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## Barriers and Facilitators of Hospice Decision-making: A Retrospective Review of Family Caregivers of Home Hospice Patients in a Rural Region(U.S.): a Qualitative Study

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4 **Family Caregivers of Home Hospice Patients in a Rural Region (U.S.): a Qualitative Study**  
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## Abstract

**Objectives** Hospice care provides a comprehensive approach to enhance quality end-of-life (EOL) care for terminally ill patients. Despite its positive recognition, hospice care (HC) enrollment is disproportionate for rural patients who are less likely to utilize hospice care when compared to their urban counterparts. The purpose of this study was to explore the barriers and facilitators for decision-making in utilizing hospice care from a retrospective perspective of family caregivers (FCG) in rural US-Mexico border region.

**Design** Qualitative study using semi-structured in-depth interviews were conducted in person by from May, 2017 to January 2018.

**Setting** HC program from a local home health agency, located in rural Southern California, U.S.

**Participants** Twenty-eight informal FCGs of patients who were actively enrolled in a HC program from the study site

**Results** About 43% of the participants knew the patients needed HC when the patients' providers initiated HC while 21% stated that they did not know what HC even was. Emerging themes relating to challenges in utilizing HC and decision-making included: 1) communication barriers, 2) lack of knowledge/misperception about HC, 3) emotional difficulties which included fear about losing their patient, doubt and uncertainty about the decision, and denial, and 4) patients not being ready. Facilitators included: 1) patient's known EOL wishes, 2) family caregiver-provider EOL communication, 3) home as the place for death, and 4) the patient's deteriorating health.

**Conclusions** Family caregivers of HC patients in rural region reported a lack of knowledge or misunderstanding of HC. Health care providers need to actively involve family in EOL care discussions from the beginning of diagnosis. Optimal transition to a HC can be facilitated by family caregivers' accurate and clear understanding about the patients' medical conditions and status and receipt of information about HC.

**Key words:** home hospice, caregiver, rural, end-of-life care, decision-making

### Strengths and limitations of this study

- The qualitative method is helpful to gain an in-depth of understanding about the family caregivers' experiences in decision-making for utilizing hospice care.
- To our knowledge, this was the first study exploring decision-making to utilize hospice care among rural family caregivers in U.S.-Mexico border.
- The findings of this study provide a greater insight to what extent family caregivers understand hospice care and engage in communication with the patients' providers.
- This study only included the family caregivers. Future studies could include patients in a dyad study which may provide different perspectives.

# Barriers and Facilitators of Hospice Decision-making: A Retrospective Review of Family Caregivers of Home Hospice Patients in a Rural Region (U.S.): a Qualitative Study

## Introduction

With an aging population in the United States (U.S.), and an increased life expectancy, there is a growing need to address quality end-of-life (EOL) care.<sup>1</sup> Hospice care (HC) has been considered an optimal care for patients with a terminal illness diagnosis as it provides a holistic approach in responding to a patient's physical, psychological, social and spiritual needs.<sup>2-4</sup> The use of palliative and hospice services for patients and families has been found to improve their satisfaction with quality of health care,<sup>5,6</sup> increase the likelihood that patients' wishes will be followed,<sup>7</sup> and has decreased rates of patients' intensive care admissions, as well as a reduction in the receipt of invasive procedures.<sup>8</sup>

Decision-making for EOL care, including utilizing HC involves a dynamic, complex process in aiding patients to reflect upon their goals-of-care, preferences for health care, and EOL communication with family and health care providers.<sup>9,10</sup> Family members are often closely involved in EOL care decision-making for their loved ones. Their role is critical at this point, particularly in the event when a patient who is incapacitated.<sup>11</sup> During the decision-making process, family caregivers (FCG) experience intrapersonal and interpersonal emotional challenges such as burden, guilt, and self-doubt about making the right decision.<sup>12-14</sup> Family conflicts sometimes arise during this transition, impacting decisions for utilizing HC.<sup>15</sup>

Living in rural regions in the U.S. is associated with having a lack of health care resources, including limited access to palliative/HC and specialized health care, leaving residents with healthcare challenges.<sup>16,17</sup> Rural residents who are socio-economically underserved, encounter various obstacles in healthcare decision-making due to low-health literacy and a lack of knowledge and information, regarding HC. Such obstacles may be compounded for

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3 racial/ethnic minorities such as Latinos, residing in rural areas who might also have language and  
4 communication barriers as well as cultural norms that focus on FCG responsibilities.<sup>18,19</sup>  
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7  
8 There are a number of studies with FCGs of HC patients; however, they mostly focus on  
9 caregiving burden, caregivers' unmet needs, and its impact on their quality of life.<sup>20-22</sup> Some  
10 studies with caregivers provide valuable insight about their attitudes toward HC,<sup>23,24</sup> and little is  
11 known about the challenges/barriers they face and what facilitates the decision to use HC among  
12 the family caregivers in rural regions. In light of the paucity of studies that have explored FCGs  
13 involvement in decision-making for utilizing HC, this study explored barriers and facilitators for  
14 decision-making in utilizing HC among the caregivers of family members who were currently  
15 enrolled in a home hospice program in a rural Southern California border community.  
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## 26 **Methodology**

### 27 **Study design and setting**

28  
29 This qualitative study utilized in-depth interviews to explore FCGs' barriers and  
30 facilitators for decision-making in utilizing HC from a retrospective perspective. All patients  
31 were enrolled and actively receiving hospice services from a local home health agency, located  
32 in a rural Southern California-Mexico border region. This home care agency is the largest agency  
33 providing in-home health care services, for patients and their family members in a rural region  
34 and the poorest county in Southern California.  
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### 44 **Subject and Recruitment Procedures**

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46 A purposive sampling method was used to recruit FCGs. Our study goal was not to  
47 compare racial/ethnic experiences by group; although, we included both Latino and white  
48 caregivers, which mirror the similar population proportion in the region. Eligibility criteria  
49 included FCGs who were of 18 and older; were currently providing care to the patients; and were  
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3 cognitively competent. During patient home visits, HC staff members presented a flyer,  
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5 describing the research study to FCGs. Those who were interested in participating in the study  
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7 left their contact number with the staff members to schedule an interview.  
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10 From the 53 caregivers who expressed interest in participating in the study, seven later  
11  
12 declined to participate; five requested rescheduling the appointment but did not answer upon a  
13  
14 follow-up phone call; five could not be reached (no answer) and seven patients passed away  
15  
16 prior to their caregivers making an appointment. A total of 29 individual FCGs participated in  
17  
18 the study; however, one participant was removed due to insufficient data resulting in a total  
19  
20 sample size of 28.  
21  
22

### 23 **Patient and public involvement**

24  
25  
26 There was no patient or public involvement in setting the research design or conducting  
27  
28 the study.  
29

### 30 **Data collection**

31  
32  
33 Data were collected via face-to-face interviews by a trained bilingual/bicultural research  
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35 assistant from May, 2017 to January 2018. Interviews were conducted in the FCG or the  
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37 patient's home, using a semi-structured interview guide which was developed and informed by  
38  
39 the team's program of research on this topic and existing literature review (please see Table 1).  
40  
41 Questions in the interview guide explored FCGs' perceptions and experiences of decision-  
42  
43 making for utilizing HC, particularity relating to challenges and facilitators experienced by the  
44  
45 caregivers. In order to assess the extent of involvement in decision-making for HC, we also  
46  
47 assessed caregivers' awareness about the patient's need for HC and the primary decision maker.  
48  
49 Each interview took about 30-40 minutes, and was conducted in either Spanish or English. All  
50  
51 qualitative interviews were audio-taped.  
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## Data Analysis

Thematic analysis process delineated by Braun and Clarke<sup>25</sup> was utilized for analysis in this study. Authors, (E.K. and D.F.) immersed themselves in the data by actively reading the 28 transcripts multiple times, searching for patterns and meanings. Notes and early impressions were documented independently by categorizing. An initial list of codes was generated independently to meaningfully and systematically organize the data after categorizing. Disagreements in assignment or description of codes were resolved through discussion and consensus, leading to refinement of themes. Through this iterative process of refinement of the initial themes, subthemes and a more in-depth meaning emerged of the participants' experiences.

## Ethical consideration

The study received ethics approval from the University Institutional Review Board (Blinded for review). All participants were informed about the study purpose and its procedures including the nature of voluntary participation if they did not wish to continue. All participants were consented and their privacy and confidentiality was assured.

## Results

### *Participants' Socio-demographic information*

Table 2 and 3 describes the FCGs' socio-demographic and health-related variables, respectively. The average age of the caregivers was 60.7 and the majority were female (n=28, 82.1%). More than two thirds identified as Latino/Hispanic (n=19; 67.9%) and one fourth of the participants (n=7, 25%) preferred Spanish for an interview. Majority of participants were adult children of the patients (n=21, 75%), followed by a spouse (n=6, 21.4%). Almost all identified themselves as main FCGs (n=26, 92.9%) with the majority (n=20, 71.4%) living with the patient.

### **End-of-Life Care related Information**

1  
2  
3 Over half of the participants (n=15, 53.6%) had a discussion with a provider about HC.  
4  
5 Only about one-fourth (25%, n= 7) were informed of the patients' life expectancy. About 43%  
6  
7 stated they only knew that their patient needed HC when their HCP raised the issue and 21. 4%  
8  
9 stated that they did not know what hospice was when it was presented. About 61% of  
10  
11 participants reported that patients were cognitively impaired when they were referred to HC.  
12  
13 More than half of the FCGs (53.6%) believed that the patient was not aware of their terminal  
14  
15 status. In the majority of cases, the patient's hospice decision was made by the family members  
16  
17 (n = 23, 82.1%).  
18  
19

### 20 21 **Qualitative Themes/Sub-themes**

22  
23 Themes relating to barriers and facilitators for decision-making for utilizing HC is  
24  
25 summarized in table 4.  
26  
27

### 28 **Challenges in Decision-making for Utilizing Hospice Care**

#### 29 Lack of knowledge/ Misperceptions about hospice care

30  
31 Participants expressed a lack of knowledge about HC hindered their hospice decision-  
32  
33 making about utilizing HC for their patients. A participant stated "*I didn't really know what*  
34  
35 *hospice care was. It made it difficult to make a decision*" (#26, Daughter). Participants thought  
36  
37 hospice was strictly for patients who were expecting an imminent death. "*I had the wrong*  
38  
39 *information of the word hospice... it [hospice] was that death was already was going to arrive*  
40  
41 *and they were already going to die*" (#22, Wife).  
42  
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#### 46 Communication barriers

47  
48 Participants identified a lack of EOL communication with patients' healthcare providers  
49  
50 which they felt inadequately prepared for making HC related decisions. One participant stated  
51  
52 "*They have too many patients so all they do is go in there and they check them say you're fine*  
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3 *and then you are out... I don't think the conversation [with the provider] is really a conversation.*  
4  
5 *They are too busy ... and you know sometimes we have questions and we don't get them*  
6  
7 *[provider] (#5, Daughter). Another participant recalled the introduction of HC was from home*  
8  
9 *health agency, not a provider. "We ended up, um, going through the home health and they were*  
10  
11 *the first ones to bring it up. So that's why I think that they're, for whatever reason, I think there's*  
12  
13 *a big disconnect with the doctors" (#28, Son). Difficulty with understanding medical jargon led*  
14  
15 *to other challenges to communication with the providers. "Talk to us with understandable terms*  
16  
17 *because sometimes they use medical terms that we do not understand (#17, Wife).*

### 21 Emotional Difficulties

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24 Participants experienced a range of emotions in their decision-making process, which at  
25  
26 times delayed the ultimate decision for utilizing HC. Emotional difficulties related to HC  
27  
28 included fear of losing their patient, doubt/uncertainty, and denial of impending death were  
29  
30 described.

31  
32  
33 Fear about losing their loved one. Participants associated hospice with death, which  
34  
35 increased their fear and anxiety about losing the patient. "*Just simply with the word "terminal",*  
36  
37 *one gets nervous, you start to imagine the worst, that's why it was difficult to think about putting*  
38  
39 *him in [hospice]... (#6, Daughter). For some participants, hospice placement meant accepting*  
40  
41 *their patient's impending death. "It is very difficult for me because it is like one does not want to*  
42  
43 *accept what is coming, one does not want to get used to the idea that the end will come, so one*  
44  
45 *does not want to lose their patient. So, that's why it was difficult for me. ... (# 22, Wife).*

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49 Doubt and uncertainty about the decision. A participant shared her sense of self-doubt  
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51 she had with her decision when she was informed of the limited options for acute care under  
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53 hospice program:  
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3 *The doctor talked to me about hospice during the day of the last visit. He said that my*  
4 *mom was terminal... I agreed and we did apply for the hospice. I could say on the third*  
5 *or fourth day, I was not sure whether I was doing the right thing or not... Um, because*  
6 *they told me that once she is in hospice, I cannot go to the hospital or call it 911... that*  
7 *was kind of difficult (#19, Daughter).*

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15 Denial. The word hospice resonates with death and some participants had difficulty  
16 accepting the patient's impending death. *"I kept thinking, well maybe they [physicians] are*  
17 *wrong, you know. ... I don't want to face the fact that I'm going to lose her. So I kept thinking*  
18 *"no she doesn't need that (hospice) yet" .... (#12, Daughter). Denial was the main source of*  
19 family conflicts in making decisions for utilizing HC:  
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26 *"I heard about hospice, um, was eight months ago ...I brought it (hospice care) up with*  
27 *my family members. They were like, "No way. That's for people that are dying." "My dad*  
28 *is not dying, you know, what are you talking about?" I think it's just been really hard for*  
29 *them to let go of, to accept that the situation..." (#21, Daughter).*

### 30 31 32 33 34 35 Patients not being ready

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38 The perceived "right time" or "being ready" for utilizing hospice was contingent upon the  
39 FCGs' subjective estimation of life expectancy. Some participants projected their patient's life  
40 expectancy longer than what they were told: *"I knew that my mom was going to live a little bit*  
41 *longer... I would have thought of as categorically, she wouldn't have fit into that."* (#9,  
42 Daughter). Participants used the patient's physical appearance as a factor to make a decisions for  
43 utilizing hospice: *"My uncle had gone into hospice in December a year and a half ago. He was*  
44 *really bad. ...When I found out what hospice meant that they gave them primarily pain*  
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3 medication but no fluids or foods (artificially), I didn't think that she [mom] was that far gone...  
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5 (# 4, Daughter).

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8 One participant reported delaying hospice referral due to a previous experience with the  
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10 health care provider's inaccurate estimate of the patient's life expectancy, which confirmed her  
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12 belief about premature hospice admission:

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15 *"She was in hospice for about a month, maybe two months. In one of the RN visits, she*  
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17 *[nurse] just came and told me that I need to gather my family because my mother had*  
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19 *about 3 days left, so I should started calling the family so they could just say their*  
20  
21 *goodbyes, which turned out not to be true, because it has been four years of that... You*  
22  
23 *know I thought that my mom was not ready for hospice ...in my mind hospices for*  
24  
25 *terminal patients and my mother was not terminal. I still think she has a lot more [to live]*  
26  
27 *you know"* (#7, Daughter).

### 30 31 **Facilitators in Decision-making for Utilizing Hospice Care**

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33 Despite the various challenges for decision-making in utilizing HC, participants referred  
34  
35 patients for HC. They identified several facilitators, which allowed them move to forward in  
36  
37 making a transition to HC.

#### 38 39 Patient's known EOL wishes.

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42 Participants' previous communication with patients on EOL care helped them to follow  
43  
44 their patient's wishes: *"Throughout the years, she either told me or my sisters ... she doesn't*  
45  
46 *want to be like a vegetable ... we understand and we want to do what is best for her* (#5,  
47  
48 Daughter). Another participant elaborated, *"After my father passed away. She made a medical*  
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50 *directive"* (#28, Son).

#### 51 52 EOL communication with the patient's provider

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3 Providers' explanations about HC and its available services positively influenced  
4 decision-making on utilizing HC. "*He [patient's provider] told me that there was going to be*  
5 *staff who would be checking him at home to [make him] more comfortable, that he would be with*  
6 *family, and that would make him feel more comfortable and that we would not be there in the*  
7 *hospital all the time"* (#12, Daughter). Another participant recalled the provider explaining the  
8 limitations and consequences of life-sustaining treatments, which guided the family to reach the  
9 consensus for utilizing HC:  
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19 *"At first we [family] wanted to revive him if something happens to him, right? But they*  
20 *explained to us that when they revive him it's a lot, they suffer more because they break*  
21 *bones and it's worse, so we just decided ... we're going to leave it"* (#6, Daughter).  
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### 26 Home as the place for death

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28 Honoring the patient's wishes to die at home was important in the decision-making  
29 process. One participant described how she used a photo to assess the patient's preference for  
30 the placement of her EOL. "*I asked my mom and where she wants to take her last breath ... I*  
31 *showed her a picture of home... at home or in the hospital and she said home... ... I'm not going*  
32 *to put her in no [nursing] home or in what is it called those nursing homes....* (#14, Daughter).  
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39 Placement for care at home facilitated the acceptance of HC for family members. The participant  
40 stated;  
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44 *That was one of the questions, that one of my brothers says he goes to hospice, but wait a*  
45 *minute, is it going to be at home. [I said] "Everything's going to be the same. It's just that*  
46 *it's just going to be a different type of care. That's it."* And they go, *oh yeah if it's going*  
47 *to be at home... Sure. So he was more willing to accept the word [of hospice]... (#21,*  
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### Right Timing: worsening prognosis

Participants acknowledged their observations of their patients' poor prognosis as an indicator of readiness for hospice admission. "It's a time element. I could see that my mother was waning and getting toward the end of her life (#9, Daughter). Recognizing that no curative approach was viable, a participant realized that HC was optimal. "I knew it was coming, because I couldn't take care of my mom anymore and because we needed extra help to come and take care of her to bathe and make sure she had her medications and her supplies" (#10, Daughter). Witnessing the patient's deteriorating health, another participant recognized the need for greater support and HC was optimal:

*"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).*

## Discussion

### **Challenges in Decision-making for Utilizing Hospice Care**

Communication barriers were identified as a challenge in hospice decision-making. Our study participants addressed the difficulty in making decisions in utilizing HC, and in having adequate conversations with the healthcare providers. This might be a concern particularly in rural areas, where there is a high ratio of provider-patient numbers due to the shortage of health care providers. Previous research reports that rural patients' experiences fragmented care coordination which is exacerbated with poor communication with the providers.<sup>19</sup> Structural barriers (i.e., shortage of physicians, limited resources) exacerbates poor healthcare access and widens the gaps in EOL care increases caregivers' burden on EOL decision-making.

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2  
3 Family caregivers' lack of knowledge and misconception of HC were apparent.  
4  
5 Consistent with results from previous studies,<sup>10,24,26-28</sup> our participants were not well aware  
6  
7 about HC and misunderstood that this service is only for those with impending death. The  
8  
9 concept of HC is particularly foreign for the Latino population, because the word "hospice" in  
10  
11 Spanish refers to infirmary setting such as an institution or other restrictive place, which is  
12  
13 different than the meaning of hospice provided in the U.S.<sup>24,29</sup> Community-based educational  
14  
15 opportunities can perhaps raise an awareness of HC. Such insufficient knowledge and  
16  
17 misperception about hospice appeared to evoke caregivers' strong emotions regarding placement  
18  
19 of their family members in hospice settings. Negative notion about HC associated with death,  
20  
21 intensified the caregivers' fear of losing the patient. Hospice admission, which limits acute care  
22  
23 options, was troublesome for some caregivers who considered this action was giving up on the  
24  
25 patient. In our study, the family's denial for the patient's terminal condition became a source of  
26  
27 conflict, with each other. Family members' reluctance to accept the patients' terminal diagnosis  
28  
29 was an obstacle for decision-making in utilizing HC, which has also been demonstrated in  
30  
31 previous studies.<sup>24,30</sup> This in turn delayed the decision-making process. Although denial could  
32  
33 be temporary and a healthy coping mechanism, it was found to be an obstacle for advance care  
34  
35 planning.<sup>31</sup>

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37  
38 It is unclear, if the caregivers' denial of their patient's terminal condition is related to  
39  
40 their lack of knowledge about the patient's prognosis or is it an emotional reaction. Caregivers'  
41  
42 accurate understanding of the patient's prognosis is necessary to facilitate decision-making, yet  
43  
44 only 50% of these participants had EOL communication with the providers, and more than half  
45  
46 had never been informed of their patient's life expectancy. Family caregivers' accurate  
47  
48 understanding about HC is essential for making informed decisions in healthcare. Precise  
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3 estimation of patients' life expectancy is difficult yet providers introducing advance care  
4 planning including HC as an option earlier in the course of illness, can perhaps help patients  
5 and family members better understand the patient's prognosis and plan EOL care accordingly.  
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### 11 12 **Facilitators in Decision-making for Utilizing Hospice Care**

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15 Despite some challenges, our participants identified some facilitators that helped them  
16 navigate the decision-making process for utilizing HC. Similar to a previous study,<sup>34</sup> patients'  
17 known EOL wishes made their decisions viable, and also become a source of family coping.<sup>12</sup>  
18  
19 Previous study reports that patients' known wishes via communication or written documents help  
20 family members better understand the patients' goals of care<sup>35</sup> and are also effective in meeting  
21 patients' wishes such as decreasing use of life-sustaining treatment and increasing the use of  
22 hospice and palliative care.<sup>36</sup> It is unknown to what extent family caregivers engaged in EOL  
23 communication, but only half of our participants were able to discuss HC with patients. Almost  
24 60% of the patients were cognitively incompetent by the time that HC was referred. Health care  
25 providers who facilitate advance care planning need to include family members earlier, which  
26 may increase communication among patients, family, and providers, thereby easing the transition  
27 to acceptance of the diagnosis. Introduction of advance care planning facilitated with patients  
28 and their family members at the beginning of a chronic illness would be deemed beneficial for  
29 healthcare providers and their patients, thereby making the process of care smoother, especially  
30 when decisions regarding invasive or clinical procedures need to be made without the patient's  
31 full cognitive capacity. Results from this study highlights the importance of facilitating patient-  
32 family EOL communication at the beginning of a diagnosis.  
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3 Our participants found their communication with the patients' providers on HC helped  
4 them to make a relatively easy transition to HC for the patients. Participants recalled providers'  
5 explanations about the risk of life-sustaining treatments, functions and resources of HC being  
6 beneficial. Our findings highlighted the importance of EOL communication extending beyond  
7 prognostic information. Education for patients and their FCGs' needs to address the process of  
8 transition to HC, with goals and functions of HC, that is available as support/resources.  
9  
10 Interestingly, only half of the participants reported to having HC related communication with the  
11 patients' providers. Health care providers assessing the FCGs' extent of knowledge about HC  
12 and initiating EOLEOL communication will be imperative.  
13  
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15 Although preferences for the place of death varied by the participant's (patients and  
16 caregivers), setting and the severity of illness, most preferred to die at home.<sup>37</sup> In our study,  
17 placement of death was an integral part of EOL care planning, particularly among Latino patients.  
18 Providing care at home gave a sense of comfort for the FCGs in that patients received quality of  
19 care during their final moments <sup>14</sup> thereby fulfilling patients' wishes. Some of our participants  
20 emphasized their determination for not placing patients in nursing homes. Health care providers  
21 need to assess the patients' and family caregivers' preference for placement of care and provide  
22 clear information about home HC and its resources.  
23

#### 24 Limitations

25 This study is the first study exploring barriers and challenges in decision-making for  
26 utilizing HC among FCGs in rural Southern U.S.-Mexico border. While our study broadens an  
27 understanding about caregivers' decision-making process in utilizing HC, it has some  
28 limitations. Participants were recruited from one site with all patients being Medicare  
29 beneficiaries, which limits the demographics of this rural setting. Although we did not aim to  
30 seek for representativeness, future studies including multiple sites with a greater sample size can  
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3 improve representativeness. Our study focuses only on FCGs' perceptions and experiences;  
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5 however it might be beneficial to include patients and family caregivers in a dyad in the future to  
6  
7 explore group difference in terms of barriers and challenges in decision-making for utilizing HC.  
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10 Another limitation that is important in a future study is the social and cultural context of  
11  
12 ethnically diverse populations whose beliefs and values may differ from the larger population.  
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14 This information may be addressed through identification of the social determinants of health  
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16 that people experience in their daily lives and are colored by their long held practice with health  
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18 and illnesses. This information may be helpful in educating healthcare providers in the  
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20 development of culturally appropriate interventions.  
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### 23 24 Conclusion

25  
26 Increasing attention to quality EOL care calls for our understanding about the dynamics  
27  
28 of decision-making in the utilization of HC by FCGs for their loved ones. Findings from this  
29  
30 study add valuable insights to existing literature and further broadens our understanding about  
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32 what hampers and facilitates decision-making processes when it becomes necessary to utilize  
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34 HC. FGCs' EOL communication (including HC) with patients and patient's providers was  
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36 particularly important in guiding them to make optimal decisions when utilizing HC. This study  
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38 confirms that it is imperative for health care providers to actively engage patients and their  
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40 family members in the development of ACPs at the time of diagnosis, especially in light of the  
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42 social cultural differences among populations.  
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Table 1. Interview guides

A Priori Concepts	Questions
Experiences in hospice decision-making	Can you describe how your EOL decision-making was?
Challenges for hospice decision-making	Looking back, what held you back from making a decision for hospice care?
Facilitators for hospice decision-making	What factors contributed to your decision for hospice for your patient?
	Were there any delays in hospice decision-making process? Please describe them

Table 2. Participant Characteristics

ID #	Gender	Age Range	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

Table 3. End of- Life Communication Related Variables (N= 28)

Variables	n/%
Hospice discussion between caregivers and patient's physician	
<i>Yes</i>	15(53.6%)
<i>No</i>	13(46.4%)
Life expectancy being informed	
<i>Yes</i>	7 (25%)
<i>No</i>	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?	
<i>Not at all</i>	15(53.6%)
<i>Somewhat</i>	2(7.1%)
<i>Fairly/very well</i>	11(39.3%)
When did the caregiver first think that pt. need hospice care?	
<i>Knew hospice was needed only when physician raised the topic</i>	12(42.9%)
<i>Knew hospice was need before physician discussed possibility of hospice care</i>	6(21.4%)
<i>Did not know what hospice was</i>	6(2.4%)
<i>Did not know hospice was needed until days after physician raised the topic</i>	4(14.3%)
Who made final decision for hospice care?	
<i>Patient alone</i>	1(3.6%)
<i>Family</i>	23 (82.1%)
<i>Family and patient together</i>	3(10.7%)
<i>Family and nurse together</i>	1(3.6%)

Table 4. Summary of Qualitative Themes

Topic	Themes	Sub-themes	Characteristics	
<b>Barriers</b>	Communication barriers		<ul style="list-style-type: none"> <li>Engaging in EOL communication with the patient's provider was difficult</li> <li>Providers need to use the lay terminology to help the caregiver's understanding</li> </ul>	
	Lack of knowledge or misperception about hospice care		<ul style="list-style-type: none"> <li>Did not know what hospice was</li> <li>Hospice is for the patients with imminent death</li> </ul>	
	Emotional difficulties	<i>Fear of losing patient</i>		<ul style="list-style-type: none"> <li>The word of "terminal" makes difficult to think about hospice placement</li> <li>Placing a patient in hospice care means accepting his/her death</li> </ul>
		<i>Doubt and uncertainty about decision</i>		<ul style="list-style-type: none"> <li>Hospice admission will limit the opportunities to use acute care (i.e., hospital admission for treatment).</li> <li>Not sure if the hospice was the best decision</li> </ul>
		<i>Denial</i>		<ul style="list-style-type: none"> <li>Patient's diagnosis might be inaccurate</li> <li>Difficulty of accepting patient's terminal condition</li> </ul>
	Patients not being ready		<ul style="list-style-type: none"> <li>Patient does not appear to be terminally ill</li> <li>Patient already outlived the given life expectancy</li> </ul>	
<b>Facilitators</b>	Patient's known EOL wishes		<ul style="list-style-type: none"> <li>Following the patient's wishes is important</li> </ul>	

Caregiver-Provider  
EOL communication

- Information about the functions and benefits of hospice care was helpful
- Understanding the limitations and consequence of life-sustaining treatments helped to come up with realistic plan

Place for death

- Patient desires to die at home

Patient's deteriorating  
health

- Patient's declining functions need appropriate care

For peer review only



### Author Contributorship Statement

EK has contributed to designing and conceptualizing the study, performing data analysis, interpreting the results and drafting the manuscript.

DF has contributed to performing data analysis, interpreting the results, and writing the manuscript.

SS has provided substantial input and revised the manuscript.

FN has contributed to revising the manuscript.

### Competing Interest

There are no competing interests among the authors.

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### Data Sharing Statement

The participant data are deidentifiable. All data relevant to the study are included in the article.

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## 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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4 **Family Caregivers of Home Hospice Patients in a Rural US-Mexico Border Region: a**  
5 **Qualitative Study**  
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## Abstract

**Objectives** Hospice care provides a comprehensive approach that enhances quality end-of-life (EOL) care for terminally ill patients. Despite its positive aspects, hospice care (HC) enrollment is disproportionate for rural patients who are less likely to utilize hospice care when compared to their urban counterparts. The purpose of this study was to explore the decision-making experiences relating to utilizing hospice care from the retrospective perspective of family caregivers (FCGs) in a rural US-Mexico border region.

**Design** Qualitative study using semi-structured in-person interviews were conducted from May, 2017 to January 2018.

**Setting** HC program from a local home health agency, located in rural Southern California, U.S.

**Participants** Twenty-eight informal FCGs of patients who were actively enrolled in a HC program from the study site

**Results** About 43% of the participants knew the patients needed HC when the patients' physicians initiated HC while 21% stated that they did not know what HC even was. Emerging themes relating to challenges in utilizing HC and decision-making included: 1) communication barriers, 2) lack of knowledge/misperception about HC, 3) emotional difficulties which included fear about losing their patient, doubt and uncertainty about the decision, and denial, and 4) patients are not ready for HC. Facilitators included: 1) patient's known EOL wishes, 2) family caregiver-physician EOL communication, 3) home as the place for death, and 4) the patient's deteriorating health.

**Conclusions** Family caregivers of HC patients in a rural region reported a lack of knowledge or misunderstanding of HC. Health care providers need to actively involve family members in patient's EOL care planning. Optimal transition to a HC can be facilitated by FCGs' accurate and clear understanding about the patients' medical conditions and status and receipt of information about HC.

**Key words:** home hospice, caregiver, rural, end-of-life care, decision-making



### Strengths and limitations of this study

- The qualitative method is helpful to gain an in-depth of understanding about the family caregivers' experiences in decision-making for utilizing hospice care.
- To our knowledge, this was the first study exploring decision-making to utilize hospice care among rural family caregivers in U.S.-Mexico border.
- The findings of this study provide a greater insight to what extent family caregivers understand hospice care and engage in communication with the patients' physicians.
- This study only included the family caregivers. Future studies could include patients in a dyad study which may provide different perspectives.

# 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

## Introduction

With an aging population in the United States (U.S.) and an increased life expectancy, there is a growing need to address quality end-of-life (EOL) care.<sup>1</sup> Hospice care (HC) is the interprofessional, multi-dimensional care provided to patients with a terminal status (less than 6 months life expectancy) and their families, and includes a wide range of services including pain and symptom management, bereavement services, and psychosocial and spiritual care.<sup>2</sup> Hospice care is considered optimal care for patients with a terminal illness diagnosis as it provides a holistic approach in responding to a patient's physical, psychological, social and spiritual needs.<sup>3-5</sup> The use of hospice services for patients and families has been found to improve their satisfaction with the quality of their health care,<sup>6,7</sup> increase the likelihood that patients' wishes will be followed,<sup>8</sup> decrease rates of patients' intensive care admissions, and reduce the receipt of invasive procedures.<sup>9</sup> Decision-making for EOL care, including HC, involves a dynamic, complex process in aiding patients to reflect upon their own goals-of-care, preferences for health care, and EOL communication with family and health care providers.<sup>10,11</sup> Despite the benefits of hospice care, underutilization of hospice care still remains a concern. Factors contributing to hospice decision-making have been identified at the individual level (i.e., patient and family's lack of knowledge, attitudes and beliefs toward hospice care), interpersonal level (i.e., patient-provider relationship), and structural or macro level (i.e., health insurance reimbursement).<sup>12-15</sup> These challenges do not occur one at a time. Rather their interplay results in a web of complex constraints, complicating the decision-making process.<sup>13</sup>

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3 Family members are often closely involved in the decision-making of EOL care for their  
4 loved ones. Their role is critical, particularly in the event when patient are incapacitated and  
5 unable express their own wishes for care.<sup>16</sup> During the decision-making process, family  
6 caregivers (FCG) often experience intrapersonal and interpersonal emotional challenges such as  
7 burden, guilt, and self-doubt about making the right decision.<sup>17-19</sup> Family conflicts can arise  
8 during this time, impacting decisions for utilizing HC.<sup>20</sup> Moreover, socio-cultural and  
9 geographic circumstances can place family members as primary caregivers, which often involves  
10 making important healthcare decisions. For those who live in rural regions, there is often a lack  
11 of health care resources, including limited access to hospice and specialized health care, thus  
12 leaving patients and caregivers with additional healthcare challenges.<sup>21,22</sup> In this context, hospice  
13 care decision-making is often impacted by low health literacy and a lack of knowledge about  
14 available HC resources. Such obstacles may be compounded for racial/ethnic minorities (e.g.,  
15 Latinos) who might also have language barriers as well as cultural norms that focus on FCG  
16 responsibilities.<sup>23,24</sup> There are a number of studies with FCGs of HC patients; however, they  
17 mostly focus on caregiving burden, caregivers' unmet needs, and its impact on their quality of  
18 their lives.<sup>25-27</sup> Some studies with caregivers provide valuable insight about their attitudes  
19 toward HC,<sup>28,29</sup> yet little is known about the challenges they face and what facilitates their  
20 decision to use HC.

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22 Social and cultural contexts contribute to unique understanding of the cause (etiology),  
23 course (symptomatology), and cure (appropriate treatment or response) of illness.<sup>30</sup> Explanatory  
24 models<sup>30,31</sup> offer a useful framework for exploring sociocultural experiences of families affected  
25 by terminal illness, as the cause, course, and response to terminal illness among individuals and  
26 families living in rural areas may influence their decision to enroll in hospice care. While a  
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3 review of cultural conceptualizations of hospice/ palliative care found more similarities than  
4 differences across culturally diverse populations,<sup>32</sup> research on hospice care decision-making  
5 has not yet examined the experiences among residents in rural US-Mexico border regions. This  
6 pilot exploratory study gives voice to the experience of hospice care decision-making among  
7 FCGs living in a rural US-Mexico border community in Southern California. In particular, this  
8 study explored the challenges and facilitators involved in the decision to utilize hospice care  
9 from the perspective of caregivers of family members currently enrolled in a home hospice  
10 program in the Southern US.-Mexico border.  
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### 21 **Methodology**

22 We followed the Standards for Reporting Qualitative Research (SRQR) reporting  
23 guideline to write this paper.<sup>33</sup>  
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### 28 **Study design and setting**

29 This study utilized qualitative interviews to explore FCGs' challenges and facilitators  
30 regarding decision-making in utilizing HC from a retrospective perspective. All patients were  
31 enrolled and actively receiving hospice services from a large home health agency that provides  
32 in-home health care services in a rural region, located in the poorest county in Southern  
33 California.  
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### 42 **Subject and Recruitment Procedures**

43 A purposive sampling method was used to recruit FCGs. Our study goal was not to  
44 compare racial/ethnic experiences by group; although, we included both Latino and non-  
45 Hispanic white caregivers, which mirror the similar population proportion in the region.  
46 Eligibility criteria included FCGs who were 18 and older; were currently providing care to the  
47 patients; and were cognitively competent. During patient home visits, HC staff members  
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3 presented a flyer which described the research study to FCGs. Those who were interested in  
4 participating in the study provided their contact number with the staff members to schedule an  
5 interview.  
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10 From the 53 caregivers who expressed interest in participating in the study, seven later  
11 declined to participate; five requested rescheduling the appointment but did not answer upon a  
12 follow-up phone call; five could not be reached (no answer) and seven patients passed away  
13 prior to their caregivers making an appointment. A total of 29 individual FCGs participated in  
14 the study; however, one participant was removed due to insufficient data resulting in a total  
15 sample size of 28.  
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### 24 **Patient and public involvement**

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26 There was no patient or public involvement in setting the research design or conducting  
27 the study.  
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### 31 **Data collection**

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33 Data were collected via face-to-face interviews by a trained bilingual/bicultural research  
34 assistant from May, 2017 to January 2018. Interviews were conducted in the FCG's or patient's  
35 home, using a semi-structured interview guide which was based on previous literature on hospice  
36 care decision-making (see Table 1). Questions in the interview guide explored FCGs'  
37 perceptions and experiences of decision-making for utilizing HC, in particular as it relates to  
38 hospice care communication with the physician, patient, and among family members.<sup>20,28</sup> In  
39 order to assess the extent of involvement in decision-making for HC, we also assessed caregiver-  
40 provider communication (who informed them of the patient's incurable condition and initiated  
41 the hospice communication).<sup>34</sup> Each interview took approximately 30-40 minutes, and was  
42 conducted in either Spanish or English. Participants' nonverbal behaviors (i.e., facial expression,  
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body language, and difficulty of articulation) were reported in the transcripts which later were used to add contextual meaning. The researcher also engaged in debriefing sessions with the research assistant to examine any event or circumstances (i.e., interruption during the interview) and its impact on the quality of interviews. All qualitative interviews were audio-taped.

### **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 such representation from the *helping professions*, we were careful to not impose our assumptions and presuppositions of the health and hospice care system in the development of the interview guide nor in the interpretation of the data. The bilingual/bicultural researcher and research assistant who conducted the interviews took care in being objective and not ‘fill in’ words for participants, which might seem natural when one can relate so much to the sociocultural background and context that the participants came from. Also aligned with our professional standards, our research was designed to give voice to participants and honor their experiences as unique or common as it might seem to them.

### **Data Analysis**

Thematic analysis process delineated by Braun and Clarke<sup>35</sup> was utilized for analysis in this study. Authors, (E.K. and D.F.) immersed themselves in the data by actively reading the 28 transcripts multiple times, searching for patterns and meanings. Notes and early impressions were documented independently by categorizing. An initial list of codes was generated independently to meaningfully and systematically organize the data after the categorizing process. Disagreements in assignment or description of codes were resolved through discussion

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3 and consensus, leading to refinement of themes. Through this iterative process of refinement of  
4 the initial themes, subthemes and a more in-depth meaning emerged of the participants'  
5 experiences.  
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### 10 **Ethical consideration**

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12 The study received ethics approval from the San Diego State University Institutional  
13 Review Board (HS-2017-0168). All participants underwent an informed consent processes, e.g.,  
14 purpose and procedures, the nature of voluntary participation if they did not wish to continue,  
15 potential risks and benefits of study participation, and assurance of privacy and confidentiality.  
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## 21 **Results**

### 22 ***Participants' socio-demographic information***

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24 Tables 2 and 3 describe the FCGs' socio-demographic and health-related variables,  
25 respectively. The average age of the caregivers was 60.7 and the majority were female (n=28,  
26 82.1%). More than two thirds identified as Latino/Hispanic (n=19, 67.9%) and one fourth of the  
27 participants (n=7, 25%) preferred Spanish for an interview. The majority of the participants were  
28 adult children of the patients (n=21, 75%), followed by a spouse (n=6, 21.4%). About 71%  
29 (n=20) of the caregivers lived with the HC patient and those who did not (n=6) lived within 12  
30 miles of the patient's home. Almost all were active participants in their HC patient's care.  
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### 42 **End-of-Life care related information**

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44 The majority (n=22, 78.6%) were informed of the patient's illness being incurable yet  
45 only approximately half of the participants (n=15, 53.6%) had had a discussion with a physician  
46 about HC. Home health care staff (n=11, 39.3%) first initiated the conversation about hospice  
47 care as an option, followed by the physician (n= 9, 32.1%). Only one-fourth of the FCGs (n=7,  
48 25%) were reportedly informed of the patients' life expectancy. About 61% (n=17) of the  
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3 participants reported that patients were cognitively impaired at the time. More than half of the  
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5 FCGs (n=15, 53.6%) believed that the patient was not aware of their terminal status.  
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### 8 Qualitative Themes/Sub-themes

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10 The most common themes relating to challenges and facilitators that emerged from our  
11  
12 analysis are presented below, followed by the less common themes.  
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#### 14 **Challenges in Decision-making for Utilizing Hospice Care**

##### 15 Communication barriers

16  
17 The participants identified a lack of EOL communication with their patients' physicians,  
18  
19 hence they felt inadequately prepared for making HC related decisions. One participant stated,  
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21 *"They have too many patients so all they do is go in there and they check them, say you're fine,*  
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23 *and then you are out... I don't think the conversation [with the physician] is really a*  
24  
25 *conversation. They are too busy ... and you know sometimes we have questions and we don't see*  
26  
27 *them [physician] (#5, Daughter). Another participant recalled the introduction of HC was from*  
28  
29 *home health agency, not a physician. "We ended up, um, going through the home health and they*  
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31 *were the first ones to bring it up. So that's why I think that they're, for whatever reason, I think*  
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33 *there's a big disconnect with the doctors"* (#28, Son). Difficulty with understanding medical  
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35 jargon led to other challenges in communication with the physicians. *"Talk to us with*  
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37 *understandable terms because sometimes they use medical terms that we do not understand* (#17,  
38  
39 *Wife).*

##### 40 Lack of knowledge/ Misperceptions about hospice care

41  
42 The participants expressed a limited or lack of knowledge about HC which hindered their  
43  
44 ability to make decisions about hospice for their loved ones. As expressed by a participant, *"I*  
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46 *didn't really know what hospice care was. It made it difficult to make a decision"* (#26,  
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3 Daughter). Participants thought hospice was strictly for patients who were expecting an  
4 imminent death. *“I had the wrong information of the word hospice... it [hospice] meant that*  
5 *death was already going to arrive and they were already going to die”* (#22, Wife).  
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### 8 9 10 Emotional Difficulties

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12 The participants experienced a range of emotions in their decision-making process, which  
13 at times delayed the ultimate decision for utilizing HC. Emotional difficulties related to HC  
14 included the fear of losing their family member, doubt/uncertainty, and denial of their loved  
15 one’s impending death.  
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19 Fear about losing their loved one. Some participants associated hospice with death,  
20 which increased their fear and anxiety about losing their loved one. *“Just simply with the word*  
21 *“terminal”, one gets nervous, you start to imagine the worst, that's why it was difficult to think*  
22 *about putting him in [hospice]... (#6, Daughter). Hospice placement meant accepting their*  
23 patient’s impending death, *“It is very difficult for me because it is like one does not want to*  
24 *accept what is coming, one does not want to get used to the idea that the end will come, so one*  
25 *does not want to lose their family member. So, that's why it was difficult for me. ... (# 22, Wife).*  
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29 Doubt and uncertainty about the decision. A participant shared her sense of self-doubt  
30 regarding her decision for hospice when she was informed of the limited options for acute care  
31 under the hospice program:  
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35 *The doctor talked to me about hospice during the day of the last visit. He said that my*  
36 *mom was terminal... I agreed and we did apply for the hospice. I could say on the third*  
37 *or fourth day, I was not sure whether I was doing the right thing or not... Um, because*  
38 *they told me that once she is in hospice, I cannot go to the hospital or call 911... that was*  
39 *kind of difficult* (#19, Daughter).  
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3        Denial. The word hospice resonates with death and some participants had difficulty  
4 accepting their patient's impending death. *"I kept thinking, well maybe they [physicians] are*  
5 *wrong, you know. ... I don't want to face the fact that I'm going to lose her. So I kept thinking*  
6 *"no she doesn't need that (hospice) yet" .... (#12, Daughter). Denial was the main source of*  
7 *family conflicts in making decisions for utilizing HC:*

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

#### 19 20 21 22 23 24 Patients are not ready for HC

25  
26        The perceived "right time" or "being ready" for utilizing hospice care was contingent  
27 upon the FCGs' subjective estimation of life expectancy. Some participants projected their loved  
28 one's life expectancy longer than what they were told: *"I knew that my mom was going to live a*  
29 *little bit longer"* (#9, Daughter). Other participants used the patient's physical appearance in  
30 comparison to other family members who had previously utilized HC as an index in making HC  
31 decisions: *"My uncle had gone into hospice in December a year and a half ago. He was really*  
32 *bad. ...When I found out what hospice meant that they gave them primarily pain medication but*  
33 *no fluids or foods (artificially), I didn't think that she [mom] was that far gone..." (# 4, Daughter).*

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

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51        *"She was in hospice for about a month, maybe two months. In one of the RN visits, she*  
52 *[nurse] just came and told me that I need to gather my family because my mother had*  
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3 *about 3 days left, so I should start calling the family so they could just say their*  
4 *goodbyes, which turned out not to be true, because it has been four years of that... You*  
5 *know, I thought that my mom was not ready for hospice ...in my mind hospice is for*  
6 *terminal patients, and my mother was not terminal. I still think she has a lot more [to*  
7 *live]” (#7, Daughter).*

### 14 **Facilitators in Decision-making for Utilizing Hospice Care**

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16  
17 Despite the various challenges for decision-making in utilizing HC, participants admitted  
18 their loved ones into HC. They identified several facilitators, which allowed them move forward  
19 in making a transition to HC.  
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#### 22 Patient's known EOL wishes.

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26 Participants' previous communication with patients on EOL care helped them to follow  
27 their loved one's wishes: *“Throughout the years, she either told me or my sisters ... she doesn't*  
28 *want to be like a vegetable ... we understand and we want to do what is best for her (#5,*  
29 *Daughter).* Another participant elaborated, *“After my father passed away, she made a medical*  
30 *directive” (#28, Son).*

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

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40 Physicians' explanations about HC and its available services positively influenced  
41 decision-making on utilizing HC. *“He [patient's physician] told me that there was going to be*  
42 *staff who would be checking him at home to [make him]more comfortable, that he would be with*  
43 *family, and that would make him feel more comfortable and that we would not be there in the*  
44 *hospital all the time” (#12, Daughter).* Another participant recalled the physician explaining the  
45 limitations and consequences of life-sustaining treatments, which guided the family to reach the  
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consensus for utilizing HC:

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3       *“At first we [family] wanted to revive him if something happens to him, right? But they*  
4       *explained to us that when they revive him it's a lot. They suffer more because they break*  
5       *bones and it's worse. So we just decided ... we're going to leave it” (#6, Daughter).*  
6  
7

#### 8 9 10 Right timing: Worsening prognosis

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12       The participants acknowledged their observations of their patients' poor prognosis as an  
13       indicator of readiness for hospice admission. *“It's a time element. I could see that my mother was*  
14       *waning and getting toward the end of her life (#9, Daughter). Witnessing their loved one's*  
15       *deteriorating health and recognizing that no curative approach was viable, the participants*  
16       *realized that HC was optimal for a quality end of life. Hospice care provided the support that was*  
17       *needed:*  
18  
19

20  
21       *“She was at that point where they couldn't do anything else. She knew it and we knew*  
22       *it. ...to be honest with you, it made it a lot easier on us because of not having to go to*  
23       *doctor's appointments and stuff, having somebody come to the house and uh, so it really*  
24       *made it a lot easier on us too to just do that” (#24, Daughter).*  
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#### 27 28 29 30 31 32 33 34 35 Home as the place for death

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37       Honoring the patient's wishes to die at home was important in the decision-making  
38       process. One participant described how she used a photo to assess the patient's preference for the  
39       placement of her EOL. *“I asked my mom where she wants to take her last breath ...I showed her*  
40       *a picture of home... at home or in the hospital and she said home... ... I'm not going to put her in*  
41       *no [nursing] home .... (#14, Daughter). Placement for care at home facilitated the acceptance of*  
42       *HC for family members. The participant stated;*  
43  
44

45  
46       *That was one of the questions that one of my brothers asked. So he goes to hospice, but*  
47       *wait a minute, is it going to be at home? [I said] “Everything's going to be the same. It's*  
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3 *just going to be a different type of care. That's it." And they go, oh yeah if it's going to be*  
4 *at home... Sure. So he was more willing to accept the word [hospice]... (#21, Daughter).*  
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## 8 **Discussion**

### 9 **Challenges in Decision-Making for Utilizing Hospice Care**

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11 Challenges with communication influenced decisions regarding hospice care. In  
12 particular, our study participants found difficulties with having adequate conversations with the  
13 physicians about hospice care. It needs to be noted that the majority of the participants were  
14 informed of the patients' incurable condition by primary care physicians (n=10) followed by  
15 hospitalists including ER doctors (n=8) and specialists (n=4). However, only about 50% of the  
16 study participants had hospice communication with the physicians. While hospice care referral  
17 needs to be approved by a physician with the patient's or family's consent, in our study the HC  
18 communication did not always take place with the physician. Communication regarding HC  
19 referrals was made by the physician via the home health nurses who were in contact with the  
20 physicians. We found in our study that the person who introduced hospice as an option was the  
21 home care staff (39.3%), followed by the physician (32.1%). This data suggests that information  
22 regarding the patient's prognosis does not necessarily lead to the physician's EOL/Hospice  
23 communication. Given that such information was provided by different specialists in home care,  
24 the lack of communications/referrals among the physicians might be a plausible explanation for  
25 this gap.  
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46 There are multiple reasons that might explain a late referral. Previous research with rural  
47 patients shows that fragmented care coordination within rural communities and also between  
48 rural and urban care facilities may hinder the timely access to health care services.<sup>24</sup> Yet another  
49 body of literature focused on medical decision making examined biomedicalization and the  
50 political economy of hope as sources of influence over physician behavior and communication in  
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3 ways that may postpone the discussions and referrals to hospice.<sup>13,14</sup> In the study conducted by  
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5 Teno and colleagues,<sup>36</sup> bereaved family members considered inadequate physician  
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7 communication and not recognizing the patient as dying as the two leading concerns regarding  
8  
9 late referrals and poor transition to hospice care. Researchers addressed the flaws in Medicare  
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11 hospice benefit (MHB) in the U.S. health care system as it assumes the physicians' accurate  
12  
13 estimation of life expectancy with patients' clear clinical trajectories which allow them to  
14  
15 accordingly make decisions for shifting from curative to palliative care/comfort care.<sup>12,13</sup>  
16  
17 Physicians' precise estimation of patients' life expectancy can be very challenging and their  
18  
19 clinical judgment about whether or not the active treatment is working does not immediately lead  
20  
21 to their hospice care referral.<sup>13,14</sup> Rather, multiple factors such as patient-provider relationships,  
22  
23 the provider's professional identity, and MHB reimbursement all interplay, thus complicating  
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25 hospice referral.<sup>13,14</sup> Hospice/palliative care-related communication with physicians also vary  
26  
27 by the specialty of the provider (i.e., oncologist, primary care physician) and the type of patients'  
28  
29 illness as specialists take a different approach to estimate patient's prognosis.<sup>14,36,37</sup> (e.g.,  
30  
31 cancer). Our study did not assess the patterns of communication by the types of specialists.  
32  
33 Future studies exploring the FCG's perception about timing for hospice care referral and their  
34  
35 communication with the physicians by the patient's type of illness may provide us better context  
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37 regarding patient/family-physician communication in rural settings.  
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45 Nevertheless, our participants' major concerns relating to lack of HC communication  
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47 with the physicians were mostly due to the physicians' lack of availability. Even for those who  
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49 engaged in HC communication, information processing still remained challenging due to lack of  
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51 clarity in the explanation. For rural populations with limited English-language proficiency and  
52  
53 low health literacy, the providers' additional support (i.e., tailoring health communication,  
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3 linguistic/culturally concordant communication) is necessary. This might be challenging in rural  
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5 regions with prevalent structural barriers (i.e., shortage of physicians, limited resources), thus  
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7 exacerbating HC coordination and referrals. Palliative care programs which provide comfort care  
8  
9 regardless of stage of illness, can be effective in making a smooth transition to HC which  
10  
11 provides comprehensive and supportive services to terminally ill patients and family members  
12  
13 for their physical, psychological and spiritual needs. Nevertheless, palliative care services,  
14  
15 especially in the hospital setting, are limited in rural regions due to the lack of specialists and  
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17 resources. Implementing hospice telehealth in which hospice care support can be provided via  
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19 computer or mobile devices, or coordinating with community-based home health agencies that  
20  
21 offer hospice care services, might provide for more timely referrals into hospice care.  
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26 Family caregivers' lack of knowledge and misconception of HC were apparent.  
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28 Consistent with results from previous studies,<sup>11,29,38</sup> our participants were not well aware about  
29  
30 HC and misunderstood that this service is only for those with impending death. The concept of  
31  
32 HC is particularly foreign for the Latino population, because the word "hospice" in Spanish  
33  
34 refers to an infirmary setting such as an institution or other restrictive place, which is different  
35  
36 than the meaning of hospice provided in the U.S.<sup>29,39</sup> Community-based education or outreach  
37  
38 can perhaps raise an awareness of HC. For example, the Promotora approach has been found to  
39  
40 be effective strategy to promote public health (i.e., cancer screening) in Hispanic communities.  
41  
42<sup>40,41</sup> Seymour and colleagues<sup>42</sup> found that peer education program using volunteers is a useful  
43  
44 approach in engaging with community members in relation to advance care planning. Using their  
45  
46 knowledge about the characteristics and resources of the community, Promotores can reach out  
47  
48 and further mobilize resources to facilitate ACP. Collaborating with community-based  
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50 organizations, trained Promotores can be integrated as a part of their outreach to the community  
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3 particularly on providing education and instrumental support (i.e., translation and dissemination,  
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5 to the community residents. This may bridge the gaps of health care access in rural regions with  
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7 limited health care resources.  
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10 The participants' insufficient knowledge and misperception about hospice appeared to  
11  
12 evoke strong emotions against placement of their family members in hospice care. Hospice  
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14 admission, which limits acute care options, was troublesome for some participants who  
15  
16 considered this action as giving up on their loved one. In our study, the family's denial of their  
17  
18 patient's terminal condition became a source of conflict. Family members' reluctance to accept  
19  
20 their loved one's terminal diagnosis was an obstacle for utilizing HC, which has been found in  
21  
22 previous studies.<sup>29,43</sup> Emotional reactions to HC might be closely associated with cultural  
23  
24 context in which cultural beliefs, values and preferences for EOL care play a significant role in  
25  
26 HC decision-making. For example, Latinos prefer family providing care<sup>38</sup> and maintaining  
27  
28 secrecy about prognosis.<sup>28</sup> Future research comparing Latinos and non-Latinos relating to their  
29  
30 HC decision-making might be beneficial to broaden our understanding about cultural aspects of  
31  
32 hospice decision-making and further develop culturally salient interventions.  
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### 37 **Facilitators in Decision-making for Utilizing Hospice Care**

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40 Despite some challenges, our participants identified some facilitators that helped them  
41  
42 navigate the decision-making process for utilizing HC. Similar to a previous study,<sup>44</sup> patients'  
43  
44 known EOL wishes helped family members better understand the patients' goals of care<sup>45</sup>, and  
45  
46 thereby made their HC decisions viable. With known patient's EOL wishes, our participants'  
47  
48 recognition of their loved one's worsening symptoms and deteriorating functioning facilitated  
49  
50 HC decision-making. Findings from research conducted by Norton and colleagues<sup>37</sup> highlight  
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52 that transition to hospice care is better facilitated by shared understanding among patient, family  
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3 and the physicians reaching the conclusion that no further active treatment works and hospice is  
4 an ultimate optimal option. FCG's reaching a conclusion that their loved one's functioning is no  
5 longer improving with active treatments could be the important decision-making point which  
6 emotionally and psychologically prepares the FCGs for moving forward with HC transition.  
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12 Our participants found their communication with the patients' physicians on HC helped  
13 them and their patient to make a relatively easy transition to HC. Participants recalled  
14 physicians' explanations about the risk of life-sustaining treatments, and the function and  
15 resources of HC being beneficial. Our findings highlighted the importance of EOL  
16 communication extending beyond prognostic information. Education for patients and their  
17 FCGs' needs to address the process of transition to HC, the goals and functions of HC, and  
18 available support and resources. Health care providers assessing the FCGs' extent of knowledge  
19 about HC and initiating EOL communication will be imperative. Introduction of advance care  
20 planning facilitated with patients and their family members at the beginning of a chronic illness  
21 is beneficial for healthcare providers and their patients, thereby making the process of care more  
22 smooth, especially when decisions regarding invasive or clinical procedures need to be made  
23 without the patient's full cognitive capacity.  
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40 In our study, placement of death was an integral part of EOL care planning, particularly  
41 among Latino patients. Providing care at home gave a sense of comfort for the FCGs in that  
42 patients received quality of care during their final moments <sup>19</sup> thereby fulfilling patients' wishes.  
43 Some of our participants emphasized their determination for not placing patients in nursing  
44 homes. Health care providers need to assess the patients' and family caregivers' preference for  
45 placement of care and provide clear information about home HC and its resources. It is also  
46 important to consider how FCG's characteristics might impact HC decision- making. FCGs'  
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3 level of education, health literacy, and their perception about the patient-provider relationship  
4 play a significant role in decision-making process.<sup>15,46</sup> Gender role is another important factor for  
5 understanding FCG's hospice decision-making. Previous studies<sup>47,48</sup> have found that caregiving  
6 responsibilities and the level of performance care are influenced by gender norms. In our study,  
7 the majority of FCGs were female and daughters and most of them reported either living together  
8 or near the patients. Our participant's perspectives toward HC and its priorities might have been  
9 influenced by the intersection of gender and relationship to the patients. Hence, considering  
10 family's personal and interpersonal factors into dialogues might lead to a better understanding of  
11 HC decision-making.  
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### 23 **Limitations**

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26 This study is the first study exploring challenges and facilitators in decision-making for  
27 utilizing HC among FCGs in rural U.S.-Mexico border. While our study broadens an  
28 understanding about caregivers' decision-making process in utilizing HC, it has some  
29 limitations. Participants were recruited from one site with all patients being Medicare  
30 beneficiaries. More than one third who originally agreed to participate in the study were not  
31 available which might lead to selection bias. Although we did not aim to seek for  
32 representativeness, future studies with multiple sites and a larger sample size can improve  
33 representativeness. Our study focuses only on FCGs' perceptions and experiences; however it  
34 might be beneficial to include patients and FCGs in dyads and also include caregivers of patients  
35 who never went into hospice care. For example, caregivers of patients who were not in hospice  
36 care might encounter more complex challenges which prevent their access of hospice care.  
37 Hence exploring group differences in HC decision-making may offer better contextual  
38 explanations for HC among rural patients. Another limitation to be addressed in a future study is  
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3 the social and cultural context of ethnically diverse populations whose beliefs and values may  
4 differ from the larger population. This information may be addressed through identification of  
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6 the social determinants of health that people experience in their daily lives and are influenced by  
7  
8 their long held practice with health and illnesses. This information may be helpful in educating  
9  
10 healthcare providers in the development of culturally appropriate interventions.  
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### 14 **Conclusion**

15  
16 Increasing attention to quality EOL care calls for our understanding about the dynamics  
17  
18 of decision-making in the utilization of HC by FCGs for their loved ones. Findings from this  
19  
20 study add valuable insights about the complexity of HC decision-making. Challenges and  
21  
22 facilitators to HC emerged as FCGs described their decision-making process guided by their  
23  
24 personal, interpersonal and socio-cultural experiences. Our study indicates the FCGs' overall  
25  
26 lack of EOL care involvement with the patient's physicians, leaving them less informed and  
27  
28 prepared for HC. It is imperative that health care providers assess FCGs' extent of knowledge  
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30 and their concerns about HC. There is a need for early integration of EOL care discussions into  
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32 their practice to facilitate transition into HC.  
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Table 1. Interview Guides

A Priori Concepts	Questions
Timing of decision-making for hospice care	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 hospice care Question 2: Describe conflict, if any, on hospice decision-making

Table 2. Participant Characteristics

ID #	Gender	Age Range	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

Table 3. End of- Life Communication Related Variables (N= 28)

Variables	n/%
Hospice discussion between caregivers and patient's physician	
<i>Yes</i>	15(53.6%)
<i>No</i>	13(46.4%)
Life expectancy being informed	
<i>Yes</i>	7 (25%)
<i>No</i>	21(75%)
Patients' mental status at the time of hospice referral	
<i>Competent</i>	11(39.3%)
<i>Impaired</i>	17(60.7%)
How well did the patient understand of his/her terminal condition?	
<i>Not at all</i>	15(53.6%)
<i>Somewhat</i>	2(7.1%)
<i>Fairly/very well</i>	11(39.3%)
Who informed you that the patient's illness could not be cured?	
<i>Primary care physician</i>	10 (35.7%)
<i>Hospitalists</i>	8 (28.6%)
<i>Specialists (i.e., oncologist, cardiologist, neurologist)</i>	4(14.3%)
<i>No one</i>	6 (21.4%)
Who first initiated the conversation about hospice as an option?	
<i>Family member</i>	5(17.9%)
<i>Home health care staff</i>	11(39.3%)
<i>Physician</i>	9(32.1%)
<i>Other</i>	3 (10.7%)

### Author Contributorship Statement

EK has contributed to designing and conceptualizing the study, performing data analysis, interpreting the results and drafting the manuscript.

DF has contributed to performing data analysis, interpreting the results, and writing the manuscript.

SS has provided substantial input and revised the manuscript.

FN has contributed to revising the manuscript.

### Competing Interest

There are no competing interests among the authors.

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### Data Sharing Statement

The participant data are deidentified and unidentifiable. All data relevant to the study are included in the article.

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## Standards for Reporting Qualitative Research (SRQR)

**Title:** 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

No.	Topic	Item	Page Number
	<b>Title and abstract</b>		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	2
	<b>Introduction</b>		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-6
S4	Purpose or research question	Purpose of the study and specific objectives or questions	6
	<b>Methods</b>		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	6-7
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability	8
S7	Context	Setting/site and salient contextual factors; rationale <sup>a</sup>	6
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale <sup>a</sup>	6-7
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	9
S10	Data collection methods	Types of data collected; details of data collection	7-8

	procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale <sup>a</sup>	
S11 Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	7, Table1
S12 Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6-7
S13 Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	8
S14 Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale <sup>a</sup>	8-9
S15 Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale <sup>a</sup>	7-8
<b>Results/Findings</b>		
S16 Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	9-20
S17 Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	9-20
<b>Discussion</b>		
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	15-20
S19 Limitations	Trustworthiness and limitations of findings	20-21
<b>Other</b>		
S20 Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	25
S21 Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	25

# 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 provides a comprehensive approach that enhances quality end-of-life (EOL) care for terminally ill patients. Despite its positive aspects, hospice care (HC) enrollment is disproportionate for rural patients who are less likely to utilize hospice care when compared to their urban counterparts. The purpose of this study was to explore the decision-making experiences relating to utilizing hospice care from the retrospective perspective of family caregivers (FCGs) in a rural US-Mexico border region.

**Design** Qualitative study using semi-structured in-person interviews were conducted from May, 2017 to January 2018.

**Setting** HC program from a local home health agency, located in rural Southern California, U.S.

**Participants** Twenty-eight informal FCGs of patients who were actively enrolled in a HC program from the study site

**Results** About 43% of the participants knew the patients needed HC when the patients' physicians initiated HC while 21% stated that they did not know what HC even was. Emerging themes relating to challenges in utilizing HC and decision-making included: 1) communication barriers, 2) lack of knowledge/misperception about HC, 3) emotional difficulties which included fear about losing their patient, doubt and uncertainty about the decision, and denial, and 4) patients are not ready for HC. Facilitators included: 1) patient's known EOL wishes, 2) family caregiver-physician EOL communication, 3) home as the place for death, and 4) the patient's deteriorating health.

**Conclusions** Family caregivers of HC patients in a rural region reported a lack of knowledge or misunderstanding of HC. Healthcare providers need to actively involve family members in patient's EOL care planning. Optimal transition to a HC can be facilitated by FCGs' accurate and clear understanding about the patients' medical conditions and status and receipt of information about HC.

**Key words:** home hospice, caregiver, rural, end-of-life care, decision-making

### Strengths and limitations of this study

- The qualitative method is helpful to gain an in-depth of understanding about the family caregivers' experiences in decision-making for utilizing hospice care.
- To our knowledge, this was the first study exploring decision-making to utilize hospice care among rural family caregivers in U.S.-Mexico border.
- The findings of this study provide a greater insight to what extent family caregivers understand hospice care and engage in communication with the patients' physicians.
- This study only included the family caregivers. Future studies could include patients in a dyad study which may provide different perspectives.

# 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

## Introduction

With an aging population in the United States (U.S.) and an increased life expectancy, there is a growing need to address quality end-of-life (EOL) care.<sup>1</sup> Hospice care (HC) is the interprofessional, multi-dimensional care provided to patients with a terminal status (less than 6 months life expectancy) and their families, and includes a wide range of services including pain and symptom management, bereavement services, and psychosocial and spiritual care.<sup>2</sup> HC is considered optimal care for patients with a terminal illness diagnosis as it provides a holistic approach in responding to a patient's physical, psychological, social and spiritual needs.<sup>3-5</sup> The use of hospice services for patients and families has been found to improve satisfaction with the quality of their healthcare,<sup>6,7</sup> increase the likelihood that patients' wishes will be followed,<sup>8</sup> decrease rates of patients' intensive care admissions, and reduce the receipt of invasive procedures.<sup>9</sup> Decision-making for EOL care, including HC, involves a dynamic, complex process in aiding patients to reflect upon their own goals-of-care, preferences for healthcare, and EOL communication with family and healthcare providers.<sup>10,11</sup> Despite the benefits of HC, underutilization still remains a concern. Factors contributing to hospice decision-making have been identified at the individual level (i.e., patient and family's lack of knowledge, attitudes and beliefs toward HC), interpersonal level (i.e., patient-provider relationship), and structural or macro level (i.e., health insurance reimbursement).<sup>12-15</sup> These challenges do not occur one at a time. Rather their interplay results in a web of complex constraints, complicating the decision-making process.<sup>13</sup>

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3 Family members are often closely involved in the decision-making of EOL care for their  
4 loved ones. The timing of decision-making is especially important for enrolling in HC when the  
5 focus of treatment shifts from curative to comfort care only for patients who have less than six  
6 months to live. While both HC and palliative care provide symptom management to relieve  
7 suffering, the provision of HC shifts the focus of medical treatment onto symptom  
8 management.<sup>16</sup> Notably, decisions around accepting HC are different than enrolling in palliative  
9 care because patients no longer receive life-prolonging or curative treatments in HC.<sup>16</sup> Family  
10 member's role is critical in the decision-making process, particularly in the event when a patient  
11 is incapacitated and unable express their own wishes for care.<sup>17</sup> During the decision-making  
12 process, family caregivers (FCG) often experience intrapersonal and interpersonal emotional  
13 challenges such as burden, guilt, and self-doubt about making the right decision.<sup>18-20</sup> Family  
14 conflicts can arise during this time, impacting decisions for utilizing HC.<sup>21</sup> Moreover, socio-  
15 cultural and geographic circumstances can place family members as primary caregivers, which  
16 often involves making important healthcare decisions.

17  
18 For patients and families who live in rural regions, there is often a lack of healthcare  
19 resources, including limited access to hospice and specialized healthcare, thus leaving patients  
20 and caregivers with additional healthcare challenges.<sup>22,23</sup> Such obstacles may be compounded for  
21 racial/ethnic minorities (e.g., Latinos) who have language barriers and unique cultural norm  
22 relating to EOL decision making.<sup>24,25</sup> Latinos were found to have a lack of knowledge or lack of  
23 information about hospice<sup>26,27</sup> and less likely to have intention or use HC.<sup>11,26,28</sup> Cultural values  
24 such as family-centered care with specific FCG responsibilities and secrecy about prognosis in  
25 an attempt to protect patients from emotional harm also affect their perception toward HC and  
26 end-of-life decision making.<sup>11,29</sup> Rural Latinos living in US/Mexico border region encounter

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3 structural challenges including limited or shortage of healthcare resources including access to  
4 specialists, transportation issues, language barriers and low health literacy<sup>24,25,30</sup> which might  
5 negatively impact the coordination of care for transitioning from active care to HC and results in  
6 delaying hospice referral. Lack of EOL care and late referrals to HC increase is associated with  
7 caregivers' greater unmet needs and concerns and overall low satisfaction.<sup>31,32</sup> Most research on  
8 this topic examines caregiving burden, unmet needs, and the impact of caregiver's well-being.<sup>33-</sup>  
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<sup>35</sup> However, very little is known about caregiver attitudes in decision-making to enroll in HC. Additionally, we have less information about the factors that facilitate or hinder their decisions to use HC particularly among caregivers of rural Latino patients.

Social and cultural contexts contribute to unique understanding of the cause (etiology), course (symptomatology), and cure (appropriate treatment or response) of illness.<sup>36</sup> Explanatory models<sup>36,37</sup> offer a useful framework for exploring sociocultural experiences of families affected by terminal illness, as the cause, course, and response to terminal illness among individuals and families living in rural areas may influence their decision to enroll in HC. While a review of cultural conceptualizations of HC found more similarities than differences across culturally diverse populations,<sup>38</sup> research on HC decision-making has not yet examined experiences among residents in rural US-Mexico border regions. This pilot exploratory study gives voice to the experiences of HC decision-making among FCGs living in a rural US-Mexico border community in Southern California. In particular, this study explores the challenges and facilitators involved in the decision to utilize HC from the perspective of caregivers of family members currently enrolled in a home hospice program in the Southern US.-Mexico border.

## Methodology

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3 We followed the Standards for Reporting Qualitative Research (SRQR) reporting  
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5 guideline to write this paper.<sup>39</sup>  
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### 7 **Study design and setting**

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10 This study utilized qualitative interviews to explore FCGs' challenges and facilitators  
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12 regarding decision-making in utilizing HC from a retrospective perspective. All patients were  
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14 enrolled and actively receiving hospice services from a large home health agency that provides  
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16 in-home healthcare services in a rural region, located in the poorest county in Southern  
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18 California.  
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### 20 **Subject and Recruitment Procedures**

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24 Purposive sampling was used to recruit FCGs. Our study goal was not to compare  
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26 racial/ethnic experiences by group; although, we included both Latino and non-Hispanic white  
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28 caregivers, which mirror the similar population proportion in the region. Eligibility criteria  
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30 included FCGs who were 18 and older; were currently providing care to the patients; and were  
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32 cognitively competent. During patient home visits, HC staff members presented a flyer which  
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34 described the research study to FCGs. Those who were interested in participating in the study  
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36 provided their contact number with the staff members to schedule an interview.  
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40 From the 53 caregivers who expressed interest in participating in the study, seven later  
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42 declined to participate; five requested rescheduling the appointment but did not answer upon a  
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44 follow-up phone call; five could not be reached (no answer) and seven patients passed away  
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46 prior to their caregivers making an appointment. A total of 29 individual FCGs participated in  
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48 the study; however, one participant was removed due to insufficient data resulting in a total  
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50 sample size of 28.  
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### 53 **Patient and public involvement**

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3 There was no patient or public involvement in setting the research design or conducting  
4 the study.  
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### 7 **Data collection**

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10 Data were collected via face-to-face interviews by a trained bilingual/bicultural research  
11 assistant from May, 2017 to January 2018. Interviews were conducted in the FCG's or patient's  
12 home, using a semi-structured interview guide which was based on previous literature on HC  
13 decision-making (see Table 1). Questions in the interview guide explored FCGs' perceptions and  
14 experiences of decision-making for utilizing HC, in particular as it relates to HC communication  
15 with the physician, patient, and among family members.<sup>21,29</sup> In order to assess the extent of  
16 involvement in decision-making for HC, we also assessed caregiver-provider communication  
17 (who informed them of the patient's incurable condition and initiated the hospice  
18 communication).<sup>40</sup> Each interview took approximately 30-40 minutes, and was conducted in  
19 either Spanish or English. Participants' nonverbal behaviors (i.e., facial expression, body  
20 language, and difficulty of articulation) were reported in the transcripts which later were used to  
21 add contextual meaning. The researcher also engaged in debriefing sessions with the research  
22 assistant to examine any event or circumstances (i.e., interruption during the interview) and its  
23 impact on the quality of interviews. All qualitative interviews were audio-taped and transcribed  
24 into Microsoft Word documents and entered into NVIVO for data management purposes.<sup>41</sup>  
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### 44 **Researcher characteristic and reflexivity**

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46  
47 This study was conducted by researchers across disciplines in the health and human  
48 services, including social work, nursing, and public health. With such representation from the  
49 *helping professions*, we were careful to not impose our assumptions and presuppositions of the  
50 health and HC system in the development of the interview guide nor in the interpretation of the  
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3 data. The bilingual/bicultural researcher and research assistant who conducted the interviews  
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5 took care in being objective and not ‘fill in’ words for participants, which might seem natural  
6  
7 when one can relate so much to the sociocultural background and context that the participants  
8  
9 came from. Also aligned with our professional standards, our research was designed to give  
10  
11 voice to participants and honor their experiences as unique or common as it might seem to them.  
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13

## 14 **Data Analysis**

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16  
17 Thematic analysis process delineated by Braun and Clarke <sup>42</sup> was utilized for analysis in  
18  
19 this study. Authors, (E.K. and D.F.) immersed themselves in the data by actively reading the 28  
20  
21 transcripts multiple times, searching for patterns and meanings. Notes and early impressions  
22  
23 were documented independently by categorizing concepts that emerged from the data analysis  
24  
25 process. An initial list of codes was generated independently to meaningfully and systematically  
26  
27 organize the data after the categorizing process. Disagreements in assignment or description of  
28  
29 codes were resolved through discussion and consensus, leading to refinement of themes.  
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32  
33 Through this iterative process of refinement of the initial themes, subthemes and a more in-depth  
34  
35 meaning emerged of the participants’ experiences.  
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37

## 38 **Ethical consideration**

39  
40 The study received ethics approval from the San Diego State University Institutional  
41  
42 Review Board (HS-2017-0168). All participants underwent an informed consent processes, e.g.,  
43  
44 purpose and procedures, the nature of voluntary participation if they did not wish to continue,  
45  
46 potential risks and benefits of study participation, and assurance of privacy and confidentiality.  
47  
48

## 49 **Results**

### 50 ***Participants’ socio-demographic information***



Tables 2 and 3 describe the FCGs' socio-demographic and health-related variables, respectively. The average age of the caregivers was 60.7 and the majority were female (n=28, 82.1%). More than two thirds identified as Latino/Hispanic (n=19, 67.9%) and one fourth of the participants (n=7, 25%) preferred Spanish for an interview. The majority of the participants were adult children of the patients (n=21, 75%), followed by a spouse (n=6, 21.4%). About 71% (n=20) of the caregivers lived with the HC patient and those who did not (n=6) lived within 12 miles of the patient's home. Almost all were active participants in their HC patient's care.

### **End-of-Life care related information**

The majority (n=22, 78.6%) were informed of the patient's illness being incurable yet only approximately half of the participants (n=15, 53.6%) had engaged in a discussion with a physician about HC. Home health care staff (n=11, 39.3%) first initiated the conversation about HC as an option, followed by the physician (n=9, 32.1%). Only one-fourth of the FCGs (n=7, 25%) were reportedly informed of the patients' life expectancy. 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 the patient was not aware of their terminal status. Notably, the majority of participants were informed about their incurable condition by a primary care physician (n=11) followed by a hospitalist including an ER doctor (n=8) and specialists (n=4). However, only about 50% of the study participants had hospice communication with a physician. Additionally, the provider who introduced hospice as an option was most often the home care staff (39.3%), followed by the physician (32.1%) (see table 3).

### **Qualitative Themes/Sub-themes**

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

## Challenges in Decision-making for Utilizing Hospice Care

### Communication barriers

The participants identified a lack of EOL communication with their patients' physicians, hence they felt inadequately prepared for making HC related decisions. One participant stated, *"They have too many patients so all they do is go in there and they check them, say 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). Another participant recalled the introduction of HC was from home health agency, not a physician. *"We ended up, um, going through the home health and they were the first ones to bring it up. So that's why I think that they're, for whatever reason, I think there's a big disconnect with the doctors"* (#28, Son). Difficulty with understanding medical jargon led to other challenges in communication with the physicians. *"Talk to us with understandable terms because sometimes they use medical terms that we do not understand"* (#17, Wife).

### Lack of knowledge/ Misperceptions about hospice care

The participants expressed a limited or lack of knowledge about HC which 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. *"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

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2  
3 The participants experienced a range of emotions in their decision-making process, which  
4  
5 at times delayed the ultimate decision for utilizing HC. Emotional difficulties related to HC  
6  
7 included the fear of losing their family member, doubt/uncertainty, and denial of their loved  
8  
9 one's impending death.  
10

11  
12 Fear about losing their loved one. Some participants associated hospice with death,  
13  
14 which increased their fear and anxiety about losing their loved one. *“Just simply with the word*  
15  
16 *“terminal”, one gets nervous, you start to imagine the worst, that's why it was difficult to think*  
17  
18 *about putting him in [hospice]... (#6, Daughter). Hospice placement meant accepting their*  
19  
20 *patient's impending death, “It is very difficult for me because it is like one does not want to*  
21  
22 *accept what is coming, one does not want to get used to the idea that the end will come, so one*  
23  
24 *does not want to lose their family member. So, that's why it was difficult for me. ... (# 22, Wife).*  
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27  
28 Doubt and uncertainty about the decision. A participant shared her sense of self-doubt  
29  
30 regarding her decision for hospice when she was informed of the limited options for acute care  
31  
32 under the hospice program:  
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35 *The doctor talked to me about hospice during the day of the last visit. He said that my*  
36  
37 *mom was terminal... I agreed and we did apply for the hospice. I could say on the third*  
38  
39 *or fourth day, I was not sure whether I was doing the right thing or not... Um, because*  
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41 *they told me that once she is in hospice, I cannot go to the hospital or call 911... that was*  
42  
43 *kind of difficult (#19, Daughter).*  
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47 Denial. The word hospice resonates with death and some participants had difficulty  
48  
49 accepting their patient's impending death. *“I kept thinking, well maybe they [physicians] are*  
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51 *wrong, you know. ... I don't want to face the fact that I'm going to lose her. So I kept thinking*  
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3 “no she doesn't need that (hospice) yet” .... (#12, Daughter). Denial was the main source of  
4 family conflicts in making decisions for utilizing HC:  
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8 *“I heard about hospice, um, eight months ago ...I brought it (hospice care) up with my*  
9  
10 *family members. They were like, “No way. That's for people that are dying. My dad is not*  
11  
12 *dying, you know, what are you talking about?” I think it's just been really hard for them*  
13  
14 *to let go, to accept that the situation...” (#21, Daughter).*  
15  
16

### 17 Patients are not ready for HC

18

19 The perceived “right time” or “being ready” for utilizing HC was contingent upon the  
20 FCGs’ subjective estimation of life expectancy. Some participants projected their loved one’s  
21 life expectancy longer than what they were told: *“I knew that my mom was going to live a little*  
22 *bit longer” (#9, Daughter).* Other participants used the patient’s physical appearance in  
23 comparison to other family members who had previously utilized HC as an index in making HC  
24 decisions: *“My uncle had gone into hospice in December a year and a half ago. He was really*  
25 *bad. ...When I found out what hospice meant that they gave them primarily pain medication but*  
26 *no fluids or foods (artificially), I didn't think that she [mom] was that far gone... (# 4, Daughter).*  
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38 One participant reported delaying the decision for a hospice referral due to a previous  
39 experience with the healthcare provider’s inaccurate estimate of the patient’s life expectancy,  
40 which confirmed her belief about premature hospice -referral:  
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44  
45 *“She was in hospice for about a month, maybe two months. In one of the RN visits, she*  
46  
47 *[nurse] just came and told me that I need to gather my family because my mother had*  
48  
49 *about 3 days left, so I should start calling the family so they could just say their*  
50  
51 *goodbyes, which turned out not to be true, because it has been four years of that... You*  
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53 *know, I thought that my mom was not ready for hospice ...in my mind hospice is for*  
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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 Utilizing Hospice Care

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

#### Patient's known EOL wishes.

Participants' previous communication with patients on EOL care helped them to follow their loved one's wishes: "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). Another participant elaborated, "After my father passed away, she made a medical directive" (#28, Son).

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

Physicians' explanations about HC and its available services positively influenced decision-making on utilizing HC. "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 recalled the physician explaining the limitations and consequences of life-sustaining treatments, which guided the family to reach the consensus for utilizing HC:

"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

The participants acknowledged their observations of their 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).*

Witnessing their loved one's deteriorating health and recognizing that no curative approach was viable, the participants realized that HC was optimal for a quality end of life. HC provided the support that was needed:

*"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

Honoring the patient's wishes to die at home was important in the decision-making process. One participant described how she used a photo to assess the patient's preference for the placement of her EOL. *"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 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 Utilizing Hospice Care**

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3 Challenges with communication influenced decisions regarding HC. In particular, our  
4  
5 study found that participants had difficulties with having adequate conversations with a  
6  
7 physician about HC. The finding that eight participants were informed of the patient's terminal  
8  
9 condition by the hospitalists during the patient's visit for acute care (e.g., admission to ER)  
10  
11 suggests that existing barriers influenced care coordination or transition from acute care to HC.  
12  
13 A previous study<sup>29</sup> yielded that Latinos were referred by the various hospital staff (non-  
14  
15 physician) during the crisis hospitalization as compared to white non-Latinos being referred by  
16  
17 the specialists. Part of the problem is that a referral to HC must be approved by a physician with  
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19 the patient's or family's consent. However, in our study HC communication did not always take  
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21 place with the physician. Communication regarding HC referrals was made by the physician via  
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23 the home health or HC staff (e.g., nurse) who then initiated EOL/HC communication with FCGs.  
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25 Additionally, information regarding the patient's prognosis did not necessarily lead to  
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27 communication with a physician about EOL/HC.  
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33 There are multiple reasons that might explain a late referral. Previous research with rural  
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35 patients shows that fragmented care coordination within rural communities and also between  
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37 rural and urban care facilities may hinder the timely access to healthcare services.<sup>25</sup> Yet another  
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39 reason is the biomedicalization and political economy of hope as sources of influence over  
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41 physicians' behavior and communication in ways that may postpone discussions and referrals to  
42  
43 hospice.<sup>13,14</sup> In the study conducted by Teno and colleagues,<sup>43</sup> bereaved family members  
44  
45 considered inadequate physician communication and not recognizing the patient as dying as the  
46  
47 two leading concerns regarding late referrals and poor transition to HC. Researchers addressed  
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49 the flaws in Medicare hospice benefit (MHB) in the U.S. healthcare system as it assumes the  
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51 physicians' accurate estimation of life expectancy with patients' clear clinical trajectories which  
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3 allow them to accordingly make decisions for shifting from curative to palliative care/comfort  
4 care.<sup>12,13</sup> Physicians' precise estimation of patients' life expectancy can be very challenging and  
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6 their clinical judgment about whether or not the active treatment is working does not  
7  
8 immediately lead to their HC referral. <sup>13,14</sup> Rather, multiple factors such as patient-provider  
9  
10 relationships, the provider's professional identity, and MHB reimbursement all interplay, thus  
11  
12 complicating hospice referral. <sup>13,14</sup> Hospice/palliative care-related communication with  
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14 physicians also vary by the specialty of the provider (i.e., oncologist, primary care physician) and  
15  
16 the type of patients' illness as specialists take a different approach to estimate patient's  
17  
18 prognosis. <sup>14,43,44</sup> (e.g., cancer). Our study did not assess the patterns of communication by the  
19  
20 types of specialists. Future studies exploring the FCG's perception about timing for HC referral  
21  
22 and their communication with the physicians by the patient's type of illness may provide us  
23  
24 better context regarding patient/family-physician communication in rural settings.  
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31 In our study, participants' major concerns relating to lack of HC communication with the  
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33 physicians were mostly due to the physicians' lack of availability. Even for those who engaged  
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35 in HC communication, information processing remained challenging due to lack of clarity in the  
36  
37 explanation. For rural populations with limited English-language proficiency and low health  
38  
39 literacy, providers need to give additional support to patients and families, tailoring health  
40  
41 communication and adapting interventions for linguistic/cultural concordant communication.  
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43 Adapting interventions for such patients might be challenging in rural regions with prevalent  
44  
45 structural barriers (i.e., shortage of physicians, limited resources). Continuing standard practice  
46  
47 without adapting care for such vulnerable patients and family will most likely exacerbate HC  
48  
49 coordination and referrals. Palliative care programs which provide comfort care regardless of  
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51 stage of illness can be effective in making a smooth transition to HC which provides  
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3 comprehensive and supportive services to terminally ill patients and family members for their  
4 physical, psychological and spiritual needs. Palliative care services, especially in the hospital  
5 setting, are limited in rural regions due to the lack of specialists and resources. Implementing  
6 hospice telehealth in which HC support can be provided via computer or mobile devices, or  
7 coordinating with community-based home health agencies that offer HC services, might provide  
8 for more timely referrals into HC.  
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17 Family caregivers' lack of knowledge and misconception of HC were apparent.  
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19 Consistent with results from previous studies,<sup>11,30,45</sup> our participants were not well aware about  
20 HC and misunderstood that this service is only for those with impending death. The concept of  
21 HC is particularly foreign for the Latino population, because the word "hospice" in Spanish  
22 refers to an infirmary setting such as an institution or other restrictive place, which is different  
23 than the meaning of hospice provided in the U.S.<sup>45,46</sup> Community-based education or outreach  
24 can perhaps raise an awareness of HC. For example, the Promotora approach has been found to  
25 be effective strategy to promote public health (i.e., cancer screening) in Hispanic communities.  
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47,48 Seymour and colleagues<sup>49</sup> found that peer education program using volunteers is a useful  
approach in engaging with community members in relation to advance care planning. Using their  
knowledge about the characteristics and resources of the community, Promotores can reach out  
and further mobilize resources to facilitate ACP. Collaborating with community-based  
organizations, trained Promotores can be integrated as a part of their outreach to the community  
particularly on providing education and instrumental support (i.e., translation and dissemination,  
to the community residents. This may bridge the gaps of healthcare access in rural regions with  
limited healthcare resources.

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3 The participants' insufficient knowledge and misperception about hospice appeared to  
4 evoke strong emotions against placement of their family members in HC. Hospice admission,  
5 which limits acute care options, was troublesome for some participants who considered this  
6 action as giving up on their loved one. In our study, the family's denial of their patient's terminal  
7 condition became a source of conflict. Family members' reluctance to accept their loved one's  
8 terminal diagnosis was an obstacle for utilizing HC, which has been found in previous studies.  
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45,50 Emotional reactions to HC might be closely associated with cultural context in which cultural beliefs, values and preferences for EOL care play a significant role in HC decision-making. For example, Latinos prefer family-centered care<sup>30</sup> and maintain secrecy about the patient's prognosis.<sup>29</sup> Future research comparing Latinos and non-Latinos relating to their HC decision-making might be beneficial to broaden our understanding about cultural aspects of hospice decision-making and further develop culturally salient interventions.

### **Facilitators in Decision-making for Utilizing Hospice Care**

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Despite some challenges, our participants identified some facilitators that helped them navigate the decision-making process for utilizing HC. Similar to a previous study,<sup>51</sup> patients' known EOL wishes helped family members better understand the patients' goals of care,<sup>52</sup> and thereby made their HC decisions viable. With known patient's EOL wishes, our participants' recognition of their loved one's worsening symptoms and deteriorating functioning facilitated HC decision-making. Findings from research conducted by Norton and colleagues<sup>44</sup> highlight that transition to HC is better facilitated by shared understanding among patient, family and the physicians reaching the conclusion that no further active treatment works and hospice is an ultimate optimal option. FCG's reaching a conclusion that their loved one's functioning is no

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3 longer improving with active treatments could be the important decision-making point which  
4 emotionally and psychologically prepares the FCGs for moving forward with HC transition.  
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8 Our participants found their communication with the patients' physicians on HC helped  
9 them and their patient to make a relatively easy transition to HC. Participants recalled  
10 physicians' explanations about the risk of life-sustaining treatments, and the function and  
11 resources of HC being beneficial. Our findings highlighted the importance of EOL  
12 communication extending beyond prognostic information. Education for patients and their  
13 FCGs' needs to address the process of transition to HC, the goals and functions of HC, and  
14 available support and resources. Healthcare providers assessing the FCGs' extent of knowledge  
15 about HC and initiating EOL communication will be imperative. Additionally, healthcare  
16 providers need to introduce advance care planning and facilitate conversations about advance  
17 directives with patients and families at the beginning of a diagnosis of a chronic illness. Doing so  
18 could make the process of managing transitions of care more smooth, especially when decisions  
19 regarding invasive or clinical procedures need to be made without the patient's full cognitive  
20 capacity.  
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38 In our study, placement of death was an integral part of EOL care planning, particularly  
39 among Latino patients. Providing care at home gave a sense of comfort for the FCGs in that  
40 patients received quality of care during their final moments<sup>20</sup> thereby fulfilling patients' wishes.  
41  
42 Some of our participants emphasized their determination for not placing patients in nursing  
43 homes. Healthcare providers need to assess the patients' and family caregivers' preference for  
44 placement of care and provide clear information about home HC and its resources. It is also  
45 important to consider how FCG's characteristics might impact HC decision- making. FCGs'  
46 level of education, health literacy, and their perception about the patient-provider relationship  
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3 which play a significant role in the decision-making process.<sup>15,53</sup> Gender role is another  
4  
5 important factor for understanding FCG's hospice decision-making. Previous studies<sup>54,55</sup> have  
6  
7 found that caregiving responsibilities and the level of performance care are influenced by gender  
8  
9 norms. In our study, the majority of FCGs were female and daughters and most of them reported  
10  
11 either living together or near the patients. Our participant's perspectives toward HC and its  
12  
13 priorities might have been influenced by the intersection of gender and relationship to the  
14  
15 patients. Hence, considering family's personal and interpersonal factors into dialogues might  
16  
17 lead to a better understanding of HC decision-making.  
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21  
22 Lastly, healthcare providers need to understand how these issues influence decision-  
23  
24 making communication and utilization of HC among patients and families living in rural areas of  
25  
26 the U.S.-Mexico Border region. While most providers receive some education about this topic,  
27  
28 they often lack time and have insufficient resources to adequately address the unique needs of  
29  
30 this population which reduces the likelihood of referring patients to HC.<sup>56</sup> Some research  
31  
32 suggests providers must have training about approaching sensitive and complex conversations  
33  
34 with vulnerable groups using a coaching tool that assists them to promote effective patient-  
35  
36 provider interactions involving emotion regulation, partnership-building, and optimal patient  
37  
38 outcomes.<sup>57</sup> Future research could address ways to support effective patient-provider  
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40 communication with providers working in rural settings to promote introducing HC to patients  
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42 and families early when facing serious illness, which is especially important for vulnerable  
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44 populations like those in our study.  
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### 49 **Limitations**

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51 This study is the first study exploring challenges and facilitators in decision-making for  
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53 utilizing HC among FCGs in rural U.S.-Mexico border. While our study broadens an  
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3 understanding about caregivers' decision-making process in utilizing HC, it has some  
4  
5 limitations. Participants were recruited from one site with all patients being Medicare  
6  
7 beneficiaries. More than one third who originally agreed to participate in the study were not  
8  
9 available but we do not have a data for explaining its reason. This might be due to participants'  
10  
11 discomfort about talking about death and dying or their own health issues. This might lead to  
12  
13 selection bias. Although we did not aim to seek for representativeness, future studies with  
14  
15 multiple sites and a larger sample size can improve representativeness. Our study focuses only  
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17 on FCGs' perceptions and experiences; however it might be beneficial to include patients and  
18  
19 FCGs in dyads and also include caregivers of patients who never went into HC. For example,  
20  
21 caregivers of patients who were not in HC might encounter more complex challenges which  
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23 prevent their access of HC. Hence exploring group differences in HC decision-making may offer  
24  
25 better contextual explanations for HC among rural patients. We did not collect the information  
26  
27 on patient's length of stay at the hospice at the time of study. As the caregivers' understanding  
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29 and perception toward HC vary by hospice length of stay, future study needs to take this into  
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31 consideration.  
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### 38 **Conclusion**

39  
40 Increasing attention to quality EOL care calls for our understanding about the dynamics  
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42 of decision-making in the utilization of HC by FCGs for their loved ones. Findings from this  
43  
44 study add valuable insights about the complexity of HC decision-making. Challenges and  
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46 facilitators to HC emerged as FCGs described their decision-making process guided by their  
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48 personal, interpersonal and socio-cultural experiences. Our study indicate that EOL  
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50 communication among patient, caregivers, and physicians are imperative to enhance FCG's  
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52 knowledge about patients' EOL care preferences and facilitate hospice decision making. Our  
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54 study indicates that CGs' overall lack of EOL care involvement with the patient's physicians,  
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3 leaving them less informed and unprepared for HC. Without effective patient-provider  
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5 communication, patients and families may experience increased emotional distress and confusion  
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7 about HC, leading to fear, doubt and uncertainty about the decision. It is imperative that  
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9 healthcare providers assess FCGs' extent of knowledge and their concerns about HC. There is a  
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11 need for early integration of EOL care discussions into their practice to facilitate transition into  
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15 HC.  
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For peer review only

Table 1. Interview Guides

A Priori Concepts	Questions
Timing of decision-making for hospice care	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 hospice care Question 2: Describe conflict, if any, on hospice decision-making

Table 2. Participant Characteristics

ID #	Gender	Age Range	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



Table 3. End of- Life Communication Related Variables (N= 28)

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

### Author Contributorship Statement

EK has contributed to designing and conceptualizing the study, performing data analysis, interpreting the results and drafting the manuscript.

DF has contributed to performing data analysis, interpreting the results, and writing the manuscript.

SS has provided substantial input and revised the manuscript.

FN has contributed to revising the manuscript.

### Competing Interest

There are no competing interests among the authors.

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### Data Sharing Statement

The participant data are deidentified and unidentifiable. All data relevant to the study are included in the article.

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## Standards for Reporting Qualitative Research (SRQR)

**Title:** 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

No.	Topic	Item	Page Number
	<b>Title and abstract</b>		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	2
	<b>Introduction</b>		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-6
S4	Purpose or research question	Purpose of the study and specific objectives or questions	6
	<b>Methods</b>		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	6-7
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability	8
S7	Context	Setting/site and salient contextual factors; rationale <sup>a</sup>	6
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale <sup>a</sup>	6-7
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	9
S10	Data collection methods	Types of data collected; details of data collection	7-8

	procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale <sup>a</sup>	
S11 Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	7, Table 1
S12 Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6-7
S13 Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	8
S14 Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale <sup>a</sup>	8-9
S15 Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale <sup>a</sup>	7-8
<b>Results/Findings</b>		
S16 Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	9-20
S17 Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	9-20
<b>Discussion</b>		
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	15-20
S19 Limitations	Trustworthiness and limitations of findings	20-21
<b>Other</b>		
S20 Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	25
S21 Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	25



# 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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Keywords:	PALLIATIVE CARE, Adult palliative care < PALLIATIVE CARE, PUBLIC HEALTH

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## Abstract

**Objectives:** Hospice care is seen as a comprehensive approach, that enhances quality of end-of-life (EOL) care, for terminally ill patients. Despite its positive aspects, hospice care (HC) enrollment is disproportionate for rural patients, who are less likely to utilize HC in comparison to their urban counterparts. The purpose of this study was to explore decision-making experiences, related to utilization of HC programs 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 semi-structured face to face interviews with FCGs. Data were analyzed using thematic analysis.

**Setting:** The HC program was situated at a local home health agency, located in rural Southern California, U.S.

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

**Results:** Conversation about HC as an option was initiated by home health care staff (39.3%), followed by physicians (32.1%). Emerging themes related to challenges in utilization 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) family caregiver-physician EOL communication; 3) the patient's deteriorating health; and, 4) home as the place for death.

**Conclusions:** Hospice Care 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 a HC program can be facilitated when FCGs are informed and have a clear understanding about patients' medical status along with information about HC.

**Key words:** home hospice, caregiver, rural, end-of-life care, decision-making

### Strengths and limitations of this study

- A qualitative methodology approach is helpful in gaining an in-depth understanding and meaning of family caregivers' experiences, in decision-making when utilizing HC.
- To our knowledge, this is the first study exploring decision-making to utilize HC among rural family caregivers in the U.S.-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 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 end of life care for this population.

# 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

## Introduction

With an aging population in the United States (U.S.), 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 interprofessional, multi-dimensional 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-utilization still remains a concern. Factors contributing to hospice related decision-making, have been identified at the individual level (i.e., patient and family's lack of knowledge, attitudes and beliefs toward HC), interpersonal level (i.e., patient-provider relationship), and structural or macro level (i.e., 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

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3 right decision for their loved-ones.<sup>13,14</sup> Family conflict may arise during this time, which can  
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5 impact decisions for HC utilization.<sup>15</sup> Timing of decision-making is particularly important for  
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7 enrollment in HC programs, especially when the focus of treatments shift from curative to  
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9 comfort care, for patients who may have less than six months to live. While both HC and  
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11 palliative care provide symptom management to relieve suffering, the provision of HC shifts the  
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13 focus of medical treatment to symptom management.<sup>16</sup> Notably, decisions around accepting HC  
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15 are somewhat different than enrolling in palliative care, because patients no longer receive life-  
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17 prolonging or curative treatments in HC.<sup>16</sup>  
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21 For patients and families who live in rural regions, there is often a lack of healthcare  
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23 resources and supportive care, including limited access to hospice and specialized healthcare;  
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25 thus, leaving patients and caregivers with additional healthcare challenges.<sup>17,18</sup> Such obstacles  
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27 may be compounded for racial/ethnic minorities (e.g., Latinos), who have language barriers and  
28  
29 unique cultural norm relating to EOL decision making.<sup>19,20</sup> Evidence suggests that Latinos  
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31 present a lack of knowledge or lack of information about HC,<sup>21,22</sup> and are less likely to have an  
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33 intention or to use HC.<sup>21,23,24</sup> Cultural values such as family-centered care, with specific FCG  
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35 responsibilities and secrecy about prognosis, is seen as an attempt to protect patients from  
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37 emotional harm. This form of values and beliefs about the use of HC, may also affect their  
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39 perception toward HC, and end-of-life decision-making.<sup>24,25</sup> Rural Latinos living in US/Mexico  
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41 border region, generally encounter structural challenges that include a lack of insurance,  
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43 transportation issues, language barriers, and a low health literacy.<sup>19,20,26</sup> These factors might  
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45 negatively impact coordination of care, for transitioning from active care to HC, which can result  
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47 in delaying hospice referrals. Lack of EOL care planning and late referrals to HC, increases the  
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49 caregivers' unmet needs and concerns, and an overall low satisfaction with HC.<sup>27,28</sup> Most  
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3 research on this topic examined caregiver burden, unmet needs, and an impact of the caregiver's  
4 personal well-being.<sup>29-31</sup> However, there is a paucity of information about factors that facilitate  
5 or hinder their decisions to use HC, particularly among caregivers of rural Latino patients.  
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10 Social and cultural contexts contribute to a unique understanding of the cause (etiology),  
11 course (symptomatology), and cure (appropriate treatment or response) of illness.<sup>32</sup> Explanatory  
12 models,<sup>32,33</sup> offer a useful framework for exploring sociocultural experiences of families affected  
13 by terminal illness, such as the cause, process, and response to terminal illness, among patients  
14 residing in rural regions. While a review of cultural conceptualizations of HC found more  
15 similarities than differences across culturally diverse populations,<sup>34</sup> research on HC decision-  
16 making, has not yet examined experiences among residents in rural US-Mexico border regions.  
17 In light of the paucity of evidence on this topic, our aim was to explore challenges and  
18 facilitators, involved in the decision-making process for HC utilization, from the FCG's  
19 perspectives. Given the complex nature of EOL care and HC related decision-making, there was  
20 a need to explore diverse perspectives of FCGs, in order to better understand the multifaceted  
21 factors that may be related to the social/cultural contexts of care, for this vulnerable population.  
22 This study explored participants' decision-making experiences, related to utilization of HC  
23 programs from a retrospective perspective with FCGs residing in a rural US-Mexico border  
24 region.  
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## 44 **Methods**

45 We followed the Standards for Reporting Qualitative Research (SRQR) reporting  
46 guideline to write this paper.<sup>35</sup>  
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### 50 **Study Design and Setting**

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3 This study utilized qualitative methodology and employed semi-structured interviews to  
4 explore FCGs' challenges and facilitators related to decision-making, in the utilization of HC  
5 from a retrospective perspective. All patients were enrolled and actively receiving hospice  
6 services from a large home health agency, that provides in-home healthcare services in a rural  
7 region, located in the most socio-economically disadvantaged county in Southern California.  
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### 14 **Subject and Recruitment Procedures**

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

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47 There was no patient or public involvement in the development of the research design or  
48 in conducting the study.  
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### 50 **Data collection**

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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 semi-structured 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 utilization 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 minutes, and was conducted in either Spanish or English language. Participants' nonverbal behaviors (i.e., 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 (i.e., 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

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3 bilingual/bicultural researcher and research assistant who conducted the interviews, took care in  
4 being objective and to not ‘fill in’ words for participants, which might seem natural when  
5 relating to one’s own sociocultural background, and its contexts that is most similar for each  
6 team member. Also aligned with our professional standards, this research was designed to give  
7 voice to participants’ and to honor their experiences, as unique or common as it might seem to  
8 them.  
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### 16 **Data Analysis**

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19 Thematic analysis processes delineated by Braun and Clarke<sup>39</sup> was utilized for analysis in  
20 this study. Authors, (E.K. and D.F.) immersed themselves in the data by actively reading the 28  
21 transcripts line-by-line multiple times, searching for patterns and meanings. Hand-written notes  
22 and early impressions were documented independently, by categorizing concepts that emerged  
23 during the data analysis process. An initial list of codes was generated independently to  
24 meaningfully and systematically organize the data after the categorization process.  
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26 Disagreements in assignment or description of codes were resolved through discussion and  
27 consensus. The final list of codes was entered into QSR NVivo to organize the text into codes  
28 and categories, thus facilitating and leading to theme refinement. Through this iterative process  
29 of refinement of the initial themes, subthemes and a more in-depth meaning emerged of the  
30 participants’ experiences.  
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### 32 **Ethical consideration**

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35 The study received ethics approval from the San Diego State University Institutional  
36 Review Board (HS-2017-0168). All participants underwent an informed consent process, e.g.,  
37 purpose and procedures, the nature of voluntary participation if they did not wish to continue,  
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potential risks and benefits of participating in the study, and an assurance of privacy and confidentiality.

## Results

### Characteristics of participants

Tables 2 and 3 describe the FCGs' socio-demographic and HC related variables, respectively. The average age of the caregivers was 60.7, with the majority being female (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.

### End-of-Life 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 about patient's incurable condition by a primary care physician (n=11), followed by a hospitalist including ER doctors (n=8), and other health care staff members (e.g., 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/Sub-themes

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3 The most common themes related to challenges and facilitators that emerged from our  
4 analysis are presented below, followed by the less common themes.  
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## 7 **Challenges in Decision-Making for Utilizing Hospice Care**

### 8 ***Communication Barriers***

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10 Participants identified a lack of EOL communication with their patients' physicians,  
11 hence they felt inadequately prepared for making HC related decisions. Even for those who  
12 engaged in HC communication, information processing remained challenging due to a lack of  
13 clarity in their explanation:  
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21 *"They have too many patients so all they do is go in there and they check them, saying*  
22 *you're fine, and then you are out... I don't think the conversation [with the physician] is*  
23 *really a conversation. They are too busy ... and you know sometimes we have questions*  
24 *and we don't see them [physician]."* (#5, Daughter).  
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31 Difficulty with understanding medical jargon led to other challenges in communication  
32 with physicians. For rural populations with limited English-language proficiency, and low health  
33 literacy, providers could have offered additional support to patients and their families, by  
34 tailoring health communication and adapting interventions for linguistic/cultural concordant  
35 communication:  
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42 *"Talk to us with understandable terms because sometimes they use medical terms that we*  
43 *do not understand."* (#17, Wife)  
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47 Another participant recalled the introduction of HC was from home health agency, not  
48 from a physician. A referral to HC must be approved by a physician with the patient's or  
49 family's consent; however, HC communication did not always take place with the physician.  
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3 Communication regarding HC referrals was made by the physician via a home health or HC staff  
4 (e.g., nurse), who then initiated EOL/HC communication with FCGs:  
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8 *“We ended up going through the home health and they were the first ones to bring it up.*

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10 *So that's why I think for whatever reason, there's a big disconnect with the doctors.”*

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12 (#28, Son)  
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### 14 ***Lack of knowledge/ Misperceptions about hospice care***

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16 As previously reported elsewhere,<sup>11,30,40</sup> our participants were unaware of HC, which then  
17 hindered their ability to make decisions about hospice for their loved ones. As expressed by a  
18 participant, *“I didn't really know what hospice care was. It made it difficult to make a decision”*  
19 (#26, Daughter). Participants thought hospice was strictly for patients who were expecting an  
20 imminent death. The concept of HC and the term used regarding hospice has often been  
21 misunderstood by Latinos. The word “hospice” in Spanish refers to an infirmary setting, such as  
22 an institution or other restrictive place,<sup>25,41</sup> which is different than the meaning of hospice  
23 provided in the U.S. healthcare system:  
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35 *“I had the wrong information of the word hospice... it [hospice] meant that death was*  
36 *already going to arrive and they were already going to die.”* (#22, Wife)  
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### 40 ***Emotional Difficulties***

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42 Participants experienced a range of emotions in their decision-making processes, which  
43 at times delayed the ultimate decision for utilization of HC. Emotional difficulties related to HC,  
44 included the fear of losing their family member, doubt/uncertainty, and denial of their loved  
45 one's impending death.  
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51 *Fear about losing their loved one.* Some participants associated hospice with death,  
52 which increased their fear and anxiety about losing their loved ones: *“Just simply with the word*  
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3 “terminal”, one gets nervous, you start to imagine the worst, that's why it was difficult to think  
4 about putting him in [hospice].” (#6, Daughter)  
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8 Hospice placement meant accepting their patient's impending death.  
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10 “It was very difficult for me because it is like one does not want to accept what is  
11 coming, one does not want to get used to the idea that the end will come, so one does not  
12 want to lose their family member.” (# 22, Wife)  
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16 Doubt and uncertainty about the decision. Hospice admission, which limits acute care  
17 options, was troublesome for some participants who considered this action as giving up on their  
18 loved one:  
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23 “The doctor talked to me about hospice during the day of the last visit. He said that my  
24 mom was terminal... I agreed and we did apply for the hospice. I could say on the third or  
25 fourth day, I was not sure whether I was doing the right thing or not... Um, because they  
26 told me that once she is in hospice, I cannot go to the hospital or call 911... that was kind  
27 of difficult.” (#19, Daughter)  
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35 Denial. The word hospice resonates with death when family has a conflict in realizing  
36 the patient's terminal condition. Family members' reluctance to accept their loved one's terminal  
37 diagnosis was an obstacle for a smooth transition to HC:  
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42 “I heard about hospice, um, eight months ago ...I brought it (hospice care) up with my  
43 family members. They were like, “No way. That's for people that are dying. My dad is not  
44 dying, you know, what are you talking about?” I think it's just been really hard for them  
45 to let go, to accept that the situation....” (#21, Daughter)  
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51 ***Patients are not ready for HC***  
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3 The perceived “right time” or “being ready” for utilization of HC was contingent upon  
4 the FCGs’ subjective estimation of life expectancy. Some participants projected their loved one’s  
5 life expectancy was longer than what they were told: “*I knew that my mom was going to live a*  
6 *little bit longer,*” (#9, Daughter). Other participants used the patient’s physical appearance in  
7 comparison to other family members, who had previously utilized HC as an index in making HC  
8 related decisions:  
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17 “*My uncle had gone into hospice in December a year and a half ago. He was really bad.*  
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19 *When I found out what hospice meant that they gave them primarily pain medication but*  
20 *no fluids or foods (artificially), I didn't think that she [mom] was that far gone.*” (# 4,  
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23  
24 Daughter)

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26 One participant reported delaying the decision for a hospice referral, due to a previous  
27 experience with the healthcare provider’s inaccurate estimate of the patient’s life expectancy,  
28 which confirmed her belief about premature hospice -referral:  
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33 “*She was in hospice for about a month, maybe two months. In one of the RN visits, she*  
34 *[nurse] just came and told me that I need to gather my family because my mother had*  
35 *about 3 days left, so I should start calling the family so they could just say their*  
36 *goodbyes, which turned out not to be true, because it has been four years of that... You*  
37 *know, I thought that my mom was not ready for hospice ...in my mind hospice is for*  
38 *terminal patients, and my mother was not terminal. I still think she has a lot more [to*  
39 *live].*” (#7, Daughter)  
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### 49 **Facilitators in Decision-making for Utilizing Hospice Care**

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3 Despite various challenges for decision-making in utilization of HC, participants  
4 admitted their loved ones into HC. They identified several facilitators, which allowed them to  
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6 move forward in making a transition to HC.  
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### 9 10 ***Patient's known EOL wishes***

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12 Participants' previous communication with patients on EOL care, helped family members  
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14 to better understand patients' goals of care,<sup>42</sup> and thereby making their HC decisions more  
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16 viable:  
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19 *"Throughout the years, she either told me or my sisters ... she doesn't want to be like a*  
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21 *vegetable ...we understand and we want to do what is best for her."* (#5, Daughter)  
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### 23 24 ***EOL communication with the patient's physician***

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26 Our participants found their communication with patients' physicians on HC helped  
27  
28 them, and their patients make a relatively easy transition to HC. Physician's comprehensive  
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30 explanations about the process of transition to HC; the goals and functions of HC; and available  
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32 support and resources, particularly at home were considered helpful for HC decision making.  
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35 *"He [patient's physician] told me that there was going to be staff who would be checking*  
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37 *him at home to [make him]more comfortable, that he would be with family, and that*  
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39 *would make him feel more comfortable and that we would not be there in the hospital all*  
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41 *the time."* (#12, Daughter)  
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44 Another participant stated:  
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47 *"At first we [family] wanted to revive him if something happens to him, right? But they*  
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49 *explained to us that when they revive him it's a lot. They suffer more because they break*  
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51 *bones and it's worse. So we just decided ... we're going to leave it."* (#6, Daughter)  
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### 53 54 ***Right timing: Worsening prognosis***

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3 Most participants acknowledged their observations of the patients' poor prognosis as an  
4 indicator of readiness for hospice admission: *"I saw it coming because she's more deteriorating.*  
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6 *She knows she needs more help. She's getting sicker and getting worse,"* (#16, daughter).  
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10 Witnessing their loved one's deteriorating health and recognizing that no curative approach was  
11  
12 viable, these participants realized that HC was optimal for quality of end of life care. HC  
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14 provided the support that was needed:  
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17 *"She was at that point where they couldn't do anything else. She knew it and we knew*  
18 *it. ...to be honest with you, it made it a lot easier on us because of not having to go to*  
19 *doctor's appointments and stuff, having somebody come to the house and uh, so it really*  
20 *made it a lot easier on us too to just do that."* (#24, Daughter)  
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### 26 ***Home as the place for death***

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28 Placement of death was an integral part of EOL care planning. Providing care at home  
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30 gave a sense of comfort for the FCGs, because patients now received quality of care during their  
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32 final moments,<sup>20</sup> thereby fulfilling patients' wishes. One participant described how she used a  
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34 photo to assess the patient's preference for the placement of her EOL wishes: *"I asked my mom*  
35 *where she wants to take her last breath ...I showed her a picture of home... at home or in the*  
36 *hospital and she said home... I'm not going to put her in no [nursing] home...."* (#14, Daughter).  
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42 Placement for care at home facilitated the acceptance of HC for some family members.  
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44 The participant stated:  
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47 *That was one of the questions that one of my brothers asked. So he goes to hospice, but*  
48 *wait a minute, is it going to be at home? [I said] "Everything's going to be the same. It's*  
49 *just going to be a different type of care. That's it." And they go, oh yeah if it's going to be*  
50 *at home... Sure, so he was more willing to accept the word [hospice] ...* (#21, Daughter).  
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## Discussion

### Challenges in Decision-Making for Utilizing Hospice Care

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 (e.g., admission to ER). Similarly, a previous study<sup>25</sup> found that Latinos were referred by various hospital staff (non-physician) during the crisis hospitalization, 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 (i.e., 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 programs 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 biomedicalization and political economy of hope, as sources of influence over physicians' behavior 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 U.S. healthcare system. It is assumed that physicians

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2  
3 accurately estimate patient's life expectancy with clear clinical trajectories, and accordingly  
4 make decisions for shifting from curative to palliative care/comfort care.<sup>8,9</sup> However, physicians'  
5 precise prognostication can be very challenging, and their clinical judgment about the  
6 effectiveness of active treatments does not immediately lead to their HC referral.<sup>9,10</sup> Rather,  
7 multiple factors such as patient-provider relationships, the provider's professional identity, and  
8 MHB reimbursement all interplay, thereby complicating hospice referral.<sup>9,10</sup> Hospice/palliative  
9 care-related communication with physicians, also vary by the specialty of the provider (i.e.,  
10 oncologist, primary care physician), and the type of patients' illnesses, especially as specialists  
11 take a different approach to estimate patient's prognosis.<sup>10,43,44</sup> Our study did not assess patterns  
12 of communication by types of physicians' specializations. Future studies exploring FCG's  
13 perception about timing for HC referral, and their communication with physicians by patient's  
14 type of illness, may provide us with better context, regarding hospice related decisions made in  
15 rural settings.

16  
17 Family caregivers' lack of knowledge and misconception of HC were apparent in this  
18 study. These findings suggest the need for community-based education or outreach in order to  
19 raise an awareness of HC. For example, the Promotora approach has been found to be an  
20 effective strategy to promote public health (i.e., cancer screening) in Hispanic communities.<sup>45,46</sup>  
21 Using their knowledge about characteristics and resources of the community, Promotores can  
22 mobilize HC related resources and provide further education and instrumental support (i.e.,  
23 translation and dissemination) to patients and families in the community. Integrating trained  
24 Promotors in community-based organizations as a part of their outreach to the community, may  
25 bridge the gaps of healthcare access in rural regions with limited healthcare resources.

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3 Our participants' misconception about hospice, appeared to evoke strong emotions  
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5 against placement of their family members in HC. Their emotional reactions to HC might reflect  
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7 cultural values and preferences for EOL care. For example, Latinos prefer family-centered care<sup>26</sup>  
8  
9 and maintain secrecy about the patient's prognosis.<sup>25</sup> Future research comparing Latinos and  
10  
11 non-Latinos experiences related to decision-making for HC might be beneficial in broadening  
12  
13 our understanding about social/cultural aspects of HC. This information will help to develop  
14  
15 culturally salient interventions for this vulnerable population.  
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### 18 19 **Facilitators in Decision-making for Utilizing Hospice Care**

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21 Despite some challenges, our participants identified some facilitators, that helped them  
22  
23 navigate the decision-making process for utilization of HC. Our findings highlighted the  
24  
25 importance of EOL communication among patients, family and health care professionals who  
26  
27 provided an important platform for HC decision making. Norton and colleagues<sup>43</sup> found that  
28  
29 when patients, families, and healthcare providers had a shared understanding about the futile  
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31 nature of medical treatment, indicating that curative treatment was not an option, then making a  
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33 transition to HC was much easier to recognize, as an important option for care. Health care  
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35 professionals need to integrate an earlier development of advance care planning, that can assist  
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37 FCGs optimize the transitions of care, especially when decisions are related to invasive or  
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39 clinical procedures that need to be made without the patient's full cognitive capacity.  
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43 It is also important to consider how FCG's characteristics might impact HC decision-  
44  
45 making. FCGs' level of education, health literacy, and their perception about the patient-provider  
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47 relationship, play a significant role in the decision-making process.<sup>11,47</sup> Gender role is another  
48  
49 important factor for understanding FCG's hospice related decision-making, as it influences  
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51 caregiving responsibilities.<sup>40,48</sup> In our study, the majority of FCGs were female and daughters  
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3 who were either living together or near the patients homes. Their perspectives toward HC and its  
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5 priorities might have been influenced by the intersection of gender, and relationship to the  
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7 patients. While most providers receive some education about this topic, they often lack time and  
8  
9 insufficient resources to adequately address the unique needs of this population, which further  
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11 reduces the likelihood of referring patients to HC.<sup>49</sup> To promote effective patient-provider  
12  
13 interactions involving partnership-building and optimal patient outcomes, providers must have  
14  
15 training on approaching sensitive and complex conversations with vulnerable populations.<sup>50</sup>  
16  
17 Future research could address ways to support effective patient-provider communication, in  
18  
19 unreserved rural settings to promote HC to patients and their families.  
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### 23 24 **Limitations**

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26 This study is the first in exploring challenges and facilitators in decision-making for  
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28 utilization of HC, among FCGs in rural U.S.-Mexico border. While our study broadens an  
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30 understanding about caregivers' decision-making process in utilizing HC, it has some  
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32 limitations. Participants were recruited from one site that housed all patients who were Medicare  
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34 beneficiaries, thereby limiting diversity among participants. More than one third of the  
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36 participants who originally agreed to participate in the study were not available; however, we do  
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38 not have data that explains their unwillingness to participate. This might be due to participants'  
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40 discomfort in talking about death and dying or their own health issues, which might lead to  
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42 selection bias. Although we did not aim to seek for representativeness, future studies with  
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44 multiple sites, and a larger sample size could improve representativeness and diversity of this  
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46 population. Our study focuses only on FCGs' perceptions and experiences; however, it might be  
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48 beneficial to include patients and FCGs in dyads with caregivers of patients who never went into  
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50 HC. For example, caregivers of patients who were not in HC might encounter more complex  
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3 challenges, which prevent their access of HC. Hence, exploring group differences in HC related  
4 decision-making, may offer better contextual explanations for HC among rural patients. We did  
5 not collect demographic data on patient's length of stay at the hospice. Including this data in  
6 future study can perhaps help us to further understand FCG's perceptions of HC utilization.  
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### 12 **Conclusion**

13  
14 Increasing attention to quality of EOL care calls to our understanding about the dynamics  
15 of decision-making in utilization of HC by FCGs. Findings from this study adds valuable insight  
16 to the complexity of HC related decision-making. Challenges and facilitators to HC emerged as  
17 FCGs described their decision-making process, guided by their personal, interpersonal and socio-  
18 cultural experiences. Our study indicates that EOL communication among patients, caregivers,  
19 and physicians, are imperative in order to enhance FCG's knowledge about patients' EOL care  
20 preferences, that facilitate HC related decision-making. Our study indicates that FCGs' overall  
21 lack of EOL care involvement with the patient's physicians, left them less informed and  
22 unprepared for HC. Without effective patient-provider communication, patients and families may  
23 experience increased emotional distress and confusion about HC, leading to fear, doubt and  
24 uncertainty about the decision they have to make for their loved ones. It is imperative that  
25 healthcare providers assess FCGs' extant of knowledge and their concerns about HC. There is a  
26 need for an early integration of EOL care discussions into their practice that helps to facilitate  
27 transition into HC.  
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Table 1. Interview Guides

A Priori Concepts	Questions
Timing of decision-making for hospice care	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 hospice care Question 2: Describe conflict, if any, on hospice decision-making



Table 2. Participant Characteristics

ID #	Gender	Age Range	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

Table 3. Hospice Care Related Variables (N= 28)

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

### Author Contributorship Statement

EK has contributed to designing and conceptualizing the study, performing data analysis, interpreting the results and drafting the manuscript.

DF has contributed to performing data analysis, interpreting the results, and writing the manuscript.

SS has provided substantial input and revised the manuscript.

FN has contributed to revising the manuscript.

### Competing Interest

There are no competing interests among the authors.

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### Data Sharing Statement

All data relevant to the study are included in the article or uploaded as supplementary information.

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## Standards for Reporting Qualitative Research (SRQR)

**Title:** 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

No.	Topic	Item	Page Number
	<b>Title and abstract</b>		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	2
	<b>Introduction</b>		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-6
S4	Purpose or research question	Purpose of the study and specific objectives or questions	6
	<b>Methods</b>		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	7-8
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability	8-9
S7	Context	Setting/site and salient contextual factors; rationale <sup>a</sup>	7
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale <sup>a</sup>	7-8
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	9-10
S10	Data collection methods	Types of data collected; details of data collection	8



	procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale <sup>a</sup>	
S11 Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	8, Table 1
S12 Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7-8
S13 Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	9
S14 Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale <sup>a</sup>	9
S15 Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale <sup>a</sup>	8-9
<b>Results/Findings</b>		
S16 Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	10-16
S17 Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	10-16
<b>Discussion</b>		
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	17-20
S19 Limitations	Trustworthiness and limitations of findings	20-21
<b>Other</b>		
S20 Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	25
S21 Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	25