Motivating Mobility: Designing for Lived Motivation in Stroke Rehabilitation

**Madeline Balaam[1], Stefan Rennick Egglestone[2], Geraldine Fitzpatrick[3], Tom Rodden[2]
Ann-Marie Hughes[4], Anna Wilkinson[5], Thomas Nind[6], Lesley Axelrod[7], Eric Harris[7]
Ian Ricketts[6], Susan Mawson[5], Jane Burridge[4]**

[1] Culture Lab, Newcastle University, Newcastle, NE1 7RU, UK, madeline.balaam@ncl.ac.uk
[2] Mixed Reality Lab, University of Nottingham, Jubilee Campus, NG8 1BB, UK, sre, tar@cs.nott.ac.uk
[3] Vienna University of Technology, Vienna, 1040, Austria, geraldine.fitzpatrick@tuwien.ac.at
[4] School of Health Sciences, University of Southampton, Southampton, SO17 1BJ, UK
[5] Centre for Health and Social Care Research, Sheffield Hallam University, Sheffield, S10 2BP, UK
[6] School of Computing, Queen Mother Building, University of Dundee, DD1 4HN, UK
[7]HCT Group, University of Sussex, Falmer, Brighton, BN1 9QH, UK

ABSTRACT

How to motivate and support behaviour change through design is becoming of increasing interest to the CHI community. In this paper, we present our experiences of building systems that motivate people to engage in upper limb rehabilitation exercise after stroke. We report on participatory design work with four stroke survivors to develop a holistic understanding of their motivation and rehabilitation needs, and to construct and deploy engaging interactive systems that satisfy these. We reflect on the limits of motivational theories in trying to design for the lived experience of motivation and highlight lessons learnt around: helping people articulate what motivates them; balancing work, duty, fun; supporting motivation over time; and understanding the wider social context. From these we identify design guidelines that can inform a toolkit approach to support both scalability and personalisability.

Author Keywords

Rehabilitation, motivation, behaviour change, stroke, home.

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms

Design, human factors.

INTRODUCTION

As HCI has responded to broader societal challenges such as sustainability [16] and healthy living [2, 7, 15] the field has increasingly explored how technologies might be used to promote behavioural change. Working in this area, the focus of this paper is on the participatory design of a range of technologies to motivate exercise for people recovering from a stroke at home. Over a three-year time frame, we have worked closely with clinicians and patients to understand the stroke experience and how we might meet the varying needs of our participants. Here we present an account of the development of distinct solutions to motivate post-stroke rehabilitation exercises for four individuals who wished to recover upper limb functionality after stroke, and who volunteered to participate in our project. Following participatory design sessions in their homes, we have deployed four prototypes for periods ranging from four weeks to seven months. All participants needed to do rehabilitative exercise regularly at home, without professional support. However, adherence to programmes of rehabilitation at home is poor [20] perhaps because rehabilitative exercise can be boring and difficult to do. In response to these challenges, the research question driving this work was whether we could improve participants' adherence to a rehabilitation schedule by developing technologies that tapped into their individual motivations, but which are supportive of broader care goals, i.e., bridging between the domestic life of individuals recovering from stroke and their clinical care programmes.

In this paper we report on the design and deployment of these prototypes and the broad lessons to be learned. Our key contribution arises from reflection on our experiences, especially around trying to design for specific individuals and specific circumstances. In so doing, we point to the limitations of theories of motivation to help the designer understand and design for individual needs. Based on our reflections, we develop requirements for a toolkit approach to support both the scalability and personalisability of support systems. The key lessons and toolkit guidelines we draw out are around themes of: helping people articulate what motivates them; balancing work, duty, fun; supporting motivation over time; and understanding the wider social context. We suggest these lessons and guidelines for other approaches that seek to support health care goals in the home setting and where supporting the lived experience of motivation is complex and diverse.

CHI 2011, May 7–12, 2011, Vancouver, BC, Canada.

UNDERSTANDING MOTIVATION

Understanding what motivates people and designing systems to support motivation is of increasing interest to the HCI community. This is evident in areas including learning [19], game play [6], sustainability [16], and the promotion of healthy lifestyles [2, 7, 15]. Motivation is also a key element in stroke rehabilitation [4], the focus of this paper.

A lot of previous work has drawn heavily on theories of motivation and behaviour change, with examples including Goal Setting Theory [21], Social Cognitive Theory [5], Self Determination Theory [10] and the Transtheoretical Model of Behaviour Change (TTM) [16]. Concepts defined by these theories have been used in a number of ways to support the design of motivational and behaviour change systems (e.g., see [2, 7, 16]). For example, the TTM's stages of change have been used directly to structure a framework that could be used to design energy feedback [16], while Graham et al [15] use a reconceptualised model of TTM as the structuring basis for the advice given in their 'quit smoking' application, QuitCoach. Consolvo et al [7] combine TTM with social psychological theories to account for how "behaviour change … impacts the individual's social world" (p405), and then present a set of design strategies for behaviour change technologies that are abstracted from an integration between theory and design goals drawn from previous systems. These are then partially instantiated in UbiFit, a system which "encourages individuals to lead a physically active life" [7]. Other authors seem to use motivational theory more as a backdrop of understanding for the design, as we do, but do not make explicit the links between theory and design decisions, e.g., as per Anderson et al's [2] use of Social Cognitive Theory with the Shakra system.

These theoretically-driven approaches and their interpretation and/or adaptation for design, are critically important for HCI, especially when we want to design applications that can be widely used (as per Ubifit [7] Shakra [2] and QuitCoach [15]). They also help build integrity by enabling designed solutions to build upon evidence-based literatures in other disciplinary areas. However, while theoretically-driven approaches are important, we suggest that we are still in the early stages of learning how to bridge the design gap between a conceptual theory and theoretically-principled design guidelines to designing for the everyday lived reality of motivation for specific individuals. The issues identified for example by Graham et al from their participants' experiences using QuitCoach point to critical design factors that are not captured specifically in any theories [15], as is also the case for some of Consolvo et al's design strategies [7].

Here, we are particularly interested in how motivation for an individual recovering from stroke plays out in the real world and so have adopted a more participative approach to the design of bespoke motivational technologies, drawing on theories where relevant.

STROKE REHABILITATION AND MOTIVATION

Stroke is one of the leading causes of physical disability [27, 28], and whilst recovery is possible, a commitment to repeated and regular specific exercises is required [27]. Rehabilitation is a process that can take many years, and because of common constraints on the resources that are available for treatment [11], it is an activity that many patients will have to lead themselves at home. One approach to addressing this has been the development of computational systems to reduce the cost of therapy in a clinical setting, including complex "robotic therapists" which can guide limbs through movements [22]. VR systems have also been used to promote rehabilitative exercise [26]. More recent approaches have focused on technologies that support self-managed rehabilitation in the home [12, 13, 18, 25], which is understandable given that returning home quickly tends to be a strong preference for people recovering from stroke [28], and given the tendency to discharge patients from the clinical setting earlier [11]. Motivation is a key issue in the home context, as individuals may have to concurrently adapt to significant changes in their lifestyle [27]. In addition, individuals managing their own rehabilitation in the home may not have access to the motivational support that can be provided by a physiotherapist during rehabilitation.

However, although motivation is a key element of self-managed rehabilitation, the majority of technologies which have been designed for this context have not focused on its complexities in relation to the individual. Instead, approaches have tended to focus on providing for interactions that are expected to be *fun* or *functional* for a wider variety of users. A common example is rehabilitative gaming [1, 12, 13, 18, 25]. However, there is a lack of evidence for the motivational potential of such systems in a self-managed context, particularly with respect to functional improvement over time, or matching such systems to individualised contexts. Also the assumption about what will be motivating is often made by the designers or with feedback from participants generated through short in-lab exposure to suggested applications.

DESIGN APPROACH

A prime aim of this formative design engagement was to explore whether a technology designed to speak to an individual's motivations could help the individual complete rehabilitative exercise in their home without the supervision of professionals. We adopted a participatory approach that was personalised rather than generic, and bottom-up design-led rather than top-down theory-led. Through long-term in-situ engagement with our volunteers, we attempted to understand their motivation holistically as a lived day-to-day experience, and to design bespoke technologies to meet their rehabilitation and motivational needs. In doing so, we adopt similar approaches to designing for the home such as in [9]. By presenting case studies of our interactions with these participants, we aim to uncover some of the issues entailed in designing for the lived motivation experience.

These qualities can remain largely hidden in more conceptual theories of motivation, yet can make a significant difference in building systems that work.

Whilst it is not feasible to consider bespoke applications for all people who have had a stroke, the work conducted here was one phase of a project aiming to develop a toolkit that physiotherapists and patients could use, taking advantage of both generic theoretically-grounded frameworks as well as bespoke elements. An important contribution arising from our experiences is the articulation of a set of lessons and design guidelines that can complement more theoretically-derived understandings of motivation to inform the design of systems to support rehabilitation at home.

Design Methodology and Study Overview

Participants were recruited through private rehabilitation clinics and stroke clubs (social organisations for stroke survivors), through a process led by physiotherapists, and approved by medical ethics boards at participating universities. Participants with significant co-morbidities were excluded, and we only considered participants who were sufficiently cognitively able to give informed consent. Following recruitment, a physiotherapist assessed participants using a battery of standardised tests to understand their physical, social and emotional status and recovery programme (full details in [17]). This information was used to inform interactions during the resultant design process and to monitor rehabilitative progress. At this stage each of the participants was highly motivated to improve function lost due to a stroke, but described difficulties in completing exercises at home.

Participants then took part in a series of three or four hour-long design sessions in their home, which were attended in each instance by two researchers: one with expertise in HCI, and one in physiotherapy. These sessions were used to identify activities to motivate rehabilitation, to understand the participants' home situation, to generate creative ideas, and to iterate through design prototypes. Detailed notes were made after each session. This process of engagement led to the construction of working prototype systems (Figure 1) that were then deployed for an appropriate period (Table 1). All logged usage data, and additional usage information was provided through weekly phone interviews and an "exit" interview after one month. Some deployments lasted longer than a month, and additional data was collected through visits or phone calls. In total we collected over 40 hours of log data, 10 hours of interviews, and made 17 phone calls and 22 home visits. This process took place in conjunction with a number of other activities including initial scoping studies and design workshops [3, 26], and an analysis of clinical needs for upper limb function.

The collected data for each participant was assembled into a document inspired by "thick description" [14]. A qualitative inductive analysis was applied to the data, with themes identified by the authors through iterative reading and interpretation of the data.

Name	Rehabilitative focus	Deployment
Ida	Grasp and release	7 months
Solomon	Grip and release	6 weeks
Rhea	Integrative exercise	4 weeks
Sophie	Shoulder and arm	7 weeks

Table 1: An overview of design work and deployments

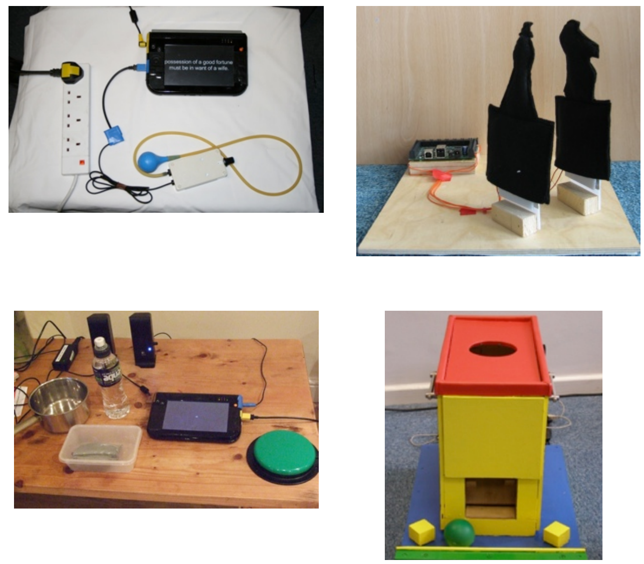

Figure 1 Images of prototypes. Clockwise from top left: 1. Rehab Reader (Ida) 2. Chess (Solomon) 3. Ball Funnel (Sophie) 4. Exercise Instructor (Rhea)

PARTICIPANT CASE STUDIES

In this section, we introduce the participants and then describe each of the design sessions and the deployment.

Ida and Eric – The Rehab Reader

Ida and Eric are a married couple, both in their seventies, who live in a small, ground-floor flat. Ida had a stroke four years before contact with the project, which affected the left side of her body. She still had difficulties with movement of her shoulder, elbow and hand, with walking, and with vision in her left eye. The initial interview with Ida suggested that she was often anxious and easily upset. Design work with Ida led to a seven-month deployment.

First Design Session

Ida seemed keen to engage in rehabilitation, and stated that a motivation was the recovery of an ability to crochet, requiring improvements in her ability to grasp, release and control balls of wool with her left hand. Ida told us that, since the stroke, she limited herself to the lounge and the bedroom, and that her husband was the sole user of the kitchen. Throughout the session, Ida remained seated in a single chair and it became apparent she spent a significant amount of time here. The chair had been positioned to provide a view onto an attractive garden, and onto a digital photo frame. Eric, who is a competent computer user, had loaded this with several thousand photos of their children and grandchildren, and it seemed to be a focus for Ida's attention, although she complained that the photos progressed too quickly. Eric was keen to introduce her to technology, but Ida stated that she didn't like computers, and that previous use of a Wii had given her headaches. She is, however, a regular user of an electronic crossword puzzle, which she did not consider to be a computer.

Second Design Session

For this session, we took along a prototype, which consisted of a tablet PC, running photo-viewing software, which accepted input from a pressure pad. Squeezing this caused the display of a new photo, and we hoped that Ida would operate this with her left hand, giving her control over a device that was similar to her existing photo-frame, and taking part in rehabilitative exercise at the same time. Ida used the device throughout much of the session. Through experimentation with a number of artefacts, we determined that, for rehabilitative benefit, the pressure pad should be replaced with a squeeze ball, and established dimensions for this. We also realized that just viewing photos could become less interesting after a while. Eric suggested a system that would allow Ida to read novels. She had been struggling to read due to her inability to hold a book, and difficulties in locating printed novels with sufficiently large font. Ida seemed keen on this idea, and for the third design session, we constructed a book-reading prototype using the same hardware platform.

Third Design Session

For this session, we located an appropriate squeeze switch, and developed software which displayed the text of a novel on the tablet screen. Each squeeze caused text to advance by one line, and properties of the font used in both interfaces were configurable, as was the background color. Ida and Eric liked this prototype, and Ida used the prototype for 20 minutes, reporting only minor fatigue, and suggesting that she would use it for an hour every day. Eric suggested that the device could provide her with a gateway to the Internet, but Ida seemed unhappy with this, and preferred the device as it was. The interface was configured to white text on a black background with a 60pt font size. Potential reading matter included a variety of novels.

First Deployment

For the first deployment, we engineered a system that was pre-loaded with a novel, chosen by Ida, and whose text was freely and legally available [24]. This system was constructed around the tablet PC and squeeze switch (figure 1), and was left with Ida to use as she wished.

Analysis of Deployment

Ida was delayed in starting to use the system due to a burst blood vessel in her eye, but after the first week, reported that she had read five chapters, that she wanted to use it more the following week, but that her husband was pressuring her to use it every day. After the second week, she reported reaching chapter 19, that her husband was pushing her less, that her hand was moving more easily than before the deployment began, but that she was experiencing some stiffness. Our physiotherapist then recommended stretching her hand after every 15 minutes of use. During the exit interview, Ida described how she was using the device for long sessions, in which she became absorbed, but was noticing an ache in her left eye. She also talked about her husband pushing her to use it even when her eye was tired, which related to his conceptualization of the system as an exercise device (he exercises every day, and wanted to push Ida to do the same). In a telephone interview after three months of deployment, Ida was reporting much slower progress, having reached a number of chapters that were less interesting. After a second call, two months later, it became clear that Ida was bored with reading a single book. At this point, we began planning for a second deployment, with a system that allowed for choice between multiple books. Logged data collected after seven months shows that Ida used the device across 14 sessions, with a mean count of 472 squeezes per session, yielding a total of 6621 individual grasp and release exercises. Sessions are highly concentrated during the first two months of the deployment, and tail off significantly for the remainder.

Solomon and Nancy– A Rehabilitative Chess Game

Solomon is in his fifties, and lives with Nancy. A stroke affected Solomon's left hand side, initially impeding walking and movement of his left arm and hand. Solomon had recently re-gained his ability to walk, and drive, but still had difficulty with activities requiring fine control of his left hand, such as tying his shoelaces. Solomon attends private physiotherapy sessions every week, and has an active life, continuing to work as an accountant, and regularly going to the gym, or tennis court. Design work with Solomon was conducted over four sessions and led to a six-week deployment.

First Design Session

Solomon was driven by work, but his stroke slowed him down; he worked fewer hours, and had lost his confidence to make complex decisions. Solomon wants to return "to normal", and a part of this is being able to work for longer periods. Solomon's fine finger control became our focus for rehabilitation, to make activities such as typing easier and quicker, along with improving his concentration levels. Our physiotherapist identified that a good starting point would be improving Solomon's ability to grip and release objects between his left hand thumb and fingers during supported reaching movements close to his body. During the session we discovered that Solomon enjoys strategic games.

Second Design Session

We took along a number of design sketches to this session to better understand what is motivating for Solomon. Solomon showed a polite positivity for each of the ideas, but his eyes light up at one which allowed him to play chess whilst also doing rehabilitation. Nancy was also enthused, pointing out that this might help Solomon improve his concentration levels. Solomon told us that he normally plays chess once a day for about 10 minutes, but would be happy to play for up to an hour if it helped in rehabilitation. We discussed whether Solomon and Nancy would want to play chess together, or whether Solomon wanted to play chess against a computer. Solomon joked that Nancy wasn't good enough competition for him, and spoke about his desire to not be dependent on her if he wanted to exercise.

Third Design Session

During this session, we presented a low fidelity prototype of the chess game, which consisted of six slim, card-shaped objects, each containing a squeeze sensor, and each representing a category of chess piece. Thus, when Solomon wanted to play a pawn, he would first squeeze and release the card representing this piece, and then use his keyboard to input coordinates of where he wanted it to move from and to. On seeing Solomon interact with the prototype it became clear that it was simply too challenging. As a result we re-designed the input device to balance game-play and enjoyment against rehabilitation needs [4]. At the end of the session the input device consisted of two squeezable input sensors. At the start of each game Solomon could choose which chess pieces these sensors represented to provide him with some control over the amount of exercise required to play a game. For example Solomon might chose to control a bishop and a knight through the squeezable sensors, and the remaining pieces simply through a keyboard (see Figure 1). At the end of the session, we still had some questions over how we would deploy this system in Solomon's home, most notably where a screen for displaying the chess game would go.

Fourth Design Session

During this session we took an almost fully working prototype to Solomon's home to discuss the practicalities of its deployment, and do a final check of its suitability as a rehabilitation device. This system was constructed using a Phidget InterfaceKit [23] and a custom-made squeeze sensor. We found that this was still too difficult for Solomon to squeeze, and that it needed to be more stable. We realised that we could use the television to display the chess game. This seemed ideal to us, and Solomon seemed happy for us to use his television in this way.

Deployment

The rehabilitative chess game (consisting of a laptop, and two squeeze sensors) was left with Solomon for six weeks. To ensure the sensors were optimally placed for Solomon's use we tailored the ergonomics of the sensor board on the day of deployment.

Analysis of Deployment

For the first week the system worked reliably, with Solomon using it regularly. However, after one week, a software bug rendered the device unusable, whose resolution required Solomon to complete a complex action on a project laptop. During the exit interview we found out that Solomon had experienced further difficulties with the device, but because of commitments at work had lacked the time and motivation necessary to contact us, or try and fix the problems himself. During telephone interviews, we also discovered that Solomon had stopped using the television as an output device for the chess game, because it had caused some tensions between him and Nancy as to who could use it. Instead Solomon had begun using the laptop as an output for the chess game, making using it feel more like work. Finally, Nancy and Solomon had both been concerned about the appearance of the device, worried that it was easy to break, and that it was unsightly, ruining the aesthetic of their living room. Nevertheless, Solomon did have some good things to say about the chess game, reporting that it had got him into the habit of doing repetitive exercise, and that this was no longer a chore. In addition, there was clear and observable improvement in Solomon's fine finger control, elbow and shoulder movement and Nancy reported that his levels of concentration were much improved.

Rhea and David – The 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. The initial interview with Rhea suggested that she experienced fatigue and anxiety, which disrupted her ability to engage in normal daily activities. Design work with Rhea led to a short deployment lasting one month.

First Design Session

Rhea told us that she wanted to become more active, but that she was worried about the safety of her neighbourhood. Rhea and David had both given up their driving licenses for medical reasons, and were limited to public transport. Rhea talked about spending too much time watching "rubbish on television" and welcomed any activity that motivated her to spend more time on her feet. Rhea had checked herself out of hospital after her second stroke, and had received very little rehabilitation support. Despite this, she had managed to improve the range of movement in her hands through exercises, but was uncertain about how to improve movement in the rest of her body. Given these observations, we suggested the concept of an "exercise machine", which would facilitate Rhea to exercise on a daily basis. She liked this idea, and stated that she wanted to use it standing up. Our physiotherapist suggested that such a machine should deliver exercises that integrated multiple movement types, and which required working against a resistance.

Second Design Session

For this session, we presented two different concepts. The first was a "music player", which rewarded exercise with access to music, inspired by an observation that there were no facilities to play music in the house. This was rejected as Rhea and David had very different tastes in music, which had caused arguments in the past. The second concept was for an "interactive exercise video", which would instruct

Rhea to perform a series of interactions with equipment attached to a static "exercise frame" to be positioned in the lounge. Both were keen on this idea, but told us that it would need to be free-standing to avoid any marks on the wall-paper. Rhea told us that she wanted to be prompted on a daily basis, at a fixed time, and we determined the frame dimensions that would be required to engage her full range of movement. Our physiotherapist suggested that a frame should cater for the grasp and release of objects, and for three-dimensional movements of her elbow and shoulder.

Third Design Session

This session involved a prototype consisting of a set of free-standing shelves, onto which objects were placed. Exercise was directed by a laptop, which played recorded audio files, and which was connected to two large buttons (one green, one red). This repeatedly prompted Rhea to do a random exercise involving objects on the shelves, and she was asked to push the green button if she succeeded and the red button if she failed. We demonstrated this to Rhea, and discussed a variety of implementation options. Rhea stated that she would want to choose when to use the system, rather than being prompted, contradicting a choice made in the second design session. She believed that she would accurately report on her performance in exercises, and that this would be enforced by her husband. She asked for exercises that involved real world objects, and we identified a number in the house that were suitable. Finally, she asked for a system that did not impose a time limit for each exercise. We then decided that exercise around a frame was too restrictive, and began work on a set of exercises that could be carried out in a free-form manner.

Deployment

For the deployment, we engineered a system consisting of a tablet PC, a single green button, and a set of speakers. Pre-recorded instructions for five exercises were supplied, but these could be performed with either the left or right hand, and with a repetition count ranging from 5 to 8. Hitting the green button caused a randomly-selected exercise to play, and incremented a number shown in red text on the screen of the tablet. This number turned green after a pre-specified number were performed in a day. Deployment of this system took place several months after the previous design session, due to building work on the couple's home. During this period, Rhea's physical abilities declined, and she could no longer manipulate the objects that had been identified, so we made some modifications. These included the replacement of a large saucepan with a smaller one, and removing some water from a plastic bottle.

Analysis of Deployment

During the weekly phone calls, Rhea told us that she was using the system daily, and that she and David had both adopted an exercise routine that her husband had learned whilst serving in the forces. During the exit interview, Rhea seemed far more energetic, and demonstrated an ease at manipulating heavier and bulkier objects than we had seen before. She also demonstrated the exercise routine that her husband had taught her, which involved a significant amount of reaching and stretching. However, a later analysis of log data showed that the system had only been used three times, all of which took place within the first week of deployment, and this was confirmed through an analysis of Windows system logs. To have improved so much, Rhea must have been exercising, and we wondered if she was only performing exercises with her husband, rather than through interaction with the system. Several weeks later, Rhea suffered a third stroke, and was hospitalized. We therefore concluded our deployment work before the impact of this stroke could be assessed. Rhea has now been discharged from hospital, and we have since learnt that she is continuing to exercise daily with her husband.

Sophie, William, and 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 the whole right side of her body. Sophie lives with her husband, and her young son, William, who was aged 18 months at the outset of the project. Sophie has an incredibly active life, facilitated by her mother Margret who is Sophie's main carer. Sophie visits her private physiotherapist regularly, attends sailing for the disabled, and cares for William. We completed design work with Sophie, William and Margret over four design sessions, after which a functioning prototype was deployed in Sophie's home for seven weeks.

First Design Session

We spent considerable time trying to understand Sophie's rehabilitation goals. Margret told us that she wanted to see Sophie using her stroke affected arm more in day-to-day activities, such as changing William's nappy (diaper). In reply Sophie stated that she was able to do most of what she needs using only her left arm. Our physiotherapist spent some time discussing the benefits of using her left arm and hand to support her right arm in daily life, and Sophie eventually agreed that this would be a suitable activity to focus on for our intervention. Understandably, Sophie's attention throughout the design session was divided between us, and William and she often broke away from the conversation to make noises that made him laugh. Sophie told us that she wanted us to provide her with something that they could do together that would be fun.

Second Design Session

We took a number of design sketches and low-fidelity prototypes to find out more about what would motivate Sophie. Two of the designs were games that Sophie could play with William, with the remaining two aimed at providing social connection between Sophie and her friends. Sophie showed no interest in the two designs for social connection, telling us that she had no friends to be better connected with. Instead, Sophie was most taken with a game where she 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, coming back out of a second hole for her son to catch and play with. Through discussions with the family, we added a facility for recording sounds onto individual balls to the design, with these being played back as the ball travelled through the tunnel. Margret was keen on this, since she felt it would provide educational opportunities for William. With a little encouragement, Sophie also thought that the addition of sound might be fun.

Third Design Session

During this session Sophie and William played with a full-sized, technology-free prototype of the Ball Funnel. Our observations suggested that the device was a little too large, and the position of the hole made it too hard for Sophie to get the ball into the hole. William seemed to enjoy bowling the ball through the Ball Funnel, repeating the activity over and over, to such an extent that we began to worry whether Sophie would get enough exercise with the device. We raised the device from floor level, so that only Sophie could bowl the ball into the hole. William seemed to equally enjoy catching and returning the ball. Overall, Sophie seemed markedly less interested in the device. We were unsure if this was down to her mood, or whether the design was simply not motivating for her. We decided to make a few small revisions to the prototype, and then leave it with Sophie and William for two weeks to see whether they would both enjoy this activity on a regular basis.

Fourth Design Session

We used this design session to collect feedback on our initial short deployment. Sophie told us that she and William had been playing regularly and the game continued to consist of Sophie bowling a ball through the Ball Funnel, and William catching and returning the ball. Margret told us that she thought the device was a "big success", and that William enjoyed playing with it on his own as well. Sophie told us that although it wasn't incredibly fun for her, she enjoyed using it because William seemed to like using it. There was continued enthusiasm for the addition of sound recording and playing, and work began investigating how this functionality could be added.

Deployment

Our final prototype consisted of a wooden box painted with brightly coloured paint, and blackboard paint. A pair of speakers were housed within the Ball Funnel, whilst the laptop was tucked under a set of drawers, and all associated cables were tidied using cable ties. We left the prototype and a set of instructions with Sophie, William and Margret to use as they wanted. Our physiotherapist reminded Sophie to use the Ball Funnel as a two-handed activity, but at this point Sophie refused to use it in this manner, telling us that this would be a step backwards.

Analysis of Deployment

A few days into the deployment the Ball Funnel stopped making sounds. This was resolved quickly, but was a recurring problem. Regardless, the Ball Funnel was initially fun for William to play with, with William dictating playtime by slapping it. Analysis of the log data suggests that Sophie used the Ball Funnel across 33 sessions, completing on average 40 movements per session. In the exit interview Sophie told us that she tried to use it everyday, and in each use tried to bowl through at least 40 balls, a goal she established for herself. The problem was however, that William became bored before the goal of 40 balls had been met, and would then start throwing the balls around the room. This became a source of frustration both for Sophie (because it made the game difficult to play without help), and Margret (because she had to spend a lot of time running around collecting the balls).

DISCUSSION

Our four engagements have illustrated a participatory, bottom-up approach to designing systems to motivate rehabilitation at home. While our design partners have all had a stroke, our design studies highlight their diversity as people and the various ways in which they orient to motivation and recovery. We believe in the home context it is imperative that the highly personal nature of the individual is recognised and designed for from the outset. The home is different to the clinical context where the highly diverse nature of individuals recovering from stroke is often backgrounded, whilst the functional needs of an individual becomes the focus of the session. Physiotherapists can successfully use generic systems, tweaked to take account of specific abilities, to guide an individual through movements, with motivation being heavily supported by the therapist. At home, there is no physiotherapist or structured session. Rehabilitation is by choice not appointment and has to be fitted in where life allows. Further, the individual's loss of function is only one component of a much more complex and messy context, that is integrated with the nature of the person, their life experiences, their family and social context, as well as the physical affordances of their home.

We go on here to draw out four lessons in designing to motivate post-stroke rehabilitation at home: helping people articulate what motivates them; balancing work, duty, fun; supporting motivation over time; and understanding the wider social context. In three of these lessons we discuss how theories of motivation (and in particular SDT [10]) were useful in encouraging a design focus that was broader than the individual, and furthermore this helped to guide very specific design decisions. Yet, the lessons discussed here also highlight how, in particular, theory offers little insight into identifying *what* will be motivating for an individual.

Lesson 1: Help People Articulate What Motivates Them

Finding the right motivational content or activity to instantiate in a system is perhaps the biggest challenge. Motivation theories were of little help here. Being (rightly) abstracted, they place more emphasis on concepts such as self-efficacy [5], goals [21], or the level of competence engendered by a task [10], rather than the nature of the task itself or what specifically will motivate an individual. This is a particularly critical issue when we seek to motivate people at home as they live their lives.

Initially, our unconscious assumption was that participants would be able to articulate activities that they would find motivating to do. In practice, we found a big difference between what participants might initially say (as might also be found in short in-lab exposure to prototype systems) and what would actually be motivating over a long period of time. Further there is a subtle but important difference between understanding an individual's hobbies, or interests and understanding how and why particular activities are motivating for them. Alongside participatory design skills, designers need to bring multiple interpersonal skills to this design problem in order to be able to listen to a person on multiple levels, focussing not simply on what is said, but what is done, and how it is done. They also need to engage with family members and the social context.

Ida and Eric's engagement, for example, highlights the importance of looking beyond what is said. Although talking about crocheting as a motivation, her attention was continuously drawn to the digital photo-frame, which provided us with design inspiration. Ida's husband then developed the idea around her love of reading which reminded Ida of her passion for reading and the difficulties she had post-stroke. Solomon and Nancy's case study further illustrates the role that a designer's interpersonal skills can play. Based on discussions during our first session, we designed and presented a range of different games and activities that involved competition, betting, and strategy. Solomon told us that all of these were good, and would motivate him to exercise but, it was the noticeable change in Solomon's body language when he saw the rehabilitative chess game design that helped us recognise that this was something that might really help motivate Solomon to undertake rehabilitative exercise.

However, for some of the participants, our design process did not manage to find the activity or content that was truly motivating. Sophie is an interesting example. Sophie stressed that as long as her son William was enjoying an activity, she would enjoy it also. However, when we observed them playing with prototypes of the Ball Funnel we were unsure whether this was the case: Sophie *said* she enjoyed playing with the Ball Funnel, but her demeanour when engaged in play told a different story. In design sessions we tried to discuss whether activities were fun or enjoyable for Sophie, but were often met with the response that fun did not feature in Sophie's life anymore.

Our experiences illustrate the complexities entailed in exploring and understanding what might motivate people and that this is really quite different from just identifying hobbies and the like. They also illustrate the work and commitment of the participant themselves, their family, and the designer in exploring their motivations. On top of the difficulty people have in articulating what motivates them, additional factors may also be in play. For example, in Sophie's case, it could be that as a young mother she felt the socially acceptable thing to say as motivating was playing with her son, but in actuality another task may have engendered more enjoyment and greater motivation for her. Associated with this, some of our participants found it difficult to critically engage with design ideas and prototypes. For the most part, our participants desperately wanted to recover from their stroke and were seemingly willing to try anything if it might improve their situation. A final barrier can be a participant's preconceptions about physiotherapy or rehabilitation. Through working with Sophie over the course of a year it was clear that she held strong pre-defined ideas that physiotherapy consisted of hard, boring, graft, and most certainly, concepts of fun, interest and engagement did not fit with these.

Lesson 2: Balance between Work, Duty and Fun

Another challenge centres on how to best balance between the hard graft needed for rehabilitation versus maintaining personal motivation and engagement for a particular activity or piece of content. Or in other words, how much exercise can be added to an activity, before the exercise overwhelms the activity. Although Solomon used his chess game, it was clear even before deployment that if the system required him to perform an exercise to move every chess piece, then it would have become simply too difficult to use to be enjoyable. In this case, and inspired by SDT [10], we were careful to provide Solomon with some control over the amount of exercise, by allowing him to choose, within a limit, the type and number of pieces which required a squeeze to move. This respected his autonomy and allowed him to negotiate the trade-off between focussing on rehabilitation and playing chess.

Similar considerations are also in play for the Rehab Reader system which was hard-coded to require one squeeze to progress each line. A different choice (such as two squeezes for progression) could have promoted a very different level of exercise and enjoyment. Also, in comparison to the chess game, the Reader promoted more exercise (on average, 472 squeezes per session, in comparison to an average of 16 squeezes per game of chess). Partly, this reflected Ida's greater physical abilities at the start of the process. It is also a product of the mapping in each activity between physical exercise and system response. Getting this mapping right is part of the process of designing rehabilitative technologies, and it may involve the negotiation of a trade-off between rehabilitation and enjoyment.

A related issue is how we as designers and technologists measure the success of our deployments. From the point of view of Sophie's log data, the Ball Funnel was really quite successful, promoting regular sessions of a supposedly playful exercise, each involving a reasonable number of repetitions. Yet from a more holistic standpoint, other qualitative data suggests that she failed to enjoy this activity, and that her engagement was due more to her regime-like approach to physiotherapy. The converse was true for Solomon whose logs showed low use but who became highly motivated to start exercising more generally. This necessity of additional data sources in understanding the full picture of use and everyday activity reflects [8].

Lesson 3: Supporting Motivation over Time

Time and variability also play a crucial role in rehabilitation and impact design decisions. What constitutes enjoyment or challenge can change from morning to evening, influenced by variables such as fatigue. It can also change day-to-day and over longer periods of time, as physical abilities improve or decline. For example Rhea's physical strength and ability changed several times throughout the project.

Sustaining interest over time is also a challenge. For example, Ida used the Reader regularly in the beginning, yet her usage dropped when she reached a section of the book that she did not enjoy. This illustrates the challenge entailed in finding a single task that can motivate an individual indefinitely. As with everyone, hobbies and interests tend to be foregrounded or backgrounded dependent on day-to-day changes in mood and activity levels. Thought must also be given to how the non-linear progression of rehabilitation post-stroke can be accounted for in design. Input devices need to support a particular rehabilitative exercise, but also need to be easily extended, or narrowed as an individual's physical ability improves, or deteriorates over time. For example, as Ida's grip improved, an ideal extension would have been a new input device that supported practising both reach and grip.

Lesson 4: Understand the Wider Social Context

The powerful influence of the social context in stroke rehabilitation at home renders the design process even more complex. The designer must not only understand the motivations of an individual, but must also design for the motivations and needs of the physical and social context where the technology will be situated. In each of the engagements the use of the device was influenced by both the motivation of the individual, and also through interactions with the social / family unit in which they were immersed. They help make systems work where the participant's disability makes it difficult to do so (i.e. Margret collecting the balls that William failed to return to his mother), and also support emotional engagement (i.e. Ida's husband, and William's initial enthusiasm for ball playing). (The value of this social emotional engagement for motivation is also shown in [7].) Whilst this support is mostly positive, it can also have a negative impact. This is especially noticeable where Sophie's rehabilitative exercise depended upon William playing the game and not getting bored, and where Ida's husband tried to push her to use the device despite physical discomfort.

Several theories of motivation take account of the social context ; for example in SDT [10] the social context is seen as a powerful mediator of the levels of competence, autonomy and relatedness that an individual feels. The reality of motivation as a lived experience, as illustrated by our case studies, highlights the complex nature of designing to help fulfil these basic needs within a social context. In order to fulfil a sense of relatedness (tied to approval [10]) any device needs to be acceptable both to the recovering individual *and* other members within the family / social unit. Regardless of how motivated an individual is to use a device, if their partner finds it aesthetically displeasing, or it interrupts their day-to-day patterns (for example, access to the television) these feelings will in all likelihood reduce approval and support for the device, and ultimately therefore an individual's motivation to use a device.

Towards a Toolkit Approach

These lessons have arisen out of engaging deeply with individuals and designing bespoke technologies to meet their needs. While this approach will not scale, each of the lessons point to some important principles that can inform the design of a toolkit approach. Bridging bespoke and generic systems, a motivational rehabilitation toolkit for use at home should consist of a set of inputs (devices that support particular rehabilitative movements), and outputs (motivating content and activities) that a therapist or family member can assemble in accordance with therapeutic needs and personal preferences. *First*, a toolkit will need to provide a diverse range of activities and content that can really help motivate an individual. Apart from supporting diversity of experience, this could help an individual to 'play' with ideas and better understand their own motivation. *Second*, individuals recovering from stroke should be given autonomy over the level of exercise they are required to do. In the home, it is crucial that a balance is made between allowing an individual to get on with their life, and supporting them in reaching their rehabilitative goals. *Third*, toolkits need to be easily configurable such that output components can be changed to reflect changing interests, motivations, available time, moods, and ability. Input devices also need to be easy to change or extend or narrow to meet the changing, and non-linear rehabilitation needs of stroke patients. *Fourth*, the design and development of toolkits must take account of the social and spatial context in which these rehabilitation technologies are deployed. The family must buy into the toolkit if they are to provide the emotional and physical engagement necessary to an individual's rehabilitation. Taking account of the whole context of use around the toolkit is crucial in creating a successful product, whilst also being crucial in evaluating a product's success.

CONCLUSIONS AND FUTURE WORK

This paper has presented formative, participatory work to inform the design of technology which motivates rehabilitation at home for people who have had a stroke. The experiences of designing for the lived reality of motivation and the very particular design decisions that had to be made, highlight the gap between abstract theories of motivation and generic systems, compared to the very specific and complex needs of people, including the family, working in a home not a clinical setting. In reflecting on the lessons learnt through the design process, we have identified key features of a toolkit approach that can bridge another gap, between bespoke and generic systems, allowing users to choose what suits them and their home life on a particular day, or to learn about what motivates them over a period of time. Future work will see us further developing one of the more successful prototypes presented here such that it can be applied in a controlled clinical study to fully explore its impact on a patient's motivation to rehabilitate, and their rehabilitation.

ACKNOWLEDGEMENTS

Many thanks to our participants. This work was supported by EPSRC grant EP/F00382X/1.

REFERENCES

1. Alankus, G., Proffitt, R., et al. Stroke Therapy through Motion-Based Games: A Case Study. *Proc. ASSETS 2010*. ACM (2010) 219-226.
2. Anderson, I., Maitland, J., et al. Shakra: Tracking and Sharing Daily Activity Levels with Unaugmented Mobile Phones. *Mobile Networks and Applications 12*, 2 (2007), 185-199.
3. Axelrod, L., Fitzpatrick, G., et al. The Reality of Homes Fit for Heros: Design Challenges for Rehabilitation Technolgy at Home. *J. of Assiss. Tech. 3*, 2 (2009), 35-43.
4. Balaam, M., Rennick Egglestone, S., et al. Rehabilitation Centred Design. *Proc. CHI 2010,* ACM (2010), 4583-4586.
5. Bandura, A. Exercise of Personal and Collective Efficiacy in Changing Societies. Self Efficiacy in Changing Societies. Bandura, A. Cambridge University Press, 1995.
6. Bostan, B. Player motivations: A Psychological Perspective. *Comput. Entertain. 7*, 2 (2009), 1-26.
7. Consolvo, S., McDonald, D., et al. Theory-Driven Design Strategies for Technologies that Support Behaviour Change in Everyday Life. *Proc. CHI 2009*, ACM (2009), 405-414.
8. Crabtree, A., French, A., et al. Developing Digital Records: Early Experiences of Record and Replay. *Comput. Supported Coop. Work 15*, 4 (2006), 281-319.
9. Crabtree, A. and Rodden, T. Domestic Routines and Design for the Home. *Comput. Supported Coop. Work 13*, 2 (2004), 191-220.
10. Deci, E. and Ryan, R. *Handbook of Self-Determination Research*. University of Rochester Chess, 2002.
11. Department of Health. National Stroke Strategy, 2007.
12. Deutsch, J. E., Borbely, M., et al. Use of a Low-Cost, Commercially Available Gaming Console (Wii) for Rehabilitation of an Adolescent With Cerebral Palsy. *PHYS THER 88*, 10 (2008), 1196-1207.
13. Flynn, S., Palma, P., et al. Feasibility of Using the Sony PlayStation 2 Gaming Platform for an Individual Poststroke: A Case Report. *J. of Neurologic Physical Therapy 31*, 4 (2007), 180-189
14. Geertz, C. Thick Description: Toward an Interpretive Theory of Culture. The Interpretation of Cultures: Selected Essays. New York, Basic Books, 1973.
15. Graham, C., Benda, P., et al. "heh - keeps me off the smokes...": Probing Technology Support for Personal Change. *Proc. OzCHI 2006*. ACM (2006) 221-228.
16. He, H. A., Greenberg, S., et al. One Size Does Not Fit All: Applying the Transtheoretical Model to Energy Feedback Technology Design. *Proc. CHI 2010*, ACM (2010) 927-936.
17. Hughes, A. M., Burridge, J., et al. A Matrix for the Development of User Centred Technologies for Upper Limb Stroke Rehabilitation: Clinical Results. *Archives of Phycial Medicine and Rehabilitation* (In preparation).
18. Jadhav, C. and Krovi, V. A Low-Cost Framework for Individualized Interactive Telerehabilitation. *Proc. IEMBS 2004,* IEEE, (2004), 3297-3300.
19. Kim, Y., Hamilton, E. R., et al. Scaffolding Learner Motivation through a Virtual Peer. Proc. Learning Sciences. (2006) 335-341.
20. Kwakkel, G. Impact of Intensity of Practice after Stroke: Issues for Consideration. *Disability & Rehabilitation 28*, 13-14 (2006), 823-830.
21. Latham, G. and Locke, E. Self-Regulation through Goal Setting. *Organizational Behavior and Human Decision Processes 50*, (1991), 212-247.
22. Lee, M., Rittenhouse, M., et al. Design Issues for Therapeutic Robot Systems: Results from a Survey of Physiotherapists. *J. Intelligent Robotic Sys. 42*, (2005), 239-252.
23. Phidget Family of Devices. www.phidgets.com
24. Project Gutenberg. www.gutenberg.org
25. Reinkensmeyer, D. J., Pang, C. T., et al. Web-Based Telerehabilitation for the Upper Extremity after Stroke. *Neural Systems and Rehabilitation Engineering, IEEE Trans on 10*, 2 (2002), 102-108.
26. Rennick Egglestone, S., Axelrod, L., et al. A Design Framework for a Home-Based Stroke Rehabilitation System: Identifying the Key Components. *Pervasive Health*, IEEE (2009).
27. Stroke Association. (2008). When a Stroke Happens. Department of Health, UK.
28. World Organisation of Health. (2004). The Global Burden of Disease - 2004 Update, The World Health Organisation.