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Towards Delivering Disease Support Processes for Patient Empowerment Using Mobile Virtual Communities

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Abstract. In existing healthcare systems, the focus is on clinical processes to assess the health condition of patients, making clinical decisions and applying therapeutic procedures all under control of health professionals. However, patients with chronic diseases usually face many disease related problems that are not immediately under control or supervision of a health professional. Taking patients with chronic cardiovascular diseases as an example, these patients are recommended to make a number of lifestyle changes: increase physical activity, change diet habits, quit smoking and adhere to a medication intake regime. In this paper we propose the use of Mobile Virtual Communities to enhance the empowerment of patients by providing the ICT mediated social support functionalities that assist patients to realize the lifestyle changes needed.

Keywords: mobile virtual communities, telemedicine, cardiovascular diseases, disease support processes, patient empowerment

1 Introduction

In the past decade, the European Union has, and still is, investing a lot in changing the way in which health services are delivered. Telemedicine is seen as a solution for the problems in current and future healthcare delivery. Originally started with remotely monitoring of the health condition of patients with chronic diseases, the emphasis today is becoming more on the self-management of patients. A project that embraces this vision is the BraveHealth project [1]. This project targets patients with chronic cardiovascular diseases, these diseases have the highest contribution to the European mortality rate (about 2 million per year), and account for about 192 billion Euro in health expenditure and about 270 million lost working days.

This paper leverages on our previous work [2] in which the research challenges and opportunities for the mobile virtual communities (MVC) in telemedicine are described. In this paper we outline the vision for CVD patient empowerment using MVCs. E-Support Groups or virtual communities for patients exists already for some time. These virtual communities mostly focus on emotional support and informational

support. In this paper, we focus on the MVCs for CVD patient empowerment including instrumental and feedback support as well.

This paper is organized as follows. Section 2 describes related work. Section 3 presents requirements for the MVC. Section 4 presents proposed concept of patient empowerment using MVC. Section 5 elaborates MVC platform architecture in order to fulfill targeted functionalities. Section 6 includes a brief discussion.

2 Related Work

Today, many dedicated virtual health communities exist, we have found over 40 different sites (English language only). *Patients Like Me* [3] is a social network for patients, the focus of this network is on giving and receiving support and information from the peers with similar health profiles. *Face To Face Health* [4] is a social network to find and connect patients with similar health experiences on a one-to-one basis. Main objective is to support storytelling and share experiences. *IBM's Patient Empowerment System* [5] is based on, and extends IBM's long tradition in the medical sector. The IBM vision is to merge the medical network with a social network in order to empower patients. *DailyStrength* [6] is a social network website where patients provide one another with emotional support by discussing their struggles and successes with each other. The site contains multiple online communities that deal with different medical conditions or life challenges. Medical professionals are also available to contact and treatments for a variety of illnesses and problems on some of the sites listed above. The virtual community sites we investigated focus on providing emotional and informational (peer) support.

3 MVC Platform Requirements

A robust architecture and technical platform is necessary to support patient mobility and empowerment needs of CVD patients. We have identified a collection of functional and non-functional requirements of such a platform based on a preliminary analysis of CVD patient needs, application scenario studies [7] and related work [8, 9, 10]. Here we only highlight some of the main functional requirements

- *Community member roles*: The platform must support user roles relevant for providing support, e.g. patient, cardiologist, nurse, practitioner, relative and friend. Also, creation of new roles and associated access rights must be supported by the platform.
- *Access*: The MVC platform must be accessible using devices that have become standard today, hence including smart phones and tablets. Human-machine interfaces must adapt according to device capabilities.
- *Language*: the MVC platform must support multiple languages.
- *Ease-of-use / usability*: The user-interface must be intuitive and easy to use. User role, skills, age, gender and any disability may affect the user-interface requirements.

- *Information access control:* Users must be able to audit who may access their health related information and they must be able to exercise control over who is allowed to see their health related information.

4 Patient Empowerment Using the Mobile Virtual Communities

The envisioned MVCs aim at accelerating disease support processes to empower CVD patients in achieving their health goals, for instance to adhere to the recommendations regarding physical activity, diet and medication [11]. Relevant types of support are known from social theory [8,9] and include informational, emotional, instrumental and appraisal / feedback support [8,9]. We see the added value of our approach especially in the domain of instrumental and feedback support from e.g. peers and aids in keeping patients motivated and ways to track their own and group performance with respect to their health goals.

The expected patient empowerment outcomes by using the prospective MVC functionalities are: being better informed, feeling more confident in the relationship with their physician, improved acceptance of the disease, feeling more confident about the treatment, enhanced self-esteem, enhanced social well-being and increased optimism and control. These outcomes are adopted from the study of patient empowerment in the online patient groups [9]. In the patient-centric view of MVCs, each community specifically addresses a particular type of CVD lifestyle facet. In each community, members take on a particular role and each role performs corresponding functions the combined result of which is focused on patient empowerment.

5 MVC Platform Architecture and Modules

Regarding the logical architecture of the MVC, we adopt the well-known and proven three-tier architectural pattern. To provide all the intended MVC disease support processes, we identified the need for the following modules:

- *MVC Platform Management:* This module is responsible to provide functionalities for managing the platform. The platform management tasks include deployment of community services, platform performance monitoring and platform auditing functionalities.
- *MVC Template Management:* The platform needs to be able to accommodate multiple communities, based on disease facets and required support type. Through this module new templates can be defined which are to be instantiated in order to create a community. The community template specifies roles and services that are to be part of communities and the rules that govern the operation and service use.
- *MVC Generics:* The MVC generics refers to the services that can be reused in different contexts. E.g. chat capabilities, the management of publication (for the purpose of information support or for educational purposes) are generic services that may appear in various communities.

- Specific MVCs: Based on the above modules, dedicated communities are created to address specific disease facets. These communities may be enhanced with new functionalities specific for the disease facet addressed.

6 Discussion

In this paper we have described ongoing work on delivering patient empowerment processes for CVD patients with the aim to maintain or improve patients' health status by focusing on CVD lifestyle disease facets. The disease facets include: diet, physical exercise/activity, medication compliance, and smoking cessation. The concept of patient empowerment, requirements, architecture and modules of proposed MVCs are elaborated. Presently, we are working on the implementation of MVC modules and performance metrics by which patients can objectively track their own performance and that of peer patients in their community. In addition, metrics for group performance are under development. In future phases of the project, the effectiveness in terms of patient empowerment using instrumental and feedback support will be evaluated in a clinical trial.

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References

1. BRAVEHEALTH: Patient Centric Approach for an Integrated Adaptive, Context Aware Remote Diagnosis and Management of Cardiovascular Diseases; <http://bravehealth.eu>.
2. Beijnum, B. J. F. van, Pawar, P., Dulawan, C., Hermens, H.: Mobile Virtual Communities for Telemedicine: Research Challenges and Opportunities, In: International Journal of Computer Science & Applications, Vol. 6, No. 2, pp. 38 - 49, February 2009.
3. Patientslikeme, <http://www.patientslikeme.com/>.
4. FacetoFaceHealthCommunity, <http://www.facetofacehealth.com/>.
5. Made in IBM Labs: IBM Reinvents the Patient Portal, Available online: <http://www-03.ibm.com/press/us/en/pressrelease/33944.wss>, March 2011.
6. DailyStrength, <http://www.dailystrength.org/>.
7. Fedele, F., Sterfanis, P. D., Ribeiro, V.: Application Scenario Studies, BraveHealth project Deliverable 1.1, September 2010. Available online: http://bravehealth.eu/pdf/Deliverable%201.1%20Application%20Scenario%20Studies_FINAL.pdf
8. Tardy C.H.: Social Support Measurement, In: American Journal of Community Psychology, Vol. 13, No. 2, 1985.
9. van Uden-Kraan C.F. et. al.: Self-Reported Differences in Empowerment Between Lurkers and Posters in Online Patient Support Groups, In: Journal of Medical Internet Research, Vol. 10, No. 2, 2008.
10. Maloney-Krichmar, D.; Preece, J.: A Multilevel Analysis of Sociability, Usability, and Community Dynamics in an Online Health Community. In: ACM Transactions on Computer-Human Interaction, Vol. 12, No. 2, pp. 201-232, June 2005.
11. Dickstein, K.: ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2008, In: European Heart Journal Vol. 29, pp. 2388–2442, 2008.