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## Original Article

# “Doctor, Make My Decisions”: Decision Control Preferences, Advance Care Planning, and Satisfaction With Communication Among Diverse Older Adults

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## Abstract

**Context.** Culturally diverse older adults may prefer varying control over medical decisions. Decision control preferences (DCPs) may profoundly affect advance care planning (ACP) and communication.

**Objectives.** To determine the DCPs of diverse, older adults and whether DCPs are associated with participant characteristics, ACP, and communication satisfaction.

**Methods.** A total of 146 participants were recruited from clinics and senior centers in San Francisco. We assessed DCPs using the control preferences scale: doctor makes all decisions (low), shares with doctor (medium), makes own decisions (high). We assessed associations between DCPs and demographics; prior advance directives; ability to make in-the-moment goals of care decisions; self-efficacy, readiness, and prior asked questions; and satisfaction with patient-doctor communication (on a five-point Likert scale), using Chi-square and Kruskal-Wallis analysis of variance.

**Results.** Mean age was  $71 \pm 10$  years, 53% were non-white, 47% completed an advance directive, and 70% made goals of care decisions. Of the sample, 18% had low DCPs, 33% medium, and 49% high. Older age was the only characteristic associated with DCPs (low:  $75 \pm 11$  years, medium:  $69 \pm 10$  years, high:  $70 \pm 9$  years,  $P = 0.003$ ). DCPs were not associated with ACP, in-the-moment decisions, or communication satisfaction. Readiness was the only question-asking behavior associated (low:  $3.8 \pm 1.2$ , medium:  $4.1 \pm 1.2$ , high:  $4.3 \pm 1.2$ ,  $P = 0.05$ ).

**Conclusion.** Nearly one-fifth of diverse, older adults want doctors to make their medical decisions. Older age and lower readiness to ask questions were the only demographic variables significantly associated with low DCPs. Yet, older adults with low DCPs still engaged in ACP, asked questions, and reported communication satisfaction. Clinicians can encourage ACP and questions for all patients, but should assess DCPs to provide the desired amount of decision support. *J Pain Symptom Manage* 2016;51:33–40. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

*Decision control preferences, advance care planning, aging, health disparities, communication*

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## Introduction

As the age of the population and the prevalence of comorbid disease continue to increase, many older adults will be faced with complex, ongoing medical decisions.<sup>1–4</sup> Advance care planning (ACP) for

medical care is considered an important process for older adults and their families because of the increased likelihood and need for medical decision-making.<sup>5</sup> However, it is currently unknown how diverse, older adults want to be involved in medical

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decision-making, or how these preferences affect ACP, decision-making about goals of care, and empowerment in and satisfaction with patient-clinician communication.

Decision control preferences (DCPs) refer to the amount of control patients prefer to have over their medical decisions. Preferences range from patients wanting to make all of their own decisions (high DCPs), sharing decision-making with their clinicians, or to having their clinicians make all of their medical decisions for them (low DCPs).<sup>6</sup> The prevalence of low DCPs among the general population is estimated to be between 13% and 44%.<sup>7–14</sup> However, many of these studies were conducted among homogeneous populations (e.g., one race/ethnic group, such as African Americans or Asians) or among younger individuals.<sup>7,10,15</sup> Among these studies, low DCPs have been associated with older age, lower education, minority status, and, for some groups, such as Mexican Americans and Korean Americans, less acculturation to the U.S.<sup>7,9,10,16,17</sup> Studies that have included older adults have only focused on one disease process, such as prostate or breast cancer, and not on a range of multimorbidity.<sup>18–21</sup>

Moreover, among chronically ill populations, it is unknown how DCPs may affect engagement in decision-making for serious illness, which includes the ability to engage in ACP, make in-the-moment decisions for serious illness, and effectively communicate with clinicians. Patients who are more passive within clinical encounters, particularly minorities, are less likely to receive information from clinicians.<sup>12,13,22–25</sup> These patients also tend to report lower satisfaction with communication.<sup>20–23</sup>

To our knowledge, no prior study has assessed the DCPs of community-dwelling, older adults with multimorbidity and from diverse cultural backgrounds or the effect of DCPs on ACP, in-the-moment goals of care decision-making, and ratings of patient-clinician communication. Therefore, in this study of diverse, older adults with multimorbidity, we hypothesize that low DCPs will be associated with older age, less education and U.S. acculturation, and minority race/ethnicity. We also hypothesize that low DCPs will be associated with low rates of ACP, in-the-moment goals of care decision-making, poor question-asking behavior, and lower rates of satisfaction with patient-clinician communication.

## Methods

### Data

Cross-sectional survey data were pooled from four cohort studies. Full recruitment procedures and interview methods have been previously described.<sup>26,27</sup> Briefly, two cohorts were recruited to test the validity

and reliability of a new ACP engagement survey ( $n = 89$ ).<sup>26</sup> The other two cohorts were recruited to pilot test the feasibility and efficacy of a novel Web site to engage older adults in ACP ( $n = 57$ ).<sup>27</sup> Each cohort was recruited from a range of sites including San Francisco General Hospital, San Francisco Veterans Affairs Medical Center, low-income senior centers, and cancer support groups in San Francisco. Data were collected between 2010 and 2012. These studies were approved by the Institutional Review Boards at the University of California, San Francisco and the San Francisco VA Medical Center.

### Inclusion/Exclusion Criteria

Participants were eligible if they spoke English, were 60 years of age or older, and had two or more chronic medical conditions. Participants were excluded if they could not hear well enough to talk on the phone, could not see well enough to read the words on a newspaper, lacked a phone (needed for follow-up interviews), or had cognitive impairment based on validated screening measures.<sup>26,27</sup>

### Study Variables

To characterize the population, we collected demographic information including age, gender, race/ethnicity, educational attainment, U.S. acculturation (i.e., whether they were born outside the U.S. and years lived in the U.S.), number of self-reported comorbidities, and social support (i.e., married and/or have adult children). We also used one self-reported, validated question to estimate health literacy.<sup>28</sup>

### Primary Outcome Measure

The control preferences scale assesses the degree of control patients prefer over medical decisions made with their doctors.<sup>6</sup> This scale has been used and validated in several international studies, and a large meta-analysis has shown association between preferred role and actual role in decision-making.<sup>29–31</sup> The question and five response options include, “How do you prefer to make medical decisions with your doctors?: 1) I make all medical decisions on my own; 2) I make the final decision myself only after considering my doctor’s opinion; 3) My doctors and I share decision making equally; 4) My doctors make the final decision for me only after considering my opinion; 5) My doctors make all medical decisions for me.” We combined responses one and two and responses four and five to create a trilevel variable: “1) I make all medical decisions on my own (high DCPs); 2) My doctors and I share decision making equally (medium DCPs); or 3) My doctors make all medical decisions for me (low DCPs).”

### Secondary Outcome Measures

We asked participants about prior ACP decisions including whether they had identified a potential surrogate decision maker, whether they completed an advance directive, and whether they had made life or death medical decisions for themselves or others.<sup>32</sup> To determine participants' capability of making an in-the-moment decision about goals of care, we asked participants to consider situations in which life may not be worth living: "When you think about your health and the future: 1) there may be some health situations or experiences that would make my life not worth living, such as never being able to wake up from a coma or never being able to talk to family or friends; 2) life is always worth living no matter what type of serious illness, disability, or pain I may be experiencing; or 3) I don't know."

We used questions from the validated Advance Care Planning Engagement Survey to measure participants' perceptions of self-efficacy and readiness to ask questions to doctors and question-asking behaviors. This survey has been shown to have good internal consistency (Cronbach alpha, 0.94), test-retest reliability (intraclass correlation, 0.70), and discriminant validity.<sup>26</sup> Of 146 participants, 107 reported their self-efficacy ("How confident are you that you could ask the right questions of your doctors to help make good medical decisions?" measured on a five-point Likert response scale from not at all to extremely); readiness ("How ready are you to ask your doctors questions to make good medical decisions?" measured on a five-point Likert scale from not at all to extremely); and action ("Have you ever asked your doctors questions?" yes or no). For individuals who reported asking questions, we further explored participants' satisfaction with the patient-clinician communication; "How satisfied were you that (a) you were able to ask what was most important to you and (b) your doctor really answered your questions?" measured on a five-point Likert scale from not at all to extremely.

### Exploratory Analysis and Outcomes

In addition to assessing participants' DCPs with their doctors, for a subset of 56 participants, we also assessed how patients would want to make medical decisions with their family and friends. Participants were given responses on a five-point scale modified from the DCPs scale,<sup>6</sup> which we combined into a trilevel categorical variable: prefer to make own decisions (high family and friend DCPs); share decisions with family and friends (medium family and friend DCPs); or family and friends make all decisions (low family and friend DCPs).

### Statistical Analysis

To describe participant characteristics, we used percentages and means with SDs. To assess the association

between participant characteristics and DCPs, we used Chi-square tests or Fisher's exact tests for dichotomous or categorical variables and *t*-tests for continuous variables. To assess the association between DCPs and ACP and question-asking behaviors, we used Kruskal-Wallis analysis of variance. In exploratory analysis, for individuals who reported low DCPs for decision-making with the doctor, we also assessed the level of DCPs for family and friends using Fisher's exact test.

### Results

A total of 146 participants met the inclusion criteria (Table 1). The mean age of the cohort was 71 years ( $\pm 10$  years), and participants had a mean number of 3 ( $\pm 2$ ) comorbidities. Forty-one percent of participants were women, 53% were nonwhite, 16% had less than or equal to a high school education, 28% had limited health literacy, and 19% were born outside of the U.S. Participants had considerable experience with ACP, with 61% reporting having a potential surrogate decision maker; 47% having completed an advance directive; and 43% having made a life or death medical decision for themselves and 36% for others. Seventy percent of participants also were able to make an in-the-moment decision about their current goals for care.

Of the 146 participants, 18% wanted doctors to make all of their medical decisions (low DCPs); 34% wanted to share medical decisions (medium DCPs); and 48% wanted to make their own medical decisions (high DCPs; Fig. 1).

### Patient Characteristics Associated With DCPs

Age was the only demographic variable significantly associated with DCPs. The mean age of participants with low DCPs was  $75 \pm 11$  years, compared with medium DCPs ( $69 \pm 10$  years) or high DCPs ( $70 \pm 9$  years),  $P = 0.003$ . Lower DCPs trended toward lower education, but this was not statistically significant,  $P = 0.09$ . Furthermore, DCPs were not significantly associated with gender, race/ethnicity, U.S. acculturation, number of comorbidities, social support, or limited health literacy.

### Prior and Current ACP

DCPs were not significantly associated with prior ACP, including choosing a potential surrogate decision maker, completing an advance directive, or making life or death decisions for self or others,  $P > 0.05$ . In addition, DCPs were not associated with the ability to make an in-the-moment decision about goals of care (Table 2).

### Question-Asking Behaviors

One hundred seven participants (73% of the original cohort) answered questions regarding

Table 1  
Participant Factors Associated With DCPs

Characteristic	Overall, N = 146	Doctor Makes Decisions (Low DCPs) n = 27	Share Decisions (Medium DCPs) n = 49	Make Own Decisions (High DCPs) n = 70	P-value
Age, mean $\pm$ SD	70.8 $\pm$ 9.9	75.3 $\pm$ 10.7	68.9 $\pm$ 9.8	70.4 $\pm$ 9.1	0.03 <sup>a</sup>
Women, n (%)	60 (41.1)	10 (37.0)	19 (38.8)	31 (44.3)	0.77 <sup>b</sup>
Race/ethnicity, n (%)					
White, Non-Hispanic	69 (47.3)	15 (55.6)	21 (42.9)	33 (47.1)	0.28 <sup>b</sup>
African American	39 (26.7)	8 (29.6)	13 (26.5)	18 (25.7)	
Latino or Hispanic	10 (6.9)	1 (3.7)	4 (8.2)	5 (7.1)	
Asian or Pacific Islander	19 (13.0)	3 (11.1)	4 (8.2)	12 (17.1)	
Multiethnic, Other	9 (6.2)	0 (0.0)	7 (14.3)	2 (2.9)	
Education, n (%)					
$\leq$ High school	23 (15.8)	6 (22.2)	11 (22.4)	6 (8.6)	0.09 <sup>b</sup>
Acculturation					
Born in the U.S., n (%)	115 (80.8)	21 (77.8)	38 (77.6)	56 (80.0)	0.92 <sup>a</sup>
Years in U.S., mean ( $\pm$ SD)	38.9 ( $\pm$ 18)	31.3 ( $\pm$ 10.2)	39.4 ( $\pm$ 18.5)	41.4 ( $\pm$ 20.5)	0.46 <sup>a</sup>
Number of comorbidities					
Mean $\pm$ SD	3.2 $\pm$ 2.3	3.6 $\pm$ 2.9	3.0 $\pm$ 1.9	3.2 $\pm$ 2.3	0.94 <sup>a</sup>
Social support, n (%)					
Married/long-term partner	52 (35.6)	9 (33.3)	16 (32.7)	27 (38.6)	0.74 <sup>b</sup>
Have adult children	95 (65.1)	19 (70.4)	33 (67.3)	43 (61.4)	0.27 <sup>b</sup>
Limited health literacy, self-reported, n (%)	41 (28.1)	7 (25.9)	16 (32.7)	18 (25.7)	0.67 <sup>b</sup>

DCP = decision control preference.

<sup>a</sup>P-values were calculated from the Kruskal-Wallis test.

<sup>b</sup>P-values were calculated from Fisher's exact test.

asking questions to doctors. We found a significant association between DCPs and readiness to ask doctors questions: participants with low DCPs had a mean five-point Likert score of 3.8 ( $\pm$ 1.2); compared with medium DCPs (4.1  $\pm$  1.2) and high DCPs (4.3  $\pm$  1.2),  $P = 0.05$ . However, no associations were found between DCPs and self-efficacy, self-reports of asking questions to doctors, or satisfaction with the doctor-patient communication (Table 3).

In exploratory analysis of the 56 participants who were asked about DCPs with respect to family and friends, none wanted their family and friends to make decisions for them, 14% wanted to share decisions with their family and friends, and 84% wanted to make their own decisions. For the nine individuals in this exploratory cohort who had low DCPs (doctor makes decisions), none reported wanting the family to help with decision-making (Table 4).

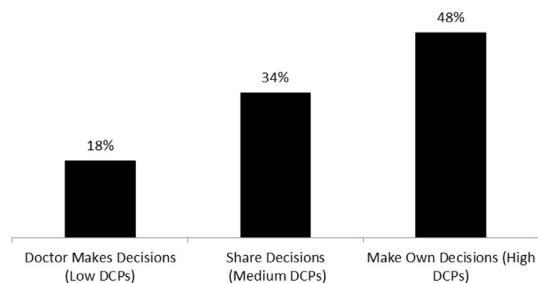


Fig. 1. Prevalence of DCPs with respect to the doctor,  $n = 146$ . DCP = decision control preference.

## Discussion

Understanding DCPs among diverse, older adults is becoming increasingly relevant given the rise in chronic illnesses and the complexity of decisions surrounding end-of-life care.<sup>5</sup> In this study, almost one-fifth of diverse, community-dwelling older adults with multiple comorbidities wanted their doctors to make medical decisions for them. Older age was the only patient characteristic significantly associated with lower DCPs. In addition, low DCPs did not preclude participants from engaging in prior ACP or in-the-moment goals of care decisions. Furthermore, although low DCPs were associated with less readiness to ask questions to doctors, it did not preclude participants from asking questions to doctors or result in decreased confidence or satisfaction with patient-clinician communication.

Our results suggest that several assumptions about patients with low DCPs should not be made. First, beyond older age, DCPs cannot be predicted based on demographic information alone. Consistent with other studies, we found that older age was associated with lower DCPs.<sup>9,10,16,33</sup> The prevalence of low DCPs in older patients has been attributed to severity of disease, lack of knowledge, low self-efficacy, and fear regarding their illness.<sup>33-35</sup> It is important to note that despite a clear association of DCPs with age, most of our older population preferred to share decisions with their doctor or make their own decisions. In addition, although there was a trend toward lower education and lower DCPs, we found no statistically significant relationship between education and

Table 2  
DCPs and Advance Care Planning

	Overall, N = 146 n (%)	Doctor Makes Decisions (Low DCPs), n = 27 n (%)	Share Decisions (Medium DCPs), n = 49 n (%)	Make Own Decisions (High DCPs), n = 70 n (%)	P-value
Advance Care Planning					
Prior care planning					
Decided on a surrogate decision maker	89 (61.0)	17 (63.0)	29 (59.2)	43 (61.4)	0.96 <sup>a</sup>
Completed an advance directive	69 (47.3)	10 (37.0)	27 (55.1)	32 (45.7)	0.21 <sup>a</sup>
Made life or death decision for self	63 (43.2)	9 (33.3)	21 (42.9)	33 (47.1)	0.32 <sup>a</sup>
Made life or death decision for others	52 (35.6)	7 (25.9)	16 (32.7)	29 (41.4)	0.33 <sup>a</sup>
Goals of care decisions: which statement do you most agree with?					
Life is always worth living	26 (17.8)	5 (18.5)	11 (22.5)	10 (14.3)	0.52 <sup>b</sup>
Some situations would make life not worth living	76 (52.1)	13 (48.2)	25 (51.0)	38 (54.3)	0.85 <sup>b</sup>
I am not ready to answer/not sure	44 (30.1)	9 (33.3)	13 (26.5)	22 (31.4)	0.78 <sup>b</sup>

DCP = decision control preference.

<sup>a</sup>P-values calculated from Fisher's exact test.

<sup>b</sup>P-values calculated from Chi-square test.

DCPs. Lower education status was found to be associated with lower levels of DCPs in some studies<sup>7,10,16,36</sup> but not associated in others.<sup>9,21,35,37</sup>

Contrary to our hypotheses and prior literature, minority status and acculturation to the U.S. were not significantly associated with lower DCPs. These results may be a result of a lack of power to assess each race/ethnic subgroup and an overall high rate of acculturation (80%). Nevertheless, results from the literature have been mixed. For example, past research among minorities has implied that certain cultural values and beliefs are associated with low DCPs.<sup>17,38</sup> In a meta-analysis of end-of-life decision-making among racially and ethnically diverse groups, Kwak and Haley<sup>39</sup> found that Korean and Mexican Americans, regardless of acculturation status, were more likely to designate a family member as the primary medical decision maker. However, other studies found no association between DCPs and minority status or acculturation to the U.S.<sup>13,16</sup> Regardless, it is important to elicit and honor different views concerning DCPs because the value of autonomy in decision-making is often culturally and contextually dependent.<sup>37,38</sup>

In addition, low DCPs cannot be used as a predictor of engagement in ACP. We found that participants with low DCPs were just as likely to have made prior ACP decisions or in-the-moment goals of care decisions as their counterparts with high DCPs. To our knowledge, this is the first study to explore the relationship between DCPs and ACP among diverse, community-dwelling, older adults with multimorbidity. One study among inpatients with end-stage cancer or advanced illness found that 15% reported low DCPs and 61% of the total cohort had thought about preferences for life-sustaining treatments, such as cardiopulmonary resuscitation. Although this study did not include an analysis to assess the association between DCPs and ACP,<sup>40</sup> the authors suggest supporting patients in ACP by first understanding their decision preferences, especially in the context of informed decision-making.

Furthermore, our results suggest that patients with low DCPs do not lack empowerment to ask clinical questions. Although participants with low DCPs reported slightly less readiness to ask questions, in this study, they were as likely as their counterparts with high DCPs to report asking questions to doctors and to feel satisfied with patient-clinician communication.

Table 3  
DCPs and General Question-Asking Behaviors

Question-Asking Behavior	Overall, N = 107	Doctor Makes Decisions (Low DCPs), n = 21	Share Decisions (Medium DCPs), n = 33	Make Own Decisions (High DCPs), n = 53	P-value
Self-efficacy, <sup>a</sup> mean (±SD)	3.9 (0.9)	4.1 (±0.7)	3.8 (±0.9)	3.9 (±0.9)	0.45 <sup>b</sup>
Readiness, <sup>a</sup> mean (±SD)	4.1 (1.2)	3.8 (±1.2)	4.1 (±1.2)	4.3 (±1.2)	0.05 <sup>b</sup>
Action: asked questions, n (%)	100 (93.5)	18 (85.7)	32 (97.0)	50 (94.3)	0.29 <sup>c</sup>
Satisfaction, <sup>a</sup> mean (±SD)					
Able to ask what is most important	4.0 (0.8)	3.8 (±0.8)	4 (±0.7)	4 (±0.9)	0.39 <sup>b</sup>
Doctor answered questions	3.9 (0.9)	3.9 (±0.7)	4 (±0.8)	3.8 (±1.1)	0.87 <sup>b</sup>

DCP = decision control preference.

<sup>a</sup>Measured on a five-point Likert scale ranging from not at all to extremely.

<sup>b</sup>P-values were calculated from the Kruskal-Wallis test.

<sup>c</sup>P-values were calculated from Fisher's exact test.

Table 4  
Relationship Between DCPs With the Doctor and Friends/Family

DCPs With Respect to Friends/Family	Doctor Makes Decisions (Low DCPs), <i>n</i> = 9 <i>n</i> (%)	Share Decisions (Medium DCPs), <i>n</i> = 14 <i>n</i> (%)	Make Own Decisions (High DCPs), <i>n</i> = 33 <i>n</i> (%)	<i>P</i> value <sup>a</sup>
Family and friends make all my decisions	0 (0)	0 (0)	0 (0)	0.58
Share decisions with friends and family	2 (22.2)	1 (7.1)	5 (15.2)	
Make own decisions with family and friends	7 (77.8)	13 (92.9)	28 (84.8)	

DCP = decision control preference.

<sup>a</sup>*P*-value calculated from Fisher's exact test.

Prior research has shown that physicians are less likely to engage in patient-centered communication with patients who lack empowerment, who do not initiate conversations, and who are not actively involved in their treatment plan.<sup>22,23</sup> However, patients who are empowered to communicate with their clinicians may still prefer to defer decisions to their clinician or family. And, as other studies have shown, even patients with low DCPs prefer to obtain information about their illness and options from their clinicians before a decision is made.<sup>18,19,35</sup> These results suggest that all patients, especially those who feel less ready, can be encouraged to engage in their health care and ask questions.

Finally, patients who report low DCPs may need additional encouragement to designate a surrogate decision maker. In the U.S., doctors are encouraged to guide and make recommendations, but are not legally allowed to make autonomous decisions for patients.<sup>41</sup> One prior study found that patients who opted for cardiopulmonary resuscitation in end-of-life discussions were twice as likely to rely on family and physicians to make resuscitation decisions.<sup>42</sup> However, in our exploratory analysis, we found that none of the participants with low DCPs wanted family or friends to take over this role. Without designation of a surrogate decision maker, conflicts may arise when deciding how to proceed according to the patient's best interest.<sup>43</sup> Although these exploratory analyses preclude definitive recommendations, for patients with low DCPs, clinicians also may need to explain the importance of and encourage the designation of a surrogate whom the patient may trust to help with decision-making.

This study has several limitations. First, although participants were recruited from several clinical sites, the study was conducted in one area of the U.S., which may affect generalizability. In addition, the relatively small sample size may have precluded our ability to detect significant differences between DCPs and patient characteristics, such as race/ethnicity, and other outcomes. Social desirability or recall bias may have also resulted in underreporting rates of low DCPs and overreporting of ACP,

question-asking behavior, and patient-clinician communication outcomes. Additionally, we cannot be certain that participants with low DCPs who engaged in prior ACP fully understood their decisions and whether these decisions would be consistent over time. Furthermore, the cross-sectional design precludes the assessment of the effect of DCPs on ACP, question-asking behavior, and patient-clinician communication over time.

Although nearly one-fifth of diverse older adults report wanting their doctors to make all of their medical decisions, this study suggests that DCPs may not be able to be assumed based on demographic characteristics alone, including race/ethnicity, literacy, and U.S. acculturation. In addition, regardless of DCPs, clinicians can encourage ACP, in-the-moment goals of care decision-making, and questions from all patients. However, clinicians also should elicit patients' DCPs to provide the desired amount of decision support and to ensure informed decision-making, especially if an appropriate surrogate decision maker needs to be identified.

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