

Qualitative Interviews Exploring Palliative Care Perspectives of Latinos on Dialysis

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Abstract

Background and objectives Compared with non-Latino whites with advanced illness, Latinos are less likely to have an advance directive or to die with hospice services. To improve palliative care disparities, international ESRD guidelines call for increased research on culturally responsive communication of advance care planning (ACP). The objective of our study was to explore the preferences of Latino patients receiving dialysis regarding symptom management and ACP.

Design, setting, participants, & measurements Qualitative study design using semistructured face-to-face interviews of 20 Latinos on hemodialysis between February and July of 2015. Data were analyzed using thematic analysis.

Results Four themes were identified: Avoiding harms of medication (fear of addiction and damage to bodies, effective distractions, reliance on traditional remedies, fatalism: the sense that one's illness is deserved punishment); barriers and facilitators to ACP: faith, family, and home (family group decision-making, family reluctance to have ACP conversations, flexible decision-making conversations at home with family, ACP conversations incorporating trust and linguistic congruency, family-first and faith-driven decisions); enhancing wellbeing day-to-day (supportive relationships, improved understanding of illness leads to adherence, recognizing new self-value, maintaining a positive outlook); and distressing aspects of living with their illness (dietary restriction is culturally isolating and challenging for families, logistic challenges and socioeconomic disadvantage compounded by health literacy and language barriers, required rapid adjustments to chronic illness, demanding dialysis schedule).

Conclusions Latinos described unique cultural preferences such as avoidance of medications for symptom alleviation and a preference to have family group decision-making and ACP conversations at home. Understanding and integrating cultural values and preferences into palliative care offers the potential to improve disparities and achieve quality patient-centered care for Latinos with advanced illness.

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Introduction

Patients with ESRD have a debilitating symptom burden and high mortality, yet palliative care is often overlooked (1–3). This is especially true for United States Latinos, who in 2014 accounted for 17% of newly diagnosed patients with ESRD and are underrepresented in the existing palliative care ESRD research (4). An observational survey in 2010 found that Latinos with ESRD were less likely to engage in end-of-life conversations and less likely to have completed an advance directive compared with non-Latino whites (5). Our 2015 observational study reported that although the majority of Latinos wanted to discuss their quality of life, symptom management, prognosis, and end-of-life care, few reported a previous end-of-life conversation with their nephrology team (6). Latinos with other advanced illnesses are less likely to die with hospice services, more likely to die in a hospital setting, and less likely to receive adequate pain control compared with non-Latino whites (7–14).

Culture influences how a patient experiences their illness and affects decision-making. Yet little is known about how the cultural values of Latinos with ESRD inform preferences for care at the end of life. This is a necessary first step to ultimately address palliative care disparities for Latinos with ESRD.

The study objective was to use semistructured interviews to gather in-depth understanding of the palliative care preferences of Latino patients with ESRD around symptom management and advance care planning (ACP) conversations, to inform culturally congruent palliative care.

Materials and Methods

Study Design and Sample

We conducted a qualitative study using semistructured interviews with adult English or Spanish speaking Latinos that have ESRD and receive thrice weekly hemodialysis at two outpatient hemodialysis facilities

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Table 1. Participant characteristics

Participant Characteristic (n=20)	Value
Age, mean±SD (range), yr	61±14 (30–78)
Women, n (%)	10 (50)
Latino ethnicity, n (%)	20 (100)
Interview conducted in Spanish, n (%)	16 (80)
Mexico is country of origin, n (%)	18 (90)
Immigrants to the United States, n (%)	16 (80)
Length of time in the United States, mean±SD, yr	16.8±7.7
Participants with an advance directive, n (%)	6 (30)
Employed, n (%)	2 (10)
Hemodialysis vintage, median (25–75%), mo	32 (16.25–40)
Charlson Comorbidity Index, mean±SD	7±2.3

in Denver, Colorado. Patients were excluded if they were non-Latino, unable to consent, pregnant, or under 18 years of age. The Colorado Multi-Institutional Review Board approved the study and all patients gave informed consent to participate. We used a purposive sampling strategy selecting equal numbers of female and male patients that met inclusion criteria as they presented at the dialysis center.

Interview Guide

The semistructured interviews included open-ended questions that explored symptom management, ACP conversations, and the circumstances that improve wellbeing as well as those that lead to distress (Supplemental Table 1) (15). The questions were developed after a comprehensive review of the literature that describes Latino end-of-life and ACP preferences. Additional probes were used throughout the interviews.

Data Collection and Analysis

The study principal investigator (L.C.) consented and interviewed eligible English or Spanish speaking participants face-to-face in the patient's native language between February and July of 2015. Interviews were conducted chairside during hemodialysis, audio-recorded, professionally translated from Spanish to English, and then transcribed verbatim. Patient demographic data were collected from patient medical chart review. Data analysis commenced at the start of the first interview and was ongoing throughout all data collection. We used an emergent, iterative approach where we refined our questioning on the basis of our analysis of subsequent interviews. We continued interviews until our analysis revealed no new themes emerging (16,17). Data were analyzed using a team-based theme analysis. We used a consensus approach to inform theme analysis across team members as we looked for similarities and differences. When differences in interpretation arose, we pursued agreement through discussion. Atlas ti version 7.5.12 was used to analyze transcribed interviews.

Results

We interviewed 20 Latinos with ESRD. Participants had a mean age of 61±12 years (range 30–78), a mean

Charlson Comorbidity Index of 7±2.3, and 50% were women. Sixteen (80%) were immigrants to the United States that had spent a mean 16.8±7.7 years in the United States. Mexico was the country of origin for 90% of participants. Interview length ranged from 52 to 84 minutes (mean 65 minutes) (Table 1). Participants described four themes: avoiding harms of medication; barriers and facilitators to ACP: faith, family, and home; enhancing wellbeing day-to-day; and distressing aspects of living with their illness (Table 2). A thematic schema illustrating the relationship between the themes is provided in Figure 1.

Theme 1: Avoiding Harms of Medication

Fear of Addiction and Damage to Bodies. Participants avoid medications prescribed for symptom alleviation. Their reasons are varied, and some describe previous negative experiences from unwanted side effects: "I believe that every medication has a side effect . . . if I can handle it, I will handle it." Others feel that medications do not alleviate symptoms and can instead lead to further damage to their bodies. Two patients expressed how their families do not approve of opiates for fear they might lead to addiction. Rather than being open with their providers about avoiding medications, many participants accept paper prescriptions or pill bottles yet never take the medication.

Effective Distractions. Instead of taking medication, participants spend time with family, keep themselves busy by working in the house, and do things they enjoy (e.g., playing the piano, listening to music) as preferred ways to distract themselves from symptoms: "(The provider) gave me some pills that I haven't taken . . . when I feel really sad . . . I distract myself with my grandkids."

Reliance on Traditional Remedies. Many participants rely on home remedies and traditional healing. One participant described using herbal mixtures she had learned from her grandmother, and many participants spoke of using mixtures with lemon to relieve nausea. Participants report that they do not inform their health care providers about their preference for traditional remedies. Traditional Latino foods were also described as having medicinal properties.

Fatalism: Sense that One's Illness Is Deserved Punishment. Many patients feel that their current illness is punishment for their parents' or their own past "bad" behavior. As such, they feel they "deserve" to suffer and do

Table 2. Themes and subthemes with illustrative quotes

Themes and Subthemes	Illustrative Quotes
<p>Theme 1: Avoiding harms of medication Fear of addiction and damage to bodies</p> <p>Effective distractions</p> <p>Reliance on traditional remedies</p> <p>Fatalism: the sense that one's illness is deserved punishment</p>	<p>"I don't like (pills). For how bad I am, from my kidneys. Like, my mom also died from diabetes. She took a lot of pills, and she died. I think that stayed on my mind a lot, so now I fear pills"</p> <p>"I went through this (discussion about medications) with my dad and I'm not interested in taking medications . . . I won't take them"</p> <p>"I'm hard on taking pills, I don't like taking pills. I never have. I'm not a pill person . . . I think they'll do something to me, like have a bad reaction to 'em"</p> <p>"My son says, 'that no medications are better mom because that way you're not drugged or anything with so many medications,' and that's the way I live"</p> <p>"I don't care for the pain meds because I don't like how they make you feel, like that groggy"</p> <p>"They have offered me medicines for nausea . . . but I have refused them. I don't like them. Since childhood, I haven't liked them. I prefer injections. You use, in Mexico, they give you lots of injections and for that reason, I'm used to that"</p> <p>"I don't want to take too many pills . . . I hear too many people saying that it (taking pills) is bad for your health. That taking too many pills affects your body, your liver . . . I try to not ask for anything . . . you can never be sure of what can hurt you"</p> <p>"I don't have time to feel sad. Since this baby came into our lives, I don't feel sad or depressed. I look forward to hearing his voice and playing with him"</p> <p>"I love to practice the piano because it has notes that can reflect the sentiment one has. It is like finding the right words that reflect your feelings and once you say those words, you feel so much better"</p> <p>"I just read and find a poem that expresses how I feel and that makes me feel better. I think that through sadness, you can feel better"</p> <p>"When my grandmother was alive, she would always say, 'well, if you have this plant, I can make you some tea, or we can get ingredients and drink this,' and she was 90-something when she passed away. I wish I could remember what grandma said I should take"</p> <p>"My wife has to rub some ointment on my back which helps the pain and then I go to sleep"</p> <p>"I like to take the Mexican medicine, it has ginger, cinnamon, stuff for breathing, it helps my cough"</p> <p>"When I feel my BP is low, I put salt under my tongue and I just lay down"</p> <p>"(My feeling this pain) is God's will. I hardly get sad, you see, because I've resigned and accepted God's will"</p> <p>"Let it be, let it be, whatever symptoms going to happen, let it happen. Can't say well, you don't want to do this or I want to do that"</p> <p>"I do believe that everything happens for a reason. I have no choice. This is it. This is as good as it gets"</p> <p>"You try to survive and then everyday living. I can't do nothing, go with the flow. That's all you can do"</p>
<p>Theme 2: Barriers and facilitators to ACP: faith, family, and home Family group decision-making</p>	<p>"It's the whole family that would make decisions because they're the ones who care for one and are looking out for their health"</p> <p>"I imagine that the children have to know what's going to happen with me. I know that the time will come and I imagine that my children are going to know what to do with me"</p> <p>"I'd need to gather my children and ask them to talk amongst themselves as to who should be the decision-maker"</p> <p>"(ACP) is important because that way the (family) won't feel bad, they won't feel, I mean, like depressed because they didn't provide the care I needed. So I talk to them and I let them know . . . my decisions"</p> <p>"I told my sister . . . and my dad that if I have a cardiac arrest, they should look at me and if they want to, disconnect me . . . its their choice"</p>

Table 2. (Continued)

Themes and Subthemes	Illustrative Quotes
Family reluctance to have ACP conversations	<p>“My daughter would not be comfortable discussing (ACP) . . . they don’t want to talk about that even if they are aware that (death) might come. But I think they prefer not knowing and when that happens, they’ll decide what to do . . . its important to have the conversation before the person can longer talk or walk . . . on the other hand, I don’t want to bother them with my illness”</p> <p>“My wife doesn’t want to touch the subject (of ACP), but I think it does help me because one is worried about the family and what’s going to happen and this and that. My wife tells me, ‘no, don’t worry’”</p> <p>“Well, they listen to what I have to say and sometimes we talk about my kidney failure. They often say that they don’t want to talk about what is going on with me and my illness, and they say ‘because I can see that you get sad,’ but I tell them that there’s nothing we can do about it, I already have it and nobody is going to take it away”</p>
Flexible decision-making conversations at home with family	<p>“Conversations should happen at home . . . I won’t have the courage to tell (family) about (ACP) issues . . . because I’m going to see them sad . . . so it’s better to have someone else talk about it”</p> <p>“At home, that way the family can understand what’s going on, what you feel when you go to dialysis, what it’s like for you here . . . and educate them . . . to let them know, this is what I go through every day . . . especially if you have kids that end up with diabetes”</p> <p>“At the house because its more private . . . there’s not so many people around like here”</p> <p>“Have these conversations when one is good, good and healthy . . . because when one is too sick, when you can’t anymore, you’re not going to be able to make (decisions)”</p> <p>“If you’re sick, you’re not going to have the right mindset on (ACP conversations). Probably when you don’t even have a problem is when you should talk about end-of-life”</p>
ACP conversations incorporating trust and linguistic congruency	<p>“A person like you, very prepared that gets the topic really well and you give us trust to open our feelings”</p> <p>“That first year is too early to have this conversation. You need to first figure out if you want to live instead of die and if you’re going to go ahead and accept the dialysis treatment and get through that day and then go ahead . . . help them live with (dialysis), cope with it first, that first year is critical”</p> <p>“It’s good that when one is already sick, when one is older, it’s good to be helped with (ACP) . . . but at the same time, to think positive. It would be good for me to talk but at the same time be positive about oneself”</p> <p>“Someone that can be careful and sensitive with how they communicate because they can say, ‘we need to talk to you because your family member is very fragile and sick.’ That can worry the family . . . Instead saying, ‘don’t alarm yourself, we need to talk about certain things.’”</p>
Family-first and faith-based decisions	<p>“I’ve never thought about advance directives. Maybe, my wishes are just that my family wouldn’t suffer so much”</p> <p>“Receiving CPR would be prolonging the suffering of my family . . . why make my family suffer more if one’s heart already stopped? It’s better to give them the bad news so that they do not live with the hope that one might wake up”</p> <p>“They asked me if I wanted to be intubated. I don’t want anything like that because why would I do something that is against the will of God? The day that God wants to take me, he will take me. I was born and I know that I will die”</p>

Table 2. (Continued)	
Themes and Subthemes	Illustrative Quotes
Theme 3: Means to improve wellbeing	
Sources of support	<p>“(The dialysis team) reassured me, told me not to be afraid; they said that there are people who’ve been on dialysis for over 20 years and they’re still here, so that encouraged me”</p> <p>“I was told I was a good (kidney transplant) candidate cause I’m taking care of myself and that’s because of my wife. She’s the one that makes sure I’m taking my pills and she fixes me the right meals . . . everything is my wife’s doing”</p> <p>“Just like I watched over them, so they’d make a career and have a profession, now they say, ‘now it’s our turn to take care of you’”</p> <p>“When I found out about my illness, I thought about many negative things. I thought I was going to die but I took comfort in God. God, who’s so big . . . I prayed and asked him to give me courage”</p> <p>“Sometimes I do feel low, but I surrender to God and he gives me peace”</p> <p>“I think that talking to others with ESRD helps . . . I have been doing (dialysis) over three years now . . . people come to me because they don’t know . . . concerns. I’m sure everybody has different concerns, some of them are going to be alike. I think that talking (to other ESRD patients) will be a good idea.”</p> <p>“Advice from someone who has been through this that can say, ‘take this or don’t take that . . . this is what I take when I feel nauseated or tired’”</p>
Improved understanding of illness leads to adherence	<p>“Actually, I’m not obligated (to have dialysis) . . . I want the symptoms to improve, to be better, because if I don’t come (to dialysis), I know I’m going to feel worse. I’m going to feel worse because the liquid stuff affects me”</p> <p>“The education on the transplant is when I decided okay, ‘I need to get on the list for the transplant and do the tests and stuff like that,’ which I just did it this year”</p> <p>“Many people think that it’s boring to come here for 3–4 hours, I think that they’re extending my lifespan. I see it as something positive to increase the duration of my life . . . I think without dialysis, I would have been suffering even more”</p> <p>“Well perhaps having hope of getting a kidney, that would help . . . I told them ‘put a kidney in me, it doesn’t matter if it’s from a dog’”</p> <p>“I stopped eating salt, and now my legs don’t swell up anymore. They’re almost normal now”</p>
Recognizing new self-value	<p>“I’m doing my Licensed Practical Nurse right now. That’s what I’m doing because . . . I want to end up in a dialysis clinic so I think I can offer something to the dialysis community”</p> <p>“I use the computer . . . this has benefited me, I’ve had a better quality of life”</p> <p>“What’s nice is, I can help around the house, I can do dishes, but afterwards, I got to sit down.”</p> <p>“I pick up my wife from work. I take her and I pick her up because she doesn’t drive . . . I make an effort and I get up and I go get her”</p> <p>“It also helps me to work because when I work I feel useful”</p> <p>“I’m satisfied the way I’m living, the way I live, the things I do. Like I said, that’s parts of life”</p>
Maintaining a positive outlook	<p>“I’m getting used to it (hemodialysis) . . . I’m not gonna let nothing get me down or nothing”</p> <p>“Illness made me look different at life . . . the way I was living, well, I was doing things different . . . now I praise the Lord every day. Feel pretty good”</p> <p>“(Hemodialysis) is the best thing for me . . . this is what gives us every day, everybody here a second chance at life, to keep holding on”</p> <p>“I appreciate time quite a bit now and I try to use it as best as I can because you only have certain hours in a day and you have to try to make the best out of those hours . . . I always believe that if you live with no purpose, then what is the purpose of living?”</p>

Table 2. (Continued)	
Themes and Subthemes	Illustrative Quotes
<p>Theme 4: Challenges of illness</p> <p>Dietary restriction is culturally isolating and challenging for families</p> <p>Logistic challenges and socioeconomic disadvantage compounded by health literacy and language barriers; communication problems</p> <p>Required rapid adjustments to chronic illness</p> <p>Demanding hemodialysis schedule</p>	<p>“One of the hardest things about dialysis is the diet. I don’t eat bananas, I don’t eat oranges”</p> <p>“And (my wife) gets mad because I ask her for food. She says, ‘well, you can’t eat that.’ I tell her, ‘I’m hungry!’”</p> <p>“When I had to change my eating habits, that change was the most difficult because like I’ve told the doctor here, ‘when you have diabetes, you want to eat everything’”</p> <p>“My diet has been the most difficult thing . . . I’ve asked my daughters, if you want me to stop drinking soda, don’t bring it over for me. I’m blind. I just listen. I hear the popping sound when they open a bottle or a can and I’ll ask my daughters to bring me a soda”</p> <p>“The saddest part is that I cannot drink. The doctor told me that I was only allowed to drink four glasses of water per day. It’s sad that you are thirsty and you can’t drink . . . you even seem to get thirstier”</p> <p>“I’ve missed dialysis because I don’t have someone to bring me over for dialysis . . . because I no longer have any aid . . . I arranged for a ride that brings me but the problem is that they always speak English”</p> <p>“A lot of the times, they (dialysis transportation) don’t do the schedule the way it should be . . . sometimes it gets there late”</p> <p>“(The transportation driver) didn’t tie the wheelchair and I went back and I hit myself. So, we fired him . . . then I got this one guy that was working good, he played the radio in Spanish and then one day, the (dialysis facility) reported that he was picking me up late . . . so I don’t know what happened. He’s out of the picture”</p> <p>“Sometimes I come here with not enough food because of the financial problems that I have”</p> <p>“I told them, ‘you guys don’t explain what’s going on with me,’ and then when they come to see me, they have an attitude like, ‘Aw, I gotta be here?’”</p> <p>“I don’t know what’s going on because when they see me, they talk amongst themselves. I don’t understand what they say because I only understand some words . . . I don’t understand English”</p> <p>“Nurse Barbarita is the only one who talks to me. She speaks Spanish but the rest (providers), they hardly do, they hardly ever speak to me”</p> <p>“I’m not going to see that doctor anymore . . . he just didn’t even give me (information about my kidneys) or anything. He says, ‘if you don’t take this, your kidneys aren’t gonna work.’ That was it! I never heard the word dialysis until I was already on dialysis”</p> <p>“At the beginning, everything was off. I was getting cramps . . . I feel better now. That first year was awful”</p> <p>“I feel like it’s the same for a lot of people, it takes about a year to get used to it (dialysis). I think your body is fighting it, fighting it”</p> <p>“It was a lot of things to get used to, going to the doctor all the time and the medications . . . a lot of changes . . . I don’t think there’s anything you can do to prepare for that kind of news. You just have to take it one day at a time and figure it out”</p> <p>“The first year, when I got home, I didn’t want to do nothing, I was tired, the headaches and everything”</p> <p>“It’s very little work I get because dialysis affected me a lot. In my work, sometimes I look for work in a shop but they don’t want to give it to me because of my schedule”</p>

Table 2. (Continued)	
Themes and Subthemes	Illustrative Quotes
	<p>“(Dialysis) changed me completely because I don’t like to be on dialysis, because it can be crazy, you know ... you can’t do nothing because you have to spend time in here ... like 4 hours”</p> <p>“I hated (dialysis) I hated that I’m having to do this forever ... it’s really troublesome to be getting up early and come here for dialysis three times a week, this is very hard for me. It seems very hard for me, more so because my knees are bad, because of my arthritis they hurt a lot when I walk. My legs hurt a lot and the pain sometimes doesn’t let me (attend dialysis).”</p> <p>“While sitting in this chair for four hours straight, I have to be asleep when I do it, or I get anxious ... I never felt anxious till I started doing this (dialysis)”</p>
ACP, advance care planning; CPR, cardiopulmonary resuscitation; LPN, licensed practical nurse.	

not want medications that might alleviate their suffering. When asked what he does to alleviate nausea discomfort, one patient responded, “I had a troubled life ... Beat people up just for the hell of it ... But I’m the one who’s got to pay for it ... now I’m being punished.”

Theme 2: Barriers and Facilitators to ACP: Family, Faith, and Home

Family Group Decision-Making. Some participants favor family group decision-making. One participant responded with, “my whole family,” when asked who he’d designate to make medical decisions for him. Participants who had not previously discussed ACP with family described leaving all decision-making to their families and trusting that their families would have their best interests in mind.

Family Reluctance to Have ACP Conversations. During the qualitative interviews, participants expressed gratitude for the opportunity to discuss end-of-life care and ACP because these topics are often on their minds, yet they feel they can’t discuss them with family. They described how their families avoid these conversations for fear it will distress the participant. One participant said of her husband, “(He) doesn’t like to talk about that, he doesn’t want to hear anything about the disease ... he gets sad and says, ‘... don’t you talk to me about that.’” Participants, however, feel these ACP conversations are necessary because they help their families understand the participants’ wishes and reduce future family medical decision-making anxiety. Participants also find the terminology confusing both because services, such as hospice, and advance directives (*e.g.*, medical durable power of attorney, Do Not Resuscitate) are not available in their home countries and many terms don’t accurately translate from English to Spanish.

Flexible Decision-Making Conversations at Home with Family. Participants prefer that ACP conversations occur at home, with a health care provider present, and at a flexible time so that family can be included: “At home over dinner ... ‘cause I think it would be better when everybody is around.” From their perspective, ACP conversations at home allow for more open and honest conversations that

encourage their families to ask questions and share fears. Participants also feel apprehensive about initiating ACP conversations alone for fear it will upset their family; participants both welcome and appreciate the support. Participants prefer that ACP conversations occur a few months after they have been started on hemodialysis, giving them time to cope and adjust to their illness, but before they are very ill and can no longer participate.

ACP Conversations Incorporating Trust and Linguistic Congruency. Participants prefer that the person guiding ACP conversations with families be someone with empathy. When asked to describe the ideal person that could guide these conversations, one participant said, “A person interested in how we feel ... that would empathize.” Participants want someone who speaks their language, who understands their culture, who is willing to meet them at home, who explains the medical words they don’t understand, who gives them time to express their fears and frustrations, and who has personal experience in providing care or advice to patients with ESRD. Participants also want the person guiding ACP conversations to maintain a positive outlook and explicitly tell families that the reason for the ACP conversation is to plan ahead and not because the participant’s health is concerning.

Family-First and Faith-Driven Decisions. Participants with previously signed advance directives described how their decision-making is grounded in what is best for their families. For example, participants who choose to receive cardiopulmonary resuscitation want their families to know they “died trying to the very end.” Those who choose Do Not Resuscitate do not want their families to have to “deal with a vegetable.” Some participants believe that signing an advance directive is not having faith in God because whether you live or die is God’s will; one participant explained, “He created medicine to revive you, then you should have it done.” Other participants with faith in God feel that declining cardiopulmonary resuscitation aligns with God’s will because, “if your heart and lungs stop, it means God is ready for you to come home.”

Theme 3: Enhancing Wellbeing Day-to-Day

Supportive Relationships. Sources of support reported by participants include family, friends, faith, health care

providers, and fellow patients with ESRD. Family is the reason they continue hemodialysis, and they are able to cope with their illness because of family support with medications and dietary changes. Faith is an important source of support: many pray when symptomatic and have faith that death will occur when it's God's will. Participants also receive comfort from their health care provider and other patients with ESRD. Other patients are a strong source of support and participants wish such peer support relationships could be formalized early on when they start hemodialysis so that they could learn "the ropes from someone who's been through this."

Improved Understanding of Illness Leads to Adherence.

Participants feel personally engaged and invested in their care (e.g., dietary restrictions, medications, and hemodialysis) once they understand that adherence to diet and hemodialysis leads to improved symptoms: "I've been trying to drink less water because at first when I drank lots of water, my legs would swell up, so I stop doing that. Salt too, I stopped using it ... I've felt better." Participants discussed how they skipped or shortened hemodialysis sessions and no longer do so because they feel physically better when they receive their full treatment. Better understanding of the transplant process improves their well-being because it gives them hope and makes them feel they are taking an active role toward an improved quality of life.

Recognizing New Self-Value. Some participants are immigrants who originally came to the United States to work and contribute to the financial wellbeing of families still residing in their home countries. They describe how their demanding hemodialysis schedule and debilitating symptoms are prohibitive of working. Finding something they can do that gives back to their families brings them joy. When asked what brings her comfort, one participant said, "teaching somebody a little bit of crochet ... the kids know that I don't have any money ... I sell my things."

Maintaining a Positive Outlook. Participants reported intentionally having a positive outlook and mindset in life. Some participants described how they focus on the "extra time" they are allowed with their friends and family because of hemodialysis. They described living each day "to its full potential" because they want to make the most of life now and not focus on the symptom burden or restrictive schedule and diet.

Theme 4: Distressing Aspects of Living with their Illness

Dietary Restriction is Culturally Isolating and Challenging for Families. Participants find that the dietary restrictions are the most distressing aspect of their illness. According to one, "All the food I had to let go ... cause I like avocados, beans, tomatoes, tortillas ... I can't handle that!" Not being able to eat traditional foods causes distress due to both loss of cultural identity and a decreased ability to socialize with loved ones. In addition, families do not understand or forget about restricted foods and serve them anyway, which results in participant feelings of guilt when families complain about needing to cook separate meals.

Logistic Challenges and Socioeconomic Disadvantage Compounded by Health Literacy and Language Barriers. Participants describe distress when they miss or are late for hemodialysis because of transportation issues. Participants don't eat well enough to have a "good albumin because

there is no money for food," and they are not aware of available food resources. Participants describe the need for an advocate, such as a clinical social worker, given their financial constraints; one oxygen-dependent participant needing a letter said, "I need my oxygen; it's a letter that (says) not to mess ... with the electricity or nothing." Participants feel their health care providers ignore or avoid speaking to them because they do not speak English. Many report that they do not understand their illness or other aspects of their medical care because of lack of communication.

Required Rapid Adjustments to Chronic Illness. The first few months after starting hemodialysis are the most challenging because the body needs time to adjust. Participants also feel frustrated and unprepared for all of the changes (e.g., additional pills, new dietary restrictions, the hemodialysis schedule) that from their perspective occur too quickly. To help future patients adjust to their illness, participants suggest coaching from other patients or caregivers of other patients with ESRD. According to one participant, it would be great to "have another patient say, 'hey, this is what's going to happen to you today' and share their experiences and open up their mind in order to ... cope with doing this, 'cause I've seen people that don't want to be here.'"

Demanding Hemodialysis Schedule. Participants report feeling bored during hemodialysis and bothered that it takes them away from their family. Participants with insomnia miss hemodialysis because they do not sleep well and cannot wake up in time for morning appointments. Participants want to work yet cannot find employment because of their demanding hemodialysis schedules. One participant wished for more flexible hemodialysis hours scheduled around family events; he said, "You can do like really early or you can do like noon ... options are good."

Discussion

Latinos with ESRD have unique perspectives and cultural beliefs that affect their palliative care preferences. To our knowledge, this is the first qualitative study to gather an in-depth understanding of the palliative care perspectives of Latinos on hemodialysis. We found that our Latino participants avoid medications, favor family group decision-making, and want ACP conversations to occur at home with someone that is culturally and linguistically congruent.

Our participants' preference for nonpharmacologic symptom alleviation is consistent with studies that report a similar preference among low-income Mexican men for counseling over medication alone to treat depression (18,19). Studies have also demonstrated the continued reliance of Latinos on traditional healing methods for treatment and symptom management (20–22). The fatalism reported by this study's participants is aligned with the well cited cultural belief that deters Latinos from engaging in their own health (23–25). Understanding how cultural beliefs and preferences affect treatment is important for providers caring for Latinos with ESRD because Latinos prefer to have their physical symptoms as well as their psychosocial or spiritual concerns addressed by nephrology staff (6).

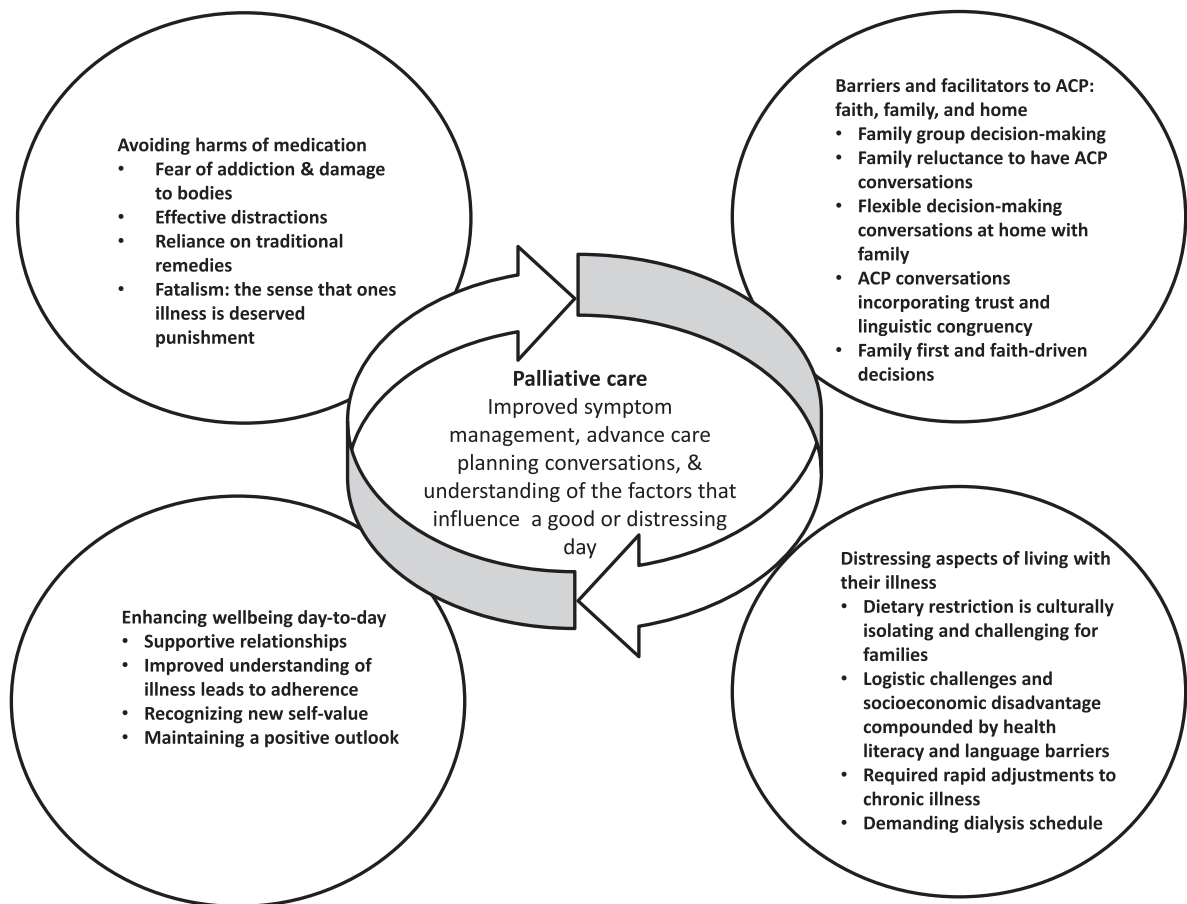


Figure 1. | Thematic schema.

Our participants prioritize family to the extent that they would prefer family-centered, group decision-making; their ACP and advance directive decisions are grounded in family values. Similarly, two cross-sectional surveys of Latino patients found that the majority rely on their family for primary caregiving and prefer limited autonomy (6,26). Our participants also provide us with insight into the ideal attributes of the person who guides ACP discussions. These attributes were consistent with the values described in a comprehensive systematic review that looked at Latino values and their integration into palliative care communication (27).

The Kidney Disease Improving Global Outcomes summary recommends integrating cultural values into shared decision-making and ACP (28). A culturally and linguistically congruent approach to reduce palliative care disparities is patient navigation (29). Community-based navigators were first utilized to improve cancer care, and, more recently, demonstrated to improve palliative care outcomes among Latinos (30–32). An ESRD-focused navigator could address the barriers described by our participants: by having ACP conversations at home including family, leading ACP conversations to avoid patient-family tension, describing palliative care options to overcome communication and health literacy barriers, and by providing person-centered care in a culturally responsive way.

Participants are distressed by dietary restrictions because they limit traditional Latino foods, thus affecting meal time with family. Similar to our findings, one study found that when dietary restriction education does not acknowledge a patient's culture, patients experience distress in food selection (33). Another study reported good dietary adherence among Latino patients with ESRD who received language-concordant dietary information and had access to Spanish translators (34). A palliative care navigator's role may include reviewing the nutrition information patients receive from their dietician in culturally and linguistically congruent ways. Our participants reported that improved knowledge leads to better adherence decision-making, which improves their wellbeing; it is possible that having a patient navigator would lead to improved dietary adherence once they understood the symptom and mortality benefits.

We identified palliative care preferences that are unique to the United States Latino community. Research shows that ethnic minorities in Western countries are less aware of and therefore less likely to use palliative care services (35). Brown *et al.* provide a "cultural competency communication skills" table with suggestions on how to approach crosscultural palliative care communication with patients with CKD. Many of our questions (Supplemental Table1) can also be used to guide palliative care conversations that seek to align care with a patient's goals and values.

This study has several limitations. The study recruited patients from two outpatient hemodialysis facilities in Colorado. The majority of our participants were of Mexican descent, and the results of our study cannot be generalized to all Latinos because Latinos are a heterogeneous group. Finally, participants were interviewed in the hemodialysis center and this setting may be disempowering or distracting. The strengths of this study are the qualitative methods that provided a rich description of a largely vulnerable community that is not represented in the palliative care literature.

A one-size-fits-all approach to palliative care for Latinos with ESRD will perpetuate existing disparities in end-of-life care. Culture affects the palliative care preferences of Latinos with ESRD on hemodialysis, and these preferences have important implications for the delivery of care. Meaningful integration of family into all aspects of palliative care and acknowledgment of individual preferences around symptom management are important mechanisms for an improved end-of-life experience.

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Disclosures

None.

References

1. Davison SN: End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 5: 195–204, 2010
2. Weisbord SD, Fried LF, Mor MK, Resnick AL, Unruh ML, Palevsky PM, Levenson DJ, Cooksey SH, Fine MJ, Kimmel PL, Arnold RM: Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2: 960–967, 2007
3. Weisbord SD, Fried LF, Arnold RM, Fine MJ, Levenson DJ, Peterson RA, Switzer GE: Prevalence, severity, and importance of physical and emotional symptoms in chronic hemodialysis patients. *J Am Soc Nephrol* 16: 2487–2494, 2005
4. United States Renal Data System. Chapter 1: Incidence, prevalence, patient characteristics, and treatment modalities, 2016. Available at https://www.usrds.org/2016/view/v2_01.aspx. Accessed March 8, 2017
5. Kurella Tamura M, Goldstein MK, Pérez-Stable EJ: Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients. *Nephrol Dial Transplant* 25: 237–242, 2010
6. Cervantes L, Linas S, Keniston A, Fischer S. Latinos with chronic kidney failure treated by dialysis: Understanding their palliative care perspectives. *Am J Kidney Dis* 67(2): 344–347, 2016
7. Cohen LL: Racial/ethnic disparities in hospice care: A systematic review. *J Palliat Med* 11: 763–768, 2008
8. Portenoy RK, Ugarte C, Fuller I, Haas G: Population-based survey of pain in the United States: Differences among white, African American, and hispanic subjects. *J Pain* 5: 317–328, 2004
9. Lewis ET, Combs A, Trafton JA: Reasons for under-use of prescribed opioid medications by patients in pain. *Pain Med* 11: 861–871, 2010
10. Born W, Greiner KA, Sylvia E, Butler J, Ahluwalia JS: Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J Palliat Med* 7: 247–256, 2004
11. Hanchate A, Kronman AC, Young-Xu Y, Ash AS, Emanuel E: Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites? *Arch Intern Med* 169: 493–501, 2009
12. Green CR, Anderson KO, Baker TA, Campbell LC, Decker S, Fillingim RB, Kalauokalani DA, Lasch KE, Myers C, Tait RC, Todd KH, Vallerand AH: The unequal burden of pain: Confronting racial and ethnic disparities in pain. *Pain Med* 4: 277–294, 2003
13. Anderson KO, Mendoza TR, Valero V, Richman SP, Russell C, Hurlley J, DeLeon C, Washington P, Palos G, Payne R, Cleeland CS: Minority cancer patients and their providers: Pain management attitudes and practice. *Cancer* 88: 1929–1938, 2000
14. Smith AK, McCarthy EP, Paulk E, Balboni TA, Maciejewski PK, Block SD, Prigerson HG: Racial and ethnic differences in advance care planning among patients with cancer: Impact of terminal illness acknowledgment, religiousness, and treatment preferences. *J Clin Oncol* 26: 4131–4137, 2008
15. Sandelowski M: Whatever happened to qualitative description? *Res Nurs Health* 23: 334–340, 2000
16. Morse JM: The significance of saturation. *Qual Health Res* 5: 147–149, 1995
17. Creswell JW: *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, Los Angeles, SAGE Publication, 2013
18. Dwight Johnson M, Apesoa-Varano C, Hay J, Unutzer J, Hinton L: Depression treatment preferences of older white and Mexican origin men. *Gen Hosp Psychiatry* 35(1): 59–65, 2013
19. Dwight-Johnson M, Lagomasino IT, Hay J, Zhang L, Tang L, Green JM, Duan N: Effectiveness of collaborative care in addressing depression treatment preferences among low-income Latinos. *Psychiatr Serv* 61: 1112–1118, 2010
20. Padilla R, Gomez V, Biggerstaff SL, Mehler PS: Use of curanderismo in a public health care system. *Arch Intern Med* 161: 1336–1340, 2001
21. Applewhite SL: Curanderismo: Demystifying the health beliefs and practices of elderly Mexican Americans. *Health Soc Work* 20: 247–253, 1995
22. Tafur MM, Crowe TK, Torres E: A review of curanderismo and healing practices among Mexicans and Mexican Americans. *Occup Ther Int* 16: 82–88, 2009
23. Flores G: Culture and the patient-physician relationship: Achieving cultural competency in health care. *J Pediatr* 136: 14–23, 2000
24. Ramirez AG, Suarez L, Laufman L, Barroso C, Chalela P: Hispanic women's breast and cervical cancer knowledge, attitudes, and screening behaviors. *Am J Health Promot* 14: 292–300, 2000
25. Powe BD, Finnie R: Cancer fatalism: The state of the science. *Cancer Nurs* 26: 454–465, quiz 466–467, 2003
26. Kelley AS, Wenger NS, Sarkisian CA: Opiniones: End-of-life care preferences and planning of older Latinos. *J Am Geriatr Soc* 58(6): 1109–1116, 2010
27. Adames HY, Chavez-Dueñas NY, Fuentes MA, Salas SP, Perez-Chavez JG: Integration of Latino/a cultural values into palliative health care: A culture centered model. *Palliat Support Care* 12: 149–157, 2014
28. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, Murtagh FE, Naicker S, Germain MJ, O'Donoghue DJ, Morton RL, Obrador GT: Kidney Disease: Improving Global Outcomes: Executive summary of the KDIGO controversies conference on supportive care in chronic kidney disease: Developing a roadmap to improving quality care. *Kidney Int* 88(3): 447–459, 2015
29. Vargas RB, Ryan GW, Jackson CA, Rodriguez R, Freeman HP: Characteristics of the original patient navigation programs to reduce disparities in the diagnosis and treatment of breast cancer. *Cancer* 113: 426–433, 2008
30. Freeman HP, Muth BJ, Kerner JF: Expanding access to cancer screening and clinical follow-up among the medically underserved. *Cancer Pract* 3: 19–30, 1995

31. Fischer SM, Sauaia A, Kutner JS: Patient navigation: A culturally competent strategy to address disparities in palliative care. *J Palliat Med* 10: 1023–1028, 2007
32. Fischer SM, Cervantes L, Fink RM, Kutner JS. Apoyo con Carino: A pilot randomized controlled trial of a patient navigator intervention to improve palliative care outcomes for Latinos with serious illness. *J Pain Symptom Manage* 49(4): 657–665, 2015
33. Mayers JD: Dietary restrictions in maintenance hemodialysis: Experiences of english speaking west Indian adults. *Nephrol Nurs J* 27: 315–319, 2000
34. Morales López C, Burrowes JD, Gizis F, Brommage D: Dietary adherence in Hispanic patients receiving hemodialysis. *J Ren Nutr* 17: 138–147, 2007
35. Brown EA, Bekker HL, Davison SN, Koffman J, Schell JO: Supportive care: Communication strategies to improve cultural competence in shared decision making. *Clin J Am Soc Nephrol* 10: 1902–1908, 2016

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