Use of Virtual Communities for the Welfare of Groups with Particular Needs

Iraklis Varlamis[†§], *Ioannis Apostolakis*[§*]

[†] Athens University of Economics and Business, [§] Panteion University and [*] National School of Public Health, Greece.

ABSTRACT

The growth of scientific, technological and technical knowledge has enhanced the ability to provide fast, precise communication of information, and effective support for patients with complex or chronic medical problems. One technique by which this can be achieved is through the development of communities of practice. This concept was conceived over 15 years ago and refers to the process of social learning that occurs when people who have a common interest in some subject or problem collaborate over an extended period to share ideas, find solutions, and build innovations. Applied to healthcare this technique can be used to bring together patients, their families, doctors and nurses into self-supportive communities, where doctors disseminate their scientific knowledge, nurses provide practical advice and families exchange empirical knowledge. The approach exploits the merits of the internet and extends group-therapy in two ways: (i) universal (distant) membership, (ii) asynchronous consultations and support. In this paper we describe the structure, roles and services of self-supportive "web communities of patients".

INTRODUCTION

Patients with complex and chronic diseases often require a combination of medical and social care. In the process of providing medical and psychological support to patients, three different types of participants can be distinguished:

- Care providers – healthcare professionals, doctors, nurses, physiotherapists, social workers, etc., who treat and support patients.
- Care givers – family members and friends who provide care for the patient in their own home. This group may also be extended to include voluntary helpers.
- Patients – the receivers of the support provided.

Modern healthcare is characterised by a drive towards community care in an effort to reduce healthcare costs. A key aspect of this is the development of 'expert' patients with care increasingly being delivered by patients themselves as well as their

---

Correspondence and reprint requests: Iraklis Varlamis, Athens University of Economics & Business, Computer Science Department, 76 Patision Str, 10443, Athens, Greece. E-mail: varlamis@aueb.gr.

families. Delivering this care requires a redesign of healthcare processes to take into account the following factors:

(i) Care providers need to keep up to date with advances in medical knowledge and to be able to exchange knowledge and experience with peers and patients in a practical format that patients can use.

(ii) The needs and demands of patients are not fixed but can vary considerably over time. Frequently in the initial stages of their disease, patients require a lot of information to enable them to better understand their disease condition and the available treatment options. However in the latter stages of their disease they are often more interested in obtaining emotional support rather than in-depth knowledge about their disease.

One way of achieving this is through the development of "Communities of Practice". This phrase was first used by Lave and Wenger in 1991 to describe groups of people with common interests, who mainly wanted to share practical knowledge and learning[1]. According to Wenger a "Community of Practice" is characterised by three functions[2]:

- **What it is about** – its *joint enterprise* as understood and continually renegotiated by its members.
- **How it functions** - mutual engagement that bind members together into a social entity.
- **What capabilities it has produced** – the *shared repertoire* of communal resources (routines, sensibilities, artefacts, vocabulary, styles, etc.) that members have developed over time.

The hypothesis on which the success of communities is based is that group therapy provides superior treatment compared to individual therapy. In order to build a successful healthcare community that combines the efforts of care givers, care providers and patients, all working towards the welfare of the latter, a well defined framework must be established. This needs to incorporate appropriate architecture, structure and rules. In addition services that facilitate co-operation and communication between participants need to be built and deployed.

The following section presents an overview of communities and illustrates the merits of the community approach. Roles in the community, services that promote interaction between community members, and the structure of the community are described, together with detailed discussion of implementation and operation issues.

THE COMMUNITIES APPROACH

Two of the most fundamental requirements of patients are the need for:

(i) Medical information

(ii) Support

When patients seek medical advice they usually visit their General Practitioner or see a hospital specialist. However, when they are merely looking for medical

information, in addition to asking medical experts, they often ask people they trust, consult books or the internet. As a result patients have a large 'zone of influence', comprising friends, family, co-workers, neighbours, etc. Patients also frequently express a desire to share their problems and findings with other patients. This makes healthcare a highly social activity that potentially could be better served by community interaction rather than patients receiving treatment in isolation. The development of healthcare communities can both inform and support patients. Both these types of community can take advantage of the benefits of the internet to increase participation and have virtual counterparts with permanent representation in time and space (i.e. global coverage). A better understanding of the structure of a virtual healthcare community can be provided by a synopsis of the two types of communities it encompasses.

LEARNING COMMUNITIES

Virtual learning communities are recent additions to the educational landscape. Such communities aim to collaboratively improve knowledge in the chosen field of the community. In the case of open learning communities everyone is allowed to participate and either offer or consume the collective knowledge. As a result, the members of a virtual learning community vary from new learners to subject matter experts both from within and outside the community.

The core activity of virtual learning communities is writing. People exchange messages with a shared goal of building understanding to produce an information base which is available to future members of the community[3]. 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 can comprise:
  • Questionnaires addressed to patients and their families
  • Personal reflections by patients of their experiences
  • Discussion forum logs
  • Virtual interviews with doctors and subject experts

Another aim of learning communities is to replace the internet as an information source for patients[4]. Although the internet is a valuable source of information, the information in many websites has not been peer reviewed or authenticated [5]. Consequently information found on the internet can sometimes be misleading and confusing. For non-medical experts this information often has to be filtered and this process can be well performed inside a learning community [6].

SUPPORT COMMUNITIES

With respect to patient support, the heart of a virtual community is usually a Web-based portal. Members can use this to:

- Access the full range of knowledge resources
- Maintain member-to-member networking groups
- Share professional practice solutions
- Conduct association business

Consequently in addition to advancing patient support this type of virtual community can also promote unity and member interconnectedness [7].

A database of member profiles allows members to locate other members based on similar interests, job titles and expertise, neighbouring geographic location or to create their own networks. A virtual community built over a web-based portal allows distant and continuous membership [8]. This increases the probability of a member being able to find other online members of his or her network, to locate information of interest to him or her, and to communicate with members outside of his or her network. Apart from the online and synchronous communication, a world-wide community also offers patients the capabilities for asynchronous consultation and support. Members can join whichever communities they choose, or just visit a community to pick up information of interest to them on a single occasion.

The ability to build virtual groups of patients can be advantageous for patients receiving treatments such as group therapy. However it can also be valuable for doctors and researchers as they are able to access:

- Maintained histories of all actions in the community
- Patients' profiles
- A history of discussions
- The results of community surveys
- Information provided by other experts

They can also interact with colleagues in various communities by posting a question, sharing an observation, or sharing a document, data, or images.

A fundamental issue that must be addressed in a healthcare community is the amount and quality of information offered in the community. Too much information can be confusing for both patients and doctors. Information consequently must be filtered and organised. In addition, since anyone is able to publish information, and it is not always easy for users to determine the origin of the information, it is possible that users may make decisions on the basis of information that is not evidence-based or reputable. To address this problem a certification authority is necessary to:

- Guarantee the expertise level of every user
- Control the quality of the published information
- Build trust among the community members

Even when the information is of high quality, users are not always capable of making their own judgments and often need support from experts. Other issues relate to the expertise of members in handling virtual discussions or providing advice remotely. These issues should be considered in the design phase in order to increase the participation of members and to improve the quality of the community services.
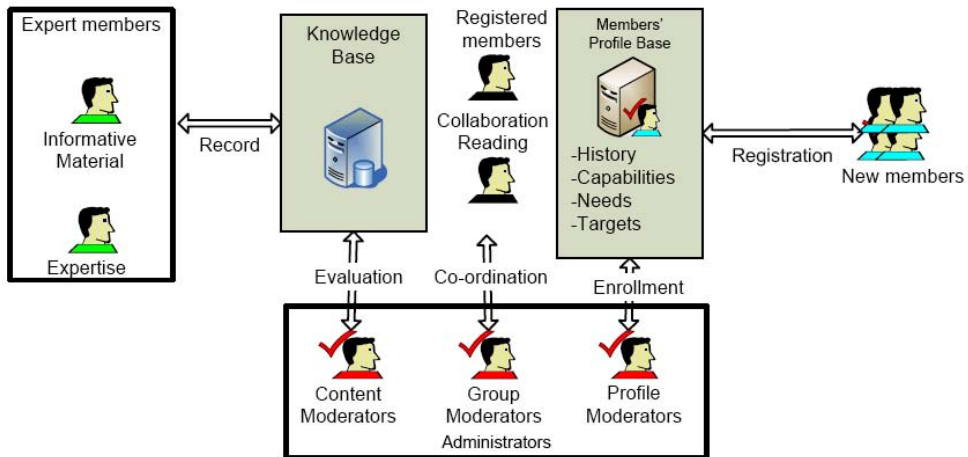
Figure 1. *The roles and tasks of the community*

THE STRUCTURE OF THE COMMUNITY

The different roles and tasks carried out by individual community members are shown in Figure 1. There are two valuable community sources of information:

- The Knowledge base
- The Profile base

The Profile base offers multilevel access to members according to their role. Once members are registered with the community they are able to collaborate and search for information.

ROLES

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 the profiles of potential members and the identification of roles. The nucleus of a community for healthcare support comprises the doctors and scientists who share their knowledge and can offer expert medical advice. The community should also 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 illnesses that the community has been established to support are fundamental members of the community. They must be able to participate in discussion groups and share their needs and problems with other patients and doctors.

An important role in the community are the group moderators who coordinate the discussion groups. To build trust inside the community it is necessary for

members to be verified to protect the community. The ***profile moderators*** have the responsibility of checking members' credentials, confirming their identities and verifying the accuracy of their profile. They must distinguish care givers from professionals, and 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*** can be established. This person is responsible for reviewing and filtering all published material and acts as a liaison between information providers (experts, doctors, scientists, etc) and information consumers (patients).

SERVICES

The services provided to the members of a community must be carefully designed to ensure that they are as useful as possible to patients. In particular when services are designed to support patients, extra care should be taken to guarantee accessibility of content and services and to avoid member exclusion.

The most widely used service is the distribution of ***informative content*** (i.e. medical documents, surveys, medical advice, news etc.). This content should be easy to locate and retrieve by patients. Provisions should also be made for making the content available in different formats, so that it can be accessible to people with disabilities (e.g. patients who are deaf or blind). In order to facilitate new users, content can be forwarded to patients via e-mail. For frequent users, content can be published in a web portal. This should be organised 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[9]. ***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 two fold:

- To support patients and their families
- To allow experts to exchange knowledge

Debates are more meaningful when topics are predefined and organised. 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.

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 users themselves, is a static profile and remains unchanged. Both patients and doctors should be able to update their member profiles 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 within the community and

exploit the expertise of members, moderator roles may be assigned to frequent members, and their feedback concerning the community operations may be sought.

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
- Participate in point-in-time surveys or straw polls on a topic that allows communities to gather consensus and determine community activity
- Start new communities related to specific problems
- Steer the content according to their collective needs

OPERATING ISSUES

A successful community cannot rely on attracting members merely by its presence. As with any successful business practice it should be member centred and member driven. Members should be supported at all times and should have all the tools that facilitate their stay in the community.

Participation in a community of practice can be completely from the inside, peripheral, or fully from the outside of the community [2]. The community designers must define the level of access to content and services for each type of participant. Administrators need appropriate solutions to manage users, to check their credentials and protect their privacy. At the same time, they should continuously be seeking to add activities that will increase participation (e.g. open forums) and motivate active members.

Content moderators need systems for the collection and evaluation of knowledge and should offer search mechanisms for amassed knowledge. Group moderators need monitoring tools in order to proactively coordinate groups, and ideally should have collaborative platforms to support their groups.

An important issue for the designers of a community is the building of trust among members. This requires the administrators to be aware of the complete profile of all full members of the community and to only allow other members to 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. The virtual identity is always bound to the same user and reflects their static profile. It allows doctors to keep a history of their patients, whilst at the same time preserving the patient's privacy and anonymity.

DISCUSSION

This paper describes the key features of virtual communities and the steps required to establish them in healthcare with the aim of enhancing patient care and support. The concept is based on communities of practice which were first described 15 years

ago and have recently been expanded to cover modern organisational structures [10]. In the business world communities of practice have been used to facilitate virtual team working, to share organisational knowledge and to accelerate the adoption of new and complex practices in the business environment [11]. Electronic networks of practice (ENOPs) can also extend communities of practice. ENOPs are computer-mediated social spaces where individuals working on similar problems self-organise to help each other and share perspectives about their shared occupational practice. As a result members can virtually participate in the community activities of a community without necessarily being a member of that community. This is achieved through coordination activities performed by third parties and communication supported by newsletters or websites[12].

The success of virtual communities will be closely related to the trust and confidence members have in the information provided to the community and also how useful they find the community. A vital factor in achieving these objectives is the inclusion of experts (doctors, nurses and scientists), in the community along with patients and their families. These experts will play a key role not only in providing advice to patients, but also in verifying that information provided to the community is accurate, scientifically sound and up to date. Other measures will also be required to achieve the objectives of ensuring trust and confidence in information provided to the community and the usefulness of the community. These may include for example moderators to verify the authenticity of members, and tools to obtain relevant information quickly and easily.

To date the use of virtual communities in healthcare is not well established. They do, however, have the potential to greatly enhance the care of patients with complex and chronic diseases. We hope that this article will stimulate and guide those seeking to establish them.

REFERENCES

1 Lave J, Wenger E. *Situated Learning. Legitimate Peripheral Participation*. Cambridge, MA: Cambridge University Press, 1991.

2 Wenger E. *Communities of Practice: Learning Meaning and Identity*. Cambridge: University Press, 1998.

3 Harasim L. What makes online learning communities successful? The role of collaborative learning in social and intellectual development. In Vrasidas C & Glass CV (eds), *Distance Education and Distributed Learning*. Greenwich, CT: Information Age Publishing, 2002, pp. 181–200.

4 Eysenbach G. The Impact of the Internet on Cancer Outcomes. *Can Cancer J Clin*; 2003; **53**: 356–71.

5 Ferguson T. From patients to end-users. *BMJ* 2002; **324**:555–56.

6 Moon J. Discussing health issues on the Internet. In: *Encyclopedia of Virtual Communities and Technologies*. Edited By: Subhasish Dasgupta, George Washington University, USA, 2005.

7   Gabbay J, May A, Jefferson H, *et al*. A Case Study of Knowledge Management in Multiagency Consumer-Informed `Communities of Practice': Implications for Evidence-Based Policy Development in Health and Social Services. *Health*, 2003; 7: 283–310.

8   Leimeister JM, Daum M, Krcmar H. Towards mobile communities for cancer patients: the case of krebsgemeinschaft.de. *International Journal of Web Based Communities (IJWBC)* 2004; 1: 1.

9   Rada R. Cancer Patient-Patient Online Discussion Groups, *Encyclopedia of Virtual Communities and Technologies*. Edited By: Subhasish Dasgupta, George Washington University, USA, 2005.

10   Wenger E, Snyder W. Communities of practice: The organisational frontier. *Harvard Business Review,* 2000: 139–45.

11   Kimble C, Li F. Effective Virtual Working through Communities of Practice, *Encyclopedia of Virtual Communities and Technologies*. Edited By: Subhasish Dasgupta, George Washington University, USA , 2005.

12   Brown JS. Duguid, P. *The Social Life of Information*. Boston: Harvard Business School Press, 2000.