Portals Help Empower Patients to Participate in Their Own Health Decisions

by Sherri Dorfman

Barbara Senker unlocked her front door and dropped her keys on the table. Two hours ago, she was diagnosed with type 2 diabetes and was still in shock. She had three days until her follow-up visit and had so many questions. Her knowledge of diabetes was limited to what she had read in magazines or discussed with her aunt about her ongoing battle with this condition.

Nervously, Senker typed "diabetes health information" into Google and saw that more than 45 million sites were found. She was overwhelmed, scared, and stressed. She stared at the computer wondering –

- What exactly am I looking for?
- Will I understand what I find?
- Will I know what this information means for me?

After several hours, she found sites from different types of organizations, including the government, health associations, pharmaceutical companies, online health information companies, hospitals, and health plans. She looked away confused. Where do I start?

Senker's quandary typifies the anxiety and frustration that hundreds of thousands, if not millions, of consumers feel every day when searching for answers. They've been diagnosed with diabetes or have problems managing weight, hypertension, or asthma. Although some patients rely completely on their doctor's advice, others want to take an active role in making decisions with their doctor.

Patient portal a vital tool
Health care experts agree there are good sources of health-related information online, but they tend to be generic and static. Through patient portals, health care delivery organizations enable patients to tap essential health information, access their medical record, and communicate with their doctor. In essence, these portals empower patients to participate in their care and treatment decisions by providing relevant health information, offering a personalized experience, being available when needed, and reinforcing required behaviors.

Relevant health information
Patients gain the most value from information pertinent to their health problems. Besides breadth and depth of content, patients value decision-support features such as an online glossary of medical terms, calculators, self-assessments, online patient communities, and the opportunity to communicate with an expert. As patients move through stages of their diagnosis and treatment, their information needs also change. For example, Senker clicks on the "just diagnosed" section within the diabetes area to understand where she is headed and how she can affect her direction.

Kaiser Permanente's award-winning patient portal KP.org is designed to educate patients like Senker with key clinical messages about what actions need to be taken and insight to explain what is happening and why. Healthwise, a Boise, ID-based company supplying content to both Kaiser Permanente and WebMD, offers an online content library called Healthwise Knowledgebase with some 6,000 topics and more than 1,000 illustrations.

Patient portals like Kaiser Permanente's also have a resources area with links to other trusted online sources to further educate patients about their conditions and treatment options. "Patients look to their physician to *endorse the source,* which may be a Web site from [the physician's group], an integrated health organization, or an association such as the National Cancer Institute," says Paul Wallace, MD, executive director of Kaiser Permanente's Care Management Institute.

Group Health Cooperative, a consumer-governed, nonprofit health care system that coordinates care and coverage in Washington and northern Idaho, has an award-winning patient portal, MyGroupHealth, which integrates an electronic medical record system with interactive Web services. MyGroupHealth also offers Healthwise content, which is reviewed by doctors and other specialists and updated quarterly. "We started with Healthwise Knowledgebase," says Jill Cooke, a Group Health Cooperative medical center administrator. "Our doctors made sure the content fits with their protocols so that it was consistent with what they are telling patients. We have also added articles on preventative care."

Personalized for the patient
Because each patient is unique with a different family history, set of health issues, and propensity for certain conditions, any given patient will likely seek health content specific to his or her situation.

Although Senker has been to the WebMD site to sign up for its diabetes e-newsletter, she visits the MyGroupHealth portal offered through her physician's

practice to access personalized information beyond health topics. This is valuable since the content is customized for her and integrated with online decision-support tools.

MyGroupHealth gives Senker access to her personal health record and lets her communicate with her physician. During a recent office visit, she asked her doctor about lifestyle changes that she needed to make. Later that day, her physician selected and e-mailed her relevant information about weight and dietary concerns.

"Ideally, information is chosen based on the patient's condition, severity, and learning preferences," states Joshua Seidman, PhD, executive director of the Center for Information Therapy (the center was founded by Healthwise and recently became an independent non-profit organization). In explaining how information therapy works, he notes that health content is first packaged through mass customization. To this content, "the doctor adds a personalized note, which helps the patient understand what the information means for him or her."

Available when needed
Senker uses MyGroupHealth to review her medical record and information from past doctor visits. In an "after-visit summary" area, she can review her doctor's instructions, diagnosis, changes in medications, orders for lab tests, and referrals to a specialist. She can also find contact information and instructions for preparing for a specialist visit.

Portals also enable patients to send secure messages to their physicians. As health information has become more widely accessible, Kaiser Permanente's Wallace has noticed a change in patient requests. "In the past," he says, "patients were asking, 'Tell me what to do.' Now patients increasingly want to know, 'What does the information mean to me?'"

Required behaviors reinforced
Patients struggle to maintain control of their lives when they have a major health issue. What will motivate patients to make the necessary changes to better manage their condition?

Using MyGroupHealth, Senker can record vital information, such as her weight, blood pressure, and glucose levels. After reviewing Senker's health record, her physician can send a secure e-mail with a positive message when her vitals are within the desired range or instructions for needed changes in medications, activities, or diet. In reviewing Senker's lab tests, her physician can

also comment on the results in her online health record.

Health care organizations are evaluating different ways to reinforce positive patient behaviors. "Kaiser Permanente is thinking about incentives, both financial and non-financial, to motivate patients," says Wallace.

Patient benefits
Although health sites can be useful in delivering personalized information, portals have the necessary communications and management tools to help patients collaborate with physicians. Patient portals are most valuable when they are an integral part of the patient's care as opposed to a stand-alone online information source.

"We have received very positive feedback from both patients and physicians using MyGroupHealth. Both feel the portal is so integrated [with] the patient's care," explains Cooke. "When a patient meets with her doctor, she watches him pull up her health record on the exam room monitor to look at details from the last few visits, the latest medication, and lab results. They discuss changes in her condition and evaluate options. The doctor documents decisions [in] the health record. The nurse prints out the instructions and reviews [them] with the patient. At any time, the patient can access the after-visit summary to review what was discussed."

Patient portals provide content and online tools to deliver the following benefits:

Encourage patient participation. With access to relevant and personalized educational information, Senker is better able to ask appropriate questions. Her learning is continuous as she moves through different stages of her diagnosis and treatment. When a medical event triggers the need for additional information, Senker is prepared to tap into appropriate sources.

Increase patient satisfaction. Between appointments, patients can e-mail their doctors to get their questions answered. Senker may not want to call and interrupt her busy doctor for a quick answer. She may be unsure how to get her exact question and concerns to her doctor. A secure patient portal ensures that the intended message is delivered and that the physician can review the patient's record before devising a thoughtful response. The ability to query her doctor by e-mail gives Senker a sense of control and confidence, and the response helps reduce her worry and confusion.

Enhance patient safety. Both the patient and the doctor can access the patient record, ensuring they are both on the same page before, during, and after a visit. Together, they can devise a plan that is reinforced through online communication as well as tracked and monitored in the patient's electronic health record. Ideally, the health record also contains pertinent information from visits with specialists to provide a holistic view of the patient's care.

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