

Additional File 1: Semi-structured interview guide

Interview Questions

Thank you again for participating in this interview. As we mentioned in the consent form, our research team is interested in learning more about your family's background, your experience having a child diagnosed with tuberculosis (TB), your thoughts and feelings about TB medications and how your child's illness has impacted your household. We are also interested to learn what additional information, resources or support may have been helpful to you and your family when your child was first diagnosed and over the course of his/her illness. We will be taping the interview with an audio recorder. Please do not refer to yourself or to your child by name in order to keep the recording confidential.

Background

- What village are you and your family from? What tribe do you belong to?
- Who lives in your household? Who are the child's guardians?
- What language(s) do you mostly speak at home? (If not Swahili ask: Do you also speak Swahili?)
- How old is your child? What is the highest level of schooling that he/she has completed, or what grade is he/she in currently?
- What is the occupation of each adult who regularly resides in the household? What is the highest level of schooling that they have completed?

Tuberculosis disease

- When did you notice your child was sick (*with current illness*)?
 - What made you think he or she was sick?
 - What did you do next?
- In your village, what action do people usually take when they notice that a child is sick, with signs and symptoms similar to what your child had?
- Have you ever heard about the disease called tuberculosis, or TB?
 - If so, when did you first hear about this sickness?
 - Tell me what you know about TB.
 - Where did you get this information?
- Does your child talk about his or her sickness?
 - If so, what does he or she say?
 - Does he or she talk about TB?
 - What do you think he or she knows about TB?
- There are many places where a person can seek medical care for TB illness. Tell me about any other places you may have visited for your child's health before bringing him/her to Haydom Lutheran Hospital.
- Please tell me about how your family decided to come to Haydom Lutheran Hospital instead of another health facility (for example, a private dispensary).
- How did you find out that your child had TB?

- How did you feel about getting that news?
- How long ago did your child receive his/her TB diagnosis?
- How did you and your family initially deal with the diagnosis?
- Based on what you have learned about TB, can you explain to me how a person gets it? In your own knowledge/words, how does TB spread?
 - How do you think your child got TB?
 - What do you think can be done to prevent TB?

Daily life (adults)

- Please describe a typical day in your life *before* your child became ill with TB (from the time you woke up in the morning until the time you went to sleep at night).
 - What, if anything, is different about your daily routine now that your child has TB?
 - In what ways has having a sick child changed your responsibilities inside and/or outside of the home?
- How has the child's father's routine, work and responsibilities been impacted by your child's TB illness?
- What has been the impact on your family's finances to have a child with TB?

Daily life (children)

- Please describe a typical day in the life of your child *before* he/she became ill with TB.
 - What, if anything, is different about his/her daily routine now that he/she has TB?
- (*For school-aged children only*) How has having TB impacted your child's schooling?
 - In what ways has having TB impacted his/her relationships with friends? How about relationships with other children in your neighborhood or village? How has TB illness affected your child's relationships with other children in his/her school?
- Having a child with TB can also have an impact on healthy children living in your household. In what ways has having a sick child affected your other children's lives, feelings and/or routines?

Family + community members

- How have extended family members (uncles, aunts, grandparents, cousins, half siblings, etc.) reacted to your child's illness?
- How have your neighbors and your community reacted to your child's illness? Has your relationship with neighbors/community members changed in any way since your child was diagnosed with TB? Please explain.

Medical care + treatment

- After being diagnosed with TB, some people find it challenging to attend medical appointments/DOT office visits. Tell me about some of the barriers or challenges that you and/or your child faced in attending TB medical appointments.

- Please describe a typical day when your child has to attend a TB medical appointment/DOT office visit.
 - What do you do?
 - Where do you travel and how do you get there?
 - How much time is spent traveling to the clinic and back home again?
 - How much money do you spend that day on meals / childcare / transportation / medication / other expenses?
 - What is your household's average monthly earnings?
- (*For limited Swahili proficient participants only*) In what ways, if any, has being a [*insert local language here*] speaker impacted your child's medical care and the attention your family receives at the clinic?
 - Tell me about an experience that you had with a TB health care worker, nurse, doctor or clinic when they did not speak your language.
- What additional information, resources or support would be helpful for a family after their child is first diagnosed with TB (assistance with transportation to medical appointments/dispensaries, child care, nutritional assistance, etc.)?
 - What additional resources or support might make life easier for families with sick children throughout the course of their illness, from beginning to end?

Medication

- Can you please show me the TB medication that your child takes?

Questions for child:

- Some people give “famous names” to their medications. What do you commonly call these tablets?
- What do you know about these TB medicines?
- What do you think about taking these TB medicines?
- If you have ever taken the tablets that are mixed into water before drinking, what do you think of this type of medicine?
 - Tell me about the taste.
 - How easy or difficult is it for you to take this medicine?

Questions for parent/guardian:

- Some people give “famous names” to their medications. Do you call these tablets something different from what your child calls them?
- What do you know about these TB medicines?
- What do you think about your child having to take these TB medicines?
- If your child has ever taken the tablets that are mixed into water before drinking, what do you think about this type of medicine?
 - What does your child think about the taste?
 - How easy or difficult is it for your child to take this medicine compared to other pills that they take?

- Some patients find it challenging to take TB medications as prescribed by their health care providers. Some parents of children with TB also find it difficult to administer medications to their children.
 - Tell me about how easy or difficult it was for you and your child when he/she first began taking the TB medication.
 - Is it any different now?
 - Tell me about a time when your child missed his or her treatment.

Research

- As our interview comes to a close, I wanted to ask you a few final questions about your experience participating in this research study.
 - Please tell me about any previous experiences that you or your relatives have had participating in research studies at HLH or elsewhere.
 - How did you decide to enroll your child/yourself in the study? What motivated you to do so?
 - What did you find most rewarding about the experience? Most challenging?
 - We are always trying to learn ways in which we could do a better job in our work. If you could give one (or more) recommendation to improve the research experience for participants and their families, what would it be?

Other

- Is there anything else you would like to add that we have not talked about?