Background

- Hypoplastic Left Heart Syndrome (HLHS) is a complex congenital heart defect in which most or all of the left side of the heart is small and underdeveloped.
- With surgical advancements, the mortality rate of children with HLHS has decreased significantly. These survivors can face serious life long complications that affect not only the child but the family as a whole.
- To provide effective support for these families, it is important to assess how they manage their child’s health condition within their family.

The Family Management Measure (FaMM) is a 53-item questionnaire consisting of six subscales measuring different aspects of family management:

- Child’s Daily Life (CHILD)
- Condition Management Ability (ABILITY)
- Parental Mutuality (MUTUALITY)
- Condition Management Effort (EFFORT)
- Family Life Difficulty (DIFFICULTY)
- View of Condition Impact (IMPACT)

Methods

- Quantitative pilot phase of a mixed methods study.
- Questionnaires mailed to parents of children with HLHS.
- FaMM is a 53-item questionnaire consisting of six subscales measuring different aspects of family management:
- Subscales in which higher scores indicate greater normality:
  - Child’s Daily Life (CHILD)
  - Condition Management Ability (ABILITY)
  - Parental Mutuality (MUTUALITY)
- Subscales in which lower scores indicate greater normality:
  - Condition Management Effort (EFFORT)
  - Family Life Difficulty (DIFFICULTY)
  - View of Condition Impact (IMPACT)
- Five other standardized measures were administered:
  - CVS: Child Vulnerability Scale
  - PedsQL Cardiac and Generic modules: Pediatric Quality of Life Inventory
  - CD-RISC: Connor-Davidson Resiliency Scale
  - PSI: Parent Stress Index
  - PSDQ: Parenting Styles and Dimensions Questionnaire

Sample: 13 families of a child with HLHS who is 2-9 years old
- 8 mothers
- 5 mother/father dyads
- Data were entered into REDCap and analyzed using Excel and SPSS.

Results

RQ1. As seen in Figure 1, there is a continuum present in the pilot data reflecting a range of the scores on the FaMM. The fathers have a more positive average score on all scales than the mothers (see Figure 2). We hypothesize that this result is related to the mothers in almost all cases being the sole primary care giver.

RQ2. According to the Pearson correlation values seen in Table 1 there is a high degree of correlation among the subscales of the FaMM with all of them being statistically significant. The most significant correlation in the pilot data was between the Child’s Daily Life score and the Family Life Difficulty (see Figure 3). The more complex the child’s needs are the more difficulty the family has managing the condition.

RQ3. There is a high degree of correlation between the FaMM subscales and many of the subscales of the other study measures (Table 2). Of most significance, the Parenting Stress Index correlates highly with all FaMM subscales. Another important finding is the strong relationship between the Parental Mutuality FaMM subscale and the Parenting Styles and Dimensions mutuality values. This is notable since the PSDQ mutuality value was derived from the differences between the responses for themselves and for their spouse and was not an original subscale.

Discussion

- Results of this quantitative phase of the study will be used in profiling parents to obtain maximum variation sampling to select participants for the qualitative phase of the study.
- Results of this pilot indicate that families of children with HLHS can be represented on a continuum of family functioning. This will inform the identification of families who require additional support when designing parent-based interventions, the next stage of research.
- Within a family resilience framework, the pilot results of the relationships of scores on the FaMM with the other measures will also inform development of future interventions.

References


Acknowledgements

Laura Rogers, 4th year BScN Honors Student, Douglas Rebstock, WISEST Student, Catriona Blythe, 4th year BScN Honors Student, Laura Rogers, MScRS OT (C), Gwen Rempel, RN, PhD
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