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

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

Running Head: Decision-Making in Guatemala

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Contributorship statement: Dr. Graetz conceptualized and designed the study and data collection tools, supervised pilot testing and data collection, analyzed qualitative data, drafted the initial manuscript, and reviewed and revised the manuscript.

Drs. Rivas and Antillon-Klussman contributed to study design, facilitated study approval and supervised data collection at Unidad Nacional Oncología Pediátrica, and reviewed and revised the manuscript.

Ms. Wang, Mr. Vedaraju, and Dr. Devidas conducted statistical data analysis and reviewed and revised the manuscript.

Ms. Ferrara analyzed the qualitative data and reviewed and revised the manuscript.

Ms. Fuentes and Ms. Caceres-Serrano contributed to study design, conducted pilot testing, collected data, and reviewed and revised the manuscript.

Drs. Metzger and Rodriguez-Galindo contributed to study design and reviewed and revised the manuscript.

Dr. Mack conceptualized and designed the study and data collection tools, and critically reviewed the manuscript for important intellectual content.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Abbreviations: LMICs: low- and middle-income countries; UNOP: Unidad Nacional de Oncolgía Pediátrica; St. Jude: St. Jude Children's Research Hospital

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Key words: Pediatric cancer; Guatemala; Decision-Making; Communication

Total number of text pages: 24; **Tables:** 4; **Figures:** 0; **Supporting files:** 1

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Abstract

Objectives: To examine treatment decision-making priorities and experiences among parents of children with cancer in Guatemala.

Setting: This study was conducted at Guatemala's national pediatric cancer center in Guatemala City.

Participants: Spanish speaking parents of pediatric patients (≤ 18 years of age) diagnosed with any form of cancer within the 8 weeks prior to study enrollment. The quantitative portion of this study included 100 parent participants; the qualitative component included 20 parents. Most participants were Catholic or Evangelical Spanish-speaking mothers.

Outcomes: Priorities and experiences of cancer treatment decision-making including decision-making role and experienced regret.

Results: A range of pediatric ages and cancer diagnoses were included. Most Guatemalan parents surveyed (70%) made decisions about their child's cancer together and almost all (94%) without input from their community. Surveyed parents predominately preferred shared decision-making with their child's oncologist (76%), however 69% agreed it was best not to be provided with many options. Two-thirds of surveyed parents (65%) held their preferred role in decision-making, with fathers more likely to hold their preferred role than mothers (p=0.02). A small number of parents (11%) experienced heightened decisional regret, which did not correlate with sociodemographic characteristics or preferred decision-making role. Qualitative results supported quantitative findings, demonstrating a decision-making process that emphasized trust over autonomy.

Conclusions: Guatemalan parents preferred to make decisions with their medical team and appreciated providers who were honest and inclusive, but directive about decisions. This study

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reinforces the importance of the provider-parent relationship and en`courages clinicians in all settings to ask about and honor each parent's desired role in decision-making.

Article Summary:

Strengths and limitations of this study:

- This study investigated communication and decision-making, key components of patient-centered care, in a middle-income country, a previously understudied area of research in this population.
- The convergent mixed-methods study design enabled broad assessment of decision-making priorities as well as deep exploration of decision-making processes among Guatemalan parents of children with cancer.
- Use of survey items previously validated in high-income countries allowed for comparison to published literature from these settings.
- The focus on the diagnostic period limited the ability to consider how decision-making may change over the cancer continuum.
- Study was conducted at single cancer center in one middle-income country, and thus results may not apply to other low- and middle-income countries

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Key Questions:

What is already known?

- Parents of children with cancer are faced with difficult decisions regarding care and treatment.
- In high-income Western contexts, shared decision-making is associated with improved outcomes, but little is known about decision-making in low- and middle-income countries, where 90% of children with cancer live.

What are the new findings?

- This mixed-methods study included 120 Guatemalan parents of children with cancer and demonstrated that most parents prefer to make cancer decisions with their child's oncologist (76%), and most (65%) held their preferred role in decision-making, while few (11%) experienced decisional regret.
- Qualitative data demonstrates how culture may influence models for shared decision-making.

What do the new findings imply?

- Guatemalan parents have many of the same priorities for cancer decision-making as parents of children in the United States and face similar challenges.
- These results reinforce the importance of the provider-parent relationship in all settings and encouraging cultural sensitivity.

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Introduction

From the time of diagnosis, parents of children with cancer are faced with difficult decisions regarding care and treatment. Shared decision-making is associated with improved patient-reported outcomes for adult cancer patients,[1] and research from high-income Western countries has emphasized a similar model for parents of children with cancer.[2,3] Effective shared decision-making depends on high-quality communication[4] through which pediatric oncology providers explore parents' goals of care as they present treatment options and determine a mutually acceptable action plan.

Parental values affect the extent to which they desire to be involved in decision-making, and both individual as well as community belief systems are shaped by culture. Cultural differences between patients and healthcare providers during decision-making have been demonstrated to result in erroneous assumptions and interpersonal conflict.[4] For parents of children with cancer, having their preferred role in decision making may increase trust in healthcare providers[5] and decrease regret.[3,6] Nevertheless, culture is rarely accounted for in research surrounding patient-provider communication and decision-making,[7] and very few studies have explored decision-making among pediatric cancer patients in low- and middle-income countries,[8] where >90% of children with cancer live.[9] The purpose of this mixed-methods study was to examine cancer treatment decision-making among parents of children with cancer in Guatemala at the time of diagnosis. We sought to assess the decision-making preferences and experiences of parents of children with cancer through a cross-sectional survey and used audio-recorded diagnostic conversations and semi-structured interviews to explore decision-making processes and

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influences in greater depth, including who was involved in the process, how cancer treatment decisions were made, and parental reflections on early decisions.

Methods

This study utilized a convergent mixed-methods design. Quantitative data was collected from a verbally administered cross-sectional survey. Qualitative data included diagnostic conversations between healthcare providers and parents of newly diagnosed children with cancer, and subsequent semi-structured interviews.

Participants and setting

This study was conducted at Guatemala's national pediatric cancer center: Unidad Nacional de Oncología Pediátrica (UNOP). UNOP is located in Guatemala City, Guatemala. Approximately 500 new cases of childhood cancer are diagnosed at UNOP annually, and the survival rate at UNOP is about 67%.[10]

Eligibility criteria for the quantitative sample and qualitative sample were the same and included Spanish speaking parents of pediatric patients (≤ 18 years of age) diagnosed with any form of cancer within the past 8 weeks. Parents participated in either the quantitative or qualitative portion of the study, but not both. Of 104 parents approached for the quantitative sample, 100 (96%) agreed to participate. Participants in the qualitative sample were recruited sequentially, with additional purposive sampling[11] to ensure representation of a range of pediatric ages and

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diagnoses as well as families with diverse socioeconomic and cultural backgrounds. Overall, 32 parents were approached for participation in the qualitative study and 20 parents agreed to participate. Thematic saturation[12] was reached after enrollment of 20 parents and no further participants were approached.

Ethics approval

Written informed consent was obtained in Spanish by a native Spanish speaker for all participants. This study was performed in compliance with international regulations for protection of human subjects and approved by institutional review boards (IRBs) and ethics committees at St. Jude and UNOP (IRB Number: 19-0162; Reference Number: 010262).

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Study design and data collection

For the quantitative component of the study, a cross-sectional survey was developed using items previously used in high-income countries[5,6,13] as well as novel questions specific to the study population. The survey was developed in English, translated into Spanish, pilot tested with 23 parents to establish face and content validity through iterative revision, and back translated into English to ensure the original intent of questions was preserved.

Sociodemographic information was obtained through survey questions on participant's gender, relationship to the child, languages spoken, religion, ethnicity, household income, and marital

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status. Demographic information on patients including gender, age, and diagnosis was obtained from medical record review.

Decision making preferences and experiences were assessed through the survey, first by asking parents "Who do you consider to be the person who makes most decisions in your house in general?", and "about your child's cancer treatment?". Response options included "Another parent or family member makes most of the decisions", "I am the parent most involved in making decisions" and, "I share decision-making equally with my child's other parent or family member". Parents were asked: "Which statement best describes the role your community played in helping you make decisions?". Response options included: "I/We made decisions about treatment without input from my community", "…with help from members or leaders in my community", and "My community, or a leader in my community, made the decision and told me what was best". A similar question asked about involvement of religious or spiritual leaders in decision-making.

Regarding decision-making with the child's oncologist, parents were asked to describe "the role you would prefer to play when decisions about treatment for your child's cancer are made". Response options included: "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", or "I prefer to make the decisions about treatment". Parents were then asked about "the role you actually played when making decisions about treatment for your child's cancer", with similar response options framed in the past tense. To further assess preferences for shared decision-making, parents were asked "How much do you agree with the following statement: I'd rather have doctors and nurses make

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the decisions about what's best than for them to give me a whole lot of choices". Response options included: "strongly agree", "slightly agree", and "disagree". Parents were also asked "At the time of diagnosis, which of the following statements best describes how your oncologist explained your child's treatment plan", with response options including "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", and "He/she gave me only one option".

Decisional regret was assessed using a modified version of the Decisional Regret Scale,[14,15] which asked participants to state whether they "strongly agreed", "slightly agreed", or "disagreed" with each of the following statements: "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", "The decisions were wise", and "The choices did my child a lot of harm".

The qualitative component of the study involved three audio-recorded sessions for each participating family (60 sessions total). At UNOP, the standard diagnostic procedure includes an intake conversation with a psychologist, followed by an initial diagnostic conversation with the oncologist about diagnosis and treatment plans for which the psychologist is also present. These two conversations were audio recorded as they naturally occurred, and one parent from each participating family was subsequently interviewed. Semi-structured interviews explored parents' communication perspectives and experiences, including the process for decision-making at UNOP and parental reflections. All audio recordings were professionally transcribed and translated into English with review by bilingual members of the research team to ensure adequate capture of original content.

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Complete survey and interview script are included as **supplementary materials**.

Data analysis

Quantitative data including sociodemographic information and items pertaining to decision-making were analyzed descriptively. Proportions between groups were compared using Chi-square or Fisher's exact test as appropriate. Parent responses regarding their preferred decision-making role was compared to the actual role they played. Parents whose preferences matched their experiences were considered to have held their preferred role and were compared to parents whose experiences did not match their preferences. Univariate logistic regression was used to assess the impact of sociodemographic characteristics on "preferred" versus "non-preferred" role in decision-making. A decisional regret score was calculated based on previously reported methods.[15] Because our final scale used 3 rather than 5 response options based on findings during pilot testing ("disagree", "slightly agree", "strongly agree"), points were assigned with a scale of 1, 3, and 5 with reverse scoring where appropriate, in which a score of 1 indicated the least regret and 5 indicated the most regret. Scores were decreased by 1 point and multiplied by 25 for a score range of 0 to 100. Consistent with existing literature,[15] scores of 0 were categorized as no regret, 1-25 as mild regret, and >25 as heightened regret. Univariate logistic regression was performed with sociodemographic variables as well as "preferred" versus "non-preferred" role in decision-making.

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Analysis of qualitative data was conducted by two independent coders who conducted thematic content analysis[16] on all transcripts utilizing a combination of *a priori*[17,18] and novel codes. Interrater reliability ranged from 0.72-0.88. Novel codes were identified based on recurrent themes by two authors who iteratively read transcripts. Conceptual definitions were refined through memo writing and initial coding of 12 transcripts. The final codebook is included as **supplementary material**. Codes related to decision-making included those identifying the decision-maker, the type of decision, and the reasons behind decision-making. Codes related to shared decision making at the cancer center included those expressed by providers and reflections from parents. MAXQDA (VERBI, Berlin, Germany) was utilized for data management. The Consolidated Criteria for Reporting Qualitative Studies guidelines were followed.[19]

Patient and public involvement

Neither patients, parents, nor the public were designed in the design of this research. Parents were involved in piloting the survey and we plan to involve parents further as we disseminate these results and consider interventional work.

Results

Participant Characteristics

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Demographic characteristics of participants from each sample and their children are included in Table 1. Most included participants in both samples were Spanish-speaking mothers who identified as either Catholic or Evangelical. A range of pediatric ages and cancer diagnoses were included.

Parental decision-making

Most Guatemalan parents surveyed (80%) made household decisions with the child's other parent, and 70% made decisions about their child's cancer care this way. In interviews, parents described sharing decision-making with their partners. One father said, *"I talk to my wife and we agree on a middle point…the decisions are made by my wife and me"*; a mother described how she made decisions *"with my husband, because we are a couple."* While many interviewed parents listened to advice from extended family or community members, they emphasized the parental unit as the ultimate decision maker: *"We have to talk, ask people with experience, and then we decide".* Amongst surveyed parents, almost all (94%) reported making decisions without input from their community, and most (76%) made decisions without input from religious or spiritual leaders.

In describing how they ultimately made decisions around cancer care and treatment during interviews, parents prioritized the health and survival of their children. As one parent said, *"We think of the kid first. We want to give him the best. We want to get better."* Other parents described sacrifices they were making, or were willing to make, in order to get their child

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appropriate care: *"If I must give her my heart, my kidney, I'd give it to her so she won't die. I already lived; she's starting to live. I tell her if I must die for you to be cured, I'll do it."*

Decision-making with the oncologist

When asked about their preferred role in decision-making with respect to the oncologist, most Guatemalan parents (76% of those surveyed) wanted to share decision-making with their child's oncologist. Of those that did not, 20% preferred that the oncologist made most of the decisions, while 4% preferred to make treatment decisions themselves. However, a majority of parents either slightly (21%) or strongly (47%) agreed that they would rather have their medical team make decisions about what was best than provide a lot of choices; 31% disagreed. When asked about their experiences during the decision-making process, only a few surveyed parents (4%) said the oncologist provided them with options and they chose; the rest reported that they were either given options and said the oncologist told them which was best (48%), or were not provided options (48%).

Qualitative data reflected a model of decision-making that emphasized honesty and trust in the medical team. Psychologists set the tone during initial conversations, highlighting a team approach to care and including parents as part of this team. One psychologist said: *"I know it's hard to trust in strangers, but you can ask all mothers here at the hospital, we are a team along with the parents…we don't hide information."* Another emphasized honesty saying, *"we will always tell you the truth, even if the truth is hard."* These messages were reinforced almost

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verbatim in diagnostic conversations with the oncologists: *"We promise we will always tell you the truth. Even if the information is bad, we will tell you, we will never hide information."*

However, when psychologists and oncologists talked about treatment, they emphasized the importance of starting immediately, using words like "*must"* and phrases such as *"have to"*, without providing parents with multiple options. These directives referred to treatment modalities, such as surgery or chemotherapy, necessity of hospitalization, and importance of follow-up appointments. Table 2 includes additional quotations that demonstrate the tone around decision-making set by psychologists and oncologists at UNOP.

Guatemalan parents accepted this model, expressing trust in their medical teams and deference to their providers. One parent directly told the oncologist, *"Whatever you say, you decide"*. Another parent described in an interview: *"We didn't know if it was the best, but that's like when you wear an outfit – I just wear it – it doesn't matter if it's pretty or not"*. Parents also referred to the expertise of their medical team, one saying, *"the best specialists are here, this is why I'm here"* and another, "*I didn't ask much; the experts know the solution."*

Reflections on decision-making

Two-thirds of surveyed parents (65%) held their preferred role in decision-making around their child's cancer care, while 23% had a more active role than desired and 11% had a less active role than desired. Fathers were more likely to hold their preferred role in decision-making than mothers (OR 4.32 [95% CI 1.17-15.89], p=0.02) (Table 3).

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Most parents (64%) were categorized as having no decisional regret, while 25% had mild regret, and 11% had heightened regret. Heightened decisional regret did not significantly correlate with any sociodemographic variables, or with parents having played their preferred role in decision making (OR 1.34 [95% CI 0.32-5.56, p=0.68) (Table 4). Parents in the qualitative sample predominantly expressed gratitude (“*we are grateful for this treatment”)*, peace (*“I’m a little bit more calmed”*; *“here we feel more relaxed”)*, and relief (*“They told me this was a good hospital; I felt relief”)* as they reflected on decisions they had made.

Discussion

The majority of Guatemalan parents included in this study valued shared decision-making, both with the child’s other parent and with their child’s oncologist. Providers at UNOP emphasized a decision-making model in which trust and honesty were prioritized over autonomy, and parents deferred to their providers and were predominantly satisfied with the care they received. Ultimately, most parents felt they had made the right decisions, however, 11% experienced heightened decisional regret.

There are many approaches to decision-making in pediatric cancer care.[20] In high-income Western contexts, shared decision-making has been prioritized.[21] While different definitions of shared decision-making exist, it is often presented in contrast to paternalism and generally emphasizes autonomy,[22] multiple options,[23] and two-way information-exchange.[24] Approximately three out of every four Guatemalan parents in our study reported that they

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preferred to share decision-making with their oncologists, however a similar proportion (69%) ultimately wanted their medical team to decide what was best rather than provide multiple options without a clear recommendation. These preferences are consistent with the decision-making process noted in diagnostic conversations recorded at UNOP, after which most parents expressed satisfaction. The model of decision-making at UNOP prioritizes trust, honesty, and information-exchange but maintains a predominately unidirectional flow of information (provider to parent) and does not include many choices. This model diverges from expectations for shared decision-making set forth by literature from high-income countries but is consistent with literature from other LMICs which describes an evolution in medical decision-making[25] with increasing prioritization of information-exchange[26] and autonomy over time.[27] These findings suggest there may be differences in cultural perceptions around shared decision-making, and shared decision-making may have different manifestations in different contexts.

Parents in our study also predominantly reported sharing decisions about their child's care with the child's other parent, without significant input from their community. While there is limited literature on extended family or community involvement in decision-making for children with cancer, one study conducted in the UK demonstrated decisions were primarily made without involvement of individuals outside the nuclear family,[28] consistent with our findings from Guatemala. However, approximately a quarter of parent participants in our study did describe consulting spiritual or religious advisors, emphasizing the importance of religion to this community. Previous work also suggests that although diagnosis is a one of the most stressful times for parents of children with cancer, it is a time when parents may feel most connected to one another.[29] It is possible that this emotional connection explains the shared parental decision-

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making we noted among partnered participants, however it is also possible that sociocultural expectations influence this decision-making in Guatemala. This study included more mothers than fathers, which is representative of caregivers at UNOP where mothers often attend visits while fathers remain in the community, working to support the family. Mothers at UNOP may feel obligated to discuss decisions about their child's care with the child's father, whose opinions carry more weight. In addition, we found that mothers were less likely than fathers to have their desired role in decision-making. While the percentage of parents (approximately one-third) who did not have their preferred role in decision-making is nearly identical to that seen in high-income countries, parents in Guatemala who did not have their desired decision-making role tended to have a more active role than desired, whereas those in the United States tended to have a more passive role than desired.[30] The desire of parents, and particularly mothers, to play a more passive role in decision-making may reflect cultural disempowerment, a theme that has been previously described in pediatric cancer communication in LMICs.[31,32]

Finally, parents included in this study report being primarily motivated by their child's health and well-being. This is consistent with the "good-parent" belief,[33] a concept which has been extensively studied in high-income settings[34] and includes "unselfish decisions in the child's best interest".[33] Most parents were satisfied with their decisions, however the small but relevant number of parents (11%) who experienced heightened decisional regret emphasizes the weight of cancer-related decisions and the importance of ongoing support. These findings reinforce the importance of exploring parental preferences for cancer communication and prioritizing individual familial needs, many of which may be influenced by culture.

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This mixed-methods study allowed us to evaluate decision-making among Guatemalan parents of children with cancer, including a deep exploration of motivating factors and the decision-making process at UNOP. However, there are several limitations that should be considered. To reduce burden on participants, our study design included separate qualitative and quantitative samples which limited convergent analysis. This study focused specifically on decision-making at diagnosis, and thus does not address potential shifts in decision-making preferences or experiences over the cancer care continuum. In addition, this study was conducted at a single cancer center in one small middle-income country. This was an initial step toward exploring diagnostic communication and decision-making in LMICs and allowed for comparison to literature from high-income settings, but further research is needed to determine if these findings are applicable beyond Guatemala. Moreover, Guatemala itself is a diverse country. Our study was conducted exclusively in Spanish and thus we were unable to include parents who were not proficient in Spanish. Finally, because most parents included in our study had positive reflections on their decisions, we were limited in our ability to analyze the small proportion of parents who did experience regret. This is an opportunity for future research.

Conclusion:

Almost all prior work on decision-making in pediatric cancer care has been conducted exclusively in high-income settings including the United States and Europe.[35] This study demonstrates that many parents in Guatemala, like those in the United States, want to be engaged in decision-making by their oncology teams and prioritize their child's well-being. However, shared-decision making manifests differently in the Guatemalan context and differs from

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previous definitions, most of which come from high-resourced settings. These findings suggest ways in which culture may influence priorities for care. Ultimately, this work further supports developing the provider-parent relationship in all settings by encouraging clinicians to routinely ask parents what role they want to play in decision-making and honor their responses.

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Table 1. Sociodemographic characteristics of participating caregivers and their children

	Quantitative sample (total = 100)	Qualitative sample (total = 20)
Participant	**N (%)**	**N (%)**
Relationship to patient		
Mother	76 (76%)	13 (65%)
Father	22 (22%)	7 (35%)
Grandparent	1 (1%)	0 (0%)
Sibling	1 (1%)	0 (0%)
Gender		
Male	23 (23%)	7 (35%)
Female	77 (77%)	13 (65%)
Primary language		
Spanish (only)	73 (73%)	13 (65%)
Spanish and English	2 (2%)	0 (0%)
Spanish and Mayan dialect	24 (24%)	7 (35%)
Mayan dialect (only)	1 (1%)	0 (0%)
Ethnicity*		Data not collected
Ladino	55 (56%)	
Indigenous (Mayan)	25 (25%)	
Mixed race	19 (19%)	
Religion		
Catholic	41 (41%)	4 (20%)
Evangelical	52 (52%)	13 (65%)
Other identified religion	3 (3%)	2 (10%)
No religion	4 (4%)	1 (5)
Civil status*		
Married	59 (60%)	13 (65%)
United (living together as if married)	25 (25%)	6 (30%)
Separated	1 (1%)	0 (0%)
Divorced	10 (10%)	1 (5%)
Single	4 (4%)	0 (0%)
Monthly household income (Quetzales)*		Data not collected
<2000	36 (37%)	
2000-2999	23 (23%)	
>2999	39 (40%)	
Patient		
Age (years)		
0-5	38 (38%)	6 (30%)
6-10	19 (19%)	6 (30%)
11-15	31 (31%)	4 (20%)
16-18	12 (12%)	4 (20%)
Gender		
Male	61 (61%)	11 (55%)
Female	39 (39%)	9 (45%)

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Diagnosis		
Leukemia	58 (58%)	13 (65%)
Lymphoma	12 (12%)	2 (10%)
Histiocytic disorders	2 (2%)	1 (5%)
Solid tumor	25 (25%)	3 (15%)
Brain tumor	3 (3%)	1 (5%)

* Ethnicity: 1 missing; Civil status: 1 missing; Monthly household income (Quetzales): 2 missing

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Table 2. Excerpts from recorded diagnostic conversations emphasizing teamwork and honesty over autonomy

Theme	Psychologists speaking to parents during intake	Oncologists speaking to parents in diagnostic conversations
Teamwork	*"You see we are all a team."* *"I want you to know that we are a team and we will always tell the truth."* *"In here, each doctor has his specialty…each of them in their own working area, but we are still a team."*	*"We want to remark that we are a team…and we are all here to support you. We are a big team so one of us will be ready to answer all your questions. No matter if it's good or bad, you deserve to know it."* *"We are a lot of people that work for all children's recovery…There's a huge hope and you have the entire medical staff and the hospital staff next to you, working together to make [your son] better."*
Honesty	*"We will be very honest with you; we won't lie to you…Anything that comes up, I'll let you know"* *"I know no one likes bad news, but as a parent you deserve the truth…Like I told you, doctors will be very honest with you."* *"Here, they will always tell you everything."*	*"Another important thing. We are always going to be very honest with you, if anything comes up, we will seat down with you and talk to you."* *"We won't lie to you, of course it's going to be hard, this is going to feel like a roller coaster, there will be good days and there will be hard days, but we will be with you on good days and hard days."*
Lack of choice	*"What we definitely have to do is surgery, that's essential to cure this type of cancer."* *"Therefore, is so important that once we detect it, we must give treatment immediately."* *"With these, the only treatment is surgery…If we want to save [your son], we must perform the surgery."*	*"Unfortunately, he must stay here for now, but after a while he'll be able to go home for some time or to the shelter."* *"It's going to be difficult, because I'm not telling you it's going to be easy or that don't have to make sacrifices, but if you want to see [your daughter] cured, just like us, this is the road we must follow."*

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Table 3. Univariate logistic regression analysis of sociodemographic factors and preferred decision-making role

Decision-Making		
Factor	**P-Value**	**Odds Ratio**
Parent (N=96)	0.02*	
Father		4.32 (1.17 - 15.89)
Mother		1.00 (Ref)
Ethnicity (N=97)	0.70	
Ladino		1.49 (0.51 - 4.36)
Indigenous (Mayan)		1.66 (0.47 - 5.93)
Mixed race		1.00 (Ref)
Monthly household Income (Quetzales) (N=96)	0.60	
<2000		1.00 (Ref)
2000-2999		1.43 (0.46 - 4.39)
>2999		1.61 (0.62 - 4.15)
Diagnosis group (N=98)	0.12	
Leukemia		1.00 (Ref)
Lymphoma		8.25 (1.00 - 68.35)
Solid tumor		1.59 (0.59 - 4.30)
Others (Histiocytic disorder + Brain tumor)		3.00 (0.31 - 28.59)

*significant p-value

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Table 4. Univariate logistic regression analysis of heightened decisional regret

Decisional regret		
Factor	**P-Value**	**Odds Ratio**
Parent (N=98)	0.68	
Father		1.34 (0.32 - 5.56)
Mother		1.00 (Ref)
Ethnicity (N=99)	0.16	
Ladino		1.41 (0.15 - 13.48)
Indigenous (Mayan)		4.50 (0.48 - 42.25)
Mixed race		1.00 (Ref)
Monthly household Income (Quetzales) (N=98)	0.27	
<2000		1.00 (Ref)
2000-2999		0.75 (0.17 - 3.35)
>2999		0.27 (0.05 - 1.44)
Diagnosis group (N=100)	0.57	
Leukemia		1.00 (Ref)
Lymphoma		0.57 (0.06 - 5.02)
Others (Brain tumor + Histiocytic disorder + Solid tumor)		0.45 (0.09 - 2.25)
Decision Engagement (N=98)	0.71	
Preferred		0.78 (0.20 - 2.96)
Not preferred		1.00 (Ref)

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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?

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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?

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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.

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- 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.

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

1. What is your gender? [IF THEY DO NOT UNDERTAND 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

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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

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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?

	A lot	*A little*	*Not at all*
Caused by an infection	☐	☐	☐
Due to heat or cold	☐	☐	☐
Lacking hygiene or nutrition	☐	☐	☐
Because of a sacred mission	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Due to bad thoughts *(malhecho)*	☐	☐	☐
Sent by the devil *(diabólico)*	☐	☐	☐
Supernatural; originating from natural elements (e.g. waterfalls, mountains, wind, darkness)	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Lack of respect for nature or the elements of the environment	☐	☐	☐
Bad relationships with the community	☐	☐	☐
Caused by God or another religious figure	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Caused by uncontrol cell growth	☐	☐	☐
Caused by fear or surprise *(susto)*	☐	☐	☐
Caused by medications	☐	☐	☐

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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

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☐ I prefer not to know the likelihood this treatment affecting my child

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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

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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

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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

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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

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☐ 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

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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 like, 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

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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 like, 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 nosey 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.

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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 RESONDENT 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

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☐ 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

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

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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:** *Verbal behaviors that validate or support the patient's emotional or motivational state*	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

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		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.

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			Descriptions of lack of information as a barrier to decision making

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

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

Running Head: Decision-Making in Guatemala

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Contributorship statement: Dr. Graetz conceptualized and designed the study and data collection tools, supervised pilot testing and data collection, analyzed qualitative data, drafted the initial manuscript, and reviewed and revised the manuscript.

Drs. Rivas and Antillon-Klussman contributed to study design, facilitated study approval and supervised data collection at Unidad Nacional Oncología Pediátrica, and reviewed and revised the manuscript.

Ms. Wang, Mr. Vedaraju, and Dr. Devidas conducted statistical data analysis and reviewed and revised the manuscript.

Ms. Ferrara analyzed the qualitative data and reviewed and revised the manuscript.

Ms. Fuentes and Ms. Caceres-Serrano contributed to study design, conducted pilot testing, collected data, and reviewed and revised the manuscript.

Drs. Metzger and Rodriguez-Galindo contributed to study design and reviewed and revised the manuscript.

Dr. Mack conceptualized and designed the study and data collection tools, and critically reviewed the manuscript for important intellectual content.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Abbreviations: LMICs: low- and middle-income countries; UNOP: Unidad Nacional de Oncolgía Pediátrica; St. Jude: St. Jude Children's Research Hospital

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Key words: Pediatric cancer; Guatemala; Decision-Making; Communication

Total number of text pages: 24; **Tables:** 4; **Figures:** 0; **Supporting files:** 1

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Abstract

Objectives: To examine treatment decision-making priorities and experiences among parents of children with cancer in Guatemala.

Setting: This study was conducted at Guatemala's national pediatric cancer center in Guatemala City.

Participants: Spanish speaking parents of pediatric patients (≤ 18 years of age) diagnosed with any form of cancer within the 8 weeks prior to study enrollment. The quantitative portion of this study included 100 parent participants; the qualitative component included 20 parents. Most participants were Catholic or Evangelical Spanish-speaking mothers.

Outcomes: Priorities and experiences of cancer treatment decision-making including decision-making role and experienced regret.

Results: A range of pediatric ages and cancer diagnoses were included. Most Guatemalan parents surveyed (70%) made decisions about their child's cancer together and almost all (94%) without input from their community. Surveyed parents predominately preferred shared decision-making with their child's oncologist (76%), however 69% agreed it was best not to be provided with many options. Two-thirds of surveyed parents (65%) held their preferred role in decision-making, with fathers more likely to hold their preferred role than mothers (p=0.02). A small number of parents (11%) experienced heightened decisional regret, which did not correlate with sociodemographic characteristics or preferred decision-making role. Qualitative results supported quantitative findings, demonstrating a decision-making process that emphasized trust and honesty.

Conclusions: Guatemalan parents preferred to make decisions with their medical team and appreciated providers who were honest and inclusive, but directive about decisions. This study

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reinforces the importance of the provider-parent relationship and encourages clinicians in all settings to ask about and honor each parent's desired role in decision-making.

Article Summary:

Strengths and limitations of this study:

- This study investigated communication and decision-making, key components of patient-centered care, in a middle-income country, a previously understudied area of research in this population.
- The convergent mixed-methods study design enabled broad assessment of decision-making priorities as well as deep exploration of decision-making processes among Guatemalan parents of children with cancer.
- Use of survey items previously validated in high-income countries allowed for comparison to published literature from these settings.
- The focus on the diagnostic period limited the ability to consider how decision-making may change over the cancer continuum.
- Study was conducted at single cancer center in one middle-income country, and thus results may not apply to other low- and middle-income countries

Data sharing statement: Extra data is available upon reasonable request by emailing the corresponding author.

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Key Questions:

What is already known?

- Parents of children with cancer are faced with difficult decisions regarding care and treatment.
- In high-income Western contexts, shared decision-making is associated with improved outcomes, but little is known about decision-making in low- and middle-income countries, where 90% of children with cancer live.

What are the new findings?

- This mixed-methods study included 120 Guatemalan parents of children with cancer and demonstrated that most parents prefer to make cancer decisions with their child's oncologist (76%), and most (65%) held their preferred role in decision-making, while few (11%) experienced decisional regret.
- Qualitative data demonstrates how culture may influence models for shared decision-making.

What do the new findings imply?

- Guatemalan parents have many of the same priorities for cancer decision-making as parents of children in the United States and face similar challenges.
- These results reinforce the importance of the provider-parent relationship in all settings and encouraging cultural sensitivity.

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Introduction

From the time of diagnosis, parents of children with cancer are faced with difficult decisions regarding care and treatment. Shared decision-making is associated with improved patient-reported outcomes for adult cancer patients,[1] and research from high-income Western countries has emphasized a similar model for parents of children with cancer.[2,3] Effective shared decision-making depends on high-quality communication[4] through which pediatric oncology providers explore parents' goals of care as they present treatment options and determine a mutually acceptable action plan.

Parental values affect the extent to which they desire to be involved in decision-making, and both individual as well as community belief systems are shaped by culture. Cultural differences between patients and healthcare providers during decision-making have been demonstrated to result in erroneous assumptions and interpersonal conflict.[4] For parents of children with cancer, having their preferred role in decision making may increase trust in healthcare providers[5] and decrease regret.[3,6] Nevertheless, culture is rarely accounted for in research surrounding patient-provider communication and decision-making,[7] and very few studies have explored decision-making among pediatric cancer patients in low- and middle-income countries,[8] where >90% of children with cancer live.[9] The purpose of this mixed-methods study was to examine cancer treatment decision-making among parents of children with cancer in Guatemala at the time of diagnosis. Guatemala is a small but culturally diverse country; with 40% of the population comprised of 24 distinct ethnic groups who speak >20 different languages. We sought to assess the decision-making preferences and experiences of parents of children with cancer through a

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cross-sectional survey and used audio-recorded diagnostic conversations and semi-structured interviews to explore decision-making processes and influences in greater depth, including who was involved in the process, how cancer treatment decisions were made, and parental reflections on early decisions.

Methods

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This study utilized a convergent mixed-methods design. Quantitative data was collected from a verbally administered cross-sectional survey. Qualitative data included diagnostic conversations between healthcare providers and parents of newly diagnosed children with cancer, and subsequent semi-structured interviews.

Participants and setting

This study was conducted at Guatemala's national pediatric cancer center: Unidad Nacional de Oncología Pediátrica (UNOP). UNOP is located in Guatemala City, Guatemala. Approximately 500 new cases of childhood cancer are diagnosed at UNOP annually, and the survival rate at UNOP is about 67%.[10]

Eligibility criteria for the quantitative sample and qualitative sample were the same and included Spanish speaking parents of pediatric patients (≤ 18 years of age) diagnosed with any form of cancer within the past 8 weeks. Both components of the study were conducted in the outpatient psychology and oncology clinics at UNOP. Parents participated in either the quantitative or

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qualitative portion of the study, but not both. Of 104 parents approached for the quantitative sample, 100 (96%) agreed to participate. Participants in the qualitative sample were recruited sequentially, with additional purposive sampling[11] to ensure representation of a range of pediatric ages and diagnoses as well as families with diverse socioeconomic and cultural backgrounds. Overall, 32 parents were approached for participation in the qualitative study and 20 parents agreed to participate. Thematic saturation[12] was reached after enrollment of 20 parents and no further participants were approached.

Ethics approval

Written informed consent was obtained in Spanish by a native Spanish speaker for all participants. This study was performed in compliance with international regulations for protection of human subjects and approved by institutional review boards (IRBs) and ethics committees at St. Jude and UNOP (IRB Number: 19-0162; Reference Number: 010262).

Study design and data collection

For the quantitative component of the study, a cross-sectional survey was developed using items previously used in high-income countries[5,6,13] as well as novel questions specific to the study population. The survey was developed in English, translated into Spanish, pilot tested with 23 parents to establish face and content validity through iterative revision, and back translated into English to ensure the original intent of questions was preserved.

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Sociodemographic information was obtained through survey questions on participant's gender, relationship to the child, languages spoken, religion, ethnicity, household income, and marital status. Demographic information on patients including gender, age, and diagnosis was obtained from medical record review.

Decision making preferences and experiences were assessed through the survey, first by asking parents "Who do you consider to be the person who makes most decisions in your house in general?", and "about your child's cancer treatment?". Response options included "Another parent or family member makes most of the decisions", "I am the parent most involved in making decisions" and, "I share decision-making equally with my child's other parent or family member". Parents were asked: "Which statement best describes the role your community played in helping you make decisions?". Response options included: "I/We made decisions about treatment without input from my community", "…with help from members or leaders in my community", and "My community, or a leader in my community, made the decision and told me what was best". A similar question asked about involvement of religious or spiritual leaders in decision-making.

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Regarding decision-making with the child's oncologist, parents were asked to describe "the role you would prefer to play when decisions about treatment for your child's cancer are made". Response options included: "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", or "I prefer to make the decisions about treatment". Parents were then asked about "the role you actually played when making decisions about treatment for your child's cancer", with similar response options framed

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in the past tense. To further assess preferences for shared decision-making, parents were asked "How much do you agree with the following statement: 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". Response options included: "strongly agree", "slightly agree", and "disagree". Parents were also asked "At the time of diagnosis, which of the following statements best describes how your oncologist explained your child's treatment plan", with response options including "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", and "He/she gave me only one option".

Decisional regret was assessed using a modified version of the Decisional Regret Scale,[14,15] which asked participants to state whether they "strongly agreed", "slightly agreed", or "disagreed" with each of the following statements: "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", "The decisions were wise", and "The choices did my child a lot of harm".

The qualitative component of the study involved three audio-recorded sessions for each participating family (60 sessions total). At UNOP, the standard diagnostic procedure includes an intake conversation with a psychologist, followed by an initial diagnostic conversation with the oncologist about diagnosis and treatment plans for which the psychologist is also present. These two conversations were audio recorded as they naturally occurred, and one parent from each participating family was subsequently interviewed. Semi-structured interviews explored parents' communication perspectives and experiences, including the process for decision-making at UNOP and parental reflections. All audio recordings were professionally transcribed and

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translated into English with review by bilingual members of the research team to ensure adequate capture of original content.

Complete survey and interview script are included as **supplementary materials**.

Data analysis

Quantitative data including sociodemographic information and items pertaining to decision-making were analyzed descriptively. Proportions between groups were compared using Chi-square or Fisher's exact test as appropriate. Parent responses regarding their preferred decision-making role was compared to the actual role they played. Parents whose preferences matched their experiences were considered to have held their preferred role and were compared to parents whose experiences did not match their preferences. Univariate logistic regression was used to assess the impact of sociodemographic characteristics on "preferred" versus "non-preferred" role in decision-making. A decisional regret score was calculated based on previously reported methods.[15] Because our final scale used 3 rather than 5 response options based on findings during pilot testing ("disagree", "slightly agree", "strongly agree"), points were assigned with a scale of 1, 3, and 5 with reverse scoring where appropriate, in which a score of 1 indicated the least regret and 5 indicated the most regret. Scores were decreased by 1 point and multiplied by 25 for a score range of 0 to 100. Consistent with existing literature,[15] scores of 0 were categorized as no regret, 1-25 as mild regret, and >25 as heightened regret. Univariate logistic regression was performed with sociodemographic variables as well as "preferred" versus "non-preferred" role in decision-making.

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Analysis of qualitative data was conducted by two independent coders who conducted thematic content analysis[16] on all transcripts utilizing a combination of *a priori*[17,18] and novel codes. Interrater reliability ranged from 0.72-0.88. Novel codes were identified based on recurrent themes by two authors who iteratively read transcripts. Conceptual definitions were refined through memo writing and initial coding of 12 transcripts. The final codebook is included as **supplementary material**. Codes related to decision-making included those identifying the decision-maker, the type of decision, and the reasons behind decision-making. Codes related to shared decision making at the cancer center included those expressed by providers and reflections from parents. MAXQDA (VERBI, Berlin, Germany) was utilized for data management. The Consolidated Criteria for Reporting Qualitative Studies guidelines were followed.[19]

Patient and public involvement

Neither patients, parents, nor the public were involved in the design of this research. Parents were involved in piloting the survey and we plan to involve parents further as we disseminate these results and consider interventional work.

Results

Participant Characteristics

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3 Demographic characteristics of participants from each sample and their children are included in
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5 Table 1. Most included participants in both samples were Spanish-speaking mothers who
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8 identified as either Catholic or Evangelical. A range of pediatric ages and cancer diagnoses were
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10 included.
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15 Parental decision-making
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19 Most Guatemalan parents surveyed (80%) made household decisions with the child's other
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21 parent, and 70% made decisions about their child's cancer care this way. In interviews, parents
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23
24 described sharing decision-making with their partners. One father of an 18-month-old with
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26 leukemia said, *"I talk to my wife and we agree on a middle point…the decisions are made by my*
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29 *wife and me"*; a mother of a 6-year-old with leukemia similarly described how she made
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31 decisions *"with my husband, because we are a couple"*. While many interviewed parents
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33 listened to advice from extended family or community members, they emphasized the parental
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36 unit as the ultimate decision maker: *"We have to talk, ask people with experience, and then we*
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38 *decide"*(father of a 17-year-old with Hodgkin Lymphoma). Amongst surveyed parents, almost
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40 all (94%) reported making decisions without input from their community, and most (76%) made
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42 decisions without input from religious or spiritual leaders.
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47 In describing how they ultimately made decisions around cancer care and treatment during
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49 interviews, parents prioritized the health and survival of their children. One parent said, *"For the*
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52 *sake of my baby, we're going to do everything in our power to cure her"* (mother of a 10-year-
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54 old with leukemia). Other parents described sacrifices they were making, or were willing to
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make, in order to get their child appropriate care: *"If I must give her my heart, my kidney, I'd give it to her so she won't die. I already lived; she's starting to live. I tell her if I must die for you to be cured, I'll do it"*(father of a 17-year-old with glioblastoma).

Decision-making with the oncologist

When asked about their preferred role in decision-making with respect to the oncologist, most Guatemalan parents (76% of those surveyed) wanted to share decision-making with their child's oncologist. Of those that did not, 20% preferred that the oncologist made most of the decisions, while 4% preferred to make treatment decisions themselves. However, a majority of parents either slightly (21%) or strongly (47%) agreed that they would rather have their medical team make decisions about what was best than provide a lot of choices; 31% disagreed. When asked about their experiences during the decision-making process, only a few surveyed parents (4%) said the oncologist provided them with options and they chose; the rest reported that they were either given options and said the oncologist told them which was best (48%) or were not provided options (48%).

Qualitative data reflected a model of decision-making that emphasized honesty and trust in the medical team. Psychologists set the tone during initial conversations, highlighting a team approach to care and including parents as part of this team. One psychologist said to the parents of a 5-year-old with leukemia: *"I know it's hard to trust in strangers, but you can ask all mothers here at the hospital, we are a team along with the parents…we don't hide information."* Another emphasized honesty, as she spoke to the parents of an 18-month-old newly diagnosed

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with leukemia, saying, *"we will always tell you the truth, even if the truth is hard."* These messages were reinforced almost verbatim in diagnostic conversations with the oncologists: *"We promise we will always tell you the truth. Even if the information is bad, we will tell you, we will never hide information"* (oncologist to the same parents).

However, when psychologists and oncologists talked about treatment, they emphasized the importance of starting immediately, using words like "*must"* and phrases such as *"have to"*, without providing parents with multiple options. These directives referred to treatment modalities, such as surgery or chemotherapy, necessity of hospitalization, and importance of follow-up appointments. Table 2 includes additional quotations that demonstrate the tone around decision-making set by psychologists and oncologists at UNOP.

Guatemalan parents accepted this model, expressing trust in their medical teams and deference to their providers. A mother of a 16-year-old newly diagnosed with leukemia directly told the oncologist, *"Whatever you say, you decide"*. Another parent described in an interview: *"We didn't know if it was the best, but that's like when you wear an outfit – I just wear it – it doesn't matter if it's pretty or not"* (father of an 18-month-old with leukemia). Parents also referred to the expertise of their medical team, one saying, *"the best specialists are here, this is why I'm here"* (father of a 17-year-old with osteosarcoma) and another, "*I didn't ask much; the experts know the solution"*(father of a 4-year-old with leukemia).

Reflections on decision-making

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Two-thirds of surveyed parents (65%) held their preferred role in decision-making around their child's cancer care, while 23% had a more active role than desired and 11% had a less active role than desired. Fathers were more likely to hold their preferred role in decision-making than mothers (OR 4.32 [95% CI 1.17-15.89], p=0.02) (Table 3).

Most parents (64%) were categorized as having no decisional regret, while 25% had mild regret, and 11% had heightened regret. Heightened decisional regret did not significantly correlate with any sociodemographic variables, or with parents having played their preferred role in decision making (OR 1.34 [95% CI 0.32-5.56, p=0.68) (Table 4). Parents in the qualitative sample predominantly expressed gratitude ("*we are grateful for this treatment"*(mother of a 5-year-old with leukemia)*)*, peace (*"I'm a little bit more calmed"* (mother of a 5-year-old with leukemia); *"here we feel more relaxed"*(father of a 4-year-old with leukemia)*)*, and relief (*"They told me this was a good hospital; I felt relief"*(father of an 18-month-old with leukemia)*)* as they reflected on decisions they had made.

Discussion

The majority of Guatemalan parents included in this study valued shared decision-making, both with the child's other parent and with their child's oncologist. Providers at UNOP emphasized a decision-making model in which trust and honesty were prioritized. Parents deferred to their providers and were predominantly satisfied with the care they received. Ultimately, most parents felt they had made the right decisions, however, 11% experienced heightened decisional regret.

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3 There are many approaches to decision-making in pediatric cancer care.[20] In high-income
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5 Western contexts, shared decision-making has been prioritized.[21] While different definitions of
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7 shared decision-making exist, it is often presented in contrast to paternalism and generally
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9 emphasizes autonomy,[22] multiple options,[23] and two-way information-exchange.[24]
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11 Approximately three out of every four Guatemalan parents in our study reported that they
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13 preferred to share decision-making with their oncologists, however a similar proportion (69%)
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15 ultimately wanted their medical team to decide what was best rather than provide multiple
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17 options without a clear recommendation. These preferences are consistent with the decision-
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19 making process noted in diagnostic conversations recorded at UNOP, after which most parents
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21 expressed satisfaction. The model of decision-making at UNOP prioritizes trust, honesty, and
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23 information-exchange but maintains a predominately unidirectional flow of information
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25 (provider to parent) and does not include many choices. This model diverges from expectations
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27 for shared decision-making set forth by literature from high-income countries but is consistent
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29 with literature from other LMICs which describes an evolution in medical decision-making[25]
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31 with increasing prioritization of information-exchange[26] and autonomy over time.[27] These
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33 findings suggest there may be differences in cultural perceptions around shared decision-making,
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35 and shared decision-making may have different manifestations in different contexts.
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45 Parents in our study also predominantly reported sharing decisions about their child's care with
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47 the child's other parent, without significant input from their community. While there is limited
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49 literature on extended family or community involvement in decision-making for children with
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51 cancer, one study conducted in the UK demonstrated decisions were primarily made without
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53 involvement of individuals outside the nuclear family,[28] consistent with our findings from
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Guatemala. However, approximately a quarter of parent participants in our study did describe consulting spiritual or religious advisors, emphasizing the importance of religion to this community. Previous work also suggests that although diagnosis is a one of the most stressful times for parents of children with cancer, it is a time when parents may feel most connected to one another.[29] It is possible that this emotional connection explains the shared parental decision-making we noted among partnered participants. However, it is also possible that sociocultural expectations, including patriarchal pressure, may influence decision-making in Guatemala. This study included more mothers than fathers, which is representative of caregivers at UNOP where mothers often attend visits while fathers remain in the community, working to support the family. Mothers at UNOP may feel obligated to discuss decisions about their child's care with the child's father, whose opinions carry more weight. In addition, we found that mothers were less likely than fathers to have their desired role in decision-making. While the percentage of parents (approximately one-third) who did not have their preferred role in decision-making is nearly identical to that seen in high-income countries, parents in Guatemala who did not have their desired decision-making role tended to have a more active role than desired, whereas those in the United States tended to have a more passive role than desired.[30] The desire of parents, and particularly mothers, to play a more passive role in decision-making may reflect cultural disempowerment, a theme that has been previously described in pediatric cancer communication in LMICs.[31,32]

Finally, parents included in this study report being primarily motivated by their child's health and well-being. This is consistent with the "good-parent" belief,[33] a concept which has been extensively studied in high-income settings[34] and includes "unselfish decisions in the child's best

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interest".[33] Most parents were satisfied with their decisions, however the small but relevant number of parents (11%) who experienced heightened decisional regret emphasizes the weight of cancer-related decisions and the importance of ongoing support. These findings reinforce the importance of exploring parental preferences for cancer communication and prioritizing individual familial needs, which may or may not be influenced by culture.

This mixed-methods study allowed us to evaluate decision-making among Guatemalan parents of children with cancer, including a deep exploration of motivating factors and the decision-making process at UNOP. However, there are several limitations that should be considered. To reduce burden on participants, our study design included separate qualitative and quantitative samples which limited convergent analysis. This study focused specifically on decision-making at diagnosis, and thus does not address potential shifts in decision-making preferences or experiences over the cancer care continuum. In addition, this study was conducted at a single cancer center in one small middle-income country. This was an initial step toward exploring diagnostic communication and decision-making in LMICs and allowed for comparison to literature from high-income settings, but further research is needed to determine if these findings are applicable beyond Guatemala. Moreover, Guatemala itself is a diverse country. Our study was conducted exclusively in Spanish and thus we were unable to include parents who were not proficient in Spanish. Finally, because most parents included in our study had positive reflections on their decisions, we were limited in our ability to analyze the small proportion of parents who did experience regret. This is an opportunity for future research.

Conclusion:

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Almost all prior work on decision-making in pediatric cancer care has been conducted exclusively in high-income settings including the United States and Europe.[35] This study demonstrates that many parents in Guatemala, like those in the United States, want to be engaged in decision-making by their oncology teams and prioritize their child's well-being. However, shared-decision making manifests differently in the Guatemalan context and differs from previous definitions, most of which come from high-resourced settings. These findings suggest ways in which culture may influence priorities for communication and care. Ultimately, this work further supports developing the provider-parent relationship in all settings by encouraging clinicians to routinely ask parents what role they want to play in decision-making and honor their responses.

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Table 1. Sociodemographic characteristics of participating caregivers and their children

	Quantitative sample (total = 100)	**Qualitative sample (total = 20)**
Participant	**N (%)**	**N (%)**
Relationship to patient		
Mother	76 (76%)	13 (65%)
Father	22 (22%)	7 (35%)
Grandparent	1 (1%)	0 (0%)
Sibling	1 (1%)	0 (0%)
Gender		
Male	23 (23%)	7 (35%)
Female	77 (77%)	13 (65%)
Primary language		
Spanish (only)	73 (73%)	13 (65%)
Spanish and English	2 (2%)	0 (0%)
Spanish and Mayan dialect	24 (24%)	7 (35%)
Mayan dialect (only)	1 (1%)	0 (0%)
Ethnicity*		Data not collected
Ladino	55 (56%)	
Indigenous (Mayan)	25 (25%)	
Mixed race	19 (19%)	
Religion		
Catholic	41 (41%)	4 (20%)
Evangelical	52 (52%)	13 (65%)
Other identified religion	3 (3%)	2 (10%)
No religion	4 (4%)	1 (5)
Civil status*		
Married	59 (60%)	13 (65%)
United (living together as if married)	25 (25%)	6 (30%)
Separated	1 (1%)	0 (0%)
Divorced	10 (10%)	1 (5%)
Single	4 (4%)	0 (0%)
Monthly household income (Quetzales)*		Data not collected
<2000	36 (37%)	
2000-2999	23 (23%)	
>2999	39 (40%)	
Patient		
Age (years)		
0-5	38 (38%)	6 (30%)
6-10	19 (19%)	6 (30%)
11-15	31 (31%)	4 (20%)
16-18	12 (12%)	4 (20%)
Gender		
Male	61 (61%)	11 (55%)
Female	39 (39%)	9 (45%)

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Diagnosis		
Leukemia	58 (58%)	13 (65%)
Lymphoma	12 (12%)	2 (10%)
Histiocytic disorders	2 (2%)	1 (5%)
Solid tumor	25 (25%)	3 (15%)
Brain tumor	3 (3%)	1 (5%)

* Ethnicity: 1 missing; Civil status: 1 missing; Monthly household income (Quetzales): 2 missing

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Table 2. Excerpts from recorded diagnostic conversations emphasizing teamwork and honesty over autonomy

Theme	Psychologists speaking to parents during intake	Oncologists speaking to parents in diagnostic conversations
Teamwork	*"You see we are all a team."* (to parents of an 18-month-old with leukemia) *"I want you to know that we are a team and we will always tell the truth."* (to parents of a 5-year-old with Wilms tumor) *"In here, each doctor has his specialty…each of them in their own working area, but we are still a team."* (to parents of a 5-year-old with leukemia)	*"We want to remark that we are a team…and we are all here to support you. We are a big team so one of us will be ready to answer all your questions. No matter if it's good or bad, you deserve to know it."* (to parents of a 5-year-old with leukemia) *"We are a lot of people that work for all children's recovery…There's a huge hope and you have the entire medical staff and the hospital staff next to you, working together to make [your son] better."* (to parents of a 6-year-old with leukemia)
Honesty	*"We will be very honest with you; we won't lie to you…Anything that comes up, I'll let you know"* (to parents of a 5-year-old with Wilms tumor) *"I know no one likes bad news, but as a parent you deserve the truth…Like I told you, doctors will be very honest with you."* (to parents of a 17-year-old with glioblastoma) *"Here, they will always tell you everything."* (to parents of a 4-year-old with leukemia)	*"Another important thing. We are always going to be very honest with you, if anything comes up, we will seat down with you and talk to you."* (to parents of a 14-year-old with leukemia) *"We won't lie to you, of course it's going to be hard, this is going to feel like a roller coaster, there will be good days and there will be hard days, but we will be with you on good days and hard days."* (to parents of a 14-year-old with leukemia)
Lack of choice	*"What we definitely have to do is surgery, that's essential to cure this type of cancer."* (to parents of a 3-year-old with Wilms) *"Therefore, is so important that once we detect it, we must give treatment immediately."* (to parents of a 5-year-old with leukemia) *"With these, the only treatment is surgery…If we want to save [your*	*"Unfortunately, he must stay here for now, but after a while he'll be able to go home for some time or to the shelter."* (to parents of a 4-year-old with leukemia) *"It's going to be difficult, because I'm not telling you it's going to be easy or that don't have to make sacrifices, but if you want to see [your daughter] cured, just like us, this is the road we must*

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	son], we must perform the surgery." (to parents of a 17-year-old with osteosarcoma)	*follow."* (to parents of a 4-year-old with leukemia)

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Table 3. Univariate logistic regression analysis of sociodemographic factors and preferred decision-making role

Decision-Making		
Factor	**P-Value**	**Odds Ratio**
Parent (N=96)	0.02*	
Father		4.32 (1.17 - 15.89)
Mother		1.00 (Ref)
Ethnicity (N=97)	0.70	
Ladino		1.49 (0.51 - 4.36)
Indigenous (Mayan)		1.66 (0.47 - 5.93)
Mixed race		1.00 (Ref)
Monthly household Income (Quetzales) (N=96)	0.60	
<2000		1.00 (Ref)
2000-2999		1.43 (0.46 - 4.39)
>2999		1.61 (0.62 - 4.15)
Diagnosis group (N=98)	0.12	
Leukemia		1.00 (Ref)
Lymphoma		8.25 (1.00 - 68.35)
Solid tumor		1.59 (0.59 - 4.30)
Others (Histiocytic disorder + Brain tumor)		3.00 (0.31 - 28.59)

*significant p-value

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Table 4. Univariate logistic regression analysis of heightened decisional regret

Decisional regret		
Factor	**P-Value**	**Odds Ratio**
Parent (N=98)	0.68	
Father		1.34 (0.32 - 5.56)
Mother		1.00 (Ref)
Ethnicity (N=99)	0.16	
Ladino		1.41 (0.15 - 13.48)
Indigenous (Mayan)		4.50 (0.48 - 42.25)
Mixed race		1.00 (Ref)
Monthly household Income (Quetzales) (N=98)	0.27	
<2000		1.00 (Ref)
2000-2999		0.75 (0.17 - 3.35)
>2999		0.27 (0.05 - 1.44)
Diagnosis group (N=100)	0.57	
Leukemia		1.00 (Ref)
Lymphoma		0.57 (0.06 - 5.02)
Others (Brain tumor + Histiocytic disorder + Solid tumor)		0.45 (0.09 - 2.25)
Decision Engagement (N=98)	0.71	
Preferred		0.78 (0.20 - 2.96)
Not preferred		1.00 (Ref)

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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?

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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?

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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.

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- 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.

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

1. What is your gender? [IF THEY DO NOT UNDERTAND 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

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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

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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?

	A lot	*A little*	*Not at all*
Caused by an infection	☐	☐	☐
Due to heat or cold	☐	☐	☐
Lacking hygiene or nutrition	☐	☐	☐
Because of a sacred mission	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Due to bad thoughts *(malhecho)*	☐	☐	☐
Sent by the devil *(diabólico)*	☐	☐	☐
Supernatural; originating from natural elements (e.g. waterfalls, mountains, wind, darkness)	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Lack of respect for nature or the elements of the environment	☐	☐	☐
Bad relationships with the community	☐	☐	☐
Caused by God or another religious figure	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Caused by uncontrol cell growth	☐	☐	☐
Caused by fear or surprise *(susto)*	☐	☐	☐
Caused by medications	☐	☐	☐

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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

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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

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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

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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 ***<u>would prefer</u>*** 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 ***<u>actually played</u>*** 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 <u>your community</u> 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 <u>your religious/spiritual leaders</u> 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

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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

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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 like, 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

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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 like, 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 <u>doctors in general?</u>**

- 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 nosey 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.

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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 RESONDENT 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

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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

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

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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:** *Verbal behaviors that validate or support the patient's emotional or motivational state*	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

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		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.

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			Descriptions of lack of information as a barrier to decision making

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Cancer Treatment Decision-Making among Parents of Pediatric Oncology Patients in Guatemala: A Mixed-Methods Study

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Title: Cancer Treatment Decision-Making among Parents of Pediatric Oncology Patients in Guatemala: A Mixed-Methods Study

Running Head: Decision-Making in Guatemala

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Contributorship statement: Dr. Graetz conceptualized and designed the study and data collection tools, supervised pilot testing and data collection, analyzed qualitative data, drafted the initial manuscript, and reviewed and revised the manuscript.

Drs. Rivas and Antillon-Klussman contributed to study design, facilitated study approval and supervised data collection at Unidad Nacional Oncología Pediátrica, and reviewed and revised the manuscript.

Ms. Wang, Mr. Vedaraju, and Dr. Devidas conducted statistical data analysis and reviewed and revised the manuscript.

Ms. Ferrara analyzed the qualitative data and reviewed and revised the manuscript.

Ms. Fuentes and Ms. Caceres-Serrano contributed to study design, conducted pilot testing, collected data, and reviewed and revised the manuscript.

Drs. Metzger and Rodriguez-Galindo contributed to study design and reviewed and revised the manuscript.

Dr. Mack conceptualized and designed the study and data collection tools, and critically reviewed the manuscript for important intellectual content.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Abbreviations: LMICs: low- and middle-income countries; UNOP: Unidad Nacional de Oncolgía Pediátrica; St. Jude: St. Jude Children's Research Hospital

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Key words: Pediatric cancer; Guatemala; Decision-Making; Communication

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Abstract

Objectives: To examine treatment decision-making priorities and experiences among parents of children with cancer in Guatemala.

Setting: This study was conducted at Guatemala's national pediatric cancer center in Guatemala City.

Participants: Spanish speaking parents of pediatric patients (≤ 18 years of age) diagnosed with any form of cancer within the 8 weeks prior to study enrollment. The quantitative portion of this study included 100 parent participants; the qualitative component included 20 parents. Most participants were Catholic or Evangelical Spanish-speaking mothers.

Outcomes: Priorities and experiences of cancer treatment decision-making including decision-making role and experienced regret.

Results: A range of pediatric ages and cancer diagnoses were included. Most Guatemalan parents surveyed (70%) made decisions about their child's cancer together and almost all (94%) without input from their community. Surveyed parents predominately preferred shared decision-making with their child's oncologist (76%), however 69% agreed it was best not to be provided with many options. Two-thirds of surveyed parents (65%) held their preferred role in decision-making, with fathers more likely to hold their preferred role than mothers ($p=0.02$). A small number of parents (11%) experienced heightened decisional regret, which did not correlate with sociodemographic characteristics or preferred decision-making role. Qualitative results supported quantitative findings, demonstrating a decision-making process that emphasized trust and honesty.

Conclusions: Guatemalan parents preferred to make decisions with their medical team and appreciated providers who were honest and inclusive, but directive about decisions. This study

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reinforces the importance of the provider-parent relationship and encourages clinicians in all settings to ask about and honor each parent's desired role in decision-making.

Article Summary:

Strengths and limitations of this study:

- This study investigated communication and decision-making, key components of patient-centered care, in a middle-income country, a previously understudied area of research in this population.
- The convergent mixed-methods study design enabled broad assessment of decision-making priorities as well as deep exploration of decision-making processes among Guatemalan parents of children with cancer.
- Use of survey items previously validated in high-income countries allowed for comparison to published literature from these settings.
- The focus on the diagnostic period limited the ability to consider how decision-making may change over the cancer continuum.
- Study was conducted at single cancer center in one middle-income country, and thus results may not apply to other low- and middle-income countries

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Data sharing statement: Extra data is available upon reasonable request by emailing the corresponding author.

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Introduction

From the time of diagnosis, parents of children with cancer are faced with difficult decisions regarding care and treatment. Shared decision-making is associated with improved patient-reported outcomes for adult cancer patients,[1] and research from high-income Western countries has emphasized a similar model for parents of children with cancer. [2,3] Effective shared decision-making depends on high-quality communication [3] through which pediatric oncology providers explore parents' goals of care as they present treatment options and determine a mutually acceptable action plan.

Parental values affect the extent to which they desire to be involved in decision-making, and both individual as well as community belief systems are shaped by culture. Cultural differences between patients and healthcare providers during decision-making have been demonstrated to result in erroneous assumptions and interpersonal conflict. [4] For parents of children with cancer, having their preferred role in decision making may increase trust in healthcare providers[5] and decrease regret.[3,6] Nevertheless, culture is rarely accounted for in research surrounding patient-provider communication and decision-making,[7] and very few studies have explored decision-making among pediatric cancer patients in low- and middle-income countries,[8] where >90% of children with cancer live.[9] The purpose of this mixed-methods study was to examine cancer treatment decision-making among parents of children with cancer in Guatemala at the time of diagnosis. Guatemala is a small but culturally diverse country; with 40% of the population comprised of 24 distinct ethnic groups who speak >20 different languages. We sought to assess the decision-making preferences and experiences of parents of

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children with cancer through a cross-sectional survey and used audio-recorded diagnostic conversations and semi-structured interviews to explore decision-making processes and influences in greater depth, including who was involved in the process, how cancer treatment decisions were made, and parental reflections on early decisions.

Methods

This study utilized a convergent mixed-methods design. Quantitative data was collected from a verbally administered cross-sectional survey. Qualitative data included diagnostic conversations between healthcare providers and parents of newly diagnosed children with cancer, and subsequent semi-structured interviews.

Participants and setting

This study was conducted at Guatemala's national pediatric cancer center: Unidad Nacional de Oncología Pediátrica (UNOP). UNOP is located in Guatemala City, Guatemala. Approximately 500 new cases of childhood cancer are diagnosed at UNOP annually, and the survival rate at UNOP is about 67%.[10]

Eligibility criteria for the quantitative sample and qualitative sample were the same and included Spanish speaking parents of pediatric patients (≤ 18 years of age) diagnosed with any form of cancer within the past 8 weeks. Both components of the study were conducted in the outpatient psychology and oncology clinics at UNOP. Parents participated in either the quantitative or

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qualitative portion of the study, but not both. Of 104 parents approached for the quantitative sample, 100 (96%) agreed to participate. Participants in the qualitative sample were recruited sequentially, with additional purposive sampling [11] to ensure representation of a range of pediatric ages and diagnoses as well as families with diverse socioeconomic and cultural backgrounds. Overall, 32 parents were approached for participation in the qualitative study and 20 parents agreed to participate. Thematic saturation [12] was reached after enrollment of 20 parents and no further participants were approached.

Ethics approval

Written informed consent was obtained in Spanish by a native Spanish speaker for all participants. This study was performed in compliance with international regulations for protection of human subjects and approved by institutional review boards (IRBs) and ethics committees at St. Jude and UNOP (IRB Number: 19-0162; Reference Number: 010262).

Study design and data collection

For the quantitative component of the study, a cross-sectional survey was developed using items previously used in high-income countries [5,6,13] as well as novel questions specific to the study population. The survey was developed in English, translated into Spanish, pilot tested with 23 parents to establish face and content validity through iterative revision, and back translated into English to ensure the original intent of questions was preserved.

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Sociodemographic information was obtained through survey questions on participant's gender, relationship to the child, languages spoken, religion, ethnicity, household income, and marital status. Demographic information on patients including gender, age, and diagnosis was obtained from medical record review.

Decision making preferences and experiences were assessed through the survey, first by asking parents "Who do you consider to be the person who makes most decisions in your house in general?", and "about your child's cancer treatment?". Response options included "Another parent or family member makes most of the decisions", "I am the parent most involved in making decisions" and, "I share decision-making equally with my child's other parent or family member". Parents were asked: "Which statement best describes the role your community played in helping you make decisions?". Response options included: "I/We made decisions about treatment without input from my community", "…with help from members or leaders in my community", and "My community, or a leader in my community, made the decision and told me what was best". A similar question asked about involvement of religious or spiritual leaders in decision-making.

Regarding decision-making with the child's oncologist, parents were asked to describe "the role you would prefer to play when decisions about treatment for your child's cancer are made". Response options included: "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", or "I prefer to make the decisions about treatment". Parents were then asked about "the role you actually played when making decisions about treatment for your child's cancer", with similar response options framed

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in the past tense. To further assess preferences for shared decision-making, parents were asked "How much do you agree with the following statement: 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". Response options included: "strongly agree", "slightly agree", and "disagree". Parents were also asked "At the time of diagnosis, which of the following statements best describes how your oncologist explained your child's treatment plan", with response options including "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", and "He/she gave me only one option".

Decisional regret was assessed using a modified version of the Decisional Regret Scale,[14,15] which asked participants to state whether they "strongly agreed", "slightly agreed", or "disagreed" with each of the following statements: "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", "The decisions were wise", and "The choices did my child a lot of harm".

The qualitative component of the study involved three audio-recorded sessions for each participating family (60 sessions total). At UNOP, the standard diagnostic procedure includes an intake conversation with a psychologist, followed by an initial diagnostic conversation with the oncologist about diagnosis and treatment plans for which the psychologist is also present. These two conversations were audio recorded as they naturally occurred, and one parent from each participating family was subsequently interviewed. Semi-structured interviews explored parents' communication perspectives and experiences, including the process for decision-making at UNOP and parental reflections. All audio recordings were professionally transcribed and

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translated into English with review by bilingual members of the research team to ensure adequate capture of original content.

Complete survey and interview script are included as **supplementary materials**.

Data analysis

Quantitative data including sociodemographic information and items pertaining to decision-making were analyzed descriptively. Proportions between groups were compared using Chi-square or Fisher's exact test as appropriate. Parent responses regarding their preferred decision-making role was compared to the actual role they played. Parents whose preferences matched their experiences were considered to have held their preferred role and were compared to parents whose experiences did not match their preferences. Univariate logistic regression was used to assess the impact of sociodemographic characteristics on "preferred" versus "non-preferred" role in decision-making. A decisional regret score was calculated based on previously reported methods. [15] Because our final scale used 3 rather than 5 response options based on findings during pilot testing ("disagree", "slightly agree", "strongly agree"), points were assigned with a scale of 1, 3, and 5 with reverse scoring where appropriate, in which a score of 1 indicated the least regret and 5 indicated the most regret. Scores were decreased by 1 point and multiplied by 25 for a score range of 0 to 100. Consistent with existing literature,[15] scores of 0 were categorized as no regret, 1-25 as mild regret, and >25 as heightened regret. Univariate logistic regression was performed with sociodemographic variables as well as "preferred" versus "non-preferred" role in decision-making.

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Analysis of qualitative data was conducted by two independent coders who conducted thematic content analysis [16] on all transcripts utilizing a combination of *a priori* [17,18] and novel codes. Interrater reliability ranged from 0.72-0.88. Novel codes were identified based on recurrent themes by two authors who iteratively read transcripts. Conceptual definitions were refined through memo writing and initial coding of 12 transcripts. The final codebook is included as **supplementary material**. Codes related to decision-making included those identifying the decision-maker, the type of decision, and the reasons behind decision-making. Codes related to shared decision making at the cancer center included those expressed by providers and reflections from parents. MAXQDA (VERBI, Berlin, Germany) was utilized for data management. The Consolidated Criteria for Reporting Qualitative Studies guidelines were followed. [19]

Patient and public involvement

Neither patients, parents, nor the public were involved in the design of this research. Parents were involved in piloting the survey and we plan to involve parents further as we disseminate these results and consider interventional work.

Results

Participant Characteristics

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Demographic characteristics of participants from each sample and their children are included in Table 1. Most included participants in both samples were Spanish-speaking mothers who identified as either Catholic or Evangelical. A range of pediatric ages and cancer diagnoses were included.

Parental decision-making

Most Guatemalan parents surveyed (80%) made household decisions with the child's other parent, and 70% made decisions about their child's cancer care this way. In interviews, parents described sharing decision-making with their partners. One parent of an child with blood cancer said, *"I talk to my wife and we agree on a middle point…the decisions are made by my wife and me"*; a parent of another child with blood cancer similarly described how she made decisions *"with my husband, because we are a couple"*. While many interviewed parents listened to advice from extended family or community members, they emphasized the parental unit as the ultimate decision maker: *"We have to talk, ask people with experience, and then we decide"*(parent of a teenager with lymphoma). Amongst surveyed parents, almost all (94%) reported making decisions without input from their community, and most (76%) made decisions without input from religious or spiritual leaders.

In describing how they ultimately made decisions around cancer care and treatment during interviews, parents prioritized the health and survival of their children. One parent said, *"For the sake of my baby, we're going to do everything in our power to cure her"* (parent of a child with blood cancer). Other parents described sacrifices they were making, or were willing to make, in

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order to get their child appropriate care: *"If I must give her my heart, my kidney, I'd give it to her so she won't die. I already lived; she's starting to live. I tell her if I must die for you to be cured, I'll do it"*(parent of a teenager with a brain tumor).

Decision-making with the oncologist

When asked about their preferred role in decision-making with respect to the oncologist, most Guatemalan parents (76% of those surveyed) wanted to share decision-making with their child's oncologist. Of those that did not, 20% preferred that the oncologist made most of the decisions, while 4% preferred to make treatment decisions themselves. However, a majority of parents either slightly (21%) or strongly (47%) agreed that they would rather have their medical team make decisions about what was best than provide a lot of choices; 31% disagreed. When asked about their experiences during the decision-making process, only a few surveyed parents (4%) said the oncologist provided them with options and they chose; the rest reported that they were either given options and said the oncologist told them which was best (48%) or were not provided options (48%).

Qualitative data reflected a model of decision-making that emphasized honesty and trust in the medical team. Psychologists set the tone during initial conversations, highlighting a team approach to care and including parents as part of this team. One psychologist said to the parents of a child with blood cancer: *"I know it's hard to trust in strangers, but you can ask all mothers here at the hospital, we are a team along with the parents…we don't hide information."* Another emphasized honesty, as she spoke to the parents of a child newly diagnosed with blood cancer,

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saying, *"we will always tell you the truth, even if the truth is hard."* These messages were reinforced almost verbatim in diagnostic conversations with the oncologists: *"We promise we will always tell you the truth. Even if the information is bad, we will tell you, we will never hide information"* (oncologist to the same parents).

However, when psychologists and oncologists talked about treatment, they emphasized the importance of starting immediately, using words like "*must"* and phrases such as *"have to"*, without providing parents with multiple options. These directives referred to treatment modalities, such as surgery or chemotherapy, necessity of hospitalization, and importance of follow-up appointments. Table 2 includes additional quotations that demonstrate the tone around decision-making set by psychologists and oncologists at UNOP.

Guatemalan parents accepted this model, expressing trust in their medical teams and deference to their providers. A parent of a teenager newly diagnosed with blood cancer directly told the oncologist, *"Whatever you say, you decide"*. Another parent described in an interview: *"We didn't know if it was the best, but that's like when you wear an outfit – I just wear it – it doesn't matter if it's pretty or not"* (parent of a child with blood cancer). Parents also referred to the expertise of their medical team, one saying, *"the best specialists are here, this is why I'm here"* (parent of a teenager with a solid tumor) and another, "*I didn't ask much; the experts know the solution"*(parent of a child with blood cancer).

Reflections on decision-making

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Two-thirds of surveyed parents (65%) held their preferred role in decision-making around their child's cancer care, while 23% had a more active role than desired and 11% had a less active role than desired. Fathers were more likely to hold their preferred role in decision-making than mothers (OR 4.32 [95% CI 1.17-15.89], p=0.02) (Table 3).

Most parents (64%) were categorized as having no decisional regret, while 25% had mild regret, and 11% had heightened regret. Heightened decisional regret did not significantly correlate with any sociodemographic variables, or with parents having played their preferred role in decision making (OR 1.34 [95% CI 0.32-5.56, p=0.68) (Table 4). Parents in the qualitative sample predominantly expressed gratitude (*"we are grateful for this treatment"*(parent of a child with blood cancer)*)*, peace (*"I'm a little bit more calmed"* (parent of a child with blood cancer)); *"here we feel more relaxed"*(parent of a child with blood cancer)*)*, and relief (*"They told me this was a good hospital; I felt relief"*(parent of an child with blood cancer)*)* as they reflected on decisions they had made.

Discussion

The majority of Guatemalan parents included in this study valued shared decision-making, both with the child's other parent and with their child's oncologist. Providers at UNOP emphasized a decision-making model in which trust and honesty were prioritized. Parents deferred to their providers and were predominantly satisfied with the care they received. Ultimately, most parents felt they had made the right decisions, however, 11% experienced heightened decisional regret.

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There are many approaches to decision-making in pediatric cancer care. [20] In high-income Western contexts, shared decision-making has been prioritized. [21] While different definitions of shared decision-making exist, it is often presented in contrast to paternalism and generally emphasizes autonomy, [22] multiple options, [23] and two-way information-exchange.[24] Approximately three out of every four Guatemalan parents in our study reported that they preferred to share decision-making with their oncologists, however a similar proportion (69%) ultimately wanted their medical team to decide what was best rather than provide multiple options without a clear recommendation. These preferences are consistent with the decision-making process noted in diagnostic conversations recorded at UNOP, after which most parents expressed satisfaction. The model of decision-making at UNOP prioritizes trust, honesty, and information-exchange but maintains a predominately unidirectional flow of information (provider to parent) and does not include many choices. This model diverges from expectations for shared decision-making set forth by literature from high-income countries but is consistent with literature from other LMICs which describes an evolution in medical decision-making [25] with increasing prioritization of information-exchange [26] and autonomy over time.[27] These findings suggest there may be differences in cultural perceptions around shared decision-making, and shared decision-making may have different manifestations in different contexts.

Parents in our study also predominantly reported sharing decisions about their child's care with the child's other parent, without significant input from their community. While there is limited literature on extended family or community involvement in decision-making for children with cancer, one study conducted in the UK demonstrated decisions were primarily made without involvement of individuals outside the nuclear family,[28] consistent with our findings from

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Guatemala. However, approximately a quarter of parent participants in our study did describe consulting spiritual or religious advisors, emphasizing the importance of religion to this community. Previous work also suggests that although diagnosis is a one of the most stressful times for parents of children with cancer, it is a time when parents may feel most connected to one another.[29] It is possible that this emotional connection explains the shared parental decision-making we noted among partnered participants. However, it is also possible that sociocultural expectations, including patriarchal pressure, may influence decision-making in Guatemala. This study included more mothers than fathers, which is representative of caregivers at UNOP where mothers often attend visits while fathers remain in the community, working to support the family. Mothers at UNOP may feel obligated to discuss decisions about their child's care with the child's father, whose opinions carry more weight. In addition, we found that mothers were less likely than fathers to have their desired role in decision-making. While the percentage of parents (approximately one-third) who did not have their preferred role in decision-making is nearly identical to that seen in high-income countries, parents in Guatemala who did not have their desired decision-making role tended to have a more active role than desired, whereas those in the United States tended to have a more passive role than desired.[30] The desire of parents, and particularly mothers, to play a more passive role in decision-making may reflect cultural disempowerment, a theme that has been previously described in pediatric cancer communication in LMICs.[31,32]

Finally, parents included in this study report being primarily motivated by their child's health and well-being. This is consistent with the "good-parent" belief, [33] a concept which has been extensively studied in high-income settings [34] and includes "unselfish decisions in the child's

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best interest".[33] Most parents were satisfied with their decisions, however the small but relevant number of parents (11%) who experienced heightened decisional regret emphasizes the weight of cancer-related decisions and the importance of ongoing support. These findings reinforce the importance of exploring parental preferences for cancer communication and prioritizing individual familial needs, which may or may not be influenced by culture.

This mixed-methods study allowed us to evaluate decision-making among Guatemalan parents of children with cancer, including a deep exploration of motivating factors and the decision-making process at UNOP. However, there are several limitations that should be considered. To reduce burden on participants, our study design included separate qualitative and quantitative samples which limited convergent analysis. This study focused specifically on decision-making at diagnosis, and thus does not address potential shifts in decision-making preferences or experiences over the cancer care continuum. In addition, this study was conducted at a single cancer center in one small middle-income country. This was an initial step toward exploring diagnostic communication and decision-making in LMICs and allowed for comparison to literature from high-income settings, but further research is needed to determine if these findings are applicable beyond Guatemala. Moreover, Guatemala itself is a diverse country. Our study was conducted exclusively in Spanish and thus we were unable to include parents who were not proficient in Spanish. Finally, because most parents included in our study had positive reflections on their decisions, we were limited in our ability to analyze the small proportion of parents who did experience regret. This is an opportunity for future research.

Conclusion:

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Almost all prior work on decision-making in pediatric cancer care has been conducted exclusively in high-income settings including the United States and Europe.[35] This study demonstrates that many parents in Guatemala, like those in the United States, want to be engaged in decision-making by their oncology teams and prioritize their child's well-being. However, shared-decision making manifests differently in the Guatemalan context and differs from previous definitions, most of which come from high-resourced settings. These findings suggest ways in which culture may influence priorities for communication and care. Ultimately, this work further supports developing the provider-parent relationship in all settings by encouraging clinicians to routinely ask parents what role they want to play in decision-making and honor their responses.

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Table 1. Sociodemographic characteristics of participating caregivers and their children

	Quantitative sample (total = 100)	Qualitative sample (total = 20)
Participant	**N (%)**	**N (%)**
Relationship to patient		
Mother	76 (76%)	13 (65%)
Father	22 (22%)	7 (35%)
Grandparent	1 (1%)	0 (0%)
Sibling	1 (1%)	0 (0%)
Gender		
Male	23 (23%)	7 (35%)
Female	77 (77%)	13 (65%)
Primary language		
Spanish (only)	73 (73%)	13 (65%)
Spanish and English	2 (2%)	0 (0%)
Spanish and Mayan dialect	24 (24%)	7 (35%)
Mayan dialect (only)	1 (1%)	0 (0%)
Ethnicity*		Data not collected
Ladino	55 (56%)	
Indigenous (Mayan)	25 (25%)	
Mixed race	19 (19%)	
Religion		
Catholic	41 (41%)	4 (20%)
Evangelical	52 (52%)	13 (65%)
Other identified religion	3 (3%)	2 (10%)
No religion	4 (4%)	1 (5)
Civil status*		
Married	59 (60%)	13 (65%)
United (living together as if married)	25 (25%)	6 (30%)
Separated	1 (1%)	0 (0%)
Divorced	10 (10%)	1 (5%)
Single	4 (4%)	0 (0%)
Monthly household income (Quetzales)*		Data not collected
<2000	36 (37%)	
2000-2999	23 (23%)	
>2999	39 (40%)	
Patient		
Age (years)		
0-5	38 (38%)	6 (30%)
6-10	19 (19%)	6 (30%)
11-15	31 (31%)	4 (20%)
16-18	12 (12%)	4 (20%)
Gender		
Male	61 (61%)	11 (55%)
Female	39 (39%)	9 (45%)

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Diagnosis		
Leukemia	58 (58%)	13 (65%)
Lymphoma	12 (12%)	2 (10%)
Histiocytic disorders	2 (2%)	1 (5%)
Solid tumor	25 (25%)	3 (15%)
Brain tumor	3 (3%)	1 (5%)

* Ethnicity: 1 missing; Civil status: 1 missing; Monthly household income (Quetzales): 2 missing

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Table 2. Excerpts from recorded diagnostic conversations emphasizing teamwork and honesty over autonomy

Theme	Psychologists speaking to parents during intake	Oncologists speaking to parents in diagnostic conversations
Teamwork	*"You see we are all a team."* (to parents of an child with blood cancer) *"I want you to know that we are a team and we will always tell the truth."* (to parents of a child with a solid tumor) *"In here, each doctor has his specialty…each of them in their own working area, but we are still a team."* (to parents of a child with blood cancer)	*"We want to remark that we are a team…and we are all here to support you. We are a big team so one of us will be ready to answer all your questions. No matter if it's good or bad, you deserve to know it."* (to parents of a child with blood cancer) *"We are a lot of people that work for all children's recovery…There's a huge hope and you have the entire medical staff and the hospital staff next to you, working together to make [your son] better."* (to parents of a child with blood cancer)
Honesty	*"We will be very honest with you; we won't lie to you…Anything that comes up, I'll let you know"* (to parents of a child with a solid tumor) *"I know no one likes bad news, but as a parent you deserve the truth…Like I told you, doctors will be very honest with you."* (to parents of a teenager with brain cancer) *"Here, they will always tell you everything."* (to parents of a child with blood cancer)	*"Another important thing. We are always going to be very honest with you, if anything comes up, we will seat down with you and talk to you."* (to parents of a teenager with blood cancer) *"We won't lie to you, of course it's going to be hard, this is going to feel like a roller coaster, there will be good days and there will be hard days, but we will be with you on good days and hard days."* (to parents of a teenager with blood cancer)
Lack of choice	*"What we definitely have to do is surgery, that's essential to cure this type of cancer."* (to parents of a child with a solid tumor) *"Therefore, is so important that once we detect it, we must give treatment immediately."* (to parents of a child with blood cancer) *"With these, the only treatment is surgery…If we want to save [your son], we must perform the surgery."*	*"Unfortunately, he must stay here for now, but after a while he'll be able to go home for some time or to the shelter."* (to parents of a child with blood cancer) *"It's going to be difficult, because I'm not telling you it's going to be easy or that don't have to make sacrifices, but if you want to see [your daughter] cured, just like us, this is the road we must follow."* (to parents of a child with blood cancer)

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	(to parents of a teenager with a solid tumor)	

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Table 3. Univariate logistic regression analysis of sociodemographic factors and preferred decision-making role

Decision-Making		
Factor	**P-Value**	**Odds Ratio**
Parent (N=96)	0.02*	
Father		4.32 (1.17 - 15.89)
Mother		1.00 (Ref)
Ethnicity (N=97)	0.70	
Ladino		1.49 (0.51 - 4.36)
Indigenous (Mayan)		1.66 (0.47 - 5.93)
Mixed race		1.00 (Ref)
Monthly household Income (Quetzales) (N=96)	0.60	
<2000		1.00 (Ref)
2000-2999		1.43 (0.46 - 4.39)
>2999		1.61 (0.62 - 4.15)
Diagnosis group (N=98)	0.12	
Leukemia		1.00 (Ref)
Lymphoma		8.25 (1.00 - 68.35)
Solid tumor		1.59 (0.59 - 4.30)
Others (Histiocytic disorder + Brain tumor)		3.00 (0.31 - 28.59)

*significant p-value

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Table 4. Univariate logistic regression analysis of heightened decisional regret

Decisional regret		
Factor	**P-Value**	**Odds Ratio**
Parent (N=98)	0.68	
Father		1.34 (0.32 - 5.56)
Mother		1.00 (Ref)
Ethnicity (N=99)	0.16	
Ladino		1.41 (0.15 - 13.48)
Indigenous (Mayan)		4.50 (0.48 - 42.25)
Mixed race		1.00 (Ref)
Monthly household Income (Quetzales) (N=98)	0.27	
<2000		1.00 (Ref)
2000-2999		0.75 (0.17 - 3.35)
>2999		0.27 (0.05 - 1.44)
Diagnosis group (N=100)	0.57	
Leukemia		1.00 (Ref)
Lymphoma		0.57 (0.06 - 5.02)
Others (Brain tumor + Histiocytic disorder + Solid tumor)		0.45 (0.09 - 2.25)
Decision Engagement (N=98)	0.71	
Preferred		0.78 (0.20 - 2.96)
Not preferred		1.00 (Ref)

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Supplemental Material

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

Dylan E. Graetz MD MPH, Silvia Elena Rivas MD, Huiqi Wang MS, Yuvanesh Vedaraju MS, Gia Ferrara MSGH, Ana Lucia Fuentes, Ana Caceres-Serrano PhD, Federico Antillon-Klussmann MD PhD, Meenakshi Devidas PhD MBA, Monika L. Metzger MD MS, Carlos Rodriguez-Galindo MD, Jennifer W. Mack MD MPH

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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?

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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?

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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.

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- 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.

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

1. What is your gender? [IF THEY DO NOT UNDERTAND 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

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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

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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?

	A lot	*A little*	*Not at all*
Caused by an infection	☐	☐	☐
Due to heat or cold	☐	☐	☐
Lacking hygiene or nutrition	☐	☐	☐
Because of a sacred mission	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Due to bad thoughts *(malhecho)*	☐	☐	☐
Sent by the devil *(diabólico)*	☐	☐	☐
Supernatural; originating from natural elements (e.g. waterfalls, mountains, wind, darkness)	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Lack of respect for nature or the elements of the environment	☐	☐	☐
Bad relationships with the community	☐	☐	☐
Caused by God or another religious figure	☐	☐	☐

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

	A lot	*A little*	*Not at all*
Caused by uncontrol cell growth	☐	☐	☐
Caused by fear or surprise *(susto)*	☐	☐	☐
Caused by medications	☐	☐	☐

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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 <u>your preference</u> 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 <u>likelihood of being cured</u>?
☐ 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 <u>affect your child's life in the future?</u>
☐ 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

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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

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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

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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

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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

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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 like, 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

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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 like, 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 <u>doctors in general?</u>**

- 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 nosey 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.

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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 RESONDENT 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

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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?

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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:** *Verbal behaviors that validate or support the patient's emotional or motivational state*	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

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		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.

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			Descriptions of lack of information as a barrier to decision making

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STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page number
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	4
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6
Objectives	3	State specific objectives, including any prespecified hypotheses	6-7
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7-8
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	7-8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-10
Bias	9	Describe any efforts to address potential sources of bias	12
Study size	10	Explain how the study size was arrived at	7-8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	11
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	11
		(*b*) Describe any methods used to examine subgroups and interactions	11
		(*c*) Explain how missing data were addressed	11
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	N/A
		(*e*) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	13
		(b) Give reasons for non-participation at each stage	7-8
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	24-25
		(b) Indicate number of participants with missing data for each variable of interest	24
Outcome data	15*	Report numbers of outcome events or summary measures	13-16; 28-29
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted	13-16;

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		estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	28-29
		(*b*) Report category boundaries when continuous variables were categorized	27-29
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	13-16
Discussion			
Key results	18	Summarise key results with reference to study objectives	16-17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20
Generalisability	21	Discuss the generalisability (external validity) of the study results	20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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