



# Barriers and facilitators of Hispanic/Latino parents caregiving for a childhood cancer survivor: a qualitative study

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## Abstract

**Purpose** This qualitative study aimed to explore Hispanic parents of childhood cancer survivors (CCS) perceptions of facilitators and barriers to their caregiving experience.

**Methods** We conducted semi-structured phone interviews with 15 Hispanic/Latino parents (English and Spanish). Parents were recruited using a purposive sampling method in a safety-net hospital in Los Angeles County from July–September 2020. Interviews were audio-recorded, professionally transcribed, and analyzed in the language they were conducted. Two coders independently coded interviews following reflexive thematic analysis and elements of grounded theory methodology.

**Results** Most caregivers were mothers caring for leukemia CCS who had finished treatment more than 2 years prior. Caregivers expressed gratitude to social workers for introducing and aiding with the application process for safety-net programs that enabled caregivers to focus on their child's care and well-being. Caregivers revealed the importance of supportive communication with the medical team, particularly after their child's treatment was considered complete. All caregivers found caring for a child with cancer overwhelming, and many described deteriorations in their health and well-being. Financial instability, transportation difficulties, and work disruptions were identified as barriers, resulting in caregiver distress. Caregivers also shared the challenges they experienced navigating the healthcare system, seeking care despite lack of legal residency, and staying afloat despite limited employment opportunities.

**Conclusion** Improving navigation to resources and improving relationships with the medical team may reduce the perceived caregiving burden among Hispanic/Latino caregivers throughout their family's cancer journey.

**Keywords** Caregivers · Childhood cancer survivors · Barriers · Facilitators · Hispanic

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## Introduction

In the United States, parents and childhood cancer survivors (CCS) with lower socioeconomic and education levels and lack of health insurance have a greater risk of experiencing social inequalities along the childhood cancer continuum [1]. From diagnosis through therapy, parents of CCS experience a significant financial burden due to direct (e.g., medical and non-medical expenses) and indirect costs (e.g., loss of income) [2]. Years after treatment, parents of CCS have a higher risk for poverty [3] and experience financial toxicity due to their child's cancer diagnosis [4]. Moreover, long-term survivors of childhood cancer experience increased risk for adverse socioeconomic outcomes, including lower educational attainment, higher rates of unemployment, and annual productivity loss compared to individuals without a history of cancer

[1, 5, 6]. Thus, parents and CCS are more likely to face challenges with the management of cancer.

Patient and caregiver needs are not adequately addressed during the transition from therapy to survivorship care, particularly in patients from culturally and medically underserved backgrounds [7–9]. Hispanic/Latino parents and CCS are more likely to report health disparities due to social and structural determinants of health (SDOH) such as individual and family level socioeconomic status, underinsurance, immigration status, and perceived ethnic/racial discrimination [10, 11]. Additionally, in the broader survivorship research, Hispanics/Latinos have a greater prevalence of unmet supportive care needs and limited access to information [12, 13]. Specific to the Hispanic/Latino immigrant experience, immigration legislation act as an additional barrier in navigating the healthcare system and worsen quality of life [13].

Safety-net clinics are frequented by low-income, uninsured, or Medicaid recipients considered vulnerable populations [14]. Given the intersecting complexities of the safety-net setting, we partnered with a pediatric hematology-oncology clinic that serves a primarily Hispanic/Latino, recently immigrated, Spanish-speaking, and Medicaid population to conduct a qualitative study. This study aimed to understand the experiences of Hispanic/Latino caregivers of CCS during and after their child's cancer treatment. Specifically, we examined parents' perceptions of factors that are facilitators or barriers to their caregiving experience.

## Methods

We conducted semi-structured in-depth interviews with Hispanic/Latino parents caring for their child diagnosed with cancer. This study was approved as exempt by the University of Southern California's Institutional Review Board (IRB).

### Interview guide

An interview guide was designed as part of our study protocol to address the study's research question about key components and characteristics of the caregiving experience, based on literature review. The list of guiding questions was open-ended and explored four key areas (see Supplemental File 1). Relevant to this study, the interview guide questions included: "what are some things that make it easier for you to take care of your child's health?" and "what are some things that make it harder for you to take care of your child's health?" In addition, probes were used to clarify, expand, and understand participant responses.

## Recruitment

Participants were recruited using a purposive sampling method from July to September 2020. To be eligible, participants had to be: a parent or family member who has acted as a primary caregiver for a pediatric cancer patient who was in remission; the primary caregiver or child self-identified as Hispanic/Latino; and proficient in English or Spanish.

Eligible caregivers of pediatric cancer patients were recruited from a large public safety-net hospital (LAC + USC Medical Center in Los Angeles, CA). Participants were identified based on the inclusion criteria by an oncologist (R.C.) at LAC + USC. We anticipated fifteen parents/caregivers would be an acceptable sample size given homogenous participants and continuously recruited until the interviewer (C.O.) determined that the data were adequate to address the study's research question (e.g., that we reached thematic saturation) [15, 16].

## Procedures

### Data collection

After identification, participants were approached in person during their clinical visits or contacted via phone. They were given flyers and a study information sheet in their language preference (i.e., English or Spanish). If participants expressed interest in the study, R.C. contacted C.O. to connect the two over the phone. During the initial phone meeting, C.O. would discuss the purpose of the study and schedule the participant for an interview. Twenty parents were successfully reached, and all expressed initial interest and were scheduled to be interviewed over the telephone at an arranged time. Among those twenty parents, C.O. was unable to complete interviews with five parents as they did not respond after initial scheduling despite being called up to 3 times.

Prior to the data collection, the interview guide was piloted with two Hispanic/Latino parents (one Spanish and one English speaking) and adjusted as necessary. All interviewees received explanation of the study's purpose and interview procedure prior to giving verbal informed consent. Interviews were conducted from July to September 2020. Due to the COVID-19 pandemic and stay-at-home advisory in California, interviews were conducted exclusively by phone to ensure patient safety and comply with institutional mandates. The interviews were recorded using a digital audio device and transcribed by a bilingual professional transcription service. Interviews lasted approximately 60 min and included a short socio-demographic

survey administered after the interview which included self-reporting CCS age at diagnosis, current age, cancer type, etc. (see Supplemental File 2). Participants were mailed a \$25 gift card at the conclusion of the interview. Field notes were taken during the interview, and the interviewer wrote case summaries after each interview that described the general impressions and initial ideas related to the research question. All interviews were conducted in English or Spanish based on the participant's language preference by C.O., a bilingual Hispanic/Latina PhD student in health behavior research with training in qualitative research methods.

## Data analysis

Interviews were transcribed and analyzed in the language in which they were conducted. The transcribed data were checked for accuracy by randomly selecting files to review against the audio file. Reflexive thematic analysis as described by Braun and Clarke was employed in data analysis [17]. Additionally, elements of grounded theory methodology were used to identify processes occurring in the data and memo-writing strategies [18].

First, C.O. and a resident physician (L.C.), the two bilingual coders, read through all interview transcripts to understand the caregivers' stories and overall data patterns. Second, open coding of the data were done inductively and independently by the two coders trained in qualitative data analysis. Identifying codes was done semantically, meaning the coders searched for explicitly stated ideas, concepts, meanings, and experiences. After codes were generated and organized into an initial codebook, the two researchers met with other team members (R.C. and K.M.). Five meetings occurred where an external qualitative consultant guided the process. These meetings were an iterative process where the research team discussed and compared the coding scheme and how to proceed with clustering the codes to develop initial themes. Gerunds supplemented these preliminary inductive codes to denote observable and conceptual actions in the data [18]. A codebook was created after the research team agreed on the themes and subthemes.

Transcripts were uploaded into Dedoose, a qualitative data analysis software program, to organize data and apply final codes. During this step, the interviews were reanalyzed using the final codebook to facilitate the consistent application of the themes. Analytical memos were also written to document thinking processes and connections within the data [18]. A final set of themes and subthemes were defined, and salient quotes were extracted. If the selected quote was in Spanish, it was translated into English by a bilingual team member; the English quote was then presented in the results. The Spanish version was included as a Supplemental Table to authentically present the participant's words (see

Supplemental File 3). The Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist was used to ensure the study's rigor (see Supplemental File 4) [19].

## Results

Participants' characteristics are shown in Table 1. Caregivers who participated in this study predominantly cared for CCS with leukemia (67%) who had finished treatment more than 2 years ago (60%). They were mainly foreign-born (67%), Spanish-speaking (67%), mothers (93%), and between 23 and 58 years old. The majority of participants had less than a high school education, a household income < \$40,000, and public health insurance. Overarching themes of facilitators and barriers to parents' caregiving for childhood cancer survivors are provided in Table 2.

### Factors that are facilitators

#### Role of family dynamics

Caregivers expressed gratitude for their flexibility and fluidity in family roles that eased the balancing of direct caregiving and other obligations. In one common example, the caregiver's oldest child (often a daughter) would provide childcare support, allowing one parent to provide direct care to the CCS and the second parent to work for income. Another caregiver (a single parent) shared that her other (non-sick) children moved in with their grandparents while the CCS (leukemia at 4-year-old) was in treatment because she needed to dedicate all her time to her cancer-affected child.

A few caregivers expressed that formalizing caregiving roles and responsibilities for CCS was important. Both divorced and married parents expressed that alternating and/or dividing caregiving responsibilities improved parental communication, and both parents developed familiarity with the child's medical care. Additionally, duty alternation provided respite care for the primary caregiver.

#### Navigating financial resources

Faced with financial hardship at diagnosis, caregivers described the hospital functioning as a connector to support services. The hospital's staff would introduce caregivers to safety-net programs such as transportation and food services, social security and disability benefits, and financial and housing assistance. Additionally, the hospital's social worker-assisted caregivers in tackling application complexity, stringent documentation requirements, and language barriers.

**Table 1** Participant characteristics ( $n = 15$ )

Demographic characteristics	<i>n</i> (%)
Parent	
Language	
Spanish	10 (66.7%)
English	5 (33.3%)
Gender	
Male	1 (6.7%)
Female	14 (93.3%)
Age in years, range	39 (range: 23–58)
Marital status	
Single	2 (13.3%)
Married/Living with partner as married	10 (66.6%)
Divorced/Separated	3 (20%)
Highest education level	
< Highschool	9 (60%)
Highschool/GED	3 (20%)
Some college/vocational training	3 (20%)
Household income	
< 20,000	5 (33.3%)
20,000–39,999	5 (33.3%)
40,000–59,999	3 (20%)
60,000–79,999	2 (13.3%)
Birthplace	
U.S. born	4 (27%)
Foreign-born	11 (73%)
Household composition	Range: 5–9
Type of health insurance	
Public	8 (53.3%)
Employment (private)	2 (13.3%)
None	5 (33.3%)
Childhood cancer survivor	
Cancer type <sup>a</sup>	
leukemia	10 (66.7%)
Hodgkin lymphoma	2 (13.3%)
Other <sup>b</sup>	3 (20%)
Age at time of diagnosis	Range: 1–14 years
Current age	Range: 5–22 years
Gender	
Male	9 (60%)
Female	6 (40%)
Length of time finished treatment	
< 1 year	4 (26.7%)
1–2 years	2 (13.3%)
2+ years	9 (60%)

<sup>a</sup>CCS cancer type is self-reported by caregivers

<sup>b</sup>Other-type of cancers consist of sarcoma, ovarian, and unknown (parent unable to recall type of cancer)

**Table 2** Major themes of barriers and facilitators of parents caregiving for childhood cancer survivor

Barriers
Magnitude of caregiving responsibilities
Encountering financial hardships
Illness misconceptions
Immigration and citizenship status
Facilitators
Role of family dynamics
Navigating financial resources
Relationship with God
Relationship with medical care team

Caregivers perceived these programs/benefits as a way to gain or maintain financial stability, despite suffering financial deprivation, allowing them to focus on their child's care and well-being. Some parents described how these financial resources helped them stabilize their living situation.

“[They] helped us [get] a place to stay, provided us with mattresses and many things necessary to start living there... And then, little by little, we were able to get ahead. By the time...[my husband] was able to work... we [became] more stable.” (Mother, Spanish-speaking, 36 years, leukemia at 11-years-old)

Not all families received enough assistance to thrive; one caregiver described these financial resources as allowing for mere “survival”. Another caregiver, a single parent, shared that the only way he could provide for his children during cancer therapy was to receive social security benefits.

### Relationship with the medical team

Caregivers indicated that supportive communication (both verbal and nonverbal) from and trust in their child's care team was essential both during and after cancer therapy. Caregivers found effective and compassionate delivery of information (e.g., sharing diagnosis news, answering parent doubts and questions) to be a source of support. For example, one Spanish-speaking caregiver appreciated that the doctor told the parents first about the diagnosis and then checked how they wanted to proceed with sharing the news with the patient (Hodgkin lymphoma at 9 years old).

It was imperative that the medical team regularly conveyed information to the patient and caregivers and assessed understanding regarding details of both cancer treatment and post-cancer-treatment side effects. Caregivers described how their child's physician showed concern, empathy, respect, and sensitivity by being attentive to both patient and caregiver needs. In one example of a CCS, who was diagnosed with anxiety after completion of chemotherapy, the care team routinely called to check in on the family.

Trust in the inpatient care team (e.g., doctors and nurses) to guide cancer management facilitated care discussions and improved shared decision-making. Most caregivers described a process of developing trust through repeated positive interactions where availability, responsiveness, and attentiveness were shown. A thirty-year-old English-speaking caregiver said: “They always kept us positive [and] motivated. The nurses [provided] great service.” (leukemia at 1 year old). Another caregiver shared:

“Throughout the whole month, they made me feel [as if my child was] the only patient there.” (Mother, English-speaking, 35 years, leukemia at 5-years-old)

Parents also reported the importance of “care continuity” and how it led to comfort within the hospital, making it “a second home”. One caregiver recounted why the hospital felt like a second home:

“I felt [that the] nurses and all of them [were] like my second family.” (Mother, Spanish-speaking, 48 years, leukemia at 14-years-old)

### Relationship with God or their ‘Creator’

Most caregivers described the importance of having a relationship with God or their ‘Creator’ regardless of whether they practiced a religion. During the treatment period, caregivers believed their child would be cured because God had given doctors “science to care for cancer.” A 48-year-old Spanish-speaking caregiver (other-type of cancer at 3-year-old) mentioned that she relinquished control because she trusted God would “put it in the best hands of the doctors... and that he reaches the hands of everything they did.” After treatment (leukemia at 14-year-old), a 41-year-old Spanish-speaking caregiver identified that God was her “insurance” and described that she managed her fear that her child’s cancer would return with her belief that “he is the one who covers [her] for everything and protects [her] from everything”.

Their relationship with God was also a source of emotional strength. Caregivers emphasized that their faith in God gave them “all the strength, the security, and support [they needed]”. One participant described how through her relationship with God, she discovered the strength she needed to provide care for her child without becoming overwhelmed. A 48-year-old Spanish-speaking participant (leukemia at 14-year-old) explained that cancer therapy was a “difficult process, but [God] gave [them] the strength to overcome it.”

Caregivers described the effect of receiving a cancer diagnosis on their religiosity and the consistency of their practice. They described how God held them together [“el me sostuvo”]. A 43-year-old Spanish-speaking caregiver recalled, “...now that my son got sick, every day, I started to pray, to thank God for one more day of life.” Overall,

caregivers found their religious practice to be an effective coping mechanism.

“I started to pray and ask God to be calm.... [I read] many prayers from the Catholic Church.... [I read] some prayers to sleep, so that I can rest.” (Mother, Spanish-speaking, 43 years, Hodgkin lymphoma at 14-years-old)

“Because I was pregnant, I did not eat, I did not sleep, and...He always kept me well. [He] kept my pregnancy well.” (Mother, Spanish-speaking, 41 years, leukemia at 14-years-old)

### Factors that are barriers

#### Magnitude of caregiving responsibilities

All parents expressed how caregiving resulted in fatigue and feelings of caregiving hopelessness. Frequent doctor visits, complex medication regimens, and prolonged hospitalization stays all complicated caregiving. Hospital stays were especially challenging for those with other children at home to care for, as caregivers found themselves torn between being at the hospital with the patient or at home with other children. Caregivers also described fear of their immunocompromised child interacting with others:

“You don’t want to isolate him...but unfortunately, that’s how it has to be for him to get better”. (Mother, English-speaking, 35 years, leukemia at 4-years-old)

Caregivers highlighted the difficulties of balancing caring for themselves and the patient. In one extreme example, one caregiver had two strokes during her child’s therapy but could not stop caregiving. Minimal sleep, interrupted rest in the hospital, and mental/emotional challenges contributed to caregiver burnout, and illness. Caregivers found little time for self-care. Caregivers expressed struggles with a perceived necessity to conceal distressing emotions from their children. Even with access to supportive resources, caregivers describe struggles with burnout:

“[Nobody] understood what [I] needed, or... [that I] needed that time just to sit there and eat a full meal comfortably [emotional], just not worrying about anything. Or being able just to be, just to have a breather, a day where you don’t have to worry about anything. A lot of people don’t have that. And it was really, really, really hard.” (Mother, English-speaking, 30 years, leukemia at 1-year-old)

Even after completion of cancer therapy, caregivers experience flashback emotions in triggering environments. A 41-year-old Spanish-speaking caregiver described her unprocessed emotional traumas and a persisting fear of

losing her child to a cancer relapse and that she is afraid to “put [her] guard down.”

Most caregivers described helplessness regarding both the ability to provide support and a sense of control over outcomes. Caregivers witnessed uncontrolled pain as well as substantial deterioration in physical health and behaviors (e.g., weight loss, insomnia, and food intake). They struggled to provide help with limited knowledge leading to a sense of helplessness. Emotionally they also struggled but expressed that they would pretend to be “strong” while constantly giving positive encouragement to the patient and siblings. However, caregivers sometimes also recalled times that they would not know how to provide reassurance.

Caregivers indicated that CCS psychological health (e.g., emotional, mental, and behavioral) impacted their own well-being. Caregivers reported CCS mood swings and resistant attitudes, which caregivers attributed to medication side effects. One caregiver mentioned that during these mood swings, her child would become angry at her or get extremely depressed. Another caregiver shared how her child would blame her for events out of her control, placing a strain on their relationship. Unpredictable emotions compounded with a lack of knowledge of methods to effectively provide discipline in the setting of a chronic illness resulted in caregiver frustration and despair.

“She thought [I] was a bad mom...Because every time they would do something to her [like] biopsies, I was there with her... I don’t think she understood what was going on at that age.” (Mother, English-speaking, 32 years, leukemia at 3-years-old)

Caregivers also described situations in which CCS mood disorders (e.g., depression, anxiety) arose during and after treatment and were often associated with necessary anti-cancer medications and/or due to the stress of therapy. One patient developed psychosis or delusions (e.g., schizophrenia spectrum disorders), which often impact caregivers’ perceptions of well-being and safety. For example, the caregiver shared that her child “heard voices” and would cry all the time:

“She [started] psychological treatment because it was already too much...In fact, one night she got up and the voices told her to kill us and things like that. It was already a danger.” (Mother, Spanish-speaking, 36 years, leukemia at 11-years-old)

### Encountering financial hardships

Financial instability, transportation difficulties, and work disruptions were all disclosed as barriers to caregiving. Caregivers had problems paying rent and bills, and they experienced hunger and food insecurity. Some described

having to sell or pawn possessions, and some experienced housing instability and/or homelessness. Several caregivers described the stress and challenges of living with an unstable income as their partners could only find work as day laborers [*“jornaleros”*].

Some (often single) caregivers described their struggle to provide income and full-time caregiving, forcing them to accept public financial assistance (e.g., Social Security benefits). Other caregivers struggled to provide for their families despite incomes that precluded qualification for public financial assistance. Among all caregivers, financial worries manifested as a strain on mental well-being, with fears of “living in the streets” resulting in anxiety and feelings of depression.

Caregivers struggled with work disruptions. From diagnosis, most caregivers had to miss work; others felt they had little choice but to stop working entirely to provide care, resulting in lost income and job insecurity. Caregivers shared how they would be fired and described difficulty in maintaining employment or finding a job that would not retaliate for missing work to provide care. For single parents, work disruptions were unavoidable, and married caregivers also experienced this form of financial stress.

“And my husband actually worked, but every time I called him, he [would go] to the hospital [for our child]. And well, he wasn’t working that day ... And [then] I said to him: ‘Where are we going to get money for rent? For the bills? ... Where are we going to get money from?’” (Mother, Spanish-speaking, 43 years, other-type of cancer at 4-years-old)

Transportation difficulties were a barrier to caregiving. Many families had access to a single car or no car, creating challenges to access treatment and post-treatment surveillance. Public transportation was stressful due to their child’s fragile health, especially when they needed to take multiple buses. Traveling long distances, paying for bus route transfers, and/or having to pay for multiple family members was a financial burden. Further, when caregivers were limited to one car, attending to the child’s medical care needs often meant missing or leaving work which resulted in financial stressors. Navigating both the transportation system and the complex urban topography was particularly challenging to recent immigrant families.

### Immigration and citizenship status

Some caregivers shared anxieties surrounding the lack of legal residency status. Caregivers reported that fear arising from their child’s cancer was compounded by the fear of deportation, particularly associated with the possibility of familial separation. Lack of legal residency status also limited employment opportunities, with available options

often lacking stability. One caregiver described that when she applied for social services, her mixed-status household and the nature of her husband's employment made it difficult and stressful:

“I went to take the application to get food stamps and they asked me for... verification of [the] work of the father of my daughters. He is a day laborer. He goes out [each day] to see if they give him a job. If he were lucky, he [would work that day] and if not, he comes back [home] ... so how do I do the verification?” (Mother, Spanish-speaking, 48 years, other-type of cancer at 3-years-old)

Caregivers also described that not having any extended family members in the United States limited the amount of familial support they could receive, and as a result, they often felt “alone.” More than one caregiver stated that “[I] did not have anyone [here]”. This was echoed by another caregiver who shared:

“I have acquaintances, but no direct family...Just friends.” (Mother, Spanish-speaking, 36 years, leukemia at 11-years-old)

### Illness misconceptions

Caregivers found that misconceptions about cancer were a common barrier to caregiving; public perception and attitude about the diagnosis often resulted in a negative cultural stigma. Religion was sometimes perceived as a negative force in the lives of caregivers; they described individuals that would constantly blame parents for the child's diagnosis using their religious beliefs as the justification. One parent recalled being told that their child's diagnosis was a punishment for the parent's sins and that they were “paying [their] dues.”

Additionally, caregivers reported hearing insensitive comments regarding the cancer diagnosis, and some thought these negative public perceptions and attitudes resulted from ignorance surrounding childhood cancer. Some caregivers received unqualified medical advice in the form of religious beliefs (e.g., advice to avoid medical treatment and/or to substitute religious practice for medical therapy). Caregivers also felt stigmatized for having a child with cancer and/or “rejected” (“rechazada”) by family/friends due to the delicacy of their child's health.

“People [don't] realize that little kids get [cancer] as well, not just older people”. (Mother, English-speaking, 30 years, leukemia at 1-years-old)

Caregivers also relayed accusatory stigma stemming from cultural beliefs that hindered relationships and how these

accusations would arise from a common harmful perception of the disease. More than one caregiver shared how family members would blame the child's cancer diagnosis on the caregiver and impacted familial relationships.

“Mexican people or Latin people think that you get sick because you don't take care of yourself... It's hard for people to accept that...something is just wrong naturally.” (Mother, English-speaking, 30 years, leukemia at 1-years-old)

### Discussion

This study captured the perspective of Hispanic/Latino parents of childhood cancer survivors on the facilitators and barriers to caregiving. Four themes emerged as facilitators to caregiving: (1) familial flexibility and fluid roles concerning caregiving; (2) external (often public) financial resources and assistance in navigating the application process; (3) caregivers' self-described “relationship with God”; and (4) a positive relationship with the medical care team. Additionally, caregivers revealed challenges/barriers to caregiving: (1) large burden and magnitude of caregiving responsibilities; (2) financial hardships; (3) illness misconceptions; and (4) uncertain immigration and citizenship status.

Our study provides insight into how for Hispanic/Latinos caregivers, the blend of financial and legal status barriers creates resource gaps and may adversely impact cancer care management [20]. Caregivers described difficulties balancing full-time caregiving with financially providing for their families. These findings are consistent with previous studies that have demonstrated that parents with household incomes < 200% Federal poverty level (FPL) are more likely to report financial hardships and income losses because of work disruptions compared to those in higher-income households [21]. Additionally, parents with income at < 200% FPL also disproportionately report higher distress and anxiety from financial burden [22]. Lack of legal residency or having a mixed-status household makes additional challenges such that multiple caregivers mentioned they lacked job security and employment benefits. Some parents said they did not have enough financial support despite qualifying for government assistance.

Conversely, we also found that financial resources and assistance helped make the cancer experience more manageable for Hispanic/Latino caregivers and CCS, especially for foreign-born and immigrant populations. Generally, Hispanics/Latinos have lower socioeconomic positions and education status than non-Hispanic white populations, impacting access to and quality of health care, such as receiving timely care, difficulties navigating the United States healthcare system, and unmet cancer

information and psychosocial needs [23–26]. While patient navigation has predominantly been described in improving cancer screening rates and adherence to follow-up care [25, 27], our study revealed the importance of patient navigation for successful application to safety-net programs. Caregivers universally expressed gratitude and appreciation for social workers that connected them to support services including transportation and food services, social security and disability benefits, and financial and housing assistance.

Caregivers in our study identified that their relationship with God was highly important for them throughout their child's cancer journey as a source of emotional strength and a coping mechanism to manage their fears of cancer and cancer recurrence. This aligns with prior literature showing that Hispanic/Latino adult cancer survivors and spousal caregivers consider religion both a source of support and endorse using religion or spiritual beliefs as an effective coping mechanism for psychological distress [25, 28]. As well as a previous review of Latino caregivers of children with illness or chronic conditions that highlights the role of religion and spirituality as a coping strategy [29]. Taken together, our findings suggest that supporting access to spiritual and religious networks may assist caregiving throughout the cancer continuum. However, we found some caregivers had negative experiences with religious people who blamed them for their child's cancer diagnosis, supporting the notion that negative religious beliefs adversely impact health behaviors and outcomes [30, 31]. These results suggests that the social environment of faith-based organizations or churches can be targeted to address cancer misinformation and stigma.

The unique role of *familism* in Hispanic/Latino culture is reflected in the desire and prioritization of extended family (and friends) to be actively involved with healthcare management. [32] Our results highlight the importance of providing educational/informational tools for parents to share with family and/or friends given studies indicate an overall lack of knowledge about the needs of cancer survivors and caregivers among Hispanics/Latinos [25, 28, 33]. Caregivers reported experiencing negative cancer stigma about their child's diagnosis, and distress over family and/or friends that did not know how to support them. Similar to previous findings, we found that cancer-related stigma contributed to parents' feelings of isolation from family and friends [34]. Resources and/or trainings to improve communication with extended family about child cancer diagnosis may ease caregiver stressors and feelings of social isolation. It may be possible that this unmet need could be addressed by social workers in the hospital/clinic setting as Hispanic/Latino parents and CCS are more likely to receive health information from hospital resources compared to non-Hispanic white populations [35, 36].

Additionally, our results draw attention to young caregivers as we found youth added unique challenges. Caregivers discussed the challenge of caring for both CCS and other children, as well as balancing caregiving with self-care. Young caregivers are at different developmental stages than older caregivers, often with other young children to care for and with a lack of personal resources (e.g., savings, benefits, etc.), which may increase caregiving difficulty [37]. Further, caregivers shared the need to conceal distressing emotions from their children due to their child's age both during the time of treatment and long after treatment completion, however, they were the ones that continued to experience flashback emotions in triggering environments. Younger age cancer caregivers tend to report poorer mental health outcomes than older caregivers, particularly those with higher caregiving intensity [38]. In fact, caregivers of children with disabilities are more likely to report a higher score of psychological distress than non-caregivers [39]. These findings emphasize the healthcare system's crucial role in supporting young caregivers, especially among underserved populations. One caveat of these results is the young age at which CCS were diagnosed (before 14 years); therefore, caregivers' needs may be compounded by both the child's young age and their own.

## Strengths and limitations

Strengths of the study include a focus on a sample of Hispanic/Latino caregivers and CCS within a safety-net setting, an understudied and at-risk population. The application of different data collection and analysis procedures to ensure the study's rigor, including memoing throughout data collection, analysis, and interpretation. Limitations of the study included recruitment from a single clinical site. Also, this study consisted primarily of mothers (but not exclusively) who cared for a child with leukemia, potentially underrepresenting fathers and children with other cancer types who may have different experiences. Additionally, since our demographic information was self-reported instead of gathered from patient medical records, we did not have detailed information such as leukemia subtypes, length of therapy, and the intensity of the therapy, which may have impacted caregivers' experience. However, leukemia is the most common childhood cancer, and mothers are frequently their children's primary caregivers. Additionally, the majority of Hispanic/Latino participants were of Mexican descent, and the experience of other Hispanic subgroups may differ, especially if parents were born in other countries. Finally, all interviews were conducted by phone due to the COVID-19 pandemic, potentially influencing what participants were comfortable sharing and limiting nonverbal communication. However, previous methodologic studies suggest that phone



interviews are beneficial and strengthen the effectiveness of qualitative data collection [40].

## Conclusion

These results provide greater insight and detail about the complexities and factors that impact cancer care management for highly underserved Hispanic/Latino caregivers. Importantly, the results indicate-specific resources and coping behaviors that facilitate caregiving. Our findings underscore the need to integrate a routine assessment of socioeconomic needs and the implementation of referral systems that incorporate patient navigators in clinical care practice for Hispanic/Latino families. Cancer care should provide supportive services for young and highly underserved Hispanic/Latino caregivers to help effectively address the burdens of caring for sick children and managing financial, familial, health, and well-being outcomes. Understanding the personal experiences of parent caregivers, an understudied population, is essential as their insights can lead to recommendations at various levels. Their message can influence the familial experience of other caregivers, local healthcare settings, or contribute to legislative efforts. Of particular importance is that these services be provided by bilingual healthcare providers that understand and are aware of local policies as they may hinder Hispanic/Latino families.

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**Data availability** Enquiries about data availability should be directed to the authors.

## Declarations

**Conflict of interest** The authors declare they have no relevant financial or non-financial interests to disclose.

**Ethical approval** All procedures performed in this study involving human participants were in accordance with ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approvals were obtained from the University of Southern California Institutional Review Board.

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