



Beyond Bedside Manner: Patients Help Doctors' Plan of Care

By Barbara Mannino

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Understanding a doctor's orders is only part of becoming a health literate patient, the other part is patients knowing their bodies.

"We consider a person's experience of his or her own health, how they pay attention to their symptoms and changes in their condition, how well they know themselves and take healthy action as all part of health literacy and a patient-centered definition of health care [integral to health-care reform]," says Patti Brennan, a professor at the University of Wisconsin-Madison School of Nursing.



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Brennan, also serves as national program director of Project HealthDesign, a project that capitalizes on advancements in information technology to investigate how soliciting patients' observations of daily living (ODL's) could improve care for chronic illnesses.

"Patients may not cure their conditions, but engagement in their own treatment plan will help to keep them stable," Brennan says.

Project HealthDesign uses secure Web sites, smart phones and other wireless monitoring devices and encourages patients to record ODLs, the sensations, feelings, thoughts, attitudes and behaviors that provide clues about a person's health state.

The data, collected from patients at hospitals across the country, is transported to a patient's doctor and charted to create visual trend lines on a Web site that can be viewed and interpreted by clinicians.

"ODL'S complement traditional signs of a chronic disease or condition," says Brennan. People pay attention to pretty idiosyncratic feelings, thoughts and patterns which help physicians, caregivers, family members and patients themselves identify potential health concerns which can result in timelier care.

The information also helps to create a personal profile of the patient. Patterns can be charted to impact personalized modifications in treatment plans, and physicians like Tom Delbanco, who practices at Beth Israel Deaconess Medical Center, will tell you these personalized modifications are an important component of care.

Opening Doctors' Notes to Patients

Delbanco, along with registered nurse Jan Walker, is working on OpenNotes, a research investigation that encourages patients to read their doctor's notes following every medical encounter.

Starting in June, OpenNotes took the first giant step in bridging the gap between a doctor's medical knowledge and a patient's knowledge of self, exploring the pros and cons of easy access to health data afforded by electronic medical records.

Casting a wide public net, the OpenNotes team surveyed more than 15,000 patients and 200 doctors on their attitudes toward this practice including patients at Boston's Beth Israel, Geisinger Health System in Danville, Penn, and Seattle's Harborview Medical Center, three diverse populations that were actually enlisted to review their records for 12 months starting in

June and ending summer 2011.

In addition to monitoring patient and physician reaction to the process--how it changes the quality of communication and interaction, care and outcomes, as well as doctor workload--the project will conclude by asking participants: Will you want to continue to access the notes?

Delbanco hopes the answer is "yes."

"The best way to understand one's medical information is to convene and agree. If we teach patients about their illness, they will be enabled to be more aggressive with their doctors and outcomes will improve."

PatientsLikeMe

Ben Heywood would agree. In 2004, Heywood, joined forces with his brother Jamie and a friend Jeff Cole, all MIT engineers, to establish PatientsLikeMe, a privately-funded company dedicated to making a difference in the lives of patients diagnosed with life-changing diseases.

The three had personal experience with Amyotrophic lateral sclerosis, or ALS. The trio wanted to create an organization to empower patients to take control of their diseases through access to tools, information, and "the collective wisdom of all patients with a given illness."

"Why tell a patient how sick or well he is with a disease he can do nothing about?" asks Heywood. Instead, patients can learn how others are functioning in the real world with the same condition and pick up information that may help them improve their everyday quality of life.

Beyond informal online exchanges, PatientsLikeMe provides participants with medical information. "We respect the language of the patient and communicate in their voice which we've mapped to medical ontologies," says Heywood, noting that the group plans to expand the roster of disease states it covers. It already has 1,000 requests for added diseases.

PatientsLikeMe also partners with health-care providers like pharmaceutical and biotech companies, sharing anonymized, permission-based data from its patient community to drive treatment research and improve medical care.

The organization's full team of scientists and engineers also work with the patient community in clinical research; patients share real world experience with a particular treatment which PatientsLikeMe translates into detailed analytics in a time frame, protracted when compared to more drawn out company-based clinical trials.

Keeping Information Private

An open transfer of information opens the window to concerns over keeping patient information private. According to Walker, there will be a contrast between patient-doctor confidentiality and the choice to make personal information private or share it with relatives and friends.

Surely, there will be discussions centering first on the responsible use of personally contributed data down to how it is stored and trusted as part of a patient's directive respected as any directive in print.

There is a striking analogy to the evolution in personal banking from doing business face-to-face to relatively full transparency online, says Walker. "Now everything occurs in the push of a button. Why should healthcare be any different?"

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