Patient Engagement in a Rapidly Changing Communication Environment: Reflections of a Cancer Survivor

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The shared decision-making paradigm calls for patients to become as knowledgeable as they can about their illnesses and treatment options. To foster their engagement, patients today have unprecedented access to an array of health information and communication applications facilitated by the Internet revolution. In this commentary, the author, a long-term cancer survivor, reflects on his recent experiences with heart disease and discusses how he has benefited from advances in communication technologies in his quest to become an informed patient, at the same time reminding the reader about the ever-enduring salience of the patient–clinician relationship.


“Sir, are you ok?” asked the nursing student as she lifted me from the concrete floor onto a bench from where I had fallen backward and passed out. I knew things were serious as the woman informed my wife, “He hardly has any pulse.” Soon, the sirens of the ambulance and fire truck shattered the calmness of the evening; the date was October 10, 2010 (or, 10/10/10).

I had experienced an episode of “cardiac syncope,” a malfunction of my heart’s electrical system that could have resulted in a cardiac arrest and death. This was not the first time I was facing a life-threatening event. In 1994, at the age of 25, I was diagnosed with aggressive non-Hodgkin Lymphoma. Intense treatments for 3 years, including multiple cocktails of chemotherapies and radiation, resulted in long-term remission. However, in 2007, I was diagnosed with congestive heart failure, a late effect of my cancer treatments.

During the course of the years, while dealing with cancer and heart disease, I have benefited from an ever-evolving health communication environment. In the 1990s, I relied on print media, face-to-face communication with clinicians, and e-mail-based patient support groups to facilitate my engagement in my cancer care. My cardiac illness has exposed me to more 21st-century communication vehicles, including the exponentially increasing health-related content on the Internet, YouTube videos, e-mail interactions with clinicians, online message boards and chat rooms, and a remote home health monitoring system. One thing that has not changed with time, however, is the salience of high-quality patient–clinician communication.

Making an Informed Decision

The cardiac syncope episode led my cardiologist to strongly recommend that I get an implantable cardioverter defibrillator (ICD), a device the size of a cell phone that is placed under the skin of the chest with multiple wires connected to the heart. The ICD can function as both a pacemaker and a defibrillator to deal with abnormal heart rhythms. My cardiologist gave me a DVD that had additional information about the device and the surgical procedure to implant it. For a second opinion, I e-mailed a congestive heart failure expert at a reputable academic hospital with whom I consulted on an annual basis; he concurred with my cardiologist’s recommendation.

To gain more knowledge so that I made an informed decision, I turned to the Internet. I quickly consumed all information from reputable Web sites and realized that indeed experts considered this decision to be a no-brainer. To understand more about what life would be like to live with an ICD, I searched for posts and conversations on several cardiac message boards and chat rooms. YouTube videos opened for me a world of cardiac patients and physicians who talked in detail about the benefits of an ICD and their individual experiences. The jury on the Internet had spoken, and its verdict was also in favor of the surgery.

Merlin—The Technological Wonder

During my first postsurgical medical visit, I was given Merlin, a device that sits next to my bed in my house in Maryland and remotely monitors the activity of the ICD every night. In the event of any abnormal heart rhythm resulting in an intervention from the ICD, Merlin downloads data from the ICD and transmits it to the manufacturer’s computer servers in California. The server then sends a notification of the event in an e-mail to my cardiologist’s account, which is accessed by a nurse every morning to check for potential alerts from the devices of all their patients. The nurse then discusses the detailed report transmitted by Merlin with the cardiologist, resulting in a follow-up conversation with the patient as needed. In addition to such “unscheduled” transmissions, Merlin is also programmed to download data from my ICD, once every month. Thus, without my visiting his office, my cardiologist gets a monthly report of all my cardiac activity.

A few months after my surgery, I received a call from my cardiologist’s nurse. I was told that they had received an alert from
Merlin and that the doctor would like to replace my current beta-blocker with another drug. Given that I had been on the beta-blocker for 4 years, I wanted to know more about the nature of the alert to understand the rationale behind the doctor’s decision. The nurse had no clue and she promised to investigate further with the nurse who had downloaded the report. A few hours later I received a cryptic message that although there was nothing serious, the doctor wanted me to take the new drug. Not satisfied with this explanation, I insisted on speaking with my doctor who I was told was not accessible. Concerned about what might have happened, I scheduled an appointment the next morning with another cardiologist in the same practice, who finally explained the rationale behind experimenting with a new drug. The explanation took no more than 5 minutes but cost me both time and money as a result of an unnecessary medical visit. Clearly, although communication technologies such as Merlin can significantly facilitate patient care, they cannot make up for inefficiencies in care coordination and interpersonal communication.

Health-Care Delivery in a Changing Communication Environment

The shared decision-making paradigm calls for patients to become as knowledgeable as they can about their illnesses and medical options (1). As a patient, I am fortunate to have unfettered access to a wide array of health information and communication applications facilitated by the Internet revolution. Easy access to online communication can, however, have multiple consequences. Although it can help validate the opinion of clinicians and address an immediate information need, it can also create anxiety and confusion, resulting in a need, which may not have existed otherwise, to access the health-care system to seek clarification from one’s trusted clinicians.

To facilitate patients’ engagement in their care, Berwick suggests that health-care professionals will have to play the role of a coach, a knowledge broker for whom practicing medicine would involve helping patients optimize their learning from information gained from multiple sources (2). Health-care systems need to be redesigned, Berwick urges, such that knowledge is on call 24/7 for all patients (2). When patients need information, they should receive just that, and not end up getting a medical visit, as was my experience. Furthermore, team-based approaches will have to be implemented so that the responsibility of providing timely information to the patient need not always rest with the physician. How best can health-care organizations tailor efforts to facilitate engagement of patients with varying levels of access to and skills in using modern communication tools has to be a question of the highest priority, to be addressed by efforts to reform health care in the United States.

As far as I am personally concerned, I am not sure what other illnesses are in store for me in the future. However, I know that if and when I do face a new health crisis, I will continue to rely on the expertise of my clinicians but will also draw as much as I can from advances in communication technologies of that time. In the meantime, I will sleep soundly at night, as I know Merlin is watching over me.

References

Note
This paper reflects the personal opinions of the author and does not represent any official position of the National Cancer Institute.

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