ORIGINAL ARTICLES

Patient Desire for Information and Decision Making in Health Care Decisions:

The Autonomy Preference Index and the Health Opinion Survey

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OBJECTIVES: To compare results on the Autonomy Preference Index (API) and the Health Opinion Survey (HOS), two instruments that measure patient desire for information and involvement in decision making.

DESIGN: Cross-sectional survey.

SETTING: University-based primary care outpatient longitudinal and acute care clinic.

PATIENTS: 167 patients with benign prostatic hyperplasia, back pain, or mild hypertension seen from October 1991 to December 1992.

MEASUREMENTS AND MAIN RESULTS: On the API and the HOS (both scaled from 0 to 1), the patients had intermediate desire for involvement in decision making (median API: 0.42; HOS: 0.36) and higher desire for information (median API: 0.97; HOS: 0.57). With either instrument, the desire for information exceeded that for involvement in decision making ($p < 0.0001$). The API information scores were higher than the HOS information scores ($p < 0.0001$), probably because the HOS focuses on patient behavior rather than desire. Variation in desire for information and involvement in decision making was substantial and largely unexplained.

CONCLUSIONS: Most patients have a high desire for information, the desire for information and involvement in decision making varies substantially among patients, and the API is preferable to the HOS for researchers interested in focusing solely on patient desire for information.

KEY WORDS: autonomy; decision making; patient-centered decision making; Autonomy Preference Index; Health Opinion Survey.
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Patient autonomy, including the provision of information to patients and the integration of patients in medical decision making, has been promoted for several important reasons. First, many medical treatment decisions require the physician to inform and involve the patient in decision making because patients' preferences must be incorporated into the treatment decision to achieve optimal health outcomes.[1, 2] This situation arises because of the wide variation that exists in preferences among patients, even among those with similarly severe diseases.[3] For example, in the setting of benign prostatic hyperplasia, surgical treatment may be effective in relieving urinary symptoms but exposes the patient to the risk of impotence, incontinence, and retrograde ejaculation.[4] The decision to undergo surgery, therefore, should depend on how the patient feels about relief of symptoms compared with the chance of side effects.[1] Second, some studies have demonstrated that more active patient participation in medical care decisions is associated with improved control of disease and better functional outcomes.[5-10] Third, better patient satisfaction with medical care has been associated with informing and actively involving patients in their care.[11-14] Finally, ethical considerations may demand that the patient be informed about and play an active role in health care decisions.[15-18]

Although the importance of patient autonomy has been argued on several grounds, little is known about the degree to which patients themselves want to be involved in decisions concerning their medical care.[19-23] Two questionnaires have been developed to assess patients' desire for autonomy. The Autonomy Preference Index (API) and the Health Opinion Survey (HOS) both assess the degree to which patients 1) desire information regarding their medical care and 2) wish to be involved in decisions concerning their medical care.[24, 25] However, these two instruments approach measurement of these constructs differently.

The goals of our study were to: 1) compare the API and HOS measurements of patient desire for information and involvement in decision making; 2) determine whether there is a difference between desire for information and desire for involvement in decision making in a specific patient population; and 3) identify patient characteristics that are associated with desire for information and for involvement in decision making. We sought to address these questions for primary care patients facing treatment decisions.

METHODS

Subjects and Procedures

During the period from October 1991 to September 1992, participating primary care providers at the Dartmouth – Hitchcock Medical Center in Lebanon, New Hampshire, and the Veterans Affairs Hospital in White River Junction, Vermont, identified patients facing management decisions for symptomatic benign prostatic hyperplasia, mild hypertension (average systolic reading less than 200 mm Hg and average diastolic reading 90 to 99 mm Hg over three measurements spanning at least one month), or persistent low back pain (pain lasting at least four weeks with conservative treatment). Inclusion and exclusion criteria for the study (available from the authors on request) were designed to identify patients for whom more than one treatment option was reasonable. The study we report here was part of a larger study to gain insight into the standard practice for caring for patients with these conditions. At the start of the broader project, we used only the API to assess patient autonomy; the HOS instrument was added later to allow for a comparison of the two instruments in our population. We describe only those patients who completed both the API and the HOS instruments.

Providers completed an enrollment form to document the eligibility of each patient they identified for the study. The study research assistant then contacted each eligible patient and described the study. Consenting patients completed a questionnaire that included demographic information as well as the API and HOS instruments. Each subject completed the questionnaire and returned it by mail. The research assistant contacted by telephone those patients who failed to return their questionnaires within seven days and asked them to complete and return the questionnaire.

Measures

The HOS[25] is a 16-item questionnaire that generates an overall score and two subscale scores: desire for information and behavioral involvement. The HOS has been validated using observed patient behaviors and convergent and divergent criteria as measured by other questionnaires (MMPI,[26] Health Locus of Control,[27] Social Desirability[28]). Subscale internal consistency is judged to be good (Kuder Richardson reliability 0.76 and 0.74, respectively) and test – retest reliability is adequate (0.59 and 0.74). Reported correlation between subscales is modest (r = 0.26).

The API is a 23-item questionnaire that also yields an overall score and two subscale scores: information seeking and decision making preference. Validation of the API was done using concurrent, convergent, and face validity testing in general patient populations. Internal consistency of each subscale was excellent (Cronbach's alpha coefficient 0.82 for both). Test – retest reliability for the subscales was also high (Pearson product – moment correlation 0.83 and 0.84, respectively).

Both the API and the HOS seek to measure general desire for information and involvement in decision making rather than the current health condition of the patients. However, these two instruments have important differences. The API frames the information questions primarily in terms of *what the patient feels the physician should do*, whereas the HOS asks *what the patient usually does* to seek information. For example, the API asks the patient to respond to the statement, "Your doctor should explain the purpose of your laboratory tests"; the HOS asks the patient to respond to the statement, "I usually ask the doctor or nurse lots of questions about the procedures during a medical exam." For the decision making subscales, the API focuses on *what the patient feels he or she should do* with regard to making decisions, whereas the HOS assesses *the patient's desire to participate in self-care.* For example, the API includes the item, "You should decide how frequently you need a check-up"; the HOS includes the item, "Except for serious illness, it's generally better to take care of your own health than to seek professional help."

The API generates information and decision making subscale scores that range from 0 to 100. The HOS yields information scores that range from 0 to 7 and behavioral involvement scores that range from 0 to 9. For our analysis, we normalized subscale scores on both the HOS and the API to fall between 0 and 1. To normalize, we divided each API subscale score by 100, the HOS information score by 7, and the HOS behavioral involvement score by 9. Thus, in our study a score of 0 represents little or no desire for information or involvement in medical decisions and a score of 1 indicates a high desire for information or involvement.

Statistical Methods

We used the Wilcoxon signed-rank test, a nonparametric analog to the paired t-test, to determine whether the information scores differed from the decision making scores. To assess the degree to which the information scores were correlated with the decision making scores, we calculated the Spearman rank correlation coefficient, a nonparametric measure of association. We also used the Spearman rank correlation coefficient to correlate the scores for the two instruments (e.g., HOS information score vs API information score). To check for significant differences in scores across the two instruments, we used the Wilcoxon signed-rank test.

Table 1
Subject Demographics (n = 167)

	Benign Prostatic Hyperplasia (n = 52)	Low Back Pain (n = 45)	Mild Hypertension (n = 70)	All (n = 167)
Age—median (range)	67 (42–83) years	51 (27–80) years	53 (24–92) years	59 (24–92) years
Gender—male	52 (100%)	29 (64%)	45 (64%)	126 (75%)
Education—more than high school	29 (56%)	23 (51%)	36 (51%)	88 (53%)
Race—white	51 (98%)	43 (96%)	70 (100%)	164 (98%)
Married	42 (81%)	31 (69%)	53 (76%)	126 (75%)
Living with family or friends	46 (88%)	36 (80%)	61 (87%)	143 (86%)
Full- or part-time employment*	12 (23%)	23 (51%)	47 (67%)	82 (50%)
Annual family income ≥ $25,000	27 (52%)	17 (37%)	43 (62%)	87 (51%)

**Including homemaking.*

To determine associations between the demographic variables and the information and decision making scores, we used a two-step strategy similar to that described by Ende et al.[24] First, we performed univariate analysis to determine which of the demographic variables had significant associations with each of the scores. We determined univariate associations using linear regression for continuous variables (e.g., age), the Mann-Whitney U test for binary categorical variables (e.g., gender), and the Kruskal-Wallis test for categorical variables with more than two groups (e.g., condition: benign prostatic hyperplasia, low back pain, or high blood pressure). We then performed backwards stepwise linear regression to determine which set of demographic variables provided the greatest explanation for the variance in each of the four scores.

RESULTS

Patient Demographics

During the enrollment period, 226 patients were referred to the study. Of those, 33 either declined to participate or failed to return their questionnaires (refusal rate = 14.6%). The HOS was introduced to the questionnaire after the study began. One hundred sixty-seven subjects completed both the HOS and the API; 59 subjects completed the API only. The findings for these 59 subjects were not statistically significantly different from those for the 167 subjects in terms of sociodemographic variables or API scores. The results reported reflect the 167 subjects who completed both the HOS and the API.

Table 1 shows the demographic data for the patients enrolled in the study. Although the demographics varied by the condition for which the patients were enrolled, most of our subjects were white, male, and well-educated. These demographic findings reflect the patient population for these diseases in the longitudinal and acute care clinics at the Dartmouth – Hitchcock Medical Center.

Desire for Information and Desire for Decision Making

Figure 1 shows the histograms of the information and decision making subscale scores for the API. The mean and median desire for information subscale scores using the API were 0.93 and 0.97 respectively, with an interquartile range of 0.91 to 1.00. In contrast, the mean and median decision making subscale scores were both 0.42, with an interquartile range of 0.32 to 0.53.

Figure 1 reveals three important points. First, the histogram for patient desire for information (Fig. 1a) was skewed strongly to the right: most desire for information scores were relatively high. Second, there was wide variation in the patients' desire for involvement in decision making (Fig. 1b). Finally, the desire for information scores were higher than the decision making scores ($p < 0.0001$, Wilcoxon signed-rank). The mean difference between the information and decision making scores using the API was 0.52 (95% confidence interval: 0.49 to 0.54).

Figure 2 depicts the histograms of the information and decision making subscale scores for the HOS. The mean and median desire for information subscale score were both 0.57, with an interquartile range of 0.46 to 0.68. The mean behavioral involvement subscale score was 0.40, the median was 0.36, and the interquartile range was 0.26 to 0.53.

There was substantial variation among the patients

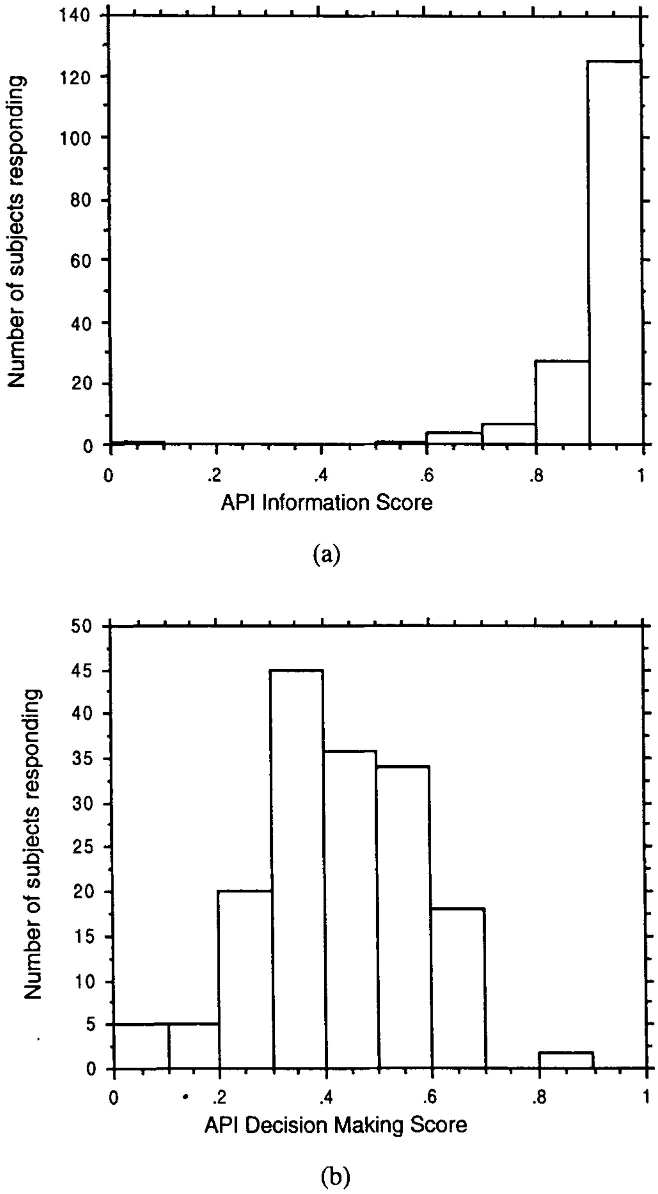

FIGURE 1. Histograms for Autonomy Preference Index (API) scores. Scores are normalized to range between 0 and 1. (**A**) Desire for information scores. (**B**) Desire for involvement in decision making scores.

in the HOS information and decision making subscale scores. The HOS information scores were higher than the decision making scores ($p < 0.0001$, Wilcoxon signed-rank). The mean difference between the information and decision making scores with the HOS was 0.17 (95% confidence interval: 0.14 to 0.20). The HOS information scores fell across a wider range of values than did the API information scores.

Comparison of Instruments

For both information and decision making, there is a significant correlation between the API and the HOS. The API and HOS information subscales are mildly correlated (Spearman's rho = 0.25, $p = 0.0013$), and the API information score is higher than the HOS information score (mean difference = 0.36; $p < 0.0001$, Wilcoxon signed-rank). The API and HOS decision making scores are more strongly correlated (Spearman's rho = 0.65, $p < 0.0001$), and the API decision making score is slightly higher than the HOS decision making score (mean difference 0.02; $p = 0.0397$, Wilcoxon signed-rank).

Within both the API and the HOS instruments, the information subscale and the decision making subscale scores are positively correlated. For the API, the information and decision making scores produced a Spearman's rank correlation coefficient of 0.27 ($p = 0.0005$); for the HOS, the Spearman's correlation was 0.45 ($p < 0.0001$).

Correlation of Demographic Characteristics with Subscale Scores

Table 2 shows the results of the univariate analyses of each demographic variable on each of the four scores. In general, higher desires for information and decision making are associated with younger age, more education, employment, and female gender. The patients with reported incomes of more than $25,000 per year had higher HOS desires for information and involvement in decision making than did those patients who reported annual incomes of less than $25,000. The subjects who lived alone had a greater desire for information as measured by the API than those who lived with family or friends, but this relationship did not hold for the HOS instrument nor for patients' desires for involvement in decision making (as measured by either the API or the HOS).

Table 3 shows the results of the stepwise linear regression for each score. Each column represents a score from one of the two instruments; each row represents a demographic variable. Each cell in the table gives the correlation coefficient for each demographic variable and instrument score; blank cells indicate variables not retained in the regression model. The intercept, r^2, and p-value for the regression model of each score are given at the bottom of each column. Table 3 reveals three important points. First, very little of the variance we observed in the API information and decision making scores is explained by the sociodemographic variables we analyzed ($r^2 = 0.04$ and 0.08, respectively). Second, age is negatively correlated with desire for information and involvement in decision making regardless of the metric employed: in general, older patients had lower information and decision making scores. Finally, when assessed using the HOS, desire for information and involvement with decision making is correlated with age, gender, and education beyond high school. Younger patients, female patients, and more educated patients had, in general, higher HOS information and decision making scores.

Desire for Decision Making by Clinical Problem

The API decision making score includes vignettes to assess patient desire for involvement in decision making for three medical conditions: upper respiratory tract infection, mild hypertension, and possible myocardial infarction. We scaled total decision making scores for each vignette to allow comparison of patient scores for desire for involvement in decision making among the three clinical conditions. We found that the median decision making score decreased as the clinical condition increased in seriousness (upper respiratory tract infection: 0.42; mild hypertension: 0.33; possible myocardial infarction: 0.17; each differs from the others, $p < 0.0001$). The decision making scores for the mild hypertension vignette were not different for patients with mild hypertension than they were for patients with persistent low back pain or benign prostatic hyperplasia.

DISCUSSION

Our study has three important findings. First, patients' desire for information is high, and is likely to exceed that for involvement in decisions surrounding their care. This result is not surprising: it seems reasonable that patients who want to be involved in decision making would also desire information; thus, one might expect that on the whole, desire for information would be at least as great as desire for involvement in decision making. It follows from this finding that clinicians should not assume that a patient who has little desire for involvement in decision making will have little desire for information. In fact, among the patients who had HOS decision making scores lower than the median, 32% had HOS information scores higher than the median.

Second, there is substantial variation among patients in their desire for information and for involvement in decisions concerning their medical care, regardless of the instrument used. For example, although the median HOS information score was moderate (0.57), the individual patient scores ranged from 0.18 to 0.86. Furthermore, although some demographic strata (younger age, female gender, and higher education) may be associated with greater desires for information and decision making, most of the variance in patient responses remains unexplained. The variation we observed suggests that rigid recommendations about how much information to provide to patients and about how much to involve patients in decision making are likely to be inappropriate for some patients. This finding also motivates further research into the etiology of patient desires for information and involvement in decision making.

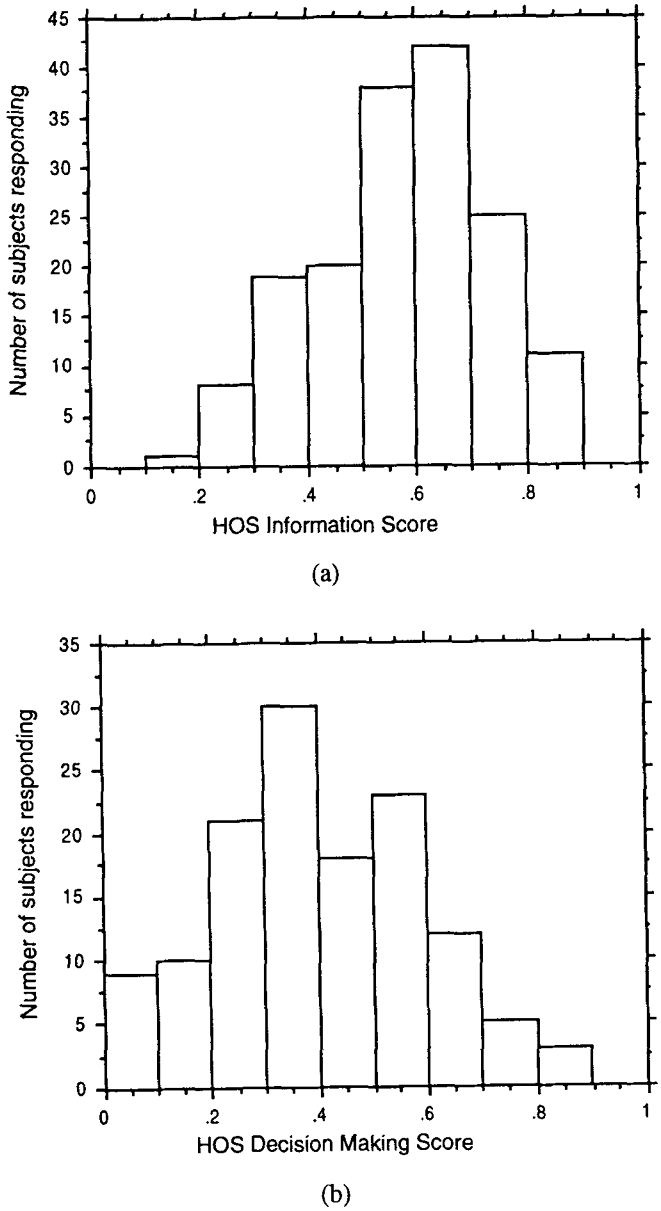

FIGURE 2. Histograms for Health Opinion Survey (HOS) scores. Scores are normalized to range between 0 and 1. (**A**) Desire for information scores. (**B**) Desire for involvement in decision making scores.

Finally, the two instruments we studied differ in their assessments of patients' desires for information. The API results indicate that, in general, patients have a relatively high desire for information, whereas the HOS results suggest that the same patients have a relatively lower desire for information. Close examination of the API and the HOS information subscales suggests two possible explanations for this finding. First, the items of the API that relate to information focus on the desire of the patient for information. In contrast, the items of the HOS relating to information focus on behaviors the patient has taken in the past to obtain information concerning his or her medical condition. For example, the

API asks the patient to agree or disagree with the following statement: "Your doctor should explain the purpose of your laboratory tests." The HOS asks the patient to agree or disagree with the following statement: "Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health." It is quite possible that patients have latent desires for information that are not acted on. If patients have desires for information that do not lead to information-seeking behavior, the API information score (which focuses on desire for information) may be higher than the HOS information score (which focuses on behavior). Second, three of the seven information items in the HOS are strongly related to decision making ("I'd rather have doctors and nurses make the decision about what's best than for them to give me a whole lot of choices"; "It is better to trust the doctor or nurse in charge of a medical procedure than to question what they are doing"; and "I'd rather be given many choices about what's best for my health than to have the doctor make decisions for me"). Because our results suggest that patients have a lower desire for involvement in decision making, and because three items on the HOS information subscale measure desire for involvement in decision making rather than desire for information, the HOS may underestimate patients' true desires for information. To investigate this possibility, we deleted these three items from the HOS information score and rescaled the estimates to fall between 0 and 1. The mean HOS information score rose from 0.56 to 0.65, a modest but statistically significant increase ($p < 0.0001$). However, even after deleting from the HOS information subscale questions that focus on decision making rather than desire for information, the HOS yielded substantially lower information scores than did the API (mean of 0.65 vs 0.93, $p < 0.0001$). We believe this difference is due to the focus of the HOS on information-seeking behavior rather than on patient desire for information. To the degree that one is interested in separating more clearly patient desire for information from desire for involvement in decision making, and in focusing on desire for information (rather than on behavior), the API is a more suitable instrument than the HOS.

Do patients want to be involved in decisions concerning their care? Based on similar results from their studies with the API, Ende and colleagues have argued that "patients do not want to be the principal decision makers."[24] The results of our study suggest that many patients have little desire to be involved in medical decision making. We believe, however, that both information and decision making scores from either the API or the HOS should be interpreted with caution for at least three important reasons. First, it is not clear that an information or decision making score less than 0.5 implies that patients should not be offered information or involvement in decisions. Generating numerical scores from category responses requires that one assume that the psychometric distances between the categories be

Table 2
Univariate Analysis of Sociodemographics on Autonomy Preference Index (API) and Health Opinion Survey (HOS) Scores*

	API		HOS		
	Information	Decision Making	Information	Decision Making	Trend
Age	0.067	0.0011	<0.0001	<0.0001	Decreases with age
Gender—male	0.81	0.077	0.0004	0.0001	Lower for men
Education—more than high school	0.36	0.019	0.0002	0.0007	Higher for those with more education
Race—white	0.38	0.99	0.52	0.39	—
Married	0.33	0.39	0.21	0.21	—
Living with family or friends	0.042	0.66	0.51	0.32	Higher for those living alone
Full- or part-time employment†	0.051	0.019	0.0099	0.0008	Higher for those employed
Annual family income ≥ $25,000	0.99	0.45	0.0095	0.012	Higher for those with large incomes
Condition§	0.075	0.22	0.013	0.0083	Lower for benign prostatic hyperplasia

Each entry presents the p-value of the association between that variable and each of the four measures.
†Includes patients who designated themselves to be homemakers.
§Benign prostatic hyperplasia, low back pain, or high blood pressure.

Table 3
Stepwise Regression of Sociodemographic Variables on Autonomy Preference Index (API) and Health Opinion Survey (HOS) Scores*

	API		HOS	
	Information	**Decision Making**	**Information**	**Decision Making**
Age	−0.00165	−0.00259	−0.00368	−0.004
Education—more than high school	—	0.053	0.077	0.091
Gender—male	—	—	−0.053	−0.097
Intercept	1.024	0.537	0.778	0.657
r^2	0.038	0.084	0.234	0.227
p-value	0.0067	0.0003	<0.0001	<0.0001

**Each row/column entry represents the coefficient for the variable (row) in the regression model for the score of interest (column). Blank entries signify that the sociodemographic variable was not used in the final regression model. For example, the API decision making scores decreases −0.00259 for every year of age, and increases by 0.053 for those who received education beyond high school.*

equal, an assumption that may not hold. Second, desire for information and involvement in decision making may depend on the patient's medical condition. Ende and colleagues found that desire for decision making decreased as the seriousness of the hypothetical health problem increased, a finding that we observed in this study as well. Ende et al. also found that desire for involvement in decision making was correlated with functional status. These findings suggest that some patients may want to be actively involved in decisions concerning their medical care. Third, the threshold score for providing information or engaging the patient in the decision making process may also vary depending on the medical condition. For example, providing extensive information about rhinoviruses and the physiology of the immune response to a patient presenting with a common cold is likely to be time-consuming but offer little improvement in the outcomes of interest to the patient. In such a situation, the patient's desire for information would have to be quite high to warrant a lengthy discussion. In contrast, for patients facing treatment decisions involving breast cancer, their desire for information would not have to be as high for most physicians to provide substantial information about treatment options.

Should clinicians encourage patients to be more involved in decision making, especially those patients who are hesitant about such involvement? The answer depends in part on whether such patients are expressing a fundamental preference about involvement or are unaware that identifying the appropriate therapeutic course may require engaging them in the decision making process. Other than to demonstrate that some patients receive low scores for involvement in decision making, our study is silent on this issue. Further research into the etiology of patient preferences for involvement in decision making would help clinicians better understand how to handle such patients.

Our study has important implications for clinicians, policymakers, and researchers. We remind clinicians that in general, patients have a high desire for information concerning their care. This finding holds even for patients with little desire for involvement in decision making. Policymakers should be aware that, although patient desire for information is in general high, there is substantial variation in desire for information and involvement in decision making among individual patients. Rigid recommendations about how much information patients should receive and the degree to which patients should be involved in medical decision making may be inappropriate when applied to individual patients. Finally, we remind researchers that the HOS information subscale focuses more on information-seeking behavior than information desire alone, and that it may not separate fully patient desire for information from desire for involvement in decision making. We recommend that researchers interested in focusing solely on patient desire for information use the API rather than the HOS.

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