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Telehealth for “the Digital Illiterate” – Elderly Heart Failure Patients’ Experiences

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Abstract. Telehealth solutions should be available also for elderly patients with no interest in using, or capacity to use, computers and smartphones. Fourteen elderly, severely ill heart failure patients in home care participated in a telehealth study and used digital pens for daily reporting of their health state—a technology never used before by this patient group. After the study seven patients and two spouses were interviewed face-to-face. A qualitative content analysis of the interview material was performed. The informants had no experience of computers or the Internet and no interest in learning. Still, patients found the digital pen and the health diary form easy to use, thus effortlessly adopting to changes in care provision. They experienced an improved contact with the caregivers and had a sense of increased security despite a multimorbid state. Our study shows that, given that technologies are tailored to specific patient groups, even “the digital illiterate” may use the Internet.

Keywords. Telemedicine, digital pen, heart failure, home care services

Introduction

Using a computer or a smartphone is a matter of course for most of us. Still this is not for all, especially if you are of old age [1] and suffer from one or more severe health conditions.

The prevalence for heart failure (HF) is >= 10 % among those 70 years and older [2]. It is associated with comorbidities, poor quality of life, and high mortality [3]. HF patients receiving non-hospital care are geographically separated from the healthcare-providing organisation, making symptom control more difficult.

Telehealth programmes for HF home care patients [e.g. 4-6] are suggested to have positive impact on both mortality and morbidity [4, 7]. However, most often programmes require that patients use a computer, a tablet or a mobile phone together with other medical equipment. In order to also let patients who have never used such technologies or the Internet, i.e. “the digital illiterate”, to be included in a telehealth clinical trial, we developed a telemonitoring system, *the Health Diary*, for elderly HF home care patients, based on digital pen technology. Here, Internet use comprise of not only browsing or sending emails, but any use of Internet-connected networks. Digital pen technology has been tried and evaluated with cancer patients [8-9] but, to our knowledge, never by HF patients—a patient group with high mean age [10]. We

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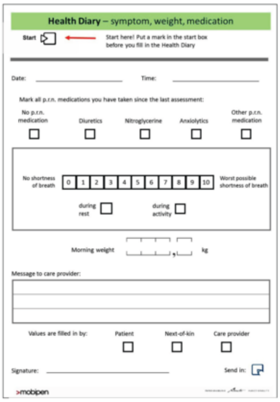
implemented the system in clinical use in a 13 months long study between November 2010 and December 2011 at the hospital-based home care (HBHC) clinic, Linköping University Hospital.

The aim of this paper was to explore and describe the patients' and spouses' experiences in using the system.

1. Methods

Permission to carry out the study was given by *The Regional Ethical Review Board in Linköping*. The digital pen technology (www.anoto.com) comprises the pen and ordinary paper with a printed close-to-invisible pattern read by a camera inside the digital pen. The pen is used as an ordinary ball-point pen, but the strokes made by the pen are recorded and transferred via mobile internet to a server [11].

The Health Diary system supported daily reports on shortness of breath, intake of p.r.n. medications, weight and other measurements by use of the digital pen and a health diary form (see Figure 1). The diary also allowed free text messages to the care provider. The system generated alarms if patient-reported values were below/above certain limits [10]. Inclusion criteria comprised Swedish-speaking patients with HF, not being cognitively impaired, able to perform the assessments with or without help from a spouse. Written consent was collected from all participating patients. A nurse instructed the patients on how to handle the equipment. The patients performed daily assessments and measurements which were immediately reported by filling in the health diary. The system was monitored by health professionals.



Health Diary – symptom, weight, medication

Start ☐ Start here! Put a mark in the start box before you fill in the Health Diary

Date: ____________ Time: ____________

Mark all p.r.n. medications you have taken since the last assessment:

No p.r.n. medication	Diuretics	Nitroglycerine	Anxiolytics	Other p.r.n. medication
☐	☐	☐	☐	☐

No shortness of breath 0 1 2 3 4 5 6 7 8 9 10 Worst possible shortness of breath

during rest ☐ during activity ☐

Morning weight ___ , _ kg

Message to care provider:

Values are filled in by: Patient ☐ Next-of-kin ☐ Care provider ☐

Signature: ____________ Send in:

>mobipen

Figure 1. Health Diary Form

Fourteen home care patients (11 men, mean/median age 84/83 years at inclusion) diagnosed with HF, NYHA class II-IV, with a median of two previous hospital admissions during the last 12 months were included in the study. Five patients died during or shortly after the study, one was in a too poor condition to be interviewed, and one left the study shortly after inclusion. Seven patients and two spouses gave their consent to be interviewed face-to-face in their homes by one of the authors (LL). An interview guide was used and concerned, e.g., experiences from using the technology and method, the patients' health status during the study, and, possible changes in contact with the care provider and care participation. The interview guide served as support for the interviewer's memory and to trigger the discussions [12-13]. In order to explore patients' and spouses' experiences in using the system a qualitative content analysis of the interview material was accomplished by four researchers. Content analysis focuses on the subject and context, and it points out differences and similarities between and within categories [14].

2. Results

Four sub-categories showing patients' experiences of using the digital pen technology and health diary for daily assessments were identified and described in the two categories *Difficult seeing one's own change* and *Multimorbid, but with a sense of security and trust*. Selected original quotations, translated into English, from each category are presented to illuminate the patients'/spouses' experiences.

Difficult seeing one's own change, with the sub-categories: *Technology acceptance and new daily routines despite the indifference to technology in general* and *Difficult seeing one's own gain in health insights and increased care participation.*

Technology in general, including computers and mobile phones, was regarded as "not interesting" and "a bit scaring". None of the informants had experiences from using computers. They expressed that they *did not have use* for computers and the Internet – and did not want to learn *how to use* them – still, they realised that they were going to miss a lot of information this way.

> ”Technology and things? No, I know nothing about such things!" (Patient 14)
> ”We got a DVD from our daughter but we haven't tried it. And then one is afraid of pushing the buttons" (Patient 11)
> ”There are still some older people without computers, so it [Internet access] shouldn't be taken for granted [that everyone can] 'go in there and have a look'" (Spouse 04)

During the study the patients began using new daily routines for the reporting of assessments and measurements, and they thought that handling the digital pen was an easy task.

> ”I can manage, 'cause that's nothing special, as long as I can read and hold the pen" *(Patient 14)*

Two patients needed help from a spouse when reporting but believed that they could manage themselves. The informants did not notice the change from being non-users to users of Internet services; neither patients nor spouses reflected over the fact that they were using the Internet when reporting with the digital pen.

Both patients and spouses expressed that they now kept track of the patient's symptoms and signs, and that the care provider's advice was better followed. However, especially the patients had difficulties seeing their own gain in health insights and that they had increased their own care participation.

> ”[Before inclusion] I thought 'what's the *use* of measuring?'" *(Patient 05)*
> "I take the medicine I'm prescribed, that I do." *(Patient 09)*
> ”Perhaps I listen to the body more, and listen to what *they* [the care providers] say" *(Patient 11)*

Multimorbid, but with a sense of security and trust, with the sub-categories: *A sense of increased security and closer contact with the care provider due to trust* and *A sense of stability despite the multimorbidity.*

None of the patients were admitted to hospital care due to HF deterioration. Issues related to HF were detected by care providers via the system allowing patients to be cared for at home. The informants trusted that the care provider checked and used the reported assessments, and this resulted in a sense of increased security and of being in a "closer" contact with the care provider. Both patients and spouses had this feeling of being closer to the HBHC clinic even when they didn't get home visits or had telephone contact with the care providers.

> "It [the digital pen] is a…security." *(Patient 08)*

The patients described that they had one or more comorbidities which affected their overall health status. Despite their multimorbid state a few patients expressed a sense of a less unstable heart during the study inclusion, compared to before inclusion. This sense was expressed as being closely connected to the sense of a greater security.

> ”It's always good to have them [the care providers] come *here*, to avoid going to the hospital, and not have to chase a doctor" *(Patient 08)*
> "[Interviewer:] Has the health diary reporting affected your health in some way?
> [Informant:] Absolutely! I feel much more secure." *(Patient 12)*
> ”I have felt so healthy a while now…it's so different!" *(Patient 12)*

3. Discussion

The frailty of elderly patients with severe HF, and one or more comorbidities, can be comparable to elderly palliative cancer patients [15]. This is not a point in life when a person easily learns how to use new technologies. In two earlier studies palliative cancer patients in the end of their lives effortlessly used digital pen technology for reporting of symptoms and intake of pain medications. Study results, as in this study, showed that also these patients and their spouses participated more in the care and had a sense of increased security by the method used [8].

Common use of the Internet started about 20 years ago and has rapidly spread among the population. In Sweden, around 90 % are Internet users and the so called digital divide is shrinking, albeit at a progressively slower rate now leaving the majority of older people "outside" of the growing information society. The most common reasons for not using the Internet are "no interest" and "complicated technology" [1]. This is not unique for Sweden [16-18]. Many countries in Europe are now implementing telehealth and eHealth services targeted at citizens, such as patient access to health records [19]. Citizens, including many elderly, are also increasingly using the Internet for their health information needs [20]. We live longer – nearly every fifth person in high-income countries is over 65 years of age [21] – and the risk of contracting diseases increases when the later stages of life approach [22]. This implies a need for alternative technologies and solutions, in order not to exclude the old and severely ill "digital illiterates" when developing telehealth systems.

The HF patients in our study had no experiences of using the Internet but quickly accepted and managed to handle the digital pen technology for daily reporting of their health status, making them more empowered and increased their own participation. In conclusion, our study shows that, given that technologies are tailored to specific patient groups, even "the digital illiterate" may use the Internet.

The Health Diary project is now being evaluated in a larger (three years) intervention study in which elderly patients with severe HF and/or chronic obstructive pulmonary disease (COPD) participate and use the same technology and method for assessment and reporting. This study will be evaluated according to quality of care, participation, perceived control, technology acceptance and usability, self-care, and health-economic efficiency.

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References

[1] O. Findahl, *Swedes and the Internet 2012*. The Internet Infrastructure Foundation, 2012, .SE. ISBN: 978-91-979411-7-4

[2] ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012. *Eur J Heart Fail* (2012), 14(8): 803-869.

[3] T. Thorvaldsen, L. Benson, M. Ståhlberg, U. Dahlström, M Edner, L.H. Lund, Triage of Patients with Moderate to Severe Heart Failure: Who Should be Referred to a Heart Failure Center?, *J Am Coll Cardiol* (2013), doi: 10.1016/j.jacc.2013.10.017.

[4] S.C. Inglis, R.A. Clark, F.A. McAlister, J. Ball, C. Lewinter, D. Cullington, S. Stewart, J.G. Cleland. Structured telephone support or telemonitoring programmes for patients with chronic heart failure. *Cochrane Database Syst Rev*. (2010) Aug 4;(8):CD007228.

[5] A. Giordano, E. Zanelli, S. Scalvini. Home-based telemanagement in chronic heart failure: an 8-year single-site experience. *J Telemed Telecare*. (2011), 17(7):382-6.

[6] A. Steventon, M. Bardsley, J. Billings, J. Dixon, H. Doll, S. Hirani, M. Cartwright, L. Rixon, M. Knapp, C. Henderson, A. Rogers, R. Fitzpatrick, J. Hendy, S. Newman; Whole System Demonstrator Evaluation Team. Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial. *BMJ*. (2012) Jun 21;344:e3874.

[7] J. Polisena, K. Tran, K. Cimon, B. Hutton, S. McGill, K. Palmer, R.E. Scott. Home telemonitoring for congestive heart failure: a systematic review and meta-analysis. *J Telemed Telecare*. (2010),16(2):68-76.

[8] L. Lind, D. Karlsson, B. Fridlund. Patients' use of digital pens for pain assessment in advanced palliative home healthcare. *Int J Med Inform*, (2008) Feb;77(2):129-36.

[9] L. Lind & D. Karlsson. Electronic patient-reported symptom assessment in palliative end-of-life home care. *Health Systems*, (2013) 2, 171–180.

[10] L. Lind & D. Karlsson. Digital pen-based telemonitoring of elderly heart failure patients. *Stud Health Technol Inform*. (2013), 192:1062.

[11] L. Lind & D. Karlsson. A system for symptom assessment in advanced palliative home healthcare using digital pens. *Med Inform Internet Med*, (2004) Sep-Dec;29(3-4):199-210.

[12] M.Q. Patton. *Qualitative research and evaluation methods*. 3rd ed. ISBN: 0-7619-1971-6. Thousand Oaks, CA: Sage; 2002

[13] S. Kvale. InterViews: An Introduction to Qualitative Research Interviewing. Thousand Oaks, CA: Sage; 1996

[14] U.H. Graneheim & B. Lundman. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. (2004) Feb;24(2):105-12. Review

[15] M. Brännström & K. Boman. A new model for integrated heart failure and palliative advanced homecare--rationale and design of a prospective randomized study. *Eur J Cardiovasc Nurs*. (2013) Jun;12(3):269-75.

[16] World Internet Project, *International Report 2013*. Can be downloaded from the internet web site: www.worldinternetproject.net (accessed 2014-02-05)

[17] V. Hanson. Technology skill and age: what will be the same 20 years from now? *Univ Access Inf Soc* (2011), 10:443–452

[18] E. Neter & E. Brainin. eHealth literacy: extending the digital divide to the realm of health information. *J Med Internet Res*, (2012), *14*(1).

[19] S. de Lusignan, P. Ross, M. Shifrin, M. Hercigonja-Szekeres, B. Seroussi. A Comparison of Approaches to Providing Patients Access to Summary Care Records Across Old and New Europe: An Exploration of Facilitators and Barriers to Implementation. In *MEDINFO 2013: Proceedings of the 14th World Congress on Medical and Health Informatics* (Vol. 192, p. 397). IOS Press, 2013.

[20] H.K. Andreassen, M.M. Bujnowska-Fedak, C.E. Chronaki, R.C. Dumitru, I. Pudule, S. Santana, V. Henning, R. Wynn. European citizens' use of E-health services: a study of seven countries. *BMC Public Health*, (2007), 7(1), 53.

[21] The World Bank. Internet web site: http://data.worldbank.org/indicator/SP.POP.65UP.TO.ZS (accessed 2014-02-05)

[22] E. Davies & I.J. Higginson (Editors) *Better Palliative Care for Older People*. 2004. ISBN 9289010924. Available from http://www.euro.who.int/ (accessed 2014-02-05)