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

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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 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 decisions regarding care and treatment. Shared decision-making is associated with improved patient-reported outcomes for adult patients with cancer, and research from high-income Western countries has emphasised a similar model for parents of children with cancer. Effective shared decision-making depends on high-quality communication 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 healthcare providers during decision-making have been demonstrated to result in erroneous
assumptions and interpersonal conflict. For parents of children with cancer, having their preferred role in decision-making may increase trust in healthcare providers and decrease regret. Nevertheless, culture is rarely accounted for in research surrounding patient–provider communication and decision-making, and very few studies have explored decision-making among paediatric patients with cancer in low-income and middle-income countries (LMICs), where >90% of children with cancer live. 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 Pediátric 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%.

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 sampling 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 saturation 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 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, which asked participants to state whether they ‘strongly agreed’, ‘slightly agreed’, ‘disagree’ or ‘strongly disagree’ with the statement ‘I feel I made the wrong decision’.

**Participants**

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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 χ² 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. 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, 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 analysis on all transcripts using a combination of a priori 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.

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
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).

### Table 1 Sociology-demographic characteristics of participating caregivers and their children

| Participant | Quantitative sample (total=100) | Qualitative sample (total=20) |
|-------------|---------------------------------|------------------------------|
| N (%)       | 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)                      |

*Ethnicity: one missing; civil status: one missing; monthly household income (quetzales): two missing.
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 providers. A parent of a teenager newly diagnosed with a solid tumour said, ‘Whatever you decide…you make the decision’ (parent of a child with blood cancer). Another parent described in an interview: ‘We didn’t know if it was the best, but that’s 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.’ (parent of a teenager 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 a 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
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cared by 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. 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, a concept which has been extensively studied in high-income settings and includes ‘unselfish decisions in the child’s best interest’. 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. 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-resource 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.

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