USE OF ELECTRONIC PERSONAL HEALTH RECORDS FOR SELF-MANAGEMENT SUPPORT: AN E-HEALTH MODEL BASED ON A QUALITATIVE STUDY OF CHRONICALLY ILL ADULTS

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Background: Chronic illnesses are costly to older adults and society but e-health tools are available to help manage this burden. One e-health tool that has been promoted to facilitate self-management support of chronic illness by policy makers, health advocates, providers, and consumers is the electronic personal health record or patient portal (PHR). Federal incentives are in place to mandate that providers and health care organizations offer PHRs to patients and caregivers. However, little is known how consumers actually use these systems for self-management support and productive patient-provider interactions.

Objectives: the aim of this study is to investigate why and how experienced adult healthcare consumers with chronic illness use PHRs for self-management support and productive patient-provider interactions as defined by the Chronic Care Model (CCM). Findings of this study were used to enhance the CCM with an overarching framework of e-health technology that supports all major components of the model.

Methods: This qualitative descriptive study, drawing on a grounded theory approach used a group of chronically ill, English-speaking, adults who were identified by their providers as skilled users of a tethered PHR/patient portal. Eighteen purposively selected research participants ages 50-65 were interviewed in two communities including subjects living in rural areas.

Results: Participants included 7 females and 11 males with a mean age of 60 and an average of 3.0 chronic illnesses. The majority of the participants were employed and had a minimum education level of a bachelor’s degree. Participants reported a mean of 19.8 PHR use episodes per year e.g., review laboratory results or communicate with a provider. The participants had, on average, 2.9 years of experience with the system and reported that they had 2.5 providers using PHRs and 2.5 of their providers did not. There were four major thematic categories that described the perceptions of the chronically ill using PHRs identified through an analysis of the transcripts: (a) patient-based factors (b) system-based factors (c) interaction factors and (d) training opportunities. The participants were very positive about using PHRs for self-management support, preparation for appointments and communication with the health care team. However, participants did raise concerns about provider messaging confusion, inadequate system design, PHR navigation concerns and the desire for greater access to the comprehensive electronic health record.

Implications: Based on the study findings, the authors propose an enhanced version of the CCM adapted for e-health. The model includes facilitators for self-management support and patient-provider interaction. Knowledge gained from the experienced PHR users suggest that improvements to the PHR and providing PHR use education to patients and the provider team will increase the utility of the system among experienced users and encourage new users to embrace adoption and use in both urban and rural environments.