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PAPER

Factors associated with oncology patients' involvement in shared decision making during chemotherapy

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Abstract

Objective Oncology patients are increasingly encouraged to play an active role in treatment decision making. While previous studies have evaluated relationships between demographic characteristics and decision-making roles, less is known about the association of symptoms and psychological adjustment characteristics (eg, coping styles and personality traits) and decisionmaking roles.

Methods As part of a larger study of symptom clusters, patients (n = 765) receiving chemotherapy for breast, gastrointestinal, gynecological, or lung cancer provided information on demographic, clinical, symptom, and psychological adjustment characteristics. Patient-reported treatment decision-making roles (ie, preferred role and role actually played) were assessed using the Control Preferences Scale. Differences among patients, who were classified as passive, collaborative, or active, were evaluated using χ^2 analyses and analyses of variance.

Results Over half (56.3%) of the patients reported that they both preferred and actually played a collaborative role. Among those patients with concordant roles, those who were older, those with less education and lower income, and those who were less resilient were more likely to prefer a passive role. Several psychological adjustment characteristics were associated with decision-making role, including coping style, personality, and fatalism.

Conclusions Oncology patients' preferences for involvement in treatment decision making are associated with demographic characteristics as well as with symptoms and psychological adjustment characteristics, such as coping style and personality. These results reaffirm the complexities of predicting patients' preferences for involvement in decision making. Further study is needed to determine if role or coping style may be influenced by interventions designed to teach adaptive coping skills.

KEYWORDS

cancer, chemotherapy, coping, oncology, personality, shared decision making

1 | BACKGROUND

Shared decision making (SDM) is an important aspect of the patientclinician relationship and communication processes.1 In 2001, the Institute of Medicine encouraged overhauling the organization and delivery of health care and highlighted SDM as a key mechanism of patient-centered care.² More recently, with the passage of the Affordable Care Act (specifically, section 3506), SDM gained even greater prominence.3

Cancer treatment decisions are numerous, can be stressful, often unfold over years, and have important consequences for patients and family members in terms of quality and length of life, as well as treatment costs. Patients with cancer who participate more actively in the decision-making process and those who experience effective SDM may fare better with regard to physical and mental health, and quality of life, and tend to report greater patient satisfaction, less distress, and less regret. 4,5 Conversely, more control by physicians was associated with poorer reported health.6

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The Control Preferences Scale (CPS) was developed to assess the degree of control an individual prefers and actually exerts in the context of treatment decision making. It has emerged as one of the most commonly used instruments to assess decision-making role. Patients' preferred and actual decision-making roles are typically reported as "active," "collaborative," or "passive" depending on their degree of preferred and actual involvement in decision making.

In oncology patients, several associations have been described between patient characteristics and decision-making role. A meta-analysis of CPS data from over 3400 oncology patients found that younger individuals and those with more education tended to prefer a more active decision-making role, while women were less likely to describe their role as active despite expressing a preference for a more active role.⁸ In other studies, patients with poorer general health, more advanced stages of disease, lower physical functioning, and more comorbidities tended to prefer and actually play a less active role.^{7,9,10} Psychological characteristics may also influence decision-making role preferences and behaviors. In several studies that examined the relationships between emotional state, depression, anxiety, and decision-making roles, a passive role was associated with higher levels of depression, ^{11,12} a more negative mood, and greater mood disturbance.¹²

While previous work has established that certain demographic and psychological factors are related to patient involvement in decision making, less is known about how coping relates to role. According to Lazarus and Folkman, coping comprises those thoughts and behaviors used to manage the internal and external demands of situations that an individual appraises as stressful. 13 When faced with a threat, such as a diagnosis of cancer or the prospect of choosing between two or more treatment regimens, patients use varied coping strategies to manage the stressor. While numerous ways of describing and grouping various coping strategies have been described, one of the most widely used categorizations is that of engagement vs disengagement coping.¹⁴ Engagement coping describes a strategy of coping that involves both problem-focused coping (targeted at the stressor itself) and emotionfocused coping (efforts to minimize distress triggered by the stressor). For example, a problem-focused approach to coping with cancer treatment option may involve soliciting information about different treatments, while an emotion-focused coping approach may include seeking emotional support from a loved one.

The other broad category of coping is disengagement coping, which involves strategies like avoidance, denial, and wishful thinking and may manifest as acting as though the stressor does not exist. Disengagement coping is generally ineffective in reducing distress in the long term. The process of deliberation itself has been suggested to represent a multidimensional coping process. In theory, more active participation in treatment decision making may represent an engagement coping strategy, while more passive involvement may signify a disengagement coping strategy. However, limited prior work has examined empirically the relationship between treatment decision making in oncology patients and coping strategies.

Factors such as gender, age, personality, and coping style may all influence one's appraisal of a threat and potential outcomes. ¹⁸ Indeed, recent work has shown that personality, defined as "dimensions of individual differences in tendencies to show consistent patterns of thoughts, feelings, and actions," may be related to a patient's coping

strategy or their capacity for coping. ^{19–21} In theory, personality traits should influence patients' preferences and behaviors with regard to cancer treatment decision making because they influence a patient's coping methods. ¹⁴ As suggested recently, an understanding of coping strategies may lead to a more nuanced concept of decision-making role. ²² Therefore, it is important to understand a patient's decision-making role in relation to coping and personality traits. To our knowledge, no study has examined the relationships between coping approaches, personality traits, and decision-making roles among patients with various cancer diagnoses.

Therefore, the purposes of this study, in a sample of patients undergoing chemotherapy (CTX) for breast, gastrointestinal (GI), lung, or gynecological cancer were to (1) describe associations between demographics and decision-making role, (2) examine relationships between psychological characteristics (anxiety and depression) and decision-making role, and (3) identify relationships between decision-making role and psychosocial adjustment characteristics, such as coping style, personality, and mental adjustment to cancer.

2 | METHODS

2.1 | Patients and settings

This cross-sectional analysis used data from a larger, longitudinal study that evaluated the symptom experience of oncology outpatients receiving CTX.²³

Eligible patients were 18 years or older; had a diagnosis of breast, GI, gynecological, or lung cancer; had received CTX within the preceding 4 weeks; were scheduled to receive at least 2 additional cycles of CTX; were able to read, write, and understand English; and gave written informed consent. Patients were recruited from 2 Comprehensive Cancer Centers, 1 Veteran's Affairs hospital, and 4 community-based oncology programs. For the present analyses, a total of 1553 patients were approached and 941 consented to participate (60.1% response rate). The major reason for refusal was being overwhelmed with their cancer treatment.

Of the 941 participants, 862 completed the CPS. Of these, 765 (88.7%) were concordant in terms of their actual and preferred roles and were included in this analysis. Throughout this paper, "role" refers to those patients whose preferred role matched their actual role. The majority of patients had a collaborative role (56.3%), with fewer patients preferring either the active (23.3%) or passive (20.4%) role (Table 1).

2.2 | Instruments

2.2.1 | Demographic characteristics

A demographic questionnaire obtained information on age, gender, ethnicity, marital status, living arrangements, education, employment status, and income.

2.2.2 | Clinical characteristics

The Karnofsky Performance Status (KPS) scale is widely used to evaluate functional status in patients with cancer and has well-established

TABLE 1 Demographic and clinical characteristics by decision-making role among patients with concordant roles (n = 765)

Characteristic	Active (1), n = 178, 23.3% Mean (SD)	Collaborative (2), n = 431, 56.3% Mean (SD)	Passive (3), n = 156, 20.3% Mean (SD)	Statistics
Age, y	53.7 (11.8)	57.6 (11.1)	58.9 (12.5)	F = 9.9; P < .0001; 1 < 2 and
Education, y	16.7 (3.1)	16.3 (3.0)	15.8 (3.0)	F = 4.1; P = .017
Karnofsky Performance Status score	80 (11.7)	81 (12.3)	80.1 (12.1)	F = 0.2; P = .654
Number of comorbidities	2.2 (1.4)	2.5 (1.4)	2.4 (1.3)	F = 3.2; P = .040; 1 < 2
Self-Administered Comorbidity Questionnaire score	5.2 (3.1)	5.7 (3.2)	5.3 (2.8)	F = 2.1; P = .122
Time since cancer diagnosis, y	2.0 (3.4)	2.3 (4.2)	2.0 (3.6)	F = 0.4; P = .673
Median time since cancer diagnosis, y	0.44	0.45	0.43	
No. of prior cancer treatments	1.9 (1.5)	1.7 (1.5)	1.6 (1.6)	F = 0.4; P = .660
No. of metastatic sites including lymph node involvement	1.2 (1.3)	1.2 (1.2)	1.4 (1.3)	F = 1.6; P = .212
	% (N)	% (N)	% (N)	
Gender				
Female	81 (144)	80 (343)	71 (111)	$\chi^2 = 5.8$; $P = .056$
Male	19 (34)	20 (88)	29 (45)	
Ethnicity				
White	74 (131)	72 (201)	66 (100)	$\chi^2 = 3.4$; $P = .764$
Black	6 (10)	7 (30)	9 (14)	
Asian or Pacific Islander	10 (18)	12 (49)	14 (21)	
Hispanic mixed or other	10 (18)	10 (40)	10 (16)	
Married or partnered (% yes)	68 (120)	68 (291)	64 (99)	$\chi^2 = 0.7$; $P = .658$
Currently employed (% yes)	40 (71)	36 (153)	28 (43)	$\chi^2 = 5.6$; $P = .062$
Income				
<\$30 000+	17 (28)	16 (63)	17 (23)	KW, P = .019
\$30 000 to <\$70 000	14 (22)	20 (78)	32 (44)	
\$70 000 to <\$100 000	16 (25)	15 (59)	16 (22)	
≥\$100 000	53 (86)	49 (191)	36 (50)	
Cancer diagnosis				
Breast	49 (87)	39 (167)	30 (47)	$\chi^2 = 17.4$; $P = .008^a$
Gastrointestinal	27 (48)	30 (128)	35 (55)	
Gynecological	17 (31)	19 (80)	17 (27)	
Lung	7 (12)	13 (56)	17 (27)	
Type of prior cancer treatment				
No prior treatment	14.1 (25)	21.5 (91)	25.7 (39)	$\chi^2 = 8.3$; $P = .219$
Only surgery, CTX, or RT	49.2 (87)	43.3 (183)	40.8 (62)	
Surgery and CTX, or surgery and RT, or CTX and RT	20.9 (37)	21.7 (92)	18.4 (28)	
Surgery and CTX and RT	15.8 (28)	13.5 (57)	15.1 (23)	

Abbreviations: CTX, chemotherapy; KW, Kruskal-Wallis; RT, radiation therapy; SCQ, Self-Administered Comorbidity Questionnaire; SD, standard deviation.
^aCompared with patients with gastrointestinal or lung cancer, patients with breast cancer were more likely to prefer an active role.

validity and reliability. Using the KPS, patients rated their functional status from the lowest possible score of 30 ("I feel severely disabled and need to be hospitalized") to the highest possible score of 100 ("I feel normal; I have no complaints or symptoms").²⁴

The Self-Administered Comorbidity Questionnaire (SCQ) consists of 13 common medical conditions simplified into a language that can be understood without prior medical knowledge. Patients indicated if they have the condition; if they received treatment for it (proxy for disease severity); and if it limited their activities (indication of functional limitations). For each condition, the patient can receive a maximum of 3 points. The total SCQ score ranges from 0 to 39. The SCQ has well-established validity and reliability. Page 13.

2.2.3 | Control Preferences Scale

The CPS, developed by Degner and Sloan, was used to assess patients' preferred and actual roles in decision making about their cancer treatment. Patients responded to 2 questions (ie, the role they have actually been playing in dealing with their cancer diagnosis and the role they would have preferred) by choosing 1 of 5 statements (ie, A = I prefer to make the decisions about which treatments I will receive; B = I prefer to make the final decision about my treatment after seriously considering my doctor's opinion; C = I prefer to leave all decisions regarding my treatment to my doctor; D = I prefer to have my doctor make the final decision about which treatment will be used, but seriously consider my opinion; and E = I prefer that my doctor and I share responsibility for

deciding which treatment is best for me). Patients who preferred statements A or B were classified as active patients, those who preferred statement C or D were considered passive patients, and those who preferred statement E were classified as collaborative patients. The CPS has well-established validity and reliability in oncology patients.⁸

2.2.4 | Psychological symptoms

The Center for Epidemiological Studies-Depression scale (CES-D) consists of 20 items selected to represent the major symptoms in the clinical syndrome of depression. A total score can range from 0 to 60, with scores \geq 16 indicating the need for individuals to seek clinical evaluation for major depression. The CES-D has well-established validity and reliability. In the current study, the Cronbach α for the CES-D total score was 0.89.

The Spielberger State-Trait Anxiety Inventories (STAI-T and STAI-S) each have 20 items that are rated from 1 to 4. The summed scores for each scale can range from 20 to 80. The STAI-S measures a person's temporary anxiety response to a specific situation or how anxious or tense a person is "right now" in a specific situation. The STAI-T measures a person's predisposition to anxiety as part of one's personality. Cutoff scores of \geq 31.8 and \geq 32.2 suggest high levels of trait and state anxiety, respectively. ^{28,29} In the current study, the Cronbach α 's for the STAI-T and STAI-S were 0.92 and 0.96, respectively.

2.2.5 | Psychosocial adjustment characteristics

The Connor-Davidson Resilience Scale is a 10-item instrument, scored on a 5-point Likert scale, that evaluates self-perceived ability to handle adversity (eg, "I am able to adapt when changes occur"). 30 Items are scored on a 5-point Likert scale ("not true at all" to "true nearly all of the time"). Total scores range from 0 to 40, with higher scores indicative of higher self-perceived resilience. In this study, the Cronbach α for the Connor-Davidson Resilience Scale was 0.90.

The Brief COPE scale is a 28-item instrument, rated on a 4-point Likert scale, that was designed to assess a broad range of coping responses among adults for all diseases.³¹ Higher scores indicate greater use of the various coping strategies. In total, 14 dimensions are evaluated using this instrument (with their respective Cronbach α's), namely, self-distraction (0.46), active coping (0.75), denial (0.72), substance use (0.87), use of emotional support (0.77), use of instrumental support (0.77), behavioral disengagement (0.57), venting (0.65), positive reframing (0.79), planning (0.74), humor (0.83), acceptance (0.68), religion (0.92), and self-blame (0.73). Each dimension is evaluated using 2 items. The Brief Cope has well-established validity and reliability in oncology patients.³²

The Mental Adjustment to Cancer Scale, consisting of 40 items each rated on a 4-point Likert scale, was designed to measure patients' cognitive and behavioral responses to a cancer diagnosis and its treatment. 33,34 Five subscales were originally derived—fighting spirit, anxious preoccupation, helplessness/hopelessness, fatalism, and avoidance. These can also be subsumed under higher-order subscales, termed positive and negative adjustment. The Cronbach a's for 4 of the 5 subscales were as follows: 0.81 for fighting spirit, 0.62 for anxious preoccupation, 0.82 for helpless/hopeless, and 0.53 for fatalism

(as the avoidance subscale consists of only 1 item, a Cronbach α could not be calculated for this subscale).

The NEO Five-Factor Inventory (NEO-FFI) is a 60-item instrument that was used to assess personality. The NEO-FFI measures the "Big Five" domains of personality—ie, Neuroticism (self-reproach, negative affect), Extraversion (sociability, positive affect, activity level), Openness to experience (aesthetic and intellectual interests, unconventionality), Agreeableness (prosocial or non-antagonistic orientation), and Conscientiousness (dependability, orderliness, goal-striving). Higher scores indicate higher levels of each domain. In this study, the Cronbach α 's for the NEO-FFI were as follows: 0.87 for Neuroticism, 0.80 for Extraversion, 0.77 for Openness to experience, 0.76 for Agreeableness, and 0.84 for Conscientiousness.

2.3 | Study procedures

The study was approved by the Committee on Human Research at the University of California, San Francisco, and by the institutional review board at each of the study sites. Eligible patients were approached by a research staff member in the infusion unit to discuss participation in the study. Written informed consent was obtained from all patients. Patients who had received CTX within the preceding 4 weeks completed questionnaires in their homes during the week prior to the administration of the next cycle of CTX (ie during the recovery period). Medical records were reviewed for disease and treatment information.

2.4 | Data analysis

Data were analyzed using SPSS version 22 (IBM, Armonk, New York). Descriptive statistics and frequency distributions were calculated for demographic and clinical characteristics. Analysis of variance, χ^2 tests, and Kruskal-Wallis tests with Bonferroni corrected post hoc contrasts were used to evaluate for differences among the patients based on their decision-making roles. To address the issue of multiple testing, a more conservative *P*-value of <.01 was considered statistically significant. All calculations used actual values and adjustments were not made for missing data, which were assumed to be random. Therefore, the cohort for each analysis depends on the largest set of complete data among each decision-making role group.

While theoretical differences exist between factors that may be associated with preferred role versus those associated with actual role, initial analysis of these data showed that the concordance rate between preferred and actual role was nearly 90%. On the basis of this finding, there was limited statistical power to detect differences between concordant and discordant patients with regard to the variables of interest. Therefore, analyses were constrained to those with a concordant role (n = 765).

Multinomial logistic regression, in which the dependent variable was decision-making role, was conducted in which the demographic and clinical variables were forced into the model (age, education, gender, and cancer type). These variables were either significant in univariate analyses or considered highly relevant to this analysis based on prior literature. Since coping and personality were the factors of primary interest to this study, coping and personality variables that were significant in univariate analyses were considered for inclusion in the

multinomial regression, based on a backward stepwise elimination strategy. Variables were removed from the model if their *P*-value was >0.05.

3 | RESULTS

3.1 | Differences in demographic and clinical characteristics

As shown in Table 1, patients who had a passive role were more likely to be older, less educated, and have a lower income. However, decision-making role did not differ significantly by gender or ethnicity.

Decision-making role also varied significantly by cancer type. Patients who had a passive role were more likely to have lung or GI cancer than breast cancer. Compared with patients who had an active role, patients who had a collaborative role had more comorbid conditions. Decision-making role did not vary significantly by KPS score, number of metastatic sites, or years since diagnosis.

3.2 | Differences in physical and psychological symptoms

Decision-making role groups did not vary significantly with regard to depression, state, or trait anxiety (Table 2).

TABLE 2 Physical and psychological symptoms by decision-making role among patients with concordant roles (n = 765)

Characteristic	Active (1), n = 178, 23.3% Mean (SD)	Collaborative (2), n = 431, 56.3% Mean (SD)	Passive (3), n = 156, 20.3% Mean (SD)	Statistics
Center for Epidemiologic Studies-Depression Scale	12.6 (9.8)	12.5 (9.4)	12.4 (9.4)	F = 0.02; P = .980
Spielberger State-Trait Anxiety Inventories				
State anxiety	33.8 (13.3)	33.4 (12.0)	33.1 (12.5)	F = 0.09; P = .907
Trait anxiety	34.6 (11.0)	34.9 (10.6)	34.6 (10.2)	F = 0.15; P = .861

TABLE 3 Psychosocial adjustment characteristics by decision-making role among patients with concordant roles (n = 765)

Characteristic	Active (1), n = 178, 23.3% Mean (SD)	Collaborative (2), n = 431, 56.3% Mean (SD)	Passive (3), n = 156, 20.3% Mean (SD)	Statistics
Connor-Davidson Resilience Scale	30.3 (6.2)	30.4 (6.3)	28.8 (6.4)	F = 3.8; P = .022
Brief COPE				
Active coping	4.1 (1.6)	4.0 (1.6)	3.5 (1.8)	F = 8.7; P < .001; 1 and 2 > 3
Planning coping	3.4 (1.8)	3.4 (1.7)	2.7 (1.9)	F = 8.9; P < .001; 1 and 2 > 3
Positive reframing	3.4 (1.9)	3.5 (1.9)	2.8 (1.9)	F = 8.3; P < .001; 1 and 2 > 3
Acceptance	4.6 (1.3)	4.7 (1.3)	4.6 (1.4)	F = 1.1; P = .339
Humor	2.8 (1.9)	2.3 (2.0)	1.9 (2.0)	F = 8.4; P < .001; 1 and 2 > 3
Religion	2.6 (2.3)	3.0 (2.3)	3.0 (2.2)	F = 2.1; P = .122
Emotional support	4.3 (1.5)	4.5 (1.6)	3.9 (1.9)	F = 7.2; P = .001; 2 > 3
Instrumental support	3.2 (1.8)	3.5 (1.7)	2.9 (1.9)	F = 5.5; P = .004; 2 > 3
Self-distraction	3.5 (1.6)	3.4 (1.7)	3.4 (1.9)	F = 0.5; P = .608
Denial	0.5 (1.1)	0.5 (1.1)	0.4 (1.0)	F = 0.9; P = .337
Venting	2.0 (1.6)	2.0 (1.6)	1.6 (1.5)	F = 2.7; P = .068
Substance use	0.2 (0.5)	0.2 (0.7)	0.2 (0.9)	F = 0.5; P = .629
Behavioral disengagement	0.2 (0.6)	0.2 (0.7)	0.2 (0.6)	F = 0.4; P = .667
Self-blame	0.9 (1.3)	0.8 (1.2)	0.8 (1.2)	F = 0.2; P = .819
Mental Adjustment to Cancer				
Fighting spirit	51 (5.7)	52.1 (5.7)	51.4 (5.5)	F = 2.3; P = .104
Anxious preoccupation	23 (4.2)	23.5 (3.5)	22.8 (2.3)	F = 2.6; P = .074
Helplessness/hopelessness	8.6 (3.0)	8.9 (2.9)	9.2 (2.9)	F = 1.6; P = .211
Fatalism	16.2 (3.2)	17.3 (3.1)	18.7 (3.4)	F = 24.2; P < .001; 1 < 2 < 3
Avoidance	1.5 (0.7)	1.5 (0.8)	1.5 (0.8)	F = 0.3; P = .736
Positive adjustment	52.9 (6.2)	54.6 (6.2)	54.2 (6.0)	F = 4.2; P = .015
Negative adjustment	28.9 (7.5)	30.1 (7.1)	30.4 (7.3)	F = 2.0; P = .136
NEO Five-Factor Inventory				
Neuroticism	42 (11.2)	42.2 (10.4)	44.0 (10.0)	F = 1.6; P = .201
Extraversion	53.0 (11.0)	53.5 (11.2)	52.3 (11.5)	F = 0.6; P = .552
Openness	57.1 (11.6)	55.3 (11.2)	53.0 (10.6)	F = 5.5; P = .004; 1 > 3
Agreeableness	54.7 (10.4)	55.7 (11.8)	55.3 (10.9)	F = 0.5; P = .630
Conscientiousness	51.5 (9.8)	50.9 (10.2)	50.4 (10.9)	F = 0.4; P = .655

TABLE 4 Multinomial logistic regression: final model

	Model Fitting Criteria		Likelihood Ratio Tests			
Effect	-2 Log Likelihood of Reduced Model	χ²	df	Significance		
Intercept	1285.660	0.000	0	_		
Cancer type	1289.875	4.215	6	.648		
Gender	1287.161	1.501	2	.472		
Age	1293.332	7.672	2	.022		
Education	1286.566	0.906	2	.636		
Positive reframing	1298.765	13.105	2	.001		
Fatalism	1318.795	33.135	2	<.001		

3.3 | Differences in psychosocial adjustment characteristics

Table 3 shows the relationship between decision-making role and resilience and levels of fatalism. Compared with those who had a collaborative role, patients who had a passive role were less resilient. Of all 3 groups, the group with patients who had a passive role had the highest levels of fatalism. Decision-making role varied significantly by coping style with patients who had a passive role being less likely than those who had an active or collaborative role to use the following coping strategies: active coping, planning, positive reframing, and humor. Furthermore, patients who had a passive role were less likely than those who had a collaborative role to use emotional or instrumental support-oriented coping strategies. In terms of personality, differences in decision-making role were significantly related to only 1 of the 5 personality dimensions—ie, patients who had a passive role had lower levels of Openness to Experience than those who had an active role. Last, patients who had a collaborative role reported higher levels of positive adjustment than those who had an active role.

3.4 | Multinomial regression analysis

The overall model was tested with a likelihood ratio test and was significant ($\chi^2 = 73.01$; df = 16; P < .001). The overall goodness-of-fit deviance test had a very high P-value (.935), also indicating a good model fit. The overall model had a McFadden pseudo- R^2 of 0.054, indicating that the model explained approximately 5% of the variance in decision-making role.

The final model (Table 4) includes the 4 variables that were forced into the model (age, education, gender, and cancer type). The only 2 variables of the coping and personality variables that were retained in the final model from the backward stepwise approach were fatalism and positive reframing. Gender, education, and cancer type did not make significant unique contributions to the model, whereas age (P = .022), fatalism (P < .001), and positive reframing (P = .001) did make significant unique contributions to the model.

Pairwise comparisons revealed that older patients were more likely to be in the collaborative role group than in the active role group. All 3 pairwise comparisons were significant for fatalism, ie, patients who had a collaborative role endorsed higher levels of fatalism than those who had an active role, and patients who had a passive role endorsed higher levels of fatalism than those who had either an active role or a collaborative role. Finally, patients in the collaborative

role group endorsed higher levels of positive reframing than those in the passive group.

4 | CONCLUSIONS

Several new findings emerged from this study, particularly with respect to the relationship between psychosocial adjustment characteristics and decision-making roles in oncology patients undergoing CTX. Compared with those who had an active role, patients who had a passive role were less likely to use engagement coping strategies (active coping, planning coping, and positive reframing) and had a less open personality. This confirms our hypothesis that coping and decision-making role are strongly related. Prior work has tended to theorize coping approaches and decision-making role as separate phenomena; however, our data indicate that decision-making role and coping style may be intimately connected as part of a singular process.

It is possible that decision-making role may indeed be a subcomponent of one's overall coping approach. Carver's definition of engagement coping includes a patient who asks questions and seeks information from their physician. ¹⁴ It then follows that a patient who asks questions and participates in SDM would identify their role as an active role. Therefore, on the basis of the relationship between engagement-type coping strategies and active role in our data, we theorize that decision-making role is 1 component of a coping style.

The relationship between decision-making roles and coping suggests that the degree of involvement in decision making may be a manifestation of the patient's typical (or most prominent) coping mechanisms. The finding that decision-making preferences are closely associated coping styles suggests, as Singh noted previously, that underlying traits may be more responsible for enduring decision-making styles. Thus, overemphasizing the "active" role may be rooted in mistaken assumptions about the malleability of decision-making styles. While our data suggest that decision-making role preference may be more of a trait-like characteristic, little is known about whether individuals' decision-making role preferences change over the course of illness. To address the role of time and disease course in decision-making role preference, longitudinal prospective studies should be done.

Patients with a passive role tended to have a more fatalistic stance, which is consistent with the work by Shields and colleagues.³⁶ While the term "fatalism" has evoked a negative connotation in the past, recently, the construct it represents was reconceptualized as having both positive and negative valences.³⁷ For instance, "fatalism" can

take the form of acceptance (eg, "I've put myself in the hands of God"). reframing (eg, "I've had a good life, what's left is a bonus"), or negatively, as a lack of control or self-efficacy (eg, "I feel I can't control what's happening to me."). Instead of a resignation to a predetermined fate, adopting a fatalistic attitude may be a logical response to previous poor health outcomes personally or in one's community.³⁷ In this way, the relationship between fatalism and preference for a more passive role may be influenced by patients' past experience with health and disease and may serve as a mechanism by which patients cope with navigating the cancer treatment process. By evaluating these factors in the same sample, this study adds to our understanding of the relationships between decision-making role and coping strategies, fatalism, and personality. Prior work by Powe et al has shown that fatalism may be modifiable and may thereby serve as a means to engage patients further in treatment decision making.³⁸ Given the unique contribution of fatalism to the model, focusing on interventions to address fatalistic beliefs may be an important way to enhance patient participation.

In addition to a more fatalistic stance, those patients who had a more passive role tended not to use a humor-based coping strategy—to our knowledge, a previously unreported finding. Humor is generally seen as an adaptive coping mechanism and has been associated with positive psychological changes following a diagnosis of cancer. This finding, along with the other data from the present study, suggests that patients who prefer a passive role may use less adaptive coping strategies.

Our findings are consistent with previous work that found that older age and lower education were associated with preference for a passive decision-making role.8 However, this study contributes a slightly different impression of the preferences of oncology patients with regard to decision-making role. Compared with a pooled analysis of data from 3491 patients,8 in our study, a higher percentage of patients preferred a collaborative role (56% in our study vs 34% in Singh et al), and more of them (90% vs 84%) actually played their preferred role. It is possible that the higher percentage of patients who played a collaborative role and the level of concordance between preferred and actual role in our study was influenced by changing expectations for involvement and an increasing emphasis on SDM in health care. 36 Higher education is known to be related to a preference for a more active role,³⁹ so it is possible that the higher-than-average level of education of this sample affected these findings. Furthermore, unlike previous research, our study found no significant relationship between gender and decision-making role preference.8

With regard to clinical characteristics, decision-making role was associated with the type of cancer and number of comorbidities. Consistent with a previous report,⁴⁰ our study found that breast cancer patients were more likely to play a collaborative or active role than patients with other cancer types. Shields et al hypothesized that greater public awareness and the wealth of available information about breast cancer may help foster a sense of greater activism in these patients.³⁶ However, differences were not found between preferred role and number of metastatic sites. These previously unstudied relationships suggest that one's current health status, rather than stage of disease, may be more important in determining patients' level of involvement or support needed. Further investigation into the role that overall functioning versus disease severity plays in SDM is warranted.

Limitations of this study include data from a single time point, which prevents longitudinal inference. Future studies should collect data about decision-making roles over time to identify trends in how the progression of treatment and/or illness, relationships with clinicians, and other factors may be related to a patient's role. In addition, as patients were not asked about their decision-making role in relation to a specific treatment decision, it is possible that variability in the kinds of treatment decisions patients faced may have influenced the findings. Despite the fact that this study included a sample recruited from 6 different sites, the patients tended to overrepresent some demographic groups. The majority of patients in this study were highly educated, had a high income, were Caucasian, and had breast cancer. Moreover, the refusal rate of 40% could have led to a selection bias: ie, participants in this study may have been those who felt more able to complete a series of questionnaires while undergoing CTX. These characteristics suggest that our findings may not be generalizable. Therefore, further work is needed to identify and address disparities and barriers to participation in SDM by underserved groups, including those not represented by the current sample.

In conclusion, this study found that coping is related to decision role even after controlling for demographic characteristics. Given the potential benefits of playing a more active role, 1 it is important that clinicians find ways to engage all patients in the decision-making process while not abandoning those who prefer a passive role by overemphasizing patient autonomy. Clinicians should be aware that some patients might cope with their illness by seeking support and by playing a less active role in decision making. These preferences may be influenced by fatalism, personality, coping style, illness factors, culture, and demographics-indicating that decision-making role preference is a complex and multifaceted entity. Clinicians should individualize their approach, finding ways to engage all patients in decision making to the extent that patients feel supported and valued, while maintaining awareness that participation in SDM could be a way for patients to cope with and understand their illness. Further study is warranted to explore the ways in which decision-making role may change with time and to determine if role or coping style may be influenced by interventions designed to teach adaptive coping skills.

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REFERENCES

- Gattellari M, Butow PN, Tattersall MH. Sharing decisions in cancer care. Soc Sci Med. 2001:52:1865–1878.
- Institute of Medicine (U.S.). Committee on Quality of Health Care in America: Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, D.C.: National Academy Press; 2001.
- 3. Oshima Lee E, Emanuel EJ. Shared decision making to improve care and reduce costs. *N Engl J Med*. 2013;368:6–8.
- 4. Brown R, Butow P, Wilson-Genderson M, Bernhard J, Ribi K, Juraskova I. Meeting the decision-making preferences of patients with breast

- cancer in oncology consultations: impact on decision-related outcomes. J Clin Oncol. 2012;30:857–862.
- Kane HL, Halpern MT, Squiers LB, Treiman KA, McCormack LA. Implementing and evaluating shared decision making in oncology practice. CA Cancer J Clin. 2014;64:377–388.
- Kaplan SH, Greenfield S, Ware JEJ. Assessing the effects of physicianpatient interactions on the outcomes of chronic disease. *Med Care*. 1989;27:S110.
- Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. Can J Nurs Res. 1997:29:21–43.
- 8. Singh JA, Sloan JA, Atherton PJ, et al. Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the Control Preferences Scale. Am J Manag Care. 2010;16:688–696.
- Atherton PJ, Smith T, Singh JA, et al. The relation between cancer patient treatment decision-making roles and quality of life. Cancer. 2013;119:2342–2349.
- Hitz F, Ribi K, Li Q, Klingbiel D, Cerny T, Koeberle D. Predictors of satisfaction with treatment decision, decision-making preferences, and main treatment goals in patients with advanced cancer. Support Care Cancer. 2013;21:3085–3093.
- Vogel BA, Helmes AW, Hasenburg A. Concordance between patients' desired and actual decision-making roles in breast cancer care. Psycho-Oncology. 2008;17:182–189.
- 12. Hack TF, Pickles T, Ruether JD, et al. Predictors of distress and quality of life in patients undergoing cancer therapy: impact of treatment type and decisional role. *Psycho-Oncology*. 2009;19:606–616.
- Folkman S, Moskowitz JT. Coping: pitfalls and promise. Annu Rev Psychol. 2004;55:745–774.
- Carver CS, Connor-Smith J. Personality and coping. Annu Rev Psychol. 2010;61:679–704.
- Balneaves LG, Long B. An embedded decisional model of stress and coping: implications for exploring treatment decision making by women with breast cancer. J Adv Nurs. 1999;30:1321–1331.
- Witt J, Elwyn G, Wood F, Brain K. Decision making and coping in healthcare: the Coping in Deliberation (CODE) framework. *Patient Educ Couns*. 2012;88:256–261.
- 17. Hack TF, Degner LF. Coping with breast cancer: a cluster analytic approach. *Breast Cancer Res Treat*. 1999;54:185–194.
- Folkman S, Lazarus RS. Coping as a mediator of emotion. J Pers Soc Psychol. 1988;54:466–475.
- McCrae RR, Costa PT. Personality in Adulthood: A Five-Factor Theory Perspective. New York: Guilford Press; 2003.
- Orom H, Penner LA, West BT, Downs TM, Rayford W, Underwood W. Personality predicts prostate cancer treatment decision-making difficulty and satisfaction. *Psycho-Oncology*. 2009;18:290–299.
- Hyphantis T, Almyroudi A, Paika V, Degner LF, Carvalho AF, Pavlidis N. Anxiety, depression and defense mechanisms associated with treatment decisional preferences and quality of life in non-metastatic breast cancer: a 1-year prospective study. *Psychooncology*. 2013;22:2470–2477.
- Lifford KJ, Witt J, Burton M, et al. Understanding older women's decision making and coping in the context of breast cancer treatment. BMC Med Inform Decis Mak. 2015;15:1–12.
- 23. Kober KM, Cooper BA, Paul SM, et al. Subgroups of chemotherapy patients with distinct morning and evening fatigue trajectories. *Support Care Cancer*. 2016;1–13:
- Karnofsky DA, Abelmann WH, Craver LF, Burchenal JH. The use of the nitrogen mustards in the palliative treatment of carcinoma. With particular reference to bronchogenic carcinoma. Cancer. 1948;1:634–656.

- Sangha O, Stucki G, Liang MH, Fossel AH, Katz JN. The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. Arthritis Rheum. 2003:49:156–163
- 26. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Üstün BT, Stucki G. Identification of candidate categories of the International Classification of Functioning Disability and Health (ICF) for a Generic ICF Core Set based on regression modelling. BMC Med Res Methodol. 2006;6:36
- Radloff LS. The CES-D scale a self-report depression scale for research in the general population. Applied psychological measurement. 1977:1:385–401.
- 28. Fletcher BS, Paul SM, Dodd MJ, et al. Prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. *J Clin Oncol*. 2008;26:599–605.
- Spielberger CG, Gorsuch RL, Suchene R, Vagg PR, Jacobs GA. Manual for the State-Anxiety (Form Y): Self Evaluation Questionnaire. Palo Alto, CA: Consulting Psychologists Press; 1983.
- Campbell-Sills L, Stein MB. Psychometric analysis and refinement of the Connor-Davidson Resilience Scale (CD-RISC): validation of a 10item measure of resilience. *J Trauma Stress*. 2007;20:1019–1028.
- 31. Carver CS. You want to measure coping but your protocol's too long: consider the Brief COPE. Int J Behav Med. 1997;4:92–100.
- Scrignaro M, Barni S, Magrin ME. The combined contribution of social support and coping strategies in predicting post-traumatic growth: a longitudinal study on cancer patients. *Psychooncology*. 2010;20:823–831.
- Watson M, Greer S, Young J, Inayat Q, Burgess C, Robertson B. Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychol Med.* 1988;18:203–209.
- Watson M, Homewood J. Mental Adjustment to Cancer Scale: psychometric properties in a large cancer cohort. *Psychooncology*. 2008:17:1146–1151.
- Costa PT, McCrae RR. Revised NEO Personality Inventory (NEO-PI-R) and NEO Five Factor Inventory (NEO-FFI) Professional Manual. Odessa: Psychological Assessment Resources Inc.: 1992.
- 36. Shields CG, Morrow GR, Griggs J, et al. Decision-making role preferences of patients receiving adjuvant cancer treatment: a university of Rochester cancer center community clinical oncology program. Support Cancer Ther. 2004;1:119–126.
- Drew EM, Schoenberg NE. Deconstructing fatalism: ethnographic perspectives on women's decision making about cancer prevention and treatment. Med Anthropol Q. 2011;25:164–182.
- 38. Powe BD, Weinrich S. An intervention to decrease cancer fatalism among rural elders. 1999;26:583–588.
- Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. Soc Sci Med. 1994;39:279–289.
- Beaver K, Bogg J, Luker KA. Decision-making role preferences and information needs: a comparison of colorectal and breast cancer. Health Expect. 1999;2:266–276.

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