Healthcare Social Networks for Patients with Cardiovascular Diseases and Recommendation Systems

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Abstract

Background: The theme of Online Social Networks Health - OHSN is becoming increasingly important in the lives of patients. According to the literature, these environments provide an opportunity for them to express their views and share experiences of health situations, allowing them to forge relationships to give or receive emotional support.

Objective: To evaluate the impact of OHSN Minha Saúde in the lives of patients with heart problems.

Methods: Descriptive study conducted with patients in the cardiology clinic of Hospital Universitário Antônio Pedro (HUAP/UFF) in the first half of 2013. The study included interviews with 91 outpatients with cardiovascular problems. Of these, 45 (49.45%) patients with a mean age of 56.0±12.0 met the inclusion criteria for the study and agreed to participate. A questionnaire was applied to determine the user profile. Usability and accessibility tests were conducted following the Web Content Accessibility Guidelines 2.0. A network called Minha Saúde (My Health) focused on patients with cardiovascular problems was developed. In this environment, the following modules were available: Social management, a Health Care Plan (HCP) and a Friendship Recommender module (FRS). The participants agreed to participate in this network. Once the study period was finished, new questionnaires to assess the satisfaction, characteristics and benefits of the social network were applied.

Results: The results indicate the presence of barriers and lack of familiarity with the participants’ social networks. The content generated reveals interesting aspects from a psycho-emotional point of view, including: providing emotional support, better adherence to treatment, sharing information on diseases and getting life experiences.

Conclusion: The impact of the network was positive, allowing the participants to connect with people with similar health conditions, despite the lack of familiarity with the virtual environment.

Keywords: Social networking; Cardiovascular diseases; Discussion forums; Social support

Introduction

Online Social Health Networks (OHSN) are virtual environments where patients can share/express experiences, questions, opinions, emotions and build relationships in order to give or receive support¹². In these environments, patients and families can discuss treatment options, exchange ideas, discuss the symptoms and/or monitor/manage their health status.

There is a growing interest among researchers in studying how these virtual environments affect the health conditions of patients. Several studies discussed the advantages of social networks³⁻⁵. Some examples of these environments are: Patientslikeme (http://www.patientslikeme.com), Dailystrength (http://www.dailystrength.org) and Inspire (https://www.inspire.com).
Patients with chronic diseases are often not able to leave their homes because of a disability, disease severity, lifestyle or simply advanced age. Virtual communities appear as an option for social integration, allowing to establish empathy ties among participants.

It is also known that, in the world, over 2 million new cases of heart diseases are diagnosed per year. Patients with cardiovascular problems using or joining online social networks can benefit from the positive experiences, giving and/or receiving emotional support and motivation to continue with treatment. This type of network also makes it possible to bring together users with similar health problems to create friendships.

To gather or bring together people with similar characteristics and interests on social networks, Friendship Recommender Systems (FRS) are commonly used. This article presents a summary of the work undertaken by the authors, whose purpose was to evaluate the impact of the OHSN Minha Saúde on the lives of patients with cardiovascular problems.

**Methods**

A network called Minha Saúde (My Health — https://www.minhasaude.org), focused on patients with cardiovascular problems, was developed. In this environment the following modules are available: Social Management, a Health Care Plan (HCP) and a Friendship Recommender module (FRS). It is worth noting that usability and accessibility initiatives (WAI - Web Accessibility Initiative) were used. Figure 1 shows the main features of the network Minha Saúde. Figure 2 shows a screenshot of Minha Saúde user’s page.

The module Social Management allows to manage the patients’ personal and clinical information supplied by different devices with an Internet connection. Patients may use anonymous identity and do different things.

The Health Care Plan (HCP) module was created to support the patient’s health monitoring and manages the following information: physiological data (blood pressure, temperature, weight, heart rate), daily activities (running, cycling, walking, swimming, dancing, studying), emotional states (good, excellent, bad, sad), health conditions or symptoms (fainting, feet swelling, headache, fatigue, tinnitus, tiredness) and shows statistics of all information collected in the module, illustrating the evolution of their health condition.

Finally, the Friendship Recommender System (FRS) module is based on a hybrid approach of Recommender Systems, considering the user-generated content (Content-based Recommendation) and their social relations (Content-plus-link). The purpose is to advise patients that have a similar set of characteristics such as monitoring of health state, medical condition and interests, as described in a previous study.

Interviews were conducted with 91 outpatients from the cardiology clinic of Hospital Universitário Antônio Pedro da Universidade Federal Fluminense (HUAP / UFF) with mean age 60.0±9.0 years, 57 (62.63%) of which were females. Among the respondents, 64 (70.32%) had a computer and, of this group, 54 (84.38%) had Internet access at home, but only 29 (45.31%) were familiar with computers. These data served as a filter to select volunteers for the study.

Thus, 45 (49.45%) patients with mean age 56.0±12, 70% females, with access to a computer or smartphone at home, decided to join the network Minha Saúde. To characterize their profile, the questionnaire User Profile was applied. Besides that, blood pressure assessment devices were provided to the participants to encourage them to monitor their health. Besides that, a study on accessibility and usability was carried out following the Web Content Accessibility Guidelines (WCAG 2.0) for the elderly in three well-known OHSNs and in the network Minha Saúde. This study included 9 elderly participants aged 65-75. It should be noted that during the period of the study, more than 300 people joined Minha Saúde, but only 15% were HUAP patients.

The project was submitted and approved by the Research Ethics Committee of HUAP / UFF under no. 126219 and all participants signed an Informed Consent Form according to Resolution CNS 466/12.

The work methodology involved two steps: data collection and FRS proposal validation.
Figure 1
Main features of the network Minha Saúde

Figure 2
Network Minha Saúde: user’s screen
Results

To validate the FRS proposal, experiments were carried out for six months. In this period, 872 messages were posted by the participants to exchange information and accounts of the disease. Of those, 595 (68.23%) were public and 277 (31.77%) were private messages. This revealed the patients’ fear of sharing health problems. Public messages and comments revealed complaints of health symptoms and concerns, but the responses included words of encouragement and motivation.

Regarding the HCP module, we found that the patients supplied physiological information almost daily, being limited to those who had medical devices at home. For this particular case, the next task is to automate the data collection process using non-intrusive and wireless devices. On the other hand, the number of patients who updated the HCP was: 27.0% on physiological control, 51.0% on physical activity and 49.0% on health situations.

During the study period, 1787 friendship recommendations were generated. The users created 258 (14.44%) friendship requests and 63.0% of them were successfully completed, i.e., the friendship request has been accepted. In addition, 11.97% of the recommendations were rejected, which may mean that the participants were not interested in meeting other patients with similar interests. Finally, 73.59% of the recommendations were ignored (Table 1).

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Results from the Recommendation System</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recommendation Status</strong></td>
<td><strong>Recommendations (n)</strong></td>
</tr>
<tr>
<td>Accepted</td>
<td>258</td>
</tr>
<tr>
<td>Rejected</td>
<td>214</td>
</tr>
<tr>
<td>Ignored</td>
<td>1315</td>
</tr>
<tr>
<td>Total</td>
<td>1787</td>
</tr>
</tbody>
</table>

The content generated by the participants referred to: publications (blogs, groups and news), comments and private messages.

New interviews were conducted with the participants. Data were collected from the questionnaire Characteristics and Benefits of joining *Minha Saúde*. The questionnaire consisted of 20 questions, adapted from Hess25.

- How did you find this Social Network?
- What did you learn from other Network members?
- What did you learn here that you could not learn anywhere else?
- Why did you decide to get involved in this Social Network? among other questions.

The following positive and negative points were found from the answers to the questionnaire (Chart 1):

<table>
<thead>
<tr>
<th>Chart 1</th>
<th>Positive and negative comments to the questionnaire Characteristics and Benefits of <em>Minha Saúde</em></th>
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<tbody>
<tr>
<td><strong>Positive points</strong></td>
<td><strong>Negative Points</strong></td>
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<tr>
<td>- They liked to talk to other people they did not know but who they knew were suffering from the same disease;</td>
<td>- They missed specialists (doctors and nurses);</td>
</tr>
<tr>
<td>- They liked the support among them in terms of sharing insights, everyday events and prayers;</td>
<td>- They complained about other patients’ frequency of participation;</td>
</tr>
<tr>
<td>- They liked to feel they were being heard;</td>
<td>- They complained about the lack of reply to private messages;</td>
</tr>
<tr>
<td>- They liked to do self-control in the Health Care Plan.</td>
<td>- They complained about the lack of options to configure the list of friendship recommendations;</td>
</tr>
<tr>
<td></td>
<td>- For the emotional submodule, they recommended more elements of choice (e.g.: excited, tired, amazed, bothered) to have more options to express how they are feeling.</td>
</tr>
</tbody>
</table>
Discussion

Initial results showed that there are barriers in the use of social networks, particularly among the elderly, as such patients have little experience in virtual environments. This presents a challenge to improve human-computer interaction and make it more accessible.

The HCP module proved to be a promising opportunity to encourage patients to self-care and monitoring of their health, but there were some limitations associated with age, level of education and the time spent to enter data in the system. A solution to the last problem would be the availability and use of intelligent wireless devices (e.g. wearable devices) for automatic data collection.

Both Minha Saúde and other OHSNs may represent quality information repositories, as these environments are suitable for using computational techniques and finding out patterns of behavior, while respecting the participants’ privacy and ensuring their anonymity. From the knowledge extracted, psychological changes can be perceived such as, for example, anxiety, stress or depression and proper help can be offered to them to complement the treatment they are following. However, these data should be validated by experts, such as psychologists, hence forming a more accurate opinion, as a going concern is the reliability of the information disclosed in these environments.

Conclusion

The impact of the network was positive, allowing the participants to connect with others of similar health status. In this sense, OHSNs can be important information resources for both health experts, family members, and for patients with chronic diseases that have limitations because of the disease.

Potential Conflicts of Interest
This study has no relevant conflicts of interest.

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References

5. Lima-Medina E.L. Rede social para pacientes com problemas cardíacos e sistemas de recomendação entre pacientes. [Dissertação de Mestrado]. Niterói: Instituto de Computação, Universidade Federal Fluminense; 2013.