

**Original Article**

# Multiple Stakeholders' Perspectives Regarding Barriers to Hospice Enrollment in Diverse Patient Populations: A Qualitative Study



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**Abstract**

**Context.** Although studies show disparities in hospice care utilization, many questions remain regarding the causes of these disparities. Most studies focus on a single ethnic/racial group, and most use physician informants. None compare and contrast views of multiple stakeholders or use a systems approach within a single geographic region.

**Objectives.** To gain an in-depth understanding of causes of hospice enrollment disparities in diverse patient populations within one state in the U.S.

**Methods.** We conducted in-depth, individual interviews with multiple stakeholders in hospice care for diverse communities in Rhode Island. We identified participants through purposeful and snowball sampling strategies, aiming for a maximum variation sample. Interviews were audio-recorded, transcribed verbatim, and analyzed using a multistep grounded theory approach.

**Results.** Participants, self-identifying from a wide variety of ethnic backgrounds, included physicians, nurses, social workers, chaplains, nursing assistants, administrators, and caregivers. Five themes emerged regarding patient- and provider-level barriers to hospice enrollment: 1) universal challenges of goals of care (GOC) conversations; 2) cultural norms and beliefs; 3) language barriers; 4) provider-specific challenges; and 5) trust. In minority populations, the central theme of GOC conversation challenges was intensified by the other four themes. Suggested solutions included 1) increased palliative care training; 2) "cultural interpreters" from local communities; 3) specially trained "GOC language interpreters"; 4) improved workforce diversity; and 5) community-level advocacy.

**Conclusion.** The disparity in hospice enrollment among diverse patient populations is a complex and nuanced problem, involving numerous interrelated barriers. Addressing this disparity will require innovative solutions at multiple levels. *J Pain Symptom Manage* 2019;57:869–879. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

**Key Words**

*Hospice, disparities, qualitative study, goals of care, end of life, communication*

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**Introduction**

The field of hospice and palliative medicine has made great strides in facilitating improvements in patient care toward the end of life (EOL); however, many challenges remain in ensuring that patients are accessing high-quality EOL care and hospice services, including adequacy of goals of care (GOC)

conversations, patient and family barriers, and systems issues.<sup>1,2</sup> These challenges appear more pronounced among ethnic and racial minority populations, with many studies demonstrating disparities in hospice enrollment<sup>3–9</sup> and EOL outcomes<sup>10</sup> in these populations compared with the general population.

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Although it is clear that disparities in hospice enrollment exist, a limited number of studies explore the reasons for these disparities or potential solutions. Most studies have focused on specific patient demographic groups<sup>9,11–15</sup> or physician barriers to GOC conversations with diverse populations.<sup>16–19</sup> Few have attempted to identify differences between patient populations<sup>20,21</sup> or explore potential solutions for specific populations.<sup>13,22</sup> We are aware of only one that focused on health systems challenges.<sup>23</sup>

Past studies provide insights into potential causes of hospice enrollment disparities, such as cultural beliefs, complex family dynamics, misinformation about hospice, language barriers, and limited health literacy;<sup>13,14,16,24–26</sup> however, studies are few and have variable sample sizes and designs. In addition, most studies use one kind of informant, most often physicians, with none seeking opinions of other health care providers (e.g. hospice social workers) who care for hospice patients. Furthermore, we found no articles that interviewed workers from community organizations supporting diverse patient populations and none that compared and contrasted the views of different stakeholders within one community or state. Finally, although some studies focused on barriers in specific demographic groups, few explored barriers facing diverse communities as a whole.<sup>3,6</sup>

In Rhode Island (RI), an internal quality improvement project at the largest hospice organization in the state revealed that, similar to national findings, hospice enrollment among ethnic minority groups was significantly lower than predicted by RI language and racial demographics, despite outreach efforts (unpublished data, 2014). In this study, we take a systems approach to explore the barriers to hospice enrollment in diverse populations in RI. In a systems approach to health care delivery, an effort is made to consider multiple interrelated factors that might be contributing to the problem of interest. An Institute of Medicine (IOM) report<sup>27</sup> describes four levels to consider, based on the work of Ferlie and Shortell<sup>28</sup>: 1) patient; 2) care team (providers); 3) organization (infrastructure, resources); and 4) environment (regulatory, market, and policy framework).

The specific goals of this exploratory study are to 1) obtain multiple stakeholders' in-depth perspectives regarding causes of hospice enrollment disparities in RI and 2) gain insights into interventions that might address hospice enrollment disparities in diverse communities.

## Methods

Given the paucity of previous studies addressing our specific study goals and the exploratory nature of our inquiry, we chose a qualitative methodology to gain

in-depth insights from a variety of stakeholders about EOL care in RI in general and about hospice enrollment among diverse populations in particular.

### Design

Individual, key-informant interview, qualitative study.<sup>29,30</sup>

### Setting

All participants were based in RI, a state in which over 20% of the population speaks a language other than English at home, 8.7% speak English less than "very well," 15.5% of residents are Hispanic or Latino, and 8.2% of residents are black or African American. The residents of Providence, the largest city in RI, are 42% Hispanic or Latino and 15.6% black or African American.<sup>31,32</sup>

### Participants

We used a purposeful sampling strategy, aiming for a maximum variation sample of key stakeholders in hospice care.<sup>29</sup> We identified initial participants from professional knowledge of their expertise in hospice/palliative care or health disparities. Snowball sampling identified additional key informants throughout the state.<sup>29</sup> We prioritized interviewing participants from ethnic or racial minority groups in RI. We continuously identified participants who could provide a variety of perspectives, including a variety of health care professionals, professionals working with diverse communities, patients, and caregivers of hospice patients. Our exclusion criteria were as follows: 1) non-English speaking, 2) age less than 18 years, 3) in legal custody, and 4) unable to consent to participation in project.

### Data Collection

One researcher conducted in-depth, individual, semistructured interviews with all participants using an interview guide (Table 1). The interview guide, developed from a combination of literature review and theory, was designed to be open-ended enough for the emergence of unexpected participant insights yet specific enough to address our central study questions. We slightly modified the guide for each participant type (health care worker, nonhealthcare worker, patient/family, organizational leadership), so each topic fit into the expertise of the participant. We conducted all interviews in English. All interviews were face-to-face with the exception of one phone interview. We audio-recorded and transcribed interviews verbatim, with all identifiers removed. Each participant also completed a demographic form regarding their profession, self-identified race/ethnicity, and languages spoken. Data collection continued until we reached saturation.

Table 1  
Semistructured Interview Guide

Question Topic	Example Questions
Thoughts about EOL care Role of EOL care in your work	<ul style="list-style-type: none"> <li>• What are your thoughts about the state of EOL care in RI?</li> <li>• What are the challenges you face while discussing EOL care?</li> <li>• In your opinion, do disparities exist in EOL care in RI?</li> </ul>
Work with diverse patient populations	<ul style="list-style-type: none"> <li>• Do you work with patients from different ethnic or racial backgrounds? What are the most common groups?</li> <li>• Are there any specific worries that your community has around hospice or medical care in the last segment of someone's life?</li> </ul>
Challenges of EOL work with diverse patients	<ul style="list-style-type: none"> <li>• How do you find out what a person needs in regard to their culture?</li> <li>• How do members of [the community that you serve] talk or think about EOL care?</li> <li>• What gets lost in translation? What's different if there isn't an interpreter?</li> </ul>
Role of culture and religion	<ul style="list-style-type: none"> <li>• What role does culture or religion play in making EOL decisions for these populations?</li> <li>• Is there anything that you think health care workers should know about the specific cultural or religious beliefs of people in your community?</li> </ul>
Are patients informed? Community resources for EOL care	<ul style="list-style-type: none"> <li>• Do you think that your patients are well informed about EOL care?</li> <li>• What community resources are most important for supporting clients with EOL decision-making?</li> </ul>
Strategies for working with diverse patients	<ul style="list-style-type: none"> <li>• What strategies have you developed to minimize challenges when working with patients of different ethnic or racial backgrounds?</li> </ul>
Health care system changes	<ul style="list-style-type: none"> <li>• What aspect of the health care system would you like to see changed to improve hospice access for patients in this ethnic minority group?</li> <li>• What change to social determinants would best help to improve hospice access for clients?</li> </ul>
Personal background and beliefs	<ul style="list-style-type: none"> <li>• Are there any aspects of your own background or beliefs that you would like to share which inform the things we've discussed today?</li> </ul>
Community self-identification Personal experience with EOL care	<ul style="list-style-type: none"> <li>• Do you identify as a member of any particular community?</li> <li>• In your own life, have you ever played the role of the family member during a goals of care conversation?</li> </ul>

EOL = end of life; RI = Rhode Island.

### Analysis

Our multistep analysis procedure, conducted by two researchers, was based on the grounded theory approach with analysis modifications to optimize rigor.<sup>29,30</sup> We first individually read and analyzed 10 interview transcripts to identify the main codes from each interview (open coding).<sup>29</sup> We then conducted iterative group analysis meetings to reach consensus regarding the codes arising from the transcripts, resulting in an initial code list. We then proceeded with data analysis in an ongoing manner, during which two researchers first coded and analyzed each interview individually, searching for themes and subthemes in the data, and then held group analysis meetings to optimize the rigor of our analysis.<sup>29,30</sup> During these meetings, we engaged in an exchange of data interpretation, which allowed us to resolve discrepancies in our respective analyses and modify our joint interpretation as we incorporated more data into the analysis.

Once data saturation approached, we achieved initial consensus regarding major themes and subthemes in the data. We next categorized the relationships between themes and created an initial model illustrating these relationships (axial coding).<sup>29</sup>

To further optimize rigor and confirm the accuracy of our theoretical model, we added a second layer of analysis to our process. One researcher formally coded all interviews using QSR International's NVivo 11 software and then separated data by code using NVivo 11.

Two researchers then individually analyzed these coded segments across all interviews. We again had group analysis meetings to reach a final consensus regarding themes and subthemes. This involved exploring and resolving any potential conflicts between our two analysis methods and clarifying the relationships between themes (selective coding).<sup>29,30</sup> We then adjusted the theoretical model based on this final analysis.

Finally, one researcher chose representative quotations for themes and subthemes. Once we ensured that quotations represented a wide variety of participants, we removed identifying designations from the quotations to ensure participant anonymity.

### Ethical Considerations

We obtained institutional review board approval from Brown University. We obtained written consent for all in-person interviews and audio-recorded verbal consent for the singular phone interview. We maintained strict confidentiality of data.

## Results

### Participant Demographics

We interviewed 22 individuals from RI (Table 2). Participants include various health care professionals (physicians, nurses, social workers, chaplains), health-care administrators (from various organizations and RI Department of Health), employees of local community organizations, and caregivers (family members) of

Table 2  
Participant Characteristics Aggregated by Participant Category

Participant Category	Job Title <sup>a</sup>	Self-Reported Race <sup>a</sup>	Self-Reported Ethnic Group <sup>a</sup>	Self-Reported Languages Spoken (Other than English)
Physician N = 5	(3) Hospice/Palliative Care (1) Hematology/Oncology (1) Pediatrician (1) Primary Care (3) Administrative Leadership of Hospice and Palliative Care Organizations/Hospital Services (multiple organizations; adult and pediatric)	(1) Black/African American (3) White/Non-Hispanic (1) Other	(1) French Canadian (1) Irish (1) Italian (1) Other (2) Not reported	(2) Spanish (3) N/A
Administrator N = 3	(2) Leadership, Rhode Island Dept. of Health (1) Administrative Assistant at Hospice Agency (1) Leadership, Health Equity Institute	(1) Black/African American (1) Hispanic/Latino (1) White (1) African	(1) Cape Verdean (1) Portuguese (1) Angolan (1) Puerto Rican (1) Dominican (1) African (1) African American (1) Irish (1) French	(2) Spanish (1) Portuguese (1) Cape Verdean Creole (1) French (1) Twi (2) N/A
Chaplain N = 2	(1) Hospice Chaplain (1) Pastoral Care Director at Hospital (1) Priest	(1) Black/African American (1) White/Non-Hispanic	(1) African American (1) Irish (1) French	(2) N/A
Nurse or certified nursing assistant N = 6	(4) Hospice Nurse Case Manager (providing direct patient care) (3) Administrative Leadership of Hospice & Palliative Care Agencies (multiple agencies) (1) Care Transition Nurse at Hospice Agency (1) Hospice Certified Nursing Assistant	(4) White/Non-Hispanic (1) Cape Verdean (1) African American	(1) Cape Verdean (1) Portuguese (1) French (1) Part Native American (2) Not reported	(2) Portuguese (1) Creole (1) Spanish (4) N/A
Social worker N = 3	(2) Caseworkers at Non-Profit Community Organization Serving Immigrant Populations (1) Oncology Clinical Social Worker	(1) Hispanic/Latino (1) Asian (1) White/Non-Hispanic	(1) Cambodian (2) Not reported	(1) Khmer (1) Spanish (1) N/A
Patient caregiver N=3	(3) Family Member of Hospice Patient (1) Retired Medical Interpreter (1) Certified Nursing Assistant (1) Restaurant Owner	(1) Hispanic/Latino (2) Asian	(1) Cambodian/Khmer (1) Chinese (1) Dominican	(1) Spanish (1) Cambodian (1) Chinese

<sup>a</sup>Participants often held multiple professional titles, and they often identified with multiple races and/or ethnicities. Therefore, the number of titles, races, and ethnicities listed are often more numerous than the number of participants in any given category.

hospice patients. Although we attempted to enroll hospice patients, all potential patient participants were excluded because of language barrier or illness too severe to tolerate an interview. Ages ranged from 22 to 72 years (mean = 51). Five participants were male, and 17 female. Self-described ethnicities included Cape Verdean, Portuguese, Italian, Angolan, Chinese, Dominican, Irish, French, African, Native American, Cambodian, and Khmer. Interviews ranged in length from 15 to 82 minutes (mean = 46).

### General Findings

Most participants identified multiple structural issues that contribute to disparities in access to health care in general, such as lack of insurance or immigration status (IOM Level 4—environmental challenges)<sup>27</sup>; however, participants voiced a consensus that once patients accessed the RI health care system (possibly via hospitals' charitable care systems or the RI community health center system) and desired a

hospice referral, hospice services were readily available. Many described the rapid response time and the provision of charitable care by RI hospice organizations as greatly facilitating access to hospice care. Therefore, participants voiced a consensus that RI had made strides in organizational-level challenges (IOM Level 3 challenges).<sup>27</sup> Most participants reported that the main barrier to hospice care in RI centers on the effectiveness of GOC conversations (IOM Levels 1 and 2—patient and care team barriers, respectively).<sup>27</sup> Many described numerous difficulties associated with having GOC conversations with the general population and how these challenges are further intensified with diverse patient populations.

Therefore, when participants focused on specific barriers to hospice enrollment among ethnic and racial minority populations in RI, five major themes emerged in the data: 1) general communication challenges in GOC conversations; 2) cultural norms and beliefs; 3) language barriers; 4) provider challenges;

and 5) trust. During axial and selective coding, it became apparent that “challenges with GOC conversations” was the central theme. Participants described the many universal challenges associated with the delicate and nuanced communication necessary for effective GOC conversations and subsequent decision-making by patients and families. These universal challenges seem to be intensified by the four other main themes in patients from ethnic or racial minority populations, which significantly contributes to disparities. Figure 1 illustrates the relationship between these five themes and subthemes, including potential solutions suggested by participants. Tables 3 and 4 provide sample quotations for each.

**Theme 1: General Communication Challenges in GOC Conversations**

**Subtheme 1: Discomfort with Death.** Most health care workers described EOL conversations as being emotionally challenging and the common urge to avoid them whenever possible. One physician stated, “Sometimes I can get very close to people, and I don’t want to do it too, so sometimes it’s my own personal barrier.” Some participants commented that barriers frequently stemmed from patients who had difficulty accepting their terminal diagnosis, as explained by a chaplain: “There’s a large segment of the population who does not—

never comes to an understanding of or a willingness to accept the fact that they’re dying or that their loved one is dying.”

**Subtheme 2: Health Literacy About Hospice.** Numerous participants discussed lack of knowledge and misconceptions about hospice care. The most common misconception concerned the idea that individuals only enter hospice immediately before death. Although most health care workers discussed limited hospice health literacy in patients, several also mentioned limited understanding within the medical community. One nurse who worked in both hospice and hospital settings said, “A lot of my coworkers at the hospital really don’t understand what I do. They think, ‘Oh, your job is so sad. You just get people, and they die.’”

**Subtheme 3: Desire to Maintain Hope.** Many participants discussed how families often feel that accepting hospice care is “giving up” on their loved one. They describe difficulties navigating families’ hope for the patients’ recovery. One nurse commented: “I think overall most doctors hesitate to take away that hope, and most patients have a very hard time shifting hope.”

**Subtheme 4: Religious Beliefs Versus Medical Advice.** Several participants commented on both the beneficial and potentially detrimental impact of religious belief in EOL care. Religion brings comfort at EOL

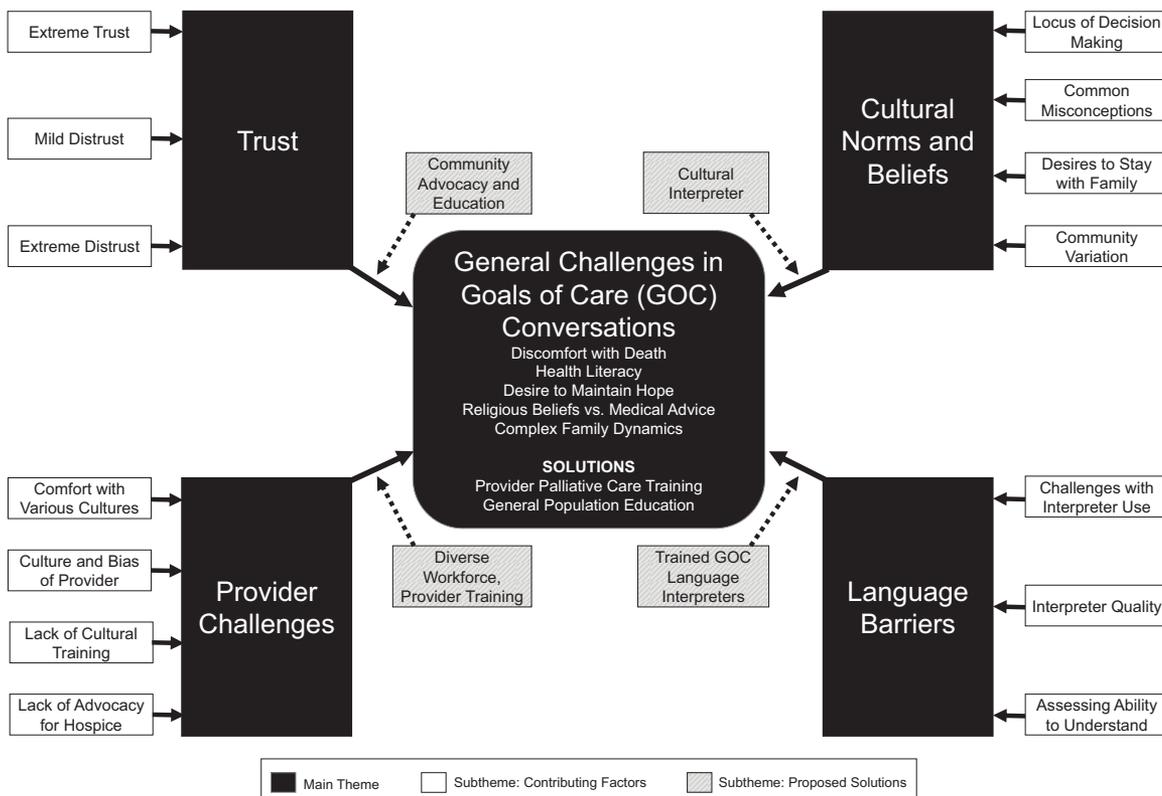


Fig. 1. Theoretical model: relationship between themes and subthemes.

*Table 3*  
**Participants' Beliefs Regarding Factors Contributing to Hospice Enrollment Disparities**

Themes	Subthemes: Contributing Factors	Example Quotations
General challenges in goals of care (GOC) conversations	<ul style="list-style-type: none"> <li>• Discomfort with death</li> <li>• Health literacy</li> <li>• Desire to maintain hope</li> <li>• Religious beliefs vs. medical advice</li> <li>• Complex family dynamics</li> </ul>	<p>"I think a big thing is getting a patient to understand where they are in their disease ... getting them to understand that we're not talking about curative treatment anymore, we're talking about quality of life, and hospice is a way to provide that at home."</p> <p>"I don't know if the community is aware of how many options they have, or what care or services are provided by hospice."</p>
Cultural norms and beliefs	<ul style="list-style-type: none"> <li>• Locus of decision-making</li> <li>• Common misconceptions</li> <li>• Desire to stay with family</li> <li>• Community variation</li> </ul>	<p>"If the person itself – the provider is not linguistically competent, [it is necessary] that you have trained interpreters, and trained interpreters is not just somebody who can translate the language but can translate the culture."</p> <p>"If I went in there that first visit and started talking about morphine, well I'm the angel of death, you know, I'm there just to give them medicine and help them along their way!"</p>
Language barriers	<ul style="list-style-type: none"> <li>• Challenges with interpreter use</li> <li>• Interpreter quality</li> <li>• Assessing ability to understand</li> </ul>	<p>"The [translator] had the right words. It was more than just the language. It was comfort level in the translation, and it was using exact language and understanding the value of that exact language."</p> <p>"She's perfectly like capable of understanding, like she's fine. She just didn't understand because they were telling [her] in English."</p>
Provider challenges	<ul style="list-style-type: none"> <li>• Comfort with various cultures</li> <li>• Culture and bias of provider</li> <li>• Lack of cultural training</li> <li>• Lack of advocacy for hospice</li> </ul>	<p>"I feel bad because I don't know all the cultural barriers that I'm even missing."</p> <p>"Docs don't like to give up, and by the time these patients are referred to us, they're not living that long. You know, I've had patients die when I was sitting there doing the paperwork with them, you know."</p> <p>"I have biases, you have biases, we all come into experiences bringing our own biases and then bringing the weight of the culture and society that we live in or associate with."</p>
Trust	<ul style="list-style-type: none"> <li>• Extreme trust</li> <li>• Mild distrust</li> <li>• Extreme distrust</li> </ul>	<p>"For many communities, there's distrust in the health care system, and so not being as aggressive as possible until the very end, that somehow that may be doing your loved one a disservice. And so there may be more of a reluctance to take the hospital's word or your doctor's word that your loved one is dying."</p>

*Table 4*  
**Participants' Suggested Solutions for Decreasing Hospice Enrollment Disparities**

Theme	Subtheme: Proposed Solutions	Example Quotations
General challenges in goals of care (GOC) conversations	<ul style="list-style-type: none"> <li>• Increased provider palliative care training</li> <li>• Increased education for the general population</li> </ul>	<p>"I think that education is the key. Education of all providers in terms of the ability to have those conversations and the ability to manage symptoms well so that patients have that trust. I think that it's all about education."</p> <p>"[Providing] education to the new providers of what EOL care is, and that good EOL care doesn't mean giving up treating patients, but what's the right time for that EOL care."</p>
Cultural norms and beliefs	<ul style="list-style-type: none"> <li>• Cultural interpreter</li> </ul>	<p>"You need a cultural broker on a conversation I think, I believe around EOL care. Someone who truly understands the culture of that person, the culture of that family, so they can help translate and incorporate that into whatever care plan you may make."</p>
Language barriers	<ul style="list-style-type: none"> <li>• Trained hospice/GOC language interpreter</li> </ul>	<p>"She knew, we had talked about the patient ahead of time, she knew where we were going, and she used exact translation, and she wasn't uncomfortable because she understood why this was so important."</p> <p>"Even though I don't necessarily speak the other person's language, I know when I've got a translator who's saying it with the same emphasis on compassion that I hope they would feel if it was coming directly from me."</p>
Provider challenges	<ul style="list-style-type: none"> <li>• Diverse workforce</li> <li>• Provider training</li> </ul>	<p>"I think definitely more, more, more diversity in staff. And I know that there's a lot of other things that go into that, and it's a lot of education and things like that, that constrict ... the diversity in that."</p> <p>"I think we need more education about what the different cultures – how to communicate with different cultures. I'm severely lacking in that, and I know my colleagues are as well, so I think that's my biggest barrier, that we do not even know what's out there."</p>
Trust	<ul style="list-style-type: none"> <li>• Community advocacy</li> <li>• Community education</li> </ul>	<p>"Maybe the churches that these people belong to or the temples that they go to would have, you know, announcements, maybe bulletin boards saying if your family member needs hospice care, you know, contact this number."</p> <p>"And we've got grants and we've got free training, and then they go back in the community, and that's how we build our reputation. Reach into the community, train them, and go back into the community."</p>

for many individuals; however, the belief in miracles, for example, could lead to prolonged suffering due to nonmedically indicated life-sustaining measures. A health care administrator elaborated using her family's religiosity as an example: "*We would probably keep in mind the medical model, but also be very religious in being hopeful that God is, you know, a higher power, and he has the final say.*"

*Subtheme 5: Complex Family Dynamics.* Many participants discussed challenges in balancing patients and family wishes, especially if they conflicted. Participants explained that complex family structures and the desire to withhold information from certain family members amplified these challenges.

*Subtheme 6: Solutions—Increased Training and Education.* Most participants recommended improving palliative care training for all health care professionals and education for the general population as necessary for overcoming communication challenges in EOL care. They added that specific training about hospice services and how to conduct (or participate in) high-quality GOC conversations would both be important.

## *Theme 2: Cultural Norms and Beliefs*

*Subtheme 1: Variations Between and Within Communities.* An overarching theme in almost all interviews was the inability to know patients' desires regarding EOL care solely from their cultural background. Although learning a patient's culture is important for context, assumptions should not be made about their wishes based on culture. One nurse explained: "*It's a process of education for myself too, and you know, every family is different. There isn't the textbook family, Spanish or Portuguese family, and you kind of learn, learn where to go from there.*"

*Subtheme 2: Common Misconceptions.* Several participants believed that some misconceptions about hospice appear more frequently in some ethnic minority populations. One example is that hospice must occur in an inpatient setting. Another is that patients will die within days of going into hospice, either from their disease or from the hospice agency's medications; for example, several Portuguese-speaking hospice workers noted that they do not mention the word "morphine" during the first visit with many Portuguese families due to the risk of immediate hospice revocation before trust can be established.

*Subtheme 3: Desire to Stay With Family at EOL.* All patient caregivers expressed the desire to have their terminally ill family members remain home. Several other participants describe this desire existing within their own personal ethnic minority communities and

in those they have observed, explaining that families believe patients will receive better care at home surrounded by loved ones; however, the prevalent misconception that hospice requires inpatient care often prevents hospice enrollment.

*Subtheme 4: Locus of Decision-Making.* Some participants noted that in many communities, decision-making happens collectively within the family unit. In contrast, the American health care system favors autonomous decision-making by patients. A few health care workers mentioned that this discrepancy makes navigating GOC conversations more challenging with some ethnic minority patients/families.

*Subtheme 5: Solution—Cultural Interpreter.* Many participants expressed the need for increased training about various cultural beliefs related to EOL care. One health care administrator suggested the novel concept of trained cultural interpreters, stating: "*Trained interpreters is not just somebody who can translate the language but can translate the culture.*" The cultural interpreter would therefore be a liaison and advocate between an ethnic minority population and health care system, specifically around hospice and EOL care.

## *Theme 3: Language Barriers*

*Subtheme 1: Interpreter Challenges.* Most physicians described the inconsistent efficacy of interpreters in EOL care. One significant challenge is a lack of precise language during the interpretation. Many physicians skilled in GOC conversations describe carefully choosing their words, tone, and body language when having these conversations. Any discrepancy in word choice during interpretation is a major barrier to successful conversations. Several physicians described experiences in which the interpreter's reticence to use the words "die" or "death" and their uncomfortable body language hindered GOC conversations and rapport with patients.

*Subtheme 2: Quality of Interpreter Types.* Opinions about the best type of interpreter for GOC discussion varied. Health care workers agreed that they preferred in-person interpreters to phone interpreters because of their increased potential to create rapport; however, disagreement existed regarding using English-speaking family members versus in-person language interpreters. Most health care workers preferred language interpreters because of hospital guidelines and the increased certainty of accurate translation; however, some preferred English-speaking family members because of the ability to build trust and convey compassion.

*Subtheme 3: Challenges in Assessing Comprehension.* Some health care workers discussed the difficulty in assessing patients' comprehension of medical information when speaking a different language than their patient. They lose subtle clues, indicating a lack of understanding when using interpreter services. One participant also mentioned the difficulty of using the "teach back" method through an interpreter.

*Subtheme 4: Solution—Trained GOC Language Interpreters.* Participants offered multiple ways to address language barriers for diverse patients. Several mentioned increasing staff diversity and hiring more bilingual hospice workers. A hospice nurse suggested training specialized language interpreters for GOC conversations. She argued that translation of these delicate conversations would be enhanced by interpreters trained in choosing words precisely, conveying compassion, and improving their comfort with discussing death.

#### *Theme 4: Provider Challenges*

*Subtheme 1: Provider Comfort With Various Cultures.* Multiple administrators discussed how the relative lack of diversity in the RI population influences the comfort of providers in caring for patients from racial or ethnic minority communities. They explained that people become more comfortable working with diverse patients after more experience. As one stated, "I don't think we've become diverse enough to really understand the cultures that we deal with."

*Subtheme 2: Culture and Bias of Provider.* A few participants discussed the personal bias that providers bring into their work. These participants discussed how the culture of the provider and biases in the culture of medicine could potentially affect their patients' care. One physician explained: "I think there is institutional racism that affects all of us and how we interact with people in unconscious ways."

*Subtheme 3: Lack of Provider Cultural Training.* Most participants mentioned the lack of training about various cultural backgrounds as a barrier to care for ethnic minority populations. The health care providers commenting on this topic endorsed receiving little training on various cultural beliefs surrounding EOL care. One health care administrator stated, "I think medical schools continue to, unfortunately ... provide mostly lip service to the training in terms of culturally and linguistic competency of the workforce."

*Subtheme 4: Lack of Provider Hospice Advocacy.* Many participants stated that the likelihood of a patient getting enrolled in hospice depended heavily on their doctor's views about hospice. One chaplain stated,

"Some doctors fight hospice tooth and nail. So if you have that doctor as a primary, you're not going to get it unless you do something."

*Subtheme 5: Solution—Diverse Workforce and Provider Training.* Participants suggested many potential ways to decrease provider-level barriers to high-quality EOL care for diverse patients. These included increasing hospice staff diversity to bring cultural knowledge to the workplace and improving cultural training to understand some relevant beliefs of specific patient populations (while attempting to avoid preconceived ideas based on a patient's identity).

#### *Theme 5: Trust*

Trust in the medical system was a prominent theme in the interviews; however, the theme varied considerably across and within different ethnic minority groups. Although it is impossible to draw conclusions about the beliefs of specific groups, the existence of such variability in trust is noteworthy.

*Subtheme 1: Extreme Trust.* One variation is an extreme trust in the medical system. This was mainly, though not exclusively, discussed in regard to the Southeast Asian communities in the area. One social worker from a nonprofit organization stated, "They said they do whatever the doctor wants them to do. The doctor knows best," when commenting on her Southeast Asian clients.

*Subtheme 2: Mild Distrust.* Other participants commented on a mild distrust or suspicion of the American health care system from ethnic minority patients. This was mainly in reference to African American, Cape Verdean, and Portuguese patients in RI. Participants commented on concerns that they heard from patients regarding whether doctors withheld care or gave inappropriate medication based on patients' ethnicities.

*Subtheme 3: Extreme Distrust.* A few participants, specifically those working with African American populations, mentioned a subset of patients who refused to engage with medical care due to extreme distrust of the system. One chaplain mentioned the death of a person from his church because of his refusal to receive surgery after a diabetic infection. Participants often linked this to historical mistreatment and medical experimentation in the African American population.

*Subtheme 4: Solution—Community Advocacy and Education.* Almost all participants discussed the importance of improved community education regarding hospice care. Many recommended conducting

outreach from local hospice organizations to community organizations and utilizing an interpreter to reach non-English-speaking communities. Many participants also emphasized the need for grassroots change by informed members of ethnic minority communities. Several argued that to gather widespread support for hospice care within diverse populations, education must come from within the community.

### *Interrelationship Between Themes*

Higher-order analysis of these themes and sub-themes revealed complex relationships between them. Some of these relationships are described previously. [Figure 1](#) provides an overview of these relationships.

### **Discussion**

To our knowledge, this is the first qualitative study using a diverse, multistakeholder approach to seek an intricate understanding of the barriers to hospice enrollment in diverse patients who are entitled to receive this service. By interviewing various health care workers, health care leaders, employees of community organizations, and caregivers of hospice patients, this study captures detailed multidimensional perspectives in one geographic region.

From a systems perspective, our study suggests that in RI, although IOM Level 4 (policy level)<sup>27</sup> barriers such as access to health insurance and immigration status clearly continue to contribute to disparities, strides have been made in Level 3 (organization level)<sup>27</sup> barriers to hospice access for ethnic and minority populations. Participants describe the charitable care available through both hospitals and hospice organizations as a strength of the RI system; however, Level 2 (provider level)<sup>27</sup> and Level 1 (patient level)<sup>27</sup> barriers continue to significantly contribute to disparities in hospice enrollment in RI. We have been unable to find a similar systems-level analysis in the literature for other states or cities in the U.S. Hagen et al.<sup>23</sup> conducted a multimethod study exploring systems barriers to advanced care planning in Alberta, Canada. Although they identified numerous patient, provider, systems, and resource barriers, this study did not attempt to explore racial or ethnic disparities.<sup>23</sup>

Study participants focused on numerous patient- and provider-level barriers to hospice enrollment. The central theme of universal challenges in GOC conversations was intensified by the four other main themes (cultural beliefs/norms, language barriers, provider challenges, and trust). The theoretical model ([Fig. 1](#)), which grew from our analysis, helps elucidate relationships between themes and suggests avenues for further research. To our knowledge, no similar theoretical model has been published elsewhere.

Many of our specific findings are consistent with previous research. This study reinforced that language barriers and challenges with interpreter use continue to limit the efficacy of GOC conversations.<sup>14,16,26</sup> It adds to previous findings by elucidating the significant barrier that imprecise translation and poorly conveyed empathy in GOC conversations pose if the language interpreter does not understand the fundamentals of palliative care or shows discomfort during translations about death.

As in other studies, our findings reinforce the need to appreciate the tremendous variability in beliefs both between and within cultural groups, as well as within families,<sup>11,13,15,20,21,24</sup> in order to avoid stereotyping and bias interfering with provision of high-quality care<sup>33,34</sup>; however, our study adds to the literature by elaborating on some common misconceptions and fears that may span multiple different communities, such as fear of morphine and the belief that hospice requires removal from home and family.

This study also adds to the understanding of the importance of trust between patients and the health care system in receiving hospice services. Although past studies discuss the impact of patients' mistrust of the health care system on receiving EOL care,<sup>16,17</sup> this study reveals how different levels of trust, including extreme trust, can impact care; for example, lack of trust might result in a patient refusing hospice care offered by a physician;<sup>16,21</sup> however, extreme trust and a "doctor knows best" attitude could also result in lack of hospice enrollment, regardless of the patient's wishes, if their physician is uncomfortable or unfamiliar with hospice. This study, therefore, provides a more nuanced understanding of the impact of trust on hospice utilization.

In addition to previously identified approaches,<sup>1,13,22,25</sup> this study also identifies novel ideas for addressing hospice enrollment disparities; for example, an administrator described the need for an EOL cultural interpreter, someone to serve as a cultural proxy between the patient and the health care system, specifically around the issue of EOL care. In addition, a hospice nurse suggested having specifically trained hospice language interpreters who have education in GOC conversation techniques to improve translation, rapport, and compassionate care. The diverse participants in this study provided an opportunity for the emergence of innovative solutions that may not have been discovered by interviewing physicians alone, who are the most commonly studied group on this subject.

Limitations of this study include that it was conducted in a single state in the U.S.; therefore, findings may not be transferable to other locations; however, the multistakeholder, systems approach we employed may be a useful methodology to employ in other settings. In addition, because we sampled a diverse

group of participants, each participant type consisted of a very small number of interviews, and while we attempted to enroll patients, language barriers and/or advanced illness prevented their participation; however, each interview yielded detailed information, and because analysis focused on common themes across diverse populations, many findings may be broadly relevant.

Significant disparities remain in hospice enrollment among racial and ethnic minority patients in the U.S. This prevents the provision of high-quality EOL care to many patients who are eligible to receive this benefit. This in-depth, qualitative study provides a nuanced understanding of multiple, interrelated barriers to hospice enrollment in these populations and suggests avenues for innovative solutions. Further research is needed to determine the most effective interventions for addressing these barriers at multiple levels.

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