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Coping with Chronic Lower Back Pain:

Designing and Testing the Online Tool ONESELF

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Abstract

A website was designed in order to help patients with chronic lower back pain (cLBP) to cope with their condition, relying on the concept of health literacy. A sample of 748 chronic or potentially chronic LBP patients were recruited through health professionals and mass-media channels. Patients were asked to regularly visit the site for a period of twelve months. The intervention was evaluated quantitatively (both pre-use and post-use surveys, logfiles) and qualitatively. Users appear to have taken less painkillers than before in the period they accessed the site. Most users reported that the site contributed to increasing their knowledge about back pain, and helped them managing their back pain. Communication with doctors and family and colleagues improved. A qualitative evaluation showed several positive effects including self-comprehension, improvement of argumentative abilities, orientation and development of self-confidence.

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Chronic pain can have a profound impact on sufferers' lives, and it is often associated with a loss of confidence and self-esteem. While the great majority of cases of low back pain [resolve on their own](#), the risk of recurrence and development of chronic disease is significant.

The internet is praised in the literature for its potentialities for enhancing patients' coping with conditions (Kirsch & Lewis, 2004; Payne & Kiel, 2005; Wantland, 2004). The World Wide Web gives individuals or health care organizations the chance to gather and disseminate information, and it enables people to seek health information without having to leave their homes (Brashers et al., 2002). Moreover, the internet is a direct device in health care, as evidenced in Interactive Health Communication Applications (IHCAs)--computer-based, usually web-based, information packages for patients that provide health information, social support, decision support and behaviour change support (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004; Murray, Burns, See Tai, Lai, Nazareth, 2005; Van Uden-Kraan et al., 2008, 2009; Winkelman & Choo, 2003). The internet also makes the latest research on pain management easily accessible (Demiris, 2006; Eysenbach, 2003; Hoch & Ferguson, 2005; Kirsch & Lewis, 2004; Street, 2003; Wantland, 2004;). Many patients use online information on health and medical subjects, often before talking with their physicians (Hesse et al., 2005).

Building ONESELF

Objectives and Relevance

In spite of the internet's vast potential for health care, websites on back pain are for the most part affected by a major limitation: They are restricted to providing information and **general advice**, which often does not spark users' interest and does not meet their expectations (Payne & Kiel, 2005; Skelton, Murphy, Murphy, & O'Dowd, 1995, 1996; Weissenberger et al., 2004;). Providing large amounts of information on a website usually assumes that individuals will select contents that is relevant for them and pass over what does not apply to them. Offering large amounts of information makes it difficult for users to find the information that can be used to improve their condition.

We intended to overcome this limitation and attempted to create a website that offered applicable support to users. We called the site ONESELF. Testing this intervention, we tried:

- to gather specific information on the ways patients used the website on back pain;
- to conduct an in-depth evaluation of the beneficial effects of the website on patient's knowledge and ways of coping with the condition;
- to draw some conclusions for optimizing the design and operation of internet-based applications in the area of back pain.

Chronic low back pain (cLBP) continues to be one of the most common and challenging problems in primary health care. It is associated with enormous costs in terms of direct health care expenditures and disability-related losses. Both surgery and drug therapy are expensive approaches to

reduce suffering and the economic and social consequences associated with cLBP. Effective self-management of this condition, however, can reduce health care costs and increase productivity in the workforce because of fewer absences. Beyond the simple financial savings, the patients' quality of life can improve substantially if they find ways to cope with their pain.

Project Design

The project was organized in five major phases. *Preparation* took place from October 2005 to January 2006 and consisted in gathering and reviewing the experiences with an earlier version of the website developed in a pilot study. A focus group with 5 rheumatologists, 2 physiotherapists and 2 general practitioners, and in-depth face-to-face interviews with 6 patients (3 aged 65+ without acute pain and 3 patients younger than 65 affected by acute low back pain) were conducted for this.

In a second phase (January to May 2006) we *improved the website*. Results from both the pilot study and the new experience from the preparation phase were used for this.

In the *intervention phase* (June 2006-May 2007), a sample of users (see below) were offered access to the website for a period of 12 months. Use was monitored, and a usability test was performed in May 2007 to rate the consistency of the website in terms of contents, technology and usability.

Fourthly, *evaluation* by standardized and in-depth interviews was conducted between June 2006 and June 2007. Users were asked to fill out a pre-use questionnaire upon registration, and a post-use questionnaire was distributed among users by email in May 2007. The quantitative analyses in this article are based on either the pre-use (N = 371) or the post-use (N =

129) questionnaires. Qualitative interviews were performed with a sample of 18 patients. See below for more details on both analyses.

Evaluation of the results took place from June 2007 to June 2008.

ONESELF operated on the general conviction that the provision of information promotes good health outcomes: If a provider or organization presents information at the right reading level, in the right language, using culturally appropriate images, the recipient will respond appropriately and adopt healthier practices.

On a first level, *declarative* knowledge is of interest. This is the “knowledge of the what,” which patients have or develop when they hear/read and understand certain medical-related statements, e.g. diagnoses, explanations conditions and the benefits/side effects of treatments and drugs. On a second level, *procedural* knowledge plays a key-role. This term refers to the “knowledge of the how”. Procedural knowledge is knowledge directly applied to a task, e.g. to treat a certain disease. It tends to be less general than declarative knowledge and results in the ability to perform specific activities, e.g. to follow a certain treatment, to take a certain drug or to do a specific exercise. Above these two types of knowledge, on a third level, *integration of knowledge* and information is of interest (Nutbeam, 2000, 2008; Schulz & Nakamoto, 2006). For integration, a patient has to assess any advice received, consider its value and act accordingly. Patients do not merely acquire information, they have to evaluate it, and the advice received, for what they are and for what they imply, as well as to decide to act in consequence of the information and advice, e.g. to stop taking pain-killers. The website ONESELF was designed to increase users’ declarative

and procedural knowledge and to support the integration of this knowledge towards a behavioral response.

ONESELF did not pursue monetary or economic goals. Registration and access to the site was free. The site did not contain any advertising. Its development and the evaluation research was publicly funded by the Swiss National Foundation.

Structure and Operation of the Website ONESELF

Based on the above goals, the first kind of information we made available online were basic texts on low back pain. These texts were expected to meet users' needs for declarative information, thus forming a base for understanding and interpreting more complex patterns about their condition. In light of this, we designed a first section in the website – called *Library*, where we inserted a set of basic contents (see Illustration 1 for the opening page of the *Library*). A team of rheumatologists advising the project reached a general consensus on the vital information to be offered to patients in a normal face-to-face consultation. Among this were the nature of back pain, its etiology, the structure and functions of the vertebral column and the importance of postures and physical activity. To ensure patient involvement in designing the site, we also gave patients the possibility of requesting other basic information. We added to the *Library* a form headed “Propose a topic” where patients could indicate what they would like to know more about.

ADD SCREENSHOT OF LIBRARY OPENING PAGE (Illustration1)

Exploiting the audio channels supported by the internet, we also created a section titled *Radio (La Radio)* - for which we recorded ten 2-

minute lessons given by rheumatologists on further basic contents including “sports and back pain” and “the perception of pain”. These contents were chosen by the rheumatologists on the basis of the questions that they were most often asked during consultations. Here, again, patients could request a specific recording on the topics they were most interested in.

Procedural-oriented information was delivered to patients in two main formats, in the *Library* as illustrated *texts* that describe and show how to perform specific actions (e.g. to get out of bed in the morning) and as *exercises* found in a section of the website called *Gym*. The procedural-oriented information in the *Library* contained documents that explain and illustrate the correct postures for performing certain actions considered difficult by patients, such as lacing up one’s shoes, carrying shopping bags, getting out of cars. The *Gym* contained videos showing exercises selected on the basis of the major disabilities reported by patients who used ONESELF (see link below for an example). In particular, it contained stretching, stabilization and mobilization exercises. Each video was accompanied by photos and a written description of the exercise, its difficulties and its correct execution. This section was maintained by two physiotherapists who guide patients in the selection and performance of the appropriate exercises. The physiotherapists could be contacted by patients directly on the website.

<p>INSERT LINK TO OPEN AN EXAMPLE OF THE</p> <p>FILMS AVAILABLE IN THE GYM</p>
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To foster patients’ integration of the information delivered by ONESELF, the website offered a *Forum* and a *Chat room* where patients could meet and interact with other patients and the health professionals on

the team. These were the sections where patients could ask for further information and discuss it in synchronous (via the *Chat room*) or asynchronous (via the *Forum*) ways. Once a week, at a specific time of the day announced on the homepage of the website and via a weekly newsletter, a health professional was available online in the *Chat room* to discuss specific topics. The topics of the discussions were selected on the basis of the conversations published in the *Forum* in the week preceding the meeting. Every week, patients were invited on chat room homepage to propose any topic they would like to be addressed. The messages posted by patients in the *Forum* were monitored daily by a content manager, who also ensured that the requests were appropriate for the subject and the nature of the website. When new messages appeared, the content manager contacted a health professional according to pre-agreed schedules for the online presence of the experts.

Another section was added to further enable interaction between patients and health professionals: *The specialist answers*. Here patients could find videos and other kinds of electronic material (e.g. short PowerPoint presentations) on topics suggested by patients in medical consultations. A last section, titled *Tell a story*, could be used by patients to edit their stories and comment on stories presented by other users.

Methods Used in Evaluating ONESELF

Recruitment of Participants and Logfile Recording

In November 2005 the health professionals involved in the project began to recruit patients. They introduced the website to their patients and asked about their interest in taking part in the project. To enlarge our

sample, we held a press conference on 16th June 2006, having invited the major daily journals in Ticino. Three days later, on 19th June the project leader and managers gave an interview to the local radio station RSI (Radio Svizzera italiana) where they presented the project. On 30th October 2006, the rheumatologists involved spoke about ONESELF on TSI 1 (Televisione Svizzera italiana, the local television station). Also, we offered users the option to register to the site all through the 12-month intervention period.

Advertising the site was very successful. Our final data set contains information on 748 users. Logfiles were recorded for the users, beginning some months into the period ONESELF was fielded. Some were supplemented by information about users' frequency of logging in to the site gathered from records. The supplemented log files (available not quite from the beginning of the project) indicate that 462 of these users logged in to ONESELF at least once during the period from September 2006 to November 2007. The other users must have logged in at least once before that, but never returned after September 2006.

Quantitative Analysis

A total of 371 users filled in a pre-use questionnaire. These users were recruited in the following ways: a) by health professionals (70/19%); b) by friends and relatives (34/9%); c) by radio (48/13%); TV (79/21%); newspapers (93/25%); the internet (34/9%); and others (13/4%). Information on socio-demographic characteristics of users is available from the authors.

One hundred twenty-nine users answered the questions in the post-use interview. Panel analyses of the change between pre-use and post-use

interview are based on 112 users who filled in both questionnaires. Especially the post-use survey had a low response. It cannot be determined whether and how the low response affected the results. Therefore we cannot completely rule out bias in the answers to the post-use survey. Our arguments, however, rely only in part on this survey and are in part confirmed by our qualitative studies, which induces us to think that there is some value in the post-use survey despite the low response.

Analyses are concerned, among other subjects, with the question of whether the intensity of a person's use of the website is related to the perceived utility of the site for users' ways of coping with their back pain, and with differential effects of the site on heavy and light users. Intensity of use was measured in two ways, as the number of days logged on to ONESELF (available for the period September 2006-November 2007) and by the total time spent online with ONESELF (available for the period January 2007-November 2007). For analytic purposes, intensity of use was grouped into three categories as Table 1 shows. The categories were defined in a way that delivers three groups of about equal size for the analyses of the group of users who responded to the post-use interview. Comparing high, medium and low use groups was done as a compensation for the unavoidable fact that there was no control group to assess the website's effects.

Insert Table 1 about here

Qualitative Analysis

The main aim of the qualitative analyses was to have an in-depth understanding of how people made used of ONESELF. After a preliminary investigation of how they normally cope with their back pain, we aimed at

understanding their use of the site by inquiring into its positive and negative aspects.

The data were collected between January 2007 and January 2008. To recruit participants, an email was sent to all the registered users who were suffering from cLBP (indeed, it was possible to register into ONESELF without suffering from cLBP), who were living in the Italian part of Switzerland (for practical reasons), who had been registered in ONESELF for 6 months and who had visited the website at least 3 times. The latter two conditions were set to ensure participants' minimal experience with the website). A second mail was sent after 2 weeks as a reminder to all the individuals who had not answered. Eighteen individuals filling the selection criteria accepted to participate in the evaluation. The final sample - purposively and conveniently - is diversified in terms of sex (9 men, 9 women), age (28-72 years old), length of suffering from cLBP (1-30 years), diagnosis (slipped disc, spinal stenosis, etc.), level of education, frequency of use of the website (3-250 instances of access in 6 months). Thirteen people agreed to participate in the evaluation immediately, while five accepted only after a recall in which we explained that we were very interested in their experience, even if they had the impression that the website had been useless for them. Semi-structured interviews were conducted at the participants' homes or at Lugano University. The interviews (about 45 minutes long) were recorded and transcribed verbatim. An essentially inductive approach was used to code the interviews, to link and group the identified codes into larger categories, and to define more abstract concepts around which to organize the various arguments. These operations allowed

for reduction and interpretation of the large amount of data and were realized with the support of ATLAS.ti, a software for qualitative analysis.

Results

Coping with back pain

In inquiring about patients' traditional ways (i.e. without ONESELF being available) to prevent pain and to cope with it, three main approaches to the management of pain were found:

1. To decrease the risk that a pain attack will occur, participants state that they have to become sensitive to potential pain triggers and must learn to recognize early warning signals. In other words, they have to monitor their body and to understand under which conditions back pain appears. People also say that excessive focusing on the suffering body can nevertheless involve some risks. Possible negative side effects of vigilance and self-observation can be fear-avoidance behaviors and reduced activity levels. In other words, to observe one's own body is necessary, as long as it does not mean becoming obsessed by the thought of pain.

"Your thought says: 'How am I walking? Look. Am I walking badly? (...) But you have to be careful. A sick person should try to not become too obsessed about it (...). The first thing to heal backache is that a person has to unplug his brain from the pain, and this is the most important thing. In other words, a person has to force his brain not to think about his backache too much. Because in the end, want it or not, when someone has backache, it's difficult to heal". (Man, 65, retired)

2. Observation of the body is not enough to prevent back pain: Once people understand the signals that announce the return of pain,

they must modify their habits in order to make use of the knowledge developed about themselves. Changing one's habits has many implications. First, one must introduce new activities that help prevent pain (for example to increase exercise) and eliminate or reduce behaviors that are considered detrimental to one's back (for example to sit for many hours in front of the computer).

Second, one must adjust usual positions and movements, such as taken and carried out in driving a car, lifting weights, getting up from bed. Changing habits can entail adversary reactions in a person's [social circles](#). Indeed, as the intensity of pain can usually not be proved by medical evidence, sufferers run the risk of not being believed by their family, friends and colleagues, or of having their problem not taken seriously. Their attempts to change their habits can therefore be looked at with suspicion by others and considered, for example, the consequence of a psychological rather than a physical problem, or a sign of lacking stoicism.

"I'm not able to work a certain amount of hours, say 9 or 10 o'clock, and then arrive home tired, so tired that the only alternative is the couch because I have pain, I have so much pain that I'm not able to exercise anymore. No, now the priorities have really changed. (...) And people find that really hard to understand. (...) I can only work standing. So I can work in the classroom, but I cannot do two weeks in the office. Because I'm not able to, it's not that I don't want to!' (...) Yes, my colleagues understand really well, there is no problem (*ironic*), but then when you have to put it into practice, namely to organize the shifts, they say 'oh yes, I forgot!'" (Woman, 37, corporate teacher)

3. In spite of all the efforts of prevention, sometimes pain appears anyway. When this happens, it is necessary to reduce it, in order to continue living as normally as possible. The informants use several strategies to do that, which can be grouped into two main categories. The first strategy is medication. Taking painkillers is a helpful solution, as it is possible to control pain quickly. It has some disadvantages, however. Medicine can have negative side effects which can be worse than the pain. For example, many informants have experienced stomach aches they attribute to their taking pain killers, and they think that long-term effects of taking medication include the risk of addiction. A second main strategy is using alternative treatment methods. The participants mention a variety of techniques to mediate the effects of pain, such as mud baths, acupuncture, physiotherapy, yoga, stretching, massages and relaxation. These techniques, however, also carry some risks. Given the incurable and complex character of cLBP, it is unlikely that alternative treatment methods succeed in eliminating pain. Moreover, their extreme variety can induce the individual to believe that a true cure exists, and that the only problem is to find it among a myriad of available options. Activism and frustration can be generated by such an attitude, as well as remarkable costs in terms of money, energy and time. As neither medication nor alternative treatment methods can completely eliminate pain, the participants think that, as part of the self-management of cLBP, they have to accept a certain amount of pain in their daily lives.

“You should force yourself even to do a tiny bit. (...). A person should learn to live with the pain, and to bear it, and to trivialize it (...). Certain things you need to be able to bear them.” (Man, 65, retired)

Patterns of Using ONESELF

Intensity of use according to log file analysis.

Between September 2006 and November 2007, 462 persons logged in to ONESELF at least once. Most of these users logged in a few times only; the median number of days logged on is 11. The range, however, goes up to a few people logging on practically every day. We know much more about the users ($n = 276$) who logged on at least once during the period from January to November 2007 because logfiles are available for this period. The median total time of use among this group is 16 minutes and 39 seconds. The range goes up to a user who spent 47 hours and 40 minutes online with ONESELF, but this is an exceptional case, with the second most eager user spending just a little more than 31 hours with the site. The different sections of ONESELF were accessed with different intensity. The total time spent by all 276 users in the different sections is listed in Table 2. The *Library* was by far the most intensely used section, with a total of 127 hours. The *Gym* and the *Forum* were used for about 64 hours each. All other sections were used much less intensely, at around 10 hours in all cases except the *Emergency room* and the *Homepage*.

Table 2 about here

Qualitative analysis: A typology of patterns of use of ONESELF.

The analysis of the interviews suggests that a user's habits and expectations play a major role in explaining the impact of ONESELF. In

particular, people seem to have taken advantage of ONESELF differently, depending on their previous awareness of cLBP and their level of self-management. Four main patterns of use of ONESELF were identified. They have to be considered as Weberian ideal types, and are described in detail below. The description already contains, at the end, brief mention of the effects of ONESELF to be expected for every type. This is done to make it easier for the reader to link use patterns and effects, in spite of the fact that effects of ONESELF are treated in more detail in the next section. We identified these four patterns:

1. *Selective use.* Most of the users could be defined as experienced self-managers, in the sense that they had a rather high level of awareness and self-management of cLBP even before knowing ONESELF. These people usually had been suffering from cLBP for many years, were familiar with the medical language concerning cLBP, had a rather clear idea about their diagnosis, and knew that they had to play an active role in dealing with their health problem. Moreover, they already had found their own way to cope. Obviously, the level of awareness and self-management varied from an individual to another, but all selective users were already engaged in a process of self-management. These people expected to find information on ONESELF that was useful in their own situation, as well as further support for their ongoing self-management. Their use of the website was focused, looking only for precise information. Their use of ONESELF could be low or high, depending on their needs. However, even if the website was used only occasionally, it

had a generally positive impact because it helped in reinforcing their ongoing self-management. In particular, ONESELF provided orientation and helped in maintaining a high level of awareness and motivation for self-management.

2. *Enthusiastic use.* Two users could be defined as novices in terms of self-management. These participants were aware that a medical solution to cLBP did not exist and were ready to accept that they had to become actively involved in their cLBP care. However, they did not know how to do it. One man had been suffering from cLBP for many years, but in a very light form; his back problem had worsened only in the last year. The other person was a new sufferer (less than one year). As they had no clear ideas about how to deal with their cLBP, enthusiastic users tended to consider all the material available on the website as a potential support. Therefore, they made a general and regular use of ONESELF, navigating in all the sections, reading all the contributions, paying attention to the testimonials, being interested in interacting with the health professionals and with other sufferers, etc. For these users, the impact of ONESELF was definitely positive and can be described as an introduction to self-management.

3. *Magic use.* Three users could be defined as passive self-managers: They adhered to a traditional biomedical model of cLBP and were convinced that the solution of their problem had to be found by health professionals. These people went to ONESELF to find a definitive medical solution for their cLBP. At the beginning, passive

self-managers tended to use the website frequently and broadly: They explored all the sections, they visited the *Forum* and the *Chat room*, and they interacted with the health professionals and other users as well. They reported a certain enthusiasm when they discovered the existence of the website. After some weeks, however, their use of the website became more and more sporadic. They were frustrated by ONESELF and tended to stop visiting it. They returned from time to time only to see if something “really new” had been discovered. For these users, ONESELF produced a kind of stagnation in their efforts at self-management: No change is noticeable in their way of dealing with cLBP. On the contrary, magic users rather reported that ONESELF confused and discouraged them. We label this the “magic” use because the users seem to be waiting for some magic to do away with their pain.

4. *Wait-and-see use.* Three users could be defined as latent self-managers. Two of them had been suffering from cLBP for several years, while one was a new sufferer. For all of them, cLBP was at the moment a marginal problem, in the sense that pain was intermittent and light. These users did not really need to engage in a long-term process of self-management: When pain appeared, they usually dealt with it through some easy coping strategies, such as taking painkillers, going to the chiropractic, etc. Apart from these specific moments, people paid no particular attention to their back. Chronic back pain was a part of their life, but it was not so intrusive that they decided to do something substantial in order to

deal with it. Even if their lifestyle was not particularly influenced by cLBP, wait-and-see users were worried about a possible aggravation of the situation in the future. Their motivation for the use of ONESELF was therefore to stay informed on possible treatments. Wait-and-see users went to the site occasionally and mostly not with specific intentions. They navigated all the sections to see if there was some new information that could be interesting and useful, but they did it in a superficial way. ONESELF was therefore used as a kind of preparation to self-management: At the time of use the suggestions of the website were not followed, but people knew that the website was available in case of necessity.

Quantitative Analysis: Effects of ONESELF

There are two kinds of questions that allow an assessment of the effects of ONESELF. The first kind is questions that were asked in both the pre-use and the post-use questionnaire, which consequently allow to assess the change that took place during the period that patients used ONESELF. Two major questions belong to this group, inquiring about the taking of painkillers and taking more or less painkillers than usual in the last six months. These questions do not mention ONESELF at all. The other type of question is direct inquiries about what users did since they began to use ONESELF, or about their perception of effects and the utility of the site. These questions were, of course, asked in the post-use interview. They inquired about an increase in knowledge by using ONESELF, the site's contribution to managing pain, an increase in exercising, an increase or decrease in visits to the doctor, an improvement of communication with

one's doctor and with family and colleagues, and more or less searching for information in other places than ONESELF.

Indirect questions in pre- and post-use questionnaires.

A desirable consequence of all treatment of back pain would be a decreasing necessity to take pain killers. Among the 107 users who responded to both the pre-use and the post-use questionnaire and the respective questions, 59 indicated that, before they had started to use ONESELF, they were not taking painkillers, and 75 said that after using the site for some time. There is a net change of 16 people (= 15% of the users) who switched to the desirable answer. Gross change is of course higher: 22 users changed their answer from yes to no between the two interviews and only 6 in the other direction (Table 3).

Table 3 about here

Is this change a consequence of using the website ONESELF? If so, one could expect that heavy users show more change towards the positive than medium or light users. This, however, is not necessarily so. If measured by total time spent on ONESELF, net change towards the positive is 4 persons among the heavy users ($n = 44$), 6 persons among the medium users ($n = 46$) and also 6 persons among the light users ($n = 39$). This does not support the assumption of a beneficial effect of a more intense use of the website on avoiding painkillers, though the users in this study did in fact say they took less of them (see below).

If measured by number of days ONESELF was visited, however, the picture is different. The net change towards the positive of 16 persons distributes unevenly among the use intensity groups: 8 persons among the

heavy users ($n = 40$), 5 persons among the medium users ($n = 43$) and just 3 persons among the light users ($n = 46$). This does support the assumption of a beneficial effect of a heavy use of the website on avoiding painkillers, though it seems unrelated to the total time spent with the site. Rather, the frequency of visits seems more important.

The self-perception of taking more or less painkillers in the last 6 months was also asked in both interviews. In the pre-use questionnaire 30 respondents gave no answer to the question about taking more or less painkillers in the last six months. These respondents are excluded from the following analysis, which is based on the remaining 77 users. In the interview prior to using ONESELF, 11 users had indicated they were recently taking less painkillers. This number is up to 23 in the post-use interview. Before use began, 32 respondents indicated they were recently taking more painkillers. This number went down to just 6 users. That is to say: After using ONESELF for a while, a total of 38 (or 49%) of the users gave more positive answers than before using ONESELF to the question about their recent use of painkillers as compared to usual. Only 10 users gave more negative answers, creating a level of net change to the positive of 28 people in 77 (= 36%, Table 4).

Table 4 about here

Is this related to intensity of use? If the number of days logged on is considered, 8 of the 28 cases of net change towards the positive come from the group of light users ($n = 24$), 7 from the medium users ($n = 26$) and 13 from the heavy users ($n = 27$). In percentages this amounts to 33, 27 and 48%, suggesting that use and the recent behavior with regard to taking

painkillers are weakly related. If the total time spent online with ONESELF is considered, 5 of the 28 cases of net change towards the positive come from the group of light users ($n = 23$), 11 from the medium users ($n = 25$) and 12 from the heavy users ($n = 29$). In percentages this amounts to 22, 44 and 41%, suggesting that use of the site and the recent behavior with regard to taking painkillers are also weakly related.

The panel questions provide evidence that less painkillers were taken as respondents used ONESELF, mostly independent of the intensity of using the site, or at least: The evidence is too weak to posit a relationship between the intensity of use and the taking of painkillers.

Direct inquiries in post-use questionnaire.

Generally many users reported benefits of using ONESELF as answers to a set of questions asked in the post-use survey. Based on all users who completed this survey ($N = 129$), we can say that 25% reported that ONESELF contributed much to increasing their knowledge about back pain, and an additional 58% said ONESELF had contributed sufficiently to knowledge. Users also acknowledge in majority ONESELF's contribution to managing their back pain: 12% said the site had contributed much, and 57% said it had contributed sufficiently to managing pain.

The next most frequently acknowledged benefits were improvement of communication with doctors (56%) and family and colleagues (55%). A majority of users (55%) also reported that their search for information had decreased (including decidedly decreased) as far as other websites are concerned, and 45% reported the same of other sources of information. This can be taken as an indicator that users were satisfied with the information

supplied by ONESELF. Roughly one in three users reported they exercised more (including decidedly more) since starting to use ONESELF, while just 2% said they exercised less since then.

Is the incidence of reporting benefits related to intensity of use? The answer to this is given in Figure 1, which shows the frequency of positive answers to the questions just described, and split these into three groups respectively of different intensities of use as detailed in Table 1 above. The indicator of intensity was the number of days ONESELF was visited.

There seems to be a pattern that the medium use group reports the least benefits, while the high use group does this the most often. Chi-square-tests were run for all eight questions, and none of them showed significant overall differences. Only the results for improvement of communication with one's doctor approached significance ($\chi^2 = 5.240$, $df = 2$, $p = .073$), but were (as shown) not linear. Judged by the standardized adjusted residuals (-2.3), the high share among heavy users of respondents indicating they had searched less information from other sources reach significance. All in all, however, the results cannot be interpreted as indicating that high levels of use of ONESELF go along with reporting more benefits of the site. Rather those who visited the site seldom also agreed that it was beneficial.

Figure 1 about here

The other indicator, total time spent online with ONESELF, produces a similar, though not identical picture (not shown). The pattern of the medium use group reporting the least benefits again appears in six of the eight questions, though none of the differences are even close to

significance. The only result that looks like the pattern expected if there were a relationship between intensity of use and reported utility is for the improvement of communication with one's doctor. It is, however, also not significant ($\chi^2 = 4.452$, $df = 2$, $p = .108$).

We have to state: There is no indication that heavy users report more benefits of ONESELF than medium or light users. The absence of such a relationship in the presence of rather favorable replies to the questions about benefits allows two interpretations. Either a low level of contact with ONESELF is enough to produce a positive assessment of the site's benefits which cannot be further augmented by more contact, or the users' experience with the site did not have an influence on their further visiting it. In case of the first interpretation one could conclude that the site was of a quality that even cursory contact produced some of the desired effects. In case of the second interpretation one could conclude that there were some users who visited the site again and again although they did not find the benefits that we inquired about. Also, as use data are available only for a period that began some months after the project had started, it is conceivable that some patients who hardly returned to the site in the period monitored had been rather heavy users earlier, in the period not monitored.

Effects of ONESELF in Qualitative Analysis

Positive effects.

The interviewed sample consider ONESELF very useful to build an individualized understanding of their situation: The richness and trustworthiness of the information, the possibility to interact with health professionals to obtain specific answers and the stability of the material

helped them to construct their personal frame of reference about the nature and the course of their cLBP. People report that medical consultations were usually too short to elaborate a meaningful representation of their health problem. In ONESELF, on the contrary, people could take all the time they needed to navigate in the website and to confront their situation with the information provided. In this way, they could improve their *self-comprehension*. « It gives you descriptions and you say: ‘this stuff here... I see it, I see it ! I recognise myself in it, I recognise myself here !’ » (Man, 58, teacher)

ONESELF helped people in acquiring words about their health condition. Users could improve their *capacity to speak about their situation* in a way that people – and especially health professionals - could comprehend it and believe it to be true. « I have had the chance to clarify some things concerning the problem and thus be able to discuss it better with my doctor.» (Woman, 28, academic researcher)

ONESELF provided users with basic *orientation* and information that suggested them how to behave towards cLBP. For example, people could learn new exercises or brush up on old ones. « I have my 4 or 5 standard exercises, that cat one, that dog one, that one to stretch yourself out, those I always do. Then every now and then I catch one of your exercises and so I do a bit of your exercise too.» (Man, 58, teacher)

ONESELF helped people to acquire *self-confidence* in their ability to manage cLBP. Some users felt reassured because they had a trustworthy place where they could address concerns. Some people felt emotionally supported by the presence of other sufferers. Moreover, successful

testimonials gave evidence that self-management was possible. « When you are going through a moment when you have backache and you read a testimony which says ‘yes, there is someone who was able to do it’, it gives you hope.» (Woman, 28, academic researcher)

ONESELF reminded people of the necessity of self-management. First, the quality and the continual update of the website encouraged people to visit ONESELF again and to continue thinking about self-management. Second, people did not have to make any effort or make any clear decision to obtain information and support. These were provided directly through the newsletter. It was enough to open the mailbox for reasons that could be independent of cLBP to get a reminder of the website and of the necessity of self-management. ONESELF thus contributes to the *maintenance of a high level of motivation and adherence to self-management*. « Usually I went on the website when I read the newsletter. I read the letter and then I’m there, it’s like a conditioned reflex. » (Woman, 49, nurse)

Negative effects.

According to some people, ONESELF provided too much information, risking patients’ *confusion* about their health problem and making it more difficult for them to identify the best way to treat it. « There is a lot of information, probably almost too much, don’t you think? It’s a problem to select it.» (Man, 47, bank director)

Some persons perceived the information offered on ONESELF as neither new nor relevant. In this case, the use of ONESELF lead to feelings of *discouragement* and hopelessness: People had the impression that again there was no solution for their problem. One woman provides a poignant

illustration in this respect. Frantically searching for a solution to her cLBP, she found information on the website generally interesting, but not really new. Moreover, she was convinced that it did not fit her specific situation. As a consequence, she developed a kind of bitterness: For her ONESELF seemed to confirm that there was no help for her.

Summary and Conclusion

Chronic pain can have a profound impact on sufferers' lives, and it is often associated with a loss of confidence and self-esteem. While often self-limiting and resolving on its own, back pain often becomes chronic. The internet is praised for its potentialities of enhancing patients' coping with conditions. Yet online websites on back pain are for the most part limited to providing information, but fail to help users apply that information in their everyday efforts to cope with their condition. ONESELF aimed at exploring to what extent an interactive website is a proper response to enhance patients' self-management of cLBP.

The website was designed to enhance users declarative, procedural and integrative knowledge of their conditions and of the ways to cope with it. A sample of 748 chronic or potentially chronic LBP patients were recruited through health professionals and mass media channels. Patients were asked to regularly visit ONESELF for a period of twelve months. The intervention was evaluated quantitatively (both pre-use and post-use surveys, logfiles) and qualitatively.

Summary of Results

Most users visited the site only a few times, but a few turned to it frequently and for long periods of time. The sections used most intensively

were the *Library*, the *Gym*, and the *Forum*. A typology of user patterns shows four ideal types: *Selective users* are already experienced self-managers and pick out, to their advantage, what is helpful in their personal situation. *Enthusiastic users* with recently developed or aggravated conditions seek for help on the website frequently and intensively to acquire new ways of coping. *Magic users* are more passive and, despite early intensive use, loose interest as the cure they expected did not emerge. *Wait-and-see users* do not suffer from intensive pain and look for information that may be of use at a later time when their condition may have worsened.

As to the effects, there is clear indication that the users of ONESELF took less painkillers than before in the period they accessed the site. Most users reported that ONESELF contributed to increasing their knowledge about back pain. Patients also acknowledged in majority ONESELF's contribution to managing their back pain. The next most frequently acknowledged benefits were improvement of communication with doctors and family and colleagues. A majority of users also reported that their search for information had decreased as far as other websites are concerned, and almost every second reported the same of other sources of information. Roughly one in three users said they exercised more since starting to use ONESELF, while just 2% said they exercised less since then.

The participants in the qualitative study mention several positive effects of the use of the website on attitudes and behaviors related to self-management, including self-comprehension, improvement of argumentative abilities, orientation and development of self-confidence. Knowledge gains were not restricted to declarative and procedural levels; users were able to

incorporate the knowledge gained by ONESELF into their ways of coping with the condition.

However, results also suggest that not all the users have taken advantage of ONESELF in the same way. The individual's previous awareness of cLBP and level of self-management explains this diversification. ONESELF displayed a visible utility only for people who were already engaged in a process of self-management or at least who were inclined to do it. This was the case for selective and enthusiastic users. On the contrary, magic and wait-and-see users did not experience an immediate positive impact following the use of ONESELF.

Implications for Operating Health Care Websites

Overall, the qualitative analysis suggests that patient-centered websites monitored by health professionals could be particularly useful in developing and enhancing self-management of cLBP. ONESELF helped most of the users to build their own frame of reference about the nature and the course of their health problem, to develop their argumentative abilities, to find their own way to deal with cLBP, to improve their feeling of self-confidence, and to maintain a high level of motivation for self-management. These effects could be reached thanks to the specificities of the website, that is its interactivity (people could ask specific questions to health professionals), multimediality (material was provided in written, audio and video form), usability (the website was easy to use and accessible from home without the necessity of intermediaries), dynamism (the website was updated weekly) and trustworthiness (material was controlled by health professionals according to the criteria of evidence-based medicine). With

ONESELF, people could benefit from the “law of the least effort”: They could obtain rich and tailored information and support without moving from home and without being forced to actively search for it, as they automatically received a newsletter that informed them about the updates of the website.

There were several difficulties linked to the amount of time that health professionals could devote to the project. ONESELF has minimized the risk of overloading health professionals with work by subdividing their tasks and scheduling exactly when each of them has to enter the website and answer patients’ requests. Despite their initial concerns, the health professionals involved in this project became more and more interested in conducting online interactions with users, since, from the point of view of their daily practice, ONESELF has helped them in at least two ways: First, by referring patients to ONESELF for general background, health professionals can focus the time during the consultation on more urgent matters; second, ONESELF can help screening requests from patients that do not need a face-to-face encounter to be answered.

Overall, websites such as ONESELF have some potential for improving techniques of self-care. Effective self-management of cLBP can reduce health care costs and increase productivity of the workforce because of fewer absences. Beyond the simple financial savings, ONESELF has the potential of substantially improving the quality of life of chronic patients.

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Table 1

Grouping of Users into Three Categories for Intensity of Use

		All users	Users with supplemented logfile data	Users with unsupplemented logfile data	Respondents to pre-use interview	Respondents. to post-use interview	Respondents to both interviews
Number of days ONESELF was visited							
Low	0-10	516	230	193	142	46	31
Medium	11-100	169	169	46	166	43	41
High	101+	63	63	37	63	40	40
Total		748	462	276	371	129	112
Total time spent online with ONESELF in seconds							
Low	0	472	186	-	214	39	34
Medium	1-1500	166	166	166	88	46	39
High	1501+	110	110	110	69	44	39
Total		748	462	276	371	129	112

Table 2

Total Time Spent with Different Sections of ONESELF, January to November
2007

	Total time spent online (n = 276)
Library	127 hours 4 minutes
Gym	64 hours 27 minutes
Forum	63 hours 40 minutes
Radio	10 hours 37 minutes
Chat room	10 hours 12 minutes
The specialist says	10 hours 1 minute
Testimonials	9 hours 27 minutes
Emergency room	4 hours 27 minutes
Homepage	10 minutes
Total	300 hours 6 minutes

Table 3
Taking Painkillers Pre- and Post-use

		Normally taking painkillers according to post-use survey		
		No	Yes	Total
Normally taking painkillers according to pre-use survey	No	53	6	59
	Yes	22	26	48
Total		75	32	107

Question wording: "Do you normally take painkillers for your back pain?"

Table 4

Number of Respondents who Took More or Less Painkillers at Time of Interview, Pre- and Post-use

		Took ... painkillers in the last six months according to post-use survey			
		Less	Same amount	More	Total
Took ... painkillers in the last six months according to pre-use survey	Less	3	7	1	11
	Same amount	9	23	2	34
	More	11	18	3	32
Total		23	48	6	77
Question wording: "In the last six months, have you taken more or less painkillers, or about the same?"					

Figure 1

Reported Benefits of Using ONESELF by Intensity of USE (Measured in Total Days ONESELF Was Visited)

