Chapter 16

E-Patients Empower Healthcare: Discovery of Adverse Events in Online Communities[1]

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ABSTRACT

E-patients can empower themselves and improve healthcare. In online communities, patients may discuss adverse events that are inadequately addressed in the literature. The author as a patient joined various online patient discussion groups and identified several such adverse events. For each such adverse event, the patient findings, the medical literature, and the implications are noted. Extracts from the literature that were provided to the patients were welcomed by the patients. Possible approaches to financially supporting such activities are sketched.

INTRODUCTION

The President of the United States in an address to the nation said (Obama, 2008):

> *"In addition to connecting our libraries and schools to the internet, we must also ensure that our hospitals are connected to each other through the internet. That is why the economic recovery plan I'm proposing will help modernize our health care system – and that won't just save jobs, it will save lives. We will make sure that every doctor's office and hospital in this country is using cutting edge technology and electronic medical records so that we can cut red tape, prevent medical mistakes, and help save billions of dollars each year."*

The emphasis on electronic medical records is a natural one for a provider-centric nation. However, another benefit from greater digitization and connectivity of the world in health care matters is the emergence of patient power or the *e-patient*. A Dutch study showed that patients may use blogs to advance some of the principles of Web 2.0, as the author noted (Adams, 2008): "enabling patients to be more active in documenting and managing information related to their health experiences". What is the role of the patient in the e-health world?

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In the already classic, oft-cited article "Will Disruptive Innovations Cure Health Care", the authors propose two key steps to improving the health care system (Christensen *et al.*, 2000):

- create and then embrace a system where the clinician's skill is matched to the difficulty of the medical problem and
- invest less money in high-end, complex technologies and more in technologies that simplify complex problems.

The *empowerment of patients* online fits nicely into this desiderata. Patients have varying expertises and common experiences across the globe. They can meet with one another and share stories and insights both about their medical conditions and their doctors. The technology is simple and already well developed for other commercial purposes. What evidence exists to support this contention that patients by moving online and sharing information about health can help the health care system?

A E-Patient Network with support from the Robert Woods Johnson Foundation has developed a wikipedia-based white paper titled "e-Patients: How they can help us heal healthcare" for which the conclusion is this (Ferguson, 2009):

"The creation of optimal health care may depend on our ability to embrace our first generation of e-patients, providing them with the autonomy, authority, and empowerment they desire and deserve and inviting them to join us in a combined effort to improve healthcare for everyone. It will be only by joining forces with these new colleagues that we can hope to solve the pervasive problems that plague the healthcare system: quality, cost, access, and consumer satisfaction."

Many different aspects of this e-patient revolution are being explored. For instance, the support that might be provided for patients seeking health care information online has been addressed with the conclusion that patients seek information differently and sometimes inefficiently and ineffectively but online support tools could improve that search behavior (Keselman *et al.*, 2008). *Customer Relationship Management* systems are extensively used in healthcare systems (Calhoun *et al.*, 2006). Data mining of web information is an alternative way to learn what consumers think.

This paper explores the means by, and extent to, which participants in online patient-patient discussion groups provide useful information about *medical adverse events.*An adverse event occurs when some intervention by a healthcare provider produces an unwanted reaction. For instance, radiation treatment for oral cancer can cause obstructive sleep apnea. The literature on adverse events addresses their causes, how to reduce them, and the impact they have on patients, staff, and health care organizations (Misson, 2001). Typically, health care professionals investigate adverse events through the medical record (Duff et al., 2005).

Many online patient groups are established by volunteers on free sites, such as groups.yahoo.com (Rada, 2006). However, some healthcare entities maintain patient online discussion groups. For instance, Joslin Diabetes Center runs an online, diabetes discussion group for the public, and experts from the Center provide feedback online. Kaiser Permanente maintains numerous discussion groups moderated by Kaiser's professionals, but access is restricted to enrollees in the Kaiser Plan. Healthcare professional in online moderator roles might address adverse events, among other things.

Listening to patients is a key to reducing adverse events (Cleary, 2003):

"by relying on the observations and insights of patients such as Mr. Q., the physicians and staff will be able to close the gap between Mr. Q.'s experience and what they can achieve."

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