Published in final edited form as:

ANS Adv Nurs Sci. 2017 ; 40(4): 319–336. doi:10.1097/ANS.0000000000000184.

The Pediatric Cardiac Intensive Care Unit Parental Stress Model: Refinement Using Directed Content Analysis

Amy Jo Lisanti, PhD, RN, CCNS, CCRN-K^{1,2}, Nadya Golfenshtein, PhD, RN¹, and Barbara Medoff-Cooper, PhD, RN, FAAN^{1,2}

¹University of Pennsylvania, School of Nursing

²Children's Hospital of Philadelphia

Introduction

Congenital Heart Disease (CHD) is the most common birth defect, effecting 1% of all live births across the globe[1]. Neonates born with complex CHD require intervention or surgery in the neonatal period to survive and are cared for in a Pediatric Cardiac Intensive Care Unit (PCICU). Over the last three decades, the mortality rates for these infants have decreased markedly to a rate of only 2.9% due to medical and surgical advancements in care [2, 3]. Although survival rates have increased, morbidities are numerous, including feeding difficulties, growth failure, and long term neurodevelopmental delay[4, 5]. Parents of infants born with complex CHD experience extreme stress, often beginning during the prenatal period at the time of fetal diagnosis, and continuing during the infant's hospitalization and postoperative course, as well as post-discharge [6–8]. Mothers, in particular, have very high stress levels that continue well into the first year. Mothers are often the primary caregivers to their infants and must face care needs which are unrelenting and complex. In addition, stress can impair parental communication and behavior, impacting the relationship and interaction of the parent with the child and other family members[9–13]. Long-term maternal stress for mothers of children with CHD has been linked to child behavior problems and can affect optimal parenting [14].

Parental stress has been well described over the last 30 years in the settings of neonatal and pediatric critical care units. However, the trajectory of care for infants post open heart surgery is quite different from the maturing and growing preterm infant. Past research in other settings cannot elucidate the nature of the stress experience of parents during the most critical period of their infant's birth, surgical correction or palliation for complex CHD, and recovery. Until recently, the unique stressors and stress response of mothers whose infants underwent cardiac surgery in the neonatal period had not been described. Franck and colleagues found that mothers and fathers perceive stressors from their child's appearance and behavior, parental role alteration, and the sights and sounds of the hospital environment [15]. Child appearance and behavior was the highest source of stress for both mothers and fathers across several time points throughout the hospitalization. Parents of infants less than

1 year of age had significantly higher stress than parents of older children. Another study by Lisanti and colleagues examined the stressors and stress response of mothers during the infant's admission to a PCICU[8]. Infant appearance and behavior was the highest rated source of stress. Mothers also experienced elevated stress response of state anxiety. Trait anxiety and parental role alteration predicted approximately one quarter of the variance in state anxiety for mothers in the PCICU. Lisanti's study was also the first to describe a new theoretical framework, the PCICU Parental Stress Model, which describes the stress of parents who have infants being cared for in a PCICU. Both studies acknowledged the need to examine additional variables affecting the stress experience of parents in the PCICU. The purpose of this study was to explore and clarify specific foci of parental stress for mothers of infants with complex CHD in the PCICU. The secondary purpose was to expand, further develop, and refine the PCICU Parental Stress Model so that it can be used to guide practice, education, and future research in this unique population and setting.

Theoretical Framework

The PCICU Parental Stress Model was originally adapted from several iterations of parental stress models developed by Dr. Margaret Miles and colleagues[16, 17]. According to Lazarus and Folkman, psychological stress is a relationship between a person and a stressor, whether internal or external, that is appraised by the individual as "taxing or exceeding his or her resources and endangering his or her well-being" [18](p19). The individual perceives a stimulus as stressful and reacts with a stress response [19]. The original model by Miles and colleagues was built on the foundation of Lazarus and Folkman's general stress theory and applied to the critical care setting by identifying potential stressors that stimulate stress responses in parents.

Expanding on this early work, The PCICU Parental Stress Model was created based on revisions from prior stress models developed by Miles and colleagues, and through synthesis of both classic and recent literature (Figure 1) [8, 20]. The full description of the model, its early development and revisions has been previously described [20]. The PCICU Parental Stress Model posits that parental stress in the critical care setting emanates from three categories of parental stressors: infant, parent, and environment, within which are 10 individual types of stressors. These three categories of stressors combine and the total amount of stressors contribute to a stress response in parents. According to the original model, personal factors such as trait anxiety and the timing of diagnosis also influence the stress experience for parents whose infants are diagnosed with complex CHD and are being cared for in the PCICU.

Parental stress responses can be both physical and psychological. Examples of physical stress responses are somatization, heart rate and blood pressure changes, and variations in circulating catecholamines [21]. Examples of the psychological responses to stress are stress emotions, often referred to in the literature as psychological distress. Stress emotions include "anger, envy, jealousy, anxiety, fright, guilt, shame, and sadness" [22](p36). Parents can experience a range of emotions during their infant's PCICU admission, which can be a direct response to personal factors and stressors from the infant, parent, or environment.

Study Design and Methods

Research Methods

A descriptive qualitative approach was used to explore maternal perceptions of stress and stress responses in the PCICU setting. This methodological approach allows for an exhaustive understanding of a phenomenon and “is especially useful for researchers wanting to know the *who*, *what*, and *where* of events” [23] (p339). To examine the issue of stress in the PCICU, we conducted three focus groups between July 2015 and March 2016 at a large children’s hospital in the northeast mid-Atlantic region. A professional focus group moderator led each session using a semi-structured interview guide with open-ended questions addressing the sources and effects of stress on mothers. Each focus group consisted of four to five mothers and was 90 to 120 minutes in length. Participation by mothers was voluntary and occurred after informed consent. Mothers were provided with lunch during the focus groups and given a gift card at the end as a token of appreciation for their time and participation. Focus group sessions were recorded and transcribed verbatim. Data collection occurred until saturation was reached[24]. Data were coded using a directed content analysis approach and N-Vivo technology. According to Hsieh and Shannon, directed content analysis is useful when a theory exists about a phenomenon that needs further refinement or development through qualitative research [25]. In a directed approach, coders use pre-determined codes based on the guiding theory or model. For this study, codes within stress response and each category of stressor (infant, parent, and environment) from the PCICU Parental Stress Model were utilized. Themes emerging from the data that were not described in the model were identified and coded as appropriate. Initially, the N-Vivo technology was used by a nurse scientist to code the data. A second nurse scientist reviewed the qualitative data and validated the codes, reconciling any differences using the theoretical framework. A third nurse scientist then reviewed the final coding. All three nurse scientists participated in the study design, data collection, and analysis, ensuring confirmability by maintaining an accurate audit trail[24]. This study was approved by the Institutional Review Board of the hospital where the focus groups were conducted.

Subjects

A purposive sample of English-speaking, biological mothers of infants with complex CHD admitted at birth for surgical intervention and cared for in the PCICU were eligible to participate. Purposive samples are recommended for qualitative descriptive studies [23]. A total of 14 mothers of infants in PCICU consented and participated in the three focus groups. The majority of mothers were white, married, and well-educated (Table 1). All but one mother had received prenatal diagnosis of their infant’s complex CHD. Mean age for the mothers was 30.5 years, ranging from 21 to 43 years old ($SD = 6.4$). At the time of the groups, the mothers’ infants ranged in age from 11 to 63 days old ($M = 24.1$; $SD = 14.7$). All of the infants had been hospitalized since birth for a variety of cardiac defects, of which 71% had single ventricle physiology and 29% had two ventricle physiology (Table 2). A majority of the infants had experienced at least one surgery during the hospitalization ($n = 13$).

Results

Mothers described stressors that fit within the categories of infant, parent, and environment, as the PCICU Parental Stress Model suggests. Mothers also discussed their response to stress in the PCICU. A new theme of time emerged from the data, not originally posited by the PCICU Parental Stress Model. After data analysis was complete, a revised version of the PCICU Parental Stress Model was created to reflect the new knowledge gained from this study (Figure 2).

Infant

Mothers in this study identified stressors arising from the category of infant. Codes that emerged within this category included infant appearance and behavior, and the actual and perceived severity of illness.

Infant Appearance and Behavior—Almost every mother told stories of their extreme stress from seeing their infant in the PCICU, particularly after open heart surgery, and that nothing could have prepared them for that moment.

I would look at pictures of other babies who had HLHS [Hypoplastic Left Heart Syndrome] surgery and with tubes and everything, but no matter how much people prepare you on, you are never prepared to see your child with tubes and wires and the chest open. It's been really hard for me to see him that way.

Even a mother with a medical background described the anguish and stress in seeing her infant after cardiac surgery.

I'm a veterinarian so I see a lot of gory stuff, but when I walked up and saw my son for the first time after the surgery, I was close to passing out [crying], I had to sit down. I tried to prepare by looking at pictures of other peoples' babies and things like that, but it's just too much.

In addition to their infant's appearance, mothers discussed the behavior of their infants as a source of stress, particularly when the infants did not exhibit normal newborn behavior as a result of the presence of medical equipment or the impact of the cardiac condition and surgery. One mother stated, *"My son, he doesn't know how to suck on things. He doesn't know how to take a bottle or how to breastfeed. These are stuff that he never ever done at all. Ever."* Another mother described how the medical devices influenced the infant's behavior: *"He is intubated and when he cries, you don't hear him crying."* Mothers also voiced stress from the inability to interact or assess their infant's behavior. One mother shared, *"She was under lights and we don't have much interaction with her and it's really hard to."*

Actual and Perceived Severity of Illness—The PCICU Parental Stress Model posits that within the infant category of stressors, infant severity of illness can be a source of stress to mothers. In this study, mothers described two facets of infant severity of illness that encompass both the actual and the perceived severity of the infant's illness: critical status changes during the hospitalization and the realization that the infant's illness was the beginning of a long road and chronic illness. This diametrical phenomenon of critical events

in the present compiled with the perceived chronicity of the future caused significant stress for mothers.

Critical status changes during the hospitalization: Mothers described that each day it seemed that something was happening with their infants. Infants after surgery from complex CHD often have a nonlinear recovery and can experience a myriad of complications, causing the hospital experience to have many surprises for mothers and emotional ups and downs[26]. When describing her stress, one mother agreed with another mother in the focus group, saying, *“One day it would be good, the next it will be horrible and kind of back and forth... I understand what you mean by the roller coaster ride because in the past two weeks that’s all it was.”*

Another mother shared her stressful experience after her infant’s cardiac arrest:

Then it became more stressful because he was doing well on his first surgery but the next day we came to the hospital and he flat lined, and they saved him and put him on ECMO [extracorporeal membrane oxygenation] the next couple of days and then took him off... It was kind of back and forth like ‘he is doing really well’ and then like ‘he dies’, and then ‘he is doing really well’ and then like ‘he dies’. So that was so stressful.

Beginning of a long road: In addition to contending with the day-to-day changes in their infant’s health status, mothers must manage the reality that their child also has a chronic illness and that this hospitalization is only the beginning of a long road ahead. Mothers made comments such as, *“It seems like it’s never going to end,”* and, *“I think for the most of us our child is going to live with a complex heart disease for their rest of their lives. So this is the beginning of a hard road.”*

Even in the midst of their infant’s critical care hospitalization, mothers expressed stress about the long road ahead and what that would mean for their caretaking responsibilities after discharge. Mothers mentioned their concerns about learning *“how to hold him down when you feed him,” “putting the feeding tube”* in place, or not being able to *“buzz over to the nurse”* if they need help or are worried that something is wrong. One mother stated, *“I know that they have classes to help you to learn how to do stuff and they won’t send you home if you don’t feel comfortable taking care of your baby, but it still makes me nervous.”*

Another mother described her resolve despite the stress:

I know that my son is going to be sent home with a machine so it’s definitely [going to] be completely different than what we are all used to. But that is something that we have to do, we just have to figure it out while our kids are here. He had this surgery... he came along this far.

Parent

Mothers described stressors arising from themselves as a parent in their situation with a baby in the PCICU. Additional codes emerged within the parent category that were not previously described by the PCICU Parental Stress Model. In total, the codes of parental role alteration, worry/uncertainty of outcome, loss of normalcy, loneliness, life circumstances,

and family dynamics were highlighted as stressors by most of the mothers in the focus groups. Mothers also described circumstances in their personal life impacting their stress, such as maternal health, finances, and distance from home.

Parental Role alteration—Mothers expressed a longing to participate in parenting activities to care for their baby. Mothers felt unable to do *“all sorts of little things that are normal,”* mentioning tasks such as diaper changing or breastfeeding. One mother stated, *“You feel helpless. You want to comfort your baby but you cannot touch him.”* Another mother shared that when her baby appeared to be in pain, *“All I can do is sit back.”* This inability to protect, comfort, and care for their child was a source of extreme stress for mothers.

In addition, mothers highlighted two specific areas within parental role alteration that caused additional stress: holding and time alone with their baby. They also mentioned that the ability to hold and be alone with their baby was stress reducing.

The hardest part was when he was intubated for several days after he was born and we weren't able to hold him and that has been really hard. He was extubated so we were able to hold him for couple of days before his surgery which was very nice. You feel very comfy and cozy when you hold him and it made us feel better.

Mothers mentioned that little time exists to be alone with their baby in the PCICU. They longed for uninterrupted time.

There is very little time alone with your child. I guess that there is so much going on with your child. There are like 50 specialists wanting to talk to you while you are there, and there is just a very little time not to hear about blood pressure. I understand why it is like that, but it is just very little time being there without being interrupted.

Worry/Uncertainty about outcome—Another stressor within the parent category that mothers discussed as stressful was the worry and concern they felt over the unknown health outcome for their child. *“It's just the unknown,”* one mother said crying. Another mother stated, *“It's like a nightmare that you just cannot wake up from. You wish to wake up, and that this is nothing but a bad dream but you just cannot... Not knowing the outcome.”* Mothers worried about short and long-term outcomes of their child's illness. One mother described her worry each day over what she would have to hear from her baby's physician: *“It was very difficult for us and it continues to be very difficult, because in her case they just don't know what is going on with her. So they do tests every day and we come here and the doctor comes down and... what he is going to tell us today?”*

Loss of Normalcy—Mothers described a sense of loss that their normative life experience was gone forever. They felt stressed because *“there is just always in the back of your mind that things are not going to be normal.”* One mother stated, *“My whole life before is not what I'm going back to. This is reality right now, and I have an emotional response to that. That's hard. How will this ever get back to normal. I'm stressed about the future. How long*

will this last?” The loss of normalcy felt to mothers that it would never subside. *“There’s not light at the end of the tunnel for this world for my baby and that’s hard to swallow.”*

Loneliness—Although mothers longed to have time alone with their baby and cited this as a source of stress, they also admitted that feelings of loneliness affected them as well. One mother said, *“I tend to just break down and start crying after a while because I feel alone. I don’t want to feel alone, I need other people’s presence. I don’t want to feel like I’m fighting this obstacle by myself.”* Another mother commented, *“My husband, he cannot be here every day. We’ve got three kids at home. So I’ve been here by myself. It’s hard, especially when you don’t have nobody here.”* In addition, mothers felt apprehensive about being home alone after their baby was discharged from the hospital. *“It scares me to think that I’ll be there mostly by myself... but I won’t be able just to buzz over to the nurse like come help me.”*

Life Circumstances—Mothers mentioned that they also faced stressors outside of their infant’s hospitalization, including issues such as their health, finances, and distance from home.

Maternal health: Many of the mothers in the focus groups were dealing with health issues, including prenatal health, intrapartum issues, and postpartum recovery, at the same time they were stressed about the health of their infant, describing problems such as asthma, high blood pressure, and swelling. *“I was scared for my own health because they were worried I was getting preeclampsia, so that was scary.”*

Finances: A few of the mothers discussed stress related to their finances. One mother stated: *“That was the other pressure... I was very worried about our finances, I am still worried about that... which is on top of... worrying about your child living or not living.”*

Far distance from home: Some of the mothers lived a far distance from the hospital and had to relocate a few weeks before their infant’s birth so that they could be near the birth hospital when they went into labor. Mothers in this situation felt stressed being so far from home. One mother stated, *“I live far from the hospital, so I’m here 24/7 every day, I don’t leave, I don’t go nowhere.”*

Family Dynamics—Mothers’ relationships with their spouses, parents, children, and other friends and family members were sometimes an additional source of stress. The marital relationship in particular was at risk for severe strain during the infant’s critical illness. *“My husband and I just wanted to strangle each other.”* Another mother said,

I feel that stress can rip apart relationships pretty easily... because you don’t want to feel anything, not even love for your husband... You have to proactively secure your marriage, you have to do it again and again and again.

Mothers also mentioned feeling stress from their own parents. *“It’s just hard when your parents don’t seem to get it.”* Disagreements or misunderstandings occurred, causing additional stress for mothers.

I would call my mom to tell her. I have two sisters that live close by and she would pass them the information incorrectly... maybe I didn't explain it well, but then it would result in all these phone calls from my sisters with completely wrong information. High alarm and it's more stress on us because we feel that we have to re-explain everything.

Mothers with other children experienced mixed emotions when discussing their situation with their children. Mothers were sad when they were not able to be near them. *"I was crying because I miss my other kids. Makes me sad. This is not where I want to be."* Mothers who had responsibilities to their other children during their infant's hospitalization also had additional stress. *"We are staying in a family home... so we have 4 rooms for us and the kids are staying with us, and my family has been back and forth... and it was really scary bringing all the kids down and bringing all the things was nerve-racking."*

Finally, mothers were negatively affected by other family members, specifically through their communication.

I'm sick of people telling me it's going to be okay, like the family- 'it's all going to work out - you'll see.' You know, it probably will, but when you're in that, like all you can do is deal with the minute you are in, you don't want to hear someone say it's all going to be okay.

Personal Factors—Mothers described personal factors influencing their stress experience. The PCICU Parental Stress Model pictures personal factors as separate from the three categories of stressors. However during the coding process, coders agreed that personal factors belonged within the parent category of stressors since mothers were describing inherent factors within themselves. Themes within the personal factors included personality and gender.

Personality: Mothers acknowledged differences in their personalities affecting their stress experience. *"I don't talk a lot."* *"I'm a doer."* *"I'm an emotional person"* *"I'm not an emotional person."* *"I am very emotional but I have strong personality."* Mothers felt that these dissimilarities also influenced which stressors elicited more or less of a stress response.

Gender Differences: Mothers also noted gender differences in the stress experience between mothers and fathers. Mothers believed that fathers were affected by different stressors and *"handled it so much differently."* *"I think we get stressed out of different things I guess. He cannot really handle hearing details about stuff because the details are always changing and the change adds more stress. I like to know details because it helps me to process better."*

Environment

When mothers were asked about what caused stressed for them during their infant's hospitalization, mothers discussed stressors arising from the environment of the PCICU. One stressor included the sights and sounds of the ICU, as the PCICU Parental Stress Model

posits. Three additional codes of stressors emerged: the lack of privacy, never leaving, and constant activity.

ICU Sights and Sounds—The PCICU Parental Stress Model posits that one category of stressors for parents is the sights and sounds of the ICU, which includes the monitor and equipment, noises and alarms, other sick children, other parents and family members of sick children, and the large number of multidisciplinary staff. Mothers in this study agreed. *“There is constantly something, a doc or a nurse or a beeping screen.”* Mothers also described interactions with other parents and families as stressful. During the hospitalization, mothers develop relationships with each other and begin to have concern for other sick children as well as their own. One mother stated *“In the hospital, we are all worried about each other and each other’s babies. You get to know the other babies and parents in the pod.”*

Lack of Privacy—Mothers agreed with each other in the focus groups that the lack of privacy in the PCICU environment was stressful for them. *“It is very hard to find a quiet place in the hospital that it is peaceful and just be able to sit and relax for a few minutes.”* Several of the mothers shared how this affected their ability to have private conversations with their husbands. *“There is always someone in the room with you, and it’s like nowhere in the hospital you can have a private conversation unless you go to the bathroom and lock yourself for a few minutes.”* One mother pleaded,

Tell the doctors to give us an hour without bothering us. Just give me an hour, or couple of minutes to be with my child without everyone storming on top of me. I held him for the first time after the surgery and felt like everyone was just storming around me. ‘Can I just stare at the child that I made? Just leave me alone.’ I feel like when I am actually with him, I just need time.

Never leaving—Mothers expressed difficulty in leaving their newborn infant in the hospital room alone. Although they want to stay with their baby, they said that never leaving the hospital was a source of stress. *“Being in the hospital 24/7 is stressful.”* One mother shared, *“When I get a sleep room, I cannot sleep there. I have to rush back because I think, what if something is going on?”* Another facet to the stressor of never leaving was that mothers described the stress of the length of the hospitalization. *“My husband and I have been here with our baby for over two months now.”*

Constant Activity—Most of the mothers admitted a sense of constant activity and feeling of busyness while their infant was hospitalized in the PCICU. One mother explained, *“By the time you are here, it’s constant one thing after another. Even trying to pump, all the doctors coming in... so overwhelming. I had one night when I got depressed with everything going on.”* The constant activity was stressful to some mothers while others appreciated that it helped time to pass more quickly. One specific task mentioned by several mothers that required significant time and energy was mechanical breast pumping to initiate lactation. *“I had to pump every two hours... I felt like I’ve been running around doing that.”*

Stress Response

As a result of the stressors experienced by mothers during their infant's hospitalization in the PCICU, mothers were affected by two categories of stress responses: psychological and physical.

Psychological—Psychological responses described by mothers included emotions, shutting down, and Post-Traumatic Stress Disorder (PTSD).

Emotions: Several mothers were very tearful throughout the focus groups and expressed feelings of deep sadness. *"I cried every day."* Mothers felt sad about their infants and also for themselves. One mother felt a challenge to not feel sorry for herself:

For me, the consequence of stress is that I start to lose sight of why: that God has brought us here for a reason. I get really focused on my circumstances. It's all about me and how I'm feeling, and I lose sight of everyone else and there are other people here going through very similar or other things... I know that the rest of the world is going on but all I want to do is throw myself a pity party and be stuck there.

Mothers also described a sense of anger in response to the stress they were feeling. *"I went through this rage that if anyone had crossed my path I just was like 'don't look at me.' I wanted to rip everyone's head off. I wasn't pleasant."* Guilt was another emotion recounted by mothers. *"I feel guilty because I'm focusing on me."* Guilt was also present during daily decision-making: *"Every night I think 'maybe I should stay here tonight, maybe I should stay here tonight' and we don't and it's hard."*

Many mothers articulated avoidance behaviors. *"You just want to shut down all together so you don't feel pain, any good or bad emotions."* Mothers also wanted to discontinue communication. *"I didn't want to feel pitied. I didn't want to talk about it, anyone knowing about it. Don't come to me telling me no positive stories."*

Post-traumatic Stress Disorder (PTSD): Mothers specifically cited PTSD as a response to their stress. One mother described post-traumatic symptoms: *"Every time I am going back home I have a flashback of my son going to cardiac arrest."* Another mother shared her diagnosis with the focus group: *"I was recently diagnosed by the hospital psychiatrist with PTSD and it is very not uncommon to have with everything that we were going through here."*

Physical—Mothers believed that the stress they were experiencing was causing physical symptoms, including elevated blood pressure and headaches. *"I was just feeding the cycle of my blood pressure because I was worried about it... and I wasn't sure you know. I was like 'I have a headache'... and I was like, 'Of course I have a headache, because I'm freaking out right now.'"* One mother explained, *"So much stress can make you sick."* Another mother became so sick after seeing her infant for the first time after surgery that she was taken to another hospital. *"I couldn't breathe... so they had to take me [to the hospital]. I have asthma so they had to put me on the asthma thing and watch me for a while. My blood pressure was extremely high. My feet and hand were beyond swollen."*

Another mother mentioned stress affecting her ability to breathe deeply. *"[My baby] had this surgery two days ago and I realized I haven't taken deep breaths since then. I felt like I was holding my breath... When you hold your breath, I feel that it's kind of like stress is not going to go away."* Mothers also experienced changes in their eating and sleeping patterns. *"I didn't eat for 5 days."* *"I'm not sleeping well."* One mother expressed her desire to feel less stressed so that she could *"have more energy.... I don't want to constantly sleep."*

Time Points of Heightened Stress

During the focus groups, mothers were asked about the things that caused them stress and how the stress affected them. Although not originally stated in the aims for this study, the element of time points of heightened stress emerged as a distinct theme. Mothers highlighted specific time points of heightened stress, from the time they received their infant's diagnosis with CHD to their infant's present hospitalization. Five distinct time points emerged: Prenatal Diagnosis, Postnatal Diagnosis, Labor and Birth, Day of Surgery, and Waiting Game.

Prenatal Diagnosis and Postnatal Diagnosis—Mothers described the diagnosis of their infant's complex CHD, whether prenatal or postnatal, as *"extremely scary and stressful."* If prenatally diagnosed, the stress continued throughout the rest of the mothers' pregnancy. *"In the whole pregnancy it's been terrible."* Some mothers were grateful for the prenatal diagnosis because it gave them time to process the difficult news. *"I was nervous since this is my first baby, and knowing that he will have surgery soon after he is born added to that. But I was very thankful that we were knowing about it since the second half of my pregnancy."*

Labor and Birth—As mothers' due dates approached, some mothers had to travel away from home and live near the birth hospital so that their infant could be delivered safely by the cardiac team and be admitted directly to the PCICU. Mothers described this period of time as very stressful. *"The last couple of days of my pregnancy were like extremely stressful."* When labor began, stress continued through the infant's birth. *"So when it was time to go in labor and that was a very stressful moment, like, what it would be like? They pulled the baby out... and that was the scariest moment."*

Day of Surgery—After the birth of their infants, mothers emphasized the day of surgery as the next time point of extreme stress. The day of surgery was described by mothers as *"stressful"* and a *"nightmare."* One mother said, *"During the surgery they had to do CPR and that was the worst call in my life because they said he didn't respond, so we rushed over here and that's very scary."*

Waiting Game—The time period after the infant's cardiac surgery and subsequent recovery in PCICU was characterized by mothers as a *"waiting game."* Stress arose from this time period particularly with status changes in the infant or in the infant's plan of care. *"Every time we go back [home] we are kind of waiting to see if the phone is going to ring that he had something bad and we need to come back."* This often occurred as the infant's discharge date approached. *"She was just like 'yes! we are going home' and then 'we are*

not. ' And I told to my husband 'I wouldn't believe we are going until we get the papers and I will be outside the door.' ”

Discussion

Mothers in this study provided themes to support, refine, and expand the PCICU Parental Stress Model. Mothers validated that their stress arises from three categories of stressors: infant, parent, and environment. Within the infant stressor category, mothers confirmed that infant appearance and behavior are a significant source of stress. Studies from both NICU and PCICU settings have found that infant appearance and behavior is the highest source of stress for mothers during the critical care admission[8, 13, 15]. Despite attempts by nurses to provide anticipatory guidance to mothers on the appearance of their infant after cardiac surgery, mothers were overwhelmed by their infant's appearance and felt that nothing could have prepared them.

Infant severity of illness was also confirmed by mothers to be a source of stress. When mothers described the severity of illness of their infants, they highlighted the critical status changes during the hospitalization and the feeling that the infant was in the early stages of a chronic illness. Mothers described their infant's hospitalization as a roller coaster ride, with many emotional ups and downs. In a recent phenomenology study describing the experience of parents when their child undergoes cardiac surgery, Wei also found that parents used the term “roller coaster” to depict their emotional journey[27]. Critical status changes can occur in any infant after cardiac surgery for any type of CHD. These rapid swings in the infant's status from one extreme of doing well to the other extreme of critically unwell is extremely stressful for mothers. Severity of illness is usually defined in studies by the type of physiology, surgery, or severity scoring[20, 28, 29]. These studies report mixed results on the impact of severity of illness on maternal stress. This may be partly due to the variation in how actual severity of illness is measured for CHD and that no studies have examined perceived severity of illness on maternal stress response after cardiac surgery. Additional research is needed to determine the relationship between actual severity of illness and perceived severity of illness on maternal stress response.

Mothers supported several themes within the parent stressor category, including parental role alteration, worry/uncertainty in outcome, life circumstances, and personal factors. Parental role alteration has consistently been reported in the literature as one of the greatest sources of stress for mothers with infants in critical care settings[8, 15, 30–32]. As mothers described their feelings of altered parental role, they highlighted two specific parental functions, which when unable to perform, were stress provoking: holding and time alone with their baby. These two practices are among the most innate maternal functions and they are inhibited in the PCICU setting. Mothers are desperate to touch and hold their infants and be with them without intrusions from others. Unfortunately, mothers are rarely able to initiate bonding moments in the PCICU without assistance from staff [33]. Nurses are well-positioned to support maternal-infant bonding and reduce maternal stress in the PCICU by facilitating infant holding during a quiet time and minimizing interruptions.

Worry and uncertainty over outcome has been found to contribute to parental stress in other populations and settings and often occurs during the early parenting experience for parents of infants with complex CHD[8, 33–36]. Its impact, however, on stress response and the overall functioning of parents is unknown. Menahem and colleagues examined locus of control in mothers of children with CHD and found that mothers' preoperative and postoperative scores on the locus of control questionnaire revealed that mothers perceive circumstances due to luck or chance[37]. The authors posited that it may be a natural outcome from an infant's CHD diagnosis, "a random event out of their control and with a perceived unpredictable outcome at least prior to surgery. Why it persisted despite a good surgical outcome remained unclear" [37](p606–607). The authors contend that locus of control was influenced by the parents' inability to predict the future and worrying over the ultimate outcome of their child's CHD. Worry over the uncertainty of outcome merits further exploration as a variable in parental stress research. Life circumstances, such as financial burden, has received some attention in published literature. One study explored predictors of distress and hopelessness for parents of children with CHD. Findings suggested that the parents who were concerned about their finances have a two to three times higher risk level of distress than parents who do not have financial concerns [38]. Socioeconomic status has not shown to impact parental stress, but this study's findings suggest that the stress may arise from specific financial circumstances as opposed to a certain level of income, as examined by studies in other critical care settings [39].

The mothers in this study provided additional concepts with the parent category, including loss of normalcy, loneliness, and family dynamics. In Rempel's grounded theory study on parenting a child with hypoplastic left heart syndrome, a specific form of complex CHD, the first stage of parenting was described as an adjustment to the loss of a parent's expectation of a perfect child[33]. Rempel acknowledged that parents did not describe the experience of a normal grieving process after learning about their infant's cardiac condition. The current study suggests that this loss of normalcy also contributes to maternal stress. Acknowledging the condition and grieving its potential impact is an important first step towards normalization for families of children with chronic illness[40]. Normalization has been described as integral in the life of families with children who have CHD[36, 41]. More research is needed to understand the relationship between the loss of normalcy, grief, family functioning, and short and long term stress for parents of infants with complex CHD. Loneliness was a new theme that emerged from data analysis in this study and has not been a focus in most of the published studies on parents of infants or children with CHD. Lawoko and Soares found that social isolation was a contributor to psychosocial morbidity, including depression, anxiety, and somatization, in parents of outpatient children with CHD[42]. In this study, mothers reflected on their feelings of loneliness as a part of the stress experience. The relationship between loneliness and stress for mothers in the PCICU requires further study for this population.

Family dynamics is a broad category, encompassing the mother's relationships with the infant's father, grandparents, siblings, and other family members. Studies have shown a relationship exists between the number of siblings and the stress response of mothers [8, 43]. Other family support systems, such as social support, has been described as beneficial for parents of children with CHD [39, 44]. This study suggests that these relationships, while

often supportive, may also experience strain during the stressful time of the infant's diagnosis, birth, cardiac surgery, and recovery. Once strained, mothers may perceive stress from miscommunication or differences in perspectives with others. Families may need assistance navigating these issues during the infant's hospitalization [45].

Personal factors, the final theme within the parent category, included personality traits and gender. Mothers discussed differences in personality that affected their stress experience. Trait anxiety is defined as an individual's tendency towards becoming anxious and can be conceptualized as a personality characteristic. During the revision of the PCICU parental stress model, trait anxiety did not emerge as a distinct coded theme, but can be considered a personal factor and was therefore moved into the parent category. Trait anxiety has been found to influence the stress experience for parents of critically ill children in other studies [8, 13, 46]. Gender differences are well-known to influence the stress experience, as noted by mothers in this study [10, 13, 47]. Mothers, in particular, have been shown to perceive greater stress and anxiety in the intensive care environment, when compared with fathers [13, 15, 47, 48]. Studies and interventions addressing stress for parents in the PCICU must attend to gender differences. More research is needed to describe the differences in the nature of the stress experience between mothers and fathers.

The PCICU environment, with its sights and sounds, constant activity, and lack of privacy created an atmosphere full of strain and tension for mothers. These stressors were compounded by the fact that some of the mothers' infants required long hospitalizations and were therefore trapped in the ICU environment for a prolonged period. Studies have shown that the sights mothers see and the sounds mothers hear unique to the ICU environment cause inordinate stress [49–51]. The ICU sights and sounds have been also significantly associated with symptoms of PTSD in mothers of critically ill children [9].

Mothers in this study supported the PCICU Parental Stress Model's assertion that stress response includes both psychological and physical components. Many studies have also supported this phenomenon. Fear, anxiety, depression, somatization, fatigue, sleep disturbance and PTSD, have all been associated with stress in the ICU [9, 43, 52–56]. Standards of care vary across PCICUs and few provide structured, mental health programs for parents that offer psychological screening and treatment for these issues. A paucity of literature exists describing the physical health of mothers whose infants are receiving intensive care, but emerging evidence suggests that mothers who are more unwell have increased stress [57]. More research is needed exploring the link between maternal health, stress, and the psychological and physical symptoms of stress response in the setting of the infant's PCICU stay.

Finally, this study's results revealed a new element of stress, not originally depicted by the PCICU Parental Stress Model: time. Mothers described specific time points of heightened stress that aggravated the overall stress experience for mothers. These time points included the infant's prenatal and postnatal diagnosis, labor and birth, day of surgery, and the time frame before discharge that mothers termed a "waiting game." Additional studies have described similar time periods of inordinate and overwhelming stress [4, 27]. Studies examining parental stress for this population should focus on the time points of diagnosis of

CHD, birth, the day of surgery, and the subsequent ICU hospitalization as the infant recovers. Of note, during revision of the PCICU Parental Stress Model, the timing of diagnosis was removed from its original classification as a personal factor and placed into a separate timeline to include all of the points of heightened stress revealed by this study's results.

While most of the themes within the PCICU Parental Stress Model were supported by this study, some themes were not discussed by mothers. Infant pain, unmet needs, ICU staff, and unexpected admission did not emerge as distinct themes in this small study, but these have been described in other research studies [30, 31, 35, 58–61]. Because mothers are inundated with a great number of stressors, perhaps mothers focused on the most salient stressors as opposed to providing an exhaustive list.

Implications

Pediatric cardiovascular nurses are uniquely positioned in the PCICU to influence the stress experience of mothers whose infants are being cared for after surgery for complex CHD. As nurses provide anticipatory guidance for mothers before their infant's surgery, they can warn mothers of the significant shock that occurs upon seeing the infant postoperatively despite receiving preparatory education through standard prenatal visits and unit tours. Nurses can partner with mothers to develop a plan for support for that significant moment. Nurses can also proactively intervene so that mothers perceive less stress from infant behavior during the infant's postoperative recovery [10]. Education on how to read infant cues and assistance in the interpretation of cues at the point of care may reduce maternal stress response and enhance maternal-infant interaction at the bedside[62]. Nurses can also enhance mother's participation in care and mitigate parental role alteration. The COPE intervention has been successful to reduce parental stress and anxiety for parents of children with critical illness through augmentation of the parental role. Enhanced participation of parents in cue-based care is one of the core components of the COPE intervention, developed by Melnyk and colleagues and implemented in neonatal and pediatric intensive care [52, 63]. Nurses can also provide additional support to mothers when their infants experience abrupt changes in their clinical status, such as an acute decompensation postoperatively. Nurses need to be mindful, however, that even when the infant appears stable, mothers may be stressed because their perception of the infant's severity of illness is elevated or by the thought that their infants are facing a life-long chronic illness.

Nurses can change certain aspects of the critical care environment to reduce stress in mothers, creating opportunities for mothers to spend time with their infants alone without interruptions and enhancing privacy[64]. The provision of developmentally appropriate clustered care, when care is given followed by a period of rest, may minimize maternal perception of constant activity occurring with their infant, as expressed by mothers in this study. Nurses can coordinate an afternoon "quiet time" where no medical interventions are scheduled to be performed and staff interruptions are limited [65]. Some of these efforts may not be feasible during certain critical periods of the infant's postoperative recovery, but nurses can practice with enhanced sensitivity and provide additional support to mothers during these periods.

Nurses can advocate for psychological screening and treatment strategies to address mothers' physical and mental health conditions during their infants' hospitalization[66]. Studies examining parental stress for this population should focus on the time points of diagnosis of CHD, birth, the day of surgery, and the subsequent ICU hospitalization as the infant recovers. Nurses can lead the development of structured interventions, such as in-hospital parent education and support groups, to reduce parental stress throughout the PCICU admission and target these time points as well[66].

Many of the nursing interventions described as implications for this study, including clustered care, parent participation in care, and cue-based care, are components of individualized, family centered, developmental care, an approach to care that has become the standard of care for neonatal intensive care [67, 68]. In the last five years, four papers have emerged in the scientific literature calling for a paradigm shift for PCICUs to strategically incorporate developmental care practices [8, 10, 69, 70]. This study provides further evidence that developmental care would benefit the patient-family experience and improve outcomes, specifically to reduce maternal stress. Staff nurses and advanced practice nurses can provide the necessary leadership to create multidisciplinary efforts to enact policy and culture changes across PCICUs to adopt individualized, family-centered, developmental care as standard practice.

Limitations

This descriptive qualitative study used directed content analysis to support and refine the PCICU Parental Stress Model. Additional studies with larger, more heterogeneous sample sizes are needed to further develop the model and explore relationships among the variables. The small and homogeneous sample of mothers decreases this study's generalizability. Additional studies need to include fathers to explore paternal experiences of stress and determine whether the revised PCICU Parental Stress Model can be applied to fathers as well. Future research must include mothers and fathers with more diverse ethnic and cultural backgrounds to ensure that no other components are missing from the PCICU Parental Stress Model. Other stressors or responses to stress could emerge from samples of mothers and fathers with varying ethnic backgrounds, language barriers, less social support, or lower levels of education.

Conclusions

Although mostly consistent with the original PCICU Parental Stress Model, this study's findings contributed to adding one additional theme within the model, time points of heightened stress, and expanding the categories of stressors by naming additional stressors within each category of infant, parent, and environment. The majority of themes and categories posited by the revised PCICU Parental Stress Model were found to be supported by literature. The model is useful for elucidating the stress experience for parents with infants hospitalized in a PCICU for cardiac surgery. Staff nurses, advanced practice nurses, and nurse researchers can utilize the revised PCICU Parental Stress Model to enhance their practice, education, and science for this unique population and setting.

Acknowledgments

A grant from the Cardiac Center at Children's Hospital of Philadelphia

References

1. Association, A.H. Heart disease and stroke statistics. 2009. Available from: <http://www.americanheart.org/downloadable/heart/1240250946756LS-1982%20Heart%20and%20Stroke%20Update.042009.pdf>
2. Gilboa SM, et al. Mortality Resulting From Congenital Heart Disease Among Children and Adults in the United States, 1999 to 2006. *Circulation*. 2010; 122(22):2254–2263. [PubMed: 21098447]
3. Welke KF, Shen I, Ungerleider RM. Current assessment of mortality rates in congenital cardiac surgery. *Ann Thorac Surg*. 2006; 82(1):164–70. discussion 170–1. [PubMed: 16798208]
4. Hartman DM, Medoff-Cooper B. Transition to home after neonatal surgery for congenital heart disease. *MCN Am J Matern Child Nurs*. 2012; 37(2):95–100. [PubMed: 22357070]
5. Wernovsky G. Current insights regarding neurological and developmental abnormalities in children and young adults with complex congenital cardiac disease. *Cardiology in the Young*. 2006; 16:92–104.
6. Rosenberg KB, et al. Referral for fetal echocardiography is associated with increased maternal anxiety. *J Psychosom Obstet Gynaecol*. 2010; 31(2):60–9. [PubMed: 20443657]
7. Torowicz D, et al. Infant temperament and parental stress in 3 month old infant following surgery for complex congenital heart disease. *Journal of Developmental & Behavioral Pediatrics*. 2010; 31(3):1–7. [PubMed: 20081430]
8. Lisanti AJ, et al. Maternal Stress and Anxiety in the Pediatric Cardiac Intensive Care Unit. *Am J Crit Care*. 2017; 26(2):118–125. [PubMed: 28249863]
9. Colville GA, Gracey D. Mothers' recollections of the Paediatric Intensive Care Unit: associations with psychopathology and views on follow up. *Intensive Crit Care Nurs*. 2006; 22(1):49–55. [PubMed: 16343906]
10. Lisanti AJ, et al. Developmental Care Rounds: An Interdisciplinary Approach to Support Developmentally Appropriate Care of Infants Born with Complex Congenital Heart Disease. *Clin Perinatol*. 2016; 43(1):147–56. [PubMed: 26876127]
11. Miles MS, Holditch-Davis D. Parenting the prematurely born child: pathways of influence. [Review] [105 refs]. *Seminars in Perinatology*. 1997; 21(3):254–66. [PubMed: 9205979]
12. Seideman R, Watson M, et al. Parents stress and coping in NICU and PICU. *Journal of Pediatric Nursing*. 1997; 12(3):169–177. [PubMed: 9198340]
13. Shields-Poe D, Pinelli J. Variables associated with parental stress in neonatal intensive care units. *Neonatal Netw*. 1997; 16(1):29–37.
14. McCusker CG, et al. A controlled trial of early interventions to promote maternal adjustment and development in infants born with severe congenital heart disease. *Child Care Health Dev*. 2010; 36(1):110–7. [PubMed: 19961494]
15. Franck L, Mcquillen A, et al. Parent stress levels during children's hospital recovery after congenital heart surgery. *Pediatric Cardiology*. 2010; 31:961–968. [PubMed: 20495910]
16. Miles MS, Carter MC. Assessing parental stress in intensive care units. *MCN*. 1983; 8:354–359.
17. Holditch-Davis D, Miles MS. Mothers' stories about their experiences in the neonatal intensive care unit. *Neonatal Network*. 2000; 19(3):13–21.
18. Lazarus, RS., Folkman, S. *Stress, Appraisal and Coping*. New York, NY: Springer; 1984.
19. Lazarus, RS. *Psychological stress and the coping process*. New York, NY: McGraw-Hill; 1966.
20. Lisanti, A. *Digital Dissertations*. 2014. Maternal stressors and stress response in a pediatric cardiac intensive care unit.
21. Sapolsky RM, RLM, MAU. How do glucocorticoids influence stress responses? Integrating permissive, suppressive, stimulatory, and preparative actions. *Endocrine Reviews*. 2000; 21(1):55–89. [PubMed: 10696570]
22. Lazarus, RS. *Stress and emotion: A New Synthesis*. New York, NY: Springer; 1999.

23. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000; 23(4):334–40. [PubMed: 10940958]
24. Speziale, HJS., Carpenter, DR. *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. 4. Philadelphia, PA: Lippincott Williams & Wilkins; 2007.
25. Hsieh H, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*. 2005; 15(9):1277–1288. [PubMed: 16204405]
26. Johnson EA, et al. Surgical Quality Predicts Length of Stay in Patients with Congenital Heart Disease. *Pediatr Cardiol*. 2016; 37(3):593–600. [PubMed: 26739006]
27. Wei H, et al. Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing. *Heart & Lung*. 2016; 45(2):154–160. [PubMed: 26831373]
28. Mörelius E, Lundh U, Nelson N. Parental stress in relation to the severity of congenital heart disease in the offspring. *Pediatric Nursing*. 2002; 28(1):28–34.
29. McCusker CG, et al. Determinants of neuropsychological and behavioural outcomes in early childhood survivors of congenital heart disease. *Arch Dis Child*. 2007; 92(2):137–41. [PubMed: 17030557]
30. Foster J, et al. Parental stress and satisfaction in the non-tertiary special care nursery. *J Adv Nurs*. 2008; 61(5):522–30. [PubMed: 18261061]
31. Gale G, et al. Parents' perceptions of their infant's pain experience in the NICU. *International Journal of Nursing Studies*. 2004; 41(1):51–58. [PubMed: 14670394]
32. Joseph RA, et al. Ethical issues in newborn care. Stress in fathers of surgical neonatal intensive care unit babies. *Advances in Neonatal Care*. 2007; 7:321–325. [PubMed: 18097216]
33. Rempel GR, et al. Parenting under pressure: a grounded theory of parenting young children with life-threatening congenital heart disease. *J Adv Nurs*. 2013; 69(3):619–30. [PubMed: 22616855]
34. LaMontagne LL, Pawlak R. Stress and coping of parents of children in a pediatric intensive care unit. *Heart Lung*. 1990; 19(4):416–21. [PubMed: 2098003]
35. Youngblut JM, Brooten D, Kuluz J. Parents' reactions at 24–48 hrs after a preschool child's head injury. *Pediatric Critical Care Medicine: A Journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*. 2005; 6:550–556.
36. Lee A, Rempel GR. Parenting children with hypoplastic left heart syndrome: finding a balance. *J Spec Pediatr Nurs*. 2011; 16(3):179–89. [PubMed: 21702878]
37. Menahem S, Poulakis Z, Prior M. Children subjected to cardiac surgery for congenital heart disease. Part 2 - parental emotional experiences. *Interact Cardiovasc Thorac Surg*. 2008; 7(4):605–8. [PubMed: 18490367]
38. Lawoko S, Soares JJ. Distress and hopelessness among parents of children with congenital heart disease, parents of children with other diseases, and parents of healthy children. *J Psychosom Res*. 2002; 52(4):193–208. [PubMed: 11943238]
39. Aamir M, et al. Predictors of Stress Among Parents in Pediatric Intensive Care Unit: A Prospective Observational Study. *Indian Journal of Pediatrics*. 2014; 81(11):1167–1170. [PubMed: 24728700]
40. Deatrick JA, Knafl KA, Murphy-Moore C. Clarifying the Concept of Normalization. *Journal of Nursing Scholarship*. 1999; 31(3):209–214.
41. Gantt L. As normal a life as possible: Mothers and their daughters with congenital heart disease. *Health Care for Women International*. 2002; 23:481–491. [PubMed: 12171698]
42. Lawoko S, Soares JJF. Psychosocial morbidity among parents of children with congenital heart disease: A prospective longitudinal study. *Heart & Lung*. 2006; 35(5):301–314. [PubMed: 16963362]
43. Busse M, et al. Parents' responses to stress in the neonatal intensive care unit. *Crit Care Nurse*. 2013; 33(4):52–9. quiz 60. [PubMed: 23908169]
44. Tak YR, McCubbin M. Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. *J Adv Nurs*. 2002; 39(2):190–8. [PubMed: 12100663]
45. Hakio N, et al. Parents' experiences of family functioning, health and social support provided by nurses--a pilot study in paediatric intensive care. *Intensive Crit Care Nurs*. 2015; 31(1):29–37. [PubMed: 25439139]

46. Scrimin S, et al. Anxiety and stress in mothers and fathers in the 24 h after their child's surgery. *Child Care Health Dev.* 2009; 35(2):227–33. [PubMed: 19228156]
47. Shaw RJ, et al. Acute stress disorder among parents of infants in the neonatal intensive care nursery. *Psychosomatics.* 2006; 47(3):206–212. [PubMed: 16684937]
48. Dudek-Shriber L. Parent stress in the neonatal intensive care unit and the influence of parent and infant characteristics. *American Journal of Occupational Therapy.* 2004; 58(5):509–520. [PubMed: 15481778]
49. Haines C, Perger C, Nagy S. A comparison of the stressors experienced by parents of intubated and non-intubated children. *J Adv Nurs.* 1995; 21(2):350–5. [PubMed: 7714294]
50. Spencer, Edwards. Neonatal intensive care unit environment: A review from the parents' perspective. *Journal of Neonatal Nursing.* 2001; 7(4):127–131.
51. Wereszczak J, Miles MS, Holditch-Davis D. Maternal recall of the neonatal intensive care unit. *Neonatal Netw.* 1997; 16(4):33–40.
52. Melnyk BM, et al. Creating Opportunities for Parent Empowerment: Program Effects on the Mental Health/Coping Outcomes of Critically Ill Young Children and Their Mothers. *Pediatrics.* 2004; 113(6):e597–607. [PubMed: 15173543]
53. Franck LS, et al. Measuring neonatal intensive care unit-related parental stress. *J Adv Nurs.* 2005; 49(6):608–15. [PubMed: 15737221]
54. Preyde M, Ardal F. Effectiveness of a parent “buddy” program for mothers of very preterm infants in a neonatal intensive care unit. *Canadian Medical Association Journal.* 2003; 168(8):969–973. [PubMed: 12695379]
55. Turan T, Basbakkal Z, Ozbek S. Effect of nursing interventions on stressors of parents of premature infants in neonatal intensive care unit. *Journal of Clinical Nursing.* 2008; 17(21):2856–2866. [PubMed: 18637857]
56. Board R, Ryan-Wenger N. Stressors and stress symptoms of mothers with children in the PICU. *J Pediatr Nurs.* 2003; 18(3):195–202. [PubMed: 12796862]
57. Wu CY, Hung CH, Chang YJ. Predictors of Health Status in Mothers of Premature Infants with Implications for Clinical Practice and Future Research. *Worldviews Evid Based Nurs.* 2015; 12(4): 217–27. [PubMed: 26220369]
58. Curley M, Wallace J. Effects of the nursing Mutual Participation Model of Care on parental stress in the pediatric intensive care unit. *Journal of Pediatric Nursing.* 1992; 7(6):377–385. [PubMed: 1291673]
59. Fisher MD. Identified needs of parents in a pediatric intensive care unit. *Crit Care Nurse.* 1994; 14(3):82–90.
60. Lam J, Spence K, Halliday R. Parents' perception of nursing support in the neonatal intensive care unit (NICU). *Neonatal, Paediatric & Child Health Nursing.* 2007; 10(3):19–25.
61. Franck LS, et al. Parental concern and distress about infant pain. *Archives of Disease in Childhood.* 2004; 89(1):F71–F75. [PubMed: 14711862]
62. Loo KK, et al. Using Knowledge to Cope with Stress in the NICU: How Parents Integrate Learning to Read the Physiologic and Behavioral Cues of the Infant. *Neonatal Netw.* 2003; 22(1):31–37. [PubMed: 12597089]
63. Melnyk BM, et al. Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics.* 2006; 118(5):e1414–27. [PubMed: 17043133]
64. Carter BS, Carter A, Bennett S. Families' views upon experiencing change in the neonatal intensive care unit environment: from the 'baby barn' to the private room. *Journal of Perinatology.* 2008; 28(12):827–829. [PubMed: 18596717]
65. Laubach V, Wilhelm P, Carter K. Shhh... I'm growing: noise in the NICU. *Nurs Clin North Am.* 2014; 49(3):329–44. [PubMed: 25155533]
66. Hynan MT, et al. Recommendations for mental health professionals in the NICU. *J Perinatol.* 2015; 35(Suppl 1):S14–8. [PubMed: 26597800]
67. Altimier LB, et al. Developmental care: changing the NICU physically and behaviorally to promote patient outcomes and contain costs. *Neonatal Intensive Care.* 2004; 17(2):35–39.

68. Kenner, C., McGrath, JE. Developmental care of newborns and infants: guide for health professionals. Philadelphia: Mosby; 2010.
69. Torowicz D, et al. A developmental care framework for a cardiac intensive care unit: a paradigm shift. *Adv Neonatal Care*. 2012; 12(Suppl 5):S28–32. [PubMed: 22968003]
70. Sood E, et al. Developmental Care in North American Pediatric Cardiac Intensive Care Units: Survey of Current Practices. *Adv Neonatal Care*. 2016; 16(3):211–9. [PubMed: 27140031]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Figure 1.

The PCICU Parental Stress Model

©2017 by the American Association of Critical-Care Nurses. Used with permission.

(Lisanti, Allen, Kelly, Medoff-Cooper, 2017).

Figure 2.

The PCICU Parental Stress Model - Revised with new themes/categories in red.

Table 1

Maternal demographics

Variable	Category	No.	%*
Maternal Race	Black/African American	1	7
	White	13	93
Marital Status	Single	1	7
	Married	13	93
Level of Education	Graduated High School	2	14
	Partial college	2	14
	College graduate	5	36
	Master's degree	4	29
	PhD/doctoral	1	7
Number of children	1	4	29
	2	5	36
	3	2	14
	4	3	21

Table 2

Infant Demographics

Variable	Category	No.	%*
Gender	Male	11	78.6
	Female	3	21.4
Cardiac Physiology	Single Ventricle	10	71.4
	Two Ventricle	4	28.6
Cardiac Diagnosis	Tricuspid Atresia	1	7.1
	Epstein's Anomaly	1	7.1
	Double Inlet Left Ventricle	1	7.1
	Double Outlet Right Ventricle	1	7.1
	Double Outlet Left Ventricle	1	7.1
	Hypoplastic Left Heart Syndrome	4	28.6
	Aortic Valve Atresia	1	7.1
	Aortic Arch Anomaly	3	21.4
	Interrupted Aortic Arch	2	14.3
	Coarctation of the Aorta	1	7.1
	Transposition of the Great Arteries	2	14.3
	Ventricular Septal Defect	1	7.1
	Atrioventricular Canal Defect	1	7.1

* Note: does not total to 100% due to multiple diagnoses.