Partnering With Patients to Help Heal Healthcare

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In Crossing the Quality Chasm, the Institute of Medicine (IOM) identified patient-centeredness as one of the key attributes of a high-quality healthcare system. The IOM defines patient-centeredness as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” Although many physicians endorse this principle, in the day-to-day practice of medicine, these goals are often not achieved. There are multiple reasons for this, including time and financial pressures, strong physician beliefs with respect to diagnostic and treatment strategies, and lack of emphasis in medical education on learning how to convey information, learn patient preferences, and ensure that treatment choices reflect patient values and goals. Healing healthcare, however, should not be seen solely as a responsibility of physicians and other healthcare providers. In the 21st-century internet-enabled world, patients and caregivers are actively taking steps to partner with healthcare providers in improving their own care and that of their families. Below I discuss some examples and how Circulation: Cardiovascular Quality and Outcomes can contribute to this process.

The most common type of patient engagement takes the form of researching symptoms and illnesses on the internet. A 2011 survey found that 66% of internet users have looked online for information about a specific disease or medical problem, and 56% of internet users have looked online for information about a medical treatment or procedure. A smaller but significant number of internet users seek information and support through online patient communities. Examples include Association of Cancer Online Resources (www.acor.org), FMD Chat (http://fmdchat.blogspot.com/), and RareConnect (https://www.rareconnect.org/en).

Although patients have long served as research participants, it is increasingly recognized that research to inform patient-centered care requires participation by patients in identifying the questions to ask and outcomes to assess. In the past, studies have often included end points that do not matter to patients in their daily lives and that are not closely linked to risk of complications or mortality. Patients and caregivers can improve the quality and relevance of research by providing their perspective on what matters to them. The Patient-Centered Outcomes Research Institute (PCORI) is engaging patients and caregivers in shaping its research program using 2 different approaches. Under the first approach, research teams applying for PCORI funding involve patients and stakeholders in each step of the research, including the proposal, design, conduct, and dissemination of the research. Under the second approach, patients and other stakeholders propose questions for further research and then serve on advisory panels to evaluate and prioritize the questions.

Briefly, several other initiatives are facilitating patient engagement:

- With the advent of electronic health records, several new programs are giving patients easy access to their physician’s visit notes, making it easier for patients to participate in their care.
- Consumer Reports, AARP, and several other organizations are partnering with the Choosing Wisely initiative of the ABIM Foundation to disseminate information to patients on making wise medical decisions (http://www.choosingwisely.org/partners/choosing-wisely-consumer-partners/).
- As part of a new initiative called Patient-Focused Drug Development, the Food and Drug Administration is meeting with groups of patients in specific disease areas.
- Several guidebooks are available on how to engage with patients or be an engaged patient.

For a patient or caregiver, the motivation to enter into advocacy usually begins with a serious illness or condition. The fear and frustration of navigating a fragmented and at times uncaring healthcare system while simultaneously managing new symptoms, diagnoses, and treatments lead some of us to seek ways to make things better. The realization that managing an illness requires difficult choices, often made under time restraints and conditions of uncertainty, motivates us to take steps to be better prepared for the future. Thus, when my daughter was diagnosed with familial hypercholesterolemia and I had to decide when she should start statin therapy, I entered into a process of self-education on the science behind the condition and its treatments. I now help other patients and parents of children with familial hypercholesterolemia by answering questions in an online community (https://www.facebook.com/groups/429521030486632/#/groups/47098361977/).

Achieving more patient-centeredness will require a shift in the culture of medicine and this Journal is contributing to that by, among other things, publishing research that focuses on what patient-important outcomes have been achieved. In addition, the Journal has committed to publishing a series of
articles on the science of shared decision making and how it can be implemented in clinical practice. I have accepted an invitation to serve as a patient advocate member of the editorial board, a first for an American Heart Association journal. As a member of the editorial board, I hope to help with disseminating the Journal’s scholarship to both scientists and the general public. The Journal recently launched a Twitter account (https://twitter.com/CircOutcomes) and is considering the use of other social media. Other initiatives include the provision of plain-language summaries of research and publishing articles and perspectives by patients and caregivers, a practice already pioneered by other journals.

Achieving patient-centeredness will require patients and providers to acquire new skills and the ability to work in partnership. Circulation: Cardiovascular Quality and Outcomes is committed to supporting patients’ role as crucial decision makers and coproducers of health.

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None.

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