Information and communication technology – a person-centered approach to stroke care

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ABSTRACT

This report describes the possibilities of information and communication technology (ICT) in stroke care, addressing a person-centered care (PCC) approach. Attention is paid to user involvement, design, videogames, and communication between health care professionals mutually as well as with patients, and how to share performance data with an electronic health record. This is the first step towards a supportive ICT system that facilitates interoperability, making healthcare information and services available to citizen’s across organizational boundaries.

1. INTRODUCTION

Swedish health care is currently organized much like a production process, meaning that health is treated as a product. Patients are led through a number of routine based procedures and the goal is that they should come out healthy at the end of the process. This method is efficient when treating emergency patients, but less efficient when treating chronically ill patients. For chronically ill patients treatments could become more efficient by being more adapted to particular needs. Since the chronically ill continuously utilize the health care sector throughout their life, gains for this patient group could be substantial (Spigel and Olsson, 2011).

Stroke is a common cause of long-term disability in the developed world (Jones et al, 2012). The person surviving a stroke demands regular personalized rehabilitation according to the individual problem profile and her/his own choice of engaging training activities. The clinically confined rehabilitation is good but worldwide decreasing in time extent. Community or home-based rehabilitation is increasingly looked to as a solution (The National Board of Health and Welfare Sweden, 2011). Upper extremity (UE) paresis is a common problem following stroke and the paretic UE is typically weak, slow, and lacking in coordination and dexterity (Langhorne et al, 2009). Skilled UE performance requires the effective and efficient gathering and processing of sensory information relevant to the task at hand. Research implies that practice on tasks that are automated influence performance and underlie brain activity (Shiffrin and Schneider, 1977), indicating that the premotor cortex plays a role in UE recovery (Johansen-Berg et al, 2002). For the treatment of sensory stimuli in the brain, we have to work out a certain ways in which multiple sensory stimuli, such as motion, visual and auditory information must be coupled. Some studies suggest that video gaming may help stroke patients because of the brain's unusual potential for remodeling, in which it creates new nerve cell connections (Saposnik and Levin, 2011).

The point of departure in the project is with respect to the survivor's continuity of care; the lack of concordance within stroke care. The amount of rehabilitation required to bring stroke survivors to their full
potential varies across individual cases. Unfortunately the limitations of conventional health care imply that many stroke survivors do not receive the rehabilitation they require (The National Board of Health and Welfare, 2011). In optimizing stroke care in order to satisfy these demands we propose an ICT solution based on communication, shared decision making and therapy. Therefore, empowerment for self-care management through effective engagement strategies (therapy) represents an essential component in this research. It is well documented that poor patient engagement is an important contributor to poor self-care management (Fjaertoft et al, 2011; de Weerd et al, 2011). Thus, engaging stroke survivors as active participants i.e., partners in their own health care will have better outcomes (Ekman et al, 2011). Further, it may take time to adjust with the complexities of being at home to develop stroke survivor’s personal resources and strategies (Jones et al, 2012).

The assumption is that such interventions cannot solely be undertaken in institutions but in people’s homes, where most of the continuous and daily training actually takes place. Rehabilitation is an essential part in stroke care. In Sweden, stroke care is based on current principles as recommended within the National Guidelines for Stroke Care (The National Board of Health and Welfare, 2009). Inpatient stroke care consists of four main phases:

- Initial presentation, recognition and identification.
- Referral and initial assessment, and recommendations.
- Inpatient rehabilitation, admission, assessment, intervention, discharges planning.
- Discharge and follow-up.

In this paper we concentrate on the third stage, which supports inpatient rehabilitation. The requirement for admission to a specialist inpatient rehabilitation unit in Sweden is determined by the need for an intensive interdisciplinary rehabilitation program that cannot be delivered in an outpatient or community setting, along with the need for nursing care and/or medical treatment. Inpatient rehabilitation is provided by an interdisciplinary team, offering the full range of specialist assessments and interventions. The team includes the following specialist: clinical neuropsychologist, nurses, occupational therapists, physiotherapists, rehabilitation medicine physicians, speech and language therapists, social workers, and administration support. To identify appropriate management strategies to guide stroke care and to coordinate goals and planned activities from all involved actors, a plan of care is usually established. The plan of care is based on needs identified in the pre-discharge stage, a written document which provides an agreement between stroke survivors, their families and health care professional on how to manage day-to-day rehabilitation (The National Board of Health and Welfare, 2009).

The present work addresses the increasing demand on co-operation between different care units, maintaining the continuity of stroke care. Further we wanted to explore the usability of a videogame for UE rehabilitation among occupational therapists (OT’s) and stroke survivors.

2. MATERIAL AND METHODS

2.1 Subjects

The study was carried out at Sahlgrenska University Hospital, Neurorehabilitation unit, Västra Götaland County, Sweden. Stroke survivors were identified by occupational therapists (OT’s) working at the Neurorehabilitation unit. OT’s were defined as anyone with a significant professional involvement with stroke survivors as part of their day-to-day role. A workshop was organized to investigate the perception and technology acceptance of the OT considering gaming for UE rehabilitation. The first two authors gave a brief introduction of the research study through a short presentation followed by an introduction of the interactive videogame, starting from the very basics of the game play.

2.2 System Components

A prototype video game was developed for UE rehabilitation, using Microsoft’s Kinect gesture control device on a PC. Using its depth, image, and audio sensors, the device translates user’s physical gestures into on-screen actions. In the prototype video game players were presented with a series of colored boxes that could be struck using one of their upper extremities (UE). The boxes moved sideways from right to left on a computer screen and when a box had crossed the vertical center line on the computer screen, the box changed color from blue to red. At the same time as a box (black circle) crossed the centerline a new box would fly in (dotted circle), see Fig. 1. In order to gain feedback (hits) the player had to strike (grasp) the red boxes, i.e. the motion of one arm hitting into the air towards the red box on the computer screen. To acquire hits, the red
boxes had to disappear, and an alert, hit or miss (voice feedback) appeared. A command line interface was used as the user interface, i.e. typing in commands to start the video game and adjust game parameters.

2.3 Usability Evaluation and Play Testing

Information from OT’s true interview and usability trials of the prototype game were gathered. Semi-structured interview was constructed to obtain feedback about the subject’s perception of the game. It included the following questions. (1) Was the game relevant for OT’s? (2) Was the game relevant for UE rehabilitation? 3) Was it easy or difficult to find game information on the computer screen? 4) Was it easy to remember how to restart the game, e.g. after taking a brake e.g.?

2.4 Design and Development of a Model for a Healthcare Platform for Distributed and Mobile Use within Stroke Care

A healthcare platform was created with a set of generic care components with a patient-centered approach to support stroke care to improve effective care coordination and quality using a plan of care directly related to management of activities and catching of results of specific activity instances. Hence, the information was structured so that it could be used in different contexts, for different purposes, in the health care process and for monitoring and managing activities. The model reflects the principles as recommended by the National Information Structure (2012) which ensures that the correct information is documented and put into context on the general level (Johansson et al, 2009).

3. RESULTS

3.1 Usability Evaluation and Play Testing

Fourteen occupational therapists (N = 14) and four inpatients participated. The prototype was revised during spring 2012. The major problems identified such as how to begin and stop, data entry, continue data entry and label information was found by 80 %. These problems were addressed and corrected by modifying the interface to make the data entry and labeling more intuitive. In general, this usability test uncovered functional and interface design flaw. The OT’s and patients pointed out the following criteria as very important:

- Games should have properties that are relevant to therapists and that can be both manipulated and measured.
- Games should target various body movements; it’s best if these can be assessed for quality of movement.
- Motor demands of the games should change independently from cognitive demands.
- The game should accommodate both sitting and standing positions.

![Figure 1. A screenshot from the player's perspective, in the upper left corner reaching for a red box (black circle) and at the bottom right corner a blue box (dotted circle) flies in.](image-url)
Fig. 2 illustrates the user interface with different labeled buttons for retrieving different exercises and record screen activity (top line). Specific instructions for each player to start the exercise were given, “Imagine that there is an invisible button in front of you, now raise your arm and press your hand in the air”. Once the program has seen your hand, it says "Now I see your hand " and a red circle pops up on the screen in front of the player at height of the hand. Should the program lose the hand, it says that "now I do not see your hand anymore”. For the program to see the hand again one has to press the hand in the air again. The program answers "now I see your hand".

![Figure 2. The user interface after the prototype was revised.](image)

In the second row the user can select game parameters true drop-down lists (dotted box in fig 2), i.e. adjusting the velocity of the incoming box, the number of boxes to be used and on which height the boxes should fly in, see fig.1.

- **Velocity (Hastighet).** Sets how fast the rectangles to move from 1 – 10.
- **Rectangles (Rektanglar).** How many rectangles should appear on the screen simultaneously 1 or 2.
- **Y-min.** At the lowest level, a rectangle could fly in.
- **Y-max.** At the highest level, a rectangle could fly in.

3.2 Strategies to Provide an ICT Environment to Support a Patient Oriented Process and PCC Planning

An iterative modeling approach based on different user perspectives, resulted in an interacting model with a structure described in terms of the rehabilitation process for stroke care. The plan of care (Fig. 3) shows activities such as diagnoses, goals, interim goals, planning, assessment, implementation, and timing, use of resources, responsibilities, evaluation and communication. Targeting time priority for activities formulated, each team member has a clearly defined role appropriate to their individual skills. Further, activities can undergo different stages or status changes: proposed; accepted, started, interrupted, or complete. The model developed has its foundation in the individual needs for stroke survivors to high-quality care interventions and professional needs for collaboration between different healthcare professionals and organizational levels.

![Figure 3. Screenshot of the plan of care covering health care activities.](image)
Furthermore, the plan of care can include many efforts over a long period. Each activity leads to some sort of performance that is perceived, interpreted and assessed. Moreover, the use of technical standards allowed us to facilitate data exchange, processing clinical data from the video game into the plan of care.

4. DISCUSSION

An important and central part of this work is user involvement, in this case representing OT colleague in occupational therapy at Sahlgrenska University Hospital. The acceptance level tended to be high. This was in line with an earlier survey among the OT’s, although barriers were identified that hinder its use (Haixia et al., 2012). Thus integrating video gaming as a part of clinical practice requires user involvement. Correctly formed design, with adequate user/OT’s goals on what can be achieved increases the likelihood that video gaming is used in routine clinical practice. User’s goals can be for example that they easily get an overview of certain information or that they will not feel stupid when they use the system. The OT’s goals can be for instance the effect on motor function that one would be achieved by placing the videogame in use. Further we focused on improved access as a critical enabler for effective patient engagement. The strategy was to create and collect information along the patient-centered process that included goal relevant activities, i.e. assessments, foresight, individual’s condition over time etc. The model provided information defined as in the inpatient rehabilitation process, according to the National Guidelines for Stroke Care (The National Board of Health and Welfare, 2009).

The game is based on motor planning and feedback, i.e. figuring out how to get one’s UE to carry out the goal for motor action. Execution is the actual performance of the planned action. The planning and sequencing of a motor task is based on a person’s body scheme; that is, an awareness of UE, and how they move through space. The synchronization between movement and sensory stimuli, i.e. reaching for a visual object in which timing, coordination and sensory information is incorporated. Further there is a combination of bimanual task involved. For instance, bimanual training has been shown to benefit motor performance after stroke (Lin et al., 2010). The next step will be integrating auditory feedback and monitoring movements. Recent research suggests that auditory cueing could lead to an efficacious technique that improves movement coordination (Zatorre et al., 2007; Chen et al., 2009). Monitoring movements offers the possibility to record and observe movements. Erteelt (2006) showed that the observation of a movement on a television screen activates motor areas of the brain that have been damage due to a stroke. This seems to have clinical relevance for stroke rehabilitation, because the same area of the brain is activated when a person sees someone else perform a movement that is automated affects underlying brain activity. Neurophysiologic basis for this recruitment relies on the discovery of mirror neurons described by Rizzolatti et al (2004). These neurons discharged when an animal performed an object-related task with the hand or the mouth and when it observes the same or a similar task done by another individual. These results suggest that mirror neurons are involved in the coding of goals through action (de Vries and Mulder, 2007).

The goal was making information and services easily accessible to citizens and to define an information structure that facilitates interoperable, supportive ICT systems with access to information across organizational boundaries. The effective use of resources of complex healthcare data the concept of scalability becomes evident. A scalable system can handle increasing numbers of requests without adversely affecting response time and throughput. Moreover, registry functionality incorporating care plan templates with customizable appropriateness would give the possibility to visualize different care teams and place them along a health-care continuum. A further option would be the ability to have ongoing dialog between multiple caregivers related to an extended process oriented EHR. Gagnon et al (2012) stressed the importance on user involvement as a one of the key factor for successful ICT implementation and that acceptance and resistance are crucial factors in adoption of information system (van Offenbeek et al., 2012).

Since the beginning of the twentieth century we have conducted several research studies on virtual reality technology and telemedicine providing rehabilitative exercises and communications for stroke survivors at home (Ryemark et al., 2002; Pareto et al., 2011). Further we estimated the possible impact on direct health care costs and on quality of life for patients from introducing such a treatment into practices for stroke survivors (Spegel and Olsson, 2011). The results from these studies show that there are possible quality of life gains to be made by introducing such a regime into stroke care.

5. CONCLUSIONS

Increased knowledge in self-care management strategies true participation in shared decision making will enable stroke survivors to take charge of their own care. Through sharing parts of the EHR, information could be used as a teaching tool to encourage patient’s engagement and partnership (Frampton, 2008). In this
way advanced technology as movement recognition, exercising in virtual environments, and remote supervision can be used and relate to a PCC process using structured information.

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5. REFERENCES


