Supplemental Information

INTERVIEW GUIDE

Hello, may I speak with ________? This is __________, and I’m calling from Washington University in St Louis. Is now still a good time to discuss our research project?

Great, thank you. Have you had a chance to review the consent document from the previous e-mail?

[If no: “Do you have access to your e-mail to review that form now?” If not: “Okay, I can read the consent document to you over the telephone.”]

Do you consent to participation in this study?

1. Great. In the following questions, I am going to ask about communication with your child’s medical team. By medical team, I mean the nurses, doctors, nurse practitioners, physician assistants, and staff that were involved in your child’s cancer care. Keeping this in mind, can you tell me what good communication with your child’s medical team means to you? [If unsure how to answer, could be re-stated as “When you think of good communication with your child’s medical team, what comes to mind?”]

[2. Now, what comes to mind when you think of poor communication with your child’s medical team?] (No need to ask if first question elicits negative experience.)

Great. Thank you for sharing those thoughts. During this interview, I am hoping to explore many different aspects of communication between you and your child’s medical team. This communication might include the way you were spoken to, the information you received, even non-verbal things like the way the doctor or nurse stood, or whether they made eye contact with you. Even paperwork can be a form of communication. It would be great if you could consider all of these aspects of communication during this interview.

3. Next, I’d like to ask you about some of your communication experiences while your child was being treated for cancer.

3.1. Can you tell me about a time when your medical team communicated really well with you?
   a. What made this experience good?
   b. What did this good communication help you to do?
   c. What other experiences stand out as good communication?
   d. What else you would like to add?

3.2. Can you think of an example when the medical team communicated poorly with your child?
   a. What made this experience bad?
   b. What did it make harder for your child to do?
   c. What could have made this communication better?
   d. What other experiences stand out?
   e. Anything else you would like to add?

3.3. Okay, now I’d like to ask about a time when communication did not go well? Can you share an experience?
   a. What made this experience bad?
   b. What did it make harder for you to do?
   c. What could have made this communication better?
   d. What other experiences stand out?
   e. Anything else you would like to add?

3.4. Can you think of an example when the team communicated poorly with your child?
   a. What made this experience bad?
   b. What did it make harder for your child to do?
   c. What could have made this communication better?
   d. What other experiences stand out?
   e. What else you would like to add?

3.5. Can you tell me about anything you wish your child’s medical team would have done but they didn’t?

4. Now, I’d like to ask about your interactions with your child’s medical team.

4.1. What types of things were your doctors most likely to talk with you about?
   a. What things were hard for you to talk about with your child’s doctors?
b. What things do you wish your doctors would have talked with you about but they didn’t?

4.2. What types of things were your nurses most likely to talk with you about?
   a. What things were hard for you to talk about with your child’s nurses?
   b. What things do you wish your nurses would have talked with you about but they didn’t?

4.3. How was communication with the other specialists that took care of your child?
   c. What was frustrating about this communication?
   d. What went well with this communication?

4.4. Now I’d like you to think about times when you were home. How frequently did you try to contact your child’s medical team in between appointments or hospital stays?
   a. What were you contacting them about?
   b. Who answered your questions?
   c. How did that go?

5. Now, I am interested in learning more about what you might have wanted or needed from your medical team at different stages of treatment.

5.1. What were the best things your medical team did to support you and your family just after your child was diagnosed with cancer?
   a. Were there things your child’s medical team could have done to help you but didn’t?

5.2. (Only for survivorship parents) What were the best things your medical team did to support you and your family around the time your child completed treatment?
   a. Were there things your child’s medical team could have done to help you but didn’t?

5.3. (Only for bereavement parents) What were the best things your doctors did to support you and your family while your child was living with advanced cancer?
   b. Were there things your child’s medical team could have done to help you but didn’t?

5.4. (Only for bereavement parents) What were the best things your doctors did to support you and your family after your child died?
   c. Were there things your child’s medical team could have done to help you but didn’t?

6. Thank you so much for all of your thoughts so far. This has been very helpful. We are almost finished. I only have a couple more questions for you.

6.1. What communication advice do you have for a medical team talking to a family who just learned about their child’s cancer diagnosis?
   a. (Only for survivorship parents) What about advice for the medical team after the child has finished their cancer treatments?
   b. (Only for bereavement parents) What about advice for the medical team when a child is living with advanced disease?
   c. (Only for bereavement parents) What about advice for the medical team when a child has died?

6.2. What communication advice do you have for the parents of a child who was just diagnosed with cancer?
   a. (Only for survivorship parents) What about a parent whose child just completed treatment?
   b. (Only for bereavement parents) What about a parent whose child is living with advanced cancer?
   c. (Only for bereavement parents) What about a parent whose child unfortunately did not survive cancer?