

Four Kinds of Hard: An Understanding of Cancer and Death among Latino Community Leaders

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Abstract

Early integration of palliative care after a diagnosis of cancer improves outcomes, yet such care for Latino populations is lacking in rural regions of the United States. We used a participatory action research design with Latino community leaders from emerging immigrant communities in North Carolina to explore sociocultural perspectives on cancer and death. Thematic analysis was conceptualized as *Four Kinds of Hard* represented by four themes: Receiving an Eviction Notice, Getting in the Good Book, Talking is (Sometimes) Taboo, and Seeing Their Pain Makes us Suffer. These themes captured fears of deportation, coping with cancer through faithfulness, ambivalence about advance care planning, and a desire to spare families from suffering. Findings suggest strategies to improve conversations about end-of-life wishes when facing advanced illness and death. This study demonstrates the importance of training Latino community leaders to improve palliative care and bridge service gaps for Latino families living in emerging rural communities.

Keywords

Southeastern United States, cancer, hispanic people, palliative care, participatory action research, Latino

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Background

Cancer is the leading cause of mortality among Latino people living in the United States, accounting for 21% of deaths (American Cancer Society [ACS], 2018). Compared to Whites, Latino persons with cancer are less likely to be diagnosed at an early stage, use screening tests, have access to high quality treatment, receive adequate follow-up care (ACS, 2018), and are more likely to have an infection-related cancer (Zonderman et al., 2014). Additionally, first generation Latino immigrants in the United States have higher incidence rates of cancer than those residing in the country of origin (ACS, 2018).

Minorities and the poor in the United States continue to bear a disproportionate burden of cancer, especially in terms of stage at diagnosis, incidence, and mortality (Zonderman et al., 2014). Rodríguez-Prat et al. (2019) examined the relationship between an individual's feeling of being a burden and a wish to hasten death. Findings depicted the interrelatedness of pain, suffering, hardships, and burden in the experiences of individuals with life-limiting illnesses. Two interrelated themes revealed a loss of identity due to the emotional and psychological burden of an advanced illness

and the negative impacts on a person's immediate social environment. In another study, the burden of cancer was greater among foreign-born, monolingual Spanish-speakers. This group reported low self-efficacy in patient-provider communication, which led to poorer health-related quality of life (Moreno et al., 2018).

Although the early integration of palliative care after a diagnosis of cancer has been shown to improve outcomes (Temel et al., 2010), people of Latino heritage, the fastest growing ethnic group in the United States, face serious health disparities in palliative and end-of-life (EOL) care. LoPresti et al. (2016) found that Latino persons with cancer were more likely to reject hospice care, prefer life-saving measures, and be less likely to have a Do Not Resuscitate order

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when compared to other ethnic groups. Further, Latino individuals also relied more on religion as a coping mechanism and had more fatalistic views of their illness (LoPresti et al., 2016). Latino ethnicity is not a major predictor of referral to supportive and palliative care, but Latino persons have a significantly higher symptom burden than Whites after referral and, in urban areas, are less likely to receive hospice services (Elk et al., 2018).

North Carolina is home to rapidly growing Latino communities in rural areas that lack the infrastructure to provide culturally and linguistically relevant health care (Larson et al., 2017). As the Latino population continues to age in place, issues of cancer management and EOL care will increase. Only 38 out of 100 North Carolina counties have palliative care specialists and rural areas are least likely to have these services (Lake, 2020). No known studies examined palliative care access for rural-dwelling Latino persons. Thus, the purpose of the overall study was to develop a theory-based, community palliative care program for Latino persons with cancer in rural eastern North Carolina. This article focuses on the first part of the larger study, which elicited the cultural perspectives of Latino community leaders about cancer and death to inform a palliative care training program. Viewpoints of these leaders were situated in the context of the structural inequalities found in this region.

Palliative Care Interventions

To address disparities in palliative and EOL care, researchers have sought evidence-based interventions that utilize community members to fill service gaps and reach underserved populations. Two successful initiatives in urban areas included a patient navigator program for Latino families to address EOL preference and pain management (Fischer et al., 2015, 2018) and a theory-based intervention with community health workers to increase palliative care use with African Americans (Kubi et al., 2020). In a randomized controlled trial with 240 self-identified Latino persons who had an advanced medical illness and 120 family caregivers, Fischer et al. (2015, 2018) determined that training Latino community navigators to conduct home visits and provide palliative care information was successful in increasing use of advance directives, pain management strategies, and hospice services. Further, this study revealed that Latino individuals prefer interventions which occur outside of the clinical setting. Cupertino et al. (2015) trained 22 Latino lay health workers from rural parts of Kansas in cancer and research ethics. These investigators concluded that it was feasible to engage lay health workers to deliver community-based cancer education and serve as an important adjunct to clinicians in underserved, rural communities.

Although progress has been made in developing community-based models of palliative care for Latino ethnic groups, most have been based in locations with geographic, political, and social differences from rural North Carolina and do not

address the issues associated with advanced cancer. Pilot work in this region has demonstrated the feasibility of training members of the Latino community to lead discussions about death and dying (Hagwood & Larson, 2019). Other studies recognized the work of lay spiritual leaders, known as *rezadoras* in Latin American communities, who assisted families in the care of loved ones at the end of life. *Rezadoras* were called upon to sing prayers during the final stages of life and, in so doing, relieve suffering of both the dying individual and family (Traister et al., 2016).

Lay advisors can fill service gaps by connecting community members with the health care system. By living in the same communities, Latino lay advisors can often communicate in the language of preference and understand the structural barriers to accessing care. In addition, these community leaders can advocate on behalf of Latino families and use shared values and beliefs to facilitate conversations about EOL decision-making (Boucher, 2017).

Conversations about Cancer

Lillie et al. (2020) outlined factors of importance in increasing the cultural acceptance and accessibility of advance care planning communications for American Indian and Alaska Native communities. They found a preference for having EOL conversations with trusted community members and local health professionals, such as nurses, and emphasized the need for such conversations to incorporate religious and cultural values. Shen et al. (2020) reported that optimistic religious beliefs (e.g., belief in miracles) held by Latino persons with advanced cancer hindered advance care planning discussions. These patients also preferred using their native language to discuss EOL care desires. Several investigators found that Latino persons welcomed medical providers during family EOL discussions, indicating that the opinions of clinicians are respected and valued (Peterson et al., 2019; Shen et al., 2020). On the other hand, in a systematic review of patient and clinician communication, Cervantes et al. (2016), reported frustration among Latino patients due to lack of interpreters, but that a trusting relationship and a clinician who exhibits optimism improved communication and made the patient feel in control of their decisions.

In a review article, Del Río (2010) found that the decision-making tendency of Latino persons is family centered, believing that the family should make decisions about the use of life support. Yet, other investigators reported that familism, a cultural value that emphasizes strong family ties, could inhibit EOL conversations when Latino family members withheld the knowledge of cancer to protect the individual from their diagnosis (Kreling et al., 2010; Savage et al., 2015). In a study of 51 elderly Dominicans and Puerto Ricans in East Harlem, Boucher (2017) determined that conversations about death and EOL were considered private matters and discussed only within the family, if at all. The value of filial piety meant that parents expected their children to care for them during illness;

however, they seldom discussed EOL care, focusing instead on their wishes for funeral arrangements. Another traditional view that influences EOL conversations is the notion of a “good” death, which is affected by time and place. In a systematic review, investigators found Latino persons believed medical intervention disrupts the natural progression of a “good” death (Crist et al., 2019). Furthermore, a “good” death occurs at the right time, after a person has imparted their wisdom to the family members they are leaving behind.

In a recent hospice needs assessment, Ko et al. (2018) reported that half of the caregivers to Latino persons with a serious medical illness had never engaged in EOL conversations. Those who preferred life-sustaining treatments, and those who feared that the physician would stop treatment too soon were less likely to engage in EOL discussions. However, caregivers who had knowledge of and understood advance directives were more likely to have these conversations.

Only two studies described talking with children about death. Logger et al. (2019) reported the willingness of Latina mothers to discuss a cancer diagnosis with children to prepare them for life after the mother’s passing. Conversations about death and dying with children have occurred around the *Día de los Muertos* [Day of the Dead], a Mesoamerican cultural celebration that honors the deceased. Gutiérrez et al. (2015) conducted 61 interviews with children and reported a more positive perspective toward death when centered around this cultural tradition.

Theoretical Model

Fear of cancer and the experience of diagnosis provoke existential concerns that can lead to physical, psychological, and social distress for cancer patients. Some theoretical models address existential concerns across the cancer continuum (Lee & Loiselle, 2012), yet other investigators noted that spiritual values and social support outweighed common existential threats from cancer (Blinderman & Cherny, 2005). Kagawa-Singer (2000) reported that culture affects the meaning of cancer, including the threat to identity posed by the disease. Since little is known about the factors that impact Latino responses to cancer and death, this study adopted the broader Ethnocultural Gerontological Nursing (ECGN) model formulated by Phillips et al. (2015). While not specific to cancer, this model provides a guide for developing research at the intersection of aging, ethnicity, and health. The model considers how the social context, including macro-level factors of the political climate, stereotypes and attitudes, and historical traditions, shape the social meanings formed by individuals. These social meanings, in turn, vary depending on micro-level factors such as health status, personal experiences, and communication. Health outcomes emerge from the interactions between these factors over the life course.

Ruiz et al. (2016) adapted the ECGN model to understand the aging experience of older Latino persons and how these

factors impact health outcomes. Important macro-level factors included the sociopolitical environment where people live and work as immigrants in low wage jobs, often without legal documents or access to social services, and exposure to US stereotypes leading to experiences of prejudice and discrimination. Other macro-level factors were cultural and historical traditions characterized as core values, such as loyalty to family, the desire to maintain harmony in interpersonal relationships, and the need to show respect to authority figures. Further, Ruiz et al. (2016) noted that foreign-born Latino persons living in homogeneous ethnic enclaves benefited from social supports that eased the stress of immigration and its impacts on health. Missing from the Ruiz et al. (2016) study, however, was a discussion of the role of spirituality in Latino responses to the EOL. Crist et al. (2019) reviewed 22 articles on EOL decision making among Mexican American older adults and noted that spirituality was a central dimension in shaping notions about a “good death,” proscriptions for the dying experience and expectations of family members in the dying process. Thus, we adopted use of the key macro and micro-level variables specified in the ECGN model as refined by Ruiz et al. (2016), with the addition of spirituality, to inform the study.

In summary, some Latino subgroups are negatively impacted by advanced cancer at a higher rate than other ethnic groups because of unique cultural and social factors. Cancer burden and conversations about cancer greatly influenced how Latino persons manage and cope with a cancer diagnosis. Lay advisor interventions in limited geographic and urban areas showed promise in reducing health disparities among ethnic minority groups. No studies were found that delineated the sociocultural perspectives about cancer and death among Latino leaders.

Method

We used a participatory action research design (Israel et al., 2013), guided by the ECGN model, with the overall goal of developing a community palliative care program for Latino persons with advanced cancer and their caregiver(s). Participatory action research foregrounds the experiences and social interactions of community members to improve health outcomes through action and change. This article describes the first part of a larger study, which elicited the cultural perspectives of Latino leaders about cancer and death to inform a community palliative care program. The larger study aimed to train and match leaders to Latino persons with advanced cancer and then assess trained leaders’ engagement with these individuals regarding home-care symptom management and EOL care decisions.

This project, initiated in January 2020, grew out of previous collaboration and research with Latino advocacy groups in eastern North Carolina (Hagwood & Larson, 2019; Larson et al., 2017). The 7-member research team consisted of three community members; two palliative care nurses from local

hospitals and the director of a Latino advocacy group; and four university researchers with expertise in community health nursing, palliative and cancer care, anthropology, and biostatistics. Three of the team members were of Latino heritage. A major epistemological assumption in participatory action research is the inclusion of members of the ethnic or cultural group as co-investigators to ensure equity and power-sharing in the research. Community members bring local knowledge to the study, known as the emic (insider) viewpoint. The academic researchers contribute an etic (outsider) viewpoint, that is not complicated by membership in the culture. The synthesis of emic-etic viewpoints produces a new understanding of the phenomenon of interest. Weekly team reflection and discussion throughout the study created shared understanding and trust.

The team utilized a focus group approach based on a constructivist paradigm, where knowledge emerges from experience and interactions of the individual with others and the environment (Lincoln et al., 2018). Focus groups promote self-disclosure in a safe environment, encourage interaction, and expose multiple perspectives, while minimizing the researchers' position of power (Krueger & Casey, 2015). Further, advantages of focus groups are in their contribution to decision-making and policy development, and insight on behavior and motivation (Krueger & Casey, 2015). The study was approved by the university institutional review board, which included a waiver of signed informed consent.

Sample and Setting

The target sample of 15 Latino community leaders was established a priori. In addition, the research study sites were chosen based on counties with a high Latino population density. To recruit these leaders, team members traveled over 1,100 miles, distributing project information and meeting with staff at churches and advocacy groups (i.e., *Manos Unidas*, Catholic Charities), local health departments, community health centers, hospitals, and schools. The most effective recruitment strategy was personal networking and in-person meetings, which is consistent with Latino values (García et al., 2017). Eligibility criteria included Latino men or women considered community leaders; over 18 years of age; able to read and write Spanish and English; willing to help Latino families with cancer; residing in the project's target counties; and having reliable transportation. In addition, efforts were made to recruit from the diverse Latino subgroups living in the region, including individuals from Mexico and Central America. Investigators have noted that immigrants from Mexico and Central America share common cultural values and beliefs, and similar motivations to migrate to the United States (Portes & Rumbaut, 2001). Initially, we recruited 18 leaders; however, three declined prior to beginning the program due to family and/or work responsibilities. At the time of recruitment, team members explained the study purpose and voluntary nature of participation and obtained verbal informed consent.

Table 1. Demographic Characteristics of the Latino Community Leaders (N = 15).

Baseline characteristics	N	%
Age (in years)		
20–30	5	33.3
31–50	5	33.3
≥51	5	33.3
Sex		
Female	14	93.4
Male	1	6.6
Latino heritage		
Central American	3	20
Mexican	11	73.4
Puerto Rican	1	6.6
Last grade completed		
≤High school	8	53.3
College	7	46.7
Married		
Yes	14	93.4
No	1	6.6
Employment		
Not working	4	26.6
Work full time	11	73.4
Preferred language		
Spanish	3	20
English	2	13.4
No preference	10	66.6
Preferred religion		
Catholic	8	53.3
Protestant	7	46.7
Has made home visits		
Yes	11	73.4
No	4	26.6
Talked with family about advanced care planning		
Never thought about it	5	33.3
Thinking about/planning to	5	33.3
Already did it	5	33.3

A total of 15 community leaders from four rural counties in eastern North Carolina participated in one of three focus groups. The majority were women and married (see Table 1). There were comparable numbers of young, middle age, and older adults. The majority (73%) were of Mexican origin and others were from Central America and Puerto Rico. Most (73%) reported previous experience with helping people in their community. When asked if they had talked with their decision maker about advance care planning 33.3% had never thought about it, 33.3% were thinking of/or planning to do it soon, and 33.3% had already talked with the decision maker.

Data Collection

Three focus groups, as recommended by Krueger and Casey (2015), were conducted with the participants from the target

counties. At the beginning of each focus group, the moderator reviewed the consent form, answered clarifying questions, and reiterated that participants could leave at any time without penalty. Anonymity was ensured by having participants select a pseudonym, which they placed on a name tent at the table where they sat. Finally, ground rules were read aloud by the moderator that delineated the importance of respect and privacy for all.

An experienced bilingual moderator (Kim Larson and Holly Mathews) facilitated each focus group. Co-moderators, also members of the research team and trained in focus group methodology, took fieldnotes and managed recording devices. Moderators followed a semi-structured interview guide (see Supplemental Figure 1) with questions informed by the ECGN model and refined after a pilot study (Hagwood & Larson, 2019). For example, the first question asked participants what came to mind when they heard the word cancer. This question elicited responses such as fear and avoidance. Another question asked participants how their families talked about death and dying when they were growing up. Participants shared experiences about the importance of funerals and the difficulties of caring for dying family members in their home country. The use of open-ended questions empowered participants to direct the discussion and share their understandings of the topics. The groups ranged in length from 50 to 60 minutes and were conducted in English; questions were translated into Spanish when necessary. Audiotapes were transcribed verbatim and verified by two research team members within 1 week.

Data Analysis

Transcripts were read by all team members who independently developed In Vivo and descriptive codes (Saldaña, 2015) for the answers to each of the interview questions utilizing key variables postulated in the ECGN model. In particular, the macro and micro-level factors provided the context for coding the data. The research team met weekly to discuss coding and resolve discrepancies based on researcher reflexivity, which involved active engagement in identifying and correcting biases. This occurred through the discourse of diverse opinions within our interprofessional community-academic partnership. Four team members conducted a key word in context analysis (Bernard, 2017). Key words are those used most often in a corpus of qualitative data. Every utterance associated with the key word is examined to explore the context of its use across a group of respondents and to clarify the range of meanings associated with it. The analysis highlighted the importance of pain and suffering (one's own and that of others), hardships (material and emotional), and talk (referencing participants' cultural and social interactions around death and dying). Next, constant comparison was used to reach agreement on emergent themes and exemplars. Constant comparison is an iterative process of recoding and recategorizing data as they present

themselves and creating new categories when codes do not fit into existing ones (Fram, 2013). To enhance credibility the themes were shared with participants to invite their reflections and additional comments (Tracy, 2010). This study, which included three focus groups that were not stratified, sought to identify core issues, and thus assessed code saturation at 80% using procedures from Hennink et al. (2019). Specific exemplars that support the findings are noted by focus group (FG) number (e.g., FG 1).

Results

The overarching sociocultural context of cancer and death was framed as Four Kinds of Hard, characterized by the themes: Receiving an Eviction Notice, Getting in the Good Book, Talking is (Sometimes) Taboo, and Seeing Their Pain Makes us Suffer. As community leaders and natural helpers, the participants had previous experience in making home visits to Latino families with serious medical illnesses. Participants in all three focus groups described recent encounters with cancer and death that highlighted the prevalence of late-stage diagnosis, as noted in this excerpt,

the past two or three years we've actually had three family members that passed you know, back after back, so it's very scary to think about and realize that one day you're here like you can be perfectly fine and then the next day you're not. (FG 2)

The first two themes, Receiving an Eviction Notice and Getting in the Good Book reflect the influence of macro-level factors recognized in the ECGN model (political world, attitudes and stereotypes, and cultural and historical traditions), including spirituality. The last two themes, Talking is (Sometimes) Taboo and Seeing Their Pain Makes us Suffer, reflect the influence of micro-level factors in the ECGN model (demographics, health status, and communication). Collectively, hardship was the unifying belief that these leaders used to connect the Four Kinds of Hard for Latino persons facing cancer and death.

Receiving an Eviction Notice

The first kind of hard aligned with the sociopolitical environment, which included a history of immigration from Mexico and Central America into rural areas of the United States lacking established Latino communities resulting in fear of deportation. This notion of deportation was expressed by one participant, ". . . cancer is like a notice of eviction, you're moving somewhere else" (FG 1). Eviction, synonymous with deportation, suggests that a cancer diagnosis for some immigrants literally threatens their ability to stay or even survive in their new homeland. Additionally, the fear that signing documents might lead to detection by authorities also causes concern with advance directives. One participant depicted the situation in this way,

. . . they don't like to ask for help, they don't. Because they fear that one, a lot of them are migrants, they don't have papers and they don't know if there's an organization there; and they are going to deny it, and like, 'oh no I don't need no help'; or they don't want to go to the doctor for follow-up, if they tell they have cancer one time, no they might deport me. (FG 3)

Lack of financial resources further limits the ability of Latino persons to cope with cancer. One participant described a friend's situation, "She got little ones and um it's affecting her because she don't have that income also to do the treatments and which I mean she's getting help but she have to go too far away distance for her to get treatments. . ." (FG 2). When family members are unable to help, a feeling of hopelessness can result, as noted here, "It's like you know the person who has cancer goes through pain but so does the family too, especially if they don't know what to do, how to help. They feel hopeless" (FG 1).

Hopelessness can be compounded by negative attitudes and stereotypes, and a lack of supportive social networks in the United States. One participant stated, "It is difficult to put certain rules to the family because we are in a country that, maybe, has dehumanized us a lot and you see more disintegration of families when there is a sick family member in the home" (FG 1). Moreover, since many emerging Latino communities are situated in rural areas where interpreters are scarce, people do not know where to go or how to communicate their needs. Another explained, "That's one of the reasons I wanted to do it [the palliative care training program]. . . we need somebody that speaks our language to help us because they come from another country" (FG 1).

As community leaders, the participants highlighted concerns about the larger sociopolitical environment and how the negative stereotypes experienced by Latino persons with cancer limit options and resources available to them. It is in this context that spiritual and religious values become an important guide for how best to cope with illness and death.

Getting in the Good Book

Participants reported that leading a good life would result in a better death, one that ended in heavenly ascent, as noted in this comment, "we do believe that you know if you pass away. . . that 1 day you will go to heaven if you keep doing what God's telling you. . ." (FG 2).

Knowing that one's name was in the good Book, referring to the Bible, made it easier for the person to accept death. The second kind of hard was not getting one's name in the good Book, as this participant commented:

God would have a big Book and your name would come up and all your good things would be there, and all your bad things would be in the Book [too]. You would have all your life until then [death] to make sure you were in the right Book. (FG 1)

Knowing if you had made it into the good Book, however, could be difficult when some interpreted cancer itself as stemming from sin. One discussed how members of her church referred to persons with cancer, "because so many people that have [cancer] and we say, sometimes mistakenly, those who are at church say that it was because she was a sinner. No, I am a sinner and I haven't had it!" (FG 1).

Hope and prayer were common methods of caring for a loved one with cancer. One participant remarked, "So, it was 3 months of hope and prayer and giving him the best of life he could have. . . we were there [in Mexico] for 3 months and yes, he passed away" [begins to cry] (FG 1). Several participants reported, however, that returning to the home country to take care of a loved one dying with cancer was a notable hardship, "my mother was in North Carolina, she had to travel [to Mexico], that was something hard, she had to stay over there and care for him [her father] for his last couple of weeks" (FG 3). A few participants were familiar with *rezadoras*, lay spiritual leaders known to practice in eastern North Carolina. As natural helpers, participants reported membership in church prayer groups that provided significant material and spiritual support for Latino families.

Religious and spiritual values were crucial for Latino persons coping with cancer in rural areas. The pain of confronting death was eased by understanding that one's name was in the good Book and by the prayers and comfort provided by others. Yet on the micro-level of day-to-day interaction, family members and patients still had to navigate the complexities of talking about cancer with one another.

Talking is (Sometimes) Taboo

The third kind of hard for participants was the contradiction between the cultural view that talking about cancer and death is taboo but that such talk was often necessary to prepare for and learn the wishes of the dying. Through prior home visits participants had exposure to these contradictions. When asked how they would talk about a terminal cancer diagnosis, one of the older participants stated,

I do not want to think that one of my children or someone from my family has that [cancer]. So, I prefer that, this is a taboo subject. How we say, I do not want to even name it in relation to my loved ones. (FG 1)

Other participants wanted to know if they had a terminal diagnosis so they could prepare. As one stated: "I would! That way I can prepare. Not just me but my family, my children, just you know, this is something that, you know, it's not gonna go away and, you know, I just [want] to [have] my peace" (FG 2). Several participants discussed how death was a part of life: "Death is a part of life is what I told my daughter. We stay here now but we don't know tomorrow. Sometimes it's hard to talk about that" (FG 3). Cancer was

described by many participants as death, pain, and suffering, yet one participant had a different experience,

I didn't have parents, they died. . . my sister raised me and really no one explained to me what death was, I had to live it directly because, I don't know what happened, but in my family, the family died off due to [multiple] accidents. . . it was because it was their turn, I think. So, I liked to be in funerals. . . I did not feel so much pain like I am seeing that you all are expressing, that you feel so much pain because someone died, no, I did not live that pain. I felt that it was part of life. (FG 1)

Some participants noted that attending funerals prepared them to talk more about funeral arrangements with the dying rather than discussing their preferences for EOL care. A young participant, who had not discussed advance care plans or designated a health care decision maker remarked,

At least we are better prepared. You know, me I feel like I am so open about it. I have, I'm already paying for my Dad's funeral, pre-paying for it. I told my Mom once I finish paying for it, I'll start on hers. I've got mine pre-paid. (FG 3)

Attending funerals was mentioned in each focus group as an approach to talking about the topic of death, especially with children. One participant remarked, "I grew up pretty much going to funerals. So, I let my kids experience that. . . because they need to be ready for, if I die or my husband dies" (FG 2). Another participant used the image of a flower to explain death to her grandson,

I say honey. . . we are all going to die, just like the flowers. . . and I show him, look that flower is dead but then another one is going to come. So, I guess it's just a way of looking at it [death], learning to look at it in a more positive way, which is hard. (FG 1)

While some participants described talking with children about death, others described how death was kept from children. One of the youngest participants sadly explained that she did not learn about her grandmother's cancer diagnosis until just before she died in an intensive care unit. These examples emphasize the priority placed on experience over talk. Going to funeral services and attending burials was participatory rehearsal for one's own death but explicit talk about EOL care remained taboo for many. This contradiction constituted a hardship for those who wished to help prepare family members in advance and spare them from suffering.

Seeing Their Pain Makes us Suffer

The fourth kind of hard was described as suffering caused by seeing loved ones in pain. These community leaders had first-hand exposure to pain and suffering through visits with Latino families with cancer. A participant explained, "I have encountered people with cancer and seeing them go through the pain it hurts me" (FG 1). Another emphasized the dual

nature of pain for patients and family members, ". . . just like pain within themselves knowing that they have this um diagnosis and also pain for the family watching their loved one suffer like emotionally, physically, mentally" (FG 2).

As a result, many expressed the desire to spare their own family members such suffering: "If I get to the point, don't let me lay there for that long making my kids suffer more than what they already are. Especially when the doctors told you there isn't much they can do. It's really hard" (FG 3). To avoid suffering and pain, several participants wanted to be given a medication that would hasten death,

I would ask the doctor, is there something you can give me to just kill me or is there something I can take to kill myself. Because, like [the other participants] said, I do not want my family to see me going through suffering and pain. (FG 1)

Participants reported that families do their best to help those in pain, but the measures they can take are limited. One noted the importance of managing symptoms with alternative therapy: ". . . they were giving him home remedies to help out with the pain, help him sleep through it, and things like that" (FG 3). Others emphasized supportive care: "Support in all aspects, taking care of them, being there for them, maybe just, I guess, sing a song, read a book, ways the person would feel, let's say, less pain" (FG 1).

In the end, all families would arrive at the point where there was nothing more to be done. The family viscerally experienced the pain of the patient and reciprocally, the patient felt pain as their family members watched them. While many persons with cancer desire to hasten death to spare relatives from suffering, family members often fear the loss of their loved ones as the ultimate pain. One participant described this situation,

It was hard to see how slowly he was losing his strength. He got to the point where he couldn't get up, get off the bed, go to the bathroom on his own. Or feed himself, until he got to the point where he couldn't eat at all. And so, it's just really hard. . . you get to a point where there is nothing else you can do and it's going to happen. (FG 3)

Discussion

This study found that community leaders from emerging Latino communities in rural North Carolina conceptualized experiences of cancer and death in the Latino community as Four Kinds of Hard. Consistent with traditional gender norms in the Latino community, most of the leaders were women who had experience in caring for persons with cancer and making home visits to community members. As a result, their insight into the causes and forms of suffering among Latino families provided rich information and essential context to this study.

Although all people confronting cancer must deal with hardships, not everyone must do so while living in

the shadows without access to services and confronting the prejudice and discrimination stemming from negative stereotypes. The importance of immigration status cannot be overstated. For individuals without permanent legal residence, a cancer diagnosis created anxiety about deportation, a reluctance to seek help, and a fear of signing official documents (Bravo, 2017; Jaramillo & Hui, 2016). The significance of this study was the identification by community leaders of the ways that macro-level sociopolitical factors limit the palliative care options for Latino families with cancer, intensifying their micro-level experiences of pain and suffering. These results, through an emic-etic synthesis, suggested a new understanding of the phenomenon of EOL and palliative care within the Latino community. These insights will inform the larger study to reach underserved Latino families with cancer and link them with palliative care services and other resources.

Sociodemographic and communication barriers were highlighted by these leaders. Undocumented individuals lack access to welfare or other safety net services including health insurance, while many Latino persons with legal status are afraid to access these for fear that they too might be targeted (Jaramillo & Hui, 2016). Such fears are heightened when local law enforcement agencies cooperate with the US Immigration and Enforcement Agency allowing them to apprehend Latino persons stopped for routine traffic violations when suspicious of their immigration status (Larson et al., 2017). Many Latino persons, therefore, pay out of pocket for medical care and thus may experience more negative outcomes due to the high costs of cancer diagnosis and treatment. These difficulties are further intensified by limited English proficiency and health literacy and, in emerging communities, by the lack of trained interpreters and agency personnel who can communicate in Spanish (Jaramillo & Hui, 2016).

The ECGN model did not differentiate between the experience of urban and rural Latino persons, although Ruiz et al. (2016) did suggest that families living in established communities might have some protection from the worst effects of immigration on health. Our data, on the other hand, demonstrated that Latino persons living in rural and emerging immigrant communities experienced both a lack of access to culturally and linguistically appropriate health services and an inadequate palliative care infrastructure. Participants reported that the ability of Latino persons to cope with cancer was further hampered when they were fearful about seeking help or did not have social networks available to provide support.

While the ECGN model noted that attitudes and practices related to death are part of cultural and historical traditions, participants placed these ideas, instead, within a clear religious framework. The way they handled confronting death was by living a good life to ensure the certainty they would enter heaven and be freed from suffering. Prayer and visitation were also important community-based measures for

symptom management. These findings confirm the conclusions of Crist et al. (2019) about the role of prayer and religious observances in EOL care and of religious beliefs in shaping attitudes toward death. Moreover, in an environment of legal uncertainty and a general lack of resources and services, organized religion fills a gap by providing various types of material and social support that would otherwise be lacking.

The other unique kind of hard reported by these participants emphasized the suffering people experience when seeing the pain of others. They noted that Latino individuals with cancer are afraid of being a burden on loved ones which would increase their suffering. Likewise, family members often feel hopeless and experience pain when they are unable to ease the patient's suffering (Boucher, 2017). This situation represents the other side of the value of familism, which Ruiz et al. (2016) posited as an important cultural tradition. Participants in another study strongly valued family loyalty, respect for elders, and a duty to care for one's own, yet their attempts to enact these values were sometimes problematic and painful (Cervantes et al., 2016). As with other kinds of hard, this level of suffering was exacerbated by the experience of pain and suffering in two countries (Bravo, 2017). The community leaders in our study reported trying to help loved ones with cancer, but they often lacked palliative care assistance and adequate knowledge of symptom management.

A particular kind of hard was talking explicitly about advance care planning with family members. Participants stressed, instead, the primacy of action over talk, noting that attendance at funerals was a more common way to prepare for death than advance care planning. Not surprisingly, at the beginning of the training 10 of the 15 participants had not signed advance directives. Our data suggested that the concept of preparation could be broadened to integrate funeral arrangements with EOL decision-making. Lillie et al. (2020) emphasized the importance of making advance care planning conversations culturally relevant, while Ko et al. (2018) stressed the need to include family caregivers in these conversations. Shen et al. (2020) further recommended integrating religious beliefs in advance care planning. Latino leaders trained in palliative care can draw on the cultural meaning of a "good death" to explain how such preparations could reduce the potential suffering of family members (the negative side of familism) (Logger et al., 2019). They can also distribute relevant materials in the native language to improve understanding of palliative care, hospice, and advance care planning. As residents in the same communities, they are available to assist families in completion of advance directives. Building on the respect that Latino people have for physicians (Lillie et al., 2020; Peterson et al., 2019; Shen et al., 2020), community leaders can encourage Latino families to share their EOL wishes and concerns with physicians and practice ways to initiate such conversations effectively in the clinical setting.

Strengths and Limitations

Specific strengths of this project included further refinement of the ECGN model for research and nursing practice by an interprofessional team in partnership with Latino community leaders. Team members successfully recruited community leaders from four rural counties, who varied in age, level of education, and national heritage. This study is also the first to report on the perspectives of Latino leaders and their experience with cancer and death, from rural communities in the southeastern United States. The use of focus group discussions yielded a rich corpus of data that helped inform the larger study.

We noted several limitations. The use of purposive sampling through personal contacts made within the community might have resulted in a biased sample as all participants were permanent legal residents. In addition, the majority were female; however, this reflects the tendency of women in Latino communities to be caregivers. The sample size was small and confined to one geographic region, yet potentially transferable to similar Latino populations in rural emergent immigrant communities. Lastly, the use of the ECGN model to inform data collection and analyses may have limited the mutual development of understandings by participants and researchers that is possible when locally embedded knowledge and empowerment is privileged.

Conclusion

As the Latino population in the United States continues to age, it is even more imperative to address effective delivery of palliative care and understand the cultural perspectives on cancer and death that influence EOL decisions. This project elicited the cultural perspectives of Latino leaders who affirmed the need for, and feasibility of, trained community members to initiate conversations about advance care planning and symptom management among Latino families with cancer. In partnership with interprofessional health care teams, trained community leaders can bring best practices in palliative care to underserved families, and their new skill set can enhance their natural helping abilities in communities and churches. Our research further suggests that community leaders can provide valuable direction for the development of palliative care services for underserved groups and can assist in the delivery and ongoing refinement of such educational initiatives within the context of a continued commitment to participatory action research.

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by the international community, and was preferred by the majority of the community leaders in this study.

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Supplemental Material

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