

CLINICAL REVIEW

Not All Patients Want to Participate in Decision Making

A National Study of Public Preferences

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BACKGROUND: The Institute of Medicine calls for physicians to engage patients in making clinical decisions, but not every patient may want the same level of participation.

OBJECTIVES: 1) To assess public preferences for participation in decision making in a representative sample of the U.S. population. 2) To understand how demographic variables and health status influence people's preferences for participation in decision making.

DESIGN AND PARTICIPANTS: A population-based survey of a fully representative sample of English-speaking adults was conducted in concert with the 2002 General Social Survey ($N = 2,765$). Respondents expressed preferences ranging from patient-directed to physician-directed styles on each of 3 aspects of decision making (seeking information, discussing options, making the final decision). Logistic regression was used to assess the relationships of demographic variables and health status to preferences.

MAIN RESULTS: Nearly all respondents (96%) preferred to be offered choices and to be asked their opinions. In contrast, half of the respondents (52%) preferred to leave final decisions to their physicians and 44% preferred to rely on physicians for medical knowledge rather than seeking out information themselves. Women, more educated, and healthier people were more likely to prefer an active role in decision making. African-American and Hispanic respondents were more likely to prefer that physicians make the decisions. Preferences for an active role increased with age up to 45 years, but then declined.

CONCLUSION: This population-based study demonstrates that people vary substantially in their preferences for participation in decision making. Physicians and health care organizations should not assume that patients wish to participate in clinical decision making, but must assess individual patient preferences and tailor care accordingly.

KEY WORDS: decision making; patient-physician communication.

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The Institute of Medicine states that physicians should encourage patients to be active participants in the process of care and clinical decision making to the degree that they are willing to do so.^{1,2} Patients may wish to participate in a variety of ways including seeking and exchanging information, discussing options in care, and making the final decisions about treatment.³⁻⁵ Patients who are active participants in the process

of their care may have improved medical outcomes.⁶⁻⁹ To this end, consumer groups and medical organizations alike encourage patients to engage in making decisions in collaboration with their physicians.^{3,6} Yet, not all patients want to participate to the same degree. Some may wish to be active in discussing treatment options but may ultimately want to rely entirely on their physicians to make decisions on their behalf.^{2,6,10-15}

Ideally, physicians should offer patients the opportunity to participate by sharing responsibility and actively engaging patients in the process of making decisions. Physicians require accurate information regarding individual patients' preferences in order to achieve this goal and to avoid inaccurate or biased assumptions about the patient's wishes. In addition, understanding the range and distribution of preferences in a population is important to health care organizations seeking to tailor patient education and health promotion programs appropriately.

Questions about patient preferences remain unanswered. How much do people embrace the collaborative model? Are there demographic and sociocultural differences associated with such preferences? Studies to date offer conflicting answers¹⁵⁻¹⁸ due to small study populations, the methods used to measure preferences,^{3,19} and the specific medical condition considered.

We designed a population-based study to better understand public preferences for participation in decision making and sociodemographic characteristics associated with these preferences. A nationally representative sample of U.S. households was utilized to assess preferences making highly generalizable population-based analyses possible.

METHODS

The General Social Survey

The General Social Survey (GSS) is a biennial probability sample of all English-speaking persons 18 years of age or older, living in U.S. households. The GSS is conducted by the National Opinion Research Center (NORC) and is the largest sociology project funded since 1973 by the National Science Foundation. In the survey, 1 respondent is selected per target household, so that the probability of selection is proportional to the number of adults in the household. The survey is conducted in face-to-face interviews that last approximately 90 minutes. Respondents are limited to English-speaking adults. Our study included specific survey questions added to the 2002 GSS. The NORC ethics board approved the study.

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Measures of Preferences for Participation in Decision Making

In order to measure preferences, we reviewed models of decision making including work by Charles et al.^{4,5} and Deber et al.^{12,13,20} Our goal was to use items to measure different aspects of participation in decision making and where possible to incorporate measures of patient preferences developed by other investigators.^{21–26} This included items pertinent to seeking and exchanging information (sometimes called problem solving) and items related to discussing options in making decisions (aspects of decision making). In order to select a small number of items for our final questionnaire, we pilot tested items previously developed. These items were modified based on extensive cognitive testing of a pilot questionnaire and feedback from respondents regarding clarity of wording and full understanding of the underlying concept.

The resulting 3 questionnaire items comprised the following statements: “I prefer to rely on my doctor’s knowledge and not try to find out about my condition on my own” (Knowledge); “I prefer that my doctor offers me choices and asks my opinion” (Options); and “I prefer to leave decisions about my medical care up to my doctor” (Decision). Respondents were asked to rate each item on a 6-point scale ranging from “strongly agree” (1) to “strongly disagree” (6) with categories for moderate and slight agreement or disagreement between the anchors.

Statistical Methods

Effects of demographic characteristics on preferences were assessed using proportional odds regression models. Also known as ordered logistic regression models, the analyses could take into account the ordered categories of responses ranging from strongly agree to strongly disagree. For purposes of analysis, the Options score was reverse coded (Option R) such that responses with larger numerical values correspond to increasingly patient-directed preferences for the 3 participation scores. Age was expressed in decades centered at 45 years to increase interpretability of regression coefficients. Correlations among the 3 scores were assessed using Spearman’s rank-order correlation coefficient. We conducted a range of sensitivity analyses to ensure that conclusions were not dependent upon the specific statistical model selected. Because the GSS samples households rather than individuals, we employed survey weights that reflected the number of adults in each household sampled in the ordered logistic analyses. Because full probability sampling with predesignated respondents is used in the GSS, these survey weights fully account for the survey design in our statistical analyses.²⁷ All computations were performed using Stata statistical software (Stata Corporation, College Station, TX).

RESULTS

The 2002 GSS had a 70.1% response rate. The final sample included 2,750 respondents, 56% of whom were female, with an average of 46 years old (Table 1). The sample included 14.5% African-American and 7.3% Hispanic respondents. Overall, approximately 14% had less than a high school education, 54% had finished high school, and 32% had more than a high school level of education.

Table 2 details the distribution of responses to the 3 participation questions. Of note is that virtually all respondents

Table 1. Demographics

| | |
|------------------------------------|-------------|
| Number (N) | 2,765 |
| Mean age, y (SD) | 46.3 (17.4) |
| Female, % | 55.6 |
| African-American, % | 14.5 |
| Hispanic, % | 7.3 |
| Has health coverage, % | 86.6 |
| Has regular doctor, % | 83.3 |
| Saw regular doctor in last year, % | 83.3 |
| Education, % | |
| <High school | 14.5 |
| High school | 53.8 |
| >High school | 31.7 |
| Self-rated health, % | |
| Excellent | 26.2 |
| Very good | 28.1 |
| Good | 28.7 |
| Fair | 13.4 |
| Poor | 3.6 |

(96%) answered positively when asked whether they prefer to be offered choices and to be asked their opinions by their doctors (Options). Further, 72% of those respondents felt strongly about this preference. In contrast, there were substantial differences in the degree to which individuals wanted to rely on their doctors for information (Knowledge) and for making the decisions about care (Decisions). An almost equal number of respondents favored physician-directed as favored patient-directed answers. Fifty-two percent preferred to leave final decisions to their physicians and 44% preferred to rely on physicians for medical knowledge rather than seeking their own information. Whereas Knowledge and Decision were positively correlated (Spearman rank 0.52), each was negatively correlated (approximately -0.18) with the Options score. This suggests that preference for participation in medical decisions is not a single-dimensional construct, but may instead, like the Charles model, consist of 3 distinct components: options, knowledge, and decisions.

The distribution of responses was virtually identical across income categories. The preferences of individuals with and without health insurance did not differ after controlling for other demographic features and were therefore omitted from subsequent analyses.

Table 3 shows the results from the final multivariate models in the form of odds ratios for the independent effects of age, gender, race, or ethnicity, education, health status, and access to a regular doctor. The Options preference did not differ by educational attainment. However, preferences for both Knowledge and Decision became more patient directed as level of

Table 2. Preferences for Participation in Decision Making

| | Knowledge (%) | Options (%) | Decision (%) |
|---------------------|---------------|-------------|--------------|
| Strongly agree | 421 (15) | 1,986 (72) | 394 (14) |
| Moderately agree | 453 (16) | 521 (19) | 638 (23) |
| Slightly agree | 345 (13) | 145 (5) | 412 (15) |
| Slightly disagree | 399 (15) | 43 (2) | 361 (13) |
| Moderately disagree | 413 (15) | 31 (1) | 378 (14) |
| Strongly disagree | 715 (26) | 19 (1) | 562 (20) |
| Total | 2,746 (100) | 2,745 (100) | 2,745 (100) |

Knowledge, options, and decision denote the 3 questions asked about preferences concerning aspects of decision making. The exact wording of each question is given in the text.

Table 3. Ordered Logistic Regression Models Fit to Demographic Characteristics

| | | Knowledge | P Value | Option | P Value | Decision | P Value |
|--------------------|--------------|-----------|---------|--------|---------|----------|---------|
| Age (decades) | | 0.95 | | 0.99 | .752 | 0.95 | .06 |
| Age squared | | 0.91 | <.001 | 0.95 | .003 | 0.92 | <.001 |
| Female | | 1.75 | <.001 | 1.68 | <.001 | 1.53 | <.001 |
| Race/ethnicity | White | 1.00 | | 1.00 | | 1.00 | |
| | Black | 1.06 | .671 | 0.99 | .974 | 0.68 | .003 |
| | Hispanic | 0.59 | .001 | 0.84 | .373 | 0.67 | .016 |
| | <High school | 0.66 | .005 | 0.98 | .884 | 0.74 | .039 |
| Education | High school | 1.00 | | 1.00 | | 1.00 | |
| | >High school | 1.63 | <.001 | 0.97 | .771 | 1.44 | <.001 |
| Has regular doctor | | 0.75 | .009 | 0.93 | .635 | 0.66 | <.001 |
| Health status | Excellent | 1.00 | | 1.00 | | 1.00 | |
| | Very good | 0.76 | .013 | 0.72 | .027 | 0.72 | .003 |
| | Good | 0.78 | .031 | 0.72 | .027 | 0.72 | .003 |
| | Fair | 0.80 | .121 | 0.69 | .040 | 0.89 | .449 |
| | Poor | 0.74 | .278 | 0.36 | .001 | 0.55 | .035 |

Table gives adjusted odds ratio. Age and age squared are linear and quadratic terms for age measured in decades and centered at 45 years. "Has regular doctor" indicates whether the respondent reported having a regular doctor or clinic.

educational attainment increased. For example, the adjusted odds ratio for Decision was 0.74 for those with less than a high school education and 1.4 for those with greater than high school education, compared to the reference group of high school education.

Women were more likely than men to prefer a patient-directed approach across all 3 dimensions (adjusted odds ratio 1.75 for Knowledge, 1.68 for Option, and 1.53 for Decision). Hispanic respondents were more likely than African-American or white respondents to give physician-directed responses to the question about Knowledge (adjusted odds ratio 0.59), and both Hispanics and African Americans were more likely than whites to prefer leaving decisions about medical care up to their doctors (adjusted odds ratio 0.67 and 0.68, respectively).

Those who reported their health as generally excellent expressed greater preference for self-reliance in obtaining medical information than those who did not rate their health as highly. A similar pattern was seen for both Options and Decision. Notably, those who reported their health to be poor preferred a more physician-directed approach than those in the intermediate categories of very good, good, and fair. Compared to those with excellent health, the adjusted odds ratios for Knowledge, Options, and Decision were 0.74, 0.36, and 0.55, respectively, for those in poor health. Individuals with a regular doctor (83%) tended to prefer reliance on the physician for medical knowledge and for making decisions, but they were not different with respect to Options.

An age effect was apparent on all 3 questions. In our cross-sectional sample, preferences became increasingly patient oriented up to a maximum at approximately 45 years. With increased age thereafter, preferences became more physician oriented. From the most patient-directed point at age 45, preferences shift almost an entire point on the 5-point scale by age 85 toward physician-directed decisions. A similar pattern described the relationship between age and the variables of Knowledge and Options.

DISCUSSION

In *Crossing the Quality Chasm*,¹ the Institute of Medicine recognized that some patients may not want to be active participants. At the same time, however, the report encourages

physicians to engage patients in clinical decision making. These recommendations are consistent with ethical principles and with state laws requiring discussion of possible treatment options with patients.^{28,29} Despite the ethical and legal proscriptions, our study revealed wide variation in preferences for participation in decision making within a nationally represented sample of the English-speaking U.S. population. We found that approximately half of respondents preferred to rely on physicians for information about their condition and half preferred to leave final treatment decisions up to the doctor. This is consistent with the findings of Deber et al.,^{12,13,20} who found that the majority of patients wished physicians to do the "problem-solving tasks," which include using information to make a diagnosis. The findings are also consistent with the "paternalistic model" identified by Charles et al.,^{4,5} in which patients rely on physicians to make treatment decisions rather than using a more collaborative process. Our finding that roughly half this representative sample prefers a physician-directed approach makes it imperative for physicians to be aware of the views and preferences of individuals so they can tailor care. While a collaborative model of decision making is popular and may be desirable, it is by no means universally held by the public.

In contrast, the vast majority of people want to discuss options and share their opinions about treatment with physicians. During discussions about options, patients can clarify their views and can share their personal reflections about the advantages and disadvantages of treatment approaches. This deliberation is a bilateral interaction in which physician and patient weigh the choices in light of an individual patient's wishes, desires, and personal circumstances.^{4,5} Our findings support the idea that this component of decision making is widely valued by patients.

We also evaluated the demographic characteristics associated with decision-making preferences. Our statistically representative sampling design makes this a robust component of our study and offers new information beyond previous smaller and narrower samples of patients. Compared to men, a greater percentage of women in our study preferred active involvement in all aspects of decision making. This is consistent with other studies of decision making³⁰ and with evidence that women are more likely to prefer a collaborative style of communication with their physicians by assuming an active role in the process

of their health care.³¹⁻³³ For example, women will come to physicians' offices prepared with medical information sought and gained through alternate sources such as the Internet.³⁴ Our data are also consistent with the finding that women are often the health advocates for the members of their family.³⁵

There was a greater preference to delegate decisions about treatment to physicians among African-American and Hispanic respondents than among white respondents. This is particularly relevant given evidence of racial disparities in health care.³⁶⁻⁴² While it is unclear why these disparities exist, van Ryn suggested that physician behaviors might contribute to the disparities through their beliefs about patients' expectations,^{38,43} interpretation of patients' symptoms,⁴⁴ interpersonal behavior, and clinical decision making with different racial groups. Cooper-Patrick et al. suggested that physicians may engage African-American patients' participation in decision making to a lesser extent than white patients.⁴⁵ Patients may also contribute to the disparities due to literacy barriers, different styles of communication, or differences in self-efficacy in managing their health.⁴⁶ While the factors underlying racial disparities are complex and multifactorial, we found that members of racial minority groups are more likely to prefer a physician-directed style even when controlling for socioeconomic status and education. It is possible that this preference may contribute to the observed racial differences in the management of clinical conditions.

Our study found that older people tend to prefer a physician-directed style of care, independent of health status. A recent survey of 1,500 primary care patients in Sweden also found that older patients were more likely to defer to physicians for decisions about treatment independent of the presence of chronic illness.⁴⁶ While prior studies have suggested this pattern,^{17,30,35,46,47} limitations in study designs have confounded age-related decline in health with preferences for a physician-directed style.

Further, we found that a shift in preference toward a physician-directed style begins after 45 years of age. This shift may be due to changing beliefs and attitudes toward health care associated with aging or it may be a cohort effect.^{46,48,49} With regard to the latter, it is possible that "baby boomers," now in their early fifties, will differ from the trend we have found here: they may want a more active participatory style of care when they are older. Certainly the boomers are more highly educated health care consumers than the present older generation.

In addition, we found that respondents in poorer health markedly preferred a physician-directed style of decision making. This is intriguing because one might argue that it is most important for patients to be actively involved in making decisions when they are ill and confronted with treatment choices.^{20,50} Patients who are knowledgeable about their condition(s),^{8,51-53} actively participate in their care,⁵⁴⁻⁵⁸ or are involved in decision making^{20,59} enjoy improved health outcomes. Perhaps those who are ill may feel more dependent on trusted professionals to whom they wish to relinquish control.¹⁵ In light of our results, and in contrast to current recommendations, physicians may need to assume responsibility for making serious and life-determining decisions on behalf of frail patients, particularly those without family members to advocate on their behalf.

Our study has several limitations. The cross-sectional design precludes delineation of the age correlation with prefer-

ences due to a cohort or longitudinal effect. Similarly, we cannot determine whether people who become ill change their attitudes about decision making from their previous baseline views. The respondents in our study included only English-speaking adults and hence we cannot generalize our findings to the non-English-speaking population. However, it is likely that some of the same effects we found related to race and ethnicity may be present in the non-English-speaking population as well. Last, while the Options question performed well in pilot testing, it was less useful in the final sample due to the highly skewed response.

This study of a representative sample of the English-speaking U.S. population provides compelling evidence that members of the public vary in preferences for seeking medical knowledge and making medical decisions. It underscores the fact that it is imperative for physicians to assess the needs of individual patients and understand the role each patient wishes to play in his or her care. Given the potential benefits of active involvement, encouraging patients to participate in their own care seems appropriate. Our study design provides insights into understanding the preferences of the public at large and is thus a significant advance over research based on smaller, non-population-based samples. While the preferences of each individual patient is paramount, understanding population preference patterns may help physicians and health care organizations develop better educational programs for their specific patient populations.

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