

## Health Social Networks as Online Life Support Groups for Patients With Cardiovascular Diseases

Edhelmira Lima Medina<sup>1</sup>, Orlando Loques Filho<sup>1</sup>, Cláudio Tinoco Mesquita<sup>2</sup>

Instituto de Computação - Universidade Federal Fluminense<sup>1</sup>; Hospital Universitário Antônio Pedro - Universidade Federal Fluminense<sup>2</sup>, Niterói, RJ - Brasil

### Abstract

The number of patients who use the internet in search for information that might improve their health conditions has increased. Among them, those looking for virtual environments to share experiences, doubts, opinions, and emotions, and to foster relationships aimed at giving and getting support stand out. Therefore, there is an increasing need to assess how those environments can affect the patients' health.

This study was aimed at identifying scientific studies on the proliferation and impact of virtual communities, known as health social networks or online support groups, directed to cardiovascular diseases, which might be useful to patients with certain conditions, providing them with information and emotional support. A systematic review of the literature was conducted with articles published from 2007 to 2012, related to cardiovascular diseases and collected from the following databases: PubMed; Association for Computing Machinery (ACM); and Institute of Electrical and Electronics Engineers (IEEE). Four articles meeting the inclusion criteria were selected.

The results were interesting and relevant from the health viewpoint, identifying therapeutic benefits, such as provision of emotional support, greater compliance to treatment, and information sharing on diseases and on life experiences.

### Introduction

Every year, two million new individuals are diagnosed with cardiovascular disease worldwide<sup>1</sup>. Patients living with that chronic condition, in addition to careful monitoring of their health status, need emotional support to cope with problems hard to treat. In this context, health social networks<sup>2</sup> are virtual environments where online support groups constitute an alternative aimed at creating relationships between patients with similar interests (Figure 1).

### Keywords

Cardiovascular Diseases; Social Network; Discussion Forums; Information Services; Information Exchange.

#### Mailing Address: Edhelmira Lima Medina •

Av. Visconde do Rio Branco, 51, Centro. Postal Code 24020-000, Niterói, RJ - Brasil  
E-mail: edhyly@ic.uff.br, edhelime@gmail.com  
Manuscript received December 10, 2012; revised manuscript December 19, 2012; accepted March 14, 2013.

DOI: 10.5935/abc.20130161

According to the International Telecommunication Union (ITU)<sup>\*</sup>, currently more than one billion people use social networks worldwide. Brazil ranks fourth among countries with the greatest participation in those networks, according to the study by *comScore*<sup>\*\*</sup>. In the context of social networks, there are groups of patients, who look for specific environments to share experiences, doubts, opinions, and even emotions. Consequently, there is an urgent need to investigate how such environments influence health aspects. Aiming at filling that gap, we selected several studies<sup>3-5</sup> that highlight the following factors that can be used to identify the benefits originating from the participation in those groups: opportunity to improve quality of life; analysis of behavior and emotions; analysis of contents; and therapeutic support.

There is a great proliferation of health-oriented online support groups, and Brazil is one of the major users of social networks; however, studies on such groups are scarce. Technology dissemination and the increasing number of patients with chronic diseases have motivated the appearance of such groups in Brazil. Orkut, one of the major relationship sites in Brazil, has several communities of patients with a large number of users, such as "Hypertension/High Blood Pressure", with almost 3,000 participants, and "Diabetes", with over 20,000 participants. This shows the potential and demand for that type of online environment.

Thus, this article was mainly aimed at reporting the results of a literature review on the use of online support groups in therapeutic scenarios and at identifying their influences and impacts (positive or negative) on patients with cardiovascular disease.

### Methods

Because this study focus on cardiac disease, a systematic review of the literature was conducted with articles published from 2007 to 2012 and collected from the following databases: PubMed; (ACM)<sup>\*\*\*</sup> and (IEEE)<sup>\*\*\*\*</sup>. The search for scientific articles was restricted to those assessing the use of 'health social networks' by people with cardiovascular problems, but no result was obtained with the expression 'health social networks'. Thus, the keyword 'online support groups' was used.

<sup>\*</sup>ITU - International Telecommunication Union (report "Trends in Telecommunication Reform").

<sup>\*\*</sup>comScore - <http://www.comscore.com/> - specialized in measuring the digital world and digital marketing intelligence - accessed in October 2012.

<sup>\*\*\*</sup>ACM (Association for Computing Machinery).

<sup>\*\*\*\*</sup>IEEE (Institute of Electrical and Electronic Engineer) are relevant references in the areas related to Computing Science

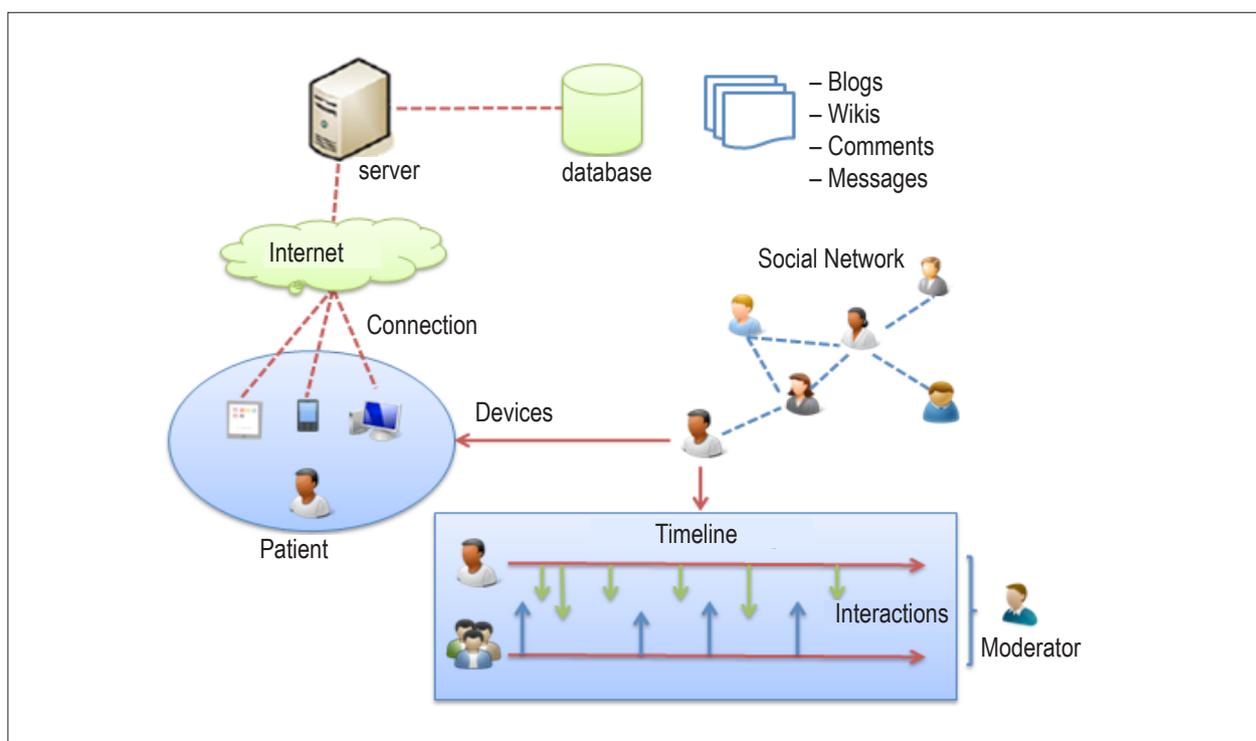


Figure 1 – General model of a social health network.<sup>4</sup>

The following terms were searched: social network; support groups; virtual communities; and online patient social network. They were searched isolated or associated with the following health descriptors that are part of the Medical Subject Headings (MeSH) vocabulary: heart; cardiac failure; cardiovascular disease; hypertension patients; and health. In the PubMed database, the search was performed solely with the terms 'online support groups' and 'health virtual communities', with no association with other descriptors, because PubMed is a database on life sciences and biomedical topics.

In IEEEExplore, the terms 'social network' and 'health online' were used for the search. In the ACM database, all descriptors were searched and associated so that the major term, 'online support groups', was combined with the following health descriptors: diseases; medicine; patients; heart; and health. The exclusion criteria comprised articles with incomplete information and articles not related to cardiovascular diseases.

## Results

Four articles, which met the inclusion criteria, were selected and are summarized in Table 1. Those articles provide information on online support groups, which is one of the variation labels of the health social network for patients with cardiovascular diseases. It is worth noting that no article written in Portuguese was identified for analysis. We describe each of those four articles.

### HeartNet website

A pioneer study on the impact of online communities for people with heart conditions was conducted in 2007 by Boniface et al<sup>6</sup>. The National Heart Foundation (WA division) and the Edith Cowan University developed the HeartNet website, a virtual community, in the format of a discussion forum, aimed at assessing whether those virtual environments influence or encourage the practice of empathy between their members.

The samples (approximately 600 members) consisted of individuals with the same disease, same education level, same social class, and similar ages. Based on those data, and using qualitative and social techniques (observation and analysis of interviews), the study identified six major characteristics detected from the communication between participants, specifically:

*Mutual support*: characterizes the interaction of receiving and exchanging information between patients and identifies a sense of empathy of the emotional type. This is based on the fact that some patients had provided information about their own experiences, which served as an answer to doubts or questions of new members. The latter were committed to motivate the former regarding their health care. The aim is to receive support during one's time of need from those whom one had supported before. According to the authors, the expressions "well done, hang in there or good luck" were frequent motivation comments. Find below a fragment of a comment from one patient reported in the HeartNet article<sup>6</sup>.

**Table 1 – Articles selected (PubMed, ACM and IEEE) on online support groups for patients with cardiovascular problems**

Article/Publishing vehicle	Objective	Results
Bonniface L, Green L., Finding a new kind of knowledge on the HeartNET website. Journal compilation. Health Info Libr J. 2007;24 Suppl. 1:67-76.	To assess the impact of an online community of patients with cardiovascular diseases regarding the development of empathy and reciprocity.	The participants' postings showed that the search for information led them to a place where they felt comfortable asking difficult questions and acquiring knowledge and experience from other members.
Lindsay S, Smith S, Bellaby P, Baker R. The health impact of an online heart disease support group: a comparison of moderated versus unmoderated. Health Educ Res. 2009;24(4):646-54.	To assess the influence of a controlled environment on changes in behavior and health management of patients.	Experiments conducted for nine months, divided into two phases, demonstrated that environments controlled by a moderator have greater influence on online support group participants (adoption of good health practices) as compared to uncontrolled ones.
Hess RF, Weinland JA, Beebe K. 'I am not alone': Survey of Women with Peripartum Cardiomyopathy and Their Participation in an Online Support Group. Comput Inform Nurs. 2010;28(4):215-21.	To determine the benefits of participation in an online support group based on a survey of active members.	According to a survey, interacting in a virtual community resulted in several benefits, mainly hope and motivation to continue treatment.
Hess RF, Weinland JA. The Life-Changing Impact of Peripartum Cardiomyopathy: An Analysis of Online Postings. MCN Am J Matern Child Nurs. 2012;37(4):241-6.	To describe the contents of postings made on a social network from the following viewpoints: physiological, psychological, sociocultural, spiritual and personal development.	The following postings were identified: discussion of symptoms; exchange of advice; interactions with health providers; uncertainty about subsequent pregnancies; expressions of spirituality; and possibility of recovery from heart disease.

*"...I know what you are going through and I promise you, every day is an improvement. Very gentle hugs to you:) Remember to push through the pain to breathe deeper. It's worth it."*

*Support seeking as self-help:* was identified in some messages of participants, which evidenced that, although no direct answers were given to one's posts, the comments usually ended with an acknowledgment. According to the authors, it might be that participants somehow felt that their words were being heard by others. Here is a fragment of Dixie's post:

*"... Thank you, I needed to get that out. Phew, a few more healing tears. All good stuff I suppose. Thanks guys it did help to write about all that."*

*Support giving as stored currency or debt paying:* this item is related to the culture of reciprocity. Reciprocity occurred when patients returned and engaged to the site right after concluding their treatments (having cured their diseases). This implies that patients become aware of the importance of their participations and assume a responsible attitude, repaying the support received inside the group. Here is a fragment of Margo's post:

*"... I might be fit and healthy now but in 5 years' time I might need that site again and if we don't support it and it's not there I'm back to square one."*

*Moderating information:* considered an important characteristic in a website where members post medical-related information. This is control of information by the group's moderator, essential in order to reduce health risks associated with misleading information or misinformed opinions, identified in the postings.

*The dilemma of sharing:* this characteristic is associated with two types of behavior detected in the group: the first contradictory feeling was willing to share one's own health problems and, at the same time, the desire for privacy (internal dialogue). Here is a fragment of Cherie's post:

*"... I of [have] got to the point of thinking well maybe I don't really want to talk about [my heart disease] ... 'cause it's you know ... I don't want to overly dwell on it and ... but I'm probably more motivated to help others who haven't gone through the process..."*

The second behavior relates to the patient's actions inside the group, as a supporter (ie, one's problem is smaller than those of the others), or as a receiver (ie, aimed at drawing as much attention as possible as a victim of disease). The latter was considered a negative online competition, because that behavior could discourage the participation of other members.

However, the analysis of all interactions could not conclude they were all beneficial for the participants. Situations implying the contrary were identified, being named by the authors as 'support as bad debt'.

*Support as bad debt:* related directly to the dissatisfaction caused by the lack of reciprocity in posts. This type of dissatisfaction made some patients feel frustrated or discouraged to continue participating in the group.

The analysis of those characteristics showed that the online support group influenced certain changes in the behavior of the patients. The fact that some of them took their time to answer questions, post messages and open discussions was considered an act of philanthropy. According to the book *"The Gift Economy"* by David Cheal, that act is known as "gift economy", a concept from social sciences referring to the 'culture of gift', and, in online support groups, the time dedicated is considered a gift given to people.

Finally, the analysis of interventions of the online support group members suggests a change in the quality of life of the patients/members regarding their emotions, because the interventions helped to reduce the patients/members' isolation, allowed their access to a condensed set of information, and provided mechanisms to allow them to profit from experiences about certain diseases, later resulting in social benefit. It is worth noting that those characteristics were subjectively assessed in a previous study<sup>7</sup> by the same author in 2006, half of them being recognized as therapeutic and beneficial to the patients' quality of life.

#### Moderated and unmoderated support group

In 2009, Lindsay et al<sup>8</sup> carried out a comparative study between a moderated online support group and an unmoderated online support group, both focusing patients with cardiovascular problems. The aim of that study was to assess the influence of a controlled environment on the health behavior of patients. The moderators (professionals in charge) encouraged the participation of patients, posting questions and topics of interest, aiming at facilitating the collaboration process, and, thus, fostering learning in an active and effective form. In addition, the moderators should monitor the discussions, aiming at creating a comfortable and friendly environment among participants.

That study sample comprised 108 patients from a deprived area of Greater Manchester in the United Kingdom. Each participant received a computer and a one-year free access to the Internet. The study lasted nine months, and the assessment was divided into two phases. The first phase (controlled) lasted six months and was followed up by a moderator involved in a strategic function, with the establishment of limits and objectives of discussion for the group. In that phase, the participants communicated in two ways: either direct access to the forum or sending individual messages, the communication between pairs being identified. The second phase (non-controlled) lasted the remaining three months, and the interventions of the members were frequently anonymous.

To identify the real situation of the participants of the online support group, a questionnaire was used in both phases. The questionnaire included the following topics: history of residence, work and job; health conditions; and health care insurance. To identify changes in behavior, tests were applied on a weekly basis until study completion. Such tests related to exercises serving as indicators in the analysis of results. The exercises considered the frequency of patient's participation/interaction in the group, smoking (number of cigarettes), diet control (measured by the consumption of food poor in fat), and number of health care visits.

The study showed that, during the first phase, there was higher participation in the support group, reflected in the tests. In the second phase, right after the moderator withdrew his support, no significant changes were observed, but it is worth noting that several members decided to interact anonymously (only private messages

sent to partners). Thus, the monitored or unmonitored environment did not affect the participants' behavior definitively.

It is worth noting that during the first phase (controlled phase), the indicators 'diet' and 'medical visits' decreased mildly, but the trend did not persist in the second phase, which might be interpreted as a benefit from participating in that type of online support group with a moderator.

Finally, the authors recognized that, in those online health communities, moderators play a key role in the communication process and in maintaining good health practices, thus reducing medical visits, from which the elderly could also benefit.

#### Peripartum Cardiomyopathy Group I

In 2010, Hess et al<sup>9</sup> published a study on the advantages and disadvantages of the participation of women diagnosed with peripartum cardiomyopathy (PPCM) in online support groups. After receiving ethical approval from the Human Research Committee of Malone University, Canton, Ohio, USA, those authors required access to the data (email and personal data) of participants of the online PPCM group to its moderator. An invitation was posted in the online group to participation in the project, to which 23 women answered positively. Each participant received the following three documents: survey on the characteristics of the online support group; patient's consent; and a demographic questionnaire.

The survey sent was an adaptation from the dissertation of Agnew LS, 2001 (title: "Características e benefícios de Grupos de Suporte Online para pacientes com Câncer"). The survey consisted of 20 open-ended questions focusing the following topics: how women found out the specific online group; the frequency of communication and participation in the group; how they interacted with other members; what was learned in the group; conversation topics; how the online group changed their lives; and if the group was considered part of their families. From their answers, the following could be identified: emotional reactions (sadness, fear, repulsiveness, and anger); sentimental reactions (pessimism, hope, and courage); psychological behaviors originating from the situation they were experiencing; and psychological disorders, such as depression and anxiety.

The participants have also highlighted some benefits, such as getting and sharing information on their disease, exchanging stories, being understood by other women, and gaining hope. The latter benefit was the most appealing, because participants stated that it was good to know there were people cheering for their health improvement. However, there was less consensus about the impact of group interaction on their quality of life.

The demographic questionnaire also revealed interesting information on social condition, marital status, educational level, and age group (19-34 years). The result of that questionnaire showed that participants easily sought/found information in the internet, which led them to participate in the group.

Finally, the analysis of the posts revealed the concern of the women about their diseases, death risk, and pregnancy. Successful stories of women who overcame their diseases and could have children were classified as hopeful and a positive experience for the group participants.

### Peripartum Cardiomyopathy Group II

In 2012, Hess et al<sup>10</sup> conducted another study with 156 patients with PPCM, who generated 247 posts in the PPCM group created in MySpace. The objective was to identify in the content posted the following Neuman Systems Model variables: physiological, psychological, sociocultural and spiritual aspects; and personal development.

In the postings and for each aspect, the following were identified: discussion of symptoms; exchange of advice; interactions with health providers; uncertainty about subsequent pregnancies; expressions of spirituality; and possibility of recovery from PPCM.

In addition, that last study assessed the relationship between patients and health professionals and the dissatisfactions caused by mistaken diagnoses or uncertainties, which caused stress to patients. In addition, nurse practice implications and the help they could provide to patients and their families as professional facilitators in an online group were analyzed.

## Discussion

Nowadays, patients and their families use the internet as a technological ally to understand the health-disease process, to get information about symptoms, medications, and therapeutic approaches, and to discuss common preoccupations with other patients. In Brazil, health themes are already present in virtual communities and have an increasing potential. However, most virtual environments neither are specialized in health themes nor propitiate an ideal environment for patients to establish relationships with people affected by the same health issue.

Several implications and potential benefits originating from the participation and interaction of patients in online support groups could be identified from the articles analyzed as follows: benefits from therapeutic treatments<sup>11-13</sup>; opportunity of a social life to patients who live in isolation; benefits resulting from the experiences of others; and, maybe the most important, the possibility to get emotional support. It is worth noting, in the groups, the presence of moderators (specialists), who help to take advantage of/control/assess the quality of the information that circulates. That type of participant can be a key resource in the process of interpretation and adaptation of the information created in those virtual environments.

However, analyzing and managing large amounts of data, distinguishing between reliable and unreliable sources, are complex tasks. In addition, they do not systematically identify behaviors<sup>13</sup> or psychological disorders of participants, and can cause omission or loss of

relevant information. In this context, intelligent programs are appropriate resources to extract knowledge by using techniques, such as data mining and analysis of feelings; the latter would be useful to identify hidden behaviors, such as anguish, sadness and anxiety, related to the patients' diseases.

Finally, the results about the impact of those virtual environments on health are promising because such virtual environments can act as additional therapies and contribute to reduce psychological disorders, such as anxiety, depression and stress. Nevertheless, the risks for emotionally sensitive patients that can result from communicating and exposing information in such environments should be more extensively analyzed and understood.

## Conclusions

Online support groups are a large repository of quality information related to general and specific diseases, such as cardiovascular diseases, and an appropriate environment to foster or create a support community between participants.

Based on the experiences of the cases studied and with the help of computing tools, a project focused on patients with heart failure was developed and is shown in Appendix I.

## Acknowledgements

The authors thank CAPES and FAPERJ for partially financing this study.

## Appendix I

Motivated by the promising advantages of online support groups, our research team along with Cardiology professionals of the Hospital Universitário Antonio Pedro (HUAP), from the city of Niterói, developed a social health network called "Minha Saúde" (my health, in Portuguese), aimed at people with heart failure. That social health network was created to provide patients and physicians with a virtual space to share information, treatments, and experiences, and, mainly, where they could give and receive support to cope with their health preoccupations.

That social health network, in addition to the typical modules to store and manage clinical profiles, chat, post, create groups and make acquaintance, counts on a 'care plan' module, through which patients connected to the internet (desktop, laptop, tablet, cell phone) can control their health by inputting physiological data (blood pressure, temperature, weight, heart rate), daily activities (running, cycling, walking), emotional states and current situations or symptoms (fainting, swollen feet, headache, tinnitus).

It is worth noting the possibility of collecting physiological data directly from medical devices by use of wireless communication. All data collected are stored in a repository

"Minha Saúde" social network available at <http://www.minhasaude.org>

and can be shared with the Intelligent Computing System of Home Health Support [in Portuguese, sistema Computacional Inteligente de Assistência Domiciliar à Saúde (SCIADS)]<sup>14</sup>. That enables the remote monitoring of the patients' health conditions, supporting the physician's decision making when necessary.

Finally, it is worth noting that the "Minha Saúde" project was approved by the Committee on Ethics and Research of the Universidade Federal Fluminense (protocol Nº 126.219). Its major objective is to assess the impact of social health networks on the behavior and quality of life of patients with heart failure at the HUAP.

### Author contributions

Conception and design of the research and Writing of the manuscript: Medina EL, Loques Filho OG, Mesquita CT; Acquisition of data and Analysis and interpretation of the data: Medina EL, Mesquita CT; Obtaining funding and

Critical revision of the manuscript for intellectual content: Loques Filho OG.

### Potential Conflict of Interest

No potential conflict of interest relevant to this article was reported.

### Sources of Funding

This study was partially funded by Fundação Carlos Chagas Filho de Amparo à Pesquisa do estado do Rio de Janeiro.

### Study Association

This article is part of the thesis of master submitted by Edhelmira Lima Medina from Universidade Federal Fluminense.

### References

- De Bacco MW, Sartori AP, Sant' Anna JR, Santos MF, Prates PR, Kalil RA, et al. Risk factors for hospital mortality in valve replacement with mechanical prosthesis. *Rev Bras Cir Cardiovasc.* 2009;24(3):334-40.
- Domingo MC. *Managing Healthcare Through Social Networks.* Teach University. IEEE Computer Society. 2010;43(7):20-5.
- Preece J. Empathic communities: balancing emotional and factual communication. *Interacting with Computers.* 1999;12:63-77
- Farnham SD, Cheng L, Stone L, Zaner-Godsey M, Hibbeln C. HutchWorld: clinical study of computer-mediated social support for cancer patients and their caregivers. *CHI.* 2002;1(1):375-82.
- Yu B. The emotional world of health online communities [poster]. In: Conference 2011; Seattle, WA, February 8-11. *Proc ACM Conf.* 2011;806-7.
- Bonniface L, Green L. Finding a new kind of knowledge on the HeartNET website. *Health Info Libr J.* 2007;24 Suppl 1:67-76.
- Bonniface LN, Green LR, Swanson MG. Communication on a health-related website offering therapeutic support. Phase 1 of the HeartNET website. *Australian Journal Communication.* 2006;33(2/3):89-108.
- Lindsay S, Smith S, Bellaby P, Baker R. The health impact of an online heart disease support group: a comparison of moderated versus unmoderated. *Health Educ Res.* 2009;24(4):646-54.
- Hess RF, Weinland JA, Beebe K. "I am not alone": a survey of women with peripartum cardiomyopathy and their participation in an online support group. *Comput Inform Nurs.* 2010;28(4):215-21.
- Hess RF, Weinland JA. The life-changing impact of peripartum cardiomyopathy: an analysis of online postings. *MCN Am J Matern Child Nurs.* 2012;37(4):241-6.
- Wicks P, Keininger DL, Massagli MP, de la Loge C, Brownstein C, Isojärvi J, et al. Perceived benefits of sharing health data between people with epilepsy on an online platform. *Epilepsy Behav.* 2012;23(1):16-23.
- Hwang KO, Ottenbacher AJ, Green AP, Cannon-Diehl MR, Richardson O, Bernstam EV, et al. Social support in an internet weight loss community. *Int J Med Inform.* 2010;79(1):5-13.
- De Araujo GD, Serqueria FS, Teixeira F, Mancini F, Lopes De Domenico EB, Guimaraes MP, et al. Análise de sentimentos sobre temas de saúde em mídia social. *J Health Inform.* 2012;4(3):95-9.
- Carvalho ST, Copetti A, Loques O. Um sistema computacional inteligente de assistência domiciliar a saúde. *J Health Inform.* 2011;3(2):51-7.