


BMJ Open Cancer treatment decision-making among parents of paediatric oncology patients in Guatemala: a mixed-methods study

Dylan E Graetz ,¹ Silvia Rivas,² Huiqi Wang,¹ Yuvanesh Vedaraju,¹ Gia Ferrara,¹ Lucia Fuentes,³ Ana Cáceres-Serrano,³ Federico Antillon-Klussmann,^{2,4} Meenakshi Devidas,¹ Monika Metzger,¹ Carlos Rodriguez-Galindo,¹ Jennifer W Mack⁵

To cite: Graetz DE, Rivas S, Wang H, *et al.* Cancer treatment decision-making among parents of paediatric oncology patients in Guatemala: a mixed-methods study. *BMJ Open* 2022;**12**:e057350. doi:10.1136/bmjopen-2021-057350

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-057350>).

Received 14 September 2021
Accepted 26 July 2022



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For numbered affiliations see end of article.

Correspondence to

Dr Dylan E Graetz;
dylan.graetz@stjude.org

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 paediatric patients (≤ 18 years of age) diagnosed with any form of cancer within the 8 weeks prior to study enrolment. 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 paediatric 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 socio-demographic characteristics or preferred decision-making role. Qualitative results supported quantitative findings, demonstrating a decision-making process that emphasised 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 reinforces the importance of the provider-parent relationship and encourages clinicians in all settings to ask about and honour each parent's desired role in decision-making.

INTRODUCTION

From the time of diagnosis, parents of children with cancer are faced with difficult

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study investigated communication and decision-making, key components of patient-centred 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 a single cancer centre in one middle-income country, and thus results may not apply to other low-income and middle-income countries.

decisions regarding care and treatment. Shared decision-making is associated with improved patient-reported outcomes for adult patients with cancer,¹ and research from high-income Western countries has emphasised a similar model for parents of children with cancer.²⁻³ Effective shared decision-making depends on high-quality communication³ through which paediatric 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 health-care 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 providers⁵ 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 paediatric patients with cancer in low-income and middle-income countries (LMICs),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 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 used a convergent mixed-methods design. Quantitative data were 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 paediatric 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 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 sampling¹¹ to ensure representation of a range of paediatric 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 saturation¹² was reached after enrolment of 20 parents and no further participants were approached.

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.

Socio-demographic 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 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 in 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.

Complete survey and interview script are included as online supplemental materials.

Data analysis

Quantitative data including socio-demographic information and items pertaining to decision-making were analysed descriptively. Proportions between groups were compared using χ^2 or Fisher's exact test as appropriate. Parent responses regarding their preferred decision-making role was compared with the actual role they played. Parents whose preferences matched their experiences were considered to have held their preferred role and were compared with parents whose experiences did not match their preferences. Univariate logistic regression was used to assess the impact of socio-demographic 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 three rather than five 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 0–100. Consistent with existing literature,¹⁵ scores of 0 were categorised as no regret, 1–25 as mild regret and >25 as heightened regret. Univariate logistic regression was performed with socio-demographic variables as well as 'preferred' versus 'non-preferred' role in decision-making.

Analysis of qualitative data were conducted by two independent coders who conducted thematic content analysis¹⁶ on all transcripts using a combination of a priori^{17 18} and novel codes. Inter-rater reliability ranged from 0.72 to 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 online supplemental 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 centre included those expressed by providers and reflections from parents. MAXQDA (VERBI, Berlin, Germany) was used 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

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 paediatric 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 emphasised 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). Among 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 prioritised 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 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

Table 1 Socio-demographic characteristics of participating caregivers and their children

Participant	Quantitative sample (total=100)	Qualitative sample (total=20)
	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)

Continued

Table 1 Continued

Participant	Quantitative sample (total=100)	Qualitative sample (total=20)
	N (%)	N (%)
Female	39 (39)	9 (45)
Diagnosis		
Leukaemia	58 (58)	13 (65)
Lymphoma	12 (12)	2 (10)
Histiocytic disorders	2 (2)	1 (5)
Solid tumour	25 (25)	3 (15)
Brain tumour	3 (3)	1 (5)

*Ethnicity: one missing; civil status: one missing; monthly household income (quetzales): two missing.

for you to be cured, I'll do it' (parent of a teenager with a brain tumour).

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 emphasised 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 emphasised honesty, as she spoke to the parents of a child newly diagnosed with blood cancer, 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 emphasised the importance of starting immediately, using words like 'must' and phrases such as 'have to', without providing parents with multiple

Table 2 Excerpts from recorded diagnostic conversations emphasising 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 a 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 tumour) ‘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 tumour) ‘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 tumour) ‘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.’ (to parents of a teenager with a solid tumour)	‘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)

options. These directives referred to treatment modalities, such as surgery or chemotherapy, necessity of hospitalisation 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 tumour) and another, ‘I didn’t ask much; the experts know the solution’ (parent of a child with blood cancer).

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 to 15.89), $p=0.02$) (**table 3**).

Most parents (64%) were categorised as having no decisional regret, while 25% had mild regret, and 11% had heightened regret. Heightened decisional regret did not significantly correlate with any socio-demographic variables, or with parents having played their preferred role in decision-making (OR 1.34 (95% CI 0.32 to 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 emphasised a decision-making model in which trust and honesty were prioritised. Parents deferred to their providers and were predominantly satisfied with

Table 3 Univariate logistic regression analysis of socio-demographic factors and preferred decision-making role

Decision-making		
Factor	P value	OR
Parent (N=96)	0.02*	
Father		4.32 (1.17 to 15.89)
Mother		1.00 (ref)
Ethnicity (N=97)	0.70	
Ladino		1.49 (0.51 to 4.36)
Indigenous (Mayan)		1.66 (0.47 to 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 to 4.39)
>2999		1.61 (0.62 to 4.15)
Diagnosis group (N=98)	0.12	
Leukaemia		1.00 (ref)
Lymphoma		8.25 (1.00 to 68.35)
Solid tumour		1.59 (0.59 to 4.30)
Others (histiocytic disorder +brain tumour)		3.00 (0.31 to 28.59)

*Significant p value.

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 paediatric cancer care.²⁰ In high-income Western contexts, shared decision-making has been prioritised.²¹ While different definitions of shared decision-making exist, it is often presented in contrast to paternalism and generally emphasises autonomy,²² multiple options²³ 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 prioritises 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-making²⁵ with increasing prioritisation of information-exchange²⁶ and autonomy over time.²⁷ These findings suggest there may be differences

Table 4 Univariate logistic regression analysis of heightened decisional regret

Decisional regret		
Factor	P value	OR
Parent (N=98)	0.68	
Father		1.34 (0.32 to 5.56)
Mother		1.00 (ref)
Ethnicity (N=99)	0.16	
Ladino		1.41 (0.15 to 13.48)
Indigenous (Mayan)		4.50 (0.48 to 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 to 3.35)
>2999		0.27 (0.05 to 1.44)
Diagnosis group (N=100)	0.57	
Leukaemia		1.00 (ref)
Lymphoma		0.57 (0.06 to 5.02)
Others (Brain tumour +histiocytic disorder +solid tumour)		0.45 (0.09 to 2.25)
Decision engagement (N=98)	0.71	
Preferred		0.78 (0.20 to 2.96)
Not preferred		1.00 (ref)

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, emphasising 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 USA 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 paediatric 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 settings³⁴ 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 emphasises 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 prioritising 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 centre 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 analyse 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 paediatric cancer care has been conducted exclusively in high-income settings including the USA and Europe.³⁵ This study demonstrates that many parents in Guatemala, like those in the USA, want to be engaged in decision-making by their oncology teams and prioritise 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 honour their responses.

Author affiliations

¹Global Pediatric Medicine, St Jude Children's Research Hospital, Memphis, Tennessee, USA

²Unidad Nacional de Oncología Pediátrica, Guatemala City, Guatemala

³Department of Psychology, Unidad Nacional de Oncología Pediátrica, Guatemala City, Guatemala

⁴Universidad Francisco Marroquín Facultad de Medicina, Guatemala City, Guatemala

⁵Department of Population Science, Dana-Farber Cancer Institute, Boston, Massachusetts, USA

Twitter Dylan E Graetz @DylanGraetzMD

Acknowledgements The authors would like to thank psychologists Pilar Alvarado, Inés Ordoñez, Paulina Salazar and Debby Velleman for their efforts assisting in qualitative data collection, as well as child psychologists Ana Lucia Espinoza Asturias and Gabriela Maria Garcia Palencia for their efforts assisting in survey administration, and the entire Medicina Integral team at Unidad Nacional de Oncología Pediátrica for supporting this work. We would also like to thank the parent participants who made this study possible.

Contributors DG is responsible for the overall content of this manuscript as guarantor. DG conceptualised and designed the study and data collection tools, supervised pilot testing and data collection, analysed qualitative data, drafted the initial manuscript and reviewed and revised the manuscript. SR and FA-K contributed to study design, facilitated study approval and supervised data collection at Unidad Nacional Oncología Pediátrica and reviewed and revised the manuscript. HW, YV and MD conducted statistical data analysis and reviewed and revised the manuscript. LF analysed the qualitative data and reviewed and revised the manuscript. LF and AC-S contributed to study design, conducted pilot testing, collected data and reviewed and revised the manuscript. MM and CR-G contributed to study design and reviewed and revised the manuscript. JM conceptualised 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.

Funding This work was funded by American Lebanese Syrian Associated Charities of St. Jude Children's Research Hospital and a Conquer Cancer Young Investigator Award (award number 17290). Any opinions, findings and conclusions expressed in this material are those of the authors and do not necessarily reflect those of the American Society of Clinical Oncology or Conquer Cancer.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

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).

Provenance and peer review Not commissioned; externally peer reviewed.



Data availability statement Data are available upon reasonable request.

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ORCID iD

Dylan E Graetz <http://orcid.org/0000-0002-4541-6910>

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