Internet-Based Patient Education Intervention for Fibromyalgia: A Model-Driven Evaluation

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Abstract

Patients suffering from chronic diseases constantly face the need to learn how to self-manage their health condition and often turn to the Internet to seek help and support from health professionals and laypeople. Internet-based interventions can be an effective tool for patients' education and have been shown to positively impact patients' health outcomes. Focusing on the process leading from Internet usage to health outcomes, this paper reports a model-driven evaluation of a specific Internet-based intervention for patients affected by fibromyalgia syndrome. The evaluation is based on a cross-sectional survey of 209 fibromyalgia patients who were involved in the Internet intervention. Analyses were conducted using a structural equation modeling approach. The analysis mostly confirms the assumed theoretical model with minor and theoretically sound modifications. Results show that the usage of certain tools of the application impacts patients' health knowledge, which in turn impacts self-management. Improvements in self-management ultimately lower the impact of fibromyalgia syndrome. These results are discussed, alongside major implications for the evaluation of Internet-based interventions.

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 (Lorig and Holman 2003). 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 (Fox and Purcell 2010).

A growing body of literature shows that the Internet can have a positive impact on patients affected by chronic diseases (Lorig et al. 2008; Wantland et al. 2004). Different kinds of interventions proved to be effective to some extent, such as online-support groups (van Uden-Kraan et al. 2008), tailored messages (van Koulil et al. 2008), online exercises (Schulz, Rubinelli, and Hartung 2007) and a combination of these strategies in a unified online self-management program (Lorig et al. 2006; Schulz et al. 2010). A recent 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. This systematic review included 27 randomized trials centered on the Internet as the main intervention. The majority of the studies reported that Internet-based interventions were significantly more effective than routine medical care in improving self-management skills and health outcomes (Glueckauf and Lustria 2008).

Given these indications from the literature, it is relevant to gain a deeper understanding of how Internet-based interventions that provide patients with visual, audio, and textual educational material impact their health status and quality of life. To address this general question, the present study focuses on a specific chronic condition: Fibromyalgia syndrome (FMS). According to the American College of Rheumatology (Wolfe et al. 1990),

FMS is a condition characterized by chronic widespread pain and tenderness in 11 or more of the 18 specific tender point sites. 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 (Belt, Kronholm, and Kauppi 2009; Clauw, 2008; Arnold et al. 2008). Alongside these somatic factors, there are other psychological dimensions that are observed in fibromyalgia patients, such as anxiety, stress, depression and many more (Wilson, Robinson, and Turk 2009; Buskila and Cohen 2007; Goldenberg 1989).

The rationale for developing Internet-based interventions to support fibromyalgia patients lays in the strong impact of this syndrome on psychological factors and quality of life. The perceived level of pain, the dissonance due to legitimacy issues, the lack of coping strategies and social support produce undesirable consequences such as depression, job loss, and social isolation. As a sum, FMS badly impacts the overall quality of life (Choy et al. 2010) and requires a high level of continuity of care and social support.
Moreover, from an economic perspective, FMS is estimated to cost 7,813 euros per year per patient, and the incremental cost of worsening conditions is between 865 and 1,453 euros per year per patient (Annemans et al. 2008; Spaeth 2009).

Moving from these considerations, we developed an Internet-based intervention to enhance self-management and health outcomes of fibromyalgia patients. The aim of this paper is to present a model-driven evaluation of this intervention. Before reporting the results of the evaluation, we briefly introduce the Internet-based intervention and the theoretical model on which our study is based.

The Internet-based Intervention

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 FMS. ONESELF was developed in collaboration with health professionals (rheumatologists, physiotherapists, general practitioners) and it is consistent with Evidence Based Medicine guidelines. The application enabled asynchronous and synchronous interactions with health professionals and laypeople. Asynchronous interaction with health professionals was reached through a *virtual library* that provided users with relevant information on the disease. A *first aid* and a *frequently asked questions* section (*FAQ*) published brief and practical information on the syndrome management. A *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 an *online forum* and a *chat*. 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.

The Model-based Intervention

ONESELF is meant to improve patients' self-management and health outcomes by increasing their knowledge through information, and empowerment through the provision of social support. Each section of the website is designed to tackle one of these constructs.

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, the main focus is 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" (WHO 1998: p.4). The literature conveys different conceptualizations of health literacy. A shared definition has been provided by Ratzan and Parker (2000: p.ix) 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 (Wagner et al. 2009).

A number of frameworks have been developed to show the relationship between health literacy, health behavior,

and health outcomes (Paasche-Orlow and Wolf 2007; Ishikawa and Yano 2008; Nutbeam 2008; Wagner et al. 2009). They claim that health literacy is related to health knowledge, which in turn determines health behavior and health outcomes.

Moving from these considerations, we designed a model that aims to explain the pathways from the usage of ONESELF's informative sections and patients' knowledge, self-management, and health outcomes. As expanded in the methodological section, self-management is operationalized in terms of physical exercise and drug intake. The postulated model is represented in Figure 1.

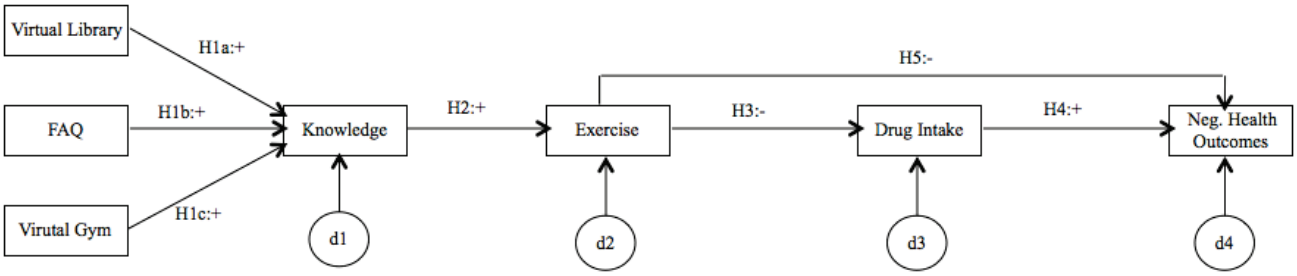

Figure 1. The model of ONESELF effects. Exogenous variables are allowed to be correlated.

According to this model, the usage of the virtual library, the FAQ section, and the virtual gymnasium impacts patients' knowledge, which, in turn, impacts their level of physical exercise. Hence, the level of exercise impacts the amount of health outcomes. This relationship is partially mediated by the level of drug intake. These relationships can be translated in a set of directional hypotheses:

H1: The more a patient affected by FMS uses the informative sections of ONESELF, the more knowledgeable s/he becomes about the disease and self-management strategies.

This hypothesis can be further specified as follows:

- H1a: The more a patient uses the virtual library, the more knowledgeable s/he becomes.
- H1b: The more a patient uses the FAQ section, the more knowledgeable s/he becomes.
- H1c: The more a patient uses the virtual gymnasium, the more knowledgeable s/he becomes.

H2: The more knowledgeable a patient is, the more s/he engages in physical exercise to self-manage his/her condition.

H3: The more a patient is engaged in physical exercise to self-manage his/her condition, the less drugs (such as painkillers) s/he consumes.

H4: The less a patient consumes drugs, the less s/he experiences negative health outcomes.

H5: The more a patient is engaged in physical exercise to self-manage his/her condition, the less s/he experiences negative health outcomes.

Methods

Sample

The sample includes 209 patients who have suffered from FMS on average for 5.6 years (SD = ± 4.7). Patients were recruited by physicians. Inclusion criteria were a) availability of Internet access, b) sufficient confidence in using a computer (self-reported), and c) formal diagnosis received from a rheumatologist.

Since mainly women are affected by FMS (Wolfe et al. 1995), the final sample consists of 95 percent female and 5 percent male patients between the age 25 and 74. The mean age is 49 years (SD = ± 10.0). The majority of patients (95 percent) completed at least 8 years of school, of which 82 percent also have a high school or a university degree. ONESELF is designed for Italian-speaking users. Thus, 56 percent of the sample has Italian nationality, 42 percent Swiss nationality, and 2 percent are of other nationalities, however, fluent in Italian. Table 1 summarizes all sample characteristics.

Website Usage and General Evaluation

Although ONESELF was first released in June 2008, half of the users suffering from FMS subscribed to ONESELF only after December 10, 2008. The average number of days between the date when patients subscribed to the website and the date when data were collected via an online questionnaire was 167 days (SD = ± 67.6). Based on patients' self-report, the applications that provide social

support (online forum, section on testimonies, chat) were used more often than applications with information about FMS (virtual library, virtual gymnasium, FAQ). Half of the 209 patients visited the online forum and the section on testimonies at least 3-5 times, whereas the virtual library and the virtual gymnasium were used by half of the sample only 1-2 times. Two exceptions are the chat and the FAQ section. In contrast to the other two social support applications, the chat was not used at all by 57 percent and only 1-2 times by 22 percent of the patients. And whereas the virtual library and the virtual gymnasium as two informative applications were used less frequently, the FAQ section was visited by 48 percent at least 3-5 times. Accordingly, the chat was considered the least, and the FAQ section the most useful application rated on a 7-point Likert scale (mean for chat = 3.1, SD = ± 2.3; mean for FAQ = 5.0, SD = ± 2.0, where 1 = "not useful at all" and 7 = "completely useful"). All in all ONESELF received a positive feedback with 88 percent being quite or completely satisfied with the website.

Table 1. Descriptive sample characteristics

	N	*%*	*Mean*	*SD*
Sex				
Male	11	5.3		
Female	198	94.7		
Age			48.9	± 10.0
Education				
No education	4	1.9		
Elementary school (5 years)	7	3.3		
Secondary school (9 years)	35	16.7		
High school (13 years)	133	63.6		
University	30	14.5		
Nationality				
Swiss	87	41.6		
Italian	118	56.5		
Other	4	1.9		
Years affected by FMS			5.6	± 4.7
Knowledge about FMS			6.7	± 1.7
FIQ score			54.0	± 20.1

Measures

Data were collected by the means of an online questionnaire. Emails were sent to the patients with a link to the questionnaire. Measures relevant to test the assumed model assessed the usage of website applications, knowledge about FMS and its management, self-management indicators, and health outcomes.

Usage of website applications was measured as the frequency with which patients visited each application to retrieve information or get social support. It was assessed on an ordinal scale where patients indicated if they never used an application or if they used it 1-2 times, 3-5 times, 6-10 times, 11-20 times, or more than 20 times. In order to test the impact of informative applications (virtual library, virtual gymnasium, FAQ) on knowledge about FMS and its management, the median split method was used to create three dummy variables where 0 indicates "low frequency" and 1 indicates "high frequency" according to the median for each application (median for virtual library = "1-2 times", median for virtual gymnasium = "1-2 times", median for FAQ = "3-5 times"). This method of dichotomization is criticized for various reasons, including loss in individual differences and reduction of effect size (MacCallum et al. 2002). However, it produced two equally sized groups for each informative application necessary for the further analysis where a structural equation modeling approach was used. Conceptually, these groups still reflect the frequency of usage, and can thus convey meaningful results related to the effectiveness of the application.

Knowledge about FMS and its management was assessed with ten multiple-choice questions adapted from the website of the Mayo Clinic (www.mayoclinic.com [Last visit May 2008]). Questions covered symptoms and prevalence of FMS, treatment options, the effectiveness of medication, and self-management strategies. The proposed answers included only one correct alternative. To avoid guessing, an "I don't know" option was added to each set of proposed answers. All correct answers were summed to get a single knowledge score ranging from 0 to 10. In the present sample the average number of correct answers was 6.7 (SD = ± 1.7).

Self-management was assessed by two single indicators based on patients' self-report. One indicator assessed whether patients have changed the amount of physical activity since subscribed to ONESELF (*Exercise*) on a 5-point scale. The other indicator assessed whether they have reduced the drug intake for their FMS since subscribed to the website (*Drug Intake*) on a 4-point scale.

(Negative) health outcomes were measured with the Fibromyalgia Impact Questionnaire (*FIQ*) (Burckhardt, Clark, and Bennett 1991; Bennett 2005; Italian version by Sarzi-Puttini et al. 2003). The *FIQ* is a validated questionnaire that consists of 20 indicators to assess patients' disability to carry out everyday activities, patients' intensity of pain, and the interference of FMS on patients' sleep and emotional state. The *FIQ* is a self-report measure that provides a single score ranging from 0 to 100 where a higher score indicates a greater impact of FMS on the patient (*Negative Health Outcomes*). According to Bennett (2005) the average FMS patients scores about 50. In the present sample the average score was 54 (SD = ± 20.1).

Results

Data were analyzed using a structural equation modeling approach. All variables entered in the model are single manifest indicators.

The model in Figure 1 was evaluated with AMOS 18.0 using a maximum likelihood algorithm. The model is statistically overidentified. Prior to analysis, the data were evaluated for multivariate outliers by examining leverage indices for each individual. Outliers were defined as a leverage score four times higher than the mean leverage, which was 0.08. Two outliers were detected. They represent the only two individuals who scored 0 in the knowledge test. Model-based outliers were evaluated using a limited information approach in which each predictor was separately regressed onto the variable on which it has a direct effect. The analysis used ordinary least squares regression. Standardized dfbetas were examined for each individual and each predictor. An influential model-based outlier was defined as any individual with an absolute standardized dfbeta greater than 1 for a given coefficient. No model-based outliers were evident, and thus the decision has been made to keep the two non-model-based outliers.

Multivariate normality was evaluated using Mardia's test. The multivariate coefficient was not statistically significant. Univariate indices of skewness and kurtosis were examined to evaluate the normal distribution for each variable in the model. The largest absolute value for skewness was 0.83 and for kurtosis 1.34. Given that normality was not considered to be an issue.

A full information maximum likelihood method was used to deal with missing values. To evaluate the model, goodness of fit indices were examined. The overall chi-square test of model fit was statistically significant (χ^2 (11) = 37.41, $p < 0.000$). The Root Mean Square Error of Approximation (RSMEA) was 0.11, and the p value for the test of close fit was 0.01. The Comparative Fit Index (CFI) was 0.77. All indices point towards poor model fit. The standardized residual covariances revealed some statistically significant points of ill-fit in the model. Furthermore, the modification indices suggested adding in the model a direct path from *Virtual Gym* to *Exercise*, which would lead to a drop in the chi-square by 25.79 units. The suggested path is theoretically sound, meaning that individuals who use the virtual gymnasium more frequently also engage in physical activity more often inspired by the exercises proposed and taught to them. All indices now point towards good model fit. The standardized residual covariances revealed only one statistically significant point of ill-fit in the model, but the modification indices showed no more theoretically sound suggestions to improve the chi-square.

Figure 2 shows the final model with all significant path coefficients. For purposes of presentation, the correlations between exogenous variables are omitted. The residuals indicate the proportion of unexplained variance in the endogenous variables. The application usage variables in the model were able to account for approximately 3 percent of the variance in *Knowledge*. *Knowledge* and the usage of *Virtual Gym* explain 14 percent of the variance in *Exercise*. *Exercise* accounts for 10 percent of the variance in *Drug Intake*, which in turn explains 10 percent of the variance in *Negative Health Outcomes*.

The path coefficients from *Virtual Library*, *FAQ*, and *Virtual Gym* to *Knowledge* (and *Exercise* respectively) represents mean differences between the patients that used the applications more frequently and the ones who used them less frequently, according to the median split of each informative application. Knowledge of patients using the virtual library at least 3-5 times (high frequency group) is significantly higher than the knowledge of patients using the virtual library up to 2 times (low frequency group). Interestingly, knowledge of patients using the FAQ section at least 6-10 times (high frequency group) is significantly lower than the knowledge of patients using the FAQ section up to 5 times (low frequency group). This result can be explained by the fact that the FAQ section was consulted only by patients whose level of prior knowledge was low. Unfortunately, due to the cross-sectional nature of the dataset, it is not possible to control for autoregressive effects of knowledge. This kind of control can invert the direction of the path coefficient.

The usage of the virtual gymnasium did not have a significant impact on patients' knowledge. However, patients using the virtual gymnasium at least 3-5 times (high frequency group) reported a significantly higher amount of physical exercise than the patients using the virtual gymnasium up to 2 times (low frequency group).

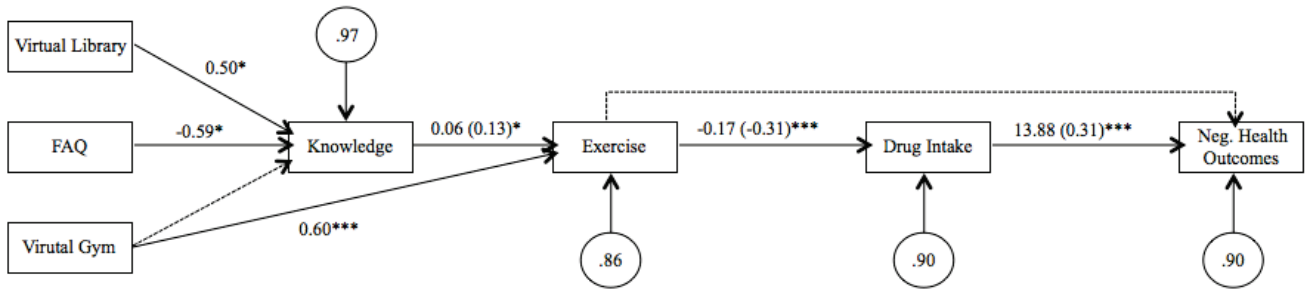

Figure 2. Final model with unstandardized coefficients; standardized coefficients in parentheses; $p<0.05$*, $p<0.001$***, dashed arrow indicates no significant path coefficient. Exogenous variables are allowed to be correlated.

Moreover, knowledge has a significant impact on physical exercise, meaning that a one score increase in knowledge was predicted to increase the amount of physical exercise by 0.06 units.

The amount of physical exercise has a significant impact on drug intake, meaning that a one-unit increase in physical exercise was predicted to decrease the amount of drug intake by 0.17 units.

Eventually, the level of drug intake significantly affected negative health outcomes. This means that a one-unit decrease in drug intake predicted a decrease of 13.88 units on the *FIQ* score (which corresponds to an improvement in health status).

In sum, hypotheses H1a, H2, H3, and H4 were confirmed. For what concerns H1b, the reversed relationship can be due to a lack of control for prior knowledge, as previously explained. Regarding H1c, contrary to our assumption, analyses showed a theoretically sound direct relationship between the usage of the virtual gymnasium and the level of physical exercise, without the mediation of knowledge. In the same line, H5 could not be confirmed, as the relationship between the level of physical exercise and improvement in health outcomes turned out to be fully mediated by the level of drug intake.

Discussion and Limitations

The model-driven evaluation of the Internet-based intervention was overall satisfactory. The usage of informative applications could explain 3 percent of the variance in patients' knowledge about FMS. Although this result may seem weak, it should be interpreted in light of the many other factors that can intervene in the process of knowledge acquisition such as patient-oriented information provided by health professionals and other healthcare providers as well as traditional media and other online applications. In particular, the effect of the usage of virtual gymnasium on the amount of physical exercise was considerable. Together with increased knowledge, it could explain 14 percent of the variance of the amount of exercise. This improvement of the physical component of self-management resulted in a significant reduction of drug intake. This reduction accounted for 10 percent of the variance in negative health outcomes, meaning that the improvement in self-management behavior positively impacted patients' health status.

Despite these significant effects, the relationships assumed in the model of Internet effects and confirmed by the structural analysis should not be interpreted in a strictly causal sense. Since the data come from a cross-sectional survey, no causality can be demonstrated. However, previous reviews on quantitative/experimental studies confirmed the relationships between Internet-based applications and health knowledge (Murray et al. 2007), and knowledge, self-management and health outcomes (DeWalt et al. 2004; Paasche-Orlow et al. 2005). Conclusions from these studies support the soundness of the theoretical model on which the evaluation was based.

Some limitations of the study should be mentioned. First, measures are mainly self-report, which may lead to an under- or over-estimation of the usage of applications and self-management behavior as well as health outcomes. Second, the model was tested with single manifest indicators, which do not reflect the multidimensionality of some constructs. Third, exogenous variables took into account only the frequency with which the applications were used. However, knowledge acquisition also depends on the quality of interaction. For example, a patient who visited the virtual library only once but spent many hours to study the published material can be comparable to a patient who visits the virtual library more than once but spent less time reading its contents.

Conclusion

The evaluation of Internet-based interventions for chronic patients is essential to gain insights into the mechanisms that lead from their applications to improved health outcomes. While several studies on this topic are strictly experimental, theory-driven evaluations are mostly needed. In this respect, our study contributes to the discussion of the effectiveness of Internet-based interventions to improve self-management of chronically ill patients while keeping a theoretical perspective on the issue.

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