The Potential of Telemedicine for Patients with Chronic Disorders Experiencing Problems with Their Functioning

Miriam Vollenbroek-Hutten, Hermie Hermens, Richard Evering, Marit Dekker-van Weering, Stephanie Jansen-Kosterink, Rianne Huis in 't Veld

Roessingh Research and Development BV Enschede, The Netherlands e-mail: <u>m.vollenbroek@rrd.nl</u>, <u>h.hermens@rrd.nl</u>, <u>r.evering@rrd.nl</u>, <u>m.vanweering@rrd.nl</u>, <u>s.kosterink@rrd.nl</u>, <u>r.huisintveld@rrd.nl</u>

telemedicine Abstract—It is hypothesized that applications can make rehabilitation care more effective and efficient. Besides the demonstrated potential of image/audio-based technology, it is expected that telemedicine applications, which use biomedical and ICT technology, to support physical and cognitive behavioral rehabilitation at home or daily life style management, both under remote supervision of professionals, are considered very promising. Compared to traditional rehabilitation methods, these telemedicine applications enable the patient to receive more intensive treatment at moments they prefer, or when care/coaching is needed, instead of when scheduled. In addition they also have the advantage that no translation of the learned skills to everyday life is needed. However, these telemedicine applications are often too much technology driven and insufficiently guided by the need of end users and the added value of these applications is still insufficiently known as a proper evaluation methodology is scarcely applied and large studies are lacking. This paper addresses these two aspects by describing a concept for development of end user driven telemedicine applications followed by an evaluation methodology that enables us to show the added value when applied in every day care. This is illustrated for telemedicine applications that focus on physical rehabilitation of patients with a chronic disease who are experiencing problems with physical functioning. Based on the results available so far, it can be concluded that these telemedicine applications are well accepted by patients and are at least as effective as traditional care.

Keywords-telemedicine; chronic disease; physical reconditioning; ambulant monitoring; home treatment; feedback. Miriam Vollenbroek-Hutten, Hermie Hermens, University of Twente Faculty of Electrical Engineering Mathematics & Informatics Enschede, The Netherlands e-mail: <u>m.vollenbroek@utwente.nl</u>, <u>h.hermens@utwente.nl</u>

I. INTRODUCTION

Both the European and American population is aging. With regard to The Netherlands, it is expected that the number of people aged over 65 years will increase to about 24% of the total population by 2050. Besides the increase in the proportion of elderly in the population there is also an increase in the number of people suffering from one or more chronic illnesses. Currently in The Netherlands, 1 of 4 people suffers from a chronic disease and it is expected that this number will rise sharply in the coming years. Since both the elderly and those with chronic diseases have higher care consumption this increase means a surge in pressure on our healthcare system.

Treatment of chronic diseases focuses on the relief of symptoms and related complaints as well as on increasing self-management by patients; this with the overall aim of increasing quality of life and level of participation in society. There are various treatments for patients with chronic disorders: such as drug treatments but also nonpharmaceutical treatments, like physiotherapy and multidisciplinary treatments are becoming increasingly important. It is however not realistic to continue these treatments in the way they are currently provided. This is due not only to the growing number of people in need of such care, but also due to the decline in labor capacity and the rise in costs that the care system is facing. In addition, our current way of care provision is strongly geared towards professional guidance with the patient not sufficiently in the driver's seat.

Prompted by these trends, but also facilitated by the new possibilities of technology, it is expected that telemedicine can contribute to more cost-effective patient centred care. This style of care provision is considered of utmost importance for our current and future care.

According to the Dutch Technical Appointment (NTA) telemedicine is defined as a process in healthcare, characterized at least by the following two features (NTA 8028; [1])

• Distance is bridged by using Information and Communication Technology (ICT)

• There are at least two actors involved, at least one of them is an approved care professional or acts on behalf of an approved care professional

The use of ICT in healthcare is a relatively recent development. In 1906, the Dutch physiologist Willem Einthoven transmitted Electrocardiograph (ECG) signals over telephone lines. He investigated ECG signals from patients in the Hospital from his laboratory located 1.5 km away. However, this was for research purposes only [2]. Medical care on a distance started in the 1920s when physicians were linked by radio to ships at sea to assist in medical emergencies [3]. Nowadays a Google search using the term 'ICT and healthcare' results in about 16.820.000 hits.

One of the areas in healthcare where telemedicine applications are considered to be of potential is the rehabilitation that merely aims at supporting patients in acquiring and maintaining an active lifestyle. Recently, the first systematic reviews related to telemedicine in this field have been conducted. Kairy et al. [4] performed a systematic review on clinical outcomes, clinical processes, such as attendance and compliance, healthcare utilization and costs associated with tele-rehabilitation for individuals with physical disabilities. They included 28 papers, published between 1993 and 2006, that used an experimental or observational study design. They concluded that tele-rehabilitation can lead to similar clinical outcomes compared to traditional rehabilitation programs, with possible positive impacts on some areas of healthcare utilization. However, the majority of the reviewed papers concerned technology that focused on image/audio-based technology. Other more advanced technologies such as sensor based technology and virtual environments, are hardly considered. LaPlante and Peng [5] published a systematic review in 2011 that included 31 articles which they analyzed in terms of study design quality, intervention characteristics and support for e-health in physical activity interventions. This review demonstrated that it is increasingly common to use various e-health technologies to address physical activity, but they also concluded that it is impossible at this moment to give definitive evidence for the effectiveness of e-health technologies as insufficient systematic and proper evaluation studies have been performed. In addition, a recent review [6] concluded that there is even less evidence regarding the costs or costeffectiveness of telemedicine applications, as well as the fact that there is insufficient evidence of the added value. The fact that telemedicine applications are still too technology driven and insufficiently guided by the needs of end users is also considered to hamper implementation and successful uptake of telemedicine applications by its stakeholders, including healthcare institutes, health professionals and health insurance companies [7].

This paper focuses on these two aspects, a concept for development of end user driven telemedicine applications and an evaluation methodology which enables us to show the added value of telemedicine when applied in every day care. This is illustrated by reference to telemedicine applications which focus on physical rehabilitation of patients with chronic disease who are experiencing problems with physical functioning. Firstly, the telemedicine applications will be addressed by describing the overall concept as well as some examples for physical rehabilitation. Subsequently an evaluation methodology is described as well as results of evaluation studies using this methodology on telemedicine applications that are used in the care of patients with chronic low back pain, chronic fatigue or a pulmonary disease.

II. POSSIBLE TELEMEDICINE APPLICATIONS FOR PHYSICAL REHABILITATION

A. The concept of telemedicine

Looking at rehabilitation in a broad sense, the aim is to enable a patient to participate in our society at the highest possible level of activity. There are different rehabilitation methods available to achieve this and they have certain key aspects in common, namely (re)learning adequate motor skills, regaining important functions such as force and, mobility and improving a patient's activity level. In traditional care, these treatments are performed during patient visits to the professional's premises where the patient receives feedback from the professional on how the patient performs and tips on how to further improve. Opportunities for introducing telemedicine in this rehabilitation process lie in applications that enable patients to train at home and work on their recovery more independently while being remotely supervised by their healthcare professional. Such telemedicine applications can be realized by means of biomedical technology used in combination with ICT. Hermens and Vollenbroek-Hutten [8] described an overall concept for these telemedicine applications, which is graphically presented in Fig 1.



Figure 1. The concept of a telemedicine service

This figure shows that different building blocks are needed for a telemedicine service.

Sensing:

In traditional treatment, a professional assesses the performance of the patient during training and, based on this, feedback is provided. In the case of telemedicine applications, where face to face treatment is at least partly replaced by technology, it is required that performance can be quantitatively assessed within the patient's daily environment and therefore some kind of sensing is usually needed. Which parameters to use for sensing the patients' performance depends on the diagnosis and the aim of the telemedicine application. Examples are: range of motion if mobility is being trained; muscle activation patterns where treatment aims at reduction of tension or at coordination, or activity levels when the goal is improvement of physical activity. The techniques useful for assessing performance can also differ. Some possible techniques are: subjective information (e.g. diaries), sensors temporarily attached to the body (e.g. ECG, EMG) and environmental sensors (e.g. wireless sensor networks [8].

Feedback

Once insight into a patient's performance is gained, the next step is to give the patient insight into his own performance by providing adequate extrinsic feedback. Extrinsic feedback is feedback provided on top of intrinsic feedback and mostly provided by an external source [9]. Feedback in treatment of patients with chronic disorders can serve different goals such as motor skills learning, creating awareness, motivating the patient to change, changing into and maintaining new performance levels [10]. In the case of telemedicine applications, feedback can be provided via different loops as also shown in Fig. 1. The shortest loop is local feedback provided directly on the monitored information. The second loop is feedback provided via a portal. This loop enables integration of data from different sources as well as over longer period of time. The third loop is professional feedback in addition to feedback received via the first two loops. Research shows that both patients and professionals prefer a combination of feedback via the first two loops, namely feedback by technology with feedback by professionals (third loop) [11].

Backend and portals

Backend and portals concern transport and storage of the measured signals, the processing of these signals as well as support of secured access to the data via internet. In most of the cases a 'decision-support system' is needed in order to extract relevant characteristics from the data and to adequately inform or warn patients and professionals as well as to trace technical failures [12]. The portals that provide access to the data in a user friendly and secure manner. In case multiple professionals are involved in the care of a patient it is important that the system, supported by a good policy management, can decide who needs to be warned and,

which information needs to be presented to which healthcare professionals.

Care and coaching

Formal and informal care givers may be involved in the care process to coach/support the patient. In order to adequately support them it is important to ensure that telemedicine applications are implemented in this daily care process in a proper manner. Telemedicine applications can be implemented as aftercare, as partial replacement of traditional care or as an addition alongside regular care. Considering the challenge to decrease the pressure on our healthcare in terms of costs and required labor capacity it is important that implementation as partial replacement is pursued.

B. Examples of telemedicine applications

Starting from this overall architecture different kinds of telemedicine applications can be realized for physical reconditioning of patients with chronic diseases. Below some examples are given.

Rehabilitation exercises at home

Patients with chronic disorders need to exercise and keep exercising a lot to improve and/or maintain their condition and motor skills. Rehabilitation at home refers to telemedicine applications that enable patients to perform these exercises at times and places they prefer while still being adequately supervised by professionals. Patients get access to individually tailored exercise programs through technology. Examples of these are presented in Fig. 2.

The picture on the left shows web-based exercise programs as developed in the FP7 project Clear (ICT: PSP CLEAR 224985) [13] and the Dutch project CoCo (CALLOP9089) [14]. A healthcare professional, often a physiotherapist, creates an individually tailored exercise program for each patient by making a schedule with the patient showing what exercises to execute and when. Exercises are chosen out of a data base of exercises. At home the patient logs into the system with a username and password and gets access to his personalized exercise program. Exercises are presented to the patient by means of video, spoken word and text. The patient has the opportunity to send text messages to the professionals or a teleconference can be scheduled.



Figure 2. Examples of telemedicine applications for active rehabilitation at home

The picture on the right shows a Home Care Activity Desk (HCAD) equipped with sensors for arm-hand function training. This application was developed by the European project HELLODOC (FP6 ETEN, 517508) [14]. This system consists of a portable unit with seven sensorized tools, which is installed in the patient's home. The seven sensorized tools are: a key, light bulb, book, jar, writing, checkers and keyboard. With this portable unit a set of exercises can be performed such as reaching, grasping, lateral pinch, pinch grip, holding, manipulation and finger dexterity. The unit is equipped with two webcams, which allow also videoconferencing and recording. The videos and the results of the exercises were uploaded to the hospital server where all the data and videos were collected. The therapist used this information for the weekly videoconference with the patient [15].

Life style management

Patients with a chronic disease often need to change their lifestyle to prevent deterioration or recurrence of complaints. An example of this is deploying and maintaining an active lifestyle. Telemedicine applications for life style coaching support patients in the development and maintenance of healthy behaviour by monitoring the patient's daily lifestyle and giving direct feedback on this to the patient. The monitored data can also be stored in databases and made accessible to his formal and informal care professionals via web-portals to adequately support the patient in this process. An example of such a telemedicine application is shown in Fig. 3.

The picture on the left shows the sensor for activity monitoring. In the middle of the illustration, an example can be seen of the direct feedback that is provided to the patient on his mobile phone. On the right is a screenshot of the portal that gives both the patient and professionals insight into the data and changes over a longer period of time.

Remote monitoring and alarming

For many patients it is difficult to recognize important disease-related symptoms and complaints and to act adequately on them. For example a worsening of complaints for patients with a pulmonary disease can be a reason to start an antibiotic or Prednisolon treatment.



Figure 3. Examples of a telemedicine application for lifestyle management

Remote monitoring and alarm applications focus on guarding the (changes in) health status of a patient by monitoring and interpretation of his vital body signs or primary complaints. This should be achieved as far as possible without affecting the patient's daily life but ensuring that help is provided if necessary. Fig. 4 gives an example of a remote monitoring and alarm service.

This application for patients with pulmonary diseases monitors the patient's changes in complaints on a daily basis by asking the patient whether the most relevant aspects of their complaints are different than usual. Based on the patient's scores over consecutive days an advice is given to the patient whether or not to start a medication treatment. Data of the patient are made accessible for his healthcare professional who is alerted in case a medication treatment has to start. This enables him to adequately advise the patient.

III. EVALUATON

A. Methodology

Once a telemedicine application has been developed, the next step is to demonstrate the results when the system is used in everyday practice. Outcome measures usually focus on the technical feasibility of the system and on user satisfaction. In general, the results of such studies show that telemedicine applications are technically stable and that patients and professionals have a positive attitude towards using them. This type of evaluation is however not sufficient to justify subsequent large scale implementation. For this, a broader evaluation is necessary [9]. DeChant et al. [16] proposed a staged approach for the evaluation of telemedicine applications, starting early in the development phase and dependent on the maturity of an application. The first phase evaluation is aimed at investigating whether the requirements of the patients are met and whether the application is technically stable. At this stage the user group is small, because the results are mainly used to develop a more mature application. After the first phase evaluation, evaluation of a mature application (stage 2) focuses on the clinical outcome. If these results are positive, evaluation becomes even more extensive, using multiple endpoints such as effectiveness, efficiency or accessibility of care (stage 3). The last evaluation phase (stage 4) focuses on external validity and investigates whether the application is as effective when implemented in places other than where it was developed.



Figure 4. Examples of a telemedicine application for remote monitoring and alarming

B. Clinical studies

Taking the DeChant [16] framework as starting point evaluation studies have been performed for the rehabilitation-at-home applications and the life style management applications. Results of these studies are presented below.

Rehabilitation exercises at home

After a small positive prognostic cohort study, a further developed version of the web-based exercise program was implemented at The Roessingh Center for Rehabilitation (RCR) (The Netherlands) in outpatient pain and pulmonary rehabilitation programs in two different modalities: as addition to and as partial replacement of the traditional rehabilitation. For evaluation a study was performed in which eligible patients were divided into a control and an intervention group. The control group followed the traditional rehabilitation program. The intervention group followed the same program but with the web-based exercise program implemented, dependent upon patient's ability to train as addition or as replacement of one visit to the rehabilitation center per week. The large scale evaluation focused on multiple outcome parameters namely experiences (satisfaction, compliance and usability) and clinical benefit. Clinical benefit was assessed by using a Visual Analogue Scales; pain intensity for chronic pain patients and level of dyspnoea for COPD patient. The trial is ongoing; currently 212 patients are informed about the service and 187 patients have given written informed consent to participate. Eighty-four patients were allocated to the control group and 103 patients were allocated to the intervention group. Preliminary results for the first 125 patients who have finished the treatment show that the overall grading of the web-based telemedicine exercise service was sufficient and that the ease of use was rated good. On average, these patients scored 7.2 on a scale of 0-10 indicating that usability is good. The first results on clinical benefit show that both implementation modalities (as addition / as partial replacement) are at least as effective as traditional care. In the telemedicine (n = 66) and the traditional care group (n= 69) about 55% and 49% of the patients show a clinically relevant improvement on the primary outcome parameter, respectively. However, these percentages are not significantly different from each other.

The Home Care Activity Desk (HCAD), which was also redesigned after an initial demonstration study, was evaluated in a randomized multicenter trial within the European project Hellodoc [17]. In this study usual care was compared to the HCAD intervention for arm/hand training. The intervention with the HCAD system at home lasts one month, whereby the patients had to train at least once a day, 5 days a week for an average of 30 minutes. Usual care (control group) consisted of regular physical and ergonomic therapy with an average of three times a week for 45 minutes. Follow up measurements were performed after one month of treatment. Eighty-one patients with chronic Stroke, TBI and MS patients were recruited in Italy, Spain and Belgium. Outcome measures used were the Action Research Arm Test and the Nine Hole Peg Test. Results showed that the overall satisfaction of patients and therapists concerning the HCAD system was high. The outcome measures do not differ significantly between the two groups; and patients maintain or even improve on their arm/hand function.

Life style management

Evaluation of the activity-based feedback application for supporting the patient in deploying a better activity pattern during the day started with a prognostic cohort study of 17 patients with chronic low back pain who carried a tri-axial accelerometer and a PDA for 15 days (baseline and 2 weeks of feedback [18]. Patients received continuous and timerelated personalized feedback and were instructed to follow the activity pattern as displayed on the PDA (norm value). Results showed that the technical performance was rated good in nine patients (56%), moderate in four patients (25%) and bad in three patients (19%). The overall compliance was rated good in seven patients (44%), moderate in five patients (31%) and bad in four patients (25%). A positive trend was seen in the activity pattern of the patient that moved towards the norm value during the feedback weeks, however the difference failed to reach the level of significance (F=1.932; p=.149). In contrast, the pain intensity levels decreased significantly in the second week of feedback compared to baseline and the first week of feedback (F=5.401; p=.005).

In addition to this study, a second study was performed on 30 patients with chronic fatigue syndrome with the aim determining the compliance with the system and the amount of change in physical activity patterns of those who comply [19]. For this a longitudinal study was performed as part of a randomized controlled trial in which a feedback program was introduced in an existing rehabilitation program. The existing rehabilitation program comprised 9 weeks of inpatient cognitive behavioural therapy in weeks 1, 3, 5, 7 and 9. The feedback application was implemented during the four periods when patients were at home in between the weeks of inpatient treatment. Compliance with the feedback system was around 90% during each of the four feedback periods, however only fifteen patients (50%) complied with all four feedback periods (compliers). The Wilcoxon signed ranks test showed that for the group of compliers the physical activity level, expressed as percentage of the goal value, during feedback period 1 (103%), feedback period 2 (98%), feedback period 3 (94%) and feedback period 4 (98%) were significantly higher (p<0.01) and closer towards the goal compared to the baseline period (84%) and these changes were most obvious in the morning and afternoon.

IV. CONCLUSION AND FUTURE WORK

The results of the present paper show that patients and professionals are positive about telemedicine services for rehabilitation purposes. In addition, the clinical benefits achieved with telemedicine applications are promising as the clinical benefits appear to be at least as good as the results achieved with traditional rehabilitation care. However, the level of evidence to date is, also according to the DeChant [13] framework, not sufficient and needs attention in future. Next to this, another aspect that is considered important for future work is the technology used. The technology should be relegated even more to the background as is currently the case. For this, the technology should be more adaptive, intelligent and become a real buddy of the patient. Concerning the telemedicine applications itself the integration of social media, group dynamics but also serious games are considered important, especially for long term adherence to exercising.

To finalize, although there are still many challenges, the potential of telemedicine in rehabilitation care becomes conspicuous on a daily basis and the positive effect of our methodology is evident.

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