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Doctors see patients taking a greater role in their own care



The trend is toward doctors and patients working as a team. (franckreporter / E+)

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he practice of medicine has moved away from a paternalistic model toward one of collaboration between doctor and patient. This has happened as the information age, propelled by the Internet, has plunged us into an ocean of health information.

In the past, doctors may have been happy with passive patients who followed orders and didn't ask questions, said Dr. Andrew Ellner, co-director of the Harvard Medical School Center for Primary Medicine. Today the most innovative medical programs recognize that such an approach does not promote optimal health outcomes for patients. "Patients need to be empowered to speak up and be partners in figuring out what's going on and designing care plans with their physicians," he said.

There are barriers to this transition, however. Judith Schaefer, research associate at Group Health Research Institute in Seattle, noted that physicians traditionally have been trained to ask specific clinical questions and then to diagnose and treat conditions rather than engage in collaborative partnerships that help patients manage their conditions day to day. And patients often feel intimidated by their doctors, are used to being given little time and don't feel empowered to ask questions. Both are frustrated.

Patients now, though, are becoming more engaged than ever. They have access to more information, are communicating with one another, and better understand the risks and benefits of options. They understand they have a role to play in their own care decisions, said Sarah Krug, founder of the Health Collaboratory, an organization that uses data and innovation to promote health. She said access to medical information through patient portals and patient education that reflects a patient's own values and preferences can increase motivation and satisfaction.

Levels of engagement vary by patient, however, and Krug pointed out that not all have the confidence or desire to make difficult decisions. The notion of partnership may not be for everyone, she explained, but it's important for physicians to tailor the health journey to accommodate the levels at which patients wish to and are able to engage.

Some problems that inhibit effective communication between patients and doctors can be overcome. Claudia Nichols, founder of Pilot Health Advocates, suggests that it is always productive for a patient to write down goals for a meeting with a physician, especially when a condition is serious or chronic. Another tactic is for the patient to take an advocate or caregiver to an appointment.

Nichols believes that adding a competent advocate (professional or otherwise) to one's health care team can help, reflecting a patient's commitment to quality health care and increasing physician engagement. "Doctors are usually appreciative when patients have made the effort to educate themselves about conditions, treatments and prognoses," Nichols said. "And an educated patient is better able to communicate and more likely to avoid medical mistakes."

Improved health literacy also increases positive outcomes for patients, according to Krug. Physicians need to find ways to help them understand and act upon the health information they receive. It's important, she said, for doctors to communicate information in a way that patients can comprehend, determine what they understand, and refer them to additional resources that help them learn more about their conditions.

Dr. George Thibault, president of the Josiah Macy Jr. Foundation, believes that shared decision-making is the future of medicine. Once a course of action has been decided upon, he explained, both doctor and patient are responsible to see that the plan is carried out. "The evidence shows that when patients are able to participate, outcomes are better," he said.

As the shift in practice and philosophy in medicine begins to move forward, new paradigms and programs are being funded and tested. Dr. Lisa Rubenstein, professor of medicine and public health at the VA Greater Los Angeles Health Care System, thinks the patient-centered medical home or the group health model is the way of the future. It involves team care designed around the patient and includes various health-care practitioners in addition to a doctor. Rubenstein said that, in her experience, when support staff such as nurses, physician assistants and nutritionists work together, patient questions and involvement are encouraged, and doctors are able to focus on the most serious problems.

Dr. Lawrence Smith is a professor of medicine and the founding dean of the Hofstra North Shore-LIJ School of Medicine. Because the school is so new, not yet 8 years old, he's been able to create a forward-looking curriculum with a focus on teaching effective communication skills and putting knowledge into action. The program surrounds students, from day one, in patient encounters in the hospital, in the streets, in ambulances and at their homes. "Illnesses are diseases that are different in each patient and occur in the context of social, economic and cultural environments, and it's vital to teach doctors who patients are and where they come from," Smith said.

At the Johns Hopkins School of Medicine, a curriculum designed around the idea that relationships between doctors and patients improve health outcomes is in its seventh year. The Aliki Initiative is a residency training program for select students that focuses on understanding that patient health and well-being can be at their best only when physicians know patients as individuals. Cynthia Rand, co-director of the initiative, said initial studies show fewer readmissions of heart-failure patients cared for by trainees in the program, compared with other programs.

Dr. Tom Delbanco is a professor of medicine at Harvard Medical School, an internist at Beth Israel Deaconess Medical Center in Boston and the co-founder of OpenNotes, a national initiative started in 2010 that is working to give patients ready access to all visit notes written by doctors, nurses and other clinicians. Records typically available to patients allow them to see test results and medications, but few grant access to the full record, including physician commentary.

Primary-care physicians in medical institutions throughout the country, including the Mayo and Cleveland clinics, are participating in OpenNotes, and more than 5 million patients now have access to them. Evidence from follow-up studies suggests that opening notes to patients may make care more efficient, promote dialogue and help patients become more actively involved with their own health care, yet resistance in many areas of the country is still strong.

As we embark on a 21st century medical journey, the practice of medicine is in flux, striving to find its footing in a rapidly changing culture. "To be effective," Smith said, "we have to communicate, and if we don't understand the context in which we are communicating — the patient's life experience — it's ludicrous to think we can make needed changes in care."

Barbara Sadick is freelance reporter.

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