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## Impact of a Parent Education Program on Parents of Children with Complex Congenital Heart Disease Prior to Discharge Home

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Impact of a Parent Education Program on Parents of Children with Complex Congenital Heart  
Disease Prior to Discharge Home

Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Nursing  
Practice at the University of Kentucky

By

Laura Elkhoury

Louisville, KY

2023

## **Abstract**

**Background and Purpose:** Children with complex medical needs, such as children with complex congenital heart disease, are at risk for hospital readmission, morbidity, and mortality related to disease complications. Parents must be adequately prepared to care for their children following hospital discharge to prevent hospital readmission and complications. This study seeks to evaluate the impact of an education intervention on parental knowledge and stress related to caring for their child with complex medical needs.

**Methods:** The study design is a quasi-experimental, nonequivalent control pre-test/post-test design. The pre-test was administered prior to the educational intervention, with the post-test administered one week following the intervention. The data was analyzed using IBM SPSS software version 28. Parental knowledge was analyzed using Wilcoxon signed-rank test. The impact of the intervention on parental stress and perceived parental benefit were analyzed using descriptive statistics.

**Results:** A total of three parents participated in the study. There was no statistically significant difference in the results of the pre and post-test. The study noted a qualitative impact on perceived parental stress and parental benefit.

**Conclusions:** Assessment of parental knowledge in the complex congenital heart disease population is challenging, but crucial to complete prior to patient discharge. The impacts of a parent education program in this population may be beneficial based on impacts on parental stress and parent verbalization of benefits. Future studies should focus on long-term effects of parent education programs with a larger sample size to accurately determine impact.

## **Dedication**

This project is dedicated to my family, friends, and the patients I care for at work. The completion of this project would not have been possible without the support of my parents, grandmother, brothers, fiancé, and friends. Thank you for believing in me and supporting me through these past three years. Completing this project would not have been possible without your continued support and belief in my abilities. I would also like to thank everybody at work who has supported me through countless night shifts, helped with schedule changes, and encouraged my work with this project. I work with the most special people, and I am so grateful for everybody's encouragement.

The inspiration for this project comes from my work in the Cardiac Intensive Care Unit (CICU) at Norton Children's Hospital. Every patient I have cared for inspires me through their resilience and strength, and my work is dedicated to ensuring their future is bright with the best outcomes possible.

## **Acknowledgements**

This work would not have been possible without the support of my advisor, committee members, and Dr. Amanda Thaxton Wiggins. Thank you to my advisor, Dr. Leslie Scott, who has supported and guided me through my DNP program and project. I am thankful for the Zoom meetings, words of encouragement, and support throughout this program. My committee member, Dr. Cameron Stephenson, has supported me during clinical courses. I am grateful for his support, feedback, and encouragement during clinical.

My work with my clinical mentor, Dr. Misty Ellis, began before my time in the DNP program. I am thankful I had the opportunity to learn from her during our time working together in the CICU at Norton Children's Hospital. Her dedication to cardiac patients and nursing education, as well as quality improvement in the CICU have inspired me in my work as a nurse as well as a DNP student. I am grateful I have continued to learn from her during the development of this project. Her feedback during the beginning stages of this project encouraged me to continue and develop this project into what it is today.

The help of Dr. Thaxton Wiggins was integral in completing the statistical analysis of this project. I am grateful she took the time to meet with me, provide feedback, and ensure this portion of my project accurately depicts my work. Her kindness and support were crucial in completing the final steps of this project.

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# Impact of Parent Education Program on Parents of Children with Complex Congenital Heart Disease Prior to Discharge Home

## **Introduction**

Children with complex medical needs must be adequately cared for while at home following hospital discharge. Children born with congenital heart disease (CHD) require education specific to their anatomical defect to ensure parents understand the importance of interventions performed as well as medication and equipment management. The development of this parent education program seeks to provide education for parents of children with complex CHD as well as evaluate the impact on their knowledge level and anxiety related to caring for their child.

Following discharge, parents must feel confident in their abilities to recognize warning signs that indicate their child may need emergency care. Without proper medication administration and follow-up, children with CHD are at an increased risk of mortality (Best et al., 2019). Parent education in the complex CHD patient population must be enhanced to improve patient prognosis and decrease the risk of mortality related to inadequate disease treatment.

## **Background and Significance**

According to the Centers for Disease Control and Prevention (CDC) (2020), 1% of newborns in the United States have some form of CHD. Of this population, 25% have a critical defect requiring surgical intervention in their first year of life. This leads to the child requiring medical care that can become increasingly complex. Children with CHD who require special healthcare needs comprise 60% of children within the United States, and this care must be continued while they are outside of a medical setting; this is in comparison to only 20% of children without heart disease that have special healthcare needs (Chen et al., 2016). Children are

vulnerable to the ability of their parents or caregivers to be educated and be able to properly care for them as they are cognitively and physically unable to care for themselves alone. Without having proper education, the child is at risk for morbidity and mortality related to ineffective disease management.

In order to prevent complications secondary to ineffective disease management, parents must receive necessary education while their child is hospitalized. Consequences of inadequate parental education are related to medication and feeding management. Complex discharge instructions, such as those requiring administration of multiple medications or follow-up appointments, have been associated with parental errors (Glick et al., 2017). Inability to recall information related to medication dosing or importance of administering medications according to the prescribed schedule puts the child at risk for complications related to these errors. In addition, infants with CHD are at an increased risk of weight loss and failure to thrive. In an analysis of the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC), 75% of infants were found to be at risk for poor weight gain or failure to thrive following stage one palliation (Moza et al., 2021). Poor weight gain is associated with prolonged hospitalizations, increased use of medications, and morbidities (Moza et al., 2021).

Readmission rates in patients with complex CHD have been found to be two to four times higher than patients with simple CHD, with readmission often occurring within the first two weeks following discharge (Islam et al., 2016; Mackie et al., 2008). Additional factors related to hospital readmission include age at discharge and length of initial hospital stay, with infants being at high risk of readmission (Islam et al., 2016). It should be noted that there is a gap in the literature related to modifiable factors contributing to hospital readmissions given the complexity of care in this population.

In addition to morbidity related to disease complications, children with complex CHD are at risk for mortality following stage one palliation, termed interstage mortality. Congenital heart surgeries are categorized based on complexity and risk of mortality following the procedure; the Society of Thoracic Surgeons-European Association for Cardio-Thoracic Surgery (STAT) score is a tool used to assess this risk and complexity (O'Brien et al., 2015). Operations are categorized one through five, with category one having the lowest risk of death and category five having the highest risk (O'Brien et al., 2015). Stage one palliative surgeries, such as the Norwood procedure, is a STAT category five, indicating single ventricle patients in this stage are at the highest risk of mortality. An analysis of single ventricle patients discharged home following stage one palliation found that over half of the deaths occurred at home or in the emergency department; 20% and 33%, respectively (Ahmed et al., 2021). Identified barriers related to mortality occurring outside of the intensive care setting include familial and socioeconomic challenges, distance from surgical center and lack of competency with caregiving (Ahmed et al., 2021). These findings indicate significant consequences for patients with complex, single ventricle physiology, as they are at a great risk of mortality while at home following stage one palliation.

Parent education in the cardiac intensive care unit (CICU) is typically the responsibility of the bedside nurse and can be overwhelming due to the nature of an intensive care setting; time constraints and lack of personal knowledge related to the parents' education needs can contribute to inadequate education while the child is hospitalized. Standard bedside education is often met with barriers, including the stressful environment of the ICU and inconsistencies due to caregiver responsibilities outside of the hospital. An analysis of discharge education and preparation in the neonatal intensive care unit found that the most significant barriers impacting discharge

readiness were related to communication, lack of parental engagement, and insufficient resources (Raffray et al., 2014). Data specific to education in the CHD population is limited; however, Newall et al. (2008) and Goossens et al. (2014) have found that structured education programs improve parent and patient knowledge of their disease and management. These education programs are provided in addition to standard bedside education to further increase parental knowledge.

### **Purpose and Objectives**

To overcome barriers related to the intensive care unit, parent education should be done in an environment that is conducive to learning. The typical setting in which parents receive most of their education currently is the intensive care unit, which is stressful due to the high stimulation. The intensive care unit is considered a high stress environment as it is unfamiliar and patients are often impacted by several stressors, such as lack of control, unfamiliar and unusual noises, unexpected changes, and presence of unfamiliar medical devices (Gültekin et al., 2018). Parents are further impacted by loss of control, helplessness and their role change as a caregiver (van den Hoogen & Ketelaar, 2022). As the intensive care unit has been demonstrated to be a source of psychological distress, it can be challenging for parents to understand and process what they are taught. This is significant as a lack of knowledge can be detrimental to patients if their parents do not understand their discharge instructions.

### **Purpose**

The introduction of a Parent Education Program for parents of children with complex CHD at Norton Children's Hospital provided parents with an additional opportunity to learn about their child's disease and requirements of their care. This education was provided in a quiet environment away from their child's bedside to ensure the parents were able to process the

information and ask questions throughout. This intervention was completed with the goal of increasing parental knowledge and confidence in caring for their medically complex child following discharge home.

## **Objectives**

The CHD Parent Education Program aimed to provide education to at least 80% of CHD parents until time of discharge, ensure parents exhibited a 30% increase in knowledge at the end of hospitalization from baseline, and verbalized decreased stress in caring for their child following completion of the program. The specific outcomes to be accomplished included increased parental knowledge and decreased parental stress.

## **Literature Review**

### **Search Strategies**

The question of focus for research was, “In parents of children with complex congenital heart disease, how does a structured parent education program, compared with standard bedside education, impact parental knowledge prior to discharge?” Database searches of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed were used, using keyword and title search. Search keywords included ‘single ventricle’ and ‘parent education,’ as well as ‘congenital heart disease’ and ‘education’ for additional data. The initial search yielded 26 articles, which was expanded to 318 articles with the use of alternate keywords. Exclusion criteria were articles that were published prior to 2012, not written in English, and those focusing on education specific to fetal ultrasonography and detection of CHD. Parent education within the overall congenital heart disease population were included given limitations in literature specific to complex CHD. A total of seven articles were selected for review.

## Summary of the Literature

The studies evaluated educational interventions in the United States, China, Belgium, India, and Australia. Sample sizes ranged from 20-317, with the population focus ranging from simple congenital heart defects to complex physiology. Two of the studies assessed parental knowledge of their child's heart defect using interactive media and videos (Ha et al., 2018; Zhang et al., 2020). Structured education programs were the focus of four of the studies; these studies evaluated parent education that was provided inpatient by nurses using a combination of handouts and verbal discussion. Education prior to discharge was the focus of most studies, however, one study evaluated outpatient education sessions (Goossens et al., 2014). Discharge programs were specifically assessed in three studies (Ni et al., 2016; Nieves et al., 2017; Staveski et al., 2015), with only one providing additional training to nurses for more consistent discharge education (Staveski et al., 2015). Mannarino et al. (2020) was the only study that evaluated day of discharge bedside education using handouts.

Education provided over the course of hospitalization, as opposed to one session, contributed to parental satisfaction and confidence; education provided on day of discharge was found to be “overwhelming” and parental questions were not always answered (Mannarino et al., 2020). The combination of parent education, home surveillance monitoring and follow-up phone calls, has led to a decrease in mortality for infants with hypoplastic left heart syndrome (Nieves et al., 2017). A combination of methods has been shown to be effective when discussing the child's care, particularly when care is complex and requires interdisciplinary collaboration.

A summary of the evidence shows that structured parent and patient education lead to increased knowledge and self-efficacy. Two randomized controlled trials were included; however, they were limited by their small sample sizes and evaluation of simple cardiac defects

(Ha et al., 2018; Zhang et al., 2020). The remaining studies consisted of qualitative studies, descriptive studies, and non-randomized controlled trials (Goossens et al., 2014; Mannarino et al., 2020; Ni et al., 2016; Nieves et al., 2017; Staveski et al., 2015). The literature lacks strong, systematic reviews or meta-analyses of best practices in parent education for complex CHD patients.

### **Current State, Desired State and Gaps in Practice**

The approach to parent education varies among cardiac centers, leading to inconsistencies in the literature. Data specific to the complex CHD population is limited and is often excluded due to medical complexity (Mannarino et al., 2020). Providing education specific to the heart defect and treatment alone was noted in several studies (Ha et al., 2018; Zhang et al., 2020). This provides challenges when seeking to assess parental knowledge of their child's care post discharge. Additional education related to management of the defect is not always indicated due to the lack of complexity and decreased need for frequent follow-up following repair. Future research and interventions should focus on complex heart defects, as these defects are addressed infrequently in the literature, but often require more thorough and frequent interventions.

The complex CHD population has complicated needs that require parental preparedness and knowledge when discharged home; however, data related to parental knowledge in this population is limited. To address parental education needs, the intervention provided must be specific to the complexity of care required. The CHD Parent Education Program seeks to provide education based on the learner's preferred method in a private room to support long-term retention of the information and parental confidence.



## **Conceptual Framework**

Implementation of the CHD Parent Education Program was guided by The Iowa Model, which was developed to transform research, practice, and education. The first step of the model is identification of the problem and “triggers” indicating change is necessary (Brown, 2014). The problem has been identified to be a problem within the organization, as documentation of parent education is a challenge among nursing. This may be due to several barriers, such as nursing time constraints and availability, nursing knowledge of the heart defect, and parental barriers. These barriers contribute to delayed parent education, when ideally education is completed throughout the patient’s hospitalization. As a result of these barriers, formation of a plan and implementation of the program to improve parent education was indicated. This project provides additional education for parents away from the bedside. This opportunity will ideally address barriers related to nursing and parent availability. The evaluation consists of ensuring the program is effective and realistic to integrate into practice within the CICU at Norton Children’s Hospital. With adequate resources and support of staff, the implementation of this education program will be realistic.

## **Methods**

### **Design**

To address the needs of parents of children with complex congenital heart disease (CHD), the CHD Parent Education Program provided an educational intervention using a quasi-experimental, nonequivalent control pre-test/post-test design. The pre-test administered prior to the educational intervention identified specific education needs and gaps in knowledge, while the post-test administered assessed the effectiveness of the intervention. The post-test was administered one week following the intervention to assess retention of the information. Parental

satisfaction and perceived impact on stress were assessed immediately following the intervention.

## **Setting**

### **Agency Description**

The study took place in the Cardiac Intensive Care Unit (CICU) at Norton Children's Hospital in Louisville, Kentucky. The CICU is a part of Norton Children's Heart Institute, which provides specialized cardiac care for children throughout Kentucky and Southern Indiana. Through collaboration with the National Pediatric Cardiology Quality Improvement Collaborative, Norton Children's Heart Institute seeks to "improve outcomes and quality of life for newborns with single ventricle heart defects" ("Norton Children's Heart Institute," 2021). Specialized care is provided for patients with complex CHD and includes medical management as well as cardiac procedures, which may include cardiac catheterizations, surgeries, and extracorporeal membrane oxygenation. Throughout their hospital stay, parents must be educated to ensure they understand the procedures performed as well as the impacts on medical management as their child begins to meet criteria for discharge. Adequate discharge education is crucial for parents, and parental knowledge is supported with the use of teach-back programs such as "Homeward Bound," which is utilized in the CICU. Homeward Bound is a program used to assess parental discharge readiness and is often initiated for 24-48 hours during the weekend prior to discharge. During this program, parents are required to demonstrate complete readiness for discharge; they are responsible for being knowledgeable about all aspects of their child's care, such as being able to administer all medications and feedings correctly. Homeward Bound requires parents to demonstrate readiness and nurses to provide education when deficits are noted; it is a crucial component of discharge preparedness for complex CHD patients.

## **Project Congruence**

The CHD Parent Education Program aligns with Norton Children's Heart Institute mission of improving outcomes and quality of life for patients with single ventricle heart defects ("Norton Children's Heart Institute," 2021). The education program sought to ensure parents are prepared and confident in providing care for their medically complex child following discharge. The program focused on education related to the child's heart defect, procedures, medications, and any equipment used for feeding. The skills and knowledge obtained during the classes serve as a foundation for discharge education and can be assessed as the patient is preparing for discharge.

## **Stakeholders**

The involvement of the principal investigator (PI), as well as the DNP project committee, nurses, management, CHD patients and parents as stakeholders were crucial for the success of this project. The PI was responsible for identifying parents for education as well as providing the education intervention. The DNP project committee includes Dr. Leslie Scott as the Committee Chair, Dr. Misty Ellis as the Clinical Mentor, and Dr. Morgan Chojnacki as Committee Member. Cardiovascular (CV) clinicians and outpatient CV providers work closely with the families throughout the patient's hospitalization and provide support following discharge; thus, they are crucial stakeholders for this project.

If the education intervention is sustainable long-term, this will aid the nurse clinicians in their discharge readiness education. Within the CICU, nursing support from bedside nurses was crucial as they are at the bedside to provide additional education before and after the intervention. The nurse manager of the CICU was a crucial stakeholder as their support is required if changes are made to the education methods used. The primary stakeholders in this

project include patients with complex CHD and their parents; their support and participation in the project made this intervention successful.

### **Facilitators and Barriers to Implementation**

The CICU within Norton Children's Hospital is a supportive learning environment that strives to improve quality of patient care and outcomes through facilitation of educational opportunities and interdisciplinary collaboration. Nursing education and updates are provided frequently to ensure interventions performed are evidence based; this will support the initiative of the CHD Parent Education Program in improving parent education. Interdisciplinary collaboration is crucial to ensure the patient is prepared for discharge and requires the collaborative work of the surgeons, providers, respiratory therapists, pharmacists, and dieticians. This effort is emphasized with team rounding, which occurs daily and addresses the patient's plan. The common goal is recovery to support the patient being discharged home safely.

Prior to beginning the project, the PI considered potential barriers to implementation. These barriers included the complexity of CHD patients, participant involvement, and time constraints. Every parent in the CICU must receive discharge education, however, this education varies depending on their child's defect and any other comorbidities. To decrease the impact of this barrier, the intervention allowed parents to have adequate time to seek information specific to their child. Participant involvement in the program is crucial, however, census of CHD patients in the CICU prior to their first discharge home varies. The program relies on parental willingness to participate, but personal barriers may prevent them from doing so. Parents may be unwilling or unable to participate due to responsibilities such as their jobs or other children. Time constraints should be considered for both parents and staff educators as discharge education can be complex and requires adequate time for the learner. For long term

implementation, this project requires staff willingness to dedicate time outside of their required work hours to provide additional parent education.

### **Sample**

The population for the study consisted of a convenience sample of eight parents of children with complex CHD preparing for discharge during the months of November and December 2022. These defects were not limited given there are many combinations of defects contributing to the complexity of their anatomy. Parents over the age of 18 and all education levels were included to ensure all parents have equal opportunity to receive education specific to their child's care. The inclusion of vulnerable populations, such as women, minorities, and parents with lower educational attainment were crucial to address potential barriers within this population.

Due to the specificity and complexity of the topics addressed within the intervention, exclusion criteria include parents of children with simple CHD and other chronic illnesses, such as asthma or diabetes mellitus. Simple defects include ventricular septal defect, atrial septal defect, patent ductus arteriosus, which would be categorized as STAT one; however, these were only excluded if the defects occur in isolation and do not contribute to more complex physiology. The intervention focused on improving outcomes in children with complex CHD and additionally excluded patients whose parents have decided to cease further surgical treatment or withdraw life sustaining care.

A total of eight parents met the inclusion criteria for the study during the time of data collection. The participants were selected based on the complexity of their children's defects, which included transposition of the great arteries, hypoplastic aortic arch with ventricular septal defect and Tetralogy of Fallot with pulmonary atresia, and hypoplastic left heart syndrome. Of

these patients, two were preparing for discharge during the time of the study and had parents available at the bedside to discuss the project. Due to the nature of the education intervention, parents were not approached if their child was not identified as being in the process of preparing for discharge, or if their discharge plans changed during the data collection period. Examples include patients requiring the use of inotropes for blood pressure stability and patients requiring mechanical ventilation. Of the population identified, four parents met the inclusion criteria of the study and were eligible for enrollment. The sample population enrolled four parents and three parents participated in the study.

## **Procedure**

### **IRB Approval**

Prior to beginning the study, approval was obtained from the Norton Healthcare Research Office and Institutional Review Board (IRB) and the University of Kentucky IRB. Subsequently, permission to access patient data via the electronic health record was obtained through the Norton Research Office.

### **Evidence-based Intervention**

The intervention was developed using the idea of structured parent education, which was found to be effective in several studies (Goossens et al., 2014; Newall et al., 2008; Ni et al., 2016; Staveski et al., 2015). It should be noted that this study focused on the complex CHD population, which is excluded from most studies due to complexity. The intervention consisted of three components, which included: 1) a pre-test consisting of five questions to assess baseline parental knowledge, 2) an education intervention focusing on important aspects of care following discharge, 3) a post-test consisting of the same five questions, administered one week following the intervention and 4) a survey (see Appendix A). The education material and assessment of

parental knowledge were evaluated for accuracy and to establish content validity by an advanced practice provider with extensive experience in the management of children with CHD in critical care. The survey sought feedback focusing on the format and content of the questions, the education intervention, and ways to improve in the future. The survey was administered immediately after the intervention, and time was allotted for discussion at the end.

The education intervention consisted of a PowerPoint and hands on learning. The PowerPoint consisted of both general information as well as patient specific information (see Appendix B). General information included a brief overview of normal human anatomy and physiology, important signs and symptoms to monitor for, sternal precautions, and important reminders. Given the importance of monitoring for specific findings common in the complex CHD population, four slides focused on common concerns with visuals including photo and video. For example, videos of respiratory distress were included to allow parents to understand what is meant by terminology often utilized by providers and nurses, such as retractions and tachypnea. Patient specific information was modified for each patient and included detailed information about their heart defect, the surgery performed, how their anatomy differs in comparison to normal pediatric anatomy, and important things to know about their defect (see Appendix B). Throughout the PowerPoint presentation, time was allotted for questions. For example, for each concerning symptom, the PowerPoint transitioned to questions for the participants such as, “What do you see happening here? Why do you think this is concerning?” This allowed for discussion of the concerns, emphasis of why it is important for their child specifically, and assessment of participant understanding throughout the presentation.

Following the PowerPoint presentation, a hands-on portion was included based on the participant education needs. Specific education needs among the CHD parent population include

practice with devices such as nasogastric or gastric tubes for medications and feedings, administration of medication via subcutaneous injection, and practice with feeding supplies. Prior to the intervention, information via the patient chart was obtained to evaluate the needs of the participants. For example, one participant required hands-on practice for gastric tube maintenance and administration of feedings and medications, as well as practice administering subcutaneous enoxaparin. Practice materials were obtained from the CICU education department to allow the participant to practice following demonstration of use.

### **Measures and Instruments**

Demographic variables were obtained from the participants during the pre-intervention survey; this data includes their age, ethnicity, marital status, and educational level (see Appendix A). Demographic data was obtained for statistical analysis of the variables to assess for trends in the data. Patient specific data obtained via chart audit includes their age, gender, heart defects, and surgical interventions that have been performed. This data was significant to obtain to ensure the material taught to the parents was appropriate to their child. Permission to access their child's chart was obtained via informed consent.

Outcome measures focus on parental knowledge and satisfaction with the program, and parental stress. Parental knowledge was assessed by evaluating the scores and answers of the pre-test in comparison to the post-test. Parental satisfaction and perceived impact on stress were assessed with the post-intervention survey.

### **Data Collection**

Once eligible participants were identified, informed consent was obtained following discussion of the project and its purpose. The class was scheduled based on the availability of the participants and included options on the weekends as well as in the evenings. This was intended



to reduce potential barriers related to responsibilities outside of the hospital. The duration of the class was estimated to be approximately one hour, with up to one additional hour allotted for discussion as well as questions or concerns by the participants.

The intervention was completed in the conference room of the CICU. This room is often utilized as a meeting room for various purposes as it is a large space equipped with a computer and large display screen, tables, and chairs. The room is located away from the patient area of the CICU and was specifically chosen as the location for the class to allow for uninterrupted time and privacy. The intervention began with an introduction to the class and time for completing the pre-test and demographic survey. Participants were encouraged to answer all questions to the best of their ability.

Following completion of the pre-test and demographic survey, the PowerPoint presentation was shown. The PowerPoint presentation addressed all topics addressed in the pre-test. Following the presentation, the hands-on portion allowed for participants to practice necessary skills. Questions were encouraged throughout all portions of the class to emphasize understanding prior to continuation. One week following the intervention, the post-test results were obtained. This time frame allowed for assessment of retention of the information, as opposed to rote memorization following the class.

### **Data Analysis**

All three participants completed all aspects of the intervention, including the demographic survey, pre-test, and post-test. Two participants completed the post-test at seven days following their education intervention. One participant completed the post-test at nine days following the education intervention due to work responsibilities and inability to complete the test when provided on day seven.

The demographic data and post-intervention survey were analyzed using descriptive statistics including means, medians, and percentages. Wilcoxon Signed-Rank test was used as a non-parametric statistical analysis given the small sample size to assess the change of results between the pre and post-test. Statistical analysis was performed utilizing SPSS version 28, with statistical significance being determined with the p-value being less than or equal to 0.05.

## **Results**

### **Demographics**

The study consisted of three participants, who were parents of infants with CHD; one married couple and one mother ( $n= 2$  infants included). The majority of parents were ages 26-30 years (67%) and were Caucasian (67%), as well as had a four-year degree (67%) (see Table 1).

### **Findings**

The results showed the pre-test scores had a mean of 50.67 ( $SD= 21.6$ ) and ranged from 26-66%. The post-test scores showed an improvement, with the mean being 78.3 ( $SD= 11.5$ ) and range from 65-85%. There was no statistically significant difference between the test results ( $p= 0.285$ ; see Table 2). An analysis of each test question was done to determine if there were differences based on the question (see Table 2). Based on the test question scores, each question had an improved score from the pre-test. An analysis of the questions showed that question #2 had the lowest scores (38.6% for the pre-test, 50% for the post-test).

Parental satisfaction with the class, impact on stress, and preferred learning methods were also assessed. All three participants (100%) stated the class was beneficial, as well as decreased the stress they felt. All three participants (100%) felt the education was provided in a way that was easy to understand. 67% of participants preferred a combination of learning methods (reading and doing), while 33% of participants prefer only “doing” as their learning method. The

question, “How can this class be improved?” was open-ended to allow participants to provide feedback regarding the class. One participant noted, “Videos of how the heart operates, and the surgery itself... for those who are not as involved.” Another participant did not have feedback specific to the class and noted, “It was great. Very wonderful experience. Thank you.” Another participant stated, “Have more often.”

### **Discussion**

This study sought to improve knowledge and decrease stress levels in parents preparing for discharge from the CICU with their medically complex child. The results of this study should be interpreted with the understanding that the sample size was small ( $n=3$ ), which may lead to bias. Further studies are required in order to accurately assess the impact of a parent education program in the complex CHD population.

#### **Parental knowledge**

Analysis of the pre-and post-test data shows a mean improvement following the intervention. The pre-test scores had a mean of 50.67 ( $SD=21.6$ ) and the post-test scores had a mean of 78.3 ( $SD=11.5$ ). The post-test scores were set to be completed at seven days following the intervention, however, one post-test was completed at nine days related to participant inability to complete the test at the set time. These results were shown to have no statistical significance ( $p=0.285$ ).

Prior to administration of the pre-test, content validity was verified by Misty Ellis, CPNP-AC/PC. Test questions focused on key components of post-discharge care for complex CHD patients and addressed topics such as the patient’s heart defect, medication management, and signs and symptoms to monitor for. The answers were graded based on key words being included in the answer; for example, 0.33 or 0.5 points being given if some components were

addressed. For the question, “what should you do if a medication dose is missed?” the key words assessed in the answer were “call” and “clinician,” with partial points being given if the answer did not include “clinician,” or included another member of the care team, such as the doctor. Question #2, “what are three important things to remember when caring for your child at home?” was noted graded based on key words such as “missed medication doses,” “scheduled appointments,” and signs and symptoms to monitor for. All participants correctly identified signs and symptoms to monitor for, but received partial points as they did not include “keep all scheduled appointments,” or “call with any medication questions or missed doses.” These partially correct answers are likely related to the wording of the question itself. Future assessments of knowledge related to these topics should be assessed using more specific wording.

### **Impact on parent stress**

All participants (100%) verbalized decreased stress following the intervention. Discussion following the intervention allowed parents to provide feedback related to the intervention itself, including method of delivery, location, and timing with discharge education. Assessment of preferred methods of learning were crucial prior to the intervention as the intervention used combined methods for learning (reading and doing), which were the preferred methods for 67% of the participants. One participant (33%) preferred “doing” as their learning method, which was included at the end of the presentation.

The feedback provided was positive overall, and the parents expressed appreciation for the opportunity to participate in the program. The qualitative impact of the program, which are the overall impact on parental stress and helpfulness of the intervention, are significant based on parent statements including, “have more often,” and “very wonderful experience.” The value of

additional education in the complex CHD population has been noted in several studies, as parents often feel they have not received enough education for discharge. Of note, both patients were discharged within four weeks of participating in this study. It would be significant to assess long-term impacts of this study on parents, including overall readiness for discharge and feelings of stress when the patient is home.

### **Implications for Practice**

The impact of a Parent Education Program in the complex CHD population has been suggested to be useful based on the results of this study. The small sample size is a limitation in interpreting the results. However, the complex CHD population within the CICU is small, and a positive discharge education experience for even one patient is significant. Future studies within this population are required to analyze the impact on the complex CHD population overall.

Complex CHD patients are often preparing for discharge over the course of several months. The data collection period for this study was two months, however, there are many factors that impact hospital length of stay and discharge plans among cardiac centers. According to Hill et al. (2016), the NPC-QIC registry notes the highest risk of mortality is during the initial stage one palliation hospitalization (7-39%). This study focuses on complex CHD patients, many of which are immediately following stage one palliation. Morbidity and mortality during this stage impact the number of participants who can participate in studies analyzing parent education. Patients must meet criteria for discharge, including stability in hemodynamics and adequate weight gain. As a result, future studies must assess parent education over a longer time to decrease time barriers if patients do not demonstrate discharge readiness.

The impact of this parent education program should be assessed for long-term effects on the parents and patients. It would be significant to note the impacts of this program on patient-

related factors, such as morbidity related to disease complications, readmission within 30 days of discharge, quality of life, and mortality. The literature suggests complex CHD patients are at high risk of complications following discharge, however, it is unclear if parent education is directly correlated with these complications. Continued studies in this population are crucial to improve lives of CHD patients and their parents following hospital discharge.

### **Limitations**

This study has several limitations due in part to the small sample size. Patient acuity during the time of data collection limited eligible participants. For the intervention to be relevant and appropriate to the patient's current clinical course, they must be in the process of discharge preparation. Patients requiring mechanical ventilation, continuous intravenous medications, and those with post-operative complications were not appropriate for discharge education.

Additionally, patients with complex CHD who are listed 1A for heart transplant are medically unable to be discharged home until they have received a transplant. Several identified complex CHD patients were unable to participate due to being listed as high priorities on the transplant list. During the time of data collection, several potential complex congenital heart disease patients were excluded as a result. Future interventions must take into consideration the unpredictable nature of CHD and adjust the intervention period appropriately.

Parental availability for consent and discussion of the study was another significant limitation. Parents must be available and willing to participate in the program and their child's care. Candidates were identified based on their complex CHD, but parental involvement was sporadic. The PI was unable to reach parents to obtain consent and discuss the program. This poses a challenge for discharge education and may contribute to limited knowledge in CHD parents.

Due to the complexity and gravity of complex CHD, parents must exhibit preparedness and knowledge when caring for their child. One identified candidate was excluded due to involvement of child protective services secondary to lack of parental involvement and failure to demonstrate competency in their care. Patients who are unable to be discharged home with their parents were excluded as discharge preparation is halted. If patients are identified as being at risk, and are planned to return for surgery, they would remain in the care of the cardiac ICU until their next surgery.

### **Conclusion**

The complex CHD population is a critical population to assess parental discharge readiness and preparation. While studies assessing parent education methods in this population are limited given significant barriers, it is crucial to continuously assess education needs to ensure they are prepared for discharge. This study notes the impacts of a parent education program, in addition to standard bedside education, may be beneficial to parents who are willing to participate.

Significant limitations in this study include lack of parent availability, short data collection period with the resultant small sample size. Future studies should assess the impact of a similar program over a long period of time to determine if changes need to be made to the cardiac center's education program. The results of this study align with the literature that suggest additional education is beneficial for parents in the CHD population.

Parental knowledge of their child's care has a significant impact on parent stress and comfort level caring for their child after discharge home. It would be crucial to assess the impact of additional parent education on patient outcomes. In assessing this, it can be determined if

parents who are equipped with the knowledge, resources, and expertise in caring for their child can help contribute to improved quality of life and outcomes in the complex CHD population.



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## Tables

Table 1. Summary of demographic characteristics of parents enrolled (N= 3)

Variable	Frequency	Mean
<b>Relationship to patient</b>		
Mother	2	66.7%
Father	1	33.3%
<b>Gender</b>		
Female	2	66.7%
Male	1	33.3%
<b>Age</b>		
26-30	2	66.7%
31-35	1	33.3%
<b>Educational Background</b>		
Some college	1	33.3%
4-year degree	2	66.7%
<b>Race</b>		
Caucasian	2	66.7%
African American	1	33.3%
<b>Ethnicity</b>		
Hispanic/Latino	1	33.3%
Not Hispanic/Latino	2	66.7%
<b>Marital Status</b>		
Single	1	33.3%
Married	2	66.7%

Table 2. Pre-and post-test knowledge assessment results

Question	Correctly identified, pre-test score (%)	Correctly identified, post-test score (%)
What is your child's heart defect?	2.5/3 (83%)	3/3 (100%)
What are three important things to remember when caring for your child at home?	1.16/3 (38.6%)	1.5/3 (50%)
What requires immediate action and emergency care?	1.5/3 (50%)	2.5/3 (83%)
When should you call the on-call provider and/or nurse clinician?	1.5/3 (50%)	2.25/3 (75%)
What should you do if a medication dose is missed?	1/3 (33%)	2.5/3 (83%)
	<i>mean (SD)</i>	<i>mean (SD)</i>
Total score, % <sup>a</sup>	50.7 (21.6)	78.3 (11.5)

<sup>a</sup>Wilcoxon signed-rank test  $p = 0.29$

## Appendix A: Instruments

### Instrument A1: Subject Demographic Questions

(1) Relationship to patient: \_\_\_\_\_

(2) Gender

- Male  Transgender  
 Female  Non-binary

(3) Age

- ≤19 years  36-40 years  
 20-25 years  41-45 years  
 26-30 years  >45 years  
 31-35 years

(4) Educational Background

- No formal school  
 Some high school  
 Some college  
 Four-year degree  
 Graduate degree  
 Other (specify) \_\_\_\_\_

(5) Race and Ethnicity

- Hispanic or Latino  
 Not Hispanic or Latino  
-----  
 Caucasian  
 African American  
 American Indian  
 Asian  
 Other (specify) \_\_\_\_\_

(6) Marital Status

- Single  
 In a relationship, not  
married  
 Married  
 Widowed

## Instrument A2: Pre and Post Test- Assessment of Subject Knowledge

- (1) What is your child's heart defect?
- (2) What are three important things to remember when caring for your child at home?
- (3) What requires immediate action and emergency care?
- (4) When should you call the on call cardiac provider and/or the nurse clinician?
- (5) What should you do if a medication dose is missed?

### Notes:

- The answers to this test were multiple choice and select all that apply. The PI coordinated with the cardiovascular nurse clinicians in the CICU who are responsible for discharge preparation to ensure the answers matched what is provided to the parents prior to discharge.
- This test was used as the pre-test immediately prior to the intervention and as the post-test, one week following the intervention.
- The content validity of these questions has been verified by Misty Ellis, CPNP-AC/PC.



### Instrument A3: Post-Intervention Survey

- (1) Was this class beneficial?
  - a. Yes
  - b. No
  
- (2) Was the education provided in this class easy to understand?
  - a. Yes
  - b. No
  
- (3) How can this class be improved? \_\_\_\_\_
  
- (4) Did this class decrease any of the stress you may be feeling?
  - a. Yes
  - b. No
  
- (5) How do you prefer to learn?
  - a. Reading
  - b. Writing
  - c. Listening
  - d. Doing
  - e. Combination of the above (Circle which ones apply)


**Notes:**

- The answers to this test were multiple choice and fill in the blank (#3).
- This test was completed immediately following the intervention.

## Appendix B: PowerPoint slides

### CONCERN #2


- What do you see here that is concerning?
- What do you think this means?
- **Swelling (edema):** This is seen as puffiness of face, hands, and/or feet and happens when there is an excessive amount of fluid in the body
- Swelling is not good for the body. Why?
  - The heart will have to work harder to push blood to the rest of the body
  - Depending on where the fluid is, this could also make it difficult to breathe.
- A good analogy to better understand this would be: Imagine drinking 30 ounces of water then immediately going for a 3-mile run.



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### CONCERN #3

- What do you see here that is concerning?
- What do you think this means?



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### REAL SCENARIOS


- In a UK study done in 2016, parents were recruited to evaluate complications after discharge
- These complications are **scary** and some are difficult to discuss but emphasizes the importance of trusting your instinct and calling if you have any concerns!
  - **Patient 1:** Mother felt "something was wrong but did not know what it was; mother's instinct." Patient had an aortic aneurysm and needed surgery
  - **Patient 2:** Decreased feeding, vomiting, abdomen "not quite right." Patient had a wound infection and needed emergency wound debridement
  - **Patient 3:** Excessive crying and screaming. Patient collapsed at home and did not survive
  - **Patient 4:** Respiratory distress, purple fingertips → Blocked left shunt, emergency surgery needed
  - **Patient 5:** "Breathlessness," sleeper, screaming and inconsolable → Blocked shunt, patient did not survive

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### STERNAL PRECAUTIONS- DO'S AND DON'TS

- **Sternal precautions:** These are in place because your child had open heart surgery. We want to protect this area while the incision is healing

<p><b>DO:</b></p> <ul style="list-style-type: none"> <li>✓ Pick your child up using the 'scoop' method</li> <li>✓ Bathe your child with soap and water without soaking them</li> <li>✓ Monitor for:                     <ul style="list-style-type: none"> <li>-Swelling</li> <li>-Redness</li> <li>-Drainage</li> <li>-Open areas to incision</li> </ul> </li> </ul>	<p><b>DON'T:</b></p> <ul style="list-style-type: none"> <li>✗ Pick your child up under their arms for <b>6 weeks</b></li> <li>✗ Soak them under the water</li> <li>✗ Use any lotions or creams on the incision</li> </ul>
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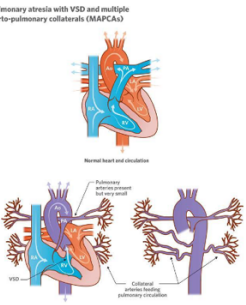
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Figure B1. Example, PowerPoint slides used for general education.

### CONGENITAL HEART DISEASE

- **Your child's defect:** Tetralogy of Fallot with pulmonary atresia, VSD and MAPCAs
- **Your child's surgery:** Unifocalization of MAPCAs and placement of BT shunt

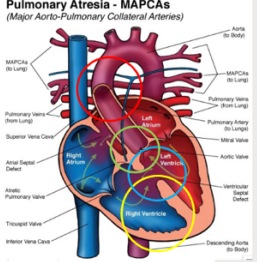
What does this mean?



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### THE BREAK DOWN...

- **Tetralogy of Fallot with pulmonary atresia:**
  - (1) **Thickened right ventricle:** The RV has to work hard because it is pumping against **high** pressure
  - (2) **Complete pulmonary obstruction:** The valve that opens to send blood to the lungs is completely closed. Blood must get to the lungs in a different way (MAPCAs)
  - (3) **ventricular septal defect:** a hole between the left and right ventricles of the heart
  - (4) **transposed aorta:** the artery that carries oxygen to the body is out of place and comes out of BOTH the left and right ventricle (instead of just the left)
- **Major Aortopulmonary Collateral Arteries (MAPCAs):** These are 'extra' arteries that go to the lungs. Remember that pulmonary atresia means NO blood goes to the lungs, so these are present to try to get blood where it needs to go.



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### UNDERSTANDING YOUR CHILD'S ANATOMY AND THEIR SURGERY

- **Heart:**
  - No blood flow to the lungs → surgery was required to make sure blood could get to the lungs. A shunt (small tube) was placed to connect the pulmonary artery with the carotid artery. This will make sure blood flows to the lungs.
- **Lungs:**
  - The shunt makes sure blood gets to the lungs, BUT we do not want too much blood to get to the lungs. This would mean less blood gets to the rest of the body.
- **Kidneys:**
  - If there is too much blood going to the lungs, that means less blood goes to other important organs, such as the kidneys. This would make your child to urinate less frequently. This would make waste products build up where they shouldn't.
- **Brain:**
  - If there is too much blood going to the lungs, that means less blood goes to other important organs, such as the brain. If this happens, your child's behavior would change (such as crying more).

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### IMPORTANT THINGS TO KNOW ABOUT THIS DEFECT

The shunt that was placed is VERY small (3.5 millimeters)



Blood must flow through the shunt to get blood to the lungs. To prevent a clot from blocking this, your child must receive blood thinners (Loxoven shots)

Being sick (vomiting, diarrhea) increases the risk of a clot. **Why is this?**

We want to make sure enough blood gets to the lungs AND the body. Not too much in either place ☺

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Figure B2. Example, PowerPoint slides used for specific education for patient with Tetralogy of Fallot with pulmonary atresia.