Supplementary Material

Interview Guide

Introduction
Hi, my name is _______ and I am part of the team that is conducting research about how parents of babies in the NICU (neonatal intensive care unit) deal with uncertainty, such as when medical problems come up and there may be no way to know how these problems will affect their child in the future.

We will be recorded our interview with you to help us understand this concept of uncertainty. Everything we record will be deidentified, meaning that it cannot be linked to you or your baby. Nothing you say here will be connected to your child’s name or medical record, so we hope you will feel free to share your honest opinions and experiences. It is just as important for us to hear about negative experiences as positive ones, so we hope you will share these with us. What you say will not affect your child’s care now or in the future.

If at any time you want to stop or take a break, please let me know. You can decide at any point if you do not want to answer particular questions.

Do you have any questions before we get started?
Is it okay if I turn on the recorder at this time?
Okay, now that I have turned on the recorder, can you confirm that you agree that I can record this interview? Thanks.

Today is (provide date here) and this is participant number (enter number here).

Introduction

• I would like to start by learning about your baby’s experience in the NICU. Can you please tell me why your baby is/was in the NICU?

Now I would like to ask some questions about times during your baby’s hospital stay when there was something that came up that made their future even more unclear or unknown and it was hard to predict what their life would be like either in the next few hours to days, or even longer than that, in the first several months or years of their life.

I would like you to remember a specific time where something like this happened; something about your baby’s health that brought up questions about how they would do. Some examples of this might include: your baby having a head ultrasound that showed bleeding and it was not clear how this would affect them; an X-ray that showed something was wrong about your baby’s belly, but it was not clear if that meant they would need to not eat for a short period of time or some other procedure; your baby having their breathing tube removed and not knowing if they would breathe well on their own or not, or your baby having an eye exam that showed that their eyes were showing some possible problems from being born early, but it was not clear how bad it was or if they would need to have something done about that.

If you remember several situations like this, I would like you to think about the one where you have the clearest memory of a doctor or nurse talking to you it.

• Can you think of such a medical problem? (if no, provide more examples and give more time).
  ➢ What was this situation? (Check here that this is truly prognostic uncertainty; if not, provide more examples).

Communication of uncertainty

• Who told you about this problem?
  ➢ If doctor — was it a neonatologist or someone else? Do you remember if it was a doctor in training (that is, a resident or a fellow) or an attending doctor?
  ➢ If nurse — was it your bedside nurse or a nurse practitioner?

• Can you tell me a little bit more about how they told you? I would like you to paint a picture for me what that interaction looked like.
  ➢ Further probe:
    □ When and where did they talk with you? (on rounds or some other time, in baby’s room or somewhere else)
• What did they tell you?
• How did they tell you this?
  ➢ Further probes:
    ▪ Do you remember about what they said about what happens to babies who face this kind of medical problem?
    ▪ Did they give you statistics?
    ▪ Or compare the situation to something else like <insert example>? 
    ▪ Or write something down for you?

• What were you thinking then?
• Is there anything that you wish the provider had done differently about how they told you?
  ➢ Further probes:
    ▪ Would you have wanted them to give you more statistics, written things down for you, asked you more questions, 
      used more metaphors, or any other way?
    ▪ Would you have wanted them to tell you in a different place and time with other people present?

• What was most helpful about how the provider communicated with you?
• What about how other providers communicated with you?
• What was most unhelpful or even hurtful about how they communicated with you?
• Would you have wanted someone else to be the one telling you? Why?

**Parent experience of uncertainty**

• Did this situation change your hopes and dreams for your child?
• What were your worries or fears about the future after talking to the provider?
• What did you do to deal with these worries or fears?
  ➢ Further probes/clarification:
    ▪ Some people want more information, others prefer spiritual ways, others find other ways of support through 
      online Facebook groups.

• Did you think your way of dealing with these worries or fears was helpful or not?
  ➢ Probe:
    ▪ Did you first try some things, realize they were not helpful and then try something else?

• Did you try to seek further information to clarify or understand this situation on your own?
  ➢ Further probes:
    ▪ How did you seek this out? Other parents? Internet? Family? What types of information did you seek out (e.g., 
      information about how other children do in this situation, experience of parents in similar situations, specific 
      information related to the diagnosis)?
    ▪ Was this helpful? Why/why not?

• What do you think could have helped you more in retrospect?

**Integration**

• Do you think the way in which the provider told you about this situation changed how you dealt with it? Why/why not?
• Could they have done something differently to help you?

**Closing**

• Is there anything else that we have not discussed that you think is important for us to know?

Thank you so much for volunteering for our study and for agreeing to be interviewed today. We hope that this will help us learn more about how the different ways doctors and nurses communicate can affect parents. I am also going to ask that you complete this brief questionnaire before you leave. Like we discussed earlier, you will receive a gift card. Do you have any additional questions at this time? I am now going to turn off the recorder. Thank you so much for your time.