Physicians in health care management: 8. The patient–physician partnership: decision making, problem solving and the desire to participate

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How reasonable are expectations that patients will participate in care decisions? The previous article in this series reviewed models of the patient–physician relationship and views on the extent to which patients want to be informed; it also described one information tool — the interactive videodisc. This article reviews literature on the extent to which patients wish to be involved in making decisions about their care. Neither "sensitive paternalism" nor "informed consent" appears to be ideal. The author suggests a distinction between two elements of choice: problem solving and decision making. This distinction helps in identifying appropriate roles for patient and provider, thereby leading to genuine shared decision making.

Dans quelle mesure les attentes concernant la participation des patients aux décisions dans le domaine des soins sont-elles raisonnables? Dans le premier de deux articles sur ce sujet, on a présenté des modèles de rapports entre patient et médecin, des points de vue sur la mesure dans laquelle les patients veulent être informés et un outil d'information, le vidéodisque interactif. Cet article passe en revue la documentation qui traite du degré de participation aux décisions sur les soins souhaité par les patients. Ni le «paternalisme complaisant» ni le «consentement éclairé» ne semblent être la solution idéale. L'auteur suggère de faire la distinction entre deux éléments du choix : la résolution de problèmes et la prise de décisions. Cette distinction aide à définir les rôle qui conviennent au patient et au fournisseur de soins, ce qui permettra un véritable partage de la prise de décisions.

What role do patients wish to play in their care? In a previous article[1] in this series I noted current challenges to the paternalistic view of the patient–physician relationship and showed that most patients wish to be informed about their care. Wanting to know, however, is not the same as wanting to be in charge. The confusion between these two roles is reflected in the various terms used in articles on this subject. Some writers discuss "participation," which appears to envision continued physician control with more extensive patient involvement. Others propose "shared decision making."[2] At the other end of the continuum, some articles speak in terms of "control." Recent studies have distinguished between a patient's desire to be informed and his or her desire to be involved. Conclusions to be drawn from these studies depend on how the question is phrased.

Early studies suggested that many patients wished to participate. In a pioneering study by Cassileth and associates[3] 87% of young patients (20 to 39 years of age),

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Articles in this series appear in issues published the 15th of each month; the first article appeared in the Jan. 15, 1994, issue.

62% of those 40 to 59 years of age and 51% of those over 60 selected "I prefer to participate in decisions about my medical care and treatment" rather than "I prefer to leave decisions about my medical care and treatment up to my doctor." A study of inpatients with cancer, which used the same measures, found that 92% of the patients surveyed wanted all information, good or bad, and 69% preferred to participate in medical decisions.[4] However, the term "participate" was not defined.

Other studies showed less patient interest in participation. Larsson and collaborators[5] surveyed 666 patients on a surgical waiting list 1 week before their operations about their involvement in the decision to operate. Only 8% of the patients saw the decision as their own, 41% saw it as a joint physician–patient decision, and 29% said it was the physician's idea. Although 73% of the patients responded that they had been involved in the decision making "as much as they wished," the researchers stressed that "patient satisfaction can just as well be understood as resulting from low expectations with respect to one's own influence." In fact, a sizeable proportion of the patients were not convinced that the operation was the correct decision.

In a study in the United States 210 patients with hypertension were asked, "Who do you think should make the decisions about medicines for treatment of high blood pressure?" Most (47%) replied that they preferred that the clinician make the therapeutic decisions "using all that is known about the medicines," 31% preferred that the clinicians "should make the decision but strongly consider patient's opinion," and only 19% preferred shared decision making "on an equal basis." The investigators also surveyed 50 of the patients' physicians and found that they were poor judges of the decision-making preferences of their patients.[6]

The proportion of patients wishing to share in decision making varies among studies. A study of patients with cancer in Canada found that most preferred shared control; in light of recent legal efforts to entrench substitute decision making, it is interesting that these patients stated they would rather give control to their physicians than to family members.[7] Another study found that 32 of 60 outpatients with cancer would prefer to participate in making decisions, either with the physician on an equal basis, on their own but taking the physician's opinion into consideration, or on their own on the basis of their own knowledge. The other 28 preferred that the physician make decisions, either solely according to existing knowledge or taking the patient's opinion into consideration. The investigators noted that the patients oriented toward participation were less likely to agree to enter a hypothetical clinical trial, perhaps because they saw entering a trial as giving over treatment decision making to the physician.[8]

On the whole, these study results lead to the conclusion that, although almost all patients want information, not all want to participate in decision making.[4,9–11] However, this judgement may be premature.

In the previous article I showed that providing patients with more information could lead to better outcomes. Participation also appears to improve outcomes. Brody and colleagues[12] categorized patients as either active or passive on the basis of their responses to the question "What role do you want to play (or did you play) during today's visit [to the physician]?" Patients who selected "The doctor takes (took) the initiative and decides(d) what is (was) best for me," or "The doctor considers(ed) some of my ideas but still makes (made) most, if not all, of the final decisions," were considered passive. Patients who selected "The doctor and I make (made) the final decisions together," or "I make (made) all of the final decisions," were considered active. Almost half of the patients were thus considered active. When self-reported health outcomes were measured 1 week later, the active patients tended to be more satisfied with their physicians, show more improvement in overall medical condition, have fewer illness concerns and express a greater sense of control over their condition than the passive patients.

Characteristics of patients who wish to participate

What characterizes patients who wish to play a more active role in decision making? Many articles conclude that the desire for involvement is associated with a "complex relationship between the variables of age, degree of illness, and the presence of the 'significant other'" — usually a spouse.[4]

Several studies have shown that age is the most important predictor of patient preference for participation in decision making, with younger patients desiring greater involvement.[3,6] "The younger the patients, the more closely they conformed to the well-informed participant standard of patient behavior; the older the patients, the more likely they were to prefer the older, non-participatory patient role."[3] There is also empiric evidence that better-educated people prefer greater involvement in decision making than less-educated ones.[3,6,13,14] Patients with severe illnesses may prefer not to participate in their medical care.[6,11] Blanchard and coworkers[4] concluded that patients who preferred to leave decisions to physicians were primarily older men with serious illnesses, almost all of whom were married; they suggested that these patients were dependent on their wives and physicians.

Sensitive paternalism and informed consent

At first glance, the research evidence, although mixed, suggests that few patients wish to participate in decision making. What are the policy implications of this finding?

One option is to abandon the ideal of shared decision making. Paternalism could be retained, and physi-

cians might become more effective agents if they were more sensitive to the problems and concerns of patients. This "new paternalism" would include, in most cases, a recognition that patients wish to be informed and, therefore, should receive better information than has traditionally been the case.

Faced with evidence that many patients do not wish to "participate," some researchers have indeed concluded that respect for patient autonomy requires a return to such "sensitive paternalism."[15] Waterworth and Luker,[16] on the basis of unvalidated structured interviews with 12 patients concerning their perceptions of involvement in treatment and nursing-care decisions, concluded that nurses who encouraged involvement might be coercing patients to comply with their wishes because patients would "toe the line" to please the nurse. The investigators stated that patients should not be forced to collaborate and that the promotion of individualized care is not synonymous with patient involvement.[16] It is striking that such resistance to patient empowerment appears to persist, in the guise of provider beneficence, in a profession (nursing) that has been emerging as a strong patient advocate. However, as Katz has noted, some providers still see patient empowerment as a threat.[17]

Sensitive paternalism is similar to the "informed consent" model: the clinician proposes a course of action, and the patient has a right to veto that action. However, informed consent fails to deal with the realities of medical decision making. Some of the practical difficulties were investigated by Lidz and associates.[18] They observed interactions between patients and staff and interviewed patients in two inpatient wards and a surgical outpatient clinic. They noted that patients often wanted information for a variety of reasons: to facilitate compliance with treatment, as an indication that physicians respected them as people or to veto a decision that a physician had made. Only 10% of the patients played an active role in decision making; indeed, many believed that decisions about treatment were the physician's responsibility. The outpatients were more likely to question physicians or to take an active role in decisions than the inpatients, and patients with a long-term illness were usually more actively involved than those with an acute illness, possibly owing to their greater experience with the health care system. The investigators concluded that the legalistic approach to informed consent, which relies on carefully worded forms, was inferior to the encouragement of genuine patient participation. They also stressed that medical decisions are rarely made during a single episode but evolve over time; therefore, physicians and patients must decide on an anticipated course of treatment rather than a single procedure or event.

Timing is crucial to the transmission of information. Informed consent may be ineffective if patients are under too much emotional stress to "take in" the information. Wade[19] studied patients scheduled to undergo cholecystectomy who were given preoperative counselling. After counselling the patients completed a questionnaire about the surgical procedure, risks, possible complications and the need for operative self-care. Several weeks after discharge, patients were mailed a second questionnaire about the counselling they had received. On the initial questionnaire, 90% of the patients had correctly identified the risk of death from elective cholecystectomy. However, after discharge, 54% of those who had correctly answered the question on risk of death before surgery reported that they had not been informed that death could result. Failure to recall disclosure of risk was not associated with preoperative pain, emotional distress or medication. As a result of this finding, Wade advised physicians to obtain consent in writing and to provide comprehensive counselling, with particular attention to confused patients and those with complications.

There is a subtle but important distinction between the legal notion of "informed consent" and the ideal of shared decision making. Informed consent does not mean that the patient is an active partner in care, and, therefore, it cannot achieve the benefits of a model in which the patient is an informed partner who understands and sets treatment goals. Birke, Himmelweit and Vines[20] expressed similar views, noting, "Informed choice has to mean that: doctors should inform, but not decide. . . . To make such decisions, people need to know what the alternatives are and the likely effects of each option; if doctors do not know the answers they should share the extent of their ignorance as well as their knowledge with the people they might treat." Such information must include the social as well as medical consequences of treatment options. Is the shared-decision-making ideal compatible with the research evidence?

Do providers know what their patients want?

A practical barrier to sensitive paternalism is that physicians are often poor judges of what their patients wish to know. In a classic study of choices between surgery and radiotherapy for patients with lung cancer,[21] most of the clinicians were unaware that some of their patients would have preferred radiotherapy. Physicians are not even good judges of the extent to which their patients wish to be involved. Strull, Lo and Charles[6] noted that physicians underestimated their patients' preference to discuss therapy in 29% of cases and overestimated it in 11%. The investigators concluded that there was no substitute for asking patients directly.

If sensitive paternalism is rejected on pragmatic, legal and ethical grounds, what are the alternatives? One is to decide that the patients in the studies reviewed who preferred not to participate are misinformed and need to be educated to be more autonomous. Another is to suggest that the research evidence has been misinterpreted. Although there may be patients who wish to remain passive, some confusion has arisen because the studies have

not clearly defined "participation" and have confused two dimensions of choice, which I will term "decision making" and "problem solving." This distinction can help clarify roles for patients and clinicians.[22,23]

Decision making and problem solving

Baumann and I define "problem solving" as the search for the single "correct" solution to a problem; in contrast, we define "decision-making" situations as those in which a choice must be made from among several alternatives, often involving trade-offs of harms and benefits.[22]

The key distinction for medical choice is that the values assigned to potential outcomes are not relevant to problem solving. For example, a radiograph may show that my leg is broken, whether I would like it to be broken or not. There is only one correct answer to the diagnosis, which may or may not be ascertained. Problem solving thus requires that the problem solver have a set of skills and a knowledge base that enable him or her to identify the alternatives and the probability of each outcome. Such tasks do not require patient or public involvement.

Knowledge of the alternatives, however, does not dictate what action should be taken. Values and preferences must be ascertained when decision making comes into play. Once one must select a possible course of action, the value assigned to different outcomes may become crucial. Decision making usually requires prior problem solving. Sensitivity analysis, a technique of decision analysis, can also help clarify which outcomes must be evaluated. For example, if one option proves optimal over the full range of values placed on certain outcomes, then preferences for those outcomes are not relevant to decision making. Although it may be appropriate to give patients this information, these preferences need not be considered in their decision making. Dividing the choice into its problem-solving and decision-making components thus highlights which decisions require patient participation.

For example, in the previous article I described the interactive videodisc program designed to inform patients with benign prostatic hyperplasia.[1] The choice of surgical treatment or "watchful waiting" is a decision that depends on the patient's preferences for certain outcomes (e.g., living with his current symptoms, the risk of impotence as a result of surgery),[24,25] but prior problem solving by experts is needed to inform the patient about his choices and the accompanying probabilities and to determine which of his preferences must be assessed.

The distinction between decision making and problem solving is relatively recent; with my colleagues I am currently testing it empirically.[26,27] However, it is compatible with many of the findings reported.

The contractual model of patient–physician interaction can be seen to be based, in part, on this distinction; this model assumes that the physician should take responsibility for problem solving but that decision making should be shared with the patient. Similarly, Kassirer[28] believed that physicians risk "usurping patients' prerogatives." Kassirer stressed the importance of "patient participation" and noted the difference between "probability (information that the physician provides)" and utility, which must be assessed by the patient.

The reports I have reviewed that suggest that patients do not wish to be decision makers did not note this distinction. It is unclear whether patients involved in the studies were rejecting a role in problem solving, as opposed to not wanting involvement in decision making.

It is important to distinguish this rationale for patient involvement in decision making, with clinician responsibility for performing the problem-solving tasks, from some of the claims of the patients' rights movement, which define involvement as also including an active patient role in the problem-solving tasks. For example, women's health collectives have been teaching women to conduct their own gynecologic examinations.[29] Similarly, some feminist groups have called for women to perform their own artificial inseminations. However, many patients may feel unwilling and unprepared to take on a participatory role that includes problem solving. In our view, patients' preference not to participate in problem-solving tasks should not be interpreted as unwillingness to participate in making decisions about their care.

Although they did not use this distinction, some of the participation-oriented patients quoted by Cassileth and associates[3] indeed appeared to express a wish to be involved in problem solving (e.g., "It's my body and my disease," "You have to take responsibility for your own body," or "I want to know everything so I can help take care of myself"). However, only one of the remarks from patients not wishing to participate could be seen as a rejection of decision making: "I need as little to worry about as possible." Others appeared to be rejecting only the problem-solving role: "The layman is not qualified to make decisions," "I am not qualified," or "It's the doctor's job: he'll take care of the details." One wonders whether such patients would be willing to be involved in decision making and to select their preferred treatment if they had been provided with the necessary information and support.

The conclusion reached by Ende and collaborators[11] that "patients prefer that decisions be made principally by their physicians, not themselves, although they very much want to be informed" could have a similar explanation. When asked "whether a cardiologist should be consulted" if a patient discovered he or she was having a heart attack, patients, not surprisingly, felt a need for expert input. Items in the locus-of-authority scale developed by Beisecker and Beisecker,[10] which purport to deal with participation, also deal mainly with problem-solving tasks. Items include "What information should

be covered in the patient's medical history," "Which drug to use," "What dosage of a given drug to use," and "Whether to have a patient undergo diagnostic tests." Evidence supporting our contention that many patients desire shared decision making is provided by a Harris poll, cited by Ende and collaborators,[11] that showed that 72% of patients surveyed preferred the option that "the doctor [discuss] alternatives with the patient and the two of them decide together how to proceed" over unilateral control by patient or physician.

Conclusion

We postulate that most patients prefer to have experts perform the problem-solving tasks but wish to take an active role in decision making.

To achieve this type of patient–physician partnership, patients will require sufficient information to make full and informed choices. At the least, they will need clarification of the following

- The available alternatives.
- The potential outcomes of each alternative.
- The costs, risks and benefits of each alternative.
- The values of each potential outcome.

If this view proves correct — as our preliminary research results suggest — clinicians have a key role in ensuring that such information is available and understandable and in supporting patients in making informed and wise choices.

This work draws on research done for the Royal Commission on New Reproductive Technologies, which is not responsible for the conclusions reached. I thank Hélène Bouchard and Ann Pendleton for their help with the literature review and Andrea Baumann, Nancy Kraetschmer and John Trachtenberg for assistance with the research on decision making. Funding for the project "Medical decision making: Who and how? Patient empowerment and decision rules" was provided by the Social Sciences and Humanities Research Council (grant 410-92-0725).

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