



Patient Empowerment and Health Information Technology

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White Paper

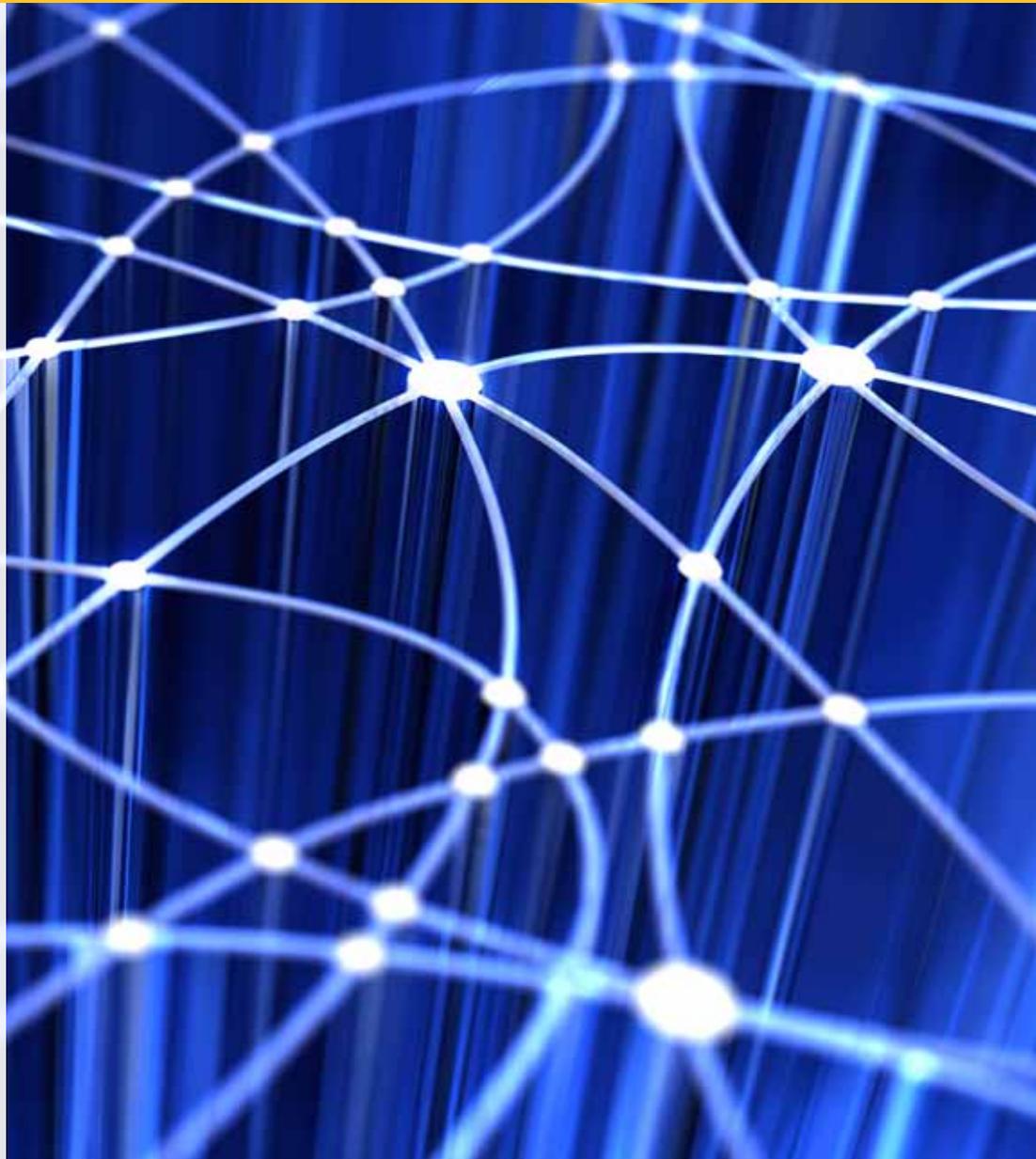
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Abstract

Patient empowerment, patient-centered care, and increased patient engagement are frequently listed as critical elements in prevention and wellness, coordinating care, improving quality and safety, and reducing costs. Health information technology (health IT), including health IT used by patients, can play an important role in patient empowerment. This paper discusses various roles that patients, family members, and health professionals have when managing different health concerns, and the increasing use of technologies that can help patients be informed, engaged, committed, and collaborative in managing their health and care. Matching a particular technology to individual patients depends on the role they and other members of their health team want to play, their skills and abilities, the context of their situation, and the strengths and limitations of the technology for specific activities.

Introduction

Health care has clearly shifted from a paternalistic model toward an increased focus on patient-centered care, patient engagement (AHRQ, 2002), and patient empowerment. Although entities may not agree on the definition of these terms, several scholars and organizations have helped to clarify their meaning and illustrate their importance. The Institute of Medicine Quality Chasm report (Institute of Medicine, 2001) defined patient-centered care as “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” Epstein and colleagues (2010) elaborate that patient-centered care means providing the right care to the right person at the right time, and it is often determined by the quality of interactions between patients and clinicians. Berwick (2009) argues the shift needs to intensify and identifies the tension between “professionalism” and “consumerism”—placing a priority on safety and effectiveness from a health system point of view, versus a priority on consumer-defined value and quality, even if it conflicts with professional best practice or judgment.

Starfield (2011) recently highlighted some key differences between patient-centered care and person-focused care. She suggests that patient-centered care generally refers to interactions during health care visits, which may be episodic and focused on managing diseases versus a more holistic approach. On the other hand, she believes that person-focused care aligns more with interrelationships over time, viewing diseases as interrelated phenomena and considering episodes as part of life-course experiences with health, bringing out the challenge Berwick identifies. Gruman and colleagues (2010) argue that one element is often missing from descriptions of patient-centered care: the recognition that patients are not merely the objects of care, but that they are also full-fledged participants in it. This perspective points out a key link between patient-centered care and patient engagement activities. Johnson (2011) describes patient engagement as “active participation in health

care, including accessing appropriate care, attending and preparing for appointments, and using additional available resources to maintain a high level of involvement in care.”

Regardless of the specific definitions or terminology one uses, the relationship between the patient and his/her clinician is a key part of the picture. The Institute of Medicine described a patient-clinician partnership model as central to the vision of a “learning health care system” that is “designed to generate and apply the best evidence for the collaborative health care choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care” (Institute of Medicine, 2008). It embodies bidirectional communication with patients playing an active role in their health care (Institute of Medicine, 2008), supporting collaboration.

To be active in one’s health and health care, a patient—especially someone who manages a chronic condition—must be informed and capable of interacting productively with others on the health care team (Wagner, 1999). In this partnership model, informed and engaged patients are better positioned to collaborate with professionals, cultivating a trusting physician-patient relationship based on mutual respect and shared understanding. The Patient Protection and Affordability Care Act of 2010 (<http://www.cms.gov/LegislativeUpdate/downloads/PPACA.pdf>) highlights the importance of active patients who make informed health care decisions supported by medical evidence. The Act established the Patient-Centered Outcomes Research Institute to identify and facilitate patient-centered outcomes research emphasizing patient engagement.

Johnson’s operational framework for patient empowerment brings several related concepts together to stimulate research and clinical awareness. Health care empowerment is described as “the process and state of participation in health care that is characterized as (1) engaged, (2) informed, (3) collaborative, (4) committed, and (5) tolerant of uncertainty” (Johnson, 2011). This framework hypothesizes that personal resources, intrapersonal factors, and cultural/social/environmental factors affect patient empowerment. While patient-centered or consumer-facing technologies are not explicitly identified in the framework, their impact is growing—especially in communications, information acquisition, computer-assisted decision support, and self-monitoring. Amidst the flood of health-related internet, mobile, and desktop tools for consumers, helping patients navigate technologies that empower them to improve their health care experience, safety and quality, and partnerships is a challenging task. All of this information and data suggest expanding roles for patients.

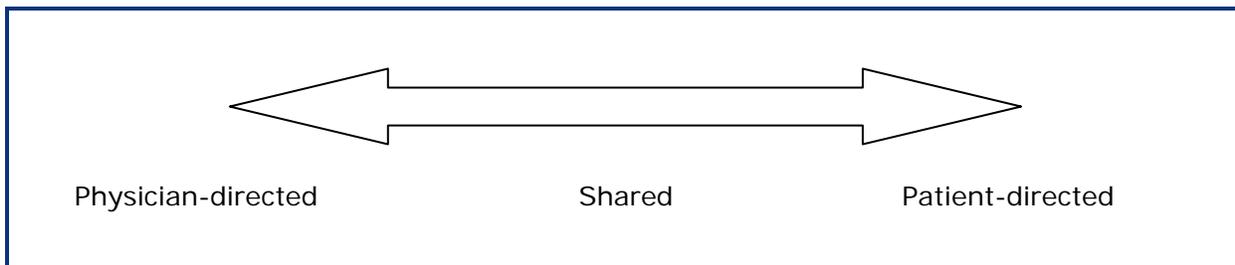
Patients’ Role in Their Health and Health Care

In the early 1950s medical paternalism was evident as researchers advocated the “sick role” of the patient, a weakened state in which a physician makes decisions on behalf of the patient and provides strong medical guidance (Varul, 2010). Emanuel and Emanuel (1992) described this as the “paternalistic” model of a physician-patient relationship. This model continues to apply today, especially when patients and physicians have vastly different levels of knowledge, experience, and authority concerning health matters, or when

physicians hold to this stance. It is natural for patients facing a serious or unfamiliar health situation to rely on a trusted physician's experience and expertise to direct their care. Even patients in routine medical situations often feel comfortable following the doctor's orders when they expect treatment and recovery to follow a predictable course with strong science or experience guiding medical decisions, such as the decision to remove an appendix in the context of acute appendicitis.

But certain patients, even those who are comfortable with physician-directed care, take a different approach in some situations. They recognize that medical practice involves trial-and-error, uncertainty, and adjustments in decisions over time. They understand that even established care guidelines, while intended for everyone, should be tailored to individuals based on the individual's treatment response, preferences, and culture. Health-related decisions should be made on the basis of not only the physician's expertise, but regular patient feedback about symptoms, treatment challenges, preferences, and even beliefs about alternative diagnoses. Emanuel describes an alternative to the physician-directed paternalistic approach: informed decision making, with varying degrees of physician involvement to provide facts ("informative"), share opinions ("deliberative"), and elicit patient values ("interpretive"). Not only patients, but a growing number of health professionals believe that patients must participate in their care actively to attain the best outcomes and experience of care possible (Buetow, 2009). In reality, the roles of patients and physicians are not static or simple, simultaneously incorporating multiple points along the patient-physician relationship continuum from self-directed care to physician-directed care (see Figure 1).

Figure 1. Range of decision making for patients and clinicians



Just as physicians may not play a role in care decisions if access to them is limited, there are limits to the role that patients can take. Many patients do not have the necessary health literacy (including numeracy) skills to participate easily (AHRQ, 2010); others lack the financial or social support. Some patients are too sick to meaningfully engage, while others simply prefer or choose not to be involved or engaged. Several studies found that few patients want a fully autonomous role; most preferred to share decision making or leave decisions up to the clinician (Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Levinson, Kao, Kuby, & Thisted, 2005; Robinson & Thomson, 2001). Role preferences differ significantly by patient gender, age, race, ethnicity, and other characteristics. Some patients report anecdotally that their doctor has rejected their attempt to become more engaged in their

care. Successful patient engagement depends on many patient and clinician factors, including their personal traits.

Those who can play a more active role in their health care do so in a number of ways. Seeking health information is one of the most common aspects of an active patient's role. According to the Pew Research Center, health information is one of the most frequent topics that internet users research online (Pew Internet, 2011). Social networking sites provide numerous opportunities to obtain real-time information, though it may be unverified. Many consumers feel challenged to find useful and appropriate health information, may not trust the sources of this information, and may doubt the objectivity and accuracy of the information they find (Monroe, 2002).

Other activities that increase patients' participation include asking questions, stating preferences, and generally being involved in decision making. One nationally representative survey assessed the U.S. public's preferences for participation in medical decision making (Levinson et al., 2005). Respondents expressed preferences for patient-directed or physician-directed styles in seeking information, discussing options, and making the final decision. Nearly all respondents (96%) preferred to be offered choices and asked their opinions. However, 52% preferred to leave treatment decisions up to the physician, and 44% preferred to rely on physicians for medical knowledge about their condition.

Patient preferences for participation are not static but often shift as their health or health concerns change, their health team involves new people, their cognitive skills develop or decline, and they practice new behaviors. Certain common situations, such as (a) facing a new health problem, (b) managing a chronic condition, (c) dealing with critical, emergent, or end-of-life concerns, or (d) proactively focusing on prevention and maintaining health, pose predictable challenges to the patient across a variety of conditions. As technology use expands rapidly among health professionals through a major government initiative called HITECH (Blumenthal et al., 2010), consumer adoption of technology and use by patients is increasing even more rapidly (Fox, 2011).

Technologies for Patient Empowerment in Health and Health Care

Patients use a variety of technologies to manage their health and health care. Common sources of information include (a) medical content via internet sources that offer information ranging from general medical knowledge to tailored health advice or practical advice through text documents, videos, and the medical literature; (b) e-mail and other communication tools, including patient portal messaging systems, online community blogs, and text messaging; (c) online communities offering social support, decision-making advice, health news, personal broadcasting of health status, and group help in solving a problem or answering a question; (d) patient portals—organizational websites offering patients and their caregivers secure and convenient access to information from their medical chart, claims, or administrative information—as well as many more interactive services such as health history tools, screening forms, linked reference information, and electronic messaging with health care providers; (e) data-capture tools such as pedometers, glucose

sensors, pain or mood scales, weight management systems, and fitness tracking devices that patients increasingly use to self-monitor and share data with others (see Table 1).

Table 1. Technologies and Supported Patient Activities

| | Technology | Supported Patient Activities | Technology Examples |
|---|---|---|---|
| A | Online messaging | Communicate; remind; follow-up care; pre-visit preparation | E-mail; Patient portal messaging systems; blogs; text messaging |
| B | Medical and health information on the internet | Learn about diseases, symptoms, condition, medicines, lab tests, procedures, treatment options, risks, prognosis, care process, treatment guidelines, key online resources, technologies, access to care, pre-visit preparation, etc. | Multum (medicines), Healthwise (disease/condition), Medline Plus, Healthfinder.gov |
| C | Online community for health conditions and health | Learn from patient experiences; give/receive social support; share information, personal status; images; links; videos; access online messaging and internet medical content | PatientsLikeMe; DiabetesMine; TalkAsthma.com |
| D | Patient portal from provider, payor, employer | Source of personalized medical chart info, administrative info, claims info, communication, and other interactive services (depending on the sponsoring organization) | MyHealthManager (Kaiser); MyChildrens (Childrens Hosp Boston); Patient Gateway (Partners) |
| E | Data-capture and personal health record tools | Documenting health and health care information; self-monitoring; sharing data with caregivers and other nonprofessionals; sharing data with the health team | Microsoft Healthvault; Dexcom |

These “patient-facing” technologies support a range of patient activities, but how does that translate to support for patient engagement, patient empowerment, and patient-centered care? The following examples describe how technology use can help patients to be more informed, engaged, collaborative, committed, and tolerant of uncertainty.

Informed. The vast amount of information resources available on the internet, through proprietary applications, through online communities, and via patient portals, can help patients to be informed. Eighty percent of online consumers use the internet to seek health information (<http://pewinternet.org/Reports/2011/HealthTopics.aspx>). Whether searching for information compiled by patients with input from health professionals about a rare disease such as leiomyosarcoma (<http://www.leiomyosarcoma.info>) or an extremely common condition such as diabetes (<http://www.DiabetesMine.com>), patients have a wide variety of sources from government sites such as the National Institutes of Health

(<http://health.NIH.gov>) or Centers for Disease Control and Prevention (<http://www.cdc.gov/DiseasesConditions>), to nonprofit commercial sources such as Healthwise (<http://www.healthwise.org/solutions/consumerengagement.aspx>), which supplies many types of referenced and reviewed information, to health information sources such as WebMD (<http://www.webmd.com>) or an increasing number of websites offered by individual health professionals, practice groups, hospitals, and nonprofessionals. Video resources on YouTube (<http://www.youtube.com>) provide instruction on topics as diverse as how to self-administer an insulin injection, use an insulin pump, or recognize the sound of a barking cough in a child with whooping cough (pertussis), although the verity of the information needs to be judged by the user.

The medical chart information accessed via patient portals is important not only because it helps patients to review their lab results, appointment schedule, medications, immunizations, and other personalized medical information, but because it fosters shared understanding among patients and health professionals (Ralston et al., 2010). Regulations favoring patient direct access to laboratory test results are part of the HITECH Act (Blumenthal, 2010), and newly proposed CLIA legislation (U.S. Department of Health and Human Services, 2011) would permit laboratories to share information directly with patients rather than only with the physician, preempting state law. Having embedded informational links near a test result offers patients considerable background information to help them understand more about a test, its normal range, and the possible clinical meaning of a result before or after they meet with their doctor. Chart information also helps patients to share accurate details with a family caregiver or another health professional.

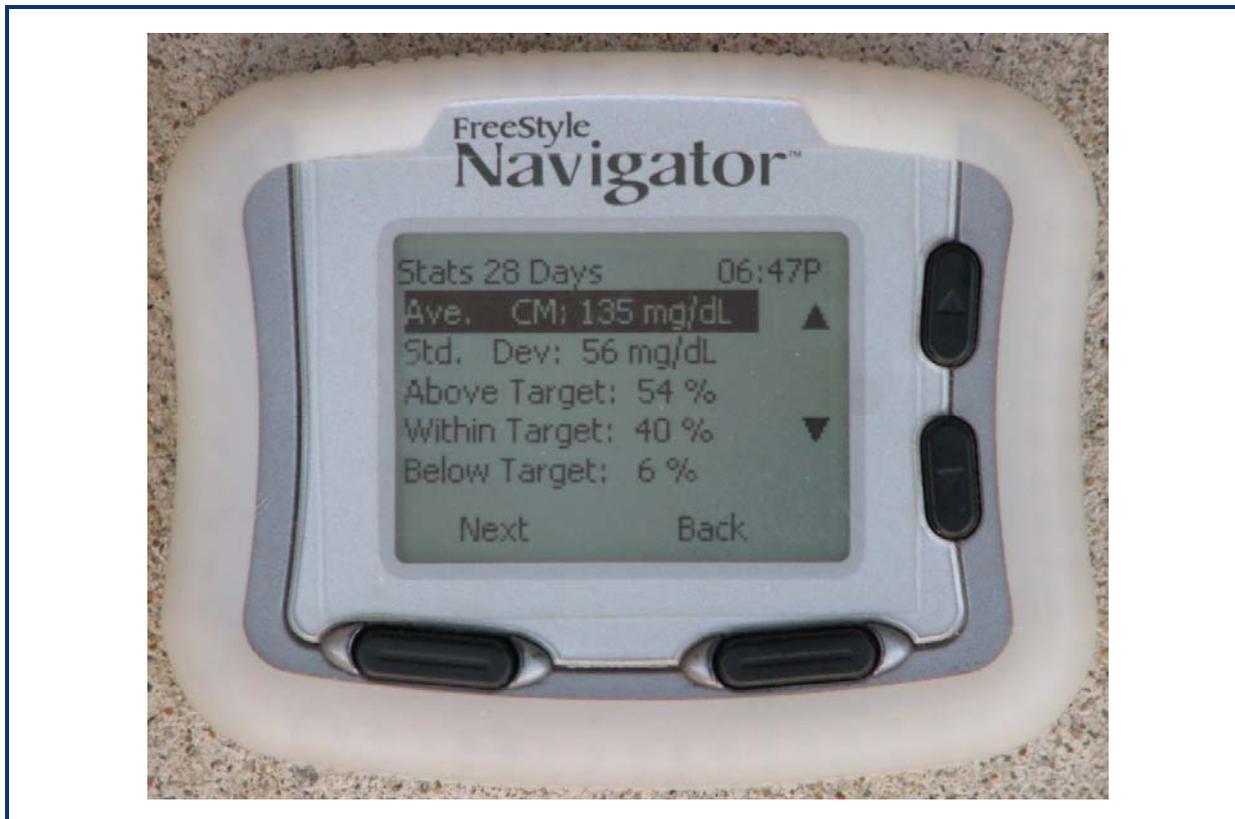
Collaborative. E-mail and communication tools make it easier for patients and health professionals to share and discuss lab test results, diagnostic findings, and questions that arise during treatment or after an office visit or phone call. Many patients want to communicate directly with their physician online (The Commonwealth Fund, 2007) and physicians, especially in large practices, are increasingly offering this service because it can be efficient, satisfying for the patient, and partnership building (Ralston et al., 2010). Increasing the dialogue helps strengthen patients' and physicians' understanding of one another's roles, responsibilities, and goals in the care process. Specifically, online communication makes it easier for patients and health professionals to respond to one another's suggestions or requests in the same way a phone call might help, but such communications fit more seamlessly into patient/physician workflow, are quicker to receive, and require less time for a thorough response. Reliable communication helps to establish and build a sense of trust. Patients who experience great service—prompt replies to online requests, and staff enthusiasm for using online messaging tools—are more likely to adopt online messaging tools (Wald, 2010).

Engaged. Health care engagement, described by Johnson as active participation in health care decisions, excellent follow-through for planned activities (such as appointments, procedures, lab tests, medication use, dietary recommendations, self-management, etc.), and seeking appropriate care when needed, is supported through personal information management tools such as electronic calendars with reminders, secure internet patient portals, and mobile applications to improve just-in-time communication and information

sharing. When a patient is managing a chronic condition such as diabetes, engagement can be challenging because every few hours the patient should stop to check a blood sugar, give an insulin injection, take another medication, etc. In contrast, health care engagement for a young, healthy person consists mainly of seeking routine episodic care, such as scheduling a pap smear every 2 to 3 years. Online communities and connections with friends and family through online social networks can be particularly helpful in reminding and motivating an individual to follow through on care activities, when otherwise they might forget or lack the motivation to do so.

Committed. Since it takes time and effort for an individual to engage actively and consistently in health activities such as information-seeking, follow-through on tests and appointments, communicating with family and friends, and collaborating with health professionals, technology that saves time or reduces effort can provide high value to patients. Online messaging tools help by reducing phone tag and reaching multiple individuals at once. With these tools, health professionals and caregivers can more easily notice and keep track of appointments, medication refills, or lab tests. Feedback from monitoring tools can be motivating. For example, insulin-dependent patients using CGMS (Continuous Glucose Management System) who can view their 28-day average glucose are better able to see the connection between tight hour-by-hour glucose control and averages over time (see Figure 2).

Figure 2. 28-Day Average Glucose Patient Report From A Handheld Continuous Glucose Monitoring (CGM) Device



Understanding and tolerating uncertainty. Uncertainty in health care is ubiquitous, but not always transparent to patients. Many diagnostic and treatment decisions are made despite incomplete data. Treatments may appear to be helping when they are not—such as when a viral illness improves after an inappropriate prescription for antibiotics, or a new episode of major depression that “breaks through” the protection against more frequent episodes by an effective antidepressant. Medical science is incomplete—as new learning closes some medical information gaps, others appear. Health professionals, patients, and caregivers make errors in judgment despite their best efforts to avoid doing so.

Technology can help patients to deal with uncertainty in a number of ways. Communication technology connects patients with experts and others in online communities for support, advice, and strategies to help them better understand and manage an uncertain situation. Researching the medical literature can help characterize uncertainties such as the likelihood for a specific treatment’s success, or measures of patient quality of life with certain types of cancer treatment, or selecting an antibiotic before the type of infection has been confirmed in the laboratory. Many tools used by health professionals, such as risk calculators (<http://www.martindalecenter.com/Calculators1B.html>), can also be used by savvy patients to improve and quantify their understanding of uncertainty.

Technology Fit for Patients

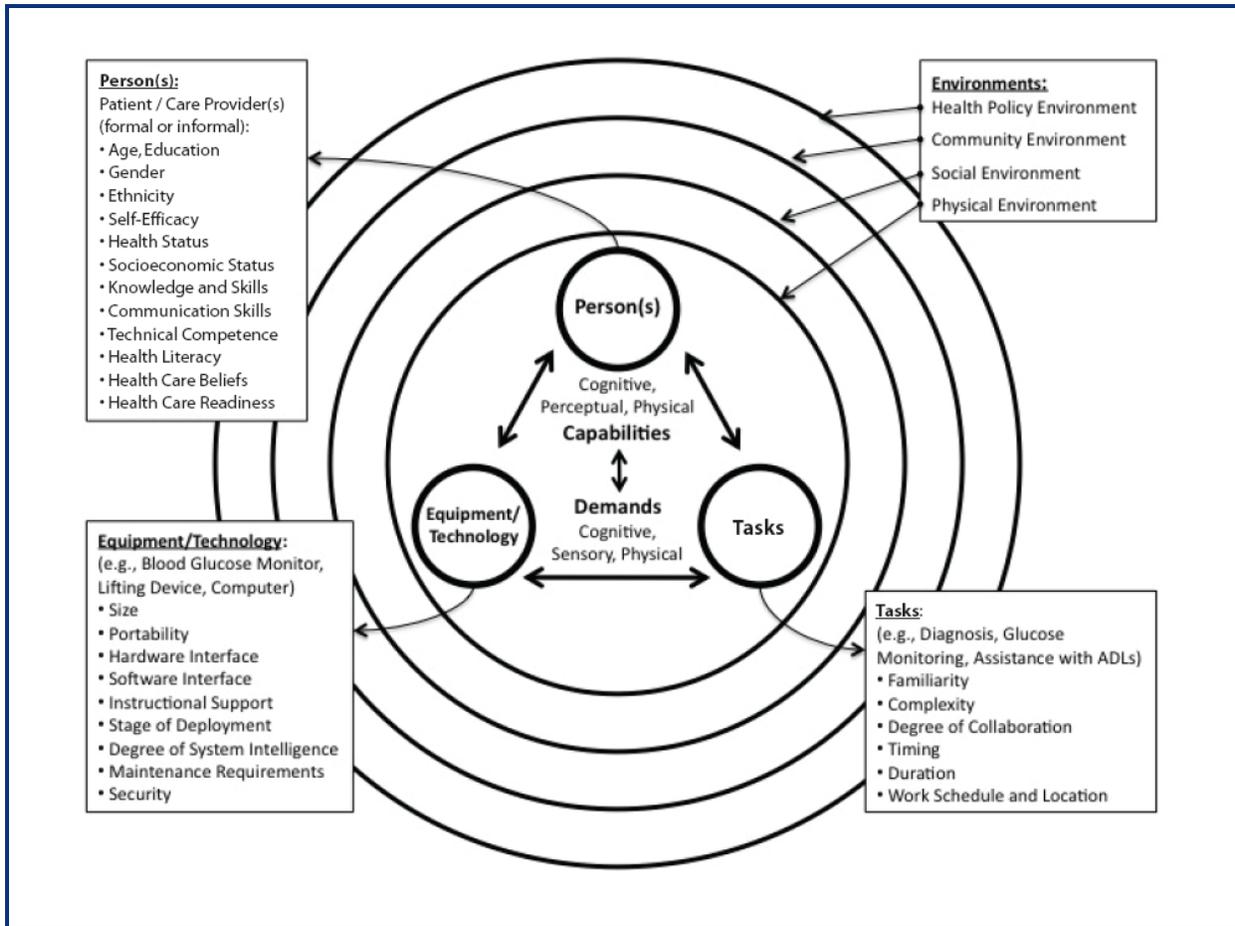
What makes a technology work well for some patients, but not others? And if it doesn’t seem to work, what can be done?

To begin, it’s helpful to identify the anticipated value of using the technology for health—the patient expectations. Sometimes value is easily identified—perhaps it is to save time, make communication easier, make decisions, or provide useful information. In other cases, the value may not be as apparent. Patients receiving lab test explanations from their doctor may not realize that using a patient portal for direct access to the data could help them understand results better or avoid mistakes. Patients with cancer might discover online stories and suggestions from other cancer patients with similar experiences, which can help emotionally when facing difficult decisions. Patients may not realize that online tools exist to help them monitor and quantify symptoms including depressed mood, anxiety, and chronic pain—producing rating scales that can provide insight to the patients themselves and their providers.

Even if the value of a technology is recognized by the patient, they may not use it. A human factors model (see Figure 3) helps to describe how technology factors, user activities, and user characteristics interact in a complex way with surrounding physical, social, community, and health policy environments in determining the overall experience a patient might have with a specific technology (Czaja & Nair, 2006). Perceptions and minute details can interfere with technology adoption and use. In one investigation, for example, diabetes patients were encouraged to take pictures of restaurant food using a camera phone to receive help judging the carbohydrate content of the meal. But they felt awkward snapping photos of their food in public, leading to failure of that particular approach (Brennan, 2009). On the other hand, technology can be more seamlessly adopted when existing routines are

leveraged. For example, patients with asthma who use technology-enhanced inhalers can automatically capture dose time, location, date, and amount, and have the ability to share reports with their care team (http://www.projecthealthdesign.org/projects/current_projects/breatheasy). Adding passive data capture and management to an existing workflow (e.g., use of the inhaler) can simplify and accelerate patients' adoption of technology.

Figure 3. Human Factors Model



Source: Czaja and Nair [adapted from Czaja et al. (2001)].

Health professionals can take a similar approach to recommending information technologies to patients that they do for other patient resources and treatments. They can (a) assess current patient technology use and readiness, including friends and family who might provide support and help; (b) offer specific recommendations about key resources to access, such as a patient portal, information website, online community, or other resources; and (c) ask patients—routinely—what tools and resources they are using, and if they'd recommend them. Such information not only helps to guide and support patients in their own use of technology, but also helps keep the provider up to date about resources that could be helpful to others.

Patients should plan to ask members of the health team (professionals, family members, other patients they know, any online contacts they may have) for technology suggestions and recommendations related to their health concerns. They can search online for reputable internet sites, find mentors to provide guidance, and strive to practice becoming more informed, engaged, committed, collaborative, understanding, and tolerant of uncertainty. One website, the Center for Advancing Health (<http://www.cfah.org>), offers many tools and resources to consider. Another, the Society for Participatory Medicine (<http://participatorymedicine.org>), offers an excellent white paper describing “e-patients” (http://e-patients.net/e-Patients_White_Paper.pdf), who are “equipped, empowered, enabled, and engaged in their health and health care decisions.” Many other internet resources are available, and patients should be encouraged to invest time in exploring, sharing, and learning how to become an e-patient, whether their use of technology is extensive or minimal.

Conclusion

Health care has long been recognized, at its core, as an information and communication business. Health professionals, long underserved by technology, are now catching up through government-sponsored incentives for health IT adoption and other initiatives. Patient empowerment through an active role in health activities and decisions can be advanced through the use of consumer-facing health technology, although much work is needed to promote increased patient use, demonstrate the impact of appropriate technology through research and experience, and motivate individuals to more effectively engage and collaborate in health and health care activities. For patients with sufficient motivation, technology can lower the barriers to taking action. Health professionals can provide important support to their patients by educating and encouraging them in the use of appropriate technology for health. Patients, their caregivers, and the entire health team have an opportunity and a responsibility to share new technologies, gain experience, and learn from one another.

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