What an Informed Patient Means for the Future of Healthcare

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Abstract

Professionalism is the basis of medicine’s contract with society, and the principle of patient autonomy is a fundamental value of our profession. Physicians must respect patient autonomy by being honest and empowering patients to make informed decisions about their health.

What information do patients need to understand in order to be able to take care of their health? How do we make sure that information is adequately communicated so that everyone who needs it can access and understand it? Health literacy is increasingly recognised as essential for successful access, navigation, self-care and management of health and wellness in America. Unfortunately, there is a large gap between the literacy demands of the health system and the health literacy skills of most Americans. A recent Institute of Medicine report concludes that nearly half of American adults have difficulty understanding and acting upon health information. Low health literacy is associated with less knowledge of diseases and self-care, worse self-management skills, lower medication compliance rates, higher rates of hospitalisation and worse health outcomes.

Health literacy problems are magnified as patients are increasingly asked to take more responsibility for their health in a healthcare system that is increasingly complex, specialised and technologically sophisticated. Most would agree that it is hard to be a patient these days; health literacy is needed for navigating and understanding what you need to do. Improving health literacy is essential for improving quality, reducing disparities and reducing costs.

Understanding and being able to use essential information is critical for good health. The principle of patient autonomy is fundamental to professionalism, which forms the historical basis of medicine’s contract with society. Physicians are challenged to ensure that patients are completely and honestly informed in order to ensure that they are empowered to decide on the course of therapy. Modern health systems increasingly make extraordinary and complex demands on patients, including those required to access, use and follow through with suggested diagnostic studies, therapies and self-management plans. In this context, health literacy, defined as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions, is of growing importance. What is the role of the informed patient in the 21st century healthcare system of the US? To explore this, I present a brief clinical case of a future patient with a common clinical problem. This is followed by a description.
of various dimensions of information needed to function successfully as a patient, what is known about the health literacy abilities of the average American today, and a discussion of the specific health literacy challenges for achieving a health literate public.

1. The Case

In his 2005 Shattuck Lecture, Senator William Frist described this hypothetical patient from the year 2015.[2]

Mr R. is a 44-year-old with multiple chronic illnesses, including diabetes mellitus, hypercholesterolaemia and hypertension. He takes one pill a day that is a combination of aspirin (acetylsalicylic acid), an ACE inhibitor, a medication to control his blood sugar and a cholesterol-lowering medicine. He has a radio-frequency computer chip implanted in his abdomen to monitor his blood chemistries and blood pressure. He is obese, he quit smoking 8 years ago and his father died of a myocardial infarction in his 50s. Mr R. has a health savings account and a high-deductible insurance policy for health coverage and has a primary care provider that he selected after carefully comparing online information about pricing, performance and credentials. He owns his privacy-protected electronic medical record and regularly communicates with his medical team using e-mail and video conferencing. Mr R. acutely develops chest pain and the cardiologist in the ‘nanocath’ laboratory injects nanorobots intravenously, and the 90% lesion in his left anterior descending coronary artery is repaired. Before Mr R. returns home, the insurer has already paid the hospital and the physicians. Because of the recognised quality of this hospital, payments are slightly higher than those of its competitors. The co-insurance and deductibles are automatically deducted from Mr R.’s health savings account, and he even gets a 10% deductible because he had met all his self-management goals for the year.[2]

The ensuing discussion of this case by Dr Frist recaps the three fundamental driving forces of the patient-centred, consumer-driven, provider-friendly transformed health system of the future. These forces are those of information, choice and control.[2]

Health literacy can be thought of as currency for negotiating the healthcare system, and the currency is of growing importance.[3] For the patient of the future described above, health literacy is essential for informed choice about providers for primary care and acute care, self-management of chronic conditions, and meaningful communication with health providers.

2. Health Literacy of the ‘Average’ American

Health literacy has been defined by the American Medical Association as “a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment.”[4] Healthy People 2010 and the recent Institute of Medicine (IOM) report define health literacy as an individual level construct. Importantly, the IOM report details that health literacy is a shared function of social and individual factors, including reading, writing, numeracy, listening, speaking and conceptual knowledge.[5] Health literacy is based on the interaction of an individual’s skills with health contexts, the healthcare system, the education system, and social and cultural components. These definitions demonstrate that health literacy can help explain one’s ability to access, understand and apply health information successfully in order to function in daily life and within the healthcare system.

What do we know of the health literacy skills of Americans today? Data from large national studies demonstrate that the average literacy skills of US adults are not adequate for understanding and using the health and healthcare system of our country. About 90 million adults have literacy skills that test below the high school level, and the majority of these adults are native-born English speakers.[5] The literacy levels are lower among the elderly, those with lower educational levels, immigrants with limited English proficiency, those...