Experiences of mothers of infants with congenital heart disease before, during, and after complex cardiac surgery

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ABSTRACT

Objective: Experiences of mothers of infants undergoing complex heart surgery were explored to build evidence-based family-centered interventions.

Background: Congenital heart disease is the most frequent birth defect in the United States and is common worldwide.

Methods: Eight mothers recalled through journal entries their experiences of the days before, during, and after their infant's surgery and shared advice for other mothers. Colaizzi's phenomenological method was utilized for data analysis. A validation survey of seven additional mothers from a support group occurred via email.

Results: Six themes were identified and validated: Feeling Intense Fluctuating Emotion; Navigating the Medical World; Dealing with the Unknown; Facing the Possibility of My Baby Dying, Finding Meaning and Spiritual Connection, and the umbrella theme of Mothering Through It All.

Conclusions: Through a clearer understanding of experiences as described by mothers, health-care providers may gain insight as to how to better support mothers of infants undergoing heart surgery.

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Congenital heart defects (CHD) are the most common type of birth defect in the United States, affecting about 8 of 1000 live births per year, with a prevalence of between 6.9 and 9.3 per 1000 live births worldwide.1–3 Infants diagnosed with a moderate or severe CHD require medical intervention soon after birth and follow-up care for life. Surgical advances and early intervention have markedly improved the quality of life and lifespan for many of these children.

Despite advances in antenatal screenings, some parents of infants with CHD are unaware of the diagnosis during the mother's pregnancy. Just hours, days or weeks after the celebration of the birth of the child, these parents are faced with the realization that their baby was born with a potentially life-threatening condition. Moreover, parents of these infants quickly learn that the only treatment option for their baby is complex heart surgery—a procedure itself that carries a significant risk of morbidity and mortality.

Researchers looking at psychological impact found parents of children needing surgical repair of a CHD have increased distress just before the child's heart surgery.4 Heuer5 and Tomlinson et al6 highlighted the stress of parents with a child in the intensive care unit where these children receive their postoperative care. When parents were followed through the recovery period, investigators found that stress remained moderate to high throughout the child's hospitalization.7 Moreover, some parents may be at increased risk of posttraumatic stress disorder following their child's open heart surgery.8 Uttens and colleagues9 noted that mothers report a higher level of stress than fathers during the time period prior to the heart surgery. Specifically, mothers of infants with CHD awaiting cardiac surgery reported more distress and problems coping. Qualitative studies focused on the experience of these mothers have been limited; greater details of their experience may assist nurses and physicians in refining support interventions for these families.

In 2011, the American Academy of Pediatrics recommended all hospitals provide newborn screening for congenital heart disease...
by assessing oxygen saturation within the first 24 h of birth. If this practice is accepted as standard of care, the frequency of early diagnoses of CHD will likely increase. Health care providers in non tertiary care centers who previously had limited exposure to this population may find themselves in need of further guidance to best support parents during the infant’s diagnostic and transfer processes. The purpose of this qualitative descriptive study was to explore the lived and recalled experiences of mothers of infants with moderate to severe CHD who were diagnosed post-natally and needed heart surgery prior to their first birthday. We asked mothers to recall via journal entries their experiences of the time before, during, and after the surgery and to provide advice for other mothers who have a child with CHD requiring surgery. Our ultimate aims are to build family-centered education and support interventions and to offer insight to other families who have an infant that needs complex heart surgery.

Method

Research design

This study used a qualitative descriptive research design with phenomenological overtones to capture the essence of the mothers’ recalled experiences. Results described here were part of a broader (unpublished) study with the same purpose and methods that included older children as well. This larger study looked at additional aspects such as sources of hope, support, inner strength, and stress levels of these mothers.

Journaling was selected as the data collection method because as a non-intrusive form of personal sharing it allows participants full control over their narration. Journal data were collected over a six-month period, from September 2007 to March 2008. To align with Colaizzi’s phenomenological analysis steps, a validation process was implemented in 2012.

Setting

The primary study participants were recruited through a tertiary urban pediatric medical center in the Pacific Northwest, following approval by the hospital’s institutional review board. The medical center provides a wide variety of ambulatory and inpatient services for children with acute and chronic health conditions who come from a broad geographical area, including other states. The regional chapter of a support group for parents of children with CHD was used in the validation component of the study.

Sample

The convenience sample was recruited by the principal investigator from mothers of infants with moderate to severe CHD who were having or had complex heart surgery in the last 5 years. Ten mothers of infants under one year were contacted, 9 consented in writing to participate, and 8 of these returned journal entries. Mothers who did not speak English were excluded. Fathers were not included as they were not part of the original study. Table 1 summarizes the demographic data of these mothers and infants at the time of surgery. All of the infants survived their surgical experience.

Seven mothers (Table 2) from a regional parent support group who met the original eligibility criteria completed the e-mail validation survey. Similar to the primary study participants, these mothers reported having a child with moderate to severe CHD who underwent heart surgery at less than one year of age; all of these infants survived.

Procedure

Mothers expressing interest in the study were invited to participate. Following informed consent each mother was given a binder containing a one page demographic questionnaire and journal templates for each time point: days before surgery, day of surgery, and days after surgery. Journal templates had a place for the date, and began with: “Please share your experience of the events <from that day> — describe in words (or draw) your thoughts and feelings.” No further instructions were given. Seven of the eight mothers wrote their journals retrospectively, 1–4 years after the infant’s surgery. One participant (#112) provided prospective data.

Additionally, original subjects and the survey group were asked to respond in writing to an open ended question, “Do you have any thoughts or insights from this experience (of having of child undergo heart surgery) that you would like to share with other mothers?”

Data analysis

Colaizzi’s steps to analysis of phenomenological data were used. This process includes reading the data for a feel of participant’s experiences, identifying significant statements, formulating meanings for these statements, and organizing the meanings into clusters of themes so that the fundamentals of the experience are fully represented. Finally, participants validate these determinations.

Two of the investigators repeatedly read the verbatim transcripts of mothers’ journal entries independently, noting statements

Table 1: Demographic data of mothers in primary study.

<table>
<thead>
<tr>
<th>ID</th>
<th>Infant’s diagnosis</th>
<th>Age of infant at first surgery</th>
<th>Multiple surgeries</th>
<th>Time from surgery to study</th>
<th>Aristotle score</th>
<th>Age of mother</th>
<th>Marital status</th>
<th>Ethnicity</th>
<th>No. of other children</th>
</tr>
</thead>
<tbody>
<tr>
<td>102</td>
<td>Cor triatriatum and partial anomalous pulmonary venous return</td>
<td>5 weeks</td>
<td>No</td>
<td>2 years</td>
<td>6.8</td>
<td>29</td>
<td>Married</td>
<td>Caucasian</td>
<td>2</td>
</tr>
<tr>
<td>103</td>
<td>Transposition of the great arteries</td>
<td>2 weeks</td>
<td>Yes</td>
<td>4 years</td>
<td>10</td>
<td>29</td>
<td>Married</td>
<td>Caucasian</td>
<td>2</td>
</tr>
<tr>
<td>104</td>
<td>Transposition of the great arteries</td>
<td>2 weeks</td>
<td>Yes</td>
<td>4 years</td>
<td>10</td>
<td>27</td>
<td>Divorced</td>
<td>Caucasian</td>
<td>2</td>
</tr>
<tr>
<td>105</td>
<td>Pulmonary atresia and VSD</td>
<td>9 days</td>
<td>Yes</td>
<td>1 year</td>
<td>11</td>
<td>28</td>
<td>Married</td>
<td>African American</td>
<td>4</td>
</tr>
<tr>
<td>106</td>
<td>VSD and congestive heart failure (required ECMO)</td>
<td>10 months</td>
<td>Yes</td>
<td>2 years</td>
<td>6</td>
<td>30</td>
<td>Divorced</td>
<td>African American</td>
<td>3</td>
</tr>
<tr>
<td>107</td>
<td>Tetralogy of Fallot with pulmonary atresia</td>
<td>9 days</td>
<td>Yes</td>
<td>1 year</td>
<td>9</td>
<td>32</td>
<td>Married</td>
<td>Caucasian</td>
<td>0</td>
</tr>
<tr>
<td>108</td>
<td>Transposition of the great arteries</td>
<td>7 days</td>
<td>No</td>
<td>1 year</td>
<td>10</td>
<td>28</td>
<td>Married</td>
<td>Caucasian</td>
<td>1</td>
</tr>
<tr>
<td>112</td>
<td>Tetralogy of Fallot</td>
<td>3 months</td>
<td>Yes</td>
<td>1 week</td>
<td>8</td>
<td>34</td>
<td>Married</td>
<td>Pacific Islander</td>
<td>4</td>
</tr>
</tbody>
</table>

*Missing case numbers refer to cases not meeting inclusion criteria.

*Aristotle basic score indicates the complexity of the surgical procedure. Range: 0.5–15, with higher scores indicating increased complexity.*
that seemed indicative of the mothers’ experiences. One investigator was a pediatric nurse practitioner who worked with families of children having complex heart surgery and the other investigator, also a pediatric nurse, was a qualitative researcher. Amidst these readings the investigators frequently met to share potential themes and clusters of themes. A constant comparative process of returning to the journal entries multiple times was used to ensure that the themes were supported in them and comprehensively represented the journal entries. Audit-trails were maintained. The investigators limited their review of the literature until after the analysis was completed to minimize bias.

A validation process was used to determine if the identified themes were representative of mothers’ experiences. As indicated, mothers in a local chapter of a national support group for parents of children with CHD were sent an email survey containing the study. Several mothers described the anxiety of waiting followed by an hour came when we finally found out the results. I felt relieved to be home and happy, so happy.

**Results**

Data analysis of the journal entries revealed six major themes during the time period of the days before surgery, the day of surgery and days after surgery: 1) Feeling Intense Fluctuating Emotion, 2) Navigating the Medical World, 3) Dealing with the Unknown, 4) Facing the Possibility of My Baby Dying, 5) Finding Meaning and Spiritual Connection, and 6) Mothering Through It All. These themes frequently occurred together and were woven throughout the descriptions of the mother’s experiences.

**Feeling Intense Fluctuating Emotion**

Various intense emotions emerged from journal entries. Mothers found themselves on a roller coaster of feelings, ranging from shock and fear to feeling “truly blessed” and “joyous relief.” Several mothers described the anxiety of waiting followed by an experience of joy and gratitude when they were finally able to see their child again after surgery. “Finally the hour came when we were called back to see my son’s surgeon… I felt relieved to the point where I cried with joy the minute I stepped out of the room, I was happy, so happy.” (112) Other times mothers described feeling helpless and fragile while trying to be the source of strength and unconditional love for their child. As one mother wrote, “... having no control can be scary and frustrating...” (108) one mother summarized by writing, “To define in words the emotion, questions, uncertainty, emptiness, and broken heart that I carried with me through the situation is impossible.” (102)

All validation survey mothers agreed with this theme. One noted that she “revisited many of these emotions for months and even brief flashbacks years after surgery.” (207)

**Navigating the Medical World**

For most of the mothers, the hospital and ICU environment were foreign territory—they encountered unfamiliar people speaking in the unfamiliar language of medical terminology. Navigating the Medical World in the midst of Feeling Intense Fluctuating Emotion was another challenge. Absorbing and processing the overwhelming medical information became a focus for many of the mothers. One said, “A few hours later I found myself sitting in the... NICU listening to a cardiologist fill my head with all these facts I did not understand.” (103)

Another poignant part of the medical world for mothers involved the responsibility of medical decision making and signing the consent for the heart surgery. For some this process seemed to present an additional burden: “The signing of the papers to give consent for my child was another feeling of: ‘Should I or should I not?’ I had this fear that if I did sign it and something should go wrong, I would have to live with that guilt for the rest of my life.” (112). Another mother provided a different perspective, indicating that there was no decision to make: “Sure, we had to sign a consent and such, but there really wasn’t a choice. I looked at it like: A) We cannot have the surgery and our son will die or B) We can do the surgery and there’s a chance that he will live.” (108)

As mothers found themselves having to make difficult decisions, journal entries reflected the concepts of trust and faith. “By having that chance to meet his surgeon I was able to feel confident in him, I felt rest assured that my son will be fine in his hands.” (112)

In the validation survey, 5 of the 7 mothers supported the theme of Navigating the Medical World and affirmed the comments by the mothers in the original study. One mother who worked in the medical field indicated that Navigating the Medical World wasn’t such an issue for her. Another answered “maybe,” noting that the child’s cardiologist kept the parents well informed.

**Dealing with the Unknown**

As mothers felt intense fluctuating emotion and navigated the medical world, another theme, Dealing with the Unknown, began to emerge. One area of the unknown concerned the etiology of the baby’s diagnosis. As expressed by this mother:

It was heartbreaking for me the minute the diagnosis was confirmed. Although his cardiologist had explained that it had nothing to do with my actions or thoughts I still had so many questions of, What have I done? Where did I go wrong? It took a while for me to accept that I wasn’t to blame for his sickness or his heart abnormalities. (112)

Many mothers expressed feelings of an uncertain future for their child during the days prior to surgery. “I remembered what it was like to have him in my tummy, his kicks, his hiccups and then his birth. He was so perfect, so loved—was this going to be the end?” (102) Several mothers wrote about the anxiety they felt in anticipation of the surgery and while waiting during the actual surgery.

### Table 2

Demographic data of mothers in validation study.

<table>
<thead>
<tr>
<th>ID</th>
<th>Infant's diagnosis</th>
<th>Age of infant at first surgery</th>
<th>Multiple surgeries</th>
<th>Time from surgery to survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>201</td>
<td>Tetralogy of Fallot and complete AV canal</td>
<td>5 months</td>
<td>No</td>
<td>9 years</td>
</tr>
<tr>
<td>202</td>
<td>VSD, ASD, coarctation of aorta, anomalous coronary artery</td>
<td>2 weeks</td>
<td>Yes</td>
<td>Missing</td>
</tr>
<tr>
<td>203</td>
<td>Transposition of the great arteries, pulmonary stenosis</td>
<td>13 days</td>
<td>Yes</td>
<td>9 years</td>
</tr>
<tr>
<td>204</td>
<td>Hypoplastic left heart syndrome</td>
<td>6 days</td>
<td>Yes</td>
<td>4 years</td>
</tr>
<tr>
<td>205</td>
<td>Multiple VSDs</td>
<td>5 months</td>
<td>Yes</td>
<td>1 year</td>
</tr>
<tr>
<td>206</td>
<td>Hypoplastic left heart syndrome</td>
<td>10 days</td>
<td>Yes</td>
<td>3 years</td>
</tr>
<tr>
<td>207</td>
<td>Transposition of the great arteries</td>
<td>1 week</td>
<td>No</td>
<td>2 years</td>
</tr>
</tbody>
</table>
It was also hard to wait prior to surgery; there was a point where I was just anxious to have something happen.” (108) She continued, “I viewed the day (of surgery) as a turning point. Today we will know something about how our lives are going to proceed. With our son or without him, this day offered an end to the waiting and not knowing.” (108)

The unknown during recovery resulted in feelings of intense emotion such as frustration and jilted expectations.

The exhilaration of surgery day and being at some sort of turning point started to fade after the surgery. Although the tubes and swelling is not as horrifying and unsettling as I anticipated, the whole ordeal is becoming sort of irritating…. I wanted to scoop him up and hold him, but I couldn’t of course. (108)

Unexpected crises in the postoperative period also led to uncertainty.

I was sitting in his room, reading a book when the nurse yelled,” I need a doctor in here, STAT! The room was suddenly filled with doctors and nurses, all scurrying around… She [the nurse] said that he had gone into cardiac arrest twice; the surgeon had to give him open heart massage and administered lifesaving drugs in order to save him. (103)

All seven survey respondents validated the theme of Dealing with the Unknown.

Facing the Possibility of My Baby Dying

One of the primary foci of the unknown—the possibility of one's baby dying—was an experience poignantly described by all of the mothers. For some participants this possibility became evident at the beginning of the journey. As one mother stated, “… he would need to undergo a major open heart surgery to correct the defect within a few days in order for him to survive.” (103) Another said, “There was a question that my husband and I had in mind but feared to hear the answer… Is our child going to die?” (112) This fear might not be readily noted; as described further by the same mother: “Although I signed the papers calmly, emotionally I was torn inside because I was scared for my son's life.” (112) For others this possibility became a reality during surgery and in the recovery period. “They thought he wouldn't make it through the night,” said one mother whose baby had just returned from surgery. (105)

One mother prepared or made room in her mind for the possibility that her baby may not survive. “I would pray that if it was my child's time to go to heaven, then let him go quickly and without pain.” (102) Another reflected on the struggle to acknowledge this possibility. “I know having his mom made a huge impact in his life!” (104)

Facing the Possibility of My Baby Dying

In many cases mothers were able to identify benefits or blessings present in the experience. “We, as a family have learned more than we could ever have imagined possible. We learned what was really important in life.” (102)

The role of a spiritual/religious connection was important for many mothers in giving them strength and in coping with the stress of the experience. “We just had to get through it all. I was amazed by our strength, our ability to cope and what I believe to be the presence of God.” (108)

All validation survey respondents supported the theme of Finding Meaning and Spiritual Connection. Several added that the support of their faith and church got them through this experience. As one noted, “My faith has been made stronger, not because God allowed us to keep our daughter but because I grew closer to Him through the experience.” (205)

Mothering Through It All

Mothers were faced with the challenge of how to find and promote some normalcy within the chaos of the diagnosis and surgical event. Doing their best to be a Mother Through It All was identified as the primary theme, which served as umbrella for the other themes. As one mother wrote, “My love for my child is unexplainable; it's a love that God has implanted in every mother, I believe.” (112) Some mothers wrote about the ways they experienced their role as guardian and provider for their fragile baby in the midst of Feeling Intense Emotion. One mother shared how mothering activities as provider helped her cope with the events: “Every time I tried to close my eyes, my baby's cries filled my head. I just didn't know what to do with myself. I was glad I was breastfeeding; it made me feel as though I was doing something to help my son.” (102) Another mother shared her struggle with the maternal role of guardian,

Finding Meaning and Spiritual Connection

Faced with unthinkable circumstances, some of the mothers described how through their searching they were able to make sense of and find meaning in the situation. One wrote, “I don’t know if I believe in destiny or if I just have a lot of faith, but when there's nothing else you can do, I had to believe that whatever was suppose to happen, would happen.” (108)
challenges of the situation, they described sources of support including family, friends, God, and the health care team. One mother stated, “The one person who could understand was my husband. He is my best friend, plus the father of my child.” (102) Another shared about meeting a different mother during the hospitalization with an infant that had a similar diagnosis, “I truly believe that God brought us together during the scariest time in both of our lives to help each other through.” (103)

Mothers described the challenge of finding a way to balance family needs with the needs of the hospitalized child. Stress on the marriage and the challenge of caring for others in the family was the focus of many of journal entries. “Our marriage was under major stress, with questions like, ‘Do we go to work? What bills do we pay? Who do we call? What do we do about our other kids?’” (102) Another shared, “I also had a 2½ year old daughter and I felt like I had to choose between them. It was a very hard and painful decision.” (104)

Mothering Through it All was conceptually supported by the validation survey respondents. As one mother described “I was pretty much on my own since my husband had just started a new job with difficult hours. I was grateful for my parents and sister who helped as they could but it was very stressful and I was glad she’s our only child.” (205)

Advice from mothers who have been there

In order to solicit information that could be used to help mothers in the future, mothers in both samples were asked, “Do you have any thoughts or insights from your experience… that you would like to share with other parents of a child who is going to have heart surgery?” In the primary study, six of the eight subjects responded to this question; all seven validation survey mothers responded. Many of their insights, identified through content analysis, offered support for the themes identified in the findings of this study. The advice from the mothers to other mothers included: 1) connect to the strength within you and advocate for your child, 2) recognize the unknowing and the need to find meaning, 3) Foster faith and trust through spiritual connection, 4) seek support from family, friends, and other parents with similar experiences and, 5) make time for self care (Fig. 1).

Discussion

This study was originally designed to include more mothers with a recent, lived experience; however the majority of mothers who returned the journals were 1–4 years removed from their child’s first heart surgery. As a result, we were able to capture a longitudinal recollection of the mothers’ experiences of their child’s cardiac surgical event.

As described, the mothers’ journal entries revealed six themes that reflect their experiences: Feeling Intense Fluctuating Emotion; Navigating the Medical World; Dealing with the Unknown; Facing the Possibility of My Baby Dying, Finding Meaning and Spiritual Connection, and Mothering Through It All (Fig. 2). These themes were seen throughout the peri-operative period and represent a process of mothers going back and forth among them. We found

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**Connect to the strength within you and advocate for your child**
- “That is one of the hardest things you go through but it’s worth every second with your child”
- “...never give up being your child’s strength”
- “Try to be a source of love for your child throughout the process. Try to radiate love instead of worry”
- “Become an advocate for your child and fight with all of your might if you think something is not right in your heart and soul.”

**Recognize the unknowing and the need to find meaning**
- “Just take comfort in these three things that I held onto:
  - There is no known cause for the heart defect (it is NOT your fault)
  - Everything happens for a reason and that reason may be beyond your understanding until a much later time
  - Surgery is the only option, it is not some choice you have to fret and worry over. It is what must be done to give your infant a shot at life”

**Foster faith and trust through spiritual connection**
- “All a mother can do <when> she is placed in a position where she has no control of the situation – always remember prayer and faith goes hand and hand”
- “God might not answer your prayers the way we want or in the time we expect, be he always hears and answers”.

**Seek support from family, friends, and other parents with similar experiences**
- “Establish a group of people to be your support team. These folks should be stable enough to provide encouragement, strength, service, <and> compassion ---whatever you need, when you need it.”
- “Have family or friends help out in ways you need it and in ways you won’t expect to need it, but do (meals, cleaning, shopping, etc.)”

**Make time for self care**
- “...eat, sleep, and shower. Sometimes we must remind ourselves life goes on outside of the hospital. Take a walk, just breathe.”
- “...take a break away from the hospital, even if it’s just five minutes.”

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Fig. 1. Advice from mothers who have been there.
that despite the retrospective nature and the control over content that journaling provides, mothers wrote similar comments leading to the development of consistent and comprehensive themes. Consequently, we believe that each child’s surgical experience vividly remains in each mother’s memory.

Our study supported findings from other researchers who have described the presence and impact of parental stress in this population. For example, the theme Feeling Intense Fluctuating Emotion noted throughout the diagnostic and surgical periods was one way that mothers’ psychological stress was evident. Supportive interventions such as encouraging mothers to express their emotions have been found to positively affect mothers’ adjustment to their child’s diagnosis of CHD.14,15 Other stressors found in the literature: caring for other children16,17 and the uncertainty of the outcomes6,18,19 were also described in our study in the themes of Mothering Through it All and Dealing with the Unknown. Parental experiences related to decision making about a surgical procedure to treat their child’s cardiac problem20,21 have likewise been noted by other researchers. This was reinforced in our study by the mothers’ journal entries about Feeling Intense Fluctuating Emotion once the diagnosis was made, the need to quickly become well educated about the child’s diagnosis and treatment options (Navigating the Medical World), and the always present worry that the surgery may not be successful (Dealing with the Unknown and Facing the Possibility of My Baby Dying).

Parental mourning, chronic sorrow, hopelessness, and post-traumatic stress disorder have been identified in the literature8,15,23,24 as potential concerns for parents of children with CHD. Whether being saddened over their child’s heart defect, fearing the loss of their child, facing an uncertain future or simply letting go of control, mothers in our study found solace in Finding Meaning and Spiritual Connection. As described in other research,22,25,26 these strategies can be effective coping methods for parents of infants with life-threatening conditions.

Finally, “Mothering Through It All” emerged as an umbrella theme for the other themes in our study. Other studies have also noted the centrality of parents of children having CHD surgery trying to promote everyday family connectedness and functioning.14,16,18,19,27–29 For example, Rempel and colleagues18 have
extensively studied mothers and fathers of infants with hypoplastic left heart syndrome, a very severe CHD, noting “Extraordinary parenting” as their primary finding.

In contrast to the real time interviewing technique commonly utilized in phenomenological and other qualitative research, journaling was utilized as the data collection mode in our study. We believe that this aspect of the study design allowed the mothers to have more control over the content they shared and more time for reflection. Perhaps this was because the intensity of the recalled experience was not as strong as during the actual experience. Data collected in this way also may allow mothers the opportunity to share their thoughts from an overview perspective.

We could not identify whether any potential or participating mothers found journaling to be a physical, mental or linguistic burden, or how it affected the mother’s recall. Of note, several stressors identified in previous studies (apart from the actual diagnosis and surgery) including feedings and post discharge caregiving demands, lower socioeconomic status, financial issues, immigration status, and anger were not mentioned in the journal data in this study except minimal comments about financial issues and care of other children. Perhaps the time lapse of retrospective journaling impacted the mothers’ recollection of some negative stressors.

In summary, through the use of journaling and recall, this descriptive qualitative study offers a unique lens from which to view the challenges of these mothers’ experiences.

Limitations

Since the primary study was performed at one medical center, and the participants in the support group survey came from unidentified settings, the transferability of study findings is limited. Other limitations in our sample were noted, including that only mothers of sons returned journal entries in the primary study, all infants survived their surgical experience, and most of the mothers were several years removed from their infant’s first heart surgery. Finally, all of the participants in the original study and the validation survey agreed to provide data; the experiences of this small group of mothers may not be representative of other mothers.

Implications for practice and further research

This study builds on other clinical recommendations by providing insights into the experiences of mothers of infants undergoing complex heart surgery. Providers may want to consider using the six themes as a framework for supporting mothers whose infant is facing heart surgery (Fig. 2). Moreover, when the mothers in our study shared advice for other mothers, they provided “lessons learned” and gave us specific ideas for supportive interventions (Fig. 1). For example, staff could initiate discussion with a statement such as, “Here are some things other mothers in a similar situation found helpful”. Specifically, the key points outlined by study mothers could be used as a guideline for the health care team on how to support these families. Fig. 3 provides a categorized summary based on study findings.

Further research is needed to determine if health care professionals caring for infants with other complex congenital defects requiring surgery find implications from families with CHD experiences useful. Studies that shed more light on the experiences of fathers and siblings also are needed. Research that partners parent support groups with hospitals in research endeavors could provide insight to the post discharge health care continuum.

Conclusion

When heart surgery is necessary for her child, a mother is faced with significant new challenges. This study provides insights about the experiences of mothers who have had an infant undergo complex heart surgery. We have described in six themes some of the ways that these mothers feel, think, and face challenges. In addition, this paper provides advice from mothers to other mothers with implications for the health care teams who support them. Using this information can contribute to building a framework for evidence-based interventions in the context of family-centered care.

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