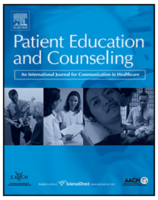
Patient Education and Counseling 92 (2013) 229–234

Contents lists available at SciVerse ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Do participation and personalization matter? A model-driven evaluation of an Internet-based patient education intervention for fibromyalgia patients

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A R T I C L E I N F O

Article history:
Received 27 June 2012
Received in revised form 8 March 2013
Accepted 9 April 2013

Keywords:
Internet
Patient education
Fibromyalgia Syndrome
eHealth
Theory-driven evaluation

A B S T R A C T

Objectives: To evaluate the effectiveness of an Internet-based patient education intervention, which was designed upon principles of personalization and participatory design.
Methods: Fifteen months after the first release of the website, 209 fibromyalgia patients recruited through health professionals completed an online questionnaire to assess patients' use of the website, health knowledge, self-management behavior, and health outcomes. These constructs were combined into an a-priory model that was tested using a structural equation modeling approach.
Results: Results show that the usage of certain tools of the website – designed and personalized involving the end users – impacts patients' health knowledge, which in turn impacts self-management. Improvements in self-management ultimately lower the impact of Fibromyalgia Syndrome leading to better health outcomes.
Conclusion: This study empirically confirmed that the adoption of a participatory approach to the design of eHealth interventions and the use of personalized contents enhance the overall effectiveness of systems.
Practice implications: More time and effort should be invested in involving patients in the preliminary phases of the development of Internet-based patient education interventions and in the definition of models that can guide the systems' evaluation beyond technology-related variables such as usability, accessibility or adoption.

1. Introduction

This paper introduces and evaluates a model of the effects of an Internet-based patient education system designed with principles borrowed from Health Communication, Artificial Intelligence (AI) and User Modeling (UM) research. Specifically, the system adopted a bottom-up approach to the design of the main functionalities, in line with concepts such as personalization/adaptivity [1,2] and participatory design [3,4]. The involvement of the end users in the design process of eHealth interventions and the elaboration of tailored messages are two factors deemed to enhance the overall interventions' effectiveness [5–7]. In line with this claim, the study combines Health Communication, Artificial Intelligence, and User Modeling in two ways: first, it evaluates a system largely based on personalization and participation principles and, second, it does so by advancing an a priori model of their impact on patients' knowledge, self-management, and health outcomes. This model, once tested and refined, can help AI researchers to improve the evaluation of their own systems, going beyond system-related constructs such as usability and adoption towards the measurement of the actual impact of a system on patients' cognitive, psychological, and physiological outcomes. Indeed, such a need for evaluating AI systems beyond their intrinsic characteristics has received attention in the last decade of AI literature. For example, Mellish and Dale [8] and Reiter et al. [9] recognized that a "task evaluation" grounded on underlying theories can prove helpful to gain a better understanding of the real impact of AI interventions. Along the same line Smith et al. [10] stress the need to provide health professionals with evidence of the effectiveness of AI systems, especially concerning health outcomes. However, in the health communication literature it is well known that the direct assessment of health outcomes can prove difficult without an understanding of the possible pathways of change between adoption and outcomes [11]. For this reason, this study advances a model of indirect or mediated effects between the usage of an eHealth system and health outcomes, involving the concepts of health knowledge [12] and self-management [13] as useful constructs to include in a model-driven system evaluation.

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http://dx.doi.org/10.1016/j.pec.2013.04.007

In order to shed light on the rationale behind the present investigation, we first propose a brief review of Internet-based patient education. We then introduce the specific intervention under analysis and illustrate how personalization and participations principles contributed to its design, eventually illustrating the model that was tested with a group of chronically ill patients, focusing mainly on the sections devoted to knowledge improvement. General conclusions about the model's predictive power and its role in systems' evaluations are eventually discussed.

1.1. Internet-based patient education

People suffering from chronic diseases constantly live in a peculiar situation. They are faced with the problem of keeping a balance between the need to adhere to a treatment and the need to live their everyday life and activities as normally as possible. In other words, they must learn how to self-manage their condition [13]. Diseases like cancer, diabetes, depression, low back pain, arthritis, fibromyalgia, though with different symptoms and consequences, all require a constant action by the patient. This need of being informed, monitored, and supported by the health professionals often leads patients to turn to the Internet to seek help [14].

A growing body of literature shows that the Internet can have a positive impact on patients affected by chronic diseases [15,16]. Different kinds of interventions proved to be effective to some extent, such as online-support groups [17], tailored messages [18], online exercises [19] and a combination of these strategies in a unified online self-management program [20,21]. A systematic review of studies focused on Internet-based intervention across a variety of chronic conditions (mental health, diabetes, cardiovascular disorders, cancer, pulmonary disorders, back pain, and others) showed that technology-based delivery of self-management programs is a viable alternative to traditional methods of delivery [22]. The majority of the 27 randomized studies included in the review reported that Internet-based interventions were significantly more effective than routine medical care in improving self-management skills and health outcomes.

1.2. The Internet-based intervention ONESELF

This study focuses on the evaluation of a specific Internet-based intervention, called ONESELF (www.oneself.ch), designed as an interactive tool to enhance self-management and health outcomes of patients affected by Fibromyalgia Syndrome (FMS). FMS is a condition characterized by chronic widespread pain and tenderness in 11 or more of the 18 specific tender point sites [23]. Although the medical evidence is still lacking precise diagnostic criteria for FMS, there are three major symptoms that are usually associated with the disease: pain, sleep disorders and fatigue [24–26]. Alongside these somatic factors, there are other psychological dimensions that are observed in fibromyalgia patients, such as anxiety, stress, depression and many more [27–29].

ONESELF was developed in collaboration with health professionals (rheumatologists, physiotherapists, general practitioners) for consistency with Evidence Based Medicine guidelines. Patients were involved since the very first phases of development in an iterative participatory process: they used a specific function (an *online forum*) to discuss relevant issues and functionalities they found to be personally relevant. These discussions generated two major outcomes: first, some topics raised were translated into articles and included in a *virtual library* and, second, some sections targeted to the users' needs were created (a *virtual gymnasium*, a *first aid* section, a *frequently asked questions* section, *testimonies*, and a *chat room*). To illustrate the process, consider the following excerpt from the online forum (translation from Italian made by the authors): "*Thanks for the touching testimony. It would be great to have such stories collected – for me and for the others – to share what works and what doesn't*. . ." (User G in response to a discussion on FMS at the workplace). The need for a place to access share life experiences emerged from this post and others in the discussion. The need was identified, discussed within the team, and translated into a new functionality: the *testimonies* section.

The application enabled asynchronous and synchronous interactions with health professionals and laypeople. Asynchronous interaction with health professionals was reached through the *virtual library* that provided users with relevant information on the disease. The *first aid* and the *frequently asked questions* section (*FAQ*) published brief and practical information on the syndrome management. The *virtual gymnasium* provided patients with tailored multimedia contents on several physical exercises that constitute the wider part of the non-pharmacological treatment of FMS. Eventually, the section on *testimonies*, where patients could post their stories and comment on stories of other people suffering from the same health condition, enhanced the dimension of social support. Synchronous interaction was designed and implemented via the *online forum* and the *chat room*. Patients used these tools to communicate with the physicians and among themselves. Since its first release in June 2008, more than 600 fibromyalgia patients mostly from Switzerland and Italy have used ONESELF.

1.3. The model of ONESELF effects

The purpose of ONESELF was to improve patients' self-management and health outcomes by increasing their knowledge through information, and empowerment through the provision of social support. Given that the different functionalities were defined and designed following users' indications, one would expect a significant impact of each section on these constructs. More specifically, patients' knowledge of FMS is assumed to be impacted by the use of the virtual library, which provided information on the syndrome, the virtual gymnasium, which taught users how to perform physical exercises to relieve pain, and the FAQ section, which provided users with practical information on the management of the syndrome. Patients' empowerment is assumed to be impacted by the online forum, which allowed users to exchange their experience of pain with health professionals and other laypeople, the chat, which allowed the same kind of support in a synchronous fashion, and the section on testimonies, which provided patients with video and textual material on coping experiences of other sufferers. In the present study, we focus on the evaluation of the informative sections devoted to knowledge improvement (virtual library, FAQ, virtual gymnasium).

The relationship between increased knowledge and behavior (in the present case, self-management) has been investigated in the literature on health education interventions, defined as "consciously constructed opportunities for learning involving some form of communication designed to improve health literacy, including improving knowledge, and developing life skills which are conducive to individual and community health" [30]. The literature conveys different conceptualizations of health literacy. A shared definition has been provided by Ratzan and Parker [31] who defined health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decision". Improving health literacy is necessary since people with limited health literacy report poorer overall health, they are less likely to make use of preventive screenings, they have a poorer understanding of treatment and a lower adherence to medical regimes, they make use of medical services in later stages of their diseases, and therefore are more likely to be hospitalized causing an enormous financial burden for the healthcare system [32].