Chapter XV

The Web-Enabled Patient

Michèle Lemaire
Anabase International Corp., USA

The past decade has witnessed major changes in the concepts of health and disease and in the respective role and responsibility of doctors and patients in health maintenance and disease management. These changes were triggered by cost-containment imperatives. Although constraining by nature, these imperatives are also enabling.

The original incentive to engage people in taking larger responsibility in their own care was economic. The strategy used to foster commitment to better health was increasing people's health awareness and making them confident they could modify their behavior, and in so doing reduce their risk for preventable diseases such as cardiovascular diseases (primary prevention) or detect diseases at earlier stages such as cancers (secondary prevention). Only recently, the concept of encouraging people to participate in their own care has been extended to patients with chronic diseases. Here, the objective is to make the patient able to practice self-care in the management of his/her disease, and the incentive is still to reduce the demand for and cost of care. Health promotion, disease prevention and disease self-management all rest on education: systematic education about diseases and risks, practical information on how to adopt appropriate behaviors, and training in self-care skills along with the message that people have the capability to change their behavior and acquire the necessary skills. These changes brought about by economic concerns can be seen as constraining, since they require active self-monitoring and self-discipline. However, as they rely heavily on health information and the development of self-confidence, their unintended consequences, enhanced by the current technology developments, are patient empowerment and a change in the doctor-patient relationship.

The Internet, by offering both unfiltered information resources and powerful communication tools, increases the capacity of the willing patient to take an active role in his/her own care. It allows him/her to do it more extensively and more efficiently. Better-informed patients, building up on real-life experiences exchanged with other patients in disease-specific forums can discuss treatment options with their physician, understand and comply with treatment guidelines, and achieve better clinical outcomes. Besides the growing
number of Internet companies and medical institutions offering medical information, we are seeing the growing number of patient-initiated Web sites that provide at once up-to-date disease-specific information, practical advice and emotional support. We are witnessing the organization of the Web-enabled patient community significantly changing the politics of medicine and healthcare. Education and peer support play a primary role in making this revolution possible. By providing the necessary logistical support, the World Wide Web makes it happen.

The purpose of this chapter is to describe an emerging trend, to identify the factors that contributed to its occurrence, and the implications this has for healthcare and the practice of medicine. The emerging trend is that of patients using each other’s experiential expertise and the World Wide Web1 on their own initiative to deepen their understanding and knowledge of their disease(s), so to enable them to team-up with their physician to address their specific care needs and hopefully improve their health outcomes. This emerging trend finds its roots in education promoted by the new medical models of health promotion and disease prevention, as well as in the self-help movement. Because Web-enabled patients do not intend to use the World Wide Web to replace their doctors, and because there is also a need to make these resources accessible to people from all boards, this emerging trend brings both opportunities and challenges to the medical community. There is a need for physicians to contribute their expertise in new ways, but it is conditioned upon their increased participation in the interactive health communication networks.

PATIENT EDUCATION: FROM PASSING DOWN INFORMATION TO EMPOWERMENT AND ITS CONSEQUENCES

The interest in health promotion and disease prevention preceded by about a decade the restructuring of healthcare delivery prompted by cost-containment imperatives. For Becker and Rosenstock (1989), the Lalonde report published in 1974, which assessed the health of Canadians, demarcates the origin of the health promotion movement. This report identified four contributing factors to death and disease, one of them being unhealthy behaviors. The American experts represented in the Surgeon General’s report (DHEW or U.S. Department of Health, Education, and Welfare, 1979) showed that about 50% of U.S. mortality in 1976 was due to unhealthy lifestyles and behaviors against 20% due to environmental factors, 20% due to human biological causes and 10% due to healthcare inadequacies. A more recent investigation (McGinnis and Foege, 1993) demonstrates that about half of the deaths that occurred in 1990 could be attributed to unhealthy behaviors, socioeconomic status and access to care. Among these contributors, the leading causes of death in the U.S. in 1990 were still tobacco, diet and physical activity patterns, and alcohol. Rather than concluding that health promotion doesn’t work, we need to recognize that in the short term, expectations should be limited to change in behaviors and public attitudes, which is the case regarding smoking. Improved outcomes can be evaluated only on the long term. Therefore, health promotion, a “combination of health education and related organizational, economic and environmental supports for behavior conducive to health” (Green, 1984, p.190), should have beneficial outcomes in terms of disease prevention and represents one promising way of reducing health expenditures. However, it requires expanding the
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