



Understanding the home hospice experience of Puerto Rican caregivers

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Abstract: Hospice use among Hispanic Medicare beneficiaries has declined in the last few years, and Hispanic caregivers have reported insufficient support around the emotional and spiritual aspects of care. Understanding the home hospice experience of Puerto Rican (PR) caregivers can yield insight into ways to improve hospice participation and quality of care for the Hispanic population. This exploratory study utilizes qualitative methods to identify PR caregivers' experience in the setting of home hospice care. Data from interviews with eight (n=8) bereaved PR caregivers of patients who received home hospice care were qualitatively analyzed. Participants were mostly well-educated (n=6/8) female caregivers caring for their parent (n=7/8) with mean age of 57 [standard deviation (SD) =13] years. Emerging domains from the study included (I) symptom management; (II) cultural and religious values; and (III) interaction with hospice providers. Caregivers found managing patients' loss of appetite, pain, anxiety, and confusion to be challenging. They identified family-centered values and religious support as culturally important, which manifested as the need for frequent communication from hospice providers and increased support and education at the end-of-life. Culturally tailored interventions that focus on managing symptoms, tailoring care to support family-centered values, integrating religious officials representative of the patient's beliefs into the hospice team, and communicating effectively with providers may reduce the burden experienced by PR caregivers in home hospice and improve outcomes for patients and caregivers. Additional research will aid in the development of evidence-based intervention and policies urging healthcare providers to offer culturally appropriate hospice care and resources to this population.

Keywords: Hospice; family caregiver; Puerto Rican (PR); culture; religion

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Introduction

Hospice provides palliative care services at the end-of-life (EoL) for patients with a terminal illness. While the use of hospice has been shown to improve patient quality of life and caregiver satisfaction (1), prior research has found disparities in hospice utilization and outcomes among different racial and ethnic groups (2-4). In particular, hospice service utilization has declined by 9.4% among Hispanic Medicare beneficiaries in 2020 (3). Hispanic

patients are more likely to receive care from lower quality hospices compared to White patients (5,6). Puerto Ricans (PRs) make up the second largest Hispanic subgroup (7,8), and studies have shown that PRs have poorer health than other U.S. Hispanic and non-Hispanic populations. Yet, the challenges experienced by PR patients and families, especially after enrolling in hospice, have not been studied adequately (2,9). Literature reviews on Hispanics and hospice show a dearth of qualitative studies, and none

address the specific needs of PR family caregivers receiving hospice care (2).

Family caregivers are critical in delivering home hospice care, but their responsibilities are demanding and burdensome (10). Among the tasks confronting family caregivers are attending to patient symptoms, administering medications, assisting with activities of daily living, and communicating with hospice providers (11). Hispanic caregivers often have unmet needs, given that Hispanic hospice family caregivers reported not receiving sufficient emotional/spiritual support when compared to their non-Hispanic counterparts (12). Furthermore, Hispanic caregivers were more likely to be depressed and in worse physical health than White caregivers (13). Therefore, understanding the experience of PR patients and caregivers, as they make up the second largest subgroup within the Hispanic population (7,8), can provide valuable insights into Hispanic community perspectives on EoL care preferences. These insights can inform hospices in improving EoL care delivery to the Hispanic population.

This exploratory study aims to identify the experiences of PR family caregivers who provide home hospice care to patients nearing the EoL. The study focuses on addressing two research questions: (I) what is the caregivers' experience with managing EoL symptoms? (II) What is the influence of cultural and religious factors on caregivers' EoL experiences? We present this article in accordance with the SRQR reporting checklist (14) (available at <https://apm.amegroups.com/article/view/10.21037/apm-24-24/rc>).

Methods

The study team collaborated with two hospice organizations in Puerto Rico to conduct interviews with bereaved family caregivers. The two organizations were selected given their research collaboration with existing team members. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013), and approved by the Institutional Review Boards (IRB) at VNS Health (#1416823-29), Weill Cornell Medicine (WCM) (#22-04024661), and Johns Hopkins (#00350937). Informed consent was obtained from all individuals.

The two hospice sites served patients and caregivers in urban and suburban areas of Puerto Rico. On average, hospice nurses visited patients twice a week, while chaplains and social workers visited once a month. Eligible participants were 18 years of age or older, English and/or Spanish speaking, identified as Hispanic, and were

caregivers for a care recipient who died receiving home hospice care. Provider referrals were obtained from each hospice organization. A list of potential participants who assented to be contacted by the research team, including the names of the care recipients and the names and phone numbers of their primary caregivers, was sent to the study team. A Spanish-speaking researcher (M.D.B.) on the team called caregivers, informed them about the study, and screened them for eligibility. Caregivers interested in participating were scheduled to meet via Zoom to obtain electronic informed consent and participate in a one-time interview. The virtual modality was convenient and allowed more flexibility in participation. Interviews were conducted between April and May 2022 with an average duration of 35.6 minutes. Participants received a \$50 gift card for their participation.

Of the 24 initial calls made by the study team, 11 did not answer their phones, and four were contacted but not interested. Nine caregivers expressed interest in participating, and eight completed the consent process and interview (15).

A trained research member (M.D.B.) conducted interviews in Spanish with participants using a semi-structured discussion guide. The study team developed the questions (*Table 1*) based on a literature review, their clinical experience, and previous work in the field. The study team comprised physicians specializing in palliative medicine. The framework of questions was exploratory and open-ended. Interviews were audio recorded, professionally transcribed in Spanish and translated to English, de-identified, and reviewed for accuracy. A Spanish-speaking member (M.D.B.) of our team who conducted the interviews reviewed the transcripts to ensure accuracy. The translation was necessary for analysis by members of the research team who did not speak Spanish and for submission to an English-language journal.

Content analysis (16,17), a method for classifying verbal data into categories of similar meaning, was used to analyze data. Codes were developed inductively and revised throughout the data analysis process. During open coding, two investigators (T.P., V.P.) trained in content analysis independently coded the transcripts based on the original data and discussion questions, identifying sections of text representing discrete concepts and applying a code. This was followed by focused coding, which involved the co-authors comparing codes within and across group discussions. A third party (D.M.C.O.) was prepared to review any discrepancies after independent coding of all

Table 1 Interview questions

Question domains	Questions
Symptom management	What were the signs and symptoms most difficult for you to manage or deal with?
Cultural needs and challenges	Were there important cultural beliefs or values you wanted your hospice team to know about? Were there cultural challenges you faced during your hospice experience?
Religious needs and challenges	Were there important religious beliefs or values you wanted your hospice team to know about? Were there religious challenges you faced during your hospice experience?

transcripts but was not utilized since all discrepancies were minor and resolved through discussions. A final set of codes was developed and organized into categories during axial coding. NVivo 12 software was used for qualitative analysis (18).

Results

The demographic data of participants is shown in *Table 2*. Participants were mostly well-educated female caregivers with mean age of 57 years. PR caregivers identified three domains: (I) symptom management; (II) cultural and religious values; and (III) interaction with hospice providers. *Table S1* provides detailed quotes.

Symptom management

Loss of appetite

Many caregivers mentioned struggling to cope with the care recipient's loss of appetite and commented that they would have benefitted from education on EoL signs and symptoms. One caregiver said, *"I thought that maybe the cancer wouldn't kill my mom, but dehydration or malnutrition might. [...] Perhaps if I had known in advance that the person is at the point where the body does not ask for food or drink and is closer to death, I would have had a different perspective..."* (Participant 7, male).

Pain

Many caregivers cited pain as a distressing symptom. One participant said, *"What hurt me the most was that he had so much pain [...] it hurt me because I couldn't help him,"* (Participant 9, female). Caregivers often had difficulty understanding whether the patient was in pain, especially if the patient hid their pain or had altered cognition. For instance, a caregiver mentioned that their care recipient *"would scream as if she was in pain, but it seemed like she*

was doing it for attention, but I don't know" (Participant 18, female). Another difficulty many caregivers shared was dealing with the side effects of the pain medications, in particular, dizziness and sedation.

Anxiety and confusion

Anxiety and confusion were challenging symptoms identified by caregivers in our sample. One caregiver stated, *"It was her confusion, not knowing where she was... That creates a lot of difficulties because the person is going to become reluctant to receive the necessary attention and care"* (Participant 7, male). Anxiety, restlessness, and confusion, stemming from a combination of factors such as neurocognitive disease, fear of death, and medication side effects, made caregivers feel helpless.

Cultural and religious values

Family-centered values

Many caregivers stated that caregiving as a family was a crucial aspect of family values. One caregiver stated, *"As caregivers, we must instill values from home, such as caring, respect for our loved ones, and the love we feel for them"* (Participant 19, female). Caregivers appreciated hospice providers who understood their family-centered values and kept them involved. Another caregiver said, *"...Puerto Ricans in general, culturally, are attached to their loved ones. We generally want to be there"* (Participant 18, female).

Religious support

Caregivers stressed the importance of religion in their lives. Furthermore, they expressed the desire for their religion to be represented in their hospice care team and to have support specific to their belief. A caregiver appreciated that when *"we told them what religion my mother was, and [hospice] adapted to that... they even brought a minister for us"* (Participant 11, female).

Table 2 Caregiver demographic data (n=8)

Characteristics	Values
Age (years), mean (standard deviation)	57 (12.98)
Gender, n (%)	
Female	7 (87.5)
Male	1 (12.5)
Ethnicity, n (%)	
Hispanic, Latino/a	8 (100.0)
Race, n (%)	
Black and/or African American	1 (12.5)
White	2 (25.0)
Other	5 (62.5)
Multiracial	3 (37.5)
Afro-Caribbean	1 (12.5)
Unspecified	1 (12.5)
Religion, n (%)	
Christian	7 (87.5)
Catholic	6 (75.0)
Methodist	1 (12.5)
Not religious but spiritual	1 (12.5)
Highest education received, n (%)	
Graduate degree	1 (12.5)
Post-graduate but no degree	3 (37.5)
College degree	2 (25.0)
High school or general education diploma	2 (25.0)
Marital status, n (%)	
Married or domestic partnership	5 (62.5)
Single	1 (12.5)
Divorced or separated	1 (12.5)
Widowed	1 (12.5)
Relationship to patient, n (%)	
Child	7 (87.5)
Spouse/partner	1 (12.5)
Patient terminal diagnosis, n (%)	
Cancer	4 (50.0)
Pulmonary disease	2 (25.0)
Vascular disease	1 (12.5)
Neurological disease	1 (12.5)

Almost all caregivers we interviewed were appreciative of the religious support from the hospice team. One caregiver stated, “*the [hospice chaplain] would come and pray with him and talk to him very well... And I believe all of that is very important for a person who believes in God...*” (Participant 9, female). The religious guidance was especially helpful in coping with fear of death and bereavement.

Interaction with hospice providers

Communication with hospice providers

The quality and frequency of communication were key to caregivers' satisfaction with hospice. The PR caregivers in our sample appreciated respectful, empathetic, and tailored communication. One caregiver said, “*When the nurse would go see my mom, she always found a way to explain the details to me and tell me what I needed to do with my mom in a way that I could understand*” (Participant 19, female). On the other hand, a subset of caregivers felt that communication from hospice providers would have been optimized with more frequent, timely responses. According to a caregiver, “*...the most relevant thing I needed in a cultural way was feedback [...] I had to call them and insist on being provided with information*” (Participant 18, female).

Support and education at the EoL

Some caregivers in our sample expressed desire for more emotional support and in-depth education about EoL symptoms. One caregiver stated, “*And in general, perhaps they could have been a bit more sensitive, perhaps when providing guidance on the stages that would come during this hospice period*” (Participant 7, male). Other caregivers wanted more guidance with financial management (e.g., funeral arrangement and managing patient's personal finances) and other resources.

Discussion

This study identified domains from PR caregivers' experiences in home hospice care. In particular, we found that caregivers struggled with certain EoL symptoms, valued family and religion, and reflected on interactions with their hospice providers.

Consistent with the literature (2,5,19,20), the caregivers in our sample struggled with managing loss of appetite, pain, and anxiety and confusion. These symptoms have been commonly reported in hospice research (21,22), which suggests that certain symptoms at EoL are likely distressing for all caregivers regardless of race and ethnicity and that

human needs at EoL are quite similar. While we did not find clear links between cultural values and caregivers' perception of distressing symptoms, existing literature (23-25) suggests that *familismo*, or an emphasis on family loyalty (obligation to provide material/emotional support, and reliance on relatives for help), is an important cultural value in the Hispanic population that influences decisions (26) around managing nutrition and hydration at the EoL (23). Therefore, Hispanic caregivers may feel that feeding is an important part of caregiving, and this belief is challenged with care recipients' loss of appetite. Further research is needed to better elucidate whether these factors truly influence caregivers' perception of distressing symptoms and if these factors are rooted in culture.

Caregivers emphasized the importance of family-centered values and religion in hospice care. Prior studies on Hispanic EoL care reported preferences for family and friends' engagement in their life (27) and for shared family decision making (28). This relates to the *familismo* noted in our participants and implies that family support facilitates hospice patient care by providing assistance with practical tasks as well as reassurance, comfort, and confidence that their needs will be met (27). Participants expressed a desire to include a religious official as a part of their hospice care team. Although some caregivers in our sample received non-denominational support, many caregivers felt that their beliefs were respected and appreciated the religious support from the hospice team. Congruent to our findings, the vast majority (80%) of Hispanics identify as religious (27,29), and religion plays a crucial role in making decisions at the EoL and defining the quality of their hospice experiences (30-32). Spiritual providers in the hospice team may act as an additional conduit of communication, thus providing another way to optimize their care. To improve hospice care for Hispanics, future care models may include supporting family decision making, integrating officials from religions commonly represented in this population, and partnering with local religious institutions.

The participants commented on the importance of communication with hospice providers in their satisfaction with their hospice experience. These patterns may reflect the traditional cultural value of *personalismo*, which has been shown to influence health-related and caregiving behaviors in Hispanic populations (33), especially at the EoL (23,26). *Personalismo* refers to the value of personal relationships, emphasizing the need for supportive, attentive, and caring relationships between caregivers and providers (24,34,35). Similarly, participants in our sample expressed appreciation

for respectful, empathetic, and tailored communication. In some instances, strong *personalismo* may cause caregivers to be skeptical towards non-family providers (34). A subset of caregivers in our sample expressed some of these sentiments and felt that they would have appreciated increased communication, support, and education. Given the importance of this value, hospice providers should strive to understand and incorporate it into their care practices to effectively support Hispanic caregivers. Building this awareness is crucial, especially considering that Hispanic caregivers may initially harbor mistrust towards providers at the start of hospice care. This aligns with existing literature suggesting that effective EoL care and advance care planning go beyond mere language translation to encompassing the acknowledgment of user's cultural backgrounds and local healthcare customs (28,36,37). Therefore, implementing more frequent visits and check-ins with a consistent care team may help address some of these concerns.

This study had certain limitations. The generalizability of our findings is limited given the sample size. Although PRs make up 9% of the population and are the second largest Hispanic population in the U.S. (7,8), our participants were recruited from hospices in Puerto Rico, which may have different levels of acculturation when compared to caregivers living in the U.S. Thus, the experiences of PR caregivers in our sample may not represent the lived experiences of other Hispanic caregivers. However, we feel that this study provides a unique glimpse into the experiences of PR hospice caregivers and that future studies are needed to understand the experience of different Hispanic subgroups. Results may be subject to recall bias due to data collection 3 to 8 months after bereavement and social desirability bias due to the personal nature of one-on-one interviews. The recruitment rate of 38% and dropout rate of 11% also pose a risk for nonresponse and sampling biases but are similar to other studies that recruit from a hospice setting (27,38-40). Despite these limitations, this study is an important start to understand PR caregivers and has implications for Hispanic hospice care.

Based on our findings, culturally tailored interventions that focus on managing loss of appetite, pain, agitation, and confusion may reduce burden among PR caregivers in home hospice. Hospice providers should also take into consideration strong family-centered values and religious preferences that may influence the care needs of this group of caregivers. It is essential for hospice providers to identify and support Hispanic patients and their family member's

cultural values, health beliefs, and care preferences. It is also necessary for providers to include family members when communicating with and providing support to patients, which may impact patients' EoL care. Given that symptom management, family-centered with religious support, and interactions with hospice providers are elements that influence hospice care, researchers should examine the specific ways that facilitate providing high-quality culturally tailored EoL care to Hispanic caregivers.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the IRB

at VNS Health (#1416823-29), WCM (#22-04024661), and Johns Hopkins (#00350937) and informed consent was obtained from all individual participants.

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Table S1 Representative quotes by domains and sub-domains

Domains	Sub-domains	Quotes
Symptom management	Loss of appetite	<i>"I thought that maybe the cancer wouldn't kill my mom, but dehydration or malnutrition might. [...] Perhaps if I had known in advance that the person is at the point where the body does not ask for food or drink and is closer to death, I would have had a different perspective..."</i> (Participant 7, male)
		<i>"The most difficult one was when they put the nasogastric tube, she had it for a week or less, it was a little difficult for me to see her in that state, to see how she was deteriorating rapidly. I think that was the most painful detail, [...] having to feed her through that tube in her nose was something very painful. It even seemed impossible to me [...]"</i> (Participant 19, female)
	Pain	<i>"What hurt me the most was that he had so much pain. [...] And he was always in a lot of pain. And I saw him like that, and it hurt me because I couldn't help him, no matter how much I wanted to."</i> (Participant 9, female)
		<i>"She would scream as if she was in pain, but it seemed like she was doing it for attention, but I don't know."</i> (Participant 18, female)
Anxiety and confusion	Anxiety and confusion	<i>"The biggest challenge with my mom was that she was a person who didn't complain about pain. [...] It can even be counterproductive because a person who is not telling you 'it hurts here' or 'it hurts there' when they are hospitalized, and you try to explain to the doctors why you brought them there, everything is more difficult. Because my mom was always a strong woman who did not complain about physical pain often, and she had a high pain tolerance... and I think that worked against her when we were taking care of her because she wouldn't tell us 'this hurts' or 'that hurts'."</i> (Participant 9, male)
		<i>"It was her confusion, not knowing where she was... That creates a lot of difficulties because the person is going to become reluctant to receive the necessary attention and care"</i> (Participant 7, male)
	Anxiety and confusion	<i>"He already felt like he wanted to go and couldn't, because apparently, from what I could understand, he thought he was going to leave me alone, and that made him feel very anxious."</i> (Participant 9, female)
		<i>"Then he also started to have- he didn't say it as such, the fear of leaving. That fear that comes, I think, of already leaving and so, we didn't leave him alone, because he would grab our hands and I had to... many times I had to sleep all night holding his hand, you know, when he let go a little, he would look for it, move his hand to grab our hand again."</i> (Participant 8, female)
Cultural and religious values	Family-centered values	<i>"As caregivers, we must instill values from home, such as caring, respect for our loved ones, and the love we feel for them"</i> (Participant 19, female)
		<i>"...Puerto Ricans in general, culturally, are attached to their loved ones. We generally want to be there"</i> (Participant 18, female)
	Religious support	<i>"My mom was a Christian and as for us, my sister is a pastor, so she provided very attentive care. She would call her often in the mornings to cover the spiritual and emotional areas as well. Because we are afraid of the unknown."</i> (Participant 14, female)
		<i>"we told them what religion my mother was, and [hospice] adapted to that... they even brought a minister for us"</i> (Participant 11, female)
Religious support	<i>"the [hospice chaplain] would come and pray with him and talk to him very well... And I believe all of that is very important for a person who believes in God..."</i> (Participant 9, female)	
	<i>"And since we don't know what will happen when we die, or even as Christians, we don't know if we will be with the Lord. My sister worked on all those fears and situations with my mom. But we also had the visit of the chaplain."</i> (Participant 14, female)	
Interaction with hospice providers	Communication with hospice providers	<i>"Most of us, Puerto Ricans are mainly Christians, by belief and culture. [...] But having that moral guide, that spiritual guide, at least in Puerto Rico, I think that's important because as a culture and as a society, we predominantly do not lean towards other beliefs apart from Christianity. [...] Well, [hospice providers] should focus on that area, I understand that it is quite important that they lean towards or take you to that type of belief or that type of ideal or ideology [...]"</i> (Participant 7, male)
		<i>"When the nurse would go see my mom, she always found a way to explain the details to me and tell me what I needed to do with my mom in a way that I could understand"</i> (Participant 19, female)
	Support and education at end-of-life	<i>"...the most relevant thing I needed in a cultural way was feedback [...] I had to call them and insist on being provided with information"</i> (Participant 18, female)
		<i>"Latinos are very spiritual, very religious, and the spirituality was very good. In that way, they took care of us, especially of my dad, because he was a deacon. [...] There was [...] that hug without hugging. That affection, they make you feel appreciated from the first call [...] Everything they explained to me had been [...] with that touch of [...] understanding, with empathy. [...] They had a lot of empathy, that warmth—the human warmth that Puerto Ricans always look for—as if they cuddle you in a way, because that's how we Puerto Ricans are, and the spirituality,"</i> (Participant 8, female)
Support and education at end-of-life	<i>"And in general, perhaps they could have been a bit more sensitive, perhaps when providing guidance on the stages that would come during this hospice period"</i> (Participant 7, male)	
	<i>"They didn't tell me about the financial aspect, that when he dies, the funeral home takes him and they give part of it to Social Security, they close everything and then we're left without money. Fortunately, we were able to withdraw money from another [non-hospice] person who told us, 'Withdraw money, because once the funeral home takes it, the bank closes everything and you have no way to withdraw money for the funeral.'" (Participant 8, female)</i>	