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Review article

Work system barriers to patient, provider, and caregiver use of personal health records: A systematic review

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ABSTRACT

Objectives: This review applied a human factors/ergonomics (HF/E) paradigm to assess individual, work system/unit, organization, and external environment factors generating barriers to patient, provider, and informal caregiver personal health record (PHR) use.
Methods: The literature search was conducted using five electronic databases for the timeframe January 2000 to October 2013, resulting in 4865 citations. Two authors independently coded included articles (n = 60).
Results: Fifty-five, ten and five articles reported barriers to patient, provider and caregiver PHR use, respectively. Barriers centered around 20 subfactors. The most frequently noted were *needs, biases, beliefs, and mood* (n = 35) and *technology functions and features* (n = 32).
Conclusions: The HF/E paradigm was effective in framing the assessment of factors creating barriers to PHR use. Design efforts should address literacy, interoperability, access to health information, and secure messaging. A deeper understanding of the interactions between work systems and the role of organization and external environment factors is required.

Contents

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1. Introduction

As clinician and patient roles evolve, responsibility for health management is shifting from clinician-governed to patient-controlled (Wasson et al., 2012). The continuing development of consumer health information technology (IT), health IT designed for use by lay people, supports this change in roles by enabling patients to actively engage in health management both alone and in partnership with formal healthcare providers (i.e., providers) (Center for Advancing Health, 2010). This engagement through consumer health IT has been accelerated by market forces such as the proliferation of consumer-facing mobile health applications (PricewaterhouseCoopers LLP, 2012; Greenspun and Coughlin, 2012) and has been promoted by the Meaningful Use initiative within the United States (The Office of the National Coordinator for Health Information Technology (ONC), 2013a; Center for Medicare and Medicaid Services, 2015): Stage 2 of this initiative (The Office of the National Coordinator for Health Information Technology (ONC), 2013a) incentivizes increased health information exchange, patient-controlled data, requirements for e-prescribing and incorporating lab results, and electronic transmission of patient care summaries across multiple settings. The recently proposed Stage 3 guidelines (Center for Medicare and Medicaid Services, 2015) extend the Stage 2 requirements for patient engagement by increasing the requirements regarding the proportion of a provider's patients who have interacted with their health records (i.e., viewed, downloaded, or transmitted their health records) and used secure messaging through the electronic health record (EHR) (Center for Medicare and Medicaid Services, 2015).

Patient engagement in health management, however, does not solely rely on actions taken by patients and providers. Rather, health management in home and community settings often depends upon the active participation of other individuals (Valdez and Brennan, 2015; Skeels, 2010), including informal caregivers (i.e., caregivers). Caregiver as well as patient and provider interest in accessing and exchanging health information has been documented (Friction and Davies, 2008). The Patient Engagement Framework (National eHealth Collaborative and Healthcare Information and Management Systems Society Foundation, 2014), championed by the Healthcare Information Management Systems Society (HIMSS) and the National eHealth Collaborative (NeHC), outlines a vision for Meaningful Use Stages 3 and 4 to further support, through consumer health IT, the full range of individuals (e.g., caregivers, family, friends, clergy) involved in patients' health management. The need to attend to caregivers' perspectives has also been recently identified within the HF/E literature (Holden et al., 2013, 2015).

Despite widespread development and promotion of consumer health IT, usage rates have remained relatively low (Valdez et al., 2015b). Proposed explanations for these low patient usage rates include low numeracy and limited technology experience (Taha et al., 2013), difficult login procedures (McInnes et al., 2013), limited family support for using advanced technologies (Mayberry et al., 2011), and fears concerning the misuse of stored information (Tjora et al., 2005). Reasons for low provider usage rates include no prior email communication with patients (Crotty et al., 2013), medical practice

location (Wynia et al., 2011), and concerns regarding appropriate reimbursement and liability (Wynia et al., 2011). Low caregiver usage rates are associated with caregiving responsibilities for a child who has a nonsevere illness (Byczkowski et al., 2014), slow Internet connection (Tom et al., 2012), insurance type (Tom et al., 2012), and fear of discrimination from insurance companies (Weitzman et al., 2012). Given the multi-dimensionality of these rationales, HF/E frameworks should be systematically applied to understand barriers to patient, provider, and caregiver consumer health IT use.

Previous research in HF/E has focused on the impact of work system factors on healthcare providers' clinical health IT use, such as EHR and computerized provider order entry (CPOE) (Holden et al., 2013; Carayon and 2006; Fuji et al., 2008; Nazi, 2013; Urowitz et al., 2012). These studies demonstrate that health IT use in professional settings is shaped not only by individual characteristics, but also by a wider range of work system factors. Multiple models of the work system (Carayon and 2006) emphasize that system outcomes are influenced by interactions between users, tasks performed, tools used to accomplish these tasks, and the physical, social, and organizational environments in which users are embedded (Holden et al., 2013). While work system models traditionally characterize the sociotechnical systems of professional work, more recent models translate this concept for patients and caregivers (Holden et al., 2013; National Research Council, 2011; Carayon et al., 2006). These models enable the concept of the work system to be applied to healthcare work conducted by both healthcare providers and lay people, facilitating the study of work system factors in the context of consumer health IT use. In this review, barriers are categorized using the HF/E paradigm developed by Karsh and colleagues (Karsh et al., 2006). Although this paradigm targets patients and providers, we extend and apply it to caregivers.

This review focuses on a specific type of consumer health IT, personal health records (PHRs), because Meaningful Use Stages 2 and 3 as well as the Patient Engagement Framework promote increased patient, provider, and caregiver PHR use within the United States. Though varyingly defined (Archer et al., 2011; Connecting for Health Personal Health Working Group, 2003; The Office of the National Coordinator for Health Information Technology (ONC), 2013b), PHRs in the present study are "Internet-based set[s] of tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" (Connecting for Health Personal Health Working Group, 2003), (p3). Common PHR functionalities include the ability to access lab results, engage in secure messaging with providers, request prescription renewals, schedule appointments, authorize referrals, and view and update medication and allergy lists (Archer et al., 2011). Studies included here report on PHRs that vary in terms of available features and of organizations through which patients were enrolled (e.g., employer, government agency, primary care physician). In contrast to previous reviews of PHRs (Archer et al., 2011; Jabour and Jones, 2013; Amante et al., 2014), this review is systematic, restricted to empirical peer-reviewed articles, focused on work system barriers to use by patients, providers, and caregivers, and based on an HF/E paradigm.