

Supplemental Material

Cancer Treatment Decision-Making among Parents of Pediatric Oncology Patients in Guatemala

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1. Interview Guide

1. Tell me about your experience at UNOP.
 - a. Who told you to come?... how did you get here?... when did you arrive?... What happened next...?
 - i. Where did you stay while your child was being diagnosed?
 - ii. Who came to the visits?
 - iii. Who visited you while you were here?
 - iv. Who did you meet with?
 - v. What testing was done?
2. Before your child was diagnosed, what did cancer mean to you? What had you heard about cancer?
 - a. Did you know anyone with cancer?
 - b. How do people in your community think about cancer?
 - c. Had you heard the word before? How did you first hear it/learn about it?
3. Tell me, did you go to another hospital or receive treatment anywhere before you came to UNOP?
 - a. If so, where?
 - b. What did they tell you about your child and his/her illness?
 - c. Did you try any medicines or remedies before coming to UNOP?
 - i. What happened with these?
4. At the time your child was diagnosed at UNOP, who explained cancer to you?
 - a. How did they explain it?
 - b. How was that similar to what you already understood/believed about cancer?
 - c. How was it different to what you understood/believed about cancer?
 - d. Did you talk to the team about these similarities/differences? Were all of your questions answered/addressed?
 - e. How does this relate to your other experiences with illness?
 - i. How is it similar/different?
5. What is your understanding of cancer now?
 - a. How did you reach this understanding?
 - b. Is this similar to or different from what your family thinks about cancer?
 - c. Is it similar to or different from what others in your community think about cancer?
 - d. Is it similar to or different from what the doctors and nurses think?
 - e. Do you still have questions or concerns?
6. Tell me about how you usually make important decisions in your family/community.
 - a. There are lots of decisions a family has to make, for example, some families have to make decisions about how to spend money or whether their children will work or go to school. Who is responsible for making decisions in your family?
 - i. Are there others who have input in decisions?
 - ii. What is your level of involvement in decisions? Would you say you are mostly responsible for decisions alone? Do you share that responsibility? With whom? Do you have more limited input?
 - b. How is this similar to or different from the way your family has made decisions about your child's cancer?
 - i. Who is responsible for coming to appointments with your child?
 - ii. How is information from those visits shared with others in your family? In your community?
 - iii. What do you need to help you make decisions about your child's diagnosis and treatment?

- iv. Does your child have a say in decisions regarding his or her care?
 - v. Have there been disagreements about what to do for your child? Tell me more about those disagreements and how your family has handled that?
7. Now I would like to learn more about how you are feeling and what you are thinking about during this time, shortly after having a child diagnosed with cancer.
 - a. Who supports you during this time?
 - b. What changes have you had to make to your life/family?
 - c. Have you felt supported by the team at UNOP? How, or how not? By whom?
 - d. What are you worried about during this time? How does the staff at UNOP address these worries?
 - e. What are you most hoping for during this time? How does the team at UNOP address these hopes?
 - f. As you think about these hopes and worries for your child, which ones stand out as being the most important to you?
 - g. How have your hopes and worries about other things in your life changed since having a child diagnosed with cancer?
8. If you had the opportunity now to speak with other parents of a child recently diagnosed with cancer, what would you tell them? What advice would you give them?

2. Survey

Instructions for the interviewer:

- When conducting this interview (starting with the section titled “Demographic questions”) read all lowercase text aloud to the respondent.
- Instructions for interviewers are provided throughout the questionnaire in capital letters. Words appearing in capital letters are meant to guide the interviewer and should NOT be read aloud.
- Read instructions written in lowercase letters aloud to the respondent to guide him/her in answering the question.
- It is important to read questions in their entirety, exactly as they are written
- Many of the questions have answer choices. It is important for the interviewer to read *all* the answer choices aloud to the respondent before pausing for a response.
- If the respondent does not understand the question, first the interviewer must repeat the whole question. For some questions, there is an alternative explanation that the interviewer can use if the respondent still does not understand the question. If, after repeating twice and using the alternative explanation (if provided), the respondent still does not understand, the interviewer can explain in a few additional words before moving on to the next question and leaving it unanswered.
- If the respondent’s answer is not clear, the interviewer should repeat all of the response options and wait for a clear answer.
- For the questions involving a scale, the scale should be handed to the respondent before the question is read. For each question, the interviewer must point out the options with his finger, for example show “strongly agree”, “slightly agree” and “disagree”. Then, the respondent must use his/her finger to indicate an option and the interviewer will record this choice on the survey.
- The interviewer will be expected to fill out the survey as it is read aloud. Circle the number corresponding to the answer chosen by the respondent. For fill-in or open text answers, write the appropriate information as stated by the respondent.
- It is important that the interviewer is familiar with the instrument before conducting the interviews.

- At the end of the interview, the interviewer should gather a copy of the corresponding patient's demographic sheet (completed by the social worker) and use the medical chart to find the corresponding answers for questions 7-13.

Introduction to the survey:

Thank you very much for your time and your participation in our study. The purpose of the study is to learn about the experiences and preferences of parents of children with cancer. We hope that the results of this survey will help us better care for parents and children who come to our hospital in the future. Your answers will not affect your child's care, and your medical team will not know your answers to our questions. We would like to hear your opinions and we are not looking for a "correct" answer. Please, be honest with us. Also, since we are going to review the data all together and anonymously it is important that we gather some information about you that may seem obvious while we talk, such as your gender. Although that seems obvious to us now, it is important that I ask these things and that you answer me honestly. Thank you for your participation.

Demographic questions – Now we are going to ask you a few questions about yourself

1. What is your gender? [IF THEY DO NOT UNDERSTAND ASK: “Are you a...?”]

- Man
 Woman

2. What is your relationship to the child?

- Parent
 Sibling
 Grandparent
 Aunt/Uncle
 Legal guardian
 Other relative (*Please specify*)

3. What language do you speak at home?
Choose all that apply

- English
 Spanish
 K'che
 Q'eqchi'
 Kaqchikel
 Mam
 Poqomchi
 Tz'utujil
 Achi
 Q'anjob'al
 Ixil
 Akatek
 Jakaltek
 Chuj
 Poqomam
 Ch'orti'
 Awakatek

- Sakapultek
 Sipakapa
 Garifuna
 USpantek
 Tekitek
 Mopan
 Xincan
 Itza
 Other (*please specify*)

4. What ethnicity are you? *Choose all that apply.*

- White/Caucasian (European descent)
 Mestizo
 Quiché
 Kaqchikel
 Mam
 Quekchí
 Black Hispanic
 Other (*please specify*) _____

5. What is your religion?

- Catholic
 Evangelical
 Other (*please specify*) ____
 No religion

6. Do you believe in the Mayan spirituality?

- Yes
 A little
 No

Medical information – *Now we will ask a few questions about your child's illness and treatment*

7. What is the name of your child's diagnosis?

8. Where in your child's body is the [USE THE WORD PARENT USED IN QUESTION #5] located?

9. Has the [USE THE WORD PARENT USED IN QUESTION #5] spread to other places in the body?

- Yes
- No

10. How long will all of your child's treatment last? *Please check one.*

- Less than 6 months
- 6 months to 1 year
- More than 1 year, but less than 2 years
- 2 years or more

11. Which of the following will be part of the treatment of your child's cancer? *Please check all that apply.*

- Chemotherapy
- Surgery
- Radiation treatment

12. What is **your** main goal of your child's cancer treatment? *Choose one.*

- To cure my child's cancer
- To help my child live longer
- To decrease symptoms from the cancer

13. What is your understanding of **your medical team's** main goal of your child's cancer treatment? *Choose one.*

- To cure my child's cancer
- To help my child live longer
- To decrease symptoms from the cancer

Information Exchange – Now we are going to ask you a few questions about how you learned about your child's illness, including what you think has caused your child's illness, and who/what information was most important, influential, or useful to you when he/she was diagnosed

14. Parents have different ideas about where cancer comes from and we would like to hear from you. How much do you think the following factors explain why your child got cancer?

	<i>A lot</i>	<i>A little</i>	<i>Not at all</i>
Caused by an infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Due to heat or cold	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lacking hygiene or nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Because of a sacred mission	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How much do you think the following factors explain why your child got cancer?

	<i>A lot</i>	<i>A little</i>	<i>Not at all</i>
Due to bad thoughts (<i>malhecho</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sent by the devil (<i>diabólico</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supernatural; originating from natural elements (e.g. waterfalls, mountains, wind, darkness)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How much do you think the following factors explain why your child got cancer?

	<i>A lot</i>	<i>A little</i>	<i>Not at all</i>
Lack of respect for nature or the elements of the environment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bad relationships with the community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused by God or another religious figure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How much do you think the following factors explain why your child got cancer?

	<i>A lot</i>	<i>A little</i>	<i>Not at all</i>
Caused by uncontrol cell growth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused by fear or surprise (<i>susto</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused by medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Please look at this paper with different color circles. On the left, there are many green circles. These indicate something that you found very important. In the middle, there are just a few yellow circles. These represent something that for you was a little bit important. And on the right, after the red line, there are not any circles. This indicates something that wasn't important for you at all.

Please, show me with your finger how useful or important each of the following things was for you as a **source of information regarding your child's cancer**.

- Conversations with your medical team at UNOP (including oncologists, psychologists, nurses, social workers)
- Conversations within your community (for example, with neighbors, community leaders...)
- Conversations with your family (siblings, grandparents, aunts, uncles)

Please, show me with your finger how useful or important each of the following things was for you as a **source of information regarding your child's cancer**.

- Conversations with leaders in your religious or spiritual community
- An understanding within yourself (including a feeling, hunch or dream)
- Reading in books or looking for information on the internet

16. Parents differ in the amount of information that they want to know about their child's *diagnosis and treatment*—some want to know everything, others want to know very little. What is your preference for details of information about your child's diagnosis and treatment? *Choose one*.

- I want to hear as many details as possible in all situations relating to my child's cancer and its treatment.
- I want to hear details only in certain situations, in other situations I do not want to hear the details
- I prefer not to hear a lot of details.

17. How *important* is it to you to know about your child's likelihood of being cured?

- It is very important for me to know the likelihood of cure
- It is not very important for me to know the likelihood of cure
- I prefer not to know the likelihood of cure

18. How important is it to you to know about how likely it is that cancer or its treatment may affect your child's life in the future?

- It is very important for me to know the likelihood this treatment affecting my child
- It is not very important for me to know the likelihood this treatment affecting my child
- I prefer not to know the likelihood this treatment affecting my child

19. Now, using the same colored circles, we would like to ask you about your preferences regarding the **way** in which your medical team communicates. Remember that, on the left, there are many green circles, and these indicate something that is very important for you. In the middle there are a few yellow circles which represent something that is slightly important for you. On the right, after the red line, there are not any circles. This indicates something that is not important to you.

We would like to know, how important is it to you that your doctors and other health professionals...

- Explain things in a way I can understand
- Are open and honest with me
- Involve me in making decisions about my child's care
- Pay attention to my emotions and feelings

How important is it to you that your doctors and other health professionals...?

- Help me deal with the things nobody knows related to my child's cancer
- Help me understand ways to take care of my child while I'm dealing with cancer
- Ask about my culture, background, and beliefs

20. At the time of diagnosis, did the doctor ask about your previous knowledge about cancer? *Choose one.*

- Yes
 No

21. How often do you feel like you are given the information that is important to you without needing to ask for it? *Choose one.*

- Always
 Sometimes
 Never

22. When you see your child's doctor, how often do you have questions about your child's care that you want to discuss but do not? *Choose one.*

- Always
- Sometimes
- Never

[IF THE RESPONDENT DOES NOT UNDERSTAND ASK: When you have questions for your doctor, how often are you too afraid to ask them?

- Always
- Sometimes
- Never

Decision Making – We are now going to ask you about how you and your family make decisions. First, in general, and then specifically how you have made decisions regarding your child's treatment.

23. Who do you consider to be the person who makes most decisions in your house in general? These might be decisions about care of the children, where the family lives, or how money is spent, for example. *Choose one.*

- I am the person most involved in making decisions.
- I share decision-making equally with my child's other parent or other family member.
- Another parent or family member makes most of the decisions in my house

24. Who do you consider to be the parent most involved in making decisions about your child's cancer treatment? *Choose one.*

- I am the parent most involved in making decisions.
- I share decision-making equally with my child's other parent or other family member.
- Another parent or family member makes most of the decisions for my child's treatment.

25. Parents differ in the ways they prefer to make treatment decisions for their children. Which statement best describes the role you **would prefer** to play when decisions about treatment for your child's cancer are made? *Please check one.*

- I prefer to make the decisions about treatment
- I prefer that my child's oncologist and I make the decisions together.
- I prefer that my child's oncologist make most of the decisions

26. Which statement best describes the role you **actually played** when making decisions about treatment for your child's cancer? *Please check one.*

- I made the decisions about treatment
- My child's oncologist and I made the decisions together.
- My child's oncologist made the decisions

27. Some families have help making decisions from people in their community, which statement best describes the role **your community** played in helping you make decisions? *Choose one*

- I/We made the decisions about treatment without input from my community
- I/We made the decisions with help from members or leaders in my community
- My community, or a leader in my community, made the decision and told me what was best

28. Some families have help making decisions from religious or spiritual leaders, which statement best describes the role **your religious/spiritual leaders** played in helping you make decisions? *Choose one.*

- I/We made the decisions about treatment without input from religious or spiritual leaders
- I/We made the decisions with help from religious or spiritual leaders
- My spiritual or religious leaders made the decision and told me what was best

29. At the time of diagnosis, which of the following statements best describes how your oncologist explained your child's treatment plan. *Please check one*

- He/she gave me different options and I chose what was best
- He/she gave me different options, and he/she told me what was best
- He/she gave me only one option

30. Using the colored circles again, but this time we would like to know **how much you agree or disagree with the following statements**. Remember that on the left there are many green circles. These indicate something you completely agree with. In the middle, the few yellow circles, indicate something that you slightly agree with. And on the right, after the red line, there are no circles. This indicates something you disagree with.

Now I would like to know what you think about the decisions you have made related to your child's cancer.

How much do you agree or disagree with...

- I have made the right decisions
- I regret the choices that were made
- I would make the same choices if I had to do it all over again
- My choices did my child harm
- The decisions were wise

Medical team – Now we are going to ask you a little bit about the team taking care of you at UNOP, and your relationship with this team.

31. We will use the circles again, but this time we would like to know **how much you agree or disagree with the following statements**. As always, on the left there are many green circles. These indicate something you completely agree with. In the middle, the few yellow circles, indicate something that you slightly agree with. And on the right, after the red line, there are no circles. This indicates something you disagree with.

How much do you agree with each of the following statements about your child's doctors?

- I trust my child's doctors
- My child's doctors ask about how my family is coping with cancer
- My child's doctors care about my child's quality of life
- My child's doctors offer my family hope

32. Using the colored circles, **how much do you agree with each of the following statements regarding doctors in general?**

- Doctors are prying too much into personal matters when they ask a lot of questions about a patient's culture, or community. [IF THE RESPONDENT DOES NOT UNDERSTAND: *This statement means that you think the doctors are being nosy when they ask many questions about a patient's community or culture.*]
- I'd rather have doctors and nurses make the decisions about what's best than for them to give me a whole lot of choices. [IF THE RESPONDENT DOES NOT UNDERSTAND: *This means that you prefer that the doctors decide without offering you choices.*]
- It is best for parents if they do not have a full explanation of their child's medical condition
- It is best for children if they do not have a full explanation of their medical condition
- Parents should not try to find out about their conditions on their own, they should rely on their doctors' knowledge.

33. How comfortable do your doctors and other health professionals make you feel asking questions? *Choose one.*

- Very comfortable
- Somewhat comfortable
- Not at all comfortable

34. How often do your doctors and other health professionals have open and honest communication with you? *Choose one.*

- Always
- Sometimes
- Never

35. How much do your doctors and other health professionals give you information and resources to help you make decisions about your child's care? *Choose one.*

- A Great Deal
- Somewhat
- Not at all

36. How well do your doctors and other health professionals talk with you about how to cope with any fears, stress, and other feelings? *Choose one.*

- Very Well
- Fairly Well
- Poorly

37. How often do your doctors and other health professionals make sure you understand the steps in your child's care? *Choose one.*

- Always
- Sometimes
- Never

38. How well do your doctors and other health professionals help you deal with the things nobody really knows about cancer? *Choose one.* [IF THE RESPONDENT DOES NOT UNDERSTAND ASK: *How well do the doctors help you manage for example, that you don't know if your child will respond to treatment, or if the cancer is going to come back?*]

- Very Well
- Fairly Well
- Poorly

39. How often do your doctors and other health professionals take into account your culture, background or religious beliefs when planning treatment for your child? *Choose one.*

- Always
- Sometimes
- Never

40. When you ask questions, how often do you get answers that are understandable?

Choose one.

- Always
- Sometimes
- Never

41. Overall, how satisfied are you with the communication with your doctors and other health professionals? *Choose one.*

- Very satisfied
- Fairly satisfied
- Not at all satisfied

42. Is there anything else you would like us to know about your experiences with communication about your child's cancer care or diagnosis?

3. Codebook

Topic	Category	Code	Definition
Direction of conversation	Clinician speaker	Oncologist to parent/family	Clear that oncologist is speaking directly to the caregiver only.
		Psychologist to parent/family	Clear that psychologist is speaking directly to the caregiver only.
Clinician patient-centered communication	Supportive talk: <i>Verbal behaviors that validate or support the patient's emotional or motivational state</i>	Verbal attentiveness	Showing understanding, paraphrasing, empathy, showing concern, worry, reassurance, optimism, legitimizing, respect, descriptions of inclusivity, validation. Include statements like "If you ever need anything come find me." "If you have more questions you can always ask" "It is my pleasure to help." "Cheer up"
	Multidisciplinary approach	Team care	Descriptions of clinicians working as a team to care for family. Does NOT include all general statements of "we" from providers.
	Direct communication	Honesty	Explicit references to honest or direct communication (e.g. "It is important that we are honest with you")
Decision making	Decision makers (who) Using for both cancer related and non-cancer related decision	Parents as joint decision makers	Descriptions of two caregivers making decisions together as explicitly stated by caregiver
		Parent as single decision maker	Descriptions of one caregiver making decisions alone as explicitly stated by caregiver
		Extended decision maker	Descriptions of decisions made that involve family beyond caregivers or community as explicitly stated by caregiver, includes God.
		Child involved in decision making	Descriptions of involving the child in decision making as explicitly stated by caregiver
		Deference to provider	Explicit statements from caregivers that they prefer provider to make decision, or that they left decision up to provider, including statements that it is not their "role" to make such decisions
		Team talk (parent)	References (made by caregivers) to decisions that were made together with medical team
	Decision making (what) (INT only)	Decisions unrelated to cancer	Descriptions of decision making (by family) that is not related to cancer or cancer treatment – only code in interview transcripts.
		Cancer decisions	Descriptions of decision making (by family) related to child's cancer care – only code in interview transcripts
	Decision making (how)	Team talk (provider): eliciting goals	Provider elicits goals from caregiver to assist with decision making
		Team talk (provider): offering choices	Provider offers options or choices to caregiver

		Team talk (provider): family as part of the team	Provider discusses caregiver as part of the team making medical decisions (e.g. “we all make the decision together,” “We need your authorization to treat,” “If you agree...”). Does NOT include verbally attentive references such as “don’t worry we will explain...” OR “we will explain X to you”
		Option talk: discussion of risks	Provider discussion of comparative risks or side effects of presented options
		No-Option talk: discussion of risks	Provider discussion of risks or side effects of one therapy without suggesting alternative
		Option talk: discussion of benefits	Provider discussion of comparative benefits of presented options
		No-Option talk: discussion of benefits	Provider discussion of benefits of one therapy without suggesting alternative
		Option talk: discussion of evidence	Provider discussion of evidence base for presented options
		No-Option talk: discussion of evidence	Provider discussion of evidence base one therapy without suggesting alternative including explaining to the family why we are treating. E.g. “if he responds, we will give him ___” “we will do this if the first round of chemo works.”
		Decision talk: preference-based	Provider elicits informed preferences and asks caregiver to decide between choices or suggests a decision based on preferences or goals expressed by caregiver.
		Decision talk: Health promotion	Framing or nudging towards decision among choices
		No-decision talk: Consequences	Provider describing potential consequences of NOT agreeing to recommended treatment plan.
		No-decision talk: Giving decision	Provider describes decision without options and without involving caregiver. Do NOT include hypothetical treatment decisions.
	Decision making (why) MAY USE IN ALL TRANSCRIPTS, PARENT SPEAKER	Family Factors- other children, financial influences	References to decisions that were made or complicated based on finances. Do NOT code all references to finances, just when they affect decision making. References to decisions that were made or complicated by other children.
		Child’s best interest- symptoms/medical facts, quality of life concern, doing what is right/being a good parent	References to decisions that were made based on medical facts or the symptoms/condition of the child. References to decisions that were made based on quality of life concern (e.g. so they can go to school, or be home with friends). Decisions made because it is “the right thing to do” for the child or because it is what “a good caregiver should do”
		Lack of agency- lack of choice, perceived threat, limited information	Decisions that were made because it felt like the only option. Decisions that were made because of fear.

			Descriptions of lack of information as a barrier to decision making
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