

Advancing care and support for women and families after stillbirth or neonatal death in Sub-Saharan Africa: A feasibility study

Interview Topic Guide

(Version 1: Women)

Interviews with women to explore experiences of care and support after stillbirth or neonatal death and the study intervention in Kenya and Uganda:

1. Introduction, setting ground rules:

Introduce self, thank participant for taking part and confirm agrees to interview taking place.

Ensure environment is comfortable. Discuss the following issues:

- Review the nature and purpose of the research.
- No right or wrong answers, aim to understand experiences.
- Confidentiality, use of data.
- Explain the use of data recorder, transcription, use of pseudonym (invite to choose), use of verbatim quotes, will be taking field notes.
- Researcher aware that discussion might bring up difficult memories, explain can decline to answer any question or prompt; can ask to stop at any time if feels need to.
- Expected duration of interview.
- Check consent form signed, complete case report form and psychological questionnaire.
- Ask if any questions.

Check recorder working

Introduce and switch on tape recorder

General prompts

- *Allow participant to respond uninterrupted and use open prompts if required to explore aspects of their experiences in depth.*
- *Can you tell me more about XXX?', 'What makes you say XXX?, How did XX make you feel?*

2. Opening questions:

Can you tell me about, your pregnancy, the birth and the death of your baby?

- Establish the sex of the baby and use daughter or son in discussion. Follow their lead if unsure.
- Allow participant to describe what happened, when and how

3. Care in facilities:

Can you tell us about the care you received whilst you were in the hospital/facility after the birth?

- Explore how they were told about the death, other communication with staff in facilities.
- Did they see/hold their baby, how was this managed?
- Explore length of stay in facility, discharge process.
- Explore awareness of the intervention e.g. bereavement champions, any specific aspects of care which were helpful.

4. Going home:

Can you tell me about your feelings and how you are coping since you came home?

How did others respond to you following the death of your baby?

- Explore – experiences with partner, family and, friends?

Have you had any contacts with health workers since you came home?

- Any routine follow up, explore advice and support
- Explore any health problems after the birth, access to care, how health issues impacted on coping with the death of the baby.

Explore awareness/access/uptake of the peer support component?

- If they accessed this explore experiences.
- Explore potential barriers to uptake (lack of access to phone, costs of calls, texts etc)

5. Present situation:

Has anything in particular helped you cope with your baby's death?

- Explore cultural, religious beliefs and traditions.
- Explore any other sources of support.

What could have improved your experience?

- Explore any factors identified by the woman, including aspects of care or support in facilities or after discharge, including the intervention that might be altered or improved.

6. This research:

How do you feel about participating in this research?

How do you feel about participating in this interview?

Is there anything else you might want to add?

At the close of the interview briefly summarise the main points to confirm interpretation with the participant. Ask if they wish to expand any responses or add anything else to the discussion. Thank the participants for their time.

Ask how they feel after talking about these experiences, do they want you to contact anyone? Family, friend, health worker?

Ensure participant has contact details for the local research team should they wish to discuss any aspect of the study.

Complete reflexive diary/field notes.