Predictors of Intensive End-of-Life and Hospice Care in Latino and White Advanced Cancer Patients

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Abstract

Background: The role of end-of-life (EOL) care preferences and conversations in receipt of care near death for Latinos is unclear.

Objective: This study examines rates and predictors of intensive EOL and hospice care among Latino and white advanced cancer patients.

Design: Two-hundred-and-ninety-two self-reported Latino ($n=58$) and white ($n=234$) Stage IV cancer patients participated in a U.S. multisite, prospective, cohort study from September 2002 to August 2008. The Latino and white, non-Hispanic participants were interviewed and followed until death, a median of 118.5 days from baseline.

Measurements: Patient-reported, baseline predictors of EOL care included EOL care preference; terminal illness acknowledgement; EOL discussion; completion of a DNR order; and religious coping. Caregiver postmortem interviews provided information regarding EOL care received. *Intensive EOL care* was defined as resuscitation and/or ventilation followed by death in an intensive care unit. Hospice was either in- or outpatient.

Results: Latino and white patients received intensive EOL and hospice care at similar rates (5.2% and 3.4% for intensive care, $p=0.88$; 70.7% versus 73.4% for hospice, $p=0.33$). No white or Latino patient who reported a DNR order or EOL discussion at baseline received intensive EOL care. Religious coping and a preference for life-extending care predicted intensive EOL care for white patients (adjusted odds ratio [aOR] 6.69 [$p=0.02$] and aOR 6.63 [$p=0.01$], respectively), but not for Latinos. No predictors were associated with Latino hospice care.

Conclusions: EOL discussions and DNR orders may prevent intensive EOL care among Latino cancer patients. Efforts should continue to engage Latino patients and caregivers in these activities.

Introduction

STUDIES SUGGEST Hispanic patients prefer more life-sustaining interventions when faced with terminal illness than non-Hispanic white patients.^{1–3} Surveys have also found Hispanics are less likely to participate in advance care planning (ACP)^{2,4–8}; favor participation in end-of-life (EOL) or prognostic discussions with physicians^{5, 6}; or are knowledgeable of and have positive attitudes toward hospice care^{9,10} when compared to non-Hispanic white individuals. However, Hispanic patients are more likely to receive life-sustaining interventions at EOL and to die in a hospital than non-Hispanic white patients.^{11–13} Authors have asserted that higher intensity EOL care among Hispanics may be consistent

with the preference for such care among members of this ethnic group.

These observations appear to run counter to a frequently cited cultural preference for home-based care near death among Hispanics.^{9, 14–17} Investigators have pointed to barriers to traditional patterns of EOL care among Hispanics in the United States to explain this apparent contradiction and the disparity in hospice use among Hispanics compared to non-Hispanic whites in early studies.^{17–19} Proposed barriers to hospice care have included neighborhood effects²⁰ (e.g., lack of hospice resources in majority Hispanic communities) and cultural and language differences with hospice providers.^{9,16,21–22} In addition, Johnson et. al pointed to higher rates of in-home, rather than in-facility, deaths among

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Hispanic hospice enrollees compared to their non-Hispanic white counterparts as further evidence of a cultural preference for home-based EOL care among Hispanics.¹⁶ However, more recent studies suggest Hispanic cancer patients may have achieved parity with non-Hispanic white cancer patients in receipt of hospice care.^{23,24} Few data exist to validate proposed barriers as the specific reason for potentially or historically lower rates of hospice use.

Similarly, limited data are available to address the role of patient-related factors (such as patient preferences) or consequences of doctor-patient communication (i.e., prognostic awareness and doctor-based ACP) in prospectively predicting the rate of intensive EOL and hospice care among terminally ill Hispanic cancer patients. An effective understanding of the role of these potentially predictive and mutable factors in receipt of EOL care may identify opportunities for interventions that ensure care near death is consistent with the patient's wishes, cultural background, and best practices at EOL.

To study the relationship of patient and communication-based factors in the prediction of EOL care for self-reported Hispanic and white advanced cancer patients, we used data from Coping with Cancer (CWC), a prospective, multisite study of racially and ethnically diverse terminally ill cancer patients. Based on prior published studies, we hypothesized patient preferences for care,^{2,5,8} terminal illness awareness,⁸ having had an EOL discussion with a physician or giving a DNR order,⁶ and religious coping²⁵ would vary based on whether the patient was Hispanic and would be important predictors of both intensive EOL care and hospice care among Hispanic as well as white patients.

Patients and Methods

Study sample

Recruitment techniques, dates, sites, inclusion/exclusion criteria, and participation rates for the CWC study have been reported previously.²⁵ Briefly, CWC recruited adult (age > 20 years) cancer patients with metastatic disease refractory to first-line chemotherapy and their informal caregivers between September 2002 to February 2008 from seven sites in the Northeast and Texas. Given the vast majority of our Hispanic participants originated in Latin or Central America, *Latino* will be used preferentially throughout the remainder of this report. Possible participants were referred by a clinician and had to exhibit adequate stamina to complete the interview as determined by the interviewer. All research was approved by the institutional review board at each site prior to any research being conducted. Interviewers were trained to assess the distress and fatigue of patients and caregivers and to respond by taking breaks, rescheduling or ending the interview. Additionally, interviewers were trained to refer patients and caregivers to local health professionals or an on-call psychiatrist for the study as needed (e.g., if the participant met diagnostic criteria for major depressive disorder).

Participants ($n=670$) were more likely to be Latino (12% versus 5.1%, $p=0.008$) and less distressed on a five-point Likert scale whose extremes ranged from one ("minimal/nonexistent") to five ("distraught") (mean score 2.53 versus 2.94; $p<0.001$). Participants were otherwise demographically similar to nonparticipants ($n=274$). When comparing non-participant and participant Latinos, there were no significant differences in gender, age, educational attainment, or level of

distress (all variables available and in common for both groups). The sample for this analysis was limited to patients who had died ($n=371$) with complete information on location of death ($n=370$), self-reported Latino or white ethnicity ($n=293$), and complete information on at least four of the five predictors of interest, resulting in a total of 292 subjects (58 Latino and 234 white patients). Black patients were not included here, because they were recently included in a comparison with white patients.²⁶ Understanding that observed differences in outcomes may be the result of diverse factors for each racial or ethnic group, and in turn require different recommendations for change to improve EOL care, we have focused only on Latino and non-Latino white differences in this paper. However, the results from our black and Latino samples are compared and contrasted in the discussion section of this paper.

Measures

Demographic and health measures

Patients and caregivers participated in separate interviews conducted by trained, bilingual interviewers in either English or Spanish. Ethnicity was assessed with the question, "What race or ethnicity do you consider yourself to be?" Response options included white, black, Hispanic, Asian-American/Pacific Islander/Indian, Other, Refused, and Do not know. Participants were allowed to select as many options as were personally appropriate, with multiple answers recorded in the Other category. However, only three participants used this option, and none included Hispanic ethnicity.

The following scales were completed: McGill Quality of Life (QOL) Questionnaire,²⁷ Structured Clinical Interview for the DSM-IV (SCID) Axis I Modules,²⁸ Karnofsky Performance Status Scale,²⁹ and Charlson Comorbidity Index.³⁰ All scales are psychometrically sound and have established reliability and validity.^{28,30-33} Patient acculturation was measured via the Brief Acculturation Scale (BAS), a five question Likert-based scale (with scores ranging from 5 to 25 with higher scores indicating individuals are more highly acculturated or use English only). The BAS was adapted from the work of Cuellar^{30,31} and investigates the use of English versus non-English language for reading, speaking, thinking, use in the home, as a child, and with friends. Patients were administered this scale if they indicated being born in a country other than the United States or if English was not their primary or native language.

Cancer type was determined via chart review. Caregivers participated in a postmortem interview to determine EOL care received in the last week of life and the location of death. A postmortem questionnaire was administered to the caregiver most closely involved in the patient's care during the last week of life within two to three weeks of death.

End-of-life care predictors

The two primary outcomes were "intensive EOL care" defined as CPR and/or ventilation within the last week of life followed by death in an intensive-care unit and in- or outpatient hospice care. Having a preference for intensive EOL care was defined as "Extend life as much as possible" rather than "Relieve pain or discomfort as much as possible" in answer to the following question: "If you could choose, would you prefer: (1) a course of treatment that focused on extending life

as much as possible, even if it meant more pain and discomfort, or (2) on a plan of care that focused on relieving pain and discomfort as much as possible, even if that meant not living as long?" Terminal illness acknowledgement was assessed via the question, "How would you describe your current health status?" Those responding "relatively healthy and terminally ill" or "seriously and terminally ill" were designated as acknowledging their terminal illness, while those answering "relatively healthy" or "seriously ill but not terminally ill" were not. The following questions (with response options of "yes" or "no") were asked to assess having an EOL discussion or a DNR order, respectively: (1) "Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?" and (2) "Have you completed a DNR order?" Religious coping was measured via Pargament's Brief RCOPE.³² A description of the scale and the rationale for its use has been reported previously.²⁵

Statistical Analysis

Ethnic differences in patient demographic and clinical characteristics were evaluated using two sample t-tests for continuous variables, Cochran-Mantel-Haenszel statistics for categorical variables and chi square statistics for binary variables. Logistic regression was used to determine the association between ethnicity and EOL care received and between ethnicity and each EOL-care predictor, using white patients as the reference group. Stratified by ethnicity, logistic regression models were used to test the association of intensive EOL care with each EOL-care predictor. All patient sociodemographic and clinical characteristics (see Table 1) were considered as possible confounders in each model if significantly associated with ethnic status or the outcome of interest. Possible confounders were adjusted for if the association between predictor and outcome was at a significance level of $p < 0.10$. The confounding variables considered in each model are documented in the footnotes of each table and within the text of the results section. Analyses were repeated including white and Latino patients from only those sites that contributed at least one Latino to the analysis.

Statistical inferences were based on two-sided tests with a significance cut-point of $p < 0.05$. Data were analyzed with the SAS System for Windows v. 9.1 (SAS Institute, Inc., Cary, NC).

Results

Patient characteristics

The sociodemographic and clinical characteristics of the sample are reported in Table 1. Of the 42 Latino patients born outside of the United States, 36 (85.7%) were born in Mexico. Other countries of origin included Cuba ($n=1$), Colombia ($n=1$), El Salvador ($n=2$), Honduras ($n=1$), and Ecuador ($n=1$). English was the native language for 12 Latino patients; interviews were conducted in English for 20 Latino participants.

Latino patients were significantly less likely to have lung cancer, be educated or insured. Latinos were more likely to be Catholic, from Parkland in Texas, and score higher on the McGill QOL Questionnaire existential domain than white patients, although their overall QOL did not differ significantly from that of white patients.

Ethnicity and EOL Care Predictors

There were no differences in the rate of positive religious coping, EOL discussions, or preferences for life-extending care among Latino and white patients (see Table 2). Latino patients were less likely to acknowledge their condition was terminal (19% of Latinos versus 47.4% white patients, aOR 0.18, $p=0.0001$) and to have DNR orders (22.4% of Latinos versus 50.4% of white patients, aOR 0.23, $p=0.0003$), controlling for the recruitment site and Karnofsky Performance Status Scale in both models. There was no association between the language in which the interview was conducted or patient acculturation and any of the EOL-care predictors (data not presented).

EOL Care Received by Ethnic Status

Intensive EOL care

Latino patients received intensive EOL care at the same rate as white patients (5.2% and 4.9%, respectively, $p=0.94$). Of the sociodemographic variables, only gender was associated significantly with receipt of intensive EOL care in univariate analyses. All Latino individuals who received intensive EOL care were male. No white or Latino patient who reported having a DNR order or an EOL care discussion at baseline received intensive EOL care in the last week of life. In analyses stratified by ethnicity, terminal illness acknowledgement was not a significant predictor of intensive EOL care in either group (see Table 3). While positive religious coping and having a preference for life-extending care were predictive of intensive EOL care for white patients (religious coping OR 6.69, $p=0.02$ and patient preference OR 6.63, $p=0.01$), neither were predictive for Latino patients. Neither patient acculturation nor having conducted the interview in Spanish was associated with receipt of intensive EOL care.

Hospice care

The rates of hospice care were similar between Latino and white patients (70.7% versus 69.5% respectively; $p=0.94$). Among the sociodemographic variables, only gender and marital status were significantly associated with receipt of hospice care in univariate analysis; this relationship was not observed for either variable in multivariable analyses. In stratified analyses, none of the proposed predictors were significantly associated with receipt of hospice care among Latinos (data not shown). Among whites, patient preferences (aOR 0.41, $p=0.02$), EOL discussions (aOR 2.20, $p=0.04$) and DNR orders (aOR 2.16, $p=0.03$) were predictive of hospice care after controlling for age, cancer type and recruitment site. Although having conducted the interview in Spanish was not associated with receipt of hospice care, acculturation was. Latino patients who were not fully acculturated were less likely to receive hospice care in univariate analysis (mean BSAS score 9.01 for Latinos receiving hospice care versus 5.14 for Latinos who did not; $p < 0.02$). However, in multivariate analysis controlling for differences in preferences for intensive EOL care, the association with hospice care was no longer significant (aOR 1.11, $p=0.12$).

Results for all analyses were repeated including only those three sites that contributed at least one Latino to the study. Results were not different except that age was no longer

TABLE 1. ETHNIC DIFFERENCES IN PATIENT CHARACTERISTICS FOR 292 ADVANCED CANCER PATIENTS

Patient characteristic	Hispanic (n=58)		White (n=234)		P
Age in years, mean (SD)	54.6	(15.4)	60.3	(11.8)	0.01
Gender, male, N (%)	29	(50.0)	128	(54.7)	0.52
Education in years, mean (SD)	7.9	(4.9)	13.8	(3.0)	<0.0001
Married, N (%)	31	(55.4)	143	(61.9)	0.37
Religion, N (%)					
Catholic	39	(67.2)	92	(39.3)	0.0002
Protestant	1	(1.7)	49	(20.9)	
Baptist	1	(1.7)	22	(9.4)	
Other	15	(25.9)	56	(23.9)	
None	2	(3.5)	15	(6.4)	
Health insurance, N (%)	10	(17.2)	175	(77.1)	<0.0001
Recruitment site, N (%)					<0.0001
Yale Cancer Center	5	(8.6)	63	(27.0)	0.009
West Haven VA Cancer Center	0	(0.0)	16	(6.9)	
Simmons Comprehensive Cancer Center	1	(1.7)	29	(12.5)	
Parkland Hospital	52	(89.7)	49	(21.0)	
Partners (DFCI, MGH) Cancer Centers	0	(0)	9	(3.9)	
New Hampshire Oncology- Hematology	0	(0)	67	(28.8)	
Cancer type, N (%)					
Lung	4	(7.1)	55	(23.8)	0.98
Colon	5	(8.9)	30	(13.0)	
Breast	7	(12.5)	21	(9.1)	
Pancreas	3	(5.4)	25	(10.8)	
Other	37	(66.1)	100	(43.3)	
Karnofsky Performance Status Score, mean (SD)	61.4	(15.6)	61.3	(19.1)	0.98
Charlson Comorbidity Index, mean (SD)	6.26	(1.66)	6.6	(2.5)	0.21
SCID diagnosis, N (%)	7	(13.0)	25	(11.2)	0.71
McGill Quality of Life, mean (SD)					
Physical domain	5.6	(1.3)	5.5	(1.3)	0.58
Psychological domain	2.8	(2.7)	3.0	(2.5)	0.63
Existential domain	8.1	(1.6)	7.4	(1.9)	0.01
Support domain	8.7	(1.5)	8.5	(1.8)	0.35

SCID, Structured Clinical Interview for DSM-IV Axis I Disorders; DFCI, Dana-Farber Cancer Institute; MGH, Massachusetts General Hospital. Missing data: Married (5), Insured (7), Recruitment site (1), Cancer type (5), Karnofsky Performance Status Score (12), Charlson Comorbidity Index (9), SCID (14), McGill Quality of Life (1).

significantly different in univariate analysis by ethnic status and some previously significant results became only marginally significant, likely due to reductions in power (results not shown). No differences were noted in direction or magnitude of associations.

Discussion

Our study found that Latino advanced cancer patients received intensive EOL care at a rate equivalent to that of their non-Latino white counterparts. This was true despite

TABLE 2. ETHNIC DIFFERENCES IN THE RATE OF PATIENT-REPORTED BASELINE PREDICTORS OF END-OF-LIFE CARE FOR 292 ADVANCED CANCER PATIENTS

	Hispanic (N=58)		White (N=234)		Unadjusted		Adjusted	
	N	(%)	N	(%)	OR	p	OR	P
Terminal Illness Acknowledgment	11	(19.0)	109	(47.4)	0.26	0.0002	0.18	0.0001
Positive Religious Coping	42	(72.4)	76	(32.5)	5.46	0.0001	1.55	0.31
EOL discussion	18	(31.6)	89	(38.4)	0.74	0.34	0.52	0.11
Preference for Life-Extending Care	14	(24.1)	50	(21.6)	1.16	0.67	1.21	0.59
DNR/Order	13	(22.4)	115	(50.4)	0.28	0.0002	0.22	0.0003

OR, odds ratio; EOL, End-of-life; DNR, Do-not-resuscitate.

Missing data: Terminal Illness Acknowledgment (4), EOL discussion (3), Preference for Life-Extending Care (2), DNR (6); OR for Terminal Illness Acknowledgment adjusted for recruitment site, Karnofsky Performance Status Score; OR for Positive Religious Coping adjusted for education, recruitment site; OR for EOL Discussion adjusted for recruitment site, Karnofsky Performance Status Score; OR for Preference for Life-Extending Care adjusted for gender; OR for DNR adjusted for recruitment site, Karnofsky Performance Status Score.

*White subjects are the reference group for the odds ratios associated with the EOL-care predictors.

TABLE 3. DIFFERENCES IN THE ASSOCIATION OF END-OF-LIFE CARE PREDICTORS AND RECEIPT OF INTENSIVE CARE NEAR DEATH, STRATIFIED BY ETHNIC STATUS

	Full Sample (N=292)				Hispanic (N=58)				White (N=234)			
	Unadjusted		Adjusted		Unadjusted		Adjusted		Unadjusted		Adjusted	
	OR	p	OR	P	OR	p	OR	p	OR	p	OR	p
Terminal Illness Acknowledgment	0.51	0.33	0.53	0.36	2.25	0.52	†		0.36	0.22	†	
Positive Religious Coping	4.15	0.04	5.28	0.02	0.75	0.82	†		6.69	0.02	†	
EOL discussion	*				*				*			
Preference for Life-Extending Care	4.57	0.02	3.79	0.04	1.62	0.71	†		6.63	0.01	†	
DNR order	*				*				*			

OR, odds ratio; EOL, End of life; DNR, Do-not-resuscitate.

Full Sample ORs adjusted for age and sex.

† No confounders remained in the model at a significance level of $p < 0.05$.

*=No patient with this predictor received intensive EOL care.

significantly lower rates of terminal illness acknowledgment and DNR orders among Latinos relative to non-Latino whites at baseline. Nevertheless, both Latino and white patients who reported having a DNR order or an EOL conversation with their physician did not receive intensive EOL care, unlike black patients in this sample, who were noted in some cases to receive intensive EOL care despite baseline reports of DNR orders and EOL conversations.²⁶ This suggests that engaging in doctor-patient communication may have similarly important effects on EOL care for white and Latino advanced cancer patients.

What it does not explain is why Latino patient preferences for EOL care were not associated with the actual care received, despite similar rates of preferences for intensive EOL care among white and Latino cancer patients and significant effects of white patient preferences on EOL care. The association of DNR orders and EOL discussions with EOL care for Latinos, in the absence of significant associations for patient preferences, terminal illness acknowledgement and religious coping, may suggest physicians play a more prominent role in the EOL decision-making of Latino compared to white patients.

On the other hand, we do not know the extent to which EOL discussions and completion of DNR orders were initiated by patients, and results may have been influenced by the preponderance of Latino patients having been recruited from Parkland Hospital, which has an active palliative care service. Furthermore, many clinicians at Parkland are familiar with Latino culture and are fluent in Spanish, which may have affected the results of this study in ways that would not be found at sites with less experience. For these reasons, further longitudinal research that recruits from more diverse sites and that can examine and compare site, provider and patient specific effects is needed. Future studies will also need to explain the role and evolution of Latino patient preferences in EOL care decision-making and how this process differs across minority groups.

The relatively high rate of hospice uptake in this study (compared to prior epidemiologic studies of hospice utilization) is likely due to (1) the limitation of this sample to cancer patients, who have tended to use hospice more than other terminally-ill populations, (2) a general trend toward greater hospice use over time among both white and Latino populations²³ and (3) the lack of language as a barrier to hospice care at the Texas recruitment site, given its bilingual staff. While

the rate of hospice use at EOL was the same for Latinos and non-Latino whites, our analysis did not identify significant patient-level predictors of hospice care among the Latino sample. However, given the modest Latino sample size in the present study, patient-level predictors of hospice care may deserve further consideration in larger, future studies of Latino cancer patients. Furthermore, other factors which were not considered in this study may be more influential in palliative EOL decision-making for Latino compared to white patients. For example, the role or preferences of caregivers and available social resources may explain more of the variance in predicting hospice care for Latinos than for white patients. Finally, factors such as health literacy and neighborhood effects should also be considered in future studies.

Despite requiring replication in a larger, more heterogeneous Latino sample, this study represents one of the most detailed, quantitative evaluations of prospective, patient-level predictors of EOL and hospice care among Latino and white terminally ill cancer patients. When considered in conjunction with the work of ourselves and others,³⁴ it suggests that concepts (such as patient autonomy and ACP and EOL discussions) which have frequently and successfully been associated with the EOL preferences and care of white cancer patients may not be effectively applied to, or across, all minority groups for the purpose of predicting future EOL care. Conversely, the EOL experience of white and Latino advanced cancer patients may be more similar to each other than to that of their black counterparts. Further investigation of the particular experience and predictors of EOL care among Latino advanced cancer patients is warranted.

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