Building a personal health record from a nursing perspective

Mikyoung Lee[a,], Connie Delaney[b], Sue Moorhead[c]*

[a] College of Nursing, 50 Newton Road, College of Nursing, University of Iowa, Iowa City, IA 52242, USA
[b] School of Nursing, University of Minnesota, Minneapolis, MN, USA
[c] College of Nursing, University of Iowa, Iowa City, IA, USA

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ABSTRACT

Objective: A complex set of needs—increased accessibility to and interest in health information, more respect for patients' rights, advanced information technologies, and pressure to seek cost-effective healthcare delivery—made the personal health record (PHR) necessary. Nursing, as essential to healthcare, must be represented in a PHR, but few studies have explored the nurse's role in the development and expansion of the PHR. The aim of this project was to design and develop an Internet-based PHR, IowaPHR, in order to demonstrate how nursing can be integrated into the PHR.

Methods: In addition to the common features of the PHR as detailed by previous studies, IowaPHR contains the following innovations: (1) the information embraces major community health concerns; (2) an interactive feature—the self-assessment and feedback field—was created by transforming a standardized nursing language into appropriate questions adjusted for consumer vocabulary level; and (3) a user-friendly interface was equipped with trends in health conditions and a diary function. This PHR was then evaluated by experts in terms of content, ease of navigation, time needed to complete tasks, ability to find desired information, and site presentation.

Results: In the evaluation of this PHR, experts assigned high scores to four items. Completion of the tasks took an average of 16.25 min.

Conclusion: Allowing self- or caregivers to observe health conditions through completion of the questions on our PHR will precisely address clinic visitors' health problems, assist in planning interventions, and promote education of and empowerment for health care. This PHR will provide a new way for nursing informatics to enhance the capacity of nursing in consumer health and to make a difference in the larger context of health informatics.

1. Introduction

As the Internet becomes more and more ingrained into peoples' daily lives, the number of people who access the Internet for health information is increasing [1–3]. In fact, seeking information related to health concerns—including disease knowledge and management, medications, or home treatment alternatives—ranks as the most popular reason given for Internet use after e-mail and researching a product or service before buying it [3,4]. Consumers are gradually becoming the main decision-makers in terms of medical and treatment decisions, having a sense of autonomy. In this era where

people desire access to their personal health information [5], it is highly anticipated that the capability of Internet, as an inexpensive telecommunication technology in healthcare delivery, will expand by enabling payers, healthcare providers, and patients/consumers direct access to health data and healthcare resources at any time and any place. This situation implies that healthcare providers have a new opportunity to influence patients' or consumers' health promotion, disease prevention, and illness management [6]. The advent of the personal health record (PHR) via the Internet corresponds to the rise in individuals' health information needs. As the PHR evolves, it is essential for nurses to be involved in designing and developing it because nurses have long been advocates for better care of patients and for public health.

2. Background

2.1. Personal health record

Names for the PHR vary from simply the electronic health record (EHR) to the personal electronic health record. While EHR seems to be accepted globally as the generic term for the vision of electronic patient care systems, PHR is described as a form of EHR; however, in essence, it is managed and controlled by patients (individuals) rather than by healthcare providers [7,8]. While there is no uniform definition for PHR [9], the concept includes an electronic application enabling individuals to access and manage their own lifelong health information and to share all or parts of such information with authorized persons in a secure and confidential environment [8,10–13]. Thus, a PHR is comprised of an aggregate of all the health care experiences of an individual.

The concept of PHR is not new; rudiments of it have been presented in paper records for decades [14]. Nevertheless, because of the increased potential, via the Internet, of timely and efficient access to a patient's complete health history, overcoming physical challenges to exchanging patient medical record information across health care institutions, the PHR is gaining in popularity [14–16]. Patients who are suffering chronic illnesses and those experiencing an unexpected health event are particularly interested in recording their care, and they expect to benefit from using a PHR for better understanding and carefully monitoring their health problems [15–18].

Today, there are many different consumer-oriented health websites, ranging from those that mainly provide searchable information without attention to whether or not the subjects are reacting on the given recommendations to "interactive" websites that guide targeted populations to be actively involved in care plans by an interrelation mechanism between individuals (to whom the information is tailored) and healthcare providers [19]. A PHR has the potential to facilitate such interaction via the latter type of website by providing a common avenue for the users to (1) collect, monitor, and organize daily health data; (2) gather knowledge; and (3) share and query health information or personal data [8,11]. While most of the health informatics applications have been conceived with a professional user model [20], in the PHR patients/individuals become the center of health care by the

changed ownership. This parallels the growing concept: inviting patients/consumers to be partners in health care [20,21].

The rising interest in the PHR has lead to its development at the national level as well as on a smaller scale [14,16]. In Europe many countries are combining PHRs with their national e-health infrastructures initiatives [14]. In the United States the Office of the National Coordinator for Health Information Technology (ONCHIT)—which was established corresponding to President Bush's executive order for the advancement of the EHR—identifies a PHR as a critical information tool to achieve one (personalized care) of its four strategic actions for delivering consumer-centric and information-rich care [22]. At the level of substantial implementation, PHR potentially can be connected to Regional Health Information Organizations (RHIOs). This is the emerging initiative of the US in given geographic areas for improving the effectiveness, efficiency, and overall quality of patient care by interconnected electronic health information systems across hospitals and databases and eventually support a National Health Information Network [23–25]. More than 100 RHIOs have been announced nationwide [26], but there has been some resistance by institutions to exchanging information among facilities and concerns of failure in competition by RHIOs' the very principle of sharing information [25].

Currently many types of PHRs are being created by vendors or agencies, although it is not sure that they are working in conjunction with a certain RHIO. However, if interoperability and sharing is not available between institutions, consumers using a PHR from Clinic A may need to complete another set of documents for Clinic B. To avoid this redundancy and to establish an efficient healthcare delivery system, it is critical to create a PHR hosted by the reliable core RHIO that can interface with diverse clinical record systems. We believe that colleges of nursing could contribute to the research and development of such a PHR and RHIO.

Moreover, when one reviews the common features of PHRs, it is noticeable that there has been no PHR that encompasses nursing care elements. Few studies have explored the nurse's role in the development and expansion of PHRs, though individual computer-mediated interventions driven by nurses have increased. Nursing is an essential part of collaborative healthcare and has been documented in health records; therefore, it is logical that nursing's perspective can be applied to compose a part of the PHR content. For example, nurses historically have taken and recorded a patient's health history at admission to the hospital or care facility; a new model asking completion of this aspect of nursing might replace this admission work, thus saving time. The nurse could then review this information and focus on the present health concern rather than spend time entering data. In addition, the patient's complete health history in this new model of the PHR includes education in that it guides what individuals need to know about their condition(s) prior to admission and provides additional information after discharge.

Given the importance and rapidly expanding use of PHRs, the overall study was intended to design and develop the IowaPHR in order to demonstrate that nursing can be included in the PHR and can contribute to consumer health in an innovative way. This article describes Phase I of the overall study: development of the PHR's structure and evaluation of its con-