Knowledge and Engagement—Participants recommended increasing the care team's awareness of the father's role, limiting individual assumptions based on gender, and emphasizing that input from fathers be valued along with input from mothers. This included ensuring that care providers address information and questions to both parents. Participants also suggested that family sleeping accommodations within the hospital allow for two parents/caregivers.

Lack of Father Supports

Supports for fathers of children with CHD were described as very limited and participants noted that fathers were often inadvertently excluded from general CHD parent support and the foci of national organizations. For example, many participants stated that online supports and peer-to-peer groups often address “heart moms” without acknowledging the presence of fathers, which may result in fathers feeling overlooked and less likely to utilize these supports. Similarly, participants often noted that during interactions with care teams, care providers would ask the mother how she is doing and offer support, without providing similar check-ins with fathers. When father-specific supports do exist, participants noted that they often have low attendance and levels of engagement.

Opportunity for Intervention: Provide Formal and Informal Supports for CHD

Fathers—Participant recommendations included developing more online support groups for fathers and increasing the number of peer-to-peer groups. However, responses were variable. Some participants stated that groups would have drastically changed their experiences, while others reported that they would not likely engage in an open discussion of their emotions. Those who were not interested in support groups noted that they would have utilized more informal opportunities to engage with other fathers, such as assisting with or coordinating events for other families of children with CHD (e.g., room set-up, volunteering at charity runs). Other suggestions included providing opportunities for couples to meet in smaller groups or sponsoring events for casual socialization, such as watch parties for sports, where conversations about CHD can be interspersed with other topics. Some noted that these events should be strategically planned to involve fathers in a way that helps them feel empowered and not vulnerable, which allows for information to be disseminated without fathers feeling “weak.” Finally, participants spoke about the value of having clinical social workers and psychologists present, which would provide an opportunity for more private support and discussion regarding how caregivers can support themselves and each other.

Discussion

This study is the first to our knowledge to engage a geographically diverse sample of CHD fathers and mothers to specifically examine sources of stress for fathers of children with CHD and opportunities for intervention to prevent or reduce paternal mental health problems. Our results extend what was previously known about how fathers experience and respond to the stress of CHD (7). The four broad themes are interconnected and bidirectional. For example, societal expectations for the role of fathers in caregiving and a limited ability for fathers to be present at the hospital due to outside work and family demands can influence assumptions made by the care team regarding a father’s role in his child’s CHD care. These assumptions can impact how care providers interact with fathers, which may result in fathers feeling overlooked as partners in care and, in some cases, disengaging from care. This is a critical issue, as paternal involvement in the care of infants and children with chronic illness has been associated with positive health effects, better medical regimen adherence, higher child health-related quality of life, and greater family resilience, including more positive ratings of the marital relationship and family environment (19–23). However, involvement in care may look different for fathers as compared to

mothers, and applying the same definition and metrics of parental involvement may mask important differences in the role and meaning of maternal and paternal parenting behavior (24).

Study results are consistent with prior research on the experiences and needs of fathers in other illness groups. Fathers of infants in neonatal units have reported similar feelings of powerlessness and exclusion in the care of their infant, and noted expectations to fulfill traditional roles of “being strong” and working to support the family (21; 25, 26). Fathers of children with severe cerebral palsy described similar challenges balancing employment with the care of their child and feeling overlooked in their child’s care due to assumptions made by the care team regarding the father’s role (27). A recent review of studies on fathers’ perceptions of parenting a child with a developmental disability revealed that fathers experience difficulty obtaining health information about their children due to limited understanding by health professionals about the types of information important to fathers (28). It seems likely that the broad themes identified in the present study represent sources of stress for fathers across pediatric illness groups and healthcare settings and that opportunities for intervention identified by parents in this study may reach beyond CHD.

Recommendations generated from parent participants in this study include the need for increased awareness (e.g., of the impact of CHD on fathers, of the important role of fathers in their child’s care), communication (e.g., with fathers directly rather than indirectly through mothers), resources (e.g., hospital accommodations enabling fathers to work remotely or sleep near the child/family), and supports (e.g., in a manner that helps fathers feel empowered rather than vulnerable). Consistent with recent recommendations by the American Academy of Pediatrics (21) and the Family Initiative’s International Neonatal Fathers Working Group (22), critical care teams should focus on including and supporting fathers, as well as engaging mothers and fathers as a co-parenting team. Fathers should be actively engaged by pediatric care providers as early as possible, including prenatal visits (21), through both verbal and nonverbal communication. Efforts should also be made to increase the representation of fathers on hospital family-advisory councils and to engage father stakeholders in hospital quality improvement initiatives to ensure that their perspectives are heard.

A small literature reports on interventions designed to meet the needs of fathers impacted by pediatric illness. Fathers of children with newly diagnosed type 1 diabetes who received a parent-mentor social support intervention via home visits and phone calls from experienced fathers reported higher confidence in managing diabetes (29), but also higher levels of worry, as compared to fathers in the control group. The authors hypothesized that this may have been related to an increased awareness of the complexity of diabetes care and potential risks. Another study of fathers of children with type 1 diabetes used surveys and qualitative interviews to develop internet-based education and support resources, including father-specific materials (30). Future research will evaluate the effectiveness of these resources. Fathers of children in the NICU who were offered a father-specific booklet and nursing support centered on information about care and equipment, tips for direct engagement with their child, and relaxation strategies reported lower levels of stress, higher fathering ability, and higher perceived nursing support compared to those in the control group (31). To date,

interventions targeting the needs of fathers of children with CHD have not been systematically implemented or evaluated.

Racial/ethnic minorities were underrepresented in the study sample and non-English speaking parents were excluded, precluding an understanding of how race, ethnicity, and language may influence sources of stress for fathers of children with CHD. Health inequities can have a powerful influence on parental experiences with pediatric healthcare and parental stress (32), and their impact on the experiences of fathers specifically should be further explored. This study also focused primarily on the experiences of fathers who were part of a traditional, heterosexual dyadic relationship, and results may not represent the experiences of fathers from diverse family structures, including single parent families, adoptive/blended families, and same-sex couples. The findings from this study may not be generalizable outside of the United States, as all participants lived and received care within the US, and may not fully capture the experiences of fathers who have limited access to or comfort with communication technology. Study results may also have been impacted by self-selection bias, as parents with certain experiences related to stress and support could have been more likely to enroll. Finally, care providers' perspectives were not assessed but should be evaluated in future studies, as care providers' beliefs and attitudes can influence interactions with fathers.

Conclusions

Taken together, study findings highlight the importance of developing models of family-based psychosocial care that consider the needs of fathers and include interventions to meet these needs. Tools to assess stressors and supports of greatest relevance and importance to fathers are needed to identify those at psychosocial risk and inform targeted interventions. However, it is important that care providers also be mindful that not every individual subscribes to traditional gender roles. Targeted interventions to prevent or reduce paternal mental health problems stemming from the demands of caring for children with CHD are likely to result in healthier families and relationships and may improve outcomes for children with CHD.

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Table 1.

Sociodemographic and Clinical Characteristics (N = 70)

	Frequency (%)
Parent Characteristics	
Fathers	25 (35.7%)
Age	
22–29	7 (10.0%)
30–39	48 (68.6%)
40–47	15 (21.4%)
Race/Ethnicity	
Non-Hispanic White	61 (87.1%)
Black or African-American	2 (2.9%)
Hispanic/Latino	5 (7.1%)
Asian	2 (2.9%)
Education Level	
High School/Associates Degree	29 (41.5%)
Bachelor's Degree	19 (27.1%)
Graduate Degree	22 (31.4%)
Married/Partnered	68 (97.1%)
Annual Household Income	
<\$50,000	20 (28.6%)
\$50,000 – <\$100,000	22 (31.4%)
\$100,000 or more	28 (40.0%)
US Region	
West	23 (32.8%)
Midwest	19 (27.1%)
Northeast	15 (21.4%)
Southeast	13 (18.7%)
Geographic Classification	
Rural	18 (25.7%)
Suburban	41 (58.6%)
Urban	11 (15.7%)
Child Characteristics	
Current Age [^]	
1–3	36 (51.4%)
4–6	29 (41.4%)
Single Ventricle Cardiac Physiology	33 (47.1%)
Prenatal Cardiac Diagnosis	40 (57.1%)
Suspected/Confirmed Genetic Syndrome	14 (20.0%)
First Cardiac Surgery < 1 month old	52 (74.3%)
Number of Cardiac Surgeries	
1	17 (24.3%)

	Frequency (%)
2	29 (41.4%)
>3	24 (34.3%)
Days in Hospital - First Surgical Admission *	37.4 (35.0)
Days in Hospital - First Year of Life *	72.6 (73.3)

[^] 5 (7.1%) children of participants were deceased;

* Mean and Standard Deviation reported

Sources of stress for fathers of children with congenital heart disease

Table 2.

Themes	Representative Quotes
Societal Expectations for Fatherhood and Standards of Masculinity	<p><i>It's not as socially acceptable for men to break down. So it was rough trying to be a rock and saying that everything would be ok, even when I had no clue what I was doing... This meant having to go to work and pretend everything was fine while secretly crumbling inside. Father 64</i></p> <p><i>Friends, family and caregivers focus more on the mom's experience than the dad's... I've had a lot of people say things to me like, "Your job is to support her" and "You need to keep up with work"... it overlooks the impact raising a child with CHD has on me as a father. Father 81</i></p> <p><i>My husband struggled with/still struggles with the fact that he can not protect our son. Our son is sick and in many ways we are helpless. My husband also has more stress induced negative consequences of CHD than I do, but I think people just do not get that since he is dad. Mother 67</i></p>
Balancing Work and Family Responsibilities	<p><i>My husband struggled with being away from us for the four months our daughter was inpatient. He had to work, so he came on the weekends. It was harder for him to adjust when we brought her home because he wasn't living it everyday like I had been for four months. Mother 92</i></p> <p><i>It makes me feel like I'm not as good of a parent as [my wife] is because I'm less involved. She also was in the hospital with him non-stop when he was readmitted, whereas I had to go back to work. So I felt very guilty about that. Father 1</i></p> <p><i>He worried about money, and being able to care for and support us all. It was hard for him to be at the hospital as much as he would have liked, since he still had to work. And, of course, he had to deal with a stressed out wife. Mother 72</i></p> <p><i>The biggest challenge I have faced as a heart dad is that I often feel overlooked in the entire picture of my daughter's care. Please hear me out, my voice is heard... a mother's voice is responded to more often. Father 77</i></p>
Feeling Overlooked as a Partner in Care	<p><i>The mother is often consulted despite the father being there. It took a lot to gain the respect mothers have to begin with... There were occasions that I would have to insist upon the doctor to come and confirm that what I was asking... "I told you so" is something a parent should not need to say in an ICU. Father 94</i></p> <p><i>My wife was the one in the room with him the whole time while I slept in a guest house wing of the hospital. It caused me a great deal of anxiety, not being able to sleep, and feelings of being disconnected from them both. Father 68</i></p> <p><i>I'm not sure my husband has support outside of me. He knows a couple other heart dads, but often ends up shunted to the side at social gatherings in favor of people making sure I'm okay. He's told me he really only feels like he can talk to me about things. Mother 80</i></p>
Lack of Father Supports	<p><i>Having more heart dads [groups] available/involved would be amazing... [it] is very evident that heart moms have a much more obvious presence. Yes, while there are heart dad Facebook groups many posts within those groups are actually dominated by heart moms. Father 44</i></p> <p><i>One of the greatest challenges was not having, or being able to find, a support group specific to my needs... I feel like the supports are designed in such a way that they are much more accessible and recommended to mothers than fathers. Father 71</i></p>

Table 3.

Opportunities for intervention for fathers of children with congenital heart disease

Themes	Representative Quotes
Acknowledge/Normalize the Impact of CHD on Fathers	<p><i>For dads who aren't comfortable processing or sharing feelings and emotions... a type of brochure or pamphlet that captures the standard feelings and emotions of a majority of heart dads navigating this process could be a helpful resource for more introverted dads to read and help them realize others feel just like they do.</i> Father 128</p> <p><i>I am hopeful that there will be more resources for heart dads in the future, but most importantly I am hopeful that there will be more awareness that heart dads need support, as well.</i> Mother 77</p> <p><i>We were able to get one of the hotel rooms in the hospital... This was invaluable - both of us could be there supporting each other, supporting our son, giving each other breaks, and allowing each other to get enough sleep. This was a game changer for emotional health.</i> Mother 67</p>
Provide Support for Balancing Work/Family Responsibilities	<p><i>Additional supports that help provide work relief so that dads can be more involved in daily care and not feel torn between providing financial support and care at the same time.</i> Mother 71</p> <p><i>The greatest help I found was not in the hugs or sympathy talks but in statistics. Knowing what the data indicates about divorce rates and sibling behavior all helps me be proactive and try to not just care for my son but for the family.</i> Father 153</p> <p><i>I would have liked... to talk to the doctors and really learn about the CHD... we blew through the CHD description... but after the surgery, a quick educational session where I could ask technical questions would have been great.</i> Father 125</p>
Recognize/Promote Father Knowledge and Engagement	<p><i>I think general education about the fact that fathers are also primary caregivers. I loath the general feeling that dads don't know what is going on with their child's health. My husband can answer questions, is competent, can provide all medical care. I think being appreciated as an active participant in the health of our child it goes a long way in support.</i> Mother 67</p> <p><i>I would've loved having a drawing or model of how our son's heart actually looked. None of the drawings in books or information sheets that were available were even close to our son's anatomy. I carried around a snapshot on my phone of a whiteboard drawing the surgeon sketched as my best tool for understanding his anatomy for the longest time.</i> Father 68</p> <p><i>[Provide] actual heart dad groups... They do exist but not as frequent. It is always great to connect with another dad as you share that in common but also your other interests such as sports, hobbies, etc. Even though we love our kids, we tend to talk about them to some degree but then that works into another conversation about other things.</i> Father 155</p>
Provide Formal and Informal Supports for CHD Fathers	<p><i>My husband would find the best support through volunteering to speak to or mentor other heart families or kids. Especially if sports are involved. If heart dad's are approached through the point of helping others, they may be more likely to get involved and heal themselves in the process.</i> Mother 109</p> <p><i>If I had to do it again, I would seek out some form of counseling to help me. I think... I was so concerned with just making it to the next day that I didn't really care for myself at all. They kept telling us it's like the oxygen masks on the airplane-- you have to take care of yourself first, before you help your child, but that's a hell of a lot easier said than done.</i> Father 64</p>