Review

The diffusion of virtual communities in health care: Concepts and challenges

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Abstract

Objective: This paper provides an overview and discussion of virtual communities in health care. Furthermore, we aim to discuss in this context ethical, legal and technical considerations and the current status of research in this domain.

Methods: We searched medical and social science literature including survey studies, randomized and non-randomized controlled interventions and reviews.

Results: 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. Ethical challenges including the concepts of identity and deception, privacy and confidentiality and technical issues, such as sociability and usability are discussed.

Conclusion: Virtual communities may empower patients and enhance coordination of care services; however, there is not sufficient systematic evidence of the effectiveness of virtual communities on clinical outcomes or patient empowerment. Researchers need to address issues, such as sample sizes and experimental design to further the research field in this domain.

Practice implications: When practitioners utilize virtual community tools to communicate with patients or colleagues they have to maximize sociability and usability of this mode of communication, while addressing concerns for privacy and the fear of de-humanizing practice, and the lack of clarity or relevance of current legislative frameworks.

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1. Introduction

A virtual community can be defined as a social unit that involves members who relate to one another as a group and interact using communication technologies that bridge geographic distance. The term “virtual” implies properties that unlike these of a traditional community where there is the assumption of geographic proximity, are based on the utilization of advanced technologies enabling interactions and exchange of information between members who may not have a face-to-face interaction at any point in time. A report resulting from the workshop held at the ACM Computer Human Interaction (CHI) conference on the theory and practice of physical and network communities identified several core attributes of virtual communities [1], such as a shared goal or interest among members that provides the main reason for forming and maintaining a community, repeated and active member participation, access to shared resources, defined policies for the type and frequency of access and reciprocity of information, support and services.

A virtual community in health care refers to a group of people (and the social structure that they collectively create) that is founded on telecommunication with the purposes of collectively conducting activities related to health care and education. Such activities can include actual delivery of health care services, staff or patient education, a platform for providing support, discussing health and treatment related issues and problems, sharing documents, consulting with experts and sustaining relationships beyond face-to-face events.

The stakeholders and participants of such communities can be a mix of health care providers and educators, patients and caregivers. More specifically, these communities could be networks including:

- health care professionals (providers and researchers) only;
- patients/informal caregivers only;
- health care professionals and their patients and family members/informal caregivers;
- members of the general public.

Examples of virtual communities that include only health care professionals can be virtual care delivery and research teams. Advanced telecommunication networks enable health care providers to interact and work on cases as members of so-called virtual teams. Such teams can ensure continuity of care as they utilize a common platform for exchange of messages, opinions and resources. Virtual teams are considered essential to successful disease management and to providing continuity of care for the patients.

Virtual communities involving only patients and their family members include applications that function as self-help groups of individuals diagnosed with the same medical condition or undergoing the same treatment. One study [2] found that virtual self-help groups could provide many of the processes used in face-to-face self-help and mutual aid groups. The emphasis in such virtual communities is on mutual problem solving, information sharing, expression of feelings, mutual support and empathy.

Virtual communities involving both health care providers and patients include applications that enhance disease management or provide alternative ways of communication between providers and patients beyond face-to-face meetings. Finally, virtual communities open to the general public may include educational services, discussion forums and other activities without requiring that their members assume an official role in the care delivery process and identify themselves as such (i.e. educational services and discussions can be open to the public without requiring that a participant is patient diagnosed with a specific diagnosis or member of a specific health profession).

Technologies for virtual communities include, among others, online message boards and automatic mailing list servers for asynchronous communication, or videoconferencing, Internet relay chat, group and private chat rooms for synchronous communication. Some of the discussion groups are not “moderated”; that is, there is no individual or group responsible for reviewing and filtering posts that are thought to be provocative, inappropriate or in violation of any of the rules of the virtual community. Anybody may post any message they wish. In such non-moderated groups, the community relies largely on the normative processes of their own internal social norms “to define and enforce the acceptable behavior of the community members [3]”.

This paper provides an overview and discussion of virtual communities and specifically, patient and caregiver-centric support groups, peer-to-peer networks and virtual teams. Furthermore, we aim to discuss ethical and legal
considerations as well as privacy and security issues associated with virtual communities and analyze the concept of patient empowerment in this context and issues of identity and deception in a virtual health care community.

2. Methods

For the purposes of this in-depth review of virtual communities we analyzed the current literature. The aim of the review was an in-depth study of virtual communities; thus, studies were included that describe specific virtual community applications or that evaluate the effectiveness of such applications. We searched for both randomized and non-randomized controlled trials, cohort studies, before and after studies and interrupted time series to determine the effectiveness of virtual communities in health care. Our analysis also included observational and qualitative studies and cross-sectional surveys. We included studies published in English. We used the broad definition of virtual communities allowing for any type of technology (Internet, videoconferencing, wireless networks, etc.). In order to cover all relevant literature we included not only medical literature but also that of social sciences. We searched Medline (Ovid, 1966–May 2005), Embase, PsycINFO (Ovid, 1972–May 2005), Web of Science (ISI, 1980–May 2005) and Computer and Information Systems Abstracts (CSA, 1981–May 2005). Main search terms included the terms “virtual community” and “peer-to-peer network” as well as combinations of the MeSH terms “community networks”, “consumer participation”, “videoconferencing”, “telemedicine”, “Internet” and “peer group”. A total of 56 studies were identified originally and 9 were excluded as they described technical implementation details of innovative applications but did not discuss involvement of participants. Studies were organized in terms of the targeted groups, i.e. virtual communities for health care providers, researchers, patients and community members. Obviously, some studies were classified under more than one group, as becomes obvious in the discussion that follows. Furthermore, ethical considerations were identified in both experimental studies and concept papers and are presented as part of the challenges associated with the concept of virtual communities.

3. Results

In the following, we discuss the types of virtual communities (classified by the intended members, i.e. health care providers, researchers, patients and caregivers) and the ethical and legal challenges associated with this concept.

3.1. Virtual health care delivery teams

Chronic illnesses require specialized and complex treatment protocols that involve a team of healthcare professionals and disciplines to address the multiple dimensions of care and social, psychosocial and clinical needs of patients. Such teams are essential to effective care provided to ensure continuity and to improve the patient’s quality of life. However, there are often practical constraints, such as time conflicts, geographic distances, other coordination challenges and limited resources that limit the type and frequency of interactions among health care professionals. The use of advanced telecommunication technologies provides an opportunity to bridge geographic distance and create “virtual” health care teams.

In order to understand the concept of a “virtual team” we first need to examine how a team is defined and what dimensions it encompasses. Lorimer and Manion [4] defines a team as a “small number of consistent people committed to a relevant shared purpose, with common performance goals, complementary and overlapping skills, and a common approach to their work”. The physical presence of team members at the same location and same time is not inherent as a requirement for the creation of a team. Rather, it is the nature of the interactions, namely the interdisciplinary character of the information exchange that becomes essential to an effective team. Health care providers of different disciplines (such as physicians, nurses, social workers, physical therapists, etc.) can create a team in which they combine their knowledge and expertise to provide a comprehensive plan of care.

Heinemann [5] describes four domains of team function that can guide interdisciplinary team development: (1) structure (composition of team members and representation of disciplines); (2) context (relationship to the larger institution); (3) process (of team functioning, hierarchy and communication) and (4) productivity. In this context, the third domain referring to the process is the one that would be defined differently for virtual teams. The communication in this case could be web-based synchronous interaction or video-mediated (via videoconferencing) or in an asynchronous manner using message boards and discussion forums. It can be argued that this mode of communication could lead to increased overall productivity of the team as professionals contribute at their own discretion and convenience, having the opportunity to review the files, notes and records carefully before communicating a message to the rest of the team. On the other hand, the cost-effectiveness of such applications has to be investigated as some of the required software and hardware as well as the underlying infrastructure may be costly so that start-up and maintenance costs could be justified by well-documented benefits of time saving, productivity increase and improved overall performance.

A system developed by Pitsillides et al. [6] aims to support the “dynamic creation, management and coordination of virtual medical teams for the continuous treatment” of home care patients. This system was designed using a patient centric philosophy and focused on care delivered at the patient’s home and not a health care facility. The goal was to create a virtual team that will be accessible to patients and families at...
all times, to improve communication among the team members and to improve the collection of monitoring data that will support decision-making. The team in this project includes oncologists, family physicians, home care nurses, physiotherapists, psychologists, social workers and the patient. The system architecture utilized the Internet and included a centralized electronic medical record system and mobile agents and devices distributed to members of the team.

A further demonstration of the virtual interdisciplinary team concept is the Telehospice Project at the University of Missouri [7]. The goal of hospice care is to improve the quality of dying patients’ last days by offering comfort and dignity, focusing on palliation and the relief of suffering. Good pain and symptom management for patients at the end of life requires the intervention of all disciplines in a holistic approach [8]. This approach mandates an interdisciplinary approach to managing care at the end-of-life. Numerous barriers, such as physical limitations and geographic distance prevent patients/families from attending IDT meetings in which they would represent their experiences, values and concerns.

The Telehospice Project at the University of Missouri utilizes commercially available videophones that operate over regular phone lines to enable patients at home and their caregivers to interact with hospice providers at the clinical site [7]. This interaction enables the “virtual” participation of patients in interdisciplinary team meetings and allows for them and their caregivers to interact with hospice providers, even ones who they would not normally meet at their home (i.e. hospice medical director) [9].

The concept of mobilized workforces leads to concerns about data security. Threats to the security created or accessed by mobile workers include possible theft of mobile devices, unauthorized access or even malicious attacks against the system’s network, such as hacker attacks and viruses. A further concern is that of a possible marginalization of patients and caregivers or rural health care providers who do not have Internet access or in general, the appropriate infrastructure to participate in a virtual team. This point is discussed later under the issue of the digital divide which, in this context becomes an important ethical consideration.

3.2. Virtual research teams

The Internet and other advanced technologies enable health care researchers to communicate and exchange information. One such pioneering initiative is create a virtual community of cancer researchers with access to a vast array of previously unavailable scientific data [10]. This international initiative labeled the Strategic Framework, aims to revolutionize medical science by fostering a new context of information exchange and creating a large virtual research community. The UK’s National Cancer Research Institute (NCRI) outlined its plans with the support of the US National Cancer Institute and other global leading cancer organizations.

The UK NCRI identified the need for faster, more efficient and accurate ways of accessing, analyzing and disseminating research datasets and findings in cancer research in order to achieve state of the art and continuously improved cancer treatments. Within the proposed virtual community, scientists in different fields of cancer research will agree on how best to record data in areas as different as genomics, medical imaging and epidemiology that will be made available to the entire research community using the web and other advanced technologies.

The Comprehensive Health Enhancement Support System (CHESS) developed by the University of Wisconsin is a platform that provides services designed to help individuals cope with a health crisis or medical concern, but also invites researchers to utilize resources and share knowledge and findings [11]. The system provides timely access to resources, such as information, social support, decision-making and problem solving tools when needed most. The CHESS application and its modules and consortia are good examples of a virtual community that serves individual patients’ and caregiver needs while also providing an active laboratory for researchers and organizations.

3.3. Virtual disease management

The concept of disease management refers to “...a set of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant [12]”. These interventions aim to enhance the care plan and the provider–patient relationship while emphasizing prevention of deterioration and complications using evidence-based practice guidelines. In addition, further goals include the improvement of outcomes, decrease of costs, patient education and monitoring.

The concept of “virtual disease management” is defined by the utilization of information technologies such as the Internet to allow patients suffering from chronic conditions to stay at home and be involved in the care delivery process. Such technologies can link home care with hospital and ambulatory care, and facilitate information exchange and communication between patients, family members and care providers. Patient education is an essential component of disease management and can be supported by the transmission of tailored health information or automated reminders to patients or their caregivers. The integration of commercially available household items, such as television sets, mobile phones, videophones, medication dispensing machines, and handheld computers introduces new communication modes and patient empowering tools.

The Internet has been used as a platform for several disease management applications and in different clinical areas. Disease management for asthma patients, for example, has the potential of early detection and timely intervention as demonstrated by the home asthma tele-monitoring (HAT) system [13] which assists patients in the daily routine of asthma care with personalized interventions.
and alerts health care providers in cases that require immediate attention.

The National Cancer Institute Common Terminology Criteria for Adverse Events schema for seven common symptoms was adapted into a web-based patient reporting system, accessible from desktop computers in outpatient clinics and from home computers [14]. In a study by Basch et al. [14] 80 patients with gynecologic malignancies beginning standard chemotherapy regimens were enrolled and encouraged to log in and report symptoms at each follow-up visit, or alternatively, to access the system from home. Numerous toxicities (grades 3–4) entered from home prompted clinician interventions. Patients were capable of reporting symptoms experienced during chemotherapy and their reporting often led to clinical interventions and changes in the care plan indicating that the use of Internet can be beneficial for the treatment and monitoring of home patients diagnosed with cancer [14].

A distributed computer-based system for the management of insulin-dependent diabetes was developed and evaluated within the Telematic Management of Insulin-Dependent Diabetes Mellitus (T-IDDM) project funded by the European Union. The objective was to utilize Internet technology and monitoring devices to support the normal activities of the physicians and diabetic patients by providing a set of automated services enabling data collection, transmission, analysis and decision support [15].

A web-based telemonitoring system providing direct transmission of home spirometry to the hospital was developed and evaluated demonstrating that home monitoring of pulmonary function in lung transplant recipients via the Internet is feasible and accurate [16]. Another application utilizing commercially available monitoring devices and the Internet was developed within the TeleHomeCare Project at the University of Minnesota aiming to enable patients at home, who were diagnosed with congestive heart failure, chronic obstructive pulmonary disease or required wound care, to interact with health care providers at the agency. Personalized web pages allowed patients to interact with their providers and fill out daily questionnaires including questions about vital signs, symptoms, and overall well-being and nutrition [17].

3.4. Patient and caregiver peer-to-peer applications

A peer-to-peer system enables any unit within a network to communicate with and provide services to another unit within the network. All peers are of the same importance to the system; no single peer is critical to the functionality of the system and the application functions without the control or authorization of an external entity. Peers can be assumed to be of variable connectivity and can join and leave the system at their own discretion.

One such application in the health care field is PeerLink [18] designed for people with disabilities. Persons with disabilities have high need for timely and complex information coordination and resource sharing. Most of the existing web-based structures and applications rely heavily on third parties to maintain and update information, resulting in high maintenance costs and limited direct control by users with disabilities. PeerLink is an information management system that allows users to share information instantaneously with others, and to selectively share personal and local community resource information according to their own specifications.

The widespread diffusion of the Internet has enabled the creation of electronic peer-to-peer communities for people with common interests, clinical conditions or health care needs to gather “virtually” to ask questions, provide support and exchange experiences. In May 2005, Yahoo!Groups (http://www.yahoo.com) listed more than 68,000 electronic support groups in the health and wellness section.

Sharf [19] studied the communication taking place at Breast Cancer List, an online discussion group which continues to grow in membership and activity. Three major dimensions of communication were identified: exchange of information, social support and personal empowerment. The study concluded that the list fulfills the functions of a community, with future concerns about information control and the potential to enhance patient–provider understanding.

Hoybye et al. [20] used ethnographic case-study methodology to explore how support groups on the Internet can break the social isolation that follows cancer and chronic pain. They studied the Scandinavian Breast Cancer List and using participant observation and interviews, followed 15 women who chose the Internet to battle social isolation. Study findings indicate that these women were empowered by the exchanges of knowledge and sharing experiences within the support group.

Tate et al. [21] conducted a randomized trial to compare the effects of an Internet weight loss program and concluded that adding e-mail counseling to a basic web-based weight loss intervention program significantly improved weight loss in adults at risk of diabetes. Another study by Houston and Cooper [22] focused on the characteristics of users of Internet-based depression support groups and found indications that web-based support groups can play a positive role in the treatment of depression.

In a recent study [23], researchers compiled and evaluated the evidence on the effects on health and social outcomes of computer-based peer-to-peer communities and electronic self-support groups. The study conclusions were that no robust evidence exists, as of yet, of consumer led peer-to-peer communities, partly because most of these communities have been evaluated only in conjunction with more complex interventions or involvement with health professionals [23]. However, given the great amount of non-moderated web-based peer-to-peer groups, further research is needed to assess when and how electronic support groups can be effective [23].
3.5. Ethical challenges

The administration of virtual communities faces challenges as such communities often include members from countries around the world. The first challenge relates to the conduct of not only professional but also personal interactions online or via communication technologies with a decreasing number of face-to-face interactions. Virtual support groups while having the potential to bring people together from all over the world and allow for anonymity might be desired for a specific medical condition, might be lacking the sense of touch and inter-human close contact that occurs in face-to-face meetings. Virtual communities represent a physically disembodied social order. While this virtual order exists in parallel with social structures in physical space, some argue that it will eventually compete with a structure or network of entities, which occupy spatial locations. It is often stated that “the fabric of human relationships and communities rests on real presences, real physical meetings and relationships”. It remains to be investigated whether the conventional notions of a social contract, personal rights, justice and freedom survive in a virtual world.

The concept of virtual health care communities is relatively new and there are no specific guidelines or regulations addressing some of these ethical considerations. The American Medical Informatics Association (AMIA) has provided guidelines for the electronic communication of patients with health care providers [26]. Based on these guidelines, a turnaround time for messages should be established, patients should be informed about privacy issues, and messages should be printed out and included in the patients’ charts. Patients must be warned not to use the online mode of interaction in an emergency and should be aware of all recipients of their messages as well as general privacy issues.

For the conduct of virtual visits using videoconferencing technologies in home care, the American Telemedicine Association [27] has produced a set of clinical guidelines for the development and deployment of such applications. These guidelines refer to patient, technology and provider criteria. Patient criteria involved a set of recommendations, such as the need for informed written consent obtained from patients, selection of patients able to handle the equipment and training. Technology criteria refer to the operation and maintenance of equipment, establishment of clear procedures and safety codes. Health provider criteria refer to training issues and after hours support.

Such guidelines by professional organizations address some important concerns and provide an appropriate framework for the integration of virtual health care communities in the care delivery process. However, many issues, such as licensing, accreditation or concerns of identity deception and dependency discussed later, have not been fully addressed yet by legislative or professional entities.

3.5.1. Communication in virtual communities

In the context of virtual communities it is important to address the actual process and frequency of communication between members. In a content analysis of an online cancer support group, Klenk et al. [28] identified a typology of information exchange, which includes information giving and seeking, statements of encouragement and support, statements of personal opinion and statements of personal experience. Rafaeli and Sudweeks [29] argued that studying threads or chains of interrelated and interdependent messages could provide a representative snapshot of communication in virtual communities. Burnett [30] presented a typology for information exchange in virtual communities. According to this classification, behaviors within virtual communities may be divided into two broad categories: non-interactive behaviors and interactive behaviors. The primary non-interactive behavior in virtual communities is referred to as “lurking”, which is the act of limiting one’s participation to the passive role of observing rather than also contributing to the discussion. Interactive behavior, on the other hand, based on the typology by Burnett, includes collaborative or positive interactive behavior, hostile behavior or behavior not specifically oriented toward information. The study of the communication content and frequency between members of virtual health care communities can reveal the impact of the virtual community on the patient–provider relationship.

3.5.2. Identity and deception

Identity is an essential component of members of virtual communities. Being aware of the identity of those with whom one interacts is essential for understanding and evaluating the interactions. Determining one’s identity in the “disembodied” world of a virtual community becomes a challenge as many of the basic cues about personality and social role one is accustomed to in the physical world, are absent [31].

Members of virtual communities become attuned to the nuances of communication styles. Members are being distinguished by their own “voice” and language. There are specific identity clues that refer to the location or the hardware of the member (such as the IP address, domain name and browser type) and more general clues that refer to the writing style, tone and language used by the member. However, these identity clues are not always reliable [31]. Members of a virtual community who have the intention to deceive the community about their identity could deliberately misuse such clues. A term that is often used in online
communities is “trolling” which refers to an individual who attempts to falsely convince members of a community that he/she shares the group’s common interest or concern with the intention to ultimately damage the feeling of trust in the community or disseminate inaccurate information, bad advice or anger participants.

Another dimension of identity deception is impersonation, namely a case where one user pretends to be another member of the virtual community providing false identity cues that lead other members of the community to believe that he/she is the member the impersonator is portraying to be.

While the issue of identity deception has been often studied in online communities where members share common hobbies or cultural interests, the impact of this behavioral pattern has not been studied extensively in the context of health care related virtual communities. In such cases, the impact of deception can go beyond impacting the trust among members of the community and lead to a damaging effect on members’ health care status.

Numerous cases of deception in virtual communities have been reported in the media and scientific literature. One of the earlier cases of deception that received great attention was that of the disabled “Joan” [32,33], a young disabled and disfigured woman who chose not to meet people face-to-face due to her disability but formed relationships within an online community. When it was revealed that Joan did not really exist and was a persona created by an impersonator, a male psychiatrist in his fifties, members of the online community expressed that they felt outrage and betrayal, while several members stated they were mourning the loss of “Joan [33]”.

Feldman [34] reports several cases where people in online support groups falsely claim to suffer from specific medical conditions. In one case, Barbara became a member of a cystic fibrosis support group claiming she was approaching the end of her life at home receiving palliative care by her sister Amy. Members of the support group exchanged messages with this individual over a long period of time and expressed their support and offered help. They all expressed distress when Amy announced to the community that Barbara had passed away. Members of the community, however, identified spelling errors and other identity clues in the communication with Amy and questioned the story. Amy admitted to being an impersonator pretending to be both the patient at the end of life and the caregiver.

The identity issue of virtual community members becomes obviously essential in the context of virtual medical teams, online communities that aim to enhance continuity of care or peer-to-peer communities where members exchange experiences and advice for a specific clinical condition.

3.5.3. Privacy and confidentiality

The healthcare sector is facing many challenges in regard to the privacy and confidentiality of individual health information in the information age. Information privacy is the patient’s right to control the use and dissemination of information that relates to them. Confidentiality is a tool for protecting the patients’ privacy. In 1998 in the US the Notice of the Proposed Rule concerning Security and Electronic Signature Standards was introduced as part of the Health Insurance Portability and Accountability Act (HIPAA) that was passed in 1996. This rule proposes standards for the security of individual health information and electronic signature use for health care providers, systems and agencies. These standards refer to the security of all electronic health information and have a great impact on the design and operation of e-health applications.

For disease management applications that are web-based, ownership of and access to the data have to be addressed. In many web-based applications in home care, patients record monitoring data and transmit them daily to a web server owned and maintained by a private third party that allows providers to login and access their patients’ data. This type of application calls for discussion and definition of the issue of data ownership and patients’ access rights to parts or all of their records. The implications are not only possible threats to data privacy but extend to ethical debates about the restructuring of the care delivery process and introduction of new key players.

Advanced information technology is being employed to protect information transactions from unauthorized third parties. However, it remains largely unexplored how to safeguard a consumer's consent to view their private information in a virtual environment [35]. Coiera and Clarke [35] propose a framework for obtaining and determining electronic consent (e-consent) within health care. They argue that an electronic system should permit access to confidential patient information by checking “that patient consent exists for the information request by invoking methods that check for explicit, inferred or implied consent [35]”. The authors emphasize that the concept of e-consent should not require an expensive administrative infrastructure to support the obtaining and determining and monitoring of consent. There are several forms of patient consent (e.g. general consent, general consent with specific finials, general denial, etc.) The actual health care domain, type and purpose of a virtual community application and the individual patient preference will detect which type would be applicable to a given system. While the concept of e-consent by Coiera and Clarke [35] has been introduced as a theoretical framework, it addresses the privacy concerns associated with virtual communities and as such it should be integrated into the design of systems so that they are equipped with a mechanism that documents and employs the specific inclusion and exclusion criteria pertaining to patients’ consent intentions.

Virtual communities have the potential to bring people together bridging geographic distance; thus, the Internet and other advanced telecommunication technologies can cross national borders and link people from different
countries for the purposes of health care delivery and education. In these cases the premise that electronic health care data protection depends on national laws is insufficient in providing a clear framework for the definition of a data privacy violation. As Kluge argues [36], it is important to define “ethical guidelines for the protection of electronic health care data that must focus solely on fundamental ethical principles” and not on national laws.

As the number of web-based applications in health care increases and institutions exchange information on a global level, a code of ethics for the protection of patient records needs to be developed to address this new reality based on the notion, as Kluge puts its [36], that the “action domain of health information professionals assumes global dimensions”.

3.5.4. The digital divide

One of the premises of the use of advanced technologies is health care is its potential to increase access to care for rural and urban under-served patients. This hypothesis can be explored by investigating how virtual communities address decreased utilization of services, particularly at the entry to care and the associated structural, financial or personal barriers. When discussing access barriers in relation to Internet and other telecommunication technologies, the digital divide comes to mind. This term is used to refer to the gap in computer and Internet access between population groups segmented by income, age, educational level or other parameters. In 2000, for example, in the US households with an income of US$ 75,000 or higher were more than six times as likely to have Internet access than families with income less than US$ 15,000 [37]. Several efforts have been made to address this divide focusing primarily on providing access to computers, the Internet, and training. While lower socio-economic groups are increasingly gaining Internet access, it is considered likely that the digital divide will persist as new technologies become available. For example, as sophisticated multimedia services become an integral part of Internet-based applications, broadband access may become as important for accessing health care sites as narrowband access is today for obtaining web-based health information. In that case, the digital divide can exist between two groups that both have PC hardware and Internet access, simply due to different access protocols. Furthermore, access to infrastructure is only one dimension of the digital divide, of which health literacy and appropriate web content are additional key components. The concept of accessible design, discussed later under technical challenges, is also relevant to the concern of a digital divide, as applications that utilize features incompatible with the level of experience or functionality of specific user groups (e.g. senior users with functional limitations) may isolate or exclude these groups depriving them from potential benefits of health monitoring and education.

3.5.5. Liability, accountability and malpractice

Although virtual community applications have been growing and expanding, the legal and regulatory environment has not progressed as rapidly. Interstate communities that link providers and patients raise licensure questions, such as whether physicians can be practicing medicine in a remote state where they do not have a practicing license. The question of accreditation also remains largely unexplored. Is there a need for separate standards for “virtual” practice? What should be the regulations for a “remote physician” who wants to admit patients? Should, in the cases of a virtual health care team that links providers in different institutions, the “host” site continuously monitor “remote” physicians’ competence to the same extent it does with its own medical staff members? The ambiguity lies in the fact that liability issues may arise in cases of “virtual” malpractice; however, the current legislative framework is not equipped to fully address such cases.

3.6. Technical challenges

3.6.1. Sociability and usability

Preece [38] introduces the terms sociability and usability in the context of virtual communities as two concepts that link knowledge about human behavior with appropriate planning and design of online communities. Sociability refers to the collective purpose of a community, the goals and roles of its members, and policies and rules defined to foster social interaction. The members’ information needs can be addressed within the online community according to the social framework and the defined polices. Each virtual community is unique and its growth or development can be unpredictable. Developers and designers can influence the development trend by clearly communicating the purpose and policies of the community.

Usability in general refers to the accessibility of the design and the specifics of an interface that lead to rapid learning, increased skill retention and minimizing error rates. The implication for virtual communities, according to Preece [38], is that a usable virtual community is one where members are able to communicate with each other, find information, and navigate the community software with ease.

3.6.2. Design accessibility

A large portion of patients requiring home care services or disease management interventions are elderly and in some cases have functional limitations due to aging and/or their diagnosis. A functional limitation describes a “… reduced sensory, cognitive or motor capability associated with human aging, temporary injury, or permanent disability that prevents a person from communicating, working, playing or simply functioning in an environment where other people in the population can function [39]”. While the concept of virtual communities is based on the use of the Internet and other advanced technologies, the fastest growing segment of the US population (i.e. people over the age of 50 years) are at
a disadvantage because software and hardware designers often fail to consider them as a potential user group. Accessibility issues are important quality criteria for web-based interventions, but are frequently ignored by designers and evaluators [40]. The design of a usable web-based information system becomes a challenge when it targets users inexperienced with the technology and with possible functional limitations. Therefore, systems targeting home care patients should have reached a high level of functional accessibility [41] and undergone rigorous usability tests. Several design considerations can be taken into account when developing systems for the elderly or other populations with functional limitations [41].

3.7. A call for research in the domain of virtual health care communities

Patient empowerment is a concept that has emerged in the health care literature in the last few years. It is based on the principle that patients are entitled to access health information and determine their own care choices. Feste argues that the empowerment model introduces “self-awareness, personal responsibility, informed choices and quality of life [42]”. Empowerment can be perceived as an enabling process through which individuals or groups take control over their lives and managing disease. Advances in telecommunication technologies have introduced new ways to enhance and supplement communication between health care professionals and patients. The implication is a shift of focus for system designers who had primarily focused on designing information technology applications that addressed the needs of health care providers and institutions only. As a result, the data models included episodic patient encounters as one group of health care related transactions, but did not aim to evolve around the life course of the individual patient or ensure continuity of care. New technologies and advancements in informatics research call for the development of informatics tools that will support patients as active consumers in the health care delivery system. Virtual communities are one of the tools that enable a shift from institution-centric to patient-centric information systems.

In order to establish evidence-based guidelines for the design and maintenance of virtual communities, it is obviously necessary to further the research agenda beyond exploratory pilot studies to clinical trials and interventions that follow an experimental design.

In order to increase the generalizability of findings, researchers need to also document the social context and recruitment approaches to involve new members in a virtual community, the implied and stated rules that govern the virtual community, its rate of growth and utilization rates, the business model or funding agency and strategies to promote the application and involve communities.

Finally, it is important to develop assessment tools for patient empowerment. Most applications aim to empower patients; yet, measuring this effect is challenging as there is a lack of validated and reliable assessment tools. Obviously, such an assessment tool would cover several underlying constructs, such as disease knowledge, locus of control, trust, accessibility to services and availability of options. Studies that follow a pre–post design based on the employment of a potential survey can reveal how a virtual community influences these underlying constructs.

4. Discussion and conclusion

4.1. Discussion

Virtual communities are emerging in many health care related domains. Such communities aim to support patients, caregivers, families and health care providers and facilitate information exchange, provide support and enhance communication among people who do not have to be physically present at the same time at one location. Whether such communities are based on moderated or non-moderated discussions, it is important to have a clear, published and easily accessible set of rules and regulations or code of conduct for the members of the virtual community. Members of such a community need to claim ownership of the community so that they can be encouraged to provide constructive critiques and improve overall performance.

4.2. Conclusion

Powerful technologies and trends are emerging in the health care field. Advanced technologies that enable people to communicate and form virtual teams and communities can revolutionize the health care field and support a paradigm shift, namely the shift from institution-centric to patient-centric or consumer-centric systems. Policy, ethical and legal issues associated with virtual health care communities will have to be addressed. Furthermore, extensive research initiatives are needed that will determine the impact of virtual health care communities on clinical outcomes, the overall process and quality of and access to care. Such initiatives should go beyond pilot-testing an innovative application and employ experimental design methods to investigate the utility of virtual health care communities and the extent to which they empower patients and their caregivers. As advanced web-based applications continue to emerge and grow, system designers, health care settings, organizations and policy makers need to be prepared to properly adopt these technologies and develop the capacity to evaluate and make informed decisions about their appropriate use.

4.3. Practice implications

When practitioners utilize virtual community tools to communicate with patients or colleagues they have to
maximize sociability and usability of this mode of communication, while addressing concerns for privacy and the fear of de-humanizing practice, and the lack of clarity or relevance of current legislative frameworks. Virtual communities have the potential to become powerful tools for practitioners; however, extensive research is needed to document the effectiveness of this mode of communication.

References


