



# Decisional Control Preferences in the Hispanic Population in the Bronx

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## Abstract

Hispanic Americans are among the fastest growing minority groups in the USA, and understanding their preferences for medical decision-making and information sharing is imperative to provide high quality end of life care. Studies exploring these decision control preferences (DCPs) are limited and found inconsistent results. (1) To measure DCPs of Hispanic patients in the Bronx. (2) To measure disclosure of information preferences of Hispanic patients in the Bronx. This is a cross-sectional survey. One hundred nineteen cancer patients who self-identified as Hispanic and were waiting at the oncology clinic at Montefiore Medical Center Cancer Center. Proportions of patients endorsing DCPs and disclosure of information preferences are reported. The relationship between patient characteristics and DCPs was tested using chi-squared tests of homogeneity. The majority (63, 52.9%) preferred shared decision-making with their doctors, families or both, while 46 (38.7%) had an active decision-making style. A minority (9, 7.6%) had a passive decision-making style, deferring to their families, and only 1 (0.8%) deferring to the physician. No demographic characteristics significantly predicted DCPs. The majority of patients agreed or strongly agreed that they wanted to hear all of the information regarding their diagnosis (94%), treatment options (94%), treatment expectations (92%), and treatment risks and benefits (96%). These results confirm our hypothesis that most Hispanic patients prefer either an active or shared decision-making process rather than a passive decision-making process. Most patients prefer disclosure of diagnosis, prognosis, and plan.

**Keywords** Healthcare disparities · Advanced cancer · Health communication · Palliative care · Hispanic Americans

## Introduction

Understanding patient medical information-sharing and decision-making preferences is important to ensure patient satisfaction with decision-making [1]. Decision control preferences (DCPs) are defined as patient's preferences for medical decision-making processes. Categories of DCPs include active (decisions made by patient his or herself), shared with

family, shared with doctors, shared with family and doctors, and passive (paternalism, or decisions made by physician and/or family without participation of the patient) [2].

Many physicians experience difficulties in identifying patients' DCPs. Bruera et al. compared the medical decision-making preferences of patients with advanced cancer to their physicians' perceptions of these preferences [3]. This study found concordance between patient preferences and physician perceptions of these preferences in only 45% of the cases. Similarly, Degner et al. studied 1012 women diagnosed with breast cancer and found a concordance of only 42% between DCPs and their self-reported decision-making experiences [4]. This discordance may lead to decision-making processes that are not aligned with patient preferences, causing frustration or unnecessary burden on patients [5].

DCPs have been well studied in North America, especially in non-Hispanic white patients, using the Control Preference Scale (CPS) [6, 7]. Among 3491 mainly non-Hispanic white cancer patients, 26% preferred to choose their cancer treatment (active DCP), 49% wanted to collaborate with the physician in making decision (shared DCP), and 25% wanted the physician to make decision for them (passive DCP) [7]. However, studies focusing on Hispanic Americans have been smaller and more limited.

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Hispanic Americans are among the fastest growing minority groups in the USA, accounting for 16.3% of the population in the 2010 census [8]. Studies exploring decisional preferences in Hispanic population, especially with cancer, are limited to selected cancer centers in the USA, which may not be representative of the Hispanic-American population at large [9]. This lack of knowledge and understanding of the true decision-making preferences of specific populations and cultures could result in physicians making stereotypic assumptions in their interactions with these patients [10]. New York City is one of the most diverse cities in the world, and close to 29% of the population identify themselves as Hispanic or Latino [8, 11], making it an ideal place to study Hispanic and Latino populations not represented in previous studies.

Historically, Hispanic patients with advanced cancer have been perceived as preferring passive decisional control, especially older patients and patients in the palliative care setting [12, 13]. A study by Blackhall et al. performed in Los Angeles, California 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 [12]. 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 [13]. However, a recent multicenter study surveyed 387 Latino cancer patients from outpatient palliative care clinics in Argentina, Chile, Guatemala, and MD Anderson Texas, USA regarding preferred decisional control and medical care satisfaction [9]. This study found that 48% patients preferred shared decisional control, 31% preferred active decisional control, and 21% preferred a passive approach. Interestingly, 92% patients wanted to know their diagnosis and 94% wanted to know their prognosis. This study also noted those older patients and those who wanted to know their diagnosis seemed to be more satisfied with the way treatment decision were made. However, an important limitation was that Hispanic patients in this study were not a representative sample of the general Hispanic populations living in the USA because of their higher education and socioeconomic status. The Bronx is the only New York borough with a Hispanic majority. According to a 2013 Census Bureau estimate, 55% of Bronx's population identified themselves as Hispanic. Almost 40% of them are from Puerto Rico and Dominican Republic. The majority (55.7%) of the population in the Bronx speak non-English languages at home and over 580,600 people (45.2% of the population) speak Spanish at home [14].

Given the lack of information in underserved communities, this study aims to explore medical information-sharing and decision-making preferences of Hispanic patients in the Bronx exploring preferences for decision-making process; active, shared with family, shared with doctors, shared with family and doctors, passive; and to determine disclosure of information (diagnoses, prognosis, and plan of care) preferences.

## Methods

We conducted a cross-sectional survey of 119 cancer patients self-identified as Hispanic at the Oncology Clinic at Montefiore Medical Center Cancer.

The Montefiore/Einstein institutional review board approved this protocol, and all participants provided verbal informed consent. All participants completed the survey with the help of a research coordinator during the visit to the outpatient center.

## Participants

A patient was enrolled in the study at the time of a new or follow-up visit to any oncologist or palliative care physician at the cancer center. Researchers attended Tuesday or Friday clinic sessions four times a month and requested clinic schedules from the front desk staff. Researchers approached patients on the schedule that were present in the waiting room to screen for eligibility.

## Inclusion Criteria

Patients were included if they had a cancer diagnosis confirmed by chart and medical records were at least 18 years old, self-identified as Hispanic, and were able to converse in English or Spanish.

## Exclusion Criteria

Patients were excluded if they did not provide informed consent, or if they had cognitive impairment limiting the ability to understand the nature of the study and consent process, as determined by trained study personnel.

## Outcome Measures

A questionnaire was administered in English or Spanish by a trained bilingual research assistant or by the PI, who is also bilingual. Research assistants were physician assistants or medical students. The questionnaire included demographic questions, the CPS and questions regarding information-sharing preferences as measured by a Likert scales. The questionnaire can be found in the appendix.

## The Control Preferences Scale (CPS) [15, 16]

Patients' DCPs were assessed with the CPS. We used the triadic form (patient-family-physician) of this questionnaire (Appendix Table 2), 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 Table 3). The decision-making preference was assessed with the following question: “Thinking about decisions that you are making regarding your cancer treatment, for example, decisions to start chemotherapy, how do you prefer to make decisions about your care?” The patients had 15 answer options and chose one option that was later categorized as passive, shared, or active decision-making. 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/or physician.

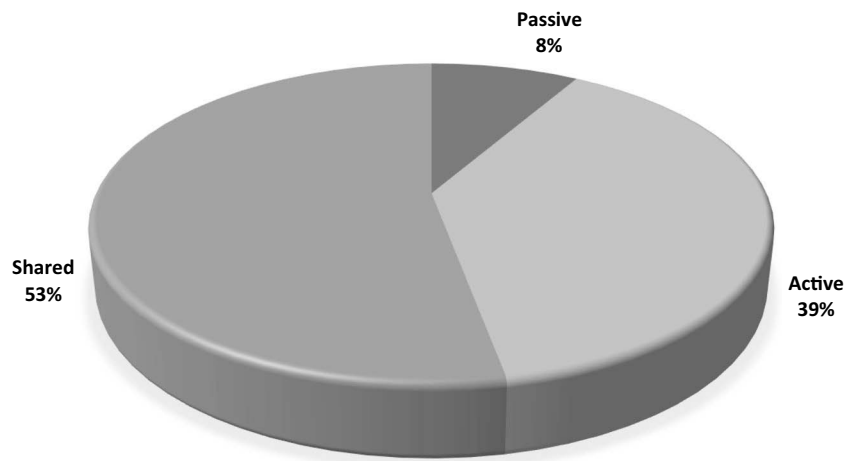
In this study, the CPS was chosen because it has been successfully used to assess DCPs in previous studies by other groups in more than 3000 cancer patients [9, 17].

Questions regarding information preferences included (1) I want to receive all information about my diagnosis (my cancer); (2) I want to receive all information about treatment options (such as chemotherapy, radiation, etc); (3) I want to receive all information about treatment expectations, including whether treatment is curative or not; and (4) I want to receive all information about treatment risks and benefits including expected survival. Participants were asked to indicate level of agreement with each prompt using a Likert scale ranging from strongly disagree to strongly agree.

**Table 1** Characteristics and medical decision-making preferences of self-identified Hispanic patients enrolled in the study ( $n = 119$ )

Characteristic, $n$ (%)	Medical decision-making preference				$P$ value
	Total	Passive	Active	Shared	
Age, mean (SD)	61.6 (14.2)	67.9 (3.3)	61.0 (2.1)	61.0 (1.9)	= 0.342
Female	69 (58.0)	7 (10.1)	25 (36.2)	37 (53.6)	= 0.652
Male	50 (42.0)	3 (6.0)	21 (42.0)	26 (52.0)	
Marital status					= 0.419
Single	36 (30.2)	2 (5.6)	16 (44.4)	18 (50.0)	
Divorced	17 (14.3)	3 (17.6)	5 (29.4)	9 (52.9)	
Married	45 (37.8)	5 (11.1)	18 (40.0)	22 (48.9)	
Widowed	21 (17.6)	0 (0)	7 (33.3)	14 (66.7)	
Education					= 0.098
None	15 (12.6)	4 (26.7)	3 (20.0)	8 (53.3)	
Less than high school	46 (38.7)	2 (4.3)	20 (43.5)	24 (52.2)	
High school	29 (24.3)	1 (3.4)	10 (34.5)	18 (62.1)	
Some college/university	29 (24.3)	3 (10.3)	13 (44.8)	13 (44.8)	
Language used during clinical visits					= 0.077
Spanish	11 (9.2)	1 (9)	8 (72.7)	2 (18.2)	
Spanish with interpreter	54 (45.4)	6 (11.1)	16 (29.6)	32 (59.3)	
English	54 (45.4)	3 (5.6)	22 (40.7)	29 (53.7)	
Nationality					= 0.645
Puerto Rico	56 (47.1)	7 (12.5)	22 (39.2)	27 (48.2)	
Dominican Republic	39 (32.8)	2 (5.1)	15 (38.5)	22 (56.4)	
USA	7 (5.9)	0 (0)	4 (57.1)	3 (42.8)	
Mexico and others	17 (14.3)	1 (5.9)	5 (29.4)	11 (64.7)	
Primary Cancer					= 0.075
Hematological	50 (42.0)	2 (4.0)	21 (42.0)	27 (54.0)	
Gastrointestinal	18 (15.1)	1 (5.6)	7 (38.9)	10 (55.6)	
Lung	15 (12.6)	0 (0)	4 (26.7)	11 (73.3)	
Genitourinary/gynecological	6 (5.0)	0 (0)	4 (66.7)	2 (33.3)	
Other	20 (16.8)	4 (20.0)	8 (40.0)	8 (40.0)	
I do not know	10 (8.4)	3 (30.0)	2 (20.0)	5 (50.0)	
Time since diagnosis					= 0.345
< 1 year	74 (62.2)	5 (6.8)	29 (39.2)	40 (54.1)	
1–5 years	32 (26.9)	2 (6.3)	13 (40.6)	17 (53.1)	
> 5 years	11 (9.2)	2 (18.2)	4 (36.4)	5 (45.5)	
I don't know	2 (1.7)	1 (50.0)	0 (0)	1 (50.0)	

**Fig. 1** Subject’s decisional control preferences ( $n = 119$ ). Preference was recorded as active if the patient indicated that they preferred to make their own medical decisions ( $n = 46$ ), passive if they preferred the family ( $n = 9$ ) or the doctor ( $n = 1$ ) to make decisions, or shared if they preferred to share the decision with their family ( $n = 38$ ), their doctor ( $n = 3$ ) or both ( $n = 22$ )



**Statistical Analyses**

Descriptive statistics were used to summarize the data. The relationship between patient characteristics and DCPs was tested using a chi-squared test of homogeneity, evaluating the frequencies of endorsing each category of decisional control preferences (passive, shared, active) across categories of patient characteristics including gender, age > 64, educational level, marital status, primary language, country of origin, and cancer diagnosis.

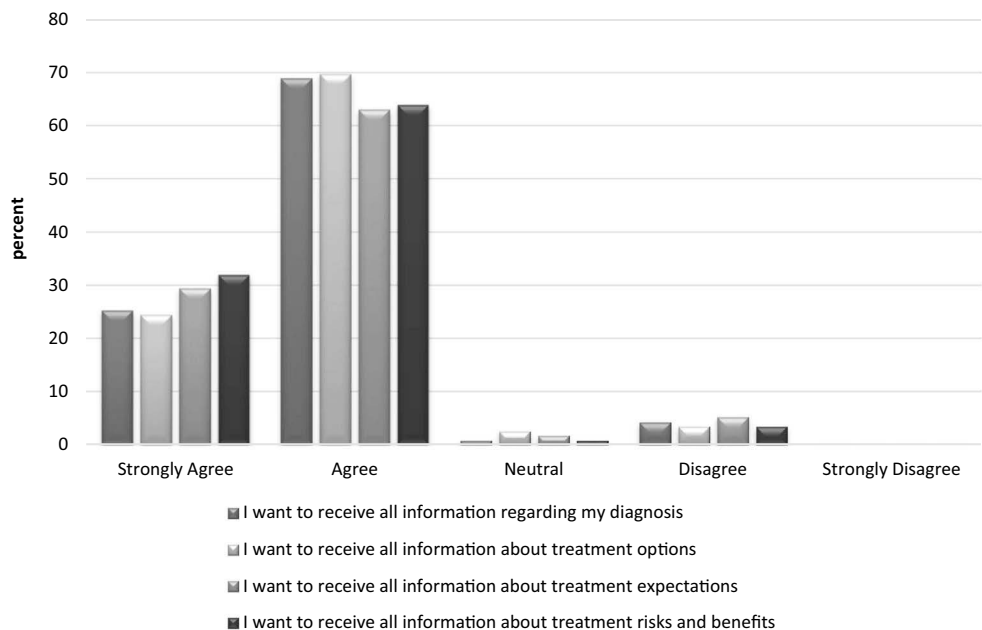
**Results**

Characteristics of the 119 patients interviewed are shown in the Table 1. The majority of patients (63, 52.9%) preferred shared decision-making, while 46 (38.7%) preferred an active

style. A minority (10, 8.4%) had a passive style (Fig. 1). Among the 60 who preferred shared decision-making, most (60, 95%) preferred sharing decisions with family (38, 60%) or family and the doctor (22, 35%), and only 3 (5%) preferred sharing decisions with the physician alone. Nine of the 10 that preferred a passive style preferred family to make decisions, and only 1 preferred the physician to make the decision alone. No patient characteristics were significantly associated with DCPs.

The majority agreed or strongly agreed that they wanted to hear all of the information regarding their diagnosis, that they wanted to receive all the information about their treatment options, that they wanted to receive all information about treatment expectations, and that they wanted to receive all information about treatment risks and benefits (94, 94, 92, and 96%) respectively (Fig. 2). No patient characteristics significantly predicted informational preferences (Table 1).

**Fig. 2** Subject responses to prompts ( $n = 119$ )



## Discussion

Upon this writing, this is the first study of DCPs of Hispanic patients with cancer in an inner city setting serving a low income and medically underserved population. As mentioned in different studies, Hispanic patients with advanced cancer have been perceived as preferring passive decisional control, especially older patients and patients in the palliative care setting [4, 9, 13]. It is especially important to understand the medical decision-making preferences of Hispanic patients since they are the fastest growing minority group in the USA, and there may be misconceptions regarding their preferences among US physicians.

The findings in our present study show that contrary to some perceptions [4, 9, 12, 13], Hispanic American patients do not prefer a passive decisional control process. In fact, in our study they preferred a passive decisional control process less often (8.4%) than patients in previous studies of non-Hispanic whites (24%) [7] and Hispanic patients in the USA and Latin America (21%) [9]. Among those with both shared and passive styles, our patients did not endorse physician-centric decisional control. The differences in our study compared with others may represent a difference in the relationship between our patient population and the health care community that should be further explored.

Other studies have explored characteristics that predict passive decisional control preferences. Passive decision preferences have been associated in elderly and less acculturated Hispanic patients [18]. The average age of our patient population was similar to previous studies. However, 45% of patients in our study spoke English, indicating that our population may have been more acculturated compared with previous literature. However, acculturation was not specifically measured in this study. Another consideration is that patient's decision-making style may also vary based on the decision that has to be made; they may want to be less involved if the condition is life threatening, which could explain the much larger proportion of patients that preferred physicians to make decisions regarding life-prolonging technology [12, 19]. Additionally if recommendations are clear, patients may not prefer an active role, but may want to be more involved if the right decision is not clear [19].

In our study, the majority of patients preferred some sort of shared decision-making (53%), reflecting the importance given to family participation in Hispanic culture in the Bronx; the family may even serve as deliberators in important medical decisions. This observation can help guide clinicians caring for Hispanic patients because this study confirms the importance of family participation in serious medical decisions. This was consistent with a previous multicenter survey of 387 Hispanic patients in the USA and LATIN America including countries of Chile, Argentina, and Guatemala where they found that 182 patients (47.6%) preferred shared decisional control

[9]. Also, similar to previous literature, our patients endorsed wanting to information on diagnosis and prognosis [9].

These findings are important because they indicate that physicians' perceptions of patient preferences may be even less accurate than previously thought. Bruera et al.'s study of patient preferences versus physician perceptions of treatment decision preferences in cancer care in Hispanic patients found that physicians predicted that patients preferred passive approaches 32% of the time, which greatly overestimates the preferences for a passive approach in our study [3].

Our main limitation is generalizability our study to Hispanic population in the USA. Our population is mostly Dominican and Puerto Rican which may be different from other cities in the USA. However, this study adds to the literature by including populations under-represented in previous literature.

Our findings suggest that Hispanic cancer patients in the Bronx prefer shared decision-making with family. It might not be appropriate to predict desire for involvement based on ethnicity or language alone. Medical providers can improve efforts to promote a more collaborative or active role for patients in medical decision-making in cancer. It is important to keep in mind the importance of family participation in Hispanic culture. Further studies are needed to assess other psychosocial and cultural predictors influencing preferences for involvement in medical decision-making, as well as preferred role congruence among Spanish speaking Hispanics.

## Compliance with Ethical Standards

**Conflict of interest** The authors declare that they have no conflicts of interest.

## Appendix 1

**Table 2** CPS (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 2

**Table 3** Classification of decisional control preferences based on the CPS (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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