

Confidential

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Interview Part 1

Thank you for taking the time to complete our questionnaire. The goal of our project is to explore how women choose the mode of ending their pregnancy (surgical or labor induction) when faced with a lethal fetal diagnosis as well as assess how these women are cared for. It is our hope that this will allow us to understand a woman's experience at this difficult time in addition to identify factors which may help or hinder the healing process. Most questions are followed by a free text box where you can respond; there is no limit to the number of characters you can type. The questionnaire should take approximately 60 minutes to complete; you do not have to complete the questionnaire in one sitting. If you choose to save and quit, you will be issued a validation code which you **MUST** record. You will also be emailed a link allowing you to return where you left off; you need the validation code to re-enter the survey. The remaining questions require a short answer or selection from a drop down menu. Again, thank you for your participation; if you have any questions you may contact Jessica Greenblatt, MD at jgreenblatt@mcw.edu.

By clicking "yes", you indicate that you have read the consent form and agree to participate in the survey. If you do not wish to participate in this survey please check "no".

- Yes
 No

The first few questions pertain to receiving the fetal diagnosis.

1. What diagnosis did you receive for this pregnancy?

2. How far along, in weeks, were you in the pregnancy at the time of diagnosis?

- < 12
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23

3. How do you refer to the entity that was lost?

- Fetus
- Baby
- The Pregnancy
- By the name you gave
- Other

Specify other

4. What was the gender?

- Male
- Female
- Unknown

5a. Had you ever heard of this diagnosis before?

- Yes
- No

5b. Did you know of anyone else whose pregnancy was affected by a lethal fetal diagnosis?

- Yes
- No

6. What reaction(s) did you have about the way in which your doctor presented the diagnosis?

7. At the time of diagnosis, what feelings did you experience that surprised you?

In the next few questions, I'd like you to walk me through how, after deciding to end the pregnancy, you made the decision to proceed with a surgical procedure (D&E) or labor induction.

8. What options, if any, were you aware you had for this pregnancy prior to speaking with your Family Planning physician (Drs. Walczak, Broekhuizen or King)?

9. What factors went into your decision to choose either labor induction or a surgical procedure?

10. Who, if anyone, influenced your decision making?

11. Did your reflection on your personal values influence this decision and if so, how?

12. What personal health conditions, if any, did you consider when choosing between labor induction and a surgical procedure?

13. What feelings were connected to making the decision to undergo labor induction or a surgical procedure?

14. Who did you tell about your decision and who did you decide not to tell?

15. What kind of support did you receive from others?

The next questions pertain to your experiences with different aspects of healthcare.

16. What features about your clinic experience stand out in your mind, whether positively or negatively? (For example: staff, physical environment, physician consultation)

17. What features about your hospital experience stand out in your mind, whether positively or negatively? (For example: staff, physical environment, nurses, physicians, resident physicians)

18. What, if any, sort of service, ceremony or ritual did you have or consider having?

19. What was your experience returning home and to your usual activities?

20. What suggestions do you have for doctors, nurses, Fetal Concerns staff, billing staff or anyone else that would be helpful in providing the best care for someone else experiencing a similar situation?

21. What else would you like to share that you haven't yet that could help me understand your experience?

The next questions are useful in our analysis of the data. These questions should take less than five minutes to complete.

22. What is your relationship status

- Committed relationship
- Married
- Separated
- Divorced
- Single

How many years?

- 1-2 years
- 3-5 years
- 6-10 years
- >10 years

How many years?

- 1-2 years
- 3-5 years
- 6-10 years
- >10 years

23. What is your highest level of education achieved?

- Did not complete high school
- Completed high school/GED
- Some college
- 2 year College
- 4 year College
- Graduate/Professional degree
- Doctorate
- Other

Specify

24. What is your age?

-
- 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - >45

25. What is your race/ethnicity?

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Hispanic or Latino
- Other

Specify Other

26. What religion or philosophy do you identify with?

- Protestant Christian
- Roman Catholic
- Jewish
- Muslim
- Hindu
- Buddhist
- Agnostic
- Atheist
- Other

Specify Other

27. What kind of insurance do you have?

- Public (e.g. Medicaid, Badger Care)
- Private (e.g. Aetna, Humana)
- None

28. Are you currently employed?

- Yes
- No

What is your occupation?

Next, please list your pregnancy history, not including this pregnancy.

29. How many times have you been pregnant (confirmed by ultrasound)? _____

29a. How many times did you deliver at term (37 weeks or more)? _____

29b. How many times did you deliver preterm (21 weeks or later but prior to 37 weeks)? _____

29c. How many miscarriages or ectopic pregnancies (spontaneous pregnancy loss prior to 21 weeks) have you had? _____

29d. How many elective abortions have you had? _____

29e. How many living children do you have? _____

Interview Part 2

Thank you for taking the time to complete our questionnaire. The goal of our project is to explore how women choose the mode of ending their pregnancy (surgical or labor induction) when faced with a lethal fetal diagnosis as well as assess how these women are cared for. It is our hope that this will allow us to understand a woman's experience at this difficult time in addition to identify factors which may help or hinder the healing process.

Most questions are followed by a free text box where you can respond; there is no limit to the number of characters you can type. The questionnaire should take approximately 30 minutes to complete; you do not have to complete the questionnaire in one sitting. If you choose to save and quit, you will be issued a validation code which you **MUST record. You will also be emailed a link allowing you to return where you left off; you need the validation code to re-enter the survey. The remaining questions require a short answer or selection from a drop down menu.**

Again, thank you for your participation; if you have any questions you may contact Jessica Greenblatt, MD at jgreenblatt@mcw.edu.

- 1) 1. Several months ago we asked you about your experience regarding the diagnosis of a lethal fetal anomaly and your decision to end the pregnancy; what are your feelings now? _____
- 2) 2. As you reflect on your experience, how do you think you would feel if labor induction or D&E (ie surgical procedure) were not available? _____
- 3) 3. How do you think you would feel if you had chosen to undergo the opposite method (D&E if you chose labor induction and vice versa)? _____
- 4) 4. What has been your experience since returning home to your usual activities? _____
- 5) 5. Who have you shared your experience with?
 - Spouse
 - Parents
 - Siblings
 - Children
 - Other Family
 - Friends
 - Support Group
 - Other
- 6) Specify _____
- 7) 5a. What were their responses? _____
- 8) 6. Who or what is a source of support at this time? _____
- 9) 6a. To what extent do you feel your sources of support understand your loss? _____
- 10) 6b. What additional support do you wish to receive at this point in time? _____
- 11) 7. What advice would you offer women going through a similar experience? _____

12) 8. What else would you like to share that you haven't yet that could help me understand your experience?

Thank you once again for taking the time to complete our questionnaire. We understand this is a difficult experience and appreciate your willingness to be open and candid. If you have any concerns or questions, please email me at jgreenblatt@mcw.edu.

- 13) 9. Would you like to receive an invitation by email to a focus group at the conclusion of the study? The goal of the focus group is to ensure that our interpretation of the information you gave us is accurate and reflects the experiences of the women who participated in this study.
- Yes
 No
- 14) 10. Would you like to receive a copy of the final study report by email after completion of the study and analysis of the data?
- Yes
 No