Patients Are Destined to Manage Their Care

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Illustration by Eric Hart.

The healthcare system of today provides this very common scenario:

> **Patient:** When will I get my lab results?
> **Provider:** I will call you some time next week.
> **Patient:** What happens if you do not call?
> **Provider:** If you do not hear from me, then you can assume the results are fine!

Of course, that is only one of two true potential outcomes when the patient does not hear from the provider. The other reason for the provider not calling is that the results have been misplaced, and with no mechanism or checks and balances in the system to ensure an effective follow-up, the patient is unaware that his or her health results may not be so "fine."

It is this very scenario that has placed healthcare, at this point in time, at the beginning of an inevitable evolution, some might even say a revolution! This inevitability, termed patient destiny, pertains to the fact that more and more patients are demanding better healthcare information. Patients must be able to access their own personal health information in order to ultimately partner with providers in the management of their health and wellness care. Just as customers accessing their information have reduced costs in many other industries, such as banking (Leonard 1996), it is a general assumption that the same will hold true in healthcare.

In healthcare, giving patients the means to obtain information for themselves will alleviate the mounting pressures within the system.

At present, unfortunately, patients are seldom able to easily access their own personal information (e.g., the specific results of diagnostic tests or laboratory work) (Winkelman et al. 2005). As a result, it is often difficult for patients to enter into a dialogue with their doctor (or any other care provider) about treatment and other options because the healthcare provider is the only one with the information (Leonard 2004; Ross and Lin 2003). One truism seems to be constantly ignored: It is not possible for patients to actively manage their health without the requisite information. This is not just a "nice to have." This is a must. This is ultimately our destiny!

A Series of Arguments

In order to defend this statement, we provide a well-constructed, logical argument that employs sound principles from the theories of management, management science and information systems.

Argument 1: Consumers Want Information … and They Need It Now

The rise in consumerism has created a demand from the public for better information and better service in almost every area of their lives. The public wants information in the way they want it, and when they want it. We have rapidly progressed through the information age into a "knowledge era." Information must now be contextualized in order to generate knowledge, thereby making the information relevant and, more importantly, actionable.

Argument 2: Patients Are the Consumers of Healthcare Services

Although many healthcare entities and systems now state that their mission is to place the patient at the centre of healthcare, we challenge that the true implication of this message has been severely underappreciated. Without the patient, there is no need for healthcare professionals. The patient is the one constant throughout the healthcare system. As such, combined with argument 1, patients in the near future will begin to demand better healthcare information. Patients want access to their own patient information, to know more about their illness or disease paths, treatment options and success rates.

Argument 3: Ultimately, Consumers Are Key Decision-Makers

When consumers (patients) are faced with difficult healthcare questions, they seek advice – from their doctor(s), other health professionals and their own personal network. Even though physicians will provide the best medical support, ultimately it is the patients who have to decide whether they want this drug treatment or that surgery. It has been suggested that not all patients have the maturity, the cognitive ability to comprehend or the desire to make these types of decisions. While this may be true, there is still a large percentage of the patient population (typically the chronically ill) who have the desire, ability and right to make their own decisions as their own healthcare paths are determined through their choices and actions.

Argument 4: Moving the Work and Cost Base to Consumers Gains Efficiency over Time

The historic transition to an electronic access of personal funds (from the hands-on interaction with a bank teller) was not easy. Many people resisted the change and worried that computers would make more mistakes than humans and that all sorts of problems would ensue. Of course, today most would strongly resist any movement to retreat to the earlier ways. The main reason is that people have become used to having access to information about their financials. This has led to more informed and effective decision-making. It should be emphasized that the financial services sector did not adopt technology in order to provide more information to their customers or the users of the financial system. Rather, these initiatives were a direct attempt to cut costs. Inadvertently, this consumer self-management has indeed led to the cost reduction and efficiency gains – not in the technology itself, but by reducing the need for bank hours and personnel. In healthcare, giving patients the means to obtain information for themselves will alleviate the mounting pressures within the system.

Final Consequence

Patients must be able to access their health record and other patient information if they are to make informed and effective decisions about their health management. It is not possible for patients to actively manage their health without this requisite information.

Research on the Early Adopters

It is our hypothesis that the patient leadership will come from the chronically ill (either individually or within a group) by demanding better access to health system and service information. Over 40% of the population of economically developed nations has at least one chronic illness, accounting for nearly two-thirds of all medical expenditures in these countries (Shine 2002). Further, it has been documented that a mere 5% of the patient group accounts for approximately 50% of overall healthcare spending (Halvorson and Isham 2003). The focus on chronic disease management must begin now and should incorporate self-management tools. Prototypes of web-based, patient-centred portals have been demonstrated to support self-management of illness and enhance understanding of the complications of poorly controlled disease (Berendt et al. 2001; de Clercq 2001). Patients living with chronic illness are also more likely to use health information than their healthier counterparts (Hejlesen et al. 2001), although each chronic illness has specific, recognizable challenges for affected patients in symptom comprehension, information management, task fulfillment and social interaction (Wagner and Hibbard 2001).

These "early adopter patients" want access to their own patient information – and they want to be able to understand what it is that they are reading. In addition, they want to know more about their illness or disease and they want information on treatment options and health outcomes. Often, they would like to get in touch with other patients to exchange experiences and to get advice. After all, it is only when they interact with other patients that they get real information about what they are going, or will go, through.

As stated, when patients are faced with their own healthcare challenges, they seek advice from a variety of sources. What they lack is the medical background to take in all the information and process it to make an informed choice. It is our belief that in the healthcare system of the future, we will see physicians, and other professionals, act as advisors to patients rather than telling patients what to do (the old model). Gone will be the day when patients will feel that they are not free to question facts or to seek options.

The Future

Change occurs only when it is forced to happen – so we must begin to put pressure on the system to support patients in gaining access to their own health information. In essence, a health industry–wide strategy of patient awareness and education is now required. In order for patient destiny to be successful, the patient stakeholder group needs to be actively involved in all areas of healthcare decision-making. All consumers of healthcare – the healthy and the ill – need to be presented with a forum for a comprehensive discussion on healthcare, one that deals with the trends of rising consumerism and greater expectations relating to information access and delivery. We must promote an "effective and coordinated consumerism" perspective within healthcare. Hopefully, this will provide an incentive to all consumers to become more involved in their own care and health management and to demand more from health providers. We believe that when patients gain access to their own health records and information, their active decision-making will result in large improvements in health outcomes and extended overall health system benefits.

It is hoped that the healthcare system of tomorrow will augment the previous scenario as follows:

Patient: When will I get my lab results?

Provider: They will automatically be sent to your patient record account directly from the lab; it should take a few days.

Patient: What happens then?

Provider: If everything is fine, and there is an indicator on the lab result in green, then there is no need to see me until your next regular appointment. If the results are not in green, then we need to get more information or further tests need to be done – in any event, please contact my office.

Ultimately, the big payback from an overall information technology investment in healthcare will only occur when patients begin to access their own personal records and information and partner in managing their health and wellness. HQ

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