SMART: DEVELOPING INFORMATION AND COMMUNICATION TECHNOLOGY FOR SELF MANAGEMENT OF STROKE AND CHRONIC CONDITIONS AT HOME

PM WARE, J HAMMERTON, SJ MAWSON, GA MOUNTAIN
The Centre for Health and Social Care Research, Sheffield Hallam University, Sheffield UK S102BJ {t.ware@shu.ac.uk}
H ZHENG, R DAVIES, N BLACK,
University of Ulster
N D HARRIS, S WILSON, T STONE, C ECCLESTON
University of Bath
H.HU, H. ZHOU
University of Essex

Abstract. This paper reports on a stream of work by a consortium of universities (SMART consortium) developing ICT to support rehabilitation and self management for stroke survivors and others with long term conditions. Firstly, it reports on the completion of a proof of concept project enabling feedback on repetitive movement practice for stroke rehabilitation; secondly, it summarises the collaboration between the SMART consortium and an industrial partner to develop the equipment for testing in community practice; and thirdly it proposes a comprehensive personalised self management system for those with stroke and other long term conditions to monitor and manage their health and well being. The focus throughout the paper is on the work with users in developing and testing software interfaces and equipment.

1. Introduction

Stroke is a huge cause of disability in UK with over 100,000 people a year having their first stroke (Stroke Association, 2001). It has a dramatic impact on survivors' ability to maintain their independence. A year after stroke 35% of surviving stroke patients are significantly disabled and many need considerable help with daily tasks such as bathing, dressing and feeding (DoH, 2001). Stroke rehabilitation aims to maximise the functional and cognitive abilities of survivors to help regain independence and control over their own lives. In the UK, the National Service Framework for Older People recommends that rehabilitation should continue until maximum recovery has been achieved (DoH, 2001) but 64% of stroke survivors were unable to access specialist stroke rehabilitation in 2002 (Intercollegiate Working Party, 2002) . In some locations, provision may be basic, with rehabilitation being targeted solely at discharge from hospital and with little monitoring following return home (Tyson and Turner, 2000; Rudd et. al, 2001). Although there have been recent improvements in specialist in-patient stroke care, there is still limited after-care, as only 22% of Hospital Trusts have specialist stroke teams to support rehabilitation after discharge home (Intercollegiate Working Party, 2005).

Intensive, repetitive, task-specific exercises such as sit-to-stand or reaching or hand-to-mouth movements may be necessary for months or years to promote motor relearning and recover movement function (Miltner et. al., 1999; Rossini et. al, 2003). Therefore, it is important that people are motivated and actively involved in these exercises and it is a challenge to find ways of making repetitive exercises desirable and meaningful (Lotze et. al., 2003; Maclean, 2002). Information and Communications Technologies have the potential to transform radically the delivery of healthcare and to address future health challenges (The Royal Society, 2006). Advances in ICT have already given rise to a variety of tools to complement direct efforts by therapists (Liebermann et. al., 2006) and pilot programmes have shown that tele-rehabilitation can be effective in providing services to underserved regions (Clark et. al. 2002; Sellers et. al., 1998). Interviews with people who have experienced stroke confirmed a lack of satisfaction with rehabilitation services and a desire (or unmet need) for more directed rehabilitation in the critical period immediately post discharge (Pound and Gompertez, 1999; Stroke Association, 2001). In this context there is good rationale for using ICT and sensor technology to support rehabilitation systems in people's own homes that encourage choice and self management in treatment programmes.

2. SMART Consortium stroke rehabilitation project

The Smart Consortium is one of the research groups funded under the EQUAL funding stream of the UK Engineering and Physical Sciences Research Council. The project examined the appropriateness and effectiveness of technology to support stroke rehabilitation. The aim is to enable stroke patients to carry out exercises and activities at home, that can be observed and measured both by the patient themselves and also remotely by clinicians. A prerequisite for any successful ICT system is to incorporate users' views at an early stage in the design and development process. Throughout the project, the research team therefore used focus groups of stroke patients, carers and rehabilitation professionals to give feedback on the development of the system (Mountain et. al., 2006). In the first year and in conjunction with the Stroke Association, we conducted a series of four groups which provided us with a number of principles to guide the development of the system. The key findings were that any device should be compact, simple to operate and maintained by staff in the event of problems; usable by stroke patients preferably without the help of the carer to encourage independence; available alongside the work of therapists and able to give encouraging feedback to patients about outcomes even when progress was slow. People affected by stroke liked the idea of seeing progress through some sort of measurement that might be able to identify changes that they or a physiotherapist might not see but could still be measured.

3. Methods

A review of available technology (Zheng, Black and Harris, 2005; Zhou and Hu, 2005) was carried out and a specification was developed for a rehabilitation system that used movement sensors (integrated accelerometer, magnetometer, and gyroscope technology) attached to the wrist and upper arm to record reach and grasp and hand to mouth, upper limb exercises. The system allows data from the two Xsens mtx sensors (Xsens, 2007), connected to a waist-worn control unit, to be sent using wireless communication to a multimedia computer in the user's home (Zheng et. al., 2006). The information is displayed as a 3D animation presentation, and this can be replayed by users and therapists. Graphical analysis of key kinematic variables presents information on the number of repetitions, time taken for each movement, and various measurements of range of movement for the elbow. A web-based platform allows therapists to have remote access to patient activity, to add comments on their progress and to make decisions about further treatment (Zheng et. al., 2005).

Following development of prototype software we started the second phase of user and carer consultation by convening a series of groups with a total of 16 participants, to give detailed feedback on the screen interface and sensor attachment methods, By having users try on the different types of sensor attachment, such as arm sleeves, wrist bands, chest straps and thermoplastic shells, we were able to see for ourselves how the sensor was positioned and relate this to users' perceptions of comfort and recognition of the correct placement. Users were interested in a measure which rated how close their movement was to a target movement of a normal arm. They were also interested in the display of their previous attempts at the exercises on screen to demonstrate where they were coming from as well as to see what they were trying to achieve. Users were also keen to be able to access their movement history together with notes made in earlier stages of rehabilitation. Following detailed analysis of the focus group feedback, the specification of the system was revised and further iteration of the software was produced. Twenty-one usability tests were carried out with people recruited from four stroke groups and a stroke rehabilitation ward. Subjects were encouraged to think aloud during the tests and were asked for their opinions after completing (or failing to complete) each task in the hierarchical task analysis. The resulting changes to the system included the replacement of a tree style navigation (used to locate exercises previously recorded) by a calendar; the introduction of a touchscreen to overcome difficulties with controlling standard input devices; buttons were made larger and colour coded for function while labels, explanations and images helped to provide clues for navigation. An on-screen keyboard was incorporated to enable users to write diary notes and graphs showing summary data for the movement variables (shoulder flexion-extension and forearm supination-pronation) were implemented (Wilson et. al., 2007).

The final stage of the project was testing the system over a two week period, with 2 male and 2 female stroke survivors at home who had been discharged from local health authority community rehabilitation (with an age range of 37-73 years and time since stroke between 8 months and 4 years). The system was demonstrated to them and they were encouraged to carry out at least daily reaching exercise programme. We wanted to see how participants would fit the exercises into their normal routine and asked them to keep a diary of their use of the system to note any problems. A user manual was available for them to refer to and the researchers were able to give advice by phone or visit if they needed help. At the end of the trial period we videoed a rehabilitation session and carried out a debriefing interview Independent outcome measures were taken before and after the testing period. These were a Timed Up and Go test (measuring in seconds how long it took for the user to get up from a chair and walk a specified distance); a Motor Assessment Scale (Carr et. al., 1985) measuring ability to move the arm; and three TELER (2007) goals assessing personalised functional goals such as tying shoe-laces or being able to use cutlery.

4. Results

The qualitative data from the interviews provided useful feedback to inform further work. The issues that arose from the interviews demonstrated that users preferred real-time display to viewing the practice movement after the recording had taken place; that users wanted on-screen analysis to show a comparison between their movement and a target; that they wanted a chart showing progress over time; and that the charts showing distance reached and time taken were poorly understood. They also preferred fully wireless sensors, rather than just the wireless link to the PC. All the users indicated that they found using the system motivating in different ways. One of the men did not use the system to compare his recorded movements with the screen target model but was motivated by the sense that he was being recorded and that someone could therefore check up on him. The other male user however, was interested in the analysis of his movement in comparison to the target and he was motivated to remedy his own movement. He used the different screen presentation of the movement from the top, the side and the front of the body to identify how his reaching exercise needed to improve. A female user also used the different views of her recorded exercise to see how her arm was rotating as she moved, something she had not fully appreciated by doing the exercises on her own. The other female used markers on her screen to measure how far she had raised her arm and was motivated to increase the distance she had reached. Fifty per cent of the outcome measures showed improvement, 40% showed no change and 10% showed deterioration in function. Since the numbers of participants were small and the proof of concept research design did not include a control group, a causal relationship is not established. However, the testing indicates that the measures chosen were sensitive enough to show change over time. Analysis of the recordings showed that on average participants used the equipment 3 times a day, with an average of 31 repetitions per day, on 12 of the 14 days it was being tested. These results provided proof of concept, in that a robust rehabilitation system can be managed at home and used to provide useful and motivating feedback within the daily routine of a stroke survivor.

5. System development

Development of the updated system has taken place in collaboration with Philips Research Department, which was developing a Stroke Exerciser (Philips, 2007). The fused system (TARGET) uses fully wireless sensors together with a real-time display of the upper limb movement. An additional trunk sensor has been added, as requested by therapists. The system operates on a laptop computer, which is more easily used in people's homes than the separate touch screen and multimedia PC that the SMART system had used. The graphical display gives information on individual movements as well as a summary of movements over time. Following a survey of therapists to identify the most common and useful rehabilitation movements, a library of four exercise tasks has been developed. These were recorded verbally and on video and incorporated into the TARGET system to enable stroke survivors to choose which movements to practice. Figure 1 shows the SMART system being used by a researcher and Figure 2 shows the TARGET system in a home environment. Work is currently underway to assess the usability of the system, concentrating on user interface and sensor attachment.

Figure 1. SMART system.

Figure 2. TARGET system.

6. Future developments

There have recently been a range of government policy initiatives in the UK that support self managed care of people with long term conditions to encourage independence, choice and control and that promote the development and use of ICT to support people in their own homes (DoH, 2005, 2006). There are a number of other conditions, such as chronic pain and chronic heart failure where health and social care services are struggling to meet demand for treatment and rehabilitation. These conditions have different intervention models: chronic pain for which the therapeutic goals are largely *accommodative*; stroke for which the therapeutic goals are largely *restorative* and CHF for which the therapeutic goals are largely *preventative.* The SMART Consortium is addressing issues by creating a home based personalised self management system (PSMS). The focus of the development will be on working with users to develop user scenarios of their daily routines and life goals to inform software designers. This is a distinguishing feature of the project in comparison with other ICT self management systems, with the focus being upon the technological system (SAPHE, 2007). The architecture of the proposed PSMS system consists of a number of sensors that can detect overall activity as well as sensors that track specific movements (as in the SMART system). It will also enable the monitoring of vital signs and activities of daily life. The information from these sensors will generate a user profile for each patient, together with other details provided by therapists, such as personal life goals, care plans and medical history. Remote communication will provide the facility for the therapists and health professionals to access the system from a remote location to review the care plan, and to advise any changes to the life goals (Zheng et. al, 2008).

7. Summary and Conclusions

Concerns regarding the increasing prevalence of a number of long term conditions including stroke, the rising costs of traditional face-to-face healthcare delivery and a philosophical move towards promoting self reliance and patient empowerment have led to the introduction of self management initiatives in many countries. The UK government is promoting the use of technology in self management and preventive approaches to health and social care. Although previous work has demonstrated the feasibility of applying ICT to support home stroke rehabilitation there remains important work to be done on proving cost effectiveness and clinical efficacy with a larger patient population. There are still fundamental issues that need to be researched such as how information on changes in chronic conditions can be fed back to users to help them not only understand their condition but also change their behaviour. Further work is needed to explore the user acceptability of monitoring by therapists from a remote location and the impact this has on both user and therapist motivation to work with the technology. Continuing user testing of the proposed PSMS and TARGET system will help to provide information to understand these issues. Pilot trials in the home setting will be used to provide feedback to the multidisciplinary team of scientists, therapists and clinicians and provide tailored interventions to assist users and therapists.

Acknowledgements

The SMART Consortium is funded by the Engineering and Physical Sciences Research Council (www.fp.rdg.ac.uk/equal). Consortium members include Sheffield Hallam University, University of Sheffield, University of Bath, University of Essex and the University of Ulster. The Consortium recognises the contribution of the Stroke Association (www.stroke.org.uk) and Philips Research Department (www.philips.com). SMART Website www.thesmartconsortium.org.

References

Carr, J.H., Shepherd, R.B., Nordholm, L., Lynne, D.: 1985, Investigation of a new motor assessment scale for stroke patients, *Physical Therapy*, **65** (2), 175-80.

Clark, P.G., Dawson, S.J., Sheideman-Miller, C. and Post, M.L.: 2002, Telerehab: Stroke teletherapy and management using two-way interactive video, *Neurology Reports*, 26, 86-92.

Department of Health: 2001, *National Service Framework for Older People*, DoH, London.

Department of Health :2005, *Supporting People with Long Term Conditions*, DoH, London

Department of Health: 2006, *Our Health, Our Care, Our Say*, DoH, London.

Intercollegiate Working Party: 2002, National Sentinel Stroke Audit 2001/2, Royal college of Physicians, London.

Intercollegiate Working Party: 2005, National Sentinel Stroke Audit 2006, Royal College of Physicians, London.

Lotze, M., Baun, C., Birbaumer, N., Anders, S. and Cohen, L.: 2003, *Brain*, **126** (4), 866-872.

Liebermann, D.G., Buchman, A.S., and Franks, I.M.: 2006, Enhancement of motor rehabilitation through the use of information technologies, *Clinical Biomechanics* 21:8-20

Maclean, N., Pound, P., Wolfe, C., Rudd, A.: 2002, The concept of patient motivation, *Stroke* 33,444.

Miltner, H.R.W., Bauder, H.: 1999, Effects of constraint-induced movement therapy on patients with chronic motor deficits after stroke, *Stroke,* ***3*0**, 586-92.

Mountain, G.A., Ware, P.M., Hammerton, J., Mawson, S.J., Zheng, H., Davies, R., Black, N.D., Zhou, H., Hu, H., Harris, N. and Eccleston, C.: 2006, The SMART Project: A user led approach to developing and testing technological applications for domiciliary stroke rehabilitation, in Clarkson P, Langdon J, and Robinson P (eds*), Designing Accessible Technology,* Springer-Verlag, London.

Philips, [online] www.research.philips.com/newcentre/archive/2006/carelab/061025-ultra.html (Accessed December 2007).

Pound, P. and Gompertez, P.: 1998, A patient-centred study of the consequences of stroke. *Clinical Rehabilitation*, 12, 338-347.

Rossini, P.M., Calautti, C.: 2003, Post-stroke plastic reorganisation in the adult brain, *Lancet Neurology*, **3**, 493-502.

Rudd, A.G., Irwin, P., Rutledge, Z., Lowe, D., Wade, D.T. and Pearson, M.: 2001, Regional variations in stroke care in England, Wales and Northern Ireland: results from the National Sentinel Audit of Stroke, *Clinical Rehabilitation*, 15, 562-572.

SAPHE, [online] http://ubimon.doc.ic.ac.uk/saphe (Accessed December 2007)

Sellers, W. L., Varley, J. and Waters, S.: 1998, Remote locomotor monitoring using accelerometers: a pilot study, *Folia Primatologia*, 69, 82-85.

Stroke Association: 2001, *Speaking Out about Stroke Services*, The Stroke, London.

TELER, [online] www.teler.com (Accessed December 2007).

The Royal Society: 2006, *Digital Healthcare*: the impact of information and communication technologies on health and healthcare, The Royal Society, London.

Tyson, S. and Turner, G.: 2000, Discharge and follow-up for people with stroke: what happens and why, *Clinical Rehabilitation,* 14, 381-392.

Wilson, S., Davies, R., Stone, T., Hammerton, J., Ware, P., Mawson, S., Harris, N., Eccleston, C., Zheng, H., Black, N. and Mountain, G: 2007, Developing a telemonitoring system for stroke rehabilitation*, in Proceedings of Ergonomics Society Annual Conference*, Nottingham, Taylor and Francis.

Xsens, [online] www.xsens.com (Accessed December 2007).

Zheng, H., Black, N.D. and Harris, N.: 2005, Position-sensing technologies for movement analysis in stroke rehabilitation, *Medical & Biological Engineering & Computing*, 43, 413-420.

Zheng, H., Davies, R.J., Black, N.D.: 2005, Web-based monitoring system for home based rehabilitation with stroke patients, *Proceedings of 18th IEEEE International Symposium on computer based medical systems*, Ireland.

Zheng, H., Davies, R., Black, N.D., Ware, P.M., Hammerton, J., Mawson, S.J., Mountain, G.A. and Harris, N.: 2006, The SMART Project: An ICT decision platform for home based stroke rehabilitation system, *Proceedings of the International Conference on Smart Homes and Telematics.*

Zheng, H., Nugent, CD., McCullagh, PJ., Black, ND., Eccleston, C., Hawley, M., Mawson, SJ., Wright, PJ. and Mountain, GA.: 2008, Towards a Decision Support Personalised Self Management system for Chronic Conditions in *Proceedings of IEEE International Conference on Networks, Sensing and Control,* China.

Zhou, H. and Hu, H.: 2005, Inertial motion tracking of human arm movements in home-based rehabilitation, *Proceedings of IEEE Int. Conf. on Mechatronics and Automation,* Ontario, Canada, 29 July – 1 August, 2005, pp. 1306-1311.