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Decisional Control Preferences, Disclosure of Information Preferences, and Satisfaction Among Hispanic Patients With Advanced Cancer

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Abstract

Context—Studies to determine the decisional control preferences (DCPs) in Hispanic patients receiving palliative care are limited.

Objectives—The aims of this study were to describe DCPs, disclosure of information, and satisfaction with decision making among Hispanics, and to determine the degree of concordance between patients' DCPs and their self-reported decisions.

Methods—We surveyed 387 cancer patients referred to outpatient palliative care clinics in Argentina, Chile, Guatemala, and the U.S. DCPs were measured with the Control Preference Scale, disclosure preferences with the Disclosure of Information Preferences questionnaire, and satisfaction with care with the Satisfaction with Decision Scale.

Results—In this study, 182 patients (47.6%) preferred shared decisional control, 119 (31.2%) active decisional control, and 81 (21.2%) preferred a passive approach. Concerning diagnosis and prognosis, 345 (92%) patients wanted to know their diagnosis, and 355 (94%) wanted to know their prognosis. Three hundred thirty-seven (87%) patients were satisfied with the decision-making process. DCPs were concordant with the self-reported decision-making process in 264 (69%)

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Disclosures

The authors declare no conflicts of interest. AU: PLS CONFIRM THIS LAST SENTENCE IS ACCURATE.

patients (weighted kappa, 0.55). Patients' greater satisfaction with the decision-making process was correlated with older age (P 0.001) and with a preference for enhanced diagnostic disclosure (P 0.024). Satisfaction did not correlate with concordance in the decision-making process.

Conclusion—The vast majority preferred a shared or active decision-making process and wanted information about their diagnosis and prognosis. Older patients and those who wanted to know their diagnosis seemed to be more satisfied with the way treatment decisions were made.

Keywords

Palliative care; decisional control preferences; disclosure of information preferences; advanced cancer

Introduction

Satisfying the decisional control preferences (DCPs) of patients with advanced cancer is an important component of providing quality care. However, most physicians experience difficulties in identifying the DCPs of these patients. Degner et al. studied 1012 women diagnosed with breast cancer and found a concordance of only 42% between the patients' DCPs and their self-reported decision-making experiences.¹ Moreover, 15% of patients in that study reported that they were forced to assume a decision role they did not want. In a subsequent study, Bruera et al. compared the medical DCPs of patients with advanced cancer to their physicians' perceptions of these preferences.² Bruera and colleagues found concordance between patient preferences and physician perceptions of their preferences in only 45% of the cases.²

DCPs have been well studied in North America, predominantly in non-Hispanic white patients. In a meta-analysis of six studies, Jasvinder et al. assessed patient DCPs using the Control Preference Scale (CPS) and showed that among 3491 cancer patients, 26% preferred to choose their cancer treatment, 49% wanted to collaborate with the physician in making this decision, and 25% wanted the physician to make the decision for them.³

In contrast, there is a dearth of information about DCPs in the palliative care population,⁴⁻⁷ and more specifically, in Hispanic patients with advanced cancer. Historically, Hispanic patients have been perceived as preferring passive decisional control models within the context of a traditional or paternalistic model of medical decisional control, particularly in palliative care settings.^{8,9} However, these views have been based primarily on anecdotal accounts with little empirical foundation. This lack of knowledge and understanding of the true DCPs of specific population(s) and cultures could result in physicians making stereotypic assumptions in their interactions with these patients.¹⁰

To address this dearth of knowledge as it relates to Hispanic patient populations,¹¹ we conducted a cross-sectional study to determine the DCPs of Hispanic cancer patients in Latin America and the U.S. In a previous article, we reported that Hispanics from the U.S. had more active DCPs than Hispanics from Latin America.¹² The objective of this paper was to report our findings regarding the association between DCPs, sociodemographic and clinical characteristics, and Hispanic patients' preferences for disclosure of diagnostic and

prognostic information. We also determined the concordance between patients' DCPs and their self-reported DCPs related to their cancer care and identified the factors that influence patient satisfaction with the decision control process.

Methods

We conducted a cross-sectional study among 387 patients with advanced cancer referred to outpatient specialist palliative care services in four countries (Argentina, Chile, Guatemala, and the U.S.). The study was conducted at M. D. Anderson's Outpatient Supportive Care Center in Houston, Texas, and the outpatient palliative care clinics of the Hospital Sótero del Río, Santiago, Chile; Tornú Hospital, Buenos Aires, Argentina; and the Instituto de Cancerología (INCAN), Guatemala City, Guatemala.

The rationale for the multinational sample was to compare the effect of acculturation to the U.S. on DCPs among American Hispanic patients. All participating Latin American countries have consistent patterns of immigration to U.S. Our goal was to assess a comparative sample of Hispanic patients from both Central and South America.

The institutional review board of each of these centers approved the study, and all participants provided written informed consent. All patients enrolled at M. D. Anderson were Hispanic and identification of Hispanic origin was based on the definition from prior studies (Spanish-speaking and having originated from Latin America) and patient self-report.^{13–15} The following routine introductory statement was used prior to the assessments to minimize the bias in responses: "People from different cultures may have different preferences in the way decisions about their health care are made, as well as how much information they may want to know about the diseases they may have. However, patients sometimes disagree about these preferences. In this study, researchers want to learn about any differences in health care decision making and information-sharing preferences of patients among a group of people from different Hispanic backgrounds."

Patient Population

Patients who met the eligibility criteria during a follow-up visit to the supportive/palliative care clinic were enrolled. The patient inclusion criteria were: 1) diagnosis of advanced (locally recurrent or metastatic) cancer; 2) age ≥ 18 years; 3) normal cognitive status as determined by the treating physician; and 4) availability of a designated caregiver.

Outcome Measures

Sociodemographic variables and performance status (using the Karnofsky Performance Status scale) were assessed in all study patients.

Control Preference Scale (CPS)—COMP : DO NOT CHANGE THE PRECEDING SET UP. Patients' DCPs were assessed with the CPS.^{16, 17} We used the triadic form (patient-family-physician) of this questionnaire (Appendix I), which assesses the patient's DCP involving the family and the physician. Patients had 15 answer options and were instructed to choose one option, which was later categorized as a passive, active, or shared DCP (Appendix II).

The preference for a passive role may reflect a paternalistic model whereby the patient prefers to delegate the decisional role to the physician or family; a preference for an active role suggests that the patient alone has the decisional authority; and with a preference for shared decisional control, the decisional role involves the patient, family, and physician.¹⁸ The decision-making process was assessed with the following question: “How were the decisions about your care actually made?” The patients had 15 answer options and chose one option that was later categorized as passive, shared, or active decision-making.

In this study, the CPS was chosen because it has been successfully used to assess the DCPs in previous studies by other groups and our team in more than 3000 cancer patients.^{2,3,19,20}

Disclosure of Information Preferences.^{21, 22}—This questionnaire assessed whether patients wanted to be given full information regarding their diagnosis and prognosis. Patients were asked to rate their agreement with two statements: “I want to receive all information about my diagnosis” and “I want to receive all information about my chances of being cured.” Agreement with these statements was rated on a 0 to 4 scale, where 0=completely disagree, 1=disagree, 2= undecided, 3=agree, and 4=completely agree.

Satisfaction with the Decisions and Care—This assessment was conducted using a modified version of the Satisfaction with Decision Scale.²³ This three-item assessment tool was used to determine the patient’s satisfaction with the degree of information received, the way in which decisions were made in her/his care, and with the decisions themselves. Patients were asked to describe their degree of agreement with the following statements on a scale from 0 to 4: 1) “I am satisfied with the information I received about my care;” 2) “I am satisfied with the way decisions about my care were made;” and 3) “I am satisfied with the decisions about my care.” In our study, patients were asked to rate their satisfaction with the overall decision-making process regarding their cancer care in general rather than any specific clinical decision. **AU: IS CHANGE TO PREVIOUS SENTENCE OKAY WITH YOU?**

The assessment tools were translated into Spanish by bilingual investigators and independently back translated by bilingual Latin Americans to determine semantic and linguistic equivalence between the two versions.

Statistical Analyses

Descriptive statistics were used to summarize all study variables. Bivariate analyses using Chi-squared tests were conducted to examine the associations between patient DCPs and their sociodemographic and clinical characteristics, as well as their preferences regarding disclosure of diagnostic and prognostic information. A weighted kappa statistic was calculated to determine the concordance between patients’ DCPs and their self-reported decision-making experiences related to their cancer care. Chi-squared tests also were used to identify the associations between patients’ satisfaction with the decision-making process and patient characteristics; concordance between DCPs and experience; and disclosure of diagnostic and prognostic information preferences. A multinomial logistic regression model was constructed to identify the factors that influence patients’ DCPs, and a logistic regression model was constructed to identify predictors of patient satisfaction. Independent

variables were included in the model if P was < 0.15 in the bivariate analyses. A P -value of 0.05 or less was considered statistically significant.

Results

Population demographics and characteristics for the study patients are presented in Table 1. Most of the patients were female (61%), and had a good performance status level.

The DCPs of the patients in the study group were active in 119 (31%); shared in 182 (48%); and passive in 81 (21%). Study results showed moderate agreement (weighted kappa, 0.55) between patients' DCPs and the way in which decisions were made. As a result, 69% of the patients participated in the decision-making process according to their preferences. No differences were detected in concordance rates across DCPs (i.e., preferences were met in 67% of the active, 70% of the shared, and 69% of the passive groups) (Table 2).

Most of the patients (89%) wanted information about their diagnosis, and 92% wanted to know their chances of being cured. No relationship was found between patients' DCPs and their preferences concerning disclosure of information about diagnosis (Fisher's exact test, $P=0.5$) or prognosis (Fisher's exact test, $P=0.36$).

Bivariate analyses revealed statistically significant differences in DCPs by country, age, and educational level. Younger patients, those with higher educational levels, and those living in the U.S. were more likely to prefer active decisional control (Table 3). Specifically, patients age 60 or younger were 1.8 times more likely to prefer an active DCP compared with those older than age 60 (odds ratio [OR], 1.3; 95% confidence interval [CI] 1.3, 2.5). Gender ($P=0.92$), marital status ($P=0.90$), performance status ($P=0.19$), and disclosure of preferences regarding information about diagnosis ($P=0.29$) or prognosis ($P=0.15$) were not significantly associated with DCPs. In the multivariate analysis, only level of educational attainment was a significant predictor of DCP.

Eighty-six percent of the patients reported being satisfied with the information they had received about their care, 87% said they were satisfied with the way in which decisions about their care were made, and 90% were satisfied with the self-reported decisions about their care (Table 4). Bivariate analysis showed that older patients, those who wanted to know their diagnosis, and patients who wanted to know their prognosis were more satisfied with the way in which their decisions were made (Table 5). However, gender ($P=0.73$), marital status ($P=0.86$), educational status ($P=0.44$), and performance status ($P=0.84$) were not significantly associated with the decision-making process. In the multivariate analysis, the predictors of satisfaction were being age 60 or older (OR, 3.3; 95% CI 1.5, 7.5) and having a preference for diagnostic disclosure (OR, 3.4; 95% CI 1.2, 9.2).

Discussion

Most patients in this study preferred a shared DCP (57.2%), although the number of patients who prefer an active (31.2%) or passive (21.2%) role is still significant. Our findings differ from those of other studies of this population, in which DCPs were assessed. A study by Blackhall et al. found that 40% of Hispanics believe that the physician should make

decisions about life-prolonging technology, but more than 40% also believe that the patient should make this decision.⁸ Kelley et al. also found that 46% of older Hispanic patients prefer to involve the family in the decision-making process, and 63% prefer to limit their autonomy.⁹ However, compared with the studies by Blackhall et al.⁸ and Kelly et al.,⁹ in our study we used a CPS questionnaire used in prior decisional control studies and our study was conducted in outpatient cancer patients receiving palliative care rather than older Hispanic patients recruited from a community setting. More research is necessary to characterize potential difference between Hispanics and non-Hispanics.

In our study, we found higher active and shared DCPs and lower passive DCPs than expected in Hispanic-only cancer patients. These data are similar to those seen in prior studies on DCPs in non-Hispanic white North American patients. In fact, we identified an even higher percentage of preferences for active decision making (31.2% vs. 26%) and a lower percentage of passive DCPs (21.2% vs. 25%) in our study than what were recently reported in a pooled analysis of North American studies using the CPS.³

Younger age and higher educational level are variables that previously have been associated with active DCPs in North American populations.³ This study has produced similar findings, and our multivariate analysis further confirmed educational level as an important predictor of active DCPs among Hispanic patients. Interestingly, disclosure of information preferences was not related to DCPs in our study. Therefore, patient preferences for a passive role in DCPs were not associated with *not* wanting to know their diagnosis or prognosis. The vast majority of the 345 patients (92%) did want to know their diagnosis, and 355 (94%) wanted to know their prognosis. Similar results have been found in a study by Hack et al. in women with breast cancer.²⁴ Also, as previously reported,¹² we found that among Hispanics from the U.S., acculturation did not seem to play a role in DCP determination.¹² Our findings suggest that patients with low levels of acculturation such as those requiring translation to communicate with health care providers did not differ compared with those with high levels of acculturation.

Our results are clinically relevant because they show that most Hispanic patients of our sample prefer a shared role in DCPs regarding their care and want to be informed; the patient's preference should not be assumed solely on culture. Instead, the strategy should rather focus on exploring the individual preferences of each patient before beginning the decisional control process or the disclosure of information.

We found moderate concordance between the DCP and the self-reported decision making process of the patients in this study. Sixty-nine percent experienced a decision-making process that matched their preferences. This concordance is higher than concordance rates reported in other studies using the CPS. For instance, Degner et al. found a concordance rate of 42% between DCP and self-reported experience.¹ Bruera and colleagues identified a concordance rate of 45% among 78 cancer patients, and later a concordance rate of 42% between patients' DCPs and physician perception in 57 women with breast cancer.¹⁹ Pardon et al. reported a concordance rate of 71% between the DCP and the self-reported decision-making process of the patients.²⁵ However, in this study the decisions were focused on advance directives rather than overall cancer care, as investigated in our study.

Our study was conducted in palliative care settings at the follow-up visit. Other studies have shown that enhanced patient-physician communication and relationships provide and reinforce information for the patient and help move the patient toward a decision based on their preferences.²⁶⁻³² This may explain the higher concordance between patient preferences and the self-reported decision control process found in this study.

Patient satisfaction with the way decisions about their care were made was very high in this study (87%). Gattellari and colleagues demonstrated an association between satisfaction and the decision-making process, especially in patients with shared DCPs.³³ We did not find this type of association in our study. One possible reason why we did not observe an association between satisfaction and concordance in DCPs may be because patients expressed a high level of satisfaction (87%) and this is likely to be related to the excellent communication skills among palliative care teams. Gattellari et al., however, conducted their study primarily among oncology patients.³³ It is possible that the different settings of care had an impact on overall satisfaction. Our finding of lack of concordances between patient satisfaction and DCP is interesting because prior studies have shown that in complex decisions, when tradeoffs are unknown, preferences should be constructed during decision making.³⁴ Future studies should be conducted to better characterize the association between patients' DCPs and satisfaction.

Our findings suggest that older patients and patients who wanted to know their diagnosis were more satisfied with the way their care decisions were made. Disclosure of information is a goal of care for palliative care teams. It could be hypothesized that when we force disclosure of information on a patient who does not want to know, we could be diminishing his or her satisfaction. Decision making at the end of life in Hispanic patients involves a complex communication process that requires individualizing messages to each patient and carefully and properly assessing their understanding and preferences. The mismatch for at least 18% (87% less 69%) who were satisfied with the decision-making process but who did not have one that match their preference (Table 2 and Table 4) likely may be the result of the higher emphasis that a patient in this study makes on disclosure of information and discussion of therapeutic alternatives rather than self-reported decision making. In a study by Strull et al. of 210 hypertensive patients and 50 clinicians to evaluate degree of participation in decision making, similar findings were observed.³⁵ In their study, Strull et al. found that clinicians underestimate patients' desire for information and discussion but overestimate patients' desire to make decisions.³⁵

This study has several limitations. An important limitation is the lack of validation of the triadic version of the CPS. There are currently better scales to measure the decision-making process itself, whether observed by a third party or perceived.³⁶ Future palliative care research should take advantage of these methods to better characterize DCPs. Also, the concept of shared decision making in this study is slightly different from the tradition concept of shared decision making, which only involves the patient and the physician rather than the patient-physician-family. As a result of this difference, there may be instances in which decisions involving patient-family may be classified as "shared" rather than as an "active role." As well, item 14 in the triadic questionnaire, "shared between myself and my family," was classified as the shared DCP group because in the design of the study, we

proposed to address the issue according to the patient’s perspective. In a prior study of 88 palliative care patients, Miccinesi et al. showed that patients would like to share their DCPs with family.³⁷ Future studies also should investigate the perspectives of other groups, such as health care providers, on the role of family in patients’ DCPs.

We considered our sample to be homogeneous to study DCPs of a this understudied yet fast growing subset of the population of patients with advanced cancer in the U.S. because all the study participants spoke a common language (Spanish) and originated from Latin America, as assessed during the study enrollment by patients’ self-report. However, no validated measure was used to assess Hispanic origin. Also, future studies on DCPs in patients with advanced cancer in Latin America should include patients who are non-Spanish speaking.

Another possible limitation of this study is selection bias. In this sample, Hispanic individuals living in the U.S. prefer a more active role than do Hispanic patients from other countries. Patients recruited at M. D. Anderson Cancer Center for this study may not be representative of Hispanic patients in the U.S. because of their higher educational level; however, this population is useful for the study sample because acculturation does not play an important role in their DCPs.

Conclusion

Hispanic patients in this study did not adhere to a traditional paternalistic decision-making model. In our study, most of the Hispanic patients with advanced cancer seen at the outpatient palliative care clinic preferred a shared role in DCP, wanted to be informed about their diagnosis and chances of being cured, and were satisfied with the decision-making process. Moderate agreement was found between the DCP and the self-reported decision-control process. Hispanic patients with a higher level of education preferred a more active role in the DCP. However, we found no association between the patients’ DCPs and their preferences for disclosure of information. In this population, satisfaction with the way the decisions were made was associated with older age and disclosure of diagnosis. Based on the data from this study, future studies are warranted.

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Appendix I Control Preference Scale (Patient-Family-Physician Items)

1. By myself.
2. By myself after hearing the doctor’s opinion or input.
3. By myself, after hearing my family’s opinion or input.
4. By myself after hearing both my family and the doctor’s opinion or input.

5. By my family.
6. By my family after hearing my opinion or input.
7. By my family, after hearing my doctor’s opinion or input.
8. By my family, after hearing both my doctor’s and my opinion or input.
9. By the doctor.
10. By the doctor after hearing my opinion or input.
11. By the doctor after hearing my family’s opinion or input.
12. By the doctor after hearing both my family’s and my opinion or input.
13. Shared between myself and the doctor.
14. Shared between myself and my family.
15. Shared between myself and both my family and doctor.

Appendix II Classification of Decisional Control Preferences Based on the Control Preference Scale (Patient-Family-Physician Items)

Preference	Response Options
Active	1, 2, 3, or 4
Passive	5, 6, 7, 8, 9, 10, 11, or 12
Shared	13, 14, or 15

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Table 1Study Population Characteristics (*N* = 387)

Characteristic	<i>n</i> (%)
Gender	
Female	234 (61%)
Age, mean (range)	58 (20–90)
Karnofsky Performance Status, mean (SD)	70 (15)
Country	
Argentina	99
Chile	100
Guatemala	97
USA	91
Marital status	
Single	47 (13%)
Married/partner	248 (64%)
Divorced/separated	47 (13%)
Widowed	40 (9%)
Education level	
Less than high school	212 (55%)
High school / tech school	113 (29%)
Some college or higher	62 (16%)
Diagnosis	
Head and Neck	19 (5%)
Lung	47 (12%)
Gastrointestinal	96 (25%)
Genitourinary (no prostate)	17 (5%)
Prostate	30 (8%)
Gynecological (no breast)	59 (15%)
Breast	52 (13%)
Other	67 (17%)

SD = standard deviation.

Table 2

Concordance Between Patients' Decisional Control Preferences and the Self-Reported Decision-Making Process

Self-reported preferences	Patients' Decisional Control Preferences			Concordance
	ACTIVE	SHARED	PASSIVE	%
Active	80	26	12	67%
Shared	16	128	13	70%
Passive	23	28	56	69%
Total ^a	119	182	81	N=382

Concordance: 264/382 (69%), weighted Kappa, 0.55.

^aData missing for five patients.

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Table 3

Decisional Control Preferences by Patient Characteristics (N = 384)

Patient Characteristic	N (%)	Active (%)	Shared (%)	Passive (%)	P-value
All respondents	384 (100)	31	47	22	NA
Age					
60	207 (56)	37	44	19	0.040
> 60	162 (44)	24	51	25	
Country					
Argentina	99 (26)	32	52	16	<0.001
Chile	100 (26)	13	60	27	
Guatemala	97 (25)	30	43	27	
USA	91 (23)	52	24	14	
Educational level					
Less than high school	212 (55)	24	52	24	<0.001
High school/technical school	113 (29)	32	49	19	
Some college or greater	62 (16)	57	31	12	

Table 4

Patient Satisfaction With the Decision-Making Process and Disclosure of Information

I am satisfied with the information I have received about my care				
Completely Disagree	Disagree	Undecided	Agree	Completely Agree
9 (2%)	18 (5%)	17 (5%)	128 (33%)	206 (53%)
I am satisfied with the way the decisions about my care were made				
Completely Disagree	Disagree	Undecided	Agree	Completely Agree
5 (2%)	20 (5%)	17 (4%)	127 (33%)	210 (54%)
I am satisfied with the decisions about my care				
Completely Disagree	Disagree	Undecided	Agree	Completely Agree
5 (2%)	9 (3%)	16 (4%)	130 (34%)	218 (56%)

Note: Data is missing for eight patients.

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Table 5Satisfaction With the Decision-Making Process by Patient Characteristics (*N* = 384)

Patient Characteristics	<i>N</i> (%)	Not Satisfied (%)	Satisfied (%)	<i>P</i> -value
All respondents	384 (100)	11	89	NA
Age				
60	203 (56)	15	85	0.006
> 60	158 (44)	6	94	
Country				
Argentina	97 (26)	3	97	0.036
Chile	100 (26)	13	87	
Guatemala	92 (24)	14	86	
USA	90 (24)	14	86	
Preference for decision-making process				
Active	119 (32)	10	90	0.796
Shared	179 (47)	12	88	
Passive	79 (21)	10	90	
Actual self-reported experience of decision-making process				
Active	118 (31)	7	93	0.164
Shared	154 (41)	12	88	
Passive	104 (28)	14	86	
Concordance between decision-making preference and experience				
Yes	256 (68)	10	90	0.219
No	119 (32)	14	86	
Diagnostic disclosure preference				
Wants disclosure	345 (92)	10	90	0.010
Does not want disclosure	30 (8)	27	73	
Prognostic disclosure preference				
Wants disclosure	355 (95)	10	90	0.045
Does not want disclosure	19 (5)	26	74	