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“The Worst Thing About Hospice Is That They Talk About Death”: Contrasting Hospice Decisions and Experience among Immigrant Central and South American Latinos to US-born White, Non-Latino Cancer Caregivers

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Abstract

Hospice care is promoted as a model for improving end of life care and decreasing burden on caregivers. However, hospice use is low in Latinos and little is known about how Latinos make hospice decisions and experience hospice once enrolled. We used qualitative methods to conduct in-depth interviews and focus groups with 15 Latino bereaved hospice family caregivers and 15 White Non-Latino bereaved hospice family caregivers to describe hospice experiences and evaluate whether cultural factors affected the experience. We identified differences in decision-making and caregiving experience that were influenced by culture. For example, cultural values of denial, secrecy about prognosis and a collective, family-centered system influenced hospice decisions and experience in Latinos but not Non-Latinos. This study identifies a significant dilemma; that is, how to discuss hospice with a patient and family who prefer not to discuss a terminal prognosis. Future research is needed to extend these preliminary results; such results may be useful for designing interventions to improve end of life care and caregiving in Latinos.

Keywords

Hospice; Latino; End of Life; Cancer; Caregiving; Communication

Introduction

Latinos now make up approximately 15% of the U.S. population and are projected to be the largest minority group by the year 2015.¹⁻² Cancer is the second leading cause of death in this growing population.³ Over the coming decades these demographic trends, coupled with the aging of the Latino population, will create an increased need for end of life services for this group.

Hospice is a major model for end of life care. However, Latinos have been less likely than White Non-Latinos to use hospice services, even though their needs may be greater.⁴⁻⁶ For instance, Latino patients may be under-treated for cancer pain,⁷⁻⁹ and their caregivers may have more depression in the bereavement period than Non-Latino caregivers.¹⁰ Recently, there has been an increased effort by hospice organizations to reach out to Latinos.¹¹ However, little is known about how Latinos make decisions about hospice care or how they experience hospice care once enrolled. Moreover, despite some research on ethnic and cultural differences in attitudes toward death and dying,¹²⁻¹⁸ there are limited data on whether Latino cultural values affect hospice decisions. Latino cultural values that may affect end of life care decisions include the emphasis on the family vs. individuals (collectivism), family decision-making (familism), and preferences for indirect communication (e.g., prognosis is not discussed openly).^{12,15,19-21} In contrast, studies of cancer communication in White non-Latino cancer patients show that this group generally wants prognostic information and values autonomy based on information.²² Since hospice is based on the principles of patient autonomy and acceptance of death,²³ it is possible that Latino communication preferences and cultural norms may conflict with acceptance and use of hospice services. There is a paucity of data to address this question and most of what we do know about Latinos and end of life care comes from research with Mexican Americans.^{12,16,19,24} The goal of this study is to begin to fill gaps in our knowledge about

cultural influences on hospice use by providing a qualitative description of the hospice decisions and experiences of Central and South American Latino hospice caregivers and comparing them to White non-Latino hospice caregivers from the same urban locale. Our results are intended to generate hypotheses for future research about how to best educate health care providers about Latinos' end of life preferences and to suggest potential interventions to improve the quality of care for broader groups of Latinos and their families at the end of life.

Methods

This study was conducted by members of the Latin American Cancer Research Coalition (LACRC). The LACRC is a National Cancer Institute (NCI-funded) Community Network Program based in the metropolitan Washington, DC area. The study protocol was approved by the Institutional Review Board of Georgetown University and the participating hospice.

Setting and Population

We recruited a purposive sample of Latino and White non-Latino cancer caregivers from a large hospice in the metropolitan Washington, DC area. Criteria for inclusion were being an adult (21 and older) primary caregiver for a cancer patient that had died in the US within the past 12 months and having used hospice for care of the patient. Participants were contacted by the hospice and asked to participate. They were given written and oral information about the study in English and Spanish and provided written or oral consent in the language they preferred. Caregivers either attended focus groups held at the hospice or were interviewed individually by telephone. Participants were given a \$20.00 stipend for their time and participation.

We interviewed a total of 15 Latino hospice family caregivers and 15 White non-Latino hospice caregivers. Although recruitment methods were the same for both groups, Latinos were much more difficult to recruit than White non-Latinos, especially for focus groups. There were several reasons that Latinos were difficult to recruit for the study. First, there was only a small potential sample of Latino hospice users. Next, we had anecdotal evidence that many Latinos returned to their native countries at the end of life. Third, many of the Latino caregivers of cancer patients that did use hospice related that they were not comfortable talking in a group about this topic, since it was considered private, or secret, information. Therefore, we offered to interview these caregivers individually (n=5). This option was also offered to the White non-Latino group, but they were all comfortable with the focus group setting.

Focus groups and individual interviews were conducted in Spanish or English according to the respondent's language preference. Groups were moderated by Dr. Barbara Kreling of the LACRC and a trained bilingual hospice staff member. In-depth interviews followed the same guide as for the focus groups and were conducted by two bilingual staff members.

Instruments and Procedures

We developed a protocol and probes for group discussion and interviews based on themes suggested by the work of Colon (2003), Kagawa-Singer (2001) and Barclay (2007) concerning communication styles and the role of the family in end of life decisions.^{5,25-26} The protocol was developed to encourage a discussion of the family's role and the caregivers' experiences. The protocol included establishing rapport and creating a respectful, listening environment. Examples of the primary prompts used in each group/interview included: 1) what did you, as a caregiver, know about hospice before the patient's illness; 2) how was the hospice decision made? Who referred the patient; 3) how did the

caregiver and patient communicate with doctors and with each other about prognosis; 4) who was in charge of decisions, the patient or family; 5) how were hospice care and the death in hospice experienced; and 6) did the family want more or less information about the death than they were given. Groups lasted approximately two hours and in-depth interviews ranged from 30 minutes to 90 minutes. Each caregiver also completed a brief demographic questionnaire.

All interviews and focus groups were audio-taped with permission. The tapes were transcribed and Spanish tapes were translated into English. Translations were reviewed by bilingual staff.

Data Analysis

Responses were compiled and two researchers read the complete set of transcripts to identify salient themes, recurring ideas or terms and patterns of beliefs.^{27–29} Specific transcript passages were clustered under the themes within each interview question. This process was conducted separately for Latinos and White non-Latinos and results were then compared question by question. Contrasts that emerged were confirmed by reexamining all the data.

We linked resulting thematic data to cultural views using several steps.³⁰ First, we compared results for both groups to explore whether differences might represent an underlying cultural belief or value. Next, we compared our data with existing literature from both cultures and with established theories about cultural norms.^{27–29} Last, we assumed that themes unique to the Latino participants were related to the group context or from cultural beliefs. For instance, the theme of secrecy was identified in our data. We compared this theme to existing literature about Latinos and end of life discussions and to existing literature about Whites and end of life discussions. This theme was consistent with other findings for Latinos but not for Whites, suggesting a cultural link. Following the process of identifying potential cultural linkages we selected representative quotations to provide depth and to illuminate salient themes.

Results

The hospice caregivers in this sample were well educated, with 100% of the White non-Latinos and 87% of the Latinos reporting some college or a college degree; similar proportions of each ethnic group were insured (100% and 87%, respectively for White non-Latinos and Latinos). Caregiver ages ranged from 38 to 88 years (mean 55.1 years, SD 13.3). Hospice caregivers were either daughters (14 of 30) or spouses of patients (13 of 30). The patient family members they cared for were between 17 and 93 years old and they had various types of cancer. Overall hospice length of stay ranged from 1 to 180 days (mean 39 days, SD 43.7); in this small sample there was no significant difference in the length of stay by ethnic group ($p=.56$).

The Latino caregivers were primarily from Central or South America and had been in the US for an average of 23.6 years (range 7 to 40 years); only two Latino caregivers had been in the US for less than 10 years. The Latinos were all bilingual, with 12 of 15 reporting “very good” English proficiency. There appeared to be differences between Latino and White non-Latino cancer caregivers in hospice knowledge, hospice decision-making, and communication and hospice experience (Table 1).

What did families know about hospice before the patient’s illness?

Most White non-Latino hospice caregivers had knowledge of hospice before the patient’s illness. Many had experience with hospice caring for another relative. In only one case did the caregiver think hospice was just a place rather than home and institutional services. In

contrast, few Latinos who used hospice had previous experience with hospice. Most had misconceptions about hospice or no knowledge before the patient was enrolled. For instance, most thought hospice was a place for poor, old people or a place for paralytic people:

“I didn’t know what hospice was. I thought it was a place worse than a hospital.”

How was the hospice decision and referral made?

For White non-Latinos, a decision to use hospice was made by the patient and family after a recommendation from an oncologist and discussion about the effectiveness of treatment and prognosis:

Following a discussion of the results of chemotherapy, the doctor said she doesn’t have more than 6 months to live. *“He said she was terminal. Our three sons were there. The doctor suggested hospice.”*

All conversations with the doctor were with both patient and husband. They asked an oncologist, *“How much time?”* In this meeting, he said, *“call hospice”*.

In contrast, Latinos reported the hospice decision as taking place during a crisis hospitalization. They said they were referred by (various) persons in the hospital, not a physician, but that they didn’t know the profession of the person who referred them:

On an emergency hospital visit, *“As soon as we went inside the hospital there was a young lady that asked me if someone had ever explained to me about hospice. I told her no. Soon after I gave her my phone number I left. Just as I came in my door at home someone called me.”*

Thus, it appears that there might be ethnic group differences in knowledge and referral processes.

Was the dying experience different for Latino than for White non-Latino caregivers?

In dealing with death and dying, White non-Latino caregivers were open about prognosis, acknowledging that hospice enrollment meant the patient would die. This information was also useful to the caregiver and patient:

“We asked the oncologist to tell us how much time she had. The doctor said, ‘Call hospice.’ So we called hospice. The hospice nurse told us how close she [the patient] was (to the death) and told him when to call our sons.” “Hospice was so reassuring,” the husband said.

Latino caregivers did not express this openness about and acceptance of death. Rather, many Latino caregivers reported denial, preferences for less information, and maintaining secrecy about prognosis. For instance, persistent denial was maintained by many Latino caregivers, even after enrollment in hospice, despite information given by physicians and hospice staff:

“I had a lot of faith. I thought I was lucky and that he was getting better. He was already at hospice but I did not think he was going to die. Then the day the doctor called me and told me come tomorrow because ‘he is dying’..... I never thought that he was leaving me...”

White non-Latino caregivers reported valuing information about the details of what to expect when the patient was dying:

“Hospice made me ‘comfortable’ by telling me what was going to happen near the end.”

In contrast, Latino caregivers did not want detailed information about death and the dying process. One said:

“They gave me a pamphlet of what to expect. It explained all the steps my mother would go through until the day she would die. I did not want to read it. It was a plan or a guide I did not want to know or wanted to do. They told me I had to read it to be prepared. Even though it was practical advice about how to handle “the end” I felt it was very drastic.”

Non-Latino caregivers were comfortable with discussions of prognosis between doctor and patient and between doctor and family:

A woman whose father was diagnosed with colon cancer said, “...the Primary Care doctor told him. Dad then talked about ‘passing’ to all of us.”

Most Latinos, however, reported being surprised and disturbed by the open communication in hospice with patients and caregivers about death:

“The worst thing about using hospice care? The way they talk to you about death.”

Latino caregivers also reported feeling that truth telling about prognosis was harmful to the patient and cruel to the family. Latino caregivers felt that it was their responsibility to protect the patient from the knowledge of his or her illness, to deny death was imminent, and to act as if the patient were getting well. In most families, they would not discuss the family member’s death among themselves because they didn’t want to “hurt” each other:

“Well, as a Latino the fact that they tell you straightforward that your husband is dying..... the doctor tells you ‘he is at the end of his life’; it sounds a little cruel... I knew there was no cure for him. Everything they were doing for him was palliative, that all the medicine that was used for nausea and vomiting was palliative only. However, still it made me angry when the doctor told me he is dying.”

Were there cultural differences in who was in control of decisions?

White non-Latino caregivers reported that patients felt they were in control of their own decisions, with few exceptions. Some maintained control by choosing when and how to tell other family members about their diagnosis or prognosis. For instance, some chose not to tell grown children about the recurrence of cancer until near the end.

A husband stated “My wife shared all her discussions with her doctor with me. The Doc said she had less than one year so we called hospice. My wife made all her own decisions. We have five children. She didn’t let them know about her cancer until we got hospice.”

In Latino families, however, control resided with the family and the patient was “protected” from information and the responsibility of making decisions:

One woman made decisions for her mother together with her five sisters. She said, “Talking about hospice (to her mother) was tricky. The last chemo she was feeling really, really bad, it just was brutal on her.... we said Mom, we are going to stop treatment until you gain a little bit more weight... you can take the chemo again, we don’t know how long it’s going to be. And they (hospice staff) would use the badge that said palliative care. She didn’t realize that she was having hospice care, no. I think that’s probably because of what she and I had talked about way before during her first cancer that she just didn’t want to know. And I think that’s a pretty Latin American way of thinking.”

Were there differences in satisfaction with hospice?

White non-Latinos had positive expectations for hospice care because of previous knowledge or experience. Although they were mostly satisfied with care, some complained about not getting enough service or that hospice was not there at night when needed. Interestingly, Latinos were more satisfied with hospice than Whites since they had low or no expectations and were positively surprised by hospice services.

Discussion

This is one of the few studies of cancer caregiving in Central and South American Latinos. Our results suggest that there may be cultural differences between this Latino group and White non-Latinos. Although each case is unique and stereotyping is to be avoided, in our sample Latino caregivers reported being more secretive about death than White caregivers and preferred not to receive detailed information about the dying process. In addition, Latino families were the primary locus of decision making control while patients made more of their own decisions in White families. Finally, it seems that there were differences between Latinos and White non-Latinos in knowledge about hospice and pathways to utilization of hospice services.

Our finding that Central and South American Latinos held a lot of denial and preferred not to talk directly about end of life care is consistent with what is known about general Latino cultural preferences for indirect communication.^{12,16,19,24} In addition, it appears from our results that the family is the locus of communication in Latino families, shielding the patient from information they believe might be harmful to the patient. A corollary of this family-centric channel of communication was that the family was the decision making body. Others have observed similar results about communication, family roles and/or denial in Latinos from Mexico, Central America and Cuba.^{12,16,19,24}

The observation that White non-Latinos preferred more direct discussions and to gather more information than Latinos has also been noted in other studies.^{12, 22} For instance, a recent study of 116,974 bereaved family members (97% White, non-Latino) found that regular and honest communication and information about the patient's condition was strongly associated with rating hospice care as "excellent".³¹ Indeed, the standard medical practice is to speak openly and directly to patients about the death and dying process. However, our results support prior research on cultural communication preferences and suggest that providers may need to use a somewhat less direct approach when discussing end of life care with Latino families. Quantitative surveys of larger, more representative samples and direct observations of communication during encounters for end of life care will be important to better understand how to deliver bad news and prepare Latino patients and their families for death in a culturally competent manner. Approaches that have been suggested are to assess each case individually to avoid stereotyping by using case structured assessment tools and employing culturally tailored strategies for delivery of bad news.^{12-13,25-26}

Hospice knowledge is low in the general US population.³² Most persons believe hospice to be an institutional setting for end of life care, and do not know that hospice includes at-home services. As was seen in our study, minority group members seem to have even less information about hospice than the general population.^{20,33} Hospice translates to *hospicio* in Spanish, meaning "orphanage" or "place for poor people." Thus, end of life discussions with Latinos may need to include more education about hospice than is required for Non-Latinos. Our results also suggest that educational materials may need to be culturally tailored to Latino communication preferences (i.e., using indirect means of talking about death) and be targeted to families, not just translated from English materials.

Latinos in our study were less likely to report being referred by an oncologist than White non-Latinos. Perhaps the family's preference for secrecy influenced the oncologist not to discuss and refer patients to hospice. Alternatively, providers may perceive Latino patients as being un- or under-insured for hospice care and so may not initiate these discussions. Another possible explanation for the patterns of referral we observed may be related to language barriers. This idea is supported by the result of Taxis and colleagues who noted that Mexican-American Latinos reported language barriers to using hospice services.²⁰ Colon also found that Latinos were less likely than other groups to be referred to hospice by a physician; when they were referred, it was usually by non-physician hospital staff.⁵ There have been conflicting results in other studies of physician referral for Latinos at the end of life. For instance, Wallace and Lew-Ting found that minority patients were under-referred to hospice by physicians in the US but Karim and colleagues did not find referral differences by ethnicity in the UK.³⁴⁻³⁵ These contradictory results may be related to differences in the health care systems and/or the demographic characteristics of the specific minority populations studied (e.g., related to legal status, insurance coverage, English ability). It will be important to conduct additional research on patient-physician-family communication about hospice in Latinos, given the central role of physicians as authority figures in Latino culture and as the gatekeepers to hospice services.

There are several caveats that should be considered in evaluating our results, including the sample size and characteristics, the use of two modes of data collection and methods of cultural attribution. Caregivers in this qualitative study were a small, purposive, convenience sample of hospice caregivers self-selected to participate. Thus, we could not study barriers to hospice enrollment among non-users. Our Latino caregiver participants were mostly from Central and South America and may be different than Latinos from other U.S. geographic areas that may have more Mexicans, Puerto Ricans, Dominicans, or Cubans. Latinos in our sample were also more acculturated than the population of Latinos in the DC area.³⁶ This is likely to underestimate the impact of culture on hospice experiences, since well acculturated Latinos are more likely to subscribe to more Americanized views of death and dying.¹²

Combining data from focus group interviews and in-depth telephone interviews may have biased results, although the question protocols were the same. The inclusion of individual interview data may have also resulted in an over-representation of participants reporting concerns about privacy and secrecy surrounding death and dying, although this theme has been reported in other Latino samples.^{5,16,37} It will be important to extend our results and further compare Latinos and Whites using the same data collection methods.

The results of this preliminary study identify a potential significant dilemma; that is, how to discuss hospice with a Latino patient and family who may prefer not to discuss a terminal prognosis directly. If confirmed, this "secrecy dilemma" will challenge attempts not only to increase Latino participation in hospice but to provide care for Latinos who are in hospice care.^{13-14,21,25-26} In the context of current knowledge, our preliminary results suggest three methods to address the "secrecy dilemma" and other cultural differences in end of life care. First is community education to raise the level of knowledge about palliative and hospice care in the Latino community. Next is the use of case assessment tools to ascertain communication preferences and the family's preferred role in decision-making.^{12-13,25-26} Finally, providing culturally-sensitive end of life navigation may help Latino patients and families to communicate with their health care team and obtain hospice services earlier in the process. The cultural sensitivity required for such navigation may require a trained bilingual, bicultural community member who is aware of the values of secrecy and denial as well as familism. He or she could use wording that is sensitive (i.e. "future care" rather than "terminal care") and could assess the family's preferences for communication. Most importantly, he or she could be a familiar contact person and "sounding board" for

information along an unfamiliar journey. Providing high quality end of life care to patients of diverse backgrounds and beliefs remains an important challenge and unmet need.

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Reference List

1. United States Census Bureau. [Accessed 2008] U.S. Department of Commerce, Economics and Statistics Administration. Population by age, sex, race and Hispanic and Latino origin for the United States. <http://www.census.gov/population/www/cen2000/briefs/phc-t9/tables/tab01.pdf>
2. Passel, JS.; Cohn, DU. [Accessed 2008] U.S. Population Projections: 2005–2050. Pew Research Center Social and Demographic Trends. <http://pewhispanic.org/files/reports/85.pdf>
3. American Cancer Society. Cancer Facts & Figures. Atlanta: American Cancer Society; 2009.
4. National Hospice and Palliative Care Organization. Facts and figures on hospice care in America. Washington, DC: National Hospice and Palliative Care Organization; 2007.
5. Colon M, Lyke J. Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *American Journal of Hospice and Palliative Medicine*. 2003; 20(3):182–190. [PubMed: 12785039]
6. Lackan NA, Ostir GV, Freeman JL, Kuo YF, Zhang DD, Goodwin JS. Hospice use by Hispanic and non-Hispanic white cancer decedents. *Health Serv Res*. 2004; 39(1):969–983. [PubMed: 15230937]
7. Juarez G, Ferrell B, Borneman T. Influence of culture on cancer pain management in Hispanic patients. *Cancer Pract*. 1998; 6(5):262–269. [PubMed: 9767344]
8. Cleeland CS, Gonin R, Baez L, Loehrer P, Pandya KJ. Pain and treatment of pain in minority patients with cancer. The Eastern Cooperative Oncology Group Minority Outpatient Pain Study. *Ann Intern Med*. 1997; 127(9):813–816. [PubMed: 9382402]
9. Werth JL Jr, Blevins D, Toussaint KL, Durham MR. The influence of cultural diversity on end-of-life care and decisions. *American Behavioral Scientist*. 2002; 46:204–219.
10. Pinquart M, Sorensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist*. 2005; 45(1):90–106. [PubMed: 15695420]
11. National Hospice and Palliative Care Organization. [Accessed October, 2008] NHPCO's 2004 Facts and Figures. http://www.nhpco.org/files/public/Facts_Figures_for_2007
12. Blackhall LJ, Frank G, Murphy S, Michel V. Bioethics in a different tongue: the case of truth-telling. *J Urban Health*. 2001; 78(1):59–71. [PubMed: 11368203]
13. Koenig BA, Gates-Williams J. Understanding cultural difference in caring for dying patients. *West J Med*. 1995; 163(3):244–249. [PubMed: 7571587]
14. Crawley LM, Marshall PA, Lo B, Koenig BA. Strategies for culturally effective end-of-life care. *Ann Intern Med*. 2002; 136(9):673–679. [PubMed: 11992303]
15. Braun KL, Onaka AT, Horiuchi BY. End-of-life preferences in Hawaii. *Hawaii Med J*. 2000; 59(12):440–446. [PubMed: 11191257]
16. Gelfand DE, Balcazar H, Parzuchowski J, Lenox S. Mexicans and care for the terminally ill: family, hospice, and the church. *Am J Hosp Palliat Care*. 2001; 18(6):391–396. [PubMed: 11712720]
17. Scharlach AE, Kellam R, Ong N, Baskin A, Goldstein C, Fox PJ. Cultural attitudes and caregiver service use: lessons from focus groups with racially and ethnically diverse family caregivers. *J Gerontol Soc Work*. 2006; 47(1–2):133–156. [PubMed: 16901881]
18. Volker DL. Control and end-of-life care: does ethnicity matter? *Am J Hosp Palliat Care*. 2005; 22(6):442–446. [PubMed: 16329196]

19. Sabogal F, Marin G, Otero-Sabogal R, et al. Hispanic familism and acculturation: what changes and what doesn't? *Hispanic Journal of Behavioral Sciences*. 1987; 9(4):397–412.
20. Taxis JC, Keller T, Cruz V. Mexican Americans and Hospice Care: Culture, Control, and Communication. *Journal of Hospice & Palliative Nursing*. 2008; 10(3):133–141.
21. Tellez-Giron P. Providing culturally sensitive end-of-life care for the Latino/a community. *WMJ*. 2007; 106(7):402–406. [PubMed: 18030829]
22. Kaplowitz SA, Campo S, Chiu WT. Cancer patients' desires for communication of prognosis information. *Health Commun*. 2002; 14(2):221–241. [PubMed: 12046799]
23. Clark D. The philosophy of terminal cancer care. Originating a movement: Cicely Saunders and the development of St Christopher's Hospice, 1957–1967. *Ann Acad Med Singapore*. 1987; 16(1): 151–154. [PubMed: 3592584]
24. Klessig J. The effect of values and culture on life-support decisions. *West J Med*. 1992; 157(3): 316–322. [PubMed: 1413777]
25. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "You got to go where he lives". *JAMA*. 2001; 286(23):2993–3001. [PubMed: 11743841]
26. Barclay JS, Blackhall LJ, Tulsky JA. Communication strategies and cultural issues in the delivery of bad news. *J Palliat Med*. 2007; 10(4):958–977. [PubMed: 17803420]
27. Woolcott, HF. *Transforming qualitative data: Description, analysis, and interpretation*. Thousand Oaks, CA: Sage; 1994.
28. Marshall, C.; Rossman, GB. *Designing qualitative research*. Newbury Park, CA: Sage; 1989.
29. Morse, JM.; Field, PA. *Qualitative Research Methods for Health Professionals*. Thousand Oaks, CA: Sage Publications; 1995.
30. Pasick RJ, Burke NJ. A critical review of theory in breast cancer screening promotion across cultures. *Annual Review of Public Health*. 2008; 29:351–368.
31. Rhodes RL, Mitchell SL, Miller SC, Connor SR, Teno JM. Bereaved family members' evaluation of hospice care: what factors influence overall satisfaction with services? *J Pain Symptom Manage*. 2008; 35(4):365–371. [PubMed: 18294811]
32. National Hospice and Palliative Care Organization. *Delivering Quality Care and Cost-Effectiveness at the End of Life: Building on the 20-Year Success of the Medicare Hospice Benefit*. Washington, DC: National Hospice and Palliative Care Organization; 2002.
33. Rhodes RL, Teno JM, Welch LC. Access to hospice for African Americans: are they informed about the option of hospice? *J Palliat Med*. 2006; 9(2):268–272. [PubMed: 16629555]
34. Wallace SP, Lew-Ting CY. Getting by at home. Community-based long-term care of Latino elders. *West J Med*. 1992; 157(3):337–344. [PubMed: 1413781]
35. Karim K, Bailey M, Tunna K. Nonwhite ethnicity and the provision of specialist palliative care services: factors affecting doctors' referral patterns. *Palliat Med*. 2000; 14(6):471–478. [PubMed: 11219877]
36. Singer, A.; Friedman, S.; Cheung, I.; Price, M. *The world in a zip code: Greater Washington, DC as a new region of immigration*. Washington, DC: The Brookings Institution; 2001.
37. Smith AK, Sudore RL, Pérez-Stable EJ. Palliative care for Latino patients and their families: whenever we prayed, she wept. *JAMA*. 2009 Mar 11; 301(10):1047–1057. E1. [PubMed: 19278947]

Table 1

Differences in Caregiver Reports of Hospice Experience by Ethnicity

Topic	White non-Latino Caregivers	Latino Caregivers
Previous Knowledge of Hospice	Most had previous experience with and knowledge of hospice.	A few had previous experience; many had no knowledge or had misconceptions.
Who Referred the Family?	Oncologists as part of prognosis discussion.	Few by oncologist – most from other staff at hospital, such as social worker.
Insurance/Financial Issues	Not raised.	Believed they could not afford service.
Desire for Information	Wanted specific information about what to expect when a person is dying. Wanted information about timing so others could be present for death.	Didn't want death to be discussed openly. Didn't want information about symptoms of imminent death.
Appraisal of Prognosis	Acknowledged that hospice patient was dying.	Didn't fully believe hospice patient was dying.
Openness vs. Secrecy	Patient and caregiver wanted information for decision-making. Some caregivers didn't want to discuss death directly with patient.	Didn't want discussion of death even within the family.
Distrust	Not raised.	Some Latinos thought hospice was a place with inferior care for poor people who were dying.
Autonomy/patient control versus Collectivism/family control	Patient wanted information and made decisions with family. Patient was in charge when able.	Family wanted to receive information and make decisions – not patient. Family was in charge.
Expectations/Satisfaction	High expectations. Satisfied with hospice with some exceptions.	No expectations. Satisfied with hospice in spite of death talk.