# Virtual Mentor

**STATE OF THE ART AND SCIENCE**
**The Patient, the Physician, and Dr. Google**
Bradford W. Hesse, PhD

In July of 2002, I watched as my wife, a practicing obstetrician/gynecologist, was deluged with telephone calls as scores of her patients began processing the news that the National Heart, Lung, and Blood Institute had halted the combined estrogen and progestin arm of the massive Women's Health Initiative clinical trial because of concerns of risk over invasive breast cancer. What was perplexing about the experience, I recall, was that many of the women calling had already downloaded a preprint of a *JAMA* article explaining the institute's decision a full week before the print issue had arrived at my wife's desk. Naturally, the callers were filled with questions. One of my wife's more innovative solutions was to invite interested patients to a journal club review of the online article, so that they could go over and digest the new information together.

What I was watching firsthand was playing out in physicians' offices around the country. In 1999, a study of online information revealed that health-related concerns dominated much of what people were looking for on the newly opened "information superhighway" [1]. Patients were doing an end run around traditional medical sources and were beginning to search online for answers to their health-related questions. What they found, though, was a hodgepodge of medical information, from cutting-edge study data to dubious advertisements for miracle cures [2].

Often it was difficult to tell what the source of information on a web site might be, and many ostensibly credible web pages were actually masking a spate of ulterior motives. Direct-to-consumer advertisers were especially prevalent in this space, with new online companies making it easy to skirt local jurisdictional restrictions on the sales of pharmaceuticals. Phishing (i.e., the fraudulent practice of sending people to a bogus web site that collects their personal account information) and "pharming" (i.e., the tactic of enticing consumers to download malevolent software in the guise of updating antivirus software) added to the lack of trustworthiness [3].

In spite of the obstacles, online patients were able to navigate their way to trusted medical organizations. In 2001, for example, worries about bioterrorism following the national anthrax scare drove an unexpected amount of traffic to the Centers for Disease Control and Prevention's web site. What readers found was presented in a highly technical way and was difficult to interpret. Accessing journal articles only added to the confusion, as patients tried to make sense of a specific field's jargon and complex statistical treatments of findings [4]. There was a prevailing sense that patients appreciated being able to get at original source material easily through the web, but that they needed help interpreting it.

Seeking an alternative to more formal sources, patients also began using the Internet to find similarly diagnosed others through listservs and discussion groups [5]. It wasn't long before these groups of online patient communities became their own sources of information about side effects, solace from others who were experiencing similar disease trajectories, and advice on how to navigate the complexities of a fragmented health care system [6]. Some commentators wondered whether the "disintermediating" influence of the web (that is, the ability to bypass traditional information gatekeepers) would signal a "crisis in trust" of the medical profession as it had for the financial and travel industries [7].

To understand what these changes in the information environment meant for health and health care, the National Cancer Institute launched the Health Information National Trends Survey (HINTS) in 2001. The HINTS program was created as a biennial, general population survey of adults 18 years and older to monitor the public's use of a changing health information environment to improve their own health. Data files, reports, top-line briefs, linked lists of published papers, and a method for comparing variables within the dataset over years are all on the NCI's website [8]. The results have been enlightening.

Rather than signaling a "crisis of trust" in physicians, the HINTS survey suggested that the American public was continuing to place its greatest degree of confidence in its doctors [9]. That trust actually increased with the proliferation of online health information [10]. But regardless of the growing trust in their doctors, patients continued to say that the Internet remained their "first source" of health information when reporting what happened the last time they looked. That is, because of its simple convenience, the Internet was the starting point for most people's questions about their health. "Dr. Google" was clearly entering into the picture as an invisible part of the patient's solution strategy [11].

As more and more medical information went online, patients reported increased confusion about what the abundance of online medical information meant for their own health [12]. The public experienced what journalist David Schenk called "data smog," bombarded by constant health scares, raw data, and impenetrable scientific language [13]. Lastly, as some medical organizations began experimenting with secure e-mail channels and compensated physicians for time interacting with patients, HINTS data portrayed a slow but steady rise in the number of people who interacted with their physicians through e-mail [14]. There is some evidence that these new online channels may save medical costs and patients' time by allowing nonurgent inquiries to be addressed without an office appointment [15].

What, then, does this mean for the ethics of clinical practice? Health systems researcher Edward Wagner suggested that health must be a product of an activated patient working in collaboration with a prepared health system [16]. In this sense, the rise in number of patients going online to seek information for the "vital decisions" [17] they make in their lives can be viewed as a positive trend. What patients find in

the unfettered, unregulated environs of the global web, however, will continue to vary in quality and reliability.

In this environment, the role of clinical systems in improving the educational experience of patients may actually become more important, not less so. Many highly reputable health care systems and government agencies are creating informative patient portals that invite engagement and support an active approach to preventive care. Credible online sites can even serve as a type of "information prescription" to patients who are seeking to learn more but do not know which information to trust [18].

These efforts are a start, but may not be enough. Information technology and patient brochures are only part of the solution. To create a prepared and responsive health system, designers should look for ways to protect—not obliterate—time for the personal counseling patients may need to make sense of an overwhelming information environment. From a thorough review of the patient communication literature, Arora et al. recommended that in addition to exchanging information a responsive health care system should also find ways to: (a) enable patients to manage their own care; (b) foster healing relationships with the care team; (c) support patients in making sound decisions, taking evidence-based medical knowledge and personal values into account; (d) manage the uncertainty associated with medical diagnoses and probabilistic treatment recommendations; and (e) help patients deal with and respond to their own emotions [19].

Unlike other sectors, the health care sector must rely on a shared understanding of complex processes to be optimally effective [20]. According to the Institute of Medicine, that shared understanding can and should be extended to patients [21]. Online supports for patient engagement may eventually become an integral part of the process [22]. In fact, new data from the Livestrong Foundation suggest that patients do better at self-management once they begin to feel comfortable with their ability to search for and find medically relevant information from a variety of sources [23].

Rather than creating an environment of "disintermediation" (information in the absence of an intermediary), then, the Internet may be creating an environment of "apomediation" (information "surrounding" all parties) [24, 25]. In this world, the ethics of sound health care will likely put the medical team in the position of interpreter or guide, while patients continue to hone their information-seeking abilities and to polish their health problem-solving skills. More to the point, health systems engineers and administrators should strive to create an atmosphere in which physicians and their patients are fully supported in their ability to digest new data and process new information together [26].

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Bradford W. Hesse, PhD, is chief of the Health Communication and Informatics Research Branch, an extramural funding branch of the Behavioral Research Program at the National Cancer Institute in Bethesda, Maryland. He serves as a lead for the University of Pennsylvania's Center of Excellence in Cancer Communication Research program, and he directs the Health Information National Trends Survey (HINTS).

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