



# Stem Cell Transplant Experiences Among Hispanic/Latinx Patients: A Qualitative Analysis

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## Abstract

**Background** Hispanic/Latinx (H/L) patients with cancer treated with stem cell transplant are vulnerable to adverse outcomes, including higher mortality. This study explored their unmet transplant needs, barriers, and facilitators.

**Methods** Eighteen English- or Spanish-speaking H/L patients ( $M$  age = 59.2) who had a transplant in the past year were interviewed about their transplant experience and rated their interest in receiving information about transplant topics (0 = not at all to 10 = extremely).

**Results** Content analysis revealed five main themes: (1) pre-transplant barriers and concerns; (2) complex relationships with medical teams; (3) informational mismatch; (4) impacts on daily life after transplant; and (5) methods of coping. Participants were most interested in information about ways of coping with transplant ( $M=9.11$ ,  $SD=1.45$ ) and words of hope and encouragement ( $M=9.05$ ,  $SD=1.80$ ). At just above the scale's midpoint, they were least interested in information about side effects and unintended consequences of transplant ( $M=5.61$ ,  $SD=3.85$ ).

**Conclusions** Cultural factors, social determinants, and structural inequalities give rise to unique needs in this growing patient population. Healthcare team members and researchers can better meet the needs of H/L transplant recipients through attention to described considerations, such as financial barriers, communication difficulties, family dynamics, and coping styles.

**Keywords** Hispanic/Latinx · Stem cell transplant · Cancer disparities · Culturally informed interventions · Psychoeducational

## Introduction

Cancer is the leading cause of death for Hispanics/Latinx (H/L) in the USA [1]. Multifactorial social determinants of health models considering the intersection of socioeconomic, political, cultural, psychosocial, and medical factors

help to explain disparities seen in cancer outcomes for H/L patients [2]. For example, structural and sociopolitical forces have led to differential access to high-quality insurance which impacts screening opportunities and courses of treatment which in turn impact prognosis and treatment success [2]. H/L patients with cancer specifically have been identified as vulnerable to adverse cancer outcomes [3], and this vulnerability is reflected in disparities in the outcomes of H/L patients treated with hematopoietic stem cell transplant, including higher treatment-related mortality [4], lower 1-year and 3-year adjusted survival rates [5], and higher risk of treatment failure (death or relapse) [6], compared to non-H/L patients. The growing number of H/L patients undergoing transplant [7] for hematologic cancers and other diseases makes it increasingly urgent to gain a thorough understanding of the patient experience for H/L in order to provide optimal care.

Stem cell transplant, while often extremely effective and sometimes the only option for achieving remission

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[8–10], is a highly challenging cancer treatment that commonly includes high-dose chemotherapy and at times total body irradiation [11, 12]. The transplant regimen causes substantial physical symptoms and emotional reactions during treatment and in the early post-transplant period [13–15], when patients must be closely monitored for potentially life-threatening complications [16, 17]. A range of physical and psychological symptoms (e.g., pain, fatigue, distress) are commonly reported in the peri-transplant period and can persist for years post-transplant for many patients, impacting their quality of life and functioning [18–20]. Several studies have shown psychosocial factors to be predictive of survival in patients who have undergone transplant [21–23]. Efforts have been made to develop supportive interventions for patients undergoing transplant; however, no published interventions in transplant have included cultural and linguistic tailoring for H/L patients [24, 25].

Culturally tailored behavioral interventions have shown superior effects on health and well-being outcomes relative to standard treatment [26]. H/L patients with cancer have been shown to have worse distress and health-related quality of life compared to non-Hispanic Whites (NHWs) [27, 28]. Given the complexity of transplant treatment and recovery, as well as the central role that patients and their caregivers play in ensuring optimal transplant outcomes [29], developing supportive resources that are culturally tailored and accessible in English and Spanish is critical to providing quality comprehensive care to H/L patients. Key aspects of H/L culture such as *familism*, prioritization of family over self, and *simpatía*, the desire to avoid potentially conflictual social interactions, are not considered in interventions that are not tailored for this population, which can limit their effectiveness [30].

While there has been a call for increased cultural consideration in healthcare to improve patient experience and outcomes [31], little work has been done to explore the unique needs of H/L patients undergoing transplant. A review by Barata and colleagues reported that patients with hematologic malignancies experience significant unmet psychological, physical, informational, financial, and spiritual needs and that transplant is a risk factor for greater levels of unmet needs [32]. Similar qualitative work focused on H/L transplant recipients had yet to be conducted until the current study. To address unmet needs in this population, this study explored the lived experience of H/L transplant recipients, before, during, and after transplant. By using a qualitative study design, this study provides valuable nuanced insight into the specific needs and concerns of H/L transplant patients, filling the existing knowledge gap and guiding future development of culturally informed interventions.

## Methods

### Study Design

To identify unmet needs and challenges faced by H/L patients when undergoing transplant, authors developed a semi-structured interview guide based on prior research and themes from a related study's patient narratives [2, 30, 33, 34]. Open-ended questions focused on participants' concerns about undergoing transplant, information received about transplant, resources needed or wanted throughout the transplant and recovery process, and how the transplant influenced their daily lives and family dynamics. This study was approved by the IRBs of Georgetown University and Northwestern University.

### Recruitment

Potential participants who identified as H/L and had completed transplant in the past 12 months were identified through physician referral from three study sites: Northwestern Medical Center, Hackensack Meridian Health, and Georgetown Lombardi Comprehensive Cancer Center. Potential participants were mailed a study description and consent. Study staff called participants to verify eligibility, answer any questions, and see if they wanted to participate. All study materials were in English and Spanish.

### Procedures

A single interviewer, a bilingual research coordinator trained in qualitative interviewing, conducted semi-structured interviews via telephone from February to July 2021. The interview also included one quantitative question, "How much would you want to learn about each of these things right now on a scale of zero (not at all) to ten (extremely)," listing types of information about transplant. All patients were outpatient at the time of interview. Participants could complete the study in English or Spanish and were offered \$100 compensation. Interviews lasted 50 min on average, were audio-recorded, and were translated and transcribed for analysis. Translation was conducted by an IRB-certified vendor, GMR Transcription, which has a 99% accuracy guarantee, and translations were verified for accuracy by bilingual study staff.

### Analysis

A minimum of two authors read each transcript, and six authors met to develop a codebook based on topics related to interview questions as well as themes that emerged from reading transcripts. The majority of authors on the codebook team had doctoral degrees in psychology or sociology

and extensive experience in psycho-oncology intervention development, minority health, and qualitative research. Using conventional content analysis [35], one team member coded all the transcripts using MaxQDA qualitative software. An iterative process of coding was used such that any new themes that emerged after coding began were added to the codebook, and all transcripts were then re-coded for inclusion of any new thematic content. All coded transcripts were reviewed by a second coder and discussed again with the primary coder to establish consensus coding. No new themes emerged after coding 14 out of the 18 interviews, suggesting thematic saturation and signaling the end of recruitment. After consensus coding, the larger study team identified the main findings.

## Results

Table 1 reports characteristics of the 18 participants. Analysis revealed five main themes: (1) pre-transplant barriers and concerns; (2) complex relationships with medical teams; (3) informational mismatch; (4) impacts on daily life after

transplant; and (5) methods of coping. Representative quotes are provided illustrating each theme. Additional quotes can be found in Table 2.

### Pre-transplant Barriers and Concerns

#### Financial and Logistic Barriers

The burdens of high medical costs were exacerbated by some participants' inability to work. While insurance coverage helped eliminate financial worries for some, others lacked coverage or were underinsured. As one participant (07802) said, "What worries me most is how to pay because I know that insurance does not cover everything. I worry a lot. I can say that even my sleep has been ruined because I think about how to pay the debts I have for the treatments... I don't want to die, like everyone else, right? Nobody wants to die."

The logistics of getting a transplant, such as the need to travel for long periods of time, was a source of "tremendous stress" (03400) and costly. And as one participant noted, insurance "doesn't cover the hotel" (18101). Some

**Table 1** Demographic characteristics of participants ( $N=18$ )

Variable		Frequency	Percentage
Gender	Male	5	27.8
	Female	13	72.2
Age	40–49	5	27.8
	50–59	3	16.7
	60–69	6	33.3
	70–79	4	22.2
Ethnicity	Hispanic or Latinx	18	100
Household income	Less than \$20,000	5	27.8
	Between \$20,000 and \$40,000	3	16.7
	Between \$40,000 and \$60,000	4	22.2
	Between \$80,000 and \$100,000	1	5.6
	Over \$140,000	2	11.1
	Prefer not to answer	3	16.7
Education	No high school diploma	5	27.8
	High school graduate or GED	6	33.3
	Some college but no degree	1	5.6
	Occupational, technical, or vocational program	1	5.6
	4-year college degree	3	16.7
	Graduate degree	2	11.1
Marital status	Single or never married	5	27.8
	Separated	1	5.6
	Married	12	66.7
Language	English	7	38.9
	Spanish	11	61.1
Transplant type	Autogenic	14	82.4
	Allogeneic	3	17.6

**Table 2** Additional illustrative quotes

Theme	Domains	Quote
Pre-transplant barriers and concerns	Financial and logistic barriers	The latest treatment was very expensive. Talk about a ton of money there. How we will pay... The hospital, they provided different social workers, different avenues... That gave us a little light, that we can afford it. Because sometimes it's like, 'I can't afford it, so I may have to just do nothing.' (01102)
	Procedure concerns	The only thing that affected me was that I thought the transplant would be painful. I didn't know what it was about. I was afraid that the treatment would be done on my spine. (04410)
	Familial concerns	I'm a mother... I'm like, thinking what's gonna happen to them [my children] even though they're adults, but I'm still their mother. (13805)
Complex relationships with medical teams	Trust in medical team	We were in such a great hospital... They are so renowned that I didn't worry about any of the risks or anything. We found out about the treatment, and we wanted to do it right away. (10811)
	Trust in medical team	It was a bit difficult [before the transplant] because, well, they [the medical team] explained the benefits and the cons. So, we were quite scared, but with tranquility, calmness, and ... a lot of faith in God and trust in the doctors, well I think that's what helped me a lot. (15414)
	Language barriers	I don't speak English. Sometimes that's why you refrain from talking or asking questions. You can't explain to them what you feel... (04410)
	Medical literacy barriers	The language affected my relationship with the oncologist because although I speak a good bit of English, there are many terms or words that professionals use, and we older people have a hard time with... I wouldn't say it affected me 100 percent. I would say maybe 25 percent. (07802)
Informational mismatch	Both too much and too little information	It's a lot of information. When you start, there is a lot of paper to read, and in those moments, you do not want to read. I mean, the doctors explained to me in the appointments, but they did not explain to me the whole process of the transplant, so I had many doubts in my head. There was a lack of communication, they gave me more information, and they gave it in Spanish because the transplant is a treatment that you need to know well, how it is, what comes after that. The most difficult thing is not the transplant, but what comes after, and when they are medical terms, it is very difficult to understand... For example, they didn't tell me that I wasn't going to drive, the doctor told me that now; they didn't tell me that I had to stay 100 days and after that, they would give me the vaccinations. Everything is in the papers they gave me, but as I told you, it is so much information on paper that you can't concentrate to read so much... (09818)
	Need for more information	I think it would have been good if they had told me from the beginning what the treatment was going to be about so that I would have wanted to do it. I was afraid of feeling a lot of pain because one does not know what the treatment consists of. As I told you, I thought it was in the spine because they talked about the bone marrow cells, so that was my fear; I did not know if the bone marrow was different from the stem cells. (04110)
	Need for more information	When I had the transplant, all the values were going down and as I have knowledge of laboratories, I was worried; why is everything going down?... I asked the doctor... She told me that that was the way it was, that everything was going zero, after the transplant, everything was going to go up, it is normal. She explained it to me. When I saw that all my body values were going down, I thought I was dying, and they didn't want to tell me. (07802)
Impacts on daily life	Mental and emotional health	I didn't really expect to feel emotional... But the reality is that when you feel at your most vulnerable physically, you can be that way mentally too. (06401)
	Mental and emotional health	It's a change complete. I don't wanna go to stores. I got into a big depression, let's put it that way. (13850)
	Mental and emotional health	[I] changed mentally, emotionally... I'm not the same... You're going down the stairs, and you're scared you might fall, and your life would be over. (13850)
	Family dynamics	I'm doing well at home. My husband is taking care of me. I mean, my husband stopped working for a few months as well to take care of me because he didn't want me to stay home alone. So, I feel very supported. He's always here for me. He pays attention to what happens to me and what I do. (17820)

**Table 2** (continued)

Theme	Domains	Quote
	Family dynamics	I was a very independent person... And now with this illness, just imagine. Sometimes the doctor tells me, 'You're going to need someone who can offer you a glass of water.' (11816)
Methods of coping	Social support	My children, my family, everyone, everyone. Although they may not be here, their calls to give me strength, to give me encouragement... We are only ten siblings. That is all... but we never feel isolated from each other even though we live in different places. That has a lot of influence on the atmosphere, on the emotional state in people's minds... So, communication is very important to me. (08804)
	Religious beliefs	I [had] my stem cells blessed, and I think that was very important... The pastor or minister came in, ... and I had written down all of the affirmations so that I could read them on my own. And she took those affirmations and went away, and she wrote a prayer based on my affirmations. (03400)
	Religious beliefs	The most important thing for me is to ask our Lord for strength to be able to endure and bear whatever comes because when you are going to go through that, you don't know what changes there will be in you, what you are going to feel. So, just entrust yourself to God, he is the only one who is in control of the life of us humans. As I told you, I feared to die, then I did not think about that anymore, I only thought about getting cured and that everything would be all right. (04410)
	Positivity	I was concerned about my physical and emotional change. He [my doctor] told me how the next stages could help me. He always told me, 'Changes come, and the treatments are tough, but you also have to be positive.' He always tells me the same thing. (07802)
	Positivity	I try to be optimistic because I was diagnosed with depression a while ago... I try to not listen to the depression. And since I know that I have support from my family, from my husband, that's what really motivates me to be positive. (15414)

participants did not seek care at certain clinics because of the travel it would require. Another reported how the burden of travel impacted her donor, a sibling living in a country in South America, saying, "At one point during that time, I was afraid that they would deny her the visa [and] that they wouldn't be able to give me the transplant" (09818).

### Procedure Concerns

Participants also expressed concerns about undergoing the transplant procedure, including about how the process worked, which was often related to not understanding the procedure. For instance, one participant (05405) thought the procedure "was like a cut in the stomach." Another (14413) thought they would "open my back like a C-section." He later received a video on the process and said, "that is when I felt calmer and when I relaxed because it was not the way I had thought."

### Familial Concerns

Other participants noted concerns about the impact of transplant and/or cancer on family members and caregivers, like a participant (02411) who said, "I have three small children. I worry

about leaving them." Some participants did not want to worry their families. For instance, one participant (13805) did not tell her family about her transplant until she went to the hospital because "I didn't want them to be so worried... My family, we're very tight, so it was a big impact... I was like the root, and they're the branches, so they all depend on me." Another participant (05405) whose family lives in Puerto Rico, and is, therefore, separated from the patient's care said, "I see that [my family doesn't] understand much of this. They believe I am already cured."

## Complex Relationships with Medical Teams

### Trust in the Medical Team

Despite these barriers and concerns, participants had deep trust in their medical team, impacting their decision to undergo transplant. One participant (03,400) said, "As far as I am concerned, [my doctor] is the mothership, and I'm gonna do everything she says..." Other participants linked their religious faith to their trust in their doctors, like one (17820) who said "my doctors have the hands of angels, and I love them. I love them, and I trust them. I try to do everything they tell me to do."

## Language Barriers

Even though participants trusted their care teams, many revealed communication issues that resulted in misunderstandings about procedures and, sometimes, a lack of question asking. Some communication issues were rooted in language differences between the patients and providers. One participant (05405) said, “With the cancer doctor, I hardly speak because...he doesn’t speak Spanish and I don’t speak any English. With the nurses I talk a little bit, but they say one thing and I think the doctor says another.” Multiple participants noted how a family member used to come to appointments as a translator, but COVID-19 visitor restrictions prevented this. Another participant (07802) described the importance of speaking the same language as the physician, saying, “When a person speaks in their primary language with a doctor or a lawyer, whatever, the ideas and the questions one can ask come deeper into the mind of the person. If I want to ask you a question now, it comes to my mind what I am going to ask you. But if we speak English, I am worried because I am not understanding you very well, and even if I want to ask you a question, I am not going to ask it the way I want to ask it, or you are not going to give me the right answer.”

## Medical Literacy Barriers

Other participants spoke English with their medical team, but still had difficulty with medical terminology. One (12812) said that “there’s some terminology that you don’t understand, even though the doctor tries to explain to you sometimes. I sometimes had a hard time understanding the doctor... It can be frustrating... if you don’t know... what the doctor is trying to tell you, because the doctor’s speaking in terms of medicine terms.”

## Informational Mismatch

Participants also described having both too much and too little information about their transplant from their medical teams. For example, one participant (09818) described the overwhelming amount of information and how “you can’t take it all in until afterwards. [Medical team members] don’t stop, they are like robots.” Another (03400) said, “The pre-transplant coordinator, before you go into the inpatient, she actually read me all of the side effects, including death, that could happen during the transplant twice—two different times... That made me absolutely crazy.” This feeling of being overwhelmed by information, particularly negative information, was also apparent in participants’ responses to the closed-ended questions about topics they would like to learn about. On a scale of zero (not at all) to ten (extremely), all topics had an average response of at least eight, except

for the topic that described information on “negative things that happen during transplant,” which had an average of 5.6 (see Table 3).

Participants shared that they initially found that the amount of information was overwhelming; however, they later found elements of the transplant process surprising and ended up feeling like they did not have enough discussions with or information from their medical teams. One participant (02411) said, “To be honest, I didn’t want to know [that information]. Like what the transplant was like – I wanted to trust one hundred in [my doctor] and I didn’t want to research...because I feel that when you do too much research, like you block yourself psychologically.” Later in the interview, however, she said she needed more information about how the transplant would change her life. She (02411) said, “I don’t think we ever discussed the subject about how my life was going to change after the transplant...I would have liked him to tell me about the side effects because even when I was the donor, it’s still a difficult experience, right?...They should talk to you more about the side effects you are going to experience after you come out of the hospital.” In addition to information on side effects, participants reported needing more information on the procedure itself, hospital stay, recovery process, and meaning of lab results.

## Impacts on Daily Life After Transplant

### Physical Well-Being

All participants described the physical side effects they had experienced since undergoing transplant, including muscle weakness, fatigue, and appetite issues, impacting longer-term functional changes. They discussed not being able to do things around the house, like one participant (16823) who said, “I feel uncomfortable not being able to do things... I’m [typically] very active... [now] I can’t bear to stand very long.”

### Mental and Emotional Well-Being

Participants also experienced emotional and mental health changes due to transplant, including feelings of depression, anxiety, stress, and fear. Weakened immune systems caused participants to fear getting sick, which was heightened from the COVID-19 pandemic and caused participants to feel isolated. As one participant (07802) said, “I got the transplant at a very difficult time, the pandemic... It mainly affected me emotionally in the sense that I had to stay away from people, not so much because of the pandemic but because of the transplant... It’s not a normal life.... I am worried that I might get polio... I am not inoculated against polio, hepatitis; supposedly the transplant erased everything.”

## Family Dynamics

The physical and emotional challenges of transplant intersected with, and sometimes amplified, changes to family dynamics. In fact, a patient described being the caretaker in the family until her transplant (06401) saying, “I always pride myself on being detail-oriented, and researching things... But when it came to my own care, it was the complete opposite... it would be hard for me to process it all. So, [my husband] just said, ‘Well, I’m gonna step in.’” Many patients’ family members took time off work to serve as caregivers, if their workplaces allowed or they were financially able. Another participant (03400) said her husband and caregiver lost weight while caring for her because of the stress. Others noted the difficulties they themselves had with the transition, particularly the loss of independence. A participant (09818) said “they don’t want me to do anything. They just want me to rest. But I also want to do things because I can’t be like this.”

## Methods of Coping

### Social Support

Finally, participants detailed the ways that they coped with the physical, emotional, and familial changes of transplant. One way they coped was through instrumental and emotional social support. Participants said that family and friends (outside of their caregivers) provided meals and cleaned. Participants found cards, messages, phone calls, and video calls important sources of encouragement. One participant (09818) said, “The support of my family and friends plays a very important role, ... when you want to cry, they are there. I have never felt alone... They have always been there supporting me, telling me positive words, ‘You can do it, you are a fighter.’ That helps you a lot.” This support was also important to those who had friends and family that lived far away or outside of the USA. One participant (04410) said, “We always communicate with each other as a family, even with the family back in my country... That helps me a lot.”

**Table 3** Quantitative rating of types of transplant-related information desired. “How much would you want to learn about each of these things right now on a scale of 0 (not at all) to 10 (extremely).”

Topics	Mean	SD	Range
What to expect physically	8.3	2.5	0–10
What to expect emotionally	8.5	2.5	0–10
Ways of coping with difficulties	9.1	1.5	5–10
Words of hope and encouragement	9.1	1.8	5–10
Resources (like books or websites) people found to be helpful	8.0	3.0	0–10
Positive things that happen during transplant	8.6	2.8	0–10
Negative things that happen during transplant	5.6	3.9	0–10
Answers to practical questions to meet your own needs	8.6	1.8	5–10
Answers to practical questions to meet your family’s needs	8.3	2.7	0–10

## Religious Beliefs

Many patients also explained the importance of their religious beliefs, a source of hope and comfort throughout the transplant process. One participant (13805) said “my only help is... I believe in God. When I feel down, depressed, or sad, or anything, I just take the Bible or pray, and I ask God every day to protect everybody around me. And if he wanna keep me here, to leave me here.”

### Positivity

Many participants found a positive mindset helpful for dealing with the stress of the transplant and recovery. As one participant (16,823) said, it is important to “not think that you’re going to die at that moment. You have to be positive.” And for some, the importance of positivity was reinforced by their physicians, like a participant (12812), who said, “My oncologist... she goes to me, ‘Okay. If this doesn’t work, there’s always this other medication that we can try.’ She was very positive, which was great because when you’re in this condition, you don’t wanna hear nobody negative.” Consistent with qualitative responses, the highest rated topics on the quantitative question about interest in learning about different transplant topics (see Table 3) were ways of coping with transplant difficulties ( $M=9.11$ ,  $SD=1.45$ ), closely followed by words of hope and encouragement ( $M=9.05$ ,  $SD=1.80$ ).

## Discussion

This study contributes to the sparse literature about H/L transplant recipients’ experiences, identifying specific financial, logistic, informational, physical and emotional tolls of treatment, and participants’ efforts to adjust following transplant. Results from this study are consistent with constructs from a conceptual model that highlight how elements of H/L culture, psychosocial factors, and experiences with healthcare may uniquely influence the cancer experience and outcomes in H/L patients diagnosed with cancer [2].

Economic barriers were a frequently voiced concern for participants. The H/L population in the USA is overrepresented in low-income brackets [36] and are also nearly three times more likely than NHWs not to have health insurance [37]. Economic limitations may be coupled with other systemic barriers that exacerbate the challenges of transplant, including limited access to treatments and regular care, decreased work flexibility for the patient and their caregivers, less access to medical leave or disability benefits, and lower educational opportunities [2, 38]. Indeed, participants expressed significant emotional and health effects prompted by economic hardship and inadequate insurance coverage.

Consistent with research in H/L individuals with other types of cancer diagnoses and treatments [2], communication barriers were evident for the majority of participants. Multiple participants remarked on their challenges communicating with non-Spanish-speaking medical staff, citing hurdles of both language and medical terminology. Importantly, these communication barriers impacted participants' ability and desire to ask questions of providers. Interview responses illustrated a relationship between communication challenges and increased uncertainty and misunderstanding about treatment processes and outcomes, which can influence treatment decision-making and spur increased anxiety. When patients and providers have language concordance, evidence indicates improved communication outcomes and treatment satisfaction [39]. As such, attention must be given to reducing language barriers through solutions such as use of Spanish-speaking medical staff and trained translators.

In addition to language incongruence, culturally bound communication styles may influence transmission of information between H/L patients and their care team. Participants expressed unequivocal trust in their doctors, reminiscent of the cultural value *respeto*, conceptualized as respect for authority figures (such as doctors) and tendency to listen to what they say [40]. Due to the life-threatening nature of cancer and frequency of interactions with the oncology team, patients might value trust in their medical team in oncology settings more so than other settings such as primary care [41, 42]. *Simpatía*, the desire to avoid potentially conflictual social interactions, and *personalismo*, an emphasis on politeness and courtesy [43], may drive a tendency toward pleasant and socially desirable exchanges between H/L patients and their doctors, which could influence the amount and type of information exchanged. H/L patients may hesitate to ask questions or bring up topics with their medical team that have the potential to be perceived as violating *respeto*, *simpatía*, and *personalismo*. Prior work has shown the value of communication training for oncology staff [44] and results here highlight the language and culture considerations that need to be integrated when working with H/L patients preparing for transplant. Cultural awareness training on communication dynamics as well as training on

using clear, simple language with warm, empathic delivery in line with the cultural value of *cortesía* (courtesy) may promote patient comprehension and satisfaction, which has been related to more adherent follow-up care [45, 46]. Provider understanding of *respeto*, *simpatía*, and *personalismo*, for example, could increase provider awareness of the need to sometimes be more active in eliciting questions and concerns due to patient hesitancy to offend. Likewise, culturally tailored interventions for patients could include assertiveness training with an emphasis on the difference between aggressive and assertive styles and in parallel help patients manage potential family conflict related to assertive communication [30].

Participants also shared their approaches for coping with emotional distress and physical limitations during transplant, including a focus on religion. Spiritual well-being is related to quality of life in survivors, and the broader cancer literature finds that H/L patients are more likely to engage in spiritual or religious coping than are NHWs [47–49].

A coping theme of positivity also emerged. Previous qualitative interviews with patients who had undergone transplant similarly conveyed patient reports of working to maintain a positive story and believe in a favorable ending to increase feelings of courage [50, 51]. The positivity present in interviews was complemented by lower scores on desire to learn about negative things that happen during transplant from the quantitative assessment administered in this study, with the average score on this item just above the midpoint of the 0–10 scale compared to the other scale items which scored eight points or higher. This, along with language and communication challenges, likely contributed to the reported dissatisfaction with the amount of information received by H/L participants regarding their transplants. Interview responses elucidated a type of tension between not wanting to hear negative information about the transplant but later feeling surprised or unprepared during negative events. Emphasis on positivity and reluctance to discuss negative aspects of treatment could be indicative of disengagement coping, including avoidance and denial, which could be directly addressed in a tailored intervention.

*Familism* and *allocentrism*, which emphasize familial closeness and prioritization of family over self, can serve as a protective factor and help promote well-being in patients with cancer [52–54]. Participants shared that talking to and being cared for by family made them feel supported and provided strength and encouragement. The emphasis placed on social support and family can, however, lead to additional distress and feelings of isolation in H/L if adequate family support is not available. Examples of such situations in the interviews included when close others are not living in the USA, or when family members have differing views on the patient's illness and treatment. Similar to work conducted with H/L breast cancer survivors and their caregivers [55], tension within



*familism* may exist such that support could be beneficial, but patients are hesitant to seek support for fear of burdening or worrying their family. Culturally tailored interventions may help patients maximize support from their extended family while also helping patients identify helpful sources of support outside of the family. Psychosocial interventions may also emphasize how intervention benefits extend to benefit the family, which could increase uptake of such interventions.

*Familism* can also interact with cultural gender roles where, stereotypically, dominance and self-reliance are valued for men (*machismo*) whereas passivity and a nurturing-spirit are valued for women (*marianismo*) [56]. Patients may engage in behaviors that strive to uphold these roles and could experience distress if their functioning and needs during transplant and recovery are not consistent with cultural gender norms. This has implications for both intervention content (e.g., using cognitive restructuring to draw attention to additional components of the masculine role) and intervention delivery (e.g., offering private, digital therapeutic options that may feel less stigmatizing).

Despite improvements in treatment for hematologic cancers [57, 58], increases in survival have not been equivalent for H/L and NHWs, which may be related to lower utilization of stem cell transplant among H/L [59], likely driven in part by economic and access barriers [2]. Efforts are being made to decrease underrepresentation of minorities in national bone marrow registries and to increase diversity in HLA haplotypes to expand access to transplant. Additionally, efforts are ongoing to expand access to graft sources for H/L patients (e.g., haploidentical and umbilical cord blood grafts) [60]. As access expands and more H/L patients undergo transplant, the availability of culturally appropriate psychoeducational interventions to support treatment and recovery will be important. Understanding how to meet the needs and aid in coping during the transplant process among H/L patients also has the potential to influence patient engagement with follow-up care that can impact their long-term outcomes. Some concerns appear to apply to H/L patients with cancer more broadly, while the intensity and complexity of transplant and post-transplant care add concerns unique to this cancer population.

## Strengths and Limitations

Interviews were conducted within 12 months of transplant, reducing recall bias and making findings more directly applicable to the burden of treatment regimens today. Another strength of this study was that it included Spanish language monolinguals, who are likely to be underserved and often excluded from research. A focus of future research should be an extensive analysis of differences between English-speaking and Spanish-speaking patients, which our small subgroup sizes did not allow for. While a strength of this study is its

multisite design, future efforts should be made to understand the needs of transplant patients on a larger, nationwide scale because the US H/L population is diverse. Additionally, this was a primarily female sample, and future qualitative work is needed to investigate potentially unique needs that lie at the intersection of gender and ethnicity among H/L. Finally, this study only collected a limited set of self-report medical variables and did not include medical chart review, making some diagnostic and treatment specifics, such as inpatient/outpatient status for transplant, unknown for this sample.

## Conclusions

Many of the existing studies commenting on ethnic disparities in transplant call for further examination of the role of cultural factors and social determinants [6, 60, 61]; this study helps to answer that call as the first qualitative assessment of needs in H/L patients who have undergone transplant. Results provide greater understanding of the challenges and facilitators to well-being during and after stem cell transplant in this understudied population of transplant recipients. This work highlights the need for development of linguistically and culturally tailored educational and supportive interventions for H/L patients undergoing stem cell transplant. This report begins to identify themes that can be used to inform recommendations for intervention tailoring; continued exploration into most effective translation is needed during intervention design efforts due to the complexity of the themes. Tailoring interventions to be patient-centered and compatible with cultural values and beliefs can help increase patient acceptability and uptake of interventions, thus facilitating increased benefit, and potentially helping to reduce the well-documented disparities for H/L patients receiving transplant.

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## Declarations

**Ethics Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

**Statement Regarding the Welfare of Animals** This article does not contain any studies with animals performed by any of the authors.

**Conflict of Interest** Betina Yanez, Chloe Taub, and Diana Buitrago are consultants for Blue Note Therapeutics. Jonathan Moreira participated on a drug advisory board for CTI BioPharma Corp. All other authors have no declarations of interest.

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