

A Health Virtual Community Model

A Bottom Up Approach

Christo El Morr
School of Health
Policy and
Management
York University
Toronto, Canada
elmorr@yorku.ca

Shadi Saleh
Department of Health
Management and
Policy
American University
of Beirut
Beirut, Lebanon
ss117@aub.edu.lb

Walid Ammar
Ministry of Public
Health
Beirut, Lebanon
mphealth@cyberia.ne
t.lb

Nabil Natafgi
Department of Health
Management and
Policy
American University
of Beirut
Beirut, Lebanon
nmn13@aub.edu.lb

Karen Kazandjian
Department of Health
Management and
Policy
American University
of Beirut
Beirut, Lebanon
kk03@aub.edu.lb

Abstract— This paper presents a model for Health Virtual Communities (Health VCs) based on a case study of a Health VC for chronic disease management designed for rural and disadvantaged communities in a developing country. It provides an analysis of the components needed in the Health VC and the necessity of a flexible design. The model provides a list of characteristics that a Health VC design should have in order for it to provide a viable, value-added experience to users who have heterogeneous capacities in terms of access to Information and Communication Technologies (ICT). It establishes a first attempt towards a framework for a Global Health VC analysis and design.

Keywords- Health; Global Health; Online Communities; Modeling; developing countries; rural eHealth; LMIC.

I. INTRODUCTION

Since its inception, the Internet provided a great opportunity for people to meet online and form the first Virtual Communities (VCs). VCs drove a lot of research to understand the way people cooperate in them and the challenges and opportunities they provide. Researchers explored the possibility of use of VCs in identity building [1], and looked into the design issues involved in connecting people together [2] to drive trust [3-5], and enable reciprocal awareness [6]. Besides, the ability of a community to generate and use knowledge was investigated [7, 8] and diverse VCs were implemented, such as, human rights monitoring [9]. Health Virtual Communities (Health VCs) were not late to emerge and to carry their own problems and prospects [10, 11].

Global Health Virtual Communities and Challenges have recently been investigated and a first attempt towards a model for Global Health VCs was proposed by El Morr [12]. In this paper, we will start with a background about health virtual communities (Section II). We will then introduce a previously suggested model (Section III). We will then explain the project (Section IV) and describe how we did apply it in global health project where the team had to build a health virtual community to enhance equity in the supply and demand of primary health care services in Lebanon and suggest its modification to the model based on experience (Section V). We will then conclude the paper (Section VI).

II. HEALTH VIRTUAL COMMUNITIES

Health Virtual Communities can be defined as a group of people using information and communication technologies to deliver health care services; they cover a wide range of clinical specialties, technologies and stakeholders [13]. The stakeholders and participants of Health VCs are health care providers, educators, patients, and health professionals (e.g. nurses). Health VCs can be divided into three types depending on the objectives they aim to achieve; a VC can be (1) *Professional Centered*, (2) *Patient Centered*, or (3) *General Public Centered*.

Examples of *professional centered* VCs include knowledge exchange and research teams [14-17]. Members in these communities are health professionals that interact and work in virtual teams in order to exchange knowledge and create new knowledge if possible [7]. Professional-Centered VCs provide support for healthcare professionals in their activities.

Patient centered VCs involve usually patients, their family members, and a health professional from the community [18-20]. Patient centered VCs permit professionals-to-patient and patient-to-patient communication and support [5, 21-26]. Indeed, health care professionals can form virtual teams to provide care and support in disease management; besides, individuals diagnosed with the same chronic [27] or life threatening disease, or undergoing the same treatment, can exchange and share health information and personal stories. Thus, a patient centered VC ensures continuity of care through the exchange of messages and resources. Patient-centered VCs facilitate care delivery mechanisms to provide support for patients while they are away from the point of care. Patient support is paramount; its lack has a serious impact on health [28-31].

General public centered VCs are open and include educational services, discussion forums, and access to health information. The aim would be for the patients to be in charge of their health care by personal action (i.e., manage their disease) [32]. Many research projects demonstrated the importance of education in empowering patients [32-39]. Some general public VCs are disease specific while others target a specific social group (e.g. women) [40-42]. General

public VCs aim to disseminate knowledge to the wider population, promoting self-management of healthcare and empowering patients [32-39, 43].

III. A VIRTUAL COMMUNITY MODEL

El Morr has suggested a model for collaborative virtual communities [10, 44] and developed it later to encompass global health virtual communities [12], and suggested a model shown in Figure 1.



Figure 1. A Global Health Virtual Community Model

The model stipulates that a global health virtual community should have the following fourteen features:

The **degree of mobility** specifies if the VC members are '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).

It should have an **inclusive design** that supports diverse users, and conduct a **participatory approach** to encourage their participation. The global health VC should be **supportive** to users, **workflow adaptive**, and should adapt its behavior (interface) to the different kinds of users by being **profile sensitive** and therefore personalizable.

The **policy sensitive** aspects reflect the need for the VC to be able to adopt different security, privacy and trust mechanisms.

A successful global health VC should be **culturally adaptive and environmentally adaptive** reflecting different environments' priorities and contexts.

One of the challenges is for it to provide **infrastructure adaptive** features by being able to accommodate less expensive and advanced technologies. Finally, it should provide means to share resources between stakeholders acting as a **value catalyst** tool.

IV. THE PROJECT

The collaborative research team includes researchers from the American University of Beirut, Ministry of Public Health (MoPH) in Lebanon, the United Nations Relief and Works Agency (UNRWA), York University, and University of Toronto.

In Lebanon, a Low-Middle Income Country (LMIC), chronic diseases constitute an important public health problem accounting for around 84% of all deaths based on the 2008 estimates of the World Health Organization (WHO) [45]. Specifically, age-standardized death rates from cardiovascular diseases (CVDs) and diabetes reached 404.4 and 262.7 per 100,000 individuals [46]. This burden of chronic diseases is further aggravated in the context of disadvantaged populations in many of the rural areas and Palestinian refugee camps in Lebanon. For instance, residents of underserved rural areas in many regions in Lebanon, as well as the Palestinian residents in the refugee camps, lack equitable and sustainable access to modern care services for chronic illnesses. Non-governmental organization (NGO)-run primary health care centers and dispensaries are considered the only facilities available in the aforementioned underprivileged rural areas and often suffer from limited availability of resources [47].

This project constitutes an eHealth [48] proactive integrated approach that couples community-based and health care initiatives to managing chronic diseases.

Ten Primary Health Care (PHC) centers located in rural areas and enrolled in the Lebanese Ministry of Public Health (MoPH) PHC National Network (Network) and six United Nations for Relief and Works Agency (UNRWA) centers will comprise the study population. The ten MoPH and six UNRWA centers are randomly assigned into the intervention and control groups (five MoPH and three UNRWA centers in each for eight intervention sites). Each PHC center belonging to the Network has a defined catchment area with an average of 30,000 inhabitants [49]. The ten participating MoPH centers will be chosen from five rural areas in Lebanon (2 centers from each area – one as control and one as intervention).

A. The Intervention

The eHealth intervention will have two components:

- 1) **PHC center-based** in which eHealth will target the physicians (supply) and patients suffering from diabetes and hypertension (demand) treated in these centers, and
- 2) **Community-based**.

1) PHC center-based

a) Health Provider Side

The Provider side eHealth intervention will comprise two main initiatives:

(1) Online modules for treating diabetes and hypertension focusing on (a) clinical guidelines and (b) physician-patient communication strategies (smoking cessation, increasing compliance, etc.).

(2) Online forums and Frequently Asked Questions (FAQs) mainly dedicated to peer-to-peer knowledge sharing of treatment and communication techniques, as well as a database of Questions and Answers (Q&A) on such techniques.

b) Patient Side

On the other hand, the Patient side eHealth interventions will comprise one main level: the current patients will receive cell phone text messages or short message services (SMSs) that include simple weekly medical information about their respective disease and the importance of compliance and generic reminders of appointments and regular physician follow-up.

2) Community-based

A community-based intervention will be conducted that includes screening for diabetes, hypertension and obesity in the catchment area of each of the eight (5 MoPH and 3 UNRWA) intervention centers. Allied health professionals (nurses or medical technologists) will perform household screening of individuals using a purposefully designed chronic illnesses screening kit that measures the following components: (a) blood glucose level, (b) blood pressure, (c) waist circumference, and (d) Body Mass Index (BMI). The results of the four screening tests will be remotely entered on a software application alongside other demographic data pertaining to the individual including name, gender, age, and others. In the event that the individual is identified to have symptoms of one or more of the three screened diseases, the individual will be offered an appointment with a primary care physician in the PHC intervention center of the corresponding catchment area. The appointment will be scheduled remotely and during the visit through a specifically designed application linked with the PHC intervention center pre-loaded appointment sheet. In addition, patients will be offered an on-the-spot brief Disease Self-Management Education (DSME) provided by the allied health professionals. The DSME interventions will aim to strengthen the patients' capacity, to enhance their quality of life and to prevent acute and chronic complications, while keeping costs acceptable.

B. The eHealth Solution: Virtual Community

To ensure an eHealth solution that works for all the centers on both the providers' and the patients' sides, a health virtual community was set in place. The virtual community aimed to provide the necessary tools on an already existent physical connection between the healthcare community centers and the MoPH. The VC design included:

- 1- A website that allows the healthcare providers to access the FAQs and send their questions to the

moderator who will reply to the requests by creating a new FAQ, if necessary. Moreover, the website publishes online modules for treating diabetes and hypertension focusing on clinical guidelines and physician-patient communication strategies.

- 2- A software module that allows the data entry for health clinical indicators; the module was integrated with the primary health care information system in place at the centers.
- 3- An SMS messaging system was designed to integrate with the module in order to send the patients' appointment reminders and weekly educational information (e.g., medications, compliance).
- 4- The appointment scheduling system was designed as a software application. The software will also run educational presentations about the diseases.
- 5- The educational system to be delivered to the potential patient during screening was designed to be delivered on in an electronic format (notepad).

The overall VC system design is presented in Figure 2:

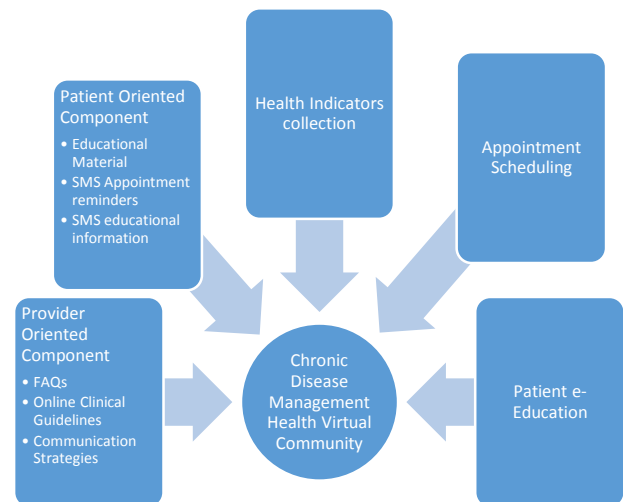


Figure 2. A Health Virtual Community Model for Chronic Disease Management in rural and disadvantaged communities.

V. A HEALTH VIRTUAL COMMUNITY FOR EQUITABLE CHRONIC DISEASE MANAGEMENT

We launched the health virtual community project in September 2013 and we applied the VC characteristics, as shown in Figure 1, as a structured tool to explore the high-level system's requirements, from a VC standpoint. We provide here a summary of the system analysis process as a case study to discuss the model and we propose an updated version of it.

Degree of Mobility: Most of the parts of the system need not to be mobile. The only mobile part required will be to provide the community field workers with a mobile patient screening and scheduling system. Thus, we adopted a *hybrid* approach containing a fixed as well as mobile component. Therefore, we suggest to update the degree of mobility we

have discussed above, to include not only still and mobile options but a *hybrid* option as well.

Degree of Virtuality: The community is virtual since members will have to work remotely.

Degree of Cooperation: In our project, a tight cooperation is required between community members in order to ensure the right scheduling and patient care delivery at the right time by the right person. Nevertheless, the scheduling software present in the health community centers was not able to support remote access from the field workers' laptops; consequently, we opted for an off-line solution where field workers have to schedule screened patients off-line and then to synchronize their appointments once they reach the health care center they are affiliated to. In case of conflict, the field worker would call the screened patient to reach an alternative appointment.

Degree of Uniformity: The community is heterogeneous since it involves doctors, nurses, field workers, researchers, data analyst, etc. Each would require special tools to work. The model in Figure 2 shows the main aspects of our VC. One component is patient oriented and used by patients (SMS messages), another one is health provider oriented and used by providers (online forum and FAQs). Field workers to schedule appointments will use a component; another one will be used at the healthcare centers to collect patient indicators. Regarding the patient e-education material, even though Lebanon has a high penetration of internet (52%) and cell phone use (3,350,000 mobile-cellular telephone subscriptions, equivalent to 78.65 subscriptions per 100 inhabitants)[50], smart phones were not judged to be a good tool in the rural communities and therefore we decided that the field worker leaves a printed material with the screened patients. That last solution makes the material accessible in an easy way known to all.

Inclusive Design: The design was inclusive since its inception. The doctors and community field workers will be consulted from the beginning of the project to ensure that the clinical guidelines conform to their expectations in terms of language and presentation. That ensures an inclusive design providing better chances for adoption by end-users.

Participatory Approach: The community of healthcare providers will be using the system in their work environment. We expect that they will find interest in participating in the forum and accessing the FAQs. We will measure the participation via embedded software tools that will provide some participation indicators (number of hits, number of logins, number of questions, etc.).

Supportive: A coordinator will be supporting the members of the VC.

Workflow Adaptive: The workflow was local, decided by the MoPH, and therefore was not an issue in our project.

Policy Sensitive: The privacy and confidentiality laws and regulations were implemented based on the standards set by the MoPH. The appointment data are stored locally in each community center. The MoPH owns and manages the clinical software run in each center and provides remote update on it.

Culture Adaptive, i.e., **culturally sensitive:** The researchers used English and Arabic and were fluent in both. Field workers will use mostly Arabic to communicate with the

local population in the rural areas. The culture at work was framed by the information system in place set by the MoPH. No special adaptation will be made to local cultures.

Environment Adaptive: There is no "environmental" issue. The research tackles many diseases that have the same prevalence across the country.

Infrastructure Adaptive: The eHealth research team decided on many delivery strategies for the educational modules. During the screening, a notepad (e.g., electronic pad) will be the delivery means for all patients scheduled for appointment. However, since 4G networks have been penetrating the market in a rapid pace, a software that delivers the same message is also scheduled for development, ensuring many delivery channels for potential patents. The SMS messaging system will be delivered by a local company; it has Application Programming Interface (API) that allows the designers to embed the SMS messaging strategy in the VC.

Value Catalyst: A training session will be designed in order to train doctors and field workers on the clinical guidelines and their benefit, the value of the screening process and the input of the clinical indicators (during the intervention).

Based on our analysis, we find that the model proposed in Figure 1 is very useful in capturing the VC requirements; it gives an accurate high-level description of our project. However, we propose to include a "hybrid" component in the description of the degree of mobility; in our case, some aspects of the VC are fixed while others are mobile. We suggest that we add a "synchronous/asynchronous" aspect in the degree of cooperation; in our case, the cooperation is neither fully dynamic nor fully based on a messaging mechanism; for instance, the scheduling will occur in an asynchronous way (synching will occur once the fieldworker reaches the community center) without neither involving a messaging mechanism nor a dynamic collaboration.

Profile Sensitivity: Taking into consideration the limited use of the VC, there were no disparities in users profiles. Different users will access different parts of the VC; consequently, the user interface adaptability to user profile was not an issue.

Finally, we found it more useful to classify the different features presented in Figure 1 into categories. The result is shown in Figure 3.

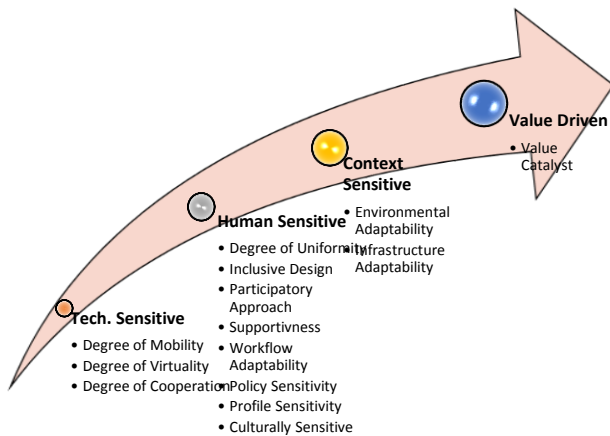


Figure 3. A Health Virtual Community Model

VI. CONCLUSION

This paper presented a previously established health virtual community model and analyzes its components based on a research project in a developing country. Through the analysis and design phases of our health VC project, the model proved to provide a useful way that helped to identify a suitable course of action and to describe its different components. It finally suggests two important modifications to the mode and provides a different, more system design friendly, classification of its components.

In the context of the Lebanese public health, the project is expected to enhance the equity in access to the chronic disease management in poor and underprivileged areas in the country, through the patient-oriented component (e.g. SMS reminders and educational information). The provider-oriented component would enable the caregivers to establish better communication strategies with their patients, reduce professional isolation and enhance access to updated knowledge.

In the context of research in virtual communities, our model establishes a framework for global health teams to ask the right questions when they are in the analysis and design phases of a Health VC information system. To the best of our knowledge this is the first time we have a model for that purpose. The model needs to be verified and tuned during the next few months. Future research will fine tune the model, develop the Health VC and implement it. The Health VC will be used in day-to-day activities in the chosen centers and indicators will be collected in order to measure its impact on chronic disease management in comparison.

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