

An internet-based approach to enhance self-management of chronic low back pain in the Italian-speaking population of Switzerland: results from a pilot study

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Summary

Objective: To illustrate the development and pilot evaluation of a website designed to enhance self-management of chronic low back pain for the Italian-speaking population of Switzerland.

Methods: 20 patients affected by chronic low back pain used a website – specifically created for the project – for a period of five months, under the monitoring of a team of health professionals. Evaluation was carried out by means of a telephone questionnaire administered at baseline and at the end of the intervention, and intermediate online user-testing performed in the fourth month of the intervention. A control group of 15 patients was created to assist the evaluation.

Results: Compared to the control group, results from the pilot evaluation suggest a decrease in the intensity of back pain in people with access to the website; an increase in physical activity; a reduction in both medical consultation and the use of painkillers, and a gain in declarative and procedural knowledge. This coincides with a general positive assessment of the website.

Conclusion: The study supports the need to test the proposed approach on a wider scale.

Key words: Health promotion – Health communication – Internet – Management of chronic low back pain – Doctor-patient interaction – Tailoring.

Chronic low back pain is a major public health problem because of its high impact on disability and health costs (Schmidt & Kohlmann 2005; Dunn & Croft 2004; Walker 2000; Waddell 1996; Badley et al. 1994). Among musculoskeletal disor-

ders, chronic low back pain, typically defined as pain that has persisted for longer than 3 months (Santos-Eggimann et al. 2000; Merskey & Bogduk 1994), accounts for more than half of the number of cases (Clinical Standards Advisory Group 1994). Chronic recurrent back pain is one of the most common symptomatic reasons people seek health care. In Switzerland low back pain generally is the second main cause of medical consultation with a frequency of 5–15 % of all consultations (Keel et al. 1996; Molo-Bettelini et al. 1996). From a sample of 1100 Ticino people, 56.4 % suffer from low back pain (Office fédéral de la statistique 1997). Similar figures are reported in studies about other countries (Bowsher et al. 1991; Brattberg et al. 1989).

Both at the institutional and academic level, the above considerations drive the need to design strategies to enhance self-management of chronic low back pain (van Tulder et al. 2002). On one side, this self-management includes strategies like relaxation and physical exercises (Indahl 1998; Frost 1995). On the other side, strategies should also enable patients to cope with pain in daily life, reducing depression and anxiety and improving self-efficiency (Simmonds 1996). Nowadays, the internet is generally acknowledged as an instrument that can offer exclusive multimedia and interactional tools to enhance self-management of a chronic disease (Wantland et al. 2004; Kirsch & Lewis 2004). Despite this acknowledgement, however, research on the effectiveness of internet-based interventions in the area of chronic low back pain shows mixed results. There is evidence that online information and services (Koestler et al. 2005) can make a positive impact on people affected by chronic low back pain. A randomized study dated 2002 (Lorig et al. 2002) concludes that an e-mail discussion group can positively affect health status, and can have a place in the treatment of chronic recurrent back pain. Similarly, a controlled trial dated

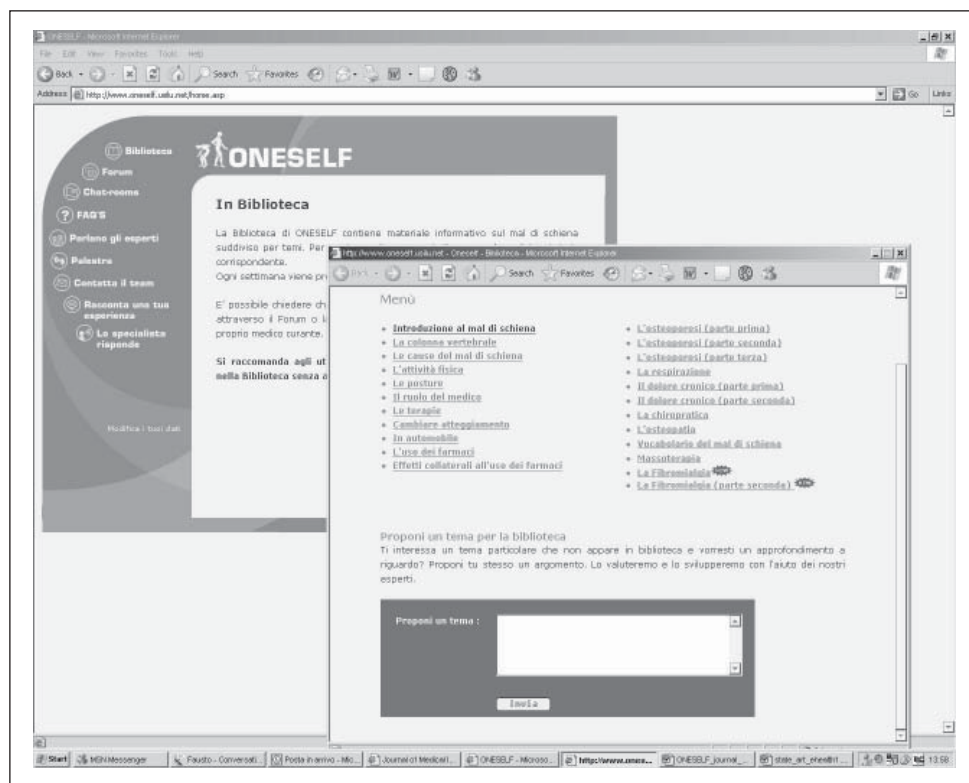


Figure 1 The Library of ONESELF

2004 (Buhtman et al. 2004) demonstrates that internet-based self-help with telephone support holds promise as an effective approach for treating disability in association with back pain. In contrast to these studies, however, the literature also stresses some crucial limitations of current online information on low back pain generally. More specifically, regardless of the American Medical Association's guidelines for medical information websites (Winker 2000), research highlights the poor quality of information about low back pain, available to typical patient users on the internet (Schulz & Setola 2005; Butler & Foster 2003; Li et al. 2001). In particular, medical web sites have generally been shown not to provide enough personalized information. This lack of tailored information creates – from the patients' point of view – an information gap between general knowledge about prevention and treatments, and capacities to develop correct behaviours, or to modify and change ones that may be wrong (Payne & Kiel 2005; Weissenberger et al. 2004; Skelton 1996; Skelton 1995).

In the perspective of promoting more effective online applications in the field, the literature points to a rather unique solution: health care professionals must have an active role in developing online contents and maintaining medical websites (Butler & Foster 2003). Moreover, they should develop a proactive attitude towards patients who surf the internet for health information in order to promote more effective search and evaluation and application techniques (Molassiotis & Xu

2005; Task & Hong 2005; Genius & Genius 2005; Morahan-Martin 2004). But this solution, although it is unanimously acknowledged, is in itself far from being unproblematic. There are difficulties linked to the amount of time that health professionals should devote to projects of medical websites. Doctors are, in fact, increasingly limited by time constraints. Also, there is still a tendency to see the use of new technologies as causing damaging interference to the doctor-patient relationship. The trend among health professionals is still to link the use of the internet to a deprofessionalisation resulting in a demystification of their expertise. The lack of studies assessing the impact of doctor-patient online communication makes health professionals sceptical about the modalities of conducting therapeutic discussions via internet (Broom 2005; Hart et al. 2004).

Based on this concept, this paper discusses the development of the project "Oneself", financed by the Swiss National Science Foundation (under the NRP 53: Musculoskeletal Health – Chronic Pain), that we conducted between June 2004 and June 2005. This project, by answering some of the problematic aspects of online information sketched out above, attempted to test the potential efficacy of the internet as a medium for enhancing self management of chronic low back pain. In the following sections, we shall, firstly, examine the development of a patient-oriented website for back pain sufferers – specifically created for the project – and, secondly, present and



Figure 2 The Gym of ONESELF

discuss the results from a pilot evaluation of its efficacy and acceptability in the target group.

Methods

This project had three main phases: the development of the website and questionnaires, the pilot intervention and the subsequent evaluation.

Development and structure of the website

Our approach rested on two main assumptions:

- (1) A policy of providing tailored information is the best response to enhance patients' self-management of low back pain (Kreuter et al. 2000). It will lead patients to a more active approach by providing them with information which considers their specific contextual situation.
- (2) Sharing experiences on how to manage chronic back pain with other patients and discussing experiences with health professionals helps patients to assess their own situation in a more complete way and increases the patients' willingness to face their own situation and attenuate the barriers towards an active approach (Rubinelli et al. 2006). This applies in particular when communication among patients is assisted by medical advice and other expertise.

Based on this premise and on the discussions recorded during a focus group with 10 rheumatologists from the Lega Ticinese per la Lotta contro il Reumatismo and 2 physiotherapists, we developed ONESELF as an interactive website to provide patients with a considerable amount of treatment information and encourage them to obtain the kind of information that they desire about their problem. The website was not conceived as a diagnosis tool and never publishes advice in the form "This is what you must/should do". Different multimedia materials allow patients to get up-to-date information about chronic low back pain. Moreover, patients can interact with health professionals who answer their specific questions. On a more general level, ONESELF was designed to enable patients:

- to obtain the information they want quickly (within 2–3 days maximum, via email or through the chat-room or forum of the website);
- to discuss with health professionals either in a synchronous or asynchronous way;
- to access the experience of other people with similar problems.

The website, which can be accessed at www.oneself.usilu.net, and contains seven main sections, which are:

- The Library with educational material on the nature and management of chronic low back pain

Table 1 Demographic characteristics of participants

	Treatment group		Control group	
	N	%	N	%
Caucasian	20	100	15	100
Age in years, mean	45.4		45.13	
Sex: female	5	25	5	33.3
Education: post high school	5	25	3	20
Occupational situation				
Full-time working	20	100	13	86.66
Homemaker			1	6.66
Retired			1	6.66
Marital status				
Unmarried	4	20	4	26.66
Married	13	65	8	53.33
Divorced, separated	3	15	2	13.33
Widowed			1	6.66

- The Gym with videos and description of exercises selected on the basis of the major disabilities of people with chronic low back pain
- A forum and chat-rooms
- “The experts say that” and “The specialists answer that”: in these two sections patients can find videos and other kinds of electronic materials on topics proposed by health professionals on the basis of patients’ frequently asked questions.
- “Tell a story”, where users can share their stories and comment on stories presented by other users.

To promote the tailoring of information, we decided to initially insert only a set of basic contents, which was later in the project extended in light of users’ demands. Our team of health professionals came to consensus on the key elements of the basic content on chronic low back pain generally, including its aetiology, the vertebral column, postures and physical activity. As to the virtual Gym, the physiotherapists involved in the project selected a set of exercises subdivided into the three main categories recommended for back pain: stretching, mobility and stabilisation. Users were advised to discuss the best program for their condition with their doctor or physiotherapist. The general materials use simple language to make each point clear, with illustration and graphics to reinforce understanding as shown. After development, we tested the basic contents with a sample of patients with different levels of health literacy. All the sections of the website were structured so that users could request the information they wanted in addition to the basic contents already published. Thus, for example, the Library had an interactive box where users could send their requests to the content manager who then distributed them to the health professionals according to their specialisation.

Pilot intervention

After development of the website, we conducted a 5-month trial to evaluate the efficacy of the website in a chronic low

back pain management intervention. Patients were recruited from the Ticino health professionals involved in the projects. To be enrolled, patients had to: (1) have suffered from low back pain for more than three months; (2) show no “red-flag” symptoms; (3) be aged 18–65 years; (4) have internet access and an e-mail account; (5) have good understanding of and writing abilities in Italian. In addition to this, patients had to positively opt for the program. Patients were excluded if they had major disabilities due to factors other than low back pain, and if they had conditions requiring individual medical or surgical treatment or pregnancy. We included a total of 20 patients in the treatment group and 15 in the control group. Patients were arbitrarily allotted to the two groups, neither with any criterion in mind, nor with a formal random assignment being applied. A statistical comparison between the two groups (see Tab. 1) showed no remarkable differences concerning age, sex, education, occupational situation and marital status.

After informed consent was obtained, patients in the treatment group were asked to start visiting the website. Patients in the control group were not informed of the existence of the website and did not receive any specific material on back pain. 3 out of 12 health professionals who took part in the focus group agreed to develop the contents of the website, as well as to maintain daily online interactions with users. To minimize the risk of overloading them with work, we subdivided the 5-month period of the intervention into ten two-week periods and scheduled exactly when each health professional had to enter the website and answer users’ requests, mainly on the forum. Creation of new texts was also organized in order to minimize health professionals’ duties. Health professionals were only asked to provide the most technical information according to their expertise and specialisation. Full texts were then composed by a linguist who acted as content manager of the website. Before publication, the new texts were sent back to health professionals for final approval. The content

manager did a daily control of all the feedback received in order to guarantee that the community was useful to all its members. When new requests by patients appeared online, the content manager categorized them and sent them to the health professional/s according to their specialisations. The content manager could block or delete messages on issues considered inappropriate for the community. However, in the five months of the intervention, no message ever caused any sort of problem.

To give readers a better idea of some of the procedure for tailoring the information adopted in our study, we present, here, an example of a contribution published in November 2005. On November 16th, one of the users of ONESELF, after remarking that his job forced him to sit on a chair for several hours a day, asked for some exercises to be done at his desk. One of our health professionals, who answered his messages, asked him to specify more closely what kinds of ergonomic problems he had. The user replied immediately. The content manager, who had noted this interaction, asked one of the physiotherapists of the ONESELF team to write a contribution to be published online. Photographs and detailed descriptions of some exercises were prepared within a week. The contribution entitled “Desk-gym” was published on November 24th. Finally, we asked health professionals to act as moderators on the messages posted on the forum of the website: when they thought that a message could lead to negative effects (in the case of chronic back pain it is rather frequent, for example, that patients influence each other to give up jobs or daily activities), the health professionals normally replied with a message clarifying potentially unhelpful approaches, suggestions or beliefs of patients. During the intervention, tailored material was created and published on the website according to the following schedule:

- Library: a new article was published weekly for a total of 20 articles written under the supervision of the health professionals. The topics included: physical activity, postures, use of medicaments, chronic pain (in general), management of pain, osteoporosis, fibromyalgia.
- Gym: a new set of exercises (based on 9 exercises under the categories of stretching, mobilisation and stabilisation) was added every month and a half.
- The experts say that/ the specialists answer that: a new multi-media document (in the format of video, Pdf or audio) was published every three weeks. Topics included: special techniques for exercising and exercises for pain-management (such as autogenic training)
- Tell a story: it was updated according to the personal stories sent by users.

As for the forum, in the five months of monitoring, 280 messages were inserted by both patients and health professionals.

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Users requested advice on a set of topics categorised into the following topics: daily activities, traditional and alternative therapies, osteoporosis, smoking and diet, physical exercise, philosophy of life, stress and pain (Rubinelli et al. 2006).

Measures and outcomes

During the intervention, data were collected simultaneously from both groups by validated telephone questionnaires at baseline and five months after baseline collection. At baseline, we obtained data on demographic aspects, on patients' attitudes towards the health system and self-management of their problem – on the basis of the Pain Stages of Change Questionnaire (Kerns et al. 1997) – as well as on procedural knowledge (following a set of 15 items structured by the health professionals during a focus group, such as, for example, ‘when I drive on a long journey, I normally take a break every hour and a half’, with response-options “I agree”, “I do not agree”, “I do not know”), on the use of the health system in the past six months (number of consultations with response options of: once, twice, three times, more than three times, none), on the medical information-seeking process in the past six months (number of times the patient had looked for information on chronic low back pain; type of sources consulted – including health professionals, relatives and friends, newspapers and magazines, internet, other – and self-report evaluation of the sources) and on disability level. Disability was measured using the revised Roland-Morris Scale that was developed specifically to assess disability caused by back pain (Roland & Morris 1983; Stratford et al. 1996; Beurskens et al. 1995). To assess the intensity of pain on the day of the interview and in the preceding week, patients were asked to mark a scale from 0 to 10, where a lower score indicated less disability. In the final questionnaire, data concerning the use of painkillers in the last six months (two items on whether the patient normally took back-pain-relievers, with “yes” or “no” response options, and whether in the last six months s/he had taken more or fewer pain-relievers than usual, with the three response-options “same level as usual”, “more pain-relievers than usual” and “fewer pain-relievers than usual”) and the level of physical activity in the last six months (two items on whether the patient regularly did physical exercise, with “yes” or “no” response options, and whether in the last six months s/he had done more or less physical exercise than usual, with the three response-options “more exercise than usual”, “less exercise than usual” and “exercise as usual”) were also obtained in addition to the initial baseline data. Also, in the final questionnaire administered to the treatment group we gained additional data on the perceived general utility of the website ONESELF and on the perceived specific utility of the website ONESELF in the self-management of chronic low back pain,

	Treatment group (means)		Control group	
	Baseline	Final	Baseline	Final
How do you feel today?	3.4	3.4	5.1	5.3
How did you feel last week?	5.0	3.9	6.1	6.3
N=	20	20	15	15

Table 2 Intensity of back pain

Question: "On a scale from 1 to 10 (1 = no back pain and 10 = the worst back pain), could you indicate the intensity of your back pain?"

	Treatment group (N = 20)		Control group (N = 15)	
	Baseline	Final	Baseline	Final
"Do you regularly do physical exercise?" Yes (%)	— ^a	65.0	— ^a	64.3
"Did you do more or less physical exercise than usual during the last six months?" (%)	— ^a		— ^a	
More exercise than usual	— ^a	70.0	— ^a	14.3
Less exercise than usual	— ^a	15.0	— ^a	14.3
As usual	— ^a	15.0	— ^a	71.4
"How many times have you been to the doctor or to other health care professionals because of back pain during the last six month?" (Mean)	3.1	1.9	2.5	2.1
"Do you normally take back pain-relievers?" Yes (%)	— ^a	20.0	— ^a	40.0
"During the last six months, have you taken more or fewer pain-relievers than usual?"				
Same level as usual	— ^a	70.0	— ^a	80.0
More pain-relievers than usual	— ^a	5.0	— ^a	13.3
Less pain-relievers than usual	— ^a	25.0	— ^a	6.7

Table 3 Patients' self reports

^a No data available at baseline.

and on the perceived utility of the website as a tool to improve the relationship with health providers (in all three cases self-report items that consisted of a four-point ordinal scale with 1 = very useful; 2 = useful; 3 = less useful; 4 = not useful). The analyses presented here concentrate on the primary outcome (intensity of perceived pain) and a few self-report measures on coping as well as knowledge and evaluation of the site.

In order to gain data on the way patients used the website and their perceived understanding of the information they saw on the pages, we performed intermediate user testing via an on-line questionnaire delivered at the end of the fourth month of the intervention. In the questionnaire we asked for the level of comprehensibility of the information provided (with a three-point ordinal scale with 1 = low; 2 = good; 3 = very good) and for the sections of the website considered more useful.

In addition to the traditional end-points in intervention studies in chronic low back pain such as pain, disability, and health care utilization, we concentrated in the pilot study on coping with pain as the primary outcome variable. In our pilot study, we hypothesized that changes in procedural knowledge,

socio-emotional determinants resulting from taking part in a virtual community and physical activities would go along with the primary outcome measure.

Results

In the five months of navigation, users accessed the website on average 11.5 times. None of the users withdrew from the project. Intensity of back pain, as reported by patients, was higher in the control than in the treatment group in the baseline measure, but appears to have decreased for the treatment group, but not for the control group (Tab. 2) when asked about the pain they had felt last week. On a scale from 10 = most severe imaginable pain to 1 = no pain, the treatment group average fell from 5.0 to 3.9. For the control group, without access to the homepage, the average remained largely unchanged (6.1 to 6.3). If asked about pain on the day of the interview neither the treatment group average nor the experimental group average changed much over the course of the experiment.

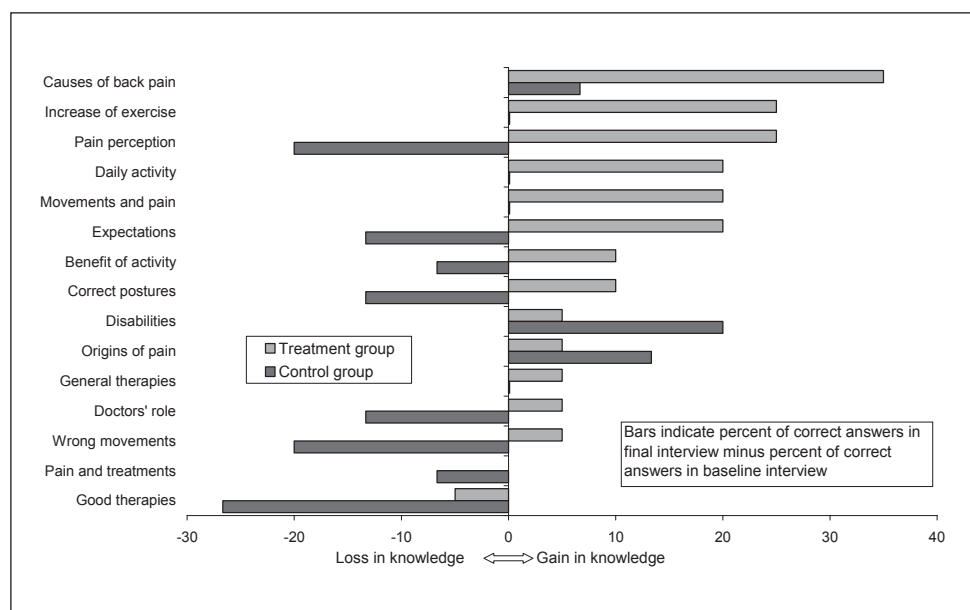


Figure 3 Knowledge items – Treatment and Control Group

Two thirds of both the treatment and the control group regularly did physical exercises to ease their pain, and one third of each did not (Tab. 3). The groups did not differ in this respect. However, when asked about whether they had exercised more or less in the past six months, more than two thirds of the treatment group said they had exercised more, while again more than two thirds of the control group indicated they were exercising as much as before, not more, not less. Access to and use of the homepage may have made patients do exercises more frequently.

There are indications that patients with access to the website sought treatment less frequently than patients without such access (Tab. 3). Before the website was installed, patients in the treatment group reported to have visited, on average, their physician slightly more than three times. After five months of access to the webpage, the reported average was down to slightly less than two visits. The reduction was much lower in the control group, from 2.5 down to 2.1 visits in six months.

One in five patients with access to the website reported they had taken pain killers regularly, but 2 in five said that in the control group (Tab. 3). If asked about the frequency of taking pain killers, large majorities in both groups said that they had recently been taking the same doses as before, but 25 percent of the patients in the treatment group said they were now taking fewer painkillers than they used to. Not more than 6.7 percent (one in fifteen patients) in the control group said the same thing.

As pointed out earlier, the above seemingly beneficial effects of the website may have been moderated by a gain in

knowledge. Knowledge was measured by offering patients 15 items and asking whether they agreed. Some items were overwhelmingly answered in line with research evidence, for others only a few of the patients gave the right answer. As is shown in Figure 3, disregarding these differences, the treatment group's average knowledge levels for 13 of the 15 items improved over the course of the experiment. For one item the level remained the same, for one it sank. The control group patients displayed higher knowledge in only three items, lower knowledge in eight, and no change in the remaining four.

The overall evaluation of the website coincides with generally favourable assessments of it. On a scale of 1 = very useful to 4 = not useful, website users on average gave a mark of 1.5. When asked about whether the site helped them cope with their pain, they also overwhelmingly said yes. Again on a scale of 1 = very useful to 4 = not useful, users on average gave a mark of 1.4. On a similar scale, the average of the replies to the question of whether the website improved patients' interaction with their physicians came down to 1.9. Patient who had used the site had, to summarize, much praise for it. These data matched when compared with data collected through the user testing. On the basis of a three-point ordinal scale with 1 = low; 2 = good; 3 = very good, 16 out of 18 patients considered the quality and level of comprehensibility of the information provided very good, while the other 2 considered them good. As for the self-perceived utility of the website, on the basis of a four-point ordinal scale with 1 = not useful; 2 = less useful; 3 = useful; 4 = very useful, 15 out of 18 patients considered this useful, 2 very useful and 1 less useful (this patient only used the website two times).

Discussion

This study provides evidence for the feasibility and hints at the efficacy of a patient-oriented website such as ONESELF for enhancing self-management of chronic low back pain. All patients who utilized the website were positive about the design and functioning of the website. Data from a preliminary pilot study suggested an enhancement of the level of physical activity, a reduction in taking pain-killers and medical consultations, and an increase in knowledge as potential effects of the website. The differences seem to go in the desired direction, namely an enhancement of pain-coping behaviours in patients affected by chronic low back pain, with the main implication of an improved quality of life. In addition to this, the experience of ONESELF suggests that an online professional presence leads to positive results and is compatible with health professionals' daily duties, provided the presence of content managers who monitor and ensure fluency and control of the interaction between users, as well as take care of the editing of the texts drafted by health professionals. Indeed, all the health professionals involved in our study agreed to continue to contribute to ONESELF and explore it on a larger scale. They became more and more interested in conducting online interactions with users during the time of the intervention. Moreover, while the health professionals had expressed fears about a deprofessionalisation of their expertise in discussions before the project began, during the project they felt that such an initiative could actually become a fruitful enrichment of face-to-face interactions with their patients. Our preliminary pilot study on the efficacy of ONESELF had, however, some limitations. First of all, since our results concern a small group of self-selected patients, no definitive conclusions can be drawn. Moreover, conditions at the beginning differed in a decisive aspect as patients in the control group reported higher pain levels than patients in the treat-

ment group. Thirdly, there was no formal random allocation of patient to treatment and control groups, and we did not test how often people in these two groups visited a health professional or what medical treatment (if any) they had in the period of the study. Bearing these limits in mind, the study highlights the need for further investigations with a larger sample. Also, we assumed that involving patients in a virtual community with other patients leading them to share their experience and to engage in coordinated behavior would be one factor that enables them to manage their chronic low back pain actively. In our study, however, we were not able to test this fully due to the small number of patients in the treatment group. Finally, more data are needed on the application of the initiative on a larger scale. In the pilot study, only 3 health professionals helped developing the contents to be published, as well as monitoring the website. We still need to assess how much professional effort is needed to manage a website with a larger number of users. In principle, one of the strengths of a website is that it could reach wide parts of the population. But, an enlargement would imply a rather significant reorganization of the professional team behind the website. A follow-up quantitative study on the effects should work with randomised samples, use validated measures for the outcomes where applicable, and measure all outcomes at baseline as well as after intervention.

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