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Perspective

Patient engagement: challenges and opportunities for physicians

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Despite recent moderation of health care cost inflation,¹ there is ongoing demand for strategies to achieve high-quality, accessible, and efficient health care in the United States. These strategies are introducing profound changes to a health care system needing to assure care coordination and collaboration across the health care team. For people with chronic illnesses, the team is increasingly multidisciplinary, including physicians, nurses, managers, clinical pharmacists, respiratory therapists, nutritionists, and behavioral health providers.

These challenges are driving the introduction of new models for organizing care (eg, patient-centered medical homes and accountable care organizations) and new models for payment (eg, “pay for performance,” shared savings, and bundled, “value-based,” and global payment programs).

They also are requiring patients to bear more of the cost, through higher deductibles, coinsurance, and copayments.² These changes are intended to create incentives for patients to make more prudent choices about how they live, make health and health care decisions, and obtain and use health care. The shift of financial responsibility and risk to patients can be positive, if patients respond by seeking information that leads to improvements in their behavior and health. However, given the complexity of the decisions they must make,³ there is risk that patients will not have access to useful, understandable, and usable information when they need it.

Traditionally, physicians have played a central role in helping patients make informed decisions. Yet practicing physicians face time and resource constraints and have not historically been trained to consider the financial, environmental, behavioral, and socioeconomic issues that are increasingly critical to improving the health of people with chronic conditions such as asthma and allergic diseases. The Internet and other new and emerging digital solutions have created opportunities and resources for patients to

more freely access information. As a result, patients seek information from other sources, in addition to (and in some case instead of) their physicians. This creates concern that patients will rely on information that might be inaccurate, not based on evidence, or not relevant to them or their specific situation.⁴

There is a growing and visible movement toward “patient engagement”—strategies to promote the active involvement of patients in their health and health care—that is influenced by the demand for and ability of patients to access more information. The benefits and importance of effective patient engagement are being studied and documented. There is a growing body of evidence that demonstrates that patients who are more actively involved in their health care achieve better health outcomes and incur lower costs.⁵ In this article, we provide an overview of the policy and technology landscapes that influence how and how effectively patients can engage in their own care. Then we consider how physicians can take advantage of these changes to improve outcomes for their patients. These challenges and opportunities are especially important for physicians who care for patients with asthma and allergic diseases, because guidelines (such as Guidelines for the Diagnosis and Management of Asthma [EPR-3]⁶ and Clinical Guidelines for the Diagnosis and Management of Food Allergy⁷) emphasize that patient self-management is the cornerstone of effective therapy.

The Policy Landscape

Recent policy initiatives are propelling changes that give patients a more active and participatory role in treatment, medical innovation and drug discovery, clinical and pharmaceutical research, and access to data. A critical step occurred in 2001, when the Institute of Medicine—in the landmark report, *Crossing the Quality Chasm*⁸—called for reforms to achieve a patient-centered health care system: one that is “respectful of and responsive to individual patient preferences, needs, and values, and (ensures) that patient values guide all clinical decisions.” The Institute of Medicine continues to explore and recommend changes in the health care delivery system that are centered more on the patient

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and family. Innovations include patient decision aids, patient and family advisory councils, and shared decision making.⁹

The Health Information Technology for Economic and Clinical Health Act of 2009 established the Medicare and Medicaid Electronic Health Record Incentive Programs to provide payments to adopt, implement, upgrade, or demonstrate meaningful use of electronic health records. Patient engagement is implicit in the regulations; many physicians are implementing approaches such as patient portals to provide patients greater and timelier access to their health data.

There are other patient engagement efforts focusing on providing patients' access to their health information. These projects include Blue Button¹⁰ and OpenNotes.¹¹ The Blue Button initiative lets people download their health records so they can use them to have more control over their personal health information and their health care. OpenNotes is an effort to help physicians build better relationships with their patients by giving patients access to clinicians' notes. In some cases, patients (and referring physicians) also access notes written by others who write visit notes.

The Patient Protection and Affordable Care Act of 2010 incorporated patient engagement in its provisions.¹² The act encouraged the formation of new models of care delivery to organize health care teams, technology, and knowledge around patient needs.¹³ Several demonstration projects have focused on chronic diseases including asthma and allergies, offering lessons learned and best practices for physicians contemplating such delivery models.^{14,15}

The Patient-Centered Outcomes Research Institute (PCORI) is a nonprofit, nongovernmental entity charged to improve the quality and relevance of evidence to help patients and caregivers make informed health decisions. Since 2012, PCORI has worked vigorously to increase capacity to engage patients with asthma. For example, PCORI funded several asthma-focused projects addressing disparities among African American children and developed guidelines to incorporate patients into research processes.¹⁶ PCORI launched "patient-powered research networks" that are built by communities of patients in partnership with researchers to bring the patient's voice directly into studies of health improvement strategies.

In 2012, the Prescription Drug User Fee Act included the Patient-Focused Drug Development initiative.¹⁷ This initiative is designed to systematically collect and address patients' perspectives on their conditions and available therapies to treat their condition. The goal

is to learn from patients about the impact of their disease on their daily lives. As part of this effort, the Food and Drug Administration works with patient and disease advocacy groups and pharmaceutical companies so that the patient perspective informs drug development.

In May 2015, the Food and Drug Administration issued draft guidance for the collection and use of patient preference information in medical device development. The guidance includes a proposed framework to obtain the perspectives of patients who live with a disease or condition and use devices in their care. Medical device manufacturers are implementing approaches to obtain patient input and feedback.¹⁸

In 2015, President Obama launched the Precision Medicine Initiative¹⁹ to pioneer a new model of research to accelerate biomedical discoveries and provide physicians with new tools, knowledge, and therapies to select which treatments will work best for which patients. Participation and input from patients, physicians, researchers, professional and medical specialty societies, and patient advocacy groups are necessary to the development and launch of the effort.

In July 2015, the House of Representatives passed the 21st Century Cures Act to advance the development of new medical therapies and bring better, faster cures and treatments to patients. The initiative highlights the need for patient perspectives to be better integrated into medical product development and regulation.²⁰ Once implemented, legislation will promote increased health data sharing and interoperability.

The Technology Landscape

Information technology (including health information technology) is evolving rapidly. The Internet has profoundly altered the way people search for information about their health and health care.²¹ The widespread adoption of smartphones and "apps" allows for rapid data collection and information delivery to patients with chronic illness. "Wearable devices"—such as smartwatches and exercise trackers and devices that people wear or are embedded in their clothing—can provide continuous monitoring of patients' physiologic data.²² Many organizations have launched electronic clinical data and patient registries to help people track their illness, compare treatments, report their experiences, support one another, and contribute data for research.²³ These registries^{24,25} are potentially powerful tools to understand variations in treatment and

Table 1
Selected strategies for patient engagement

Incorporating patient-reported and patient-generated data
Leveraging patient engagement work undertaken by patient and disease advocacy groups and specialty societies
Helping patients identify and access appropriate and trustworthy sources of information such as monitored online peer-to-peer patient communities
Working with patient advocacy and public health groups to assure access to and appropriate coverage and payment for treatments, medications, patient education, and case management
Working with professional associations and patient advocacy groups to track and monitor new approaches and mechanisms for delivery reform and related payment issues, such as telemedicine, remote monitoring, and communicating with patients by e-mail and smart devices or telephones
Contributing to the growing multidisciplinary evidence base regarding the benefits, risks, and challenges of patient engagement
Identifying best practices and lessons learned for engaging patients
Asking patients if they would like to participate in research
Demonstrating the relation of patient engagement to better quality of care and cost savings
Accessing patients' preferences
Encouraging patients access to their medical records and data to help assure the accuracy of their health information
Increasing patients' involvement in their care and care coordination
Obtaining patient-reported data and outcomes and patient perspectives and preferences on medication and treatment approaches and choices
Confirming patient values, needs, and goals as part of shared decision making
Asking patients what is important to them
Introducing opportunities for patients and families to provide feedback about care delivery and follow-up, treatment, and care plans
Informing physician–patient communications
Assuring that patients understand their diagnosis and treatment plan by focusing patient education on treatment plans, adherence, and condition self-management
Increasing patients' knowledge, skills, and abilities to obtain, process, and understand basic health information and services needed to make appropriate health decisions
Forming patient advisory boards or councils to provide input, feedback, and opinions

outcomes, to examine factors that influence prognosis and quality of life, to describe and understand patterns of care, to assess effectiveness and monitor safety and harm, and to measure quality of care.²⁴ Together, these information technologies allow for data collection on an unprecedented scale—providing “big datasets” to which powerful analytics can be applied. At the same time, these technologies provide for near real-time delivery of information. As analytics evolve and operate on datasets that include detailed information about millions or tens of millions individuals, and as “just-in-time” information delivery systems (the Web and smart-phones) continue to diffuse, patients will have access to information that is more “engaging”—more timely, more personalized, and more relevant to them.

Challenges and Opportunities: What This Means for Practicing Physicians

Patient engagement—in care delivery, decision making, research, and clinical and technologic innovation—is the “new normal.”²⁶ Physicians should consider how to leverage and respond to patient engagement. Patients need information about diagnosis, treatment, and self-management; physicians have historically been the source. However, as demand increases, alternative information sources become more prevalent and the amount of information increases, and physicians are likely to be more effective if they guide patients to trustworthy sources rather than try to serve as information providers. Those “trustworthy sources” must be reliable and specifically designed to meet the information needs of patients. These require a commitment to evidence and to patient service and a deep understanding of the populations seeking information (eg, patients with asthma) and of the individuals who comprise those populations (and the differences among them). The commitment to evidence will assure that the information is scientifically sound and current. The commitment to patient service will assure that the information provided to individuals is based on the topics most relevant to their lives and is useful to them.

Physicians and the organizations that represent them also have an important role to play in creating an environment that allows for more capable patient engagement. There is an important role for them in promoting efforts to address health literacy issues and encouraging to patients to access their own health data. We suggested earlier that physicians can help their patients find trustworthy sources to guide their health care decisions and clearly can encourage them to assume more responsibility for managing their own health.

Patient engagement requires that physicians build and sustain ongoing and long-term bidirectional partnerships with patients, their families, and their caregivers. Physicians and their specialty organizations can consider new and enhanced collaborations and strategies to further engage patients and recognize that doing so can lead to better patient experiences and outcomes. Strategies for doing so are presented in Table 1.

Summary and Conclusions

Interactions between patients and providers at all levels contribute to patient experience and profoundly influence patients’ willingness and ability to engage with the health care system. Innovations in health care delivery, financing, and technology have created new opportunities for clinicians to enhance delivery and access to health services and information. The evolution to a more patient-centered system is not simple, but physicians will be expected to play a central role in assuring that their patients’ care is coordinated across the continuum.

Care delivery and preventive service are not confined to physician offices, ambulatory care clinics, and acute-care hospitals.

Asthma and allergy care, treatment, and management occur in multiple settings including the home, school, and community. This provides opportunity for patients, families, and caregivers to work closely with physicians to improve their health and health care outcomes.

Increased patients’ participation in their own care, fueled by ongoing changes in public policy and enabled by technologic innovations, creates new opportunities for physicians to drive health care improvements and better outcomes for their patients. Physicians will want to recognize and capitalize on those opportunities. Patient organizations (such as the Asthma and Allergy Foundation of America) are natural partners and collaborators. Leveraging opportunities for collaboration should improve the lives of patients with chronic illness and increase the value of the relationship between those patients and the physicians who care for them.

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