

Identifying Gaps in Parental Support for Families with Hypoplastic Left Heart Syndrome: A Quality Improvement Study



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Background

Hypoplastic Left Heart Syndrome (HLHS) is a congenital heart defect in which the left side of the heart is underdeveloped and nonfunctional. Children born with HLHS do not survive more than a few hours or days after birth without pharmacological and surgical intervention. According to the Center for Disease Control and Prevention, there are about 1000 newborns each year diagnosed with HLHS (1).

Typically diagnosed via anatomical ultrasound *in utero*, HLHS is a condition that brings incredible stress and many decisions to expectant parents. For parents who decide to continue the pregnancy, they can elect to provide palliative care/perinatal hospice to their child or pursue surgical intervention that involves three open heart surgeries performed at approximately 3 days, 3 months, and 3 years of age.

Even with these combined surgical interventions, HLHS patients have approximately 50% chance of survival to 5 years of age (2). Moreover, many HLHS patients will eventually undergo heart failure and need cardiac transplantation to survive. Taken together, the severity of this congenital heart defect and poor prognosis, even after staged surgical intervention, create an incredibly difficult situation for families of HLHS children (3).

Methods

Care Team and Parent Interviews

This QI study was conducted in collaboration with the Mayo Clinic Wanek Program for HLHS and was acknowledged as exempt from IRB review (45 CFR 46.102). Dr. Campbell (KC), ML and EO conducted interviews with 12 clinicians on the HLHS care team and 2 mothers of HLHS children. Signed consent was obtained from all participants and interview audio was recorded and transcribed. Open-ended interview questions for clinicians and parents focused on parental support and identifying gaps in the HLHS care delivery model. Interview questions evolved with participant feedback.

Care Team Network Analysis

Members of the HLHS care team were also asked to complete a questionnaire to indicate (a) in which stages of care they participate, (b) level of interaction with parents and patients, and (c) frequency of interactions (3 = daily, 2 = weekly, 1 = monthly, 0 = never) with other members on the care team.

Creation of Fishbone Diagram

Individually, KC, ML, and EO selected essential quotes and topics from the interview transcripts, and then collaborated to prioritize common problems and align them within different stages of the HLHS timeline (Figure 1).

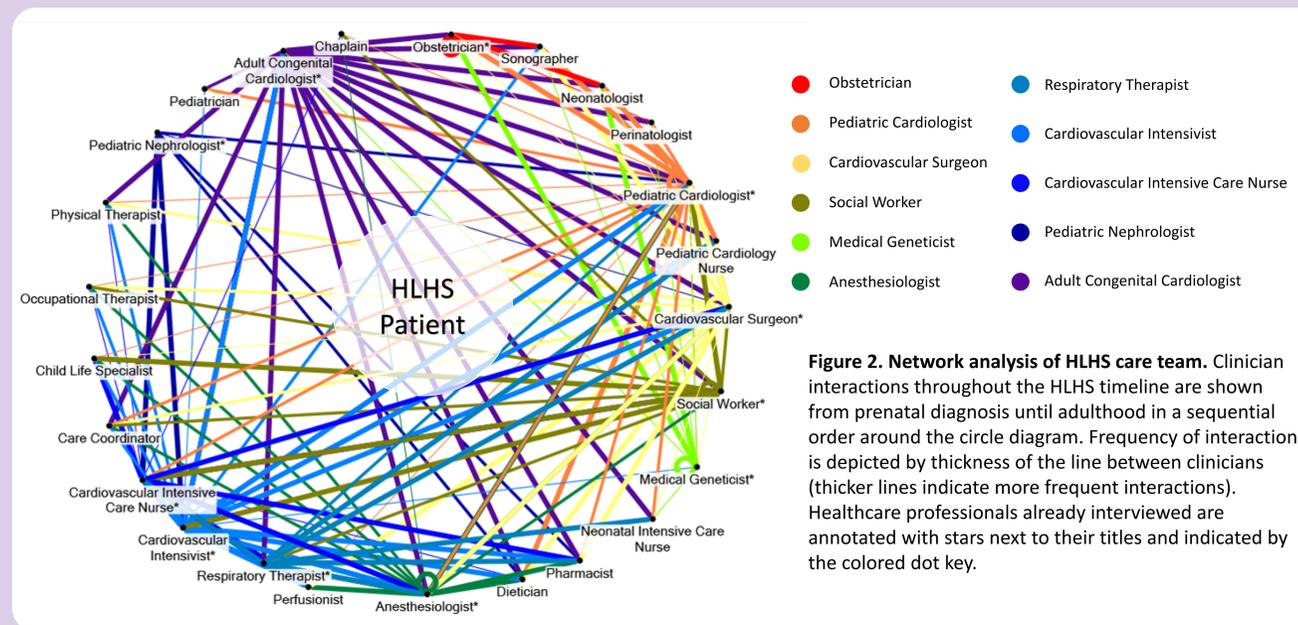


Figure 2. Network analysis of HLHS care team. Clinician interactions throughout the HLHS timeline are shown from prenatal diagnosis until adulthood in a sequential order around the circle diagram. Frequency of interaction is depicted by thickness of the line between clinicians (thicker lines indicate more frequent interactions). Healthcare professionals already interviewed are annotated with stars next to their titles and indicated by the colored dot key.

Table 1: Interprofessional Care Team

	Profession	Interviewed
Prenatal	Obstetrician	X
	Sonographer	
	Neonatologist	
	Perinatologist	
Perinatal	Pediatric Cardiologist	X
	Pediatric Cardiology Nurse	
	Cardiovascular Surgeon	X
	Social Worker	X
Surgical Intervention	Medical Geneticist	X
	Neonatal Intensive Care Nurse	
	Pharmacist	
	Anesthesiologist	X
Outpatient	Perfusionist	
	Respiratory Therapist	X
	Cardiovascular Intensivist	X
	Cardiovascular Intensive Care Nurse	X
Adult	Care Coordinator	
	Child Life Specialist	
	Occupational Therapist	
	Physical Therapist	
	Pediatric Nephrologist	X
	Pediatrician	
	Adult Congenital Cardiologist	X
Chaplain		

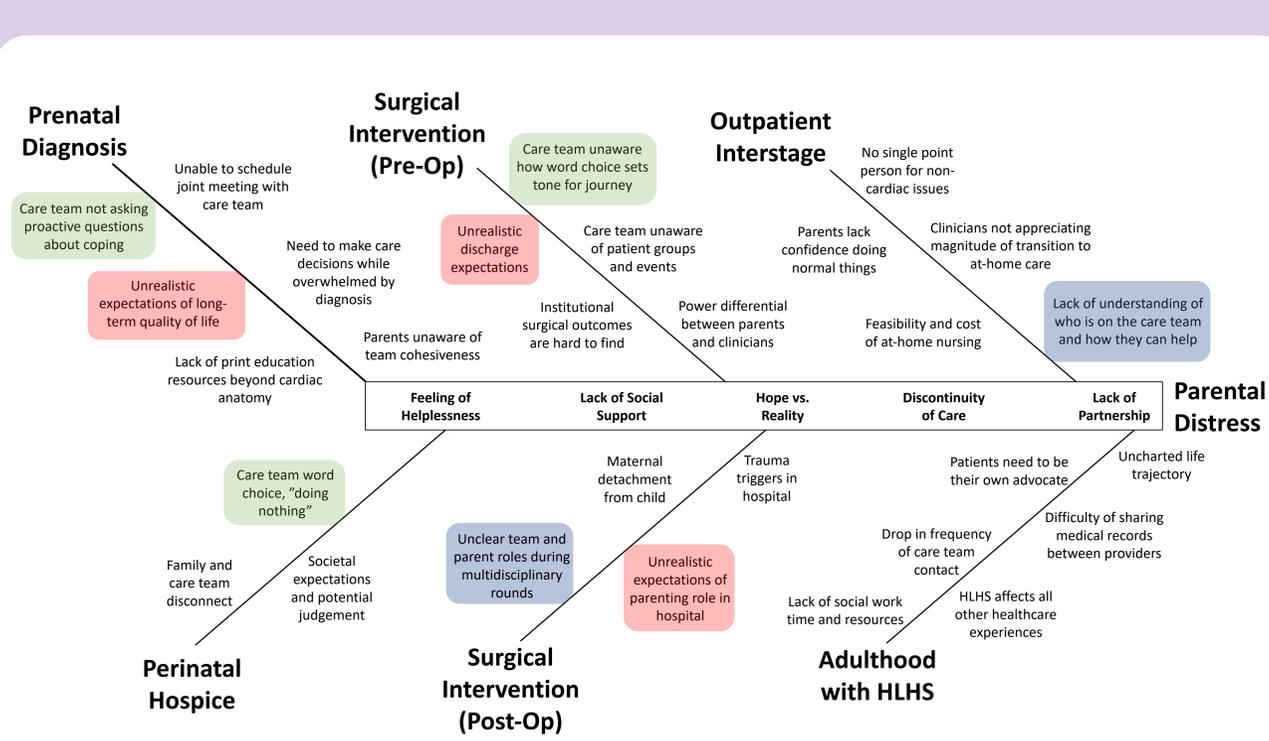


Figure 1. Fishbone diagram of problems leading to parental distress across the HLHS care timeline. Problems identified in all stages of the HLHS journey are illustrated on the central backbone. Any problems unique to one stage throughout the HLHS journey are depicted on individual branches. Prioritized problems are highlighted with colored boxes (Green = importance of care team word choice, Red = unrealistic parental expectations, Blue = unclear interprofessional team roles).

Results & Future Directions

Gaps in maternal support were identified across the entire timeline of HLHS care, many of which could be resolved at low cost. Prioritized opportunities for quality improvement include, (1) educating the care team on the effect of word choice on a parent's HLHS journey, (2) setting realistic parenting expectations following surgical intervention, and (3) helping parents better navigate and leverage the complex interprofessional care team. The project was strengthened by insight from the broadly interprofessional care team and a formative focus on mothers' decisions between perinatal hospice and surgical intervention. The limitations of this pilot project include an inability to interview the entire interprofessional care team and the evolution of the survey instrument based on clinician feedback. Our findings will inform individualized interventions for both the care team and HLHS parents to support sensitivity in clinician word choice, improved parent-child bonding, and cohesive partnership between parents and the entire care team.

References

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