

Supplement 2: In-depth Interview Guide

1. Let us talk about your baby. Can you tell me why you are here?

Probe: present condition, knowledge about diagnosis

2. Talking about your experience, how do you feel about having your baby admitted here?

Probe: different feelings- positive and negative, spouse's feelings

3. What stresses you about having your baby admitted here?

Probe: baby, environment, peers, staff

Alternate question if the participant doesn't respond: Can you tell me an instance when you felt negative (e.g. anxious/ sad/ angry/ helpless)

And positive (e.g. happy) such emotions in the NICU?

Probe for various emotions mentioned in Question 2

5: What do you feel/think the baby goes through? Do you discuss it with anyone?

Probe - Pain?

- Discuss with immediate family, peers, neighbours, NICU staff.

6. How do you cope when you are faced with this situation?

Probe: present condition, knowledge about diagnosis

7. Do you have any earlier experiences with seeking care for sick babies?

Probe - In your family? Among you friends?

8. Let us discuss about the expenses related to your baby's condition. Can you tell me how you and/or your family mobilized the money for your child's treatment? *(assess if guardian is willing to speak. If yes, continue. If not, reassure him/her and ask if they can answer now. Else, come back again)*

Source	Yes?
It was free	
Salary/Savings	
Working overtime	
Mortgaging of assets (jewellery, land, livestock, etc)	
Selling of assets (jewellery, land, livestock, etc)	
Borrowed from relatives/friends without interest	
Borrowed from relatives/friends with interest	
Loan (moneylender, bank)	
Health insurance a) BPL free/poor free b) Government employee c) RSBY d) Private Insurance e) NRHM scheme f) ESI g) Any other, specify..... g) None	
Others, specify	

9. Has the illness affected the family financially? What changes or adjustments did you have to make in your daily life due to your child's illness?

Probe- cutting down costs), Work, Household chores, Accommodation, Baby sitting

Others- child education, food security, changes in spouse's life

Closing questions:

10. What is the one thing that is on your mind right now?

11. What help could you have received to make this entire experience better?

Probe- Health, finances, support (peer, family, health system)

Is there anything else you would like to tell me? Do you have any questions for me?

-Thank you for your patience and time.

- End of interview-

