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### Parent Decision Making With Fetal Surgery

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# Parent Decision Making with Fetal Surgery

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## Children's Mercy Kansas City

### Introduction

- Parents who find out that their unborn baby is diagnosed with Spina Bifida have the option of fetal surgery.
- Parents face a short timeframe from diagnosis to decision, and weigh risks and benefits to both mother and baby.

### Study Aims

- To learn more about how parents make the decision to pursue fetal surgery. Few studies have looked at this aspect of family-centered healthcare.
- To determine the use of the Shared Decision-Making framework to describe parent interaction with the healthcare team.

Antiel et al, 2016; Adzick et al, 2011; Fry & Frader, 2018

### Preliminary Conclusions

- Parents find comfort and meaning in fetal surgery as a mechanism for caring for their unborn child and entering the parent role.
- Parents arrive at this decision primarily through their personal values, connection with other parents' shared experiences, and connection with the healthcare team.
- We hope to use this initial qualitative study to shape parents' care and lay the groundwork for future studies on the psychosocial impact of fetal surgery.

**"I'm just so grateful for the surgery because it gave my daughter a life that she deserves to live." - Parent**

### Methods

- This is a qualitative study using semi-structured interviews and purposive sampling.
- Interviews were transcribed verbatim; an inductive approach was used to analyze data from the interviews.
- Thematic analysis was conducted by the study team.

### Preliminary Findings

- Parents' decision making focused primarily on their baby and the potential benefits that could be gained from surgery.
- Decision making was quick, decisive and heavily influenced by other parents they connected with online. Compassion and support from the healthcare team was important to parents as they considered options.