Mobile Health Care and Health Behavior Change – Development of a System for Virtual Counseling based on Written Diary Questionnaires and Situational Feedback.

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Abstract

In the future virtual e-health counseling through the mobile phones will be an important feature of health care. Patients are shortly in face to face contact with health care personal. Many patients face challenges living with chronic diseases and the patients have to change health behavior and life style to life as healthy as possible with a high degree of quality of life. Development of new ways of health counseling should also apply principles of universal design as accessibility for all and ease of use.

We have designed a system for virtual counseling through written questionnaire diaries and situational feedback – the <u>www.wsf.hio.no</u> that is delivered to the patient through an internet enabled mobile phone. The system is applied in a pilot study with patients with widespread chronic musculoskeletal pain and is currently running in a randomized controlled study within the same patient group.

The system ensures safe contact with the patients and has been running successfully for 30 month. The patients are able to use the cell phone with a short f2f instruction. The therapists can easy follow patients' responses independent of place. The researcher can easily extract data from the system.

At the present moment the 2^{nd} generation of the system will be redesigned in order to improve the functionality further and to be tested out in other patient samples – contributing to increase the universal accessibility of new methods in health counseling.

Introduction

The health care system has changed and is continuously changing. Patients are living longer and chronic illnesses and health problems as chronic pain, obesity and diabetes 2 are increasing. The health care costs are increasing and it is a challenge to reduce the influence of the chronic illnesses in order to keep patients as healthy as possible with their condition and if possible also contribute by staying at work. The Coordination Reform (2009) is sketching the scene and demands in future health care. Internet and computer technology (ICT) will play a larger role in the future health care and this also challenge nurses' and other health care professions' roles in future health care. Nurses have a competence that make them especially well suited for giving health related counseling, often in cooperation with physicians, physiotherapists, nutrition specialists and psychologists in the multi-professional team.

Several challenges face health care professionals when we want to design interventions that include modern communication technology in order to support patients with chronic health complaints in changing health related behavior. Internet – and new mobile phone technology presents possibilities for new ways of health care counseling not limited to face – to face encounters or verbal communication. However, the use of new technology also challenges the different users as this kind of work involves different stakeholders as patients, health care professionals, it-systems developers; researchers and will also have consequences for organizational structure and economics.

In the perspective of universal design; accessibility for all, ease of use and flexibility are important criteria for evaluation this kind of health counseling.

Patients' responsibility for taking care of own health problems and patients rights to be an active partner in health care are specified in legal documents (The patients' rights law). Many patients wish a partnership relationship with health care personal. Patients' with chronic diseases often have too little contact with health care personal; internet use has increased with lots of health information; and autonomy and participation in own health care. Self-management seem to be an important feature, but not sufficient for all patients. They will need tailored information and counseling (Glasgow et al., 2001). Main ways of tailoring are done by personalization, adaptation and feedback(Dijkstra, 2005)ecent research suggests that internet technology is a promissing way to change a patient's health behaviour (Prochaska,

Zabinski, Calfas, Sallis, & Patrick, 2000; Tate, Jackvony, & Wing, 2006). New means of communication, such as smart phones and the internet have become widely available and provide excellent opportunities for low threshold counseling using situational feedback for improving patient's self management of chronic complaints like fibromyalgia, diabetes and irritable bowel syndrome. Traditionally patients are taught management skills in a clinical setting, and may not be able to successfully use these skills in daily care. This may be due to the non-situational nature of many interventions studied so far. Therefore we wanted to explore if enhancing self-management of chronic pain by providing immediate feedback that is directly related to patient's daily life ("situational" feedback) is more effective than conventional interventions in a clinical setting. We also assume that this may be even more effective when the patient receives quick response feedback using mobile communication technology, i.e. any place any time.

Another aspect of this research is enhancing the accessibility of highly qualified therapeutic assistance beyond the need to be in a specific place as in the hospital or the health care clinic. The patient can be anywhere, at home, at work, out for a walk etc. receiving this kind of care. The therapist can also do her work only being dependent on internet connection.

The aim of this paper is to describe the virtual counseling system we have developed called Web-Situational-Feedback (https://www.wsf.hio.no) for giving situational feedback to patients with chronic widespread musculoskeletal pain / fibromyalgia (Kristjansdottir et al., 2009; Kristjansdottir et al., 2010). We have built on the experiences of our Dutch collaborator at the NIVEL (The Netherlands Institute for Health Services Research). The Dutch group had develop a system for PDA's (Kruise, Sorbi, Bensing, Van Dulmen, & Spreeuwenberg, 2004) and had developed an intervention based on cognitive behavioral therapeutic principles for patient with Irritable Bowel Syndrome (Orlemans, van Cranenburgh, Herremans, Spreeuwenberg, & Van Dulmen, 2010).

We have developed a new system for internet enabled cell phones, as well as building on third generation of CBT related to the content of the patient intervention. We will shortly outline established principles for developing complex intervention and the rationale for giving situational feedback. Then we will present the technological structure of wsf.hio.no: the system concepts and function and also describe how security is maintained and results

regarding successful running and maintenance of the system seen from the perspective of the researcher.

Webased intervention through the mobile phone – questionnaire diaries and written situational feedback.

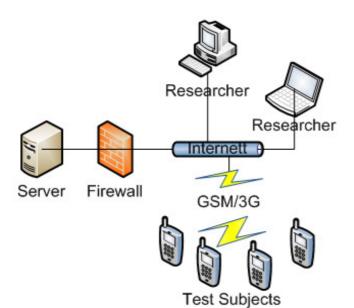
Maintaining daily symptom diaries appears to offer a valid and reliable way of assessing complaints and complaint-related cognitions and behaviors at the moment that they occur. Dairies have been used with patients with different pain complaints, such as migraine (Peters et al., 2000) rheumatic pain (Strand et al., 2007) and also in fibromyalgia (Fors, Sexton, & Gotestam, 2002; Tennen, Affleck, & Zautra, 2006). Most diaries are developed on a paper and pencil bases. As these data are not immediate available for health care providers, such data have delayed therapeutic use. Electronic diaries on pocket computers (PDAs) or smart phones / internet enabled cell phones have many advantages: Reliable storage of data is guaranteed, immediate transfer of data to researcher or counselor; and a transmission of feedback tailored to the data being sent (Prochaska et al., 2000; Tate, Wing, & Winett, 2001). The frequency of completing diaries can easily be adapted to the complaints that have to be monitored and the compliance is high(Morren, Van Dulmen, Ouwerkerk, & Bensing, 2009).

Therapeutic Internet interventions are usually characterized by being web based educational interventions, or self-guided or human-supported web based therapeutic interventions (Barak, Klein, & Proudfoot, 2009). Some studies have applied sms in the counseling process. The principles of behavior support by automatic generated messages has been applied in intervention aiming at smoking cessation (Brendryen, Drozd, & Kraft, 2008; Wangberg, 2008; Wangberg, 2009). An intervention like this is regarded a complex intervention. Several steps are regarded as necessary (Craig et al., 2008), first the intervention developed should be based on best available evidence and appropriate theory being tested out in pilot studies to target out uncertainties in design. Both quantitative and qualitative studies should be applied during development phase. Small scale randomized controlled trials is used to determine effect size before trying out in larger multicentre studies.

Our intervention is based on cognitive behavioral principles; working with cognitions, emotions and health related behavior as physical activity and relaxation (Kristjansdottir et al., 2009; Kristjansdottir et al., 2010). An important aspect is applying principles of operant learning by reinforcing positive activities and experiences by means of empathic positive communication. Our feedback furthermore stimulates the patients to reflect on own behavior, values and experiences in the process of changing behavior. Self-management of chronic pain is increasingly seen as an important tool in providing adequate care to patients with FMS and other types of Chronic Non-malignant Pain.

Cognitive behavioral therapy has shown to enhance self-management in terms of successful cognitive and behavioral coping in a number of fibromyalgia patients (Adams & Sim, 2005; Dijkstra, Vlaeyen, Rijnen, & Nielson, 2001; Goldenberg, Burckhardt, & Crofford, 2004; Thieme, Flor, & Turk, 2006). In our study we want to counteracting dysfunctional cognitions and behaviors at the moment they occur by giving immediate, situational feedback and thereby we may increase the patient's self-management skills.

The science of behavior change through internet interventions is not well developed (Ritterband, Thorndike, Cox, Kovatchev, & Gonder-Frederick, 2009). Ritterband et al. have formulated a model for behavior change through use of website and the internet. Nine different components and nonlinear steps were specified: (1) the user, (2) influenced by environmental factors, (3) affects website use and (4) adherence, (5) which is influenced by support and (6) website characteristics. Website use leads to (7) behavior change and (8) symptom improvement through various mechanisms of change. (9) The improvements are sustained via treatment maintenance. As this is a complex field their model show that in order to design successful interventions aiming at health behavior change theories from several disciplines need to be combined. They have not specified the use of a cell phone, but their specifications in the model can be of help when designing systems and planning research in this area.



Technological structure of the virtual counseling system at https://wsf.hio.no

Network design

The system as displayed in figure 1, is primarily based on the HTTPS

standard (secure web protocol), encrypted communication between the cellular devices and researchers computers, and the server. Diary questionnaire data is securely transported from the cell devices, and stored on the server.

The server is a dedicated server, with access restricted to technical personnel, researchers and test subjects only. The server is placed behind a firewall, only accepting incoming communications over secure protocols (HTTPS for the research application and SSH for system maintenance). The primary aim of the networks design is to secure sensitive data. Some very basic measures are taken to ensure that data and identity of the test subjects are protected from any hacks, cracks or attacks – and all sensitive communication is encrypted, and protected with usernames and passwords.

How the research system works

The server can randomly decide when a user is to fill in a diary questionnaire or this can be set to fixed times. The server notifies the test subject by SMS. When the test subject receives the SMS on the cell phone – he/she logs on to the secure web application and completes the diary questionnaire. The server records the data, and can notify the researcher by SMS that a form is completed. This is optional. The researcher can log on to the server at any time, randomly or determined by the approximately time for patients' reply and records any comments to questionnaire. Then the researcher/therapist can posts a personal feedback to the test subject. The test subject is then again notified by a SMS that feedback is available for retrieval on the server.

System Design

The system is built on top of Open Source Content Management System – Drupal. It has a modular design with questionnaire builder, mobile access, SMS gateway and schedules. The patient data security is maintained through a combination of HTTPS, system design and proprietary mobile authentication system.

System Concepts and different functions

The main concepts of our developed system are based on a system that collects patient data using mobile phones and the internet. The patients can complete diary entries independent of location. Patients receive notifications with a direct questionnaire link. Scientists and therapists monitor the process and give situational feedback. There is a time tracking of all operations. The different concepts and functions are shown in figure 2. The "Project" is the main container of all information. The "Surveys" gives the possibility of constructing Forms/Questionnaires, diary entries, management and responses and feedback. The "Schedule" gives the possibility to determine project time span and scheduling of the diaries. The different "Roles" are "Supervisor", "Scientist", "Therapist" and "Patient". The supervisor has access to all features in the system, creating new projects and managing the roles. The scientist can construct questionnaires, read questionnaire responses, respond to patients and export data from the projects to excel, but do not manage new projects and setting up new schedules. The "therapist" has access to the assigned project(s) and can read diary questionnaires and give feedback. The"patient" is each telephone in the system. In the first project we lend the patient's telephones. An unlimited amount of projects can be defined as well as telephones linked to the system.

The researcher interface

The basic operations in the system on the research group side is the possibility to easy (a) create, change and manage projects, (b) manage project members, (c) manage questionnaires/forms, (d) manage schedules (fixed and random intervals/time), (e) have bidirectional live communication and feedback with the patients and (f) export data. Several researchers can have access to the system independent of physical space.

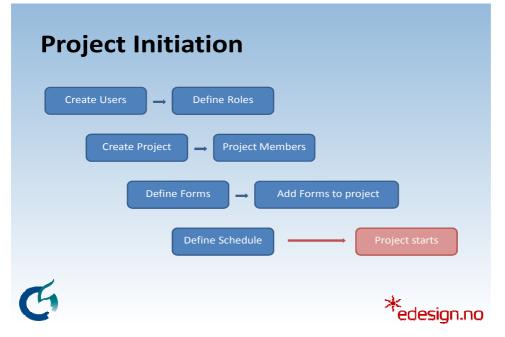


Figure 2. Concepts and functions of the system

The diary questionnaires

Creating diaries is done thorough the define form function. Different types of forms can be developed. The answer modus can be checkbox(es), selects, radios, textfield and files. It is possible to determine if answer to a question is optional or mandatory.

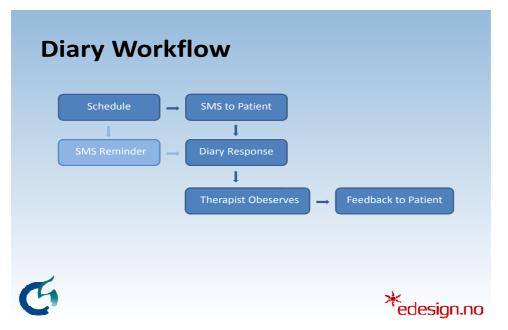


Figure 3. Diary workflow

The diary workflow is shown in Figure 3. It is possible to schedule reminders and also to decide on how long a questionnaire is open to be answered. In our study we have two reminders with 20 minutes in between and the opening time for the diary-questionnaires is set to 1.5 hour. The patients receive feedback within 2 hours.

Data storage and safety

To ensure protection of identity, no personal data concerning the test subjects is stored on any of the devices in the survey-network. All communications and storage of data is based on a unique identifier of each cellular device. All forms have a unique key that makes the questionnaire available for one cell phone only for a certain amount of time. No Patient Names are Stored in the System. A nickname may be applied to each device/test subject in order to ease interpersonal communication. As communication by SMS over the GSM/3G net is completely unsecure, SMS is only used for communicating to the test subjects when a questionnaire is to be answered, and when feedback is available from the researcher. The

actual feedback will be available to the user from a secure web page as well as the diary questionnaire. The communications are encrypted with HTTPS and each cell phone are equipped with a Private key. Furthermore information access is defined by roles.

Worst Case Scenario

As we are dealing with personal data we have also specified a risk assessment: The only place sensitive data is stored, is the server. The server is protected by only allowing secure connections. If the server was to be hacked, it would not be possible to connect any data to any specific person in the research group – because this information is not stored there. A hacker could at "best" obtain the unique identifiers to the phones, and match phones and questionnaire data. However, the personal identity of the test subjects still would be protected.

Pro's and Con's

Our system was developed by two persons working full time during tree month and has now run successfully for 30 month. We have counseled around 40 patients for five weeks each in the main project beside several test projects. The patients are filling in three diary questionnaires every day and receive personalized written feedback from one of the three counselors on weekdays for four weeks.

We have developed a system that has a time tracking of all events. We are able to deliver real time feedback. The data security is high. This improves the chances of sufficient compliance. In our pilot study the compliance of the diary questionnaires was 88%. It is easy for the counselor to access patients' answers to the diary questionnaires. Furthermore it is easy for the researcher to get the data exported to excel files for use in other statistical programs.

There are also some challenges. As there are patients that are going to use the system; there can be technological barriers related to their ability to use a new unfamiliar cell phone as our patients are between 20 - 70 years old. This can be alleviated by mandatory patient training. In our present study we meet face to face with the patients to assess their need for counseling. We then give a short instruction on how to use the cell phone together with a short booklet of information on this and the patients fill in their first diary questionnaire. Our pilot study showed that the cell phones were easy to use (Kristjansdottir et al 2010). This is indicated by the high compliance (88%) in answering diary questionnaires in the pilot study. Time delay

in internet communication can influence the validation process, especially related to submitting answered diary questionnaires back to the server. System malfunction is often the main reason that this kind of projects fail. Our system has had only minor troubles during the running period that can be viewed as a normal part of system maintenance.

Concluding remarks and future perspectives

We have described the virtual counseling system developed at Oslo University College. The system has been running for 30 month with minor trouble. Thereby the delivery process by the technological system has proven to be successful as well as the system as research system. Our pilot study also showed that the intervention we have developed is feasible to patients taking part in that study (Kristjansdottir et al 2010). Our ongoing randomized controlled study will show if the intervention is effective in the contexts it is used. The randomized controlled trial in patients with IBS showed reduction of symptoms and improved function in the intervention group (Orlemans et al 2010). When planning budgets for this kind of intervention, development as well as maintenance support should be included.

At the present moment the system will be applied in a new project to support patients with diabetes type 2 in their struggle to self manage their health related activities in the study "E-care: Stimulating self-management in patients with type 2-diabetes through situational feedback via mobile phones. A randomized controlled trial". This is a collaborative study with The Norwegian Centre for Integrated Care and Telemedicine in Tromsø within the EU-project "RENEWING HEALTH". In this study we will combine our virtual counseling system with a self help-tool for diabetes self management the "FEW TOUCH" application (Årsand, 2009). As the technological development in the field offers new solutions that can improve the functionality and ease of use of our virtual counseling system we will redesign it and develop the 2nd generation of the system in our process of developing more universal accessible health counseling.

References

Adams, N. & Sim, J. (2005). Rehabilitation approaches in fibromyalgia. *Disabil.Rehabil., 27,* 711-723.
 Årsand, E. (2009). *The Few Touch Digital Diabetes Diary. User-involved Design for mobile self-help Tools for People with diabetes. ,.* PhD University of Tromsø, Norway, Faculty of Science.
 Parak, A. Klein, R. & Droudfoot, J. C. (2000). Defining interpret supported thermouting interpreting.

Barak, A., Klein, B., & Proudfoot, J. G. (2009). Defining internet-supported therapeutic interventions. *Ann.Behav.Med.*, *38*, 4-17.

- Brendryen, H., Drozd, F., & Kraft, P. (2008). A digital smoking cessation program delivered through internet and cell phone without nicotine replacement (happy ending): randomized controlled trial. *J.Med.Internet.Res., 10,* e51.
- Coordination reform (2009). <u>http://www.regjeringen.no/en/dep/hod/kampanjer/the-coordination-reform.html?id=524777</u> [On-line].
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, 337, a1655.
- Dijkstra, A. (2005). Working mechanisms of computer-tailored health education: evidence from smoking cessation. *Health Educ.Res., 20,* 527-539.
- Dijkstra, A., Vlaeyen, J. W., Rijnen, H., & Nielson, W. (2001). Readiness to adopt the self-management approach to cope with chronic pain in fibromyalgic patients. *Pain, 90,* 37-45.
- Fors, E. A., Sexton, H., & Gotestam, K. G. (2002). The effect of guided imagery and amitriptyline on daily fibromyalgia pain: a prospective, randomized, controlled trial. J.Psychiatr.Res., 36, 179-187.
- Glasgow, R. E., Hiss, R. G., Anderson, R. M., Friedman, N. M., Hayward, R. A., Marrero, D. G. et al.
 (2001). Report of the health care delivery work group: behavioral research related to the establishment of a chronic disease model for diabetes care. *Diabetes Care*, *24*, 124-130.
- Goldenberg, D. L., Burckhardt, C., & Crofford, L. (2004). Management of fibromyalgia syndrome. *JAMA*, 292, 2388-2395.
- Kristjansdottir, O., Fors, E. A., Van Dulmen, S., Eide, E., Finset, A., Wigers, S. H. et al. (2009). Webbased situational feedback to support the use of positive coping strategies in women with generalized chronic pain - a feasibility study. *European Journal of Pain*, *13*, S34.
- Kristjansdottir, O., Fors, E. A., Van Dulmen, S., Eide, E., Finset, A., Wigers, S. H. et al. (2010). Written situational feedback via mobile phone to support self-management of chronic widespread pain: Development and usability testing of an internet intervention based on acceptance and commitment therapy (ACT). *submitted*.
- Kruise, D. A., Sorbi, M. J., Bensing, J., Van Dulmen, S., & Spreeuwenberg, P. (2004). Electronic guidance of behavior relevant to migraine: a pilot in low-back pain. In Couturier EGM & M. J. Sorbi (Eds.), *Headache and Migraine* (Utrecht: Anglo Dutch Migraine Association.
- Morren, M., Van Dulmen, S., Ouwerkerk, J., & Bensing, J. (2009). Compliance with momentary pain measurement using electronic diaries: a systematic review. *Eur.J.Pain, 13,* 354-365.
- Orlemans, S., van Cranenburgh, O., Herremans, P.-J., Spreeuwenberg, P., & Van Dulmen, A. M. (2010). Intervening on cognitions and behaviour in irritable bowel syndrome: an RCT using pocket computers . *submitted*.
- Peters, M. L., Sorbi, M. J., Kruise, D. A., Kerssens, J. J., Verhaak, P. F., & Bensing, J. M. (2000). Electronic diary assessment of pain, disability and psychological adaptation in patients differing in duration of pain. *Pain, 84,* 181-192.
- Prochaska, J. J., Zabinski, M. F., Calfas, K. J., Sallis, J. F., & Patrick, K. (2000). PACE+: interactive communication technology for behavior change in clinical settings. *Am.J.Prev.Med.*, 19, 127-131.
- Ritterband, L. M., Thorndike, F. P., Cox, D. J., Kovatchev, B. P., & Gonder-Frederick, L. A. (2009). A behavior change model for internet interventions. *Ann.Behav.Med.*, *38*, 18-27.
- Strand, E. B., Kerns, R. D., Christie, A., Haavik-Nilsen, K., Klokkerud, M., & Finset, A. (2007). Higher levels of pain readiness to change and more positive affect reduce pain reports--a weekly assessment study on arthritis patients. *Pain, 127,* 204-213.
- Tate, D. F., Jackvony, E. H., & Wing, R. R. (2006). A randomized trial comparing human e-mail counseling, computer-automated tailored counseling, and no counseling in an Internet weight loss program. *Arch.Intern.Med.*, *166*, 1620-1625.
- Tate, D. F., Wing, R. R., & Winett, R. A. (2001). Using Internet technology to deliver a behavioral weight loss program. *JAMA*, *285*, 1172-1177.

- Tennen, H., Affleck, G., & Zautra, A. (2006). Depression history and coping with chronic pain: a daily process analysis. *Health Psychol., 25,* 370-379.
- Thieme, K., Flor, H., & Turk, D. C. (2006). Psychological pain treatment in fibromyalgia syndrome: efficacy of operant behavioural and cognitive behavioural treatments. *Arthritis Res. Ther.*, *8*, R121.
- Wangberg, S. C. (2008). An Internet-based diabetes self-care intervention tailored to self-efficacy. *Health Educ.Res., 23,* 170-179.
- Wangberg, S. (2009). *Internet-based Interventions to support health behaviours. The role of self-efficacy.* University of Bergen.