

Listening to Hispanic/Latino Voices: Insights on Serious Illness Care Experiences

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Problem Statement

Hispanic people are the largest ethnic community in the U.S. and are projected to make up nearly **one in four** individuals by **2035** (U.S. Census). Addressing the unique challenges this population faces when living with a serious illness is critical.

A recent **CAPC literature review** highlighted how Hispanic/Latino patients with serious illness experience significant inequities in health care access and quality. Our findings include:

- Hispanic patients with serious illness receive lower-quality pain treatment.
- Compared to White patients, Hispanic patients often experience worse non-pain symptom management.
- The costs of care for Hispanic patients with serious illness are often higher than costs for White patients.
- For some Hispanic patients, language impacts experiences with serious illness.

Core challenge: Gain insight into these findings through qualitative interviews with Hispanic/Latino patients experiencing serious illness.

Project Description

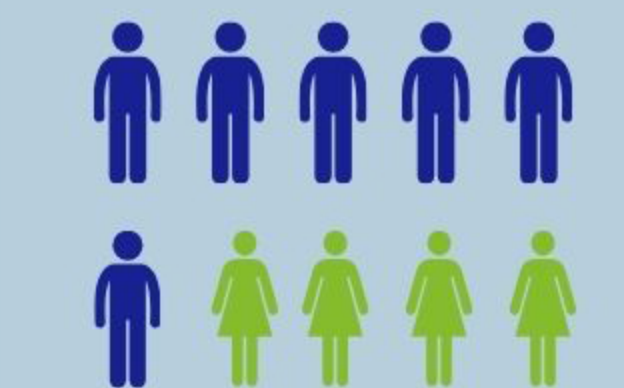
Virtual interviews were conducted via zoom with **10** Hispanic/Latino patients who were living with a **serious illness**. Our goal was to identify patient-reported barriers in care to inform equitable, culturally attuned palliative and serious illness care strategies.



The participants were located across (5) States/Territories:
Georgia, Florida, Puerto Rico, New York, and Texas.

While all participants identified as Hispanic/Latino, some self-identified as **Puerto Rican, Spanish, Mexican and Cuban**, highlighting the diversity within this population.

Participants included individuals with Cancer, Cystic Fibrosis, HIV and other serious illnesses.



6 participants self-identified as male and 4 as female.

Interviews covered the following topics:

- Time with providers
- Family Role
- Symptom & pain management
- Spirituality & religion
- Finances & Insurance coverage
- Racism & Bias
- Location of Care
- Racial & Ethnic Identity

Results

Areas where interviewees identified obstacles & supports when navigating their serious illness:

Time with Provider:

- **80%** reported short, rushed appointments and limited time with their providers.
- A few utilized patient portals or self-research to fill gaps.
 - “If you’re not willing to give me a fair amount of time, don’t give me an appointment.”
 - “There were times where I’d have to call 5 times to get a response.”

Family Role:

- While **70%** viewed their family as a support, **30%** reported shielding their family from difficult news. Many expressed feelings of being a burden to their loved ones.
 - “I know I am a burden. My husband is my knight in shining armor.”
 - “When I need to do something about my health, I never tell my family. After I finish, I tell them.”

Symptom & Pain Management:

- **60%** reported ongoing difficulty with pain management; **30%** said insurance was the main barrier to getting the pain medications they needed.
 - “My main issue is comfort to sleep. I take Advil to ease the pain a little. I don’t have a doctor here who can tell me what to take. I’m scared of drugs.”
 - “My team manages what they can. It’s more for tracking my symptoms to prevent them from getting worse, but they don’t improve my pain.”

Spirituality:

- **30%** said faith was central; **20%** described themselves as spiritual but not religious.
 - “My faith has been more of a support than even my family.”
 - “I’m spiritual, and that helps me cope.”

Financial/ Insurance:

- **All** participants described financial and insurance challenges, from delayed surgeries to costly daily medications.
 - “It took me seven months to raise the money for surgery.”
 - “One of the meds I need just to eat is a \$35 copay — even with insurance.”
 - “Dealing with the insurance company is a pain. They make you jump through hoops.”

Racism and Bias:

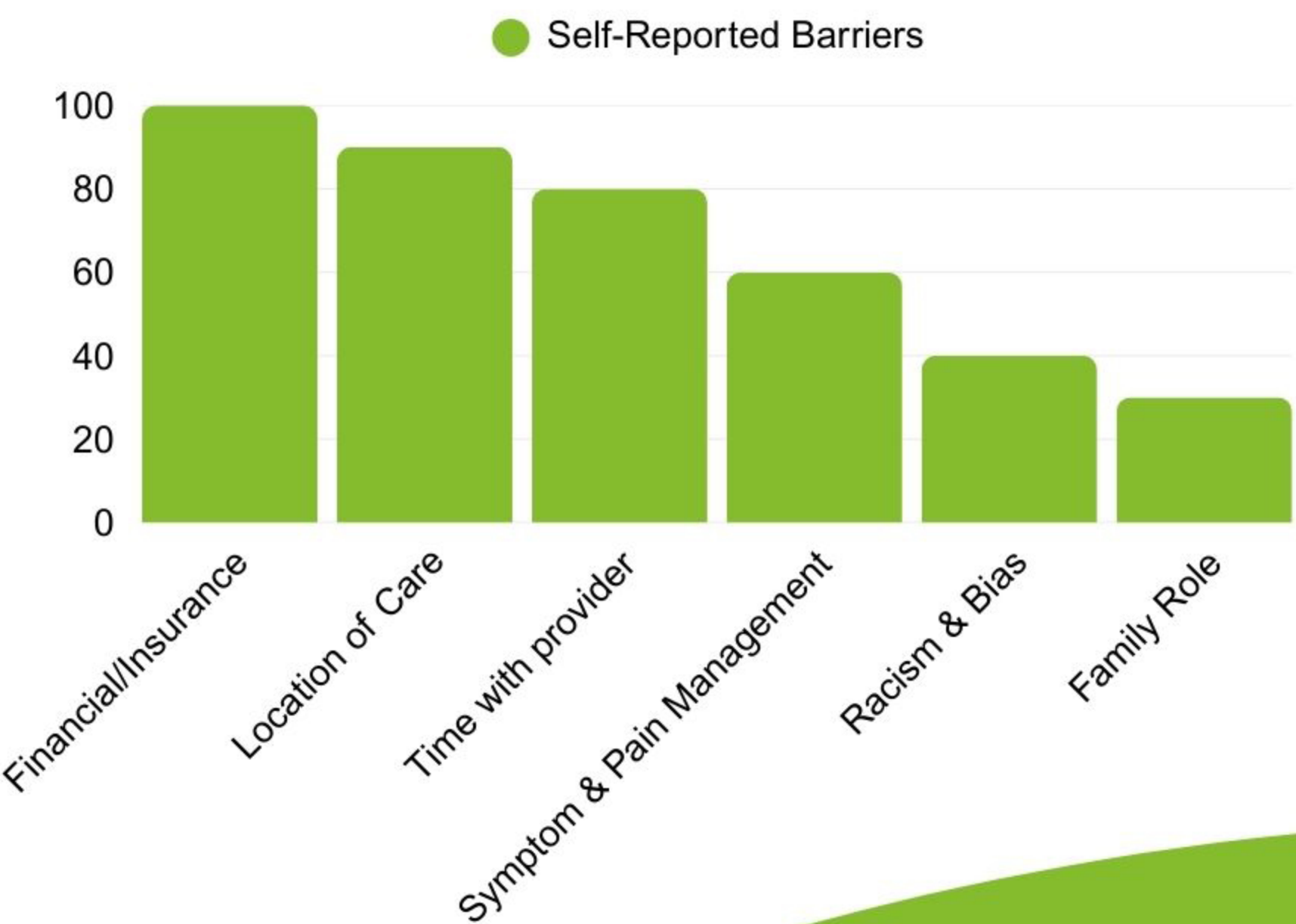
- **40%** described experiences of bias or discrimination; **30%** reported positive experiences with diverse or inclusive care teams.
 - “They look at you with hatred... I never went back in.”
 - “As a Latino man, you have to prove yourself to get the care you need.”

Location of Care:

- **90%** expressed frustration with the location of their care; telehealth views were mixed; hospitals were often disliked and patients valued consistent care teams.
 - “Close to home and with doctors who know me — that’s what I want.”
 - “I hate the hospital. Even the smell makes my blood pressure rise.”

Discussions

- Across illness types and locations, patients consistently highlighted time and empathy as their most important needs.
- Communication gaps were nearly universal, forcing patients to act as their own advocates.
- Family and spirituality were deeply woven into coping and decision-making but often invisible to providers.
- Socioeconomic and insurance hurdles amplified suffering, with delayed surgeries, denied FMLA, and costly medications.
- Experiences of bias—especially among women and Latino men—show structural inequities in serious illness care.



Insights

What providers can do to improve serious illness care for Hispanic/Latino patients:

- Acknowledge family and cultural values in decision-making.
- Integrate spiritual care into routine practice.
- Screen for financial barriers and connect patients to resources.
- Build rapport and continuity — trust strengthens across repeated visits.
- Actively counter bias through humility and equity-focused care.