

THE EXPERIENCES AND CARE NEEDS OF PARENTS
WHOSE CHILDREN ARE BORN WITH CONGENITAL HEART DISEASE

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A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the School of Nursing.

Chapel Hill
2015

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ABSTRACT

Holly Wei: The Experiences and Care Needs of Parents whose Children are Born with
Congenital Heart Disease
(Under the direction of Cecelia I. Roscigno and Kristen M. Swanson)

Congenital heart disease (CHD) is the most prevalent birth defect in the United States. Little research was found regarding parents' experiences of having a child with CHD and their desires for providers' actions in healthcare environments. The purposes of this dissertation were to synthesize research regarding the experiences of families of children with CHD; phenomenologically describe parents' experiences of having a child with CHD; and explain parents' perspectives on healthcare providers' actions during their encounters.

To achieve these purposes, four separate, but related, papers were written. They were: 1) a literature review synthesizing families' experiences of having a child with CHD; 2) a methods paper detailing steps of conducting a phenomenological study; 3) a phenomenological study exploring parents' experiences of having a child with CHD; and 4) a directed content analysis evaluating parents' perceptions of healthcare providers' actions guided by the Swanson's Caring Theory.

Four major foci were addressed in the published research on families of children with CHD in the last 15 years. The foci were: parents' psychological health, impact on family life, parenting challenges, and family-focused interventions.

The methods paper described the philosophy of phenomenology and strategies of choosing sample size, interviewing, and analyzing data using an interdisciplinary team.

Examples were provided about the contribution of an interdisciplinary team to enhance the quality of a phenomenological research project.

Parents experienced a “rollercoaster” of emotions as their child underwent surgery. Critical times were when parents received their child’s diagnosis, were informed that their child required heart surgery, handed their child over to the surgical team, and visited their child for the first time after surgery. Related stressors were the uncertainty of outcomes after surgery, the loss of parental control, the physical appearance of their child after surgery, and the fear of the technological atmosphere in the intensive care unit. Parents’ experiences moved from shocking to blessing.

The five caring processes of the Swanson’s Caring Theory captured parents’ perspectives on providers’ actions. Providers’ caring actions carried parents through their critical times.

This study suggested that future research was warranted to better understand how providers could best meet these parents’ caring needs.

To my family:
Zhiwen, Trent, Aaron, and Ella.
I could not have done this without you all.

ACKNOWLEDGEMENTS

This endeavor would not have been possible without the help and guidance of many. I would like to give my sincere thanks to the following individuals and institutes for their generous help and support.

I would like first and foremost to express my gratitude to my patients and their families, who have sparked my curiosity and impelled me to know more about their experiences and needs. It is their experiences and caring needs that have kept me focus and follow my passion.

I would like to give my sincere thanks to my research funders and the funding institutes. During my dissertation study, I received The Jane Winningham Smith Scholarship twice from the School of Nursing at University of North Carolina at Chapel Hill. Thank you Mr. and Mrs. Smith for your generosity to the school to support doctoral students. Mrs. Smith was a passionate nurse herself. Your contributions have truly left deep imprints in many students' studies. Thank you! Next, I would like to say how honored I was to be the first recipient of The Dr. Lester Sauvage Research Fund from the Hope Heart Institute in Bellevue, WA. Dr. Sauvage was a great caring cardiac surgeon who pioneered bypass graft surgery and many other groundbreaking procedures and devices that are still being used today. He was well known for his patient care – he would sit with patients and their families when they came out of surgery, feed them jello and help them wash their hair, and talk to them about the importance of having a purpose in their life. His caring actions have touched me dearly. I am so honored to be able to acknowledge him in my papers. Thank you!

I would like to say a big thank you to the nurses and nurse managers at the UNC Children's Hospitals. They greeted me and welcomed me with their open arms when I went to their units. The selected nurse managers were Pat Yee and Stephanie Bohling (5 Children/Children's Intermediate Care Center [CICC]), Jennifer Flipping (Neonatal Critical Care Center [NCCC]), Jenny Dixon (Children's Specialty Clinics), and Roger Saunders (Pediatric Intensive Care Unit). I owe an immense appreciation to the nurses on the CICC unit and NCCC for their help and support. Thank you all.

I would also like to thank some individuals who have contributed to my dissertation study. They are Paul Mihas, Star Mitchell and Dr. Yunxian Zhou. I want to thank them for their assistance in my data coding and analysis process. Paul was a tremendous anchor to my study in many ways. Thank you Paul for your expertise in qualitative research methods, ATLAS software, and analytic procedures, and your endless reading of my papers. Thank you Star and Yunxian for your assistance in coding. It was such a pleasure to work with you all.

I would like to thank the professors and staff at the school of nursing at UNC Chapel Hill for their wonderful teaching and support. I could not have possibly accomplished this PhD journey without your teaching and support. I would like to give my thanks to Kathy Moore, Lica, Scott, Deannie, Jessica, Kathy L, Brandy, Karen, Jill, and so many more from UNC-CH, and Toni and Doug from Seattle University. Thank you all so much for your help and support!

Now, I would like to give my genuine gratefulness and appreciation to my dissertation committee. First of all, I would like to say thank you to Dean Kristen Swanson, my faculty adviser at the School of Nursing at UNC Chapel Hill and my mentor at the College of Nursing at Seattle University. Dean Swanson is a nursing theorist and a phenomenological scholar. It is Dean Swanson who took me on as her student and directed me to the path that I am on today.

She was the greatest adviser/mentor any student could ever dream for. Thank you Dean Swanson for your great guidance. Thank you for being my “bulldozer and propeller”, who cleared the road ahead and then propelled me forward. Thank you for making me feel there’s nothing that I could not accomplish. I could not ask for a better mentor than you. Thank you! Next, I would like to thank Dr. Cecelia Roscigno. Dr. Roscigno is my faculty adviser. She is a phenomenological scholar. Dr. Roscigno took me on as her student in the middle of my PhD journey. Since then, she has been a solid anchor to me. She offered me a green field when I needed a shade, and provided me a flowing river when I wanted a drink. Thank you Cecelia for always being there for me and making me feel I was superior. I am so thrilled you are my faculty advisor.

Following, I would like to say a huge thank you to Dr. Beth Black. Dr. Black is an expert on parents of children diagnosed with fetal anomalies. She helped me tremendously to see a different side of the parents in my study. She also taught me strategies on how to recruit, interview, and analyze the data. Her advice has opened my visions to my future studies. Thank you Dr. Black for your wisdom and prodigious support. The next committee member I want to thank is Dr. Diane Hudson-Barr. Dr. Hudson-Barr is an expert on families of children with critical conditions. She helped me greatly with the design, data collection, and data analysis. With her expertise on families, she has helped me immensely on the parents’ interview process.

Following I would like to recognize Dr. Cherri Hanson. Dr. Hanson is an expert on communication between providers and parents in acute care settings, such as PICU. She was a fantastic gatekeeper for my study. She connected me with so many great people in the hospital, such as pediatric cardiothoracic surgeons and psychologists who all agreed to help me with my study. Thank you Dr. Hanson for your willingness to help. Thank you!

Following, I must give my unreserved thanks to my family. You all are my soil, my water, my air, my sky, my sunshine, and my world. I am the luckiest woman on earth to have you all in my life. If it were not for you, it would not have been possible for me to pull this journey through. My dear husband has worn many hats through the years, an alumnus, a friend, a physician colleague, an adviser, a father, and a husband. I have become a better person because of you. Thank you my darling for your encouragement, your support, your trust, and your love! Next, I want to thank my older son Trent. Trent is in the School of Medicine at UNC Chapel Hill. He has helped me read my papers many many many times. Thank you Trent for your valuable feedback! The next person I want to acknowledge is my wonderful younger boy Aaron. Aaron has been a cheerleader in my life. His always-happy personality cheers me up every day. His kisses, hugs, and love mean the whole world for me. Thank you Aaron for being such a positive energy! Lastly, I want to say thank-you to our little doggie Ella. Ella is absolutely a sweetheart. She has been my companion and personal trainer. She was a companion because she always stayed by my side when I studied; and she was a personal trainer because she was the only one who could make me get out of my house and run with her. Thank you dear Ella for being such a great companion!

Thank you everyone from the bottom of my heart!!

TABLE OF CONTENTS

LIST OF TABLES	xiii
LIST OF FIGURES	xiv
CHAPTER 1: INTRODUCTION	1
Background and Significance	1
Statement of Purpose	3
Outline of Dissertation	3
Conclusion	8
References	9
CHAPTER 2: FAMILIES OF CHILDREN WITH CONGENITAL HEART DISEASE: A LITERATURE REVIEW	11
Introduction	11
Methods	12
Results	13
Discussion	21
Conclusions	22
References	24

CHAPTER 3: PHENOMENOLOGY IN HEALTHCARE: A METHODOLOGY EXPLORING PATIENTS’ AND FAMILIES’ EXPERIENCES	50
Introduction	50
Methods	51
Discussion	60
Conclusions	62
References	63
CHAPTER 4: PARENTS’ EXPERIENCES AND PERSPECTIVES HAVING A CHILD WITH CONGENITAL HEART DISEASE	72
Parents’ Experiences of Having a Child Undergoing Congenital Heart Surgery: An Emotional Roller Coaster from Shocking to Blessing	72
Introduction	72
Methods	75
Results	78
Discussion	84
Conclusions	87
References	89
Parents’ Perceptions of Healthcare Providers’ Actions in a Hospital Setting	98
Introduction	98
Methods	100
Results	103
Discussion	112
Conclusions	114
References	116

CHAPTER 5: THE SYNTHESIS OF THE DISSERTATION	120
Synthesis of the Findings	120
Limitations of Dissertation	125
Implications for Research	125
Implications for Clinical Practice	128
Conclusions	129
References	130

LIST OF TABLES

Table 2.1 - Parents' Psychological Health	33
Table 2.2 - Impact on Family Life	39
Table 2.3 - Parenting Challenges	44
Table 2.4 - Intervention Studies	48
Table 3.1 - Steps of Analytical Procedures	66
Table 3.2 - The Processes of Theme-deriving	69
Table 4.1 - Selected Interview Questions	94
Table 4.2 - Parents' Demographics	95
Table 4.3 - Children's Demographics and Clinical Characters	96
Table 4.4 - The Experiences of Parents of Children with CHD undergoing Heart Surgery	97

LIST OF FIGURES

Figure 2.1 - PRISMA flow chart of search, inclusion and exclusion screening, and accepted studies of the review on families of children with	32
Figure 5.1 - The dissertation process	121

CHAPTER 1: INTRODUCTION

Background and Significance

Congenital heart disease (CHD) is the most prevalent birth defect and a leading cause of children's deaths in the United States (Centers for Disease Control and Prevention, 2015). About 40,000 children are born with CHD in the US each year, with an incidence rate of 8-10 per 1,000 live births (American Heart Association, 2015; Centers for Disease Control and Prevention, 2015). Congenital heart disease leads to the longest hospital stays, highest mortality rates, and greatest average hospital costs among birth defects (Robbins et al., 2007). Children's CHD has imposed significant financial impacts on the healthcare delivery system (Pasquali et al., 2011) and families of children with CHD (Connor, Kline, Mott, Harris, & Jenkins, 2010; Duggan, Pearce, & Guilbert, 2001).

In 2000 and 2002, the National Heart, Lung, and Blood Institute launched a major initiative to encourage treatment interventions and clinical research on children with heart disease (Lenfant, 2002). In a literature review on studies of families of children with CHD, researchers found that since the initiatives in 2000 and 2002, the main foci of the studies were on parents' psychological symptoms, such as stress, anxiety, and depression, impact of the child's CHD on family life, and parenting challenges (Wei, Roscigno, Hanson, & Swanson, 2015).

A child's diagnosis of CHD and heart surgery are stressful events for families. While recognizing that parents had significant amount of stress (Franck, McQuillan, Wray, Grocott, & Goldman, 2010) and posttraumatic stress symptoms (Helfricht, Latal, Fischer, Tomaske, & Landolt, 2008) when their child was diagnosed with CHD and underwent heart surgery,

researchers did not study parents' appraisals of their psychological symptoms. In this review, authors identified that the topics that were most insufficiently researched were parents' experiences and expectations of care needs, and their appraisals of healthcare providers' actions when they had a child with CHD undergoing heart surgery (Wei et al., 2015).

Patients' and parents' experiences, expectations for care, and appraisals of healthcare providers' actions are important components in patient satisfaction surveys (Hospital Consumer Assessment of Healthcare Providers and System, 2015). Knowledge of parents' experiences and expectations for care is necessary in improving patients' satisfaction scores and outcomes (Institute for Healthcare Improvement [IHI], 2015). Knowing parents' experiences and expectations is also a crucial step toward building a collaborative relationship with families and improving children's healthcare quality (American Nurses Association and Society of Pediatric Nurses, 2003; Lewandowski & Tesler, 2003; Uhl, Fisher, Docherty, & Brandon, 2013).

In addition, caring has been considered as a central tenet of nursing. Knowing parents' experiences and care needs when their child is undergoing heart surgery is fundamental to a profession that is committed to caring. Only when knowing parents' experiences and expectations for care will nurses be able to formulate and implement appropriate interventions for these parents. So far very few studies have explored parents' experiences and perspectives of healthcare providers' actions when they have a child with CHD undergoing heart surgery. Therefore, it is necessary to explore and understand what parents go through when they have a child is diagnosed with CHD requiring a heart surgery.

The Purpose Statement

Therefore, the purposes of this dissertation were to (a) synthesize the current trends of studies on families of children with CHD; (b) discover parents' experiences when caring for a child with CHD requiring heart surgery; and (c) evaluate parents' perspectives on healthcare providers' caring and non-caring actions during hospital encounters.

Outline of Dissertation

To achieve these purposes, four separate, but closely related, papers were written. The four manuscripts were: 1) a literature review synthesizing families' experiences of having children with CHD, 2) a methods paper detailing steps of conducting a phenomenological study; 3) a descriptive phenomenological study discovering parents' experiences of having a child with CHD; and 4) a directed content analysis study evaluating parents' perceptions of healthcare providers' behaviors guided by the Swanson Caring Theory (Swanson, 1991, 1993, 2015). The outline of the dissertation is as follows.

Chapter 2. Manuscript on a Literature Review

Chapter 2 is the first manuscript, a synthesis of the literature pertaining to families of children with CHD (Wei, Roscigno, Hanson, & Swanson, 2015). The purposes of the literature review were to evaluate the published research on families of children with CHD from 2000 to 2014, synthesize key concepts, critique research methods, identify gaps in existing knowledge that require further exploration, and provide future research directions.

In 2000 and 2002, the National Heart, Lung, and Blood Institute launched two major funding initiatives to encourage treatment innovations and research for families and children with heart disease (Lenfant, 2002). No literature reviews, however, have been done to synthesize the research on families of these children since then.

The literature search was conducted in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA; Moher, 2009). The following databases were searched: PubMed, CINAHL, Family & Society Studies Worldwide, PsycINFO, and Women's Studies International. To capture the experiences of families of children with CHD, search terms included: “congenital heart disease”, “mother”, “father”, “caregiver”, “family”, “infant”, “child*” for child or children, and “parent*” for “parents”, “parenting”, or “parental”.

This manuscript was accepted for publication by the *Heart & Lung - the Journal of Acute and Critical Care* on August 26, 2015. doi:10.1016/j.hrtlng.2015.08.005. This review identified some specific gaps in research, which led to the studies in the following chapters.

Chapter 3. Manuscript on a Methods Paper

Chapter 3 is the second manuscript, a methods paper on conducting a phenomenological study in nursing. The purpose of this manuscript was to demonstrate ways of using an interdisciplinary research approach to conduct a phenomenological study exploring parents' experiences caring for a child with CHD.

Based on the literature review (Wei et al., 2015), one of the under-explored research areas was parents' experiences of having a child with CHD. Parents' experience was an important component of caring (Swanson, 1990, 1991, 1993, 2015). In order to provide an optimal caring environment for patients and families, it is necessary to understand patients' and families' experiences and care needs (Swanson, 2015; Swanson & Wojnar, 2004).

Phenomenology is a methodology investigating human experiences in the everyday world (Giorgi, 2009; Husserl, 1970), and an approach that healthcare providers can use to understand patients' and families' experiences in health and illness (Wojnar & Swanson, 2007). This paper was designed to illustrate the steps of conducting a phenomenological study. The manuscript described the philosophy of phenomenology, the differences between descriptive and interpretive phenomenology, the bases of choosing sample size, the strategies of conducting interviews, and the utilization of an interdisciplinary team to analyze data.

This manuscript was submitted to *the Journal of Nursing Research* and is currently under review.

Chapter 4. Manuscripts on Parents' Experiences and Perspectives on Providers' Actions

Chapter 4 includes two manuscripts, parents' experiences of having a child with CHD and parents' perceptions on healthcare providers' actions in a hospital setting.

The third manuscript - Parents' Experiences of Having a Child Undergoing Congenital Heart Surgery: An Emotional Rollercoaster from Shocking to Blessing

The purpose of the third manuscript was to describe parents' experiences when having a child with CHD undergoing heart surgery. According to the literature review on families of children with CHD published between 2000 and 2014, researchers found that the main focus of the studies was on parents' psychological symptoms, such as stress, anxiety, and depression (Wei et al., 2015). The published studies mainly quantified the symptoms, but did not explore parents' appraisals behind those symptoms.

Patients' and parents' experiences are important components in patient-provider relationship (Kavanaugh et al., 2013; Roscigno & Swanson, 2011), and patient/parent satisfaction surveys (Hospital Consumer Assessment of Healthcare Providers and System [HCAHPS], 2015). Knowing parents' overall experience is the first step toward building a collaborative relationship with families and improving children's quality of care (American Nurses Association and Society of Pediatric Nurses, 2003; Lewandowski & Tesler, 2003).

This manuscript explored parents' experiences, using a descriptive phenomenological approach. Purposeful sampling was used to recruit a group of parents that were diverse in ethnicity, education, and their children's types of CHD. In-depth interviews were conducted to gain a deep understanding of parents' thoughts and feelings when having a child with CHD.

This manuscript has been submitted to the *Heart & Lung - the Journal of Acute and Critical Care*.

The fourth manuscript - Parents' Perceptions of Healthcare Providers' Actions in a Hospital Setting

The purpose of this paper was to describe parents' perceptions of healthcare providers' actions when their child was hospitalized for heart surgery. The research question was "What were parents' perceptions of caring and non-caring actions by healthcare providers when their child was undergoing heart surgery?"

Based on the literature review by Wei et al. (2015), very little research had been done to evaluate parents' perspectives on healthcare providers' actions. Healthcare providers' actions are important components in patient/parent satisfaction surveys (Hospital Consumer Assessment of Healthcare Providers and System, 2015). Even though patient satisfaction has been raised to a high priority in healthcare, there is still little research on patients' appraisals of healthcare providers' actions.

This is a qualitative study. In-depth interviews were conducted. A directed content analysis was performed for data analysis, using the Swanson's Caring Theory as a guide to categorize providers' actions into the five caring processes of the theory.

The target journal for this manuscript is IMAGE: *Journal of Nursing Scholarship*.

Chapter 5. Synthesis of the Dissertation

Chapter 5 is the synthesis of this dissertation. In this chapter, I summarized the findings of the four manuscripts, discussed limitations of the dissertation, and specified implications for future research and clinical practice.

Conclusion

In conclusion, with 40,000 children born with CHD in the US each year, children with CHD and their families represent a significant amount of pediatric patient population. Understanding these parents' experiences and care needs will be a substantial addition of knowledge to the care of families of children with CHD.

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CHAPTER 2: FAMILIES OF CHILDREN WITH CONGENITAL HEART DISEASE: A LITERATURE REVIEW ¹

Introduction

Congenital heart disease (CHD) is the most prevalent birth defect and a leading cause of children's deaths in the United States (Centers for Disease Control and Prevention, 2015a). About 40,000 children are born with CHD each year in the US, with an incidence rate of 8-10 per 1,000 live births (American Heart Association, 2015; Centers for Disease Control and Prevention, 2015a). Congenital heart disease is among the birth defects that lead to the longest hospital stays, highest mortality rates, and greatest average hospital charges in children (Gray et al., 2009; Pasquali et al., 2011; Robbins et al., 2007).

In 2000 and 2002, the National Heart, Lung, and Blood Institute launched two major funding initiatives to encourage treatment innovations and research for children with heart disease, and both initiatives included a focus on families (Lenfant, 2002). No literature reviews, however, have synthesized the research done on families of these children since then. This paper, therefore, reviews the published research on families of children with CHD from 2000 to 2014, synthesizes key concepts, critiques research methods, identify gaps in existing knowledge that require further exploration, and provides future research directions.

¹ This chapter is an article that was accepted for publication in the Journal of Heart & Lung - The Journal of Acute and Critical Care. Accepted for publication on August 26, 2015.

Methods

The literature search was conducted in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA; Moher, 2009). Search strategies were developed by the first and third authors and a university medical research librarian. Databases searched included PubMed, CINAHL, Family & Society Studies Worldwide, Women's Studies International, and PsycINFO. Search terms used to capture the experiences of families of children with CHD included “congenital heart disease”, “mother”, “father”, “caregiver”, “family”, “infant”, “child*” for child or children, and “parent*” for “parents”, “parenting”, or “parental”. These terms were entered in different combinations to ensure an exhaustive search.

To be included, articles should be research-based, focus on families’ experiences, and published between January 2000 and December 2014. The year of 2000 was when the National Heart, Lung, and Blood Institute launched its first major initiative to encourage treatment innovations and research on children with heart disease (Lenfant, 2002) and 2014 was the time of the search. Studies were excluded if they focused only on children with CHD. Because the review was designed to synthesize current information on families of children with CHD, no studies were excluded based on a priori decisions about methodological quality.

Articles were searched using key words and phrases and selected based on the inclusion criteria. After the key words and phrases were entered into the databases, articles were screened by their titles and abstracts. Potential articles were then read in full to decide their eligibility. Articles that met the inclusion criteria were imported into Refworks, where duplicates were identified. Subsequently, a reference list search was done to identify other possible articles (Cooper, 2010).

Data analysis was done following Miles and Huberman's constant comparative analysis method (M. B. Miles & Huberman, 1994). All the articles selected were uploaded into ATLAS ti for Windows to aid the analytic process (Scientific Software Development, 2014). To begin, a list of the content to be extracted was developed, which included study purposes, conceptual frameworks, designs, and key concepts that focused on families of children with CHD. Each article was read several times with memos being done while the content was being extracted. The memos and the extracted content helped us compare findings across studies and find themes. To illustrate, an example of the analytic process was described. While reading the articles, we found that parental stress was a prominent phenomenon, which was noted in our memos. Then "stress" was coded to capture the relevant findings about that topic. Finally, initial codes, such as "stress", "depression", and "anxiety", comprised a broader theme about parents' psychological health.

Results

Ninety-four articles met the inclusion criteria (66 quantitative and 28 qualitative). The PRISMA flow chart (Figure 1) displays the stages of the literature search. Four major themes were inductively derived: parents' psychological health, family life, parenting challenges, and family-focused interventions.

Parents' Psychological Health

Parents' psychological health was defined as parents' emotional responses to their child's CHD, such as stress, depression, and anxiety. Among the supporting articles listed in table 1, 18 of the 24 (75%) articles reported that these parents of children with CHD reported greater stress, depression, and anxiety than the general population. Parents reported emotional ups and downs from the moment they were informed of their child's CHD (Brown, 2003; Werner, Latal,

Valsangiacomo Buechel, Beck, & Landolt, 2014). Upon receiving the diagnosis, they felt shock and disbelief (Fernandes, 2005) and significant stress, whether the diagnosis was made in the prenatal or postnatal period (Brosig, Whitstone, Frommelt, Frisbee, & Leuthner, 2007). When children were hospitalized, parents also reported significant stress (Franck, McQuillan, Wray, Grocott, & Goldman, 2010; Helfricht, Latal, Fischer, Tomaske, & Landolt, 2008; Saied, 2006). Franck et al. (2010) for example, surveyed 211 parents whose children were admitted for CHD interventions and found that parents' stress remained high throughout the hospital stay. Similarly, Lawoko and Soares (2002) compared parents of children with CHD to parents of children with unspecified diseases or healthy children, and found that parents of children with CHD reported significantly higher levels of anxiety, depression, and stress than the reference groups.

The other 6 of the 24 (25%) articles, however, reported that parents of children with CHD did not have higher levels of stress than parents of children without CHD or the general population. Fischer et al (2012) and Vrijmoet-Wiersma et al (2009) for example, found no significant differences in anxiety levels between parents of children with and without CHD, and other investigators found that parents of children with CHD reported significantly lower levels of psychological distress than the general population (Spijkerboer, Utens, Bogers, Helbing, & Verhulst, 2008; Visconti, Saudino, Rappaport, Newburger, & Bellinger, 2002; Utens et al., 2002). Hearps et al (2014) who studied parents of infants who had heart surgery within 4 weeks after birth, found that 60% of the parents rated their risk to have psychosocial issues as low, 36% of the parents rated at the reference levels, and only 2.6% of the parents rated their risk to have psychosocial issues at a clinically high level.

One explanation for the inconsistency of the findings across studies may be the lack of consensus on how and what to measure in regard to parents' psychological symptoms. Investigators used many different scales to measure parents' stress, anxiety, and depression, including the Parenting Stress Index (Abidin RR., 1986), the Brief Symptom Inventory (Derogatis LR, 1993), the Spielberger State Trait Anxiety Inventory (Spielberger CD, 1983), the General Health Questionnaire (Goldberg DP, 1972; W. Goldberg DP PA., 1988), the Symptom Check List-Revised (Derogatis LR., 1994), the Hopelessness Scale (Beck, Kouacs, Weissman, 1975), and the Parent Stressor Scale: Infant Hospitalization (M. S. Miles & Brunssen, 2003).

These scales measure the psychological responses from different perspectives. For instance, the Parenting Stress Index focuses on parents' stress related to parenting, e.g., "I find myself giving up more of my life to meet my child's needs than I ever expected" (Uzark & Jones, 2003, p. 165). The Parent Stressor Scale: Infant Hospitalization (M. S. Miles & Brunssen, 2003) focuses on parents' stress related to the behaviors and appearance of the hospitalized infant, hospital-related parental role interruption, and the scenes and noise of the hospital environment. The General Health Questionnaire (Goldberg, 1972; Goldberg, 1988) assesses parents' psychological distress, including somatic symptoms, anxiety, social dysfunction, and depression. The use of different measurements of parents' psychological symptoms made it difficult to compare studies and may explain the inconsistencies in findings on the presence, absence, and magnitude of psychological symptoms among parents whose child had CHD.

Family Life

This theme was derived from studies that focused on the impact of the child's CHD on various aspects of family life, such as family finances, relationships, and parents' and siblings' quality of life and health-related quality of life. The supporting articles listed in table 2 reported

that the financial cost of treating and caring for children with CHD is a big burden to families around the world (Connor, Kline, Mott, Harris, & Jenkins, 2010; Gerber et al., 2010; Mughal et al., 2011). In Nigeria, one third of the families studied spent more than 10% of their family income to treat a child with CHD (Sadoh, Nwaneri, & Owobu, 2011). In Pakistan, among families who paid medical costs without government assistance, about 40% borrowed money from their family members and friends, about 50% either took leave without pay or lost their job or business, and a small proportion of the families had to sell their property to pay their children's medical expenses (Mughal et al., 2011).

In Germany, the highest non-medical and indirect medical costs for families of children with CHD included parents' lost incomes, and the cost of transportation and siblings' child-care (Gerber et al., 2010). In the United States, Connor et al (2010) interviewed parents of children after heart surgery and found that almost all reported financial impacts immediately after receiving their child's diagnosis. Parents reported dramatic decreases in their family income due to job changes or ongoing out-of-pocket medical costs (Connor et al., 2010). In addition to the child's medical condition, medical bills and other bills dominated parents' thoughts (Connor et al., 2010). Similarly, other investigators (Duggan, Pearce, & Guilbert, 2001) found that the expenses of travelling to and from the hospital and parents' time off from work were big financial strains for families. Parents in Connor's study (Connor et al., 2010) reported that having a child with CHD was also a huge stressor for other siblings. This is consistent with the findings of Mughal's study, in which parents indicated that siblings' school performance and health were compromised (Mughal et al., 2011).

Nevertheless, although facing huge financial obligations, the majority of parents reported that their families were actually brought closer because of the child's CHD. Wray and Maynard

(2005) who surveyed 209 parents of children with CHD found that 43% reported that their families had become closer, while only 8% perceived that their families had been pulled apart. When parents were busy and emotionally stressed with procedures and hospitalizations (Brown, 2003), extended family members tried to fill parents' roles for other children at home (Ravindran & Rempel, 2011). Parents reported that they received great family support in caring for the child with CHD (Bruce, Lilja, & Sundin, 2013). Werner et al (2014) who studied parents' perceptions of the impact of CHD on families using the German version of the Impact on Families scale (Steele & Davies, 2006) found that factors predicting family impact included infants' underlying genetic defects, the duration of hospital stays and perceived social support. The longer the child's hospital stays and the less the parents' perceived social support, the greater the impact on the family. The type of CHD or number of heart medicines at follow-up did not predict the impact on the family (Werner et al., 2014).

Quality of life (QOL) and health-related quality of life (HRQOL) differed because the definitions and the aspects that investigators measured were different. Arafa et al (2008) and Landolt et al (2011, p. 38) used a 36-item medical outcome related questionnaire (SF-36) to assess parents' self-reported HRQOL, which included eight domains: physical function, role limitations due to physical problems, bodily pain, general health perception, mental health, role limitations due to emotional problems, vitality, and social function. Lawoko and Soares (2003) defined QOL as parents' physical, social, and psychological well-being and used a 14-item short form of The Go'teborg Quality of Life Scale to measure parents' satisfaction with their family situation and leisure. Despite differences in definitions, parents of children with CHD reported significantly less QOL and HRQOL than parents of children without CHD. Factors affecting parents' HRQOL included the severity of the child's CHD and the child's age: the younger the

child and the more severe the parents' perceptions of their child's heart condition, the poorer the parents' health-related quality of life (Arafa et al., 2008; Goldbeck & Melches, 2006).

Parenting Challenges

This theme was derived from studies that investigated the challenges parents faced when parenting a child with CHD and the relationships between parents' psychological health and their child's behaviors. The supporting articles in table 3 found that parenting a child with CHD was challenging (Jordan et al., 2014; Torowicz, Irving, Hanlon, Sumpter, & Medoff-Cooper, 2010), and that parents' psychological health and children's behaviors were significantly related (Majnemer et al., 2006; Schiller, 2003; Toren & Horesh, 2007).

Children with CHD, especially those with single ventricles, had more negative tempers, and were harder to be distracted or soothed than healthy controls (Torowicz et al., 2010). As noted by Rempel and Harrison (2007) when children were born with a single ventricle, they had to have their first heart surgery within the first week of their life and two more surgeries at age 3-6 months and 3-5 years. Parents of children with a single ventricle, for example hypoplastic left heart syndrome, reported that from the moment they made their first decision to continue the pregnancy, they began a journey of survivorship for their children as well as themselves (Rempel & Harrison, 2007). These parents needed to overcome uncertainties to guard their children's survivorship and to defend the treatment decisions they made for the children (Rempel & Harrison, 2007). Parents of children with hypoplastic left heart syndrome were aware that their child had to face not only the heart problems for a lifetime, but also the comorbidities of the heart defects that may place their child at higher risk for other illnesses and injuries. High levels of perceived vulnerability of their child may have led parents to overprotect their children and to be more permissive in their parenting styles than parents of healthy controls (Brosig, Mussatto,

Kuhn, & Tweddell, 2007). These parents, however, still tried to overcome their fears and provide a supportive environment for the children (Lee & Rempel, 2011; Rempel, Harrison, & Williamson, 2009; Rempel, Ravindran, Rogers, & Magill-Evans, 2013).

Parents' psychological health was significantly correlated with their children's behaviors (Majnemer et al., 2006; Schiller, 2003; Toren & Horesh, 2007). For example, Landolt et al (2014) studied mothers' perceptions of their child's internalizing problems (anxiety, depression, withdrawal, and physical symptoms) and parents' distress at the child's age of 6, 18 and 36 months and found that mothers reported higher levels of infant fussiness at 6 months and child internalizing problems of anxiety, depression, and withdrawal at 18 and 36 months of age, which were positively correlated with parenting distress. Parents who expressed more stress when their children were 1 and 4 years of age reported more children's behavior problems at both times (Visconti et al., 2002). In a three-wave study (Berant, Mikulincer, & Shaver, 2008), mothers' and children's behaviors were evaluated at the time of the child's CHD diagnosis (T1), 1 year (T2) and 7 years (T3) after the diagnosis. Mothers' avoidant attachment at T1 predicted the deterioration of mothers' mental health and marital satisfaction at T3, particularly when children had severe types of CHD. Mothers' attachment insecurities, including anxiety and avoidance at diagnosis, were significantly correlated with the child's increased emotional problems and poor self-image at T3. In another study (Majnemer et al., 2006), researchers found that children's behaviors at a 5-year-follow-up were positively correlated with parents' stress.

It is worth noting that while qualitative research conducted with parents of children with hypoplastic left heart syndrome has provided valuable knowledge of their parenting experiences, only about 960 children are born with hypoplastic left heart syndrome in the United States each year (Centers for Disease Control and Prevention, 2015b) while 40,000 children are born with

other types of CHD each year (Centers for Disease Control and Prevention, 2015a). Therefore, more research on families of children with various types of CHD may enrich our understanding of families' experiences in caring for a child with CHD.

Family-Focused Interventions

Family-focused interventions were described in five studies that were designed to help parents alleviate their psychological symptoms and care for their child with CHD. DeMaso and Gonzalez-Heydrich (2000) used a computerized psychoeducational intervention of sharing personal experiences about an illness to decrease mothers' social isolation when caring for a child with CHD. Huth, Broome, Mussatto, and Morgan (2003) used a pain education intervention to promote parents' pain knowledge, communication and attitudes, and improve the child's outcomes post heart surgery. McCusker et al (2010) used a Congenital Heart Disease Intervention Program (CHIP) intervention to improve infants' psychomotor development and reduce mothers' anxiety and worries. McCusker et al (2012) used a CHIP–School Intervention to benefit maternal mental health and family functioning. Morgan et al (2008) used a video-conferencing intervention to decrease mothers' anxiety and improve timely and proper follow-up clinical visits after discharge. Table 4 summarizes the aims, interventions and key outcomes of the interventions.

The main purposes of these interventions were to reduce parents' psychological symptoms (McCusker et al., 2010; McCusker et al., 2012; Morgan et al., 2008) and mothers' social isolation (DeMaso & Gonzalez-Heydrich, 2000). The frameworks that guided the interventions were mainly stress and coping related. They included Thompson et al's (1992) stress and coping model, Bers et al's (1998) and Gonzalez-Heydrich et al's (1998) sharing personal stories about an illness model, and Ajzen's (1988) planned behavior theory. Four of the

five studies reported significant reductions in parents' stress or anxiety after the interventions. Following the intervention that was designed to improve parents' awareness of their child's post-operative pain control, parents in the intervention group showed significant improvement in pain awareness scores, but did not show significant differences from parents in the control group (Huth et al., 2003).

Discussion

These 94 articles from 21 countries around the world provide valuable information on the impacts of children's CHD on families. A major focus of the studies was on the impact of children's CHD on parents' psychological health, and there were some inconsistencies in the findings. These inconsistencies may be attributable to the various definitions and measures used to evaluate parents' psychological responses, and the different healthcare systems, financial and political structures, and cultures related to parenting roles in different countries. Parents may have vastly different experiences with their children's CHD depending on where they live and receive care for their child.

Three quarters of the studies reviewed here were quantitative studies using parents' self-report surveys as data sources. Because survey measures are close-ended with pre-programed questions and answers, respondents may be forced to choose among the answers listed. As a result, self-report questionnaires may not detect parents' psychological implications as well as face-to-face interviews. Carey, Nicholson, and Fox (2002) for example, noted that self-report questionnaires were not as sensitive to parents' symptoms of stress as interviews were. Similarly, Jordan et al (2014) found that when measured by self-report questionnaire, mothers of infants post heart surgery gave answers about their attachment to their infants similar to mothers from the general population; however, when interviewed, mothers of infants with CHD said that their

infants' heart surgery had affected their bonding. Vrijmoet-Wiersma et al (2009) thus have suggested that self-report questionnaires might not be adequate to study parents' psychological symptoms when their children are diagnosed with CHD, and it may be necessary to use qualitative narrative techniques to understand their experiences.

While the majority of the studies in this review focused on parents' psychological issues, factors that may have affected their responses to having a child with CHD were not addressed. In addition, little research focused on understanding or addressing parents' expectations for care. Furthermore, only five intervention studies were published in the past 15 years and they were mainly based on stress and coping models; some interventions worked and some did not. Caring and relationship based theories and models may provide more effective ways to help families of children with CHD.

Limitations

While the inclusion of studies from different countries around the world was a strength of this review, it was also a source of limitations. That is inconsistencies in the research findings may have been due to cultural and political differences in these countries.

Conclusions

This review has provided information on the experiences of families of children with CHD and offers guidance for care of these families. Children with CHD represent a large segment of pediatric patients. They may require multiple heart surgeries and hospitalizations and need medical care throughout their lives (Pasquali et al., 2011). The review found that a diagnosis of CHD had significant psychosocial impacts on parents and children (Hearps et al., 2014; Toren & Horesh, 2007). A child's hospitalization for heart surgery was a major source of stress for parents (Franck et al., 2010; Helfricht et al., 2008). Also, families experienced

significant psychological stress when caring for a child with CHD regardless of the child's age or type of CHD. Therefore, clinicians should offer psychological help to families of children with CHD at any age and treatment stage of the child.

Most of the studies found that parents were anxious, stressed, and depressed. However, we do not have information on parents' appraisals of their psychological needs and care expectations from the time of their child's diagnosis or during their child's hospitalization for heart surgery. Understanding parents' appraisals of factors affecting their psychological symptoms could broaden our efforts to improve care (Institute for Healthcare Improvement, 2015). A major element in the quality of care is patients' and families' experiences (Institute for Healthcare Improvement, 2015; Patient-Centered Outcomes Research Institute., 2015) which are significantly linked with patients' outcomes (Boulding, Glickman, Manary, Schulman, & Staelin, 2011; Weber, 2013). Only when healthcare providers understand parents' experiences and care needs will they be able to formulate and implement appropriate interventions. Thus, more research on parents' perspectives on care should be done (Duffy J., 2009) Qualitative research may make significant contributions to our understanding, and longitudinal research may help identify factors influencing parents' experiences over time and during children's development.

Sources of Funding

The first author of this literature review was awarded a Jane Winningham Smith Scholarship from the School of Nursing at the University of North Carolina at Chapel Hill and was a recipient of The Sauvage Research Fund from the Hope Heart Institute during the time of completing this literature review.

Conflicts of interest

None.

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Figure 2.1. PRISMA flow chart of search

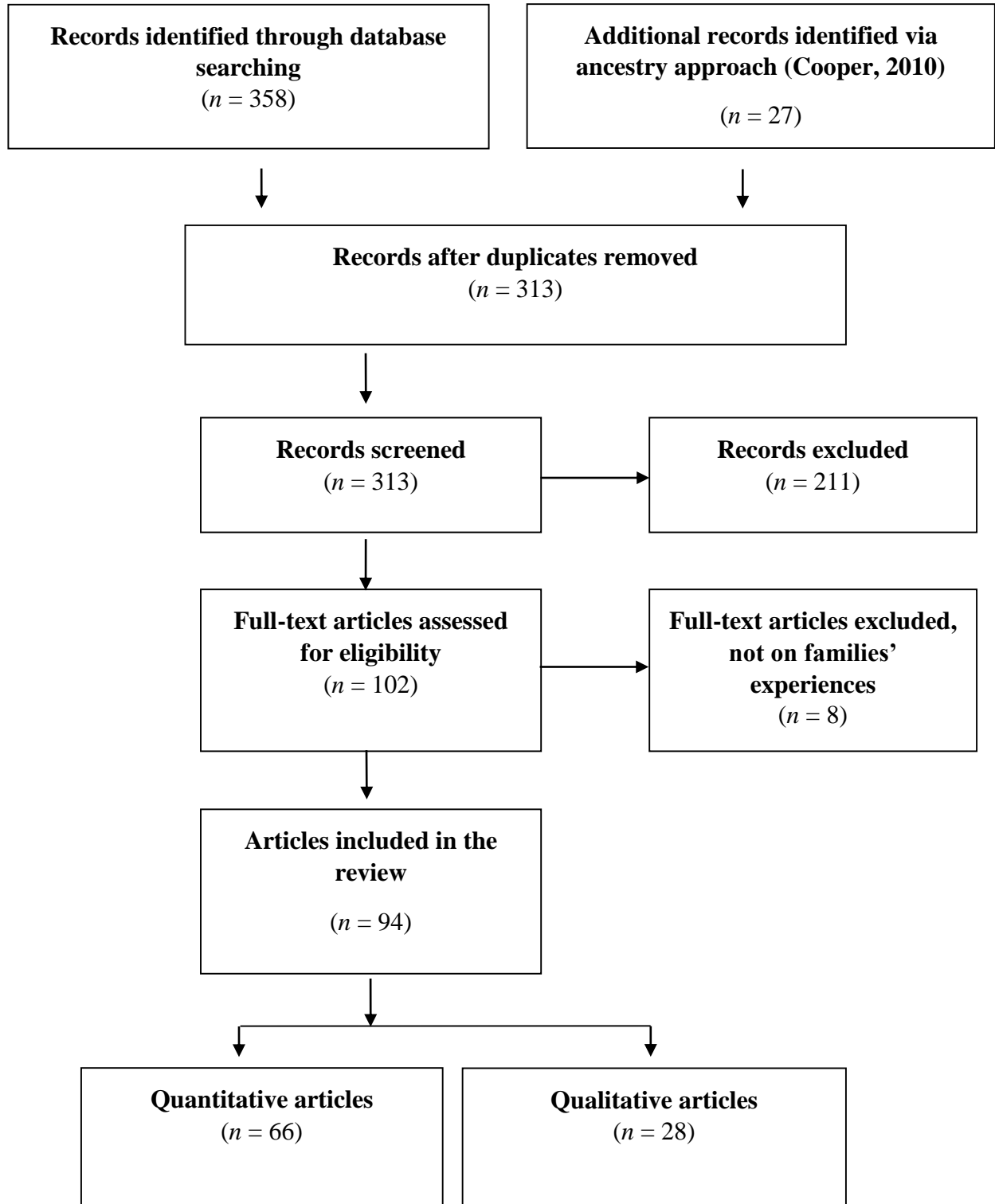


Table 2.1. Parents' Psychological Health

Author name	Aims	Approach/ theory	Sample	# of children w CHD/ age	Inclusions r/t children with CHD	Measures	Major Findings
Brosig (Brosig et al., 2007)	Psychological functioning in parents of children diagnosed CHD pre and postnatally.	Prospective Questionnaire Semi structured interview	Parents	17 infants	At the time of diagnosis, birth and 6 months after birth	Brief Symptom Inventory	At the time of diagnosis, parents in the pre and postnatal groups scored higher than test norms, but did not differ from each other. Child's CHD severity was positively associated with parental distress levels. Six months after birth, postnatal group parents did not differ from the test norms, but the prenatal group parents still scored significantly higher than the test norms.
Brown (Brown, 2003)	Parents' experiences when children were in PICU.	Cross-sectional Semi structured interview Grounded theory	Parents	37 Age not specified	Children with CHD with ≥ 1 PICU stay and after discharge from hospital	Narrative interviews	Raising a child with CHD was a process that involved finding its positive aspects in the midst of the threats to the child's life. Parents were going through ups and downs in emotions from the moment of getting the diagnosis of their child's CHD, like walking a tightrope.
Doherty (Doherty N, 2009)	Mental health and coping styles in parents of infants with severe CHD.	Cross-sectional questionnaire A combination of stress and family functioning models	Parents	70 Infants <i>M</i> 2.4(3.6) weeks	Infants recently born with CHD requiring invasive treatment	Brief Symptom Inventory	Mothers had significantly higher psychological distress levels than fathers and had different coping styles from fathers. Parents' ways of coping, their knowledge, worry and family functioning were significant predictors of their distress levels. Child's illness or demographic characteristics did not predict parents' distress levels.
Fernandes (Fernandes, 2005)	Parents' reality of having a child with CHD.	Cross-sectional Interview Phenomenology	Parents	5 <3y	Children d/x with CHD within 3 years before May 1997	Interviews	Parents expressed shock and disbelief when they heard about their child's diagnosis of CHD. Parents tried to make sense of the procedures their child went through and experienced broken hearts with their child.
Fischer (Fischer et al., 2012)	Parents' anxiety levels at discharge and predictors of higher anxiety.	Cross-sectional Questionnaire	Parents	38 < 30 d	During the initial hospital course at the time of hospital discharge	The State Trait Anxiety Inventory Dutch	State Scores: 81% of parents reported no anxiety, 14% marginal anxiety, and 5% significant anxiety. Trait Scores: 93% of parents reported no anxiety, 2% marginal anxiety, and 5% significant anxiety. Parents' education level was significantly positively associated with their state and trait scores.

Franck (Franck et al., 2010)	Parents' stress levels and influencing factors after children's heart surgery.	Prospective Questionnaire and structured interviews	Parents	211 1d-16y	Preoperative and on postoperative days 3, 5, 8, and 15	Parent Stressor Scale: Infant Hospitalization	Parents' stress levels remained moderate to high during children's hospitalization for heart surgery, regardless of the severity of CHD. There were few differences between mothers' and fathers' perceptions of the child's illness and stress. Parents who were in more poor communities and mothers who were born outside the UK reported higher stress levels.
Hearps (Hearps et al., 2014)	Parents' psychosocial risk after neonates' congenital heart surgery.	Cross-sectional Questionnaire	Parents	29 <28-112 days	Children who has heart surgery < 4wks old	The Psychosocial Assessment Tool	Psychosocial risk scores did not differ between mothers and fathers or parents who received their infant's diagnosis pre or postnatally. More than 60% of the parents rated their psychosocial risk as low, 36% rated it at reference levels, and only 2.6% rated it as clinically high. Parents' education level was positively correlated with their psychosocial risk.
Helfricht (Helfricht et al., 2008)	PTSD in parents of children undergoing heart surgery.	Prospective Questionnaire	Parents	139 0-16y	German-speaking parents of children with CHD admitted for heart surgery	German version of the Posttraumatic Diagnostic Scale	At discharge, 16.4% of mothers and 13.3% of fathers met the criteria of acute post-traumatic stress disorder. Other mothers (15.7%) and fathers (13.3%) reported significant PTSS. Six months after surgery, mothers' and fathers' PTSD rates were still 14.9% and 9.5%, respectively.
Hoehn (Hoehn et al., 2004)	Effects of child's diagnosis of CHD on parents' stress levels and decision on heart surgery.	Prospective Questionnaire and semi structured interview	Parents	31 <28d	At the time of surgery	Spielberger State Trait Anxiety Inventory	At the time of surgery, mothers did not differ on anxiety levels based on the time of receiving child's diagnosis of CHD pre or postnatally. Fathers had lower anxiety and more optimism when child's CHD was diagnosed prenatally than postnatally. Interviews indicated that regardless of the child's CHD diagnosis, parents felt they had made appropriate decisions for their child's heart surgery.
Lambert (Lambert et al., 2009)	Parents' and children's perceptions of children's health status after Fontan procedure.	Cross-sectional Questionnaire	Parents	328 10-18y	Fontan procedure survivors age 10 to 18 years between March 2003	The Child Health Questionnaire	No significant differences were found on bodily pain, family cohesiveness, or family activities between parents and children. Parents had worse perceptions of their child's health functioning than children themselves, including physical functioning, impact on

					and April 2004		school/activities, general behavior, mental health, self-esteem, and general health perceptions. Influencing factors r/t parents' worse perceptions included the severity of CHD and the noncardiac health problems in children.
	Lawoko (Lawoko & Soares, 2006)	Depression, anxiety, hopelessness, and social support over time in parents of children with CHD.	Prospective Questionnaire	Parents 433 0 - 20 y 8(0.3)y	Children with CHD age between 0 and 20 years living with parents	Hopelessness Scale; Symptom Check List-Revised	Parents of children with CHD reported depression (18%), anxiety (16%-18%), somatization (31%-38%), and hopelessness (16%) at two time points 1 year apart. Mothers consistently scored worse than fathers on the symptoms of depression, anxiety, and hopelessness. The child's CHD clinical severity did not significantly account for parent's distress symptoms over time. Parents' caregiving, financial burdens and social isolation explained their increased risk of psychosocial morbidity over time.
	Lawoko (Lawoko & Soares, 2002)	Emotional distress among parents of children with CHD, other diseases, and healthy children.	Cross-sectional Questionnaire	Parents 691 0-20y M 7(0.2)y	Children with CHD aged between 0 and 20 years living with parents	The Symptom Check List—Revised; The Hopelessness Scale	Parents of children with CHD reported significantly higher levels of distress, including anxiety, depression, stress and hopelessness than other parents in the study. Mothers in general had higher distress and hopelessness levels than fathers, with the highest being mothers of children with CHD. No differences in distress scores were found between parents of children with other diseases and healthy children. The variation in parents' distress and hopelessness were explained more by parents' employment status and financial situation than by their children's disease.
	Menahe m, Poulakis, & Prior, 2008)	Parents' emotional experiences of having a child undergoing heart surgery.	prospective questionnaire and interview	Parents 39 2-12y	Prior to child's heart surgery and 12-50 months following the surgery	The State Trait Anxiety Inventory; General health questionnaire	Prior to surgery, parents reported greater anxiety than published norms regardless of the heart defects or types of heart surgery. At follow-up, parents' scores were close to norms, but, they still did not feel in control of the situation. Mothers' emotional distress at the time of surgery resolved at 12 months or later.

Morelius (Mörelus, Lundh, & Nelson, 2002)	Effects of child's CHD on parents' stress levels.	Cross-sectional Questionnaire	Parents	58 0-9y	Mailed questionnaires to families	Swedish version of the Parenting Stress Index	No significant differences in parents' stress levels were found between parents of children with conduit implantation and ventricular septal defect repair.
Solberg (Solberg, 2011)	Infants' CHD and mothers' anxiety and depression.	Prospective Questionnaire	Mothers	162 infants	Gestation week 30, 6 months, and 18 months postpartum	Hopkins Symptom Checklist, 8-item version	Mothers of infants with severe CHD showed significantly higher levels of depression and anxiety at 6 and 18 months postpartum.
Spijkerboer (Spijkerboer et al., 2008)	Psychological distress and coping styles in parents of children with CHD.	Cross-sectional Questionnaire	Parents	109 7-15y	Children who underwent invasive CHD treatment 7 and a half years prior to study	General Health Questionnaire, Dutch version	Parents of children with CHD reported lower levels of distress, somatic symptoms, anxiety, sleeplessness, and depression and more effective ways of coping than reference groups. Mothers of children with CHD reported more somatic symptoms than did fathers. Mothers tended to seek more social support than fathers.
Toren (Toren & Horesh, 2007)	Psychiatric morbidity of parents and children who had heart surgery in childhood.	Cross-sectional Questionnaire	Parents	31 10-21y <i>M</i> 14.7(0.3)y	Children who underwent cardiac surgery 13.7±2.48y before the study	State Trait Anxiety Inventory; Beck Depression Scale; Post-Traumatic Stress Disorder Scale	Adolescents who underwent heart surgery in childhood were at risk of developing post-traumatic stress symptoms (PTSS). These adolescents still reported PTSS more than 10 years after their heart surgeries. Parents of children with PTSS scored higher on anxiety and depression surveys than parents of children without it.
Utens (Utens et al., 2000)	Psychological distress and ways of coping in parents of children with CHD.	Cross-sectional Questionnaire	Parents	84 3m-7y	Children who had heart surgery between May 1994 and May 1997 at 3m to 7y old	General Health Questionnaire Dutch version	Parents of children undergoing heart surgery showed elevated levels of psychological distress, including anxiety, sleeplessness, and social dysfunctioning, and less effective ways of coping, such as being less active in problem-solving than reference groups. Mothers of children undergoing heart surgery reported more psychological distress than fathers.
Utens (Utens et al., 2002)	Influences of child's age receiving CHD treatment on	Prospective Questionnaire	Parents	84 1-8.5y	5 weeks prior to, and 18.7 months after children's	General Health Questionnaire Dutch version	Parents' pre- and post-procedural psychological distress and ways of coping were not influenced by the child's age at heart surgery or catheter intervention.

	parents' psychological distress and coping.				heart surgery or catheterization		Parents of children undergoing heart surgery reported significantly greater psychological distress than did parents of children for catheter intervention. After procedures, parents of children with CHD reported significantly lower levels of psychological distress than ref groups.
Uzark (Uzark & Jones, 2003)	Parenting stress in parents of children with heart disease.	Cross-sectional Questionnaire	Parents	80 2-12y 6.3 (3.1)y	Children at ages between 2 and 12 years with known CHD during a cardiology outpatient clinic visit	The Parenting Stress Index-Short Form	Parents of children with CHD were more likely to report excessive parenting stress than parents of a normative population, particularly related to the child's characteristics that made the child difficult to parent. About 20% of the parents reported significant levels of stress. Parents' stress was not correlated with the severity of their child's CHD, their socioeconomic status, or the time since their child's most recent surgery. Parents' stress scores were positively correlated with the child's age.
Visconti (Visconti et al., 2002)	Effects of parents' stress and perceived social support on emotional adjustment in children with CHD.	Prospective Questionnaire	Parents	143 1-4y	Mailed questionnaires to parents 4 years after the initial study between April 1988 and February 1992	The Parenting Stress Index	Parents of children with CHD reported less stress, more social support, and fewer children's behavior problems than normative samples. Parents who expressed more stress at both time points reported more children's behavior problems. Parents with less social support expressed more stress at both 1 and 4 years. Social support was not a mediator between stress and child behavior problems.
Vrijmoet-Wiersma (Vrijmoet-Wiersma et al., 2009)	Parents' stress and perceived vulnerability when children underwent heart surgery.	Cross-sectional Questionnaire	Parents	131	Children who had open-heart surgery 2-7 years prior to study	The State Trait Anxiety Inventory Dutch; Parental Stress Index-Short Form	Parents of children with CHD did not have higher stress or anxiety scores than the reference group. Factors leading to increased levels of anxiety were the number of surgical procedures, the time since last procedure, and ethnicity. Severity of CHD did not affect parents' stress levels; but, parents of children with hypoplastic left heart syndrome reported greater stress than other parents.

Wray (Wray & Radley- Smith, 2004)	Distress and coping in parents of children with CHD and bone marrow transplant, and healthy children.	Prospective Questionnaire	Parents	75 0-16.9y <i>M</i> 5.2(3.8)y	The day before child's heart surgery and 12 months afterwards	the General Health Questionnaire	Parents of children undergoing heart surgery and bone marrow transplant showed significantly greater distress prior to procedures than parents of healthy children did. Children's CHD types did not affect parents' distress levels. Post procedures, significant reductions in the levels of distress were noted in parents of children undergoing heart surgery and bone marrow transplant.
Yildiz (Yildiz A, 2009)	Parents' stress levels when having a child with CHD.	Cross-sectional Questionnaire	Parents	147 <12y	Children with CHD at a cardiac clinic from Dec. 2004 to April 2005	The Symptom Check List-Revised	Mothers scored higher than fathers on all stress dimensions. Parents' stress levels were positively associated with the severity of their child's CHD.

Table 2.2. Impact on Family Life

Author name	Aims	Approach/theory	Sample	# children with CHD /age	Inclusions r/t children with CHD	Measures	Major Findings
Arafa (Arafa et al., 2008)	Describe the quality of life of parents of children with CHD.	Cross-sectional Questionnaire	Parents	400 0-17y <i>M</i> 5.7(5.1)	Children visiting clinics of a hospital in Egypt between February and July 2007	Health related quality of life	Parents of children with CHD reported significantly poorer health-related quality of life (HRQOL) than parents of healthy children in all domains, except for pain. Factors affecting parents' health related quality of life included the severity of the child's CHD, type of CHD, and the child's age. The younger the child's age, the poorer the parents' HRQOL.
Bruce (Bruce et al., 2013)	Meaning of support for mothers of children with CHD.	Cross sectional Phenomenology	Mother s	10 3-12y	Children with CHD born between 1996 and 2006 (3–12 years old as of 2009)	Narrative interviews	Mothers reported the support as good, poor, or absent. Good support: mothers regained their psychological wellbeing and strength by having free time and space to rest and recover. Poor support: mothers felt they were in the way of healthcare providers and unable to tend to their child's basic needs, i.e, breastfeeding, washing, or comforting their child. Absent support: mothers' psychological well-being was overlooked while the focus was on their child's survival and well-being.
Connor (Connor et al., 2010)	Meaning of cost burden for parents of children with CHD.	Cross-sectional Semi structured interview	Parents	20 <5y	Children (1d-5y) with CHD admitted to hospital for heart surgery	Six open-ended questions about "cost"	Parents described cost to be more than just monetary, but also their lifestyle and uncertainty. Costs included financial, emotional, and family burden. The complexity of the child's CHD and parent's socioeconomic status were r/t parents' higher levels of stress due to cost burden.
Duggan (Duggan et al., 2001)	Impacts of anticoagulation on families of children with CHD.	Cross-sectional Questionnaire	Parents	30 <i>M</i> 0-21y	Children with CHD requiring long-term anticoagulant therapy	A self-report questionnaire designed for the study by authors	Impacts included children's absence from school, stress due to frequent venipunctures, travelling cost and time off from work. Most parents noted the inconvenience of hospitalization, but two parents favored hospitalization for the opportunity to visit and support as needed.

Gerber (Gerber et al., 2010)	Costs for families of children with CHD at 1 and 6 years old.	Cross-sectional Questionnaire	Parents	54 <i>M</i> 15.7y	Children with CHD born between 1980 and 2000.	Questionnaire developed by study authors	Depending on CHD severity, ranging from children with no or mild CHD to life threatening, the total direct non-medical and indirect costs for children's first year of life were between an average of 1654 and 2881 euro; for the sixth year of life, 562 to 5213 euros. At both times, the highest costs were parents' lost income, transportation, and day care or babysitting.
Goldbeck (Goldbeck & Melches, 2005)	Quality of life of parents and children with CHD.	Cross-sectional Questionnaire	Parents	143 7-20y <i>M</i> 12y	Children with CHD from a German outpatient pediatric clinic	The Ulm Quality of Life Inventory for Parents	Children's self-rated quality of life and parent proxy-rated quality of life were moderately correlated. Parents of children with CHD with low quality of life agreed significantly more with their children's quality of life than parents with high quality of life scores.
Goldbeck (Goldbeck & Melches, 2006)	Effects of child's CHD on children and parents.	Cross-sectional Questionnaire	Parents	132 0-21y <i>M</i> 8.6(6)y	Children with CHD after an appointment in a cardiac clinic	The Ulm Inventory for Parents	Family social disadvantages, such as lower socioeconomic status and education and marital status, significantly affected the QOL scores of parents and their proxy of their children's QOL. The more severe the child's CHD, the lower the parent's proxy indication of the child's quality of life, especially with disadvantaged social risks.
Landolt (Landolt et al., 2011)	Parents' health-related quality of life and predictors after children's heart surgery.	Prospective Questionnaire	Parents	138 0-15y 3.1(4.6)y	At discharge from the hospital and 6 months after children's heart surgery	Health related quality of life	At discharge, several domains of parents' HRQOL were decreased. Mental domains were worse than physical domains. Mothers' quality of life was lower than fathers'. At 6 months, parents' QOL was at or above population norms. At hospital discharge, mothers who had foreign nationality, low social economic status, and PTSD had a higher risk of low mental HRQOL, and fathers who had PTSD had 18 times higher chance to have a low mental HRQOL.
Lawoko (Lawoko & Soares, 2003a)	Quality of life among parents of children with CHD, children with other	Cross-sectional Questionnaire	Parents	691 0 and 20y 7(0.2)y	Children with CHD age between 0 and 20 years living with parents	Hopelessness Scale; Symptom Check List-Revised	Parents of children with CHD tended to report lower QOL than other parents. Mothers reported lower quality of life than did fathers, with the lowest levels among mothers of children with CHD.

	diseases and healthy children.						Variables like distress, hopelessness and financial situation explained more of parents' QOL than children's CHD.
Lawoko (Lawoko & Soares, 2003b)	Perceived social support in parents of children with CHD and healthy.	Cross-sectional Questionnaire	Parents	691 0 and 20y 7(0.2)y	Children with CHD age between 0 and 20 years living with parents	Hopelessness Scale; Symptom Check List- Revised	Mothers had lower social support availability than fathers, with the lowest among mothers of children with CHD. Univariate analysis indicated that there were no differences in the availability of social support among parents of children with CHD and other diseases, and healthy children. Multivariate analysis indicated that the financial unpredictability in parents of children with CHD explained more about the variance in the availability of social support than children's disease and severity.
Mughal(Mughal et al., 2011)	Impacts of children's CHD treatment on families.	Cross-sectional Interview	Parents	211 M 39(3.2)m	Children who underwent heart treatment from March 2010 to August 2010	Socioeconomic status scale	Among the 211 children with CHD, 164 (77.7%) underwent heart surgery and 47 (22.3%) angiographic intervention. Adverse effects on families included leave without pay, losing jobs or business (46%), and selling assets (11.3%). The treatment of CHD affected siblings' schooling and health (22.7% and 26.1%, respectively).
Pinto(Pinto et al., 2012)	Impacts of living distance on mortality rates after discharge.	Cross-sectional Questionnaire	Parents	217 <30d	Children who went for heart surgery from January 2005 to June 2006	Chart review Survey by authors	Mortality in the study population was 8%, but was not correlated with home distance from the hospital. Unplanned re-admissions and interventions after discharge were 45% and 40%, respectively. After case complexity was adjusted, those living 90-300 min away had fewer unplanned re-admissions than those living <90 min away.
Ravindra n(Ravindran & Rempel, 2011)	Grandparents' involvement with the siblings of children with hypoplastic left heart syndrome	Cross-sectional Interview Grounded theory	Grand-parents	6 Pre-school	Preschool children with HLHS in 2007	Interview	Two core categories were stepping in to help as needed and safeguarding family relationships. When parents were busy attending to the child with hypoplastic left heart syndrome, grandparents stepped in to care for the siblings. Grandparents were striving to maintain family relationships while parents were in the hospital

Sadoh(Sadoh et al., 2011)	Economic burden on families in managing children's chronic CHD	Prospective Questionnaire	Parents	32 6m-5y <i>M</i> 2.2(1.7)	Children with CHD at a cardiac clinic from January to Dec. 2009	Questionnaires designed for the study	with the child with hypoplastic left heart syndrome. The average cost for care of children with CHD was 16.3 +/- 26.2 % of total income, with a range of 0.7 - 122%. Families from low socioeconomic class used significantly greater % of income on medications and total care than families from the middle or high socioeconomic classes.
Saied(Saied, 2006)	Family factors and parents' stress when children with CHD were in pediatric intensive care unit.	Cross-sectional Questionnaire Resilience Model of Family Stress, Adjustment and Adaptation	Parents	74 0-12 y 31.34m	families who had a child in the pediatric intensive care unit after heart surgery	The Family Inventory of Life Events; Parental Stressor Scale: Pediatric Intensive Care Unit Structured questionnaire	Parents reported that the pediatric intensive care unit stay was stressful. Parents rated parental role alterations and child's behaviors as the most stressful dimensions in the pediatric intensive care unit experience. Social support was not a predictor of family adjustment, but a moderator of intra-family strain, stressful family events and family functioning. Four themes were derived: parents' feelings and emotions when facing the child's CHD; CHD under mothers' careful watch; mothers' intensive care unit experience; and mothers' coping resources.
Salgado(Salgado et al., 2011)	Family experiences when children underwent heart surgery.	Cross-sectional Structured interview	Parents	7 <10y	Children undergoing heart surgery in a hospital in Brazil between March and May 2008	Structured questionnaire	Mothers noted that the importance of the heart b/o its symbolism, making them feel more emotional about their child's CHD. Mothers considered that their religiosity and social support were their coping resources.
Srichantarit(Srichantarit et al., 2010)	Daily practice of caring for a child with CHD in Thai families prior to child's heart surgery.	Prospective Interview Focused ethnography study	Parents	8 3m-17m	Thai parents of children with CHD prior to heart surgery from Sep. 2006 to Oct. 2007	Interview	Parents expressed that the goal was to do their best to get their child ready for surgery. Families understood the possibility that their child might not make through the surgery or would be difficult to take care of. Parents' decisions were influenced by their socio-cultural contexts, such as Buddhism, cultural beliefs, financial limitations, hospital systems, and family support.
Tak(Tak & McCubbin, 2002)	Family stress, social support, and ways of coping in	Secondary analysis Questionnaire Resiliency	Parents	92 <12y	Children newly diagnosed with CHD within the last 3-4	Personal Resources Questionnaire	Family stress significantly predicted parents' perceived social support and coping.

	families of children with CHD.	Model of Family Stress, Adjust and Adaptation			months of the original study		Child's age/gender/illness severity did not have significant impacts on family stress, perceived social support, or coping. Parents' perceived social support acted as a resilience factor between family stress and coping.
Werner(Werner et al., 2014)	The impacts of child's severe CHD on family.	A prospective cohort study	Parents	104 Infants	Infants who underwent heart surgery before 12 months between 2004–2006	German version of the Impact on Families; Social Support Questionnaire	Factors predicting family impacts included the incidence of underlying genetic defects, longer hospital stays, and lower levels of perceived social support. The type of child's CHD (cyanotic vs. noncyanotic) and number of heart medicines at follow-up did not predict family impacts.
Wray(Wr ay & Maynard , 2005)	Maternal perceptions of the impact of heart disease on families.	Cross-sectional Questionnaire	Parents	209 1.3-18.9 y 8.4(5.2)y	January 1995 and December 1999	Mailed research questionnaire on general psychological impact	20% of the parents perceived their child's heart disease as having negative impacts on their family life, especially when parents perceived that their children were more ill. Only 8% of parents perceived that their families had been 'pulled apart' by their child's heart disease, with 43% reporting that their families becoming closer.
Wray(Wr ay & Maynard , 2006)	Needs for support and services by parents of children with heart disease.	Cross-sectional Questionnaire	Parents	209 1.3-18.9 y 8.4(5.2)y	January 1995 and December 1999	Mailed research questionnaire on general psychological impact	59% of the parents reported unmet needs, with information being the greatest expressed need. Community-based services and support were not adequate. However, families who had not received community support did not want any interventions.

Table 2.3. Parenting Challenges

Author name	Aims	Approach/ theory	Sample	# children w CHD /age	Inclusions r/t children with CHD	Measures	Major Findings
Berant (Berant et al., 2008)	Mothers' attachment insecurities and psychological functioning of their children with CHD.	Prospective Questionnaire Attachment Theory	Mother s	63 newborns	A three-wave study, at the time of CHD diagnosis (T1), 1-year (T2), and 7-year (T3).	Mental health Inventory	Mothers' avoidant attachment at T1 predicted the deterioration of mothers' mental health and marital satisfaction over a 7-year period, particularly when children had severe types of CHD. Mothers' attachment insecurities such as anxiety and avoidance at T1 were related to children's increased emotional problems and poor self-image at T3, 7 years later.
Brosig (Brosig et al., 2007)	Psychosocial outcomes of children with hypoplastic left heart syndrome and transposition of the great arteries.	Cross-sectional Questionnaire	Parents	26 3-6y 4.7y	Children who had heart surgery between 1996 and 1999	The Parenting Stress Index; Pediatric Quality of Life Inventory; Impact on Family; Parent and child Behavior Checklists	There was no difference in quality of life scores between parents of children with CHD and parents of healthy controls. Parents of children with hypoplastic left heart syndrome expressed more negative impacts on family functions and stress than parents of children with transposition of the great arteries. Parents of children with both types of CHD were more permissive in parenting than parents of healthy controls. Children with hypoplastic left heart syndrome had more externalizing behavior problems than did children with transposition of the great arteries.
Carey (Carey et al., 2002)	Child-rearing practices and expectations in mothers of children with CHD.	Cross-sectional Questionnaire Video Observation Socialization theory	Mother s	30 2-5y 3.44 (0.93)y	Recruited from cardiac clinics	The Parenting Stress Index-Short Form	Parent-child interactions did not show differences between mothers of children with and without CHD. Interviews found significant differences between mothers of healthy children and mothers of children with CHD, who reported higher levels of vigilance in child-rearing.
Hartman & Medoff-	Caregivers' perceptions of care issues after	Cross-sectional	Mother s and grand-	15 4-10m	Neonates after open-heart surgery from	Structured interview	Primary caregivers were all mothers except one grandmother.

Cooper, (2012)	infants' heart surgery.	Focus groups and phone interviews	mothers		January 1 to June 30 2008		They reported facing feeding issues and weight gain in infants and sleep deprivation after heart surgery. Mothers reported being stressed due to infants' weight and their lack of sleep.
Jordan (Jordan et al., 2014)	Mother-infant relationships after infants' heart surgery.	Cross-sectional Structured interview	Mother s	97 102 (43)days	Infants who were <3 months when undergoing heart surgery	Maternal Postnatal Attachment Scale; Edinburgh Post Natal Depression Scale	The Maternal Postnatal Attachment scores were similar between mothers of infants post heart surgery and community norms. Based on mothers interviewed, impacts of child's CHD were associated with enhanced emotional ties (37%), bonding difficulties (23%), anxiety and worry (19%), and caregiving behaviors (11%). Bonding difficulties were correlated with lower Maternal Postnatal Attachment scores. Higher Edinburgh Post Natal Depression scores were also correlated with lower Maternal Postnatal Attachment scores.
Lan (Lan, Mu, & Hsieh, 2007)	Mothers' experience in decision-making for their child's heart surgery.	Cross-sectional In-depth Interview Phenomenology	Mother s	9 1.76y	Children who were discharged from a hospital < 6 months after heart Surgery	In-depth interviews	Five themes were derived regarding their decision-making process: understanding their child's surgery step by step, feeling role pressure as a mother and decision maker for their child, building care-taking confidence, trying to maintain their family routines while preparing for child's surgery, and striving to make the right decision.
Landolt (Landolt, 2014)	Children's behavior problems and mothers' distress; factors causing psychological issues in families of children with CHD.	Prospective Questionnaires	Mother s	408 < 3yrs	Children with CHD in the Norwegian Mother and Child Cohort Study	Fussy/Difficult scale Child Behavior Checklist; Hopkins Symptom Checklist	Children with CHD had more internalizing behavior problems than children without CHD at 6, 18 and 36 months. Mothers of children with CHD displayed high distress scores at these assessment points. Familial and individual factors related to CHD contributed to mothers' and children's mental health problems at all the time points, increasing over time.
Lee	Normalization in raising	Secondary analysis	Parents	9 2-60m M 35 m	Children with HLHS from a	Interview	Three themes were derived: normalization of their child's life, awareness of their child's vulnerability, and hopefulness appraisal. Parents

(Lee & Rempel, 2011)	children with HLHS.	Constructivist Grounded theory			Canadian tertiary referral center		strived to balance their worry and perceptions of the child's vulnerability and cherishing their child's survival through normalization strategies.
Majnemer (Majnemer et al., 2006)	Parents' perceptions of HR QOL of children with CHD after heart surgery and their stress levels.	Prospective Questionnaire	Parents	49 64.2 (11.3) months	Before and after surgery, before D/C, 12-18 months after surgery, and 5 years later	The Parenting Stress Index-short form; the Child Behavior Checklist; the Child Health Questionnaire,	Parents' stress levels fluctuated: 25% of parents indicated high levels of stress, 20% low levels of stress, and 50% in normal ranges. Parents' stress levels were positively correlated with the child behavior checklist scores. Parents' stress levels were r/t children's psychosocial health. Children's behaviors at follow-up were significantly positively correlated with parents' stress levels.
Nascimento (Nascimento et al., 2010)	Mothers' perspectives on their children's post heart surgery pain control.	Cross-sectional Semi structured interview	Mothers	17 1m-5y	Children in a pediatric clinic after heart surgery from March 2007 to May 2008	semi structured interview	Good nursing care: mothers had confidence in the nursing team to care for their child after heart surgery by observing how nurses gave pain medication. Poor nursing care: lack of information or insufficient communication between mothers and nurses.
Pridham (Pridham et al., 2010)	Motivations in parenting infants with a complex CHD during the first year.	Prospective Semi structured interview Attachment-caregiving theory	Parents	24	Parents of infants with CHD at 4, 8, and 12 months during the first year	Interview	Parents of infants with CHD reported eight motivations: supporting infants' development, protecting infants' wellbeing, relating to infants, building family relationships, protecting self from loss or blames, promoting self-wellbeing, promoting parenting identity, and accomplishing tasks.
Rempel (Rempel & Harrison, 2007)	Parenting of children with hypoplastic left heart syndrome.	Prospective In-depth interview Constructivist Grounded theory	Parents	9 2-60m	Children with hypoplastic left heart syndrome from a Canadian tertiary referral center	Interview	Parents showed extraordinary parenting with uncertainties over multiple hospitalizations and surgeries. Parents said that they had to safeguard their own and their children's survival simultaneously when caring for a child with hypoplastic left heart syndrome.
Rempel (Rempel et al., 2009)	Approaches parents used to treat their children with hypoplastic left heart syndrome.	Prospective In-depth interview Constructivist Grounded theory	Parents	9 2-60m	Children with hypoplastic left heart syndrome from a Canadian tertiary referral center	Interview	Parents sought normalization in the situation of uncertainty over their child's survivorship due to hypoplastic left heart syndrome. Parents described their children who were underweight as simply having their own developing curve.

Rempel (Rempel, Blythe, Rogers, & Ravindran, 2012)	Family management processes in caring for a child with hypoplastic left heart syndrome.	Secondary analysis Interviews The Family Management Style Framework	Parents	24 2-60m <i>M</i> 27.9m	Children with hypoplastic left heart syndrome	Interview	Parents found reasons to celebrate milestones even though children's developments were delayed. The Family Management Style Framework was helpful in guiding families through the course of their child's diagnosis and treatment of hypoplastic left heart syndrome. Parents showed a strong and transforming family management process from their child's diagnosis to recovering from the first surgery and going home.
Rempel (Rempel et al., 2013)	Experiences of parents and grandparents of children with HLHS.	Cross-sectional Grounded theory	Parents and grand-parents	15 <5 y	Children with hypoplastic left heart syndrome	Open-ended interview	A process of parenting under pressure emerged. This process was characterized by four stages: grasping and adjusting to the unimaginable, becoming attached, being vigilant for the unexpected, and facing new challenges.
Schiller (Schiller, 2003)	Parenting stress in mothers and fathers of children with complex CHD.	Cross-sectional Questionnaire Stress and Coping	Parents	36 10.2y 5 – 19y	Parents belonging to an online support group	The Parenting Stress Index-Short Form; the Ways of Coping Questionnaire	Mothers and fathers had different ways of coping. There were no significant differences between parents' perceived parenting stress. Both parents' coping and stress played predictive roles in children's psychological adjustment.
Spence (Spence, Swinsburg, Griggs, & Johnston, 2011)	Infants' well-being after heart surgery.	Prospective Questionnaire and semi structured interview	Mothers	56 neonates	9 months after discharge from NICU after heart surgery	The General Health Questionnaire	Mothers indicated good general health after discharge, as indicated by infants' feeding and sleeping. Mothers' confidence with their breastfeeding experience at discharge was significantly associated with their breastfeeding enjoyment after discharge.
Torowicz (Torowicz et al., 2010)	Children's temperament and maternal stress at child's age of 3 months.	Cross-sectional Questionnaire	Mothers	69 3m	Infants from a longitudinal study investigating the growth of infants with CHD	The Parenting Stress Index; The Early Infancy Temperament Questionnaire	Infants with single ventricles had a more negative mood and were less distractible than children with bi-ventricles or the control group. The caring demands for infants with CHD were a significant source of parental stress. Parents of infants with single ventricles were more stressed d/t infants' negative mood or difficulty to soothe than parents of infants with bi-ventricles or healthy infants.

Table 2.4. Family-focused Interventions

Authors	Aims	Children	Intervention	Outcome measures	Key findings
DeMaso (2000)	Evaluate the usefulness of a computer-based experience journal.	Child Age: 6wk-25y Phase 1. N=9 parents Phase 2 N=40 mothers	Phase 1. Tested feasibility of the experience journal – people share their experiences of an illness narratively. Phase 2. Mothers were asked to use the experience journal for at least 30 minutes.	Semi-structured interview before and after mothers used the experience journal.	This program decreased mothers' social isolation and increased their understanding of other people's feelings about having a child with CHD.
Huth (Huth et al., 2003)	Test the efficiency of a pain booklet for post-operative pain management after children's heart surgery.	Child Age: 3-16y N=51 Parents	Parents were given a pain booklet prior or the day of children's heart surgeries. Research assistant went over the booklet with parents in waiting room or PICU.	The Medication Attitude Questionnaire, Pain Self-Report. Parent Diary.	Pain education increased parents' scores on pain attitude from pre to post-test; but failed to show significant differences between groups.
48 McCusker (McCusker et al., 2010)	Help mothers cope and promote mother–infant interactions through psychoeducation,	Child Age: 2.9m N=35 Mothers	Six 1-2 hour psychoeducational sessions to provide mothers with emotional support, personalized psychoeducation on their children's CHD, equipment used, and strategies to promote infants' feeding and neurodevelopment.	Spielberger State-Trait Anxiety Inventory, The Maternal Worry Scale multidimensional coping inventory.	The CHIP significantly lowered mothers' levels of anxiety and worries compared with mothers in a control group who received standard care.
McCusker (McCusker et al., 2012)	Test a psychological intervention to support the adjustment of families and children with CHD.	Child Age: 4-5y N=90 Parents	The intervention included a 1-day workshop for parents and a follow-up session with families individually. The workshop included three sessions: 1. Problem Prevention Therapy: encourage parents to talk about their worries about their children's CHD. 2. Psychoeducation: encourage parents to promote their children's activity and normal life routines. 3. Parenting Skills: teach parents specific strategies to take care of their children with CHD, i.e. medications.	The Brief symptom inventory, the Maternal Worry Scale The Impact on Family Scale.	The CHIP-School showed benefits to maternal mental health and family functioning; yet did not make significant changes in children's behaviors, maternal worry, maternal physical illness, or family financial impact

Morgan (Morgan et al., 2008)	Compare the benefits of video conferencing and telephone calls for follow-up care after discharge.	Child Age: <3y N=27 Parents	Parents were given a link to videoconference with physicians after discharge from hospital.	Spielberger's state-trait anxiety inventory.	Mothers of children with CHD in the intervention group showed significant decreases in levels of anxiety and better follow-up care than parents in the control group.
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CHAPTER 3: PHENOMENOLOGY IN HEALTHCARE: A METHODOLOGY EXPLORING PATIENTS' AND FAMILIES' EXPERIENCES

Introduction

Phenomenology is a methodology exploring human experiences in the everyday world (Giorgi, 2009; Husserl, 1970). It is an approach that healthcare providers can use to understand patients' and families' experiences in health and illness (Wojnar & Swanson, 2007). To provide an optimal healing environment for patients and families, healthcare providers need to understand patients' and families' experiences (Swanson & Wojnar, 2004).

Using an interdisciplinary team to conduct studies is a productive way of acquiring new knowledge. Interdisciplinary research is “a mode of research by teams or individuals that integrates information, data, techniques, tools, perspectives, concepts, and/or theories from two or more disciplines or bodies of specialized knowledge to advance fundamental understanding or to solve problems whose solutions are beyond the scope of a single discipline or area of research practice” (Committee on Facilitating Interdisciplinary Research, National Academy of Sciences, National Academy of Engineering, Institute of Medicine, 2005).

Interdisciplinary approach facilitates multifaceted conversations and connections that can produce important new knowledge (Committee on Key Challenge Areas for Convergence and Health, Board on Life Sciences, Division on Earth and Life Studies, and National Research Council, 2014). Healthcare settings consist of multiple disciplines in caring for patients and families and are an environment for interdisciplinary research. Researchers still need guidance on how to use interdisciplinary expertise for research projects (American Academy of Arts and

Sciences, 2013). Therefore, the purpose of this paper is to demonstrate ways of using an interdisciplinary research approach to conduct a phenomenological study investigating parents' experiences caring for a child with CHD.

Methods

Development of a Research Idea

The sample project grew out of clinical observations that parents were stressed when their child was hospitalized for heart surgery. Based on these observations, the first author, a clinical expert and the principal investigator (PI) of the study, went to her academic mentor (the fourth author) and expressed her clinical observations and research interest. The collaboration between clinical and academic settings is an effective way for interdisciplinary research to integrate theory, education, and practice. As advised, the PI conducted a literature review on families of children with congenital heart disease (CHD). The review found that studies on families of children with CHD published in the past 15 years had recognized that parents were stressed, depressed, and anxious when their child was diagnosed with CHD; but those studies mainly quantified parents' psychological symptoms, such as stress, depression, and anxiety. There was little research on parents' experiences and care needs. Therefore, the research was designed to explore parents' experiences in caring for a child with CHD.

Formation of the Research Team

There are two research perspectives, quantitative and qualitative, both of which are essential to advance scientific knowledge (Yen, 2015). Researchers need to select an appropriate perspective based on their study purpose. To explore parents' experiences in caring for a child with CHD, a qualitative perspective was selected as most appropriate. Based on the purpose of the study, an interdisciplinary research team was formed, including the first author, a clinical

nurse expert for more than 20 years; the second author, a qualitative research consultant who was to provide guidance on coding and using qualitative software, ATLAS.ti (ATLAS.ti GmbH, (2015), 2015); and the third and fourth authors, phenomenological scholars who were to offer methodological advice. Other contributing team members included a qualitative researcher who had extensive experiences in working with families of children with severe fetal anomalies; a clinical specialist who was an expert in the case of families of children in critical conditions; a physician who worked in pediatric acute care and had conducted research on communications between parents and providers in critical care settings; a visiting professor who was a qualitative researcher, and a doctoral student. Team members came from three disciplines – nursing, medicine, and sociology. Even though six of the eight members were from nursing, the nursing scholars were from different arenas of nursing, academic, clinical, and methodology. All team members, nursing and non-nursing, brought different types of expertise to the team project, including methods, analysis, clinical locales, and cultures, which made the team an effective interdisciplinary research team.

Methodology of the Project

Phenomenology is a philosophical movement. In the nineteenth century, the positivist paradigm continued to consider the empiricist (quantitative) perspective as a standard of the scientific world. Empiricists postulated that human phenomena should be studied objectively like natural science through strictly controlled empirical methods (Husserl, 1970). In contrast to positivistic reductionism, Husserl (1970) promoted phenomenology. Phenomenology is a philosophical movement and believes that human subjectivity can be explored as a whole through their everyday experience. Phenomenology, as a philosophical movement, reflects common essences of human experience; as a methodology, emulates individuals' experience in

the everyday world; and as a research approach, explores human subjectivity via interactions between researchers (the instrument) and participants who are experts in a phenomenon (Swanson-Kauffman & Schonwald, 1988; Wojnar & Swanson, 2007). Phenomenology has greatly influenced social scientists' and healthcare providers' points of view and ways of understanding patients' experiences with their health and illness.

There are two major schools of phenomenology, Husserl's descriptive phenomenology and Heidegger's interpretive phenomenology (Wojnar & Swanson, 2007). Husserl (1970) was the originator of descriptive phenomenology. Scholars whose work drew upon Husserlian framework include Gurwitsch, Merleau-Ponty, and Alfred Schultz (Giorgi, 2009; van Manen, 2011). Colaizzi (1978) and Giorgi (1970) in psychology and Swanson-Kauffman and Schonwald (1988) in nursing developed research methods based on Husserl's descriptive phenomenology. Heidegger was the initiator of interpretive phenomenology (Heidegger, 1962). Gadamar, Sarte, and Ricoeur were Heideggerian scholars (van Manen, 2006; van Manen, 2011). Van Manen (1990) in pedagogy and Benner (1994) in nursing developed research methods based on Heidegger's interpretive phenomenology.

Husserl's Descriptive Phenomenology. Husserl's descriptive phenomenology explores the transcendental experiences of individuals who live through the phenomenon of interest (Husserl, 1970). The central tenets of descriptive phenomenology are transcendental subjectivity, eidetic essence, and intentionality (Giorgi, 2009; Wojnar & Swanson, 2007). Transcendental subjectivity is the open-mindedness to others' perceived realities; eidetic essence captures universal truths as perceived by individuals who live through the phenomenon; and intentionality is individuals' direct consciousness of an event in the everyday world (Husserl, 1970). Descriptive phenomenology is an approach to capture and describe human beings' experiences

without presumptions (Husserl, 1970). This approach can serve as a guiding framework when the common essence of a phenomenon is not adequately conceptualized and researchers have no direct personal experiences of the phenomenon of interest.

Heidegger's Interpretive Phenomenology. Heidegger's interpretive phenomenology goes beyond the description of a phenomenon. It proposes that the core of human beings' understanding is hermeneutic, meaning that understanding of the everyday world results from the interpretation of the world (Heidegger, 2013). Personal knowledge of the phenomenon of interest is necessary for this approach (Wojnar & Swanson, 2007). In contrast, the interpretive phenomenology is used when researchers have some prior knowledge of the phenomenon and intend to interpret the meaning of the lived experience (Heidegger, 2013). When researchers intend to focus on the uniqueness of people's lived experiences in a particular context, such as different cultures and politics, interpretive phenomenology can serve as a guiding framework.

The main criteria for choosing an appropriate methodology are the study purpose and research questions. Because the primary aim of this project was to explore the lived experience of parents who were caring for a child with CHD undergoing heart surgery and the first author had no direct personal experiences with the phenomenon, Husserl's descriptive phenomenology was the methodology of choice.

Methods of the Project

Design. The project was a prospective phenomenological study, using purposeful criterion sampling (Patton, 2002), in-depth interviews, and common theme analysis (Colaizzi, 1978). The Institutional Review Boards at the university and the Nursing Research Council at the hospital where the study was carried out approved the study. Parents' written informed consents were obtained prior to the first interview.

Sampling and Setting. This study was conducted in a university affiliated children's hospital on the east coast of the United States. Recruitment took place on a children's cardiac unit between July and December 2014. During the recruitment period, parents who met the inclusion criteria were invited to participate. These parents had a child who was hospitalized for his/her first congenital heart surgery; were 18 years or older of any race/ethnicity; and were able to speak and read English. No parents declined when they were invited to participate.

The precise sample size for phenomenological studies is hard to decide beforehand. Recommendations of the sample size are between 5 and 25 participants (Creswell, 2013). In this study, from the 7th parent, we could see patterns of themes. From the 10th parent, we saw information redundancy. We stopped recruiting after the 13th parent was interviewed and the data was analyzed when saturation of themes was reached.

Recruitment for the project was done on a children's cardiac unit in a children's hospital located in the southeastern United States between July 2014 and December 2014. The hospital was university-affiliated and one of the major heart centers in the state. None of the parents invited to participate in the study declined. Team members recommended looking for signs of data saturation to stop recruitment; i.e., data exhibited similar patterns and repetitions with little variations even though the sample was diverse. Recruitment was stopped when data saturation was reached, which was after the interview with the tenth family.

Data Collection

Interviewing is a primary source of data collection for phenomenological studies (Colaizzi, 1978; Patton, 2002; Swanson-Kauffman & Schonwald, 1988). There are similarities between phenomenological and other qualitative interviews. For example an interviewer is an instrument and needs to generate a trusting rapport with participants. There are also differences

between phenomenological interviews and others, such as grounded theory interviews (Wimpenny & Gass, 2000). Phenomenological interviews highlight the uniqueness of each interview, in which interviewers treat each participant as a distinctive entity, not as part of ongoing theoretical sampling. In phenomenology, it is the individual's experiences that interviewers focus on to understand the world as experienced and narrated by the participants.

In this project, the first interview took place between 3 and 7 days after a child's heart surgery. The interviews were conducted in-person on the children's cardiac unit. With the first interviews coming soon after the surgery, the interviewer intended to capture parents' immediate experiences after surgery. The second interview was conducted 4 to 6 weeks after the first interview, at which time the children were at home. The interval between the two interviews allowed parents time to reflect on their earlier experiences and examine their subsequent experiences. The second interviews were conducted either in person or via phone based on parents' preference. Interviews were audio recorded and transcribed verbatim.

The team members helped frame the interview and probing questions based on the study purpose. The grand tour question for the first interview was "Please describe what it is like to be a parent of a child who has congenital heart disease and requires heart surgery". For the second interview, parents were asked to reflect on the aftermath of bringing their child home. The grand tour question was "Looking back, what are your feelings on what you have experienced since your child's diagnosis?" Probing questions included "What was that like for you?" and "Can you please tell me more about that?"

Data Analysis

Combining the data analysis methods of Colaizzi (1978), Giorgi (1970), Swanson-Kauffman and Schonwald (1988), Wojnar and Swanson (2007), Wojnar, Swanson, and

Adolfsson (2011), the researchers adopted a team approach to analyzing the data. This approach included (a) assembling a coding team and starting analysis along with data collection; (b) bracketing when looking for patterns; (c) analyzing to find common essences across data; (d) intuiting to immerse self in the data and reflect meanings; (e) bringing participants' verbal descriptions to a written form; (f) validating via member checks to confirm understandings; and (g) incorporating participants' feedbacks in a final report.

Assembling a coding team. Data collection and analysis proceeded concurrently. A data coding team was assembled, including the first author, the visiting professor, and the doctoral student. Other team members acted as a peer reviewer (the third author who was a nurse phenomenological scholar as), a consultant (the second author who was a qualitative research expert), and a mentor (the fourth author who was a nurse phenomenological scholar). Each coder read and coded transcripts individually. The team met at least once a week to discuss their codes, then met with the peer reviewer to confirm their codes and share the discussion. The first author met with the qualitative consultant once a week to obtain advice on how to lead coder meetings and resolve disagreements on codes. The first author also sought coding insights from the mentor. Each team member provided personal, disciplinary, clinical, and methodological suggestions and recommendations. The first author acted as a liaison among team members and as the conductor of an orchestra, ensuring that each team member had his/her voice heard.

Bracketing. Bracketing is researchers' attempts of putting aside presumptions and predetermined ideas about the phenomenon of interest (Wojnar, Swanson & Adolfsson, 2011). To achieve bracketing, the researchers (a) used field notes to capture their assumptions; (b) sought feedback on their insights from other team members; and (c) assessed their personal biases. For example, as a clinician caring for families of children with CHD, the first author

assumed that parents whose child had a less complicated type of CHD, such as atrial septal defect, were more stressed than parents whose child had a more complex type of CHD, such as atrial and septal defects. She constantly reminded herself of this assumption and set it aside.

Analyzing. Analyzing is a process of finding the common essence of the phenomenon of interest (Barritt, Beekman, Bleeker, & Mulderij, 1984; Wojnar, Swanson, & Adolfsson, 2011). Facing a daunting amount of interview data, the research team (a) decided on the sections of the transcripts to be coded for that week; (b) coded the designated sections individually; (c) met to discuss the evolving codes; and (d) presented the codes to the peer reviewer for feedbacks.

During coding, the team (a) read the transcripts thoroughly; (b) wrote memos while reading; (c) extracted significant statements about the phenomenon of interest; (d) assigned meanings for the extracted statements; and (e) categorized the meanings into groups of themes shared by all participants. The researchers wrote memos to record notes about what they picked up from the data (Groenewald, 2008). The researchers used ATLAS.ti (ATLAS.ti GmbH, 2015), a qualitative data software program to help track memos, categorize similar ideas, and find common themes across transcripts. Table 1 listed the coding processes and Table 2 exemplified the process of deriving themes.

Intuiting. Intuiting is a reflective process, during which researchers are submerged into the phenomenon of interest (Wojnar, Swanson, & Adolfsson, 2011). Intuition, however, does not come easily at the beginning. In this project, researchers strived to (a) break the surface of the data and go deeper than the words in the transcripts, (b) dive into participants' experiences, and (c) allow themselves to be deeply immersed in participants' narratives, struggles, and meanings. As a result, researchers were able to position themselves in participants' place and empathetically feel what it might be like to experience the phenomenon as their own. During the

process, one of the team members (the fourth author and mentor) challenged the first author to seek metaphors and more persuasive words to convey what she was intuiting.

Describing. Describing is the process of effectively capturing informants' verbal descriptions in writing (Wojnar, Swanson, & Adolfsson, 2011). When describing, it is necessary to use sufficient empirical data to support the account. The final report should be “like a universal skeleton that can be filled in with the rich story of each informant” and “anyone who has experienced the phenomenon” (Swanson-Kauffman & Schonwald, 1988, p. 104). Therefore, the final description of this project was a framework that could fit anyone who had a child with CHD undergoing a heart surgery.

Validating by Participants. Validating by participants is a method used to increase the accuracy, credibility, and validity of findings (Colaizzi, 1978, Creset, 2013). In this project, the first author asked five parents at the end of the first interview whether they would agree to read the findings of the project. All parents agreed to read and provide feedback. After receiving their feedback, the researchers combined parents' suggestions and wrote up a tentative final report. The final report was completed after all team members gave their input.

Strategies to Achieve Rigor in the Study

Sandelowski (1986) provided specific strategies to attain rigor in qualitative studies by achieving auditability, credibility, and fittingness. From a phenomenological perspective, Giorgi (1988) acknowledged that validity was reached when the description of a phenomenon truthfully captured the intuited essence; and reliability was achieved when researchers applied the essential steps in phenomenological studies, such as bracketing, intuiting, and analyzing to ensure a precise description. In order to completely uncover participants' beliefs of a phenomenon,

Colaizzi (1978) required researchers to build a trusting relationship with participants in the research process.

From a team approach perspective, the researchers in this project made sure that a clear audit trail was kept on all decisions and discussions. Team members ensured that (a) coding categories and findings represented the data as a whole, not just a section of the data or a few participants, (b) the resources used in data collection and analysis, such as recordings and transcripts, were congruent, (c) the findings were validated by participants, and (d) team members met regularly to discuss research progress.

Discussion

It was a great advantage to have a research team made up of scholars and experts from different disciplines who could provide guidance from their specialties. These connections and conversations helped team members to learn from one another and discover new knowledge. Through the team efforts, the first author who was a clinical nurse researcher gained knowledge and confidence in conducting qualitative research, leading a team, and using qualitative software to conduct data analysis.

Conducting a phenomenological study required the researchers to work toward creating intimacy with the data. Thus, getting to know the data not only involved gaining an intellectual grasp of narratives, but also sensing the felt experiences more holistically and understanding how the narratives filled the lives of the participants (van Manen 2006). Writing memos was an in-depth method of generating this intimacy. Memos focused on experiences during data collection, the language participants used in the interviews, and the emerging codes during reading. Memos captured how participants' stories animated their presence during interviews and how participants brought their stories to the foreground of their lives. Memos also took particular

language from transcripts and allowed the researchers to linger over its meanings. In addition, the researchers used memos to see how data fit together chronologically or conceptually.

When conducting the phenomenological study, the researchers did not just evaluate participants' words in the transcripts, but also looked for what resonated in their experiences. For example, it is not just how one particular parent related to her/his child that researchers would highlight, but rather on the collective essence across all parents. Themes, such as "blaming self," went beyond a particular parent to capture the essence of the human journey with a child who was just diagnosed with CHD. Phenomenology captures experiences from the inside (van Manen 2006). The researchers looked into the data that captured an inner event, such as mood, emotion, or perception, which occupied parents' lives. It is the inner events that give us insight into the nature and arc of human experiences.

Conducting a phenomenological study with a team approach is a great way of reaching the arc of human experiences. Teamwork is an ongoing conversation that deepens understanding and allows room for reflection. The conversations among team members generated thematic language that could be examined, questioned, and refined. Through these conversations, the researchers went back and forth to analyze data in a particularistic and holistic way, making theme deriving an active process of discovery, rather than a mechanistic activity of superficial consensus. The "particularistic and holistic way" means that a single sentence may tell about an experience; but that experience is always compared with the whole. The "whole" becomes increasingly apparent in working with other coders.

Conclusions

A research team is like an orchestra, in which team members play different, but valuable roles. A PI is like a conductor, a liaison among all team members. How well the orchestra plays depends on team members' collaboration and the PI's conducting. By working together, researchers from different disciplines or different specialties in the same discipline can strengthen a study. Each team member contributes valuable cultural, clinical, research, and life experiences. To successfully apply the team approach, team members should validate and respect the differences among one another, take advantage of their different specialties, utilize one another's expertise, and make sure everyone's voice is heard. When done well, team research can provide a roadmap for innovation in many aspects of human life and healthcare.

Declaration of Conflicting Interests

The authors declared no conflicts of interest in the authorship or publication of the article.

Funding

The Jane Winningham Smith Scholarship from the School of Nursing at (University name) and the Dr. Lester Sauvage Research Fund from the Hope Heart Institute.

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Table 3.1. Analytical procedures based on the data analysis methods of Colaizzi, Giorgi, Swanson, and Barritt et al.

Steps of Analysis	Analytical Procedures	Examples of Transcripts	Results of Analysis
<p>Step 1: Read participants' descriptions about the phenomenon of interest.</p>	<p>When coding parents' experiences, researchers</p> <ul style="list-style-type: none"> a) Started with a single experience, for example, being a parent of a child with CHD; b) Began the analysis by going into each transcript with a pair of fresh eyes and an open mind; c) Felt the important elements from parents' descriptions; d) Allowed those important elements to surface by themselves; e) Used parents' descriptive language when possible; and f) Avoided interpretations and attributions beyond the data. <p>From a team approach perspective, researchers</p> <ul style="list-style-type: none"> (a) worked as a group from the beginning; (b) were open-minded with disagreements; (c) did not impose agreement among coders; and (d) strived for consensus, but allowed variations. 	<p>For example: one quote led to disagreement among coders:</p> <p>“For that whole year, I knew he had a hole [in his heart]. The whole time I was thinking it would close on its own.... For the first year, it was like I had a mask over my face because nothing was said. It was like basically it was going to close.” (Kendra)</p> <p>The coders did not agree on the precise meaning of “it was felt I had a mask over my face because nothing was said”.</p>	<p>Resolution to the disagreement:</p> <p>Team members stood back and looked at the larger context of the passage. They agreed that the participant was hoping that if doctors did not mention about the hole in her child's heart and her child was functioning fine, the hole may have possibly closed on its own.</p>

<p>Step 2: Write memos to record reflective notes about what they learn from the data.</p>	<p>To capture their thoughts and observations, researchers</p> <ol style="list-style-type: none"> Wrote memos while reading transcripts to seize the outflow of thoughts, intuitions, and observations; and Used ATLAS.ti (ATLAS.ti GmbH, 2015), a qualitative data software, to help track memos and categorize similar ideas. <p>From a team approach perspective, researchers used ATLAS ti to communicate and share their memos.</p>	<p>For example: coders noted that parents all blamed themselves for their child’s heart defects and all hoped that their child could beat the odds and did not need heart surgery.</p>	<p>Common themes that were developed based on these memos: “What did I do that caused it?” and “Hoping the child’s heart defect will fix itself”.</p>
<p>Step 3: Extract significant statements about the phenomenon.</p>	<p>To find significant statements, researchers</p> <ol style="list-style-type: none"> Read through each transcript and chose the statements that seemed to be the heart, the center, of the event for the parent; Let the center statements surface from the transcripts; and Read each transcript with fresh eyes and identify powerful statements. <p>From a team approach perspective,</p> <ol style="list-style-type: none"> Researchers did not worry about the numbers of statements identified at this time; The statements were from each transcript; and These statements were selected and shared among team members. 	<p>In our analysis, 66 important statements stood out initially. Some of the codes were: “I was under the impression that everything was fine.” (Kendra) “I felt like it was something that I did wrong during the pregnancy or I wasn’t careful.” (Auden) “Like maybe he’ll beat the odds and he won’t need surgery.” (Aster) “On the way here, it was a relief and scared at the same time.” (Lyra)</p>	<p>All coders coded separately using ATLAS.ti, a computer software to aid qualitative data analysis.</p>

<p>Step 4: Assign meanings for the extracted statements.</p>	<p>After an initial selection of the statements, researchers</p> <ol style="list-style-type: none"> Tried to assign meanings to the significant statements. Themes may not always be found from specific words in transcripts but between the lines; and Made sure that each theme have its codes from the transcripts as supporting evidence. <p>From a team approach perspective, researchers</p> <ol style="list-style-type: none"> Compared their selections and created a list of common themes; Were encouraged to discuss the intentions of their selections; and Worked through any misperceptions. 	<p>“I was under the impression that everything was fine.” (Kendra)</p> <p>“I felt like it was something that I did wrong during the pregnancy or I wasn’t careful.” (Auden)</p> <p>“Like maybe he’ll beat the odds and he won’t need surgery.” (Aster)</p> <p>“On the way here, it was a relief and scared at the same time.” (Lyra)</p>	<p>Expecting everything was fine Blaming self for child’s heart defects</p> <p>Hoping child’s heart defect will fix itself. Embracing the child’s heart surgery with relief and fear.</p>
<p>Step 5: Categorize the meanings into groups of themes shared by all participants.</p>	<p>During this step, researchers</p> <ol style="list-style-type: none"> Clustered the shared experiences across the participants; Understood the meaning of participants’ experiences through those shared experiences; and Categorized meanings into groups of themes shared across participants. <p>From a team approach, researchers</p> <ol style="list-style-type: none"> Compared themes that were clustered by each team member; Integrated themes among all team members and the ones constructed in earlier transcripts; Were faithful to participants’ descriptions when constructing common themes; Reword themes as needed based on clarifications at a later time; and Check whether the current themes were still sufficient when working with more transcripts. 	<p>Shared experiences:</p> <p>“I felt like it was something that I did wrong during the pregnancy or I wasn’t careful.” (Auden)</p> <p>“I remember going, I had coffee! Was I not supposed to have coffee? I only had a little bit of coffee but every day I had coffee.” (Lyra)</p> <p>“What did I do that caused it? Or what didn’t I do? Or what could I have done that maybe would have prevented it?” (Kendra)</p>	<p>Codes: Blaming self for child’s heart defects.</p> <p>A common theme: What did I do that caused my child’s heart defects?</p>

Table 3. 2. The process of theme-deriving, with examples from selected transcript samples

Read Transcripts, with significant statements underlined	Extract Significant Statements	Assign Meanings to the Extracted Statements	Cluster Assigned Meanings	Emerging Theme
<p>Kendra: <u>What did I do that caused it? Or what didn't I do? Or what could I have done that maybe would have prevented it?</u> I mean I did myself over by a lot of this stuff. And I know you always hear people say you can't do that to yourself and there's nothing you did or nothing you could have done. <u>But in the back of your mind you always think that maybe this is something that I did or something I didn't do.</u></p> <p>Lyra: <u>I remember going, I had coffee! Was I not supposed to have coffee? I only had a little bit of coffee but every day I had coffee.</u> You rack your brain thinking, what did I do? I think it is just human nature to go back and try to figure out. Even though I can't change the present, I would go back and try to think. <u>I know I did my best during pregnancy, and I know I ate healthy and exercised. And I took my vitamins when I needed to take them.</u></p> <p>Lani: <u>My husband blamed himself.</u> The reason is that he works in (place) that makes chemicals. And he's been there for (number) years. <u>He thought with him being at the factory, the chemicals getting into his system may have caused our children's birth defects.</u></p>	<p>“What did I do that caused it? Or what didn't I do? Or what could I have done that maybe would have prevented it?”</p> <p>“But in the back of your mind you always think that maybe this is something that I did or something I didn't do.”</p> <p>“I remember going, I had coffee! Was I not supposed to have coffee? I only had a little bit of coffee but every day I had coffee.”</p> <p>“I know I did my best during pregnancy, and I know I ate healthy and exercised. And I took my vitamins when I needed to take them.”</p> <p>“My husband blamed himself.”</p> <p>“He thought with him being at the factory, the chemicals getting into his system may have caused our children's birth defects.”</p>	<p>Mothers feel there may be something that they could have done to prevent the defects. They keep thinking about what they did or did not do right that has caused the defects.</p> <p>Mothers try to think what they have done during pregnancy and what could possibly cause their child's heart disease.</p> <p>They feel they have done what they are supposed to during their pregnancy.</p> <p>Fathers think it may be because what they have been in contact with that has led to their child's defects.</p>	<p>For their child to be born with the heart defects, mothers blame themselves and feel responsible for the defects.</p> <p>Not only mothers, but also fathers blame themselves for their child's defects.</p>	<p>Blaming self for child's heart defects.</p> <p>This theme may also be expressed using participants' own words, for example, “What did I do that caused it?”</p>

Read Transcripts, with significant statements underlined	Extract Significant Statements	Assign Meanings to Extracted Statements	Cluster Meanings	Emerging Theme
<p>Kendra: <u>“This is heart surgery. This is open heart surgery. I think it was more like I was trying to convince myself like he’s going to be fine. But then it’s like this is heart surgery. He’s only one year old. He’s just a baby. Why would you want to cut open a baby? But it’s like the devil and the angel on each shoulder. He’s going to be fine. Why are you worried about it? But this could still happen. He could still have this problem. And then it was like nah, he’s going to be ok.”</u></p> <p>Aster: <u>“I couldn’t be selfish. This is going to help him live a long prosperous life. We have to get this done now. He’s going to be a totally different person. I had to think of the outcome. Like ok. This is going to help him. This is going to make him stronger.”</u></p> <p>Kendra: <u>“It was rough. I can’t say I was in a deep depression. But it made me want him so much closer to me. I would get up in the middle of the night and get him out of his crib and just cradle him and put him in the bed with me. I would cry and sit there and talk to him. I would just sit there talk to him like it’s going to fine. This surgery will be fine. You don’t have to worry. Mommy is worried enough for all of us.”</u></p>	<p>“This is heart surgery. This is open heart surgery. I think it was more like I was trying to convince myself like he’s going to be fine.”</p> <p>“But it’s like the devil and the angel on each shoulder. He’s going to be fine. He could still have this problem.”</p> <p>“He could still have this problem. And then it was like nah, he’s going to be ok.”</p> <p>“I couldn’t be selfish. This is going to help him live a long prosperous life.”</p> <p>“This is going to make him stronger.”</p> <p>“But it made me want him so much closer to me. I would get up in the middle of the night and get him out of his crib and just cradle him and put him in the bed with me.”</p> <p>“I would just sit there talk to him like it’s going to fine. This surgery will be fine.”</p>	<p>Parents are scared of heart surgery, but want to persuade selves that their child would be fine.</p> <p>Parents are struggling to make decisions for their child’s heart surgery.</p> <p>Parents are fearful that the surgery may or may not work.</p> <p>Parents feel they should not only think about how they feel about the surgery, but also think about the benefits of the surgery for their child.</p> <p>Parents feel the need to be closer to their child because of the heart surgery.</p>	<p>Parents are scared for their child to go through heart surgery.</p> <p>They feel extremely dilemmatic about their child’s surgery.</p> <p>Parents feel they should think of the positive outcomes for their child.</p> <p>Parents want to try their best to make the right decision to</p>	<p>Facing dilemmas in making decisions for heart surgery.</p> <p>For this theme, parents’ own words, such as “it’s like the devil and the angel on each shoulder” may not be a better fit because these words showed parents’ dilemma, but do not capture the decision making.</p>

Parents try to protect their
convince child.
themselves that the
heart surgery is
going to be fine.

CHAPTER 4: PARENTS EXPERIENCES AND PERSPCTIVES WHEN HAVING A CHILD WITH CONGENITAL HEART DISEASE

Manuscript 3. Parents' Experiences of Having a Child Undergoing Congenital Heart Surgery: An Emotional Rollercoaster from Shocking to Blessing

Introduction

Congenital heart disease (CHD) is the most prevalent birth defect in the United States. Each year, 40, 000 children are born with CHD, with an incidence rate of 1 in 100 live births (Centers for Disease Control and Prevention [CDC], 2015a). Congenital heart disease is among the birth defects that lead to the longest hospital stays and highest mortality rate (Robbins et al., 2007) and children with CHD often require frequent hospitalizations for medical and/or surgical treatment (Pasquali et al., 2011).

In 2000 and 2002 respectively, the National Heart, Lung, and Blood Institute sent out two major initiatives to promote treatment interventions and encourage clinical research for children with heart disease. According to a literature review about families of children with CHD (Wei, Roscigno, Hanson, & Swanson, 2015), research studies have mainly focused on the impact of a child's CHD on parents' psychological health, their family life, parenting experiences, and the relationships between parents' psychological symptoms and child's behaviors since 2000.

Parents' psychological health was a major research focus in the past 15 years (Wei et al., 2015). Using parents' self-report surveys, some researchers (Lawoko & Soares, 2002; Lawoko & Soares, 2006; Utens et al., 2000; Utens et al., 2002; Uzark & Jones, 2003) found that parents of children with CHD reported higher levels of psychological symptoms, such as stress, anxiety, or depression, than parents of children without CHD or general public; and a few researchers

(Spijkerboer et al., 2007; Visconti, Saudino, Rappaport, Newburger, & Bellinger, 2002) found a lower level of psychological symptoms in parents of children with CHD than without.

As discussed in the review (Wei et al., 2015), qualitative narrative techniques may facilitate the self-report surveys to help us better understand parents of children with CHD. When using both parents' self-report surveys and interviews to study parents' psychological symptoms, researchers found that interviews were more sensitive to parents' stress symptoms than the self-report questionnaires (Carey, Nicholson, & Fox, 2002). Jordan et al. (2014) also found that when they studied mothers' bonding experiences with their infant with CHD, mothers reported during interviews that the bonding with their infant was affected by their infant's heart surgery; however, these mothers' answers on the self-report surveys did not show significant differences from the mothers in the general public. Vrijmoet-Wiersma, Ottenkamp, van Roozendaal, Grootenhuis, and Koopman (2009) discussed that to understand the experiences of parents of children with CHD, self-report questionnaires alone might not be sufficient.

Since 2000, there were fewer than 30 studies, in which researchers used interviews to examine parents' experiences when they had a child with CHD (Wei et al., 2015). One third of these studies examined a number of Canadian parents of children with Hypoplastic Left Heart Syndrome. This syndrome is a non-curative type of CHD and affects about 960 children, with an incidence rate of 1 in 4,344 live births in the United States each year (CDC, 2015b). Researchers found that parents of children with Hypoplastic Left Heart Syndrome were highly vigilant; had to overcome many uncertainties to make treatment decisions; had to safeguard their child's life as well as their own; and strived to provide their child as a normal life as possible (Ellinger & Rempel, 2010; Meakins, Ray, Hegadoren, Rogers, & Rempel, 2015; Rempel, Harrison, & Williamson, 2009; Rempel, Blythe, Rogers, & Ravindran, 2012).

Among the qualitative studies of families of children with CHD (Wei et al., 2015), only fewer than 10 were done in the United States since 2000. Connor, Kline, Mott, Harris, and Jenkins (2010) studied parents' views about the meaning of cost when they had a child with CHD and found that the cost was beyond monetary terms and meant lifestyle changes and uncertainties. Gantt (2002) studied the relationships between mothers and daughters who were teenagers or young adults and had CHD in their childhood and found that both mothers and daughters wanted to normalize their lives despite the illness. Fernandes (2005) interviewed five couples about their experiences when they had a child with CHD who did or did not require surgery and found that parents tried to understand the procedures their child had to go through and they experienced a broken heart with their child. Pridham et al. (2010) explored parents' motivations of parenting their infant with CHD during his/her first year and found that parents mainly focused on facilitating their infant's development, bonding with their infant, strengthening their family relationships, protecting parent-selves, and managing parenting responsibilities, such as feeding their infant and getting other jobs done.

So far, very little research has explored the patterns of parents' experiences as their child went through the course of diagnosis of CHD and heart surgery, especially parents' experiences during their child's hospitalization undergoing heart surgery. When a child was hospitalized for heart surgery, parents' stress levels remained significantly high on a parenting stress scale (Franck, McQuillan, Wray, Grocott, & Goldman, 2010). Understanding parents' experiences and identifying the critical times and stress factors during the course of their child's diagnosis and heart surgery could make a substantial contribution to the care of families of children with CHD. Therefore, this study examined parents' experiences from the time of their child's diagnosis of CHD to the time after their heart surgery.

Methods

This study was approved by the Institutional Review Board at the university and the Nursing Research Council at the study hospital.

Design

This was a descriptive phenomenological study. Descriptive phenomenology is intended to describe individuals' experiences of a phenomenon without presumptions (Wojnar & Swanson, 2007). The method encourages investigators to capture the universal realities perceived by individuals who experience the phenomenon in their everyday world.

Sample and Setting

This study was carried out in a children's hospital located on the east coast of the United States. Recruitment took place on a pediatric cardiac unit between July and December 2014. Purposeful sampling, specifically a maximum variation sampling (Sandelowski, 1995), was used. Because it was not clear whether the severity of CHD and parents' socioeconomic background affected parents' experience, we used the maximum variation sampling to warrant a diverse group of parents and a deep understanding of the phenomenon of interest (Sandelowski, 1995). Therefore, parents were invited to participate in the study if they had a child with CHD hospitalized for his/her first open heart surgery, were at least 18 years old and of any race, and spoke and read English. No parents declined when invited. One parent from each family was required to participate; but both parents were welcome. If both parents were in the study, they were interviewed individually.

The precise sample size needed for phenomenological studies is hard to decide beforehand. Recommendations for sample size are between 5 and 25 participants (Creswell, 2013). We used informational redundancy as a guide in deciding the adequacy of the sample size

(Sandelowski, 1995). In this study, after the seventh parent, we could see patterns of themes. After the tenth parent, we saw information redundancy. We stopped recruiting after the thirteenth parent was interviewed and the data was analyzed when saturation of themes was reached.

Data Collection

Two forms of data were gathered, a demographic information survey and in-depth interviews. Parents' written informed consent was obtained before their first interview. Pseudonyms were assigned to each participant to preserve humanistic characteristics and protect their privacy. Two interviews per parent were conducted if parents were available and willing. The first interview was about a week after the child's heart surgery, and the second interview occurred 4-6 weeks after the first interview. Parents completed the demographic form before their first interviews. The first interview was conducted in-person on the cardiac unit. The second interview was done in person or by phone depending on parents' choice. One parent per family was required to participate; both parents were welcome. If both parents participated, they were interviewed separately. The interviews lasted about an hour and were transcribed verbatim.

The first interview was designed to inquire about parents' experiences upon receiving their child's diagnosis, going through heart surgery, seeing their child after surgery, and being transferred from an ICU to a regular cardiac floor. The intention for the second interview was to allow parents to reflect on the entire experience from diagnosis to discharge, and provide updates on their experiences at home after discharge. Interview questions were developed based on the purpose of the study. Selected interview questions and probing questions are listed in Table 4.1.

Data Analysis

Combining the data analysis methods of Colaizzi (1978), Giorgi (1970), Swanson-Kauffman and Schonwald (1988), Wojnar and Swanson (2007), and Wojnar, Swanson, and

Adolfsson (2011), the authors used a team effort to conduct the data analysis. The process included (a) assembling a coding team; (b) starting analysis along with data collection; (c) reading transcript data thoroughly, which could take multiple times to gain a general sense of participants' overall experiences; (d) bracketing when looking for patterns; (e) writing memos while reading; (f) extracting significant statements about parents' experiences; (g) assigning meanings to the extracted statements; (h) finding commonalities across data; (i) intuiting on the data and reflecting meanings; (j) categorizing the meanings into groups of themes shared by participants; (k) describing parents' verbal descriptions in a written form; (l) validating the data via parents' member checks; and (m) incorporating parents' suggestions into a final report.

To aid the analytic process, authors used ATLAS.ti, version 7.5.6 for windows (Scientific Software Development, 2014). The authors used the software to link codes to parents' narratives, track codes among coders, and maintain a clear audit trail during the analytic process.

Strategies to Achieve Rigor in the Study

To increase the rigor of the study, a team of three coders and a peer reviewer conducted the data analysis and kept a clear audit trail about decision making (Sandelowski, 1986). The three coders, including the first author, a visiting qualitative scholar, and a doctoral student, coded the data individually and met once a week to discuss their individual coding. Then they met with the peer reviewer (the second author) to discuss their findings. The first author discussed the progress with the rest of the authors and sought further advice on coding and reporting from them. When disagreements occurred among the team members, instead of focusing on the disagreements, the team looked at the larger context and tried to understand the data from parents' perspectives, instead of researchers' interpretations.

Results

Participants

The sample included 13 parents (10 mothers and 3 fathers) of 10 children. Twenty-one interviews were conducted. Among the 13 parents, eight were available for both interviews and five were only available for one interview due to other family obligations, resulting in a total of 21 interviews. Parents' and children's demographics are shown in Tables 4.2 and 4.3. According to the surgical risk and in-hospital mortality rate, children's CHD was ranked from 1 to 5, with 5 reflecting the greatest surgical risk and highest in-hospital mortality rate, using the Society of Thoracic Surgeons European Association of Cardio-Thoracic Surgery Congenital Heart Surgery Mortality Categories (STAT Mortality Categories; J. P. Jacobs et al., 2012; M. L. Jacobs et al., 2013; O'Brien, 2009).

Experiential Model

Parents in this study exhibited similarities when describing their experiences of caring for a child with CHD. Two mothers (Tara and Lyra) actually used "rollercoaster" to describe their emotions. The ups, downs, twists, and turns of parents' emotions were noticed from parents' descriptions. Their key experiences are listed in Table 4.4 and summarized below.

It was a shock to hear about my child's heart defect. When informed about their child's heart defects, parents were shocked, overwhelmed, and heartbroken, regardless of the time of their child's diagnosis, before or after birth, or the type of their child's CHD. Their thoughts were that their child had a heart defect(s) and there was something wrong with their child's heart. Parents described their feelings as "It [the diagnosis] was very shocking" (Aster); "It was scary and heart breaking" (Auden); "I felt overwhelmed. It was scary" (Tara); "It was a shock. Your whole world changed" (Lyra); "I felt like my heart was breaking when they told

me” (Kady); “That was heart breaking” (Kendra); and “It [the diagnosis] was the most devastating thing I have ever heard in my life” (Della). One mother said: “The moment we were told about the diagnosis, it seemed that we stepped onto a roller-coaster.” (Tara)

Parents’ feelings at the time of being informed about their child’s diagnosis depended on how providers informed them about their child’s heart defect. Parents said that they were more hopeful if providers were more optimistic. One mother, Lyra, said:

When the pediatrician came in, she said: “Oh your baby has Tetralogy of Fallot.”

It’s the way she told us. I could see the sadness in her face. It made me feel like this was really bad.... When the cardiologist came in, he immediately put me at ease with his positive attitude. He told me about my son’s heart condition, and laid out the solution. I remember what really lifted my spirit was when he said:

“Shaun White, he had Tetralogy of Fallot. He won Olympic gold medals”. And I remember thinking, thank you for saying that.

Fathers’ reactions to their child’s diagnosis of CHD were twofold. They said they were not only scared about their child, but also concerned about their wife. One father said: “I was scared. But I was more scared for her [my wife] than for me” (Jerald). Another father said: “I was honestly thinking about my wife. I handle stress and those kind of things a lot better. I was concerned how she was feeling and how she was going to be” (Jerry).

What did I do that caused it? After the initial shock of hearing about their child’s heart defect, parents started to blame themselves. They reported that they thought it was their fault that their child was born with a heart defect. One mother said: “What did I do that caused it? What could I have done that might have prevented it?” (Kendra). Others said: “I felt like it was something that I did wrong during the pregnancy or I wasn’t careful” (Aster), and “Oh my god

what did I do. What did I do? Why?” (Della). One mother reported that her husband, who worked in a chemical factory, felt it was his fault. “He blamed himself. He thought, with him being at the chemical factory and the chemicals getting into his system, which may have caused our child’s heart defect” (Lani).

Hoping the child’s heart defect would fix itself. When physicians told parents that some congenital heart defects might close on their own as children grew, the parents were hopeful. One mothers said, “He [My son]’ll beat the odds and won’t need surgery. The heart defect will fix itself. I’ll go in one day and they’ll go: oh everything is fine” (Aster). Another mother said, “I was sitting there [in a clinic]. I was holding her [the patient] and looking at her. I was like ok, any time now they’ll be here and tell me we’re fine and we can go home” (Della). Still another mother said: “No one [physician] said or did anything within that year, it basically made me feel like it was going to close on its own, and maybe it already did because I hadn’t heard anything” (Kendra).

Dilemmas in making decisions for heart surgery. When parents were told that their child’s defects were not resolving and their child needed heart surgery, they had a hard time making the decision. On the one hand, parents knew the importance of having the heart defects fixed; but on the other hand, the unknowns of surgery made them fear that their child might not survive. One mother reported her struggle: “The heart defect has to be fixed.... But this is the heart, a heart surgery. He may not survive the surgery. Part of me wanted him to have the surgery and another part didn’t. It’s like the devil and the angel on each shoulder.” (Kendra).

Fathers were more worried about their wife than their child. They described their feelings that their child would be fine and the surgery would make him/her a healthier child. One father said: “I was okay with the surgery. I knew my son was going to be okay.... It’ll make him into a

healthy little boy. Run around, play baseball. I am more worried about my wife.” (Jerry).

Another said, “I was worried about my wife. I just prayed: God, please heal our son for my wife.” (Jerald).

Unable to let my child be out of my arms and given to the surgical staff. Parents embraced their child’s surgery with diverse feelings. Two of the 13 parents felt at peace and ready; but others were distraught. One of the two mothers who was ready said: “I almost got this feeling that I’m ready. Let’s do this. Game on. Let’s get this done and start the healing process” (Lyra). The other mother who was ready used prayers for support. She said: “The entire time we were sitting in the operating room section, I was reading the Bible with her. We said our prayers together....When I handed her off, it was peaceful” (Della).

The other 11 parents had a hard time handing their child over to the surgical team. Mothers said: “I just couldn’t let him out of my arm....I just couldn’t hand the baby over” (Ari); “He’s my baby. If I were to let him go, he wouldn’t be by me anymore. He would be on the table. Unconscious. I just felt bad for him. I didn’t want him to go” (Tara); and “This could really be the last time we saw him. I felt like I had lost a part of me. I had just watched a chunk of my heart get taken away” (Auden). One mother said: “The roller-coaster was at its climax after we came to the hospital, and hospital alone was a roller-coaster itself.” (Tara).

Fathers also had a hard time letting the child leave their arms. One said: “I was a mess. The hardest part for me through this process was giving him to the doctors the morning of the surgery. It was the first time I think I broke down” (Jacob). Another said, “I’m in charge of a lot of things [at work]. I’m able to control what my guys do or don’t do. Being my son, not having any control over it was hard.” (Jerry).

Sitting on pins and needles while the child was in surgery. Parents were anxious while waiting during their child's surgery. One mother said: "I felt like I was sitting on pins and needles when he was in surgery." (Kendra). Parents tried to find ways to ease their anxiety during the surgery. They said they felt better after they spoke to someone who had experienced a similar situation. One mother said: "I could not calm down while I was waiting until I talked to other people who had some similar experiences. That was really helpful." (Auden). Another said, "I felt better after I talked to a couple who were going through an even worse situation." (Tara).

Like receiving a newborn child again when surgery was done. When the surgeons came out of the operating room, parents remembered being nervous and scared. They observed the surgeons' walk, facial expressions, and the position of their jaws and eyebrows to gauge the results of their child's surgery. When they heard the surgery was successful, parents were all excited. They described feeling as if they had been given a newborn child again. One mother said: "When he said that everything went fine, it was like having a baby again. You have [my son has] another chance. It was a surreal feeling." (Lyra).

Feeling overwhelmed to see their child for the first time after surgery. Yet after parents were so happy and excited about the success of the surgery, their heart took a deep dive when they stepped into the pediatric intensive care unit (PICU) to see their child for the first time after the surgery. Their happiness and excitement rapidly turned into worries and fears again. One mother, Tara, said: "Seeing him surrounded with lots of machines was difficult for me. I started to cry because I've never seen a three month old baby surrounded by so many people and machines." Parents had a hard time to embrace their parental role interferences. One mother, Aster, said, "I wanted to hold my baby and comfort him. But I can't do it.... The beeping sounds of the machines freaked me out. I turned around and broke down."

Fathers also described being overwhelmed to see their child in the PICU. One father said, “As a dad, I felt nauseated. I felt weak. I was trying to think and comprehend. I wasn’t ok at that moment. I became fragile. I was sad and overwhelmed” (Jerald). Fathers, however, still thought of their wife. One father, Jerry, said, “My wife was scared. She went back out to the waiting room. I sat there with my son for a little bit. I was worried about my wife. I went out and consoled her. I didn’t want him [my son] to wake up without his mother. His [the patient’s] favorite person is his mama.”

Feeling relieved when their child was transferred to a cardiac unit. When informed that their child was going to leave the PICU and go to a cardiac unit, the parents were excited. They were happy that they were a step closer to going home. They said: “I was excited that it was a closer step to going home.” (Auden), and “I was happy because he was really on his way to recovery. We could really start a new chapter in life. Now he has a new heart.” (Aster).

Coming to the children’s cardiac unit was also a relief for parents. One mother said, “A relief is that we could all be in the room together and he could see his brothers. And his brothers could see him too and be there to know that he’s ok.” (Lani). Parents liked the family-centered atmosphere on the children’s floor. One said: “We heard nothing but good things about this hospital. Now, I experienced it myself. You all are great. It’s like a family here. Everybody takes care of everybody.” (Auden). Another said, “You care about the family and the patient, making things easier for families, the food, the sleep, the visiting hours” (Aster).

It was a blessing for our family. Parents said that even though it had been hard to go through what they had gone through, they would not want anything to change. At the end of the interviews, parents were asked to use a word or phrase to summarize their experiences. The

words that parents used were “blessed”, “faith”, “stressful”, “challenging”, “thankful”, and “a roller-coaster ride” and “blessed” was used most.

One father, Jerry, said: “Blessed. I’d rather him not to have this [the heart defect], but his having this condition has brought us a lot closer.” His wife, Tina, said in a separate interview: “Blessed. I’m blessed to take care of him.” Another mother, Lyra, said: “There were so many blessings out of that pain. It just strengthened us, our family, and our faith. I would never choose to do it again, but I wouldn’t change anything about it. It was a blessing.”

Discussion

The emotions of parents of children undergoing heart surgery are not linear. When having a child with CHD undergoing heart surgery, parents went through “rollercoaster”-like emotions. The ups and downs of their emotions were based on their child’s condition. At times, they were sad and despairing; and at other times, they were happy and hopeful. Parents in this study all had similar experiences regardless of the type of their child’s CHD.

This finding might explain in part why the findings of parents’ psychological symptoms were inconsistent in studies of families of children with CHD (Wei et al., 2015). Depending on the child’s condition at the time of data collection, parents may have different experiences and responses.

In this study, parents blamed themselves for their child’s diagnosis of CHD. As indicated by attribution theory, human beings try to link a cause to what they experience (Heider, 1944; Korman, Voiklis, & Malle, 2015). In this study, parents associated their child’s heart defects with what they had done during pregnancy. Knowing this, healthcare providers should reassure parents that it is not their fault that their child has CHD. Future research may need to determine how to best help parents at this stage.

These parents experienced intertwined relationships between hope and despair. This finding is similar to the findings of studies on parents of children who have suffered moderate to severe traumatic brain injury (Rosigno & Swanson, 2011) and children with cancer (Feudtner, 2005). All the parents try to focus on positive aspects of the situations and hope for miracles. Parents in this study hoped that their child could beat the odds and get better. Parents' ability to bounce back and forth between hope and despair may be explained in part by Snyder's hope theory (Snyder, 2002). This theory suggests that people are hopeful when they have a goal and think the goal can be achieved (Feudtner, 2005; Snyder, 2002). Thus, healthcare providers should keep a positive attitude and offer parents realistic hopes which can be achieved at every step of the way.

Posttraumatic growth was also observed in this study. Posttraumatic growth (Tedeschi & Calhoun, 2004; Tedeschi, Calhoun, & Cann, 2007; Tedeschi & Calhoun, 1996) is a process prompted by a major life crisis. Individuals achieve positive changes at the end of a traumatic event. Parents in this study said that many blessings came out of their "rollercoaster"-like experiences with their child's diagnosis of heart defects and surgery. In the end, their child's condition brought their families closer and straightened family relationships and faith. This is similar to Black and Sandelowski's (2010) study of couples whose child is diagnosed with severe fetal anomalies.

As indicated in the study, hospitalization is a stressful time for parents. Parents said that hospitalization was "a rollercoaster itself". The critical times as they went through their child's heart surgery were when they received the diagnosis; were informed their child had to have surgery; tried to make decisions for their child's surgery; handed their child over to the surgical staff; waited during surgery; and visited their child for the first time in the PICU after surgery.

The stressors during these times included the unknown outcomes of surgery; losing parental control before, during, and after surgery; child's physical appearance after surgery; and the fear of the hospital atmosphere and medical equipment. Parents' experiences in PICU are consistent with other studies of parents of children admitted in PICU and Neonatal ICU (Miles & Carter, 1983; Miles, Funk, & Carlson, 1993).

Notably, when a child was diagnosed with CHD, fathers were worried about their wife as well as their child. This finding is consistent with Swanson-Kauffman's (1986) and Black and Sandelowski's (2010) studies of couples who have miscarried a child and couples who have received a diagnosis of a severe anomaly of their unborn child. Fathers assumed increased responsibilities to protect their wife after the loss or diagnosis. Future research may explore fathers' roles and their protective responsibilities when something happens to their child.

Family-centered care was also an important factor in parents' experiences. Family-centered care has been embraced as a framework of care in pediatrics (American Nurses Association and Society of Pediatric Nurses, 2003; Lewandowski & Tesler, 2003). Parents were pleased that their family members could be with the child going through heart surgery in the hospital. They appreciated that providers not only cared for their child, but also their whole family. However, future research still need to explore ways to improve family-centered care in ICU settings.

Limitations

There were limitations in the type of CHD studied and the ratio of girls to boys. The study did not include high risk and high mortality types of CHD. Future research should include parents of children with more complicated types of heart defects, such as Hypoplastic Left Heart Syndrome and parents of children who did not survive heart surgery. It would be useful to

determine whether there are differences in parents' experiences when their children are diagnosed with curative and non-curative types of CHD. Future studies should consider to recruit from multiple sites to expand the types of CHD included. Despite these limitations, the study provides in-depth information on parents' experiences and reactions to their child's CHD.

This study had an unbalanced ratio of boys and girls. There were very few girls admitted during the recruitment period and we were only able to recruit one girl. It would be interesting to know whether parents have different experiences and expectations with a boy or girl.

With a qualitative perspective and a small sample, it is not our intention to generalize findings. Nonetheless, these parents provided 21 rich interviews about the experience of having a child with CHD undergoing a heart surgery.

Clinical Implications and Conclusions

When a child is diagnosed with CHD, parents go through "rollercoaster"-like emotions. This study identified some critical moments and stressors during children's hospital course. Currently, parents are offered a pre-operation orientation prior to surgery, brochures about the process of heart surgery, and tours about the waiting area and the PICU. However, these parents still need more support when their child was hospitalized for heart surgery. Future research may need to explore ways to intervene during those critical moments.

In the meantime, based on the study, some specific measures can be suggested. It is important to stay with parents and offer them informational support during the diagnosis time; consider implementing supportive rituals when parents hand their child over to the surgical staff, such as hugging time, kissing time, and picture time, etc; provide volunteers who have similar experience to talk to parents during the surgical waiting time; and have a provider accompany parents and support them when they come to see their child for the first time in the PICU.

Declaration of Conflicting Interests

The authors declared no conflicts of interest in the authorship or publication of the article.

Funding

The Jane Winningham Smith Scholarship from the School of Nursing at (University name) and the Dr. Lester Sauvage Research Fund from the Hope Heart Institute.

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Table 4.1. Selected Interview Questions

	Selected Grand Tour Questions	Probing Questions
First Interview in the hospital	<p>Could you please tell me what it was like learning from your doctors that your child had heart disease?</p> <p>Could you tell me what it was like learning that your child needed heart surgery?</p> <p>Could you tell me what it was like while you were waiting for your child in surgery?</p> <p>Could you tell me what it was like when you were told that the heart surgery was finished?</p> <p>Could you tell me what it was like when you were going to the ICU after your child's surgery?</p> <p>Could you tell me what it was like when your child was a patient in the ICU?</p> <p>Could you tell me what it was like when your child was transferred to the children's cardiac unit?</p> <p>Could you tell me what it was like when your child was a patient on the children's cardiac unit?</p>	<p>What was that like?</p> <p>How did that feel?</p> <p>What were you focusing on at that time?</p> <p>What did that mean to you?</p> <p>Why was that significant?</p> <p>How did that help or hinder you or your family?</p> <p>How could they have done that differently or better?</p> <p>What things helped during that time?</p> <p>Who were the helpful people during that time?</p> <p>How did you get through that?</p> <p>Why do you think that was different for you?</p> <p>Could you tell me more about it?</p>
Second Interview after Discharge	<p>Could you please describe a typical day with your child at home after you were discharged from the hospital?</p> <p>Looking back, could you please tell me your experiences at the time of your child's diagnosis?</p> <p>Looking back, could you tell me your experiences with the information you were presented about your child's diagnosis.</p> <p>Could you tell me your experiences with the discharge process?</p>	<p>What was that like?</p> <p>How did that feel?</p> <p>What were you focusing on at that time?</p> <p>What did that mean to you?</p> <p>Why was that significant?</p> <p>How did that help your family?</p> <p>How could they have done that differently?</p> <p>What things helped during that time?</p> <p>How did you get through that?</p>

Table 4.2. Parents' Demographics

Demographic profile Parents total (n=13 parents)	Participating Mothers (n=10)	Participating Fathers (n=3)
Age		
19	1	
20-29	4	2
30-39	4	1
40-49	1	
Race/ethnicity (13 parents)		
White	4	2
African American	5	
Hispanic	1	1
Education (13 parents)		
<High school	1	1
High school	2	2
College (without degree)	5	
Associate degree	1	
Bachelor degree	1	
Marital status (10 families)		
Single	5	
Married	4	
Divorced	1	
Family income (10 families)		
At or below 20,000	3	
At or below 40,000	3	
At or below 60,000	2	
At or below 80,000	2	
Time of Child's CHD Diagnosis		
Pre-natal	3	
Post-natal	7	

Table 4.3. Children's Demographics

Demographic profile	Boys (n=9)	Girls (n=1)
Age		
<1 month	1	
1-5 months	4	
6-12 months	2	
13-24 months	2	
5 years	0	1
Heart defects (STAT Category)*		
Atrial Septal Defect (STAT 1)	1	
Ventricular Septal Defect (STAT 1)	3	1
Atrial Ventricular Septal Defect (STAT 3)	1	
Tetralogy of Fallot (STAT 2)	3	
Pulmonary stenosis (STAT 2)	1	
Siblings		
Yes	5	1
No	4	0

* The STAT Mortality Categories (J. P. Jacobs et al., 2012; M. L. Jacobs et al., 2013; O'Brien, 2009)

Table 4.4. The Experiences of Parents of Children with CHD undergoing Heart Surgery

Parents' Experiences
It was a shock to know the child's heart defect.
What did I do that caused it?
Hoping the child's heart defect will fix itself.
Dilemmas in making decisions for heart surgery.
Unable to let my child leave my arms and be given to the surgical staff.
Sitting on pins and needles while their child was in surgery
Like receiving a new born baby again after surgery is done.
Feeling overwhelmed to see my child the first time after surgery.
Feeling relieved when transferred to a cardiac unit.
It was a blessing for our family.

Introduction

Every year, about 40, 000 children are born with congenital heart disease in the United States (Centers for Disease Control and Prevention [CDC], 2015). Congenital heart disease (CHD) is the most prevalent birth defect among children (CDC, 2015) and one of the leading causes of mortality in children with birth defects (Robbins et al., 2007). Children with CHD usually entail frequent and lengthy hospitalizations (Pasquali et al., 2011).

To improve the clinical treatment and research for children with heart disease, the National Heart, Lung, and Blood Institute led two major initiatives in 2000 and 2002 (Lenfant, 2002). A literature review on families of children with CHD shows that since then, studies have focused on the impact of the CHD on parents' psychological health, their family life, and parenting experiences (Wei, Roscigno, Hanson, & Swanson, 2015).

Majority of the studies of families of children with CHD that explored parents' psychological health showed that parents of children with CHD had significant emotional reactions to their child's CHD (Wei et al., 2015). Researchers found that parents of children with CHD reported high levels of stress, anxiety, and depression than published norms or parents of children without CHD (Lawoko & Soares, 2002; Lawoko & Soares, 2006; Utens et al., 2000; Uzark & Jones, 2003); faced uncertainties in making decisions for their child's treatment (Ellinger & Rempel, 2010; Rempel, Cender, Lynam, Sandor, & Farquharson, 2004; Lan, Mu, & Hsieh, 2007); encountered financial challenges (Connor, Kline, Mott, Harris, & Jenkins, 2010; Duggan, Pearce, & Guilbert, 2001), and experienced lower quality of life or illness-related quality of life (Arafa, Zaher, El-Dowaty, & Moneeb, 2008; Goldbeck & Melches, 2005; Landolt, Buechel, & Latal, 2011; Lawoko & Soares, 2003).

A child's heart surgery is a stressful event for families. Parents reported high levels of stress throughout their hospital stays as their child underwent heart surgery regardless of the type of their child's CHD (Franck, McQuillan, Wray, Grocott, & Goldman, 2010). They continued to have posttraumatic stress disorder (PTSD) symptoms 6 months after discharge from the hospital (Helfricht, Latal, Fischer, Tomaske, & Landolt, 2008), and feelings of not being in control of their situation at up to five-year follow-up (Menahem, Poulakis, & Prior, 2008).

As indicated in the literature review (Wei et al., 2015), parents endured higher levels of psychological symptoms, family life changes, and parenting challenges. But, few studies have explored parents' interpersonal experiences with healthcare providers as their child went through heart surgery. Understanding these parents' expectations of healthcare providers' actions and identifying their care needs could provide evidence of care to families of children with CHD. Therefore, this study examined parents' perceptions of healthcare providers' actions from the time when their child was diagnosed with CHD to the time after their child had heart surgery.

Conceptual Framework

The Swanson Caring Theory (Swanson, 1991, 1993, 2015) was empirically derived based on women with perinatal loss and caregivers in a Neonatal Intensive Care Unit (Swanson, 1990; Swanson-Kauffman, 1988; Swanson-Kauffman, 1986). This theory categorizes healthcare providers' actions into five processes: *knowing, being with, doing for, enabling, and maintaining belief*. These five processes reflect holistic caring to meet patients' and families' physical, psychological, and spiritual needs. Holistic caring is essential in making human to human connections and building trusting relationships between healthcare providers and patients and families (Swanson & Wojnar, 2004). The theory has been used in guiding clinical practice (Higdon & Shirey, 2012; Latta & Davis-Kirsch, 2011) and research (Andershed & Olsson, 2009;

Kavanaugh et al., 2013; Wojnar, Swanson, & Adolfsson, 2011). Because the purpose of the study was to describe healthcare providers' actions, the Swanson's Caring Theory was a theory of choice.

Methods

Ethical Considerations

This study was approved by the Institutional Review Board at the university and the Nursing Research Council at the hospital where the study was conducted.

Design

This is a qualitative study. A directed content analysis (Hsieh & Shannon, 2005) was used to guide the analytical process. Directed content analysis is one of the three approaches of the content analysis (Hsieh & Shannon, 2005). The three approaches are conventional, summative, and directed, and the main differences among them are their coding structures and the origins of codes (Hsieh & Shannon, 2005). Conventional content analysis is used when coding categories are originated from the text data; the summative approach focuses on counting and comparing keywords or content, and interpreting the underlying context; and the directed content analysis begins with an existing theory as a guidance for initial codes (Hsieh & Shannon, 2005). Therefore, this study used the directed content analysis to describe parents' perceptions of their care needs and healthcare providers' actions as their child went through heart surgery.

Setting and Sample

This study took place in a children's hospital on the east coast of the United States. Recruitment was carried out on a children's cardiac floor between July and December 2014. We used purposeful sampling, a maximum variation sampling to be specific (Sandelowski, 1995). Because of the uncertainty whether the types of child's CHD and parents' socioeconomic

background influenced parents' expectations, the maximum variation sampling was applied to have a diverse group of parents and ensure a deep understanding of parents' perceptions of providers' actions. Therefore, parents were invited to join the study if their child was hospitalized undergoing his/her first heart surgery, were at least 18 years old, were of any race, and spoke and read English. No parents invited declined to join. One parent per family was required; but both parents could participate. When both parents participated, they were interviewed separately.

For qualitative studies, it is hard to determine the exact sample size beforehand. We used informational redundancy to help determine the adequacy of sample size (Sandelowski, 1995). For example, after interviewing and analyzing the data of the seventh parent, authors could see some patterns of themes. Informational redundancy was obvious after the tenth parent. Authors stopped the recruitment after the thirteenth parent when saturation of themes was achieved.

Data Collection

Two forms of data were collected: demographic survey data and in-depth interviews. The first author, the interviewer, obtained parents' written informed consent before the first interview. Participants were assigned pseudonyms to protect their privacy and maintain humanistic characteristics. Parents completed the demographic survey prior to the first interview. The first interviews took place in person on the children's cardiac unit a week after the child's heart surgery, which lasted about 1 and 1 ½ hours. The second interviews were done in person at the places where parents preferred or by phone 4-6 weeks after the first interviews, which lasted about 30 minutes to an hour. Parents were interviewed individually when both of them joined the study. The interviews were audio recorded and transcribed verbatim.

Interview questions were designed based on the purpose of the study. The grand tour question for the first interview was “What kind of actions by nurses were caring to you?” “What kind of actions by physicians were caring to you?” “What kind of actions by other hospital staff were caring to you?” For the second interview, the grand tour question was “Looking back, what kind of actions by the nurses were caring to you?” “Looking back, what kind of actions by the physicians were caring to you?” “Looking back, what kind of actions by other hospital staff were caring to you?” Based on parents’ responses, probing questions were used: “How did that make you feel”, “Help me understand why you felt that way”, and “Please tell me more about that.”

Data Analysis

Data were analyzed using a directed content analysis approach (Hsieh & Shannon, 2005). Swanson’s Caring Theory guided the analytic process. Researchers were also mindful in learning things that might not be captured by the theory. The researchers (a) read the transcripts thoroughly to get a sense of parents’ overall experiences; (b) identified ways in which parents described providers’ caring and non-caring actions; (c) used the theory for initial coding categories to group providers’ actions; (d) wrote memos on impressions of the text that denoted parents’ appraisals of providers’ actions; (e) coded passages with memos into one of the caring processes; (f) assigned passages with multiple meanings into the category that best captured the meaning based on the context of that encounter; and (g) invited parents to verify the findings.

Two coders (the first author [HW] and a doctoral student), one peer reviewer (the second author [CR]), and a theorist (the third author [KS]) were involved in the coding process. The two coders coded the data individually and then met to discuss their codes. Coding discrepancies were resolved by discussing the interview and/or field data that supported their impressions. The coders then met with the peer reviewer to report their coding process and seek advice on their

methods and coding impressions. After the data were coded and reviewed by the peer reviewer, the first author discussed the coding progress with the theorist.

To aid the organization of the analysis, ATLAS.ti, version 7.5.6 for windows (Scientific Software Development, 2014), was used. The software helped organize, link codes to narratives, and track codes over time, keeping a clear audit trail during the data analysis process.

Strategies to Achieve Rigor in the Study

To attain rigor in this study, the researchers kept a clear audit trail on all decisions and discussions among team members (Sandelowski, 1986). A coding team was assembled that included four members, two coders, a peer reviewer with qualitative methodology expertise, and a theorist. To be sure that the coders and the peer reviewer were mindful of narratives that might not fit the theory, the theorist was not involved in the early part of the coding analysis. Team members made sure that (a) coding categories were clearly defined and consistent with the overall context of participants' narratives; (b) team members met regularly to discuss the research progress; and (c) the final summary of findings was confirmed by the participants.

Results

Description of the Sample

The sample consisted of 13 parents (10 mothers and 3 fathers) of 10 children. Eight parents were able to complete both interviews and five parents could only do one interview because of other family obligations, which made up 21 interviews. Parents' and children's demographic information is listed in Tables 4.2 and 4.3. The severity of children's CHD was classified using the Society of Thoracic Surgeons European Association of Cardio-Thoracic Surgery Congenital Heart Surgery Mortality Categories (STAT Mortality Categories; O'Brien, 2009), from 1 to 5, with 5 being the highest risk operation and mortality.

Categorizing Providers' Actions into the Caring Processes

When a child is diagnosed with CHD and undergoes heart surgery, parents have firsthand experiences with healthcare providers. They have an opportunity to appraise providers' actions based on their expectations during the encounters. Parents see how providers act and react in a particular context and compare providers' actions to their expectations. Healthcare providers' actions were inductively derived from parents' stories of their interactions with providers and then deductively categorized into the five caring processes of the Swanson's Caring Theory (Swanson, 1991, 1993, 2015).

Striving to understand parents' situations and their experiences (Knowing). When parents first received their child's diagnosis of CHD, they explained that they were "shocked" (Kady and Aster) and their "whole world changed" (Lyra). Even though it was heartbreaking and hard for them to grasp what their child's CHD entailed, parents wanted to be assured that there were solutions to care for their child. Lyra said: "It was the way the pediatrician told us, making me feel like it [my son's condition] was really bad. It would have been better if she had said: this is what we found and this is the solution."

Parents wanted providers to understand what they were going through. They appreciated when providers talked to them and tried to understand their experiences. One mother, Kendra, said: "I like Dr [surgeon's name] to talk to me. She asked how I was feeling. She answered my questions before I had even asked. She made me feel that she knew what I was going through". Another mother, Auden, said: "They [the surgeons] kept asking us whether we had questions. They wanted to know our concerns. It seemed they understood us like they had known us their whole lives. It was very comforting for them to be so understanding."

Parents appreciated that providers made efforts to get to know their child. Parents attributed nurses' inquiry about their child's routines at home to caring. Aster said, "They wanted to know what he [my son] was like at home. They asked if he was on a pacifier, did he do this and that. They really cared about him being upbeat." Other parents considered that providers tried to cluster their child's care, play with their child, and bring favorite toys to their fearful child before treatment procedures as caring actions.

Knowing is understanding what family members cherish. Parents appreciated a family-centered environment in which providers not only cared for the child who was sick, but also the family members who were there with the child. Parents considered family-centered care as an important caring action. One mother, Lani, said: "When a child is hospitalized, the whole family is affected. You've got to address the whole family's needs. It's not just the child going through the procedure. It's the whole family." Aster, said: "When my son was hospitalized, not only did they care about my son, they cared about my well-being. They cared about the family as much as they did the patient, making things easier for families, the food, the sleep, the visiting hours."

Accompanying parents through difficult times physically, emotionally, and spiritually (*Being with*). When parents received their child's diagnosis of CHD, handed their child over to the surgical staff in the pre-operative room, waited during their child's heart surgery, and visited their child for the first time after surgery, parents were emotionally vulnerable. One mother, Aster, cried: "When my son was in surgery, I cried uncontrollably. I wanted someone to be with me, gave me a little hand-holding, and tell me he's going to be okay." This mother's description indicated that she was looking for physical, emotional, and spiritual help. She wanted someone to be there with her (*being with* physically and spiritually),

hold her hand (*being with* physically and emotionally), and tell her that her son will be alright (*being with* spiritually and emotionally).

When parents went to visit their child in the PICU, they were overwhelmed by their child's appearance and the highly technical PICU environment. One mother, Tara, described: “When I saw my son, there were all these machines and people in the room. Everything was so fast. I started crying because I have never seen a three month old baby surrounded by so many people and machines”. She continued: “Even though I had faith and I prayed to God to give these doctors power to heal my son, seeing him surrounded by lots of machines and people was hard for me.” This mother’s description also indicated that providers should consider having someone to accompany parents for their first visit.

Parents appreciated when providers showed their willingness and readiness to help as Lani, said:

When doctors were telling us about our son's diagnosis, our nurse stood right there with us. She made sure she relayed compassion. She knew it [the diagnosis] was a lot for us to comprehend. She wanted to make sure we knew what it all entailed. She was like “if you have any questions, don’t hesitate to get me.” She was right there the whole time and it made me feel, “yeah I’m going through this traumatic situation”. And being right there made a big difference for me.

Lani’s description illustrates the importance of providers’ anticipatory presence when parents go through difficult times. It is important for providers to convey that they understand what parents go through, and that they are willing to be present alongside them. Providers need to reassure parents that they will get through their child’s surgery and recovery.

Anticipating and undertaking the things parents would do for themselves if they were able to or knew how (*Doing for*). Providers need to understand that their actions and interactions with parents shape parents' perceived culture of healthcare and govern an environment of trust. After heart surgery, parents were usually sleep-deprived, but still reluctant to leave or rest for fear that their child might need them. One mother, Ari, said: "The nurse literally sat by my son for 24 hours. The nurses constantly asked me if I needed anything and encouraged me to go and rest. I was reluctant at first, but they made me feel comfortable and safe to leave." Another mother, Lyra, said: "I was sleeping. My nurse came in and changed my baby's diaper. I could have changed it, but she did it without waking me up, allowing us, the tired parents, to get rest and [be] well taken care of during this challenging time." Another mother, Auden, said: "Our nurse in the PICU knew that we had not slept since the night before surgery. She reassured us that our son was in good hands and encouraged us to go and rest."

When hospital staff work together as a team, they build a lasting image for patients and families. From parents' perspectives, not only nurses and physicians who cared for them played a vital role in their hospital experiences, but everyone whom they came in contact with (e.g., dietary workers, clerks, housekeeping, nursing assistants, volunteers, etc) impacted parents' hospital experiences. A Hospital staff's friendly greeting and a positive attitude were the components of caring. Parents were grateful for everyone's uplifting outlooks and support, making them feel optimistic about their child's condition and future. Lyra said:

As I walked down the hall, people were smiling and being very friendly. Hospital was not just business. People here really cared [about one another]. A gentleman who transported patients in the clinic was smiling and wishing everyone the best.

I heard him say it. 'I wish you well'. 'I wish you the best'. He said that to everyone. I thought that was special.

Doing for is also doing for providers' peer colleagues. Providers' helping one another and working together as a team were also caring actions. One mother, Tina, said: "Everywhere we went, he [my son] had a team.... That they all work together taking care of him was what helped me the most". Another mother, Ari, confirmed this: "The doctors and the nurses come together. The doctors are the palms, and the nurses are the fingers." One father, Jerry, described: "When my son's oxygen level was low, there were nurses who weren't even his nurses coming into the room to check on him". Another mother, Kendra, said: "Even if his nurse was in another room. If I said I needed anything, a pillow or anything, everybody was attentive."

Although the actions described above might be performed by providers on a daily basis and considered as expected professional actions, these actions, nonetheless, were reflected as caring actions by parents. Kendra, clarified: "Everything you all [healthcare providers] do means a lot to us. Nothing is too small to a family and a child who is sick." The findings show that caring actions are those that are meaningful and positive for patients and families and can manifest the caring culture of an organization.

Guiding parents to participate and maintain their parental control at difficult times (*Enabling*). Parents referred their child's heart surgery as a critical event for their family, an event that could change their family's fate. They were heartbreaking when they heard that their child had CHD, they had a hard time to make decisions for their child to go through heart surgery, they went through what was described as a "heart wrenching" (Auden) moment to hand their child over to the surgical staff, and they were fearful that they could lose their child.

Parents compared their child's heart surgery to "a big mountain to climb", and the time of before and after the surgery as "the two opposite sides of the mountain" (Lyra). They signified the time of handing their child over to the surgical staff as the loss of their parenting role. One mother, Tara, explained: "He's my baby. If I were to let him go, he wouldn't be mine anymore. He will be on the table and unconscious. I cannot hold him and comfort him.... [sob]." A father, Jerry, said: "I am his parent. I don't want anything bad to happen to him. But knowing that everything they're about to do will hurt him, and I cannot do anything about it, it's hard."

After surgery, when parents went to see their child in the PICU, they had a hard time to adjust to their child's appearance after surgery and the PICU atmosphere. Some parents had to turn around and leave. Parents expressed that when they first went to PICU, they did not see their child, and all they saw were the numerous people, various types of machines, all kinds of beeping sounds, countless tubes, and myriads of wires. One mother, Tara, said: "I could not see my son, all I saw were people, machines, and blood coming from the tubes in his chest near his stomach." Another mother, Kendra, said:

He had IVs in his neck, his hand and his foot. Everything was bandaged up. He didn't have a shirt on. When I walked in, I could see fluid going down the tubes. That was scary....When I got ready to leave out, I said 'bye-bye', he literally tried to get out of the bed. His arms propped up and he slid his feet like he was getting ready to push up. I was like 'oh my gosh, no baby. I'm sorry.... [sob]'. He acted like he wanted to jump out of that bed and go with me. I started crying when he did that. It was like I can't take you with me. I can't. That was really rough. I think that might have been the hardest moment and experience. I want to get him out of the crib. I want to cradle him and hold him and rock him back to sleep.

And in this situation I can't. I couldn't stay with him that night and that made it worse. The next morning, I got back to the hospital as quickly as I could.

Parents experienced a loss of parental control as their child went through heart surgery. Parents could not function as a parent they used to be or wanted to be. In this situation, providers can reassure parents about the outcomes of surgery, and create an atmosphere to encourage parents to perform parenting tasks, such as comforting and caring for their child. A mother Della, explained, "A nurse told me that I could give my daughter a bath. She guided me to get everything ready and walked me through.... I felt great I could do that for her [my daughter]."

Believing that parents will get through their child's surgery and facing a future with a positive meaning if supported (*Maintaining belief*). When Parents were informed about their child's CHD, they were overwhelmed. Without any prior knowledge, they did not know what to think or expect. One father, Jerald, said: "Before my son was sick, I did not even know this place [the children's hospital] existed, where so many kids were sick. I thought when people had babies, they would be all healthy and go home." Suddenly facing a child with CHD requiring heart surgery was "overwhelming" and "devastating" (Kady, Della, Lyra, and Tara) to these parents. One mother, Kady, said: "I was numb at that time and did not know what to think." The only thing they could think at that time was a "big mountain" in front of them, which they could not possibly overcome by themselves (Tina, Jerry, and Lyra).

Parents need to be encouraged that they will be able to get through their particular situation. Providers should guide parents step-by-step, support them to be involved in their child's decision-making and care, and help them face their child's as well as their family's future with confidence. Parents appreciated when providers took their time and used layman's terms to thoroughly explain their child's diagnosis and treatment options, so that they could be confident

to make informed choices for their child. One mother, Auden, said: “He [the surgeon] knew we had a hard time to grasp what was going on. He took time to go over everything to make sure we knew what our next steps were. He used layman’s terms to help us understand.” A couple, Tina and Jerry, said similarly in separate interviews: “We knew about our son’s heart defect during pregnancy. We were very upset.... Once we went to the cardiologist, we were fine. Everyone there was very positive about the whole thing. Because of them, we had a great pregnancy.” Her husband, Jerry, also said: “I was actually looking forward to the heart surgery so that he [my son] could run around playing baseball.” Jerry had already started to think about the future of their family. Parents also appreciated if providers had an uplifting and positive attitude when being informed about their child’s condition and treatment. One mother, Lyra, said:

When the pediatrician came in, she said: “Oh your baby has Tetralogy of Fallot.” It’s the way she told us. I could see the sadness in her face. It made me feel like this is really bad.... When the cardiologist came in, he immediately put me at ease with his positive attitude. His tone of voice was that we can fix this. He told me about my son’s heart condition, and laid out the solution. I remember what really lifted my spirit was when he said, Shaun White, he had Tetralogy of Fallot. He won Olympic gold medal. And I remember thinking, thank you for saying that. He made me feel there’s nothing my son could not do.

Providers’ actions influenced parents’ reactions. Providers’ positive attitude and uplifting reassurance can help parents embrace their particular harsh situation and face their future with a new meaning. Lani, explained how a compassionate nurse helped her during a difficult time:

That time [when informed about my son’s diagnosis], I just want to go somewhere and cry. With her [the nurse] being there to say “it’s ok, he’s going to

be fine. Here's what we're going to do to make sure that he's ok. And if you need anything, we're here for you. If you need to walk away and get some air, we are right here." It makes a tremendous difference having a caring nurse who [provided us information, and helped us] understand.

Lani's description involved the five caring processes, *knowing, being with, doing for, enabling, and maintaining belief*, which were not mutually exclusive, but closely connected with one another. Several parents said they chose to come to this hospital because they heard great things about the supportive care at this hospital, which they had experienced themselves as well. The support they received from the providers helped them embrace their particular situations and have the confidence to face a future with a positive meaning for their child and family.

Discussion

The findings from this study show that coordinated and caring behaviors by all hospital employees can make a difference in helping families and hospitalized patients. Actions by the individuals of an organization are like paintbrush strokes in a picture. Each person, regardless of his/her role in the hospital, makes a vital stroke in completing the picture. How well the picture is perceived by the viewers (patients or families) depends on the nature of every color chosen (nature of caring), every stroke of the brush (each person's actions) and the overall intermix of colors and strokes (the interplay between organizational support and hospital personnel and their actions). The organization can be as big as a healthcare system or hospital, or as small as a unit or group/team (Swanson, 1993; Swanson & Wojnar, 2004). Making sure that patients and families feel well cared for is vital for a hospital's commitment to caring (Tonges & Ray, 2011).

This study also confirmed that Swanson's Caring Theory captured important elements of how individuals in a complex system deliver healthcare in a way that meets the family's need for

information, connection, and support. Like the parents in Kavanaugh et al's (2013) study, women at risk of delivering an extremely premature infant, parents in this study felt cared for and respected when they sensed that the system was made up of individuals who understood the caring processes of Swanson's theory (*knowing, being with, doing for, enabling, and maintaining beliefs*). In particular, healthcare providers' thoughtful, sensitive, and anticipatory actions that carried this group of parents through receiving their child's diagnosis and making decisions for their child's heart surgery because these were difficult times made the family vulnerable and in need of help and support.

This study has confirmed the feasibility of using Swanson's Caring Theory in complex clinical settings where multidisciplinary teams interact with families. Similarly, Tonges and Ray (2011) developed the Carolina Care Model to actualize Swanson Caring Theory in a healthcare organization. The model incorporates the caring processes into clinical nursing interventions. For example, nurses should have a caring moment talking to their patients, help patients in need regardless whom their nurses are, and make ROUNDS, acronym of "R- are you comfortable? (pain); O-other side (positioning); U-use bathroom (toileting); N-need anything?; D-door open/closed (privacy); S-safety (call bell in reach"; Tonges & Ray, 2011, p. 376). As indicated in the study, parents experienced some critical moments as their child underwent heart surgery: being informed about their child's diagnosis and that their child had to have heart surgery, giving their child to the surgical team, and seeing their child in PICU for the first time after surgery. The stressors involved in these critical times were the uncertainties of surgery, losing control as a parent, their child's physical look after surgery, and their fears about the unfamiliar environment and medical equipment. Future research may investigate how to apply the Carolina Care Model to parents in pediatric settings.

The current study has also brought providers' attention to parents' perspectives on family centered care. Findings from the study show that family is an essential component of children's lives, and caring involves not only taking care of the children, but also taking care of their families as a unit. Family centered care was considered by parents in this study as an essential part of a caring system. Parents said that it was important to take the whole family into consideration when a child was hospitalized.

Limitations and Future Research

Due to the qualitative character and a small sample size, we caution against generalizing the findings from this study to all parents of children having heart surgery. This study was lack of children with non-curative type CHD, such as children with a single ventricle. Due to the small number of children born with non-curative type of CHD each year, they were not available during the recruitment period of this study. A larger sample from more than one location may add to the information from parents of children with curative and non-curative type of CHD about their notions of caring. Due to a limited number of girls admitted during the recruitment time, we were only able to recruit one girl in the study. It may also be interesting to see whether parents have different perspectives if they have a boy or girl. Future studies may also test whether caring interactions decrease parents' stress, reduce hospitalized time, increase parents' satisfaction, and improve the child's outcomes, including readmission rates. This would provide evidence for implementing such programs of care.

Recommendations for Clinical Practice and Conclusions

This study found that healthcare providers' actions played an important role in parents' hospital experiences. Parents appreciated that providers took opportunities to get know their child as well as their family and provide the care that they needed to support the child when

returning to home. Parents also appreciated the fact that providers were with them physically, emotionally, and spiritually during critical times, such as the time of their child's diagnostic and the surgical time. Parents described their feelings as cared for when providers used layman's terms to present them information to help them understand. Parents appreciated providers who took time to encourage them to ask questions and express their feelings. Parents wanted providers to be uplifting, encouraging and inspiring. They cherished providers' notions to greet, hug, and take the time to talk to them and their child.

In conclusion, only when providers understand parents' perceptions will they be able to implement appropriate caring interventions. Swanson's Caring Theory is an appropriate framework to embrace parents' perspectives on healthcare providers' actions.

Funding

The Jane Winningham Smith Scholarship from the School of Nursing at the UNC Chapel Hill, and the Dr. Lester Sauvage Research Fund from the Hope Heart Institute.

Declaration of Conflicting Interests

Authors declared no conflicts of interest in the authorship or publication of the article.

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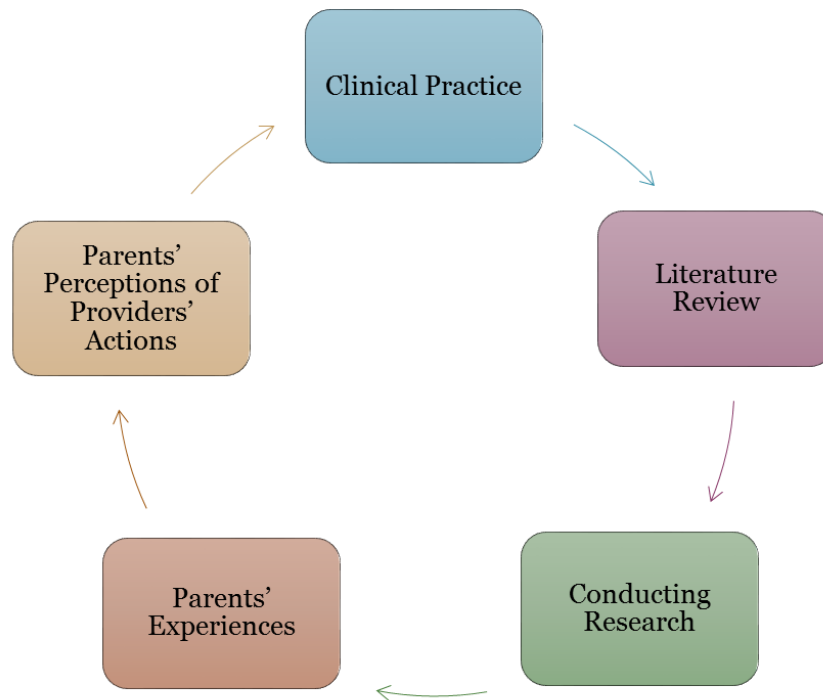
CHAPTER 5: SYNTHESIS OF THE DISSERTATION

Synthesis of the Findings

With 40,000 children born with congenital heart disease (CHD) in the US each year (Centers for Disease Control and Prevention, 2015), these children represent a significant segment of the pediatric patient population. A child's hospitalization for heart surgery is a major source of stress for parents; and parents report significant amount of stress (Franck et al., 2010) and post-traumatic stress (Helfricht et al., 2008) when their child undergoes heart surgery.

This dissertation study was built on clinical practice and will be applied back to the clinical practice (Figure 5.1). Based on clinical observations that parents of children with CHD showed psychological symptoms, a literature review was conducted on studies of families of children with CHD over the past 15 years (Wei et al., 2015). The review found that parents had significant amount of psychological symptoms when their child was diagnosed with CHD; however, researchers had not explored parents' appraisals of factors affecting their psychological symptoms (Wei et al., 2015). From this literature review, two manuscripts were developed, a phenomenological study of the experiences of parents of a child with CHD undergoing heart surgery and a qualitative directed content analysis study of parents' perceptions of providers' actions in a hospital setting. In addition, a methods paper was written detailing ways of conducting a phenomenological study of parents' experiences.

Figure 5.1. The dissertation process



The Literature Review

Ninety-four articles were reviewed: 66 quantitative and 28 qualitative studies. The impacts of a child's CHD on parents' psychological health, family life, and parenting challenges were noted. Among the impacts of a child's CHD, the impact on parents' psychological health was studied most. While 75% of the studies that focused on parents' psychological health found that parents of children with CHD reported significantly greater stress, depression, and anxiety than parents of children who were normally developed, one fourth of the studies either did not find significant differences between parents of children with and without CHD, or found that parents of children with CHD reported less stress than their counterparts. Researchers, however, did not explore parents' appraisals of why they were or were not affected by their child's CHD. Over the past 15 years, there had been only five intervention studies on families of children with

CHD. Research was thus needed to explore parents' experiences and expectations for care, which led to the next manuscript, a methods paper detailing the process of exploration of parents' experiences.

The Methods Paper

The methods paper demonstrated ways of conducting a phenomenological study using an interdisciplinary research team to explore parents' experiences when caring for a child with CHD. This paper illustrated steps in conducting a phenomenological study, including the development of a research idea, selection of research methods, and process of data collection and analysis.

The paper also described the philosophy of phenomenology, the differences between descriptive and interpretive phenomenology, the processes of developing a research idea and forming an interdisciplinary team, the bases for choosing sample size, the strategies of conducting interviews, the use of an interdisciplinary team to analyze data, and the validation and write-up of a final report.

Phenomenology is a methodology exploring human experiences in an everyday world. It provides opportunities for healthcare providers to understand their clients in health and illness. Healthcare consists of many different disciplines, which provides a great opportunity for healthcare providers to collaborate in exploring patients' and families' experiences. This manuscript helped the development of the third manuscript about parents' experiences.

Parents' Experience

This is a descriptive phenomenological study. The purpose of this study was to describe parents' thoughts and feelings when their child was diagnosed with CHD and underwent heart surgery. In-depth interviews were conducted.

This study included 13 parents (10 mothers and 3 fathers) from 10 families. A total of 21 interviews were conducted. Parents' ethnicity included White (n = 6), Non-Hispanic Black (n = 5), and Hispanic (n = 2). Children's types of CHD varied.

Parents reported that having a child with CHD, their emotions were like a "roller coaster". The ups and downs of their emotions were based on their child's conditions. At times, they were happy and hopeful; and at other times, they were sad and despairing. The critical times as they went through their child's heart surgery were when they received the diagnosis; were informed their child had to have surgery; tried to make decisions for their child's surgery; handed their child over to the surgical staff; waited during surgery; and visited their child for the first time in the PICU after surgery. The stressors during these times included the unknown outcomes of surgery; losing parental control before, during, and after surgery; child's physical appearance after surgery; and the fear of the hospital atmosphere and medical equipment. Parents depended on their healthcare providers to help them get through the critical times. In the end, parents described their experiences as moving from shock to blessing. Parents' reflections made it obvious that even though provider-patient hospital encounters were brief, healthcare providers' actions were vital to their experiences. This finding led to the fourth manuscript on parents' perspectives on healthcare providers' actions.

Parents' Perceptions of Providers' Actions in a Hospital Setting

This qualitative study examined parents' perceptions of providers' actions when their child was hospitalized for heart surgery. Purposeful sampling was used to recruit parents with diverse background and children with different types of CHD. In-depth interviews were conducted. A directed content analysis was performed guided by Swanson's Caring Theory (Swanson, 1991, 1993, 2015) for categorizing providers' actions.

The five caring processes, *knowing*, *being with*, *doing for*, *enabling*, and *maintaining belief*, were used as initial categories to examine parents' perspectives on providers' caring and non-caring actions. *Knowing* was essential in gaining parents' trust and building a professional relationship. When *knowing* what these parents went through, providers were capable of *being with* them to provide the support they might need. Parents perceived providers' teamwork as an important aspect of *doing for* their child, their families, and one another. Parents also considered offering affective support and involving families in decision-makings as great ways of *enabling*. Parents noted that providers' positive reassurance was a caring act that helped them be hopeful in facing their child's as well as their family's future.

This study found that healthcare providers' actions played an important role in parents' hospital experiences. Parents appreciated that providers took opportunities to get know their child as well as their family and provide the care that they needed to support the child when returning to home. Parents also appreciated the fact that providers were with them physically, emotionally, and spiritually during critical times. Future research is needed to explore ways to establish a supportive caring system in hospitals.

In summary, this dissertation has achieved its purposes. Specifically, the study (a) identified the major research foci of studies on families of children with CHD published in the

past 15 years and the gaps between what is known and what needs to be known; (b) led to a methods paper with detailed steps on how to conduct a phenomenological study; (c) described parents' experiences when their child was diagnosed with CHD and required heart surgery; and (d) reported parents' perspectives on healthcare providers' caring and non-caring actions.

Limitations of Dissertation

This study used a phenomenological approach to explore parents' experiences and a directed content analysis to examine parents' perceptions of healthcare providers' actions. Given the qualitative methodology and the small sample size, generalizability of the findings is limited. Because of the small sample size, taken from only one location, parents' perceptions of providers' actions may be limited. A larger sample from multi sites could broaden the information on parents' views of caring.

Children in this study were all able to recover well from their heart surgeries and go home soon after the surgery. Therefore, this study does not provide information on parents whose child had a complicated recovery after heart surgery, or who did not survive the surgery. Future research should look into those parents' experiences. It is important to know what those parents think and feel, so that appropriate caring measures can be implemented.

Implications for Research

Four areas were identified for future research: 1) ways of helping parents at the vulnerable times in their experiences, such as the times of receiving the diagnosis of CHD, being informed their child has to have heart surgery, handing their child to the surgical staff before surgery, and seeing their child for the first time in PICU after surgery; 2) fathers' roles during a family crisis; 3) caring actions in pediatric settings; and 4) family centered care in an ICU environment.

Ways of helping Parents at their Vulnerable Times

Only five intervention studies on families of children with CHD have been published in the past 15 years (Wei et al., 2015). The major purposes of these interventions were to reduce parents' psychological symptoms (McCusker et al., 2010; McCusker et al., 2012; Morgan et al., 2008) and mothers' social isolation (DeMaso & Gonzalez-Heydrich, 2000). The frameworks that guided the interventions were mainly stress and coping related. They included Thompson, Gustafson, Hamlett, and Spock's (1992) stress and coping model, Bers, Ackermann, and Cassell et al.'s (1998) and Gonzalez-Heydrich, Bromley, and Strohecker et al.'s (1998) sharing personal story model, and Ajzen's (1988) planned behavior theory. Four of the five studies reported significant reductions in parents' stress or anxiety after the intervention. The fifth study was on parents' awareness of post heart surgery pain management. Following the intervention, which was designed to improve parents' awareness of their child's post-operative pain, parents in the intervention group showed significant improvement in pain awareness scores, but they did not show significant differences in pair comparisons from parents in the control group (Huth, Broome, Mussatto, & Morgan, 2003). However, none of the interventions touched parents' critical times when their child was hospitalized for heart surgery, including receiving diagnosis, being informed their child had to have heart surgery, handing their child over to the surgical staff before surgery, and seeing their child for the first time in PICU after surgery.

Fathers' Roles during a Family Crisis Event

A thought-provoking family phenomenon was noted: when a child was diagnosed with CHD, fathers automatically took over a protective role, not only to their child, but also to their wives. This finding is consistent with Swanson-Kauffman's (1986) and Black and Sandelowski's (2010) studies of couples who miscarried a child and couples who had just received a diagnosis

of a severe fetal anomaly. Both studies found that husbands described having an increased responsibility to protect their wives after they were informed of their child's diagnosis. If fathers automatically take on the protective responsibility when something happens to their child, future research should explore fathers' role perceptions.

Caring Actions in a Pediatric Setting

Parents perceived providers' teamwork in managing their child's condition changes as an important caring action. However, some non-caring actions were also noted by parents in this study. For example, the monitors were beeping for a long time and no one attended; and when a child's pacemaker was not catching and no one could figure that out, nurses and doctors were laughing in the room and talking about non-patient related topics.

The Carolina Care Model (Tonges & Ray, 2011) is an excellent clinical practice model; but, the model may need modification to fit pediatric populations, where parents are not always present to advocate for their child. When parents are not present, no one is there to press the call bell when the child needs help, to speak up for the child when the healthcare providers are loud in their rooms, or to complain when the monitors go off and are not attended. It is up to the healthcare providers to care for these children. Therefore, future research is needed to develop a caring model that can guide pediatric healthcare providers.

Family-centered Care in an ICU Setting

This study has brought attention to parents' perspectives on family-centered care. Findings from the study showed that family is an essential component of patients' lives, and family and patient are one unit. Parents noted that it was important to take the whole family into consideration when a child was hospitalized for heart surgery. Family-centered care has been promoted for many years in nursing, but there is still a lack of consistency in implementation

(Harrison, 2010). We could see from this study that parents were happy when the child was transferred to the pediatric floor because the family could be there together with their child who was hospitalized. Future research may look into ways to promote family-centered care throughout pediatric units.

Implications for Clinical Practice

This dissertation was based on clinical practice and the intention was taken the findings back to clinical practice to ensure evidence-based practice. Findings from this dissertation study show that parents' experiences are not linear or just negative when their child undergoes heart surgery. The study also show that providers' actions affect how parents feel and what they experience. Parents especially need emotional support at vulnerable times, such as receiving their child's diagnosis, being informed that their child need heart surgery, handing their child over to the surgical staff, and seeing their child for the first time in the PICU. Providers who work in these areas should pay attention to parents' emotional needs and provide the support at those times. For example, when parents come to the PICU to visit their child for the first time after surgery, a nurse or liaison may accompany them to explain what they may see and offer support when needed.

Providers should also pay attention to children's monitors. It is important to attend to beeping monitors even though the beeps might not be serious to them. Providers also need to make an effort to explain to parents what the beeps mean so that parents will not be so worried.

When attending to patients' needs in their rooms, providers should refrain from joking or talking about non patient-related topics among themselves. All the attention should be on patients' and families' needs.

Conclusion

In this study, when their child was diagnosed with CHD, parents went through roller-coaster like emotions. Even though provider-patient hospital and clinic encounters were brief, healthcare providers made a huge difference in parents' experiences. Providers should take the opportunity to communicate with parents, inquire about their thoughts and feelings, and provide the support they need. Knowing parents' perspectives on caring and non-caring actions is an essential step for developing interventions. Only when understanding parents' thoughts about care will healthcare providers be able to implement appropriate caring interventions.

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