

Peer Review File

Article Information: <https://dx.doi.org/10.21037/apm-24-24>

Reviewer A

First, I'd like to thank the authors for conducting this interesting research. I recognize the importance of gaining deeper insights into the experiences of Puerto Rican caregivers. However, in order for this report to be considered for publication, I believe major revisions to be warranted. Please find below my suggestions to improve the report. Furthermore, I would like to suggest that the authors have their paper edited by a professional in order to improve readability.

Title:

Comment 1: The title does not make immediately clear what the research is about. An alternative could be 'Understanding the home hospice experience of Puerto Rican caregivers'.

Reply: Thank you for your input. We have taken your suggestion for the alternative title.

Changes in the text: We have changed the title to "Understanding the home hospice experience of Puerto Rican caregivers."

Introduction:

Comment 2: Much of the literature addressed in the introduction and discussion relates to Hispanic caregivers living in the US as an ethnic minority (e.g., no. 6, 27). However, as far as I understand, the current study takes place in Puerto Rico. I believe these to be two different contexts. Therefore, the introduction is in need of more explanation on the relevance of investigating the experiences of Puerto Rican caregivers in Puerto Rico as these experiences may be different from Puerto Rican caregivers living in the US.

Reply: Thank you for your comments. One reason we focused on examining PR caregivers is to understand the nuances in culture/religion in a particular Hispanic subgroup. We have made this more apparent in the introduction as to why we focused on the Puerto Rican population. Given that the cohort of participants for this brief report was Puerto Rican caregivers living in Puerto Rico, we have added this as a limitation in the discussion section.

Changes in the text:

Introduction section

"Puerto Ricans make up the second largest Hispanic subgroup (7,8), and studies have shown that Puerto Ricans have poorer health than other U.S. Hispanic and non-Hispanic populations. Yet, the challenges experienced by Puerto Rican (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)." (p. 3, lines 53-59)

Discussion section

"Although Puerto Ricans 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.” (p. 11, lines 235-239).

Comment 3. Line 51: ‘the challenges experienced by racial and ethnic groups have not been studied adequately’. This statement is based on one paper published in 2013. Since then, much literature has been conducted, also on this particular topic.

Reply: We have revised the introduction to acknowledge that more research has been conducted on this topic in recent years. We have added more recent citations to the introduction section (a survey analysis from 2017 and literature reviews from 2022 and 2017).

Changes in the text:

Introduction section

“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 make up the second largest Hispanic subgroup (7,8), and studies have shown that Puerto Ricans have poorer health than other U.S. Hispanic and non-Hispanic populations. Yet, the challenges experienced by Puerto Rican (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).” (p. 3, lines 49-59).

Comment 4. The three domains (symptom management, cultural values, religion) can be better introduced in the introduction. Why were these three domains selected? Are these especially relevant to the target population and if so, why? Especially with symptom management I am not sure why it is important to investigate this in the target population. Why might this be different for Puerto Rican caregivers?

Reply: We decided to focus one aspect of the study on symptom management because it plays a major role in hospice care, and we wanted to explore whether cultural values may impact caregivers’ perceptions of suffering at the end of life. In addition, hospice care is focused on comfort, and in many cases, family caregivers are responsible for managing symptoms when their loved one receives home hospice care. Regarding religion and culture, the literature suggests that certain ethnic/racial groups receive less religious support. Therefore, we also wanted to explore culture and religion to understand whether those factors influenced or impacted caregivers’ hospice experience.

Comment 5: Lines 65-70: I believe some of the information in this paragraph belongs in the methods section: ‘we collaborated with two hospices in Puerto Rico’ and ‘through interviews with bereaved family caregivers’ and ‘exploratory study’ and ‘We present this article in accordance with the SRQR reporting checklist’.

Reply:

The author guidelines for this journal required that we include the following statement at the end of the introduction: “We present this article in accordance with the SRQR reporting checklist.” We have moved the other parts from the Introduction to the Methods section.

Changes in the text:

Introduction section

We have deleted “For this brief report, we collaborated with two hospices in Puerto Rico to understand the medical, sociocultural, and religious factors that impact the hospice experience. Through interviews with bereaved family caregivers,” from the introduction.

Methods section

We have revised the the following sentences to include the deleted information:

“The study team collaborated with two hospice organizations in Puerto Rico to conduct interviews with bereaved family caregivers.” (p. 4, lines 78-79)

“NVivo 12 software was used for qualitative analysis (18).” (p. 6, line118)

Methods:

Comment 6: As mentioned in comment no.4, the collaboration with Puerto Rican hospices should be addressed in this section. The collaboration could also be explained more. Were the participants recruited through those two hospices? Furthermore, I wonder whether ‘hospice care services’ would be a better term.

Reply:

We have changed the term “hospice care services” to “hospice organizations,” which better reflects the context of the study. The decision to work with the two hospice organizations in Puerto Rico was based on existing research collaboration between them and members of our research team. The hospice organization provided a list of potential participants based on nurse referrals to our research team. A Spanish-speaking member of our research team recruited the caregivers via phone call. We have revised two parts of the Methods section to clarify this recruitment process and refer to the collaborators as hospice organizations.

Changes to the text:

Methods section

“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.” (p. 4, lines 78-80)

“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 (Blinded for Review) on the team called caregivers, informed them about the study, and screened them for eligibility.” (p. 4-5, lines 88-92)

Comment 7: Line 100-101: Why were the transcripts translated? Did the researchers analyzing the data not speak Spanish? How did you ensure that the translation was as accurate as possible? Was it done professionally?

Reply:

Transcripts were translated professionally using a service called CaptionSync. A Spanish-speaking member of our team, who also conducted the interviews, reviewed the translations to ensure accuracy. The translation was necessary for analysis by research team members who did not speak Spanish and for submitting the results to an English-language journal.

Changes in the text:

Methods section

“Interviews were audio recorded, professionally transcribed in Spanish and translated to English, de-identified, and reviewed for accuracy. A Spanish-speaking member (MDB) 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.” (p. 5, lines 104-108)

Comment 8: Line 103-104: Please clarify how the preliminary codebook was developed. Was it based on the analysis of the first interview? Or was an initial codebook developed even before analyzing the first interview? In the latter case, I would not describe this to be inductive, but rather deductive. If deductive, it would raise the question what this preliminary codebook was based upon.

Reply:

We have revised the text to clarify the inductive coding process we utilized in this study. The codes were developed during the coding process; we did not develop a framework or codebook before analyzing the interviews. The ‘preliminary codebook’ refers to the set of codes inductively developed after analyzing the first interview, which were revised and added to throughout the coding process. However, given that this phrase could be confusing, we have removed it from the text.

Changes in the text:

Methods section

“Codes were developed inductively and revised throughout the data analysis process.” (p. 5, lines 110-111)

Comment 9: Line 112: I would suggest deleting ‘and/or themes’. Themes are used in the context of other qualitative methods than are employed in this study. (the same goes for lines 185 and 203).

Reply: We have revised the three lines so that it no longer says “themes.”

Changes in the text:

Methods section.

We replaced “and/or themes” with “categories.” (p.6, line 117)

We replaced “themes” with “domains.” (p.9, line 185)

We replaced “themes” with “patterns.” (p.10, line 217)

Results:

Comment 10: Table 2: If possible, providing information on the specific diseases afflicting the patients would be valuable. For example, if the majority of patients had dementia, this may have colored the results.

Reply: We have added patient’s terminal hospice diagnosis to Table 1.

Changes in the text:

The following section was added to Table 2:

Patient Terminal Diagnosis		
Cancer	4	(50.0)
Pulmonary disease	2	(25.0)

Vascular disease	1	(12.5)
Neurological disease	1	(12.5)

Comment 11: Regarding section ‘symptom management’: Three patient symptoms are highlighted here as challenging. However, I am missing some information on their experiences with the contact with healthcare providers in dealing with those symptoms.

Reply: While every care for every patient and caregiver varies based on their unique hospice situation, we obtained general contact hospice staff make with patients/caregivers. We have added this to the Methods section to give readers a sense of the general practice of these hospices regarding frequency of visits.

Changes in the text:

Methods section

“On average, hospice nurses visited patients twice a week, while chaplains and social workers visited once a month” (p.4, lines 85-86)

Comment 12: Regarding section ‘symptom management’: As mentioned at number 3, I am uncertain about the relevance of this aspect of the research objective. If the section is retained, I would appreciate more insight into the Puerto Rican perspective on symptom management. Were these symptoms especially distressing for Puerto Ricans due to their cultural / religious values? The results as they are described now are quite general and could apply to any population.

Reply:

Thank you for your comments around the results generated from our symptom management analysis. Please see comment 4 regarding our reasoning behind exploring symptom management in this cohort. While one of our exploratory objectives was to explore whether cultural values may have impacted caregivers’ perception of suffering at the end of life, we did not find clear links between the two. However, many of the distressing symptoms reported by Puerto Rican caregivers are also distressing to caregivers from other racial/ethnic groups which we talk about in the discussion section. While these are not novel findings, it does suggest that certain symptoms at the end of life (e.g., lack of appetite, pain, confusion) are likely distressing for all caregivers, regardless of race/ethnicity. We have added this comment in the discussion section but also hypothesize potential cultural factors (based on existing literature) that may contribute to the results we found.

Changes in the text:

Discussion section

“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.” (p.9, lines 188-200)

Comment 13: Regarding section ‘Cultural values’: I do not immediately see the connection between ‘communication from hospice providers’ and ‘support and education at the EoL’ with ‘Cultural values’. This connection should be made clear. If there is no clear connection, the authors may want to consider restructuring the results section. Perhaps ‘Contact with healthcare providers’ should be a separate heading rather than a subheading. Cultural values and religion, in turn, may be combined into one section. In relation to the section ‘symptom management’, see comments no. 3 and 11.

Reply: Thank you for your thoughts on this section. We have restructured the results section to address this issue. Given the content in those categories, we have ‘communication from hospice providers’ and ‘support and education at the EoL’ under the umbrella of “Interactions with hospice providers.”

Changes in the text:

Results section

“Interaction with Hospice Providers

Communication with Hospice Providers

[...]

Support and Education at the EoL...” (p.8, lines 166-183)

Comment 14: Regarding section ‘Religion’: I am wondering whether it is possible to delve deeper into this topic. What makes religion so important in the lives of Puerto Rican caregivers, especially at their loved ones’ end-of-life? And what did the religious support from the healthcare providers look like? How did the caregivers feel when such support was lacking?

Reply: Thank you for this comment. We found that religion was an important aspect of caregivers’ lives but did not see any particular categories that focused on a particular belief or value that was a common thread among caregivers. The religious support from hospice is described in the methods section (please see response to comment 11). We did not have any participants who expressed a lack of religious support in our study.

Discussion:

Comment 15: The discussion may need some restructuring. I suggest starting the discussion with a few sentences summarizing all results and afterwards move on to a comparison with existing literature.

Reply: We made some modifications to the start of the discussion that summarizes the study's findings.

Changes in the text:

Discussion section

“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.” (p.9, lines 185-187)

Comment 16: Lines 190-192: A nice point is being made here that I think can be elaborated upon by putting it into the context of the results of this study as the results section describes a struggle with loss of appetite and also the family-centered values. Did you see a link between the two in the interviews? If so, please describe in the results section and reflect upon that in the discussion section.

Reply:

We did not see a clear linkage between family centered values and loss of appetite and have clarified this in the discussion section. We do present existing literature to inform the readers about is known around this topic, but call for future studies to better elucidate how cultural factors influence to role of eating at the EoL.

Changes in the text:

Discussion section

“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.” (p.9, lines 192-200)

Comment 17: Lines 193-201: The point being made here relates to co-occurrence of pain with agitation and restlessness. However, this is not addressed in the results section. I would suggest deleting this part. Unless the results of this study indicate that Puerto Ricans struggled with the co-occurrence of these symptoms, but then that should be addressed in the results section.

Reply: Thank you for highlighting this point. We deleted this particular part of the discussion.

Reviewer B

Comment 1: There are many studies like this one but the unique factor is that it is focused of Puerto Rico. This study is very simple with basic conclusions that are known from other studies. It is also possible the needs of human at the end-of-life are quite similar. A lot could be done to connect with other literature but the article appears to achieve what it aims. The title is awkward and it appears you are making a list 1, 2.

Puerto Rican caregivers’ symptom management, 1 cultural, and religious 2 experiences with hospice care

APA says number less than 10 are written out:

Puerto Rican caregivers’ symptom management, one cultural, and religious one experiences with hospice care

This much more readable

Reply: We have changed the title to make it more readable and less like a list.

Changes in the text: We have changed the title to “Understanding the home hospice experience of Puerto Rican caregivers.”