

UNDERSTANDING THE PERSPECTIVES OF LATINO COMMUNITY LEADERS ABOUT
THE BURDEN OF CANCER AND DEATH

by

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Abstract

As the population of Latinos in the United States (US) continues to expand, so too do the health disparities among Latinos. One health disparity critical for Latino populations is the underutilization of palliative care and other end-of-life (EOL) measures. Although the benefits of integrating palliative care interventions early on in a cancer diagnosis are well established, rural Latino populations of the US consistently lack the use of these services. The purpose of this study was to understand the perspectives of Latino community leaders about the burden of cancer and death in order to inform a larger community palliative care program for Latinos with cancer. We used a participatory action research design with 15 Latino community leaders from rural counties in eastern North Carolina. Three focus groups were conducted, recorded, and transcribed. Data were analyzed using thematic analysis techniques. One major finding was the burden that suffering from cancer places on both patients and their families. The burden of cancer was grouped into two categories: *Awareness of the Burden and Relieving the Burden*. These themes captured the multifaceted factors contributing to cancer burden, the effects of cancer on the entire family, particularly caregivers, and the methods used to relieve the cancer burden. Findings suggest strategies to alleviate some of the burden placed on Latino cancer patients and their families.

Understanding the Perspectives of Latino Community Leaders About the Burden of Cancer and Death

Background

For Latinos living in the United States of America (USA), the leading cause of death is cancer (American Cancer Society, 2018). Latinos face serious health disparities in palliative and end-of-life (EOL) care. Latinos are less likely than non-Latino whites (NLW) to be diagnosed with cancer at an early stage, are less likely to use screening tests, have poorer access to quality treatment, and receive less patient follow-up care (American Cancer Society, 2018).

In an attempt to reduce the health disparities among the Latino population, researchers have sought to discover barriers to care and evaluate interventions that promote comprehensive palliative and EOL care for Latinos. In a systematic review of the literature that focused on rural EOL care, LoPresti et al. (2016) found that Latino cancer patients were 2.53 times more likely to reject hospice care and prefer family caregivers. Further, Latinos were less likely to hold a do not resuscitate order, less likely to have completed advanced care planning (ACP), more likely to prefer excessive life-saving measures, more likely to rely on religion as a coping mechanism, and more likely to have fatalistic views of their condition. Investigators call for more research on how Latinos with advanced cancer cope with and make EOL decisions (Crist et al., 2019). Literature suggests that access to palliative care for Latinos would be most attainable through community-based models (Fischer et al., 2018).

Literature Review

A review of the literature was conducted using the following databases: PubMed, CINAHL, ProQuest, and PsychINFO. Search terms were “Latinos, Hispanics, Cancer, Cancer

Burden, Pain, Pain Perception, Symptom Management, and Community.” The search was focused specifically on pain and the perception of pain in Latinos with advanced cancer, which later evolved into cancer burden. The literature is organized into four categories: Demographic Disparities, Caregiver Needs, Training for Natural Helpers in the Community, and Structural Support to Manage the Burden.

Demographic Disparities

Several studies compare the experiences of Latinos to those of Non-Latino Whites (NLW). Beltran (2018) conducted a secondary data analysis of 143 Latinos and 285 NLW from the National Home and Hospice Care survey (NHHCS) and concluded that Latino ethnicity is related to experiencing more end-stage restlessness, including trouble breathing resulting in more sedation treatment. Similar to the disparities found by Beltran, the systematic review by LoPresi et al. (2016) found a significant difference in hospice use among ethnic/racial groups; hospice was most often used by Whites, followed by Hispanics, and least by African Americans. In a retrospective study, Worster et al. (2018) examined the role of Latino ethnicity in the time it took to receive a palliative care consult, patient enrollment in hospice, and patients’ overall hospital length of stay, and found no significant differences based on racial/ethnic groups. However, findings were based on one medical center in Philadelphia, with a very small sample of Latinos (2.5%). The Latino subgroups were not indicated, which limits the generalizability further. Beltran (2018) is more generalizable with data being analyzed from across the nation with the National Home and Hospice Care survey (NHHCS), but also did not indicate Latino subgroups.

Jaramillo and Hui (2016) examined the immigration process and highlighted the challenges of one undocumented male Latino immigrant with advanced cancer in Texas. The patient experienced many factors that impacted quality of life including, a delayed diagnosis,

limited social support, financial issues, fear of deportation, and language and cultural barriers, all resulting in physical pain and psychological distress for both him and his family (Jaramillo & Hui, 2016).

McDonald et al. (2015) analyzed medical records from 1,466 Latino patients and 12,977 NLW patients from a single hospital that served a population that was 43% Latino. Their research did not reveal any major differences in pain intensity between Latinos and NLW; however, they did discover that Latinos who spoke only Spanish were 30% less likely to have pain documented in their medical record, suggesting that language may be a barrier to equitable patient care. Moreno et al. (2019), on the other hand, conducted a mixed method study that incorporated comprehensive assessments with 288 Latinos in major tertiary medical centers in Chicago and San Antonio and found that Latino patients with advanced cancer expressed greater unmet needs for supportive care compared to NLW samples. Latinos lack access to palliative and hospice care and often face barriers related to cultural and environmental (immigration) factors.

One of the first studies to examine ethnic variation in cultural conceptions of death was done by Cain and McCleskey (2019) who conducted six focus groups, two with African Americans, two with Latinos, and two with Whites to grasp the cultural and social beliefs about medical aid in dying (AID). The majority of the Latino participants rejected the idea of medical AID due to their religion and culture, expressed by one of the Latino participants who stated that he would not consider medical AID for himself, but his experience with his mother would make him consider it for her situation (Cain & McCleskey, 2019).

Caregiver Needs

In a recent study, caregiver burden (CB) was found to be a significant predictor of negative EOL care outcomes for Latino cancer patients. Lee et al. (2015) studied 326 patient-

caregiver dyads with a cancer diagnosis in Korea and found that caregivers experienced “increased strain, impaired mental and physical health, and a deteriorated quality of life because of CB” (p. 1545). Leroy et al. (2016) examined the emotional distress resulting from CB and self-perceived burden (SPB) among 60 French cancer patients receiving palliative care and their principal caregivers. Patients who perceived themselves as more of a burden to their caregivers were more likely to report depressive symptoms for themselves. Both Lee et al., 2015, and Leroy et al., 2016, were conducted with ethnically homogenous populations that included no Latinos, and neither explored possible interventions or solutions for CB or SPB.

Cruz-Oliver et al. (2018), examined the effectiveness of an education intervention, “Caregivers Like Me,” which consisted of one intervention group, and included a discussion about caregiving in addition to a telenovela (soap opera). Researchers found through a post-test that attitudes toward EOL care improved, participants had a wider knowledge base of resources, and a willingness to accept professional help in order to relieve burden. Although the study did highlight the need for further caregiver relief and education, it did not examine patient attitudes about EOL and how congruent these were with caregivers, or patient perceptions of burden that might influence symptom management and perceptions of pain.

Training for Natural Helpers in the Community

Utilizing community members in informing Latinos on EOL decisions is intended to bring a culturally sensitive approach to palliative care. Cupertino et al. (2015) trained 22 Latino “promotores de salud, or community lay health workers,” from rural parts of Kansas in cancer research ethics using a leadership and cancer curriculum. Investigators found that knowledge of cancer and cancer research improved among promotores and therefore, participants became more cautious and less likely to join research studies (Cupertino et al., 2015). Results by Nebeker et al.

(2015) were similar, in that they both created and evaluated the effectiveness of an education-based intervention to train community members in cancer and EOL care. Latino promotores showed significant improvements in cancer ethics and research knowledge, proving the effectiveness of the curriculum. Although both studies showed promising results with improvements in cancer knowledge, neither took the process to the next level by evaluating the effectiveness of the promotores using this knowledge within the community.

Fischer et al. (2015) sought to determine the feasibility of a patient navigator (PN) intervention to improve the outcomes for Latino patients in palliative care. The pilot study included 64 self-identified Latino adults with life-limiting illnesses within a 20-mile radius to the Denver Health Medical Center in Denver, Colorado. Patient navigators improved advance directive documentation, pain management discussions, and hospice utilization (Fischer et al., 2015). In a randomized control trial, Fischer et al. (2018) recruited 240 self-identified Latinos with an advanced medical illness and 120 family caregivers to be placed into either an intervention or control group. In this study, the intervention group received visits from the trained lay Latino PNs and the patients were followed up with individual interviews from the researchers, who were blind to their study group. This study is currently in progress, and the findings are not yet known.

Structural Support to Manage the Burden

Factors that influence how Latinos manage their cancer burden include finances, religion, spirituality, culture, transportation, and childcare. Bakitas et al. (2015), conducted a systematic global review of the literature to discover how living in a rural area influences the delivery and quality of palliative care and to summarize the effectiveness of different planning and intervention programs. Early palliative care produced a statistically significant improvement in

patient quality of life and lower rates of depression and a trend toward improved symptom management. While this review helped highlight some potential direction for future interventions, the global nature of the studies surveyed makes it difficult to generalize the results to locally specific settings.

Cervantes et al. (2017) examined the coping methods of Latinos undergoing dialysis for End-Stage Renal Disease (ESRD) and sought to understand the preferences of Latino patients in palliative care for ESRD, including symptom management and ACP conversations. Interviews were conducted with 20 Latinos from two outpatient hemodialysis facilities in Denver, Colorado, revealing four themes in regard to Latino views on palliative care including, avoiding harms of medications, barriers and facilitators to ACP, enhancing wellbeing, and other challenges of coping.

Moreno et al. (2018) performed a secondary data analysis to measure satisfaction with care, self-efficacy, health related quality of life (HRQOL), and acculturation among 288 Latinos diagnosed with cancer, derived from baseline data of a National Cancer Institute (NCI) funded project focused on reducing symptom burden and improving adherence to treatment recommendations in for Latino cancer patients. Foreign-born, less acculturated, and monolingual Spanish-speaking survivors reported lower self-efficacy in patient-provider communication. While the studies thus far have focused on managing the burden of treatments to save lives or make the EOL more comfortable, most never examine how Latino patients conceptualize a “good death” which is likely to influence their choices about end of life care.

Fischer et al. (2017), explored similar cultural beliefs about EOL care among Latinos by capturing the barriers for minority participation in clinical trial research and examining how such barriers could be reduced or eliminated. Barriers to participation included, mistrust,

language/literacy and communication issues, lack of access to academic cancer centers, and an inability to participate due to transportation, work, and childcare (Fischer et al., 2017).

Community-based interventions that incorporate cultural beliefs about the meaning of a good death and that convey information about EOL care in ways consistent with community values and needs, are likely to be successful.

Summary

In order to reduce health disparities surrounding palliative and EOL care in Latino populations, research has been done to seek community-based interventions to provide culturally sensitive solutions for populations who are underserved. Although previous studies have established the effectiveness of community-based models for Latinos regarding palliative and EOL care, most studies have been conducted in locations with different geographic, political, and social environments from rural North Carolina. The growing number of Latino communities in rural areas of North Carolina lack the infrastructure needed to provide health care that is culturally sensitive (Larson et al., 2017). Utilizing community members to fill the gaps in healthcare among Latinos forms a connection between Latinos and the health care system. In addition, lay health advisors often share the same beliefs, values, and language with the community, making connections more seamless and comprehensive (Boucher, 2017). Rural dwelling Latinos with AC had no known culturally relevant, theory-based, community palliative care programs.

Methods

We conducted a participatory action research study design in 2020 with Latino community leaders using a community-based palliative care intervention for Latinos with advanced cancer (AC) and their caregivers in eastern North Carolina. The research team

consisted of four nurses with expertise in Latino population health, palliative care, and qualitative methods; an anthropologist with expertise in Mesoamerican civilization; a biostatistician; a Latina community leader; and two undergraduate honors students. Two of the nurses were trained in the End of Life Nursing Education Curriculum (ELNEC) and developed the palliative care training program based on this curriculum, and documents from the North Carolina Compassionate Care Project and the American Cancer Society. The study was guided by the Ethnocultural Gerontological Nursing Model (ECGN) to understand the relationship between culture, health, and aging in Latinos, which highlights both macro-level and micro-level factors that influence care for Latinos (Ruiz et al., 2016). The macro-level external factors include, political/environmental and attitudes/stereotypes/ascriptions. The macro-level internal factors include cultural/historical traditions (Ruiz et al., 2016). The palliative care training program included a focus group session that sought to gather ideas and opinions from local Latino community leaders about cancer and death. This paper reports specifically on findings from the focus groups related to cancer burden, while Larson et al., 2021, reflects on the sociocultural context of cancer and death. Cancer and death were framed by Larson et al., 2021 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.

Sample and Setting

Fifteen Latino community leaders were recruited from four counties, Duplin, Wayne, Greene, and Lenoir. Research study sites were chosen based on counties with a high Latino population status. The primary outcome of the focus groups was to develop an understanding of cultural and social attitudes of Latinos about cancer and dying.

Data Collection

We conducted three focus groups with each county-level group of Latino community leaders to ascertain their beliefs about cancer, death and dying, and EOL care. Each focus group had a bilingual moderator and co-moderator from the research team. Co-moderators took field notes and monitored the audio-recorder. The moderators (Kim Larson and Holly Mathews) are both experienced bilingual moderators. Prior to beginning the focus group discussions, participants completed the Advance Care Planning and Engagement Survey (4-items; Spanish/English) to prompt thinking about palliative care and EOL care practices. The participants selected a pseudonym which ensured anonymity. The first day of training followed the focus group discussion.

Data Analysis

Audiotapes of the focus group discussions were transcribed by the co-moderators and verified by the moderator within one week. Team members read the transcripts and conducted a Key Words in Context analysis of the transcripts from the focus groups with lay advisors. Two of the words emerging from this analysis were pain and suffering, which evolved into the themes regarding burden. Subsequently, In Vivo coding was undertaken to analyze cultural understandings of pain and perceptions of pain and the relationship of these to suffering. Relevant sub concepts from the ECGN model related to pain and pain perception among the Latino community include, political/environmental (e.g., immigration), attitudes/stereotypes/ascriptions (e.g., time of diagnosis and treatment), cultural traditions (e.g. family roles), sociodemographic (e.g., health literacy and income), health dimension (e.g., long-term conditions and late diagnoses), and communication (e.g., language barriers) (Crist et al., 2019).

Cancer burden encompassed pain, suffering, and hardships that were uncovered in the focus group discussion regarding ideas about death and dying. Multiple causes of pain were discussed and are further divided into two categories: Physical Pain and Mental Pain, as distinguished in Figure 1.

Figure 1

Causes of Pain: Physical and Mental

Causes of Physical Pain	Causes of Mental Pain
<ol style="list-style-type: none"> 1. Cancer: “My mom said, there was a point that he sometimes would pass out because of the pain” (FG 3). 2. Treatment of Cancer: “I would love to know also because sometimes like if it would be worth it to do all the treatments or you know because sometimes the treatments can be also painful” (FG 2). 	<ol style="list-style-type: none"> 1. Feeling like a Burden: “I do not want my family to see me going through suffering and pain, I don’t want to be a burden to my family because I feel like I would be a burden to my family” (FG 1). 2. Causing others Pain: “I said it was very painful seeing him because he can’t move. He just laid down in the bed with a lot of pain and you can’t do anything about it, just wait until he dies” (FG 1).

Results

Cancer burden as it relates to ideas about cancer and death was grouped into two categories: Awareness of the Burden and Relieving the Burden. The first theme, Awareness of the Burden, demonstrates the macro-level factors discussed in the ECGN model (political world, attitudes and stereotypes, and cultural and historical traditions). The second theme, Relieving the Burden, demonstrates the micro-level factors in the ECGN model (health status and communication).

Awareness of the Burden

Participants focused on both the physical and mental pain that cancer itself and the treatment can cause, as expressed by one participant who shared what comes to her mind when she hears the word cancer:

I think of pain. Um like the person diagnosed um you know like if they do receive the treatment or 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]

Many of the participants have cared for their own family members with cancer and reflected on their challenges and feelings about being a caregiver. The participants were very conscious about the burden that every member of the family experiences through a cancer diagnosis, one showing this when stating,

...how would it affect me personally because once you know you start having the symptoms, and pain and all that, you know it's going to affect whoever's around me as well because they're gonna have to deal with me as well [FG 2].

Many compared the stark differences between providing care for their family members in the US versus Mexico or Honduras. One participant shared that her mother would travel from North Carolina to Mexico to provide care for her grandfather who was dying of liver cancer. Many of the participants claimed that it is a duty for family members to care for their loved ones with cancer, reflected on by one participant who stated, "...like it doesn't fit in my head that a son would say I cannot see my mother, I'm leaving because I do not want to see her suffer" (FG 1). For many of the participants, feelings of helplessness have led to hopelessness when it comes to family members suffering from cancer.

Relieving the Burden

Participants showed strong opinions and beliefs about avoiding pain and relieving it at all costs, even to the point of killing oneself to escape pain, expressed by one participant who stated,

But I want to know if I can do something to kill myself without pain because I'm the kind of person that says I don't want pain and I don't want my family suffering watching me in that pain, so if I can do something, I can do like just get it quickly [FG 1].

Other participants had less extreme wishes and claimed they understand there would be pain and would want to know ways to lessen or manage their pain. Others discussed the longing as a companion or caregiver to do everything in your power to take away the pain for your loved ones. One participant claimed that it may reduce some of their mental pain and anguish if they were able to know early on how much time they had left to live, and what to expect regarding the pain they would be in from the cancer and its treatments. One participant reflected on the important role that family and loved ones have on reducing pain, stating, [role of the family] "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).

Another way that participants showed their support for their families was through hope and prayer. Some of the participants mentioned that home remedies and prayers are often utilized to reduce the symptoms of cancer. Others reflected on the importance of spirituality and support from church groups and others in the community, many have in fact already performed home visits to community members in need through their churches. Others think it is a good idea to prepare for death, in order to reduce some of the shock and pain that accompanies a death of a loved one.

Discussion

The findings revealed that community leaders from emerging Latino communities in rural North Carolina conceptualized the burden of cancer and death as an immense burden for the person with the cancer, as well as for the loved ones. Participants were highly focused on

relieving the cancer burden, mainly for the sake of the families and eliminating or reducing the struggle and anguish that comes with seeing a loved one suffer. The findings may provide a new perspective on Latino healthcare and can serve as a step toward evaluating the potential for an intervention to modify health disparities among palliative and EOL care in hope of creating improvement in quality of life toward the end of life for Latinos with cancer (Kearney, 2017).

Latinos have long faced disparities in healthcare, particularly when it comes to EOL planning. Recent evidence suggests that the use of lay health advisors is an effective method for reducing barriers and challenges for Latinos and achieving health equity (Fischer et al., 2018). This study supports the positive outcomes from previous studies involving “promotores de salud,” or community lay health workers, (Cupertino et al. 2015), but differs from others as it focuses specifically on EOL planning for Latinos with advanced cancer in rural North Carolina, where access to healthcare can be particularly challenging for some Latinos (Larson et al., 2017). The findings from the Latino community leaders have provided detailed insight into the cultural and traditional beliefs, ideas, and practices involving cancer burden among Latinos.

In a systematic review, Rodriguez-Prat et al. (2019) describe the relationship between pain and burden eloquently when stating “The personal dimension of the feeling of being a burden is related to the emotional and psychological effects of suffering from an advanced illness, including its impact on the patient’s sense of identity” (Rodriguez-Prat et al., 2019, p. 415). Latino patients are often challenged with the mindset that they are a burden to their family members, which in turn only increases their pain and suffering.

Likewise, family members are often left feeling as though there is nothing, they can do to help their loved ones with cancer. This leads to frustration and pain among the family members as they watch their loved ones suffer (Boucher, 2017).

Although suffering and pain are often used interchangeably, they have different meanings. Suffering is a broader concept, for example, when being a burden causes suffering. People can suffer with general hardships (lack of resources, lack of papers, lack of family) and not just from physical or mental pain. The connection is that pain (physical or mental) can cause suffering and suffering can cause pain (depicted as mental pain and anguish). Therefore, people want to avoid suffering or causing others to suffer, similar to how they want to avoid pain or causing pain to others.

The situation reflects the idea of familism described by Ruiz et al. (2016) and is described as a cultural tradition among Latinos. Another study revealed the value placed on being loyal and caring for family members, even when these values became problematic for the patients and their families (Cervantes et al., 2016). The participants in this study echoed the ideas discovered in the literature regarding loyalty and providing care for loved ones in need. Participants claimed they and their families have experienced situations in which they were caring for others but lacked palliative care skills and knowledge regarding symptom management for their loved ones.

Strengths and Limitations

Strengths of this project included the collaboration of an interprofessional team and Latino community leaders to further refine the ECGN model for research and nursing practice. A diverse sample was collected with Latino community leaders from rural counties with varying age, levels of education, and national heritage. The use of focus groups encouraged open and honest ideas about cancer and death, that will later inform the larger study.

One of the limitations of the study is the use of purposive sampling. Part of the participant recruiting was done through personal contacts within the community, which may have resulted in a biased sample. One stark similarity between all of the community leaders is

that they are all permanent legal residents. In addition, the majority of the participants were female, although this is congruent with the fact that most Latino families utilize a female caregiver. The sample size is relatively small and only reaching select counties in Eastern North Carolina. The study could potentially be transferred to similar Latino populations.

Conclusion

As the Latino population continues to grow and age in place, it becomes increasingly important to address the utilization of palliative care and seek to understand how the cultural perspectives regarding cancer and death influence EOL care and decisions. The project utilized Latino leaders to provide their own cultural perspectives about cancer and death. The partnership between Latino community leaders and interprofessional healthcare teams can bridge the gap in knowledge, access, and utilization of palliative and EOL for underserved Latinos in rural communities. In addition, the community leaders are now equipped with the knowledge and skill to bring evidence-based practice in palliative and EOL care to their churches and communities.

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Declaration of Conflicting Interests

There are no potential conflicts of interest with respect to research, authorship, and/or publication of this article.

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