

Chapter 63

Caught in the Web: The Internet and the Demise of Medical Privacy

Keith A. Bauer

Jefferson College of Health Sciences, USA

ABSTRACT

The social consequences of the internet are profound. Evidence of this can easily be found in the enormous body of literature discussing its impact on democracy, globalization, social networking, and education. The implications of the internet for medicine have likewise received a great deal of attention from policy makers, clinicians and technology theorists. Medical privacy, in particular, has garnered the lion's share of attention. Nevertheless, research in this area has been lacking because it either fails to unpack the conceptual and ethical complexities of privacy or overestimates the power of technology and policy to protect our medical privacy. The aims of this chapter are twofold. The first is to provide a nuanced explication of the concept of privacy, and, second, to argue that e-medicine and the policies supposedly designed to protect the privacy and confidentiality of personal health information fail to do so and in some instances make their violations easier to commit.

INTRODUCTION

The internet is increasingly being employed to provide medical services to patients (clinical uses)¹ and to manage, store, and transmit patient health information (non-clinical or administrative uses). The relatively new application of the internet within the field of medicine has come to be known as electronic medicine or *e-medicine*.²

E-medicine is a subset of telemedicine, which the Institute of Medicine (IOM) defines in the following manner:

Telemedicine is the use of telecommunications and information technologies to share and to maintain patient health information and to provide clinical care and health education to patients and professionals when distance separates the participants (Field, 1996).

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The IOM's definition can be made more specific, by (a) emphasizing a particular technology such as the internet, (b) making a distinction between clinical and non-clinical applications, and (c) conceiving telemedicine either as an integrated system of healthcare delivery or a mere collection of electronic tools.

For our purpose, e-medicine will primarily refer to the electronic medium of the internet and those patients and consumers who access healthcare information from medical websites or have portions of their healthcare managed online by healthcare professionals (Bashshur, Sanders, et al. 1997). Common examples of e-medicine include (a) online-accessible electronic health records (EHR), (b) electronic mail (e-mail), and (c) internet-based networks that link insurance companies, hospitals, individual healthcare professionals, and patients.

Furthermore, e-medicine is not simply medicine's use of information and communication technologies (ICTs); rather, in the context of e-medicine, ICTs such the internet *are* medical technology. According to the Office of Technology Assessment (OTA), medical technology includes "the drugs, devices, and medical and surgical procedures used in medical care and the organization and support systems within which such care is provided" (Lashof, 1981). Because the internet as well as other information and communication technology can be subsumed under "the organization and support systems within which such care is provided," the internet can be broadly construed as a type of medical technology under the OTA's definition.

E-medicine has a number of already proven benefits, including improvements in health care quality; prevention of medical errors; reduced health care costs; increased administrative efficiencies; decreased paperwork, and expanded access to healthcare (HHS, 2008). However, the continued adoption of computerized patient records and the expanding use of the internet by patients and healthcare professionals as a place to

post, find, store, and transit health-related information have only led to even greater concerns about the integrity of medical privacy and confidentiality and who should have access to health-related information. This in turn has raised additional concerns over the potentially deleterious results for healthcare quality, provider-patient relationships, and patients' overall confidence in our healthcare system(s) (Bauer, 2004).

THE CONCEPT OF PRIVACY

But what exactly are we talking about when we discuss *privacy*? Answering this question may appear intuitively straightforward, but the fact of the matter is that defining *privacy* and privacy-related concepts such as *confidentiality* is not as straightforward as it appears, as there is no universally accepted definition, theory, or justification for privacy within the philosophical, legal, and public policy literature. Because of the nebulous nature of privacy, the identification and analysis of important privacy issues associated with internet-based healthcare can be difficult. Despite this limitation, privacy can be analyzed in terms of (1) the nature of privacy, (2) the coherence and distinctiveness of privacy, (3) the contingency or cultural relativity of privacy, and (4) the normative status of privacy (Schoeman 1984). These elements of privacy are important in understanding what is meant by *privacy* and why it is ethically significant in the context of e-medicine.

The Nature of Privacy

Questions about the nature of privacy typically center on (a) examining competing definitions of privacy and (b) determining whether privacy is a moral right. Three definitions of privacy are common (Schoeman 1984). First, privacy can be defined as a *moral right* or *entitlement* that individuals have to determine what personal

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