

# BMJ Open Challenges and facilitators of hospice decision-making: a retrospective review of family caregivers of home hospice patients in a rural US–Mexico border region – a qualitative study

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## ABSTRACT

**Objectives** Hospice care (HC) is seen as a comprehensive approach, that enhances quality of end-of-life (EOL) care, for terminally ill patients. Despite its positive aspects, HC enrolment is disproportionate for rural patients, who are less likely to use HC in comparison to their urban counterparts. The purpose of this study was to explore decision-making experiences, related to utilisation of HC programmes from a retrospective perspective, with family caregivers (FCGs) in a rural US–Mexico border region.

**Design** This qualitative study was conducted from May 2017 to January 2018 using semistructured face to face interviews with FCGs. Data were analysed using thematic analysis.

**Setting** The HC programme was situated at a local home health agency, located in rural Southern California, USA.

**Participants** Twenty-eight informal FCGs of patients who were actively enrolled in the HC programme agreed to participate in the study.

**Results** Conversation about HC as an option was initiated by home healthcare staff (39.3%), followed by physicians (32.1%). Emerging themes related to challenges in utilisation of HC and decision-making included: (1) communication barriers; (2) lack of knowledge/misperception about HC; (3) emotional difficulties, including fear of losing their patient, doubt and uncertainty about the decision, denial and (4) patients are not ready for HC. Facilitators included: (1) patient's known EOL wishes; (2) FCG-physician EOL communication; (3) the patient's deteriorating health and (4) home as the place for death.

**Conclusions** HC patients' FCGs in this rural region reported a lack of knowledge or misunderstanding of HC. It is recommended that healthcare providers need to actively engage family members in patient's EOL care planning. Optimal transition to an HC programme can be facilitated when FCGs are informed and have a clear understanding about patients' medical status along with information about HC.

## INTRODUCTION

With an ageing population in the USA, and an increased life expectancy, there is an emergent need to address quality of end-of-life (EOL) care.<sup>1</sup> Hospice care (HC) is the

## Strengths and limitations of this study

- A qualitative methodology approach is helpful in gaining an in-depth understanding and meaning of family caregivers' (FCGs') experiences, in decision-making when using hospice care (HC).
- To our knowledge, this is the first study exploring decision-making to use HC among rural FCGs in the US–Mexico border region.
- Findings from this study provide a greater insight, as to the extent to which FCGs understand HC as a resource and engage in end-of-life (EOL) communication with the patients' physicians.
- In this study, we only included FCGs; therefore, it would be meaningful for future studies to include patients within a dyad design, which may provide different perspectives that can help increase quality of EOL care for this population.

interprofessional, multidimensional care, that provides a wide range of services, including pain and symptom management, bereavement services, psychosocial and spiritual care, for families and patients with a terminal status (less than 6 months life expectancy).<sup>2</sup> HC is an optimal care that provides a holistic approach in response to a patient's physical, psychological, social and spiritual needs.<sup>3,4</sup> Use of hospice services for patients and their families has been found to improve satisfaction with quality of their healthcare<sup>5,6</sup>; an increase in the likelihood that patients' wishes will be followed<sup>3</sup>; a decrease in rates of patients' intensive care admissions and a reduction in the receipt of invasive procedures.<sup>7</sup> Despite the benefits of HC, under-utilisation still remains a concern. Factors contributing to hospice related decision-making, have been identified at the individual level (ie, patient and family's lack of knowledge, attitudes and beliefs toward HC), interpersonal level (ie,

patient-provider relationship) and structural or macro level (ie, health insurance reimbursement).<sup>8–11</sup> Mostly, these challenges do not occur one at a time; rather, their interplay results in a web of complex constraints that complicates the decision-making process.<sup>9</sup>

Family members are often closely involved in decision-making for EOL care for their loved ones. HC decision making is complex, especially when a patient is incapacitated and unable to express their own wishes for care.<sup>12</sup> Family caregivers (FCGs) often experience emotional challenges such as burden, guilt and self-doubt, about whether they are making the right decision for their loved-ones.<sup>13 14</sup> Family conflict may arise during this time, which can impact decisions for HC utilisation.<sup>15</sup> Timing of decision-making is particularly important for enrolment in HC programmes, especially when the focus of treatments shift from curative to comfort care, for patients who may have less than 6 months to live. While both HC and palliative care provide symptom management to relieve suffering, the provision of HC shifts the focus of medical treatment to symptom management.<sup>16</sup> Notably, decisions around accepting HC are somewhat different than enrolling in palliative care, because patients no longer receive life-prolonging or curative treatments in HC.<sup>16</sup>

For patients and families who live in rural regions, there is often a lack of healthcare resources and supportive care, including limited access to hospice and specialised healthcare; thus, leaving patients and caregivers with additional healthcare challenges.<sup>17 18</sup> Such obstacles may be compounded for racial/ethnic minorities (eg, Latinos), who have language barriers and unique cultural norm relating to EOL decision-making.<sup>19 20</sup> Evidence suggests that Latinos present a lack of knowledge or lack of information about HC,<sup>21 22</sup> and are less likely to have an intention or to use HC.<sup>21 23 24</sup> Cultural values such as family-centred care, with specific FCG responsibilities and secrecy about prognosis, is seen as an attempt to protect patients from emotional harm. This form of values and beliefs about the use of HC, may also affect their perception toward HC, and EOL decision-making.<sup>24 25</sup> Rural Latinos living in US–Mexico border region, generally encounter structural challenges that include a lack of insurance, transportation issues, language barriers and a low-health literacy.<sup>19 20 26</sup> These factors might negatively impact coordination of care, for transitioning from active care to HC, which can result in delaying hospice referrals. Lack of EOL care planning and late referrals to HC, increases the caregivers' unmet needs and concerns, and an overall low satisfaction with HC.<sup>27 28</sup> Most research on this topic examined caregiver burden, unmet needs and an impact of the caregiver's personal well-being.<sup>29–31</sup> However, there is a paucity of information about factors that facilitate or hinder their decisions to use HC, particularly among caregivers of rural Latino patients.

Social and cultural contexts contribute to a unique understanding of the cause (aetiology), course (symptomatology) and cure (appropriate treatment or response) of illness.<sup>32</sup> Explanatory models,<sup>32 33</sup> offer a useful framework

for exploring sociocultural experiences of families affected by terminal illness, such as the cause, process and response to terminal illness, among patients residing in rural regions. While a review of cultural conceptualisations of HC found more similarities than differences across culturally diverse populations,<sup>34</sup> research on HC decision-making, has not yet examined experiences among residents in rural US–Mexico border regions. In light of the paucity of evidence on this topic, our aim was to explore challenges and facilitators, involved in the decision-making process for HC utilisation, from the FCG's perspectives. Given the complex nature of EOL care and HC related decision-making, there was a need to explore diverse perspectives of FCGs, in order to better understand the multifaceted factors that may be related to the social and cultural contexts of care, for this vulnerable population. This study explored participants' decision-making experiences, related to utilisation of HC programmes from a retrospective perspective with FCGs residing in a rural US–Mexico border region.

## METHODS

We followed the Standards for Reporting Qualitative Research reporting guideline to write this paper.<sup>35</sup>

### Study design and setting

This study used qualitative methodology and employed semistructured interviews to explore FCGs' challenges and facilitators related to decision-making, in the utilisation of HC from a retrospective perspective. All patients were enrolled and actively receiving hospice services from a large home health agency, that provides in-home healthcare services in a rural region, located in the most socioeconomically disadvantaged county in Southern California.

### Subject and recruitment procedures

Purposive sampling<sup>36</sup> was used to recruit FCGs. Although we included both Latino and non-Hispanic white caregivers, mirroring the population proportion in the region, our study goal was not to compare racial/ethnic experiences by group. Eligibility criteria included FCGs who were 18 years and older; were cognitively competent and were currently providing care for patients. During patient home visits, HC staff members presented a flyer, which described the research study to FCGs. Those interested in participating provided their contact information to the staff members. Of the 53 caregivers who expressed interest in participating, 7 later declined to participate; 5 requested rescheduling the appointment, but did not answer the follow-up phone call; 5 could not be reached (no answer) and 7 patients passed away prior to their caregivers making an appointment. A total of 29 individual FCGs participated in the study; however, one participant was removed due to insufficient data, resulting in a total of 28 participants.

### Patient and public involvement

There was no patient or public involvement in the development of the research design or in conducting the study.

**Table 1** Interview guides

A priori concepts	Questions
Timing of decision-making for HC	Question 1: Describe how the hospice decision was made. <ul style="list-style-type: none"> <li>▶ Were there any delays in hospice decision-making process? Please describe them.</li> <li>▶ What factors contributed to making immediate/delayed decisions for your loved one?</li> </ul>
Family caregiver–physician communication	Question 1: Describe your communication with the patient’s physician regarding HC. <ul style="list-style-type: none"> <li>▶ Was it adequate? (please describe)</li> <li>▶ Was it on time? (please describe)</li> </ul>
Communication among family members	Question 1: Describe your communication with your family around HC. Question 2: Describe conflict, if any, on hospice decision-making.

HC, hospice care.

### Data collection

Data were collected via face-to-face interview method by a trained bilingual/bicultural research assistant from May 2017 to January 2018. Interviews were conducted in the FCG’s or patient’s home, using a semistructured interview guide, which was based on previous literature on HC decision-making (see table 1). Questions in the interview guide explored FCGs’ perceptions and experiences, of decision-making for utilisation of HC, in particular as it relates to HC related communication with physicians, patients and with their family members.<sup>15 25</sup> In order to assess the extent of involvement in decision-making for HC, we also assessed caregiver-provider communication (who informed them of the patient’s incurable condition and initiated the hospice communication).<sup>37</sup> Each interview took approximately 30–40 min, and was conducted in either Spanish or English language. Participants’ non-verbal behaviours (ie, facial expression, body language and difficulty of articulation) were reported in the transcripts as field notes, that were later used to add contextual meaning during analysis. The researcher also engaged in debriefing sessions with the research assistant in order to examine any event or circumstances (ie, interruption during the interview) that could have impacted quality of the interviews. All qualitative interviews were audio-taped and transcribed verbatim into Microsoft Word documents. Researchers listened to audios and read the transcripts line-by-line in order to come up with initial codes before importing the transcripts into NVivo<sup>38</sup> for further analysis and data management purposes, as described below.

### Researcher characteristic and reflexivity

This study was conducted by researchers across disciplines in the health and human services, including social

work, nursing and public health. With this representation from the *helping professions*, we were careful not to impose our assumptions and presuppositions of the healthcare system and HC, when developing the interview guide and interpreting the data. The bilingual/bicultural researcher and research assistant who conducted the interviews, took care in being objective and to not ‘fill in’ words for participants, which might seem natural when relating to one’s own sociocultural background, and its contexts that is most similar for each team member. Also aligned with our professional standards, this research was designed to give voice to participants’ and to honour their experiences, as unique or common as it might seem to them.

### Data analysis

Thematic analysis processes delineated by Braun and Clarke<sup>39</sup> was used for analysis in this study. Authors (EK and DF) immersed themselves in the data by actively reading the 28 transcripts line-by-line multiple times, searching for patterns and meanings. Hand-written notes and early impressions were documented independently, by categorising concepts that emerged during the data analysis process. An initial list of codes was generated independently to meaningfully and systematically organise the data after the categorisation process. Disagreements in assignment or description of codes were resolved through discussion and consensus. The final list of codes was entered into QSR NVivo to organise the text into codes and categories, thus facilitating and leading to theme refinement. Through this iterative process of refinement of the initial themes, subthemes and a more in-depth meaning emerged of the participants’ experiences.

## RESULTS

### Characteristics of participants

Tables 2 and 3 describe the FCGs’ sociodemographic and HC related variables, respectively. The average age of the caregivers was 60.7, with the majority being women (n=28, 82.1%). More than two-thirds self-identified themselves as Latino/Hispanic (n=19, 67.9%), with one-fourth of the participants (n=7, 25%) preferring Spanish language for the interview. The majority of participants were adult children of the patients (n=21, 75%), followed by spouses (n=6, 21.4%). About 71% (n=20) of the caregivers lived with HC patients, and those who did not (n=6), lived within 12 miles of the patients’ homes. Almost all were active participants in providing HC for the patients.

### EOL care related information

Approximately half of the participants (n=15, 53.6%) had engaged in a discussion with a physician about HC. Only one-fourth of the FCGs (n=7, 25%) were informed of the patients’ life expectancy. Notably, about 61% (n=17) of the participants reported, that patients were cognitively impaired at the time. More than half of the FCGs (n=15, 53.6%) believed, that their patients were not aware of their terminal status. Majority of participants were informed

**Table 2** Participant characteristics

ID	Gender	Age range (years)	Relationship to the patient
1	M	61–70	Son
2	F	21–30	Great grand daughter
3	F	81–90	Wife
4	F	61–70	Daughter
5	F	61–70	Daughter
6	F	51–60	Daughter
7	F	51–60	Daughter
8	F	51–60	Daughter
9	F	61–70	Daughter
10	F	61–70	Daughter
12	F	51–60	Daughter
13	F	81–90	Wife
14	F	51–60	Daughter
15	M	71–80	Husband
16	F	41–50	Daughter
17	F	61–70	Wife
18	F	41–50	Daughter
19	F	51–60	Daughter
20	M	41–50	Son
21	F	51–60	Daughter
22	F	61–70	Wife
23	M	91–100	Husband
24	F	61–70	Daughter
25	F	71–80	Daughter
26	F	51–60	Daughter
27	F	61–70	Daughter
28	M	51–60	Son
29	F	41–50	Daughter

about patient's incurable condition by a primary care physician (n=11), followed by a hospitalist including Emergency Room (ER) doctors (n=8) and other healthcare staff members (eg, hospice staff) (n=5). Additionally, the provider who introduced HC as an option was most often the home care staff (39.3%), followed by the physician (32.1%) (see table 3).

### Qualitative themes/subthemes

The most common themes related to challenges and facilitators that emerged from our analysis are presented below, followed by the less common themes.

### Challenges in decision-making for using HC

#### Communication barriers

Participants identified a lack of EOL communication with their patients' physicians; hence, they felt inadequately prepared for making HC related decisions. Even for those who engaged in HC communication, information

**Table 3** Hospice care related variables (n=28)

Variables	n (%)
Hospice discussion between caregivers and patient's physician	
Yes	15 (53.6)
No	13 (46.4)
Life expectancy being informed	
Yes	7 (25)
No	21 (75)
Patients' mental status at the time of hospice referral	
Competent	11 (39.3)
Impaired	17 (60.7)
How well did the patient understand of his/her terminal condition?	
Not at all	15 (53.6)
Somewhat	2 (7.1)
Fairly/very well	11 (39.3)
Who informed you that the patient's illness could not be cured?	
Primary care physician	11 (39.3)
Hospitalists	8 (28.6)
Specialists (ie, oncologist, cardiologist, neurologist)	4 (14.3)
Other healthcare staff (eg, hospice staff)	5 (17.9)
Who first initiated the conversation about hospice as an option?	
Family member	5 (17.9)
Home healthcare staff	11 (39.3)
Physician	9 (32.1)
Other	3 (10.7)

processing remained challenging due to a lack of clarity in their explanation:

They have too many patients so all they do is go in there and they check them, saying you're fine, and then you are out ... I don't think the conversation [with the physician] is really a conversation. They are too busy ... and you know sometimes we have questions and we don't see them [physician]. (#5, Daughter)

Difficulty with understanding medical jargon led to other challenges in communication with physicians. For rural populations with limited English-language proficiency, and low-health literacy, providers could have offered additional support to patients and their families, by tailoring health communication and adapting interventions for linguistic/cultural concordant communication:

Talk to us with understandable terms because sometimes they use medical terms that we do not understand. (#17, Wife)

Another participant recalled the introduction of HC was from home health agency, not from a physician. A referral to HC must be approved by a physician with the patient's or family's consent; however, HC communication did not always take place with the physician. Communication regarding HC referrals was made by the physician via a home health or HC staff (eg, nurse), who then initiated EOL/HC communication with FCGs:

We ended up going through the home health and they were the first ones to bring it up. So that's why I think for whatever reason, there's a big disconnect with the doctors. (#28, Son)

#### Lack of knowledge/misperceptions about HC

As previously reported elsewhere,<sup>11 30 40</sup> our participants were unaware of HC, which then hindered their ability to make decisions about hospice for their loved ones. As expressed by a participant,

I didn't really know what hospice care was. It made it difficult to make a decision. (#26, Daughter)

Participants thought hospice was strictly for patients who were expecting an imminent death. The concept of HC and the term used regarding hospice has often been misunderstood by Latinos. The word 'hospice' in Spanish refers to an infirmary setting, such as an institution or other restrictive place,<sup>25 41</sup> which is different than the meaning of hospice provided in the US healthcare system:

I had the wrong information of the word hospice ... it [hospice] meant that death was already going to arrive and they were already going to die. (#22, Wife)

#### Emotional difficulties

Participants experienced a range of emotions in their decision-making processes, which at times delayed the ultimate decision for utilisation of HC. Emotional difficulties related to HC, included the fear of losing their family member, doubt/uncertainty and denial of their loved one's impending death.

#### Fear about losing their loved one

Just simply with the word 'terminal', one gets nervous, you start to imagine the worst, that's why it was difficult to think about putting him in [hospice]. (#6, Daughter)

Hospice placement meant accepting their patient's impending death.

It was very difficult for me because it is like one does not want to accept what is coming, one does not want to get used to the idea that the end will come, so one does not want to lose their family member. (#22, Wife)

#### Doubt and uncertainty about the decision

Hospice admission, which limits acute care options, was troublesome for some participants who considered this action as giving up on their loved one:

The doctor talked to me about hospice during the day of the last visit. He said that my mom was terminal ... I agreed and we did apply for the hospice. I could say on the third or fourth day, I was not sure whether I was doing the right thing or not ... Um, because they told me that once she is in hospice, I cannot go to the hospital or call 911 ... that was kind of difficult. (#19, Daughter)

#### Denial

The word hospice resonates with death when family has a conflict in realising the patient's terminal condition. Family members' reluctance to accept their loved one's terminal diagnosis was an obstacle for a smooth transition to HC:

I heard about hospice, um, eight months ago ... I brought it (hospice care) up with my family members. They were like, 'No way. That's for people that are dying. My dad is not dying, you know, what are you talking about?' I think it's just been really hard for them to let go, to accept that the situation ... (#21, Daughter)

#### Patients are not ready for HC

The perceived 'right time' or 'being ready' for utilisation of HC was contingent on the FCGs' subjective estimation of life expectancy. Some participants projected their loved one's life expectancy was longer than what they were told:

I knew that my mom was going to live a little bit longer. (#9, Daughter)

Other participants used the patient's physical appearance in comparison to other family members, who had previously used HC as an index in making HC related decisions:

My uncle had gone into hospice in December a year and a half ago. He was really bad. When I found out what hospice meant that they gave them primarily pain medication but no fluids or foods (artificially), I didn't think that she [mom] was that far gone. (#4, Daughter)

One participant reported delaying the decision for a hospice referral, due to a previous experience with the healthcare provider's inaccurate estimate of the patient's life expectancy, which confirmed her belief about premature hospice-referral:

She was in hospice for about a month, maybe two months. In one of the RN visits, she [nurse] just came and told me that I need to gather my family because my mother had about 3 days left, so I should start calling the family so they could just say their

goodbyes, which turned out not to be true, because it has been four years of that ... You know, I thought that my mom was not ready for hospice ... in my mind hospice is for terminal patients, and my mother was not terminal. I still think she has a lot more [to live]. (#7, Daughter)

### Facilitators in decision-making for using HC

Despite various challenges for decision-making in utilisation of HC, participants admitted their loved ones into HC. They identified several facilitators, which allowed them to move forward in making a transition to HC.

#### Patient's known EOL wishes

Participants' previous communication with patients on EOL care, helped family members to better understand patients' goals of care,<sup>42</sup> and thereby making their HC decisions more viable:

Throughout the years, she either told me or my sisters ... she doesn't want to be like a vegetable ... we understand and we want to do what is best for her. (#5, Daughter)

#### EOL communication with the patient's physician

Our participants found their communication with patients' physicians on HC helped them, and their patients make a relatively easy transition to HC. Physician's comprehensive explanations about the process of transition to HC; the goals and functions of HC and available support and resources, particularly at home were considered helpful for HC decision-making.

He [patient's physician] told me that there was going to be staff who would be checking him at home to [make him] more comfortable, that he would be with family, and that would make him feel more comfortable and that we would not be there in the hospital all the time. (#12, Daughter)

Another participant stated:

At first, we [family] wanted to revive him if something happens to him, right? But they explained to us that when they revive him it's a lot. They suffer more because they break bones and it's worse. So, we just decided ... we're going to leave it. (#6, Daughter)

#### Right timing: worsening prognosis

Most participants acknowledged their observations of the patients' poor prognosis as an indicator of readiness for hospice admission:

I saw it coming because she's more deteriorating. She knows she needs more help. She's getting sicker and getting worse. (#16, Daughter)

She was at that point where they couldn't do anything else. She knew it and we knew it ... to be honest with you, it made it a lot easier on us because of not

having to go to doctor's appointments and stuff, having somebody come to the house and uh, so it really made it a lot easier on us too to just do that. (#24, Daughter)

#### Home as the place for death

Placement of death was an integral part of EOL care planning. Providing care at home gave a sense of comfort for the FCGs, because patients now received quality of care during their final moments,<sup>20</sup> thereby fulfilling patients' wishes. One participant described how she used a photo to assess the patient's preference for the placement of her EOL wishes:

I asked my mom where she wants to take her last breath ... I showed her a picture of home ... at home or in the hospital and she said home ... I'm not going to put her in no [nursing] home .... (#14, Daughter)

Placement for care at home facilitated the acceptance of HC for some family members. The participant stated:

That was one of the questions that one of my brothers asked. So, he goes to hospice, but wait a minute, is it going to be at home? [I said] "Everything's going to be the same. It's just going to be a different type of care. That's it." And they go, oh yeah if it's going to be at home ... Sure, so he was more willing to accept the word [hospice] .... (#21, Daughter)

## DISCUSSION

### Challenges in decision-making for using HC

Challenges with communication influenced decisions regarding HC. Our study found there was a lack of physician-family communication related to HC, which may delay HC referral. Eight study participants were informed of the patient's terminal condition by the hospitalists during the patient's visit for acute care (eg, admission to ER). Similarly, a previous study<sup>25</sup> found that Latinos were referred by various hospital staff (non-physician) during the crisis hospitalisation, in comparison to white non-Latinos being referred by the specialists. This suggests that existing healthcare system barriers influenced care coordination or transition from acute care to HC. Rural patients encounter fragmented care coordination within rural communities, and also between rural and urban care facilities that appeared to hinder the timely access to healthcare services.<sup>20</sup> Structural barriers (ie, shortage of physicians, limited resources) in rural regions, may impose challenges for adapting interventions to be culturally inclusive, for minority patients who have limited linguistic/health literacy. Continuing standard practice without adapting care for such vulnerable patients and family will most likely exacerbate HC coordination and referrals. Palliative care programmes can facilitate a smooth transition to HC, but they are scarce in rural regions, especially in a hospital setting. Implementing

hospice telehealth via computer or mobile devices, or coordinating with community-based home health agencies that offer HC services, might provide for more timely referrals into HC.

Another reason for late HC referral might be related to the biomedicalisation and political economy of hope, as sources of influence over physicians' behaviour and communication, in ways that may postpone discussions and referrals to hospice.<sup>9 10</sup> In regard to physician's prognostication to determine patient's eligibility for HC, scholars addressed the flaws in medicare hospice benefit (MHB) in the US healthcare system. It is assumed that physicians accurately estimate patient's life expectancy with clear clinical trajectories, and accordingly make decisions for shifting from curative to palliative care/comfort care.<sup>8 9</sup> However, physicians' precise prognostication can be very challenging, and their clinical judgement about the effectiveness of active treatments does not immediately lead to their HC referral.<sup>9 10</sup> Rather, multiple factors such as patient-provider relationships, the provider's professional identity and MHB reimbursement all interplay, thereby complicating hospice referral.<sup>9 10</sup> Hospice/palliative care-related communication with physicians, also vary by the specialty of the provider (ie, oncologist, primary care physician), and the type of patients' illnesses, especially as specialists take a different approach to estimate patient's prognosis.<sup>10 43 44</sup> Our study did not assess patterns of communication by types of physicians' specialisations. Future studies exploring FCG's perception about timing for HC referral, and their communication with physicians by patient's type of illness, may provide us with better context, regarding hospice related decisions made in rural settings.

FCGs' lack of knowledge and misconception of HC were apparent in this study. These findings suggest the need for community-based education or outreach in order to raise an awareness of HC. For example, the promotora approach has been found to be an effective strategy to promote public health (ie, cancer screening) in Hispanic communities.<sup>45 46</sup> Using their knowledge about characteristics and resources of the community, promotores can mobilise HC related resources and provide further education and instrumental support (ie, translation and dissemination) to patients and families in the community. Integrating trained promotores in community-based organisations as a part of their outreach to the community, may bridge the gaps of healthcare access in rural regions with limited healthcare resources.

Our participants' misconception about hospice, appeared to evoke strong emotions against placement of their family members in HC. Their emotional reactions to HC might reflect cultural values and preferences for EOL care. For example, Latinos prefer family-centred care<sup>26</sup> and maintain secrecy about the patient's prognosis.<sup>25</sup> Future research comparing Latinos and non-Latinos experiences related to decision-making for HC might be beneficial in broadening our understanding about social and cultural aspects of HC. This information will help to

develop culturally salient interventions for this vulnerable population.

### Facilitators in decision-making for using HC

Despite some challenges, our participants identified some facilitators, that helped them navigate the decision-making process for utilisation of HC. Our findings highlighted the importance of EOL communication among patients, family and healthcare professionals who provided an important platform for HC decision-making. Norton and colleagues<sup>43</sup> found that when patients, families and healthcare providers had a shared understanding about the futile nature of medical treatment, indicating that curative treatment was not an option, then making a transition to HC was much easier to recognise, as an important option for care. Healthcare professionals need to integrate an earlier development of advance care planning, that can assist FCGs optimise the transitions of care, especially when decisions are related to invasive or clinical procedures that need to be made without the patient's full cognitive capacity.

It is also important to consider how FCG's characteristics might impact HC decision-making. FCGs' level of education, health literacy and their perception about the patient-provider relationship, play a significant role in the decision-making process.<sup>11 47</sup> Gender role is another important factor for understanding FCG's hospice related decision-making, as it influences caregiving responsibilities.<sup>40 48</sup> In our study, the majority of FCGs were women and daughters who were either living together or near the patients homes. Their perspectives toward HC and its priorities might have been influenced by the intersection of gender, and relationship to the patients. While most providers receive some education about this topic, they often lack time and insufficient resources to adequately address the unique needs of this population, which further reduces the likelihood of referring patients to HC.<sup>49</sup> To promote effective patient-provider interactions involving partnership-building and optimal patient outcomes, providers must have training on approaching sensitive and complex conversations with vulnerable populations.<sup>50</sup> Future research could address ways to support effective patient-provider communication, in unreserved rural settings to promote HC to patients and their families.

### Limitations

This study is the first in exploring challenges and facilitators in decision-making for utilisation of HC, among FCGs in rural US-Mexico border. While our study broadens an understanding about caregivers' decision-making process in using HC, it has some limitations. Participants were recruited from one site that housed all patients who were medicare beneficiaries, thereby limiting diversity among participants. More than one-third of the participants who originally agreed to participate in the study were not available; however, we do not have data that explains their unwillingness to participate. This might



be due to participants' discomfort in talking about death and dying or their own health issues, which might lead to selection bias. Although we did not aim to seek for representativeness, future studies with multiple sites, and a larger sample size could improve representativeness and diversity of this population. Our study focuses only on FCGs' perceptions and experiences; however, it might be beneficial to include patients and FCGs in dyads with caregivers of patients who never went into HC. For example, caregivers of patients who were not in HC might encounter more complex challenges, which prevent their access of HC. Hence, exploring group differences in HC related decision-making, may offer better contextual explanations for HC among rural patients. We did not collect demographic data on patient's length of stay at the hospice. Including this data in future study can perhaps help us to further understand FCG's perceptions of HC utilisation.

## CONCLUSION

Increasing attention to quality of EOL care calls to our understanding about the dynamics of decision-making in utilisation of HC by FCGs. Findings from this study adds valuable insight to the complexity of HC related decision-making. Challenges and facilitators to HC emerged as FCGs described their decision-making process, guided by their personal, interpersonal and sociocultural experiences. Our study indicates that EOL communication among patients, caregivers and physicians, are imperative in order to enhance FCG's knowledge about patients' EOL care preferences, that facilitate HC related decision-making. Our study indicates that FCGs' overall lack of EOL care involvement with the patient's physicians, left them less informed and unprepared for HC. Without effective patient-provider communication, patients and families may experience increased emotional distress and confusion about HC, leading to fear, doubt and uncertainty about the decision they have to make for their loved ones. It is imperative that healthcare providers assess FCGs' extant of knowledge and their concerns about HC. There is a need for an early integration of EOL care discussions into their practice that helps to facilitate transition into HC.

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