


# The evolution of parents' beliefs about childhood cancer during diagnostic communication: a qualitative study in Guatemala

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## ABSTRACT

**Introduction** Fatalistic cancer beliefs may contribute to delayed diagnosis and poor outcomes, including treatment abandonment, for children with cancer. This study explored Guatemalan parents' cancer beliefs during initial paediatric cancer communication, and the sociocultural and contextual factors that influence these beliefs.

**Methods** Twenty families of children with cancer were included in this study. We audio-recorded psychosocial conversations with psychologists and diagnostic conversations with oncologists, then conducted semi-structured interviews with parents to explore the evolution of their cancer beliefs. Audio-recordings were transcribed and translated from Spanish into English, with additional review in both languages by bilingual team members. All 60 transcripts were thematically analysed using a priori and novel codes.

**Results** Guatemalan parents' beliefs evolve as they learn about cancer through various sources. Sources of information external to the cancer centre, including prior experiences with cancer, media exposure, community discussion and clinical encounters, contribute to pre-existing beliefs. Many parents' pre-existing cancer beliefs are fatalistic; some are influenced by Mayan spirituality. Sources internal to the cancer centre include psychologists and oncologists, other providers, other patients and families. Psychologists acknowledge pre-existing beliefs and deliver cancer education using verbal explanations and hand-drawings. Oncologists provide diagnostic information and outline treatment plans. Both support hope by providing a path toward cure. Parents' lived experience is a culmination of sources and simultaneously independent. Ultimately most parents arrive at an understanding of cancer that is consistent with an allopathic medical model and offers optimism about outcomes.

**Conclusion** An interdisciplinary communication process that includes cancer education, is attentive to pre-existing beliefs, and supports hope may encourage acceptance of the allopathic medical model and need for treatment. Providers in settings of all resource levels may be able to use these techniques to support cross-cultural cancer communication, reduce treatment abandonment and improve therapy adherence.

## Key questions

### What is already known?

- ▶ Fatalistic cancer beliefs contribute to poor outcomes for children with cancer, particularly in low-income and middle-income countries where >90% of children diagnosed with cancer live.
- ▶ Cancer beliefs may be shaped by various sources including personal experiences, community perspectives, spirituality and experiences with healthcare providers.

### What are the new findings?

- ▶ Some Guatemalan parents hold pre-existing cancer beliefs that are fatalistic, while others may be influenced by Mayan spirituality.
- ▶ Interdisciplinary providers at a comprehensive cancer centre deliver cancer education and provide information regarding diagnoses and treatment in a manner that acknowledges pre-existing beliefs and supports hope.
- ▶ Ultimately most parents arrive at an understanding of cancer that is consistent with an allopathic medical model and optimistic about outcomes.

### What do the new findings imply?

- ▶ An interdisciplinary communication process that is attentive to pre-existing beliefs and supports hope may encourage parents of children with cancer to accept the need for treatment.
- ▶ Providers may be able to use these techniques to support cross-cultural cancer communication, reduce treatment abandonment and improve therapy adherence for families of children with cancer.

## INTRODUCTION

Individuals with cancer often come to the diagnosis with pre-existing beliefs, including ideas about why it happened, how it can be treated and its expected outcomes. These beliefs can be shaped by many different forces, including personal experiences, spiritual beliefs and community perspectives on cancer.

Unfortunately, hopelessness, pessimism, and deterministic thoughts around cancer are associated with delayed diagnoses<sup>1</sup> and poorer outcomes.<sup>2</sup> Negative cancer beliefs among marginalised populations contribute to disparities by decreasing early intervention.<sup>3</sup> Indigenous people's cancer beliefs have been identified as a barrier to seeking care,<sup>4</sup> as well as to participation in cancer communication.<sup>5</sup> Healthcare providers in low-income and middle-income countries (LMICs), where 90% of children with cancer live, have identified cancer beliefs, in addition to cost of therapy and distance to a cancer centre, as important factors in refusal and treatment abandonment.<sup>6</sup> Treatment abandonment disproportionately affects children in LMICs<sup>7</sup> and negatively impacts treatment outcomes. However, cancer beliefs of parents of children with cancer in LMICs have received limited attention in the medical literature. Understanding how beliefs are shaped through encounters with the medical system has potential to reduce treatment abandonment and improve outcomes for children with cancer.

The purpose of this study was to qualitatively explore the evolution of parents' cancer related beliefs during initial paediatric cancer communication, including the sociocultural and contextual factors that influence these beliefs. This study was conducted in Guatemala, a small but diverse country, with 24 principal ethnic groups, speaking 24 distinct languages and making up 40% of the population.<sup>8</sup> While Guatemala is a predominantly Christian country, aspects of traditional Mayan spirituality persist and have been incorporated into many Catholic and Evangelical practices.<sup>9</sup> Childhood cancer providers in Guatemala have previously investigated socioeconomic factors affecting treatment abandonment and demonstrated the impact of an interdisciplinary communication intervention.<sup>10</sup> This care model includes early involvement of psychosocial support to ensure attention to identified barriers to care, and consists of a two-step process integrating emotional support with basic cancer information. Within this clinical context, we audiotaped conversations at diagnosis between parents of children with cancer, psychologists and oncologists, in order to examine the ways in which parents and clinicians discussed the cancer diagnosis. We then interviewed parents about their current cancer beliefs as well as the evolution of their beliefs from before the child's cancer diagnosis to the present. In keeping with work on the importance of understanding an individual's explanatory model of illness,<sup>11</sup> we hypothesised that a communication process that recognised pre-existing beliefs would support parents in accepting an allopathic, or biomedical, model and a need for treatment.

## METHODS

### Setting and participants

This study was conducted at Unidad Nacional de Oncología Pediátrica (UNOP) in Guatemala City, Guatemala. Guatemala is an upper-middle income country

with a childhood cancer survival rate of approximately 65%. UNOP, founded in 2000 and supported through a public-private partnership, is Guatemala's national paediatric cancer centre. Approximately 500 new cases of childhood cancer are diagnosed at UNOP each year.

Participants eligible for the study included Spanish speaking parents of children (less than 18 years of age) with a new or probable diagnosis of any form of paediatric cancer. Parents were approached sequentially and offered participation in the study, with additional purposive sampling as necessary to include a range of paediatric ages and diagnoses, as well as parents representing diverse socioeconomic situations. Twenty families participated in all parts of the qualitative study at which point thematic saturation<sup>12</sup> was reached and no further participants were enrolled. Twelve families were approached prior to saturation and declined participation in the study. Written informed consent was obtained for all parent and provider participants. This study was performed in compliance with international regulations for protection of human research subjects and approved by the respective oversight boards at St. Jude and UNOP.

### Patient and public involvement

Neither patients, parents nor the public were involved in the design, conduct or reporting of this research. We plan to partner with parents as we disseminate these results and consider next steps for potential interventional work.

### Study design and data collection

For each family, we audio-recorded psychosocial conversations with psychologists and diagnostic conversations with oncologists. As part of a standard intake process, parents of newly diagnosed patients at UNOP first meet with a social worker and then a psychologist who elicits intake information and provides initial cancer education. Approximately 1 to 5 days following this encounter, families meet with an oncologist who discusses the child's diagnosis and outlines a treatment plan. The psychologist responsible for intake is always present for the subsequent diagnostic conversation with the oncologist. Children are not present for either conversation, as the practice at UNOP is to have the child meet separately with a child life specialist about their diagnosis. For this study, both conversations with parents were audio-recorded given the role of each conversation in education about the diagnosis, including one or both parents as available and any additional extended family or social support as requested. The recording device was activated by the psychologist and placed to side to enable conversations to occur naturally.

Semi-structured interviews were then conducted within 14 days of diagnosis with one parent per child who was present for both conversations. These interviews explored parents' experiences and perspectives on the diagnostic process including the evolution of their cancer beliefs. The interview script (online supplemental file 1) was first

developed in English, translated into Spanish and back-translated into English with iterative review by bilingual members of the study team. Audio-recorded interviews were conducted in Spanish by a Guatemalan psychologist who was trained in qualitative methods and not involved in initial intake conversations. Data collection occurred from April–August of 2019. All audio recordings were professionally transcribed and translated into English. Bilingual members of the research team reviewed texts and compared them with Spanish audio recordings to ensure translations adequately captured conversations. Caregiver quotations from conversations with providers are noted as such; all other quotations come from study interviews.

### Data analysis

We used thematic content analysis,<sup>13</sup> including a combination of a priori and novel codes. A priori codes included codes used to identify the speaker and direction of speech in naturally occurring conversations, codes from the Roter Interaction Analysis Scale,<sup>14</sup> as well as codes previously used to analyse patient participation in medical encounters.<sup>15</sup> Novel codes included various sources of information (eg, ‘prior experiences with cancer’) and concepts including ‘Mayan spirituality’, a complex notion referring to the Mayan value system and way of living, as well as cosmological beliefs impacting a person’s health and well-being in relation to the equilibrium of the natural world. Two authors (DG and GF) iteratively read transcripts and identified codes based on recurrent themes. Codes were conceptually defined and refined through use on 12 transcripts. Two researchers (DG and GF) independently coded each transcript using the final codebook (online supplemental file 1) and MAXQDA software (VERBI, Berlin, Germany). Interrater reliability was calculated for each set of transcripts and ranged from 0.72 to 0.88. Consolidated Criteria for Reporting Qualitative Studies guidelines were followed to ensure rigour.<sup>16</sup>

### RESULTS

Twenty families were included in this study. Demographic information for included families is shown in table 1. The majority of included patients (80%) had haematological malignancies. There were about equal numbers of male and female patients, and the study included all age ranges. While fathers were present for over 50% of diagnostic conversations, more mothers were interviewed (65%).

Families learnt about cancer through a variety of sources (figure 1). Some informants were external to the cancer centre, while others were within the cancer centre. External sources of information contributed to parents’ pre-existing beliefs, while sources internal to the cancer centre helped parents through the arc of their child’s diagnosis. All of these information sources influenced parents’ eventual understanding of cancer.

**Table 1** Participant demographics n (%)

<b>Patient age</b>	
<4.9 years	6 (30)
5–9.9 years	6 (30)
10–14.9 years	4 (20)
15–18 years	4 (20)
<b>Patient gender</b>	
Male	11 (55)
Female	9 (45)
<b>Diagnosis</b>	
Acute Lymphoblastic Leukemia	11 (55)
Acute Myeloid Leukemia	2 (10)
Burkitt lymphoma	1 (5)
Hodgkin’s lymphoma	1 (5)
Wilms tumour	2 (10)
Osteosarcoma	1 (5)
Histiocytosis	1 (5)
High-grade glioma	1 (5)
<b>Religion</b>	
Evangelical	13 (65)
Catholic	4 (20)
Other	3 (15)
<b>Distance from the hospital</b>	
<2.5 hours	4 (20)
2.5–5 hours	3 (15)
>5 hours	6 (30)
Unknown	7 (35)
<b>Mother’s education</b>	
No school	6 (30)
Elementary education	8 (40)
More than elementary education	1 (5)
Unknown	5 (25)
<b>Father’s education</b>	
No school	2 (10)
Elementary education	15 (75)
More than elementary education	3 (15)
<b>Mother’s occupation</b>	
Housewife	18 (90)
Day worker	1 (5)
Professional	1 (5)
<b>Father’s occupation</b>	
Unemployed	1 (5)
Dayworker	1 (5)
Farmer	9 (45)
Professional	8 (40)

Continued

**Table 1** Continued

Unknown	1 (5)
<b>Number of siblings</b>	
None	2 (10)
1–2	7 (35)
3–4	6 (30)
>4	5 (25)
<b>Parent present for psychosocial intake</b>	
Mother	9 (45)
Father	5 (25)
Both	6 (30)
<b>Parent present for diagnostic conversation with oncologist</b>	
Mother	7 (35)
Father	5 (25)
Both	8 (40)
<b>Parent interviewed</b>	
Mother	13 (65)
Father	7 (35)

**Pre-existing cancer beliefs**

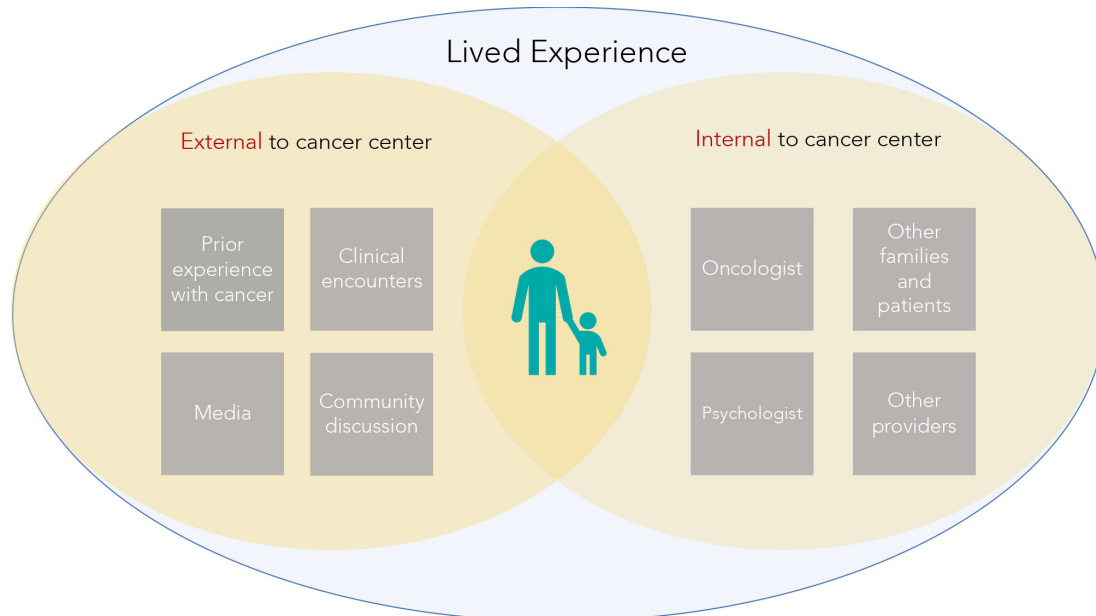
Information sources external to the cancer centre, including prior experiences with cancer and media exposure, contributed to beliefs parents held about cancer before their child’s diagnosis (table 2). Parents

often first learnt about cancer through the experiences of family members or people in their community. Fund-raising campaigns, news stories and advertisements, many produced by *AYUVI* (‘help me live’), the foundation supporting UNOP, also exposed families to childhood cancer.

For many families, previous experiences taught them cancer was incurable; “I heard about it; I saw a man who died of cancer” (provider conversation); “We got worried because in the news I’ve heard that once you have cancer you don’t have a good future”. Parents mentioned other hardships as well, including disfigurement and financial strains. There were fewer positive descriptions, however some parents did know of people who survived cancer: “I had a chance to see two old people that fought cancer and got cured” and others learnt about the potential for cure from the media. While informative, parents suggested that these sources were distant from their own experience “I don’t know where he was treated, I just met her once and she told me the story”; “When you are not living it, you don’t pay attention to it, I used to see commercials about cancer, but we never searched for information”.

**Additional sources external to the cancer centre**

After their child fell ill, but prior to arriving at the cancer centre, parents encountered additional sources of information that influenced their cancer beliefs. Community discussion was a powerful source of information for parents. As with prior experience and media exposure, parents received both discouraging and helpful



**Figure 1** Sources of information contributing to parents’ understanding of cancer. Guatemalan parents of children with cancer learn about their child’s diagnosis through a variety of sources. Some of these sources of information are external to the cancer centre, including prior experiences with cancer, media exposure, community discussion and clinical encounters prior to reaching Unidad Nacional de Oncología Pediátrica. Other sources of information are internal to the cancer centre and include the psychologist, oncologist, other providers and other patients and their families. A family’s lived experience is a unique source of information that is simultaneously a culmination of all other sources and contributes to the family’s ultimate understanding of cancer.



**Table 2** Sources of information external to the cancer centre

Prior experience with cancer	<p>“My mother-in-law died from cancer”</p> <p>“He deteriorated very fast, he was very thin; me and my family thought that disease was very difficult... then he died, it was sad.”</p> <p>“A sister from the church, they removed one of her breasts”</p> <p>“They suffered a lot because of money; you’re not only worried because of the disease but also because of money, they suffered...”</p>
Media	<p>“We’ve seen it on TV and we just know that it’s a deadly illness”</p> <p>“I heard in the media, social media, that thank God a lot of children have survived cancer and leukemia, but I that’s what I heard”</p>
Community discussion	<p>“Right now, worried because of what people say, I was waiting for another illness, something simpler, that could be cured with just one medicine, but what I’m hearing this is complicated”</p> <p>“What people say is, if he’s got cancer then go and prepare everything for his funeral”</p> <p>“There was a person who called me from my community and told me; look you’re there, if God wants to take [your daughter], that’s God’s will, that hurt.”</p> <p>“My colleagues told me about (UNOP)...they gave good references”</p> <p>“All people started saying it was evil eye and fear, so we took her to the healer.”</p> <p>“And they started telling her stuff like she was going to get scared and things like that. They told her that they were going to kill her and suggested a witchdoctor to perform some sort of a ritual with grass and stuff”</p> <p>“Well, honestly, they told me that he had got the eye, and frankly I don’t believe in that stuff because I had my older sons and none of them got that, so I said that doesn’t exist.”</p>
Clinical encounters	<p>“They told us he had cancer”</p> <p>“They didn’t want to give her anything because they didn’t know what was wrong with her”</p> <p>“Leukemia she said; she doesn’t say cancer”</p> <p>“I took him to a doctor who practices natural medicine, they gave me medicine but the thing he had in his leg didn’t disappear”</p> <p>“There the doctor in shift told me that he suspected leukemia, but he could not do anything there unless I paid the tests in a private lab.”</p> <p>“We thought if he’s going to die, we better take him home and avoid the needles and everything here. We talked to the doctor and she said no, you must trust medicine and have hope.”</p>

UNOP, Unidad Nacional de Oncología Pediátrica.

information from their community. One parent said, “many people got me scared because they said for this there was no cure and no medicines” (provider conversation). Another explained how the community helped them reach UNOP: “a friend of my husband’s boss who is a doctor recommended this hospital... that’s how we brought him here”.

In this time of need, some families consulted religious leaders who recommended prayer, and others sought out traditional healers. Mayan spirituality influenced interactions within the community and contributed to parents’ pre-existing cancer beliefs. Specifically, parents discussed ‘the evil eye’ and ‘susto’, loosely translated as fear or surprise. Some parents discussed these beliefs generally but said they did not ‘believe in that stuff’. In other circumstances, belief in Mayan spirituality directly influenced care: “she was very down, so people started saying it was evil eye and susto, so we took her to the healer...they take some plants and rub her with them to cure the susto and the evil eye” (provider conversation); “One person told us he was suffering from fear...and she told us ‘let’s cure him before you get to the hospital’, so they bathed him, they did all the ritual required in cases like these” (provider conversation). In some instances, parents

reported traditional healers cured their child of *susto*, and in others they did not: “we took her to a witchdoctor and at the end it didn’t work” (provider conversation).

With or without community support, most families had at least one clinical encounter prior to reaching UNOP. Some of these encounters were at hospitals; others were with traditional healers, “he started with a fever... so she took him to a healer...they rubbed his stomach” (provider conversation). While many families learnt of their child’s diagnosis prior to reaching UNOP, some did not. Of the families that were given diagnoses, not all were able to understand or absorb the information: “they told us everything, but I just can’t remember anything” (provider conversation). Similarly, not all providers capable of making the diagnoses were able to help: “He said, here we treat that, but we don’t have the specialty or the equipment” (provider conversation).

#### Information obtained at the cancer centre

Once at UNOP, parents continued to learn about cancer. Primary sources included the psychologist and the oncologist, however other providers including nurses, as well as other patient families, contributed to parents’ understanding of their child’s illness. Quotations from

**Table 3** Sources of information within the cancer centre

Psychologist	<p>“I understood, they explained it to me with seeds, like when a farmer sows; it’s born, reproduces and dies.”</p> <p>“Then when I came here, I changed my mind; I saw the place, the children, the psychologist talked to her, they explained it to her, and it was like a light of hope for a mom.”</p> <p>“I also liked the way the psychologist talked to me, how she prepared me for the news, how she explained everything to me. She helped me a lot.”</p>
Oncologist	<p>“I thought there was no medicine, but the doctor told me that there is medicine.”</p> <p>“My vision changed because it was told to me by a doctor, a person with experience, he gave me more hope.”</p> <p>“I feel comfortable; sometimes we forget to ask some things, but the doctor always explains to me.”</p>
UNOP generally/other providers	<p>“The nurses also, they are very lovely with the girl, they talk to her and all. I feel in family”</p> <p>“The staff, the workers, maintenance, the nurses, the doctor sometimes comes inside and chats a little and say don’t worry, you will be home soon. It’s a hope.”</p>
Other patients/families	<p>“When I’m in the room with my child, I see he still has his eyes, I ask myself, if he’s going to be one of them?”</p> <p>“I talk to the rest of the parents here, we love to talk and we become like family, we encourage each other, that’s the only thing we can do.”</p> <p>“Yes, because I feel like I’m not the only one living this. Some of them lived my situation already and they are full of strength.”</p>

UNOP, Unidad Nacional de Oncología Pediátrica.

interviews with parents illustrate how they viewed interactions within the cancer centre and examples are included in table 3. Table 4 contains excerpts from parents along their journey through psychosocial and diagnostic conversations, with corresponding reflections during interviews.

**Psychologist**

Psychologists consistently started conversations with parents by introducing themselves and outlining a plan to discuss the sensitive subject of the child’s illness. Throughout the sessions psychologists provided reassurance, telling parents “you are not alone, we are a team”, and explained to parents they were not at fault. At times, parents cried or expressed strong emotions. During these moments, psychologists paused and comforted families. In addition, psychologists provided hope by explaining that cancer is treatable and curable: “nowadays we have treatment, there are possibilities for cure”. Psychologists at UNOP often drew pictures to supplement their verbal explanations, and frequently used metaphors to explain things to parents using familiar language (eg, using seeds as a metaphor for tumour cells when talking to parents who worked in agriculture). Psychologists also directly asked families about their beliefs in Mayan spirituality and experiences with traditional healers. They did not dismiss these beliefs, but rather acknowledged the evil eye and *susto* as separate conditions, unrelated to cancer or its treatment: “something important is that we know this is not a result of evil eye or fear, because those are completely different illnesses and they are treated in different ways”.

Parents recognised this support and in interviews described that psychologists “have time to talk” and explained things “in a very nice way that was easy for me to understand...so we can feel less sad or lonely”. They

described psychologists providing them with hope for cure; “like she said, nothing is impossible; with treatment they try to cure the children” and said their explanations “gave me strength and confidence”.

**Oncologist**

Oncologists focused on the diagnosis, location of disease, prognosis and treatment plan for the child’s cancer. Like psychologists, oncologists often used a white board to draw anatomical pictures or pulled up the child’s diagnostic imaging scans on a computer. Oncologists used biomedical rather than metaphorical descriptions of cancer: “what happens with leukemia is that when the cell is formed...there’s a moment when it suffers a damage and it starts reproducing more and more. That’s leukemia”. Oncologists did not discuss Mayan spirituality with parents.

When describing their interactions with oncologists, some parents noted positive interactions: “when the doctor talked to us and he gave us the diagnosis he explained very well”; while others acknowledged a hierarchy or sentiment that they were not worth the doctor’s time, “I feel like I can’t go and talk to them...I see them busy or in a hurry, I feel like I am making them waste their time”. In interviews, parents described oncologists providing hope: “they told me not to worry, that we are going to make it, that he will receive the right treatment” and said, “they treat us kindly, and they don’t make us feel less important”.

**Other providers**

During interviews, parents referenced providers other than the psychologist or oncologist, and at times categorised UNOP providers generally as a source of information. Parents mentioned social workers, nutritionists, child life specialists and nurses as sources of information.

Table 4 Interactions

Psychosocial intake	Diagnostic communication	Interview
<p><b>Psychologist:</b> And how did you come to UNOP?</p> <p><b>Mother:</b> Because the doctor told us the baby is not well.</p> <p><b>Psychologist:</b> You took the results back to the doctor?</p> <p><b>Mother:</b> She said bring me back the results and depending on the results, I'll know what to do. She called the ambulance...</p> <p><b>Psychologist:</b> And he is sent from [that town] to UNOP?</p> <p><b>Mother:</b> Yes, because they said that if he had that illness we must come here.</p> <p><b>Psychologist:</b> What illness?</p> <p><b>Mother:</b> The told me that maybe he had cancer or anaemia</p> <p><b>Psychologist:</b> All this information is very useful to us....There are many types of cancer but we suspect that [your son] has blood cancer...Our body is made of certain particles or seed that we call cells. Cells are not even the size of an ant. They are very small. They are like microorganisms, we cannot see them with our own eyes, I need special equipment to see them....Cancer is also a cell, but this is a bad cell that instead of helping the body, it hurts it...We know it's born in the bone marrow but cancer likes to send seeds to other parts of the body.</p>	<p><b>Oncologist:</b> These leukaemia cells are in the blood but they can travel to the brain and the testicles.... The problem is that these cells can travel through the blood to the spine and then the brain. So, in leukaemia we must also give treatment through the spine. Because through the veins it won't get to the brain, there's a barrier that doesn't allow it to go up to the brain...but that is all done with anaesthesia, he won't feel pain...These medicines will be applied little by little... The complete name of the illness is acute lymphoblastic leukaemia because the leukocytes are affected, and acute because is recent, not too long ago. And it's B cells. We have B cells and T cells. T is more aggressive, in this case he's got the B, so it's good news, they respond better to the treatment, the doses of medicines are lower and there's a higher chance of healing. Do you have any question?</p> <p><b>Mother:</b> No.</p> <p><b>Oncologist:</b> I know you will have more questions but since you'll stay here you can ask us any time.</p> <p><b>Psychologist:</b> And right now, with the news it's difficult, our minds are blank and there are a lot of ideas. You don't have questions but like the doctor says, during these days you can talk to us and we will do everything to help you.</p>	<p><b>Interviewer:</b> Who was the first person who explained to you about cancer when you arrived here?</p> <p><b>Mother:</b> Doctor XX.</p> <p><b>Interviewer:</b> The doctor. How did he explain to you?</p> <p><b>Mother:</b> He told me it was a disease in the blood, that were little balls walking through the body and that's why my baby was going to receive treatment so the little balls couldn't reach his brain.</p> <p><b>Interviewer:</b> Do you feel that what you knew about cancer and what you know now after the diagnosis is different?</p> <p><b>Mother:</b> I think so.</p> <p><b>Interviewer:</b> How?</p> <p><b>Mother:</b> Because it's not the same treatment for all types of cancer.</p> <p><b>Interviewer:</b> Have you talked to your family, your community, your village about cancer and what's going on?</p> <p><b>Mother:</b> They ask me how he is doing; they call me every day to ask about his health. I see him fine. The doctors tell me he is doing well.</p>
<p><b>Psychologist:</b> Okay, I'm going to explain it to you. What did you know about cancer? What did you hear?</p> <p><b>Mother:</b> I know it's a deformation, a mutation of the cells, the bad ones. They don't die, instead they infect other good cells.</p> <p><b>Psychologist:</b> Where did you hear about it?</p> <p><b>Mother:</b> I have seen some cases when they say he's got leukaemia. I have read it's in the red blood cells. And other types of cancer, some of them can be metastatic cancer and other don't. That's all I know.</p> <p><b>Psychologist:</b> It's in the white blood cells.</p> <p><b>Mother:</b> Oh okay.</p> <p><b>Psychologist:</b> I'm going to explain it to you. I'm going to use the whiteboard for a better explanation.</p>	<p><b>Oncologist:</b> Tell me, what did they tell you when they sent [your son] here?</p> <p><b>Mother:</b> Well, the doctor told us that... they found bad cells, they maybe be leukaemia cells, cancer cells. This is why the doctor sent us here, for treatment.</p> <p><b>Oncologist:</b> We examined his blood in the microscope and we did see those same cells....We already have the diagnosis and we can confirm that [your son] has leukaemia. What do you know about leukaemia?</p> <p><b>Mother:</b> This morning the social worker talked to me and said there are two types of leukaemia, I don't remember the names.</p> <p><b>Oncologist:</b> If you want, I can explain a little bit. All the cells we have in our body are born in the bone marrow, it is located inside our bones and it creates the cells in our body. There we find the red blood cells, where the haemoglobin is, they give us colour, then we find the white blood cells, which are the body defenses...</p>	<p><b>Interviewer:</b> And did you understand what cancer is? How did you understand it after their explanation?</p> <p><b>Mother:</b> I did understand it theoretically, but I had a hard time assimilating it because he was my son. I understood it as a cell that didn't form well and it started to multiply reproducing more cells if its species. And that was what affected [my son's] cells.</p> <p><b>Interviewer:</b> Do you feel like your point of view about cancer has changed after you received the diagnosis?</p> <p><b>Mother:</b> No, in the sense that I'm worried he could relapse. I've heard some cases where the child is finishing his treatment and then he relapses or the illness comes back. That's the thing I'm worried about. I cannot change my point of view about cancer because it has a cure but the percentage of children cured is really low, to say it in a way. I'm scared to think, that's the truth.</p>

Continued

Table 4 Continued

Psychosocial intake	Diagnostic communication	Interview
<p><b>Psychologist:</b> Do you understand what I'm saying?</p> <p><b>Mother:</b> Yes.</p> <p><b>Psychologist:</b> Chemotherapy is the medicine used worldwide to treat cancer. It's a group of medicines, some are taken like a pill, some are injected in the vein, others are injected here, and here. What the medicine does is destroy these cells. You see that I didn't destroy all of them, that I left two there. Because many times, chemotherapy tries to destroy all of them but cannot do it. Some cells are left there hidden, and later they could wake up and form another mass again. So, depends on what type of mass it is, on its name and surname, what kinds of cells it's made of, and then we can decide the type of treatment....Maybe they'll give her the medicine first or the surgery, depending on the size. If it's too big, they give medicine first to reduce the tumour and reduce the risk of the surgery. Questions?</p> <p><b>Mother:</b> No.</p> <p><b>Psychologist:</b> So, tomorrow he's going to the biopsy, when they have the results, the doctor will tell us, and we'll seat all together, including the doctor, and he or she, depending who's in charge, will tell us the results, if it's benign or malign.</p>	<p><b>Oncologist:</b> It's a [tumour name]... Generally, it grows in the [lymph nodes], you have seen that the [nodes] get bigger in our neck when we get an infection, we have those [nodes] in all parts of our body, and we don't know why, a cell transforms and become malign and they start multiplying, without any control, that's why they are called malign, because if they are not stopped, they advance and keep growing. And [this] tumour, as I was telling you, is one of the most fast-growing tumours. When you first saw it, it's possible it was starting, it's not something that was there for months or weeks. It grows very quickly...So, it's not like you didn't take good care of him and didn't find out. It simply appeared like that, very fast.</p> <p>...</p> <p><b>Father:</b> Ok, good. Now, one question, how long is the treatment?</p> <p><b>Psychologist:</b> The doctor talked about six cycles, so it's more or less 6 months.</p> <p><b>Father:</b> Ok.</p> <p><b>Psychologist:</b> It could be a little bit more if it delays as a result of an infection or something like that, but in average, 6 months.</p>	<p><b>Interviewer:</b> What had you heard about [cancer]?</p> <p><b>Mother:</b> When you are not living it, you don't pay attention to it, I used to see commercials about cancer, but we never searched for information.</p> <p><b>Interviewer:</b> Have you had someone close or from the community who had cancer?</p> <p><b>Mother:</b> No.</p> <p><b>Interviewer:</b> You said that when you came here, the psychologist talked to you about cancer, how did you understand this disease?</p> <p><b>Mother:</b> She said cancer is a bunch of bad cells, but chemo will destroy the cells, even the good ones and that's why he loses hair, is nauseous and feels down; but that's the only treatment. She said we need to take care of him, take his temperature, avoid that sick people are around him and all that.</p> <p><b>Interviewer:</b> Then they gave you the diagnosis, you said you talked to the doctor and the psychologist and they explained to you again, this time specifically about your son's disease. Did you have the chance to ask questions and clear your doubts in that moment?</p> <p><b>Mother:</b> Some of them, sometimes you don't want to ask in the moment; but he said I came on time it spreads, but for now it was only in the stomach, the marrow was clean, that he was going to receive 6 months of treatment.</p>

Continued



Table 4 Continued

Psychosocial intake	Diagnostic communication	Interview
<p><b>Psychologist:</b> Now that you know agriculture, when we plant a corn seed, the first thing this seed is going to do is to produce roots, then the plant will grow, then the corn will appear and if I take the corn to eat it, the plant will die by itself. Our body is made of little things like the seeds called cells....What happens with cancer? Cancer is also a cell, these cells are no longer good, they are bad. Bad cells are born, they grow and here's the problem, they multiply in an abnormal way, they reproduce without control and in a disorganised way. Also, bad cells don't die by themselves. Because the cancer cell is very similar to when a bug comes in to infect my crops. If a bug comes in there, it will kill this plant and it will want to kill the others. If I want to plant new crops here, what should I do?</p> <p><b>Mother:</b> To clean.</p> <p><b>Psychologist:</b> Yes, clean and cure the soil. Same thing happens with cancer, I need to take it out of the body and kill it because it won't die by itself. Now the question, why does it happen? Like I told you, we are going to be very honest with you, doctors worldwide, in the United States, Mexico, South America, Europe, have been investigation the cause of cancer in children, and unfortunately, we haven't had an answer. We still don't know the cause... What I want you to know and keep in your mind and heart and also share with your husband is that this is not your fault or you husband's fault. This is no one's fault. This is an accident and something that happens because is in the child's own genetic process and unfortunately, it happens to a lot of children. It sounds bad, but it's like a bad lottery, something that happens we don't know why but we do know how to treat it. That's the most important thing. Do you understand?</p> <p><b>Mother:</b> Yes.</p>	<p><b>Oncologist:</b> Well, we have been able to confirm, after the results of all the tests, that [your son] has a mass inside his kidney....If you like, I can show a little bit here so you can see what's happening. Seat down, please. These are the tests of [your child], made yesterday [date]. These are you [child's] tests. <b>(showing images)</b> And that tumour, through the blood that is passing there constantly, can start growing and send seeds to other parts of the body....These kinds of tumours always need treatment because we already talked about the seeds they can send throughout our body... Right now, I cannot tell you without a doubt that [your child will] be cured. I don't know what kind of tumour it is yet. I don't know in what stage it is, but what I can tell you is that this is one of the most curable cancer in children.... If it's discovered at an early age, just like [your child], and if it's Wilms, 80% up to 90% can be cured. With a treatment that requires a big surgery, and medicines, [your child] probably won't need radiotherapy...Do you understand?</p> <p><b>Mother:</b> Yes.</p> <p><b>Oncologist:</b> Do you have questions?</p> <p><b>Mother:</b> You talked about surgery, and you know when to do it because you said this is growing, so do you know when to do it?</p> <p><b>Oncologist:</b> Of course, it's very fast... So, we need to do this urgently...Next Wednesday there's a space for [your child], because this cannot wait.</p> <p><b>Mother:</b> My husband was telling me that God loves us so much, because he knows why he sent us here, after those symptoms.</p> <p><b>Oncologist:</b> That's what he told you. After a bad thing, good news.</p> <p><b>Mother:</b> Thank you very much. I'm in your hands, first God and then you.</p>	<p><b>Interviewer:</b> Had you heard about cancer before this news?</p> <p><b>Mother:</b> Yes...but only about leukaemia. But I never heard about what my [child] has, you learn a lot here, you learn that there are many diseases and how they develop.</p> <p><b>Interviewer:</b> What did you know about leukaemia?</p> <p><b>Mother:</b> I heard that... in children, the blood becomes watery. That there was no cure... because where I live, a few days ago a young boy died because it. I don't know if they brought him here, but he died a few days ago, they said he had leukaemia.</p> <p><b>Interviewer:</b> How did you feel about this boy who died?</p> <p><b>Mother:</b> Sad because we were very close to his family. He deteriorated very fast, he was very thin; me and my family thought that disease was very difficult... then he died, it was sad.</p> <p><b>Interviewer:</b> When you arrived here and they talked to you about cancer, how did you feel about that boy's story?</p> <p><b>Mother:</b> I didn't know much, I learnt to fight here, fight for my son. As the doctor told me, well actually the psychologist told me first, that there is no death for cancer, there is cure. I wish all the parents will fight for their children, I know it's hard. Sometimes I feel sad and I understand but we have to fight.</p>

Continued

Table 4 Continued

Psychosocial intake	Diagnostic communication	Interview
<p><b>Psychologist:</b> Cancer is also a cell, but this is a bad cell. It's like a bug enters my land, what will the bug do?</p> <p><b>Father:</b> It starts reproducing.</p> <p><b>Psychologist:</b> Yes, and what happens to my crops?</p> <p><b>Father:</b> It kills them.</p> <p><b>Psychologist:</b> And if a leave that bug there, am I going to be able to plant again?</p> <p><b>Father:</b> No.</p> <p><b>Psychologist:</b> What do I have to do then?</p> <p><b>Father:</b> Maybe find another place in the field.</p> <p><b>Psychologist:</b> Or cure the soil. Cancer is also a cell, but it's a bad one, it's like that bug that penetrates my crops. It contaminates my crops. Cancer, instead of helping the body, it harms it.</p>	<p><b>Oncologist:</b> Any other question?</p> <p><b>Father:</b> So, he's going to stay here for 3 to 4 weeks, right?</p> <p><b>Oncologist:</b> It could be less than that or even more, that depends on how he responds to treatment, but overall, it's 3 weeks. 3 or 4 weeks they stay here because that's when we give him the most aggressive medicine trying to clean out his blood, we'll be taking care of his fever, cough or any other symptom. And when he gets better you can take him home.</p> <p><b>Psychologist:</b> One question doctor, the treatment involves chemotherapy, right?</p> <p><b>Oncologist:</b> Yes. The treatment will require him to take some syrups, pills, or saline solution. They are called chemotherapy, and they are special medicine to clean the blood, take out the cancer from the body and we achieve that through intravenous saline solutions or pills. We will explain everything; you will have everything written on a paper so you don't have troubles with all these. The important thing is that you understand this is a delicate illness and we have to take extreme good care of him. We will explain you when to bring him to the hospital. When you take him home and suddenly, he's feverish you must bring him to the hospital, to the emergency room. This is your hospital, if he falls down you bring him here, nowhere else. This will be his hospital for the next 2 years, everything he needs, we will provide.</p>	<p><b>Interviewer:</b> When you arrived here, who explained it to you? What changed in the way you understood cancer?</p> <p><b>Father:</b> They told me his type of cancer was leukaemia. I wondered where it came from, they said it was a cell that started to grow, and it was an enemy for the white cells and started to kill them all. He had fever and was very pale. We didn't know and didn't have the experience. They told me not to worry, that we were going to make it, they he will receive the right treatment... I am a farmer, so, they told me it was like when I sow and a poisonous animal kills my plant, they told me to think it like that, that's the baby's life, a cell wanted to kill him. But they also told me not to worry, that they were going to treat him with chemotherapy, I asked what that was, they said it was a medicine that looks for the enemy to eliminate it, don't worry about the symptoms, he might vomit or have fever, he might cough, but don't worry because that means that the medicine is working and also don't worry about the hair loss, he won't stay like that forever, the hair will grow back. I thank God for all the wisdom the doctors have, how they treat the child, what they taught me about cancer and how common it was. I talk to people here, there are several types of cancer, there are masses, which they operate and there is the leukaemia that is in the blood. Since today I believe that there is cure and possibilities.</p>

UNOP, Unidad Nacional de Oncología Pediátrica.

One parent said “nurses, like I said, they help you a lot with the burden”, and another described, “the lady from nutrition is very kind, I can ask her anything”. Parents illustrated how these providers helped them understand their child’s diagnosis, providing reassurance, emotional support and hope (table 3).

#### Other patients and families

In addition to providers at UNOP, parents learnt about childhood cancer from other patients and families (table 3). By observing other children, families learnt about the physical consequences of treatment including temporary side effects such as hair loss, as well as permanent outcomes including enucleation and amputation. While many parents described initial fear associated with these observations, they also explained the supportive network of families as “a comfort chain that keeps growing”.

#### Lived experience and current cancer understanding

Throughout conversations with providers, as well as in subsequent interviews, parents described their own lived experience as a source of information. This source emerged as both a culmination of previously outlined sources and simultaneously independent. It was mentioned by parents who had pre-existing beliefs about cancer: “But it’s so different to live this”, as well as those who had never heard of cancer before: “I never heard about blood cancer, until now” (provider conversation). One mother commented on how the experience of having a child diagnosed with cancer separated her from other members of her community, “The ones that have lived this they understand, the others that haven’t lived this don’t understand”. Another described the difference between hearing about cancer and experiencing her child’s diagnosis: “Yes, we heard about it, we heard about

tumors, but hearing is different than saying face to face, this is what your child has”.

In interviews, parents reflected on how little they knew when they started their journey, “we didn’t know about anything...we didn’t know what to do because of his disease”. They described worrying that they might have done something to cause their child’s cancer, or that they failed to recognise early symptoms. Parents also explained how their experiences at UNOP shaped their understanding of cancer, one saying “it’s like a 360-degree turn”. They talked about coming to terms with their child’s diagnosis: “they gave us the news...it’s hard to accept it, it takes days, you have to breathe”.

When asked in interviews about how their understanding of cancer had changed, parents often used allopathic descriptions: “She said cancer is a bunch of bad cells, but chemo will destroy the cells”. Some parents expressed understanding that their child’s illness was ‘aggressive’ and described learning about aetiology “we asked where that disease came from, she said even they didn’t know that. The disease just comes”. As parents discussed the allopathic model for cancer, some explained how their understanding differed from what they had previously thought or what their community believed about cancer, “once you have cancer you don’t have a good future...that’s what I heard until they started to explain to me here what type of cancer it was”. One father used allopathic explanations to talk to his family and community about his child’s cancer: “I explained it to them the way they explained it to me. I told them cancer is an active bad cell”. Parents also described accepting treatment saying, “the medicine has helped a lot”, and “chemo will destroy the cells”.

Almost all parents described feeling more hopeful based on experiences at UNOP. One parent described explicitly how providers at UNOP ‘motivate us and give us hope’. Parents hoped for cure, but also that their children would return to school or work, ‘recover soon’, ‘feel better’ and ‘grow, play and have happy life’. As parents expressed hope, many described a dual belief in God and medicine “Maybe He will send a miracle through the doctors” (provider conversation); “I think God gives the doctor his wisdom” (provider conversation). They prayed to God to provide a miracle, to work through or with the doctors to cure their children, and to give them patience and strength. Faith in God was expressed by parents who had referenced Mayan spirituality as well as those who had not and was acknowledged by providers throughout the diagnostic process.

Ultimately, parents described an evolution from fear or incredulity to acceptance of their child’s diagnosis (table 4). One mother explained that she previously equated cancer with death. While she never imagined it would happen in her family, she said she would not have pursued treatment without UNOP “I didn’t know this hospital”. When she was given the diagnosis, she felt sad but asked God for strength and learnt from the providers at UNOP, “I thought there was no medicine,

but the doctor told me there is medicine”. She and her husband talked and decided that accepting care was best for their son, “if there is a solution for the disease, we thank God...I feel he is better with the medicine”.

## DISCUSSION

Similar to families everywhere, Guatemalan parents included in this study learnt about cancer, and their children’s diagnoses, from a variety of sources. Some of these sources, including prior experiences, media exposure and discussions within their communities, contributed to pre-existing cancer beliefs. While some of these beliefs were aligned with an allopathic medical model, others were not. In Guatemala, Mayan spirituality contributed to beliefs that a child’s cancer may be related to supernatural causes such as *susto* or the evil eye. In addition, many of the parents in this study had negative or fatalistic beliefs about cancer. Prior to arriving at UNOP, parents equated cancer with death, disfigurement and financial strain.

Nevertheless, parents’ cancer beliefs were not stagnant. As families went through the process of receiving a cancer diagnosis, they were exposed to new sources of information that reflected the culture of their cancer centre. At UNOP, this two-step process included extensive time with the psychosocial team. Psychologists used illustrations and metaphors to educate parents regarding cancer, techniques which have been shown to be effective for cross-cultural communication.<sup>17 18</sup> Psychologists were also attentive to families’ pre-existing cancer beliefs, and specifically inquired about Mayan spirituality, even when it was not brought up by the family. As a part of their training, the psychosocial team at UNOP regularly reviews anthropological topics including Mayan beliefs and spirituality which help them provide culturally relevant care. Previous research has demonstrated that cultural differences in explanatory models can contribute to breakdowns of communication between patients and providers.<sup>19</sup> In addition, an earlier study at UNOP indicated that up to 90% of families use traditional and complementary complementary medicine while receiving cancer treatment.<sup>20</sup> By acknowledging and exploring family beliefs in Mayan spirituality, the team at UNOP allowed families to openly discuss pre-existing concerns regarding cancer causation and treatment. This communication process enabled honest discussion of traditional beliefs and therapies, while simultaneously supporting acceptance of the allopathic medical model and need for treatment as subsequently described by the oncologist.

During diagnostic conversations, oncologists provided extensive information regarding the child’s diagnosis, location of disease, prognosis and treatment plan. Like the psychologists, oncologists often used images (either drawings or anatomical scans) to convey information. Oncologists focused on allopathic rather than metaphorical descriptions of cancer, and interviews with parents



demonstrated their understanding and acceptance of this model.

Along with information, parents described receiving support from providers, patients and families at UNOP. Parents specifically identified how psychologists and oncologists gave them hope for cure, treatment and improved quality of life. As they expressed hope, parents often returned to their faith, integrating deep religious beliefs with a newer acceptance of the medical model. Some parents who expressed faith in God also alluded to traditional Mayan beliefs as they wrestled with aetiology and sought out traditional healers en route to UNOP. This suggests that for many parents in Guatemala spirituality is a complex combination of Mayan and Christian beliefs. In this study, Mayan spirituality was discussed in relation to cancer aetiology and traditional remedies, while God was associated with perseverance and hope. It is possible that this complex interplay set the stage for parents integrating new information as they received it from UNOP providers.

The combination of hope and education allowed parents to transition from fatalistic pre-existing notions of cancer, to a more positive narrative that absolved them from blame and included potential for cure. Prior work in high-income countries has explored the importance of hope throughout the cancer continuum,<sup>21–23</sup> and ‘supporting hope’ was recently identified as an additional function of cancer communication for the paediatric population.<sup>24</sup> While previous studies have focused on centres in the USA and other high-income countries, our results provide evidence for the importance of supporting hope in LMICs.

This study focused in depth on the diagnostic experience of 20 families at the only paediatric cancer centre in Guatemala. As with all qualitative research, the results may be limited in their generalisability. Further studies are necessary to explore the relevance of these themes to populations in other LMICs, as well as to the communication process at other stages of cancer care. In addition, given the large proportion of families included with haematological malignancies, our study may have over-represented the perspective of this population; additional studies may be necessary to further explore the beliefs of families with solid malignancies. Interview scripts were developed in English, and all analyses were conducted in English, while data were collected in Spanish. A bilingual research team reviewed scripts and transcriptions in both languages, however it is possible that translation of qualitative data may have affected content. In addition, we were unable to conduct interviews in traditional Mayan dialects which may have limited participation from certain communities, or the ability for some families to fully express themselves. To our knowledge, only one family declined participation in the study due to language. Overall, we had a participation rate of 62.5%. The primary reason caregivers declined participation in the study was hesitancy with the audio recordings, and the participation rate for this study is similar to that

found in previous paediatric oncology work involving audiotaping.<sup>25</sup> However, it is unclear what if any effect on our results this selection bias may have had. Finally, although this study focused on paediatric cancer, paediatric patients were not included. A child life team at UNOP separately discusses diagnoses with paediatric patients and thus they were not included in recorded conversations or interviews. Future studies are necessary to explore diagnostic communication at UNOP from the perspective of paediatric patients.

At the time of diagnosis, parents in Guatemala hold pre-existing cancer beliefs that may diverge from the medical model and are instead influenced by socio-cultural and contextual factors. The findings from this study demonstrate that a communication process that is attentive to these beliefs and overarching social concerns supports acceptance of a medical model and need for treatment, without fully supplanting pre-existing beliefs. In Guatemala, an interdisciplinary care model that includes psychosocial involvement from diagnosis has been demonstrated to reduce treatment abandonment rates, and similar models have been applied to other LMICs.<sup>10</sup> Our findings suggest that there are important pieces of this model in addition to an interdisciplinary approach, including verbal, written and pictorial education, attention to pre-existing beliefs, and supporting hope, which contribute to its success. Providers in settings of all resource levels may be able to use these techniques to support cross-cultural cancer communication, reduce treatment abandonment and improve therapy adherence. Additional studies should be conducted to validate these findings in other settings and develop targeted interventions.

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## 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”