Involving Stroke Survivors in Designing for Rehabilitation at Home

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ABSTRACT
In this position paper, we introduce the Motivating Mobility project and describe its aims of designing interactive experiences that can engage and motivate post-stroke survivors to undertake what would otherwise be boring repetitive movements at home. We outline the phases of the project and how we have engaged with users, focusing particularly on the four participants we finally worked with and the solutions we developed for them. Based on these experiences, we list some of the issues and challenges that we can bring to this workshop.

Keywords
Stroke rehabilitation, user-centred design, prototyping, motivation

INTRODUCTION
This position paper is concerned with designing rehabilitation technologies for and with people who have survived stroke for use in their own homes. This work was undertaken as part of the Motivating Mobility project, funded by the UK EPSRC. It is comprised of physiotherapists, interaction designers, user experience researchers, software engineers and electronics engineers.

Hence the work we talk about here reflects work undertaken by a large team of people and who would be co-authors on any formal publication:

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Stroke as Leading Cause of Disability
Strokes are one of the leading causes of severe adult disability, limiting physical activity and affecting independence and quality of life. There is growing evidence that post-stroke rehabilitation exercises can reduce disability [3] and increase independence. Effective home-based regimes require repetitive movements, done regularly and correctly as prescribed by physiotherapists. However, these exercises may be practiced incorrectly, and patients can find them monotonous and frustrating. New sensing technologies open up possibilities for interactive applications to help motivate and support rehabilitation in the home.

This approach is in line with a general move across the developed world to address the challenge of providing healthcare to an aging population through the use of wireless and sensor based technologies in patients' homes, e.g. as self-care and assistive technology packages. The drivers for this shift are indisputable when most developed countries are dealing with an aging population and rising healthcare costs. Apart from shifting costs and the burden of care, it can also enable people to take greater control over their health, including the management of chronic diseases.

Motivating Mobility at Home
The particular concern of our Motivating Mobility project is how to provide home-based rehabilitation focusing on upper arm movement for people recovering from a stroke.

Our overall aim is to prototype devices where patients can undertake repetitive movements without necessarily thinking of them as exercises – by analogy think here about being asked to swing your arm 500 times compared to being asked to play a game of tennis where the arm swings are embedded into an enjoyable experience. We aim to realise this through a personalisable "plug and play" rehabilitation toolkit that would facilitate the continuation of rehabilitation in the home and where a physiotherapist,

patient or carer can match appropriate input devices that facilitate desired movements, with motivating content.

To inform the overall approach we spent considerable time understanding the experience of stroke patients, their family/carers and their health professionals. We interviewed people in their homes and in community-based stroke clubs. We gave participants a range of probes to complete to access the more intangible aspects of stroke recovery and to help understand their experience of living with stroke and to understand what sorts of things they might find engaging or motivating. After analysis of this data we created a set of user case studies that captures the key aspects we wanted to design for.

We also created a clinical functional matrix mapping levels of functional ability against classes of activity (e.g., elbow/shoulder movements against grasp and release activities) and the specific movements that a physiotherapist might prescribe for a patient to help them recover some of their functionality.

The user case studies and matrix were brought together into personas, prototype storyboards and prototypes/toolkit components, which we took to workshops with patients, carers and therapists.

Subsequently we have worked closely with four stroke patients and their families who were not involved in any previous phases to develop specifically tailored applications they can use at home, designed with a view to explore a toolkit approach (the details of which are less relevant for this workshop so won't be discussed here). A physiotherapist and HCI designer worked closely together in all interactions with the participants. Together they conducted qualitative observations and interviews in the person's home, along with some standardized physiotherapist assessments, to understand their living situations, experience of stroke, functional requirements and what sorts of things they might find engaging to do that we could design around. This began an iterative design process with the participants and their families to explore design ideas over three-four design sessions. From these we developed prototypes that we then deployed in the participant's home for 4-10 weeks (varying with participant). During this time we collected log data of system usage, conducted periodic interviews by phone and also engaged in trouble shooting of the prototypes as needed. At the end of the deployment we conducted a final interview and clinical assessment.

In-home Trials

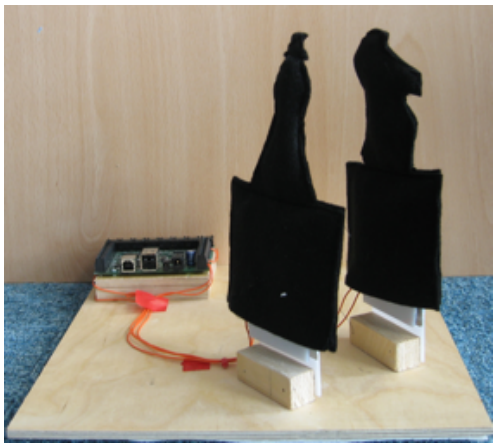
A summary of our four in-home trial participants is given in the following:

Ida and Eric – Rehab reader

Ida and Eric are a married couple, both in their seventies. Ida had a stroke four years before contact with the project, which affected the left side of her body. She now has difficulties with hand, arm and elbow movements, with walking, and with using her left eye. The prototype that was developed for her was a book reader as she loved reading but currently had problems with it. This was constructed around a tablet PC and a squeeze switch. The rehabilitation element was built in whereby Ida had to squeeze a switch to advance through lines of the book. The motivation to continue squeezing the switch was to come from engagement in the book's narrative.

Solomon and Nancy – a rehabilitative chess game

Solomon is in his fifties, and lives with his partner Nancy. Solomon's stroke affected his left hand side, initially impeding walking and movement of his left arm and hand. In the last year Solomon has re-gained his ability to walk, and drive, but he still has difficulties using his left hand and arm for activities requiring fine control. Solomon enjoys playing chess so we designed a rehabilitative chess game for him. The prototype consisted of two tangible card-shaped objects, each containing a squeeze sensor (see Figure 1). The sensors are used to represent two out of the six categories of chess piece, with Solomon choosing at the start of each game which chess pieces these sensors represented. The actual chess game was represented/played on a computer or TV screen but Solomon could use the



squeeze sensors to move the two chosen types of chess piece during the game, requiring him to do a grasp and release exercise.

Figure 1: Rehabilitative Chess Game

Rhea and David – Exercise instructor

Rhea and David are a married couple, both in their seventies, who live in a small terraced house. Rhea had a first stroke three years before contact with the project, which affected the left-hand side of her body, and a second stroke, which affected the right-hand side. Her main physical difficulties are a weakness in both hands, a limited range of movement in her shoulders, and weakness in her legs. Rhea wanted to be more active but didn't feel safe going out into the neighborhood to exercise so she was happy to have an exercise machine at home. This consisted of a set of free-standing shelves, onto which a variety of objects were placed. Exercise was directed by a laptop, which played pre-recorded audio instructions for five exercises, and which was connected to two large buttons (one green, one red) that she would hit to indicate she wanted to do that exercise. This in turn incremented a number shown in red text on the screen of the tablet which

turned green after a pre-specified number were performed in a day.

Sophie, William, Margret – The ball funnel

Sophie is in her early thirties and had a stroke in 2004 as a result of an operation on a brain tumour. Her stroke was severe impairing her whole right hand side. Sophie lives with her husband, and her young son, William, who was aged 18 months at the outset of the project. Sophie has a very active life, facilitated by her mother Margret who is Sophie's main carer. Sophie told us that she would really like us to provide her with something that she and William could do together that is fun. We designed a brightly coloured wooden box with a hole in it. Sophie used her right arm, supported by her left, to bowl a ball along a surface and into a hole. The ball then rolled through a tunnel, generating a 'fun' sound, and coming back out a second hole for her son to catch and play with.

Figure 2: The Ball Funnel

A full discussion of the results of the deployment in promoting effective rehabilitation exercises for our participants is again beyond the scope of this paper and of less relevance to the themes of the workshop. In summary, we had mixed experiences though all participants demonstrated some improvement in their functionality.

CONTRIBUTION TO THE WORKSHOP

Working with our final four participants in particular has been both rewarding and instructive about the challenge of engaging with users in designing rehabilitation systems that can be personalized to be fun and engaging.

Some of the themes and issues we can discuss at the workshop include:

- Recognizing that designing for a stroke patient is also designing for the family who need to support them both practically and emotionally in their rehabilitation. In [2] we talked about the notion of the extended user network and the need to also engage with the extended network as part of the design process.
- The challenge of balancing the needs and wishes of the carer/extended network with the patient
- The need to respect the autonomy of the patient in their own home to do what they want, how and when they want
- The challenge of designing for the home space where issues such as aesthetics and space matter [1] and where things like TVs that might ideally be a good interaction screen end up being a contested resource when others in the home just want to watch TV.
- The challenge of balancing what is recognised as good evidence-based practice from a therapeutic point of view with what the patient likes, wants, or is prepared to do.
- The challenge of trying to engage with the patient to help them identify what would be fun and motivating for them, when their life circumstances are very different from pre-stroke as well as when how they feel changes from day to day and over time.
- The challenge of trying to design with a generic toolkit approach in mind but dealing with patients who have very unique needs, both in terms of their disabilities resulting from stroke and their current stages of life.
- The challenge of trying to keep participants involved when our design-prototyping cycles take longer than anticipated.
- The challenge of creating a flexible interaction that will be motivating over the long term, and adapt to meet the changing rehabilitation needs of the patient.

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