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Do Hispanics prefer to be full code at the end of life? The impact of palliative care consults on clarifying code status preferences and hospice referrals in Spanish-speaking patients

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Abstract

Background. Hispanics often have disparities at the end of life. They are more likely to die full code and less likely to have discussions regarding prognosis and do not resuscitate (DNR)/do not intubate (DNI), despite studies showing Hispanic values comfort over the extension of life. Barriers to patient-centered care include language,socioeconomic status and health literacy.

Context. We evaluated the impact of palliative care (PC) consults on the change of code status and hospice referrals, comparing seriously ill Hispanic and non-Hispanic white patients.

Method. A retrospective cohort study of all white and Hispanic patients referred to the PC service of a county hospital from 2006 to 2012. We evaluated ethnicity, language, code status at admission and after PC consult, and hospice discharge. Chi-squared tests were used to analyze characteristics among three groups: non-Hispanic white, English-speaking Hispanic, and Spanish-speaking Hispanic patients.

Results. Of 925 patients, 511 (55%) were non-Hispanic white, 208 (23%) were English-speaking Hispanic, and 206 (22%) were Spanish-speaking Hispanic patients. On admission, there was no statistically significant difference in code status among the three groups (57%, 64%, and 59% were full code, respectively, $p = 0.5$). After PC consults, Spanish-speaking Hispanic patients were more likely to change their code status to DNR/DNI when compared with non-Hispanic white and English-speaking Hispanic patients (44% vs. 32% vs. 28%, $p = 0.05$). Spanish-speaking Hispanic patients were more likely to be discharged to hospice when compared with English-speaking Hispanics and non-Hispanic whites (33%, 29%, and 23%, respectively, $p = 0.04$).

Significance of results. Spanish-speaking Hispanic patients were more likely to change from full code to DNR/DNI compared with non-Hispanic white and English-speaking Hispanic patients, despite similar code status preferences on admission. They were also more likely to be discharged to hospice. PC consults may play an important role in helping patients to align their care with their values and may prevent unwanted aggressive interventions at the end of life.

Introduction

Latinos currently comprise 15% of the US population, a number that is expected to reach 30% by the year 2050 (Smith et al., 2009), equalling approximately 128 million according to the Pew Research Center (2019). More specifically, Latinos aged 60 and older are the fastest growing segment of the USA (Kelley et al., 2010). Because they make up a significant proportion of our society, failure to understand their end-of-life (EOL) preferences could lead to inappropriate care of seriously ill Latino patients and undue stress for their families and loved ones.

Disparities exist in advance care planning and EOL care for Latino patients. Studies and surveys have demonstrated that older Latinos compared with non-Hispanic whites are more accepting of aggressive care at the EOL (Blackhall et al., 1999; Kwak Haley, 2005). Another study showed that only 22.4% of Latino patients with advanced cancer completed a do-not-resuscitate (DNR) order vs. 50.4% of white patients (Loggers et al., 2009). As such, they are more likely to die full code (Muni et al., 2001), despite studies showing that often Hispanic patients value comfort over the extension of life (Kelley et al., 2010). Older Latinos are also less likely to use hospice services and more likely to die in hospitals when compared with non-Hispanic whites (Colon, 2005; Hanchate et al., 2009).

There is evidence that Latinos are not familiar with hospice, but if asked and explained in their language, the majority of them would be willing to offer hospice information to a seriously ill relative (Pan et al., 2015). A 2016 study showed that when EOL discussions took place, there was a 10-fold increase in DNR completion in Latinos with advanced cancer compared with White patients (Shen et al., 2016). Despite this preference, very few complete an advance directive or engage in any advance care planning.

Barriers that may explain the current disparities in EOL care for Latino patients include: (1) geographical distance between families, (2) discrimination, (3) language and health literacy, and (4) cultural/religion/spiritual themes (Smith et al., 2009). In addition, Latinos often are "present-oriented" rather than "future-oriented," and thus advance care planning for the future may not be a high priority.

More than half of the immigrants in the USA are from Latin America, and 40% of the Latinos currently residing here are among them (Smith et al., 2009). A significant number of them is undocumented. As a result, fear of deportation is frequently present. In addition, Latinos often feel discriminated. A recent survey conducted in California showed that 13% of all Latinos and 16% of immigrant Latinos reported experiencing racial or ethnic discrimination in the healthcare setting. These fears often preclude access to healthcare and lead to negative perceptions about the healthcare environment. This leads to situations in which immigrants may feel curative treatment is being withheld, and therefore opt for aggressive treatment (Smith et al., 2009).

Spanish is, by far, the most spoken non-English language in the USA, with 37.6 million persons aged 5 years and older speaking Spanish at home, according to an analysis of a recent community survey (Pew Research Center 2019). One study conducted by the Pew Hispanic Center reported that only 23% of first-generation immigrants were able to speak English well. These numbers increase the risk of miscommunication to occur in healthcare encounters, especially if no professional interpreters are used. Even when Latinos do not understand, they may signal they do, in order to appear cooperative (Smith et al., 2009). Interpreters and optimization of communication strategies would potentially minimize disparities of care.

Health literacy presents a major problem when faced with making important medical decisions. According to one study, close to half of the US population has limited health literacy (Kutner et al., 2005), and the prevalence of limited health literacy is higher among Spanish speakers (62%) compared with English speakers (46%) (Paasche-Orlow et al., 2005). In addition, health literacy is linked with educational attainment and reading skill, both of which are lower among Latinos when compared with other US racial and ethnic groups (Kutner et al., 2005). As a result, Hispanic patients are more likely to have difficulty processing written and verbal health information and navigating the healthcare environment, and are less likely to engage in shared decision-making or to report that interactions with clinicians are helpful or empowering (Baker et al., 1996; Doak et al., 1996; Sudore et al., 2006; Castro et al., 2007).

In Latin America, physicians frequently take a more directive and paternalistic role with regard to decisions involving life-sustaining treatment (Blackhall et al., 1999). For example, a physician in Latin America often can take a paternalist role making recommendations against life-sustaining treatments in the setting of a terminal illness, and families usually do not question physician decisions and recommendations in this traditional paternalistic decision-making mode.

In addition, certain cultural concepts — *familismo*, *machismo*, and *fatalismo* — may influence illness experience, decision-making, and EOL care (Talamantes et al., 2000). *Familismo* refers to the idea of the importance of family and friends who function as a single unit in the decision-making process. Decisions could be hindered if the family is unavailable due to reasons such as distance, immigration status, or economic and political restraints (Sabogal et al., 1987). *Machismo* refers to the tradition for the man to serve as the family provider and the protector. This, in turn, could influence decision-making for Latina women and potentially go against their goals and desires (Rafaelli and Ontai 2004). Latina women may defer decision-making to the men in their family and may feel uncomfortable opposing the opinion of their husbands, brothers, or fathers. Finally, *fatalismo* is the belief that one's future is preordained and out of one's control. This could lead to pessimistic attitudes that could potentially cause additional suffering (Talamantes et al., 1995).

Finally, with regard to religion and spirituality, a diverse ethnic survey of cancer patients showed an increased association of religiousness with wanting all measures to extend life (Balboni et al., 2007). Also, in focus groups, Latino surrogates indicated that suffering was to be borne as part of a test of faith (Braun et al., 2008).

Studies have previously demonstrated that palliative care (PC) consults can have a meaningful impact on the completion of advance directives in both white and non-white patients (Zaide et al., 2013). We evaluated the impact of PC consults on code status preferences, comparing seriously ill Hispanic and non-Hispanic white patients.

Methods

Study type and aim: This is a retrospective database study in which we analyzed the effect of palliative care consultation (PCC) on clarifying advanced directives/code status decisions among three specific ethnic groups.

Setting: This study took place at Santa Clara Valley Medical Center, a teaching hospital in San Jose, CA. The study included cohorts receiving PCC from 2006 through 2012.

Subjects: Subjects were categorized into three major groups based on ethnicity and language speaking: Caucasian, Latino English-speaking, and Latino Spanish-speaking. Patient characteristics included age, sex, hospice discharge, code status at admission, and code status change to DNR/do not intubate (DNI) after PCC. Code status categories were classified as full code, DNR, and/or DNI.

PCC intervention

The Santa Clara Valley Medical Center's Palliative Medicine Consultation team consisted of two board-certified hospice and palliative medicine physicians and one PC fellow, with close collaborations with a social worker, case managers, and chaplains. At the time of the study, the team evaluated around 600 patients a year. The consultation was performed at the request of the primary teams in critical care, oncology, surgery, and internal medicine. Consultations would be requested for patients with diagnosis such as metastatic cancer, multiple organ failure, end-stage dementia, end-stage heart failure, advanced COPD, stroke with poor functional status, and poorly controlled pain. Common reasons for consultations would include: (a) goals of

Table 1. Patient Demographics

Patient demographics	Total ($n = 925$)	Non-Hispanic white ($n = 511$)	English-speaking Hispanic ($n = 208$)	Spanish-speaking Hispanic ($n = 206$)
Age (mean, range) in years	58 (3–99)	60 (15–95)	48 (3–91)	61 (21–99)
<65 years old	618 (67%)	333 (66%)	172 (83%)	113 (55%)
>65 years old	299 (32%)	172 (34%)	35 (17%)	92 (45%)
Sex				
Male	519 (56%)	296 (58%)	112 (54%)	111 (54%)
Female	406 (44%)	215 (42%)	96 (46%)	95 (46%)

care, (b) pain management, (c) family conflict, and (d) hospice appropriateness evaluation. The patient's hospitalization often represented a change in the patient's condition, offering an opportunity to complete an assessment, focusing on physical, financial, psychosocial, and spiritual distress. The team designed a plan of care that:

- provided relief from pain and other distressing symptoms,
- established goals of care based on symptoms, treatment preferences, and prognosis,
- integrated the psychological and spiritual aspects of the patient and family experience, and
- offered a support system to help the family cope during the patient's illness and during the bereavement period.

The consultation was individualized to meet the unique needs of the patient and family. There was always a physical examination, a meeting with the patient and the surrogate decision-maker when applicable, and communication with the primary medical care team. The most successful consultations would occur early in the course of the hospitalization in conjunction with other therapies that were intended to reduce the illness burden, such as palliative chemotherapy or radiation therapy. The consultation included a discussion of advance directives and the benefits and risks of life-sustaining interventions related to the current medical condition. Frequently, the consultation was the first time that the patient/surrogate learned that cardiopulmonary (CPR) or respiratory support may not be an appropriate treatment for patients with an underlying advanced disease. The Santa Clara Valley Medical Center PC team also used live interpreters who were certified/trained in Spanish and often involved spiritual care and Chaplain counselling, including meetings with a Spanish-speaking catholic priest when indicated.

The study outcomes included code status changes from full code to DNR and/or DNI after PCC, and hospice referral. When appropriate, the PC team promoted a model of shared decision-making in which the team recommended treatment options based on patient and family preferences. For example, the team could recommend a DNR/DNI order and hospice referral if the patient/family goal was comfort and being at home.

Statistical analysis

The analysis was a between-group comparison of the percentage of subjects. Groups were classified as Caucasian English-speaking, Latino English-speaking, and Latino Spanish-speaking. The analysis was performed with the use of descriptive statistics and the chi-square test. Descriptive statistics of means and proportions were calculated for age, sex, hospice discharge, code status before PCC, and code status change after PCC. The chi-square test was used for comparison among groups of proportions. The p-value 0.05 was considered statistically significant.

Results

Of 925 patients, 511 (55%) were non-Hispanic white, 208 (23%) were English-speaking Hispanic, and 206 (22%) were Spanish-speaking Hispanic patients. The proportion of <65 year Latino English-speaking patients was significantly higher than that of Caucasian English-speaking and Latino Spanish-speaking patients (83% vs. 66% vs. 55%, $p = 0.002$). However, for the ≥65 year group, Latino Spanish-speaking patients were significantly higher in proportion than those of Caucasian English-speaking and Latino English-speaking (45% vs. 34% vs. 17%, $p = 0.00$; Table 1) On admission, there was no statistically significant difference in code status among the three groups (57%, 64%, and 59% were full code, respectively, $p = 0.5$). There was no significant difference in proportion among three groups based on sex.

After PC consults, Spanish-speaking Hispanic patients were more likely to change their code status to DNR/DNI compared with non-Hispanic white and English-speaking Hispanic patients (44% vs. 32% vs. 28%, $p = 0.05$). Of 243 (26%) hospice referrals that consultations generated, Spanish-speaking Hispanic patients were more likely discharged to hospice when compared with English-speaking Hispanics and non-Hispanics whites (33%, 29%, and 23%, respectively, $p = 0.04$; (Table 2 and Chart 1).

Discussion

Our study demonstrated that Spanish-speaking Hispanic patients were more likely to change code status to DNR/DNI and also more likely to be discharged to hospice when compared with English-speaking Hispanic and non-Hispanic whites.

These findings could be attributed to several factors:

First, PC teams utilized Spanish interpreters when holding family meetings. This could have had an impact on minimizing language barriers that could be affecting both the patient and family understanding of diagnosis and prognosis. Often, patients and families did not have a full understanding of these issues before meeting with the PC team possibly due to primary team uneasiness and/or lack of skill to discuss EOL options. The literature supports the finding that Hispanics often value comfort over the extension of life. Once the language barrier was overcome, it appears that families were able to align their preferences with

Table 2. Change in code status and hospice discharge with PCC

	Total	Non-Hispanic white	English-speaking Hispanic	Spanish-speaking Hispanic	*P*-value
Code status pre-PCC					
Full code	547 (59%)	291 (57%)	134 (64%)	122 (59%)	0.5
DNR/DNI	378 (41%)	220 (43%)	74 (36%)	84 (41%)	
Code status change from pre- to post-PCC					
Full code to DNR/DNI	184 (34)	93 (32%)	37 (28%)	54 (44%)	0.05
Hospice discharge					
Yes	243 (26%)	115 (23%)	61 (29%)	67 (33%)	0.04
No	682 (74%)	396 (77%)	147 (71%)	139 (67%)	

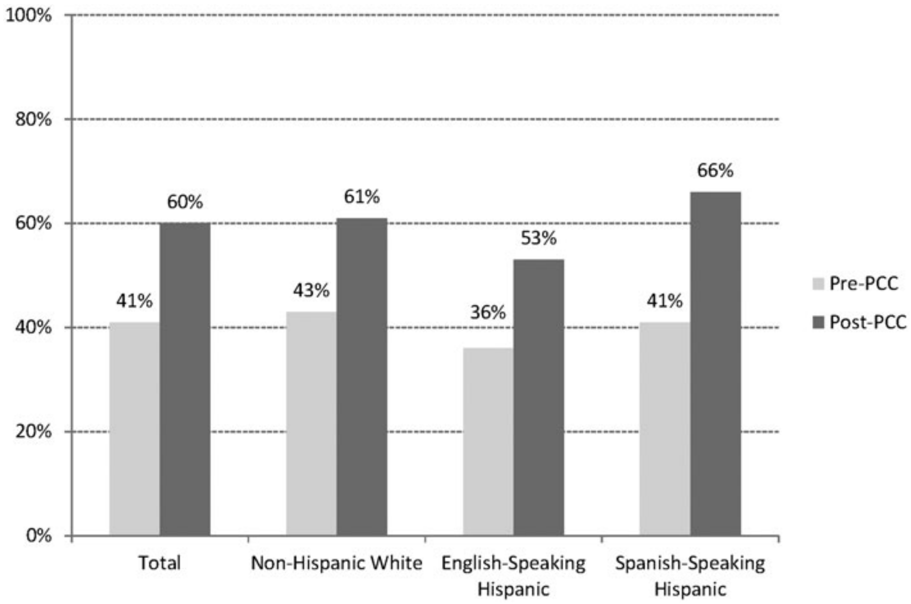

Chart 1. Absolute DNR percentage pre- and post-PCC.

a treatment plan that included changing code status to DNR/DNI and hospice.

Second, the PC team used a shared decision-making model when holding family meetings. The PC team would assess the patient/family's understanding of diagnosis and prognosis, update them about the clinical situation, and discuss goals of care, including the risks and benefits of CPR and intubation vs. DNR/DNI and hospice referral. The PC team would also assess family's preferences regarding the quantity vs. quality of life and preferences regarding re-hospitalizations vs. home hospice. Often, the PC team would recommend DNR/DNI and hospice referral if the patient/family's goals were comfort-oriented. The fact that the PC team made a recommendation could have influenced the final decision. The literature supports that many Hispanics may be more used to the pattern of paternalistic decision-making which is more common in Latin America. Perkins et al. (2002) found that Mexicans were more likely to entrust decision-making to their family members and healthcare system over whites. This suggests that Hispanic patients may be more open to medical recommendations.

Thirdly, the PC team would involve spiritual care providers, including a Spanish-speaking priest, who would offer spiritual support to the family and reinforce the message that DNR/DNI and hospice were appropriate options at the EOL in the view of the Catholic Church. Since Hispanic patients have strong spiritual faith, the involvement of spiritual care providers likely influenced the outcome of the family meeting (California Catholic Conference, 2019).

This study also had limitations. First, data were based on one hospital's patient population. Therefore, the demographics could have been skewed. Next, it was a retrospective study, and other factors may have influenced the outcomes as this study was primarily based on a few characteristics such as race, ethnicity, and languages. Thirdly, the majority of the Spanish-speaking Hispanics were older than the comparison white group, which could have made the case for a hospice referral easier.

Conclusion

Spanish-speaking Hispanic patients were more likely to change from full code to DNR/DNI compared with non-Hispanic white and English-speaking Hispanic patients, despite similar code status preferences on admission. They were also more likely to be discharged to hospice. PC consults, as described, may play an important role in helping patients to align their care with their personal values and may prevent unwanted aggressive interventions at the end of life.

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Conflict of interest. None of the authors have any conflict of interest to disclose.

References

Baker DW, Parker RM, Williams MV, *et al.* (1996) The healthcare experience with patients with low literacy. *Archive of Family Medicine* **5**(6), 329–334.

Balboni TA, Vanderwerker LC, Block SD, *et al.* (2007) Religiousness and spiritual support among advanced cancer patients and associations with end of life treatment preferences and quality of life. *Journal of Clinical Oncology* **25**(5), 555–560.

Blackhall LJ, Frank G, Murphy ST, *et al.* (1999) Ethnicity and attitutes toward life-sustaining technology. *Social Science Medicine* **48**, 1779–1789.

Braun UK, Beyth RJ, Ford ME, *et al.* (2008) Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end of life decision-making. *Journal of General Internal Medicine* **23**(3), 267–274.

California Catholic Conference (2019) Frequently Asked Questions about End-of-Life Care. Available at: https://www.cacatholic.org/teachings/embracing-our-dying/frequently-asked-questions-about-end-life-care (accessed 8 January 2019).

Castro CM, Wilson C, Wang F, *et al.* (2007) Babel babble: Physicians use of unclarified medical jargon with patients. *American Journal of Health Behavior* **31**(Suppl 1) S85–S95.

Colon M (2005) Hospice and Latinos: A review of the literature. *Journal of Social Work in End-of-Life and Palliative Care* **1**, 27–43.

Doak CC, Doak LG and Root JH (1996) *Teaching Patients With Low Literacy Skills*. Philadelphia, PA: JB Lippincott.

Hanchate A, Kronman AC, Young-Xu Y, *et al.* (2009) Racial and ethnic differences in end of life costs: Why do minorities cost more than whites? *Archives of Internal Medicine* **169**, 493–501.

Kelley AS, Wenger NS and Sarkisian CA (2010) Opiniones: End of life care preferences and planning among older latinos. *Journal of American Geriatric Society* **58**(6), 1109–1116.

Kutner M, Greenbery E and Baer J (2005) *A First Look at the Literacy of America's Adults in the 21st Century*. Washington, DC: National Center for Education Statistics. Available at: https://nces.ed.gov/naal/pdf/2006470.pdf (accessed 10 January 2019).

Kwak J and Haley WE (2005) Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* **45**, 634–641.

Loggers ET, Maciejewski PK, Paulk E, *et al.* (2009) Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *Journal of Clinical Oncology* **27**, 5559–5564.

Muni S, Engelberg RA, Treece PD, *et al.* (2001) The influence of race/ethnicity and socioeconomic status on end-of-life care in the ICU. *Chest* **139**(5), 1025–1033.

Paasche-Orlow MK, Parker RM, Gazmararian JA, *et al.* (2005) The prevalence of limited health literacy. *International Journal of General Medicine* **20**(2), 175–184.

Pan CX, Abraham O, Giron F, *et al.* (2015) Just ask: Hospice familiarity in Asian and Hispanic adults. *Journal of Pain and Symptom Management* **49**(5), 928–933.

Perkins HS, Geppert CM, Gonzales A, *et al.* (2002) Cross-cultural similarities and differences in attitudes about advance care planning. *J Gen Intern Med.* **17**(1), 48–57.

Pew Research Center (2019). Available at: https://www.pewresearch.org/fact-tank/2013/08/13/spanish-is-the-most-spoken-non-english-language-in-u-s-homes-even-among-non-hispanics/ (accessed 12 May 2019).

Rafaelli M and Ontai LL (2004) Gender socialization in Latino/a families: Results from 2 retrospective studies. *Sex Roles* **50**(5-6), 287–299.

Sabogal F, Marin G, Otero-Sabogal R, *et al.* (1987) Hispanic familism and acculturation: What changes and what doesn't. *Hispanic Journal of Behavioral Sciences* **9**, 397–412.

Shen MJ, Prigerson HG, Paulk E, *et al.* (2016) Impact of end-of-life discussions on the reduction of Latino/non-Latino disparities in do-not-resuscitate order completion. *Cancer* **122**(11), 1749–1756.

Smith AK, Sudore RL and Perez-Stable EJ (2009) Palliative care for Latino patients and their families. *JAMA* **301**(10), 1047–1057.

Sudore RL, Landefeld CS, Williams BA, *et al.* (2006) Use of a modified informed consent process among vulnerable patients: A descriptive study. *Journal of Internal Medicine* **21**(8), 867–873.

Talamantes MA, Lawler WR and Espino DV (1995) Hispanic American Elders: Caregiving norms surrounding the dying and the use of hospice services. *Hospice Journal* **10**(2), 35–49.

Talamantes MA, Gomez C and Braun KL (2000) *Advance Directives and End-of-Life Care: The Hispanic Perspective. Cultural Issues in End-of-Life Decision-Making.* Thousand Oaks, CA: Sage Publications, pp. 83–100.

Zaide GB, Pekmezaris R, Nouryan CN, *et al.* (2013) Ethnicity, race, and advance directives in an inpatient palliative care consultation service. *Palliative Support Care* **11**(1), 5–11.