

Mastery and autonomy in medication with a mobile self-report system: A project in action

Agneta Ranerup¹, Inger Hallberg², Ulrika Bengtsson² and Karin Kjellgren²³

¹Department of Applied IT, University of Gothenburg, Sweden
ranerup@ituniv.se

² Institute of Health and Care Sciences, Centre for Person-Centred Care,
Sahlgrenska Academy,
The University of Gothenburg Learning and Media Technology Study
University of Göteborg, Sweden

³Department of Medical and Health Sciences, Faculty of Health Sciences, Linköping
University

ulrika.bengtsson@gu.se, inger.hallberg@liu.se,
karin.kjellgren@liu.se

Abstract. The overall aim of this research program is to design and examine if a mobile phone-based self-report system can be used to a) mediate knowledge about hypertension b) improve adherence to antihypertensive treatment and c) increase patient participation and autonomy.

Keywords: ePROM, adherence, mobile phones, hypertension.

Background

There is a pressing need to develop effective strategies to make the delivery of healthcare more efficient and responsive to patients' needs by addressing the problem of poor adherence to medication from an interdisciplinary perspective. Adherence is defined as: 'The extent to which the patient's behavior matches agreed recommendations from the prescriber' [1]. As patients' beliefs and perceptions of their wellbeing, illness and treatment may be the key to address the question of adherence, tools for monitoring treatment need to take these factors into account [2]. Such information can only be gained directly from the patient and Patient-Reported Outcome Measures (PROMs) are commonly used for this purpose. In the past decade electronic PROMs have become increasingly popular and the use of mobile phones as a medium for patient reporting is growing. Mobile phones are also becoming an important method for patient-monitoring in chronic disease to facilitate communication between providers and patients, and their use will undoubtedly increase [3]. There are surprisingly few research studies that "focus on mobile phone technology for disease management and health monitoring" [4]. Still rapid advances in the application and development of the technology have been witnessed in such areas as the management of cancer,

asthma, diabetes, and the care of older people [5]. An increasing recognition of patients' competence: i.e., their capacity to understand medical data, to provide therapeutic goals, to make consequent decisions, and also to evaluate their own quality of life is essential for a person centered care. People may be motivated by a need for mastery and competence in areas, which allow them to feel more independent and self-confident. New behavior can be learned and many people may be capable of adapting their behavior to meet a basic need, i.e., to feel as well as possible [6]. To serve the patient's best interests and encourage patients and caregivers to actively exchange ideas, can be an important way to realize mastery and autonomy in care [7]. In the present project there exists a challenge in the combined intention to simulate adherence with the use of technology with very clear persuasive qualities and intentions [8] and, on the other hand, the intention to attain enhanced knowledge of hypertension to attain mastery and autonomy from the individual patient's point of view. The overall aim of this research program is to design and examine if a mobile phone-based self-report system (ePROM), using the patient's own mobile phone, can be used to a) mediate knowledge about hypertension b) improve adherence to antihypertensive treatment and c) increase patient participation and autonomy, taking into account patients 'common-sense' beliefs about their illness and treatment as determinants of adherence.

Method

The project requires several types of knowledge and research activities as well as multifaceted network of human actors and technologies. The project as such is based on a large population-based study of hypertensive patients' views and experience of hypertension [9]. Further, there is an intention to explore patients' and health care providers' experiences of treatment, and to identify factors in the communication between patients and healthcare providers that contribute to improved adherence to antihypertensive treatment and quality of care. In this endeavor focus groups interviews were pursued (three with patients, two with providers) June-August 2010. Between November 2010-August 2011 ten design meetings were held with participating researchers and experts. During these meetings many issues were discussed but the primary intention was to design an ePROM for the mobile phone platform. The questionnaire was pilot tested in a group of 21 patients, who were interviewed about their understanding of the question and response alternatives as to readability and relevance. In the next step the use of mobile phone for follow-up will be tested in a larger group of 50 patients during 8 weeks, with at strategic inclusion. Inclusion criteria will be: >30 years of age or older, diagnosed as hypertensive and prescribed antihypertensive medication; alert and oriented; Swedish-speaking with different ethnic backgrounds; access to a functioning mobile phone; and allowing access to information on the actual amount of drugs dispensed to the individual patient by pharmacies in Sweden from the national prescribed drug register (Läkemedelsförteckningen at Apotekens Service AB). Patients' self-reporting can be followed up as graphs in an internet-portal, which indicates that the patients in an illustrative way can relate their medical use as well as non- pharmacological treatment to how they

use as well as non-pharmacological treatment to how they feel. Such graphs can also form the basis for follow-up appointments and as authentic starting points in productive conversations and hence, motivate the patients to adhere to the treatment recommendations and alternatively, reinforce an already functional adherence. Adherence to treatment will be checked through data of prescription drugs dispensed from pharmacies in Sweden and by questions in the mobile phone. Audio/video recordings of patient – physician/nurses follow-up consultations to obtain authentic evidence of the use of the ePROM instrument in clinical practice will be analysed. Further the involved parties will be interviewed about their experiences.

Preliminary results

At this point there are two types of preliminary results. The first is in form of the views from patients and providers (physicians, nurses, pharmacists). Providers accentuated how to handle the data obtained by the mobile phone and how to relate it to hypertension. Patients wished to emphasize how they felt and lived in relation to their blood pressure. Patients expressed a wish and a need for understanding relationships and to be in control of their high blood pressure. The providers doubted the patients' ability to be participating partners in care while patients sought for knowledge and understanding. Dizziness, stress, headache and tiredness were symptoms that were suggested to be followed up on an everyday basis. The use of a mobile phone self-reporting system was preferred during times of less well-controlled blood pressure or at start or change of medication. This result has served as an input to the design process of the ePROM in a preliminary version that will be tested in the Spring of 2012. Another type of preliminary result is from the analysis of the design process. A broad analysis of actors and intentions involved in this process indicates that the network of participants involves researchers in Care Science, Sociology of Science, Education, experts on methodological aspects of the investigation and on the ePROM instrument. In line with previous research about the design of technology to be used in healthcare [10] the design work involved many types of participants with their particular knowledge. The technology included the ePROM in its mobile platform but also a web-based platform by which the patients and providers can view the data registered by the patients i.e. symptoms, well-being, life style habits and blood pressure. The discourse involved a previous research study of patients' experiences and views of hypertension [9]. Another aspect was patients' and providers' views about hypertension in the focus groups used as an input to the design. There was also a discussion about the aim of the project at large, how to safeguard the scientific quality of the study and its result, as well as of the questions that were to be a part of the ePROM. Important issues here were the areas for questions (wellbeing, health related activities, symptoms, data of measured blood-pressure, and encouraging health messages). The exact wording of questions and answers to put in the telephone from a general viewpoint as well as a viewpoint taking into account the available telephone platform were also important. Another issue was the model for distribution of the questions (frequency, timing, selection of messages for the individual person).

Outlook

The persuasive aspect [8] of this project is challenging involving a network of technologies: (1) an ePROM instrument in a mobile phone platform, (2) an instrument for measuring blood-pressure as well as (3) a web-based platform for looking at patient reported data. In this manner, the research project involves the arrangement of a situation of negotiation [11] and exchange of knowledge between the patient and the provider in the consultations associated with regular treatment. However, for this to happen both groups must have reasonable adoption rates of the technologies [8]. To go beyond this research arrangement it needs to be translated into an accepted method in healthcare. If this is accomplished the human effects in form of individual patients' mastery of chronic illness in form of hypertension as well as adherence to medication instructions is gained. For society as a whole this also has significant positive economic effects. Therefore, it would be of interest to examine the impact of adherence of this person centered hypertension management method in daily clinical practice.

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