

Should physicians discourage patients from playing the sick role?

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Résumé

MÊME SI, DEPUIS LES ANNÉES 1950, on peut sentir l'influence des modèles de soins qui mettent l'accent sur la participation active des patients dans le processus décisionnel, les conclusions que nous présentent dans ce numéro les D^r Anne M. Stiggelbout et Gwendoline M. Kiebert (page 383) nous laissent croire que les patients ne sont peut-être pas favorables à une telle idée, au contraire des éthiciens, des chercheurs et des décideurs. Dans cet éditorial, l'auteure prétend qu'il peut être plus raisonnable pour les patients de jouer un rôle passif lorsque leur état porte peu à conséquence ou que leur pronostic est peu optimiste et que les options thérapeutiques sont restreintes. Toutefois, les patients atteints d'une maladie chronique, comme le diabète, qui adoptent le «rôle de malade» risquent fort d'amoindrir leur chance de bénéficier d'un résultat optimal.

Put yourself at the patient's end of the stethoscope. You feel miserable and you're scared. The doctor begins to tell you about the pathophysiology of your illness and the options for treatment. Now, in addition to feeling miserable and scared, you're confused and overwhelmed. If the doctor makes the decisions, you'll be spared long discussions filled with words you don't understand. But if the doctor asks you to help make these decisions, you may find yourself wondering, "Shouldn't my *doctor* know what to do?"

Inviting patients to make health care decisions reveals to them the enormous uncertainty that exists in medicine. Patients who participate in their own care shoulder some of the responsibility for what happens under these uncertain conditions. Those who leave everything up to the physician can, when a poor outcome occurs, blame him or her for choosing the wrong course of action. From the patient's perspective, there may be distinct advantages to sitting back and letting health care professionals do all the work.

However, patients who actively participate in their own health care fare better than those who do not. Theoretical work on the physician-patient relationship has long supported this assertion. In 1956 Szasz and Hollender¹ proposed a "model of mutual participation" in which "essentially, the physician helps the patient to help himself." They noted that this model, a far cry from the then dominant models of "activity-passivity" and "guidance-cooperation" was, in the management of chronic illnesses such as diabetes, not only preferable but essential. Nearly 4 decades later, Emanuel and Emanuel² advocated a deliberative model of physician-patient interaction that also requires the patient's active involvement.

Researchers have documented the benefits of patient participation. For example, when Greenfield and colleagues coached patients with peptic ulcer disease³ or diabetes⁴ to negotiate medical decisions with their physicians, they found that patients who had been coached had fewer disease-related functional limitations than control patients. Vickery and collaborators⁵ showed that, compared with standard care, guided self-care for patients with upper respiratory infections led to a more efficient use of resources and to superior outcomes. Policy-makers also seem to have embraced the notion that patient participation matters: all of the clinical guidelines developed by the US Agency for Health Care Policy and Research include a guide for patients. Disturbingly, however, the findings reported by Drs. Anne M. Stiggelbout and Gwendoline M. Kiebert in this issue (page 383) suggest that although ethicists, researchers and policy-makers believe in patient involvement, patients may not.⁶



Editorial

Éditorial

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Stiggelbout and Kiebert interviewed patients with cancer, or with benign conditions requiring surgery, as well as their healthy companions and found that patients seemed to prefer a passive role in health care. The investigators hypothesized that most patients adopt a "sick role" when they are ill, preferring to be passive recipients of, rather than active participants in, health care. Their study has substantial limitations: the numbers of patients and companions interviewed were small; the investigators asked patients to respond to hypothetical circumstances rather than actual clinical situations; and the generalizability of the study, which was conducted in The Netherlands, is uncertain. Nevertheless, Stiggelbout and Kiebert's preliminary findings are provocative and troubling.

If their findings prove true, physicians face an enormous challenge. Imagine caring for a patient with poorly controlled diabetes mellitus who desires little information on diabetes and its treatment and prefers not to be involved in his own care. Think about a young woman with intraductal carcinoma in situ of the breast who, when her physician attempts to determine her preference regarding surgery alone versus surgery with adjunctive therapy, says "Oh, I don't know, doctor, you decide." Many physicians find it frustrating when patients play the sick role. Are they convinced that patients who participate in their care fare better than those who do not? Or are physicians simply eager to share some of the responsibility for difficult decisions? A number of factors likely contribute to physicians' willingness to foster patient involvement.

Stiggelbout and Kiebert's data suggest that older, sicker and less educated patients are more likely than others to adopt the sick role. This is disquieting. The patients who stand to benefit the most from information and participation may be the ones most likely to resist becoming involved. The stakes of being passive are much higher for elderly patients, those who are less educated or those with multiple problems than they are for young, well-educated patients. Physicians may have to encourage patients, especially those prone to passivity, to become active members of the health care team.

The specific diseases selected for the study may have contributed to the somewhat surprising findings. Participants were asked to consider tinea pedis, cholelithiasis, skin cancer and laryngeal cancer: both trivial and catastrophic health problems but no chronic illnesses. In chronic disease, co-management of illness by health care providers and the patient appears to be a particularly effective strategy and is winning more advocates. However, it may be perfectly reasonable for patients with tinea pedis or laryngeal cancer to take a passive role. In the former case, treatment is straightforward and the consequences of passivity are trifling. In the latter, therapeutic options are few and the prognosis is poor, and it may be equally reasonable for patients to defer decisions to their physicians.

But what are we to do if patients with diabetes or asthma decline to participate in their own care? We can only hope that patients with chronic illnesses will not be as eager to adopt the sick role as Stiggelbout and Kiebert's study patients were. Clinicians and researchers should give close attention to the exploration of chronically ill patients' attitudes toward informed participation.

The agenda for further research on the benefits of patient involvement in health care decision-making is lengthy. In addition to determining patients' preferences in chronic disease care, we need to seek evidence of the sick role in other populations and in patients faced with actual rather than hypothetical decisions. Careful comparisons of outcomes between patients who participate in their own health care and those who do not are sorely needed. Such work will enable us to determine whether sharing decisions with informed patients improves outcomes. If, as I suspect, it does, we will need to elucidate the most effective ways of providing medical information to patients and engaging them in their own care. We must identify optimal ways of eliciting patients' expectations and preferences and providing them with health-related information.

Increasingly competitive health care markets have compelled health care providers to bend over backwards to meet patients' expectations. Over the past 3 decades, the medical profession's paradigm has shifted steadily away from paternalism toward patient participation.⁶ In our headlong rush toward patient satisfaction, we may have assumed wrongly that patients desire detailed health-related information and expect to be involved in decision-making. We may need to slow down and first make sure that patients appreciate the importance of being informed participants in their own care. Should physicians let patients play the sick role? If that is truly what patients want, then we may have no choice. However, it is probably prudent to warn patients that playing such a role may prevent them from attaining optimal health care outcomes.

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