

Original Article

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An examination of Latino advanced cancer patients' and their informal caregivers' preferences for communication about advance care planning: A qualitative study

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Abstract

Objectives. Latino-advanced cancer patients engage in advance care planning (ACP) at lower rates than non-Latino patients. The goal of the present study was to understand patients' and caregivers' preferred methods of communicating about ACP.

Methods. Patients and caregivers were interviewed about cultural, religious, and familial beliefs that influence engagement in ACP and preferences for ACP communication.

Results. Findings highlighted that Latino patients respect doctors' medical advice, prefer the involvement of family members in ACP discussions with doctors, hold optimistic religious beliefs (e.g., belief in miracles) that hinder ACP discussions, and prefer culturally competent approaches, such as using their native language, for learning how to discuss end-of-life (EoL) care preferences.

Significance of results. Key cultural, religious, and familial beliefs and dynamics influence Latino engagement in ACP. Patients prefer a family-centered, physician informed approach to discussing ACP with consideration and incorporation of their religious medical beliefs about EoL care. Promising targets for improving the communication of and engagement in ACP include integrating cultural and religious beliefs in ACP discussions, providing information about ACP from the physician, involving family members in ACP discussions and decision-making, and giving instructions on how to engage in ACP discussions.

Introduction

Latino/non-Latino disparities are prevalent in advance care planning (ACP). For instance, terminally ill Latino patients are less likely than non-Latino patients to engage in ACP such as end-of-life (EoL) care discussions (32% vs. 85%) (Carr, 2011) and the completion of advance directives [living will (9% vs. 67%), DNR order (20% vs. 45%), or healthcare proxy (4% vs. 59%)] (Carr, 2011; Garrido et al., 2014). Engaging in ACP is critical to receiving preferred EoL care in line with patients' wishes (Ratner et al., 2001; Detering et al., 2010).

Prior research indicates that potential contributors to these health disparities in ACP engagement may include: (1) a lack of knowledge about advance directives (Kwak and Haley, 2005), (2) Latinos' preference for a family-centered approach to determining EoL goals of care (Kwak and Haley, 2005), and (3) distinct cultural and religious beliefs about EoL care that may reduce engagement in ACP (Blackhall et al., 1999). Thus, Latino patients may suffer greater disparities in planning for EoL care and engaging in ACP due to the present lack of clear, culturally competent communication (CCC) (Teal and Street, 2009) approaches to discussing ACP. Key beliefs such as the importance of religion and family in medical decision-making (Smith et al., 2008), a preference for a family-centered approach to decision-making (Kwak and Haley, 2005), reliance on physicians in determining needed treatment (Carrion et al., 2013), and distinct cultural and religious beliefs about EoL care specifically such as belief in miracles (Blackhall et al., 1999; Enguidanos et al., 2005; Braun et al., 2008; Cohen, 2008; Volandes et al., 2008), and death and dying more broadly (Nedjat-Haiem et al., 2012, 2013; Carrion et al., 2013) should be considered when communicating ACP to Latino-advanced cancer patients. Examining how best to discuss ACP in a way that is informative, culturally sensitive, and family-centered may illuminate how to address barriers to engagement in ACP among Latino patients.

Learning how best to discuss ACP in a way that is informative, culturally sensitive, and family-centered may be a critical first step to improving ACP engagement among Latino patients. Incorporating social (e.g., support systems) and cultural values (e.g., communicating

in native language, incorporating medical beliefs shaped by one's own culture, or upbringing) into communication has reduced racial and ethnic disparities in other areas of quality care (Beach et al., 2006) and is referred to as CCC (Teal and Street, 2009). To illuminate how to improve ACP communication with Latino patients with advanced cancer, the present study used qualitative interviewing to examine Latino patients' and their caregivers' preferred patterns of communication around ACP.

Methods

The present study consisted of qualitative methods, alongside descriptive statistics on completion rates of advance directives. First, patients and caregivers completed a brief survey designed to assess whether they had discussed components of ACP with their oncologist or caregiver/family. Second, patients and caregivers participated in an in-depth, semi-structured qualitative interview that asked them each separately about their preferences for the communication of ACP if their illness (patients) or the patient's illness (caregivers) were to become incurable or progress. Some example questions included: "Would you want to have a conversation about the type of healthcare you would want to receive if your cancer was incurable and you were in the final stages of your life? Who would you want to have present in these conversations? How would you want these conversations to incorporate your personal values and beliefs? Would you want your family members or friends to be involved in making a decision about the type of care you would want?" All interviews were conducted in English or Spanish by trained, bi-lingual staff. Interviews lasted 30–45 min.

Participants and recruitment

Patients ($n = 20$) and caregivers ($n = 9$) were recruited from outpatient cancer clinics between August 2016 and June 2017 at Weill Cornell Medicine (New York, NY). Patients and caregivers were approached and recruited as dyads, of whom approximately half of the patients ($n = 9$; 45.0%) had a caregiver who was willing to participate. Eligibility criteria included: (1) patient diagnosis of advanced cancer (defined by the presence of distant metastases and treating oncologists estimate that the patient would live ≤ 12 months); (2) patient/caregiver ≥ 21 years; (3) patient/caregiver ability to speak English or Spanish; and (4) adequate physical and psychological well-being of patient/caregiver to complete study interviews.

Measures

Demographic and clinical characteristics

Age, ethnicity, country of origin, race, gender, education, immigration status, employment, marital status, income, insurance, language of interview, and cancer site were assessed.

ACP discussions

Patients and caregivers were asked whether they had discussed components of ACP — having an EoL care conversation and discussing a living will, healthcare proxy, or DNR order — with their treating oncologist or family members/the patient. Response options for all questions included: Yes coded as "1" and No coded as "0."

Interview process

Participants were interviewed in person or over the telephone by a trained qualitative expert. This expert used a semi-structured format designed to gather information regarding patients' and caregivers' preferences on discussing ACP, including how and with whom they wanted to discuss ACP and the role of cultural and/or religious beliefs in shaping these conversations. All interviews were conducted in the patients' or caregivers' preferred language (English or Spanish).

Analytic procedures

Survey

Descriptive statistics provided information on patient and caregiver demographics, patient clinical characteristics, and rates of ACP communication.

Qualitative interview

Recorded interviews were professionally transcribed verbatim. English interviews were transcribed and then coded and analyzed. Spanish interviews were transcribed into Spanish, translated into English through a certified forward-backward translation, and then coded and analyzed in English. Transcriptions were uploaded to NVivo 11 software for analysis. Interview data were analyzed using the six-step protocol for thematic analysis proposed by Braun et al. (2014). The first step of thematic analysis consisted of two independent coders reading and rereading the interview transcriptions to determine points of potential analytical interest (MS, RP). In the second step, key descriptive phrases were used to code the data. The third step involved combining similar codes into themes. When the themes had emerged through the process of grouping similar codes, the fourth step consisted of reviewing and revising the themes to develop a thematic map. In the fifth step, the researchers refined and organized the data in each theme. The sixth and last step involved a final refinement to contextualize the findings in relation to existing theories and studies of ACP and EoL care. This final step was done by the lead researcher and the qualitative coder and the expert.

Results

Descriptive statistics

Patients had a mean age of 56.51 years (SD = 14.45), were 55.0% female, 70.0% immigrants, 85.0% unemployed, and 50.0% married. Caregivers had a mean age of 48.94 years (SD = 12.77), were 88.9% female, 66.7% immigrant, 66.7% employed, and 66.7% married. Caregivers reported the following relationship to the patients included in the study: spouse or partner ($n = 7$, 77.8%), son or daughter ($n = 1$, 11.1%), and aunt or uncle ($n = 1$, 11.1%). Half (50.0%) of interviews were conducted in English, with the other half conducted in Spanish. Among patients ($n = 20$), 15 of them were interviewed in person and 5 were interviewed over the phone. Among caregivers ($n = 9$), 7 of them were interviewed in person and 2 were interviewed over the phone. See Table 1 for a full report of all demographic and clinical characteristics.

For ACP discussions, two patients (10%) discussed their wishes for the type of care they would want if they were dying with their oncologist and 10 (50%) reported discussing it with

Table 1. Demographics and clinical characteristics for patients (n = 20) and caregivers (n = 9)

Characteristics	Patient n (%)	Caregiver n (%)
Age (years)	M = 56.51 (SD = 14.45)	M = 48.94 (SD = 12.77)
Ethnicity		
Latino		
Non-Latino		
Country of origin		
Puerto Rico	9 (45.0%)	1 (11.1%)
Dominican Republic	7 (35.0%)	3 (33.3%)
Other	4 (20.0%)	5 (50.6%)
Race		
White/Latino	18 (90.0%)	6 (66.7%)
Black	2 (10.0%)	0 (0.0%)
Other	0 (0.0%)	3 (33.3%)
Gender		
Female	11 (55.0%)	8 (88.9%)
Male	9 (45.0%)	1 (11.1%)
Education		
Less than high school	7 (35.0%)	1 (11.1%)
High school or higher	13 (65.0%)	8 (88.9%)
Immigration status		
Immigrant	14 (70.0%)	6 (66.7%)
Non-immigrant	6 (30.0%)	3 (33.3%)
Employment		
Employed	3 (15.0%)	6 (66.7%)
Not employed	17 (85.0%)	3 (33.3%)
Marital status		
Married	10 (50.0%)	6 (66.7%)
Not married	10 (50.0%)	3 (33.3%)
Income		
<\$21,000	8 (40.0%)	1 (11.1%)
≥\$21,000	12 (60.0%)	8 (88.9%)
Insurance		
Yes	20 (100.0%)	–
Language of interview		
English	10 (50.0%)	3 (33.3%)
Spanish	10 (50.0%)	6 (66.7%)
Format of interview		
In person	15 (75.0%)	7 (77.8%)
Over the telephone	5 (25.0%)	2 (22.2%)

(Continued)

Table 1. (Continued.)

Characteristics	Patient n (%)	Caregiver n (%)
Primary cancer site		
Colorectal cancer	10 (50.0%)	–
Lung cancer	3 (15.0%)	–
Esophagogastric cancer	3 (15.0%)	–
Bladder or renal cell carcinoma	2 (10.0%)	–
Pancreaticobiliary cancer	1 (5.0%)	–
Head and neck cancer	1 (5.0%)	–

their family. Three patients (15.0%) discussed DNR orders with their doctor and six (30.0%) reported discussing it with their family. Three patients (15.0%) discussed living wills with their doctor and 10 (50.0%) reported discussing it with their family. Finally, nine patients (45.0%) discussed healthcare proxies with their doctor and 12 (60.0%) reported discussing it with their family. Reporting of rates of ACP discussions with patient’s doctors and their families is summarized in Table 2.

Qualitative themes

Table 3 depicts the themes and sub-themes that emerged during the analysis of the interview data and a sample quotation from each sub-theme. Initially, patient and caregiver data were analyzed separately, but no differences emerged so all themes are presented as combined data. Two major themes emerged, which are described in detail below.

Theme 1: Latinos’ cultural, religious, and familial beliefs influence their engagement in ACP discussions.

Sub-theme 1: Latinos’ cultural beliefs include respect for the doctor’s advice. Participants reported Latino cultural beliefs that may influence engagement in ACP include respect for the doctor’s advice. Caregiver 217 discussed how this belief related to other cultural beliefs, including respect for elders:

We have respect for life and respect for the doctors’ advice, but without ignoring the patient’s decision, what they feel, help them see the options, because the patient sometimes, my mom for example in this case, she doesn’t understand things very well and you have to explain it to them several times. (Caregiver 217)

Patient 117 further professed that respect for the doctor’s advice might also serve as a foundation for personal optimism in believing that the doctor is providing the best possible treatment (Table 3).

Sub-theme 2: Latinos’ familial beliefs may require sensitivity to generational differences and broad involvement among the patient’s relatives in ACP. Patient 116 noted that a patient’s discussion of care with his or her family needed to involve sensitivity to generational differences, and particularly to how perspectives are shaped by proximity to the experience of immigration:

Table 2. Descriptive statistics for discussions of ACP with doctor, family, and patient

ACP discussions	n (%)
Patients (n = 20)	
Discussion with oncologist about wishes for care you would want if you were dying?	
Yes	2 (10.0%)
No	18 (90.0%)
Discussed DNR with doctor	
Yes	3 (15.0%)
No	16 (80.0%)
Discussed living will with doctor	
Yes	3 (15.0%)
No	17 (85.0%)
Discussed healthcare proxy/durable power of attorney with doctor	
Yes	9 (45.0%)
No	11 (55.0%)
Discussion with family about wishes for care you would want if you were dying?	
Yes	10 (50.0%)
No	10 (50.0%)
Discussed DNR with family	
Yes	6 (30.0%)
No	14 (70.0%)
Discussed living will with family	
Yes	10 (50.0%)
No	10 (50.0%)
Discussed healthcare proxy/durable power of attorney with family	
Yes	12 (60.0%)
No	8 (40.0%)
Caregivers (n = 9)	
Discussed with patient's oncologist wishes for the care he/she would want if he/she were dying	
Yes	1 (11.1%)
No	8 (88.9%)
Discussed with the patient wishes for the care he/she would want if he/she were dying	
Yes	2 (22.2%)
No	7 (77.8%)

I would [like to talk to family members about care preferences]. I'd be open to it because, see, since I'm the first generation of actually living in the United States and born in the United States, we might have differences. (Patient 116)

Differences in perspective such as the generational one described by Patient 116 may need to be taken into account because Latinos' familial beliefs may require the participation of relatives in

conversations about care. Patient 105, for example, stated that conversations about care should be conducted, "with my relatives. Yes, I mean, it'd be in a group with the doctor and my family... They [providers] don't ask if you want the family to be present and for me, I don't know, I'd always want my family to be present." Patient 107 emphasized that conversations about care should include input from relatives. Family participation in conversations about care may be considered important because it increases family involvement in care (Caregiver 208) and because it allows family members not only to have a say in plans that may affect them, but to protect the patient's interests as well (Caregiver 201).

Sub-theme 3: Latinos' religious beliefs can be overly optimistic. Participants' discussions of the intersection of care with religious faith indicated a powerful belief in the ability of a higher power to restore the patient to health. The consequence of this firm belief for all patients and caregivers who reported that they subscribed to it (Patients 105, 106, 107, 108, 109, 110, 113, 115, and 117, as well as Caregivers 201, 205, 216, and 220) was that hope was never lost, provided that faith remained strong. Patient 113 described this faith-based optimism:

God raised Lazarus from the dead, and he had been dead for 3 days and He just said, rise Lazarus and he stood up...If you have faith in God suddenly you wake up and you're cured and you don't know where it all came from, it's a miracle!...It all depends on God, because the doctor can give them the best treatment and it all depends. (Patient 113)

Patient 117 described a strongly optimistic perspective that placed faith in the ability of a higher power to guide treatment and the advancement of medical science toward a positive outcome:

I strongly believe in God and all...while they said my treatment will be for life, for the rest of my days or years, I am sure at some point there will be a more beneficial treatment, and I will be cured. (Patient 117)

Sub-theme 4: Religious beliefs may influence conversations about ACP. Self-identified Latinos of faith may feel their religious beliefs do and should influence their conversations about care with family and/or providers. Patient 108 wanted a member of the church to be included in conversations with the doctor about care, regardless of where these conversations took place: "If I'm in the hospital, [the member of the church should be] in the hospital. If I'm at home, [the member of the church should be] at home."

For Patient 117, faith was very much in the foreground of discussions about care. This patient stated that anyone involved in the conversation should be made aware that, "God is first. I always tell them [i.e., doctors] that God is first. I will do this because I'm a firm believer, I have faith, and I believe. First, I think I always put my religion first."

Advice from coreligionists and religious counselors may be greatly valued by patients and caregivers in communicating about ACP; Caregiver 208, for example, stated that wishes about the type of care were influenced by

...inviting people from the church to the house, so they can communicate with him, and helping him to understand that you have to... How can I say? For him to understand that you do need, to have faith and believe in God. (Caregiver 208)

Table 3. Themes, sub-themes, and exemplary quotations from qualitative data

Theme	Sub-theme	Sample quotation
Latinos' cultural, religious, and familial beliefs influence their engagement in advance care planning discussions	Latinos' cultural beliefs include respect for doctor's advice	"Now, to me, there are two important things: first, to have faith in the doctor that is treating me. To convince myself that this doctor is doing something consciously and certain that this is the best treatment for me; every treatment is individual, and as such, the doctor who is treating me is the best possible doctor."
	Latinos' familial beliefs may require sensitivity to generational differences and broad involvement among the patient's relatives in advance care planning	"The conversation that I would want to have, I'd want to make sure that my doctor is there and then my immediate family, whoever I need, to be in the same room so them we could all discuss what my healthcare would be."
	Latinos' religious beliefs can be overly optimistic	"It's God who I believe in and I have faith that He will do two things: first, to put into the doctor's mind the best and most adequate treatment for me."
	Religious beliefs may influence conversations about advance care planning	"I believe that at the time it becomes terminal this would have an influence because we would do the rites we Catholics do at the end of life. And due to the values that we were taught, well when the time comes to sit down and talk like a family about any one of these subjects it would influence."
Preferred culturally competent approaches for encouraging patients to communicate their end-of-life care preferences	Caregiver advisors can help patients to communicate	"I guess it would be cool to have maybe like a voluntary program, like with somebody that would volunteer. Like maybe a mentor or a buddy, like that's been through that, that can talk."
	Counseling services for families can help relatives encourage patients to communicate	"Maybe with them like having someone to talk to them, like a counselor... someone to talk with the family...To explain and tell them that they have to speak clearly with me."
	Culturally competent education can help patients to communicate	"I think that you need a little more education. I'm going to say this, with regard to education I'm surprised at the small amount of people that speak Spanish in hospitals."
	Involving family in conversations about EoL care can help Latinos to communicate	"They're the ones who are going to mourn me and know what I want."
	Culturally competent counseling services can help incurable patients with acceptance.	"You can't do it [i.e., discuss healthcare and cancer treatment, if the cancer were to become incurable] on your own. You need professional help."

Religious beliefs may influence conversations about care more if the illness becomes terminal (Caregiver 217). Caregivers and patients may desire direct communication between family, medical providers, and religious advisors, as, for example, in a meeting in which representatives of each of these groups are present (Caregiver 208). Additionally, caregivers and patients may want discussions with providers to take religious beliefs into consideration. According to Caregiver 216, for example, providers should not deprive the patient of hope by foreclosing the possibility of a miracle:

I would just say...just to be open...the fact is even though he is diagnosed with being terminally ill, there is a possibility that there is miracles and he can fight that. So, I want her or him [the provider] to believe that he [the patient] could fight this even though like he is against the odds. (Caregiver 208)

Theme 2: Preferred culturally competent approaches for encouraging patients to communicate their EoL care preferences.

Sub-theme 1: Caregiver advisors can help patients to communicate. Caregivers may be uncertain about how to fulfill many aspects of their role, including that of helping the patient to communicate EoL care preferences. Peer advisors who had experience as a caregiver, who would coach caregivers and work directly with patients, may be able to facilitate more confident communication of EoL care preferences:

We tried to talk about like even like deciding like to who do not resuscitate, resuscitate. I am trying to figure out like I don't know, maybe helpful tips for something like talking to somebody that has been through it or something, what would be the best way to bring this up and it's very hard... Like maybe a mentor or a buddy, like that's been through that, that can talk...like more on the one on one conversation... and be able to email that person or call them about that whenever I need advice. (Caregiver 216)

Sub-theme 2: Counseling services for families can help relatives encourage patients to communicate. Patient 105 noted that family often did not know how to communicate with patients about EoL care, and that this inhibited the patient's ability to communicate reciprocally with family. This patient recommended that counseling services be provided to help the family communicate more effectively with the patient:

Maybe with them like having someone to talk to them, like a counselor, do you understand?...That would be good, for someone to talk with the family...To explain and tell them that they have to speak clearly with me... My family could speak easier. Talk about it, talk things with more clarity. (Patient 105)

Patient 105 further recommended that the counseling sessions be conducted without the patient's presence to allow family members to communicate their concerns more openly, and that the counselor shares the patient's religion and includes considerations of faith in the discussion of care.

Sub-theme 3: Culturally competent education can help patients to communicate. Patients may be encouraged to communicate their EoL care preferences by becoming informed about their options and by hearing other patients communicate. Support groups may be an ideal setting for communication with other patients, and support groups specifically for Latinos may be particularly helpful for Latino patients. Asked what a patient might

need in order to communicate better with family and doctors if the cancer were to become incurable, Caregiver 217 answered, in part:

When we started this process there was no kind, nor is there, as far as I know, no support group for Latinos, and I would very much like to see this happening...It helps you to listen to other people's experiences, what they did, it may be an idea for you to do...Unfortunately, like I said, this is limited for Latinos. (Caregiver 217)

Information about EoL care options can also be conveyed in a culturally competent way through the use of Spanish educational materials, such as pamphlets (recommended by Caregiver 217), posters (Caregiver 216), or websites (Caregiver 216).

Sub-theme 4: Involving family in conversations about EoL care can help Latinos to communicate. Patients indicated that they wanted their spouses (e.g., Patients 101 and 109), their grown children (e.g., Patients 106 and 110), or both (e.g., Patient 113) involved in conversations about EoL care preferences. Other patients indicated that they wanted additional relatives to be involved; as Patient 107 said of involving family in conversations about EoL care, "they're the ones who are going to mourn me and know what I want." Patient 117 suggested that doctors might involve family:

By talking with them, gathering them together or calling them on the phone, or when I go to chemo, or whatever. In fact, they have always been around and have given their opinions and ideas, too. And I think it's important to get your children involved, even your grandchildren...I think they have been very involved, and that's essential to me. Because their decision is very important, or their opinions, rather than decisions. (Patient 117)

Sub-theme 5: Culturally competent counseling services can help incurable patients with acceptance. Caregiver 203 suggested that patients would benefit from having a therapist because "you can't do it [i.e., discuss healthcare and cancer treatment, if the cancer were to become incurable] on your own. You need professional help." Caregiver 211 also recommended counseling services for incurable patients and indicated two ways in which those services might be made more culturally competent. First, EoL counseling might be more comfortable for Latinos if it was designed to involve family members:

She is suffering and the family is suffering. But besides the family she needs a group of people to be there to help the family to accept it along with her. If it was possible, for it to be in the hospital. Some place in the hospital or in the house. You know, someone that comes every day for the acceptance that there's nothing else...And that the family, the most family possible that's around her. (Caregiver 211)

Counseling services might also be more effective for Latinos if they were inclusive of the religious beliefs of Latinos of faith (discussed in relation to theme 1, sub-theme 3, above):

I tell her, "...You have to be positive. You have to say, 'God, save me from this cancer. The doctors are doing everything possible, enter your hands'...and the doctors have the knowledge because God has given them the gift. The way he gave it to the architect, the engineer, the one who builds house and like that." (Caregiver 211)

Discussion

Results from this study indicate that Latino patients engage in ACP discussions with their families at higher rates than with their doctors and illuminate this finding by indicating Latino patients want their families heavily involved in discussions of ACP. These findings build upon prior research, indicating Latino cancer patients may have more family-centered approaches to ACP and EoL care (Kwak and Haley, 2005; Carrion et al., 2013). Namely, qualitative interviews from the present study highlighted that Latino patients prefer to have sensitivity to their family's role and religious beliefs in medical decision-making and that they often seek physician recommendations in EoL decision-making.

These key qualitative findings from the present study highlight several key points to improve best practices for discussing ACP with Latino patients. First, cultural and religious beliefs can influence whether patients want to engage in ACP. Second, clinicians need to engage patients as well as their families in discussions of ACP. Combined, these findings underscore the importance of communicating ACP in a culturally competent manner (Teal and Street, 2009), which includes addressing patients' potential religious beliefs and involving their family members and relatives in the ACP conversation. Third, the present results highlight a need for counseling services and educational materials to be offered to caregivers and patients to assist in learning how to communicate about ACP. Finally, an emerging theme from the present study was that respect for one's doctor might influence whether a patient believes ACP is critical to discuss or not. This finding is in line with prior research highlighting the role of *Respeto* (Felix-Ortiz et al., 1994) in Latin culture, which endorses the role of authority in following doctor's orders, and suggests that the oncologists may need to bring up discussions of ACP with their Latino patients with cancer. All of these approaches must be culturally competent (Teal and Street, 2009) by being offered in patients' and caregivers' native language, addressing cultural and religious norms, and having awareness of broader family involvement in EoL care decision-making.

Practice implications

Specific strategies were extracted from the present qualitative analysis. One approach includes using advisors or counselors to help patients and caregivers learn how to communicate their wishes and preferences for EoL care. This strategy could utilize a patient participatory consultation style (e.g., asking questions and stating preferences), which may better achieve goal-concordant care (Street, 1991; Hines et al., 1997; Krupat et al., 1999; Gordon et al., 2006). Another approach mentioned by participants in the present study included culturally competent education to help patients communicate about ACP. Again, this highlights both the need to address patients' lack of knowledge about ACP (Kwak and Haley, 2005) and the need for CCC (Teal and Street, 2009) and Latino support groups.

Patients and caregivers also noted the need for involving family members directly in conversations about EoL care to assist patients in communicating about EoL preferences. This finding indicates that a shared decision-making approach may be preferred among many Latino patients in the ACP and EoL care decision-making process. As such, it is critical for future research to determine best practices for communicating ACP in a way that takes the entire family unit into consideration, when desired.

Based on findings from the present study, a future intervention should include the following components: (1) involvement of the entire patient's family structure rather than simply the patient and a single, informal caregiver which is the standard approach in cancer care; (2) incorporation of spiritual, religious, and cultural beliefs into ACP discussions; and (3) clear, direct communication and recommendations from oncologists.

Finally, patients and caregivers mentioned the need for counseling services that are culturally competent to assist both with teaching family members how to encourage their loved one/the patient to communicate and to help patients cope with acceptance of their illness status. Future research should examine what these services should look like and what they should offer, incorporating stakeholder feedback in the input.

Study limitations

Despite the many strengths of this study, there are limitations that should be considered when interpreting results. First, the present sample ($n = 29$) was quite small and consisted of Latinos from multiple backgrounds (e.g., Puerto Rican, Dominican, and Mexican) and thus sub-group differences among Latinos could not be examined. It is possible that different sub-groups may prefer and benefit from differing communication strategies and this should be taken into account in future research. Second, the present study was a preliminary mixed methods study, and thus no causal inferences can be made. Building off the present study results, however, future research should examine the emerging thematic findings quantitatively to examine the most preferred approaches to communication. Finally, the present sample consisted of a variety of Latino/Hispanic patients, including English and Spanish speakers, caregivers and patients, and immigrants and U.S. born Latino participants. As such, it was difficult to determine if there were key differences in emerging themes across these groups. Future research should examine how these themes of ACP and communication around ACP might differ across these various sub-groups within the Latino/Hispanic community.

Conclusion

The present findings suggest that a CCC intervention designed to target the patients' family dynamic and incorporate cultural and religious beliefs may be the best method for improving engagement in ACP among Latino-advanced cancer patients. This form of communication may reduce current ethnic disparities in quality EoL care (Beach et al., 2006).

Data-sharing statement. These are grant-funded data that are still being analyzed and processed for future manuscripts. The authors are happy to share data, upon request, but would like to maintain ownership of the data files until all data have been published.

Ethics statement. All study procedures were reviewed and approved at each Institution's IRB (IRB Protocol Number: WCM 1510016647). All procedures were done in accordance with the required ethical guidelines for the protection of human subjects in research. Informed written consent was obtained from each participant in the present study.

Authors' contributions. M.J.S. secured funding for, designed, and conducted the study procedures, conceptualized the aims of this paper, conducted all statistical analyses and interpretation of these analyses, and led the drafting of the manuscript. C.G. helped conceptualize the aims of this paper, conducted study procedures, and assisted in the write-up of this paper. B.L. aided in

conducting study procedures and contributed to the drafting of the manuscript. E.K., H.G.P., and P.K.M. assisted in the write-up of this paper.

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