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Athina A. Lazakidou *Editor*

Virtual Communities, Social Networks and Collaboration

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Editor

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Preface

Online communities are among the most obvious manifestations of social networks based on new media technology. Facilitating ad hoc communication and leveraging collective intelligence by matching similar or related users have become important success factors in almost every successful business plan.

This special issue addresses the virtual communities and collaboration among virtual participants currently proliferating across the world. Many online communities have been created to facilitate communication, enhance or express relationships, work in a common cause, seek entertainment, and network or mentor others. Others have been formed to facilitate tasks already being performed but now needing to be done virtually. Such communities and online groups span various boundaries and include networked employees, videoconferencing, gaming setups, and electronic community groups pursuing such diverse activities as friendshipping, planning, information sharing, collaborating, system developing, having fun, and advertising. Various technologies are involved, from Facebook and Twitter to teleconferencing to mobile phones and PCs.

Researchers are just beginning to understand virtual communities and collaborations. Many issues need further study, including group dynamics and outcomes, social networking implications, technical support features, group coherence and loyalty, and how organizations can better utilize the potential benefits of such communities in both internal operations and in marketing and new product development. What leads to participation and effective collaboration in these communities needs further study, as do the issues of how and why knowledge is shared among participants. Much additional research in this area is needed.

This new book presents studies from leading researchers and practitioners focusing on the current challenges, directions, trends, and opportunities associated with virtual communities and their supporting technologies.

This new book will be an excellent source of comprehensive knowledge and literature on the topic of virtual communities, social networks, and collaboration.

All of us who worked on the book hope that readers will find it useful.

About the Editor

Athina A. Lazakidou, Ph.D., currently works at the University of Peloponnese, Department of Nursing, in Greece, as a lecturer in health informatics. She worked as a visiting lecturer at the Department of Computer Science at the University of Cyprus (2000–2002) and at the Department of Nursing at the University of Athens (2002–2007). She did her undergraduate studies at the Athens University of Economics and Business (Greece) and received her B.Sc. in Computer Science in 1996. In 2000, she received her Ph.D. in Medical Informatics from the Department of Medical Informatics, University Hospital Benjamin Franklin at the Free University of Berlin, Germany. She is also an internationally known expert in the field of computer applications in health care and biomedicine, with six books and numerous papers to her credit. Her research interests include health informatics, hospital and clinical information systems, e-learning in medicine, software engineering, graphical user interfaces, (bio)medical databases, clinical decision support systems, electronic medical record systems, telematics, and other web-based applications in health care and biomedicine.

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Chapter 1

Health-Related Virtual Communities and Social Networking Services

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Abstract The literature indicates that a virtual community in health care as a group of people using telecommunication with the purposes of delivering health care and education, and/or providing support, covers a wide range of clinical specialties, technologies, and stakeholders. Examples include peer-to-peer networks, virtual health-care delivery, and research teams. Virtual communities (VCs) offer ubiquitous access to information and exchange possibilities for people in similar circumstances. This is especially valuable for patients with chronic/life-threatening diseases as they exhibit strong needs for information and interaction. Virtual communities and virtual relationships can improve the situation of all patients by offering them a place to establish social relationships that help them to cope with their situation. Although virtual relationships offer informational and emotional types of support, they do not seem to offer practical types of support. Therefore, virtual relationships can play an important role in complementing real-life social relationships, but they can never replace them.

Keywords Virtual communities • Social networks • Healthcare communities • Online • Electronic health records

1.1 Introduction

Virtual health-care communities aim in bringing together health-care professionals and patients in order to further improve the quality of health-care services and assist health-care professionals and researchers in their everyday activities. Patient monitoring and medical consultation – the two most popular activities inside virtual health-care communities – require members' collaboration in a secure and reliable environment.

The Internet is changing the way people access health-related information and how they search for support and interaction with peers in similar situations. There exist several ways of interaction between health-care practitioners and patients.

In the case of a medical incident, patients receive medical treatment from doctors and nurses while at hospital and posttreatment 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 health-care issue turns to be a transfer of knowledge, care, and services from health-care professionals to the patients [46].

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.

Virtual communities refer to groups of people that collaborate, discuss their issues, share experiences, consult with experts, and provide and request support by using telecommunication technologies. Virtual health-care communities employ advanced and pervasive ICT technologies in order to offer ubiquitous medical services to their members. Elder members, home care patients, or members with chronic conditions utilize different types of health-care services at different points in time, in this way bridging geographic distance and time constraints [10, 44].

Virtual health-care communities aim in bringing together health-care professionals and patients in order to further improve the quality of health-care services and assist health-care professionals and researchers in their everyday activities. Patient monitoring and medical consultation – the two most popular activities inside virtual health-care communities – require members’ collaboration in a secure and reliable environment.

1.2 Online Communities and Virtual Relationships

Before looking at previous studies investigating the potential of online communities to establish social relationships there, it is important to define the two key concepts used in this research: online communities and virtual relationships. As there is no common agreement on one specific definition of online communities, for the purpose of this study they are defined using some of the key aspects that are repeatedly mentioned [12, 41]:

- Meeting and interaction of people
- Connected by a specific interest

- By means of a technical platform
- Where they have the chance to establish social relationships

Social relationships are characterized by a repeated interaction between two persons whereas the individual interaction is influenced by previous interactions as well as the expectation of future interactions [12]. To differentiate between virtual and real-world relationships, the place of the first interaction is used [39]: A virtual relationship is a relationship where the first contact took place online; a real-world relationship is a relationship where the first contact took place offline.

Especially during the early research on computer-mediated communication and web-based interaction services, numerous scholars questioned whether the characteristics of computer-mediated communication allow social relationships to be established in a virtual environment at all [38]. However, both the experience of numerous users of online interaction services and the results of several studies in this field of research document that it is possible to establish social relationships in online communities [41]. For example, Park and Floyd come to the conclusion that the emergence of social relationships through online services is common and widespread among its users. But they also discover that relationships which are initiated by virtual interaction mostly are not kept exclusively within a virtual environment but are migrated to the real world [38].

Social support plays a major role in positively influencing the well-being of patients. People join online self-help groups for the same reasons and therefore for the same problems for which people join real-world self-help groups [51]. According to Turner, the support received through online interaction services is perceived as helpful as support provided by real-world contact persons [45]. Members of online self-help groups superiorly cope with information about their disease due to the received support; furthermore, their emotional situation improves. A study conducted by Loader et al. identifies emotional as well as informational support as types of support provided by virtual relationships [30].

1.3 Patients and Virtual Health-Care Communities

Virtual communities are especially prevalent in terms of convincing communications among people who engage in similar activities. Being interested in certain activities, the concept of sharing feelings, opinions, and information is among the most distinctive characteristics of virtual communities. Present practices are shaped around the basis of establishing a web site and people becoming members of this site to share their thoughts, opinions, and experiences.

As virtual communities have started to become popular, different disciplines have started to analyze these areas in detail and obtain administrative inferences from them. One of the most important effects of the use of electronic environments in the distribution of health-care services has been the electronic prevalence of P2P (peer-to-peer) communities and virtual communities. People use health-care-related virtual

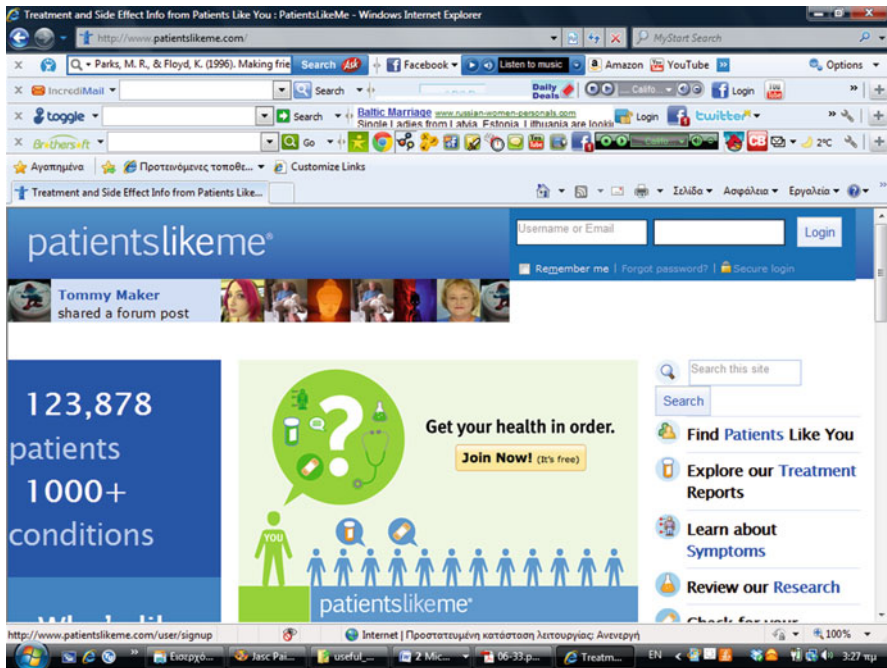


Fig. 1.1 PatientsLikeMe: <http://www.patientslikeme.com>

communities in accordance with their personal interests to share their experiences, to ask questions, to obtain or provide emotional support, and to obtain useful information that will help those.

As more and more people are comfortable sharing the intimate details of their lives online via blogs and social networks, the future of health-related virtual communities is looking brighter than ever – with thousands of people logging on to share side effects, treatment options, test results, and coping strategies. Data-rich virtual communities, such as PatientsLikeMe (Fig. 1.1), HealthCentral (Fig. 1.2), and CureTogether (Fig. 1.3), have been drawing a crowd in the past few years, offering a platform for patients with chronic illnesses such as fibromyalgia, depression, and multiple sclerosis to share information and connect.

PatientsLikeMe cofounders Ben and Jamie Heywood launched their site in 2008 after their brother Stephen was diagnosed with amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig’s disease). Earlier this year, the company tested a new design with the 100,000 members of its community and is now ready to launch the revised product to new members. CureTogether, which rates treatment options for more than 500 illnesses, boasts 26,000 members. HealthCentral, a large-scale health content site offering virtual communities, draws 17 million users to its network of health-related sites per month.

A few other virtual communities for those dealing with serious illness include Upopolis, which helps young patients, especially those in a hospital, stay wired with school friends and family in a format similar to Facebook but packed with

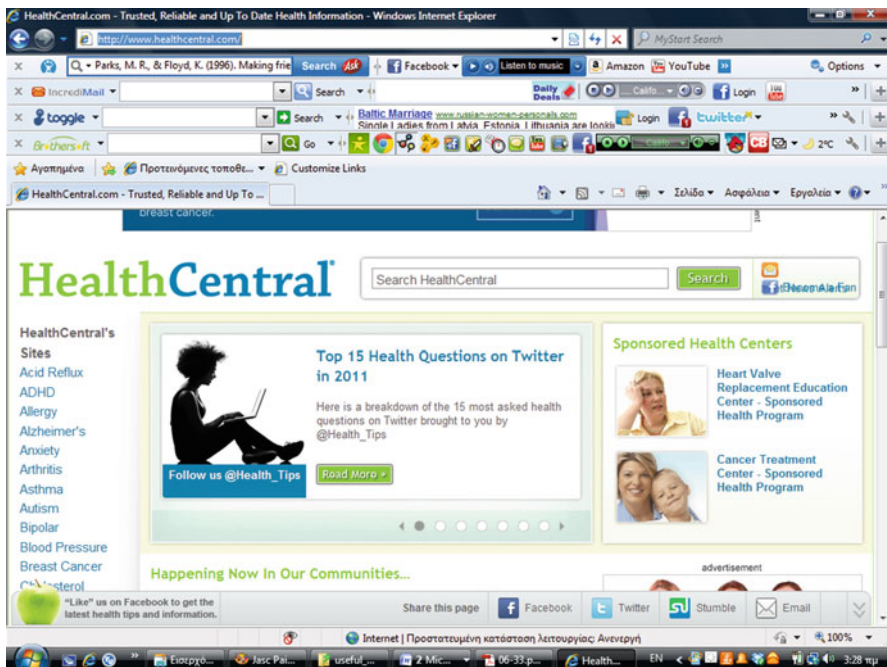


Fig. 1.2 HealthCentral: <http://www.healthcentral.com>

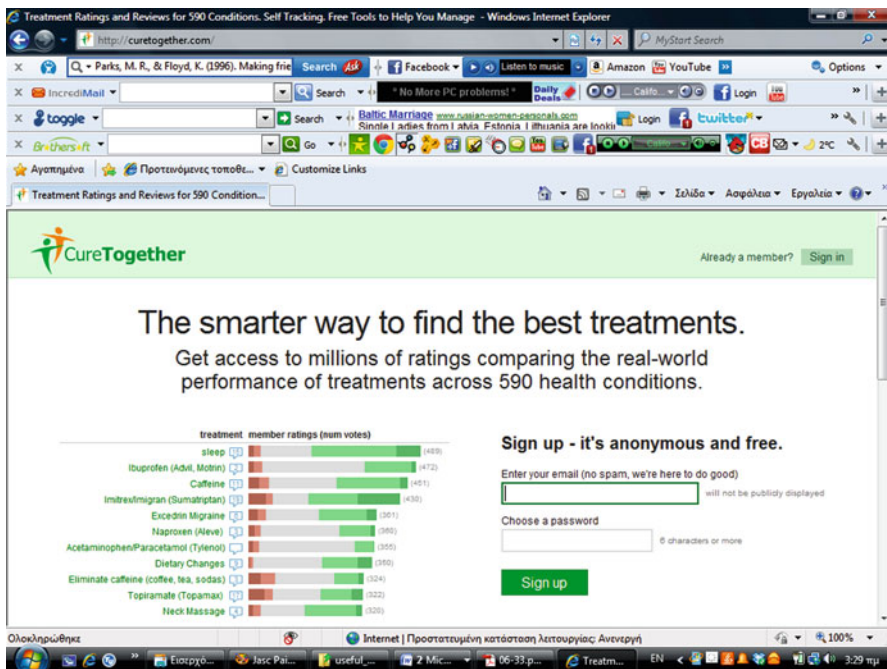


Fig. 1.3 CureTogether: <http://www.curetogether.com>

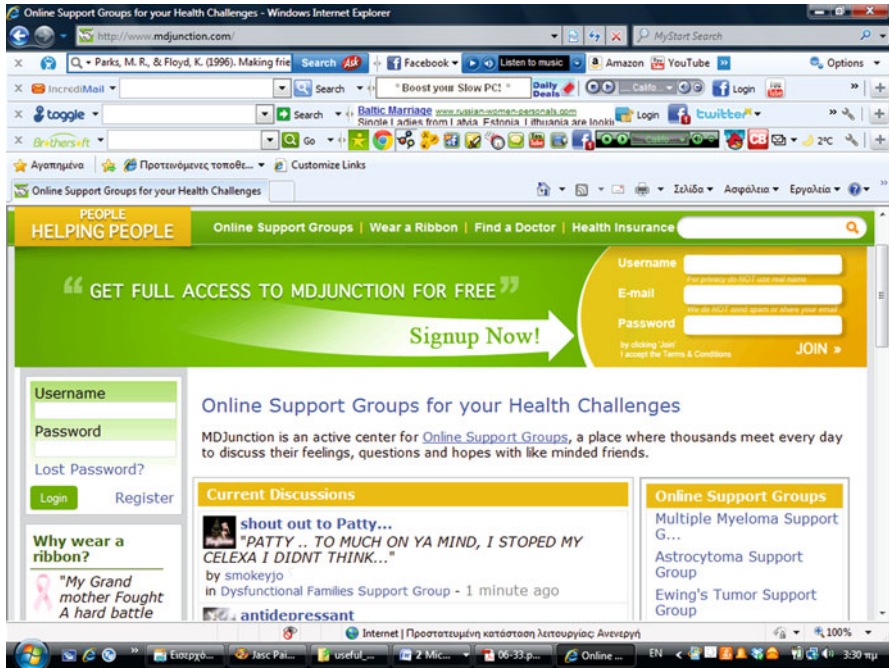


Fig. 1.4 MDJunction: <http://www.mdjunction.com>

“kid-friendly” tools. Also MDJunction offers online support groups to discuss feelings, ask questions, and share hopes about recovering from an illness with like-minded people (Fig. 1.4).

1.4 Health 3.0

Health 3.0 is a health-related extension of the concept of Web 2.0 whereby the users interface with the data and information available on the web is personalized to optimize their experience [2]. This is based on the concept of the Semantic Web, wherein web sites’ data is accessible for sorting in order to tailor the presentation of information based on user preferences. Health 3.0 will utilize such data access to enable individuals to better retrieve and contribute to personalized health-related information within networked electronic health records and social networking resources [36, 40]. The idea was also suggested in the commentary in response to the US government’s new \$1.2 billion investment as a part of the American Recovery and Reinvestment Act. The commentary explains how the idea of Health 3.0 can fit in to better develop and implement electronic health records. The ideas were the use of social media and incorporation of virtual tools for enhanced interactions between health-care providers and consumers/patients [42].

Main goals of Health 3.0 are as follows:

- Improved access to health-related information on the web via semantic and networked resources will facilitate an improved understanding of health issues with the goal of increasing patient self-management, preventative care, and enhancing health professional expertise [35, 43].
- Health 3.0 will foster the creation and maintenance of supportive virtual communities within which individuals can help one another understand, cope with, and manage common health-related issues [13].
- Personalized social networking resources can also serve as a medium for health professionals to improve individuals' access to health-care expertise and to facilitate health professional-to-many-patients communication with the goal of improved acceptance, understanding, and adherence to best therapeutic options [5, 42].

1.5 A Virtual Community for Monitoring and Tele-Healthcare

Virtual communities refer to groups of people that collaborate, discuss their issues, share experiences, consult with experts, and provide and request support by using telecommunication technologies. Virtual health-care communities employ advanced and pervasive ICT technologies in order to offer ubiquitous medical services to their members. Elder members, home care patients, or members with chronic conditions utilize different types of health-care services at different points in time, in this way bridging geographic distance and time constraints [11, 47].

1.5.1 *Community Members*

The active members of a virtual health-care community comprise patients and doctors, as well as people with interest in the community issues, such as patients' family members, researchers, etc. Members have different roles depending on their needs and expertise: Patients and family members undertake facilitator roles, while health-care professionals become moderators for discussion and contents, facilitators and mentors for the community members. The technical administration of the community is usually performed by IT experts who must be trustful community members.

In complement to the community members, several people, in the community background, guarantee the smooth operation of the community and the uninterrupted delivery of services. The IT staff that technically supports the community, the employees of the telecommunication service provider, and the directors of the organization, company, or hospital that host the virtual community are persons that do not actually participate in the community but play a key role in its secure operation.

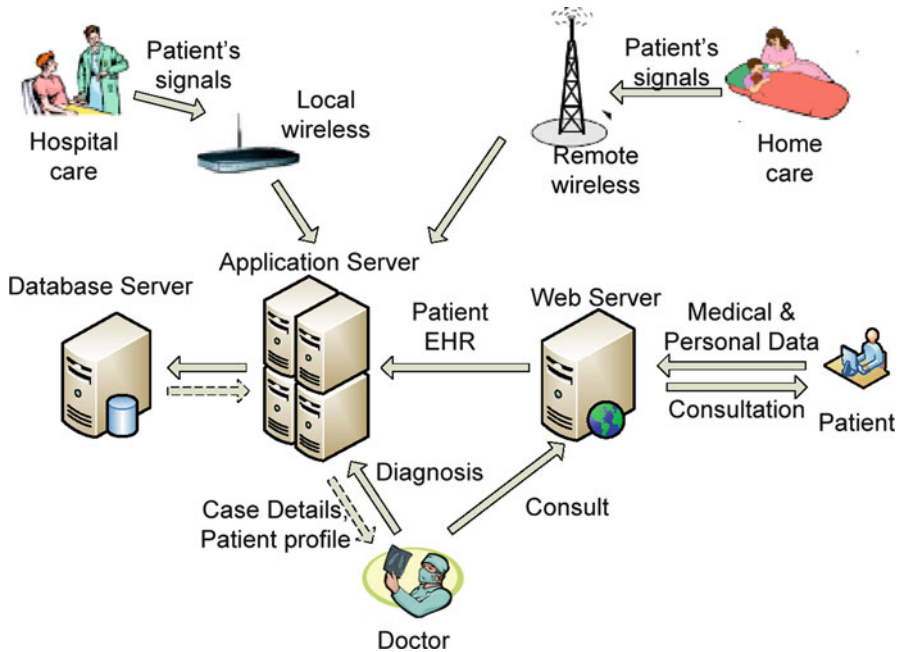


Fig. 1.5 Overview of the community interactions [8]

1.5.2 Community Activities

An overview of the interactions inside the health-care community is presented in Fig. 1.5. Health status signals are collected using wireless sensors and/or wired devices that are stored in the community servers for future reference and analysis. Patient members are also able to request for advice, diagnosis or treatment suggestion, etc., by using the community portal communication services (e-mail, forum, etc.).

The doctor from inside the hospital is able to access the patient's record (electronic health record – EHR) and make a diagnosis. The doctor replies to patients' requests but also provides consultation based on the patient's medical status signals. The hospital keeps record of patients' profiles and history, doctors' diagnoses, and of all requests and advices exchanged in the portal.

1.6 Virtual Communities for Diabetes Chronic Disease Health Care

Diabetes is classified as the world's fastest-growing chronic illness that affects millions of people. It is a very serious disease, but the bright side is that it is treatable and can be managed. Proper education in this view is necessary to achieve essential

control and prevent the aggregation of this chronic sickness. In this chapter [6], the researchers describe how they have developed a health-care social network that provides methods for distance learning, opportunities for creation of virtual self-help groups where patients can get information and establish interactions among each other in order to exchange important health-care-related information, discussion forums, and patient-to-health-care specialist communication. The mission of this virtual community is to increase the independence of people with diabetes, self-management, empower them to take care of themselves, make their everyday activities easier, enrich their medical knowledge, and improve their health condition, make them more productive, and improve their communication with other patients with similar diagnoses. The ultimate goal is to enhance the quality of their life.

Virtual communities can be tools to promote health treatment strategies, to change the patient-caregiver relationship, and to reform the way health care is delivered. In fact, they already have been used to sustain healthy lifestyle changes, encourage patients' dedication in their treatment, educate, and improve the access to needed information. The proposed diabetes health-care virtual community model promotes highly effective services supported by major communication capabilities and easy information access. One of the major benefits of the health-care social network is building online social connections with peer patients, exchange experiences, share problems, and commonly search for solutions. Chat rooms, group meetings, and consultations are all virtually brought in the patient's home, anytime, anywhere. With mobile devices, the provided services are available on the go. Medical personnel are present to verify data, strengthen trust in the system, and maintain the quality of the information provided.

Virtual communities for diabetes health care play an important role in contributing to the overall effect of diabetes treatment worldwide. "A key aspect of successful chronic disease management is active partnership between consumer and provider – this is particularly important in diabetes management, where many key activities are in the hands of the patient" [48].

The benefits from the system should be attractive for both sides: health-care delivery on one hand and business perspectives so that the system can be supported on the other hand. Being a union of web application modules, mobile device applications, all based on a secure infrastructure, the proposed diabetes virtual model enables health care anywhere, at any time, and on any device.

1.7 Conclusions

The aim of this study was to examine whether online communities meet their theoretical potential to provide an environment where social relationships can be established that help patients in coping with their situation. Generally, online communities meet these potential and provide a place where patients can interact with other people, exchange information, and establish social relationships that supplement their social network.

There are several chances and challenges for virtual communities (VCs) created by new technical possibilities. Ubiquitous accesses to VCs through mobile digital devices as well as new (mobile or rather context sensitive) services for VCs are potentially very rewarding (e.g., an emergency system for cancer patients with a locating service or a mobile pill reminder). The relevance of these innovations for VCs cannot yet be assessed. The analysis of social interactions within VCs and the effects on the social network of the members have yet to be fully investigated. Research on the exact utility of health-care-oriented VCs seems to be especially promising when focusing on the measurement of the VC's influences on the perceived quality of life and the costs of treatment.

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