

Patients' Preferences for Risk Disclosure and Role in Decision Making for Invasive Medical Procedures

Dennis J. Mazur, MD, PhD, David H. Hickam, MD, MPH

OBJECTIVE: To assess the level of involvement patients want in decision making related to the acceptance or rejection of an invasive medical intervention and whether their preference for decision making is related to their preference for qualitative (verbal) or quantitative (numeric) information about the risks of the procedure.

SETTING: A university-based Department of Veterans Affairs Medical Center.

DESIGN: Cross-sectional study using structured interviews of consecutive patients seen for continuity care visits in a general medicine clinic.

PATIENTS: Four hundred and sixty-seven consecutive patients with a mean age of 65.2 years (SD 10.70 years, range 31–88 years) and with a mean of 12.6 years (SD 2.96 years, range 0–24 years) of formal education.

MEASUREMENTS AND MAIN RESULTS: In the context of an invasive diagnostic or therapeutic intervention, patients were asked whether they preferred patient-based, physician-based, or shared patient-physician decision making. Patients were asked to give the ratio of patient-to-physician decision making they preferred, and whether they preferred discussions using words, numbers, or both. Of 467 subjects, 318 (68%) preferred shared decision making; 100 (21.4%) preferred physician-based decision making; and 49 (10.5%) preferred patient-based decision making. In terms of risk disclosure, 436 (93.4%) preferred that their physician disclose risk information to them. Of these 436 patients, 42.7% preferred disclosure of information about the probability of adverse outcomes using qualitative (verbal) expressions of probability; 35.7% preferred disclosure in terms of quantitative (numeric) expressions of probability; and 9.8% preferred disclosure in both qualitative and quantitative terms. Younger patients (odds ratio [OR] 0.96; confidence interval [CI] 0.93, 0.99), patients who had at least one stroke (OR 3.03; CI 1.03, 8.90), and patients who preferred to discuss risk information with their physicians in terms of numbers (OR 2.39; CI 1.40, 4.06) tended to prefer patient-based or shared decision making.

CONCLUSIONS: Male veterans consistently preferred shared patient-physician decision making in the context of invasive medical interventions.

KEY WORDS: informed consent; medical decision making; patient-physician communication; pharmaceutical industry; medical devices and products.

J GEN INTERN MED 1997;12:114–117.

Received from the Medical Service and Health Services Research and Development Program, Department of Veterans Affairs Medical Center, Oregon Health Sciences University, Portland.

Address correspondence and reprint requests to Dr. Mazur: Medical Service (111-P), Department of Veterans Affairs Medical Center, 3710 SW U.S. Veterans Hospital Rd., Portland, OR 97201.

Clear communication about adverse events is essential when patients and physicians deliberate about risky medical interventions. Key elements of what is to be disclosed to a patient in such discussions include the nature of the recommended medical intervention, its expected outcome, its alternatives, the risk of adverse outcomes, and the benefits of the intervention relative to its alternatives. The need for clear communication about one of these elements, medical risk, has been a focus of attention in legal cases *Slater v Baker and Stapleton* [Wils KB 1767;2:359], *Salgo v Leland Stanford Junior University Board of Trustees* [Cal App 2d 1957;154:560–79; P.2d 1957;317:170–82], and *Canterbury v Spence* [F.2d;464:772–96] and discussions on the definition of informed consent.^{1,2} Yet the law has not been an adequate tool for ensuring that physicians provide information to patients in an effective manner.^{3–7} The few studies of how patients define their role in decision making have examined only a limited range of medical contexts.^{8–12} There has been even less research on the types and format of information desired by patients when considering treatment decisions.^{13–15} Thus, we have conducted a study to assess what role the patient wants in decision making related to the acceptance or rejection of an invasive medical intervention, and whether the role patients prefer in decision making is related to the choice of terms—qualitative (verbal) or quantitative (numeric)—they prefer for discussing the probability of risks with their physicians.

METHODS

This study was approved by the Subcommittee on Human Studies of the Department of Veterans Affairs Medical Center, Portland, Oregon. All patients were followed in the outpatient continuity care general medicine clinic at this university-based medical center. Consecutive patients were asked to participate in the study by the principal investigator (DJM). All patients were asked to participate before being seen for their general medicine clinic appointment. Patients in moderate or severe states of acute or chronic pain and patients with moderate or severe cognitive problems were excluded from the study. These patients were excluded because we perceived that completion of a questionnaire was a particular burden to the symptomatic or cognitively compromised patient.

All subjects completed a structured interview. The subjects were given a written text of each question to follow during the interview. The subjects were given an opportunity to ask any questions they might have before providing an answer. The accompanying text contained three pages. Page 1 contained the following definitions. The pro-

cedure the patients were asked to consider was defined in general terms: "an invasive medical procedure used to diagnose or treat a medical condition." *Risk* was defined for the patients "as having two components. First, there may be a complication or adverse outcome. Second, there is the chance (probability) of the complication or negative outcome occurring." An invasive medical procedure used to diagnose or treat a medical condition was defined in two parts:

An invasive medical procedure used to diagnose a medical condition is a medical intervention where a sterile instrument is inserted into your body to see if you have a particular medical condition. The instrument can be used to visualize or take a picture of an organ inside your body, like the lungs, esophagus, or intestine. Or the instrument may be inserted into your body like a sterile catheter (soft plastic tube of a small size). This catheter is inserted into a blood vessel of the body. The catheter contains a device to measure how an organ is working. An invasive diagnostic medical procedure is intended to diagnose whether you have a medical condition and how severe the medical condition may be.

An invasive medical procedure used in treatment is a medical procedure that involves directly treating an organ or tissue in your body. The treatment can involve cutting into your body's tissues in a sterile procedure. Or the treatment can involve inserting a sterile catheter (soft plastic tube of small size) into a blood vessel to deliver medication to a specific organ of your body.

Within this setting of an invasive medical intervention, patients were then asked four questions contained on Page 2 of the accompanying text:

- Question 1. "Do you believe you understand the definitions given above?"
- Question 2. "Do you want your physician to tell you the risks associated with a proposed invasive medical procedure used to diagnose or treat a medical condition that your physician is recommending for you?"
- Question 3. "Do you want your physician to tell you about the chance of adverse outcomes occurring with the proposed invasive medical intervention in terms of words (like probable, possible) or in terms of numbers (like percents)?"
- Question 4. "Once you have been informed about the invasive medical intervention in terms of its risks and benefits by your physician, who do you then prefer to make the decision?"

For question 4, patients were asked which of four types of decision making they would prefer: (1) to make the decision themselves, (2) to have the physician make the decision for them, (3) to split the decision making 50:50 between the patient and the physician, or (4) to have some other ratio of shared decision making with their physician. Patients who preferred another ratio of decision making

were asked to provide the quantitative odds that they preferred. No scale was provided.

Subjects were then asked a set of questions including their age in years; highest level of formal education completed; their present health (excellent, very good, good, fair, or poor); and whether they had any of the following medical conditions: pneumonia, heart attack, cancer, or stroke. Cancer was defined as including all cancers requiring surgery or chemotherapy or both. All patient responses were recorded verbatim by writing responses at the time of the interview. Comparisons among subgroups were analyzed using Fisher's Exact Test, χ^2 analyses, and multiple logistic regression analyses.

RESULTS

Of 507 patients considered for study participation, 40 (7.9%) were excluded for being in moderate or severe pain states or having moderate or severe cognitive problems as determined by review of their medical record. The remaining 467 patients (mean age 65.2 years, SD 10.70 years, range 31–88 years; formal education completed, mean 12.6 years, SD 2.96 years, range 0–24 years) all agreed to participate in the study. Four hundred and forty patients were men; 27 patients were women.

All patients reported that they understood the definitions provided in the written text. Table 1 provides the ratio of physician-to-patient decision-making authority patients reported preferring. According to the distribution of responses, we grouped the subjects into three categories: patients who preferred a 75% or greater role in decision making (patient-based authority); patients who preferred a less than 75% but greater than 25% role in decision making (shared authority); patients who preferred a 25% or lower role in decision making (physician-based authority). Sixty-eight percent (318/467) were classified as shared authority; 21.4% (100/467) were classified as physician-based authority; and 10.5% (49/467) were classified as patient-based authority.

Within the context of an invasive diagnostic or therapeutic medical procedure, 93.4% (436/467) preferred that their physician disclose risk information to them. Of these 436 patients, 42.7% preferred disclosure of information about the probability of adverse outcome to be given as qualitative (verbal) expressions of probability; 35.7% preferred disclosure in terms of quantitative (numeric) expressions of probability; 9.8% preferred disclosure in both qualitative and quantitative terms; 8.4% reported that the disclosure could be in either format; and the remainder reported that they would leave it up to their physicians in terms of how they preferred to give the information to their patients. Neither age nor education was associated with whether patients preferred to receive risk information in terms of words or numbers.

To study whether any patient characteristics were related to decision-making preferences, we performed a logistic regression analysis. The dependent variable was

Table 1. The Ratio of Patient-to-Physician Decision Making That Patients Preferred for Invasive Medical Procedures

| Preferred Ratio Patient:Physician* | Patients Responding (n = 467) |
|--|----------------------------------|
| Mainly patient-based decision making | |
| 100:0 | 43 |
| 90:10 | 2 |
| 80:20 | 3 |
| 75:25 | 1 |
| | 49 (10.5%) |
| Shared decision making | |
| 70:30 | 3 |
| 60:40 | 6 |
| 55:45 | 1 |
| 50:50 | 301 |
| 45:55 | 1 |
| 40:60 | 6 |
| | 318 (68.1%) |
| Mainly physician based decision making | |
| 25:75 | 1 |
| 20:80 | 3 |
| 10:90 | 1 |
| 0:100 | 95 |
| | 100 (21.4%) |

*These ratios represent the relative percentages of involvement in decision making that patients desired for patients and physicians, respectively.

created by dividing the subjects into two groups. Those preferring a greater than 25% role in decision making composed the first group. The second group consisted of subjects preferring 25% or less involvement. Patients who

stated they would leave the decision to their physician or spouse were omitted from this analysis. The independent variables (Table 2) included age; formal education; the patient's general health status at the time of questionnaire completion; whether or not the patient reported ever being hospitalized for pneumonia, heart attack, cancer, or stroke; and patient preference for quantitative (numeric) only or both quantitative and qualitative (numeric and verbal) risk information from their physician versus patient preference for qualitative (verbal) only or either qualitative or quantitative (verbal or numeric).

This analysis indicated that younger patients (odds ratio [OR] 0.96; confidence interval [CI] 0.93, 0.99), patients who had at least one stroke (OR 3.03; CI 1.03, 8.90), and patients who preferred to discuss risk information with their physicians in terms of numbers (OR 2.39; CI 1.40, 4.06) tended to prefer patient-based or shared decision making with their physicians.

DISCUSSION

In this study, we found a relation between patients' preferences for the format of risk information and their views on involvement in decision making. Patients who preferred a lower level of involvement in decision making tended to prefer that physicians use qualitative probability terms to give them risk information. We also found an overall trend for patients to prefer receiving risk information from physicians in the form of qualitative (verbal) probability terms.

Our finding of a tendency for patients to prefer the use of qualitative terms goes against trends reported in the cognitive psychology literature. In their study of 64

Table 2. Relation of Patient Factors to Decision-Making Preferences*

| Patient Factor† | Patient-Based/Shared Preference (n = 367) | Physician-Based Preference (n = 100) | p Value |
|--|--|---|------------|
| | Mean (SE) | Mean (SE) | |
| Age, years | 64.35 (0.59) | 68.59 (0.79) | .002 |
| Formal education, years | 12.65 (0.15) | 12.37 (0.32) | .7 |
| Present health status, 1-5: excellent, very good, good, fair, poor | 3.19 (0.06) | 3.25 (0.10) | .5 |
| | Proportion (SE) | Proportion (SE) | |
| At least one hospitalization for: | | | |
| Pneumonia | 0.32 (0.02) | 0.28 (0.04) | .2 |
| Heart attack | 0.31 (0.02) | 0.25 (0.04) | .08 |
| Cancer | 0.09 (0.02) | 0.08 (0.03) | .5 |
| Stroke | 0.15 (0.02) | 0.06 (0.02) | .04 |
| Preference for risk information, numbers or both words and numbers | 0.51 (0.03) | 0.33 (0.05) | .001 |

*The comparison groups in this logistic regression analysis were two groups of subjects. The group having patient-based preference were those who preferred a greater than 25% involvement in decision making for invasive procedures. The group having physician-based preference chose a 25% or less role in decision making.

†All data were obtained by patient self-report.

parents, Brun and Teigen found that about 60% expressed a preference for quantitative estimates of risk information related to influenza vaccine for their children.¹³ Wallsten and colleagues found that about 70% of a group of 442 respondents preferred to receive information quantitatively.¹⁴ Many other studies examining how people interpret a broad range of qualitative probability expressions have consistently found very large intersubject variability of numeric interpretations of commonly used words, like probable and possible.¹⁵⁻¹⁷ Because of the inherent vagueness of qualitative probability terms, it has been argued that physicians and other professionals should adopt the use of quantitative probability expressions. Both groups argue for two alternative strategies: quantify probabilities whenever possible when communicating with clients,^{18,19} or use qualitative and numeric estimates together.²⁰ Our finding that the largest group of patients preferred qualitative terms in an invasive medical context suggests a lack of patient familiarity with the use of quantitative terms. The strategies recommended in these previous commentaries appear to be well suited to the empiric findings of the present study.

Our study had some limitations. First, we presented patients with surgical and sterile-catheter-related examples of invasive treatment interventions. This might be considered a broad range of interventions, and the lack of familiarity with either example may have influenced patient preferences for quantitative or qualitative information. Second, we used as our study instrument an odds-ratio scale. A different scale, e.g., an analogue scale, may give different results. Third, we did not assess whether a patient's recent experience with an invasive procedure or the duration of relationship with his or her physician might have influenced responses to the issue of sharing decisions between the patient and the physician.

REFERENCES

1. Katz J. Informed consent—a fairy tale? Law's vision. *Univ Pittsburgh Law Rev.* 1977;39:137-74.
2. Meisel A. The expansion liability for medical accidents: from negligence to strict liability by way of informed consent. *Nebr Law Rev.* 1977;56:51-152.
3. Meisel A, Roth LH. Toward an informed discussion of informed consent: a review and critique of the empirical studies. *Ariz Law Rev.* 1983;25:265-346.
4. Faden RR, Beauchamp TL. *A History and Theory of Informed Consent.* New York, NY: Oxford University Press; 1986.
5. Katz J. *The Silent World of Doctor and Patient.* New York, NY: Free Press; 1984.
6. Mazur DJ. Why the goals of informed consent are not realized: treatise on informed consent for the primary care physician. *J Gen Intern Med.* 1988;3:370-80.
7. Lidz CW, Meisel A, Osterweis M, et al. Barriers to informed consent. *Ann Intern Med.* 1983;99:539-43.
8. Vertinsky IB, Thompson WA, Uyeno D. Measuring consumer desire for participation in clinical decision-making. *Health Serv Res.* 1974;9:121-34.
9. Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med.* 1980;92:832-6.
10. Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *JAMA.* 1984;252:2990-4.
11. Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med.* 1989;4:23-30.
12. Deber RB, Kraetschmer N, Irvine J. What role do patients wish to play in treatment decision making? *Arch Intern Med.* 1996;156:1414-20.
13. Brun W, Teigen KH. Verbal probabilities: ambiguous, context-dependent, or both? *Org Behav Hum Decis Proc.* 1988;41:390-404.
14. Wallsten TS, Budescu DV, Zwick R. Comparing the calibration and coherence of numerical and verbal probability judgments. *Manag Sci.* 1993;39:176-90.
15. Mazur DJ, Hickam DH. Patient interpretations of terms connoting low probabilities when communicating about surgical risk. *Theor Surg.* 1993;8:143-5.
16. Simpson RH. Stability in meanings for quantitative terms: a comparison of meaning over 20 years. *Q J Speech.* 1963;49:146-51.
17. Cohen J, Dearnley EJ, Hansel CEM. A quantitative study of meaning. *Br J Educ Psychol.* 1958;28:141-8.
18. Eddy DM. The challenge. *JAMA.* 1990;263:287-90.
19. Fryback DG. Decision maker, quantify thyself! *Med Decis Making.* 1985;5:51-60.
20. Kenney RM. Between never and always. *N Engl J Med.* 1981;305:1097-8.