

A Model for Global Health Virtual Communities

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Abstract— This paper presents a model for Health Virtual Communities deployed on a Global Health level. It starts with an initial model built previously, and provides a thorough analysis of the components needed on a Global Health level, in order to provide a successful Global Health Virtual Community. The model provides a list of characteristics that a Global Health VC design should have in order for it to provide a viable, value-added experience to the participants.

Keywords-Community; Health; Global Health; Online Communities; Modeling

I. INTRODUCTION

In the beginning of the 1990’s, people started to create online communities, also known as Virtual Communities (VCs). The phenomenon was due to the development of the World Wide Web. Researchers started to explore ways in which people use VCs. For instance, Kivimäki et al. [1] investigated interaction patterns and identity formation in VCs including mechanisms that supported identity formation (awareness, voice, text, voice, authentication) [1, 2]. In later stages, the emergence of deviant behavior in VCs pushed the researchers to propose trust tools [3-5]. The ways in which teams are formed inside a community were also analyzed and coordination [6] and awareness [7] emerged as determinant factors in team formation. Later on, both tacit and explicit knowledge in VCs [8] [9] were captured and used of in different domains [10]. Health related Virtual Communities did also emerge, with their own opportunities and challenges [11] [12].

However, very little has been the effort to address the issues related to Global Health Virtual Communities and Challenges. In this paper, we will overview these challenges and suggest a preliminary model for Global Health VCs.

In this paper, we will present a model for virtual communities in section II, and describe the types of global health virtual communities’ challenges in section III. A global health virtual community model is described in section IV, and section V concludes the paper.

II. VIRTUAL COMMUNITY MODEL

We will take as a starting point a model for collaborative virtual communities that has been suggested by El Morr [11] [13]:

A. A Model for Collaborative VCs

Four dimensions characterize the model, shown in Figure 1: the degree of virtuality, the degree of mobility, the degree of cooperation and the degree of uniformity.

The degree of mobility specifies if the VC members is ‘Still or ‘mobile’

The degree of virtuality specifies if an encounter between members is ‘physical’ (members are physically in the same place) or ‘virtual’ (members meet online) .

The degree of cooperation specifies if the members’ awareness of each other passes through a simple notification mechanism, or if the members ‘collaborate’ dynamically and actively on a common aim

The degree of uniformity specifies if the members are extremely ‘homogeneous’ (the VC is a community of practice); or ‘heterogeneous’ (having different occupations).

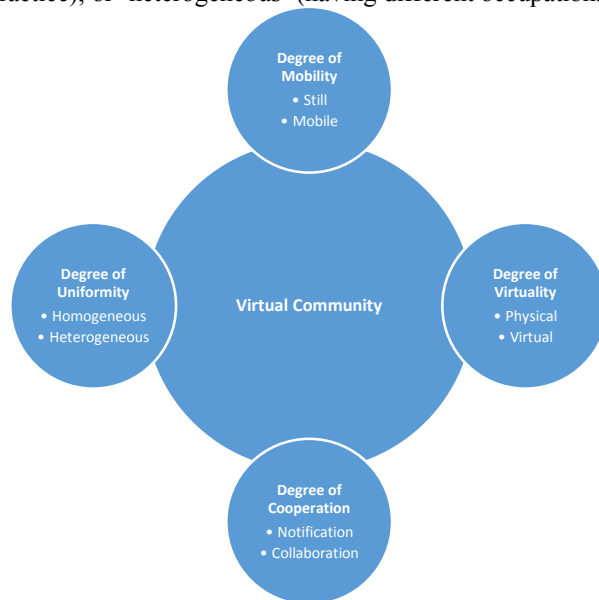


Figure 1. The four dimensions of a collaborative virtual community

This model is a generic one and we should update it to take into consideration the particularities of the health field and of the global dimension, inherent to a global health virtual community.

III. GLOBAL HEALTH VIRTUAL COMMUNITIES CHALLENGES

A global health virtual community presents particular challenges that should be dealt with in order for it to be successful. These challenges are related to the sensitivity of the health sector (e.g., confidentiality) and to the global reach of the community (e.g., cultures). In the next two paragraphs, we will analyze both of these types of challenges.

A. Health related challenges

A health VC could be patient centered, profession centered or dedicated for general public access.

Patient-centered VCs focus their activities on care delivery mechanisms to provide *support* for patients while they are away from the point of care. Patient support is important because social factors, such as isolation and lack of social relationships, have a tremendous impact on health. Research has shown that social factors have an effect on cold [14], coronary heart disease [15][16], cancer, hypertension, tuberculosis, cirrhosis of the liver, suicide, and death rate [17]. This explain the development of Health VCs that support patients with conditions such as HIV, Cancer [5, 18-26] and depression [27], and others that provide tele-monitoring capacity of patients at home [28][29].

On the other hand, VCs can be **Professional-Centered**. **Such VCs are dedicated to support professionals** in their activities around patients; they can provide knowledge sharing mechanisms [8, 30-33], enable knowledge creation and dissemination, or educate the public and non-governmental organizations [10].

Public-Centered VCs aim to educate the population (e.g., *self-management* of their disease), which empowers the public and affect positively their health [34-41] [42] [43]. In this context, mobile-based health care VCs is expected to play a key role in self-managed care [44].

B. Global Virtual Communities Challenges

A Global Health VC raises many challenges to the healthcare community. It shares some of these challenges with the local health virtual communities while it has specific ones tied to its global perspective.

1) Common challenges

Usability is still an issue in information systems development, and it is of paramount importance in healthcare. In Global Health VCs, it would be crucial to have a user interface built to enhance the user experience (e.g., patient, nurses, doctors, caregivers). The success of any global health VC is related to having a usable interface that enables users instead of disabling them. We shall call this an *inclusive design* in our model.

The other challenge is to build mechanisms to enable participation in the community; such mechanisms are essential to avoid lurking [45][46][47]. A *participatory approach* is then unavoidable.

Many failures in healthcare related information systems are related to the lack of members' support. A global health VC should be *Supportive*; such feature will boost adoption and minimize resistance to a disruptive technology.

The global health VC should also be able to integrate in the workflow in place. On a global level, the workflows of different participants may differ drastically, having to adapt to heterogeneous workflows is necessary for the global health VC to operate seamlessly in its environment. A *workflow adaptive* dimension in the global health VC is therefore important.

Security, trust, and privacy/confidentiality are important too; though, on a global level the question of data storage is sensitive. The geographical location where data is stored and the laws that would apply in case of a breach of confidentiality are global specific. However, this is a policy issue and not a mere technological challenge; policy mechanisms should be part of any global health VC model. Hence, the global health VC should be *policy sensitive*.

Finally, personalization of the information and the interface presented to the user are important so that s/he is not overwhelmed with information and irrelevant interface features. A *profile sensitive* VC would be necessary.

2) Global perspective challenges

Some of the global challenges in Global Health VCs are the cultural differences, the environmental features, the asymmetry in the infrastructure, and the perceived VC value.

A global health VC should adapt to many languages and possibly cultural differences. A successful global health VC should be *culturally adaptive*.

Users should acknowledge the differences in the local environments; for instance, a disease in one country may be irrelevant in another. The global health VC should be *environmentally adaptive*.

One of the challenges that may be faced is the asymmetry in infrastructural (e.g., a developed and a developing country may not have access to the same technologies). A global health VC should provide many channels for communication and cooperation, thus providing *technology adaptive* features.

All parties involved from different countries should be able to perceive value in the VC. The global health VC can achieve this aim by providing means to share resource between stakeholders. A fruitful global health VC should be able to be poised as a *value catalyst*.

IV. TOWARDS A GLOBAL HEALTH VIRTUAL COMMUNITIES MODEL

Based on the above analysis, we can adjust the preliminary model presented in figure 1 adding to it the features discussed above; the result is shown in figure 2.



Figure 2. A Global Health Virtual Community Model

A. A scenario

Consider an example of a global health virtual community project, involving a developed and a developing country, dedicated for chronic diseases self-management.

We will apply the above model to analyze the VC requirements and identify its high-level needs.

Degree of Mobility

Most of the parts of the system need not to be mobile. That includes a component of online education that can be browsed on a PC/laptop/tablet. However, a mobile App should be provided for people having access to smart phones in both developing and developed countries. Besides, in the developing country, the e-education can take place using targeted SMS messages. For elderly, a DVD presenting the educational material would be most appropriate in developing countries. Thus, a hybrid approach would be chosen, to incorporate online, off-line, mobile and static access to the material.

Degree of Virtuality: The community would be virtual since members would not be connected to it virtually and they are not present in the same physical space.

Degree of Cooperation: Consumer members (i.e., patients) would need only loose cooperation. A forum would be enough if there were a need to connect patients together in order for them to exchange experiences. Administrators and researchers of the VC will require special tool to enable tight cooperation.

Degree of Uniformity: The community would be heterogeneous since it would involve patients, researchers, doctors, nurses, field workers, etc.

Design Inclusivity: The design would have to be inclusive since its inception. For instance, the patients can present different degrees of disability due to age and/or pathology.

Therefore, patients would be included in the design in early stages. Besides, there would be a need to decide on the languages used to present the educational material.

Participatory Approach: A participatory approach could be not needed since members would either seek participation for the sake of their own health (e.g., patients), or for the sake of providing healthcare advices and monitor the VC (e.g., researchers, doctors).

Supportiveness: A VC administrator could be needed to support the members using the system.

Workflow Adaptability: In this particular VC, the workflow is not an issue, since the VC is patient oriented and do not interfere with the day to day activities of the healthcare providers.

Policy Sensitivity: The privacy and confidentiality laws and regulations would be implemented based on the local laws and regulations of the host server (e.g. developed country). However, policies regarding data extraction and use should be set in place in order for all parties to be able to use data without confidentiality breaches.

Profile Sensitivity: The user interface should be adapted to the patient profiles. Age and pathology would be major factors in the adaptation process; for example, elderly would need a non-cluttered, simplified, user interface.

Cultural Adaptability: The researchers would have to use both languages in effect in both countries. Therefore, the educational material should be translated.

Environmental Adaptability: There was no environmental issue since the VC is educating patients having the same chronic diseases.

Infrastructure Adaptability: Researcher could decided on many delivery strategies for the educational modules. A basic cellular communication infrastructure in the developing country could dictate an SMS delivery method for mobile users of that country. While a 4G network in the developed country would lead to developing Apps for patients with smart phone devices. Many delivery channels would then be in place.

Value Catalyst: We could expect the VC to be perceived as adding value for patients in both developed and developing countries. Beside, healthcare and economic systems in both countries would benefit from the VC role in enhancing the patients quality of health.

B. Consequences

This scenario demonstrate how would the model be applied and how it would provide help in structuring the way we identify the high-level needs of a global health VC, leading us to ask the right questions and make the right analysis and design of the system.

V. CONCLUSION

This paper analyzed the virtual community features and the health field needs and challenges in a global perspective; it then proposes to enlarge a previous VC model to make it adaptive to a global health perspective. The model provides a list of characteristics a Global Health VC design should take into consideration to implementing a viable, successful, value-added experience to the participants in a global health virtual

community. We provided a scenario to demonstrate the ability of the model to guide developers through the analysis phase of a global health VC project, and to provide a streamlined way to identify a suitable course of actions.

REFERENCES

- [1] A. Kivimäki, K. Kauppinen, and M. Robinson, "Identity in virtual communities," *SIGGROUP Bull.*, vol. 19, 1998, pp. 29-33
- [2] A. Malhotra, S. Gosain, and A. Hars, "Evolution of a virtual community: understanding design issues through a longitudinal study," presented at the Proceedings of the eighteenth international conference on Information systems, Atlanta, Georgia, United States, 1997, pp. 59-73
- [3] A. Abdul-Rahman and S. Hailes, "Supporting Trust in Virtual Communities," presented at the 33rd Hawaii International Conference on System Sciences, Maui, Hawaii, 2000, pp. 1-9
- [4] A. Ali Shaikh and R. Omer, "Formalising trust for online communities," in Fourth international joint conference on Autonomous agents and multiagent systems, The Netherlands, 2005, pp. 1245-1246.
- [5] W. Ebner, J. M. Leimeister, and H. Krcmar, "Trust in Virtual Healthcare Communities: Design and Implementation of Trust-Enabling Functionalities," presented at the Proceedings of the Proceedings of the 37th Annual Hawaii International Conference on System Sciences (HICSS'04) - Track 7 - Volume 7, 2004, pp. 1-10
- [6] Y. Zhang and M. Weiss, "Virtual communities and team formation," *Crossroads*, vol. 10, 2003, pp. 5-5
- [7] D. G. Boyer, M. J. Handel, and J. Herbsleb, "Virtual community presence awareness," *SIGGROUP Bull.*, vol. 19, 1998, pp. 11-14
- [8] Y. Merali and J. Davies, "Knowledge capture and utilization in virtual communities," presented at the Proceedings of the 1st international conference on Knowledge capture, Victoria, British Columbia, Canada, 2001, pp. 92-99
- [9] J. Yu, Z. Jiang, and H. C. Chan, "Knowledge contribution in problem solving virtual communities: the mediating role of individual motivations," presented at the Proceedings of the 2007 ACM SIGMIS CPR conference on Computer personnel research: The global information technology workforce, St. Louis, Missouri, USA, 2007, pp. 144-152
- [10] C. El Morr, J. Subercaze, P. Maret, and M. Rioux, "A Virtual Knowledge Community for Human Rights Monitoring for People with Disabilities," presented at the IADIS International Conference on Web Based Communities, Amsterdam, The Netherlands, 2008, pp. 78-84
- [11] C. El Morr, "Mobile Virtual Communities in Healthcare The Chronic Disease Management Case," in *Ubiquitous Health and Medical Informatics: The Ubiquity 2.0 Trend and Beyond*, ed: IGI Global, 2010, pp. 258-274
- [12] C. El Morr, "Health Care Virtual Communities: Challenges and Opportunities," in *Handbook of Research on Developments in E-Health and Telemedicine: Technological and Social Perspectives*, ed: IGI Global, 2010, pp. 278-298
- [13] C. El Morr and J. Kawash, "Mobile Virtual Communities Research: A Synthesis of Current Trends and a Look at Future Perspectives," *International Journal for Web Based Communities*, vol. 3, 2007, pp. 386-403
- [14] R. M. Heeler, "Social ties and susceptibility to the common cold," *JAMA*, vol. 278, January 22, 1992, pp. 1231-1232
- [15] R. B. Case, A. J. Moss, N. Case, M. McDermott, and S. Eberly, "Living alone after myocardial infarction. Impact on prognosis," *JAMA*, vol. 267, January 22, 1992, pp. 515-519
- [16] R. B. Williams, JC Barefoot, RM Califf, TL Haney, WB Saunders, et al., "Prognostic importance of social and economic resources among medically treated patients with angiographically documented coronary artery disease," *JAMA*, vol. 267, January 22, 1992, pp. 520-524
- [17] R. B. Adler, R. F. Proctor, N. Towne, and J. A. Rolls, *Looking Out Looking In*, 3rd ed.: Thomson - Nelson, 2008.
- [18] D. H. Gustafson, R P Hawkins, E W Boberg, F McTavish, B Owens, M Wise et al., "CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved," in *The 10th World Congress on Medical Informatics (Medinfo 2001)*, London,UK, 2001, pp. 1459-1463
- [19] D. H. Gustafson, R P Hawkins, E W Boberg, F McTavish, B Owens, M Wise, et al., "CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved," *International Journal of Medical Informatics*, vol. 65, November 12, 2002, 2002, pp. 169-177
- [20] Z. Temesgen, J. E. Knappe-Langworthy, M. M. S. Marie, B. A. Smith, and R. A. Dierkhising, "Comprehensive Health Enhancement Support System (CHESS) for People with HIV Infection," *AIDS and Behavior*, vol. 10, January 2006, pp. 35-40,
- [21] Y. Arnold, M. Daum, and H. Krcmar, "Virtual Communities in Health Care : Roles, Requirements and Restrictions," presented at the Multikonferenz Wirtschaftsinformatik (MKWI) 2004, Universität Duisburg-Essen, 2004, pp. 18-23
- [22] Y. Arnold, J. M. Leimeister, and H. Krcmar, "CoPEP: A Development Process Model for Community Platforms for Cancer Patients," presented at the The XIth European Conference on Information Systems (ECIS), 2003.
- [23] H. Krcmar, Y. Arnold, M. Daum, and J. M. Leimeister, "Virtual communities in health care: the case of "krebsgemeinschaft.de"," *SIGGROUP Bull.*, vol. 23, 2002, pp. 18-23
- [24] J. M. Leimeister, M. Daum, and H. Krcmar, "Towards m-communities: the case of COSMOS healthcare," in *The 36th Annual Hawaii International Conference on System Sciences(2003)*, 2003.
- [25] J. M. Leimeister, M. Daum, and H. Krcmar, "Towards mobile Communities for cancer patients: the case of Krebsgemeinschaft.de," *International Journal for Web Based Communities*, vol. 1, 2004, pp. 58-70
- [26] J. M. Leimeister, P. Sidiras, and H. Krcmar, "Success factors of virtual communities from the perspective of members and operators: an empirical study," in *37th Annual Hawaii International Conference on System Sciences(2004)*, 2004, pp. 1-10
- [27] T. K. Houston, L. A. Cooper, and D. E. Ford, "Internet support groups for depression: A 1-year prospective cohort study," *The American Journal of Psychiatry*, vol. 159, 2002, pp. 2062-2068
- [28] A. Pitsillides, B. Pitsillides, G. Samaras, M. Dikaiakos, E. Christodoulou, et al., "DITIS: A collaborative virtual medical team for home healthcare of cancer patients," in *M-Health: Emerging Mobile Health Systems*, R. H. Istepanian, S. Laxminarayan, and C. S. Pattichis, Eds., ed: Springer, 2005, pp. 247-266.
- [29] G. Demiris, D. R. Parker Oliver, D. Porock, and K. L. Courtney, "The Missouri telehospice project: background and

- next steps," Home Health Care Technology Report, vol. 1, 2004, pp. 55-57
- [30] H. Clark, "Formal Knowledge Networks: A Study of Canadian Experiences Helping Knowledge Networks Work," International Institute for Sustainable Development, Winnipeg, 1998.
- [31] T. Willard, "Helping Knowledge Networks Work," International Institute for Sustainable Development, Winnipeg 2001.
- [32] J. Davies, A. Duke, and Y. Sure, "OntoShare: a knowledge management environment for virtual communities of practice," presented at the Proceedings of the 2nd international conference on Knowledge capture, Sanibel Island, FL, USA, 2003, pp. 20-26
- [33] P. Maret, M. Hammoud, and J. Calmet, "Muti Agent Based Virtual Knowledge Communities for Distributed Knowledge Management," in International Workshop on Engineering Societies in the Agents World (ESAW), Toulouse, France, 2004, pp. 33-44.
- [34] E. T. Adolfsson, B. Smide, E. Gregeby, L. Fernström, and K. Wikblad, "Implementing empowerment group education in diabetes," *Patient Education and Counseling*, vol. 53, June, 2004, pp. 319-324
- [35] R. M. Anderson and M. M. Funnell, "Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm," *Patient Education and Counseling*, vol. 57, May, 2005, pp. 153-157
- [36] I. Aujoulat, W. d'Hoore, and A. Deccache, "Patient empowerment in theory and practice: Polysemy or cacophony?," *Patient Education and Counseling*, vol. 66, April, 2007, pp. 13-20
- [37] N. C. Elder, S. L. Regan, H. Pallerla, L. Levin, D. Post, and D. J. Cegela, "Development of an instrument to measure seniors' patient safety health beliefs: The Seniors Empowerment and Advocacy in Patient Safety (SEAPS) survey," *Patient Education and Counseling*, vol. 69, December, 2007, pp. 100-107
- [38] C. Feste and R. M. Anderson, "Empowerment: from philosophy to practice," *Patient Education and Counseling*, vol. 26, 1995, pp. 139-144
- [39] P. K. Hansford, "Empowerment through choice - enabling speech to flow," *Patient Education and Counseling*, vol. 34, May 1, 1998, pp. S76-S76
- [40] K. Johansson, S. Salanterä, J. Katajisto, and H. Leino-Kilpi, "Written orthopedic patient education materials from the point of view of empowerment by education," *Patient Education and Counseling*, vol. 52, , February, 2004, pp. 175-181
- [41] B. Luban-Plozza, "Empowerment techniques: from doctor-centered (Balint approach) to patient-centred discussion groups," *Patient Education and Counseling*, vol. 26, September, 1995, pp. 257-263
- [42] J. Meuser, T. Bean, J. Goldman, and S. Reeves, "Family health teams: A new Canadian interprofessional initiative," *Journal of Interprofessional Care*, vol. 20, 2006, pp. 436-428
- [43] HealthCanada, Handbook 3A-Service Delivery Plan for the Home and Community Care Program, 2000.
- [44] B. H. Stamm, "Creating Virtual Community: Telemedicine and Self Care," in *Secondary Traumatic Stress: Self-Care Issues for Clinicians, Researchers and Educators*, B. H. Stamm, Ed., ed: Sidran Press, 1999, pp. 179-207.
- [45] J. Koh, Y.-G. Kim, B. Butler, and G.-W. Bock, "Encouraging participation in virtual communities," *Commun. ACM*, vol. 50, 2007, pp. 68-73
- [46] B. Nonnecke and J. Preece, "Lurker demographics: counting the silent," in *Proceedings of the SIGCHI conference on Human factors in computing systems*, The Hague, The Netherlands, 2000, pp. 73-80.
- [47] L. Sproull and S. Faraj, "Atheism, Sex, and Databases : The Net as a social technology," in *Culture of the Internet*, S. Kiesler, Ed., ed: Lawrence Erlbaum Associates, 1997.