

Expert insights on the design and implementation of interactive patient websites for people with chronic pain

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Abstract. Chronic pain is a burden on an individual, social and economic level. Growing published research outlines various innovative online solutions aimed at addressing this issue, including interactive patient websites. This paper presents expert insights regarding an existing interactive chronic pain website, ‘ONESELF’, operating in Switzerland. Based on their experience, members of the research team involved in the ‘ONESELF’ project were asked to reflect about what they understood to be key considerations salient to designing and implementing such interventions. Thematic analysis uncovered five main themes that these experts used to interpret what worked, when and why in ‘ONESELF’ design and implementation: health literacy, Internet literacy, access to healthcare, adherence and attrition, and health outcomes. These findings may serve as a base to assist Australian health researchers and practitioners working toward developing effective interactive patient websites for people with chronic pain.

Keywords. Chronic pain, website, design, interactive, patient management, e-health, patient-centered care

1. Introduction

1.1. Support for People With Chronic Pain (PWCP)

On a global scale, chronic pain costs world economies billions of dollars annually and this is only expected to rise over time [1, 2, 3]. Innovative technology assisted solutions to address these issues include telehealth, virtual environments, blogging and websites [4, 5, 6]. Although preliminary evidence indicates that interactive patient management websites may have a positive effect on health outcomes, this depends on careful design and implementation. A key challenge in design and implementation of websites for PWCP is the absence of evidence-based guidelines for good practice [4].

Interactive websites for PWCP are not new. However, until recently the only authoritative websites for PWCP in Australia were those of Chronic Pain Australia, Pain Australia and the Australian Pain Management Association; while useful, they function primarily as websites for their respective associations rather than for patient-centered self-management. The first Australian website dedicated to enhancing PWCP

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self-management, ‘painHEALTH’, was launched by the Western Australia Health Department in April 2013 [7, 8].

Given the dearth of interactive websites to meet the needs of Australian PWCP, and investment required to create and maintain them, it is important to understand what considerations stakeholders need to prioritise when designing and implementing them. Accordingly, this paper aims to identify factors in the design and implementation of an interactive website called ‘ONESELF’, operating for ten years and with over 1500 PWCP users in Europe. Findings distilled from the expert reflections of members of the website’s team are analysed to suggest how Australian websites may be enhanced for effective management of chronic pain.

1.2. ONESELF

‘ONESELF’ was originally developed to further health literacy, health communication and disease-specific knowledge (Figure 1) [9, 10]. It has served as a hub to test Internet based interventions for low back pain, arthritis and fibromyalgia management. It is written in Italian language.



Figure 1. ONESELF Homepage.

The website has evolved considerably since its inauguration in 2004, leveraging interactive features in order to evolve into its current web 2.0 version [11]. Improved social support through greater interaction aims to enhance patient outcomes. New features include: gaming, revamped videos, integration with social networks, patient narratives, and (limited) personal profile creation.

Research into ‘ONESELF’ provides accounts of the beneficial impacts on patient reported outcomes (PROs), including: decreased medication usage [10], improved quality of life and chronic disease self-efficacy [9, 11]. Even so, the mechanisms by which these outcomes are achieved are not always clear.

2. Method

The research reported in this paper was conducted on site at the Faculty of Communication Science, Università Della Svizzera Italiana (USI), Lugano,

Switzerland in September and October 2013. Permission to study 'ONESELF' and interview members (as well as informed consent), was obtained.

2.1. Data Collection

Data were collected from three key members: 1) the Program Director, 2) the Web Designer/Programmer, and 3) the Health Outcomes Researcher. This enabled coverage of the following areas of interest: foundations and evolution of the intervention, technical design considerations and ideas on how user outcomes were generated. Whilst it would have added significant rigor to the study to collect data from more than three team members, this was not possible. Earlier team members have since moved on and were not available for comment. Data were collected via semi-structured interviews in English. Preliminary review into 'ONESELF' was conducted to understand its foundations and to observe health outcomes reported from use of the website. This helped formulate the interview questions. Semi structured interviews were chosen to allow for flexibility in the data collection process, further tangential inquiry and to allow each individual to contextualise their thoughts [12]. Each interview was adapted to the role of the interviewee, however all three were asked to describe their role in their own words; to discuss the initial concept of 'ONESELF' and how this changed with time; to talk about how evidence from 'ONESELF' users affected their own concept of 'ONESELF'; and to articulate key messages for clinicians and researchers from their experience of working with 'ONESELF'. Interviews lasted approximately 30-40 minutes, and were recorded and transcribed verbatim.

2.2. Data Analysis

Data were analysed inductively applying grounded theory and categorised based on broad themes found within them [13, 14]. Each interview transcript was read and analysed separately several times for familiarisation and to identify emerging themes by which the data could be coded. Data from each interview were then combined under sub-headings based on interview questions. The analysis process was repeated and themes identified until no new codes arose, suggesting saturation.

3. Results

Five themes emerged from these interviews as the underlying conceptions held by these team members about what worked, when and why in the design and implementation of the 'ONESELF' website.

3.1. Health Literacy

The first theme was health literacy. It was suggested that PWCP have differing levels of understanding of their condition. From the interviewees' perspective, amongst the 1500+ users of 'ONESELF', basic levels of health literacy remain a problem. Interviewee 1 suggesting that their cohort suffered from "*a lack of basic knowledge of one's condition...some people had problems addressing and discussing their condition*". It was discussed that the utility of interactive patient websites may lie in

their ability to allow for a freer flow of information to enhance disease specific knowledge and awareness of one's condition. Interviewee 1 proposed that *"a website may provide an adequate channel for knowledge transfer and information visualisation"*.

3.2. Internet Literacy

A problem that continues to plague online health researchers is Internet literacy as outlined by Interviewee 1: "key issue becomes Internet literacy. That was a particular problem early on and remains a problem for many researchers in this space". Confounding this is the conundrum that while the Internet may provide a means to overcome certain barriers to care, a large portion of people living with chronic disease are either under-represented on the Internet or do not have the competencies to derive the desired benefits from using it. It was emphasised that adequate attention be paid to Internet literacy because it will affect design, conduct and any outcomes generated. The key consideration here is ensuring that the target population is appropriate to complete the intervention. This perspective emerged in all three interviews, with Interviewee 3 imploring: "need to first define who needs the intervention most and what you wish to target. Start here". This sentiment was reiterated by Interviewee 2, who suggested that stakeholders should "consider avoiding features that are beyond [their] capabilities (i.e. heavy social technology early on, podcasting, sharing facilities, etc). These types of features become more convenient and useful as competence and experience increases". Alternatively, in cases where Internet interventions are to be pursued despite low levels of Internet competence, ample time and effort needs to be put in place to ensure the target population is up-skilled in using the Internet. Interviewee 1 said, "for the purposes of the 'ONESELF' project, sessions were undertaken to help patients use the Internet. As can be imagined though, this was very time consuming".

3.3. Access to Healthcare

The idea of offering information and treatments that would otherwise be difficult to achieve on the same level offline and thus bringing about improved health outcomes through better access to healthcare was a theme evidenced in the interviews. According to Interviewee 1, *"in enigmatic and socially stigmatised conditions...the Internet gave them a platform to really engage and improved overall well-being"*. This reflects empathy with the hurdle PWCP may face in terms of healthcare inaccessibility, because of geographic factors, physical reasons or because of isolation felt from living with a socially stigmatised condition: *"a website may provide greater accessibility and be able to deliver a wider scope of treatments"*.

3.4. Adherence and Attrition

Improving adherence rates and decreasing attrition remain major challenges according to the interviewees. A consideration team that members highlighted for the effective use of interactive patient websites was ensuring motivation and continued use. Interviewee 2 expressed frustration that *"...one of the most difficult things is ensuring and maintaining patient motivation. At times it felt as though you needed to beg patients to be involved, active and/or to keep using it, even though the site is designed to benefit patients"*. Evolving the platform was also a critical success factor, in other

words not only initially designing the website but also maintaining it so that it met the expectations and needs of the users, as well as keeping up with current web design trends. Interviewee 2 described this as the reason for some of the major changes the website has undergone: *“the website has changed a lot since its inauguration. It was transferred to a content management system to allow for better integration of functions”*. Along these lines, updating content was commonly agreed upon as crucial. According to Interviewee 1, *“Internet-based resources need frequent updating to keep content fresh. This contributes to adherence and attrition”*. Within the ‘ONESELF’ project, this was accomplished by ensuring that health professionals provided most of the content and contributed. Interviewees considered that the more PWCP feel that the information and interaction they are offered is tailored to them, the more likely they are to adhere and continue.

3.5. Health Outcomes

Recently, the ‘ONESELF’ research team has been studying quality of life and self-efficacy as a result of social support derived from using the website. According to Interviewee 1, the most important factor underlying social support was the patient narrative experience. Interviewee 1 believed online narratives may potentiate emotional catharsis, suggesting a link to health benefits observed from ‘ONESELF’. Health benefits noted included: improved health literacy, self-efficacy, coping, empowerment, decreased medication usage, improvements in physical exercise and overall quality of life.

4. Discussion

The themes extracted highlight that one may conceive, plan, design and implement an interactive patient website but this does not guarantee that the website can sustain effectiveness. Synthesising expert reflections on operating an interactive website for PWCP as this paper has done is a means to mine real world experiences over a substantial period with a large user group, and to ground-truth some of the academic literature in the field. Interviewees testified to the potential of personal narrative as a mechanism by which PWCP achieve health outcomes from using web 2.0 functionality, as theorised elsewhere by the authors [15]. The team’s first-hand observations support assertions elsewhere that internet resources for PWCP have traditionally been poor at supporting adherence and preventing attrition among PWCP [16]. The team’s focus on creating individualised user experiences that can be tailored to meet the changing needs of PWCP accords with findings of a recent empirical study [17]. Their pinpointing of both health literacy and Internet literacy factors speaks to the concept of a bundle of inter-related issues affecting what works and why in patient-centered health websites - this has been characterised elsewhere as e-health literacy [18].

The study has limitations. Firstly, interviewing only three experts gives meaningful but limited insights, and serves only as a preliminary to designing Australian research with a broader sample for wider applicability. Secondly, we acknowledge that results sourced from researchers involved in the project can be biased. However, garnering personal reflections was the aim of the study. Finally, ‘ONESELF’ resides under an Italian socio-cultural context. We recommend that Australian healthcare practitioners pay adequate attention to their specific cultural context.

5. Conclusion

This paper has explored how interactive websites for PWCP are understood to work, by members of a team highly experienced in working with them. This study presents a base upon which further research into innovative patient management solutions may build. Further research is warranted to examine the theories on which website designs are based and the types of interactivity through which they are thought to be effective. Investigation of the clinician's role, expertise, experiences and preferences with regard to the use of these websites by PWCP is also important to support care partnerships between patients and clinicians. More extensive research to gather evidence of the efficacy over time of these websites is needed, to support updating of clinical guidelines for using the Internet in health management. This study helps to map the way ahead for practitioners to innovate and enhance interactive websites for PWCP in Australia. The ultimate aim is to decrease the burden on stretched healthcare resources and improve patient outcomes.

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