

SELF SUPPORTIVE VIRTUAL COMMUNITIES IN THE SERVICE OF PATIENTS

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ABSTRACT

Learning Communities in healthcare is one approach in supporting practitioners and nurses to improve skills and knowledge and consequently support patients more efficiently. Web based learning communities provide additional capabilities such as global distribution of participants and asynchronous participation. The learning process in such communities is flexible and distributed, but still uni-directional: knowledge is transferred from professors to students of medicine, medical advices and support is directed from care providers to patients. In virtual Communities of Practice, apprentices ask questions and experts respond. Knowledge is created and distributed in a collaborative process, since all participants contribute their experience. In healthcare communities, especially in patient-centered ones, effort is spend on informing, training and supporting patients to become self-managed. Families, doctors, nurses inside the community target their contribution towards the patient. However, the ability of patients to help other patients, through their experiences, is neglected. Especially in the case of chronicle diseases, or psychological problems, the support of co-patients or ex-patients is valuable. This work presents a new flavor of web based communities- we call them “self-supportive communities”- which combines the merits of “communities of practice” and “learning communities”, engulfs care-providers, care-givers and care-consumers and promotes the role of patients in the community activities. Inside the community borders, patients, their family members, their doctors and nurses are able to co-operate: doctors disseminate scientific knowledge, nurses provide practical advices, family members exchange empirical knowledge and finally patients provide useful advices and support to their co-patients. The paper discusses the dimensions of the self-supportive community and illustrates the main issues for the transition to the new type of community.

KEYWORDS

Communities of practice in healthcare, learning communities, group therapy, chronicle diseases, self-supportive communities

1 INTRODUCTION

There exist several ways of interaction between healthcare practitioners and patients. In the case of a medical incident, patients receive medical treatment from doctors and nurses while at hospital and post-treatment support at home by family members and friends. In medical inquiries patients search for information and advices on the web; their main supporters are doctors and medical institutes that provide official and valid guidance. For patients with chronicle diseases or psychological problems the family members or professional care-providers keep in contact with the patient and provide permanent support. In most cases the healthcare issue turns to be a transfer of knowledge, care and services from healthcare professionals to the patients.

In this work we assume three distinct roles in healthcare, namely the care providers (or care professionals), the care givers (or volunteers) and the care consumers. *Care providers* comprise doctors and nurses, who treat and support patients as part of their work. The group is extended with researchers and scientists that produce and convey scientific knowledge. They provide guidance, medical advices and information either in person or through the web. *Care givers* comprise the friends or family of the patient who voluntarily support patients. They ask for medical advice and information regarding the problems faced by their relatives and in several cases they are more active than the real patients. *Care consumers* or “receivers” are the patients themselves. They need medical help and ask for it either directly or indirectly.

The above structure contains huge potentials which can be exploited in favour of the patients and the whole healthcare community. To give an example, we assume a diabetic who is seeking information on diabetes care. The patient visits web-sites and libraries and collects information, visits doctors and receives

useful advices and in general spends money and time in order to get informed. In the same time she hears about diets and treatments from friends or relatives that are not patients, but have their opinions on the subject. As a result, the patient gets bombarded with information, and most important, this information is not validated and organized for further reference. The same holds with doctors or nurses who are constantly informed on the scientific and industrial advances, on new products, treatments and devices, by spending hours on reading and attending seminars and courses.

Patients' needs vary over time, in the course of their disease experience: they want information in the first phase, when they learn about their disease and the treatment alternatives; later, they are more interested in compassion and request for emotional support. Several categories of patients need special and continuous care, especially patients with uncured diseases. Such patients, apart from medical treatment have need of psychological support all the time. In the same time, they prefer to stay at home and to receive care from their own people instead of been treated by nurses and doctors in a hospital. It is also important for patients to discuss their issues with other patients and receive useful advices and support.

It is obvious from the previous examples, that a lot of effort can be saved if existing knowledge is recorded, collected and organized and if all healthcare participants work in common, instead of re-inventing the wheel every time (Pincho et al, 2005).

The notion behind this article is that group work is better than any individual attempt. Inside a healthcare community: researchers and scientists will be able to disseminate their findings and guide industry and practitioners in favour of patients, care givers will exchange information and useful hints concerning patient caring and support, patients could psychologically support other patients.

In order to build a successful community that combines the efforts of care givers, care providers and patients for the welfare of the latter we should stand on a well defined framework, which comprises of architectures, structures and rules. Then we should build and deploy services that will facilitate co-operation and communication of participants. The basis for the community we discuss in this paper is a combination of learning communities and communities of practice. Upon this basis, we define the types of our community members, and explain the requirements, the privileges and gains of each role.

The following section (section 2) presents related approaches on patient-centered (Wagner et al 2005) communities and gives an overview of the two communities that will serve as our basis. Section 3, presents the different types of participants in a healthcare community, stresses the particular needs of each group of users and lists the services that promote interaction between community members. Section 4, details on the structure of the community, illustrates the actions toward a successful community and summarizes the merits from the community approach. Finally, section 5 concludes with the expected outcomes for care providers, care givers and mainly for patients.

2 RELATED WEB COMMUNITIES

When people seek for medical advice they visit doctors and arrange check-ups in hospitals. However, when they seek for medical information they tend to contact experts, or people they trust and in many cases they consult books or the internet. Often they want to share their problems and findings with other patients. To the main core of patients a much larger 'zone of influence', comprising their friends, family members, co-workers and neighbors should be added. As stated by Preece (Preece 2000):

"E-Health offers patients databases of medical information, but patients want to hear about treatments and how to deal with problems from other patients"

It is undeniable that Healthcare is a highly social activity that should be carried in common and not individually. The aim of healthcare communities should be both educational (or informative) and supportive.

Existing community approaches in healthcare, target either the healthcare professional or the patient. In the case of healthcare communities for patients, approaches are in two directions: a) communities which are built and supported by healthcare organizations and operate in favour of the patients (Arnold et al, 2004), (Butler et al 2000) and b) peer to peer self help groups, in which anyone, including patients, can help patients (Eysenbach et al 2004). Patients with chronicle diseases, addictions or psychological problems are the main participants of these communities (Winkelman & Choo 2003), (Varlamis & Apostolakis, 2006). The main reason for this is that communities require continuous participation from their members which is in accordance with patients' continuous needs. Communities which are established and moderated by healthcare

organizations and professionals have increased operational and management cost, and at the end of the day turn to be useful sources of medical information but fail to tackle individual patient problems and become patient unfriendly. Self help groups might be beneficial interventions, since they promote the role of patients, however they hide several dangers that should be considered (Alemi et al 1996).

Two community types that have been founded on the base of education and technical support are the learning communities and the communities of practice respectively. With the advent of internet, both community types have been renovated, enhanced with new types of services and increased in participation. Both community types have their web counterpart which exposes permanence in time and world-wide coverage in space. Our approach aims to combine the merits of the two community structures, overcome the aforementioned problems of approaches in healthcare communities, and increase interaction among patients, healthcare professionals, scientists and organizations. First, we provide a synopsis of the two community structures that will be employed.

2.1 Communities of practice

The term Community of Practice (CoP) (Lave & Wenger, 1991), describes groups of people with common interests, who mainly want to share practical knowledge and learn but is not restricted to this. Examples included butchers, tailors etc that joined groups in order to learn the “secrets of work” from the old-timers. However, people that needed social and psychological support, such as non-drinking alcoholics, created communities of practice, in order to help other people with advices and discussion. CoPs also apply to modern organizational structures in order to provide the learning channels between and outside an organization. The model allows knowledge to be circulated among all interrelated CoPs and increases benefit for organizations and individuals: they facilitate virtual team working, organizational knowledge sharing and adoption of novelties in the business environment (Kimble & Li, 2005).

The electronic networks of practice (ENOPs) allow members from different organizations to virtually participate in the community activities, even if they do not belong to the same organization. The coordination is performed by third parties such as professional associations and the communication is supported by as newsletters or Web sites.

2.2 Learning communities

Web based learning communities are recent additions to the educational landscape. The aim of such communities is to collaboratively improve knowledge in the field of expertise of the community. In the case of open learning communities everyone is allowed to participate and either offer or consume the collective knowledge (Kommers et al 2003). As a result, the members of a web based learning community vary from the non-experienced learner to the subject matter expert inside and outside of the community.

The core activity of virtual learning communities is writing. People exchange messages with a shared goal of building understanding produce an information base which is available to future members of the community. Learning is no longer a transmission of knowledge from a teacher to a student, but a process of knowledge construction in which each participant contributes and benefits from the ideas shared by the group. Useful knowledge sources comprise: questionnaires addressed to patients and their families, personal reflections of patients, discussion forum logs, virtual interviews of doctors and experts etc.

Another aim of learning communities is to replace Internet as an information source for patients. A common scenario wants patients to spend hours in collecting information from the internet before visiting their doctors (Ferguson, 2002). Such information can be misleading and confusing and is better to be filtered before visiting the doctor). Such filtering can be performed inside a learning community (Moon 2005).

3 A COMMUNITY FOR THE HEALTHCARE

In order to better understand the structure and operation of a virtual community for healthcare we need to distinguish among the various member types it encompasses. The next step is to define the main roles, the associated privileges and responsibilities and the foreseen interactions inside the community. The last step is to define the community components, the services that will be offered, the control mechanisms and other

issues that will guarantee a successful operation of the community. In the following paragraphs we depict the dimensions of a self-supportive community for healthcare.

3.1 Healthcare community members

A virtual community allows people from different origins to interact. Groups inside the community are formed based on common needs and interests. The needs of each group are different and sometimes contradictory. It is necessary for the community to allow members to communicate their similarities and join their forces, whilst protecting their individuality. A healthcare community can attract scientists and researchers, doctors and nurses, patients and people with personal interests in medicine and healthcare, companies. More specifically:

- Scientists and researchers join the community in order to exchange knowledge and promote their science. They communicate with patients, analyze surveys' results and population statistics and get useful feedback on patient needs, on medical issues that arise etc. They co-operate with other scientists for their experiments and disseminate their findings to companies and individuals. They also give useful directions to medical associations concerning public health.
- Medical associations provide the professionals with guidelines on patient treatment and inform patients on topics such as prevention, self protection etc. They issue specifications for companies that produce medical devices and medications.
- Healthcare companies advertise their products (devices, therapies, medical applications) to doctors, nurses and patients.
- Healthcare practitioners get informed on new findings, emerging therapies and medical approaches and sometimes get online training. In parallel, they guide nurses and patients' families on patient-care and provide researchers and associations with useful feedback on emerging patient needs.
- Patients are *receivers* of support, treatment, care, information and advertisement from all other participants. They contribute to the community, as end users of the community outcomes and as specimens of surveys.

The different participants of the Healthcare community and their interactions are depicted in Figure 1. A strongly connected, yet not complete, mesh is formed. Some edges are missing in order to protect the patients from the abundance of information and services and guarantee that the correct information reaches the correct group of people. However, this structure has two main flaws: a) it is very complicated and sometimes hinders the dissemination of knowledge inside the community and b) it considers patients as consumers of medical services and information and does not exploit their dynamics.

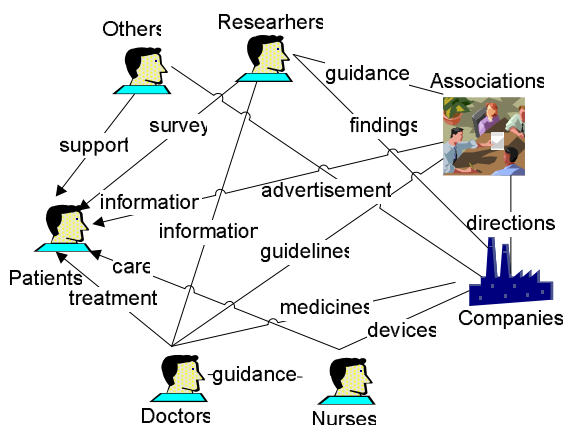


Figure 1 Healthcare community mesh

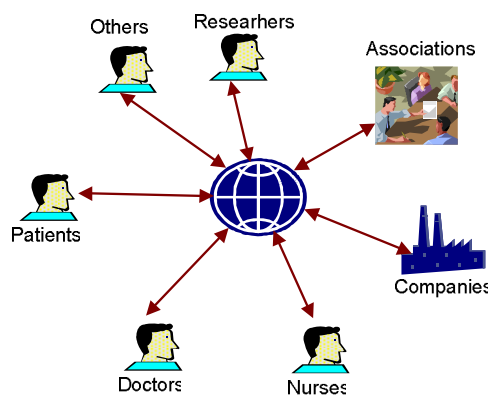


Figure 2 Virtual healthcare community

In a virtual healthcare community, all participants are able to contribute and communicate with others, and this became feasible with the advent of web. In a web based community, patients are able to directly contact associations, companies, researchers and practitioners, state their necessities, ask for advice and find a remedy to their issues. Healthcare associations, companies and researchers are able to monitor the status and trends of the community listen to the “patients’ pulse” and correspond immediately. The structure of a virtual community (Figure 2) is simpler yet more flexible. However additional effort is required for the

smooth operation of a virtual community. Each participant should be certified for the quality of information or services he/she offers and should be assigned a specific role inside the community in order to increase quality of content and services and guarantee the effectiveness of the community approach. In the following section we summarize on the internals of a community for the healthcare.

3.2 Community roles and responsibilities

A vital step in the design of a community is the definition of its borders. This includes the gathering of the initial members, the definition of potential members' profiles and the identification of roles. The nucleus of a community for healthcare support comprises the doctors and scientists who share their knowledge and offer support. The community can be expanded to include patients who need special care and their care givers. People who are simply interested but are not related to the problem treated by the community can be left outside of the community borders, or have limited access to the community services. Patients with long lasting diseases, addicts, and people with mental disorders are among those who can be benefited from a virtual community of healthcare support. These patients participate in discussing groups and share their needs and problems with other patients and doctors.

The most important role in this community refers to the coordination of discussion groups and is handled by the *group moderators*. Another role which contributes to the building of trust inside the community is the administration of user profiles. The *profile moderators* check members' credentials and guarantee the truthfulness of their profile. They protect community from fraud and guide new members to the appropriate discussion and support groups based on their profiles. They guarantee the patients identity, distinguish care givers from professionals and in the same time protect patients' privacy by assigning them a virtual identity. In order to guarantee the quality of information provided to the community members, an additional moderator role: the *content moderator*, who is made responsible for reviewing and filtering all published material and acts as a liaison between information providers (experts, doctors, etc) and consumers (patients).

The different roles and the tasks carried by each one of them are displayed in Figure 3. In the same figure the two valuable community sources; the Knowledge and Profile base offer multilevel access to members according to their role. Only registered community members are able to communicate and collaborate.

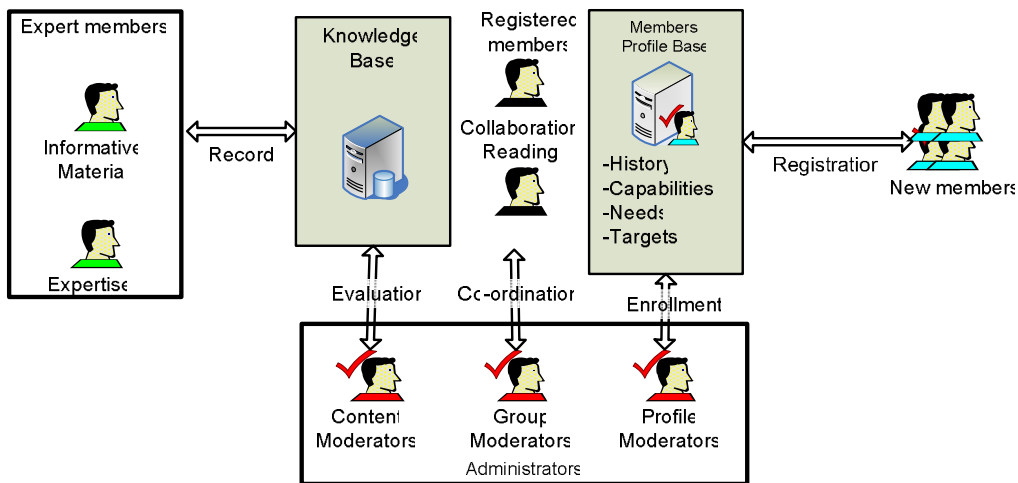


Figure 3 Community roles and responsibilities

3.3 Services

The services provided to the members of the community must be carefully designed in order to be as useful to patients as possible. Extra care should be taken to guarantee accessibility of content and services and to avoid member exclusion (Flood & O' Reily, 2006).

The most widely used service is the distribution of *informative content* (i.e. medical documents, surveys, medical advices, news etc.). Content should be easily located and retrieved from patients. This subsumes that content should be available in various formats, so that it can be accessible to people with disabilities (deaf, blind etc). In order to facilitate new users, content can be forwarded to patients via e-mail to mailing lists. For

frequent users, content can also be published in a web portal. It should be organized into meaningful categories and a search service should allow retrieval of the appropriate information.

Interaction between community members is increased with online and offline discussions (Rada, 2005). **Discussions** can be asynchronous (by posting questions and answers) or synchronous (in a discussion *forum* or in private chat-rooms). The aim of discussions is bi-fold: to support patients and their families and to allow experts to exchange knowledge. Debates are more meaningful, when their topics are predefined and organized. The discussions in the community forums should be moderated by expert users that filter information when requested, facilitate members or consult members about the forum rules. The presence of professionals (doctors, nurses etc) in a forum adds to its value and increases participation.

Education is another useful service offered in the virtual community. Education and training is addressed to doctors, nurses and directors and covers several healthcare issues such as: health legislation, information technology and telecommunications, patients' psychology, patients' medical record, medical theory and ethics, patients' care and recovery, operational and financial issues management etc. Education can also be addressed to the general population. In this case healthcare associations guide people to a better healthcare by providing online seminars concerning: nutrition, prevention, medication, accidents and first care etc.

Additional services allow members to provide information about themselves to the community and build their profile. The part of the **user profile**, which is provided by the user herself, is her static profile and remains unchanged. Both patient and doctors should be able to update their member profile so that the community knows their current interest or expertise. Another part of the profile, which evolves all the time, is the dynamic profile which encompasses all actions of a member inside the community. In order to increase member interaction with the community and exploit the expertise of members we could assign moderator roles to frequent members and request their feedback concerning the community operations.

Finally, in an autonomous community members should be able to make their own, **self-supportive groups** inside the community. Members of a group should be able to set-up or attend chat sessions on topics of interest, to participate in point-in-time surveys or straw polls on a topic to allow communities to gather consensus and determine community activity, to start new communities related to specific problems and steer the content according to their collective needs. For example, drug or alcohol addicts are able to form groups, discuss their problem with other addicts and search for solutions and support. The process is always under the supervision of one or more doctors, which can support more than one groups at the same time since they interact remotely and possibly in an asynchronous manner.

3.4 Merits of the self-supportive community approach

The heart of a virtual community is usually a Web-based portal that members use to access the full range of knowledge resources, maintain member-to-member networking groups, share professional practice solutions, and conduct association business. The purpose of establishing a virtual community for healthcare issues is to advance patient support and promote unity and member interconnectedness.

Users of healthcare services demand better support in terms of quality, quantity and efficiency. The increased demand for quality of services, even from g, the cost for personnel transfer to geographically isolated areas, the need for remote access for treatment and education and the rapid evolution of healthcare industry demand from the healthcare community to "go virtual". On the other side, the intrinsic need of patients to help co-patients, of doctors to help their colleagues and of associations to work in common can help the community to be self-supported and do not seek for external assistance.

A database of member profiles allows members to locate other members with similar interests, useful job titles and expertise, and neighboring geographic location and create their own networks. A virtual community build over a web-based portal, allows distant and continuous membership (Leimeister et al 2004), thus increasing the probability of a member to find online other members of her network, to locate information of interest or communicate with members outside of her network.

For example, a patient who lives on an island will be able to locate and reach all doctors, nurses or institutes that reside on the same or neighboring areas. In the same time he/she can receive useful advices from distant members of the community and consequently compare and filter both information sources.

Apart from the online and synchronous communication, a world-wide community, offers to patients capabilities for asynchronous consultation and support. Members can join whichever communities they choose, or just visit a community to pick up information of interest at the moment.

The ability to build virtual groups of patients is very useful in special cases of treatment such as group therapy and is valuable for doctors. The ability to maintain history of all actions in the community is very useful for doctors and researchers, who have direct access to their patients profile and history of discussions, to the survey results performed in the community, to the information provided by other experts etc. They can also interact with colleagues in various communities by posting a question, sharing an observation, or sharing a document, data, or images.

The issues that must be considered in a community for healthcare relate to the amount and quality of information offered in the community. The flood of information can be confusing both to patients and doctors and as a consequence, information must be filtered and organized. Since anyone is able to publish information and since it is not always easy to see the origin of the information, users could be making decisions on the basis of a source that might not be quality assured. A certification authority is necessary to guarantee the expertise level of every user, control the quality of the published information and build trust among the community members. Even when the information is of high quality, users are not capable to make their own judgments and need support from the experts. Other issues relate to the expertise of all members in handling virtual discussions or providing diagnosis remotely. These issues should be considered in the design phase in order to increase members' participation and improve the quality of the community services.

4 TOWARDS A SUCCESSFUL COMMUNITY

The principle behind a successful community is definitely not "build it and they will come". As any other community of practice it should be member centered and member driven. Members should be supported at all times and should have all the tools that facilitate their stay in the community.

According to Wenger (Wenger 1998) participation in a COP can be: full from inside, peripheral or full from the outside of the community. The community designers must *define the level of access* to content and services for each type of participant. Administrators need the appropriate solutions to manage users, to check their credentials and protect their privacy. In the same time, they should think of activities that will increase participation (i.e. open forums) and motivations and rewards for active members.

When the community is used for learning purposes, the necessities of healthcare professionals should be recorder and organized, *training solutions should be scheduled* in co-operation with companies and associations, potential students should be contacted and the training results should be evaluated and certified. When the community serves for patients or doctors to support other associates, the advices and information exchanged between individuals should be validated.

Content moderators need systems for the *collection and evaluation of knowledge* and should offer search mechanisms to the amassed knowledge. Group moderators need monitoring tools in order to proactively coordinate groups, and would be pleased to have collaborative platforms to support their groups. Validity can be achieved through monitoring, although, it is preferable to replace monitoring with an authorization mechanism. Advices, comments or opinions that are not signed are considered of low quality and consequently invalid. Valid information and services are issued by authorized community members only and are always signed.

An important issue for the designers of a community is the *building of trust* among members. This requires from the administrators to be aware of the complete profile of a member, whilst all other members have partial access. The protection of members' anonymity is crucial in a community of support and can be attained through the virtual identity of members. Virtual identity is always bind to the same user and stands for the static profile, thus allowing doctors to keep a history of their patients, while at the same time, preserves personal data of patients.

5 CONCLUSIONS – FUTURE WORK

This paper introduced the idea of a self-supportive virtual community of patients. The community will bring together doctors, nurses and volunteers around patients and will provide the tools for requesting and providing medical information, advices and psychological support. Healthcare associations, companies and researchers will be able to join the community, disseminate their instructions, products and findings

respectively and undertake crucial tasks such as the quality control of services and information. The use of community services will load the community database with valuable information concerning user feedback, patient needs, treatment suggestions, patient profiles and medical record history. The stockpiled information can be analyzed: by the community administrators who want to improve services, by scientists who perform medical research, by future patients who seek for a quick advice from a fellow-sufferer. The knowledge produced inside the community will be continuously filtered and managed in order to maintain quality.

The next step of this work is to formally define and create a self-supportive community for healthcare and perform a real case study. We expect that the results of a real case will raise specific operational and management issues that are hidden in first site. Our will is to build a community that will last and offer to participants for a long term.

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