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Factors influencing efficacy and satisfaction in prenatal counseling for families with single ventricle heart disease

Taylor Hartzel Houlihan, Jack Rychik MD*



- Congenital heart disease (CHD) occurs in 6/1000 live births¹
 - Can be diagnosed in utero^{2,3}
 - Single ventricle pathologies carry higher risk of adverse outcomes⁴
- CHOP developed a multidisciplinary Fetal Heart Program in 2001 to support families with CHD³
 - Offers parent education, pre- and postnatal care, surgical planning
 - Goal: better preparation, understanding, and outcomes
- To date, there is no quality assessment of this program

Objectives & Hypothesis

- Research Question
 - What aspects of CHOP's Fetal Heart Program influence the efficacy and satisfaction in prenatal counseling for families with single ventricle heart disease?
- Hypothesis
 - Access to a multidisciplinary team, targeted patient education, and preparation for clinical course of care increase the efficacy and satisfaction in prenatal counseling for families with single ventricle heart disease.

Approach & Results

Study Design

- Medical chart review to determine study candidates
- Retrospective survey administration via email

Population / study sample

- Families with a single ventricle diagnosis who utilized CHOP's prenatal counseling
- Patients who underwent surgical palliation

Outcome

- Level of satisfaction/preparation experienced after counseling
- Discover areas for improvement

Data source and collection

- Questionnaire responses assigned study IDs
- Demographics, Likert scale responses, open-ended responses recorded

Approach & Results

Survey Response

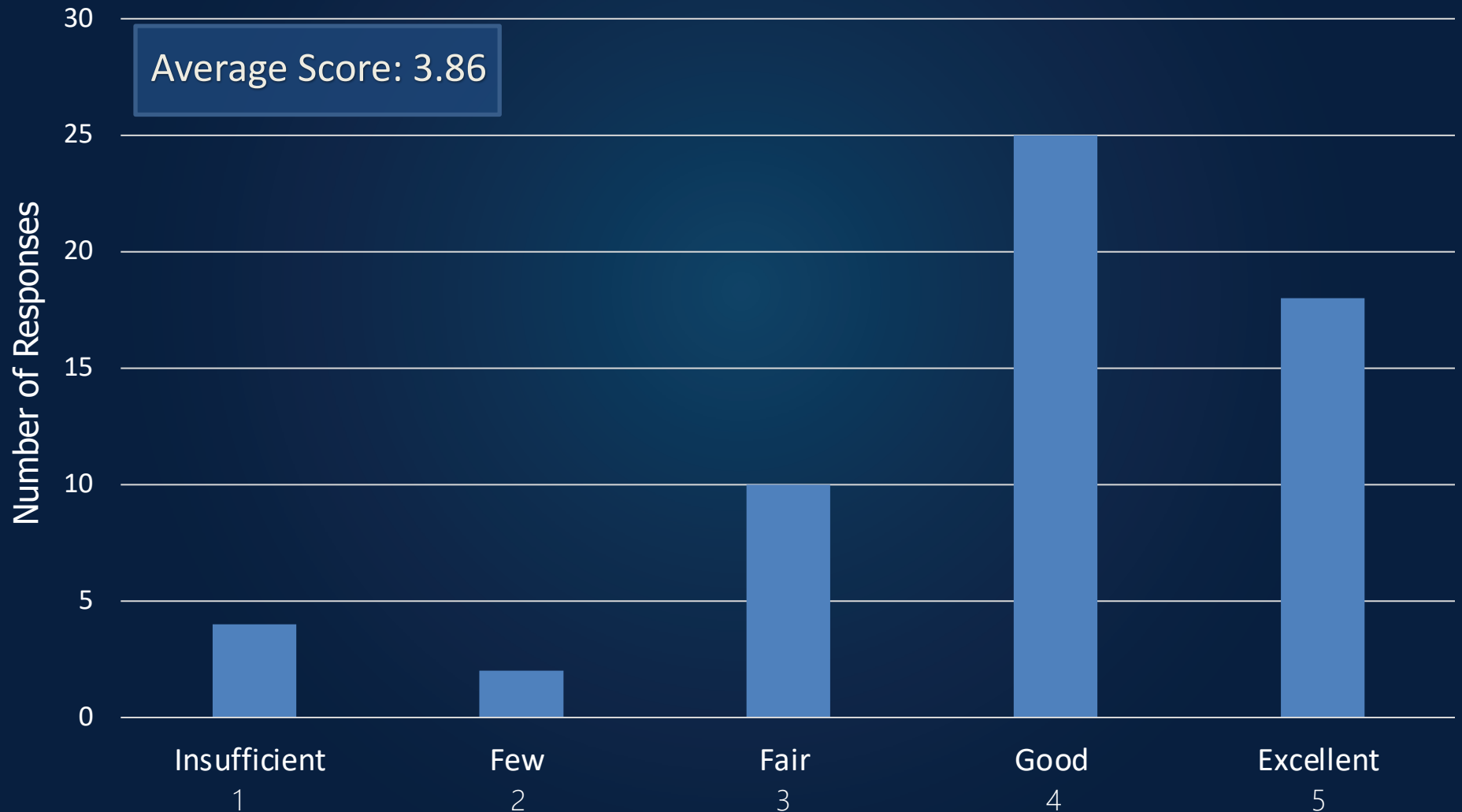
- Emailed 248 surveys
- Received 65 responses
 - 6 incomplete

Analysis

- Created average scores for Likert scales
- Used paired 2 sample t-tests to compare average scores between categories of satisfaction/preparation
- Reviewed open-ended responses

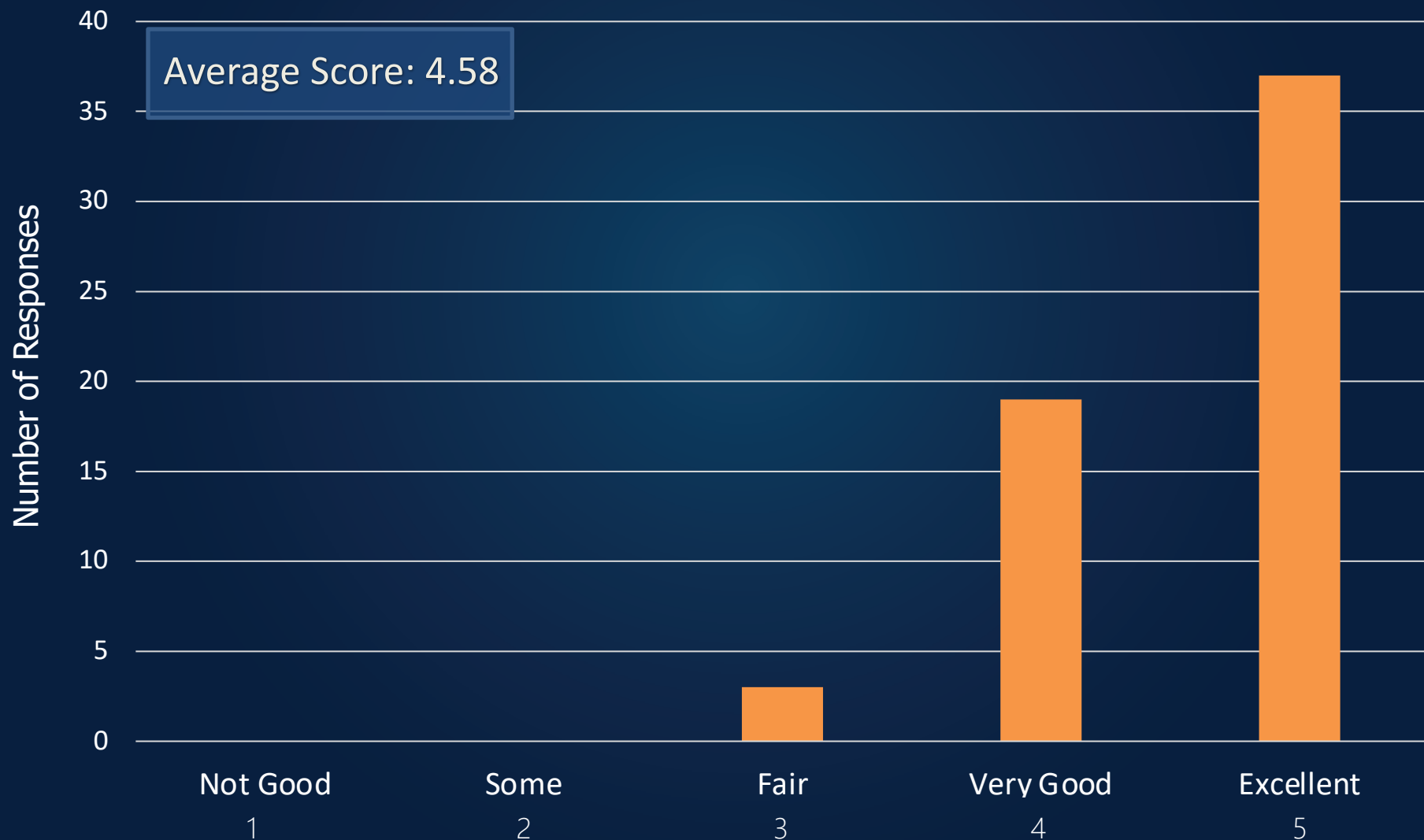
Satisfaction with Amount of Counseling Sessions

Average Score: 3.86



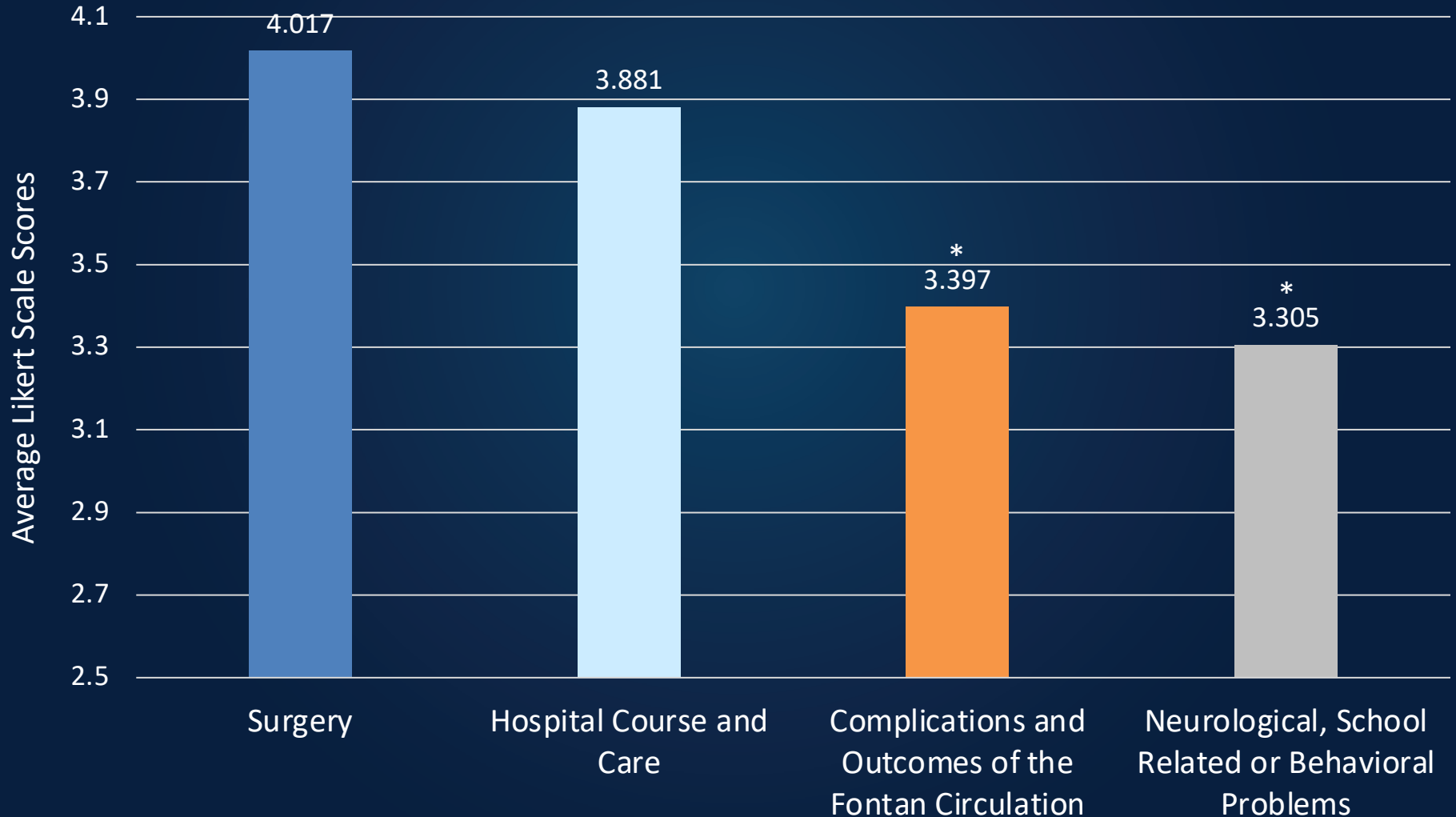


Satisfaction with Explanation about Heart Condition

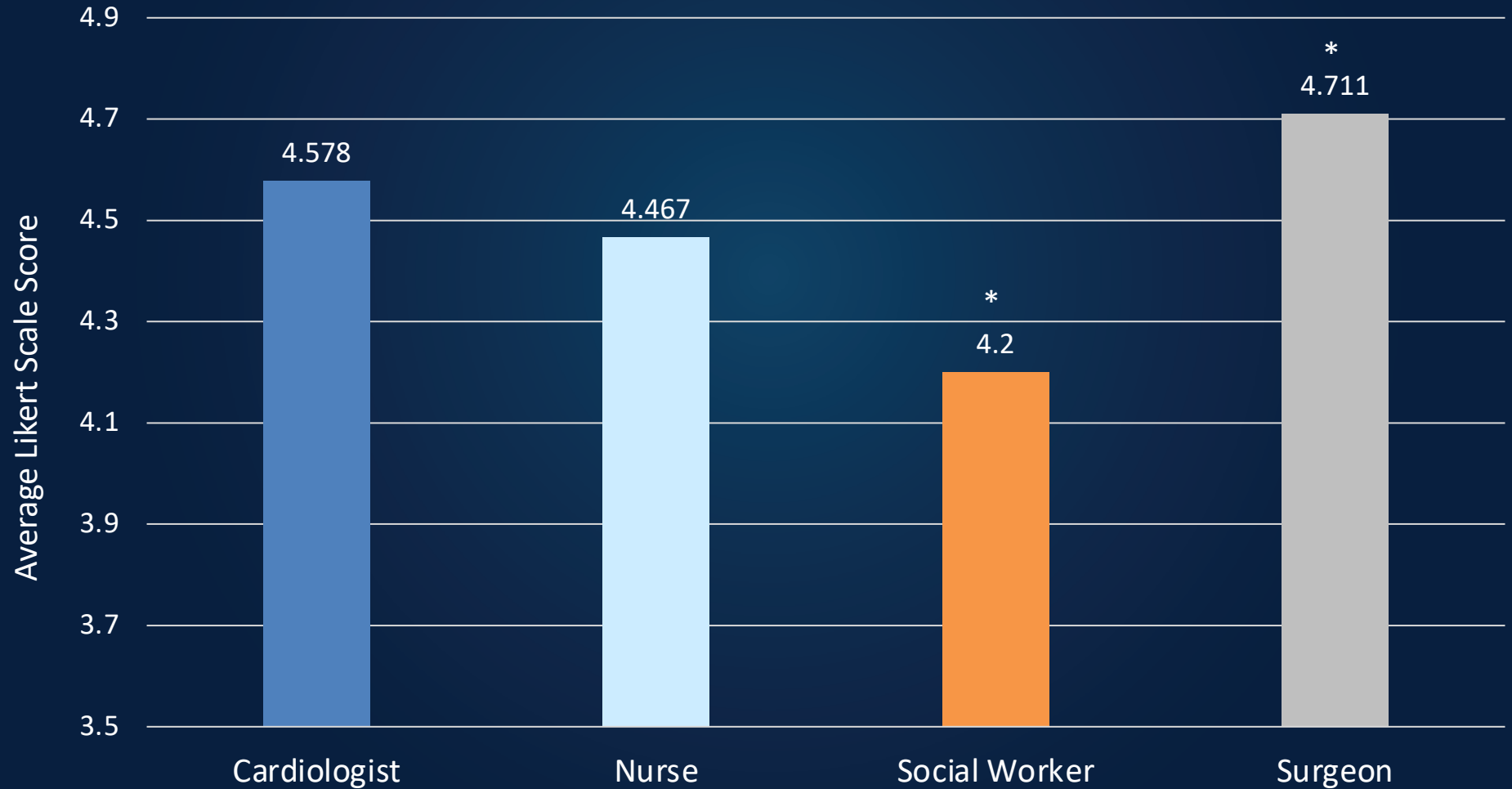




Level of Preparation



Adjusted Satisfaction with Team Members



Helpful Aspects



Cardiologists, surgeons, and nurses showed empathy, patience, and support

- Answered questions clearly
- Offered hope



Pamphlets and DVD distribution

- Amount of initial information is overwhelming



Meeting with several members of the team

- Contact information for when questions arose



Explanation of hospital stay logistics

- Tour of CICU/SDU
- Insurance help

Areas to Improve



Mental health/emotional support for parents

- Psychologist meetings during hospitalization
- Addressing trauma/PTSD
- Connecting with other CHD families



Discussions about surgical complications and appearance after surgery

- ECMO
- Stroke, seizures, vocal cord paresis, etc.



Breastfeeding Instruction

- Difficulties with feeding during and after hospital stay
- Managing feeding/pumping in CICU



Advice on how to speak to child about Fontan procedure

- Families were satisfied with:
 - Education about child's condition
 - Preparation for the surgery and hospital course
 - FHP Staff
- Families were unsatisfied with:
 - Preparation for Fontan outcomes, complications, and neurological sequelae
 - Emphasis on parental mental health and emotional support

Future Directions

- Currently writing IRB for continuation of study
 - Aim: use patient medical records to determine if complex clinical course impacted parental satisfaction with counseling
- Determining risk factors for more complicated clinical courses

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