Chapter 9

Personal Health Information in the Age of Ubiquitous Health

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ABSTRACT

We have long passed through the information age into an information perfusion in health care, and new strategies for managing it are emerging. The ubiquity of health information has transformed the clinician, the public, and the patient, forever changing the landscape of health care in the shift toward consumerism and the notion of the empowered patient. This chapter explores essential issues of ubiquitous health information (UHI), beginning with its origins in the explosion of health information and the advent of new technologies. Challenges of UHI include privacy issues, change management, and the lack of basic infrastructure. However, benefits for patients include improvements in access to information, communication with providers, prescription renewals, medication tracking, and the ability to self-manage their conditions. Benefits at the organizational level include increased patient satisfaction, continuity of care, changes in costing models and improved standardization of care as organizations streamline processes to address this change in clinical practice.

INTRODUCTION

In health care the "information age" has long passed and we have entered into the era of information perfusion. The ubiquity of health information has transformed the clinician, the public, and the patient. As technology progresses and we see exciting and

DOI: 10.4018/978-1-61520-777-0.ch009

innovative strategies for managing it emerge, ubiquitous health information (UHI) has brought on a tectonic shift that will forever change the landscape of health care.

This chapter explores the essential issues of UHI: the debates and controversies, the risks and benefits, and efforts that must be made to manage them. To begin, we trace the origins of UHI – the rise and explosion of several genres of health information in

conjunction with the evolution of new technologies. We look at the definition and components of UHI, the types of health information that are available, and the methods for their exchange. We also explore the rise of consumerism and the notion of empowered patients within the context of ubiquitous health information.

The chapter also examines the role of UHI in the changing landscape of health care. We investigate the growing number of social, economic, cultural, ethical and legal issues, as technologies allow for the dissemination and exchange of personal health information. The impact of the perfusion of information on the public and patient is explored, as well as its impact on health professionals and the type of care delivered, and the new and alternative environments in which it is carried out. The benefits and the risks of UHI are discussed, including the educational, clinical and research opportunities. And finally, we offer a consideration of future research directions, and potential frameworks for the evaluation and assessment of UHI.

BACKGROUND

Ubiquitous Heath Information Today: Towards a Definition

The perfusion of health information today can be overwhelming. Health information is now everywhere, all the time. We see messages about our health from television, radio, newspapers, the Internet, billboards and advertising. Health services and health products are an enormous industry, and controlling the messages is an ongoing battle between multiple interest groups that is being waged at the expense of those individuals who need it most – the public and the patients. Media and web sites are becoming battlegrounds over major health issues of the twenty-first century, ranging from circumcision and vaccinations to novel and alternative treatments. The social and

financial stakes are high, and information flows at a rate that is almost incomprehensible.

As new strategies for navigating this sea of information develop, so our ability to generate more information increases, contributing to this state of UHI. The emergence of new technologies, and the changing expectations of health care consumers have each influenced the explosion of UHI, both in their own right, and through an intricate relationship to each other.

It is evident that healthcare has experienced a shift toward consumerism and the notion of the empowered patient. Patients and the public are no longer satisfied with the status quo and a growing wave of public and patient expectation is mounting (Ball, Costin, & Lehmann, 2008; Hassol et al., 2004; Leonard, Casselman, & Wiljer, 2008; Leonard & Wiljer, 2007; Pyper, Amery, Watson, & Crook, 2004; Wiljer et al., 2006). The traditional health care system that was characterized by the physician driven model, an insular system of practice that neither had the means nor the inclination to share expert knowledge, is now a thing of the past. Today, patients are acknowledged as expert consumers. Health care providers work in partnership with their patients to make shared decisions, and there is the growing global trend of adopting legislation to ensure that patients are able to access, review, and amend their medical record (Beardwood & Kerr, 2005; Blechner & Butera, 2002; Chasteen, Murphy, Forrey, & Heid, 2003; Dietzel, 2002; France & Gaunt, 1994; Harman, 2005; Ishikawa et al., 2004; Jones, 2003; Kluge, 1993; Mathews, 1998; Mitchell, 1998; Pyper, Amery, Watson, Crook, & Thomas, 2002). As a result, the information asymmetry that once existed between health care professionals and the health care consumer is now significantly diminished and UHI is pervasive.

At the same time, technology is advancing. The role of information and communications technologies (ICTs) in health care is growing, and evidence of this trend is all around us. Research has

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