Hospice Knowledge and Intentions among Latinos Using Safety-Net Clinics

Claire Selsky, M.A., Barbara Kreling, Ph.D., M.P.H., Gheorghe Luta, Ph.D., Solomon B. Makgoeng, M.S.,
Jessika Gomez-Duarte, B.A., Andrea Gabriela A. Barbo, M.S.,
Jeanne S. Mandelblatt, M.D., M.P.H., and Latin American Cancer Research Coalition

Abstract

Background: Hospice use is low in Latinos but we know little about explanations for this pattern.

Objective: To describe factors associated with knowledge of and intention to use hospice for cancer care.

Methods: We conducted a Spanish-language, interviewer-administered cross-sectional survey of 331 Latino immigrants from Central and South America in safety-net clinics. Hospice intentions were measured using a hypothetical scenario. We used logistic regression and multiple imputations to test associations between cultural values, social acculturation, and other variables and knowledge and intentions.

Results: Only 29% knew about hospice and 35% would choose hospice care (once it was defined). Collectivist (group-focused) views (odds ratio [OR] 1.06 per 1-point increase, 95% confidence interval [CI] 1.01-1.12, $p = .05$), endorsing family-centric values (OR 1.03 per 1-point increase, 95% CI 1.01-1.04, $p = .004$), and higher education were associated with greater hospice knowledge after considering covariates. Greater social ties were also independently associated with greater knowledge, but knowledge was not related to hospice intentions. Individuals who believed in maintaining secrecy about prognosis were 19% less likely to choose hospice than those who did not endorse secrecy (OR 0.81, 95% CI 0.67-0.99, $p = .038$). The most socially acculturated individuals were significantly more likely to choose hospice than those with less acculturation (OR 1.19 for each 1-unit increase, 95% CI 1.06-1.34, $p = .004$).

Conclusions: Hospice knowledge may be necessary but is not sufficient to increase hospice use among immigrant Latinos. Latino social networks and organizations may provide a natural leverage point for interventions. Interventions to increase hospice use may need to consider culturally related values.

Introduction

AT 50.5 MILLION, Latinos now make up 16.3% of the U.S. population and constitute the largest minority group in the country.^{1,2} Cancer is the second leading cause of death in this growing population and Latino cancer patients have a higher case fatality rate than whites.³ Unfortunately, despite their growing need, use of cancer palliative care, pain management, and hospice services are low among Latinos.⁴⁻⁶

These suboptimal palliative care patterns may be related to several factors, including difficulty accessing and affording services, limitations in language and health literacy, and cultural norms about death and dying.⁷⁻⁹ In our earlier research we found that Latinos can be secretive about prognosis and often subscribe to the view that family, and not the patient, should be the locus of end-of-life decision making.⁷ Such views are counter to the tenets of hospice care, such as patient

autonomy at the end of life.¹⁰ Recently there has been an increased effort by hospice organizations to reach out to Latinos.¹¹ However, these efforts are hampered by the relative paucity of data on the barriers to, and promoters of, hospice use in Latinos. Moreover, despite some research on ethnic and cultural differences in attitudes toward death and dying,¹²⁻¹⁹ there are limited quantitative data on how Latino cultural values may affect hospice use, and most of what is known comes from research with Mexican Americans.^{12,16,20,21}

In this cross-sectional study we evaluate knowledge about and intentions to use hospice among a community sample of immigrant Latinos from Central and South America in safety-net clinics. We hypothesized that greater social acculturation would be associated with greater knowledge about hospice after considering other factors. We also postulated that endorsement of family-centric and other cultural values would be related to intentions to use hospice. Our results are

intended to inform future interventions designed to increase hospice use among Latinos and their families at the end of life.

Methods

This institutional review board approved study was conducted by members of the Latin American Cancer Research Coalition (LACRC). The LACRC was an academic-community partnership with community safety-net clinics providing care to Latinos in the metropolitan Washington, D.C. area.

Setting and population

The study was conducted between June and August 2010 in seven freestanding safety-net clinics that provide low- or no-cost services primarily to recently immigrated Latinos (≤ 10 years in the United States). We recruited a convenience sample from each clinic. Eligible participants were self-identified as Latino, ≥ 21 years old, and not terminally ill or currently providing end-of-life care for a family member. We obtained informed consent (in Spanish); each participant received a fifteen-dollar gift card for his or her time.

We approached 414 patients and 88% consented to participate. The most common reasons for refusal included not having time, not being interested, and having other commitments. Among the 364 completing surveys, 24 were excluded post-hoc because they were missing more than 50% of their data as a result of interview interruption by the patient due to time conflicts. Among the sample of 340, we excluded 9 who were not immigrants. The remaining 331 individuals constitute the final analytic data set.

Data collection

We developed a structured interview instrument using validated Spanish-language instruments. Trained bicultural staff (i.e., those who had lived in a Latino country and in the United States) conducted the face-to-face interviews in a private space; interviews lasted about 30 minutes; 99% were completed in Spanish.

Measures

Outcomes. We used hospice knowledge and intentions as our outcome measures. Prior knowledge of hospice was ascertained first and was evaluated using seven true-false format items probing knowledge about aspects of hospice care including eligibility, services available, and location of services. We categorized responses into high versus low knowledge categories based on the median of the distributions of correct answers in the sample (results using continuous scores were similar).

We assessed hospice intentions using responses to a standardized hypothetical scenario depicting a terminal cancer patient who was not a family member or loved one. We used an iterative process to develop the scenario. First, we used information from prior focus groups (in Spanish) to develop the basic story line and response choices in Spanish.⁷ Next, we conducted cognitive laboratory testing of the scenario in Spanish with our target population to ensure comprehension, ease of response, and neutral terminology. Finally, the Spanish version of the scenario was translated into English and then independently back to Spanish by another staff member. Any differences were resolved via conference. We chose a

hypothetical scenario with a stranger, since direct discussion of death is difficult for many Latinos.⁷

We first described hospice services so that respondents would have the basic information when indicating their intentions about use. The scenario was then read to the participant. The scenario depicts a woman from El Salvador living in the United States with terminal cancer who has ≤ 6 months to live. The woman's physician recommends hospice care at home and describes the services available (nursing, help with pain medication, social work assistance, and spiritual support). The woman considers this and other options open to her. The respondents were asked what they would advise the woman do: use hospice, leave the United States, rely only on family caregiving in the United States, continue treatment, or other. The scenario is included in Table 1.

Independent variables. Cultural attitudes and social context were the primary independent variables; prior knowledge of hospice services was also used as a predictor of hospice intentions. Latino culture was conceptualized as the beliefs, values, and customs within this group and was assessed using several measures. The first were individual questions focused on openness versus secrecy about death and dying and patient- versus family-centered locus of decision making about end of life care.⁷ Attitudes towards family roles and responsibilities for cancer caregiving were measured using a Spanish-language translation of the Cultural Justifications of Caregiving Scale.²² This scale includes 10 items with Likert responses ranging 4 points from strongly disagree to strongly agree; reliability was excellent (Cronbach's $\alpha = .89$). Collectivism was measured using an 8-item validated Spanish-language instrument developed by Dilworth and colleagues.²³ Responses ranged from 1 to 9 (Cronbach's $\alpha = .61$). We also used the 18-item Familism Scale developed by Lugo and colleagues (Cronbach's $\alpha = .80$).²⁴

Social networks were measured using the Spanish-language items from the health information national trends survey (HINTS).²⁵ Social and other aspects of acculturation were measured using the social (Cronbach's $\alpha = .70$) and language (Cronbach's $\alpha = .75$) acculturation items from the Marin and Marin scales.²⁶

Controlling variables. Controlling variables included sociodemographic characteristics, medical mistrust, and prior experience with caregiving (yes/no). Sociodemographic variables included age, country of birth (limited to countries in Central or South America given the very small number from outside these areas), length of time living in the United States, educational level, and marital status. General medical mistrust was assessed using a Spanish translation of the 7-item LaVeist Medical Mistrust Scale (Cronbach's $\alpha = .80$).²⁷

Data analysis

We evaluated the associations between hospice knowledge and intention to use hospice and study variables using *t* tests (or Wilcoxon signed-rank tests if needed) and chi-square tests (or Fisher's exact tests if needed). Next we used multiple imputation methods to impute values for missing data; most variables were missing up to 5% of values but three variables had 19%-37% missing values. The R package "MI"

TABLE 1. SCENARIO USED TO MEASURE HOSPICE INTENTIONS

This scenario is described after telling participants about hospice services:

Lupe was born in El Salvador and came to the United States to work as an adult. Lupe was living in the United States when she was diagnosed with serious liver cancer. Although her doctors gave her the best care they could, Lupe was told she would only live for another 6 months or possibly less. The doctor said he didn't have any more treatments that could help to cure her cancer.

The doctor told Lupe about her options. He said Lupe was eligible for hospice because she would live 6 months or less due to her cancer. The doctor advised Lupe to have hospice come in and help her and her family at her home. With hospice helping, nurses could visit and teach Lupe's family about how to give her pain medicine. Social workers could help Lupe's family fill out the paperwork to send to their health insurance company. Religious staff could visit Lupe and her family to provide spiritual support.

Lupe also considered continuing to try to treat the disease – though the doctor said it was not curable. Another option she thought about was leaving the United States and returning to El Salvador. She also considered staying at home and having only her family help her.

What would you advise Lupe to do?

- 1 Use hospice
- 2 Leave the United States
- 3 Have only family care for her
- 4 Continue treatment
- 5 Other
- 88 Don't know/unsure

was used to generate 10 imputed data sets.²⁸ We used logistic regression to separately model hospice knowledge and intentions to use hospice. We began by including all variables that were associated with the outcome at the $p < 0.10$ level in bivariate analysis. We then performed a backwards elimination to remove variables no longer significantly related to the outcome (at ≤ 0.10) after consideration of the other covariates. However, we specified retention of age, gender, country of birth, and years living in the United States to control for other unmeasured factors related to acculturation that might affect our outcomes of interest. We also retained experience with caregiving to control for the effects of life experiences related to death and dying. The estimates from the logistic regression models corresponding to the 10 imputed datasets were combined according to the method of Rubin.^{29,30} The predictive ability of the models was assessed using the c-statistic. All analyses were performed using statistical software SAS (SAS version 9.2 for Windows; SAS Institute Inc., Cary, NC) and R 2.13.0.

Results

This sample group had fairly low formal education levels. Two-thirds were originally from Central America. The most prevalent Central American countries were El Salvador (37% of total), Guatemala (15%), and Honduras (9%). Overall, these immigrants had lived in the United States for an average of 12.3 years. Personal experience with caregiving for an ill family member was reported by 30% of the participants (Table 2).

Hospice knowledge

Only 29% of participants stated that they had heard of hospice care; the primary sources were friends and family. The mean hospice knowledge level was 3.1 (on a scale of 0 to 7, SD 2.5). Higher education was associated with more hospice knowledge (Table 2). Interestingly, those who subscribed to higher degrees of endorsement of Latino cultural values, including collectivism, emphasis on family-centric values and

family caregiving, had higher hospice knowledge levels than those with lower endorsement of these perspectives. Social acculturation and contact with social organizations were associated with greater knowledge about hospice, but language acculturation was not.

Cultural factors and sociocultural context were significantly associated with hospice knowledge after considering covariates (Table 3). Individuals who held stronger collectivist views (OR 1.06 per 1-point increase on the scale, 95% CI 1.001-1.12, $p = 0.051$) or endorsed the importance of family-centric values (OR 1.03 per 1-point increase on the scale, 95% CI 1.01-1.04, $p = 0.004$) were more likely to have higher knowledge than those with less of a collectivist or family perspective. Participants who were affiliated with community social organizations were nearly three times more likely (OR 2.99, 95% CI 1.72-5.22, $p = 0.0001$) to have high knowledge than those who were unaffiliated. The odds of having high hospice knowledge were 1.84 times (95% CI 1.02-3.34, $p = 0.045$) greater for women compared to men, even after considering past caregiving experience. Participants with higher educational levels also had higher odds of having high (versus low) hospice knowledge than those with lower education (OR 2.72, 95% CI 1.29-5.74, $p = 0.009$).

Intent to use hospice

In the hypothetical scenario, when asked what the terminally ill patient should do, 35% stated that she should use hospice, 38% felt that she should continue treatment, 12% suggested she leave the country, and the remainder chose family care or other responses. Answering that the hypothetical patient should use hospice was associated with higher levels of familism (family needs take precedence over individual needs), cultural family caregiving and believing that the family should make decisions (Table 2). Those choosing hospice care were also less likely to believe in secrecy regarding prognosis than those who did not endorse a hospice decision.

After considering the covariates related to hospice intentions, individuals who believed in maintaining secrecy about

TABLE 2. UNADJUSTED ASSOCIATIONS WITH HOSPICE KNOWLEDGE OR INTENTIONS AMONG IMMIGRANT LATINOS (N=331)

	Overall n (%)	Knowledge		P	Intent		P
		High n (%)	Low n (%)		Yes n (%)	No n (%)	
Demographic Factors							
Age, mean (SD)	43 (SD 14)	45 (SD 15)	41 (SD 14)	0.004	44 (SD 15)	43 (SD 14)	0.546
Gender							
Male	150 (47)	63 (38)	87 (57)	0.001	56 (50)	94 (46)	0.480
Female	167 (52)	101 (62)	66 (43)		56 (50)	111 (54)	
Education							
≤High school	259 (81)	125 (76)	134 (86)	0.021	79 (71)	180 (86)	0.001
>High school	62 (19)	40 (24)	22 (14)		33 (30)	29 (14)	
Marital status							
Married	167 (52)	86 (52)	81 (52)	0.972	62 (55)	105 (50)	0.382
Not married	154 (48)	79 (48)	75 (48)		50 (45)	104 (50)	
# Years in U.S., mean (SD)	12 (SD 10)	14 (SD 11)	11 (SD 8)	0.004	12 (SD 10)	12 (SD 9)	0.903
Ever a caregiver							
Yes	95 (30)	58 (35)	37 (24)	0.025	32 (29)	63 (30)	0.769
No	226 (70)	107 (65)	119 (76)		80 (71)	146 (70)	
Cultural Factors							
Collectivism, mean (SD)	59 (SD 6)	60 (SD 5)	58 (SD 7)	<0.001	58 (SD 5)	59 (SD 7)	0.514
Missing	5 (2)	4 (2)	1 (1)		0 (0)	5 (2)	
Familism, mean (SD)	159 (SD 18)	163 (SD 16)	156 (SD 19)	<0.001	157 (SD 17)	161 (SD 18)	0.055
Missing	24 (7)	11 (7)	13 (8)		6 (5)	18 (9)	
Caregiving culture, mean (SD)	36 (SD 6)	37 (SD 6)	35 (SD 6)	0.034	35 (SD 7)	37 (SD 5)	0.012
Missing	6 (2)	1 (1)	5 (3)		1 (1)	5 (2)	
Secrecy about death, mean (SD)	2 (SD 1)	2 (SD 1)	2 (SD 1)	0.475	2 (SD 1)	2 (SD 2)	0.017
Family decision locus, mean (SD)	2 (SD 2)	2 (SD 2)	2 (SD 2)	0.393	3 (SD 2)	2 (SD 2)	0.050
Missing	6 (2)	3 (2)	3 (2)		1 (1)	5 (2)	
Medical mistrust, mean (SD)	22 (SD 5)	25 (SD 5)	22 (SD 5)	0.339	21 (SD 6)	22 (SD 5)	0.236
Missing	81 (25)	36 (22)	45 (29)		27 (24)	54 (26)	
Acculturation factors							
Social acculturation, mean (SD)	8 (SD 2)	9 (SD 2)	8 (SD 3)	0.037	9 (SD 2)	8 (SD 2)	0.008
Missing	118 (37)	54 (33)	64 (41)		39 (35)	79 (38)	
# of social organizations							
None	203 (63)	80 (48)	123 (79)	<0.001	71 (63)	132 (63)	0.967
1+	118 (37)	85 (52)	33 (21)		41 (37)	77 (37)	
Knowledge of hospice							
High	165 (51)	—	—		63 (56)	102 (49)	0.203
Low	156 (49)	—	—		49 (44)	107 (51)	
Intent to use hospice							
Yes	112 (35)	63 (38)	49 (31)	0.203	—	—	
No	209 (65)	102 (62)	107 (69)		—	—	

Significant associations shown in bold.

prognosis were 19% less likely to choose hospice care than those who did not endorse secrecy (OR 0.81, 95% CI 0.67-0.99, $p=0.038$) (Table 3). Other culturally related variables were not associated with hospice intentions but social context was important. Those who were the most socially acculturated were significantly more likely to choose hospice care than those with less social acculturation (OR 1.19 for each 1-unit increase in social acculturation, 95% CI 1.06-1.34, $p=0.004$). Those with a higher (versus lower) education level were also more likely to have chosen hospice care for the hypothetical patient. Interestingly, high hospice knowledge was not significantly related to hospice intentions after considering other covariates.

Discussion

This is the first study that we are aware of to examine correlates of hospice knowledge and intentions to use hospice

services in a Latino sample from safety-net clinics. Our results indicate that knowledge is low in this population and that few Latinos think that they would choose hospice care if needed. Culturally related constructs and social context were significantly associated with both hospice knowledge and intention to use hospice. More highly educated Latinos were more likely to report higher knowledge and intentions to use hospice than those with lower educational levels. Interestingly, greater knowledge about hospice was not associated with intentions to use hospice care.

Hospice knowledge is low in the general U.S. population.³¹⁻³³ As was seen in our study, Latinos have low knowledge about hospice. It is possible that information about hospice is "lost in translation" for Latinos. Hospice translates to *hospicio* in Spanish, meaning "orphanage" or "place for poor people." Thus, efforts to increase knowledge about end-of-life care options will need to be sensitive to language barriers and require clear communication when

TABLE 3. ADJUSTED ODDS¹ OF HOSPICE KNOWLEDGE (HIGH VS. LOW) AND INTENTIONS (YES VS. NO) AMONG A SAMPLE OF IMMIGRANT LATINOS IN SAFETY-NET CLINICS

	Knowledge		Intent	
	OR (95% CI)	P-value	OR (95% CI)	P-value
Age (per 5 years)	1.01 (0.98–1.03)	0.546	1.01 (0.98–1.03)	0.674
Gender (female vs. male)	1.84 (1.02–3.34)	0.045	1.05 (0.59–1.87)	0.865
Education (high school graduate vs. less than HS)	2.72 (1.29–5.74)	0.009	2.55 (1.32–4.93)	0.005
Number of years in U.S.	1.01 (0.98–1.05)	0.469	1.00 (0.97–1.03)	0.950
Ever a caregiver (yes vs. no)	1.64 (0.92–2.91)	0.094	0.71 (0.40–1.27)	0.248
Collectivism ²	1.06 (1.00–1.12)	0.051	–	–
Familism ²	1.03 (1.01–1.04)	0.004	–	–
Secrecy about death	–	–	0.81 (0.67–0.99)	0.038
Social acculturation ²	–	–	1.19 (1.06–1.34)	0.004
Member of community social Organizations (yes vs. no)	2.99 (1.72–5.22)	0.0001	–	–
C statistic	0.77–0.78		0.69–0.71	

¹Backwards logistic regression testing the effects of each variable, after considering the other covariates; age, number of years living in the U.S., gender, and experience of caregiving (yes vs. no) were retained in the models for face validity and to capture unmeasured aspects of Latino experiences even though they were not significantly related to the outcomes. All analyses are also controlled for clinic and region of national origin.

²Items based on scale scores are coded from low to high (e.g., a high score on the collectivism scale reflects a high degree of collectivism) and the odds ratio refers to the odds for each one-point increase in the scale score.

using translators.^{34–37} It is also possible that consideration of health literacy and/or access to Latino providers could enhance communication of and education about hospice.^{34,38} However, our result that knowledge was not independently related to intentions to use hospice suggests that translation and communication of information is important but not sufficient to increase access of Latinos to hospice care. Future interventions will need to consider these findings and likely will need to target factors beyond knowledge change.

While rates of hospice use have increased over time, Latinos have some of the lowest rates of hospice use in the United States,^{9,39–41} but this is not seen in all studies or for all causes of death.^{6,42} Since only 35% of our Latino sample would have recommended hospice services in the hypothetical scenario depicting a cancer patient at the end of life, there may indeed be an ethnicity gap in hospice use. Since education attainment was associated with intention to use hospice care, it is possible that the low educational levels among Latinos, especially immigrant Latinos, may contribute to this gap. Other factors that may promote such a gap include low insurance rates in Latinos and differences in cultural perspectives on death and dying.³⁶ It will be interesting to replicate and expand our findings to further understand barriers to hospice use in Latinos.

Our results support the idea that culturally related beliefs are one important explanation for the low rates of hospice knowledge and use in Latinos. For instance, we found that the family-centric and collectivist perspectives that are common in Latino groups were associated with higher hospice knowledge, although the strength of the association was only moderate. These relationships will be interesting to explore in future research. Since others have shown that the family is the preferred locus of communication for end-of-life care in Latino families,^{10,43} our results suggest that outreach messages could stress the fact that hospice services can be delivered at home without disruption of family-oriented values.

Many Latinos believe that families should keep the patient's prognosis a secret.^{7,10} We found that endorsement of

the idea that one should maintain secrecy about prognosis at the end of life decreased intentions to use hospice. This idea is also consistent with what is known about general Latino cultural preferences for indirect communication.^{12,16,20,21}

In our sample, 38% felt that the hypothetical cancer patient should maintain treatment with a curative intent. Others have observed that Latinos in the Medicare population prefer life-sustaining therapy more often than whites^{10,44} and have higher rates of intensive procedures (and health care costs) in the last six months of life than whites or blacks.⁴⁵ These observations suggest that Latino preferences may be inconsistent with the philosophy of hospice with its emphasis on palliative and not curative care, leading to low rates of use of hospice services.¹⁰ However, Keating and colleagues found that there were no differences in hospice use by race/ethnicity among patients in a large managed care organization,⁸ highlighting the difficulty in separating health care access from cultural values held by those with limited access.

In addition to cultural constructs, we found that higher levels of social acculturation and affiliation with social networks were important in increasing both hospice knowledge and intentions. This result suggests that some information about hospice is conveyed through Latino social networks and that these networks might be exploited as information channels.

Several caveats should be considered in evaluating our results, including our outcome measure for hospice, cross-sectional design, sample homogeneity, and the scope of items about end-of-life care and culture. We measured intentions to use hospice among a healthy community sample. While intentions correlate well with many health behaviors, we do not have any information on how well hospice intentions predict actual behavior. Volandes and colleagues have found that viewing a video of an actual patient at the end of life significantly increased intentions to use hospice,³⁴ but it remains uncertain if that translated into behavior regarding end-of-life care choices. Given the cross-sectional design of this study, we are unable to determine causal links or directionality of the observed associations. Our safety-net population was

all low income and uninsured, so that we could not test the impact of insurance and perceived health care access on hospice knowledge or intentions. We focused narrowly on hospice care and did not evaluate correlates of other aspects of end-of-life care, such as pain management, advanced directives, or health care proxies.¹⁰ We included many measures of culturally related constructs, but it is difficult to capture the essence of an individual's or group's values with survey items. There may be cultural differences between the Central and South American subgroups included in our study that were not fully captured by considering country of origin. And generalizations about Latino culture can promote stereotypes that may not be true for a particular patient facing the end of life.¹⁹

In summary, our research suggests that knowledge may be necessary but not sufficient to increase hospice use among immigrant Latinos. Latino social networks and organizations may provide a natural leverage point for interventions. Interventions to increase hospice use may also need to consider culturally related values.

Acknowledgments

This work was supported by grants U01 CA114593 and 2K05CA096940 (JM) from the National Cancer Institute and PEP-08-230-01-PEP1 from the American Cancer Society (BK). This research was also supported by the Clinical and Molecular Epidemiology and Biostatistics, Biomathematics and Bioinformatics Shared Resources at Lombardi Comprehensive Cancer Center under NCI grant #P30CA51008.

The Latin American Cancer Research Coalition included:

Stacey Banks, Larisa Caicedo M.A., Janet Cañar M.D., M.P.H., Michael Dalious M.A., Marguerite Duane M.D., M.H.A., Jessica Gomez-Duarte, Kirsten Edmiston M.D., Karol Espejo, Ronald Greger M.D., Margarita Gutierrez, Elmer E. Huerta M.D., M.P.H., Anna Maria Izquierdo-Porrera, M.D., Barbara Kreling Ph.D., M.P.H., Maria Lopez-Class Ph.D., M.P.H., Gheorge Luta Ph.D., Jeanne Mandelblatt M.D., M.P.H., Guadalupe Mota, Barbara Merritt R.N., Noel Mueller M.P.H., Nancy Pallesen M.S.W., Margarita Paredes M.D., Monique Perret-Gentil M.D., M.S., Jyl Pomeroy R.N., Dino W. Ramzi M.D., M.P.H., Christine Reesor M.S.N., F.N.P., Juan Romagoza, M.D., Michael A. Sanchez M.P.H., CHES, Claire Selsky M.A., Cherie Spencer M.S., Alicia Wilson, Bin Yi M.S.

Author Disclosure Statement

The authors do not have any commercial associations or financial interests that might create a conflict of interest.

References

1. U.S. Census Bureau, U.S. Department of Commerce, Economics and Statistics Administration. Population by age, sex, race and Hispanic and Latino origin for the United States. www.census.gov/population. (Last accessed November 6, 2011.)
2. U.S. Population Projections: 2005-2050. Pew Research Center Social and Demographic Trends. pewhispanic.org/files/reports/85.pdf. (Last accessed November 6, 2011.)
3. American Cancer Society. *Cancer Facts & Figures* 2009. Atlanta: American Cancer Society. www.acs.org. (Last accessed November 6, 2011.)
4. National Hospice and Palliative Care Organization. Facts and figures on hospice care in America. National Hospice and Palliative Care Organization. Washington, DC, 2007. www.nhpco.org. (Last accessed November 6, 2011.)
5. Colon M, Lyke J: Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *AJHPM* 2003;20:182-190.
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;39:969-983.
7. Kreling B, Selsky C, Mandelblatt J: 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. *Palliat Med* 2010;24:427-434.
8. Keating NL, Herrinton LJ, Zaslavsky AM, Liu L, Ayanian JZ: Variations in hospice use among cancer patients. *J Natl Cancer Inst* 2006;98:1053-1059.
9. Colon M: Hospice and Latinos: A review of the literature. *J Soc Work End Life Palliat Care* 2005;1:27-43.
10. Kwak J, Haley WE: Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* 2005;45:634-641.
11. National Hospice and Palliative Care Organization. NHPCO's 2004 Facts and Figures. www.nhpco.org/files/public/Facts_Figures_for_2007. (Last accessed October 1, 2008.)
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.
13. Koenig BA, Gates-Williams J: Understanding cultural differences in caring for dying patients. *West J Med* 1995;163:244-249.
14. Crawley LM, Marshall PA, Lo B, Koenig BA: Strategies for culturally effective end-of-life care. *Ann Intern Med* 2002;136:673-679.
15. Braun KL, Onaka AT, Horiuchi BY: End-of-life preferences in Hawaii. *Hawaii Med J* 2000;59:440-446.
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;18:391-396.
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;47:133-156.
18. Volker DL: Control and end-of-life care: Does ethnicity matter? *Am J Hosp Palliat Care* 2005;22:442-446.
19. Crawley LM: Racial, cultural, and ethnic factors influencing end-of-life care. *J Palliat Med* 2005;8:S58-S69.
20. Sabogal F, Marin G, Otero-Sabogal R, Marin BV, Perez-Stable, EJ: Hispanic familism and acculturation: What changes and what doesn't? *Hisp J Behav Sci* 2008;9:397-412.
21. Klessig J: The effect of values and culture on life-support decisions. *West J Med* 1992;157:316-322.
22. Dilworth-Anderson P, Brummett BH, Goodwin P, Williams SW, Williams RB, Siegler IC: Effects of race on cultural justifications for caregiving. *J Gerontol B Psychol Sci Soc Sci* 2005;60:S257-S262.
23. Bagley SP, Angel R, Dilworth-Anderson P, Liu W, Schinke S: Adaptive health behaviors among ethnic minorities. *Health Psychol* 1995;14:632-640.

24. Lugo-Steidel AG: A new familism scale for use with latino populations. *Hisp J Behav Sci* 2003;25:312–330.
25. Nelson DE, Kreps GL, Hesse BW, Croyle RT, Willis G, Arora NK, Rimer BK, Viswanath KV, Weinstein N, Alden S: The health information national trends survey (HINTS): Development, design, and dissemination. *J Health Commun* 2004; 9:443–460; discussion 81–84.
26. Marin G, Sabogal F, Marin B, Otero-Sabogal R, Perez-Stable EJ: Development of a short acculturation scale for Hispanics. *Hispanic J Behav Sci* 1987;9:183–205.
27. LaVeist TA, Isaac LA, Williams KP: Mistrust of health care organizations is associated with underutilization of health services. *Health Serv Res* 2009;44:2093–2105.
28. Gelman A, Hill J, Su YS, Yajima M, Pittau MG: MI-Missing data imputation and model checking, R packing version 0.09-14. CRAN.R-project.org/package=mi. (Last accessed September 15, 2011.)
29. Little R, Rubin D: *Statistical Analysis with Missing Data*. New York: John Wiley, 1987.
30. Rubin D: Imputation for nonresponse in surveys. New York: John Wiley, 1987.
31. Taxis JC, Keller T, Cruz V: Mexican Americans and Hospice Care: Culture, Control, and Communication. *J Hosp Palliat Nurs* 2008;10(3):133–141.
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. National Hospice and Palliative Care Organization. Washington, D.C., 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.
34. Volandes AE, Paasche-Orlow M, Gillick MR, Cook EF, Shaykevich S, Abbo ED, Lehmann L: Health literacy not race predicts end-of-life care preferences. *J Palliat Med* 2008;11:754–762.
35. Smith AK, Sudore RL, Perez-Stable EJ: Palliative care for Latino patients and their families: Whenever we prayed, she wept. *JAMA* 2009;301:1047–1057.
36. Born W, Greiner KA, Sylvia E, Butler J, Ahluwalia JS: Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J Palliat Med* 2004;7:247–256.
37. Heyman JC, Gutheil IA: Older Latinos' attitudes toward and comfort with end-of-life planning. *Health Soc Work* 2010; 35:17–26.
38. Kacheroo S: Variations in hospice use among cancer patients. *J Natl Cancer Inst* 2007;99(1):84.
39. Haas JS, Earle CC, Orav JE, Brawarsky P, Neville BA, Acevedo-Garcia D, Williams DR: Lower use of hospice by cancer patients who live in minority versus white areas. *J Gen Intern Med* 2007;22:396–399.
40. Givens JL, Tjia J, Zhou C, Emanuel E, Ash AS: Racial and ethnic differences in hospice use among patients with heart failure. *Arch Intern Med* 2010;8:427–432.
41. Hospice Facts and Figures. Hospice Association of America. www.nahc.org/facts/hospicestats10.pdf. (Last accessed November 6, 2011.)
42. Adams CE, Horn K, Bader J: Hispanic access to hospice services in a predominantly hispanic community. *Am J Hosp Palliat Care* 2006;23:9–16.
43. Kelley AS, Wenger NS, Sarkisian CA: Opiniones: End-of-life care preferences and planning of older Latinos. *J Am Geriatr Soc* 2010;58:1109–1116.
44. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES: Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med* 2009;24:695–701.
45. Hanchate A, Kronman AC, Young-XU Y, Ash AS, Emanuel E: Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites? *Arch Intern Med* 2009;169: 493–501.

Address correspondence to:

Jeanne S. Mandelblatt, M.D., M.P.H.

Department of Oncology, Cancer Control Program

Georgetown University Medical Center

3300 Whitehaven Street NW, Suite 4100

Washington, DC 20007

E-mail: mandelbj@georgetown.edu