

Social Media in Healthcare - User Research Findings and Site Benchmarking

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Abstract. Still nowadays social media is widely spread, it is recognized that general purpose sites support health issues sporadically only. In this paper, we report a user experience study of a Finnish health-oriented online social network service, Hoitonetti.fi and benchmark it to some other, comparable sites to qualitatively compare service palettes and to scope future pathways. In our research we have found out that social media can indeed efficiently support accessing and sharing healthcare information. However, our results indicate that the health portals could anyhow better engage the users. Medical professionals should author blogs, participate to discussions, and provide safety support. If sites could more actively support professionals to develop their diagnosing and care taking practices their commitment and dedication to site up keeping could be improved. Also, anonymized data gathered could be available for research. Even respective statistical tools could be incorporated to the sites by using some web 2.0 technology as Ajax. Efficient linking of external health records could be supported. Patient-secure links to general health portals as Google Health or Microsoft Health Vault could be created. All this could enable new service ecosystems to be created too.

Keywords: online social media, social websites, online social networks, healthcare, well-being.

1 Introduction

Worldwide health statistics of Continua Health Alliance reveal that there are 1 billion adults that are overweight, and 860 million individuals with chronic conditions. Also, there are 600 million individuals age of 60 or older. 75-85% of healthcare costs are due to chronic condition management. On the other hand, there is increasing loneliness, and need for social activities especially with elderly. Clearly we should rise up awareness of our own role in up keeping physical, social and mental health. Important tool for this is the developing social media that allows us to connect, communicate, socialize and interact virtually and to generate, publish and share all kind of content. Social media includes multiple services, such as online social networking, multimedia sharing (e.g. video, audio and photography), content publishing (e.g. blogs and micro-blogs), information mining and online collaboration

(e.g. wikis). Health related social websites are now quickly appearing worldwide (e.g. Google Health, Microsoft Health Vault, MedHelp.org, DailyStrength.org, and PatientsLikeMe.com). Also, there exist sites that are tailored especially for elderly (growingbolder.com, EONS.com, ELDR.com, and Seniornet.org). Important aspect in these sites is that issues relating to privacy are greatly circumvented by allowing anonymous participation. Sites apply, as a rule, internal privacy policies that are independent of governmental policies. This enables sites to be developed more freely and it gives also a greater freedom to develop new services that are based on (anonymous) user data. These include for instance tailored user interfaces tuned to follow users' personal health facts and/or on-site discussions. Also, when the site becomes bigger, user data can be used for statistical scientific research as for instance for investigation of diagnosing techniques as experienced by the site users. Also, efficiency of health care practicalities and medications for particular sicknesses can be analyzed.

In this paper, we report and discuss our user experience research of a Finnish health-related online social networking service, Hoitonetti.fi. Also, we benchmark Hoitonetti.fi with some similar sites in order to create a critical view of current state-of-the-art, and to evaluate how the medical social media could be seen to develop in the future. Findings of the user research and site benchmarking are reported in sections 3 and 4 respectively. We begin by considering the general role and potentials of social media for well-being and healthcare in section 2.

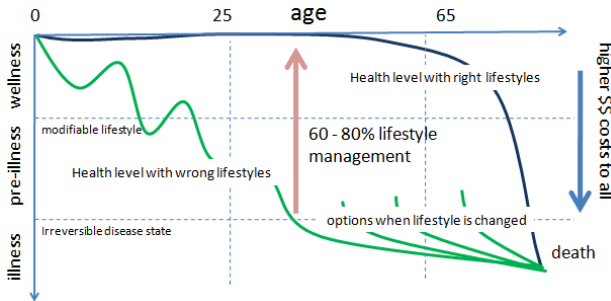


Fig. 1. Well-being vision of Continua Health Alliance (fig. is modified from [1]). We cause major part of our sicknesses; therefore we can also avoid them by fostering well-being. This can result longer life, higher-quality life in general, and cut down health care costs.

2 Social Media and Health Care

In general it is known that in an individual's life there is an association between social support and psychological well-being [2] and the importance and benefit of social support for recovery, rehabilitation and adaptation to illness are acknowledged [3]. The importance of introducing online and computer-mediated social support is thus well recognized. For example the use and contents of health-related online support groups have previously been analyzed for example in the case of an Alzheimer caregivers'

e-mail group [4] and an online bulletin board for breast cancer patients [5]. Also the use of a discussion board on a health website for older adults has been documented already few years ago [6]. The techniques of Web 2.0 essentially deployed for online social media enrich the patient-to-patient communication by providing diversified, more socially oriented ways for the patients and care givers to connect and share experiences and advices with their peers. It is generally recognized, that improved health and reduction of health care costs should be based on understanding, marketing and implementing well-being practices as early as possible. Obesity, diabetes, and most heart diseases, for instance, are nowadays known to have their roots in our ways of living. They are causing the population to fall away from their peak health potential that degrades our life's quality and creates a substantial financial burden too. In Continua Health Alliance vision [1] realization of peak health potential (following right lifestyles) is in great deal, our responsibility (Fig. 1). An important challenge is how to motivate people to follow or make the change to follow better lifestyles. Also, how the relating personal objectives should be defined and how to obtain sustainable improvements? Online social media can indeed be seen offering tools to empowerment of patients and care takers for improved care in many dimensions [7] that we investigate in this paper by a site survey and benchmarking study.

2.1 Defining Well-Being

Research of social and psychological impacts of social websites and engaging by social media sheds light to the characterization of these services. Dynamic and sustainable states of physical, environmental, economical, social, emotional, intellectual, and ethical well-being are important components of the multi-dimensional health (Table I). Therefore site service palette should address them wisely while targeting the overall health, well-being and communication.

Table 1. Some dimensions of well-being, modified from [8]

Physical	Environ.	Econom.	Social	Emotional	Intellect.	Ethical
Structures and functions of the body	The environment where we live and work	Our disposable income and financial health	Make and maintain relationships in various social contexts	Recognize and express needs and feelings adequately and appropriately	Learning to think clearly and coherently to enable rational decisions	The art of understanding and applying concepts of right and wrong decisions

3 Characterizing Hoitonetti.fi and the Site Survey

Hoitonetti.fi is a Finnish social media based health care site. The service has approximately 2300 registered users. The number of unregistered visitors highly exceeds the number of registered users. The age distribution of services spans from 10 to 80+ years most users being 50-59 years (580 users). The next largest user groups are 40-49 years (450 users), 60-69 years (380 users), and 30-39 years (320 users).

The idea behind the service is in aiming to create an interactive collection of health information, where experts' knowledge and user-originating content are combined. The site consists of registered users' profile pages and illness-specific pages (e.g. asthma) for symptoms (e.g. dizziness), treatments (e.g. antihistamines) and health measurements (e.g. haemoglobin concentration). The information pages are written by medical experts and controlled by Hoitonetti.fi maintenance staff. Users' profile pages are updated by the users themselves. Users can add illnesses, symptoms, treatments and health statistics to their profiles together with personal experiences interlinking the users' profile pages to information pages. Each information page contains also a discussion section where both registered and unregistered users can participate, share thoughts and experiences and ask questions. A key feature of Hoitonetti.fi is that its maintenance team includes responsible doctors actively monitoring and taking part to discussions. Registered users can create micro-blogs, send status messages, become friends with other registered users and join communities. Besides discussions on information and community pages, the forms of user-to-user interaction include commenting each other's updates and sending private messages and virtual hugs. While registering to the website, user can choose own screen name. Therefore, it is not required to interact by real name. The service can be used totally anonymously.

3.1 Site Survey

An online questionnaire consisting of eight open-ended questions was created in order to collect information on the users' experiences, perceptions and views of using Hoitonetti.fi. A total of 31 responses were received none of which were excluded from the analysis. Some results are gathered to Table 2. The most prevailing themes found in the analysis were 1) community, support and sharing and 2) information sourcing, medical professionals' participation and safety.

1) Community, Support and Sharing. A strikingly strong emphasis in the respondents' descriptions was on finding peer support and sharing experiences via the online social network service. They were highly valued and one of the key factors in the respondents' engagement in the service. Peer support and sharing of experiences hold an emotional aspect as well as a practical aspect.

2) Information Sourcing, Medical Professionals' Participation and Safety. Finding health related information was the single most often mentioned factor in the responses. Having a doctor answering questions was considered important and desirable service feature, but it was also considered to be an essential part in making the virtual environment feeling safe. Actually, for some of respondents, this was the reason why they initially decided to use Hoitonetti.fi. Therefore, based on our research, safety and trust are very important aspects in service experience. Note that this includes also moderation of discussions where any inappropriate communication is removed.

Table 2. Outlining survey results

Question related to	Most common codes (frequency of occurrence)
Reasons for registering to the service	<ol style="list-style-type: none"> 1. interest in the topics (2), presence of medical professionals (2), sharing own experiences and reading about other people's experiences (2), usefulness of the service (2) 2. positive atmosphere (1), finding people to talk to (1), passing the time (1), receiving support (1)
Reasons and purposes for using the service	<ol style="list-style-type: none"> 1. getting information (18) 2. sharing own experiences and reading about other people's experiences (8) 3. giving and/or receiving support and encouragement (7)
Best about the service	<ol style="list-style-type: none"> 1. giving and/or receiving support and encouragement (9) 2. friends and other users (5), positive and encouraging atmosphere (5) 3. clear and easy to use (4), hugs (4), presence of medical professionals (4)
Bad about the service	<ol style="list-style-type: none"> 1. too little or lack of information on some specific medical issues (3), too much of virtual hugging (3), usability problems (3) 2. lack of trust in the doctor's answers (2) 3. lack of information about the maintenance staff (1)
Reasons to keep using the service	<ol style="list-style-type: none"> 1. friends and other users (10) 2. giving and/or receiving support and encouragement (6), positive and encouraging atmosphere (6), 3. getting information (5)
Most useful features of the service	<ol style="list-style-type: none"> 1. information (11) 2. possibilities for discussion (8) 3. doctor's answers (4)
Problems in using the service	<ol style="list-style-type: none"> 1. usage was difficult in the beginning (7) 2. varying usability problems (3)
Requests for development	<ol style="list-style-type: none"> 1. more of medical professionals participation (4) 2. varying requests for certain medical information (3) 3. making things more clear (2)

4 Benchmarking

In the benchmarking four sites were compared of which summarizing results are extracted in Table 3. We focused on in getting overall impression of user experience in medical substance and in support of communication. Generally, all sites offer relatively high quality patient-to-patient peer support. We considered patient-to-patient interaction to include services such as adding friends, sharing messages, participating in health discussions in forums, sharing personality traits etc.

As far as expert advice was concerned, the widest variety of features was offered by MedHelp.org, where there are specialized forums and chat rooms for immediate patient-to-doctor interaction. Physicians too have own profiles revealing areas of specialization and some details of their medical careers too. Also, pictures, blog entries and previous posts of physicians were easy to access. This enabled patients to truly rely on the validity of answers that is, as we noticed in Hoitonetti.fi survey, generally highly appreciated.

Website environments differ quite a lot between the four sites. Medhelp.org offers the most complete environment and could easily compete with any other social networking website due to its seemingly high usability and variety of services offered. Patientslikeme.com follows Facebook-inspired interface with multiple services and its usage is quite straightforward especially for Facebook-users.

Table 3. Benchmarking of well-being sites

	Hoitonetti .fi	MedHelp .org	DailyStrength .org	Patientslikeme .com
<i>Target Age Group</i>	<i>elderly</i>	<i>any</i>	<i>any</i>	<i>any</i>
Patient-to-Patient Interaction				
-Discussion forums	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>
-Private/public messages	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>
-Add friends	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>
-Share health statistics	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>
-Other	<i>-Virtual Hugs</i>	<i>-iPhone Apps, -Log In with Facebook</i>	<i>-Virtual Hugs</i>	<i>-“Say Thanks” Option, -Simple Surveys to share personality traits</i>
Direct Expert Advice				
-Own space for Dr. consultations	<i>No</i>	<i>Yes</i>	<i>Yes</i>	<i>No</i>
-Proof of expertise	<i>-</i>	<i>Yes</i>	<i>Yes</i>	<i>-</i>
Anonymity				
-Nicknames	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>	<i>Yes</i>
-Real credentials	<i>No</i>	<i>Optional (Facebook login)</i>	<i>No</i>	<i>Optional</i>
Website Environment				
-Intuitive	<i>Fair</i>	<i>Yes</i>	<i>Fair</i>	<i>Yes</i>
-Friendly atmosphere	<i>Yes</i>	<i>Yes</i>	<i>Fair</i>	<i>Yes</i>
-Easy site-help	<i>No</i>	<i>Yes</i>	<i>No</i>	<i>Yes</i>
-Variety of services	<i>Fair</i>	<i>Great</i>	<i>Fair</i>	<i>Good</i>
Info services, education of patients				
	<i>-Information about symptoms, treatments, health values</i>	<i>-Latest Health News, - Research, -Doctor Blogs</i>	<i>-Health Blogs by Health Advisors</i>	<i>-User Data Statistics in Graph Form, -Disease Descriptions</i>

Hoitonetti.fi and Dailystrength.org rely on simpler interfaces and offer basic services. This might actually be quite good for some users groups, as elderly, because restricted palette of services can lower the barrier to start using the service and also to keep oneself on site because the required services are easy to access. Finally, some educational/learning environmental aspects are present in all the four sites. They support learning and information sharing by having blog entries authored by health professionals. There are also health news, disease descriptions and many kinds of information about treatments and medications. These components are especially important for medical industry to note, because these sites offer vivid customer interface to market and develop products, services and to foster new customer policies.

5 Conclusions

According to an American survey, online social networking sites like MySpace and Facebook are only rarely used for health queries and updates [9]. One of the reasons behind this could be that these sites have been developed to serve very general social networking purposes. Based on our research, we suggest that sites specifically dedicated to health issues really do serve the needs of the online patients and health care professionals much better. Tailored social media can work as a very informative tool in health-related issues and to provide group support.

We found out in our site survey that positive, open atmosphere is very important and anonymity is likely to have a major role in this. Anonymity is not only a factor in the face-to-face versus virtual discussions, but also a factor between a health specific versus general purpose online social networking service. Facebook, for instance, is a “nonymous” (as opposed to anonymous) online environment where online relationships are typically anchored to offline life since online partners can be identified and locate offline in many ways. Therefore users of Facebook tend to produce and maintain some online image of themselves that is socially desirable [10]. Users are therefore naturally very careful in managing their online identities. For example, discussing own illnesses may not be appropriate in Facebook. In the case of peer support and sharing personal experiences in health and wellbeing related issues, especially in the delicate ones, our research confirms that it is important to be able to openly expose own thoughts and feelings.

Secondly, a service dedicated specifically to health issues enhances ways of medical professionals to interact with patients and other professionals. Our findings support the notion that medical professionals need to participate to online social media and that there is a customer demand for their online presence. Their participation provides current medical information, for example in the form of answering questions and moderating online discussions. Doctors', nurses' and other medical staff's online role should be clearly distinguished from the regular users. There needs to be trust between the online patients and the online medical professionals. This can be achieved by assigning dedicated professional online profiles to the medical staff and by clearly stating their education, profession, specialties and affiliations. General purpose social networking sites do not necessarily enable maintaining specific professional online identities. On the same note, the medical staff's online participation needs to be consistent. This can be achieved for example by creating general guidelines of best practices for ways to work and interact

in the online world. Health portals could also better engage the users thus increasing their activity. Our results indicate that more activity is expected from site professionals that can be a factor in regular user site engagement too. One reason for loose professional engagement can be in lack of motivation. Therefore site should serve professionals better too. It should be possible for them to use the user data for developing their clinical practices for instance by summarizing site discussions or even enabling some data mining. Also, new earning models could be more actively developed using social media associated services. If links to medical records of Google Health would be provided, for example, potentials for new service mash-ups would radically increase, that would certainly benefit both regular users as well as professionals.

In many cases, doctors indeed need to have a face-to-face contact with the patients in order to be able to properly diagnose and advice them. Online social media can provide tools for this as well. For example, on HelloHealth.com instant messaging and video chats are utilized for online consultations. In the case where doctors are giving actual online consultations to the patients there is the need to identify both the doctor and the patient. This is in conflict with the importance of anonymity as discussed previously. Also in the case of utilizing online patient records the information is anchored outside of the site. Therefore, there is some need for identity / security rankings. They can then be agreed in site sign in or later when special communication / treatment requirements appear. Detailing this issue is among the important topics of future investigations.

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