

Supplementary Online Content

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eAppendix. Interview Guide

This supplementary material has been provided by the authors to give readers additional information about their work.

eAppendix. Interview Guide

Narrative and understanding:

- I want to hear your story.
 - o First interview: When did you first find out that your baby could have a heart problem? How did you get to the Fetal Cardiology Clinic?
 - o Second interview: I want to hear your story since your first visit to the Fetal Cardiology Clinic. What has happened?
- What did you learn from your appointment?
 - o Can you describe what is going on with your baby? What is your understanding of your baby's diagnosis and how it might affect his life and your family's life?
 - o Can you describe the options you have in your own words?
 - o Do you have questions about what is going on?
 - o Are there things you wish you knew or did not know?

Role of the providers:

- What was your experience at the Fetal Cardiology Clinic?
 - o How did you feel during the ultrasound? During counseling?
 - o Did you feel like you understood what was going on?
 - o How do you feel about the amount of information you were given?
 - What was important?
 - Are there things you wish had been communicated differently?
 - o Some parents say that when they hear a diagnosis, they then go blank and hear nothing else. Others say that they become extra focused and remember every word. How did you respond to hearing the diagnosis?
- What do you remember most about the providers in Fetal Cardiac Clinic?
 - o Was there anything that stuck out to you?
 - o Is there anything that could have gone differently?

Anticipation:

- What is the next step?
 - o How will you prepare?
 - o What will be your role?
 - o What does this problem mean to and for you and your family?
- You are going through a clearly stressful time in life.
 - o What is your greatest fear? What are you most worried about?
 - o What are you and your family hoping for?
 - o What do you imagine for your child?

Influencing factors:

- On a 1 to 10 scale, how much control do you feel like you have? Why?
- On a 1 to 10 scale, how stressed are you currently? Why?
 - o What are some of the other things going on in your life?
 - o How has the stress been affecting your family?
 - Do you have any other children?
 - Do you care for anyone else?
 - o How is this affecting your job?
 - o Is there anything in your personal medical history or in your family's medical history that has prepared you in any way for this experience?
- On a 1 to 10 scale, how well do you think you are coping?
 - o How are you coping?
 - o How do you typically respond to stress or difficult times?
 - o How are you now coming to accept this diagnosis and move forward in life?
- On a 1 to 10 scale, how supported do you feel?

- Where are you getting support from?
- Family? Friends? Internet? Church?
- Have your relationships been impacted during this pregnancy?

Resilience and empowerment:

- How difficult has this experience been for you? For your family?
 - Does anything make it better?
 - Can you think of anything your provider could do to make it better?
 - Identify another parent to talk with?
 - Give you a letter that details your child's condition simply?
 - Provide a list of reputable websites?
 - Identify a specific support group?
- Imagine a parent like you was referred to Fetal Cardiac Clinic for evaluation of a similar diagnosis:
 - What would you tell them to expect?
 - What questions would you suggest they ask?
 - What would you want the physician to make sure to say or do?