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Personal Health Informatics: The Evolving Paradigm of Patient Self Care

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ABSTRACT

The world of biomedical informatics is dynamic, diverse and complex. Clinical informatics is a subset of biomedical informatics which specializes in patient care. As technology become ubiquitous in the medical field, it is constantly changing all aspects of medicine; from the provider-patient relationship, to the care delivery mechanism, to the personal well being of patients. As the medical technology evolves, patients are increasingly becoming more and more involved with their own healthcare and using new healthcare technologies to manage their care. The spectrum of clinical informatics includes patients and their own self healthcare management. From this movement, stems the new field of personal health informatics.

INTRODUCTION

Biomedical informatics is a broad field that has been defined many times (Sullivan, 2001; Lorenzi, 2000; Van Bommel & Musen, 1997). Biomedical informatics is the union of bioinformatics and medical informatics. Bioinformatics differs from medical informatics, in the same way that research differs from clinical medicine. A subset of medical informatics is the patient care aspect, known as clinical informatics. Clinical informatics relates to patient care and technology. Clinical informatics can further be described as the union of multiple aspects of patient care, involving physicians, patients and others, also known as “consumers”. Consumer informatics is a subset of clinical informatics and has been well defined (Ferguson, 2001; Houston, Chang, Brown, & Kukafka, 2001; Dey, 2004), with the underlying theme being that “consumers” are using information technology to search, find and locate quality online health information (Kaplan & Brennan, 2001). Personal health informatics is also a subset of clinical informatics which differs from consumer informatics by focusing on the individual patient, rather than a “consumer.” Consumer informatics is broad, encompassing many different types of users, whereas, personal informatics is narrow and entails only specific patient related self management. This article will serve to define the field of personal health informatics in relation to patients’ attitudes, technologies and their applications for health information management of individual patients in order to maintain a healthy lifestyle.

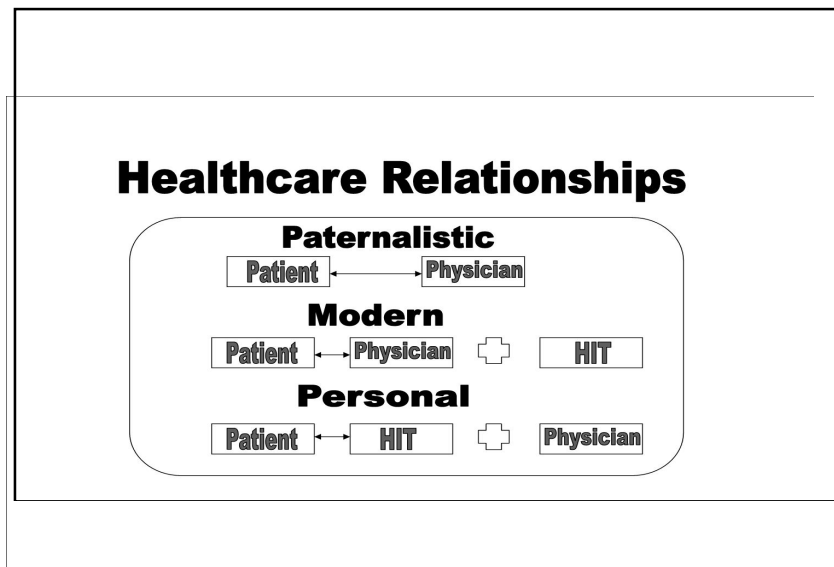
BACKGROUND

The availability of online patient information, new resources, desire for self management and care is the basis of personal health informatics. Patients have a desire to diagnose, treat and manage their own healthcare needs. By making resources available online, patients are now able to educate themselves and understand the complexities of modern medicine. Modern medicine cannot be understood unless there is a clear distinction and comprehension between a disease and an illness (Kleinman, Eisenberg, & Good, 1978). Diseases are pathologic processes that necessitate clinical intervention by a physician (medical or surgical) in order to maintain patient health. Diseases range from simple to complex. Illnesses are temporary, self limiting conditions that provide an inconvenience to the patients, such as viral infections, difficulty sleeping, runny nose, etc. The difference between a disease and an illness is the pathological course. Diseases can lead to terminal states in a patient unless treated. Illness lead to temporary states of physical discomfort, which patients can normally allow to run their course, regardless of intervention, the physical state will return to baseline. Illnesses do not always require (medical or surgical) interventions, however, many patients seek advice on how to manage such symptoms and inconveniences. Online resources enable patients to educate themselves, to manage their health, and to ultimately distinguish between disease and illness, enabling them to either seek professional advice or self management and care.

PATIENT RELATIONSHIPS

The medical relationship of patient, physicians and their resources has changed over the years. From the early days of paternalistic medicine, to very self serving patients and their own desire for optimal health, much has been written on the evolution and change in the patient-physician care model (Conti & Gensini, 2008; Kaba & Sooriakumaran, 2007; Lázaro & Gracia, 2006). From the early days of medicine until today, the physician-patient relationship has been a sacred and protected entity. New technologies are allowing patients to change that relationship. Where technology used to be the addition (or value added component) to the modern relationship, now the physician is the

value added component (Rohm & Rohm, 2007). Patients are beginning to go directly to health information technology prior to consultations with their physicians. The fundamental model of patient care has changed, now the relationship is patient and technology, with physicians being an additional resource (**Figure 1**).



As the model for healthcare changes, so too are physicians and patients. Patients have a new role in the relationship which enables self management. Health information technology, evidence based medicine, electronic resources, the internet, online tools, electronic health records (EHR), personal health records (PHR), and information proliferation have all combined to enable patients to manage their own health. Patients are the directors of their own healthcare; they serve as caregivers, researchers, diagnosticians, care managers and medical clerks in management of their own health records and needs. They are no longer passive participants, but active users of the systems available through health information technology (HIT).

PERSONAL HEALTH INFORMATICS

A majority of Americans are now using the internet as a resource for health information (Atkinson, Saperstein, & Pleis, 2009; Renahy & Chauvin, 2006). While information is readily available on the internet, many patient find the task of searching for information difficult (Keselman, Browne, & Kaufman, 2008). There are various methods to searching for online health information (Toms & Latter, 2007). Patient backgrounds and biases can affect the information search process (Lau & Coiera, 2007; Sillence, Briggs, Harris, & Fishwick, 2007). Information quantity and quality are among the important factors for patients during their searches (Dey, 2004). Personal health informatics allows individual patients to comprehend and analyze their own personal health issues; the consequences, risks, benefits, and alternatives to therapy, treatment and management. Information based on these analyzes used by patients in an individual manner that empowers them to make informed decisions about their own healthcare.

There are a number of barriers that preclude the use of personal self health management (Jimison, Gorman, Woods, Nygren, Walker, Norris, & Hersh, 2008; Campbell, 2005). The digital divide has been defined, which helps explain some of these barriers (McConaughy, Everette, Reynolds, & Lader, 1999). There have been many specific recommendations made to help bridge the digital divide (Chang, Bakken, Brown, Houston, Kreps, & Kukafka, 2004), however, most barriers to acceptance of online consumer health information is related to patient factors (Or & Karsh, 2009), not technical barriers. Online information credibility is also important to patients as they search for online information (Lemire, Paré, Sicotte, & Harvey, 2008).

Recent advances in health information technology have led to a new focus on a patient centric health records (Li, Lee, Jian, & Kuo, 2009). New websites, tools, consumer information, as well as new methodologies (Meristö, Tuohimaa, Leppimäki, & Laitinen, 2009; Logan & Tse, 2007) are being developed to aid patients in self management (Marschollek, 2007). It is important to understand patient needs when developing patient centric information modules (Civan, Skeels, Stolyar, & Pratt, 2006). There are national, as well as local projects (Watson & Brasure, 2008) that focus on patient self management. Some studies have disease focused patient management

(Boren, Wakefield, & Dohrmann, 2008) emphasis, while others are of a more general nature (McDaniel, Schutte, & Keller, 2008).

PERSONAL HEALTH INFORMATICS SPECTRUM

There is a broad spectrum of information covered in the field of clinical informatics, more specifically in personal health informatics. There is the clinical process of disease and illness. There are multiple resources for patients and physicians, and there are multiple users. This spectrum of diverse topics and their relationships has been detailed to show how personal health informatics relates to the other areas of clinical informatics (**Figure 2**). While distinct classification of disease and illness can be described as a spectrum, there are also various resources that relate to each topic, just as there are different users for each system.

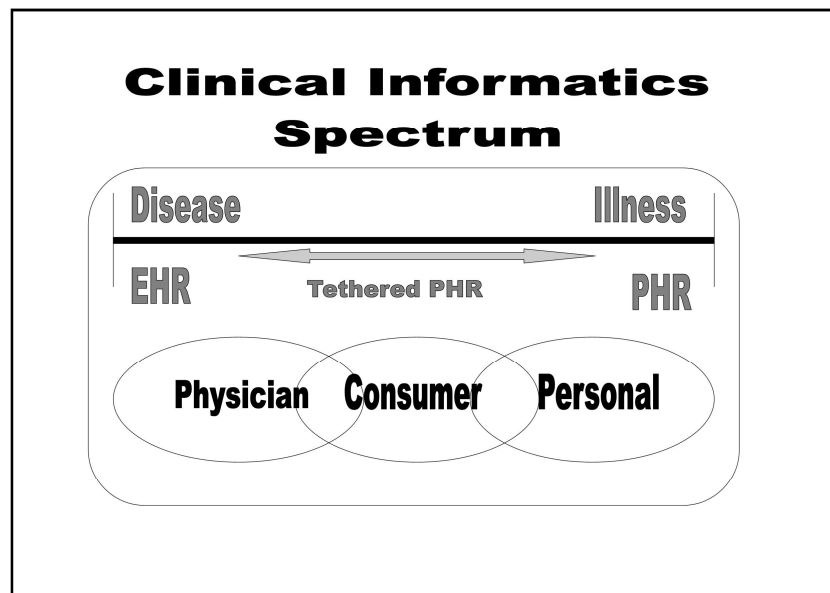


Figure 2: Clinical Informatics Spectrum

The clinical informatics spectrum details resources for medical records. While electronic health records (EHR) are used, updated, manipulated and controlled by healthcare systems and physicians, on the other end of the spectrum are personal health records (PHR) that are maintained, updated and manipulated by the individual patient. While physicians control the EHR, the patient controls the PHR. There is a wide gap between the two systems. In an EHR, the healthcare system or physician can verify the contents of the system, but the data is owned by the system. In a PHR, there is no data verification process. Patient's medical claims can be manipulated for their own self serving needs. Patients own PHR information, can access, manipulate and edit. Patients who want to control their own healthcare will undoubtedly use personal health records. Patient who control their own records will also be able to use the current online resources to aid and improve their own health.

Tethered PHRs will be another tool that patients can use to control their health, although in a limited fashion. A tethered PHR is a PHR that is linked into an EHR, where the information can be verified by a physician or healthcare system. While ultimate control lies with the providing healthcare system, the patients can use the tethered PHR to manage their health. Tethered PHRs have been shown to be superior to stand alone PHRs for overall health management (Tang, Ash, Bates, Overhage, & Sands, 2006), although improvements can always be made (Reti, Feldman, Ross, & Safran, 2010).

The spectrum of clinical informatics includes various users: physicians, consumers and patients. Clinical medicine is about outcomes. For physicians, clinical medicine starts with the patient, their individual problems and treatment plans. For patients, not all clinical outcomes require physician intervention. The fundamental basis of personal health informatics is for the patient to control their own health care needs and educate themselves (Kupchunas, 2007). Those needs may be disease based, or illness related. Each healthcare system also has specific technology tools (PHR or EHR). It is important to understand the difference between the various users because there is considerable overlap. Physicians can be consumers or patients, consumers can be physicians and/or patients, and

patients can be consumers. Although users are not mutually exclusive, their focus and goals are different. Physicians are concerned with disease management. Consumerism vs. personal health management is distinct. Consumerism and consumer informatics relates to the patient and physicians as consumers. The patient consumes information, resources, data, tools, and implies that there is an underlying business philosophy driving the consumerism. Personal health informatics has no underlying business agenda.

Information, education and tools are designed and used by the patient without an agenda related to a business. While most online resources are developed by businesses, there is hint of consumerism involved, however, patients do not have to “consume” these resources, or need to have a brand loyalty as implied by consumerism. Patients who seek personal healthcare can find any number of sites, tools, and resources that are business independent to aid in their care. While consumer and personal health informatics share many basic ideologies, they are not the same. A patient that is managing their health is not always a consumer of informatics resources, likewise, consumers, such as office managers, physicians, and other businesses are not always trying to manage their own health. Consumer informatics is not always personal health informatics, nor vice-versa.

CONCLUSION

Diversity is what makes biomedical informatics, clinical informatics and personal health informatics such dynamics fields. Healthcare relationships have evolved over the years; from paternalistic medicine to the current relationship with health IT benefits, to the quickly expanding personal informatics with self management, change and progression is constant. There are many shared components of clinical informatics with the new field of personal health informatics. While some tools, resources and information may be the same, the focus is much different – the patient. The patient is self motivated, seeking self preservation, self management and independence. There is no link to any particular business, any desire to consume certain products or services, only independence in resource management. The physician becomes an addition to the patient-HIT relationship, not a major component. On the clinical informatics spectrum, patients are tied to PHRs, illnesses and self management. By controlling their own healthcare needs, patients are quickly becoming educated and in control of their own health. Personal health informatics is changing modern medicine; the physician-patient relationship and resource management and is quickly evolving into a new paradigm for patient self care.

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