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Rachel Barsella
DePaul University, rmbarsella8815@gmail.com

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Pilot Study: Educational Tool Reduces Parental Stress at Home Post Pediatric Cardiac Surgery

Rachel Barsella^a, Kim Amer^b, Narutoshi Hibino^c

^a DePaul University, 990 W. Fullerton, Chicago, IL 60614, United States of America

^b DePaul University, 990 W. Fullerton, Chicago, IL 60614, United States of America

^c University of Chicago Medicine, 5841 S. Maryland Avenue, Chicago, IL 60637, United States
of America

Correspondence concerning this article should be addressed to Rachel Barsella, 5201 Oak Street,

Oak Lawn, IL 60453. Contact: rmbarsella8815@gmail.com

Abstract

Congenital heart disease is a prevalent health issue in patients around the world. Approximately 8 in 1,000 live births are complicated by congenital heart disease (Ndile & Kohi, 2011). Increased levels of stress and anxiety have been reported by parents of children with congenital heart disease throughout the process of cardiac surgery, hospitalization, and especially discharge home (Brown & Smith, 2018). This pilot research study utilized pre-intervention and post-intervention survey methodology to examine the impact of an educational tool on parental stress while caring for their child at home post cardiac surgery. The educational tool created by the researcher was a binder of information specific to the patient's heart diagnosis: pictures of a normal heart compared to the abnormally structured heart, pictures of the surgical repair, hospital expectations, discharge instructions, and references for home care and concerns. Comparison of pre-intervention and post-intervention surveys showed an overall decrease in parental stress related to recognizing signs of deterioration, knowing who to contact with questions, and caring for their child at home post cardiac surgery. Providing education and resources related to congenital heart disease allowed parents to further understand their child's cardiac complexities which attributed to an overall decrease in parental stress. Ensuring parents are capable and comfortable caring for their child at home after cardiac surgery may indicate positive long term outcomes for patients.

Keywords: congenital heart disease, pediatric cardiac surgery, parent stress, educational tool

Introduction

Congenital heart disease is a prevalent health issue in patients around the world. Approximately 8 in 1,000 live births are complicated by congenital heart disease (Ndile & Kohi, 2011). Health care professionals have become experts in diagnosis, repair, and monitoring of these pediatric cardiology patients. However, parents become the primary caregivers after the patient leaves the hospital setting.

Increased levels of stress and anxiety have been reported by parents of children with congenital heart disease throughout the process of cardiac surgery, hospitalization, and especially discharge home (Brown & Smith, 2018). For families of children with congenital heart disease, there are multiple occasions for stress to occur: the onset of diagnosis, commencement of surgery, transition from hospital to home, and relapse or deterioration due to complications (Brown & Smith, 2018). Research shows “poor knowledge about particular aspects of the disease and its treatment and preventative measures might have major consequences such as non-compliance, which might cause decreased quality of life and increased risk of morbidity and mortality” (Ndile & Kohi, 2011). This pilot research project has provided parents an educational tool to guide them through their child’s pediatric cardiac surgery with the aim of reducing stress during the process.

Parents are instrumental in outcomes as they take on the immense responsibility of caring for their child with chronic disease. Suggestions from prior research have discussed the need to identify and implement more appropriate ways of teaching parents to understand their child’s heart condition (Ndile & Kohi, 2011). It is important for parents to comprehend their child’s congenital heart disease in order to take responsibility in providing optimal and safe care (Yang et al., 2012). The mental health of parents caring for children with congenital heart disease has a

lasting impact on the patient's long-term outcome and should be taken into consideration (Ndile & Kohi, 2011).

After diagnosis, hospitalization, and discharge, parents become the primary caretakers for their child with congenital heart disease. This pilot study combined comprehensive resources to prepare parents to independently and safely monitor their child at home. If parents are given the tools to adequately understand their child's congenital heart disease, it should aid in decreasing the stress of the unknown after discharge. Better equipping parents to care for their child post-operatively may have even greater long term effects such as decreased hospital readmissions, earlier assessment of deteriorating patients, and better morbidity and mortality outcomes for patients with congenital heart disease.

Methods

This pilot study utilized pre-intervention and post-intervention survey methodology to examine the impact of an educational tool on parental stress while caring for their child at home post cardiac surgery. Survey methodology provided parents with clear and concise statements or questions in order to adequately understand the level of knowledge regarding congenital heart disease and stressors surrounding care at home. Administering a pre-intervention survey and a post-intervention survey in this pilot study sample provided preliminary results regarding the efficacy of the use of an education tool to reduce parental stress.

A pre-intervention survey was conducted with parents at the surgical consult appointment evaluating the background knowledge of their child's heart condition and areas of parental stress during the surgery process. The survey took 15-20 minutes to complete. Once the pre-intervention survey was completed, the parents received an educational tool to guide them from

the surgical consult through discharge and care at home. Parents were informed that they may keep the educational tool for personal use after the conclusion of the study. A post-intervention survey was conducted at the first appointment after hospital discharge (approximately two weeks) to examine the impact of an educational tool on parental stress while caring for their child at home after surgery. The follow-up survey took 15-20 minutes to complete.

The sample of this project included parents of pediatric patients undergoing cardiac surgery at Comer Children's Hospital with University of Chicago from October 2019 – January 2020. The sample was previously known due to the employment status of the researcher. The demographics of the sample included the relationship to the patient (i.e.: parents, guardian), age of the caregiver(s), employment status, education level, ethnicity, marital status, living arrangements, time of diagnosis (antenatal or postnatal), age of patient, congenital heart disease diagnosis, date of surgical consult, date of surgery, and date of first appointment after hospital discharge. See Appendix A for demographics.

The pre-intervention and post-intervention surveys were created by the researcher and written in simple, clear, non-medical terminology. The first section of the survey contained questions to be answered “Yes” or “No” regarding background knowledge of congenital heart disease. Some questions included free text answers to elaborate on “Yes” statements. For example, “Does your child take medication for their heart? If yes, please list the medication(s).” The second section of the survey contained statements to be answered on a Likert Scale (1 – Strongly Disagree to 5 – Strongly Agree) regarding issues related to parental stress discussed by the researcher in the literature review. The pre-intervention and post-intervention surveys matched in order to provide measurement before and after use of the educational tool. The post-intervention survey contained four additional free response questions regarding the experience

with the educational tool. Surveys were given to parents on paper in order to evaluate answers without bias of reading questions aloud to subjects. See Appendix B and C for pre-intervention and post-intervention surveys.

The educational tool created by the researcher was a binder of information specific to the patient's heart diagnosis: pictures of a normal heart compared to the abnormally structured heart, pictures of the surgical repair, hospital expectations, discharge instructions, and references for home care and triaging concerns. Pertinent contact numbers for questions or emergencies were included in the front of the binder. Additionally, parent resources such as the Congenital Heart Assessment Tool, were included in the binder.

To ensure rigor and reliability, survey questions about congenital heart disease knowledge were based on the Leuven Knowledge Questionnaire for Congenital Heart Disease. This tool was developed to cover four areas in which parents should be knowledgeable about their children's congenital heart disease: the disease and its treatment, the prevention of complications, physical activities, and reproductive issues (divided into sexuality and heredity; contraception and pregnancy planning) (Yang et al., 2012). Questions were modified by the researcher to the format appropriate for the study. The survey questions and educational tools were reviewed by committee members with expertise in pediatric cardiology before use with parents. The Congenital Heart Assessment Tool has been shown to provide constructive, concrete communication between parents and cardiac providers (Gaskin, Barron, & Daniels, 2016).

Participants were asked by the researcher, in person, at the surgical consult to participate in the research study. The researcher was present at the surgical consult appointment to obtain

consent, administer the survey, and provide the educational tool. The researcher followed the institution's policies regarding consent and privacy of patients.

The researcher graded the surveys related to congenital heart disease knowledge for accuracy of parents' answers. The medical chart was accessed for information pertaining to diagnosis, medications, and surgical history referenced on the survey. Once the survey was graded, the researcher entered the pre-intervention survey results into an Excel document. The researcher recorded parents' answers to each survey question related to congenital heart disease knowledge as correct or incorrect for analysis after intervention. The researcher recorded parents' answers to the Likert scale questions as 1 – 5 (Strongly Disagree – Strongly Agree). The post-intervention data was entered in the same process as the pre-intervention data, but labeled in a new column representing data after the educational tool use.

Results

Three pre-intervention surveys and three post-intervention surveys were conducted with subjects ($n = 3$). Table 1 summarizes the demographic data. The age range of patients undergoing surgery was 21 months to 8 years. The age range of subjects participating was 26 years to 51+ years. Two subjects (66.7%) were a parent of the patient and one subject (33.3%) was a guardian of the patient. Educational background varied between some high school, no degree (33.3%), some college, no degree (33.3%), and having a Master's degree (33.3%). Of the participants, two were African American (66.7%) and one was White (33.3%). Each patient undergoing surgery had an Atrial Septal Defect and was diagnosed in the post-natal time period (100%).

All of the research participants answered "yes" when asked "was the binder helpful?". Comparison of pre-intervention and post-intervention surveys showed an overall decrease in

parental stress related to recognizing signs of deterioration, knowing who to contact with questions, and caring for their child at home post cardiac surgery. Comparison of pre-intervention and post-intervention surveys showed no significant change in parental knowledge related to their child's congenital heart disease, surgical intervention, and prevention of complications such as endocarditis.

Three subjects responded to the pre-intervention and post-intervention surveys. Results of the surveys are shown in Figure 1a-h. 33.3% of subjects strongly agreed to the statement "I am comfortable in my understanding of my child's cardiac defect" on the pre-intervention survey, while 66.7% of subjects strongly agreed to the same statement on the post-intervention survey. The same percentage responded to the following statements on the pre- and post-intervention surveys:

I understand the surgical repair for my child's heart defect.

I am comfortable in recognizing signs that my child needs emergency care.

I feel capable of caring for my child at home.

I have enough resources to cope with and understand my child's heart defect.

33.3% of subjects strongly agreed to the statement "I am comfortable in knowing who to contact if my child needs emergent care" on the pre-intervention survey, while 100% of subjects strongly agreed to the same statement on the post-intervention survey. 33.3% of subjects strongly disagreed to the statement "I am nervous about caring for my child at home with his/her heart condition" on the pre-intervention survey, while 66.7% of subjects strongly disagreed to the same statement on the post-intervention survey. 33.3% of subjects strongly disagreed to the statement "I feel stress on a daily basis caring for my child with heart disease" (33.3% neutral,

33.3% agree), while 66.6% strongly disagreed or disagreed to the same statement on the post-intervention survey (33.3% agree).

There was a positive outcome related to parental stress shown by the improvement in survey responses regarding stressors at home after pediatric cardiac surgery. After the educational tool, there was an increased feeling of understanding, capability, and comfort regarding the child's heart defect and surgical repair, care at home, recognition of deterioration, and use of resources. There was a decrease in parental nervousness and daily stress of caring for their child with heart disease seen on the comparison of the pre- and post-intervention surveys.

Every subject responded affirmatively that the educational tool was helpful. One subject said the educational tool was helpful since "it shows my son what was wrong with his heart" and it was "very informative". One comment identified a subject's request for "more information" as a suggested change to the educational tool.

Discussion and Future Direction

The purpose of this pilot study was to determine the impact of an educational tool on parental stress while caring for their child at home post cardiac surgery. We found this educational tool to have an overall positive impact on parental stress. Providing education and resources related to congenital heart disease allowed parents to further understand their child's cardiac complexities which attributed to the overall decrease in parental stress.

The effectiveness of an educational tool has been discussed in prior research related to chronic disease management. Siarkowski-Amer and Pidgeon (1991) discussed how "more organized discharge teaching can help children and families to feel more confident and capable of providing home care and ease the patient's transition from hospital to home". Staveski, Parveen, Madathil, Kools, and Franck (2015) investigated the success of an educational program

showing “improvement in parent knowledge about home care after implementation of the discharge program”. Furthermore, implementation and evaluation of a standard discharge packet and educational program is instrumental in preparing parents to care for their child with congenital heart disease at home (Gaskin, 2018). These findings are consistent with the implications of our pilot study emphasizing the importance of parental involvement in the outcomes of their child’s home care.

Our pilot research demonstrated an approach to education that provides parents with the resources to reduce stress at home after their child’s cardiac surgery. Preparing parents to independently and safely care for their child at home has an influential impact on outcomes after cardiac surgery. Our pilot study outlined the importance of parental stress and its relation to better equip parents with education to manage their child at home after cardiac surgery.

Pediatric cardiology has evolved significantly with more patients surviving longer due to the improvements in cardiovascular surgery. However, advancements in surgery will never eradicate the emotions felt when parents are first told their child needs open heart surgery. The implications of providing parents with resources to cope with the stress surrounding their child’s surgery are instrumental in the progress of pediatric cardiology. Parental involvement is essential in contributing to the positive outcomes in this population at home after cardiac surgery.

Education provides parents and families the tools to better understand their child’s health condition. Our study showed the improvement in parental stress after subjects were given educational materials specific to their child’s congenital heart disease. The data from this study provides the importance of advancement in parent education and its contribution to safe, effective care at home after cardiac surgery.

There are significant implications for advanced practice nursing regarding parental stress. Providing an educational intervention that prepares parents to adequately care for their child at home after cardiac surgery is important in long term positive outcomes, such as decreased re-admissions or post-surgical complications. Ongoing improvements in nursing education contribute to well-equipped parents during the transition from hospital to home. Creating and implementing educational interventions demonstrates advanced nursing leadership that contributes to safer patient and family care.

Strengths and Limitations. Our research was a novel pilot study for an educational tool in the management of parental stress at home after pediatric cardiac surgery. Recruitment for subjects was impacted by an organization-wide nursing strike and a small pediatric cardiovascular surgery program. Additionally, Dr. Amer unexpectedly inherited the interim director position for DePaul University School of Nursing, constricting her availability during the research time frame. Despite these limitations, our pilot study demonstrated the potential usefulness of an educational tool to decrease parental stress at home after pediatric cardiac surgery.

Future Direction. One of the most important objectives for future research is to confirm the findings of the pilot study with a larger sample size, including more diversity among ethnicity groups and educational levels. Prospective studies will test the utility of the educational tool with more complex conditions and surgeries. Five additional educational tools were created for future surgeries in the program: Ventricular Septal Defect, Subaortic Membrane (Subaortic Stenosis), Tetralogy of Fallot, Pulmonary Valve Replacement, and Transposition of the Great Arteries. Further considerations regarding the design and implementation of the surveys will be discussed, such as providing an opportunity for parents to complete the surveys at home instead of at the follow-up appointment or use of a tablet to complete the survey instead of paper. It would also be

beneficial to convert the educational tools into a Spanish language format for future patient populations.

Conclusion

The purpose of our study was to determine the impact of an educational tool on parental stress while caring for their child at home post cardiac surgery. Our preliminary findings in this pilot research study indicate a measured decrease in parental stress after the intervention of an educational tool. Ensuring parents are capable and comfortable caring for their child at home after cardiac surgery may indicate positive long-term outcomes for patients. The effectiveness of an educational tool in decreasing stress should be considered by cardiovascular surgery programs when preparing parents for care of their child.

Appendix A

Demographics

To be completed by researcher:**Patient ID#:****Age of patient:****CHD diagnosis:****Date of surgical consult:****Date of surgery:****Date of appointment after discharge:**

Please complete the following information as it applies to you:

1. What is your relationship to the patient?
 - Mother
 - Father
 - Legal guardian
2. What is your age?
 - 18 - 20
 - 20 – 25
 - 26 – 30
 - 31 – 40
 - 41 – 50
 - 51 years old or older
3. What is your employment status?
 - Employed for wages
 - Self-employed
 - Out of work and looking for work
 - Out of work but not currently looking for work
 - Homemaker
 - Student
 - Military
 - Retired
 - Unable to work
4. What is the highest degree or level of school you have completed? *(If currently enrolled, highest degree received.)*
 - Some high school, no degree
 - High school or GED
 - Some college, no degree

- Trade/technical training
 - Associate's degree
 - Bachelor's degree
 - Master's degree
 - Doctorate degree
5. Ethnicity
- White
 - Hispanic or Latino
 - Black or African American
 - Native American or American Indian
 - Asian / Pacific Islander
 - Other
6. What is your marital status?
- Single, never married
 - Married or domestic partnership
 - Widowed
 - Divorced
 - Separated
7. What are your living arrangements?
- Living with partner (married or unmarried)
 - Living alone (with children)
8. When was your child diagnosed with a heart condition?
- Before birth by fetal ultrasound
 - After birth

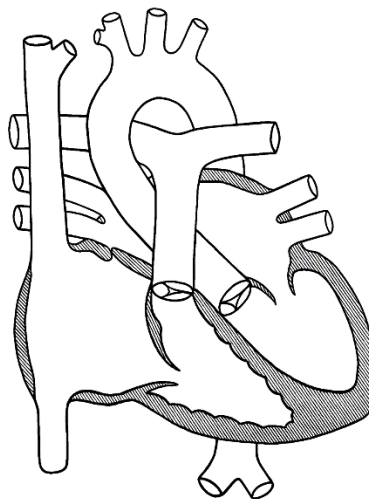
Appendix B

Pre-Intervention Survey

Patient ID # _____

CHD Pre-Intervention Survey

- | | |
|---|-----------|
| 1. Can you name your child’s heart defect?
A. If yes, please write the name of the cardiac defect. | Yes No |
| 2. Can you describe your child’s heart defect?
A. If yes, please describe or indicate on the picture where your child’s defect is located: | Yes No |



- | | |
|---|-----------|
| 3. Does your child need to come to follow up appointments with a cardiologist? | Yes No |
| 4. Has your child had cardiac surgery or intervention to fix his/her heart? | Yes No |
| 5. Will your child have to have further surgery or intervention on his/her heart? | Yes No |
| 6. Does your child take medication for their heart? | Yes No |

If yes, please answer the following questions:

- A. What is the name of the medication(s)?

- B. What is the dose of the medication(s)?

- C. How many times a day is the medication(s) given?

D. What is the reason your child takes this medication(s)?

7. If your child experiences side effects of his/her medication, should he/she stop taking them?

Yes No

8. Circle the symptoms that would require you to seek emergency cardiac care for your child:

- | | |
|------------------------------|--------------------------------------|
| Faster than normal breathing | Poor weight gain |
| Skin rash | Mouth or hands turning blue |
| Shortness of breath | Reflux/spit up |
| Eye discharge | Urinating less frequently |
| Sweating with feeding | Swollen feet, legs, eyelids |
| Heart racing/tachycardia | Tiring faster with physical activity |
| Fainting | I don't know |

9. Do you know what endocarditis is? Yes No

A. If yes, please describe in the space below:

10. Circle the risk factors for endocarditis:

- | | |
|---------------------------|--------------------------|
| Needle contamination | Poor nail and skin care |
| Smoking | Body piercing and tattoo |
| Dental abscesses | Bleeding gums |
| Bacterial skin infections | I don't know |

11. Can your child get endocarditis more than one time in his/her life? Yes No

12. Should your child have a dental check up at least once a year? Yes No

13. Does your child need antibiotics before every visit to the dentist? Yes No

Please answer the follow questions with the number most applicable to you.

1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree

- | | | | | | |
|---|---|---|---|---|---|
| 1. I am comfortable in my understanding of my child's cardiac defect. | 1 | 2 | 3 | 4 | 5 |
| 2. I am able to explain my child's heart defect to other health care providers. | 1 | 2 | 3 | 4 | 5 |
| 3. I understand the surgical repair for my child's heart defect. | 1 | 2 | 3 | 4 | 5 |
| 4. I understand how to monitor for signs of infection after open heart surgery. | 1 | 2 | 3 | 4 | 5 |

5. I understand the hospital admission expectations and routines. 1 2 3 4 5
6. I am comfortable in administering medication at home for my child's heart. 1 2 3 4 5
7. I understand why my child takes each medication(s) for his/her heart. 1 2 3 4 5
8. I am comfortable in recognizing signs that my child needs emergency care. 1 2 3 4 5
9. I am comfortable in knowing who to contact if my child needs emergent care. 1 2 3 4 5
10. I am nervous about caring for my child at home with his/her heart condition. 1 2 3 4 5
11. I felt stress at the time of my child's heart diagnosis. 1 2 3 4 5
12. I feel stress on a daily basis caring for my child with heart disease. 1 2 3 4 5
13. I feel capable of caring for my child at home. 1 2 3 4 5
14. I have enough resources to cope with and understand my child's heart defect. 1 2 3 4 5

Appendix C

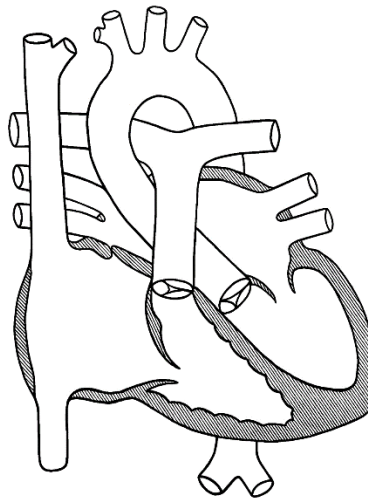
Post-Intervention Survey

Patient ID # _____

CHD Pre-Intervention Survey

14. Can you name your child’s heart defect? Yes No
 A. If yes, please write the name of the cardiac defect.

15. Can you describe your child’s heart defect? Yes No
 A. If yes, please describe or indicate on the picture where your child’s defect is located:



16. Does your child need to come to follow up appointments with a cardiologist? Yes No
 17. Has your child had cardiac surgery or intervention to fix his/her heart? Yes No
 18. Will your child have to have further surgery or intervention on his/her heart? Yes No
 19. Does your child take medication for their heart? Yes No

If yes, please answer the following questions:

E. What is the name of the medication(s)?

F. What is the dose of the medication(s)?

G. How many times a day is the medication(s) given?

H. What is the reason your child takes this medication(s)?

20. If your child experiences side effects of his/her medication, should he/she stop taking them?

Yes No

21. Circle the symptoms that would require you to seek emergency cardiac care for your child:

- | | |
|------------------------------|--------------------------------------|
| Faster than normal breathing | Poor weight gain |
| Skin rash | Mouth or hands turning blue |
| Shortness of breath | Reflux/spit up |
| Eye discharge | Urinating less frequently |
| Sweating with feeding | Swollen feet, legs, eyelids |
| Heart racing/tachycardia | Tiring faster with physical activity |
| Fainting | I don't know |

22. Do you know what endocarditis is? Yes No

A. If yes, please describe in the space below:

23. Circle the risk factors for endocarditis:

- | | |
|---------------------------|--------------------------|
| Needle contamination | Poor nail and skin care |
| Smoking | Body piercing and tattoo |
| Dental abscesses | Bleeding gums |
| Bacterial skin infections | I don't know |

24. Can your child get endocarditis more than one time in his/her life? Yes No

25. Should your child have a dental check up at least once a year? Yes No

26. Does your child need antibiotics before every visit to the dentist? Yes No

Please answer the follow questions with the number most applicable to you.

1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree

1. I am comfortable in my understanding of my child's cardiac defect. 1 2 3 4 5
2. I am able to explain my child's heart defect to other health care providers. 1 2 3 4 5
3. I understand the surgical repair for my child's heart defect. 1 2 3 4 5
4. I understand how to monitor for signs of infection after open heart surgery. 1 2 3 4 5

- | | | | | | |
|--|---|---|---|---|---|
| 5. I understand the hospital admission expectations and routines. | 1 | 2 | 3 | 4 | 5 |
| 6. I am comfortable in administering medication at home for my child's heart. | 1 | 2 | 3 | 4 | 5 |
| 7. I understand why my child takes each medication(s) for his/her heart. | 1 | 2 | 3 | 4 | 5 |
| 8. I am comfortable in recognizing signs that my child needs emergency care. | 1 | 2 | 3 | 4 | 5 |
| 9. I am comfortable in knowing who to contact if my child needs emergent care. | 1 | 2 | 3 | 4 | 5 |
| 10. I am nervous about caring for my child at home with his/her heart condition. | 1 | 2 | 3 | 4 | 5 |
| 11. I felt stress at the time of my child's heart diagnosis. | 1 | 2 | 3 | 4 | 5 |
| 12. I feel stress on a daily basis caring for my child with heart disease. | 1 | 2 | 3 | 4 | 5 |
| 13. I feel capable of caring for my child at home. | 1 | 2 | 3 | 4 | 5 |

Please answer the following questions about your experience with the educational tool (binder with heart information).

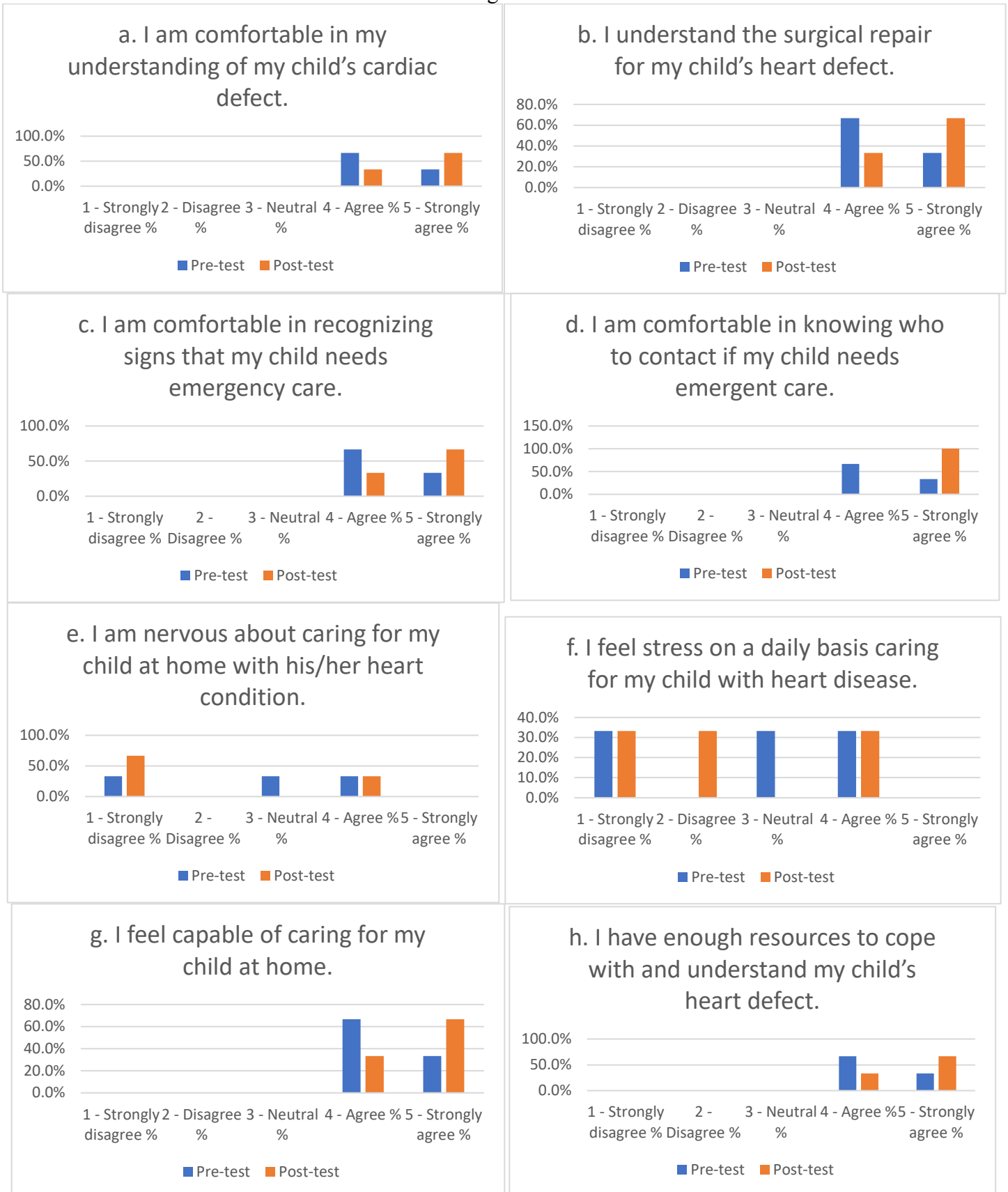
1. Was the binder helpful? Why or why not?
2. What was the most important part of the binder for you?
3. What would you change about the binder?
4. Did the binder help reduce stress while caring for your child at home after cardiac surgery?

Table I

Patient Demographics (n=7)

Age range of patients	21 mo - 8 years
Age range of subjects	26 years - 51+ years
Subjects	
Parent (%)	n = 2 (66.7%)
Guardian (%)	n = 1 (33.3%)
Cardiac defect	n = 1
Level of Education	
Some HS, no degree (%)	n = 1 (33.3%)
Some college, no degree (%)	n = 1 (33.3%)
Master's degree (%)	n = 1 (33.3%)
Ethnicity	
White (%)	n = 1 (33.3%)
Black or African Am (%)	n = 2 (66.7%)
Time of Diagnosis	
Pre-natal (%)	n = 0 (0%)
Post-natal (%)	n = 3 (100%)

Figure I



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