SOCIODEMOGRAPHIC INFLUENCES ON SPIRITUAL WELL-BEING AMONG LATINO LEADERS

by

CLAUDIA ALFORD

A Senior Honors Project Presented to the

Honors College

East Carolina University

In Partial Fulfillment of the

Requirements for

Graduation with Honors

by

CLAUDIA ALFORD

Greenville, NC

SPRING 2021

Approved by:

Kim L. Larson, PhD, RN, MPH, FNAP

East Carolina University College of Nursing

Abstract

Background: Latinos with cancer face serious health disparities in palliative care. Spirituality is vital to end of life (EOL) decision-making among Latinos, yet no studies examined how sociodemographic variables influence spirituality and EOL decision-making. The purpose of this study was to explore how education, age, and religious preference influence spiritual well-being among a subset of Latino community leaders.

Methodology: A mixed methods participatory action research study was conducted between 2020-2021 with an overall goal to assist Latinos with cancer in symptom management and EOL decision-making. Latino leaders (N=15) in eastern North Carolina participated in one of three focus groups, completed a demographic survey, and the Spanish/English Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being Scale (FACIT-Sp). The FACIT-SP measures spiritual well-being on a scale from 0-48, with subscales of Meaning, Peace, and Faith. Spiritual well-being was cross-referenced with three sociodemographic categorical variables; religious preference (Catholic vs. other), age (young vs. old), and education (low vs. high).

Results: The average FACIT-Sp wellbeing score was 40.7. Higher education suggested greater spiritual well-being in all three subscales of Meaning, Peace, and Faith. Age and religious preference showed minimal differences. A major theme, *Getting in the Good Book*, linked spirituality to a good death.

Discussion: Participants in our study scored higher in spiritual well-being as compared to Latino subgroups (ill and healthy) in other studies that used the FACIT-Sp. Higher spiritual well-being scores for persons with higher education may be related to greater exposure to diverse perspectives compared to persons with lower education who may adhere to more traditional beliefs. Thematic findings were congruent with overall spiritual well-being scores.

Sociodemographic Influences on Spiritual Well-Being Among Latino Leaders

Background

Latino persons represent the largest minority in the United States (US) and experience greater advanced cancer diagnoses and lower survival rates, yet they underutilize palliative care. In 2018, Latino patients made up only 1% of the hospice patients in North Carolina (NC), despite representing 9.6% of the NC population (Barrett et al., 2020). These disparities in palliative care may be attributed to several factors: sociocultural differences, lack of familiarity with services, and mistrust in the healthcare system (Tyson et al., 2018).

The language barrier between providers and Latinos can impede effective care for persons with advanced cancer. Limited English language skills may prevent Latino elders' ability to access caregiving resources (Ruiz et al., 2015). A qualitative study by Cervantes et al. (2017) reported that Latino patients on hemodialysis preferred advance care planning conversations to occur with someone who speaks their same language, as many do not understand aspects of their illness or care. Additionally, interpreters and adequate palliative care infrastructure are limited in rural NC communities, hindering patients' ability to communicate their needs (Larson et al., 2021). In 2019, there were 62 out of 100 counties in North Carolina without palliative care specialists, impacting primarily rural areas (Lake, 2020).

In the face of patient-provider incongruence in language and culture, Latino leaders trained in palliative care can serve as powerful agents in disseminating culturally responsive care to their community. To provide community-based interventions, it is important to understand the beliefs and values of the Latino community regarding end of life (EOL). Spiritual well-being at the EOL is a central and vital component to Latino health and decision-making (Cruz-Oliver et al., 2018). Despite the role of spirituality on EOL, there are few studies that examine how

sociodemographic variables influence spirituality and EOL decision-making. The **purpose of this study** was to explore whether and how education, age, and religious preference influences spiritual well-being among a subset of Latino community leaders.

Beliefs and Values

Latino persons experience substantial health disparities at the EOL and beliefs and values related to death and dying may influence the utilization of palliative care services. Such values include trust, safety, family, harmony, and respect (Ruiz et al., 2015; McCleskey & Cain, 2019). The Ethnocultural Gerontological Nursing (ECGN) model, when applied to older Latino individuals, examines the political climate, attitudes, stereotypes, culture, sociodemographic factors, health dimensions, and communication (Ruiz et al., 2015). This model has been used to understand macro and micro-level factors that influence health in the context of aging and ethnicity.

A cross-sectional study designed to explore perceptions concerning hospice and pain management revealed that stoicism and endurance are important Latino values in the management of pain (Carrion et al., 2015). This belief poses a barrier to expressing pain, seeking comfort care, or utilizing pain-alleviating treatments such as in palliative care. Almost 40% of Latino participants agreed that 'good patients avoid talking about pain', while only 18% of non-Latinos agreed with that statement (Carrion et al., 2015). Read and MacBride-Stewart (2017) conducted a literature review to define a "good death" and found that a muted expression of pain deters symptom management, death preparation, and condition awareness. Further findings suggest that religious or spiritual values were important to what constitutes a "good death". This review identified many studies with small samples from just one Latino subgroup. The factors that influence beliefs about EOL care are not the same across Latino subgroups. Ruiz et al.

(2015) explains how differing immigration patterns among Mexicans, Cubans, and Puerto Ricans influence older Latino adults' social support networks.

Lack of access to palliative care services is a significant barrier to care for Latinos: a result of low socioeconomic status, lack of insurance, and inadequate health and social services in rural areas (Ruiz et al., 2015; McCleskey & Cain, 2019). In a qualitative study conducted by McCleskey and Cain (2019), Latino patients valued providers who share similar characteristics such as race and background. This similarity fosters a sense of safety, shared understanding, and trust – the belief is that this provider will be sensitive and understanding of cultural values.

The qualitative study conducted by Freitas et al. (2020) involved interviews with older Brazilians undergoing cancer therapy with the purpose of understanding spirituality in relation to death, guilt, and suffering. Religious and spiritual activities were reported as resilience and coping strategies, and ultimately provided comfort for their unstable experiences. A limitation of this study was the potential lack of generalization due to the specific setting and sample.

Community Health Worker Interventions

Community health workers (CHWs) can be utilized as bridges between the community and health care institutions. A qualitative study was conducted in South Africa to identify palliative care learning needs, develop a training session for the CHWs, and to describe perceptions of the training content (Campbell & Baernholdt, 2016). This study identified emotional needs of CHWs and demonstrated the importance of debriefing for selfcare. Campbell and Baernholdt (2016) also found that narratives and role plays were useful tools for training and identifying palliative care learning needs.

Several studies have been conducted that describe implementation of culturally tailored interventions for caregivers of Latino patients, creating significant potential in transforming

palliative care for this ethnic group (Cruz-Oliver et al., 2016; Cruz-Oliver et al., 2018; Fischer et al., 2018a; Fischer et al., 2018b; Hagwood & Larson, 2019). In the randomized clinical trial conducted by Fischer et al. (2018b), trained patient navigators conducted home visits with caregivers and participants to establish relationships, provide educational materials, and create a care plan. The intervention group was more likely to have advance directives and a change in pain severity, demonstrating the effectiveness of community-based patient navigators (Fischer et al., 2018a). The strength of this study was in the rural and urban sample in Colorado. In a pilot study with two Latino health advocates in North Carolina, Hagwood and Larson (2019) reported an increase in confidence after culturally tailored palliative care training. Litzelman et al. (2017) also investigated the impact of Care Coordinator Assistants (CCAs), community health workers, on patient perceptions of conversations about advance care planning. Semi-structured interviews with 392 elderly patients as well as data collection from the electronic health record were used to evaluate the effectiveness of their quality improvement educational intervention. This intervention comprised of workshops, simulation sessions, case conferences, and guidance from a clinical decision support tool. Investigators found that conversations with the CCAs about advance care planning were helpful and important: patients were able to easily express their preferences with someone with whom they were comfortable. These results support the value in the trusting relationships between patients, their families, and community health workers, especially with regards to conversations about the spiritual and religious concerns of patients.

Underrepresentation in Research

Two systematic reviews investigated the representation of Latinos in palliative care research. In the first review, Pirl et al. (2018) reviewed 18 randomized controlled trials that led to a statement released by the American Society of Clinical Oncology (ASCO), recommending

earlier involvement of palliative care for patients with advanced cancer. The authors discussed the lack of explicit categorization of race and ethnicity, lack of diversity in trial sites, and monolingual trial designs as challenges for Latino representation. In the second review, Crist et al. (2019) found that although there is some research about influences on EOL decision-making, among Mexican Americans, it was limited to 12 unique studies over a 20-year period. Methodological problems among these studies were limited validation by subsequent studies and research was often atheoretical.

In summary, unique cultural and socioeconomic factors contribute to the palliative care disparities among Latino persons with advanced cancer. Spirituality and religion have been suggested as important aspects in EOL care. Lay advisor community-based interventions have the potential to transform Latino population use of palliative care. No studies were found that explore the influence of sociodemographic variables on spiritual well-being among Latinos.

Methods

Study Design

We conducted a mixed methods participatory action research study in rural eastern North Carolina with the overall goal of developing a community-based palliative care model for Latino persons with cancer. The first aim of the overall study was to elicit sociocultural perspectives of Latino community leaders on cancer and death with the purpose of informing a community palliative care program (Larson et al., 2021). The overall aim of the larger study was to train Latino leaders and then evaluate their engagement with Latino persons with advanced cancer in the form of home symptom management and EOL decision-making. The study was approved by the university institutional review board.

The project was initiated in January 2020 following extensive collaboration with Latino advocacy groups in eastern North Carolina. 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 (nursing (2), anthropology and biostatistics). Three team members were of Latino heritage: five out of seven team members were bilingual.

Setting and Sample

A total of 15 Latino community leaders, from four rural high-density Latino counties, participated in one of three focus groups and subsequent training programs. Eligibility criteria included self-reported Latino heritage, service to the community, over 18 years old, able to read and write Spanish and English, residence in target counties, reliable transportation, and willingness to help Latino families with cancer. Recruitment efforts were made by the team through distribution of project information and meetings at churches, local health departments, community health centers, hospitals, schools, and advocacy groups. Team members obtained verbal consent following explanation of the study purpose and voluntary nature of the research. The participants were predominately women.

Data Collection

Three focus groups (four to six persons/group) were conducted with the 15 participants. Experienced bilingual moderators facilitated each group. The moderator reviewed the consent details, clarifying questions, and the voluntary nature prior to each focus group. Ground rules were read aloud by the moderator. Other members of the research team, trained in focus group methodology, served as co-moderators. These co-moderators took field notes and managed the recording devices. The focus groups were semi-structured with open-ended questions designed to empower the participants share their experiences and elaborate on their understandings of the

topics. The focus groups were conducted in English with Spanish translations of the questions when necessary. The recordings of the focus groups were transcribed and verified by two research team members.

During the training program, the participants completed the Spanish/English Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being Scale (FACIT-Sp). This measure consists of 12 items covering three subscales; Meaning (items 2, 3, 5, 8 reverse coded), Peace (items 1, 4 reverse-coded, 6, 7) and Faith (items 9, 10, 11, 12) on a 5-point Likert-type scale ranging from 0 = *Not at all* to 4 = *Very much*. The sum of the subscale scores yields the total FACIT-Sp Well-Being score, in which a higher score indicates a higher level of spiritual well-being and quality of life. Sample items include "I find comfort in my faith or spiritual beliefs" and "I feel a sense of purpose in my life."

Several investigators have used the FACIT-Sp to examine spiritual well-being with Latino populations. Peterman et al. (2002) examined the factor structure, reliability, and internal validity of the instrument across languages (English and Spanish) and cultures. They recruited 1,617 participants from four medical centers across the mainland US with 718 (44%) being Latino. The majority (over 80%) had cancer and the remainder had other chronic health conditions. The mean total spiritual well-being score for the Latino subgroup was 38.6. The investigators concluded that the FACIT-Sp is a psychometrically sound measure of spiritual well-being for people with cancer and other chronic illnesses.

Canada et al. (2012) conducted a study using an American Cancer Society cross-sectional data set with 8,805 cancer survivors (ACS SCS-II); of whom 664 (7.5%) were Hispanic. They examined the effects of ethnicity on total spiritual well-being scores and those for the Meaning, Peace, and Faith subscales. Hispanic respondents had a mean spiritual well-being score of 37.9.

After adjustment for sociodemographic and medical factors, African Americans had higher scores on both Meaning and Peace compared to Hispanics and Whites, and Hispanics' scores on Peace were higher than Whites' scores.

More recently, Brintz et al. (2017) assessed the psychometric properties of an expanded "non-illness version" of the FACIT-Sp developed for a general Latino population. This expanded instrument includes an additional 11 items that comprise a new subscale termed "relational." Their sample was derived from the Hispanic Community Health Study/Study of Latinos (HCHS/SOL, Gallo et al. 2014) and included 5,163 self-identified Latinos across the US from various nationalities. From the reported mean scores on the original FACIT-Sp subscales of Meaning, Peace, and Faith, it was possible to tabulate an overall mean spiritual well-being score for this Latino sample of 36.8.

Data Analysis

The overall FACIT-Sp well-being score can range from 0-48. We tabulated an overall Spiritual well-being score for each participant. Next, the FACIT-Sp well-being scores were cross-referenced with three demographic categories: religious preference (Catholic and Other Religion), age (<40 and $\geq$ 40), and education ($\leq$high school and college). Microsoft Excel was used to organize and calculate the scoring. The sum function was used to calculate the subscale scores and well-being scores. Then, these scores were separated by demographic category. The average function was used to calculate the average for each subscale and overall well-being score among each demographic category. The scores were compared to FACIT-Sp well-being scores in other studies with Latino populations. Interpretation of spiritual well-being scores was informed by thematic findings from focus groups.

Results

The major finding was that mean Spiritual Well-being scores among these Latino community leaders was higher (40.7) compared to other studies with Latino populations (see Table 1).

Table 1

FACIT-Sp Compared with Other Studies

Author/Study	Total Sample (% Latino)	Health Status	Overall Scores
Brintz et al.	5163 (100%)	"Non-ill" population	36.8
Canada et al.	8405 (7.5%)	Cancer survivors	37.9
Peterman et al.	1167 (44%)	Cancer survivors	38.6
Our Study	15 (100%)	Healthy	40.7

Among all participants, spiritual well-being scores ranged from 32 to 48. The overall FACIT-Sp for participants with higher education (college) suggested greater spiritual well-being compared to those with lower education (≤ HS) (42.9 vs. 38.8). Secondary findings were that younger participants had an overall higher score than older participants (43 vs. 40.5). Religious preference revealed minimal differences in spiritual well-being scores: Catholic participants scored an average of 40.3 for spiritual well-being and other religion participants scored an average of 41.1. In addition, participants with some or a college education scored higher in all three subscales (Meaning, Peace, and Faith). There were slight differences between age and religious preference in relation to the subscales. Results for each demographic category corresponding with FACIT-Sp scores are depicted in Table 2.

Table 2

FACIT-Sp Well-being Scores

Demographic Category		Subscale Scores			Spiritual Well-Being Score
		Meaning	Peace	Faith	
Education	College	14.3	13.1	15.4	42.9
	< HS	12.8	11.9	14.1	38.8
Age	< 40	13.6	12	15.1	43
	≥ 40	13.3	13	14.3	40.6
Religious Preference	Catholic	13	12.5	14.8	40.3
	Other Religion	14	12.4	14.7	41.1

One major theme from the focus group discussions was *Getting in the Good Book*. Knowing that one's name was in the good Book, referring to the Bible, made it easier for the person to accept death (Larson et al., 2021). Exemplars from each focus group support these findings:

> So, sometimes maybe knowing a little bit of what might be ahead, of having that hope, that faith, that there is something that might make that step or that understanding a little bit easier. (FG 1)

> I think that a lot of people that go through this, they have like if they believe in something religious um they do, that's one of the first things they'll go, they'll go to like their priest or their preacher to get that emotional help. Or based on their faith. (FG 2)

> She had really bad pain, and then we asked if she wanted us to pray. She said yes then she cried a lot. We prayed and everything. Later, the next day I called her and she felt a lot better because she knew that people prayed for her… [we] visited her twice. (FG 3)

Hope, faith, and prayer were common expressions of caring for a loved one with cancer. Further, membership in a church prayer group provided both material and spiritual support for Latinos with serious medical illness, such as cancer.

Discussion

This study sought to explore whether and how sociodemographic characteristics influence spiritual well-being among Latino leaders in a rural region of North Carolina. These Latino leaders had higher mean spiritual well-being scores compared to other studies using the FACIT-SP with Latino populations. The higher spiritual well-being among these leaders may be attributed to being engaged in the community as a helper and their motivation to participate in this palliative care research initiative. Eleven of the 15 community leaders had served for many years in an important capacity as home visitors to the sick through their church affiliation suggesting they may be naturally confident and optimistic and possess an inner locus of control - contributing to their sense of well-being. Also, the sample was almost exclusively female; persons generally seen as natural care givers/helpers in the Latino community. Additionally, all leaders came from emerging Latino communities where there is a more homogenous cultural background of recent immigrants who provide a network of social support to one another. For immigrants, religion serves as a "bridge" in assimilation and a "buffer" in reinforcing connections to ethnic identity (Canada et al., 2012) Further, higher scores also may be a result of

a small sample of bilingual, healthy individuals. Lastly, *Getting in the Good Book*, emphasized the importance of hope and prayer for these leaders.

In our study, higher spiritual well-being scores for persons with higher education could be related to greater exposure to a diverse range of academic and community perspectives, compared to leaders with high school or less and the possibility of maintaining cultural views of fatalism and traditional beliefs from the country of origin. Higher scores might also indicate the FACIT-Sp questions and scoring was better understood by persons with higher educational levels. This is supported by a study conducted by Guzman (2016) with 102 rural-dwelling Latinos of Mexican origin. Participants with higher education were more assimilated to Anglo culture and teaching, whereas less education was related to a more threatening view of illness. Regarding the age variable, higher spiritual well-being scores for younger age participants could be due to the naïveté or optimism or youth and the belief that they have more time ahead in their lives to achieve purpose and meaning. We were somewhat surprised that religious preference showed minimal difference. However, this may indicate the evangelical denominations, such as Pentecostal and "Cristiano", provided equally strong spiritual well-being as did the Catholic faith.

Strengths and Limitations

A strength of this study included the utilization of textual data to assist in the interpretation of the FACIT-Sp. This study was also strengthened by collaboration with Latino leaders and an interprofessional team. Limitations include a small convenience sample of predominantly women from one geographic area. Similarities among the participants further limited the demographic comparisons.

Conclusion

To advance palliative care for rural Latinos with cancer by optimizing the potential of Latino community leaders, it is necessary to address the sociodemographic influences on spirituality and religion. Knowing how demographic factors influence spiritual well-being may allow anticipation of the spiritual and religious needs of Latino community leaders. The cultural perspective from the focus group discussions supported the FACIT-Sp data asserted the need for trained community leaders in the EOL and decision-making process.

Acknowledgments

Funding was provided by the Rita and Alex Hillman Foundation. We would like to thank the Latino community leaders for their participation in this study. The author wishes to acknowledge support provided in the form of the Undergraduate Research Mini Award from East Carolina University Office of Undergraduate Research. Special appreciation is given to Michelle Estrada, Latina community leader and Janet Moye, RN, palliative care specialist for their review of and suggestions for this manuscript.

References

American Cancer Society. (2018). Cancer facts & figures for Hispanics/Latinos 2018-2020. *American Cancer Society*. https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-hispanics-and-latinos/cancer-facts-and-figures-for-hispanics-and-latinos-2018-2020.pdf.

Barrett, N. J., Hasan, M., Bethea, K., & Johnson, K. S. (2020). The fierce urgency of now: Addressing racial and ethnic disparities in serious illness care. *North Carolina Medical Journal*, *81*(4), 254–256. https://doi.org/10.18043/ncm.81.4.254

Brintz, C. E., Birnbaum-Weitzman, O., Merz, E. L., Penedo, F. J., Daviglus, M. L., Fortmann, A. L., … Llabre, M. M. (2017). Validation of the functional assessment of chronic illness therapy-spiritual well-being-expanded (FACIT-Sp-Ex) across English and Spanish-speaking Hispanics/Latinos: Results from the Hispanic community health study/study of Latinos sociocultural ancillary study. *Psychology of Religion and Spirituality*, *9*(4), 337–347. https://doi.org/10.1037/rel0000071

Campbell, C., & Baernholdt, M. (2016). Community health workers' palliative care learning needs and training: Results from a partnership between a US university and a rural community organization in Mpumalanga Province, South Africa. *Journal of Health Care for the Poor and Underserved*, *27*(2), 440–449. https://doi.org/10.1353/hpu.2016.0078

Canada, A. L., Fitchett, G., Murphy, P. E., Stein, K., Portier, K., Crammer, C., & Peterman, A. H. (2012). Racial/ethnic differences in spiritual well-being among cancer survivors. *Journal of Behavioral Medicine*, *36*(5), 441–453. https://doi.org/10.1007/s10865-012-9439-8

Carrion, I. V., Cagle, J. G., Van Dussen, D. J., Culler, K. L., & Hong, S. (2015). Knowledge about hospice care and beliefs about pain management: Exploring differences between Hispanics and non-Hispanics. *The American Journal of Hospice & Palliative Care, 32*(6), 647–653. doi:10.1177/1049909114536023

Cervantes, L., Jones, J., Linas, S., & Fischer, S. (2017). Qualitative interviews exploring palliative care perspectives of Latinos on dialysis. *Clinical Journal of the American Society of Nephrology*, *12*(5), 788–798. https://doi.org/10.2215/cjn.10260916

Crist, J. D., Ortiz-Dowling, E. M., Shea, K. D., & Phillips, L. R. (2019). Knowledge gaps about end-of-life decision making among Mexican American older adults and their family caregivers: an integrative review. *Journal of Transcultural Nursing*, *30*(4), 380–393. doi:10.1177/1043659618812949.

Cruz-Oliver, D. M., Malmstrom, T. K., Fernández, N., Parikh, M., García, J., & Sanchez-Reilly, S. (2016). Education intervention "Caregivers Like Me" for Latino family caregivers improved attitudes toward professional assistance at end-of-life care. *American Journal of Hospice and Palliative Medicine, 33(*6), 527–536. doi: 10.1177/1049909115584315.

Cruz-Oliver, D. M., Parikh, M., Wallace, C. L., Malmstrom, T. K., & Sanchez-Reilly, S. (2018). What did Latino family caregivers expect and learn from education intervention "Caregivers Like Me"? *American Journal of Hospice and Palliative Medicine, 35*(3), 404–410. doi:10.1177/1049909117709550.

Fischer, S. M., Kline, D. M., Min, S. J., Okuyama-Sasaki, S., & Fink, R. M. (2018). Effect of apoyo con cariño (support with caring) trial of a patient navigator intervention to improve palliative care outcomes for Latino adults with advanced cancer: A randomized clinical trial. *JAMA Oncology, 4*(12), 1736–1741. doi: 10.1001/jamaoncol.2018.4014

Fischer, S. M., Min, S. J., Atherly, A., Kline, D. M., Gozansky, W. S., Himberger, J., Lopez, J., Lester, K., & Fink, R. M. (2018). Apoyo con cariño (support with caring): RCT protocol to improve palliative care outcomes for Latinos with advanced medical illness. *Research in Nursing & Health*, *41*(6), 501–510. doi: 10.1002/nur.21915

Freitas, R. A., Menezes, T. M., Santos, L. B., Moura, H. C., Sales, M. G., & Moreira, F. A. (2020). Spirituality and religiosity in the experience of suffering, guilt, and death of the elderly with cancer. *Revista Brasileira De Enfermagem*, *73*(suppl 3). https://doi.org/10.1590/0034-7167-2019-0034

Guzman, A. (2016). Exploring the chronic illness experience of rural-dwelling Latinos of Mexican origin. *Hispanic Health Care International*, *14*(4), 177–183. https://doi.org/10.1177/1540415316677720

Hagwood, D. N., & Larson, K. L. (2019). Planting the seeds: The role of Latino lay health advisors in end-of-life care. *Journal of Hospice & Palliative Nursing, 21*(3), 223-228. doi: 10.1097/njh.0000000000000513

Lake, D. (2020). A call for North Carolina to surround the seriously ill and caregivers with interprofessional collaborative teams. *North Carolina Medical Journal*, *81*(4), 249-253. https://doi. org/10.18043/ncm.81.4.249

Larson, K. L., Matthews, H. M., Moye J. P., Congema, M. R., Hoffman, S. J., Murrieta, K. M., & Johnson, L. A. (2021). Four kinds of hard: An understanding of cancer and death among Latino community leaders**.** *Global Qualitative Nursing Research, 8*(1-11). doi: 10.1177/2333936211003557

Litzelman, D. K., Inui, T. S., Schmitt-Wendholt, K. M., Perkins, A., Griffin, W. J., Cottingham, A. H., & Ivy, S. S. (2017). Clarifying values and preferences for care near the end of life:

The role of a new lay workforce. *Journal of Community Health*, *42*(5), 926–934. https://doi.org/10.1007/s10900-017-0336-5

McCleskey, S. G., & Cain, C. L. (2019). Improving End-of-Life care for diverse populations: Communication, competency, and system supports. *The American Journal of Hospice & Palliative Care, 36*(6), 453–459. doi:10.1177/1049909119827933

Peterman, A. H., Fitchett, G., Brady, M. J., Hernandez, L., & Cella, D. (2002). Measuring spiritual well-being in people with cancer: The functional assessment of chronic illness therapy—spiritual well-being scale (FACIT-Sp). *Annals of Behavioral Medicine*, *24*(1), 49–58. https://doi.org/10.1207/s15324796abm2401_06

Pirl, W. F., Saez-Flores, E., Schlumbrecht, M., Nipp, R., Traeger, L. N., & Kobetz, E. (2018). Race and ethnicity in the evidence for integrating palliative care into oncology. *Journal of Oncology Practice,14*(6), e346-e356. doi: 10.1200/jop.17.00016

Read, S., & Macbride-Stewart, S. (2017). The 'good death' and reduced capacity: A literature review. *Mortality, 23*(4), 381–395. doi: 10.1080/13576275.2017.1339676

Ruiz, M. E., Phillips, L. R., Kim, H., & Woods, D. L. (2015). Older Latinos: Applying the ethnocultural gerontological nursing model. *Journal of Transcultural Nursing, 27*(1), 8–17. doi: 10.1177/1043659615569539

Tyson, D. M., Medina-Ramirez, P., Flores, A. M., Siegel, R., & Loi, C. A. (2018). Unpacking Hispanic ethnicity—Cancer mortality differentials among Hispanic subgroups in the United States, 2004–2014. *Frontiers in Public Health*, *6*. https://doi.org/10.3389/fpubh.2018.00219