



National Pediatric Cardiology
Quality Improvement Collaborative

Research Explained

Family Function, Quality of Life, and Well-Being in Parents of Infants With Hypoplastic Left Heart Syndrome

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ABOUT THIS STUDY

The goal of this study is to research how families' function, quality of life, and well-being are affected by their child's hypoplastic left heart syndrome diagnosis and treatment.

Why is this study important?

- Hypoplastic left heart syndrome (HLHS) was considered fatal only 30 years ago, but now survival rates are better.
- Today the majority of infants born with HLHS grow and develop into adulthood.
- Parents and family members of a child with HLHS face daily stressors, frequent hospital stays, surgeries, and doctor's office visits.
- It is important to know how HLHS affects the family of the child in order to improve family function, quality of life, and well-being.
- Ultimately, families' stress levels will have an impact on the child's care and development.

How was this study performed?

- This study used data collected during the Single Ventricle Reconstruction (SVR) Trial.
- The SVR Trial included 555 infants with HLHS at 15 different hospitals – the largest study in this patient group.
- Parents/caregivers of babies with HLHS enrolled in the SVR Trial were given surveys to assess their family function, quality of life and well-being when the child was 8 weeks old, 6 months old, and 16 months old.
- SVR Trial parent/caregiver survey scores were compared with results from a samples from the general population (population norms) as well as with known results from a sample of healthy young adults, a sample of adults with health problems, and a sample of parents of children with cancer.

What were the results of the study?

- 146 parents/caregivers participated in the study (143 moms and 72 dads). Parents were 18-54 years old and mostly White/non-Hispanic. 82% of parents were married/living with a partner. 47% were first time parents.
- 26% of parents reported family dysfunction, which is better than normal controls. Moms tended to report worse family function than dads, but overall the family function scores were lower as the child got older.
- Quality of life and well-being scores were significantly lower in HLHS parents than in the population norms.
- Single parents had worse family function, but similar quality of life/well-being scores.
- Complications after procedures decreased the families' quality of life.
- The strongest predictors of families doing well were family characteristics. If a family member had strong coping skills their scores tended to be higher. If a family member had anxiety to begin with their scores tended to be lower.
- Parents with stronger social support reported higher scores of quality of life, well-being, and family function.
- Greater family resources (communication, health, and financial stability) have a positive impact on family function.

What were the limitations of the study?

- The study was limited to English-speaking parents only.
- Not all families completed their surveys at each of the three time-points.
- As parents/caregivers with the most stress may be less likely to return the surveys, this study may be under-reporting the degree of family stress.

What it all means

- Health care providers realized that it is not enough to care only for the child - you need to care for the family as well

- Children with HLHS are doing dramatically better, but their families still experience high levels of stress and worry.
- Families should be assessed by healthcare providers during hospital and office visits in order to be able to provide support and resources.
- Further research is needed on how families adapt and change their life throughout their child's HLHS journey.