

## Supplemental Material

### The Evolution of Parents' Beliefs about Childhood Cancer During Diagnostic Communication: A Qualitative Study 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. Codebook

Topic	Category	Code	Definition
<b>Direction of conversation</b>	<b>Clinician speaker</b>	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.
<b>Clinician patient-centered communication</b>	<b>Supportive talk:</b> <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"
	<b>Question-asking</b>	Ask about pre-existing beliefs	Provider asking patient/family about pre-existing understanding or experiences with cancer PRIOR to this child's experience. Does NOT include questions about previous encounters along the way to UNOP.
		Parent directed questions	Clinician asking caregiver question about medical condition, lifestyle including demographic questions e.g. about family, other children, religion
		Rhetorical questions	Questions asked and answered by clinician
		Assessment/Confirmation of understanding	Provider asks for understanding either by asking for "yes/no" or teach back and caregiver is able to demonstrate comprehension
		Soliciting questions	Provider asks family/parent/caregiver if they have any questions
	<b>Information giving</b>	Biomedical description of cancer	Clinician explaining cancer in scientific or biomedical terms or caregiver in interview referring to these descriptions
		Metaphorical description	Clinician explains cancer or any medical terminology using a metaphor. Includes references to "seeds" instead of metastases and "the blood factory". Code in interview if caregiver references these descriptions
		Diagnosis	Reference to type of cancer or name of disease specific to child. Includes caregiver asking about diagnosis, references to "the name of the disease," and to the patient having a malignant tumor. Do NOT code for things like infections
		Location of disease	Descriptions of where the disease is located within the child's body, including caregivers asking where it is located.
		Prognosis	Descriptions of prognosis for child's illness including a caregiver asking about prognosis. This includes generalizations about the child's specific prognosis (e.g. "every 10 children with ALL...7 to 8 are cured") but NOT general cancer or other specific prognoses (e.g. "today, we do cure cancer") which should be coded as general cancer information.

		Causation	Descriptions of cancer etiology, why this happens including caregivers asking about causation.
		Treatment	Descriptions of treatment (specific to cancer) for the child's illness including recommendations for treatment and questions about treatment, including potential treatment modalities. Includes references to treatment length and general discussion of treatment (e.g. "how we can treat cancer." Names of chemotherapy medicines). Does NOT include references to side effects, things like medicine for fever, or when discussing treatment in combination with other things "e.g. we don't charge for testing, staying in the hospital or treatment." Or "they know how to treat her.")
		Jargon	Use of medical terminology by provider without explanation
		Explanation of medical terminology	Use of a medical term followed directly by explanation. Does NOT include explanations of non-medical terms (e.g. consent).
		Giving general cancer information	Providing general information about cancer that does not fit in other codes. Does NOT include descriptions or education about UNOP.
	<b>Directions</b>	Instruction/Advice	Provider orients or instructs caregiver, or provides counseling or advice regarding medical condition, therapeutic regimen, lifestyle. Includes directions (e.g. "sign this document" "you must do __") and "directives" that are not supportive. Does NOT include descriptions of the treatment plan (e.g. "this is why she stays in the hospital..." "now that you are here, we will start his treatment" )
<b>Sources of Information (references made by parent)</b>	<b>Sources of information outside UNOP</b>	Prior experience with cancer	Description from parent that they had family member or knew someone in community diagnosed with cancer
		Media	Information learned about cancer or UNOP through TV, commercials, marketing in stores
		Community discussion	Parent describing how family learned about child's illness or cancer from things community members said prior to arrival. Also includes extended family members.
		Clinical encounter	Family learned about child's illness or cancer from a health care provider around this child's experience. Includes references to prior encounters in which the family DOES learn incorrect information. Does NOT include references to prior encounters in which the family did not learn anything.

	<b>Sources of information within UNOP</b>	Provider other than oncologist	References by family of information learned from psychologist, social worker, nurse or member of UNOP team other than oncologist
		Oncologist	References by family of information learned from oncologist
		Other patients/families	Information learned from other caregivers at UNOP
	<b>Additional sources of information</b>	Lived experience	References to learning about cancer from living through diagnostic experience or coming to UNOP including references to “seeing is believing” (e.g. “I didn’t know anything about cancer until I watched my child go through it”)
<b>Other</b>		Mayan spirituality	References to belief in Mayan spirituality including traditional healers and “susto”