

# Development and Adaptation of a Patient-Centered Communication Survey for Parents of Children With Cancer in Guatemala

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**PURPOSE** Surveys to assess patient and family experiences of pediatric cancer care have been primarily developed and validated in high-income Western settings with English-speaking participants. However, 90% of children with cancer live in low- and middle-income countries. We sought to develop a survey focused on pediatric cancer communication for use in a low-literacy population in Guatemala, including adaptation of many previously validated items.

**METHODS** A multidisciplinary team developed a quantitative survey on the basis of a theoretical model of important components and influences on pediatric cancer communication. The original survey included established items previously used in high-income settings and novel questions designed for this study. The survey was translated into Spanish and pilot tested with parents of children receiving treatment at Unidad Nacional de Oncología Pediátrica in Guatemala City, Guatemala, from April-June 2019. Cognitive interviews were used during pilot testing, and the survey was iteratively revised throughout this process.

**RESULTS** Early in testing, Guatemalan parents tended to choose answers at the extreme ends of response categories and socially desirable responses. Ultimately, a visual aid was developed to accompany three-item Likert scale response options. This allowed for successful administration of the survey instrument, resulting in moderate variation of response options and similar proportions to those generated when the original five-item responses were used in parent populations from the United States.

**CONCLUSION** Appropriately adapted surveys are necessary to understand patient-centered communication among pediatric oncology populations in low- and middle-income countries. Eventual validation of such tools will enable cross-cultural studies and comparative analysis of results.

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## INTRODUCTION

Surveys are routinely used to assess family experiences of pediatric cancer care. Although the use and validation of these instruments have been primarily in high-income countries (HICs), the burden of childhood cancer lies predominantly in low- and middle-income countries (LMICs).<sup>1,2</sup> Quantitative instruments are necessary to conduct generalizable research and improve patient-centered pediatric cancer care in limited-resource settings.

Communication between the health care team and family is an important part of family-centered pediatric cancer care. To date, only a few quantitative studies have examined childhood cancer communication in LMICs.<sup>3</sup> Most of these investigations used study-specific questionnaires,<sup>4-9</sup> whereas a few used scales developed in HICs<sup>10</sup> translated into local languages.<sup>11</sup> Previous work exploring barriers to instrument adaptation for

immigrant Latino participants in the United States identified not only translation but also culturally based methodologic concerns.<sup>12</sup>

Likert scales, which are used as response options for many questionnaires, have been shown to be poorly understood by low-literacy populations, resulting in selection of socially desirable and extreme responses, and missing data.<sup>13</sup> One proposed solution has been to reduce Likert anchors from five response options to 3. Although this sacrifices variability, fewer response options can improve validity and reliability.<sup>12</sup> Visual analog scales (VASs) consist of a horizontal line anchored with two descriptors and are traditionally easy to understand, administer, and score. VASs have been successfully used in low-literacy populations in HICs<sup>14</sup> and may be less vulnerable to confounding factors, such as patient age health literacy and income, than Likert-scaled items.<sup>15</sup> In LMICs, participatory action research has led to the development of user-friendly

## ASSOCIATED CONTENT

### Data Supplement

Author affiliations and support information (if applicable) appear at the end of this article.

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## CONTEXT

### Key Objective

How might a survey of pediatric cancer communication be adapted and used among a diverse parent population in a middle-income country?

### Knowledge Generated

Use of a visual aid and reduction of five-item Likert scales to three-item facilitated adaptation and administration of a survey of childhood cancer communication with Guatemalan parents. Results of adapted items demonstrate moderate variation of responses and similar proportions to those generated from the use of the original tools in high-income countries.

### Relevance

Appropriate adapted surveys will enable cross-cultural studies of patient-centered communication among pediatric oncology populations in low- and middle-income countries.

surveys that include visual depictions<sup>16</sup> and pictorial aids for Likert scales.<sup>17</sup>

We conducted a study that aimed to evaluate patient-centered communication between parents of patients with newly diagnosed pediatric cancer and health care teams in Guatemala. Guatemala is a small, but diverse country, with 24 principal ethnic groups who speak 24 different languages and comprise more than 40% of the population.<sup>18</sup> Almost 60% of the Guatemalan population lives below the poverty line and experiences socioeconomic barriers to health care, including low literacy.<sup>19</sup> For our study, we used a cross-sectional survey that included items from surveys previously validated in high-income Western settings and required significant adaptation for use with the Guatemalan population. Here, we describe our process of survey development and adaptation and use results from our study to reflect on that process, including ways that it was successful and how it may highlight considerations for future work.

## METHODS

### Study Team and Setting

This research was conducted at Unidad Nacional Oncología Pediátrica (UNOP) in Guatemala City, Guatemala. UNOP is Guatemala's national pediatric oncology center, a public/private partnership that cares for more than 500 new children with cancer each year, with an overall survival rate of approximately 65%.

The study team for this work consisted of bilingual researchers based in the United States and in Guatemala. US-based researchers included pediatric oncologists at St Jude Children's Research Hospital in Memphis, TN, and Dana-Farber Cancer Institute in Boston, MA, with expertise in cancer communication and global pediatric oncology. Guatemalan researchers included pediatric oncology physicians and psychologists at UNOP who have years of experience providing clinical care and conducting psychosocial research with the diverse population that UNOP serves.

### Study Design

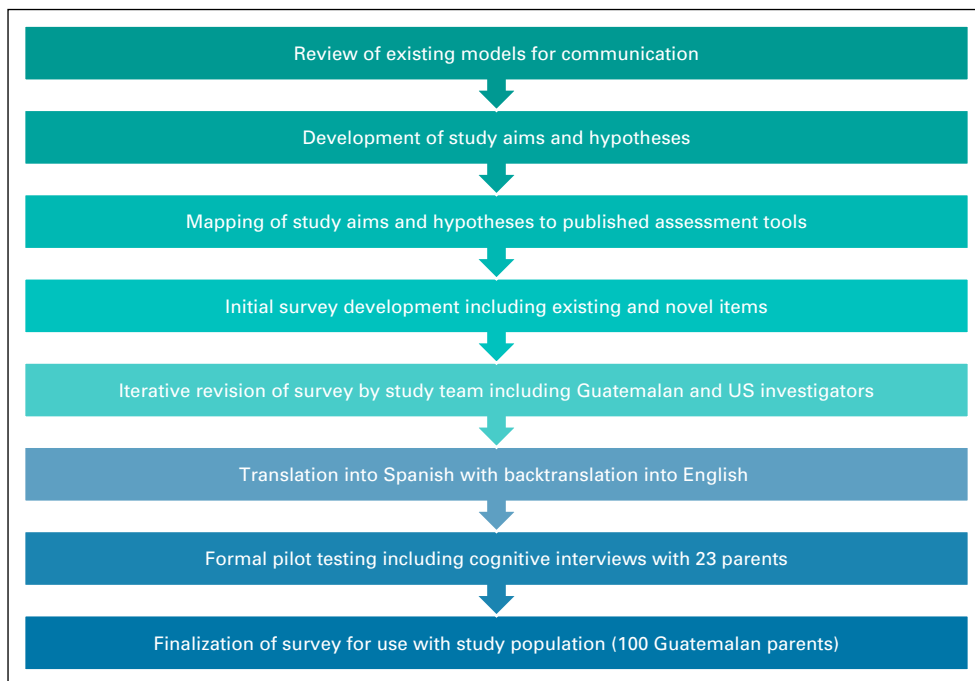
The survey described here was ultimately used in a cross-sectional mixed methods study that assessed communication priorities and experiences of parents of children with newly diagnosed cancer. The study included a qualitative component composed of audio-recorded naturally occurring conversations and interviews and the survey described in detail here, which specifically examined information exchange and decision-making processes at the time of diagnosis. Complete methodology and study results from the larger study have been previously published.<sup>20,21</sup>

### Instrument Development and Pilot Testing

The process of survey development is outlined in [Figure 1](#). A quantitative survey instrument was originally developed in English on the basis of modeled domains and study hypotheses. The study team reviewed an existing model for communication<sup>22</sup> and identified areas of particular interest and relevance to the study population. Study aims and hypotheses addressing domains were mapped to previously developed items used to assess communication and decision making in medical and pediatric oncology,<sup>23-28</sup> items adapted from the literature exploring cancer perceptions in Guatemalan Mayan populations,<sup>29</sup> and novel items developed on the basis of clinical experience at UNOP. The study team iteratively revised the questionnaire with specific attention to survey burden and simplicity and language accessibility. The questionnaire was translated into Spanish and back translated into English during this iterative process to ensure that the original intent of questions was maintained. The initial questionnaire included many questions with 5-item Likert responses. Scaled response options for questions about the importance of communication attributes, for example, included extremely, very, somewhat, only a little, and not at all important. Other questions asked how much parents agreed and included response options of strongly agree, slightly agree, neutral, slightly disagree, and strongly disagree.

Pilot testing of the survey with parents of children with cancer receiving treatment at UNOP was performed from April to

**FIG 1.** Survey development process. Flow diagram describing the process of survey development including adaptation, translation, and pilot testing.



June 2019. Parents were eligible if they were Spanish-speaking and had a child (age < 18 years) recently diagnosed (within the prior 8 weeks) with any form of cancer. Early in pilot testing, many participants had high literacy and education levels. After initial testing, we purposefully sampled low-literacy or illiterate participants to ensure survey performance across the spectrum of literacy levels.

Throughout pilot testing, Guatemalan members of the research team used a script to verbally administer the questionnaire. This script explained the purpose of the study and advised parents that they would be asked for their feedback regarding survey questions, including whether questions were clear and relevant. For the purposes of pilot testing, the instrument was divided into short sections. After each section, parents were asked questions to assess comprehension and content validity. For example, after administering a section of questions related to cancer, a parent might be asked “*When you heard the word ‘illness’, what did you think of? Can you describe it in your own words? How do you understand the idea of illness?*” The cognitive interview script also included prompts such as “*Are these questions clear to you? Do you feel that these questions apply to you and your child? Do you feel comfortable answering them?*” Researchers used parental responses, in addition to affect and body language, to identify problematic items and revise the instrument. Recruitment continued until the survey was performing well, and no further feedback was obtained; 23 parents participated in pilot testing.

The final survey was administered to 100 parents of children with cancer in Guatemala and is included in the Data Supplement.

### Ethical Approval

This study was reviewed and approved by institutional review boards and ethics committees at St Jude and UNOP and performed in compliance with international regulations for protection of human participants.

### RESULTS

Early pilot testing revealed a tendency for parents to choose extreme answers and socially desirable responses. For example, one set of questions asked parents to consider the importance of communication regarding various aspects of care. Parents were asked “how important is it to you that your medical team discusses the following things when talking to you about your child’s diagnosis.” Response options included extremely important, very important, somewhat, only a little, and not at all, and the prompts included how to care for my child during treatment, transportation to and from appointments, why my child got cancer, and what happens if my child dies. Most parents choose extremely important for all responses, and when they did not choose extremely important, they tended to choose not at all important.

To increase variability, we tested alternative questions that asked parents to rank communication priorities in order from most to least important. We found that most parents were unable to rank items, and when asked to do so, they would sit quietly not engaging at all or express their inability to deem some aspects of communication less important than others.

### Creating a Visual Aid for the Likert Scale

Given the challenges that parents experienced with response options on a Likert scale, we tried additional formats,

including a visual analog scale anchored with not at all important and extremely important. Guatemalan parents, however, continued to pick one of the extremes. If the interviewer drew a line on the scale as an example, parents might then pick that line, but did not make their own notations.

We then tested adding visual aids to our Likert scale. We started with a modified VAS containing a wide bar with five colors ranging from blue to purple (Fig 2A). We instructed parents to pick a color with blue representing strongly agree, teal representing neutral, and purple representing strongly disagree. Parents reported that they liked the visual aid but continued to find this scale challenging. One parent suggested that the colors were hard to relate to or remember (eg, why was red slightly agree?). We then tested shaded variations of the same color (Fig 2B). When this did not improve our results, we tested a colored histogram (Fig 2C) and as a second alternative, a series of circles that varied in size (Fig 2D). Parents continued to favor extreme

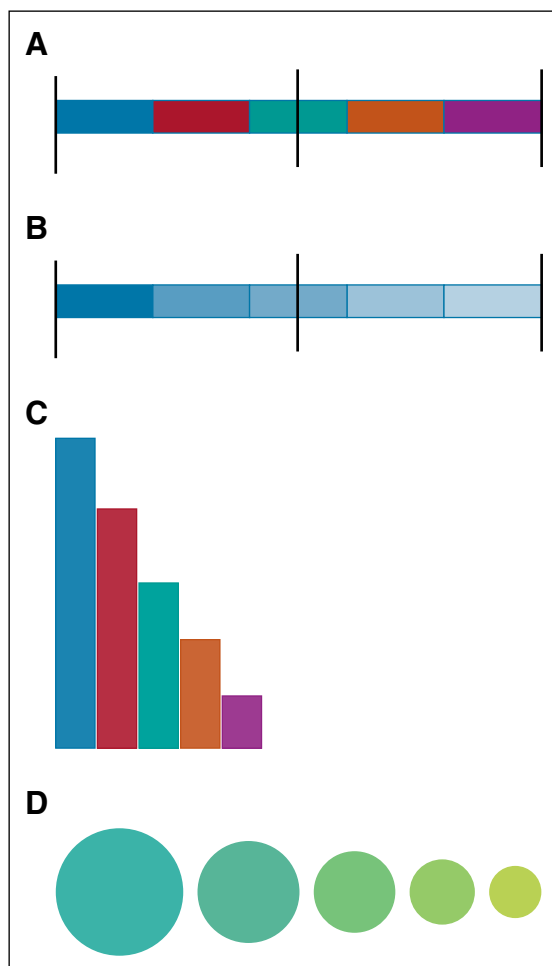
response items and reported that these scales did not help them understand or answer questions.

Next, we tested visual aids on the basis of concrete depictions of items rather than abstract colors and shapes. These included a scale of thermometers filled and the FACES scale often used for pain assessment in children<sup>30</sup> (Fig 3A). Parents reported that they did not relate to the thermometers, and most parents were unwilling to choose sad or unhappy faces. The team discussed each of these scales with parents and asked them to consider other concrete images that might be useful. Through these discussions, one of the Guatemalan researchers had the idea of testing a scale of scales. Parents use *balanzas*, or scales, while shopping in the market, and Guatemalan researchers reported that these images were widespread in newspapers as well. We created and tested a scale of scales (Fig 3B). This aid included only three images, as it was difficult to convey any further subtlety with such an image. Unfortunately, this pictorial aid did not fare better than the previously tested visual aids. Parents had trouble in distinguishing the three items and on retest often switched from the image representing agree to the image representing disagree. However, parents unanimously expressed a preference for three response choices over five, reporting that this was less overwhelming and more approachable.

Early in the process, we had tested a simple image of circles (Fig 4A). This pictorial aid included three response options: one with many circles that correlated with strongly agree or extremely important, one with a few circles that correlated with a neutral or a little (in Spanish: *mas o menos*), and one without any circles correlating with not at all or disagree. Although we had relative success with this image, we initially put it aside in hopes of finding a 5-item visual that would allow for greater variability. After our many attempts at more complicated images, we returned to this drawing and added colors on the basis of feedback from parent participants. Assessment with multiple parents demonstrated that this aid was consistently accessible, easy to respond to, and reliable on repeat testing. Although we had thought that we might use one scale or visual aid for response options involving degree of agreement and another for the level of importance, we found that our final pictorial aid (Fig 4B) was successful with both types of questions and parents did not have trouble using it with different prompts.

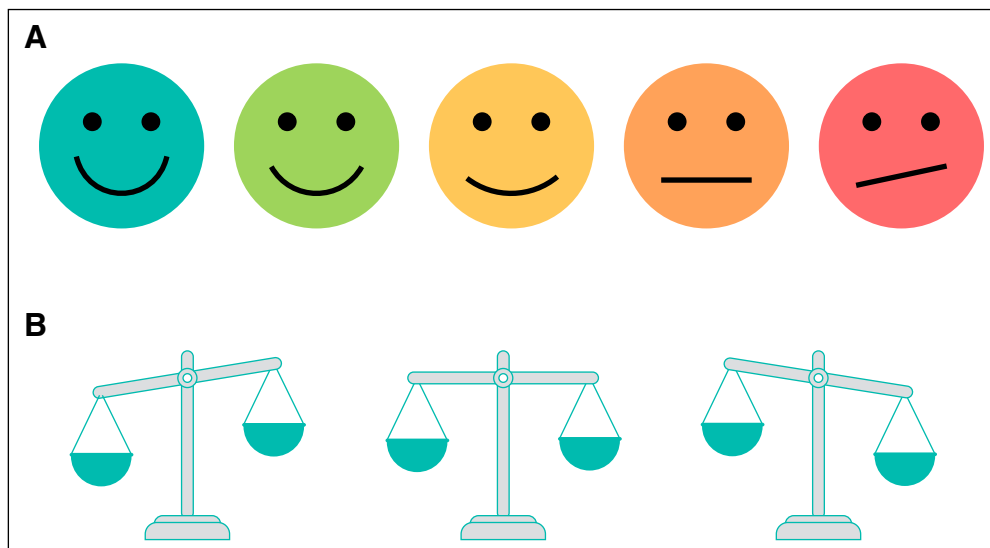
### Comprehension

In addition to the challenges related to response options, we identified difficulties with comprehension. Although the original survey was written at a sixth grade reading level and administered verbally, it quickly became evident that the language was too complex. Parents would sit silently and were unable to respond, and when asked admitted they were confused or did not understand the questions. As a result, the language was simplified substantially, and headings were added to orient parents to the topic area



**FIG 2.** Visual aids for the five-item Likert scale. Modified visual analog scales including (A) multiple colors and (B) shades of the same color, (C) a colored histogram, and (D) a series of colored circles in variable sizes were trialed to orient parents to a five-item Likert scale.

**FIG 3.** Visual aids on the basis of concrete depictions for the Likert scale. (A) Visual scales including a modified FACES scale and (B) scale of scales was trialed with both five-item and three-item Likert scale response options.



before each section. We eliminated questions that we were unable to simplify adequately to ensure comprehension and any duplicate questions or questions that did not directly address study aims. We also found that parents were easily confused by questions that were phrased in the negative, and thus, whenever possible, these questions were reworded as positives.

### Survey Responses

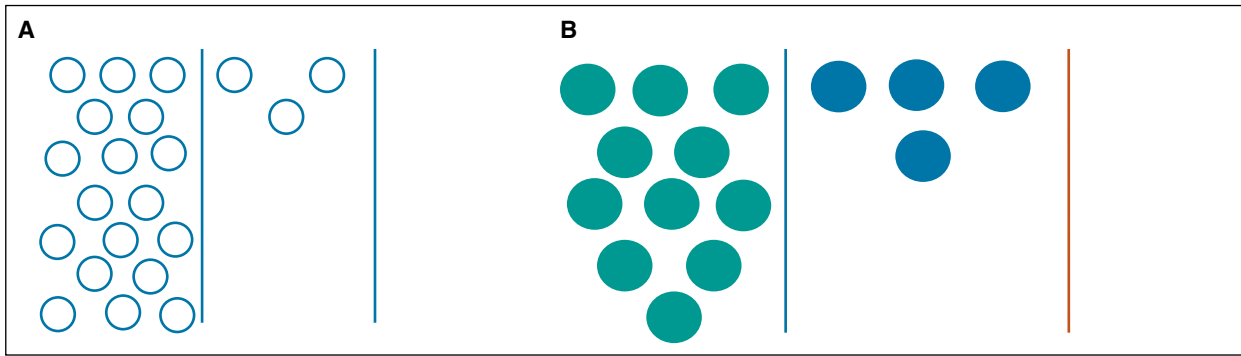
After pilot testing, we implemented the survey. We collected data from 100 parents by verbally administering a final version of our survey including the three-item Likert scale and visual aid.<sup>20</sup> This scale and aid were used for novel questions designed for this study population and adapted items that had previously included a five-item Likert scale. One of the questions specifically asked parents questions about the sources of information that they consulted to learn about their child's disease. As previously reported,<sup>20</sup> we asked parents "How important each of the following things was for you as a source of information regarding your child's cancer?" Sources included conversations with your medical team, conversations with your family, conversations with leaders in your religious or spiritual community, an understanding within yourself (including a feeling, hunch, or dream), and reading in books or looking for information on the internet. Response items included a three-item scale consisting of a lot, a little, and not at all using the finalized pictorial aid (Fig 4B). Although almost all parents (99%) responded a lot for conversations with your medical team, the other items demonstrated variability and use of all three Likert responses (Fig 5). We were similarly successful in using the scale and visual aid with questions adapted from validated items used in the United States regarding communication priorities and experiences, with original response options that included a 5-point Likert scale.<sup>31</sup> Responses to our three-point Likert scale with visual aid demonstrated moderate variation and similar proportions to those

generated by the original five-point Likert scale used in parent populations in the United States.<sup>20</sup>

However, some responses to our survey suggested that certain questions continued to be poorly understood. For example, one adapted item<sup>28</sup> asked parents "How much do you agree with each of the following statements regarding doctors in general?" with a prompt stating "It is best for parents if they do not have a full explanation of their child's medical condition." Our results showed that 99% of parents strongly agreed and 1% slightly agreed with this prompt. This distribution raises the concern that parents might not have understood the negative phrasing of the question, and most might have instead agreed that parents *should* have a full explanation of their child's condition. Since the same three-item Likert scale and visual aid were used for this question as for many others, we hypothesize that parental confusion was related to question comprehension rather than response options and specifically to the negative phrasing of this item.

### DISCUSSION

Existing tools to assess pediatric cancer communication have been validated predominately in high-resource, Western settings, among English-speaking participants.<sup>24,25,31,32</sup> Although communication tools have been used in low-resourced settings, they are most often used to assess communication among professionals, rather than between the health care team and families,<sup>33</sup> and methods for adaptation beyond translation, such as validation and reliability processes, have not been routinely reported. Previous work suggests that Likert-type scales may be challenging for low-income populations.<sup>17</sup> These challenges have been attributed to participant education or language barriers; however, there may also be cultural differences in the way meaning is assigned to the degree of variation measured by a Likert scale.<sup>34</sup> For this study, we adapted communication



**FIG 4.** Final visual aid development. Our final visual aid included (A) variable amounts of circles (B) that were ultimately colored and was successful.

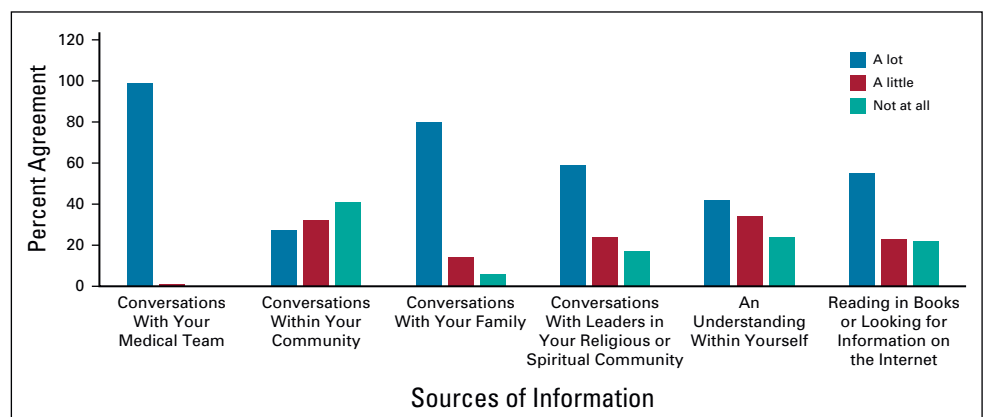
assessment tools for use with a low-literacy parent population in Guatemala. We were guided by previous work among Latino immigrant communities in the United States<sup>12</sup> and found some similarities, including success with a three-point Likert scale and a visual aid. We hope that our process offers insight into potential pitfalls and solutions of survey adaptation and ultimately encourages rigorous processes to further validate quantitative communication tools that may enable data collection in a variety of resourced settings.

Although we used a survey that was verbally administered by and to native Spanish speakers, our study population had difficulty with 5-item Likert scales. This supports findings among immigrant populations in the United States<sup>12,13</sup> and suggests that the tendency toward socially desirable and extreme responses may be cultural rather than linguistic. Previous research comparing socially desirable responses among self-identified Latino and Anglo participants further supports cultural rather than methodological explanations and hypothesizes a relationship to the more collective or familiar nature of Latino culture.<sup>35</sup> It is also possible, particularly in a medical setting, that hierarchical culture contributes to social desirability bias. Further research is needed to confirm and explore these mechanisms for socially desirable responses among Guatemalan and other Latino populations.

After testing multiple scales and visual aids, we ultimately opted for a three-item scale with a simple pictorial representation. Although we were concerned that doing so would sacrifice variability, pilot testing demonstrated that parents were hesitant to pick the less extreme options in the five-point scale. In addition, our data ultimately yielded results similar to those obtained in US-based studies including original validated five-item responses. Finally, we noted a difficulty in using negatively phrased questions with agree to disagree type response options as this required parents to work through double negatives, which led to confusion, an inability to respond, or inconsistency when the question was repeated. This finding is not unique to our population. Previous studies in high-income noncancer settings have found negatively phrased items to be less reliable<sup>36</sup> and demonstrated that when negatively phrased items are reworded, they are answered more rapidly.<sup>37</sup>

Pictorial aids have been used to enhance survey accessibility, particularly among low-literacy populations.<sup>38</sup> During development of our visual aid, we found that color scales were appealing and engaging for participants; however, too much detail was distracting. A previous study of pictorial aid development for use with caregivers of children with serious illness in another low-resource setting demonstrated variable success using a culturally based image.<sup>39</sup> Ultimately, we

**FIG 5.** Survey results. Example of results from a survey question asking parents about sources of information regarding their child's cancer, demonstrating variability across three-item Likert responses options.



found that simple shapes were more effective than the culturally relevant images that we piloted. Our final visual aid has the advantage of being free of language or culture-specific images and thus lends itself well for trial and adaptation in other low-literacy populations. Further use, exploration, and ultimately validation of this tool in similar populations are warranted.

Finally, our process emphasizes the importance of community-based participatory research, an approach that has been widely applied to studies across the cancer continuum,<sup>40</sup> including global settings.<sup>41</sup> Although the study team for this project included members of the local community with years of experience providing care to this population, a thorough approach to pilot testing revealed many unanticipated barriers to survey administration. All survey instruments, particularly those involving Likert scales, should be not only translated but also culturally adapted and carefully tested in research settings. This is particularly essential for research conducted in vulnerable

populations and LMICs. Involvement of community members before pilot testing, for example, during project concept design and survey development, is ideal.

In conclusion, a large gap remains in our understanding of patient-centered communication among pediatric oncology populations in LMICs. The use of previously validated items to collect data fosters rigor, enables comparative analysis of results, and is particularly valuable in LMICs where hospitals have limited resources for research. However, it is essential that tools are appropriately adapted beyond translation to ensure validity and reliability of collected data. Our work represents an initial step toward appropriate adaptation of quantitative survey instruments used to measure patient-centered communication in low-resource settings. We hope that it will inspire future cooperative cross-cultural studies focused on continued adaptation and eventual validation of these tools in diverse settings.

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## DISCLAIMER

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**Final approval of manuscript:** All authors

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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