



Parental Prep Talk: A Pilot Study on Parental Preferences During Prenatal Counseling for Suspected Critical Congenital Heart Disease

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Background

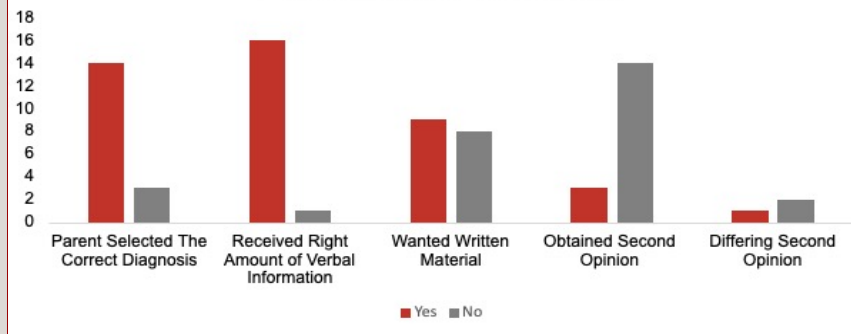
- Over 40% of congenital heart disease (CHD) are detected prenatally
- Minimal research on parental preferences regarding prenatal counseling
- Some studies suggest parents want more information at prenatal diagnosis
 - Majority older children or not prenatally diagnosed
- Goal: Assess satisfaction with, understanding of, and retention of prenatal counseling at time of birth.

Methods

- Survey of English-speaking families admitted to our institution
- Prenatal diagnosis of critical CHD
- Given within days of patient birth, but prior to intervention
- Survey answers compared to documented prenatal and postnatal diagnosis

RESULTS

Parental Survey Responses



Other Resources Parents Used

Other Children's Hospital Website	7
Riley Hospital Websites	5
Non-Hospital Websites	5
Social Media	5
Family/Friends	3
Other	3
None	5

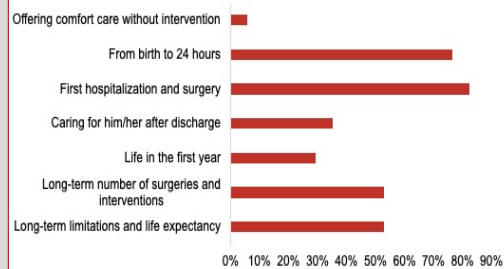
Conclusions

- Most parents of newborns with prenatally diagnosed critical CHD feel they receive "the right amount" of prenatal information
- Half would prefer more written materials
- Half recall long-term discussions
- Varied recall about interventions during the first hospitalizations
- Only one parent recalled comfort care discussions
- Majority of parents recognize their child's primary cardiac disease, but they cannot provide a cohesive description

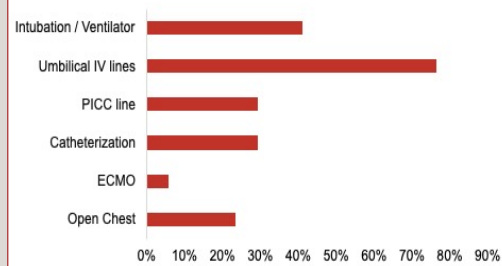
Demographics

Parent		N = 17 Parent – Infant Pairs
	Mother	11
	Father	7
Age		
	< 18	0
	18-25	4
	25 -30	5
	> 30	8
Education Level		
	Less Than High School	0
	High School Degree	7
	Associate Degree	3
	Bachelor's Degree	7
	Graduate Degree	0
# of Prenatal Visits		
	1	1
	2	4
	3* (Median)	5
	4	3
	>4	4

Parent Recall of Prenatal Discussions Concerning Treatment Plans and Outcomes



Parent Recall of Prenatal Discussions of First Hospitalization Interventions



No Financial Interests to Disclose.

Next Steps

- Continue enrolling patients
- Correlate preferences with parental demographics
- Develop and provide further written materials
- Adjust practices based on results and reevaluate parental preferences

REFERENCES

- Arya B, Glickstein JS, Levasseur SM, et al. Parents of children with congenital heart disease prefer more information than cardiologists provide. *Congenit Heart Dis.* 2013;8(1):78-85.
- Hilton-Kamm D, Sklansky M, Chang RK. How not to tell parents about their child's new diagnosis of congenital heart disease: an Internet survey of 841 parents. *Pediatr Cardiol.* 2014;35(2):239-52.