Evaluation of Parent Counseling After Prenatal Diagnosis of Congenital Heart Disease

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I have no known conflict of interest to disclose.

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Abstract

One percent of pregnancies are affected by congenital heart disease. Of those affected, about 25% require immediate hospitalization after birth and surgical management. This project is a retrospective program analysis of the fetal cardiology division within a pediatric congenital and acquired heart disease center. Caregivers of infants with a fetal diagnosis of congenital heart disease were surveyed with a 22-item questionnaire. This questionnaire measured caregivers' perceived efficacy of prenatal counseling, education, and preparation. The questionnaire was completed by 7 participants (n = 7). The questionnaire and demographic data were analyzed using descriptive statistics with and without crosstabulation. This ranked caregivers' satisfaction in prenatal care broken down into preparation and education domains. One of the most significant outcomes was the high number of potential participants excluded due to language barriers. While satisfaction was high, caregivers were unprepared for their child's transfer to the cardiovascular intensive care unit and the medical equipment their child would require. Surprisingly, data indicates that caregivers did not know which members of the interdisciplinary team they met with during their prenatal appointments. This data will be used to improve the department and standardize the care provided.

Keywords: congenital heart disease, caregiver education, preparation, fetal cardiology

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To my cohort peers, we began this journey as five strangers. We have supported each other through our highest highs and lowest lows. We have watched our families grow and dynamics change. Three years later, we walk away from this journey with lifelong friends. We did it!

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A prenatal diagnosis of a congenital heart defect is a life-altering event. Following such a diagnosis, the care is meant to prepare caregivers for their child's potential surgical and medical needs. This period is marked by numerous appointments providing parents with overwhelming statistics and technical medically complex information that they never anticipated hearing. The expectations set during this period may not be realistic or adequate compared to what the parents will experience with their child.

Problem Statement

Congenital heart defects (CHD) affect approximately 1% of all pregnancies, with 25% being considered critical due to requiring immediate intervention following birth and are associated with a high mortality rate (Bakker et al., 2019). Factors influencing the percentage of CHD diagnosed during pregnancy vary. However, an estimated 30%-60% are detected during routine obstetric care in developed nations (Van Nisselrooij et al., 2020). In these cases, patients are referred to a fetal cardiologist who confirms the heart defect through a fetal echocardiogram. Depending on when the defect was detected during gestation, the parents will have a series of appointments with the fetal cardiologist and pediatric cardiovascular surgeon, who will provide detailed verbal and written information to the patient. Depending on local statutes, termination of the pregnancy may be offered. There are no clinical practice guidelines or models prenatal to direct prenatal education. Multiple experts provide ample suggestions that can be adapted to fit each institution's mission and the population served. Regardless, one example is an interprofessional approach revealing that 95% of women rated their counseling as "good" or "very good" regardless of their child's outcome (Schneider et al., 2022).

When COVID-19 swept the world, many hospitals closed their doors to nonessential personnel and visitors; this included unit tours for caregivers. The impact on caregiver experience, satisfaction, and anxiety reduction has not been considered. In addition to the previously incorporated in-person tour, prospective parents had the opportunity to experience the intensive care unit in a fully immersive manner. This exposed them to the sights, sounds, and smells of a foreign environment that will ultimately become their newborn's first home. The authors of a recent study examined patients' anxiety when provided with standard pre-anesthesia preparation which did not include a virtual or in-person tour of the operating room or preoperative area, compared to those that were provided with a virtual tour. There was no evidence that the virtual tour decreased anxiety before or after the procedure, but it was found to be informative and lead to higher satisfaction scores (Vogt et al., 2021). Without the ability to host in-person tours, teams are opting for virtual tours and photographs for patients' preparation.

Purpose and Rationale

Advancements in surgical techniques and medical management over the last twenty years have improved the morbidity and mortality of infants born with congenital heart defects. The parents of these infants are counseled on multiple high-risk procedures, lengthy hospital stays, and the potential for additional comorbidities. This anxiety-inducing information is relayed while the parents are expected to start making their first parenting decisions, before the child is born. The purpose of this project is to examine current prenatal education and preparation for effectiveness and to reveal areas for improvement.

Background and Significance

Prenatal counseling following a diagnosis of a congenital heart defect is critical to determining the course of the patient's medical care. A comprehensive program of education that aims to prepare caregivers for their child's medical needs is in accordance with national and statewide initiatives that aim to improve healthcare literacy. During prenatal counseling, the likely course of care is determined and provided to the parents to set expectations. This education should be thorough and accurate, including potential complications or deviations from the ideal plan.

Population

Being informed that your child has a potentially life-limiting congenital defect can trigger a great deal of negative emotions in parents. Reportedly, mothers with infants in the neonatal intensive care unit experience postpartum depression up to 39% of the time, compared to 15% of women with healthy children (Lee & Loomba, 2022). Understandably, parents of children with congenital heart disease often report initial feelings of being overwhelmed, sad, and distressed upon receiving this diagnosis. It can often impair their ability to comprehend or concentrate on the medical information presented to them at the time (Tacy et al., 2022). Studies show that parents of children with CHD suffer from post-traumatic stress disorder in more than 30% of cases and major depressive episodes in 25%-50% of cases (Kasparian et al., 2019; Werner et al., 2019). Depending on the time of prenatal diagnosis, these parents are faced with critical decisions such as termination of the pregnancy, allowing natural death to occur with \birth, or pursuing aggressive surgical repair. Understanding their child's diagnosis, prognosis, and potential treatment plan is vital to make these decisions.

Prenatal Counseling

Parents receive comprehensive prenatal counseling and medical and surgical planning from a comprehensive interprofessional team to quell distress and advance patient care. The collaboration of an interdisciplinary team of pediatric cardiologists and mental health professionals who are familiar with congenital heart disease can have a positive effect on parents’ mental health in the time before and after the birth of their child (Erbas et al., 2023). Studies have shown that there are several common themes that parents look for after receiving a congenital heart defect diagnosis. These themes include written information, diagrams of the defect, an interactive website, peer support, and a tour of the cardiovascular intensive care unit (Kovacevic et al., 2019; Tacy et al., 2022). It was common practice before the COVID-19 pandemic to provide a tour for parents to explore the neonatal intensive care unit or the cardiovascular intensive care unit during prenatal preparation. During the tour, parents often had the opportunity to meet the doctors and nurses who might care for their child, view their living space at the bedside, and experience the overwhelming sensory overload that is commonplace in an intensive care unit.

Post-COVID-19 Prenatal Counseling

Since COVID-19, hospitals have become unavailable to the public for services that are not directly related to medical care. This includes family tours of intensive care units before the birth of infants with congenital heart defects. The era of post-COVID-19 prenatal counseling has included telemedicine, but with mixed reviews regarding convenience, resistance, and technical difficulties (Mehl et al., 2022). Currently, there is no guidance regarding providing a similar experience, education, or preparation during prenatal counseling without a tour. The solution offered by one institution was to provide photo documentation of the intensive care units. Photographs of patient bed spaces, equipment, and similar patients appear in this photo presentation.

Unfortunately, this well-intentioned “photo tour” cannot convey the overwhelming sensory experience of being in an intensive care unit. People are constantly coming and going from the patient's bed space, numerous machines are emitting alarms of various tones and volumes throughout the day and night, foreign smells are present everywhere, and fluorescent lights are nearly always on.

Effect on Satisfaction

Health literacy is a national and state health initiative focused on improving healthcare professionals' communication with their patients and improving individuals understanding of their health (U.S. Department of Health and Human Services, 2021). These initiatives strive to improve public health, improve healthcare outcomes, and decrease healthcare costs (U.S. Department of Health and Human Services, 2021). Medical providers can contribute to this movement by providing quality patient education. Careful prenatal counseling improves caregivers' health literacy regarding their child's diagnosis. This will lead to realistic expectations and, ultimately, increased satisfaction.

Internal Data

This project occurred at a tertiary care facility in the southwestern United States. This institution provides care across all pediatric specialties to the community and residents in neighboring states and countries. The cardiac center in this institution is categorized as a high-volume center, having completed over 1,300 procedures between July 2017 and June 2021 (The Society of Thoracic Surgeons, 2021). The organization's mission is to provide hope, healing, and the best healthcare for children and their families. Key stakeholders in this project are the fetal cardiologists and pediatric cardiovascular surgeons who provide routine prenatal counseling and the cardiovascular intensive care unit intensivists physicians and nurse practitioners who direct the care of the child before and after surgical intervention. The gap in care was identified by a registered nurse in the cardiovascular intensive care unit who was concerned about parent expectations and satisfaction during the perioperative period. If this problem remains unaddressed, parents' expectations will continue to differ from reality and satisfaction will continue to suffer.

PICOT Question

A review of the literature led to the clinically relevant PICOT question: "For parents of fetuses diagnosed with a congenital heart defect, how well does current prenatal counseling prepare parents for their infant's care within a week of surgery?"

Search Strategy

An exhaustive literature search was performed in the electronic databases PubMed, PsycINFO, and EBSCO Host: Academic Premier. These databases were chosen for their relevance to the PICOT question and ability to narrow search parameters.

The databases were searched using combinations of terms that addressed the PICOT including but not limited to *single ventricle, congenital heart disease, congenital heart defect, prenatal counseling, and satisfaction.* The results were filtered for relevance based on publication date within the last 5 years (2018-2023).

Keyword Selection

An initial search of PubMed using the key terms *congenital heart defect* AND *counseling* yielded over 600 results. This was narrowed by replacing the terms with *prenatal* AND *heart disease* AND *cardiologist*, resulting in 88 results. This was further narrowed by searching *prenatal counseling* AND *single ventricle* which yielded 19 results.

The initial search of PsycInfo yielded 768 results with the key phrases *congenital heart defect*. This was narrowed too far by searching *congenital heart defect* AND *counseling* AND *satisfaction* yielding only one result. The search was expanded to 6 results by searching *congenital heart defect* AND *satisfaction.* Searches using *single ventricle* AND *counseling* and *single ventricle* AND *mental health* yielded no results. The searches *congenital heart disease* AND *caregiver* and *congenital heart defect* AND *caregiver* yielded 22 and 11 results respectively.

The initial search of EBSCOhost: Academic Search Premier with key phrases *congenital heart disease* AND *caregiver* AND *satisfaction* was too narrow and only produced three results. With the substitution of *counseling* for *caregiver*, the yield was the same. Searching key phrases *congenital heart disease* AND *mental health* provided 190 results.

Initial, Final Search Yields, Limitations, Inclusion, and Exclusion Criteria

Through review of abstracts and titles, the database searches yielded 51 relevant studies. 10 of the most relevant studies were selected from these 51 results, including one meta-analysis and nine cohort studies. Inclusion criteria targeted studies that focused on parent or caregiver mental health during the prenatal and/or postnatal period. Additionally, only studies that included cardiac defects that required intensive care unit admission and intervention within the first month of life were considered for inclusion. Exclusion criteria were any study that surveyed parents with children who did not require intervention and intensive care unit admission within the first month of life and if the study was not available in English.

Critical Appraisal and Synthesis of Evidence

The rapid critical appraisal (RCA) process was performed based on the process developed by Melnyk and Fineout-Overhold (2019). Because of the nature of this project, many of the applicable articles were qualitative. This project’s personal and subjective nature lends itself to primarily qualitative data collection. However, combining quantitative (see Appendix A,

Table A1) and qualitative studies (see Appendix A, Table A2) provides a robust framework of supportive evidence.

In the studies, parents were surveyed or interviewed at multiple points, some starting during the diagnosis and consultation period, some after birth while in the hospital, or at home after discharge. A wide variety of demographics are represented through various methods of study. None of the studies included parents whose child had died or received a heart transplant, for concern of biased or skewed opinions.

The sample characteristics were relatively homogenous, with all but one study focusing on both mothers and fathers; the outlying study focused on the impact on fathers with input from both parents. Results from the studies also displayed homogeneity with most respondents reporting increased rates of mental health concerns. Heterogeneity was observed when looking at diagnoses for fetuses or children. They ranged from simple septal defects to critical congenital heart defects that required multistage palliation. Additionally, only 40% of the studies took place strictly in the United States. Four were international, and the remaining two combined United States and foreign efforts.

Nine of the ten chosen studies used validated and reliable assessment tools to collect data. Data from these tools were run through reliable statistical software to produce unbiased results. All information from these studies was included in the synthesis tables (see Appendix A, Table A3) to offer supportive evidence surrounding the efficacy of prenatal counseling programs.

Discussion

The evidence shows that despite written and verbal education from a neonatal or pediatric cardiologist, parents still experienced low rates of satisfaction and bonding, and high rates of mental health concerns. From the included studies, evidence clearly displays a gap in preparation for parents expecting a child with congenital heart disease. Using this information, congenital heart defect programs should consider an adjunct preparation tool that could provide the missing immersive component.

Theory/Theoretical Framework Application

When the Chronic Care Model was first introduced, it suggested improvements in outcomes could be attributed to incentives, self-management, follow-up that meets patient needs, interdisciplinary interaction, and enhanced data and feedback collection (see Appendix B, Figure B1). These concepts are well-represented in research discussing prenatal congenital heart defect counseling. Typically, once the initial diagnosis of a congenital heart defect has been made during routine prenatal care, the woman is referred to a fetal or pediatric cardiologist for further care. Care coordination after this point commonly includes appointments with the cardiologist, cardiothoracic surgeon, palliative care, nurse coordinator, and a mental health provider like a psychologist at various points before delivery. The process lacks both data collection and data feedback collection. Parents are often provided a lengthy survey via mail by the organization after their child's hospital discharge. These are rarely filled out, not followed up on, and do not inquire about the parent's satisfaction based on their pre-admission expectations.

The Chronic Care Model can improve an already effective system and produce better results. Research has shown that parents of infants with congenital heart disease are more likely to suffer from mental health concerns than parents of typical children, suffer from decreased ability to bond with their newborn, and decreased satisfaction. Improved feedback can be expected by targeting these concerns directly within the preexisting prenatal counseling system.

Implementation Framework

The implementation of this project will be guided by the Plan-Do-Study-Act cycle (PDSA). The PDSA cycle is effective because it includes implementing what is learned in the study to begin additional changes and studies (Fineout-Overholt & Stevens, 2019). This method continues the cycle of improvement and advancement. The framework mapping is circular to represent the continuous research cycle (see Appendix B, Figure 2). The mapping of this framework provides an effective strategy when investigating whether to test and observe change on a small scale before implementing it on a larger scale (Fineout-Overholt & Stevens, 2019). Initially, this cycle was based on small, repeated trials with each retrial being altered based on the previous trial's results (Fineout-Overholt & Stevens, 2019). The framework mapping is circular to represent the continuous research cycle (see Appendix B, Figure 2). There are many possibilities of what can be gleaned from this project regarding parent or caregiver consultation and preparation for congenital heart defect repair. Based on this project's quantitative and qualitative data, approved education materials for parents could be developed.

Methods

Ethical Considerations

Three ethical principles guided this project: respect for persons, justice, and beneficence. Respect for persons means that the potential research participants have the opportunity to decide whether they want to participate in the project (Reavy, 2016). The project adhered to this principle by giving potential participants the option to participate or opt out with no untoward effect. Justice is the participants' right to privacy and fair treatment (Reavy, 2016). The project upheld this principle by not collecting any participant or patient identifying information or accessing the charts of the participants or their children more than the minimum necessary. Beneficence is the final principle. It is defined as doing good for patients (O’Mathúna, 2019). The project fostered this principle by ensuring the subjects understood that their participation, or lack thereof, would not influence their or their child’s medical care, treatment plan, or outcome positively or negatively. The project’s methodology was reviewed by faculty mentors, the institutional nursing governance committee, the institutional quality improvement committee, and the Arizona State University Institutional Review Board (IRB).

Consent was obtained through a verbal interaction with a designated project team member. This team member read a script explaining the purpose of the project, ensured their privacy, and clarified that there would be no modification to their child’s medical treatment or hospital stay based on their participation or the answers provided. There was no formal consent form for the participants to fill out or sign to ensure anonymity. Verbal agreement and completion of the survey will serve as consent to participate. No identifying information was collected; therefore, the results cannot be linked to any specific patient or caregiver.

Population

Potential participants were chosen first based on the timing of their child’s initial diagnosis, location of fetal cardiac care received, age, admission to the cardiovascular intensive care unit, and timing of surgical or catheterization intervention. The child must have had a fetal diagnosis of a congenital heart defect and received fetal cardiology care within the institution where this project is conducted. Only children admitted to the cardiovascular intensive care unit directly from their birth hospital who are under the age of 30 days during their first intervention qualify. Children not meeting the above criteria or dying before the survey administration will not have qualifying caregivers. Participants who qualified based on these criteria were also required to read and write in English, be available at the patient’s bedside for survey consent and completion of project documents and be over 18 years of age.

Project Description

New admissions for four months to the institution’s cardiovascular intensive care unit (CVICU) were added to a student login for the electronic medical record (EMR). The patients were screened based on the inclusion and exclusion criteria document (See Appendix C, Table 1). Potential participants were approached by the Doctor of Nursing Practice (DNP) student. She introduced herself, explained the project’s purpose, and reviewed the verbal consent to participate. Those who agreed to participate were provided a copy of the consent agreement. The participants were also provided with the demographics form and survey to fill out (See Appendix C, Table 2).

Data Collection

Data was collected through a demographics form and a 22-question survey filled out with pen and paper. The demographic form asks for basic demographics, pregnancy, and diagnostic-specific questions. The Likert scale is a 20-question survey created for this project, adapted from a study that collected qualitative data from a series of open-ended questions through crowdsourcing (Driscoll et al., 2023). Two additional open-ended questions follow the Likert scale survey.

Data Analysis

The DNP student entered data collected during this project into Intellectus statistical software. The data analysis highlights areas of current practice working well and areas requiring change. Higher scores on the Likert scale indicated a positive trend, while lower scores indicated dissatisfaction. Scores were viewed for each question and each participant’s overall satisfaction.

Themes in the open-ended question responses will be used to inform the stakeholders directly about practice concerns. The demographic data will also identify trends in patient families that can be used to improve care delivered to different populations.

Budget

There was no budget or funding for this project. The cost of Intellectus statistical software is included in the DNP student's program so an additional cost was not incurred.

Implications for Practice Change

The evidence reveals that the existing model of care for prenatal education and consultation for caregivers of newborns with congenital heart defects is lacking. Evidence also suggests that a more integrated look at life in the hospital would be beneficial. Applying this evidence to a local pediatric congenital heart center influences permanent institutional procedures for prenatal congenital heart defect consultation. Developing an educational intervention tailored to this institution's specialized population in a medium that allows for repeated use or circulation among the intended population would have a positive impact. With the potential success of this implementation, equivalently designed educational tools can be developed for other special populations.

To design an appropriate intervention, initial data must be collected. Surveying parents of a prenatal and post-surgical child with a validated tool can assist in identifying current attitudes. The use of a tool using open-ended questions will be given to parents during the post-surgical period. This information can assist in revealing how information could have been explained better and what would have been beneficial for them to know before admission and surgery.

Using this information, a targeted education piece can be developed that focuses on the areas lacking or are absent in current practice. The potential outcomes include parental coping, satisfaction, and anxiety, depression, and post-traumatic stress disorder symptom improvement.

Potential Outcomes

This intervention will be repeated if the institution and stakeholders find it valuable. The success of the intervention may affect future congenital heart defect parents' perceptions of the birth and hospitalization of their child with congenital heart defects. Furthermore, this project may inspire future similar initiatives for parents of infants with other congenital defects. This project hopes to produce a shift in the culture of CHD families toward reasonable expectations during the admission process.

Discussion

Summary of Findings

Intellectus Statistics ™ was used to store, manage, and analyze data. Exploratory descriptive statistics using crosstabulation were used for analysis. A population of parents of infants with CHD with fetal diagnosis, *n* = 7, participated in this project. The average age of the sample was 30 (SD = 5.77), and the ages ranged from 23 to 38 years of age (See Appendix D, Table 1). Most of the sample were female 4 (57%), and the remainder were male, 3 (43%). Most of the sample were White/Caucasian 4 (57%), and the remainder were Hispanic/Latino, 3 (43%). The level of education of most participants was less than high school, bachelor's degree, or graduate/doctorate, 6 (86%); the remainder had high school/GED, 1 (14%). Most of the sample were married, 4 (57%); the remainder were not married but cohabitating, 3 (43%). Most of the sample speak English as a primary language, 6 (86%), with the remainder speaking English and

Spanish equally, 1 (14%). Much of the sample was the mother of the patient, 4 (57%), with the remainder being the father, 3 (43%) (See Appendix D, Table 2).

When asked about the fetal diagnosis, most of the sample did not remember their child's fetal diagnosis, 4 (57%), the following most frequently reported diagnosis was Shone's Complex, 2 (29%), and the least frequently reported diagnosis was coarctation of the aorta, 1 (14%). When asked about additional congenital anomalies all of the sample denied fetal diagnosis, 7 (100%). When asked about chromosomal abnormalities the majority of the sample denied fetal diagnosis, 5 (71%), with the remainder confirming 2 (29%). When asked about the name of the intervention, most of the sample did not know, 4 (57%), valvuloplasty and arch repair, 2 (29%), and arch repair, 1 (14%) (See Appendix D, Table 3).

The most frequently observed interdisciplinary appointments attended were cardiac surgery and fetal cardiology, 5 (71%), with the remainder denying 2 (29%). Lactation specialist was the next most frequently observed interdisciplinary appointment attended, 3 (43%), with the remainder denying, 4 (57%). Palliative care, nurse coordinator, and social work had the same number of attended appointments, 1 (14%), with the remainder denying, 6 (86%). Psychology had 0 appointments attended (See Appendix D, Table 4).

The observations for satisfaction had an average of 92.86 (*SD* = 12.06). The observations for the subcategory of education had an average of 58.00 (*SD* = 2.58). The observations for the subcategory of preparedness had an average of 34.86 (*SD* = 9.67) (See Appendix D, Table 5).

Limitations

Limitations to this project included delays in IRB approval and low recruitment. The institution was undergoing process changes related to quality improvement projects resulting in decreased recruitment time. Other than a decreased timeframe for recruitment, many potential subjects were excluded due to the language barrier. Additionally, it was difficult to predict when caregivers would be present at their child's bedside. Coordination with the bedside nurse was often necessary to aid recruitment.

Impact and Future Recommendations

The results of this project, along with the evidence synthesis, led to the development of several recommendations. First, written materials will be translated into Spanish. Additional languages will be offered after a Spanish set is complete. This institution uses a journey board for caregivers to track their child's hospital admission, anticipate discharge requirements, etc. A journey board for caregivers to do the same for their child's birth through transfer to the receiving cardiovascular intensive care unit. This will allow parents to discuss the anticipated interventions between delivery and transfer with the medical team. This can also answer questions that caregivers may have about being able to see and touch their child before transfer. A medical doll outfitted with various medical equipment that could be found on a newborn before and after surgery will be created for each of the five organizational fetal cardiology offices. This will give caregivers their first visual of the medical equipment that their child will likely require. Caregivers can touch the equipment without fear of hurting their child. Finally, forms that include providers' photos, names, specialties, etc., will be developed. This is a tool to help parents keep track of and recognize the multitude of providers in various specialties during fetal care, many of whom they will continue to see after admission to the cardiovascular intensive care unit.

Sustainability

This site for this project is interested in implementing the recommendations as soon as possible. The site champion is interested in repeating satisfaction surveys in the future to understand the caregiver population and assess improvement from implementing recommendations.

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Appendix A

Evaluation and Synthesis Tables

Table A1

Evaluation Table for Quantitative Studies

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice. Generalization
Bainton et al. (2022), Prevalence and associated factors of post-traumatic stress disorder in parents whose infants have single ventricle heart disease **Country:** United States and Toronto, ON, CA **Funding:** National Heart, Lung, and	Resiliency Model of Family Adaptation	**Design:** Targeted questionnaire **Method:** Completed 13 self-reported questionnaires at 3 timepoints. 1: post surgery 8 weeks of age, 2: post-Stage II surgery 6 months of age, 3: final follow up 16 months of age **Purpose:** Further evaluation of the prevalence of symptoms of PTSD in both mothers and fathers of infants with critical CHD	**N**= (215) **Demographics:** 143 mothers, 72 fathers representing 146 infants. 92% HLHS, 8% HRHS, 73% diagnosed prenatally, 10% with genetic condition, 23% with non-syndromic abnormality **Setting:** Outpatient clinic **Exclusion:** Patients that ended up with heart transplant or died; unable to read/write English **Attrition:**	**IV1:** Parents of infants diagnosed with HLHS or HRHS, having had stage 1 & 2 palliation surgeries **DV1:** Stress **DV2:** Coping **DV3:** Demographics **Definitions:** PTSD criteria: Present for at least 30 days;	**Tools:** Impact of Event Scale – Revised; Family Information Form; Life Stress Inventory; State-Trait Anxiety Index; Pediatric Inventory for Parents; Coping Health Inventory for Parents; Family Inventory of Resources for Management; Inventory of Parent's Experiences **Validity/ Reliability:** Tools used are validated	**Statistical Tests Used:** Pearson correlation and ANOVA	**DV1:** Significantly associated with more symptoms of PTSD **DV2:** Significantly associated with symptoms of avoidance and hyperarousal **DV3:** The only demographic variable significantly associated with symptoms of PTSD was parent age, older parents reporting less symptoms.	**Level of Evidence:** Case Control Study III **Strengths**: Large sample despite attrition Many different tools looking at variety of factors **Weakness**: Participant withdrawal due to parent stress. Parents who were struggling the most may not have participated at some time points or may never have consented at all. It is possible that survey fatigue due to the time commitment required to complete the questionnaires contributed to attrition rates **Feasibility**: Repeating would be difficult due to the large number of

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Blood Institute; National Institutes of Health **Bias:** None		who underwent staged surgical palliation. Also investigated potential associations of demographic, clinical, stress, and coping variables with symptoms of PTSD	Start 215 Attrition, n = 76, 13 incomplete, 104 decided not to participate. 22 ineligible (death/transplant)					questionnaires used, as this study demonstrated with its attrition **Application**: Attention to parent mental health & overall well-being during uncertain & stressful times is important. Results suggest more help is needed for parents, and screening and intervention might be beneficial. High prevalence of probable PTSD suggests future studies to better understand prevalence.
Bratt et al., (2019). Parental reactions, distress, and sense of coherence after prenatal versus postnatal diagnosis of complex congenital heart disease **Country:** Sweden	Resiliency Model of Family Adaptation	**Design:** Targeted questionnaire **Method:** Participants were given validated questionnaires during pregnancy (prenatal and control groups) and again at 2-6 months after delivery for all three groups. **Purpose:** Estimate sense	N = (133) **Demographics:** **Setting:** 3 tertiary facilities in Sweden **Exclusion:** Participants must be able understand and speak the Swedish language, infants could not be deceased or remain in intensive care when the second survey was sent.	**IV1:** Time when congenital heart defect is diagnosed influencing parents' anxiety/depression/coherence/etc. **DV1:** Prenatal diagnosis **DV2:** Postnatal diagnosis **DV3:** Control group: normal ultrasound exam (no CHD) **Definitions:** Complex cardiac defects: defects requiring surgery	**Tools:** Swedish version of Hospital Anxiety and Depression Scale, Swedish version of the Short Sense of Coherence Scale, Life Satisfaction Scale, Dyadic Adjustment Scale **Validity/Reliability:** All these scales are validated and reliable	**Statistical Tests Used:** Fisher's exact test, Mantel-Haenszel X2, Mann-Whitney *U*, Kruskal-Wallis, Wilcoxon Signed Rank test	**DV1:** significantly lower coherence score than the other two groups, also had the highest education **DV2:** higher sense of coherence and life satisfaction than the prenatal group	**Level of Evidence:** Case Control Study III **Strengths:** matching for age, sex, and parity since this variable could affect the results **Weakness:** Difference in education levels between the prenatal and control group, single ventricle defects were overrepresented in the prenatal group, different response rates from each group **Feasibility:** This could feasibly be recreated using the same demographics

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Funding: Swedish Children's Heart Foundation, the Healthcare Board, Region Västra Götaland, Grant no. 121741. M.M. from the Swedish Heart-Lung Foundation **Bias:** None		of coherence, degree of anxiety, depression, life satisfaction, and satisfaction with partner relationship in 3 groups of parents.	**Attrition:** of the 382 subjects deemed, 210 started & 133 completed the study	before 12 months of age				**Application:** Understanding that parents are at risk for moderate levels of anxiety can open the door for treatment for them before and after the delivery
Kasparian et al. (2019) Mental health care for parents of babies with congenital heart disease during intensive care unit	Phenomenology	**Design:** Meta analysis **Method:** 6 electronic databases were searched for studies reporting results of controlled trial of mental health	**N** = (339) **Demographics:** Controlled trials delivering a psychological intervention for parents of infants with a congenital anomaly in NICU, PICU, or CICU admissions.	**IV1:** congenital anomaly requiring ICU admission and surgery under 12 months of age **DV1:** Anxiety **DV2:** depressive symptoms **DV3:** attachment-related outcomes **Definitions:** Psychological intervention: any intervention based on	**Tools:** Cochrane Collaboration Tool for Assessing Risk of Bias; State-Trait Anxiety Inventory; Beck Depression Inventory; Bayley Scales of Infant Development.	**Statistical Tests Used:** Hedge's g was used to correct for bias associated with small sample sizes	**DV1:** All reported a significant reduction in anxiety following intervention **DV2:** Mixed results were yielded regarding depression. No significant	**Level of Evidence:** I **Strengths:** systematic review of 5 studies with wide coverage of socioeconomic status **Weakness:** small sample sizes, single center recruitment, lack of blinding, active control conditions, reliance on self-administered, symptom-based measures of mental health to assess

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admission: Systematic review and statement of best practice **Country:** Australia, United States **Funding:** National Health and Medical Research Council of Australia, HeartKids Australia, Neuroscience, Mental Health & Addictions Theme and SPHERE Mindgardens Clinical Academic Group **Bias:** None		intervention for parents of infants with congenital anomaly requiring surgery **Purpose:** Identify, synthesize, and critically appraise evidence on the efficacy and cost-effectiveness of mental health interventions for parents of infants with CHD. Develop recommendations for advancing health policy, practice, and research	**Setting:** NICU, PICU, CICU **Exclusion:** infants 1 year of age or do not require ICU admission **Attrition:** NA	specific psychological principles, skills or techniques, a psychological theory, or input from a mental health professional and was delivered in isolation or in conjunction with other medical, practical, or educational components. Anxiety: scores on a validated self-reported questionnaire or diagnostic status based on a structured or semi-structured clinical interview	**Validity/Reliability:** All the tools used were validated and reliable in the original trials and the review		change in depressive scores was found between intervention and control groups **DV3:** enhancing mother-infant attachment led to a greater increase in self-reported mother-infant attachment	efficacy, without reference to clinical cut-offs or diagnostic assessments to provide indications of clinically meaningful psychological change **Feasibility:** This could be reevaluated with similar results **Application:** These findings can be used to improve on parent mental health, attachment, and developmental concerns regarding the infants

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Kovacevic et al., (2021). Fetal cardiac services during the COVID-19 pandemic: how does it affect parental counseling? **Country:** Germany **Funding:** Open Access Publishing Fund of the Ruprecht-Karls-University Heidelberg **Bias:** None	Phenomenology	**Design:** Cohort Study **Method:** Parental counseling for fetal CHD was assessed by interviewing parents during follow-ups or by questionnaires issued during the visits or sent to families. Parents were all counseled by the same three fetal cardiologists and three maternal-fetal medicine specialists **Purpose:** Assess the success of parental counseling for fetal heart	**Sample:** (n=226) **Demographics:** 169 counseled before COVID, 57 during pandemic. Fetal gestation at diagnosis/counseling 23 weeks (median) before and 22 weeks (during). Mean parental age at time of counseling was 35 years (before) and 34 years (during) **Setting:** National tertiary medical centers, “pre-COVID era”: 2009-2019; COVID subgroup March 2020-December 2020 **Exclusion:** severe extracardiac malformations or genetic	**IV1:** Counseling during COVID-19 pandemic **DV1:** Parental wish for written/online data **DV2:** Sorrow Scale: parental uncertainty **DV3:** Sorrow Scale: parental concern **DV4:** Overall counseling success **Definitions:** none provided	**Tools:** Unnamed validated Likert scale questionnaire; Sorrow Scale **Validity/Reliability:** tool is reportedly validated, but it is unnamed and created specifically for this study so unable to verify	**Statistical Tests Used:** Likert scale questionnaire answers measured on 5-point scale. Sums transformed into ordinal scale with ranges 16-32 successful, 33-63 satisfying, 64-80 unsuccessful Cron-Bach’s alpha was 0.904, displaying scales’ high internal consistency Mann-Whitney U-Test used to compare differences between two	**DV1:** $p = 0.034$ **DV2:** $p = 0.44$ **DV3:** $p= 0.025$ **DV4:** $p=$ n.s. Parents counseled during pandemic were significantly more concerned and unsure of the diagnosis/therapy/ outcomes and expressed significantly increased need for written/online information.	**Level of Evidence:** Cohort Study II **Strengths:** Wide variety in sample **Weaknesses:** Due to sample size and sampling method, the generalizability of findings may be diminished; skills regarding counseling may differ among physicians and personal biases may have been imposed **Feasibility:** These results can be applied to any fetal cardiac program **Application:** these results can help direct post-COVID counseling to improve their written/online information for parents

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		disease during the pandemic and compare to results with data acquired before the pandemic; identify emerging parental needs in this contact with the aim to adapt the counseling process.	syndromes (trisomy 13 or 18) **Attrition:** 0%			independent samples Sorrow scale: more concern during COVID		
Erbas et al. (2023). Anxiety and depression levels in parents after counselling for fetal heart disease **Country:** Germany **Funding:** None **Bias:** None	Phenomenology, Resiliency Model of Family Adaptation	**Design:** Cohort Study **Method:** A longitudinal questionnaire-based study was conducted from October 2019 – April 2021 in the Department of Congenital Heart Defects **Purpose:** Assess the psychological	**Sample:** (n=24); initially 77 **Demographics:** **Setting:** Parents at one center were given questionnaire; 45 mothers, 32 fathers; mean age 33.7 years, range 20-45 years **Exclusion:** parent under 18 years old, child did not have a prenatally	**IV1:** Prenatal congenital heart defect diagnosis **DV1:** self-reported anxiety **DV2:** self-reported depression	**Tool:** Hospital Anxiety and Depression Scale (HADS) **Validity/Reliability:** In validity studies, the HADS is a suitable screening tool for gynecological and pregnant patients	**Statistical Tests Used:** Wilcoxon tests for anxiety (W = 100.5, *p* = 0.397, *Prb* = 0.330) and depression (W = 94.5, *p* = 0.297, Prb = 0.370). showed no significant effect	For anxiety, "borderline depression" and occupational fields (e.g., health and social workers) emerged as predictors. In all cases of at least borderline depression in time t1, "significant" anxiety at time t1 was present	**Level of Evidence:** II **Strengths:** use of validated mental health tool **Weaknesses:** single center study, participants self-reported anxiety and depression symptoms instead of having formal evaluation from a mental health provider which may have skewed results **Feasibility:** These results can be applied to any pediatric cardiac program **Application:** These results can help healthcare

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		state of parents expecting a child with a congenital heart defect to subsequently improve support services and minimize negative consequences for the mother and child.	diagnosed heart defect **Attrition:** 77 completed the initial questionnaire, 24 completed follow-up questionnaires					workers target who is most likely to have a negative mental health outcome or need the most mental health assistance prenatally and antenatally
Werner et al., (2019). Parental anxiety before invasive cardiac procedure in children with congenital heart disease: contributing factors and consequences	Phenomenology	**Design:** prospective cross-sectional study **Method:** Children with CHD age 0-15 years referred for cardiac surgery or catheterization were screened; parents were offered to participate in the study if at least one was	**Sample:** (n=120) **Demographics:** Parents of children age 0-15 with CHD undergoing cardiac surgery or catheterization; mean ICU length of stay 7.3 days +/- 8.8 days; 87% that underwent catheterization did not require intensive care after	**IV1:** Children with CHD **DV1:** Maternal anxiety **DV2:** Paternal anxiety	**Tool:** analogic visual scale (AVS) **Validity/Reliability:** Has been largely used as a simple, reproducible, and validated instrument for adult anxiety assessment in routine health care. So far, it has not been used to assess anxiety of parents facing	**Statistical Tests Used:** Kolmogorov-Smirnov test; Fisher's exact test; Mann-Whitney test *P* values < 0.05 were considered statistically significant	Maternal anxiety was significantly associated with level of paternal anxiety (AVS > 8/10), presence of comorbidity, distance between home and surgical center; high RACHS-1(risk adjustment for congenital heart surgery) score	**Level of Evidence:** III **Strengths:** Comparison between mothers and fathers to highlight different needs **Weaknesses:** Single center study **Feasibility:** These results can be applied to any pediatric cardiac program **Application:** These results can be used to advise parents regarding future episodes of anxiety and how they might respond differently from each other

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Country: France **Funding:** not stated **Bias:** none		available to answer questionnaire **Purpose:** Analyze parental anxiety using a visual analog scale and to explore the influencing factors	**Setting:** Tertiary care regional referral center for CHD of Marseille-La Timone University Hospital **Exclusion:** Parents must be available to answer questionnaire at time of procedure; language barrier **Attrition:** 0%		disease in their offspring.		Paternal anxiety was influenced by distance between home and surgical center.	as this may be a point of contention in the future

Table A2

Evaluation Table for Qualitative Studies

Citation	**Theory/ Conceptual Framework**	**Design/ Method/ Sampling**	**Sample/ Setting**	**Major Themes Studied/ Definitions**	**Measurement/ Instrumentation**	**Data Analysis**	**Findings/ Themes**	**Level/ Quality of Evidence; Decision for/ Application to practice. Generalization**
Gramszlo et al. (2022), Meeting parents' needs for education and preparation following congenital heart	Phenomenology	**Design:** Crowdsourcing **Method:** Participants were asked a total of 37 open	**Sample:** (n=95) **Demographics:** mothers and fathers of children with CHD that were	**RQ1:** Experience of receiving education and preparation following	**Data Collection:** Participants created a deidentified Yammer account. 37 open-ended study questions were posted to this	**State type used.** Qualitative data were analyzed using an inductive	(1) consistently met: basic education about anatomic diagnosis, etiology, and treatment options; preparation for hospital admission and typical surgical course	**Level of Evidence:** II **Strengths:** used subjects from several institutions and around the

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disease diagnosis: Recommendations from a crowdsourced study **Country**: United States **Funding**: Institutional Development Award from the National Institute of General Medical Sciences of the National Institutes of Health **Bias**: none		ended questions over a period of 6 months **Purpose:** Characterize parent reports of education and preparation around the time of pre- or postnatal CHD diagnosis, identify unmet informational needs, and generate recommendations for cardiac care teams to support the parental coping and decision-making	prenatally or postnatally diagnosed between 1-7 years prior to study participation who required open-heart surgery in the first year of life; 73.7% had surgery in the first month of life; 65.3% had prenatal diagnosis; 48.4% had single ventricle physiology; able to read and write English, and access to the internet **Setting:** Online **Attrition:** None	CHD diagnosis **RQ2** Relevant psychosocial domains **Definitions:** Crowdsourcing: internet-based, community-engaged research method that allows large groups to collaboratively solve problems of importance to the community.	online group over 6 months. 6 questions aimed at the experience of receiving education/preparation following CHD diagnosis, 31 questions relevant to psychosocial domains. Collaboration between participants was facilitated by allowing parents to view other's responses and "like" or comment on these responses. All dialogue was included as qualitative data **Data Dependability:** Self-reporting	thematic approach, focusing on subjective perceptions, feelings, and experiences.	2)inconsistently met: consideration towards parents' readiness to receive information; communication that balances seriousness and hope; preparation for possible complications after surgery; information about peer-to-peer and other social supports; information about financial support, insurance, and lodging during hospitalization; preparation for the long-term, day-to-day challenges of managing CHD; tailored education and support for parents of children diagnosed postnatally (3) consistently unmet: guidance toward reputable online resources; preparation for the emotional impact of CHD; consideration toward fathers' unique needs	country/crowdsourcing **Weakness:** limited racial, ethnic, and linguistic diversity present in the sample, likely due to recruitment method. **Feasibility:** Difficult to recreate because the questions used are not available **Application:** This study shows weaknesses in pre/postnatal education, recommendations can be used to improve practice

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							(4) recommendations were made accordingly	
Demianczyk et al., (2022). Coping strategies used by mothers and fathers following diagnosis of congenital heart disease **Country:** United States **Funding:** Agency for Healthcare Research and Quality, National Institute of General Medical Sciences, Mend a Heart Foundation **Bias:** none	Coping Orientation to Problems Experienced	**Design:** Interview **Method:** mothers (20) and fathers (14) of young children with CHD participated in semi structured interviews focused on their responses to CHD-related stressors **Purpose:** To evaluate coping strategies of mothers versus fathers and prenatal versus postnatal diagnosis	**Sample:** (n=34) **Demographics:** mothers (20) and fathers (14) of young children with CHD aged 1-3 that was transplant free and had undergone cardiac surgery with cardiopulmonary bypass at less than 6 months of age **Setting:** outpatient **Attrition:** 0%	**RQ1:** How do you handle these feelings? **RQ2:** How did that help you to feel better? **Definitions:** coping strategies: actions or behaviors parents reported doing in response to stress or other negative emotions	**Data Collection:** Coping strategies identified from qualitative data and categorized according to the COPE inventory. Coping strategies deemed unique to parenting a critically ill child were identified and evaluated **Data Dependability:** self-reporting	**State Type Used:** Chi squared examined differences in coping strategy endorsement between mothers vs fathers and prenatal vs postnatal diagnosis. Independent sample *t* tests were used to examine group differences in number of coping strategies used.	1. Mothers > fathers focus on and venting of emotions and behavioral disengagements 2. Parents with prenatal diagnosis report a wider variety of coping strategies than parents that received postnatal diagnosis 3. prenatal > postnatal reported positive reinterpretation and growth and behavioral disengagement and denial	**Level of Evidence:** V **Strengths:** Socioeconomic diversity within the sample **Weaknesses:** relied on parents' ability to recall coping strategies 1-3 years following emotionally charged experience. **Feasibility:** This could easily be repeated and possibly improved upon at other institutions **Application:** This shows that mothers and fathers cope differently, mothers more likely to engage in maladaptive strategies. These results can be used to direct parents toward

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								healthy coping strategies
Gramszlo et al., (2020). Supporting parenting during infant hospitalization for congenital heart defect **Country:** United States **Funding:** Institutional Development Award from the National Institute of General Medical Sciences of the National Institutes of Health **Bias:** None	Phenomenology	**Design:** Cohort Study **Method:** participants created deidentified profiles on Yammer and answered 37 open-ended study questions over six months. They could view each other's responses and "like" or comment on them **Purpose:** To characterize the parenting priorities of mothers and fathers of infants hospitalized with CHD and generate	**Sample:** (n=79) **Demographics:** 60 mothers, 19 fathers; all had children that had heart surgery in 1st year of life, 72.2% in the 1st month. 2/3 children hospitalized > 1 month, 49.4% discharged with a feeding tube. 89.9% non-Hispanic White. Children received care in 41 U.S. pediatric hospitals **Setting:** Parents of children with CHD having had surgery within the first year of life	**RQ1:** How did your baby's care team support your participation and involvement with your baby's care in the ICU/hospital? **RQ2:** How do you wish that your baby's care team had supported your participation and involvement with your baby's care in the ICU/hospital? **Definitions:** none provided	**Data Collection:** **Data Dependability:** self-reported data collected after the fact may be skewed or inaccurate. Children were born 1-7 years ago so various time had passed	**State type used:** Cohen's kappa coefficient 0.81-0.90	1. Establishing a bond with my baby 2. Asserting my role as a parent. 3. Coping with fear and uncertainty.	**Level of Evidence:** II **Strengths:** participants had time/space to voice opinions in writing rather than succumbing to a dominant group member (in person) **Weaknesses:** sample was not ethnically or linguistically diverse. Fathers only comprised 24% of sample. Viewing others' responses may have influenced participants before submitting their own responses **Feasibility:** Recommendations for all centers with congenital heart defect programs **Application:** Provide guidelines to improve parent

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Citation	**Theory/ Conceptual Framework**	**Design/ Method/ Sampling**	**Sample/ Setting**	**Major Themes Studied/ Definitions**	**Measurement/ Instrumentation**	**Data Analysis**	**Findings/ Themes**	**Level/ Quality of Evidence; Decision for/ Application to practice. Generalization**
		recommendations to support parenting during infant hospitalization	**Attrition:** 179 invited to participate, 108 participated, 79 completed study					support/participation during hospitalization
Hoffman et al. (2020). Fathers of children with congenital heart disease: sources of stress and opportunities for intervention **Country:** United States **Funding:** Institutional Development Award from the National Institute of General Medical Sciences of the National Institutes of Health **Bias:** None	Phenomenology	**Design:** Cohort Study **Method:** Individuals created deidentified accounts online and answered 37 open-ended questions over 6 months **Purpose:** To examine sources of stress for fathers of children with CHD and opportunities for intervention to prevent or reduce paternal mental health problems	**Sample:** (n= 70) **Demographics:** 25 fathers, 45 mothers **Setting:** Online community reaching 37 pediatric hospitals across the United States **Attrition:** 108 parents responded, 70 of those submitted responses regarding sources of stress for fathers	**RQ1:** What are sources of stress for fathers with children with congenital heart disease? **RQ2:** What are opportunities for intervention for fathers of children with congenital heart disease? **Definitions:** CHD: congenital heart disease	**Data collection:** Data was collected from the larger study and coded by a four-person team with input from the stakeholder advisory council. Responses were further divided to include those regarding fathers and stress **Data Dependability:** self-reported data collected after the fact may be skewed or inaccurate. Children were born 1-7 years ago so various time had passed	**State type used:** inductive thematic approach, focused on subjective perceptions, feelings, and experiences	**RQ1:** •Social expectations for fatherhood and standards of masculinity •Balancing work and family responsibilities •Feeling overlooked as a partner in care •Lack of father supports **RQ2:** •Acknowledge/normalize the impact of CHD of fathers • Provide support for balancing work/family responsibilities • Recognize/promote father knowledge and engagement • Provide formal and informal supports for CHD fathers	**Level of Evidence:** II **Strengths:** participants were diverse regarding U.S. region, education level, and household income **Weaknesses:** the majority identified as non-Hispanic White, leaving most ethnic groups in a severe minority, or not represented at all **Feasibility:** These recommendations should be easy to institute in most large pediatric hospitals with interdisciplinary team access **Application:** Improve support for fathers of infants with

Key: **AVS** Analogic Visual Scale **CHD** Congenital Heart Defect, **CICU** Cardiac Intensive Care Unit, **DV** Dependent Variable, **HLHS** Hypoplastic Left Heart Syndrome, **HRHS** Hypoplastic Right Heart Syndrome, **ICU** Intensive Care Unit, **IV** Independent Variable, **NICU** Neonatal Intensive Care Unit, **PICU** Pediatric Intensive Care Uni **PTSD** Post-Traumatic Stress Disorder, **RQ** Research Question

Citation	**Theory/ Conceptual Framework**	**Design/ Method/ Sampling**	**Sample/ Setting**	**Major Themes Studied/ Definitions**	**Measurement/ Instrumentation**	**Data Analysis**	**Findings/ Themes**	**Level/ Quality of Evidence; Decision for/ Application to practice. Generalization**
								CHD and provide interventions sooner/more effectively to improve their mental health

Key: **AVS** Analogic Visual Scale **CHD** Congenital Heart Defect, **CICU** Cardiac Intensive Care Unit, **DV** Dependent Variable, **HLHS** Hypoplastic Left Heart Syndrome, **HRHS** Hypoplastic Right Heart Syndrome, **ICU** Intensive Care Unit, **IV** Independent Variable, **NICU** Neonatal Intensive Care Unit, **PICU** Pediatric Intensive Care Uni **PTSD** Post-Traumatic Stress Disorder, **RQ** Research Question

Table A3

Synthesis Table

Study (Author, year)	Bainton et al., 2022	Bratt et al., 2019	Kasparian et al., 2019	Kovacevic et al., 2021	Erbas et al., 2023	Werner et al., 2019	Gramszlo et al., 2022	Gramszlo et al., 2020	Hoffman et al., 2020	Demianczyk et al., 2022
Design/ LOE	CS/II	CS/II	MA/I	CS/II	CS/II	CS/II	CS/II	CS/II	CS/II	CS/II
Sample										
n subjects	215	133	339	226	24	120	95	79	70	34
% Mothers	66	unreported	unreported	59	58	59	unreported	75	64	58
Setting										
Prenatal		●		●	●					
Postnatal Inpatient			●			●				
Postnatal Outpatient	●	●	●	●	●		●	●	●	●
United States	●		●				●	●	●	●
Purpose										
Evaluate Mental Health Symptoms	●	●			●	●				
Evaluate Coping Strategies	●									●
Evaluate Recommended Interventions			●							
Develop Recommendations			●		●			●	●	
Evaluate Pre-COVID vs Post-COVID Counseling				●			●			
Identify Parental Needs				●			●			
Identify Parents; Priorities								●		
Identify Sources of Stress									●	

Key: **CS** Cohort Study **LOE** Level of Evidence **MA** Meta-Analysis ↑ - Increased/Improved ↓ - Decreased/Worsened ↕ - No Significant Change

Study (Author, year)	Bainton et al., 2022	Bratt et al., 2019	Kasparian et al., 2019	Kovacevic et al., 2021	Erbas et al., 2023	Werner et al., 2019	Gramszlo et al., 2022	Gramszlo et al., 2020	Hoffman et al., 2020	Demianczyk et al., 2022
Tool Used										
Impact of Event Scale	•									
Life Stress Inventory	•									
State-Trait Anxiety Index	•		•							
Pediatric Inventory for Parents	•									
Coping Health Inventory for Parents	•									
Family Inventory of Resources for Management	•									
Inventory of Parents' Experiences	•									
Hospital Anxiety and Depression Scale		•			•					
Life Satisfaction Scale		•								
Analogic Visual Scale						•				
COPE Inventory							•			
Open Ended Questionnaire							•	•	•	•
Other/Unnamed				•						
Outcomes/ Themes										
PTSD	↑			↑						
Depression			↕		↑			↑		
Anxiety			↓	↑	↑	↑		↑	↑	
Bonding			↑					↓	↓	
Satisfaction		↓					↑	↓	↓	↑

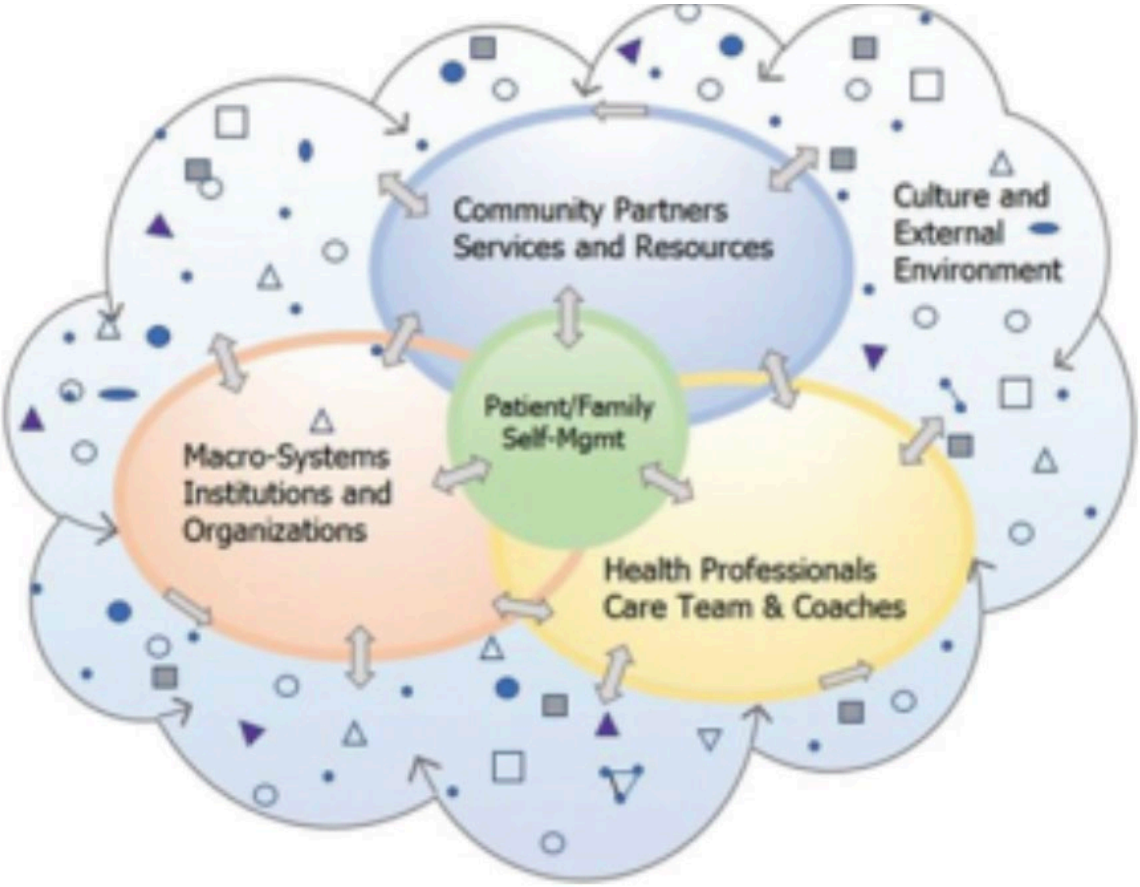
Key: **CS** Cohort Study **LOE** Level of Evidence **MA** Meta-Analysis ↑ - Increased/Improved ↓ - Decreased/Worsened ↕ - No Significant Change

Appendix B

Models and Frameworks

Figure B1

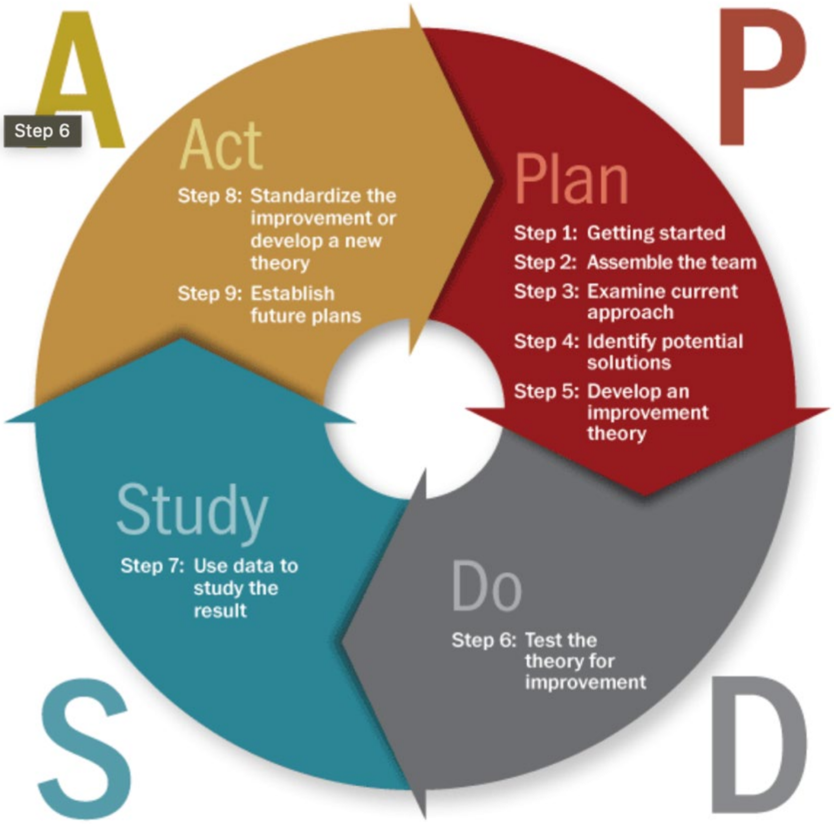
Complex Care Model



(Gilman, 2021)

Figure B2

Plan-Do-Study-Act Framework



(Tribal Evaluation Institute, 2016)

Appendix C

Table 1

Inclusion and Exclusion Criteria Determination Document

Is patient less than 30 days old?

Yes – continue
No – disqualified

Did the patient have a fetal/prenatal diagnosis of congenital heart defect?

Yes – continue
No – disqualified

Did Phoenix Children's Fetal Cardiology provide prenatal cardiac care?

Yes – continue
No – disqualified

Was the patient admitted to Phoenix Children's CVICU or CICU directly from birth hospital?

Yes – continue
No – disqualified

Has the patient had cardiac surgery or interventional cardiac catheterization within the last 7-10 days?

Yes – continue
No – not disqualified yet, reevaluate for future participation

Was the patient's only cardiac catheterization procedure a balloon atrial septostomy?

Yes – disqualified
No – continue

Is the patient deceased?

Yes – disqualified
No – continue

Is at least one parent available at bedside?

Yes – continue
No – reevaluate in the future for participation

Is the potential participant over the age of 18?

Yes – continue
No – disqualified

Does the potential participant speak, read, and write English?

Yes – continue

No – disqualified

Table 2

Caregiver Perceived Satisfaction with Prenatal Counseling After CHD Diagnosis

Participant Age ______

Gestational age (in weeks) when congenital heart defect was detected ___________________

Time from initial detection to first fetal cardiology appointment (approximately) _____________

Congenital heart defect diagnosis made by fetal cardiologist _____________________________

Did your child have additional congenital defects or abnormalities diagnosed prior to birth?

No ______ Yes (please list) ____

Did your child have any chromosomal abnormalities or syndromes diagnosed prior to birth?

No ______ Yes (please list) ____

Number of previous pregnancies _______ Number of living children _______

Name of surgery or catheterization your child had _____________________________________

Age of child at time of surgery or catheterization ______

Days since surgery or catheterization ______

Gender Identity
- Male
- Female
- Nonbinary
- Transgender MTF
- Transgender FTM
- Prefer not to disclose
- Other: __________

Relationship to the Patient
- Mother
- Father
- Stepmother
- Stepfather
- Grandparent
- Other: _________

Race
- Asian/Pacific Islander
- Black/African American
- Hispanic/Latino
- Native American/Alaskan Native
- White/Caucasian
- Prefer not to disclose
- Other: __________

Primary Language Spoken at Home
- English
- Spanish
- French
- Prefer not to disclose
- Other: ___________

Marital Status
- Married
- Living with child's other parent but not married
- Not living with child's other parent
- Single
- Widowed
- Divorced
- Other: ___________________

Level of Education
- Less than high school
- High school diploma/GED
- Some college
- Associate's degree or technical certificate
- Bachelor's degree
- Graduate School/Doctoral degree

Interdisciplinary specialties interacted with during fetal appointments (select all that apply):
- Fetal cardiology
- Cardiac surgery
- Nurse coordinator
- Social work
- Palliative care
- Psychology
- Lactation specialist
- Other: ________

22 Question Survey

The following are statements regarding your prenatal care. We would like you to indicate your opinion after each statement by putting an "x" in the box that best indicates the extent to which you agree or disagree with the statement.

	Strongly Agree 5	**Agree 4**	**Neutral 3**	**Disagree 2**	**Strongly Disagree 1**
1. After my visit with the fetal cardiologist, I understood my child's heart defect.					
2. At my visits with members of the fetal care team, my concerns were addressed.					
3. Information about my child's heart defect was presented to me in a way that was easy to understand.					
4. My grief and loss were acknowledged by the fetal care team.					
5. The fetal care team prepared me for the complexity of my child's future medical care.					
6. Pictures used to explain my child's heart defect were helpful for my understanding.					
7. Photos used to explain the surgical repair for my child were helpful for my understanding.					
8. The fetal care team gave me support and/or resources to enhance my other children's and/or extended family's understanding.					
9. The care team respected my choice for surgical intervention.					
10. The impact that my child's congenital heart defect would have on me and my family was clear.					

11. Prenatal peer support offered or recommended by the care team helped me cope with my child's diagnosis.					
12. I felt prepared for my child's birth and transfer to the cardiovascular intensive care unit (CVICU).					
13. I felt that my prenatal care team understood me and my family.					
14. I felt I could share my stress and coping with the prenatal care team.					
15. I was prepared for the hospital or intensive care unit. This includes equipment, routines, and expectations.					
16. I was prepared for what my baby would look like or have connected/attached to them shortly after birth by the prenatal care team.					
17. I was prepared for what my baby would look like or have connected/attached to them after their surgery or cath by the prenatal care team.					
18. I felt prepared for potential complications in my child's care by the prenatal care team.					
19. I was prepared for parenting a baby in the hospital or intensive care unit.					
20. I felt prepared by the prenatal care team to be included in my baby's care in the hospital or intensive care unit.					

Please answer the following questions in the space provided. If more space is needed, please continue on the back.

1. *Knowing what you know now, what advice would you give other parents after a fetal diagnosis of congenital heart defect?* ____
   ____

2. *What was most and least helpful during your prenatal appointments?*
   ____
   ____

Appendix D

Table 1

Descriptive Statistics for Age

Variable	*M*	*SD*	*n*	Min	Max
Subject Age in Years	30.00	5.77	7	23.00	38.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Table 2

Frequency for Demographic Variables

Variable	*n*	%
Gender Identity		
Female	4	57.14
Male	3	42.86
Race		
Hispanic/Latino	3	42.86
White/Caucasian	4	57.14
Level of Education		
Less Than High School	2	28.57
High School/GED	1	14.29
Bachelor's Degree	2	28.57
Graduate/Doctorate Degree	2	28.57
Marital Status		
Not Married/Cohabitating	3	42.86
Married	4	57.14
Primary Language		
English	6	85.71
English/Spanish	1	14.29
Relationship to Patient		
Mother	4	57.14
Father	3	42.86

Note. Due to rounding errors, percentages may not equal 100%.

Table 3

Frequency for Diagnosis and Interventional Variables

Variable	*n*	%
Fetal Diagnosis		
Does Not Remember	4	57.14
Shone's Complex	2	28.57
Coarctation of Aorta	1	14.29
Additional Congenital Anomalies		
None	7	100.00
Chromosomal Abnormalities		
None	5	71.43
Yes	2	28.57
Name of Intervention		
Does Not Know	4	57.14
Valvuloplasty, Arch Repair	2	28.57
Arch Repair	1	14.29

Table 4

Frequency Table for Nominal Variables

Variable	*n*	*%*
Cardiac Surgery		
no	2	28.57
yes	5	71.43
Palliative Care		
yes	1	14.29
no	6	85.71
Nurse Coordinator		
yes	1	14.29
no	6	85.71
Fetal Cardiology		
no	2	28.57
yes	5	71.43
Social Work		
yes	1	14.29
no	6	85.71
Lactation Specialist		
yes	3	42.86
no	4	57.14

Note. Due to rounding errors, percentages may not equal 100%.

Table 5

Summary Statistics Table for Interval and Ratio Variables

Variable	*M*	*SD*	*n*	Min	Max
Satisfaction	92.86	12.06	7	68.00	100.00
Education	58.00	2.58	7	53.00	60.00
Preparedness	34.86	9.67	7	15.00	40.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.