Health Information Technology: Empowering Consumers, Patients, and Caregivers

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Introduction

   Traditionally in health care, knowledge and authority have rested with medical professionals and care was delivered in professional settings. Individuals have been considered solely as "patients," i.e. defined by their relationship to doctors. Health information technology (HIT) is enabling consumers (i.e. an individual outside of a patient context), patients, and family caregivers to more fully understand health and illness, to self-manage health and illness at home when feasible, and to partner with their medical providers when necessary. As a result, there is the potential for a re-balancing of the power relationship between doctors and patients toward greater collaboration (including family caregivers), and increased attention to contexts of daily life in which "health happens." However, the available technologies and their actual implementation are currently insufficient to empower consumers, patients and caregivers to fulfill their new responsibilities.

Key Health Information Technologies

   Examples of typical HIT tools and functions for consumers, patients and caregivers include the following.

- Communication between physicians and patients via secure messaging
- Patient web portals, usually linked to a providers' electronic health record system
- Personal health records
- Web sites, social media sites, and online games
- The purchase of health-related products and services over the Internet

- Mobile, wearable, home-based or implanted devices that track and report data, such as heart rate, blood pressure and insulin levels
- Online health information searches
- Blogs, forums, and social media applications that allow people to share their experiences and pose questions [1]

Consumers, patients, and caregivers may have sole control of the technologies, for example, personal monitoring devices, or they may share control with others, such as patient portals that are part of their providers' web sites and linked to patients' electronic health records. When consumers, patients, and caregivers choose and control access to and use of health technologies themselves, they can determine how actively they participate, what information to include, who they want to share information with, and when to begin and end use, as well as define what is accomplished by using the technology. Consumers, patients, and caregivers often enter the information themselves in the device or the device collects information on command or passively. Technologies with shared control, such as patient portals, also allow consumers, patients, and caregivers to determine their level of participation (none, a little or a lot), but the types of information allowed, the rules for initiating and terminating use, as well as information sharing, are set by the organization providing the portal [2].

Medical professionals, employers, and policy makers often perceive "patient empowerment" strategies as means to the end of getting patients to take greater responsibility – both in terms of participating in decision-making and paying a larger share of costs – for their health and health care [1] [3]. Patients value HIT tools that make it easier to participate in their care. Many are eager to know at least some of what their providers know, and tools like portals are the first healthcare innovation that facilitates information sharing and communication, both of which open the door to collaboration. In their own words, they think this "levels the playing field" [4] [5].

With proper safeguards, digital health technologies can create significant opportunities to find health information; do more self-help and self-care; create and maintain personal health records; access personal health information held by providers; consult with healthcare providers through secure messaging or telehealth technologies; transact healthcare-related business; and purchase health-related goods and services electronically (digital health commerce).

Problems with HIT

While the digital divide has narrowed over time, access disparities by age, income, and education remain [6]. Issues of health literacy and usability pose barriers to HIT use across age, race, ethnicity, and literacy boundaries [2]. Nevertheless, researchers find that people with less education or limited health literacy skills will value and use HIT if someone explains the tools to them, they perceive the tools are helpful, and they receive encouragement and support registering for portals and completing tasks [1].

Other issues arise from changing definitions of what constitutes health information, in concepts of ownership and control of personal health information, and in new challenges with respect to ensuring the quality of health information being created by disparate individuals and enterprises. Health information is no longer just the clinical data that are created by doctors' visits, hospitalizations, and lab tests that reside in institutional medical records. It now includes an array of longitudinal information on, for example, prevention, wellness, previous health experiences, alternative and

complementary medicine, and over-the-counter remedies. Currently, there are no widely employed data standards to enable all these different bits of personal health information to be seamlessly integrated. [1] Second, concerns about violations of privacy rights and the confidentiality of health information will continue to influence debates about who owns or controls health information and who should have access to which information. Even if individuals are the presumed owners of their information, the reality is that current information-handling policies and practices give individuals few concrete ways to control the movement of their information among multiple parties.

Technologies coming from the consumer-oriented market are more end-user oriented than tools offered by providers, but their products tend to be divided by function and typically are not interoperable with providers' portals. This sector is driving innovation rapidly, but the unfortunate trend is a proliferation of new stand-alone products. Moreover, most consumer apps fall outside any regulatory framework that would prevent the companies from selling personal information. [2]

Conclusions

Even though HIT tools, such as patient portals and health apps, are increasingly available across the socioeconomic spectrum, consumers, patients, and caregivers still confront a healthcare system coming to terms with technology's consequences for the patient experience and healthcare service delivery. Making HIT tools available is necessary but not sufficient; making them consumer-, patient- and caregiver-centric allows the tools to be truly useful to the people who will derive the greatest benefits.

Ultimately, tools for consumers, patients and caregivers will achieve their potential when they are as highly valued and developed elements of the electronic health information infrastructure as professional tools. Momentum is building in many countries toward holding consumers and patients accountable financially and morally for their health. Before going further in that direction, those who influence health policy, practice, and technology would do well to understand which tools and approaches enable consumers, patients and caregivers with many different needs and capabilities to fully participate in managing health and care.

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References and Notes

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