

# Parent Engagement and Agency in Latin American Childhood Cancer Treatment: A Qualitative Investigation

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**PURPOSE** Parent engagement in childhood cancer treatment is central for positive outcomes. Aspects of fruitful engagement have been described mainly in high-income countries (HICs) where family autonomy is valued, health care provider-patient relationships are less hierarchical, and active family participation in health care is welcomed. In many low- and middle-income countries (LMICs), these aspects are not always valued or encouraged. We explored childhood cancer treatment engagement in Latin America as part of a larger engagement study in 10 LMICs worldwide.

**METHODS** A qualitative investigation was conducted with parents (with the exception of one grandmother and two aunts in loco parentis; n = 21) of children with cancer in El Salvador, Peru, and Mexico. Participants were recruited by two Childhood Cancer International foundations and two local hospitals. A pediatric oncology psychologist and a medical anthropologist (experienced, native Latin Americans researchers) conducted focus-group discussions and in-depth interviews that were recorded and transcribed, and analyzed data.

**RESULTS** Parents in the three countries actively engage in their child's treatment, despite challenges of communicating effectively with health care staff. Hierarchical health care provider relationships and generalized socioeconomic disparities and cultural diversity with health care staff notwithstanding, parents find ways to navigate cancer treatment by exerting their agency and exploiting resources they have at hand.

**CONCLUSION** In Latin America, engagement materializes in ways that are not necessarily reflected in existing literature from HICs and, thus, engagement may seem nonexistent. Health care teams' recognition of parents' substantial sacrifices to adhere to complex demands as treatment engagement, may positively impact the children's (and family's) quality of life, treatment experience, adherence, and posttreatment circumstances.

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## INTRODUCTION

Although childhood cancer is a rare disease affecting children and adolescents worldwide, it is a leading cause of disease-related deaths, and almost 14 million children are expected to be diagnosed between 2020 and 2050.<sup>1</sup> Nearly 65% of documented global cases occur in Latin America and the Caribbean,<sup>2</sup> a region marked by inequality and disparate access to education and health care services, especially in lower- and middle-income countries (LMICs).<sup>3</sup> Timely, appropriate childhood cancer treatment is not always available, because of multiple challenges to access and sustained long-term care,<sup>4</sup> and scattered health services across large countries, especially in South America.<sup>5</sup> Nonetheless, when proper treatment is available, many childhood cancers are curable if diagnosed early.<sup>2</sup>

In 2018, the Patient, Family and Stakeholder Engagement Task Force of the International Society of Pediatric Oncology assembled a global, multidisciplinary team of local qualitative researchers with clinical and/or research experience to document how parents and survivors engaged in childhood cancer treatment in low- and middle-income countries (LMICs). Ten countries, including El Salvador, Peru, and Mexico, participated in the study. Results of the survivors' experiences will be reported elsewhere. Here, we share findings about parents' engagement experiences in Latin America.

## Conceptual Framework

Engagement in health care treatment assumes that families are active actors who need or want to be involved in decision-making and whose opinions and values are considered throughout treatment. Thus, a partnership is established among parents, patients,

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## CONTEXT

### Key Objective

To determine how patients and families engage in childhood cancer treatment in three middle-income countries in Latin America.

### Knowledge Generated

Treatment engagement is socioculturally bound and most research on this topic is from high-income countries (HICs). Latin American inequalities maintain hierarchical relationships that shape medical encounters and hinder engagement described in literature from HICs.

### Relevance

Despite their low standing in the health care system hierarchy, we found parents' agency becomes and enables engagement. Some parents asked questions, whereas others deliberately followed a doctor's instruction without question, and both sought positive communication with their child's health care team even when meaningful communication was not always possible. Parental agency and engagement should be recognized and welcomed by health care teams in Latin America, even if it does not resemble engagement as described in the literature from HICs.

and health care staff.<sup>6,7</sup> However, as Pritchard-Jones et al<sup>8</sup> pointed out, engagement and participation are not straightforward, because patients and their families need to be somewhat medically literate and feel autonomous and comfortable asking questions that will produce understandable answers.<sup>5,6</sup> Most research on engagement comes from high-income countries (HICs) that have less rigid health care hierarchies than in Latin America and where patient, family, and health care provider dynamics include open communication and shared decision-making.<sup>8,7</sup>

In Argentina, Brage suggested that medical encounters in childhood cancer are relationships marked by power, and agency enables parents to develop strategies to “become central figures in their child's treatment.”<sup>9(p55)</sup> Agency—the ability to act, make decisions, and express individual power<sup>10</sup>—is relational, and people's expressions of agency are context dependent and respond to their sociocultural repertoires.<sup>11</sup> Caregiver participation in childhood cancer care is also believed to contribute to reducing treatment abandonment and improve outcomes.<sup>12</sup>

## METHODS

The Patient, Family and Stakeholder Engagement Task Force project leaders from multiple countries (two parents of children with cancer, a nurse, a psychologist, a pediatrician, and a social worker) wrote the terms of reference and interview guide, which were reviewed by a pediatric oncologist. All 10 LMICs in the study were recruited from within Childhood Cancer International (CCI), a support organization with 171 members (mostly nongovernmental organizations [NGOs]) from 88 countries. In Mexico, CCI member Centro de apoyo a niños con cáncer (CANICA) supported all researcher costs in Guadalajara in the southwest and recruited parents from three hospitals (including one aunt in loco parentis). In El Salvador, local CCI foundation Ayúdame a Vivir recruited the participants

(including one aunt and one grandmother in loco parentis). In Peru, researcher accommodation in Lima was provided by the Vidawasi foundation. Two pediatric oncologists (one on leave and one active) recruited parents. A total of 21 parents participated: six in Mexico, eight in El Salvador and seven in Peru. [Table 1](#) lists eligibility criteria.

In all three countries, the majority of children receive cancer treatment covered by government social security<sup>13</sup>; however, out-of-pocket costs can be insurmountable for families without local foundation support. Ongoing demand often overwhelms the foundations' resources, causing delays and threatening treatment completion ([Fig 1](#)).<sup>14</sup>

From February 2019 to September 2019, in-depth interviews and focus-group discussions in Spanish were conducted by two native qualitative researchers (a pediatric oncology psychologist and a medical anthropologist). All in-depth interviews and focus-group discussions were audio-recorded with participant oral consent and observational notes were taken. Confidentiality and the option to stop participating when desired were assured; names used in this article are pseudonyms. Data coding was performed manually and independently by the researchers and consensus on the final themes was achieved by discussion. The researchers translated the quotations presented in this article. Permission to conduct the study was granted by two relevant hospitals, one in Peru and one in El Salvador, and by the Mexican NGO, because the children had been treated in multiple hospitals.

In-depth interviews and focus-group discussions were conducted at the foundations' facilities in El Salvador and Mexico, and, in Peru, in vacated staff offices in the two hospitals. Parents spoke about many topics, including spirituality, care and control, negotiations, emotions, and survivorship experiences. Here, we present findings about poverty and communication with the health team.

TABLE 1. Eligibility Criteria

Group	Age (years)	Treatment History	Treatment Specifics	Terms of Reference (patient profile)
Patients	13-18	Finished treatment in the past 2 years.		Adolescents who have just completed treatment, currently at a minimum age of 13 years, ages 13-18 years who have completed treatment $\leq$ 2 years ago.
Survivors	> 18	Finished treatment 5-8 years ago (not > 8 years since stopping treatment).	Received treatment while between the ages of 7 and 14 years (must be $\geq$ 5 years since stopped receiving treatment without incident (ie, event-free survival).	Teens or survivors who are now young adults, who were treated when they were between the ages of 7 and 14 years, with all treatment being completed before the age of 18 years. Must be survivors, meaning 5 years incident free (ie, treatment took place $\leq$ 8 years ago).
Parents or caregivers who were main caretaker during treatment		Finished treatment in the past 5 years.		Involved/served as a carer during their child's treatment, including during in-patient treatment in the past 5 years (eg, a mother, a father, or the legal guardian and caregiver).

## RESULTS

We found two main themes: families' poor socioeconomic circumstances and communication with health care staff. The examples we present identify parental agency and engagement.

### Socioeconomic Situation

Across all three countries (and most of Latin America), physicians caring for children with cancer have graduate-level education and specialization. Their social standing and economic circumstances are quite high compared with their patients and families in the public system who face substantial economic hardship and unequal access to primary and secondary education.<sup>15,16</sup> However, the rather dire parental socioeconomic circumstances did not prevent parents from exercising agency and fully engaging in their child's treatment with their available resources.

Most parents in each country, with rare exceptions, described struggling to pay out-of-pocket treatment expenses. Most had more than one child and depended on relatives, neighbors, or their teenage children to care for younger siblings at home when they came to the hospital. Some mothers and children moved closer to the hospital during treatment, because of long travel distances, and siblings managed themselves or with a relative while their father worked. Parents reported organizing raffles, sales, and bingo games to raise money for procedures, medicines and therapies, and transportation fees.

Carla (Felipe's mother) is an indigenous woman who traveled hours to the hospital; her story exemplifies the families we interviewed. Felipe survived leukemia and his mother describes her agency to ensure her child's treatment:

When I arrived here [in the city] I knew nobody....I didn't have [money] to come to the hospital, sometimes I had to ask for help to bring [Felipe] to treatment....I'd do activities and sometimes people supported me....I'd cook chicken and *fritanga* [fried beef liver] [to sell]. I do this each time I have to come, because, really, my economy [finances] is low. (February 2019).

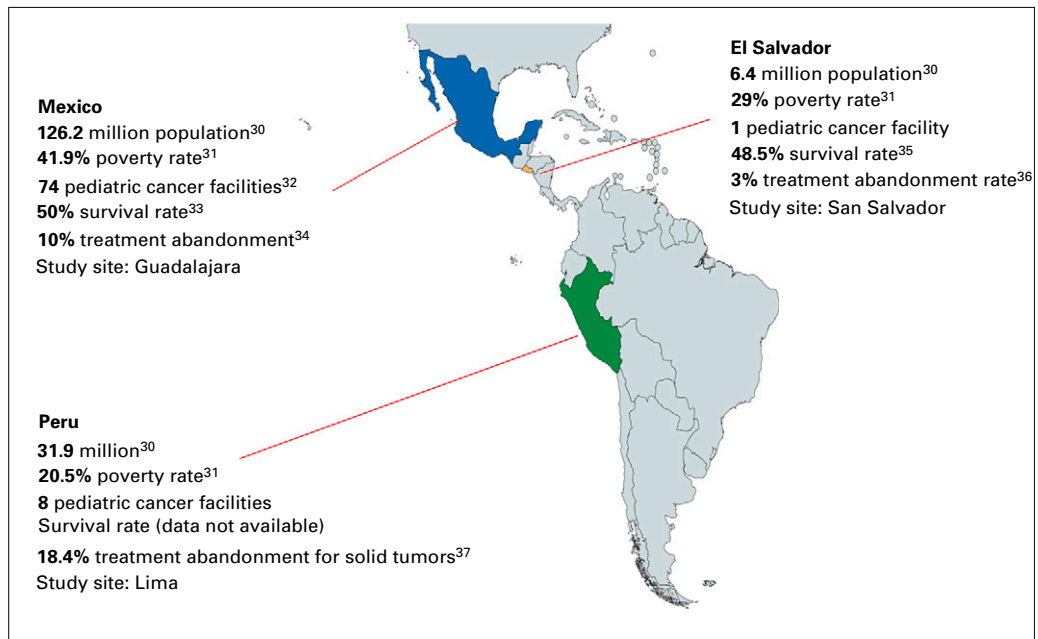
### Communication

**Positive communication during treatment.** All parents described engagement that materialized in attentiveness to their child's treatment protocol, tests results, and procedures. Parents asked questions to relevant staff members about their child's treatment and prognosis. For example, hemoglobin values were particularly important for parents to assess whether their efforts to keep their child in good health were working (eg, providing special food to boost immunity and/or discontinuing school and sports).

Elena, a mother of two and without formal education, noted that she always asked doctors about her daughter's tests results. Alicia, her youngest child survived leukemia.

I didn't go to school, but I paid attention to the hemoglobin values and to the platelets when results came in [weekly control tests]. So, [Alicia] wouldn't get anemia....I also was very attentive of her nourishment to keep the hemoglobin fine....I didn't understand much, but I always asked when the results came in....I always asked so I could know how she was [doing]. (February, 2019).

Elena's agency allowed her to overcome her limited medical literacy and lack of formal education. She learned relevant laboratory values to indicate Alicia's treatment status. She reported that her daughter's doctors patiently explained Alicia's laboratory results.



**FIG 1.** Three research sites with relevant demographic information for parental engagement.<sup>30-37</sup>

Luisa (mother of Gina, a survivor of leukemia) constantly asked questions of the health care staff. She reported that knowing Gina's health status and understanding her procedures were always priorities, and she showed her agency by explicitly expressing her need for answers:

I didn't have much trouble here [in the hospital]. I always asked, and doctor Aura, doctor Esther and doctor Clara, were always very clear ... If I had a question I would ask "but doctor, what is that that you are giving to her?" or "what is that you are going to do to her...is it really necessary? They never said "don't ask that"....I have always asked questions and when I see a doctor, I tell him "I ask a lot of questions, because I need to know." (February 2019).

#### **Negative communication experiences during treatment.**

Unfortunately, Elena's and Luisa's positive experiences were not universal. A minority of parents in El Salvador and Peru, and a majority in Mexico, said their questions were not always welcomed and their inquiries were often dismissed and discouraged by health care staff. There were instances when parents felt humiliated when asking a question. When this happened, they did not cease, but the violent interaction with the health care member diminished the parents' trust. Andrea, a middle-class, educated woman and mother of Daniel, who survived leukemia, explained:

The way they [health care staff] treat you here, they humiliate you and the more they do that the less you trust them....Still I always asked questions, some of them [health care staff] were very good, some were very cruel but [in general] they did not answer. They think they have the authority to do so and you feel helpless. If I asked something to the [Daniel's] doctor out of the consultation time, he

would turn around as if he didn't know me. (September, 2019).

Andrea described continuing to question her son's doctors despite her lack of trust, and her agency was visible in this pursuit. Alex, a hardworking man and father of Carlos (who survived leukemia), also asked questions. Sometimes he got answers, but sometimes he was silenced and dismissed. Dismissals did not prevent him from asking questions and thus expressing his agency to fully engage in his child's treatment:

I always asked questions, and doctors would explain [referring to procedures]. But there were other doctors that replied "If you don't know, do not ask" [and I would say] "well, precisely because of that is that I'm asking. Because I don't know and I need to know." (February 2019).

**No desire to ask questions.** A few parents stated that their main intention was not to ask questions but to follow the doctors' orders unquestioningly. Here, parental agency was expressed by total adherence to physician instructions. Angela, a single mother of five, fully engaged in her youngest son's leukemia treatment (she quit her job and relied on her mother's support and meager income), said:

I never asked questions to the doctors. Even if they asked me if I had any. I never had the need to, I knew exactly what I had to do. I did all that was in my power to keep my son healthy and I followed the doctors' orders to the letter. (February 2019).

Patricia, a mother of four, and her son Hugo moved to the capital city and rented a tiny room close by the hospital where Hugo received treatment of leukemia. Her other children and her husband stayed home, 8 hours away. Her

agency was expressed in her willingness to separate from her family during the 30 months of treatment. Patricia explained:

During consultations the doctors would say “madam, this is so and so” and I accepted, just like that. I didn’t ask too many questions...I would say that doctors know what they are doing and I trust them. (February 2019).

## DISCUSSION

Health care treatment engagement has been acknowledged as important for positive outcomes; however, engagement takes various forms that correspond to specific sociocultural contexts. Research on engagement in HICs is generally characterized by caregiver participation in childhood cancer treatment decision-making and autonomy,<sup>17</sup> although this is not universal, even across HICs.<sup>18</sup> There are contexts wherein health care professionals do not always value or encourage autonomy (eg, Mexico).<sup>19</sup> However, we argue the apparent lack of HIC forms of parental engagement in Latin America does not indicate a lack of engagement overall but supposes alternative forms of engagement made possible through parental agency to negotiate rigid health care hierarchies.

Latin America is marked by long-lasting inequalities maintaining hierarchical relationships between privileged and underprivileged populations, and these relationships shape medical encounters<sup>9,20</sup> and hinder engagement described in HIC literature. Otalora et al<sup>21</sup> stated about Latin America: “vulnerable consumers often lack control and agency in healthcare, especially because of their lack of expertise in relation to service providers and the vast disparities in socio-economic standards” [translated].<sup>21(p168)</sup>

Despite their low standing in the health care system hierarchy, most parents in this study expressed agency by asking questions and learning about their child’s disease, thus actively incorporating new terminology and knowledge. In Venezuela, Chacín and Chacín highlighted, “being informed allows parents to face the obstacles that come their way and in general to take care of the aspects that may interfere with the healing of their child [with cancer]” [translated].<sup>22(p207)</sup> This is reflected in the parental agency and engagement we found across three Latin American settings.

Several parents in this study described positive communication with their child’s health care team. Brage, in Argentina, described a mother of a newly diagnosed child who mentioned that the doctor actually solicited her questions. “The word leukemia...like we never heard it, we didn’t understand anything....‘I’m going to search the internet,’ I told the doctor. ‘No, ask us,’ he says” [translated].<sup>9(p100)</sup>

Unfortunately, some respondents did not always find room for asking questions, and parents mentioned that their questions were often unwelcomed. The higher frequency of

this finding in Mexico may have been related to in-depth interviews being conducted outside the hospital setting. Perhaps these parents were more comfortable sharing negative communication experiences. Although health care staff dismissals did not stop their need for answers, the parents often felt mistreated. Such episodes left bitter and deeply painful memories about their treatment experience, even when their children survived cancer. González-Salazar, in Colombia, noted parents of children with cancer develop “capacities (strategies and resources)...to meet the demands and tensions of these health-disease processes, to the management of confrontations in the relationships both within the family and with the health system.”<sup>23(p86)</sup> Thus, parents manage difficulties and overcome obstacles in communication, revealing their agency.

Difficulties establishing effective communication with health care staff and parents with unmet informational needs have been documented for families of children with cancer in South Africa, Kenya, Turkey, and Indonesia.<sup>24-27</sup> The acute and potentially life-threatening patient circumstances during complex treatment, severely limited resources, and few pediatric oncology health care providers (overburdened by a lack of support personnel and services) should be considered additional barriers to meaningful communication. Morrison et al<sup>28</sup> in the United States, stated that uncertainty and parental need for comprehensible and trustworthy information about childhood cancer is a phenomenon extending across geographies, including HICs.

We suggest that parent agency in this study becomes and enables engagement in their child’s treatment. Some Latin American parents actively searched for information even if they did not have the required medical literacy for effective communication, and they did not stop asking questions even if dismissed by health care staff. Other parents’ agency allowed them to engage by adjusting to their child’s situation and treatment requirements by closely following the doctors’ instructions without question. Not asking questions may also serve these parents, by enabling them to avoid hearing difficult information about their child’s condition, thus exacerbating existing anxiety about potentially losing their child.

Latin American parental agency and engagement should be recognized and welcomed by health care teams. Our findings acknowledge parents’ actions as active engagement through agency. This could be more effectively exploited by health care teams if they were to create a more robust relationship with positive communication. Recognition of parents’ significant sacrifices to adhere to complex demands as treatment engagement may positively affect the children’s (and family’s) quality of life, treatment experience, and posttreatment circumstances.

There are some limitations to and strengths of this study. This qualitative exploration identifies common experiences of agency as engagement of Latin American parents of children with cancer during treatment. The findings are not generalizable across the specific countries or Latin America; however, having participants from three countries with similar experiences is a strength. Interview location and recruitment strategies may have influenced the data, because of associations with physicians or being at the hospital facility.

In conclusion, given the dramatic difference in childhood cancer survival rates between HICs and low-income countries (> 70%),<sup>29</sup> parent engagement is critical for successful outcomes, quality of care, and managing risk of treatment abandonment. Although parent practices reported here do not always match engagement in childhood cancer treatment as conceptualized in HICs, we maintain that Latin American expressions of parental agency constitute legitimate forms of engagement. In contexts of structural inequality, such as Latin America, long-established sociocultural attitudes maintain a rigid hierarchical relationship between patients and their families and health care staff, and open communication is not standard practice in medical encounters. Thus, information needs are not always met and parents of children with cancer must

use their agency to pursue answers; we consider this engagement.

Latin American parents and children with cancer sustain a lengthy commitment to treatment in a context of significant poverty, low education levels, and extremely complex biomedical therapy, as documented across the region. Despite their situation, parents continued questioning health care professionals even when provoking negative reactions, although some had no questions but made a great effort to adhere to all treatment requirements despite seriously challenging circumstances. Our findings reveal Latin American parental agency and illustrate significant engagement, even if it does not always resemble parent engagement in HICs.

We acknowledge that in Latin American health care systems struggle to address public health in general (and provide complex biomedical cancer treatment), malnutrition, minimal or inconsistent supportive care availability (eg, blood products), treatment abandonment, use of traditional medicine, and weak or missing palliative and survivor care, which impacts families seeking care for their child.<sup>1</sup> This study's finding is the evidence of parental engagement and agency as key to treatment experiences, which deserves acknowledgment.

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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