Chapter 5.19
Active Patient Role in Recording Health Data

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INTRODUCTION

The healing process can be viewed as a partnership between doctors and patients, nurses and physicians or, more generally, a partnership of health professionals and health care users (Anonymous, 2008, Graham, 2007). A patient-centered approach that empowers patients to participate in decisions about their treatment and health care options asks for active participation of patients themselves, specifically, in health information gathering and exchange of this information with their health or medical records (Bachman, 2007; Stolyar, Lober, Drozd, & Sibley, 2005).

BACKGROUND

Medical or Health Record

Every physician has a number of patients in his or her care. Many patients also have a number of specialists taking care of their health. It is almost impossible for physicians to keep in mind all the information about even a single patient, let alone all patients in their care. Similarly, patients need to remember and comply with many recommendations communicated to them by their doctors. Recording patients' data is, today, a necessity, especially considering a large number of available diagnostic procedures and instruments producing information

relevant for making medical decisions. One implication of such recording is the creation of medical records in health institutions; they are created and accessed by health professionals. According to the National Library of Medicine, the MeSH (medical subject heading) term "medical record" considers "recording of pertinent information concerning patient's illness or illnesses" (http://www.PubMed.com).

However, the medical data gathered by health professionals are not enough for making good medical decisions. Information that is not strictly medical can be added to medical data. We therefore usually talk about a *health record*, consisting of data and information that affect or could affect the patient's health status, or simply describe it. A health record is a more general term than a medical record, nursing record, or dental record, and should be used as an immediate superior term to them. Keeping all the information pertaining to a particular patient in one place, and making it accessible at any time to authorized professionals, is a challenge. In seeking solutions, the information and communication technology should be consulted.

Personal Health Record

In trying to encourage people to take an active interest in their own health, patients are supported to manage their own personal health records. A personal health record can contain copies of data from the health record, which is created by health professionals, and also information entered by patients themselves (for example, subjective information such as description of symptoms, and objective information such as values of self-measured blood pressure or blood glucose levels, etc., recorded in a personal health diary).

Thus far, the literature does not give an adequate definition of a personal health record. Wikipedia defines it as "a health record that is initiated and maintained by an individual," but it is unclear who the individual is, the health professional or

the patient. According to Tang (2006), a personal health record includes health information managed by the *individual*, who is not necessarily a *patient,* an ill person. This distinction emphasizes that the personal health record is a tool used to care for health and wellness, not only illness.

CURRENT STATUS

Electronic Health Record and Personal Health Record

There are several definitions of the electronic health record and many descriptions of its characteristics and demands (Hayrinnen, 2007). According to ISO (2004), "the EHR means a repository of patient data in digital form, stored and exchanged securely, and accessible by multiple authorized users. It contains retrospective, concurrent, and prospective information and its primary purpose is to support continuing, efficient and quality integrated health care." One of the most exhaustive descriptions of electronic health records is given by the Advisory Committee on Health Infostructure of Canada (2001). According to the description in their Tactical Plan for a pan-Canadian Health Infostructure, an electronic health record is "a longitudinal collection of personal health information of a single individual, entered or accepted by health care providers, and stored electronically. The record may be made available at any time to providers, who have been authorized by the individual, as a tool in the provision of health care service. The individual has access to the record and can request changes to its content. The transmission and storage of the record is under strict security." This means that an electronic *health* record also incorporates electronic *medical* records, including digital medical images (computer tomography or similar) and biomedical signals (electrocardiography or similar), laboratory findings, the interpretation of all such findings, and physicians' recommendations

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