

Can Assessment of Health on an ICT-platform Improve Optimal Functionality and Lead to Participatory Care Among Older Adults?

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Abstract-The number of people reaching old age is increasing rapidly, challenging the society and healthcare to promote healthy and meaningful aging. There is, and has been for a few years, a big interest in collecting patient reported outcomes (PROs) as a base for clinical management. Information and Communication Technology (ICT) and assistive technology in elderly care increase and may facilitate the care of older adults as they are moved from nursing homes to private homes. An ICT-platform for reporting health issues with immediate access to self-care advice and direct communication with healthcare professionals has been developed. The overall aim of this project is to evaluate the effects of the interactive ICT-platform regarding optimal functionality and participatory care. The project will be conducted in three phases: development of the ICT-platform, feasibility evaluation and evaluation of effects. The platform is unique by integrating interactive components for direct clinical management and needs to be thoroughly evaluated before implementation in daily practice. It is hypothesized that, by using an interactive ICT-platform, it will promote participatory care and enhance the communication between older adults and their professional carers. The platform will be further developed, as well as tested in a full-scale study.

Keywords-information and communication technology; older adults; patient-reported outcomes measure.

I. INTRODUCTION

In the Western world, the number of people reaching older age is increasing quite rapidly. Better living conditions such as improvements in nutrition, health and healthcare give a higher life expectancy and can be an explanation for the increase [1, 2]. The aging and elderly populations are placing demands on society, and especially on healthcare, to promote healthy and meaningful aging, according to the World Health Organization's (WHO) concept of "active ageing" [3].

This project will establish a new and modern technique where older adults can accurately report factors that influence their health and daily life, as well as systematically and rapidly communicate these to healthcare professionals caring for them. The older adults will also have access to instant self-care advice appropriate to the level of factors they report. This will enable problems to be identified earlier and necessary interventions to be initiated more promptly and enhance the communication between older adults and healthcare professionals, an approach to healthcare that is encouraged and needed today. We also intend to develop our theoretical model, The Participatory Care Model,

which will support the implementation of a personalized interactive monitoring system for the older adults. The model focuses on allowing patients to take a participatory role in their own health and health care in an interaction with the healthcare providers i.e. being a member of the team.

II. BACKGROUND

A. Patient-reported outcomes measure

A Patient Reported Outcome Measure (PROM) includes all the aspects of a patient's health status, including disease symptoms, functioning and Health-Related Quality of Life (HRQoL), so that they are able to directly communicate these aspects to healthcare professionals without interpreting the patient's response by a caregiver or anyone else [4]. There is, and has been for a few years, a big interest in collecting PROM as a base for clinical management. Different ways have been used, for a long time pen and paper, but recently applications, such as touch screens and web-based systems, have been tested to collect PROMs [5]. Several studies in this area have shown that the use of PROM in clinical settings can simplify the detection of problems, facilitate communication between patients and clinicians, promote shared decision making and enhance patient satisfaction [6, 7].

B. Information and communication technology

Information and Communication Technology (ICT) friendly utilities and assistive technology in elderly care tend to increase since the care of older adults is not performed in nursing homes but in private homes instead [8]. The WHO defines E-health as "the transfer of health resources and health care by electronic means" [9] which makes the concept closely connected to activities on the Internet. A complement to E-health is assistive technology, which is defined by the WHO as a concept for any device or system that enables an individual to carry out an activity that otherwise would be very difficult or impossible to carry out [10]. ICT can help older adults to stay independent and healthy [11]. Overall, ICT combined with a strong governance structure and a fair performance management may result in integrated healthcare [12] and promotion of self-management [13]. Using ICT to enhance the care of and for older adults has several advantages such as providing information on how to manage occurring health issues [14]. The use of ICT has been shown to improve Quality of Life and feelings of

being safe among older adults suffering from Alzheimer’s Disease [15].

We did a scoping review to explore the concept optimal functionality in old age (people over 65 years of age in developed countries) and to integrate it with PROM. A total of 25 scientific articles were analysed. Three major themes were identified in the concept of optimal functionality in old age: self-related factors, body-related factors and external factors [16].

As far as we know, no studies regarding older adults using interactive ICT to promote optimal functionality have been made, thus showing that a knowledge gap can be seen in this area. The overall aim of this study is to evaluate the effects of an ICT- platform integrated with PROM to assess its effects on older adults’ optimal functionality and participatory care.

The specific research questions are:

- How will the mobile phone system enable older adults to enhance engagement in self-care activity in order to improve health and optimal functionality?
- How feasible, user-friendly, and accepted is the ICT-platform from the elderly and health care professional’s perspective?
- How does the use of an interactive ICT-platform contribute to participatory care?

III. METHOD

The project will be conducted in three phases. Phase 1 includes development of the ICT-platform; Phase 2 evaluates the feasibility and acceptability of the ICT-platform; and Phase 3 concerns evaluation of effects.

A. Phase 1 The development of the ICT-platform

In a literature review and interviews with older adults and nurses involved in homecare, determination of the content of the questions in the application was explored (Fig 1).

1) Review of the literature, interviews with experts, older adults (n=12, >65 years of age) and healthcare professionals (n=8) were conducted to identify indicators that promote and/or counteract a good daily life and health. Fifteen areas were identified: fever, dizziness, difficulties eating, diarrhea, constipation, pain, fatigue, difficulties sleeping, worry, depression (sadness, dysphoria), difficulties performing daily activities indoors, difficulties performing activities outdoors, difficulties performing activities with others, experience of being safe, and experience of having a meaningful daily life of which 15 questions were created.

The structure of questions included in the application is based on standardized symptom and QoL questionnaires [17, 18] that is, the questions ask for occurrence, frequency, and distress level. For example “Do you experience constipation?” If the answer is yes, the older adult is asked how often it occurs, rated by

frequency: never, sometimes, rather often, or very often. Furthermore, the older adult is asked how distressing the symptom is: not at all, a little, rather, or very much. The older adults will report at least three days during a week. A reminder message is sent if report has not been submitted. Besides the questions, the application contained evidence-based self-care advice related to the older adults’ concerns. Additionally, the application contains links to suggested relevant websites for more reading. The application also included a history graph in which the older adults could see how they reported their health status over a period of time (Fig. 1). A risk assessment model based on occurrence and frequency of the reported data was integrated into the application. Depending on the severity of the reported data, the nurse in charge could receive two sets of alarms to their work mobile phone (text messages), red and yellow alarms. Red was the more acute one meaning that the nurse would contact the older adult within a few hours; the yellow alarm meant that the nurse would contact the older adult the next day at the latest. This initiates an interaction whereby a nurse contacts the older adults for discuss their concerns.

With the help of a Swedish health management company (Health Navigator), the contents were implemented in a smart tablet as an application. The nurses in charge could also log into a web-interface and view the reports of the older adults on their computers (Fig. 2).

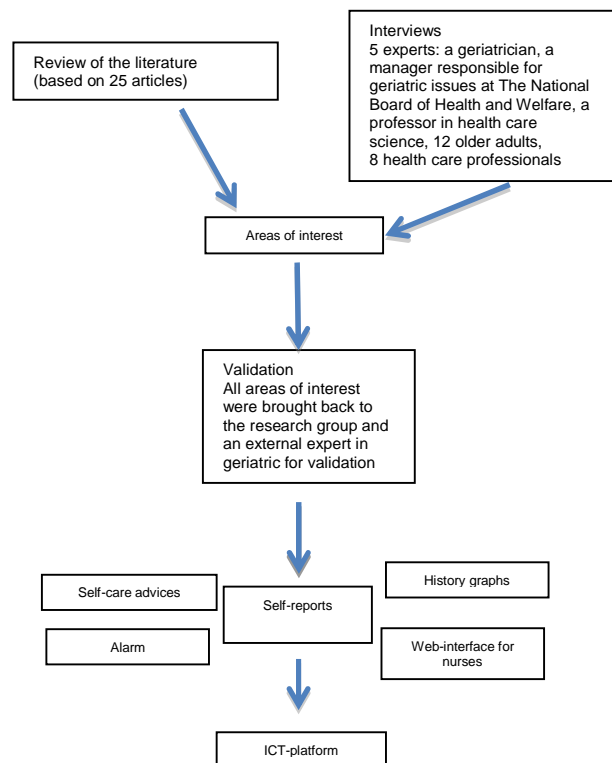


Figure 1. Outline over the platform development.

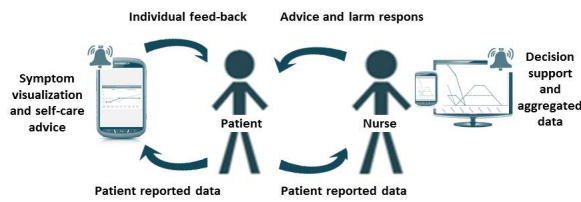


Figure 2. Illustration of the application chain.

B. Phase 2 The evaluation of the feasibility and acceptability of the ICT-platform

1) Eight older adults, ranging between the ages of 67 to 90 years of age, were included in the study. Inclusion criterions for participating in the study were being over 65 years of age, having a healthcare contact, being able to speak Swedish and also being able to read and write in Swedish. The older adults should be cognitively intact and/or not have an altered mental status. All the study participants were given a tablet (Nexus Google). The older adults tested the tablet with the ICT-application for a period of four weeks. Three nurses working with the older adults agreed to participate in the study. They were informed about the study, how the interactive system worked and how they would proceed when logging into the web-interface as well as view how the older adults have reported. The nurses were also informed on how they would handle the alarms coming into their work mobile phones.

2) Both older adults and nurses were asked to participate in individual interviews after the four weeks had passed. The older adults were interviewed individually and asked about the usability of the tablet and the application and the relevance of the questions in the health measure. The nurses were also interviewed about the relevance of the questions and about their experience of monitoring reports from the older adults and using the web-interface. Overall, the older adults found using the tablet and application as quite favourable. The application was perceived as user friendly, educational and fun to use. The questions were seen as relevant and clear but also as having a more broad perspective. The nurses in the study experienced the system as valuable and as something that could make the care with the older adults more accessible. One nurse expressed that this was a way of communicating with the older adults directly without any intermediaries.

C. Phase 3 The evaluation of effects

Next phase of this project will focus on testing the ICT-platform in a larger group of older adults (n=50) for a

period of six months. There will also be a control group not using the ICT-platform to evaluate and determine its effects. Main outcomes are areas related to optimal functionality (for examples well-being, mental health, gut health, nutritional status, health literacy, coping ability, self-care and risk for falling). Interviews with the older adults and the health care professionals will also be conducted focusing on participatory care.

IV. CONCLUSION AND FUTURE WORK

The first phases of this study show that the interactive developed ICT-platform was feasible from both the older adults and their nurses' perspective. These studies will deepen our understanding of how older adults perceive participatory care, i.e., being a member of a team, when it came to the older adults' own healthcare plans, using PROM. Conclusively, the concept of optimal functionality can in the future enhance participatory care in the sense that the older adults know and are aware of their preferences. Possible effects will be measured in a larger sample of older adults and will enable us to improve and develop the ICT-platform, as well as develop opportunities to increase older adults' optimal functionality.

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REFERENCES

- [1] K. Kinsella and H. Wan, "An Ageing World: 2008," 2008, [cited November 11, 2013], Available from: http://www.un.org/esa/population/publications/wpp2008/wpp2008_highlights.pdf.
- [2] United Nations, "World Population Prospects The 2008 Revision," 2008, [cited November 11, 2013], Available from: http://www.un.org/esa/population/publications/wpp2008/wpp2008_highlights.pdf.
- [3] World Health Organization, "Active Ageing A Policy Framework," 2002, [cited November 11, 2013], Available from: http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH_02.8.pdf.
- [4] U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research, U.S. Department of Health and Human Services FDA Center for Biologics Evaluation and Research and U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health, "Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance," Health Qual Life Outcomes, vol. 4, Oct. 2006, pp. 79, 'doi':10.1186/1477-7525-4-79.

- [5] M. Rose and A. Bejjani, "Logistics of collecting patient-reported outcomes (PROs) in clinical practice: an overview and practical examples," *Quality of Life Research*, vol. 18, Feb. 2009, pp. 125-136, 'doi':10.1007/s11136-008-9436-0.
- [6] C. F. Snyder and N. K. Aaronson, "Use of patient-reported outcomes in clinical practice," *Lancet*, vol. 374, Aug 1. 2009, pp. 369-370, 'doi':10.1016/s0140-6736(09)61400-8.
- [7] J. M. Valderas, A. Kotzeva, M. Espallargues, G. Guyatt, C. E. Ferrans, M. Y. Halyard, et al., "The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature," *Quality of Life Research*, vol. 17, Mar. 2008, pp. 179-193, 'doi':10.1007/s11136-007-9295-0.
- [8] C. Harrefors, K. Axelsson and S. Savenstedt, "Using assistive technology services at differing levels of care: healthy older couples' perceptions," *Journal of Advanced Nursing*, vol. 66, Jul. 2010, pp. 1523-1532, 'doi':10.1111/j.1365-2648.2010.05335.x.
- [9] World Health Organization, "E-Health," [cited November 19, 2013], Available from: <http://www.who.int/trade/glossary/story021/en/>.
- [10] World health Organization, "A glossary of terms for community health care and services for older persons," 2004, [cited November 11, 2013], Available from: http://www.who.int/kobe_centre/ageing/ahp_vol5_glossary.pdf.
- [11] European Commission, "Living Healthy, Ageing Well," 2013, [cited November 12, 2013], Available from: <https://ec.europa.eu/digital-agenda/node/1103>.
- [12] E. Suter, N. D. Oelke, C. E. Adair, C. Waddell, G. D. Armitage and L. A. Huebner, "Health systems integration – definitions, processes & impact: a research synthesis," Ottawa, Canadian Institutes of Health Research (CIHR), 2007, [cited January 20, 2014], Available from: http://www.calgaryhealthregion.ca/hswru/documents/reports/HEALTH_SYSTEMS_INTEGRATION_2007.pdf.
- [13] S. McLean, D. Protti and A. Sheikh, "Telehealthcare for long term conditions," *BMJ*, vol. 342, 2011, pp. d120, 'doi':10.1136/bmj.d120.
- [14] M. A. Winker, A. Flanagan, B. Chi-Lum, J. White, K. Andrews, R. L. Kennett, et al., "Guidelines for medical and health information sites on the internet: principles governing AMA web sites. American Medical Association," *JAMA*, vol. 283, Mar 22-29. 2000, pp. 1600-1606,
- [15] A. Pilotto, G. D'Onofrio, E. Benelli, A. Zanesco, A. Cabello, M. C. Margeli, et al., "Information and communication technology systems to improve quality of life and safety of Alzheimer's disease patients: a multicenter international survey," *Journal of Alzheimer's Disease*, vol. 23, 2011, pp. 131-141, 'doi':10.3233/jad-2010-101164.
- [16] S. Algilani, L. Östlund-Lagerström, A. Kihlgren, K. Blomberg, R. J. Brummer and I. Schoultz, "Exploring the concept of optimal functionality in old age," *Journal of Multidisciplinary Healthcare*, vol. 7, 2014, pp.69-79, 'doi':<http://dx.doi.org/10.2147/JMDH.S55178>.
- [17] M. Browall, E. Kenne Sarenmalm, S. Nasic, Y. Wengström and F. Gaston-Johansson, "Validity and reliability of the Swedish version of the Memorial Symptom Assessment Scale (MSAS): an instrument for the evaluation of symptom prevalence, characteristics, and distress," *Journal of Pain and Symptom Management*, vol. 46, 2013, pp. 131-141, 'doi':10.1016/j.jpainsymman.2012.07.023.
- [18] R. K. Portenoy, H. T. Thaler, A. B. Kornblith, J. M. Lepore, H. Friedlander-Klar, E. Kiyasu, et al., "The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress," *European Journal of Cancer*, vol. 30A, 1994, pp. 1326-1336,