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Family caregiver preferences for patient decisional control among Hispanics in the United States and Latin America

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Abstract

Background—Understanding family caregivers' decisional role preferences is important for communication, quality of care, and patient and family satisfaction. The family caregiver has an important role in a patient's decisional role preferences. There are limited studies on family caregivers' preferences of the patient's decisional control at the end of life among Hispanics.

Aims—To identify Hispanic caregivers' preferences of the decision control of patients with advanced cancer and to compare the preferences of caregivers in Latin America (HLA) and Hispanic American (HUSA) caregivers.

Design—We surveyed patients and their family caregivers referred to outpatient palliative care clinics in the United States, Chile, Argentina, and Guatemala. Caregiver preferences of patient's decisional control were evaluated using the Control Preference Scale. Caregivers' and patients' socio-demographic variables, patient performance status, and HUSA patient acculturation level was also collected.

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Participants—A total of 387 caregivers were surveyed: 100 (26%) in Chile, 99 (26%) in Argentina, 97 (25%) in Guatemala, and 91 (24%) in the United States. The median age was 56 years, and 59% were female.

Results—Caregiver preference of patients decisions control was passive, shared, and active by 10 (11%), 45 (52%) and 32 (37%) HUSA caregivers and 54 (19%), 178 (62%) and 55 (19%) HLA caregivers ($p=0.0023$). Caregiver acculturation level did not affect the preferences of the HUSA sample ($p=0.60$).

Conclusions—Most Hispanic family caregivers preferred the patient to make shared decisions. HLA caregivers preferred more frequently patients to assume a passive decisional role. Acculturation did not influence the preferences of HUSA caregivers.

Keywords

Decisional role preferences; family caregivers; palliative care; Hispanics; Latinos

Introduction

Understanding the family caregiver's decisional role preferences is important to ensuring communication, quality of cancer care, and patient and family satisfaction. Although the family can sometimes be a conflict source,¹ they play an important role in ensuring patient decisional control preferences.^{2, 3}

Hispanic Americans (HUSA) are the fastest-growing minority group in the United States, accounting for 16.3% of the population in 2010 and projected to account for 24.4% by 2050.⁴ There is a lack of published data on family caregiver perceptions of patients' decisional role preferences, particularly among HUSA.^{5, 6, 7} Due to differences in culture, socio-economic status, religion and family roles, decisional role preferences of Hispanic Latin Americans (HLAs) and HUSAs may vary as well.^{8, 9} The information regarding decision role preferences of HLAs is important because it may help us to understand the preferences of those who have recently immigrated to the United States.

Culture and acculturation can be important determinants of health-related attitudes, beliefs, preferences and behaviors.¹⁰ Understanding the preferences of both Latin American and US Latino patients, as well as the influence of acculturation on patient preferences, is vital given the fluid nature of immigration from Latin America and because recent immigrants and cancer patients of Latin American descent in the United States may have different preferences, perceptions and expectations than those of other groups.

To better understand HUSAs and HLA family caregivers' preferences regarding patients' decisional control, we conducted a multicenter, cross-sectional survey of family caregivers of advanced cancer patients referred to outpatient specialist palliative care services in the United States and in three Latin American countries. We hypothesized that HLA family caregivers would be more likely to prefer passive decision-making approaches than HUSA family caregivers would.

Our primary aim was to identify Hispanic caregivers' preferences of advanced cancer patients' decision control. Our secondary aims were to compare HLA and HUSA caregiver preferences and to investigate whether acculturation influences the decision making preferences of HUSA caregivers.

Methods

We conducted a prospective survey of 387 Latino caregivers of advanced cancer patients referred to outpatient specialist palliative care services in Argentina, Chile, Guatemala, and the United States. The study was conducted at the palliative care clinics of the Hospital Sótero del Río in Santiago, Chile; Tornú Hospital in Buenos Aires, Argentina; Instituto de Cancerología (INCAN) in Guatemala City, Guatemala; and The University of Texas MD Anderson Cancer Center in Houston, Texas, USA. Approval of the institutional review board at each of the four centers was obtained, and all participants provided written informed consent.

Participants

Caregivers were enrolled in the study at the time of a patient follow-up visit to supportive or palliative care after both had provided written consent. Patients met the following eligibility criteria: (a) diagnosis of advanced (locally recurrent or metastatic) cancer; (b) 18 years of age or older; (c) normal cognitive status as determined by the interviewer (by the subject's ability to understand the nature of the study and consent process); and (d) availability of a designated caregiver. Caregivers met the following eligibility criteria: (a) 18 years of age or older and (b) normal cognitive status as determined by the interviewer. Participants in the USA study center were required to be of self-reported Hispanic descent, to be first- or second-generation immigrants, and to have resided in the country for at least 5 years. The time frame of 5 years was used so that the patient would have had reasonable familiarity with the health care system and acquired financial insurance coverage that would have allowed them to access similar level of care as other patients in the United States.

Outcome measures

Socio-demographic variables—Information was collected on caregivers' age, gender, marital status, employment status, and education. Information was also obtained on patients' age, gender, and cancer diagnosis.

Karnofsky Performance scale was used to assess patient performance status.

Marin Acculturation Assessment Tool (MAAT)—The acculturation level of the USA caregiver was determined using the MAAT.¹¹ This tool was previously widely used in the Hispanic population and found to correlate highly with respondents' generation, length of residence in the United States, age at arrival, and ethnic self-identification. The MAAT, which has a reported alpha coefficient of 0.92, is composed of 12 questions answered by ranking on a scale of 1 to 5. The answers are summed and averaged, and the tool yields a score ranging from 1 to 5, with higher scores representing higher acculturation. Participants who scored 2.99 or less were considered "lower acculturated," and those who scored more than 2.99 were considered "highly acculturated" per the assessment tool scoring information.

Control Preference Scale—The family caregiver's preference for the patient's decisional control was assessed using the Control Preference Scale previously developed and validated by Degner and Sloan.^{12, 13} This scale was chosen because it is easy to administer, reliable and extensively used to assess the preferred and actual roles in health care decision making in various settings in more than 3000 cancer patients,¹⁴ and has been successfully adapted for the family caregiver in other studies,¹⁵ although is not validated in this population. Literature shows that grade of information, disease progression, and multiple variables can influence the decision-making preferences of the patient.^{16, 17, 18} The CPS is not sensitive to those variables.

We made minor modification to this instrument to include family components. The tool was translated into Spanish by bilingual investigators and independently back translated by bilingual Latin American natives to determine semantic and linguistic equivalence between the versions. This questionnaire has a triadic form (patient-family-physician) and a dyadic form (patient-family, patient-physician, or family-physician).

The triadic form assessed the family caregiver's preferences regarding the patient's decisional control preferences involving the family and the doctor. The item began, "In my opinion, decision about my relatives' care should be made the following way: ...". There were 15 answer options and the caregiver had to choose one option which was later categorized as passive, shared, or active decision making preferences.

The dyadic form of this questionnaire was composed of three items, each with seven answer options. The caregiver had to choose one option. The first question addressed the caregiver's preference regarding the role of the doctor and patient in the decision role preference: "With regards to the doctor's participation in the decisions about my relative's care...". The second question addressed the caregiver's preference regarding his or her role (as the family caregiver) and the role of the patient in the decision making process regarding the care of the relative: "With regards to my participation in decisions about my relative's care ...". The third question addressed the relationship between the family member and the physician: "With regards to the relationship between myself and the doctor in the decisions about my relative's care...". The decisional role preferences models were categorized as passive, active or shared. The first one may reflect caregivers perception of their wanting the patient to accept a paternalistic model whereby the patient prefers to delegate the decisional role to the physician or family; in the second model, the caregivers perception of their wanting the patient to have decisional role solely to her/himself or herself; and in the third model, the caregivers perception of their wanting the patient have the decisional control preference shared by the patient, family and physician.¹⁹

Statistical analysis

Descriptive statistics were performed to summarize the data. Fisher exact and χ^2 tests were used to determine associations between categorical variables. Differences between continuous variables were analyzed using t tests for normally distributed data and Wilcoxon rank-sum tests for non-normally distributed data. Multivariate logistic regression was used to correct for age and education when comparing HUSA and HLA groups with regard to decision-making preferences.

A *p* value <0.05 was considered significant. Analyses were performed using SPSS 16.0 software for Windows (SPSS Inc., Chicago, IL, USA).

Results

The median age of HLA patients was 60 years, which was significantly older than HUSA patients (56 years) ($p=0.002$). The median performance status of HLA patients was 80, significantly higher than that of 60 for HUSA patients ($p<0.001$). Among caregivers, the median age of HLAs was 48 years and that of HUSAs was 45 years ($p=0.16$). HLA caregivers had a lower education level than HUSA caregivers did ($p<0.0001$) (Table 1).

Table 2 shows the triadic decisional preferences of HUSA and HLA caregivers. Shared decisional control was preferred by the majority of both groups (52% and 62%, respectively).

The pattern of decisional control differed significantly among caregivers in the three Latin American countries ($p=0.007$).

Univariate analysis of caregivers' preferences of the patient's decision control revealed a significant difference by educational level, with caregivers with lower education having a preference of patient's passive decisional control (data not shown) ($p<0.045$). Caregivers' preferences for the patient's passive decisional control regarding health-care decision making were more prominent among HLAs than HUSAs ($p<0.0023$). This difference was maintained after age and educational level were corrected for in multivariate analysis (data not shown).

The acculturation level of caregivers in the United States was not significantly associated with decisional role preferences (Table 3).

There were increased preferences for passive decision making in HLA as compared with HUSA. In all cases shared decision-making control was the most frequent choice for both HUSA and HLA (table 4).

Discussion

In this study we found that most of the Hispanic family caregivers wanted the patient to use shared decisional control (52% of HUSA caregivers and 62% of HLA caregivers). We also found that, compared with HUSA caregivers, HLA caregivers preferred that the patient had a more passive decisional role. Acculturation did not seem to influence decisional role preferences among HUSA caregivers.

Prior studies suggest that young age and advanced education are associated with patient's preferences for an active decisional role.²⁰ Our results showed that the family caregiver's education level was significantly higher among HUSAs than HLAs in a univariate model, but that the passive decisional role differences between the groups persisted after correction for education level in the multivariate analysis.

Communication at a patient's end of life is a therapeutic necessity for the family.²¹ In most sociocultural environments, the role of the family in decision making is fundamental for satisfactory delivery of care for the patient.²² In our study, most of the caregivers perceived that the patient should share decisional control with them. Other studies have shown that patients also prefer to share decisional control. In Korea, 50% of the interviewed advanced cancer patients wanted to share their decisions with the family,²³ and in the United States, more than 90% of a sample of interviewed patients receiving dialysis wished to discuss decisions with their family.²⁴ A recent systematic review highlighted the importance of family participation in decision making among African American families.²⁵ Shrank et al. observed that Non-Hispanic White patients seemed to prefer one family member in particular when the family participates in end-of-life discussions,²⁶ whereas Kelley et al. found that most older Latinos favored family-centered decision making and limited patient autonomy.²⁷ In our study, although a preference for more active decision control by the patient was observed among HUSA caregivers than HLA caregivers, more than half of both groups preferred share decision making. Davison et al., in a Canadian sample of 80 men with prostate cancer and their partners, identify that the majority of partners wanted to play a collaborative role in treatment decision making.¹⁵ To our knowledge, ours is the first study that focused on the Latinos family caregiver's point of view about the patient's decision control.

Current evidence suggests that the shared decisional role preference is the most acceptable model to the patient.^{28, 29} According to our current data, most Latino caregivers do not want

active decision making, but most of them want to share the responsibility, implying that the decision-making process with Hispanics, physicians must include both patient and their caregiver..

Our study has important limitations, including the lack a comparison of non-Hispanic group in the USA sample. The Hispanic population in the United States is very heterogeneous, and important variations may have not been detected due to the limited sample size and the limited variability across acculturation levels. No other American ethnicities were included in our control group, and our sample was limited to one US hospital. We also have found differences between HLA caregivers by country despite similarities in language, religion and culture, but our study still suggests that HUSA and HLA families differ considerably in their decision control preferences (37% of caregivers in the United States versus 24% in Argentina, the Latin American country with the highest active rate, prefer an active decisional role for the patient). The lack of Mexican comparator group could have a somewhat lowered the impact of the results of the study as a high proportion (>55%) of Hispanics in United States are from Mexico.^{30, 31} Future studies must consider multicenter and multiethnic socio-economic samples when assessing family caregivers' preferences for the patient's decisional role. Understanding how to satisfy a family's preferences should also be considered. Lastly, further studies are needed to determine if caregivers relationship to patient could be important variable in predicting decisional control preferences.

Conclusion

Most Hispanic family caregivers preferred patients to make shared decisions. HLA caregivers were significantly more likely to prefer a passive decisional role for the patients than HUSA caregivers were. Acculturation did not seem to influence decisional role preferences among HUSA caregivers. Because patients' decisional role preferences can be challenging and many instances involves the preferences of not only the patient but also the family and physician, the decision-making roles have to be determined for each case. More research is necessary to understand this important topic.

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Table 1

Characteristics of HUSA and HLA patients and family caregivers

Patients	USA (N=91)	Latin America (N=296)	P value
	n	n	
Female gender	59	175	0.330
Diagnosis	(65%)	(60%)	
Head and Neck	8	11	0.65
Lung	9	38	
Gastrointestinal	22	74	
Genitourinary (not prostate)	5	12	
Prostate	6	24	
Gynecological (not breast)	15	44	
Breast	12	40	
Other	14	53	
Family caregivers			
Female gender	58	205	0.36
Marital status			0.45
Single	19	50	
Married/Lives with partner	56	216	
Divorced/Separated	12	21	
Widowed	1	7	
No data	3	2	
Employment status			
Full time	41	80	0.004
Part time	7	35	
Retired	9	36	
Homemaker	11	101	
Unemployed	11	25	
Other	8	13	
No data	4	6	
Education			

Patients	USA (N=91)		Latin America (N=296)		P value
	n	(%)	n	(%)	
Less than high school	12	(13.2%)	121	(41%)	<0.0001
High school/tech school	31	(34.1%)	125	(42.2%)	
Incomplete college or higher	45	(48.7%)	44	(15.1%)	
No data	3	(3.3%)	6	(2%)	

Table 2

Caregiver preferences of patient's decision control between patient, physician, and family

	Hispanics in USA				Hispanics in Latin America											
	Highly acculturated (N=63)				Lower acculturated (N=24)				Chile (N=100)					Guatemala (N=94)		Argentina (N=99)
	n	(%)	n	(%)	n	(%)	p	n	(%)	n	(%)	n		(%)	p	
<i>TOTAL PASSIVE</i>	6	(9%)	4	(17%)			0.60	16	(16.0%)	23	(24.5%)	15	(15.2%)	p<0.007		
<i>TOTAL SHARED</i>	34	(54%)	11	(46%)				73	(73.0%)	45	(47.9%)	60	(60.6%)			
<i>TOTAL ACTIVE</i>	23	(37%)	9	(38%)				10	(10.0%)	21	(22.3%)	24	(24.2%)			

Table 3

HUSA family caregiver preferences of patient's decision control by acculturation

	Highly acculturated (N=63)		Lower acculturated (N=24)		p
	n	(%)	n	(%)	
Passive	6	(9%)	4	(17%)	0.60
Shared	34	(54%)	11	(46%)	
Active	23	(37%)	9	(38%)	

Table 4

Caregiver preferences of patient's decision control between patient and physician, patient and caregiver, and caregiver and physician

A. Patient X Physician	USA (N=88)		Latin America (N=292)		P-Value
	n	(%)	n	(%)	
Passive	12	(14%)	103	(35%)	P=0.0008
Shared	39	(44%)	112	(38%)	
Active	31	(35%)	66	(23%)	
Didn't know/Preferred not to answer	6	(7%)	11	(4%)	
B. Patient X Family Caregiver	USA (N=88)		Latin America (N=290)		
	n	(%)	n	(%)	
Passive	9	(10%)	62	(21%)	P=0.0015
Shared	40	(45%)	146	(50%)	
Active	31	(35%)	70	(24%)	
Didn't know/Preferred not to answer	8	(9%)	12	(4%)	
C. Family Caregiver X Physician	USA (N=87)		Latin America (N=292)		
	n	(%)	n	(%)	
Family and Physician should not make decisions	2	(2%)	4	(1%)	
Patient and Physician should share decision-making	29	(33%)	62	(21%)	
Patient should decide after hearing physician's opinion	39	(44%)	112	(38%)	
Physician should decide after hearing Patient's opinion	12	(14%)	88	(30%)	P=0.003
Physician must decide by himself/herself	0	(0%)	15	(5%)	
Didn't know/Preferred not to answer	6	(7%)	11	(4%)	