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Online self-management interventions for chronically ill patients: Cognitive impairment and technology issues

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ARTICLE INFO

Article history:

Received 9 May 2013

Received in revised form

11 November 2013

Accepted 10 January 2014

Keywords:

Chronic disease

Health self care

Cognitive impairment

Caregiver

Smart homes

Technology adoption

Mobile technology

Internet

ABSTRACT

Introduction: As the fraction of the population with chronic diseases continues to grow, methods and/or technologies must be found to help the chronically ill to take more responsibility to self-manage their illnesses. Internet based and/or mobile support for disease self-management interventions have often proved effective, but patients with chronic illnesses may have co-occurring cognitive impairment, making it more difficult for them to cope with technologies. Many older patients are also not familiar with technologies or they may have cognitive disabilities or dementia that reduce their ability to self-manage their healthcare. On-line solutions to the needs of chronically ill patients must be investigated and acted upon with care in an integrated manner, since resources invested in these solutions will be lost if patients do not adopt and continue to use them successfully.

Objectives: To review the capabilities of online and mobile support for self-management of chronic illnesses, and the impacts that age and disease-related issues have on these interventions, including cognitive impairment and lack of access or familiarity with Internet or mobile technologies.

Methods: This study includes a review of the co-occurrence of cognitive impairment with chronic diseases, and discusses how cognitive impairment, dyadic caregiver patient support, patient efficacy with technology, and smart home technologies can impact the effectiveness and sustainability of online support for disease self-management.

Results: Disease self-management interventions (SMIs) using online patient centered support can often enable patients to manage their own chronic illnesses. However, our findings show that cognitive impairment often co-occurs in patients with chronic disease. This, along with age-related increases in multiple chronic illnesses and lack of technology efficacy, can be obstacles to Internet and mobile support for chronic disease self-management.

Conclusion: Patients with chronic diseases may have greater than expected difficulties in using Internet and mobile technologies for disease self-management, often due to cognitive impairment or unfamiliarity with technology. Approaches to dealing with such barriers include suitable integration of solutions involving patient–caregiver dyads, better design of online applications, careful attention to technology adoption and sustainability, and smart home technologies.

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<http://dx.doi.org/10.1016/j.ijmedinf.2014.01.005>

1. Introduction

There is a growing trend in the prevalence of chronic disease throughout the world [1]. In the United States, direct annual costs associated with chronic disease were estimated in 2009 at 78% of U.S. healthcare spending [2], so the use of disease self-management to shift more healthcare responsibility to the chronically ill themselves has become a major consideration in controlling healthcare costs. Consequently, there is an urgent need to understand how technology might be used to address this growing burden on the healthcare system. The goal of disease self-management is to improve health status and health behavior, reduce utilization of the healthcare system [3,4] and improve patient quality of life in both work and home settings. It may be challenging for patients diagnosed with chronic conditions to self-manage their illnesses by modifying their life styles with little or no additional ongoing support [5], so it is critical to find ways to provide and promote cost effective technologies. One approach is to provide online (Internet or mobile) patient-centered support, empowering patients to manage their own chronic illnesses with collaborative support as needed from their circle of care [6]. If carefully designed and implemented, this can be more effective and possibly more cost efficient than the traditional care model [7–9], resulting in better self-management and decision making by patients.

Online self-management interventions (SMIs) include the encouragement of behaviors such as complying with prescribed medications, monitoring symptoms, and making lifestyle adjustments such as dietary change; alcohol restriction and smoking cessation; exercise and weight loss; and preventive behaviors (e.g. oral and body hygiene, sufficient rest, etc.) [10]. Other factors may complicate this process. For example, for heart failure patients these factors include: having multiple chronic conditions; anxiety and depression; age-related issues; impaired cognition; sleep disturbances; poor health literacy; and problems with the healthcare system [10].

This paper has the following objectives:

- a) To discuss the effectiveness of online stationary and mobile systems in supporting self-management interventions for chronic illness.
- b) To review in detail the literature on co-occurrence of cognitive impairment with many chronic diseases.
- c) To consider the barriers to the use of online applications for patients, and how these barriers might be addressed in an integrated manner through a collaborative approach involving all the stakeholders.

2. Background

SMIs for chronic illnesses imply day to day patient responsibility including: taking medications, monitoring health-related data (e.g. weight, diet, exercise, blood pressure, etc.), making lifestyle changes, and taking preventive actions [11]. For an SMI to be effective, patients need not only adhere to treatment guidelines but also set goals to make the cognitive, behavioral,

and emotional changes necessary to achieve an acceptable quality of life. The psychological and social dimensions of chronic illnesses differ according to the illness, so there is no “one size fits all” approach to chronic disease SMIs. For example, care plans for asthma may focus on monitoring symptoms and better medication adherence, while diabetes and arthritis SMIs may focus more on behavioral changes such as lifestyle and cognition [11].

Self-management plans and goals are derived through collaborations between patients and healthcare professionals in their circle of care, including physicians, nurses, therapists, dieticians, etc. Patients can then use these plans and goals independently to make frequent daily decisions in managing their conditions, resulting in improvements in managing certain chronic diseases [12]. If an online disease self-management system is developed that is grounded in the chronic care model [13] and utilizes the patient’s personal health record (PHR) as a repository, it can provide the basis for improved patient-centered care [9,14,15]. The system should link to the patient’s circle of care through secure electronic communications, preventive healthcare reminders, and disease specific tools such as education, community support, patient-oriented decision support [16–18], and motivators to encourage sustainability and continued use of the system, such as online recreation and amusements.

An effective online SMI requires of the patient [19]: self monitoring (e.g. daily weight measurement), the ability and approval through empowerment to change treatment appropriately, the personality to take control of one’s own treatment, and a physician and care team who are comfortable with empowering the patient. For some patients and physicians, this may be quite natural but for others it requires a major cultural change. Tools that support SMIs include [20]: (a) Information and education about the disease, its causes and effects, strategies to forestall its progress and prevent disease complications, and effective treatments; (b) Training in managing the disease, including how to monitor symptoms (e.g. blood pressure, blood glucose and weight), setting targets and using problem-solving and coping techniques to meet those targets, developing confidence in disease SMIs; (c) Behavior modification programs such as exercise programs and smoking cessation; (d) Counseling, advice and supportive services to help patients to cope emotionally with their conditions; (e) Care partners who can assist in patient self-management activities; and (f) Access to health and social resources in the community.

The advantages of online network support for chronic disease patients include portability, timeliness, efficiency, and scalability, with few limitations due to geography or mobility [21]. Such systems can accommodate remote access from both desktop computers and mobile devices (the latter especially for those currently employed and/or otherwise active). Through online decision support [22] for patient-centered care, changes in healthcare practice can help to meet practice and patient goals. A recent systematic review of online self-management interventions for older adults with one or more chronic illnesses (mean age greater than 50) found 15 relevant articles [23]. The review showed that study participants felt greater self-efficacy for disease management, and particularly benefitted from communications and feedback from

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