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# Patients as partners in managing chronic disease

*Partnership is a prerequisite for effective and efficient health care*

When acute disease was the primary cause of illness patients were generally inexperienced and passive recipients of medical care. Now that chronic disease has become the principal medical problem the patient must become a partner in the process, contributing at almost every decision or action level. This is not just because patients deserve to be partners in their own health care (which, of course, they do) but also because health care can be delivered more effectively and efficiently if patients are full partners in the process.

Today in the United States chronic disease is the major cause of disability, is the main reason why people seek health care, and consumes 70% of healthcare spending. The differences between acute and chronic diseases are seen in the box on the *BMJ's* website. With acute disease, the treatment aims at return to normal. With chronic disease, the patient's life is irreversibly changed. Neither the disease nor its consequences are static. They interact to create illness patterns requiring continuous and complex management. Furthermore, variations in patterns of illness and treatments with uncertain outcomes create uncertainty about prognosis. The key to effective management is understanding the different trends in the illness patterns and their

pace. The goal is not cure but maintenance of pleasurable and independent living.

In most cases doctors cannot accurately detect the trends themselves. The patient knows them better, and provides information and preferences that are complementary to the doctor's professional knowledge. In general, the patient provides the individual information and the doctor the general information, and both are necessary for effective management.

The present healthcare system arose in response to acute disease. During the past 50 years, as the prevalence of chronic disease has risen, acute care practices have proved increasingly inefficient and ineffective.<sup>1,2</sup> Uninvolved patients, unnecessary hospital admission, expensive but indecisive technologies, and useless accumulation of clinical data all drove health expenditures higher and higher without evidence of commensurate improvement in health status.

In general, the contradiction between acute care practices and chronic disease problems has been ignored by policymakers in favour of a focus on organisational and financial reform. The reforms—exemplified by managed care—are generally based on an industrial model in which health care is perceived as a production process and the patient as a customer. As a customer, the

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website

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*Box of differences between acute and chronic diseases appears on the BMJ's website*

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patient is again excluded from the healthcare process except for selecting among the services offered. The model of health care as a production process has value. But the product and the producers must be accurately identified. As Hart has argued, in health care the product is clearly health and the patient one of the producers, not just a customer.<sup>3</sup> Thus the role of the patient with chronic disease is similar whether viewed from a clinical care perspective or a production perspective. In the former the patient is the principal care giver and in the latter an active producer. In both cases, the patient must become a partner of the physician.

Not long after chronic disease began its ascendancy effective and efficient methods of management were devised, particularly home care and community based services.<sup>4-6</sup> Subsequently, many effective managements emerged for diseases such as asthma, diabetes, hypertension, coronary artery disease, chronic bowel disease, and back pain. Because the patient must understand and assent to new practices and new responsibilities, an effective working relationship between patients and health professionals became essential. Taking the patient's views into account was associated with higher satisfaction, better compliance, and greater continuity of care.

Recently, three programmes have been developed that enhance the ability of patients with chronic disease to participate in their health care. Each places patients in a central role and has been tested experimentally. The first is self management education that addresses continuous use of medication, behaviour change, pain control, adjusting to social and workplace dislocations, coping with emotional reactions, learning to interpret changes in the disease and its consequences, and use of medical and community resources. Participants experience reduced symptoms, improved physical activity, and significantly less need for medical treatment. Some benefits have lasted years beyond the education. An important element for participants is learning from each other, and the principal reason for benefit is growth in confidence in their ability to cope with their disease.<sup>7,8</sup>

The second approach is group visits. These are recurrent meetings of groups of patients with their principal doctor. The agendas are largely set by the patients and concern problems they encounter from their disease. Participants experience increased quality of life,

much slower decline in activities of daily living, greater satisfaction, and reduced use of medical services.<sup>9</sup>

The third approach is remote medical management via the telephone or electronic communication. Chronic disease is particularly suitable for remote management, especially when there is continuity between the patient and service provider. In randomised trials telephone management has been shown to reduce cost and to improve the health status of participants compared with patients receiving usual care.<sup>10</sup> The article by Simon et al in this issue is a recent example (p 550).<sup>11</sup>

Better ways to manage chronic disease have been known for years—Wagner describes some further examples in this issue (p 569).<sup>12</sup> But those ways have been neglected at policy and institutional levels. The longer the neglect, the more distant effective and efficient health care will be. The bedrock of the better ways is a partnership between patients and physicians.

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