Psychiatric patients tracking through a private social network for relatives: development and pilot study

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Abstract: The treatment of psychiatric patients requires different health care from that of patients from other medical specialties. In particular, in the case of Department of Psychiatry from the Zamora Hospital (Spain), the period of time which patients require institutionalized care is a tiny part of their treatment. A large part of health care provided to the patient is aimed at his/her rehabilitation and social integration through day-care centres, supervised flats or activities. Conversely, several reports reveal that approximately 50% of Internet users use the network as a source of health information, which has led to the emergence of virtual communities where patients, relatives or health professionals share their knowledge concerning an illness, health problem or specific health condition. In this context, we have identified that the relatives have a lack of information regarding the daily activities of patients under psychiatric treatment. The social networks or the virtual communities regarding health problems do not provide a private space where relatives can follow the patient's progress, despite being in different places.

The goal of the study was to use technologies to develop a private social network for being used by severe mental patients (mainly schizophrenic patients). SocialNet is a pioneer social network in the health sector because it provides a social interaction context restricted to persons authorized by the patient or his/her legal guardian in such a way that they can track his/her daily activity. Each patient has a private area only accessible to authorized persons and their caregivers, where they

can share pictures, videos or texts regarding his/her progress. A preliminary study of usability of the system has been made for increasing the usefulness and usability of SocialNet.

SocialNet is the first system for promoting personal interactions among formal caregivers, family, close friends and patient, promoting the recovery of schizophrenic patients. Future studies should study the network's potential usefulness for improving the prognosis and recovery of schizophrenia.

Keywords: Social network, Mental health, Usability, Patient care system, Information system

Introduction

The Spanish National Health System is comprised of a set of health centres and hospitals aimed at providing specialized and continuous care to resident patients; this system's primary purpose is the medical diagnosis and/or treatment of patients, both inpatient and outpatient [1]. According to the Law of Cohesion and Quality of the National Health System (in Spanish, *Ley 16/2003 de cohesión y calidad del Sistema Nacional de Salud*), specialized health care also includes home hospitalization, palliative care, and mental health [2]. Regarding mental health, the psychiatric services are in charge of diagnosing and treating mental disorders and addictions of both inpatients and outpatients.

The treatment of severe mental patients differs substantially from other medical patients because they need a continuity of care in the community and the close support of the mental health network and their caregivers. Taking the Department of Psychiatry from the Zamora Hospital (Spain) as an example, the patients spend little time in institutionalized care in comparison to the total treatment time. Psychiatric hospitalization is ordered only in specific cases and not as a primary measure. Most of the mental health care is focused in the rehabilitation and social integration of the patients in the community. The patients spend time in day-care centres, supervised flats or sessions and activities with psychiatric support, depending on the type of mental disorder or addiction and the patient's progress. In the context of Department of Psychiatry from the Zamora Hospital, these types

of care are undertaken with the support of a non-profit private foundation, INTRAS. In this process for normalization, the support and links between the patients and their families and close friends are highly important [3].

However, it is within this context that we have identified that many relatives have a lack of information on the daily activities in which the psychiatric patients are involved when they are not hospitalized. The health centres have formal mechanisms to inform authorized persons about patient's treatment or hospitalization, but the rest of the time these people do not have information regarding the patient's progress. Patients can report directly to their relatives and people close about the sessions and activities carried out, but in a psychiatric context, this situation is rare and depends largely on the mental disorder or addiction suffered by the patient. Moreover, caring for a person with mental illness affects caregivers emotionally, financially, physically, and it elicits certain restrictions in their routine (daily hassles) [4], and the support family is a key point in the prognosis of disease [5].

Moreover, the heterogeneity of personal and social circumstances of each psychiatric patient, coupled with the workload of mental health professionals, make regular and direct communication with relatives and people close to each patient difficult. There is therefore an underlying need to improve communication with relatives and authorized persons in order to provide them with information regarding the patient's progress so as not to hinder the work of caregivers and, in turn, have a positive impact on the patient's improvement.

Currently, Internet provides access to several tools or services focused on connecting people. Nearly half of European people (48%) use social networks [6]. In Spain, this percentage is increased for those ages 18 to 55 up to 82%, according to "VI Study of Social Networks by IAB Spain" [7]. Alongside these figures, the report "Citizens facing e-health" of 2012 developed by the National Observatory for Telecommunications and Information Society (ONTSI) and Red.es reveals that 48.3% of Spanish Internet users use the network as a source of health information.

In recent years, user groups have emerged inside the most popular social networks, such as Facebook or Twitter, and virtual communities where patients, relatives and health care professionals share knowledge regarding illness, health problems or specific health conditions [8]. Numerous studies have analysed the

use and impact of social media in medicine and health care [9-12]. However, there are no tools to connect relatives with patients as a way to support their recovery. The social networks related to the health sector are focused on connecting people who are in similar situations but do not provide a private and secure space where people who have a direct relationship with the patient may partake in its improvement despite being in different geographical locations [13].

The private social network for monitoring daily progress of schizophrenic patients by their relatives, SocialNet, is a pioneer social network in the health field. SocialNet is not a common social network because it enables the definition of a social space that is completely private and secure for each patient and people who interact with him/her, either from their relatives, friends, or caregivers. Although existing social networks, such as Twitter or Facebook, can provide private spaces to the patient and their relatives, the caregivers do not have control of the information; indeed, the information published on these types of networks can be accessible by their owners and, in certain cases, by other companies. Moreover, the focus of the interaction in SocialNet is the schizophrenic patient, all the publications are related with him/her, while in other social networks, you cannot control this.

The main aim of SocialNet is to provide a social interaction context restricted to relatives and authorized persons by the patient or his/her legal guardian such that they can track the daily progress of the patient, promoting the recovery of the schizophrenic patients. Each patient has a private area only accessible to authorized persons and their caregivers, where they can share pictures, videos or texts about his/her progress.

This paper describes the functional prototype of this private social network, which it has been developed by the GRIAL Research Group from the University of Salamanca and INTRAS Foundation (http://psiquiatria.grial.eu/en).

The paper has been divided into four parts. The first part gives a description of the functional prototype, SocialNet, and the methodology used to develop it. The second part describes the methodology used to carry out the first pilot experiences as part of the usability study. Finally, the third and fourth parts provide the discussion and primary conclusions of this research.

Social Network

Methodology

The definition and development of the private social network for relatives combines two agile methods. On the one hand, Scrum [14] describes a methodology based on prioritized tasks depending on the benefit they provide to the final user of the product. This method is an agile development framework that provides the elements needed to increment the productivity of a development team based on an iterative and incremental software creation cycle [15]. On the other hand, Kanban [16] provides an approach to introducing change to an existing software development lifecycle or project management methodology. This method uses a visual control mechanism to track work as it flows through the various stages of the value stream [17].

In this case, the choice of two agile development methodologies has allowed the evolution of the prototype based on the results obtained from the different pilot phases. Moreover, the definition of the processes that take place inside the SocialNet have been modelled with Business Processes Model and Notation (BPMN).

Communication flows

According to Siemens, social networks function on the simple principle that people, groups, systems, nodes, and entities can be connected to create an integrated whole [18]. The definition and development of a social network should include the definition of how communication flows support the connection between these elements. In particular, the definition of SocialNet includes a set of communication flows to support the interaction between the different stakeholders [19]. The description of these interaction processes has been undertaken with the support of BPMN diagrams. The private social network has been built based on the metaphor of the wall as a central element of the interaction between relatives and caregivers of a patient. SocialNet is composed of a set of patients' walls that behave as a private social network itself, meaning that the patient, their relatives and authorized persons perceive SocialNet as an area of exclusive access to its social core.

The stored data within the private social network has a sensitive nature because they reveal personal information about patients and their relationship with others. The only part visible to any user is the access form to the system. The patients' data and the information regarding their evolution are not accessible to users who have not logged in to the system and do not have the proper role in the patient's wall. The privacy of each patient and their relatives inside the social network is ensured through a clear definition of the hierarchy of user roles combined with a careful definition of permissions. There are two user types: anonymous, who only have access to the login page; and logged users, who can be patients, relatives, caregivers, caregivers' supervisors, managers, or administrator users. The roles follow a hierarchy such that the passive user is the one that has fewer permissions and the administrator user has all permissions.

Regarding the security issues to deny access to searchers and malicious users to the information inside the social network [20], the selected technological platform provides the required security measures [21].

The interaction is developed around the patient's wall. The caregivers of patients are part of the wall and can publish information that they consider appropriate through using pictures, videos and texts, enriched with a set of metadata, leaving aside the sensitive topics, such as hospitalization or relapse, which must be notified following the established protocols by the Psychiatric Department. The information appears on the wall of the patient ordered chronologically and contextualized with the meta-information provided.

Relatives and authorized persons can play two roles within SocialNet, depending on the permissions granted them by the caregivers when they provide them with access to the wall. Initially, these people may have a role of passive user such they only can see the information published by others on the patient's wall. Conversely, the caregiver can provide them the role of active user, meaning that they could perform different tasks on patient's wall, such as publishing an activity, writing comments, or rating a publication. Fig. 1 shows the whole processes associated to a relative or patient with an active role in the system.
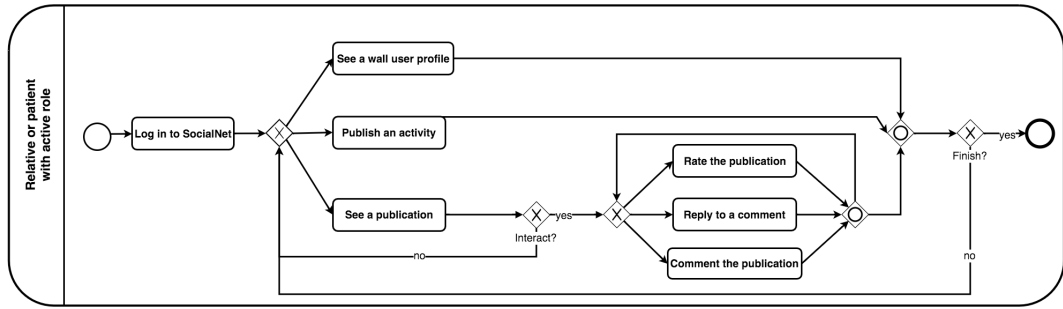
Fig. 1 Processes associated to relatives or patients with an active role on SocialNet

The patient, besides being represented within his/her private social network by the wall, also exist within the system as a user. Caregivers control the access to his/her wall. The patient is always aware of the existence of SocialNet because he/she must provide explicit consent to create his/her wall, although he/she may have no access to the published information because it depends on his/her psychological state.

In addition to the roles described above, there is another set of users whose interaction with the system is focused on ensuring the proper use of the social environment. The caregiver's supervisor is responsible for providing access to the caregivers with whom he/she coordinates and the patients appointed to those caregivers; thus, this role manages the caregiver-patient relationships and also has access to all the walls of their patients. Fig. 2 describes the process to create a new wall. This involves two types of users: the caregiver's supervisor and the caregiver in charge of the patient.

Finally, the manager role is set up to just a few users, due to its being an administration role that has access to all walls and all users.
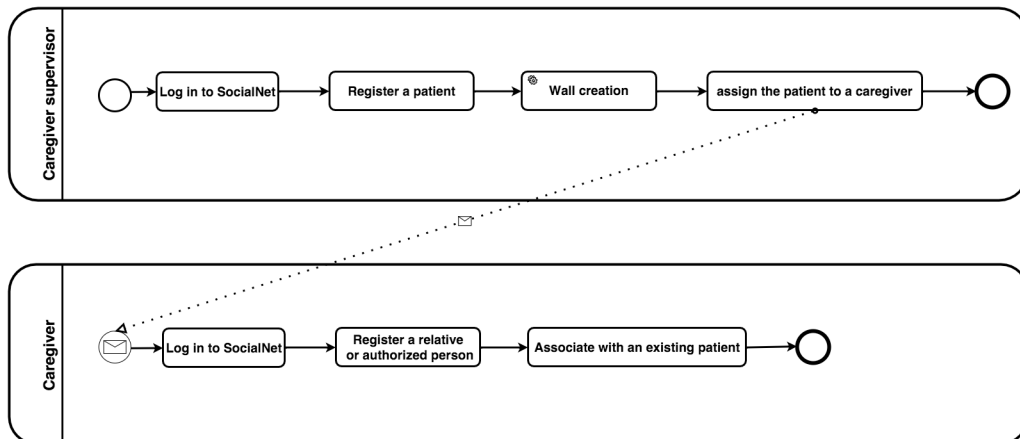

Fig. 2 Process to create a private and secure space for a patient, their relatives and authorized persons

Technology base

The functional prototype of SocialNet is based on Drupal (http://drupal.org), a Content Management System (CMS) that allows extending the functionality of its core with a huge amount of modules developed by an active and open community. In the case of SocialNet, the most important extensions installed to build it are

- Organic Groups (OG) module to build the patients' walls. This module has been customized in order to ensure the encapsulation of the data and the proper behaviour for each user role.
- Plupload module to integrate Plupload tool (http://www.plupload.com) with Drupal in order to improve the user experience when publishing multimedia content on the patient's wall.
- Media and Media element modules to provide HTML5 video and audio elements using Mediaelement.js for HTML4 browsers.
- Wysiwyg and CKEditor library (http://ckeditor.com) to provide a friendly editor to the end users. The number of editor options has been reduced in order to avoid confusing the final user.
- Views and Panels modules to control and configure the structure of the interface and the visualization of all the information shown in the social network.
- Rules and Flag modules to build the notifications system in order to send to managers and caregivers statistical indicators about each patient's wall. Moreover, the relatives receive notification when some interaction happens inside their patient's wall.
- SMTP module to use the mail server located in the infrastructure layer of the knowledge management ecosystem.
- Internationalization, Localization Update and Language Switcher Dropdown modules to provide multilingual support because must be able to adapt to any context independently of the language used by the stakeholders.
- Bootstrap module. The user interface has been based on Bootstrap, a powerful mobile first front-end framework for development responsive websites (http://getbootstrap.com).

Furthermore, two modules have been developed. The first module calculates the statistical indicators of each patient's wall in order to send them automatically to the concerned stakeholders through the notifications system provided by Drupal. The second module is centred on automate several workflows related to the creation of walls and the access of the patients and relatives to them.

Finally, a Drupal theme has been designed and developed in order to provide a simple and responsive interface that is able to adapt to any device.

Pilot experience: usability study

The first stage of the usability study of SocialNet application has been concluded. The usability study was divided in two stages: the first, which has just arrived at an end, consisted of the implementation of an expert-based usability inspection method (heuristic evaluation); the second one consists of the use of an empirical method (users' test) and is currently in course (Fig. 3).

The heuristic set used in the first stage was the one proposed by Nielsen [22]: systems' visibility; users language usage; users control and freedom; standard and consistent use of the systems' elements; mistakes prevention; minimization of the users memory load; usage flexibility and efficiency; minimalist design and aesthetics; help in the identification and recovery of mistakes and help and documentation. The usability expert provided a report of the retrieved mistakes and selected the heuristic that best corresponded to each error in order of applicability. The most unfulfilled heuristics were users' control and freedom and minimalist design and aesthetics. This design implied a qualitative methodology. We involved three family members, three formal caregivers, and three mental health workers, using the system in a controlled way. Next, the usability expert observed all features of interaction between users and system. The report made by the usability expert was based on the suggestions of experimental users and own observational conclusions.

A redesign of SocialNet interface was carried out based on the analyses of the obtained data before starting the second stage of the usability study, which consists on a user's test with the participation of five patients, five caregivers, five professionals, and five relatives. The second stage will make it possible to improve the usability study by contrasting to which extent those usability issues

identified by the experts in the first stage have a correspondence with real usability problems experienced by end users.
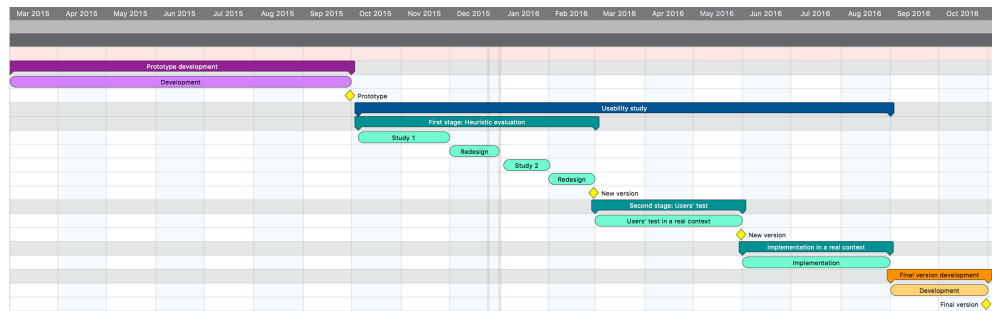

Fig. 3 Gantt chart which describes the complete process of the development and pilot study

Discussion

Using social media can be highly useful for promoting interpersonal interaction between formal and informal cares and patients and support of people suffering schizophrenia [13]. Moreover, individuals with severe mental illness can give and receive peer support using social media [23]

We have to consider that family involvement is highly important in the recovery of schizophrenic patients [24]; therefore, a system such as SocialNet can be a relevant tool for recovery of schizophrenia [25].

Even though SocialNet has been developed in a psychiatric context, it can be used in other contexts, such as nursing homes. These types of places, depending on the situation of the internee, organize different activities in addition to meeting the medical needs. Relatives and authorized persons cannot always visit their friend or family member with the desired frequency, or during the visit, the internee does not always have the ability to communicate his/her daily activities. In these cases, the private social network for relatives allows relatives and authorized persons the ability to follow closely the internee day-by-day.

Moreover, caregivers can access the tool at any time, from any device with Internet access, without having to go to the health centres because often they spend much time outside its workplace making visits to supervised flats or participating in specific activities with patients. Also, the relatives and authorized persons can check the patient's progress in real time from any type of device with Internet access. Considering that family caregivers play an important role in the quality of life and recovery of schizophrenic patients, SocialNet could help for coping of caregivers for family members with schizophrenia and improve the

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prognosis of schizophrenia [26]. Moreover, the network will be able to contribute to reduction of stigma [27].

Nevertheless, we also have to take care about the risks of using the social media [28] because of this we have focused our work in the privacy of SocialNet. Another barrier is the attitude and acceptability of professionals. In general terms, there appear to be differences in practices and attitudes toward using social media in clinical practices [29]. Because of this, usability studies as presented in this paper are very necessary before using in clinical settings. These studies should be made in two stages: heuristic for making easier the acceptability of the tool by the professionals, and user´s test for facilitating the use and desirability of SocialNet by the final users: in this case, schizophrenia patients and their relatives. Besides, this heuristic usability study is valid for all uses of the tool. However the users test should be made for the different target groups. The next stage will be a users test for schizophrenic patients but it will be necessary to do that for aging/dementia people, and other chronic diseases.

Finally, we have to consider the preferences of the patients and families [30]; therefore, the second stage of the usability study will provide an important feedback to improve the functional prototype and obtain a final product to deploy in real contexts.

Conclusions

SocialNet provides a simple way to establish communication between people with different clinical conditions living alone or in remote areas and their relatives, friends and caregivers. After a usability study, this tool can be used in clinical settings for promoting the well-being and recovery of severe mental patients and being a component of the comprehensive approach of the schizophrenia.

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