Clinical Factors That Influence Patients’ Desire for Participation in Decisions About Illness

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Background: Clinical practice often fails to optimize patient participation in decisions about serious illness. Prior studies are unclear about whether the type of decision and prior illness experience affect the patient’s preferences for participation in decision making. Most studies of patient decision making have not addressed decisions about serious illness.

Objective: To determine whether the type of illness and nature of the decision predict the patient’s preferences for involvement in making decisions.

Design: Study of randomly selected patients’ responses to vignettes about cancer, acute myocardial infarction, and diabetes coupled with cross-sectional survey and chart review.

Setting: Outpatient Veterans Affairs medical clinic.

Patients: A total of 255 patients with a mean age of 63.2 years (95.2% male; 61.9% married).

Main Results: Patients wanted to share hypothesized major decisions with their physicians (mean score, 2.9; 1=only physician, 5=only patient) but wanted less involvement in hypothesized minor decisions (mean score, 2.5). Patients with recent severe heart disease (myocardial infarction, bypass surgery, angioplasty) wanted more involvement in decisions about acute myocardial infarction than did patients with stable angina or no heart disease; prior experience with diabetes did not affect decisions about diabetes. Factor analysis of the vignette items yielded 3 types of decisions that we consider to reflect major, minor, and patient behavior decisions. Mean scores were 2.9 for major decisions, 2.1 for minor decisions, and 2.7 for patient behavior decisions.

Conclusions: Patients want to share in major decisions with their physicians but prefer to be less involved in minor decisions. For some illnesses, such as myocardial infarction, prior experience with the illness increases the patients’ desire for participation in decision making.

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Recently, healthcare practitioners have tried to promote patient autonomy and participation in clinical decision making. Active patient participation in decision making has been associated with improved outcomes for various diseases. Patient participation in decisions about serious illness is an ideal that has been difficult to realize in clinical practice. Studies have documented the low prevalence of advance directives in the adult population. Randomized trials of interventions to increase patient participation in making decisions about their health care indicate that these interventions improved functional status or psychological health.

However, studies also show that patients prefer that the physician have most of the control over decisions. This suggests that we need to better understand barriers to patient participation in decision making to improve patient participation in decision making.

There is evidence that patients’ preferences for involvement in medical decisions relate to the nature of the decisions, type of illness, and illness severity. Several scenario-based studies show that if the type of illness is more severe, the patients’ desire for participation in decision making declines. One study notes that most patients want their physicians to perform problem solving but many patients also want to participate in decisions. Furthermore, some studies have found that patients with cancer desire active participation in illness decisions, especially for major decisions such as do-not-resuscitate orders. A few studies have also found that patients with more severe illness and more chronic illnesses are more likely to have an advance directive.

To clarify the relationship among the type of illness, severity, and patient pref-
PARTICIPANTS AND METHODS

DESIGN

We performed a study comparing patients’ responses to written vignettes coupled with a cross-sectional survey and chart review.

SETTING AND PATIENT SAMPLE

We selected medical outpatients of a Veterans Affairs (VA) medical clinic by randomly sampling from the computerized appointment list. Patients 50 years or younger were oversampled by a factor of 3 to obtain adequate numbers for subgroup analyses. The VA clinic was attached to a chronic care VA hospital located in a suburban setting that cared for a large psychiatric patient population. The physicians staffing the clinic included 16 full-time VA physicians, including an author of this report (D.M.). The sample was drawn from appointments scheduled between April 1991 and October 1991. The study was approved by the institutional review board of the VA hospital.

Patients were approached at the time of their clinic visits and asked to complete the study instrument, which was embedded in an end-of-life survey. The survey was pilot tested with 15 patients. Participants were interviewed by a clinician. The clinician explained the meaning of advance directives, then conversed with the patient about the definitions of living will and durable power of attorney. If the patient was able to comprehend these definitions, the patient was deemed competent for the study. Incompetent patients were excluded, as were those specifically with schizophrenia or schizoaffective disorder, but patients with other psychiatric illnesses, including major depression, bipolar disorder, substance abuse, and panic disorder, were eligible for the survey if they were competent. The survey was mailed to patients who were missed by the survey or at their clinic visit or who did not keep their appointment if addresses were available and if patients were not currently hospitalized. Reading level was not assessed.

Of the 637 patients originally selected to be in the random sample, 13 were excluded because they were incompetent or schizophrenic, 3 because they had died, 4 because they were inpatients, and 1 because he had participated in the pilot study. Twenty-three patients were excluded at the time of the mailed survey because they had moved and had no forwarding address. Thus, 391 patients were eligible for the study; of these, 67 patients refused, 7 agreed to chart audits but did not complete the survey, 3 returned surveys with more than 50% of questions unanswered, 1 returned a complete survey with no name, and 1 returned the survey a year late. Two completed surveys were lost, and 255 patients failed to respond, leaving 255 patients who completed the survey. The response rate for those who were approached in clinic was 63.5%. The response rate for all eligible patients who kept their clinic appointment (whether approached or not) was 50.9%, and the overall response rate to both the in-clinic and mailed surveys was 43.2%.

INSTRUMENT

The patients were presented 3 vignettes about cancer, acute MI, and diabetes. Each vignette describes a hypothetical acute clinical situation and asks a series of questions about different decisions related to that situation and who should make the decisions.

Cancer Vignette

Suppose that you have colon cancer. You undergo surgery to remove the cancer but are told after the operation that some cancer is left. Your doctor tells you that you have a few years to live without additional treatment. He also tells you that you are not likely to have symptoms from the cancer for the next two years. He then suggests that you consider experimental chemotherapy or radiation therapy.

Who should make the following decisions?
1. Whether you have blood tests to measure chemicals made by the cancer.
2. Whether you have radiation therapy (high dose x-rays to kill the tumor), which may give you diarrhea, abdominal pain, and decreased appetite.
3. Whether you have experimental chemotherapy (strong drugs which kill the cancer cells but also kill normal cells). Chemotherapy may cause hair loss, vomiting, extreme weakness, and require more time in the hospital.
4. Whether you need hospice care if the radiation therapy and the chemotherapy fail to kill the cancer. Hospice will try to keep you comfortable at home and free of pain as your cancer spreads, and will give you and your family emotional support.

The demographic characteristics of the patients are shown in Table 1. The patients were predominantly white and male, with a mean age of 63.2 years. Of the patients, 61.9% were married; 55.0% had a high school education or less; and 67.0% had an annual income of less than $20000 in 1991. The mean illness severity score was 4; patients had a mean total of 3.5 illnesses with a mean within-illness severity of 1.1. Almost all the patients had a prior serious illness, that is, they had been hospitalized, been in an intensive care unit, had ventilatory support, or had survived cardiopulmonary resuscitation in the past.


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5. Whether you have more surgery, which will leave you with a hole in your abdomen that drains stool into a bag.
6. Whether you are put on a respirator (breathing machine) if the cancer spreads to your lungs and you cannot breathe on your own.

**Acute MI Vignette**

Suppose you have an attack of severe chest pain that lasts for almost an hour, frightening you enough so that you go to the emergency room. In the emergency room, the doctors discover that you have a heart attack. Your own doctor is called, and you are taken up to the intensive care unit. Who should make the following decisions?
1. Whether you are put on strict bed rest.
2. Whether you have a heart monitor to show how your heart is beating.
3. Whether you have a temporary pacemaker put in for slow heart beats.
4. Whether you have open heart surgery to prevent further heart attacks.
5. Whether you stop smoking after the heart attack.
6. Whether you start an exercise program after you get out of the hospital.

**Diabetes Vignette**

Suppose that you have diabetes. You have been taking insulin shots for the past 5 years, but you do not check your blood sugar on a regular basis. When you see your doctor for a checkup, he finds that your blood sugar is extremely high. Who should make the following decisions?

1. Whether you are admitted to the hospital for treatment.
2. Whether you check your blood sugar 4 times a day.
3. Whether your insulin dose is increased.
4. Whether you start a strict diet to lose weight.
5. Whether you get special shoes to protect your feet.
6. Whether you have your foot amputated if you develop gangrene.

The response set for each question was a 5-point Likert scale that ranged from 1 (only your physician) to 5 (only you). Patients were also asked about prior serious illnesses that affected them, their spouses, other family members, and friends. Prior serious illness was defined as one requiring hospitalization, admission to an intensive care unit, ventilatory support, or cardiopulmonary resuscitation. Demographic characteristics were assessed by patient self-report.

Chart audits were performed by a clinician using a predetermined protocol to assess the severity of comorbid illness at the time the survey was done. This severity method was modeled after methodology for ambulatory case mix described by Greenfield et al. The audits tabulated the presence of several chronic illnesses (hypertension, diabetes, coronary heart disease, congestive heart failure, cancer, gastrointestinal disease, neurologic disease, chronic lung disease, psychiatric disease, peripheral vascular disease, renal or genitourinary disease, rheumatologic disease, acquired immunodeficiency syndrome, and other illnesses) and scaled each illness’s severity from 0 to 2, where 0 indicated none, 1 indicated mild to moderate, and 2 indicated severe. Hypertension was scaled from 0 to 1 because its complications, stroke, coronary heart disease, congestive heart failure, and renal disease, were coded separately in the other categories. Coronary heart disease was classified as mild to moderate if the patient had angina or a history of MI and as severe if the patient had an MI, coronary bypass surgery, or an angioplasty within the past 6 months. Cancer was classified as mild to moderate if the patient had cancer in remission and as severe if the patient had active disease or was terminal. Diabetes was classified as severe if the patient had retinopathy, neuropathy, or nephropathy; all other types of diabetes were classified as mild to moderate. Comorbid illness severity was the simple sum of each of the individual illness severity scores.

**ANALYSES**

All statistical analyses were done using SAS statistical software (SAS Institute Inc, Cary, NC). Univariate associations were examined with Pearson product moment correlations and t tests for continuous variables and Mantel-Haenszel χ² test for categorical variables. For comparisons of 2 groups of continuous variables, t tests were used. Paired t tests were used to compare means for the same individual. Factor analyses on the vignette items were performed using the varimax rotation. For comparisons of continuous variables by 3 groups, analysis of variance was used. Analysis of covariance was used to adjust for covariables such as age, education, and marital status. All analyses were weighted to adjust for the oversampling of younger patients. All reported P values are 2-tailed.

**Table 2** shows mean participation scores for each decision for each type of illness; scores approximated a normal distribution. For the colon cancer vignette, in general, patients preferred to share responsibility with their physician about most of the decisions, although they preferred somewhat more physician control over laboratory testing. In the MI vignette, the patients preferred that physicians make decisions about bed rest and telemetry but wanted more control over decisions about smoking and exercise. For diabetes, in general, the patients preferred that the physician have more control over most decisions, although they wanted relatively more control over diet and foot amputation.

To test our study hypothesis that patients preferred more physician control for major as opposed to minor decisions, we classified each individual decision regarding an intervention as major or minor, then compared the scores for each type of decision. Major intervention decisions were radiation, chemotherapy, colostomy, and respirator use in the cancer vignette, temporary pacemaker and bypass surgery in the MI vignette, and foot amputation in the diabetes vignette. All others were minor. The mean (SD) participation score for major decisions was 2.9 (0.8); the mean (SD) score for minor decisions was 2.5 (0.6) (1 = only physician, 5 = only you; P < .001). Frequency distributions for the major and minor decisions are shown in **Figure 1**. Patients preferred to be more involved in making major decisions than minor. This finding was counter to our original hypothe-
Table 1. Characteristics of 255 Patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD, y</td>
<td>63.2 ± 10.5</td>
</tr>
<tr>
<td>Sex, % male</td>
<td>95.2</td>
</tr>
<tr>
<td>Race, % white</td>
<td>97.1</td>
</tr>
<tr>
<td>Marital status, %</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>61.9</td>
</tr>
<tr>
<td>Widowed</td>
<td>7.5</td>
</tr>
<tr>
<td>Divorced or separated</td>
<td>22.7</td>
</tr>
<tr>
<td>Never married</td>
<td>7.9</td>
</tr>
<tr>
<td>Education ≥ high school, %</td>
<td>55.0</td>
</tr>
<tr>
<td>Annual income of &lt;$20'000, %</td>
<td>67.0</td>
</tr>
<tr>
<td>No. of illnesses, mean ± SD</td>
<td>3.5 ± 1.6</td>
</tr>
<tr>
<td>Severity within illness,* mean ± SD</td>
<td>1.1 ± 0.2</td>
</tr>
<tr>
<td>Overall illness severity,* mean ± SD</td>
<td>4.0 ± 2.0</td>
</tr>
<tr>
<td>Psychiatric illness, %</td>
<td>42.0</td>
</tr>
<tr>
<td>Prior serious illness, %</td>
<td>92.0</td>
</tr>
</tbody>
</table>

*Severity for a single comorbidity (range, 0-2).
†Sum of each individual illness severity score.

Table 2. Vignette Decisions*

<table>
<thead>
<tr>
<th>Decision (n)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td></td>
</tr>
<tr>
<td>Laboratory test (247)</td>
<td>2.89 (0.99)</td>
</tr>
<tr>
<td>Radiation therapy (244)</td>
<td>3.09 (0.96)</td>
</tr>
<tr>
<td>Chemotherapy (245)</td>
<td>3.23 (0.96)</td>
</tr>
<tr>
<td>Hospice (246)</td>
<td>3.24 (0.88)</td>
</tr>
<tr>
<td>Colostomy (248)</td>
<td>3.29 (0.96)</td>
</tr>
<tr>
<td>Respirator (248)</td>
<td>3.27 (1.07)</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td></td>
</tr>
<tr>
<td>Bed rest (249)</td>
<td>2.07 (0.93)</td>
</tr>
<tr>
<td>Telemetry (249)</td>
<td>1.97 (0.85)</td>
</tr>
<tr>
<td>Temporary pacemaker (249)</td>
<td>2.45 (0.90)</td>
</tr>
<tr>
<td>Coronary artery bypass graft (249)</td>
<td>2.88 (0.95)</td>
</tr>
<tr>
<td>Stop smoking (229)</td>
<td>3.42 (1.22)</td>
</tr>
<tr>
<td>Exercise (249)</td>
<td>2.94 (0.99)</td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
</tr>
<tr>
<td>Hospitalized (249)</td>
<td>2.32 (0.89)</td>
</tr>
<tr>
<td>Check blood glucose 4 times daily (248)</td>
<td>2.54 (1.08)</td>
</tr>
<tr>
<td>Increase insulin (247)</td>
<td>1.88 (0.83)</td>
</tr>
<tr>
<td>Diet (249)</td>
<td>2.73 (0.92)</td>
</tr>
<tr>
<td>Special shoes (248)</td>
<td>2.63 (0.93)</td>
</tr>
<tr>
<td>Foot amputated (249)</td>
<td>2.67 (0.99)</td>
</tr>
</tbody>
</table>

*Decisions were based on a 5-point scale: 1 indicates “only your doctor”; 3, “you and your doctor”; and 5, “only you.”

coronary heart disease, and amputation for diabetes. Factor 2 included, for coronary heart disease, bed rest and telemetry, and for diabetes, hospitalization, adjustment of insulin, and checking glucose level by fingerstick. Factor 3 included, for coronary heart disease, stopping smoking and exercising, and for diabetes, hospitalization, checking glucose level by fingerstick, using special shoes, and adopting a diet. Thus, factor 1 included all the interventions that we initially hypothesized were major but also included laboratory tests and hospice care from the cancer vignette. Factor 2 included what seem to be more minor decisions, and factor 3 included decisions about patient behavior or more long-term decisions.

Each factor grouping had good internal consistency reliability, with Cronbach α equal to .92 for factor 1, .80 for factor 2, and .82 for factor 3. The mean (SD) participation scores as defined by factor analysis were 2.9 (0.8) for factor 1 (major decisions), 2.1 (0.7) for factor 2 (minor decisions), and 2.7 (0.7) for factor 3 (patient behavior decisions) (P < .001). Frequency distributions for these 3 scores are shown in Figure 2. Most patients preferred to make factor 1 decisions jointly with their physician. They also preferred joint decisions about patient behavior. However, patients preferred that the physician make factor 2 decisions, which appear to be minor and do not involve patient behavior.

Next we examined whether prior experience with a particular illness affected the individual patient’s responses. (We were unable to determine whether having cancer affected relevant decisions because there were only 2 patients in our study who had active disease.) The 6 individual responses for acute MI and for diabetes were averaged separately. Each average response was used as a dependent variable in an analysis of variance. The severity of each patient with coronary heart disease and diabetes were included as independent variables in the analyses for the corresponding vignette. The severity of the patients’ diabetes did not affect desire for input into future decisions.
in diabetes. However, patients with severe heart disease desired more personal input into decisions about a future acute MI in the coronary heart disease vignette than did those with no or mild-to-moderate heart disease (overall P < .05). The mean decision-making scores were 3.1 for those with severe heart disease, 2.5 for those with mild-to-moderate heart disease, and 2.6 for those without heart disease. The effects of severity of actual chronic heart disease on desire for input into future treatment decisions persisted after adjusting for age, marital status, and education. Adjustments for age, marital status, and education did not change the lack of effect from diabetes on desire for input into decisions about diabetes.

Additional analyses showed no effect of comorbid illness severity or preexisting psychiatric illness on patients’ desire for decision making. Our study population had a high prevalence of psychiatric illness, but we did exclude patients with schizophrenia and schizoaffective disorder, the most severe psychiatric patients. Our findings do suggest that depression and anxiety do not affect patients’ desire for decision making.

Our study found that patients preferred to have more input into decisions about major interventions than for decisions about minor interventions for MI and diabetes. Prior studies that used the Autonomy Preference Index (API) showed the opposite, that is, patients desired less involvement in decisions about more severe illness. However, the range of illnesses and decisions addressed by these prior studies was constricted. They addressed fairly minor illnesses, such as upper respiratory tract infection and hypertension, or minor decisions about major illnesses, eg, taking vital signs, allowing visitors, and performing cardiology consultation for MI. They did not assess decisions about major interventions such as temporary pacemaker placement and coronary artery bypass grafting. One study that presented acute illness scenarios to patients found that for most illnesses the patients wanted to discuss the situation with their physician but have the physician make the decision; the patients did want more control over the decision about terminal cancer. That study examined only 1 intervention for each acute illness and did not compare interventions within each illness or types of intervention across illness.

In our study, post hoc factor analysis suggested that decisions could be classified into 3 types: factor 1 (major decisions), factor 2 (minor decisions), and factor 3 (patient behavior decisions). Patients wanted more control over decisions about interventions that appeared major than over interventions that appeared minor. We are somewhat puzzled that laboratory tests from the cancer vignette were grouped with what appear to be major decisions in the factor analysis. Perhaps patients so fear cancer that they want to participate in all decisions about care for cancer and factor 1 is a “fear” factor. Although we considered decisions about procedures such as smoking cessation and diet modification to be minor, the exploratory factor analysis suggested that patients viewed these decisions as distinct from decisions about bed rest and telemetry. The patients preferred to share decision making with the physician for decisions about altering their own behaviors, such as smoking, diet, and exercise. This seems logical. After all, the patient must carry out any modification of his or her own behavior.

We also found some partial support for our hypothesis that prior experience with an illness would affect the patient’s preferences for decision making about future acute episodes of that illness. Patients who had a recent MI, coronary artery bypass graft, or angioplasty wanted more involvement in decisions about acute MI than patients with stable coronary artery disease or no heart disease. On the other hand, patients with chronic diabetes wanted about the same involvement in many decisions about extreme hyperglycemia than did patients without diabetes. A previous study found that patients with hypertension had no more desire for control over decisions about taking medication for hypertension than did patients without hypertension. However, many patients may view acute MI and diabetes as much more severe illnesses than hypertension, and some of the interventions we studied may have more of an impact on the patients’ lifestyle than would taking medication. A larger study could more clearly define the role of prior experience with an illness on a patient’s desire to participate in decision making.

Physicians should provide opportunities for patient involvement in decisions about serious illness be-
cause many patients want to participate in those particular decisions. Also, prior studies have documented better outcomes when patients are encouraged to participate in decisions about their care.\textsuperscript{2,6-10} Although most of these studies have focused on less severe illnesses, increased patient control may also improve outcomes of serious illnesses.\textsuperscript{8,22-23} Interventions to encourage active patient participation in decisions about serious illness are likely to improve the patient's functional status and psychological health. The physician's role may include providing information about the illness, discussing risks and benefits of various therapies with the patient, and then honoring the patient's choice.\textsuperscript{15}

The limitations of our study need to be recognized. Our study population was predominantly white and male, so our results may not be generalizable to women and minorities. Most studies have found no differences between the sexes in desire for autonomy, although one study\textsuperscript{23} of physician-patient communication did find that women participate more in discussions than men. Other studies\textsuperscript{24,25} did find differences between ethnic groups. However, our patients' scores on the API were within range of other populations that have examined aspects of physician-patient decision making with the API.\textsuperscript{11-13,15} This suggests that our study results may be generalizable to other populations.

There may be differences between responders and nonresponders to the study. We were unable to interview the people who refused or failed to respond, but respondents were comparable to veterans who use the VA clinics in Boston, Mass. In the Veterans Health Study, outpatients at Boston area VA facilities had a mean age of 62 years; 58% were married, and 58% had a high school education or less.\textsuperscript{30} Finally, our study presents hypothetical vignettes that may not correspond to a patient's action in real-life situations.

Patients appear to approach medical decisions differently according to the nature of the illness, the illness that it addresses, and their prior experience with that illness. Patients in particular may view decisions about their own health behaviors differently from decisions about interventions prescribed by their physicians and logically want to share control over those decisions. Prior experience with some illnesses, such as an acute MI, may make patients want more involvement in future decisions about that particular illness.

Physicians need to include patients in decision making, especially for severe illness and decisions about major interventions. Although patients want their physicians to be involved in the decisions, almost all patients want at least some personal involvement in decision making for major interventions. Efforts to increase patient involvement in decisions are congruent with patient preferences. Encouraging patient participation in decisions about serious illness may improve the quality of the patient's life.

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