

How Hope Influences Health Care Provider – Parent Communication for Infants with Complex Congenital Heart Conditions

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INTRODUCTION

- Communication between HCPs and parents of seriously ill children is influenced by hope, feelings, and desires for the best interest of the child.
- Effective communication is imperative to gain a holistic understanding of parent hopes, goals, and what they need most from the provider team.
- Empowering parents with information to make decisions enhances quality and safety of care.
- Vital communication skills training is necessary for both parents and providers to minimize potential misinterpretations.

Research Aim: Explore parent and provider perceptions of hope for a critically ill child and how hope influences provider-parent communication.

METHODOLOGY

- Qualitative descriptive design; analysis of parent and HCP interviews from longitudinal study of decision making for infants with complex chronic conditions (R01NR010548, Docherty (PI))
- **193** interviews from **46** participants.
- Participants included mother, father, attending MD, NP, RN caring for infants with complex congenital heart disease
- Interviews began at infant birth or diagnosis and continued monthly or following a life-threatening event, until age 12 months or death
- NVivo 12 Pro was used to assist with coding and thematic analysis.

FINDINGS

Major Themes from Interview Transcripts

Parents

Hope and feelings, decision making, perceptions of communication (pos, neg), interpretation of communication, desire for information

Mother: “the biggest thing just communication and treat people like they’re people...taking time to communicate with each other too like not just the parents but to communicate with each other.”

Health Care Providers

Hope and feelings, provider decision making, interpretation of communication, avoidance of communication from parents, interpretation of parents’ understanding and feelings

Nurse: “for me, like hopeful would mean getting the baby home, having the baby lead a normal life and having good quality of life.”

Barriers to Communication

Provider hand-off and lack of continuity, provider’s unclear phrasing, one-way communication, contradicting information

NP: “in the cardiac unit we don’t include the families on rounds...so they don’t have an opportunity to hear our thought process as we’re going along.”

Nurse: “it kind of falls on the family to ask for a doctor or physician or somebody to update them...like a daily update or anything like that does not happen unless, unless it’s specifically asked for.”

DISCUSSION

Parents perceive that providers are not as confident or hopeful as they say. **Parents** want information quickly and honestly, and feel positively when informed and supported by the provider team.

Providers wish to remain transparent, but it is often easier for them to “sugar-coat” or necessary for them to provide vague responses. Across **providers**, there are varying perceptions of parents that may affect communication and information shared.

Several **barriers** to parent-provider communication exist.



For more information regarding our discussion as well as a full list of references, please visit the following QR code:

