

Physicians in health care management: 7. The patient–physician partnership: changing roles and the desire for information

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Historical views of the patient–physician relationship assumed that the physician's role was to act in the best interests of the patient and to direct care and make decisions about treatment on the patient's behalf. However, under current legal and ethical principles, beneficence is no longer sufficient; respect for autonomy is paramount, necessitating patient participation. None the less, physicians question whether patient participation is realistic in actual clinical situations. This first of two articles reviews models of the patient–physician relationship and the literature about barriers to participation, the effect of participation on patient outcome and the extent to which patients want to be informed. The image of a dependent patient who prefers to be sheltered from harsh truths is not supported. It appears that most patients wish to have information, although there is an identifiable proportion who do not. To be understood, health information must be presented in a way that is appropriate to the patient. Format, content and timing of the material are all important. Mechanisms for incorporating such information into busy clinical practices are crucial.

Dans la relation patient–médecin, on disait autrefois que le rôle du médecin consistait à agir au mieux des intérêts du patient, à prendre en charge les soins et à décider des traitements pour le patient. Toutefois, en vertu des principes éthiques et juridiques actuels, la bénignité n'est plus suffisante. Le respect de l'autonomie est primordial et nécessite la participation du patient. Néanmoins, les médecins se demandent si la participation du patient est réaliste dans les situations cliniques réelles. Ce premier de deux articles présente un examen de modèles de relations patient–médecin et de documents sur les obstacles à la participation, l'effet de la participation sur les résultats constatés chez les patients et la mesure dans laquelle les patients veulent être informés. On n'a plus l'image du patient dépendant qui préfère qu'on lui épargne la dure vérité. Il semble que la plupart des patients désirent être renseignés bien que certains d'entre eux ne le veuillent pas. Pour être compris, les renseignements qui touchent la santé doivent être présentés d'une façon qui convienne aux patients. Non seulement le contenu des renseignements est-il important, mais aussi la façon dont ils sont présentés et le moment de leur présentation. Des mécanismes permettant d'incorporer ce genre de renseignements dans des pratiques cliniques chargées sont d'une importance cruciale.

Historical views of the patient–physician relationship assumed that it was the role of the physician, acting in the best interests of the patient, to direct care and to make decisions about treatment.¹ The paramount moral principle to be pursued was benefi-

cence: the patient's role was to comply with the physician's orders, and a good patient would not question the physician's decision.² This paternalistic approach, still common in many cultures, assumes that patients and providers have the same goals, that providers can judge

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patient preferences, that only the physician has the expertise necessary to determine what should be done, and that it is simple and appropriate to spare patients the worry of decision making or even to deceive them in order to engender faith, reassurance and hope.² This “priestly model”³ leaves little room for patient participation.

In the age of consumerism, this model has become unacceptable. Recent bioethics literature suggests that other moral principles are also important, with the obligation to respect the wishes of competent people (autonomy) taking centre stage.⁴ In an extreme model, called the “engineering model” by Veatch,³ the patient is the sole decision-maker and the physician is a technician whose role is only to give advice. Veatch’s “collegial model” gives more recognition to the imbalance of knowledge and views patients and providers as full and equal partners. Although these models have often been espoused by patient advocates, others argue that they are unrealistic. Some advocate a shared “contractual model,”^{1,3,5,6} although the term “contract” has been widely criticized as being unrealistic and encouraging “minimalist” thinking rather than a richer physician–patient relationship. The ideal appears to be shared decision making with contributions by both patient and physician.^{5,7–12} Patients bring to the relationship their “personal moral values or life-style preferences” about which they “could be expected to know more . . . than the physician could,”¹ and physicians bring their expertise about the technical aspects of diagnosis and management. As Whitbeck¹³ has noted, an emphasis on shared decision making “requires abandonment of the assumption, which is common in the medical ethics literature, that for most medical decisions there is an answer to the question, ‘Who should decide?’ The implications are profound; once it is no longer necessary for one individual to ‘own’ the decision, emphasis can shift from a formal emphasis on rights to one based on ‘sensitive communication’,”¹⁴ which is clear, effective and appropriate to the culture of the patient.

Although the current thinking in bioethics is that autonomy not only permits but requires participation by patients in decisions about their own treatment, the participatory ideal may encounter practical difficulties.

One barrier arises from “potent unconscious factors”: patients may “need to be taken care of by powerful paternal or maternal figures.”¹⁵ Patients adopting the “sick role” may revert to childlike behaviour; transference and countertransference may occur.² Authors are divided on this point. For example, does respect for patient autonomy mean allowing a patient to abdicate responsibility? In general, however, most writers argue that patients must be educated and encouraged to act as adults, whether or not they want to. Other difficulties arise if patients are too ill to make decisions or if there is a need for rapid action; these issues are beyond the scope of this review.

A more tractable barrier to partnership arises from the existing structure of medical practice. If patients are

to give truly informed consent, they need an environment in which they feel independent and able to make decisions, their goals and values are ascertained and they are educated about the risks and benefits of treatment options.⁷ In busy practices physicians rarely have enough time to gather and provide such information.^{15,16}

Fostering participation

As Greenfield, Kaplan and Ware showed,¹⁷ patients can be trained to participate in clinical decision making. In their first study, Greenfield and associates assigned patients with peptic ulcers to experimental and control groups. In a 20-minute session, subjects in the experimental group were presented with a treatment algorithm that clarified the medical process and identified relevant decisions, and then they were coached to read their medical chart, ask questions and negotiate medical decisions. The control group had a 20-minute session about the cause, complications and treatment of ulcers. Analysis of the subsequent discussions between patients and physicians showed that, although patients in the experimental group did not ask more questions than the control patients, they were significantly more involved in the interaction and twice as effective in obtaining information from their physicians. In the control group many of the interactions were what the researchers termed “one-way” communications, in which the physician directed the discussion and the patient provided facts. A comparable study involving patients with diabetes mellitus produced similar results.¹⁸ Patient participation may require careful instruction; results of a randomized study suggested that merely indicating that physicians are open to questions is unlikely to be effective.¹⁹ This study found that only the group of patients who “were asked to imagine carrying out instructions, to notice any problems which might arise and raise these with the doctor” asked more questions and made fewer errors and omissions in their accounts of recommended treatment.

However, the results of other randomized studies have been less clear. In a study involving poor black women, Roter²⁰ found that those coached by a health educator in a question-asking protocol asked more questions and kept more appointments; however, their interactions with physicians were characterized by more anger and anxiety, and less satisfaction, than those of the control group. Similarly, Blanchard and collaborators²¹ found that patients who preferred to participate in decision making were slightly but significantly less satisfied with their care than those who wanted the physician to make the decisions. Clearly, training patients to ask questions is insufficient if provider and patient do not expect decision making to be shared. It has often been claimed that clinicians believe that women — particularly poor women — are less capable of making decisions than other patients.¹⁵ Partnerships are difficult to establish under such circumstances.

Effect of participation on patient outcomes

In theory, greater patient participation enhances patient autonomy, and it has often been supported for that reason alone. However, an even stronger case could be made for patient participation if it were shown that such participation also improves outcomes.

The literature suggests that the relation between patient participation and patient satisfaction is ambiguous. Patient satisfaction is not necessarily related to a "good outcome" but may be influenced by interpersonal factors in the physician-patient relationship.²²⁻²⁴ Studies have also shown that increased participation does not always lead to greater patient happiness.^{17,20} Although these results could be explained by the failure of clinicians to respond satisfactorily to their patients' efforts to participate, they also appear to reflect a distinction noted by Ware, Snyder and Wright²⁵ between the "art of care" and the "technical aspects of care." Most patient satisfaction surveys show that "from the patient's perspective, the technical component is taken for granted, leaving the nontechnical open to scrutiny and evaluation."²⁴ However, Lerman and colleagues¹¹ found a weak but significant relation between self-reported patient involvement with decision making and patient satisfaction with the technical competence of physicians but no correlation with the art of care. Therefore, participation probably has a positive effect on balance, but it does not guarantee a satisfied patient.

However, investigators have also concluded that encouraging patients to take a more active role in their care may indeed pay off in improved outcomes.^{11,17,23,26-34} Patients who are actively involved in care may have a better functional capacity and perceive themselves as healthier than those not actively involved.³⁵ They may also have more effective relationships with their physicians.²⁴

Why are outcomes improved among patients active in their own care? One explanation is that such patients have an increased sense of control, which, in turn, may improve outcomes "by generating behaviors and attitudes that are health-maintaining."³⁶ Patients who have participated appear to be more likely to comply with treatment. Patients with cancer who wanted to be involved in treatment decisions were found to be significantly more hopeful than those who did not.²⁷ Patients with peptic ulcers¹⁷ and diabetes mellitus¹⁸ experienced better physical functioning if they were involved in medical decision making.

However, participation may have detrimental effects, especially increased anxiety, when there is no real choice offered to the patient. Rothman³⁷ noted that amniocentesis led to "the tentative pregnancy," in which the mother's emotional attachment to the fetus was conditional on favourable test results. A study of the decisions by 151 mothers about whether to have their sons circumcised found that their decisions were based on social,

traditional and religious reasons rather than on medical factors.³⁸ After the births the clinic gave some mothers their standard "partial disclosure" about the most important medical complications associated with elective circumcision and others "full disclosure" of all possible complications. The decisions taken by the mothers in the two groups did not change, but those mothers receiving the full information felt less confident in the appropriateness of their decision, and their physicians "experienced more mental strain as a result of patients' subsequent feelings of antagonism and experienced a potential loss of income with patients not seeking return visits to the clinic."³⁸ On the basis of their findings the authors suggested that physicians present the risk information during the prenatal visits, when the parents may be undecided about circumcision.

It has long been recognized that providers can have substantial power over patient decision making by controlling what information a patient receives. There has been controversy about such issues as telling patients about drug side effects. For example, is it justifiable to worry a patient by telling him or her about a very unlikely side effect? How do patients react to elaborate and frightening consent forms listing many horrific, but unlikely, possible consequences of treatment? Do such forms do more harm than good? Do they lead patients to reject appropriate treatment? Different answers will be produced depending on how beneficence and autonomy are weighed. Katz² noted that physicians are willing to admit to one another that medicine is an inexact science and that there are uncertainties; he argued that physicians should admit these uncertainties to their patients.

Perhaps the strongest argument for patient involvement is that the optimal treatment in many clinical situations is a "toss up" that depends on the values patients attach to different outcomes and to the risks of particular procedures.³⁹⁻⁴³ Choice of therapy thus requires knowledge of the patient's values. If this normative model of decision making is accepted, either the clinician must become an excellent judge of the patients' wishes or mechanisms must be found to allow patients to participate directly. Otherwise, outcomes are likely to be sub-optimal, even from a purely technical standpoint. To the extent that physicians are poor judges of patient wishes, as I will discuss in the next article in this series, it is essential to develop better mechanisms to encourage participation.

Issues about patient involvement

Three related questions about patient involvement have been discussed.

First, how much do patients wish to know about their diagnosis, possible treatments and likely outcomes? Does the way this information is presented affect outcomes?

Second, as I will discuss in the next article, to what

extent do patients wish to be involved in their therapy, including treatment decisions?

Third, if the answer to the first two questions is It depends on the patient, can we identify which patients wish to participate?

How much do patients wish to know?

A great deal of attention has been paid to how much physicians should tell patients about their diagnosis and prognosis. Recognition of the positive effect on outcomes of the patient's attitude and hopefulness had led many physicians to argue that it was inhumane and perhaps unethical to tell a patient that there was no hope for a cure. In this view beneficence is dominant; the information and choices provided to patients are manipulated "for their own good." Others have argued that physicians should tell patients the truth in all circumstances, for pragmatic reasons (a deceived patient is less likely to be compliant) and to respect patient autonomy.² In recent years medical ethicists have argued strongly that autonomy should always "trump" beneficence and that patients should therefore be informed whether or not they want the information.

Empirical studies of these issues have concentrated on such life-and-death issues as whether a patient should be told that an illness is likely to be fatal. The results of such studies must be extrapolated to less serious medical situations with caution. However, the changing view of whether patients should be told the truth is evident in a comparison of the results of two studies on physician attitudes to disclosing a cancer diagnosis. A widely cited article published in 1961 showed that 90% of the physicians surveyed did not inform patients of the diagnosis, in part because physicians were uncomfortable discussing failure or death with their patients.⁴⁴ When the study was replicated in 1979 the results showed a complete turnabout: 97% of the physicians surveyed preferred to inform the patient of the diagnosis.⁴⁵ These results may have reflected the disappearance of the stigma associated with cancer, greater public awareness of cancer signs and symptoms, and improved outcomes. Physicians may have been more comfortable discussing a cancer diagnosis once it was no longer a death sentence. However, this change likely reflected as well the increase in patient empowerment and in public scrutiny of the medical profession.⁴⁶

What do patients want to know?

Now that the ethical consensus has shifted, and physicians appear more open to disclosure of diagnostic information, what do patients want to know?

In general, it appears that patients want to be fully informed. For example, a study of patients with cancer found that most, regardless of age, wanted all of the possible information, both good and bad news.²⁷ The pro-

portion of patients wanting all information ranged from 80% of those over 60 years of age to 96% of those 20 to 39. A series of other studies had similar results about patients' desire for information.^{11,18,21,47-50} None the less, patients can find too much data overwhelming; providers must determine what information is relevant to patients and present it in a comprehensible manner.

Educational tools

Patients can be given information in a number of ways, through conversations, lectures, pamphlets, articles, books and videotapes. The more that advice needs to be personalized, because cases differ widely or patients learn differently, the more expensive and time-consuming the process is likely to be. One innovation — the interactive videodisc — merits special mention. A series of programs on videodisc is being developed as part of a shared decision-making program by a US non-profit group, the Foundation for Informed Medical Decision Making.⁵¹ The first such program was for patients with benign prostatic hyperplasia, who must choose between a watch-and-wait strategy and surgery (usually transurethral resection of the prostate [TURP]). Barry and coworkers^{40,41} showed that the benefits of TURP depended on the value to patients of various health factors, particularly their health status before surgery and the risk of impotence after surgery. When patients' quality of life suffers because of the symptoms of prostatism, surgical procedures are optimal; patients not bothered by the symptoms of prostatism and concerned about the possible complications of TURP may prefer watchful waiting or medical therapy. The interactive videodisc program describes each outcome and presents specific information tailored to the patient's clinical status. For example, if the patient indicates that he has experienced an episode of complete urinary retention, the explanation given will differ from that given to patients who have not experienced this symptom. The program can also provide the probabilities of different outcomes for patients in each clinical situation.

The value people assign to a health state may depend on their knowledge of the state and their experience with it; however, decisions must be made prospectively.⁵² The videodisc addresses this dilemma by offering patients "vicarious experience" of the results of the options available to them.

It can take time to discuss a complex case fully. Beisecker and Beisecker¹⁶ concluded that "a longer interaction [between physician and patient] may be necessary for patient attitudes regarding desire for information and participation in medical decisions to manifest themselves in information-seeking behavior." Such time may not be available in a busy clinician's office, and patients may hesitate to "bother" the physician. However, patients can use a videodisc at their own speed, obtain as much or as little information as desired and replay ma-

terial. Patients may be more willing to seek potentially embarrassing information from a nonhuman source.

The videodisc on benign prostatic hyperplasia is used at the Prostate Centre, Toronto Hospital, in collaboration with Dr. John Trachtenberg and the Foundation for Informed Medical Decision Making. We recently introduced it in other settings across Canada in collaboration with the Canadian Prostate Health Council and its members. Patients have been found to be very enthusiastic about the videodisc; its effect on providers is being evaluated as well.

Patient use of this videodisc in conjunction with discussion with his physician has become a *de facto* standard for informed consent in the United States, and it appears that the rate of surgery has been reduced as a result of patients being better informed about the treatment options. According to the Foundation for Informed Medical Decision Making (Dr. Michael Barry, Massachusetts General Hospital, Boston: personal communication, 1993), in a Veterans Administration hospital (in which ability to pay for treatment was not a factor), about one third of the patients with benign prostatic hyperplasia scheduled for surgery removed themselves from the waiting list after using the videodisc. A follow-up survey revealed that these patients had comparatively mild symptoms and that their clinician agreed that their decision not to have surgery at that time was appropriate. Many of these patients had not understood the reason for surgery; they erroneously thought it was necessary to prevent cancer. In this case patient education appears to have succeeded in improving the quality and cost-effectiveness of care. Indeed, a system to help patients avoid services that they neither want nor need is preferable to the rationing of services by providers or, worse, administrators or governments, inherent in some conceptualizations of clinical guidelines.

The shared decision-making approach is being extended to other clinical situations in which decisions likely depend on patient preferences. In this regard, there are now videodiscs about hypertension treatment, treatment of low-back pain, cardiac surgery and breast cancer treatment. Other videodiscs, including one to assist patients with stable angina, are being prepared.

The need for such elaborate mechanisms to present information depends on the clinical condition. Development of a videodisc is complicated; it requires knowledge of treatment possibilities and outcomes as well as the characteristics of patients that can affect their choices. Sessions must be held with providers to ensure that the information is fair and unbiased and with patients to make sure it is clear. Provisions must be made to update the material as knowledge changes. Producing an interactive videodisc involves much more than technology and film production. Like other information systems, it obeys the "garbage in, garbage out" rule. To be credible such information sources should be produced by groups without a vested interest in the decision made;

for example, a videodisc extolling drug therapy for benign prostatic hyperplasia would have little credibility if it was made by the manufacturer of a drug for the condition. For conditions in which cases are very similar production of a videodisc may not be worth the effort; brochures or simple noninteractive videotapes would probably be sufficient. However, the interactive videodisc has great potential to inform patients with conditions for which customized information is important, and it is likely to have a significant effect on medical practice.

In the next article in this series, I will examine how much patients choose to participate in decision making and the implications of these changing models for the roles of health care providers.

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