

End of Life Care Disparities in the Hispanic Communities of East Tennessee: Exploration of
Current Inequalities and Perceptions of Hospice and Palliative Care

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Abstract

Problem

Hispanic community members utilize end of life care services, including palliative and hospice care, less frequently than their white counterparts. The reasoning behind the lack of use is unknown.

Purpose

The purpose of this study is to determine the perceptions about end of life care of the Hispanic community; to assess disparities regarding palliative and hospice care; and to identify possible contributing factors to those disparities.

Methods

A survey was given to eight Hispanic community members who were over the age of 18 and resided in the greater Knoxville area. The research was conducted at the Centro Hispano, a local Knoxville community center for Hispanic people. The principal investigator visited the Centro Hispano during class times to recruit participants, engage in the informed consent process, and administer the surveys. Descriptive statistics and qualitative thematic analysis of the responses was conducted.

Findings & Analysis

Four themes were isolated from the data obtained: lack of basic knowledge and familiarity, the value of family, the value of religion, and professional help.

Conclusions & Recommendations

The disparity in the utilization of end of life care services by Hispanic community members is due in part to a lack of knowledge of accessible services and a lack of comfort in discussing values surrounding death with loved ones, despite a desire to use professional end of life care

services in addition to familial and religious support. It is recommended to conduct workshops in which Hispanic community members can become familiar with end of life care, discuss values with family members, and learn about the local resources available to them.

In 2030, the baby boomer age group will all be over 65 years old, one in every five residents in the United States will be at retirement age. For the first time in the history of the United States, there will be more older people than children (US Census Bureau, 2018). While these years might still seem distant, they are quickly approaching, and health care professionals must be prepared for the implications they bring.

While end of life care can be utilized at any age, it is most frequently used with the older adult population. End of life care encompasses both hospice and palliative care. Hospice care provides physical and emotional support for patients and families during times of serious illnesses; hospice care focuses on quality of life and comfort nearing death. Comparatively, palliative care provides medical and nursing care that focuses on symptom relief for patients with chronic illnesses, such as cancer or heart disease. Palliative care can be initiated even when the patient is not nearing end of life, but it is most always implemented with end of life and hospice care. There are multiple definitions of end of life, palliative, and hospice care, but these will be the definitions used for the purpose of this study.

The Hispanic population in the United States is undoubtedly growing. The Hispanic population makes up approximately 17% of the total United States population (US Census Bureau, 2017). Additionally, growth in the Hispanic population is projected to triple over the next 40 years (United States Population 2018). As a result of the combination of the growing Hispanic population and the growing older adult age group, the older population is becoming more racially diverse. In comparison to the Hispanic elderly population, the portion of caucasians over age 65 is projected to decrease by 24% in 2060 (Mather, 2016). Subsequently, the need for end of life care for Hispanics in our community is growing. However, disparities

exist regarding the use of end of life care services by the Hispanic population as evidenced by the studies below.

Kwak and Haley (2005) found that despite the overwhelming growth of the Hispanic population in the United States, Latino families are less likely than whites or other ethnic groups to choose to utilize professional end of life care. LoPresti, Dement, and Gold (2016) found in a systematic review that the majority of studies focused on the tendencies of the Hispanic community members to refuse hospice or palliative care and turn to spiritual and familial care for comfort. Furthermore, studies address the influence of certain cultural values including *machismo* and *familismo*. *Machismo* is the societal belief that the men are the sole decision-makers of the family, while *familismo* refers to the societal belief that both the nuclear and extended families are the center of daily life.

Additionally, it is pertinent to address religious values when discussing end of life care in the Hispanic population. Historically, the main religion practiced in the majority of Spanish-speaking countries is Catholicism with Protestantism as second most prominent. However, religion is changing in Latin American countries as in the rest of the world; some people still choose to go to the church every Sunday while others practice Catholicism by incorporating it into their daily lives. For others, they might identify as Catholic because that is the way they were raised despite no longer practicing (Wormald, 2014).

It is important to note here that an entire race of people cannot be generalized by a certain parameter of family or religious values. Therefore, it assuredly cannot be assumed that every Hispanic person living here in the United States goes to a Catholic church and has a male figurehead within their family. Factors such as separation from loved ones in home countries, language barriers, unfamiliarity with customs of the United States, and many more affect the

values and practices of Hispanic people living in the U.S. and specifically East Tennessee. For the sake of this research, we aim not to generalize the variety of cultures represented by the Hispanic people living in East Tennessee, but rather focus on the broader commonalities and connections between the diverse people in order to work towards a more comprehensive healthcare approach (Wormald, 2014).

There are no published studies that address *why* the Hispanic individuals make this choice. Despite the uncertainty of the exact reasoning behind the inequality, recent studies have explored methodology to diminish the disparities, such as educational videos and seminars for both the Hispanic community members and the health care professionals caring for them as evidenced by Quinones-Gonzalez (2013).

The purpose of this qualitative study is to determine why disparities exist in the use of end of life care services by the Hispanic population. It is expected that when Hispanic community members are directly asked about their experiences with and knowledge of end of life care, health care providers can have a deeper understanding of the perceptions and needs of the Hispanic community. Then, more open communication can be established between health care providers and community members that could assist in increasing the use of end of life care services by the Hispanic population.

Literature Review

A literature review was conducted exploring articles on end of life care in the Hispanic population. The databases CINAHL and PubMed were used with the key words “Latino” or “Hispanic,” and “palliative” or “end of life” or “hospice.” Inclusion criteria included scientific research and case studies conducted with legal adult participants, or people over the age of 18, and studies that occurred within the United States. Exclusion criteria included studies conducted

with children and studies that occurred outside of the United States in Spanish-speaking countries. Twelve articles were selected and addressed three areas: perceptions of the Latino population, current practice, and past interventions.

Perceptions of the Latino Population

Jaramillo and Hui (2016) conducted a case study examining the experience of a young Latino man diagnosed with end stage cancer to determine his perception of his end of life care. Of his many struggles, the researchers outlined some barriers he experienced that could affect other persons of the Hispanic population: delayed diagnosis due to infrequent doctor visits; limited social and financial support; fear due to lack of documentation; and cultural/language barriers causing anxiety for the patient and his family. In many cases, Hispanic immigrants have to relocate without their whole family, disrupting the family balance and limiting their family support.

In a second case study, Smith et al. (2009) described the perceptions of end of life care of a young pregnant woman diagnosed with leukemia. The factors identified as making the situation more difficult for her were similar to those in the previous case study: relocation of the patient creating geographic barriers to family support, lack of documentation, language difficulties, and discrimination concerns.

In a qualitative study of five Hispanic families in grief therapy, Gaudio et al., (2013) confirmed the influence of *Machismo* and *Familismo* on end of life care decision-making. A larger study on grief therapy identified seventeen families as Hispanic, yet only five met the criteria on the Family Relationships Index indicating poorer family functioning and distress. The grief therapy sessions were recorded and transcribed, and cultural themes were isolated from each family's session. All five families expressed values of family loyalty (*familismo*) and male

dominance (*machismo*) in their family structure/gender roles, which hence affected their coping mechanisms in terms of loss (i.e. joining support groups, grief counseling, involvement in awareness organizations, etc.).

In a qualitative study of Latina women with end stage cancers, Nedjat-Haiem, Carrion, Lorenz, Ell, & Palinkas (2013) showed that one of their primary concerns in end of life decision making centered around not burdening others or causing them emotional distress. The researchers aimed to explore health care professionals' experience being an advocate for Latino people through exploratory interviews with open-ended questions. From their responses, one isolated theme was the Latino people's concern for their family members during the difficult time. The researchers concluded that the presence of family and the structure of family are both important and influential in healthcare decisions.

Religion can also play a major role in a family's choice to participate in end of life care. Balboni et al. (2013) conducted a qualitative study and interviewed 343 patients with advanced forms of cancer until death. The original interviews established the patient's baseline need for spiritual care, while later interviews when the subject was nearing death focused on hospice care and aggressive end of life care measures such as admission to the hospital. The study showed that when patients from religious communities received spiritual support from the medical care team, they were more likely to engage in hospice use. The patients of ethnic minorities, including Latinos, were more likely to receive more aggressive resuscitative measures at the end of life, and more likely to die in an intensive care unit (ICU) rather than go to a hospice facility. These patients of ethnic minorities also reported stronger alliances to religion and spirituality in general.

Current Practice

Ko, Lee, Ramirez, Martinez, & Lopez (2016) conducted a descriptive research study near the Mexico border in Southern California to determine willingness to use end of life care services. They used secondary data from home health agencies as well as interviews of 189 different caregivers. Findings indicated that 83% of people were willing to use hospice services; however, willingness to use those services was dependent on factors such as the language spoken by the caregiver, including Spanish, Chinese, and Arabic. This study shows the importance of communication regarding end of life care, with the Hispanic population being more likely to need interpreting services or Spanish-speaking caregivers.

Kirkendall, Holland, Keene, & Luna (2015) studied 2,980 caregivers who had lost loved ones who had received hospice services. Caregivers who had included their patients' ethnicity were selected from 3,226 participants of a larger study. The selected individuals were more likely to participate if the patient was younger or had been an in-patient for hospice services. Participants were mailed the survey one to three months after their family member died. The researchers reported that (5%) were identified as Hispanic and that the support provided to Latino families was insufficient. Specifically, support did not address their spirituality or religious practices, and that Latino families were overall more likely to receive care incongruent to the patients' wishes.

Adams, Horn, & Bader (2005) conducted a non-experimental study to examine the demographic factors associated with hospice care. The sample included patients over 65 years of age who had died using Medicare funded hospice services and excluded those who had lived in nursing homes. The 487 subjects were chosen from 500 randomly selected charts; those charts were reviewed for the number of health care visits and overall time in hospice. The results

showed that Hispanic patients on average received fewer visits from health care support personnel, including volunteers, therapists, nurse aides, chaplains, social workers, and nurses. The Hispanic patients also had a shorter average length of hospice services in comparison to their non-Hispanic counterparts.

Price & Teno (2017) analyzed secondary data from 141,412 responses of the Consumer Assessment of Healthcare Provider and Systems (CAHPS) survey on hospice care to determine ethnic and racial variation in the quality of hospice care. All participants were family or friends of patients who had died while receiving care from 2,500 hospice facilities. Based on the analysis of the hospice facilities, their national rankings, and the demographic information of the patients, the study showed that even when Hispanic people chose to use hospice facilities, they were more likely to receive care at lower quality institutions with lower national rankings regarding respect, emotional support, or spiritual services. This study's results could possibly have been due to the Hispanic patients' socioeconomic status or residential areas.

Interventions

One intervention that has already been tried is *Nuestro* ("ours" in English) program developed by Quinones-Gonzalez (2013). This program served as an outreach into the Latino community of Pasco County, Florida, to provide education and culturally congruent resources to those needing palliative care. Increased use of and access to resources was measured by monitoring attendance sheets at local support groups and individual counseling. Results showed that after two years, Hispanic use of end of life services increased by 900%.

Chung, Augustin, & Esparza (2017) created a video of a Latino patient receiving care from her family with the assistance of a professional hospice caregiver to more accurately portray the service the patient would receive. The video was shown to Latino patients and their

caregivers to help aide in the decision-making process. Focus groups and individual interviews of physicians, hospital workers, and caregivers that were involved in the care were used to analyze the effectiveness of the video. The researchers reported that the use of a Spanish language video helped enhance understanding and receptivity of hospice services by showing the actual caregiving actions for the patient.

Cruz-Oliver, Malmstrom, Roegner, & Yeo (2017) developed an educational training program about culturally sensitive end of life care. One hundred and forty-two health care professionals of various ethnic backgrounds from New York, Miami, and Missouri were divided into two groups: one receiving a control educational video on end of life care and the other receiving a *telenovela* about caregiving. A telenovela is a show similar to a soap opera based on Hispanic culture. The group that watched the telenovela in comparison to the control video showed a greater increase in cultural understanding, willingness to engage in end of life conversations, and ability to provide culturally appropriate palliative care.

Synthesis of Findings

Interest in providing culturally congruent care is growing due to the increasing Hispanic population in the United States. Despite the growing need for end of life care, there has not been a subsequent augmentation in the knowledge and provision of culturally congruent care to people of diverse ethnic backgrounds, including the Hispanic population. Within the larger part of the Latino population in the U.S., there are similar values shared including the importance of family, gender, and religion in critical decision-making. Upon receiving end of life care, Hispanics traditionally have not received the spiritual and emotional support needed appropriate for their strong family and religious values and receive inferior quality care in general due to lower financial status.

There have been some successful interventions both within the Latino community and the health care community that have increased utilization of palliative and hospice care services. However, they have been employed without directly asking Hispanic community members what is lacking in their end of life care and what is needed. Additionally, most of these changes involve one side or the other: the Hispanic community or the health care professionals, not both groups together. An area that needs to be studied is what Hispanic community members identify as their end of life care needs which would result in the ability to tailor interventions specific to the Latino community.

There has been recent research on disparities within the Hispanic community regarding end of life care and commonly held values. However, the research has *not* addressed the exact “why” of these disparities. More data needs to be obtained through exploring the thoughts and feelings of the Hispanic patients and families directly about end of life care. The purpose of this study is to determine why disparities exist in the use of end of life care services by the Hispanic population.

Methods

A qualitative design was used to determine the perceptions about end of life care of the Hispanic community; to assess disparities regarding palliative and hospice care; and to identify possible contributing factors to those disparities. Approval from the University of Tennessee Institutional Review Board had been obtained.

Sampling Plan

A convenience sampling plan was utilized to identify 8-12 Hispanic community members or until data saturation had been achieved. Subjects were included if they were over the age of 18 and residing in the greater Knoxville area.

Data Collection Process

The research was conducted at the Centro Hispano, a local Knoxville community center for Hispanic people. The center typically serves between 40-70 local Hispanic community members each day for various classes, including literacy, English, and sewing. The principal investigator (PI) visited the Centro Hispano during class times; recruitment was initiated for the study by informing the Hispanic community members about the purpose of the study in Spanish before the classes started. After explaining the study to the class and answering any immediate questions, the PI left the classroom until the class ended. The PI then returned to explain how they can participate after the class has ended.

If a community member wished to complete the survey, they came to the researcher in an area in the lobby to engage in the consent process for the study. Community members then were able to ask more questions and gather further information about the study. Consent forms were provided in English and Spanish; participants were able to select either form. After providing informed consent, the participants were provided the survey to complete at the center. Completed surveys were turned into a folder; this folder said “survey” and had a picture of the survey on the cover. After completion of the survey, participants were given a copy of the informed consent form, as well as a listing of psychological and end of life care resources in the community.

A total of eight community members participated in the research survey. Once every study participant had completed the survey, the folder containing the surveys and the folder containing the informed consent forms were taken by the PI to be placed in the locked file cabinet on the University of Tennessee, Knoxville, campus.

Measures

The PI and the Centro Hispano worked together in creating the questions for the survey. It was important that the questions were at a literacy level appropriate for the clientele at the Centro Hispano, and that the translation from English to Spanish reflected the intended meaning of the questions. It took the subjects around ten minutes to complete the questionnaire.

Survey details.

Survey questions asked for information regarding demographics as well as perceptions of and past experiences with end of life care. For the first five questions, participants circled response on demographics: age in 10-year increments (18-29, 30-39, etc.), sex (female, male, transgender, prefer not to respond), years resided in East Tennessee in 2-year increments (1-2, 3-4, etc.), and preferred language to speak at home (English, Spanish, Another). Lastly, participants evaluated their own understanding of end of life care on a Likert scale of 1-5 with 1 being no knowledge and 5 representing a lot of knowledge.

After the demographic portion, the survey transitioned to a short answer format for questions 6-11. Participants were first asked about the values they regard as important during end of life (i.e. religion, family, independence.) Then, participants were asked what end of life care means to them. Next, participants were asked if they had ever discussed end of life care with a health care professional, and if they have ever had a close family member or friend use those services. Then, participants were asked to think about what they personally would want if they were in a situation where they needed end of life support. Lastly, participants were given the opportunity to include any additional information regarding their experiences with health care in general.

Findings & Analysis

The participants' responses to the survey were analyzed using descriptive statistics and qualitative thematic analysis. A coding scheme was developed based on the overarching themes of the responses. The subsequent data is presented as summaries and narratives taken confidentially from the survey responses. The degree of familiarity with end of life care is analyzed, as well as the subjects' perceptions of end of life care and personal values.

Of the eight participants, seven completed the survey in Spanish while one completed the survey in English. Therefore, the majority of the data that is presented has been translated into English. It is also pertinent to note that six of the eight participants reported speaking primarily Spanish in the home, one reported speaking primarily English, and one reported speaking an indigenous language in the home. Another piece of demographic information collected included the age of the participants: four of the participants were between 18-29 years of age, two between 30-39, one between 40-49, and one between 50-59. Additionally, two of the respondents regarded themselves as male and six regarded themselves as female. Lastly, information was collected regarding how long the participant has resided in the East Tennessee area: two had lived in the area for 1-2 years, three from 3-4 years, one from 5-6 years, one from 19-20 years, and one preferred not to respond.

The coding scheme that was developed includes the following overarching themes: lack of basis knowledge and familiarity; value of family; value of religion; and professional help.

Lack of Basic Knowledge and Familiarity

Under lack of basis knowledge and familiarity, it became quickly apparent that the surveyed Hispanic community members had a strong lack of knowledge regarding end of life care. In response to the question asking participants to rate their knowledge of end of life care,

four participants marked “1” for no knowledge, two marked “2” for little knowledge, and two marked “3” for some knowledge on a scale of 1-5. In addition, every participant denied ever having personally discussed end of life care with their loved ones, and only two participants have had close friends or family utilize end of life care services.

Value of Family

Another theme that was identified was the importance of family. Seven of the eight participants mentioned their families in some manner when asked about their personal values regarding end of life care. When participants were asked what end of life care specifically means to them, one participant responded saying: “I would like that my family be present to say goodbye to me with healing words.” In fact, there was a diversity of responses to this question. Four participants wrote about their definition of end of life care, two participants described what they would want if they needed end of life care, and two simply wrote that they did not know.

Value of Religion

In combination with family, religion was another major theme that appeared in the data from the surveys. Both when asked about their values surrounding end of life care and about their support preference if they needed end of life care, each time half of the participants wrote about religion, spirituality, or God. One participant relayed an anecdote of when a loved one was passing away; the participant mentioned that her friend was surrounded by people from her church as she passed. For some people, religion is also felt in their sense of community rather than a specific deity.

Professional Help

Lastly, there was a theme of a need for professional help throughout the end of life care process. In response to the survey question asking participants to think about what they would

want for their own end of life care, five of the eight participants mentioned a want for some kind of professional help: visits from a psychologist, physician, specialist, nurse, or from the hospital in general. When asked about what end of life care means to them, three of the participants who wrote about their definition of end of life care all mentioned a type of professional help from health care providers. One participant stated, “I think it is the care that is given to someone before death as much psychologically as physically.”

Conclusions and Recommendations

Overall, there is an apparent lack of awareness of end of life care in the Hispanic Community of East Tennessee. For the participants, there seemed to be an overarching struggle in answering the questions on the survey possibly due to a lack of starting knowledge of end of life care or comfort in discussing the topic. The researcher concluded from the theme “Lack of Basic Knowledge and Familiarity,” more information is needed for Hispanic community members so they can gain comfort with the topic. Furthermore, one can conclude that family and religion are important values in the end of life care process that need to be addressed accordingly for Hispanic patients. Lastly, from the data obtained through this study, Hispanic community members have a desire to utilize care and support from health care professionals during end of life. They recognized that they needed not only physically care but also psychological and spiritual support.

Therefore, one can conclude that Hispanic community members wish to have professional care while also receiving support from their religious beliefs and from family. However, as one of the themes suggest, there is a lack of knowledge regarding the professional end of life care support a person can receive. Moreover, there is a lack of understanding and comfort in discussing abstract topics related to values and death. Therefore, it is determined that

the diminished use of end of life care services by the Hispanic population is not due to disinterest in professional services and/or a preference for solely familial or religious support. Rather, the disparity is due to a lack of knowledge of services and a lack of practice in discussing values regarding death with loved ones.

There were limitations to the methodology of the study. The largest limitation is the small sample size for this study. In order to participate in the study, participants had to stay longer at the Centro Hispano after their class times. Time limitation was a deterrent to participation, as well as the lack of financial incentive. For future studies, I recommend providing gift cards or a small monetary incentive to participate. In addition, the lack of familiarity and comfort in discussing end of life care proved to be a deterrent. Most participants were not overly eager to take a survey on the topic. Providing an incentive to participate could help motivate the participants to provide detailed, enthusiastic responses considering the uncomfortable topic.

Furthermore, I recommend future studies to partner with local hospice or end of life care providing organizations to further engage with the community and collect more data. In retrospect, interacting with the portion of the Hispanic population that might already be engaged with these services would be a beneficial way to assess the situation in East Tennessee; current patients or family members of patients would be able to recount their personal, ongoing experiences with end of life care and provide valuable insight of the current condition. Additionally, intervention to improve communication and overall care quality could be started in that immediate interaction to help the family through their difficult time.

From the knowledge gained through this research study, it is recommended to conduct outreach workshops that Hispanic community members can attend with their families. At the workshops, a facilitator can initiate discussions regarding values in a larger sense as well as in

regard to health care, specifically addressing end of life care. Activities such as these could foster bonding within the families and increase comfort surrounding typically uncomfortable topics such as death and dying. Additionally, the workshop facilitator can give an overview of the different components of end of life care and address many commonly held misconceptions. There even could be a designated time in which participants could complete their own advance directive. Lastly, the facilitator can present locally culturally-congruent resources that the participants could use should the need arise. Through creating a space such as this, Hispanic community members can enhance their knowledge of end of life care, develop comfort with typically uncomfortable topics, and be enabled to take advantage of the end of life care resources available to them.

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