

Chapter 13

Digital Literacy for Health: The Promise of Health 2.0

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ABSTRACT

This paper outlines and challenges expectations and promises regarding the potential of the internet and Web 2.0 for empowering patients and citizens. It focuses on literacies required to make a meaningful (to the individual) use of these technologies for health and health care related purposes. The author briefly discusses how these should be taught and concludes that these literacies, including digital literacy and health literacy, are complex and challenging to many while the empowering claims are over-stated. Traditional sources of information and advice will remain essential to maintaining quality of health care.

INTRODUCTION

The changes that developed societies have experienced in recent decades have been given many descriptions, each emphasising a particular aspect or aspects of the ‘new’ order. For some, the developments in information and communications technology (ICT) are seen as pivotal to the process of shaping our society (Miles, 1996; Webster, 1995). The term ‘information society’ has permeated academic and policy publications, as well as

popular media, and the Internet is seen as central to production and consumption of information.

Others focus on cultural changes, proposing that we live in a world in which there is no overall ‘truth’ but there are many ‘truths’ and where we construct own meanings, history and lifestyles (Baudrillard, 1988; Bauman, 2000). We are also told that ‘liquid’ is an apt description of our societies (Bauman, 2000). Many people have nomadic lifestyles, or at least have no permanent attachment to a particular geographical place or a job. Old traditional loyalties, customary rights and obligations have been melted down, giving

DOI: 10.4018/978-1-4666-0903-7.ch013

the individual freedom to choose and to act (at least to a greater extent than before). Respect for professionals, including medics, has been undermined and the knowledge they represent has been challenged.

But freedom is a mixed blessing. Individualisation and empowerment place demands on us, to choose, to construct our own destinies, to cope with consequences of our choices and external events (Bauman, 2000). There is an obligation of care of self (e.g. to have a healthy lifestyle). We are now increasingly encouraged (and sometimes forced) to make choices with regard to diagnosis, treatments and providers (some of the choices being between traditional medicine and scientific medicine, private and public health care, and within each of those categories, of particular type of treatments and providers).

For some time now, the Internet has been seen as playing an important role in patient/consumer empowerment. Health related and lifestyle management sites have mushroomed on the Internet, and they vary in purpose, quality, content, interactivity and scope for collaboration. More recently the use of the Web, and in particular Web 2.0, is seen as potentially altering how citizens/patients engage with health care services. Web 2.0 is hailed as exciting new set of technologies for collaboration and social interaction in many domains including health care. The applications include blogs, wikis, Wikipedia, podcasts, social networking sites and mash-ups. Examples of their use in health domain include Web-based personal health records, on-line appointment scheduling, doctor-patient e-mail, health/disease or patient group focused blogs and social networking sites and HealthMap, which combines data from different people, RSS feeds and Google Earth to aggregate the information in order to examine outbreaks of different conditions.

A new term 'Health 2.0' is being used to denote the application of these new technologies in the area of health care. However, some see it as a paradigm-like shift in the way health care is de-

livered and experienced. Members of International Medical Informatics Association (IMIA) Web 2.0 Exploratory Taskforce suggest that: "Health 2.0 may go far beyond just the pervasive social networking technology of Web 2.0 to support a complete reinvention in the way that health care is delivered." (Murray et al., 2008, p. 47). Patient empowerment, and in particular communication and collaboration between patients, their caregivers, citizens and health care professionals are seen by them as key to such a re-invention of health care delivery.

The notion of patient empowerment is central to the European Union (EU) and many national and local governments' policies, and new ICT and services they facilitate (often referred to as e-health) are seen as playing an important role in achieving this goal. The EU e-health action plan (EU, 2004) includes a section on "Empowering health consumers: patients and healthy citizens". The plan stresses the importance of personal health education and disease prevention. The role of e-health services is defined as supporting managing people's own diseases, risks and lifestyles by providing timely information tailored to individuals in need. The examples of e-health services include health information networks, electronic health records, telemedicine services, wearable and portable monitoring systems and health portals.

In the UK, the government is promoting a patient-centred model of health care. This includes a vision of patients or rather consumers of health care, as we are now often referred to, having access to information on medical conditions, treatments, prevention and lifestyles, as well as data on availability of different services, performance of health care providers (e.g. through published hospital league tables, including statistics on different health specialists, e.g. surgeons). Furthermore, patients/citizens are increasingly envisaged in the policies not only as knowledgeable consumers of health information and health care services but also as co-authors of their care programmes involved

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