Original Article

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%) preferred active decisional control, and 81 (21.2%) preferred a passive approach. Concerning their 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%) patients (weighted kappa = 0.55). Patients' greater

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satisfaction with the decision-making process was correlated with older age ($P \leq 0.001$) and with a preference for enhanced diagnostic disclosure ($P \leq 0.024$). 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. J Pain Symptom Manage 2014;47:896–905.

Key Words
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.[1] 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. 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.[2] compared the medical DCPs of patients with advanced cancer to their physicians' perceptions of these preferences. Bruera et al. found concordance between patient preferences and physician perceptions of their preferences in only 45% of the cases.

DCPs have been well studied in North America, predominantly in non-Hispanic white patients. In a meta-analysis of six studies, Jasvinder et al.[3] 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 article was to report our findings regarding the association between DCPs, sociodemographic and clinical characteristics, and Hispanic patients' preferences for the 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