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Patient Preferences for Medical Decision Making Who Really Wants to Participate?

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OBJECTIVES. To identify the determinants of patient preferences for participation in medical decision making.

METHODS. Data were analyzed for 2,197 patients from the Medical Outcomes Study, a 4-year observational study of patients with chronic disease (hypertension, diabetes, myocardial infarction, congestive heart failure, and depression). Multivariate logistic regression models estimated the effects of patients' socio-demographic, clinical, psychosocial, and lifestyle characteristics on their decision-making preferences.

RESULTS. A majority of the patients (69%) preferred to leave their medical decisions to their physicians. The odds for preferring an active role significantly decreased with age and increased with education. Women were more likely to be active than men (odds ratio [OR] = 1.44, $P < 0.001$). Compared with patients who only suffered with unsevere hypertension, those with severe diabetes (OR = 0.62,

$P = 0.04$) and unsevere heart disease (OR = 0.45, $P = 0.02$) were less likely to prefer an active role. Patients with clinical depression were more likely to be active (OR = 1.64, $P = 0.01$). Patients pursuing active coping strategies had higher odds for an active role than "passive" copers, while those who placed higher value on their health were less likely to be active than those with low health value (OR = 0.59, $P < 0.001$).

CONCLUSIONS. Although a majority of patients prefer to delegate decision making to physicians, preferences vary significantly by patient characteristics. Approaches to enhancing patient involvement will need to be flexible and accommodating to individual preferences in order to maximize the benefits of patient participation on health outcomes.

Key words: patient participation; medical decision making; physician-patient relationship. (Med Care 2000;38:335-341)

The biomedical model casts patients in a passive role and physicians in positions of dominance and authority.^{1,2} However, the consumer and self-help movements have encouraged more balanced partnerships in medical decision making.^{3,4} The

benefits of increased patient participation have been demonstrated.⁵⁻¹¹

Preferences for participation vary.^{12,13} Younger educated patients prefer more active roles.^{12,14-16} Mixed results have been observed for gender.^{5,14,17}

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and disease severity.^{17,18} Prior research has been limited by (1) bivariate analyses,^{5,15} (2) use of hypothetical illness projections,^{14,18} and (3) focus on patients with self-limiting ailments.¹⁹ Research on chronically ill patients has typically been limited to a single disease.^{3,17} Moreover, patients' psychosocial characteristics, which are linked to outcomes,^{20–22} have been largely ignored.

This study extends previous work by identifying patient sociodemographic, clinical, psychosocial, and lifestyle characteristics that differentiate chronically ill patients who prefer active versus passive roles in medical decision making.

Methods

Study Design

Data were derived from the Medical Outcomes Study (MOS), a longitudinal study of health outcomes among chronically ill patients. The study details have been published extensively^{23–29} and are summarized here. The MOS was conducted in Boston, Chicago, and Los Angeles between 1986 and 1990. It included a cross-sectional study of 22,462 patients and a longitudinal panel of patients with hypertension, diabetes, congestive heart failure, myocardial infarction, or clinical depression. A total of 4,842 patients met the eligibility criteria for the longitudinal panel.^{23,26,29} Of those, 2,988 completed both baseline surveys. The analytic sample consisted of all panel-eligible patients who completed the baseline surveys and had complete data on the participation preference measure ($n = 2,472$).

Assessment of Participation Preferences

Participation preference was measured by: "I prefer to leave decisions about my medical care up to my doctor," with a 5-point scale (1 = strongly agree, 5 = strongly disagree). Variants of this item have been used in previous research.^{5,15,17} Patients who "strongly agreed" (17.1%) or "agreed" (44.5%) were considered passive, and those who "disagreed" (22.5%) or "strongly disagreed" (4.8%) were considered active. "Uncertain" patients (11.1%) were excluded, resulting in a final sample size of 2,197.

Analytic Approach

Determinants of patient preferences were identified by a series of logistic regression models. The following characteristics were evaluated: (1) socio-demographics: age, education, gender, race, income, employment status, and marital status; (2) clinical: diagnosis and severity of the MOS tracers^{25,29}; (3) psychosocial: active coping—use of active coping strategies for health problems (Cronbach's $\alpha = 0.67$, skewness = -0.26)^{20,21}; social support: perceived tangible, affection, informational, and interaction support (Cronbach's $\alpha = 0.98$, skewness = -0.71)^{20–22,30}; health distress: time feeling distressed about health (Cronbach's $\alpha = 0.94$; skewness = 1.36)^{20,31}; health value: importance of good health (Cronbach's $\alpha = 0.81$, skewness = -0.78)^{20,21,32,33}; will to function (preventing illness from interfering with life, Cronbach's $\alpha = 0.59$, skewness = -0.25)^{20,21}; and (4) active lifestyle: physical activity (single item; low, medium, high).^{21,34}

As all patients had at least one condition, unsevere hypertension was used as the reference group.^{29,35} The psychosocial variables were divided into tertiles to account for nonlinear effects.

We hypothesized younger patients,^{12,15} whites,³ women,⁵ employed persons,¹⁸ unmarried persons,⁵ and those of higher socioeconomic status^{3,12,15,18} to be more active. Patients with more severe disease¹⁸ were hypothesized to be more passive. We hypothesized that less health distress, more active lifestyle, more active coping, and greater social support, value on health, and will to function would bring about more active participation.^{20–22}

An initial multivariate model included all predictors that were significant in bivariate models. Subsequent models, nested within the initial model by eliminating nonsignificant predictors, were estimated, and fit statistics were compared. The most parsimonious model to fit the data was used to interpret relationships. All models controlled for site, physician specialty, payment system, and a count of 19 comorbidities.³⁵

Results

Table 1 describes the patient characteristics. Of the 2,197 patients, 69% preferred a passive role. Race, will to function, and active lifestyle had nonsignificant ($P > 0.05$) bivariate relationships

TABLE 1. Patient Characteristics (N = 2,197)

Patient Characteristics	Value
Sociodemographics	
Age (y): mean (SD)	57.2 (14.6)
Gender: % male	42.2
Race: % nonwhite	20.4
Income (adjusted 1985 household \$): mean (SD)	22,940 (16,272)
Education (y): mean (SD)	13.2 (3.0)
Marital status: % married	58.9
Employment status: % employed	48.7
Clinical	
% Hypertension	73.3
% Severe	3.9
% Diabetes	22.3
% Severe	8.6
% Heart disease (CHF or MI)	11.4
% Severe	2.1
% Clinical depression	15.7
Number of chronic tracer conditions: mean (SD)	1.3 (0.6)
Number of comorbidities: mean (SD)	1.3 (1.5)
Psychosocial*	
Active coping: mean (SD), % floor, % ceiling	54.1 (18.0), 1.1, 0.7
Social support: mean (SD), % floor, % ceiling	71.0 (24.3), 0.2, 11.6
Health distress: mean (SD), % floor, % ceiling	19.1 (22.2), 28.6, 0.5
Health value: mean (SD), % floor, % ceiling	73.4 (21.2), 0.3, 13.3
Will to function: mean (SD), % floor, % ceiling	71.3 (20.0), 0.1, 0.8
Lifestyle	
Level of physical activity: % high	41.2

CHF indicates congestive heart failure; MI, myocardial infarction.

*All psychosocial variables were measured on a 0–100 scale.

with participation preference. Employment status, marital status, income, health distress, and social support failed to achieve significance once other variables were in the model. The final model ($\chi^2 = 528.34$, $df = 32$, $P < 0.0001$) consisted of age, gender, education, active coping, health value, diagnosis, and severity as significant predictors ($P < 0.05$).

Table 2 presents the ORs and 95% confidence intervals (CIs). Younger patients preferred an active role. Patients aged 35 to 44 years were 6.9 times (95% CI 3.95–11.86) more likely to be active than those who were aged ≥ 75 years. Women were more active than men (OR = 1.44, 95% CI 1.15–1.80). Active role preference increased with education. College-educated patients were 3.5 times (95% CI 2.35–5.09) more likely to prefer active roles than those with < 12 years of education.

Patients with severe diabetes and unsevere heart disease were less likely to prefer an active role (diabetes: OR = 0.62, 95% CI 0.39–0.97; heart: OR = 0.45, 95% CI 0.23–0.86) than those with unsevere hypertension. The OR for severe heart disease did not achieve statistical significance because of the small group size ($n = 47$). Clinically depressed patients were more likely to prefer an active role than those with unsevere hypertension (OR = 1.64, 95% CI 1.16–2.30).

Patients with active coping strategies were more likely to prefer an active role. The odds for an active role for patients in the top and middle tertiles were 2.3 times (95% CI 1.77–3.05) and 1.5 (95% CI 1.17–1.99) the odds for those in the bottom tertile, respectively. Active role preference decreased with health value. Patients who placed higher value on their health (top tertile) were less

TABLE 2. Patient Characteristics Associated With Preference for an Active Role in Medical Decision Making (N = 2,197)

Predictors	OR	95% CI	P Value
Age (y)			
≥75	1.00 (referent)		
65–74	1.48	0.87–2.52	0.15
55–64	3.00	1.79–5.02	0.00
45–54	5.86	3.44–9.97	0.00
35–44	6.85	3.95–11.86	0.00
<35	10.53	5.74–19.34	0.00
Gender			
Male	1.00 (referent)		
Female	1.44	1.15–1.80	0.00
Education (y)			
<12	1.00 (referent)		
12	1.06	0.72–1.56	0.76
13–15	1.78	1.22–2.60	0.00
≥16	3.46	2.35–5.09	0.00
Chronic conditions			
Unsevere hypertension only	1.00 (referent)		
Severe hypertension	1.02	0.43–2.43	0.96
Unsevere diabetes	0.97	0.70–1.34	0.85
Severe diabetes	0.62	0.39–0.97	0.04
Unsevere heart disease	0.45	0.23–0.86	0.02
Severe heart disease	0.46	0.14–1.45	0.18
Clinical depression	1.64	1.16–2.30	0.01
Active coping			
Low	1.00 (referent)		
Medium	1.53	1.17–1.99	0.00
High	2.32	1.77–3.05	0.00
Health value			
Low	1.00 (referent)		
Medium	0.83	0.65–1.07	0.15
High	0.59	0.45–0.78	0.00

Estimates are simultaneously adjusted for all the variables in the table, as well as the site of data collection, medical specialty of the physician, payment system, and number of comorbidities.

OR indicates odds ratio; CI, confidence interval.

likely to prefer an active role than patients with lower health value (bottom tertile) (OR = 0.59, 95% CI 0.45–0.78).

Discussion

Although a majority of the patients (69%) desired a passive decision-making role, preferences varied by patient characteristics. Consistent with our hypotheses, patients who were younger and

who had more education, less severe illness, and an active coping style preferred more active participation. Women were more likely to be active, which is consistent with their being more active in seeking care and asking questions during visits.^{36–38} The validity of the participation preference item is strengthened from the fact that studies that have used variants of this item or other strategies have reported results consistent with our findings.^{3,5,12,14,15,17,18}

Lau et al³² posited that people will carry out actions that lead to better health only if they value health in the first place. We had expected participation preference to increase with health value. However, patients who placed higher value on their health were more passive. Patients in the top tertile of health value had a mean score of 95.3 (SD = 4.7). Such a ceiling effect for these patients could indicate extreme apprehension about health, thus resulting in deferral to physicians. Alternatively, patients having high health value may believe that optimal outcomes are best achieved by experts rather than laypersons. This finding should be explored in future studies. Clinically depressed patients had more active role preferences. The extent to which practice patterns of underdetecting³⁹ and undertreating⁴⁰ depression influence participation preferences is unclear and needs further study.

Patients' trust in physicians may mediate the relationship between patient characteristics and participation preferences. Patients with greater trust desire less control during visits.⁴¹ Also, older^{41,42} and less well educated patients⁴¹ have greater trust in physicians. Patients' confidence in their physicians' knowledge and skills is a component of trust^{41,42} and was assessed by a 10-item technical competence scale in the MOS^{43,44} (Cronbach's $\alpha = 0.85$). To explore this issue, we conducted a post hoc analysis and added the technical competence scale to the final model. Although active role preference was negatively associated with technical competence ($P < 0.001$), all reported relationships remained significant. In future, other factors that might mediate the relationships obtained herein need to be explored.

These findings are more generalizable than earlier ones, as we evaluated a number of patient characteristics in a large sample of patients with chronic diseases that have a high prevalence in the population.²³ A limitation of this study concerns the single-item dependent variable, which assessed only overall desire for involvement. Recent research suggests that preferences vary with the type of medical decision and the expertise required to make it.^{14,16,45} Our results should be interpreted in the light of these reports. Also, since single-item measures are less reliable than multi-item scales, our results should be considered as lower-bound estimates.⁴⁶ Finally, participation preference was measured once; whether preferences change over time¹⁸ needs study.

For chronically ill persons, the focus of medical care has shifted to maximizing functioning and well-being.^{22,24} Two approaches to optimizing these outcomes have been suggested. On one hand, there is substantial evidence of the positive impact of participation on health outcomes,^{6,10} and interventions have increased patient involvement.^{9,10,47} However, others recommend that care be delivered in a manner that responds to each patient's desired level of participation, whether it be passive or active.^{5,12,18} The challenge is to facilitate physician-patient relationships that would balance advocacy for active participation with individual patient preferences.

To meet this challenge, the following issues should be addressed. First, to motivate passive patients and paternalistic doctors to accept an active patient role, the beneficial effects of patient involvement on health outcomes needs to be widely disseminated.^{1,19} Second, since physicians may be inaccurate in perceiving patients' preferences,³ efforts should be made to communicate and share such preferences during visits.⁷ Finally, to better understand the dynamics of the physician-patient relationship and its impact on outcomes studies that simultaneously evaluate physician style⁴⁸⁻⁵¹ and patient preferences need to be conducted.

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