

## Cancer Patients' Roles in Treatment Decisions: Do Characteristics of the Decision Influence Roles?

Nancy L. Keating, Mary Beth Landrum, Neeraj K. Arora, Jennifer L. Malin, Patricia A. Ganz, Michelle van Ryn, and Jane C. Weeks

### A B S T R A C T

#### Purpose

Patients with more active roles in decisions are more satisfied and may have better health outcomes. Younger and better educated patients have more active roles in decisions, but whether patients' roles in decisions differ by characteristics of the decision itself is unknown.

#### Patients and Methods

We surveyed a large, population-based cohort of patients with recently diagnosed lung or colorectal cancer about their roles in decisions regarding surgery, radiation therapy, and/or chemotherapy. We used multinomial logistic regression to assess whether characteristics of the decision, including evidence about the treatment's benefit, whether the decision was likely preference-sensitive (palliative therapy for metastatic cancer), and treatment modality, influenced patients' roles in that decision.

#### Results

Of 10,939 decisions made by 5,383 patients, 38.9% were patient controlled, 43.6% were shared, and 17.5% were physician controlled. When there was good evidence to support a treatment, shared control was greatest; when evidence was uncertain, patient control was greatest; and when there was no evidence for or evidence against a treatment, physician control was greatest (overall  $P < .001$ ). Decisions about treatments for metastatic cancers tended to be more physician controlled than other decisions ( $P < .001$ ).

#### Conclusion

Patients making decisions about treatments for which no evidence supports benefit and decisions about noncurative treatments reported more physician control, which suggests that patients may not want the responsibility of deciding on treatments that will not cure them. Better strategies for shared decision making may be needed when there is no evidence to support benefit of a treatment or when patients have terminal illnesses that cannot be cured.

*J Clin Oncol* 28:4364-4370. © 2010 by American Society of Clinical Oncology

### INTRODUCTION

Studies suggest that patients who more actively participate in their care are more satisfied with their care and may have better health outcomes.<sup>1-7</sup> Such findings led the Institute of Medicine to recommend that patient centeredness be a key aim of health care organizations and that all patients be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them.<sup>8</sup>

Several studies have assessed cancer patients' preferences for participation in decision making. Patients who are younger, better educated, and healthier tend to prefer a more active role in treatment decisions.<sup>9-12</sup> Less is understood about factors that influence the actual role that patients play in treatment decisions, and most of the research has

involved patients with breast cancer. One study of patients with breast cancer found that college-educated patients younger than age 65 years were more active participants in breast cancer treatment decisions than older, less-well educated patients, as were patients who perceived that their physicians encouraged patient involvement.<sup>13</sup> Another study of older patients with breast cancer found that patients age 67 to 74 years versus older patients and those accompanied to visits had higher levels of shared decision making.<sup>14</sup>

Few data are available about whether patients' roles differ by factors related to the decision itself, although some evidence suggests that patients with breast cancer who reported having a treatment choice have higher levels of shared decision making than those who felt they had no choice of treatment.<sup>14</sup> In a large, population-based study of

From Brigham and Women's Hospital; Dana-Farber Cancer Institute; Harvard Medical School, Boston, MA; National Cancer Institute, Bethesda, MD; West Los Angeles Veterans Affairs Health-care Center; University of California, Los Angeles, Los Angeles, CA; and University of Minnesota Medical School, Minneapolis, MN.

Submitted October 30, 2009; accepted July 12, 2010; published online ahead of print at [www.jco.org](http://www.jco.org) on August 16, 2010.

Supported by Grants No. U01 CA093344 from the National Cancer Institute (NCI) to the Statistical Coordinating Center; U01 CA 093332 from the NCI-supported Primary Data Collection and Research Centers to Dana-Farber Cancer Institute/Cancer Research Network; U01 CA093324 to Harvard Medical School/Northern California Cancer Center; U01 CA093348 to RAND/University of California, Los Angeles; U01 CA093329 to the University of Alabama at Birmingham; U01 CA01013 to the University of Iowa; U01 CA093339 to the University of North Carolina; and by Grant No. CRS 02-164 from the Department of Veterans Affairs to the Durham Veterans Affairs Medical Center CRS 02-164.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

Corresponding author: Nancy L. Keating, MD, MPH, Department of Health Care Policy, Harvard Medical School, Boston, MA 02115; e-mail: [keating@hcp.med.harvard.edu](mailto:keating@hcp.med.harvard.edu).

© 2010 by American Society of Clinical Oncology

0732-183X/10/2828-4364/\$20.00

DOI: 10.1200/JCO.2009.26.8870

patients with recently diagnosed lung or colorectal cancer, we asked patients to report their roles in decisions about surgery, radiation therapy, and/or chemotherapy to assess whether characteristics of the decision influenced patients' role in that decision. We specifically assessed the strength of the evidence about benefits of a particular treatment and whether the decision was likely preference sensitive (eg, palliative therapy for metastatic cancer). We hypothesized a priori that patients would assume a more active role in decisions when evidence was uncertain and a shared role when there was evidence for a therapy or no evidence for (or evidence against) benefits of a therapy. We also hypothesized that patients would have a more active role in preference-sensitive decisions.

## PATIENTS AND METHODS

### Study Design

Data for this study were collected as part of a large national study of variations in care and outcomes of care in patients with lung or colorectal cancer conducted by the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium.<sup>15,16</sup> The CanCORS study is examining care delivered to population-based and health-system-based cohorts that totaled more than 10,000 patients diagnosed with lung or colorectal cancer during 2003 to 2005 who were living in Northern California, Los Angeles County, North Carolina, Iowa, or Alabama or who received their care in one of five large health maintenance organizations or at one of 15 sites in the Veterans Affairs Health Care System. The study was approved by the human participants committees at all participating institutions.

### Study Population

Patients age 21 years and older who were diagnosed with lung or colorectal cancer were identified within weeks of their diagnoses through rapid case ascertainment, in which registry staff directly review pathology reports in their region to obtain information on cancer occurrences.<sup>17</sup> Patients (or their surrogates, if they were deceased or too ill to participate) were interviewed by telephone approximately 3 to 6 months after diagnosis. We restricted this analysis to patients who completed the full baseline interview themselves (rather than a surrogate; N = 5,519) and discussed at least one treatment (ie, surgery, radiation, chemotherapy) with a clinician (n = 5,420). We excluded 46 patients who did not respond to the questions about their role in decisions, and 5,383 patients remained who reported their roles for 10,939 decisions.

### Data Collection

Patients were surveyed via computer-assisted telephone interviewing. Survey instruments were translated into Spanish and Chinese (with back translation) and were administered by bilingual interviewers for patients who preferred either of these languages. The American Association for Public Opinion Research<sup>18</sup> survey response rate was 51.0%, and the cooperation rate was 59.9%. Comparisons of responders and nonresponders are included in the Data Supplement (online only). Information about cancer site, histology, and stage at diagnosis was obtained from registry data and medical records. (Medical record data were available for 79% of patients in the cohort.)

### Dependent Variable

Each patient who discussed surgery, radiation, or chemotherapy with a physician was asked to report his or her role in the decision by using a modified version of the validated Control Preference Scale,<sup>11,19</sup> designed to be administered by telephone. Patients were asked, "Which statement best describes the role you played when the decision was made about [modality] for your [lung or colorectal] cancer?" Response options were as follows: "You made the decision with little or no input from your doctors," "You made the decision after considering your doctors' opinions," "You and your doctors made the decision together," "Your doctors made the decision after considering your opinion," and "Your doctors made the decision with little or no input from you. The first two responses were categorized as patient controlled (or patient

driven), the third was considered shared control, and the last two were considered physician controlled (or physician driven).

### Independent Variables

We characterized the level of evidence to support each of the treatment decisions for each patient on the basis of their cancer type and stage by using the National Comprehensive Cancer Network Guidelines (Appendix Table A1, online only). Categories included the following: evidence for the treatment, such as surgery for stages I to II lung cancer or chemotherapy for stage III colon cancer; uncertain, such as surgery for stage IIIA lung cancer or chemotherapy for stage II colon cancer; and no evidence for or evidence against, such as radiation for stages I to II lung cancer or chemotherapy for stage I colon cancer. We also characterized each treatment as preference sensitive (all treatments for stage IV cancers) or other (all treatments for stages I to III cancers). For a small number of scenarios in which information on cancer site (colon v rectum), complete stage, or histology (non-small-cell v small-cell) was not available, we were unable to code the level of evidence, and these data were categorized as unknown.

In addition, we characterized each decision on the basis of the treatment modality (surgery, radiation, chemotherapy), and we documented whether or not patients reported that they received each treatment that they discussed with a physician. Other variables of interest included cancer type, patient age, ethnicity, marital status, education, income, comorbid illness, and study site. We characterized prediagnosis health status on the basis of five items from the Short Form 12 (SF-12) health survey (ie, limitations in moderate activities, limitations climbing stairs, accomplishing less than they would have liked, limitations in work or other regular activities, and pain interference with normal work)<sup>20</sup>; we used the eight-item Center for Epidemiological Studies–Depression Scale (CES-D), applying a threshold of six or more symptoms to identify current depression.<sup>21</sup> Variables were categorized as in Table 1.

### Statistical Analysis

Item nonresponse was less than 9% for all variables. We used multiple imputation<sup>22,23</sup> to impute missing data for items other than the dependent variable (for which no data were missing for our cohort) and our variable characterizing strength of the evidence. See the Data Supplement (online only) for additional details.

We used a multinomial logit regression to examine patient and treatment factors associated with decision role (ie, patient control, shared control, or physician control) for each decision. The unit of analysis was the decision, and it included up to three observations per patient (one for each of the three treatment modalities that a patient may have discussed). We adjusted standard errors to account for correlation among repeated decisions within patients by using a robust variance estimator.<sup>24,25</sup> We included variables in the model for patient and treatment factors described under Independent Variables. We calculated rates of each category of treatment role for patient subgroups defined by each covariate, adjusted for all other covariates held at their mean value.

Because strong clinical trial data are lacking about the benefits of treatment in the elderly, we conducted a sensitivity analysis that restricted the cohort to individuals age  $\leq$  70 years. Results were similar and are not presented. We also conducted stratified analyses by treatment modality. Finally, we conducted a sensitivity analysis using ordinal rather than multinomial logistic regression. All tests of statistical significance were two sided.

## RESULTS

Among 5,383 patients who described their role in 10,939 decisions, 4,618 reported about a surgical decision, 2,359 reported about a radiation therapy decision, and 3,962 reported about a chemotherapy decision. Characteristics of patients and decisions are included in Table 1. Approximately half (52%) of the patients were 70 years or older, 53% were men, 30% were nonwhite, and 62% were married. Overall, 23% of patients reported about one role, 43% reported about two roles, and 34% reported about three roles. Among patients who reported about two roles, 54% reported the same decision role for

**Table 1.** Unadjusted Associations of Patient and Tumor Characteristics With Roles in Decisions: Multiple Observations per Patient

Characteristic	No. of Patients	No. of Observations*	Proportion Reporting			P†
			Patient Control	Shared Control	Physician Control	
Overall No. of patients	5,383	10,939	38.9	43.6	17.5	
Level of evidence for treatment						< .001
Evidence for	—	7,318	38.7	46.3	15.0	
Uncertain	—	1,539	44.8	38.8	16.4	
No evidence for	—	1,482	32.7	36.3	31.0	
Missing	—	600	41.8	41.7	16.5	
Preference sensitive‡						< .001
No	4,310	8,760	40.1	43.4	16.5	
Yes	1,073	2,179	34.4	44.5	21.1	
Treatment modality						< .001
Surgery	—	4,618	38.5	45.0	16.5	
Radiation	—	2,359	33.7	42.7	23.6	
Chemotherapy	—	3,962	42.5	42.6	14.9	
Received treatment						< .001
No	—	2,599	35.8	32.9	31.3	
Yes	—	8,340	39.9	47.0	13.1	
Cancer site						.30
Colorectal	3,005	6,079	38.3	44.5	17.2	
Lung	2,378	4,860	39.7	42.6	17.7	
Age at diagnosis, years						.006
21-55	618	1,413	36.9	44.0	19.2	
56-70	1,963	4,191	39.4	44.8	15.8	
71-80	1,585	3,184	39.3	43.8	16.9	
≥ 81	1,217	2,151	38.8	40.8	20.4	
Sex						.09
Male	2,874	5,962	39.9	43.5	16.7	
Female	2,509	4,977	37.8	43.8	18.4	
Ethnicity						.02
White	3,751	7,619	39.2	43.3	17.5	
Black	730	1,489	39.4	45.9	14.6	
Hispanic	376	765	34.5	44.8	20.7	
Asian	262	526	38.9	39.0	22.2	
Other	264	540	40.4	44.4	15.2	
Marital status						< .001
Married	3,331	6,858	38.9	44.9	16.2	
Not married	2,052	4,081	38.9	41.5	19.6	
Education						.05
< High school	897	1,764	36.0	45.3	18.7	
High school graduate or some college	2,898	5,882	38.4	44.2	17.4	
College degree or higher	1,588	3,293	41.4	41.8	16.9	
Income, \$						.06
< 20,000	1,501	2,987	40.1	42.2	17.7	
20,000 to < 40,000	1,626	3,215	36.5	46.1	17.4	
40,000 to < 60,000	991	2,032	38.8	42.6	18.6	
≥ 60,000	1,265	2,705	40.6	43.1	16.3	
No. of self-reported comorbid conditions						.48
0	2,418	4,980	38.1	44.9	17.0	
1	1,802	3,615	39.9	42.6	17.5	
2	772	1,582	39.1	41.9	19.0	
≥ 3	391	762	39.1	43.7	17.2	
Prediagnosis health status						.01
Quartile 1	1,344	2,776	36.9	43.8	19.3	
Quartile 2	1,417	2,849	37.1	44.9	17.9	
Quartile 3	1,217	2,487	41.6	41.7	16.7	
Quartile 4	1,405	2,827	40.4	43.9	15.7	

(continued on following page)

## Role in Cancer Treatment Decisions

**Table 1.** Unadjusted Associations of Patient and Tumor Characteristics With Roles in Decisions: Multiple Observations per Patient (continued)

Characteristic	No. of Patients	No. of Observations*	Proportion Reporting			P†
			Patient Control	Shared Control	Physician Control	
CES-D short form						.50
≤ 5	4,519	9,092	38.7	44.0	17.3	
≥ 6	864	1,847	40.0	42.0	18.0	
Study site						< .001
Los Angeles county	1,141	2,353	38.7	40.8	20.5	
Alabama	613	1,234	38.1	47.8	14.1	
8 counties in Northern California	1,124	2,243	41.4	39.3	19.3	
22 counties in eastern North Carolina	621	1,242	32.7	52.7	14.6	
Iowa	491	1,007	40.3	45.4	14.3	
5 HMOs	833	1,703	38.8	43.0	18.2	
15 Veterans Affairs hospitals	560	1,157	41.1	42.9	16.0	

Abbreviations: CES-D, Center for Epidemiological Studies–Depression Scale; HMOs, health maintenance organizations.

\*Observations considered as decisions.

†Using univariate multinomial logit and accounting for clustering by patients.

‡Metastatic cancer.

both. Among patients who reported about three roles, 42% reported the same role for all three.

When examining characteristics of the decisions (ie, the unit of analysis), 67% were decisions for which the evidence supported the treatment, 14% were decisions for which the evidence regarding the benefit of treatment was uncertain, and 14% were decisions about treatments for which there was no evidence to support or evidence was sufficient to recommend against their use (Table 1). Approximately one fifth of decisions was about treatments for metastatic cancers and thus were largely preference-sensitive decisions. In approximately one quarter of decisions (24%), the patient did not receive the treatment discussed.

Overall, 38.9% of decisions were patient controlled, 43.6% were shared, and 17.5% were physician controlled (Table 1). Adjusted associations of treatment characteristics are included in Table 2, and differences were generally small. Level of evidence was associated with patients' reported roles in decisions. Decisions with no evidence for (or evidence against) the treatment had higher rates of physician control, whereas decisions regarding treatments with uncertain benefit had higher rates of patient control and lower rates of shared control than decisions with evidence for the treatment.

Patients reporting about decisions that were more preference sensitive (ie, treatments for metastatic cancer) were less likely to describe a patient-controlled role in the decision and were more likely to describe a physician-controlled role than those without metastatic cancer (Table 2). Patients making decisions about chemotherapy were less likely to report physician control and were more likely to report patient control than those making decisions about surgery, and patients making decisions about radiation were least likely to report patient control (Table 2). Patients who did not receive the treatment discussed were substantially more likely than those who did to report the decision was physician controlled and were less likely to report shared control or patient control.

Several patient characteristics were associated with decision role (Table 2). Married patients were more likely than unmarried patients to report a shared role and were less likely to report physician control of decisions. Patients with better prediagnosis health statuses were less

likely to report physician control of decisions and were more likely to report patient control. We also observed variations in reported role by study site. We observed a trend toward an association between ethnicity and decision role ( $P = .06$ ), in which black patients were less likely than white patients to report physician control, and Hispanic patients were less likely than white patients to report patient control.

In analyses stratified by treatment modality, results were generally similar, except that we did not observe an association between evidence and decision control for radiation decisions (data not shown). In ordinal logistic regression models, results were nearly identical with one exception. In the original model, patients who did not receive the treatment discussed had much higher rates of physician control and lower rates of shared control than patients who received the treatment; in the ordinal models, patients who did not receive the treatment had high rates of both physician control and shared control.

## DISCUSSION

In this large, population-based cohort of individuals with recently diagnosed lung or colorectal cancer, we observed that characteristics of the decision itself were associated with patients' roles in decisions. Although absolute differences were relatively modest, we found that variability in the strength of evidence influenced patients' roles; the highest rates of shared control were for decisions with evidence for the treatment, the highest rates of patient control occurred when evidence of benefit was uncertain, and the highest rates of physician control occurred when there was no evidence to support the use of the treatment. We also observed that patients making more preference-sensitive decisions (ie, treatments for metastatic cancer) were more likely than others to describe a shared-control or physician-controlled role and were less likely to report the decision was patient controlled. Finally, we found that patients' roles in decisions differed by treatment modality, with more patient control for chemotherapy decisions and more physician control for surgery and radiation decisions.

Consistent with our hypothesis, patient control was high when the evidence about a treatment is uncertain; thus, patients' preferences

**Table 2.** Adjusted Associations of Patient and Tumor Characteristics With Roles in Decisions, Including Adjusted Differences and 95% CIs

Characteristic	Adjusted Proportion Reporting			P*	Adjusted Differences								
	Patient Control	Shared Control	Physician Control		Patient Control			Shared Control			Physician Control		
					Difference	95% CI		Difference	95% CI		Difference	95% CI	
Level of evidence for treatment				< .001									
Evidence for	39.3	43.4	17.3		Ref	—	—	Ref	—	—	Ref	—	—
Uncertain	44.8	39.5	15.7		5.5†	2.8†	8.3†	-4.0†	-6.8†	-1.2†	-1.5	-3.5	0.5
No evidence for	37.1	41.0	21.9		-2.1	-5.5	1.2	-2.4	-5.7	0.9	4.5†	2.1†	6.9†
Missing	41.9	41.9	16.2		2.6	-2.6	7.9	-1.6	-6.7	3.6	-1.0	-4.7	2.6
Preference sensitive‡				< .001									
No	41.1	42.1	16.8		Ref	—	—	Ref	—	—	Ref	—	—
Yes	34.7	43.6	21.7		-6.4†	-9.3†	-3.4†	1.6	-1.5	4.7	4.8†	2.3†	7.2†
Treatment modality				< .001									
Surgery	38.8	42.5	18.7		Ref	—	—	Ref	—	—	Ref	—	—
Radiation	36.2	44.5	19.3		-2.7†	-5.0†	-0.4†	2.2	-0.3	4.6	0.5	-1.2	2.2
Chemotherapy	43.1	41.2	15.7		4.3†	2.5†	6.0†	-1.3	-3.2	0.5	-2.9†	-4.3†	-1.5†
Received treatment				< .001									
No	37.0	33.1	30.0		Ref	—	—	Ref	—	—	Ref	—	—
Yes	40.8	45.4	13.8		3.6†	0.9†	6.3†	12.5†	9.8†	15.2†	-16.1†	-18.5†	-13.7†
Cancer site				.54									
Lung	40.3	42.6	17.1		Ref	—	—	Ref	—	—	Ref	—	—
Colorectal	39.5	42.2	18.3		-0.7	-3.6	2.1	-0.4	-3.3	2.4	1.2	-0.9	3.2
Age at diagnosis, years				.19									
21-55	37.7	43.1	19.2		Ref	—	—	Ref	—	—	Ref	—	—
56-70	39.2	44.4	16.3		1.6	-2.5	5.6	1.2	-2.8	5.3	-2.8	-5.6	0.0
71-80	39.1	44.1	16.8		1.4	-2.9	5.8	0.9	-3.5	5.2	-2.3	-5.2	0.7
≥ 81	40.5	43.1	16.4		1.3	-3.3	5.9	-1.4	-6.0	3.2	0.1	-3.2	3.3
Sex				.29									
Male	39.8	43.2	17.0		Ref	—	—	Ref	—	—	Ref	—	—
Female	37.9	44.2	18.0		-2.0	-4.6	0.6	1.1	-1.6	3.7	0.9	-1.0	2.9
Ethnicity				.06									
White	39.1	43.2	17.7		Ref	—	—	Ref	—	—	Ref	—	—
Black	40.7	44.6	14.7		1.5	-2.2	5.2	1.4	-2.3	5.2	-2.9†	-5.4†	-0.4†
Hispanic	34.1	47.4	18.5		-5.2†	-10.1†	-0.2†	4.4	-0.8	9.6	0.8	-2.9	4.5
Asian	36.8	41.0	22.2		-2.3	-8.1	3.5	-2.2	-8.1	3.7	4.5	-0.5	9.4
Other	39.8	44.8	15.4		0.6	-5.0	6.2	1.6	-4.0	7.3	-2.3	-6.0	1.4
Marital status				.005									
Married	39.9	43.5	16.5		Ref	—	—	Ref	—	—	Ref	—	—
Not married	39.7	40.5	19.8		-0.1	-2.9	2.7	-3.1†	-5.9†	-0.3†	3.2†	1.1†	5.3†
Education				.09									
< High school	37.2	43.4	19.4		-2.0	-5.5	1.5	0.7	-2.9	4.2	1.3	-1.3	3.9
High school graduate or some college	39.2	42.8	18.0		Ref	—	—	Ref	—	—	Ref	—	—
College degree or higher	42.3	41.1	16.5		3.1	0.2	6.1	-1.7	-4.6	1.2	-1.4	-3.5	0.6
Income, \$				.07									
< 20,000	41.4	42.4	16.2		Ref	—	—	Ref	—	—	Ref	—	—
20,000 to < 40,000	36.3	45.8	18.0		2.1	-2.1	6.3	-1.0	-5.2	3.2	-1.1	-4.1	1.9
40,000 to < 60,000	39.0	42.2	18.9		-3.1	-6.9	0.7	2.4	-1.3	6.2	0.7	-2.1	3.5
≥ 60,000	39.3	43.4	17.3		-0.3	-4.3	3.7	-1.3	-5.3	2.7	1.6	-1.3	4.5
No. of self-reported comorbid conditions				.77									
0	39.0	43.3	17.7		Ref	—	—	Ref	—	—	Ref	—	—
1	40.7	41.7	17.6		1.7	-1.1	4.5	-1.6	-4.4	1.2	-0.1	-2.1	1.9
2	40.3	40.8	18.8		1.4	-2.4	5.1	-2.5	-6.3	1.3	1.1	-1.6	3.9
≥ 3	39.8	43.3	17.0		0.7	-4.5	6.0	0.0	-5.3	5.3	-0.7	-4.4	3.0
Prediagnosis health status				.03									
Quartile 1	37.7	42.7	19.6		Ref	—	—	Ref	—	—	Ref	—	—
Quartile 2	38.1	43.7	18.2		0.3	-3.0	3.6	0.9	-2.4	4.3	-1.2	-3.6	1.1
Quartile 3	42.5	40.3	17.2		4.9†	1.3†	8.5†	-2.7	-6.2	0.8	-2.2	-4.6	0.2
Quartile 4	41.3	42.6	16.1		3.5	-0.1	7.1	-0.3	-3.9	3.3	-3.2†	-5.6†	-0.8†

(continued on following page)

**Table 2.** Adjusted Associations of Patient and Tumor Characteristics With Roles in Decisions, Including Adjusted Differences and 95% CIs (continued)

Characteristic	Adjusted Proportion Reporting			P*	Adjusted Differences								
	Patient Control	Shared Control	Physician Control		Patient Control			Shared Control			Physician Control		
					Difference	95% CI	95% CI	Difference	95% CI	95% CI	Difference	95% CI	95% CI
CES-D short form				.27									
≤ 5	39.4	42.8	17.7		Ref	—	—	Ref	—	—	Ref	—	—
≥ 6	41.8	40.3	17.9		2.5	-1.0	5.9	-2.7	-6.0	0.7	0.2	-2.3	2.7
Study site				<.001									
Los Angeles county	39.5	41.3	19.3		Ref	—	—	Ref	—	—	Ref	—	—
Alabama	38.1	47.1	14.9		-1.7	-6.2	2.8	5.8	1.2	10.4	-4.1†	-7.0†	-1.2†
8 counties in Northern California	41.8	39.3	18.9		2.5	-1.3	6.2	-2.2	-5.9	1.6	-0.3	-2.9	2.3
22 counties in eastern North Carolina	31.7	52.1	16.2		-8.2†	-12.5†	-3.9†	11.1†	6.3	15.9	-2.9	-5.8	0.1
Iowa	40.8	45.4	13.8		1.1	-4.1	6.2	4.0	-1.2	9.3	-5.1†	-8.0†	-2.2†
5 HMOs	38.7	43.2	18.1		-0.9	-4.9	3.2	2.0	-2.1	6.0	-1.1	-3.8	1.6
15 Veterans Affairs hospitals	39.9	43.1	17.0		0.3	-4.5	5.2	1.8	-3.1	6.7	-2.1	-5.4	1.1

NOTE. To facilitate interpretation of model results, we calculated rates of each category of treatment role for patient subgroups defined by each covariate, adjusted for all other covariates by direct standardization under the regression model. We also tested for differences between groups in the adjusted probability of each response while holding other covariates at their mean values.

Abbreviations: Ref, reference value; CES-D, Center for Epidemiological Studies–Depression Scale; HMOs, health maintenance organizations.

\*P value reflects the overall association of the variable of interest on roles in decisions using multinomial logit to adjust for all variables in the model and accounting for clustering by patients. The unit of analysis is the decision. Because each patient reported on up to three treatment decisions, we corrected the standard errors associated with the regression coefficients by using a robust-variance estimator that accounts for correlation among the repeated decisions.

†Statistically significant.

‡Metastatic cancer.

should be important. It may be that physicians encourage patients, either explicitly or indirectly, to assert more control in such settings. Similarly, the high rates of shared control when there is good evidence for a treatment’s effectiveness suggests there is ample discussion between the physician and patient about the evidence and how to respond. Nevertheless, we also expected high rates of shared control for decisions with no evidence for (or evidence against), and we instead found high rates of physician control (compared with decisions with evidence for or uncertain evidence).

In patients with metastatic cancer, high-level evidence shows that treatment offers at best only modest benefits and is accompanied by toxicity in essentially all patients. As a result, there is near uniform consensus that decisions about these treatments should reflect patients’ preferences. Surprisingly, we observed lower rates of patient control and higher rates of physician control for these inherently preference-based decisions. It is possible that patients with more severe illness want less involvement in their decisions.<sup>12</sup> It is also possible that patients do not want to own decisions about therapies that cannot cure them and that the lack of curative treatments is perceived by patients as a loss of control over their cancer and, by extension, a loss of control over the decision. Our finding of more physician control for decisions with no evidence for (or evidence against) the treatment supports this possibility. In a prior study, women who perceived having a choice about breast cancer treatment had higher levels of shared decision making than women who felt they had no choice.<sup>14</sup> It may be that the lack of good choices translates to feeling not involved in the decision. An alternative explanation is that patients may lack a vested interest in treatments that cannot cure them and may make a purposeful decision to not exercise control over decisions regarding their incurable cancer.

We observed some variation in reported patient role in decisions on the basis of treatment modality, with the highest rates of patient

control for chemotherapy decisions and higher rates of physician control for radiation and surgery decisions. These findings suggest that oncologists may be more inclined to engage patients in decisions than surgeons and radiation oncologists.

Married patients were more likely than unmarried patients to report a shared role and were less likely to report physician control of decisions; spouse accompaniment to consultations may result in more shared decision making.<sup>14</sup> Our finding that patients with better prediagnosis health status were less likely to report physician control of decisions and more likely to report patient control may reflect greater focus on maintaining health status and addressing illness. In addition, patients with poorer health status may be perceived by their physicians as poorer candidates for some treatments and thus feel they were not involved in the treatment decisions.

The strengths of this study include a large, population-based cohort of patients with cancer from various geographic areas in the United States and a rich set of potentially relevant variables, including information about role in treatment for several treatment modalities. In addition, the demographic and clinical characteristics of the full CanCORS patient cohort are similar to national estimates.<sup>26</sup> However, our findings should be interpreted in light of several limitations. First, patients surveyed 3 to 6 months after diagnosis may have had difficulty remembering the role that they played in a specific decision, or their perceptions of the role they played may have changed.<sup>6</sup> In addition, other research suggests that patients’ perceptions of involvement do not always match other measures of their involvement.<sup>6,27</sup> Second, our depression measure was collected at the time of the survey, not when decisions were made, and is not sensitive to capturing emotional distress short of major depression. Third, as with all survey research, respondents may have differed from nonrespondents; nevertheless, response rates were relatively high among patients reached. Fourth, we did not verify that physicians were aware of the evidence (or lack

thereof) and communicated it appropriately, nor did we have information about physician's communication style or other details about the decision-making process. Research suggests that surgeons' solicitation of patients' treatment preferences is associated with patient participation in treatment decision making for women with breast cancer.<sup>28</sup> Methods to better understand physician's decision styles with their cancer patients and survivors have recently been developed.<sup>29</sup> Finally, many of our patients were age  $\geq$  70 years, and strong clinical trial evidence in those patients are lacking, which makes it difficult to categorize strength of evidence. Nevertheless, our findings were similar when we restricted the cohort to individuals age  $\leq$  70 years.

In conclusion, characteristics of decisions themselves were associated with patients' roles in decisions. Specifically, patients making decisions about treatments with strong evidence had high rates of shared control, and we observed high rates of patient control when evidence was uncertain. However, patients making decisions about treatments for which no evidence supports benefit and patients making more preference-sensitive decisions, such as those for metastatic cancers, tended to be more physician controlled than other decisions, which suggests that patients may not want to take responsibility for making decisions that will not lead to a cure. Better strategies for engaging patients in decisions may be needed when there is no evi-

dence to support benefit of a treatment or when patients have terminal illnesses that cannot be cured.

#### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

#### AUTHOR CONTRIBUTIONS

**Conception and design:** Nancy L. Keating, Mary Beth Landrum, Neeraj K. Arora, Jennifer L. Malin, Patricia A. Ganz, Michelle van Ryn, Jane C. Weeks

**Collection and assembly of data:** Nancy L. Keating, Mary Beth Landrum, Jennifer L. Malin, Patricia A. Ganz, Michelle van Ryn, Jane C. Weeks

**Data analysis and interpretation:** Nancy L. Keating, Mary Beth Landrum, Neeraj K. Arora, Jennifer L. Malin, Patricia A. Ganz, Michelle van Ryn, Jane C. Weeks

**Manuscript writing:** Nancy L. Keating

**Final approval of manuscript:** Nancy L. Keating, Mary Beth Landrum, Neeraj K. Arora, Jennifer L. Malin, Patricia A. Ganz, Michelle van Ryn, Jane C. Weeks

#### REFERENCES

- Greenfield S, Kaplan SH, Ware JE Jr, et al: Patients' participation in medical care: Effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med* 3:448-457, 1988
- Kaplan SH, Greenfield S, Ware JE: Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Med Care* 27:S110-S127, 1989 (suppl)
- Stewart MA: Effective physician-patient communication and health outcomes: A review. *Can Med Assoc J* 152:1423-1433, 1995
- Guadagnoli E, Ward P: Patient participation in decision-making. *Soc Sci Med* 47:329-339, 1998
- Silliman RA, Dukes KA, Sullivan LM, et al: Breast cancer care in older women: Sources of information, social support, and emotional health outcomes. *Cancer* 83:706-711, 1998
- Street RL Jr, Voigt B: Patient participation in deciding breast cancer treatment and subsequent quality of life. *Med Decis Making* 17:298-306, 1997
- Moyer A: Psychosocial outcomes of breast-conserving surgery versus mastectomy: A meta-analytic review. *Health Psychol* 16:284-298, 1997
- Institute of Medicine: *Crossing the Quality Chasm: A New Health Care System for the 21st Century*. Washington, DC, National Academy Press, 2001
- Degner LF, Sloan JA: Decision making during serious illness: What role do patients really want to play? *J Clin Epidemiol* 45:941-950, 1992
- Deber RB, Kraetschmer N, Irvine J: What role do patients wish to play in treatment decision making? *Arch Intern Med* 156:1414-1420, 1996
- Degner LF, Kristjanson LJ, Bowman D, et al: Information needs and decisional preferences in women with breast cancer. *JAMA* 277:1485-1492, 1997
- Arora NK, McHorney CA: Patient preferences for medical decision making: Who really wants to participate? *Med Care* 38:335-341, 2000
- Street RL Jr, Voigt B, Geyer C Jr, et al: Increasing patient involvement in choosing treatment for early breast cancer. *Cancer* 76:2275-2285, 1995
- Mandelblatt J, Kreling B, Figueiredo M, et al: What is the impact of shared decision making on treatment and outcomes for older women with breast cancer? *J Clin Oncol* 24:4908-4913, 2006
- Ayanian JZ, Chrischilles EA, Fletcher RH, et al: Understanding cancer treatment and outcomes: The Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 22:2992-2996, 2004
- National Cancer Institute: *Cancer Care Outcomes Research and Surveillance Consortium*. <http://healthservices.cancer.gov/cancors/>
- Pearson ML, Ganz PA, McGuigan K, et al: The case identification challenge in measuring quality of cancer care. *J Clin Oncol* 20:4353-4360, 2002
- American Association for Public Opinion Research: *Standard definitions: Final dispositions of case codes and outcome rates for surveys*. [http://www.aapor.org/uploads/Standard\\_Definitions\\_04\\_08\\_Final.pdf](http://www.aapor.org/uploads/Standard_Definitions_04_08_Final.pdf)
- Degner LF, Sloan JA, Venkatesh P: The Control Preferences Scale. *Can J Nurs Res* 29:21-43, 1997
- Ware J Jr, Kosinski M, Keller SD: A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Med Care* 34:220-233, 1996
- Turvey CL, Wallace RB, Herzog R: A revised CES-D measure of depressive symptoms and a DSM-based measure of major depressive episodes in the elderly. *Int Psychogeriatr* 11:139-148, 1999
- Little, RJ: *Statistical Analysis with Missing Data*. New York, NY, Wiley, 1986
- He, Y, Zaslavsky AM, Harrington DP, et al: Imputation in a multiformat and multiwave survey of cancer care: Proceedings in Health Policy Statistics. Alexandria, VA, American Statistical Association, 2007
- White H: Maximum likelihood estimation of misspecified models. *Econometrica* 50:1-25, 1982
- Obtaining robust variance estimates, in: *Stata User's Guide* (vol 9). College Station, TX, Stata Press, 2005, pp 275-280
- Catalano P: Representativeness of CanCORS participants relative to Surveillance, Epidemiology, and End Results (SEER) cancer registries. Presented at the AcademyHealth Annual Research Meeting, Washington, DC, June 8-10, 2008
- Street RL Jr: Analyzing communication in medical consultations: Do behavioral measures correspond to patients' perceptions? *Med Care* 30:976-988, 1992
- Maly RC, Umezawa Y, Leake B, et al: Determinants of participation in treatment decision-making by older breast cancer patients. *Breast Cancer Res Treat* 85:201-209, 2004
- Arora NK, Weaver KE, Clayman ML, et al: Physicians' decision-making style and psychosocial outcomes among cancer survivors. *Patient Educ Couns* 77:404-412, 2009