

**Shared Decision-Making Between Physicians and Parents of Children with Hypoplastic Left Heart Syndrome: A Qualitative Study of the Communication Challenges Associated with Therapeutic Evolution.**

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**Introduction**

Children with hypoplastic left heart syndrome form a heterogenous group with significant risk of morbidity and mortality. This leads to uncertainty over the preferred course of care due to difficulty assessing the benefit of therapeutic intervention. Physicians are faced with engaging parents in a shared decision-making process that is both emotionally and cognitively complex. This study seeks to identify common features in the approach of paediatric cardiologists and trainees to communicating with parents in this context, and to ascertain their perception of post-graduate training for such communication.

**Methods**

This was a qualitative descriptive study. Data was collected using two focus groups of consultants and trainees practicing in paediatric cardiology. Transcriptions were coded using the NVivo Software programme. Thematic analysis was used for analysis and interpretation.

**Results**

Two separate focus groups were conducted with trainees and consultants, consisting of three participants each. Three central themes were identified; the delivery of medical information, building a relationship with parents and learning from experience. Consultants in our focus group placed more emphasis on social circumstances and developing relationship of trust with parents than was apparent in the trainee focus group. Both groups described limited formal communication training relevant to this scenario. Participants attributed most of their learning to exposure to teaching moments in clinical practice.

**Conclusions**

Engaging parents in a shared decision-making process remains a challenge for which there is little structured training. Consultants demonstrated an awareness of the value-laden nature of this decision. This study indicates a role for optimising learning opportunities for trainees in paediatric cardiology both in teachable moments in practice, and in more formalised training focused on adult learning needs.