

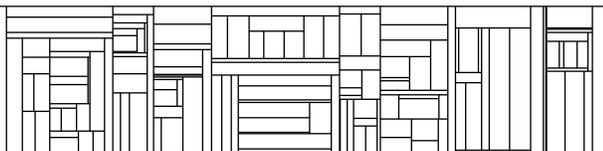
**Proceedings of
Therapeutic Strategies
A Challenge for User Involvement in Design
Workshop in conjunction with NORDICHI 2010
17. October 2010, Reykjavik, Iceland**

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Preface

As more and more interactive technologies are used in various therapeutic fields, such as rehabilitation, home care, chronic disease care, psycho therapy etc, it becomes increasingly important to consider the possibilities and challenges when end-users, such as patients, are involved actively in the design process.

We need a better understanding of the asymmetries that occur when involving designers, therapists/medical professionals and patients in design, in particular an understanding of the relation between design activities and therapeutic interventions, and the role of therapeutic strategies in relation to the process as well as the product. New methods are needed to answer to these new requirements; to what degree can we involve users and what ethical and medical considerations have to be made? Can user involvement in some cases even be harmful for the users and can we expect less resourceful users to be able to actively engage in design activities while struggling to overcome e.g. a life-threatening situation?

Such design situations challenge the basic perspectives of traditional participatory design because equal dialog and co-determination is not possible. Still, these users' participation can be crucial for the outcome and letting e.g. a therapist or relative speak on the patients behalf can be contra-productive.

The present collection of papers forms the proceedings of the workshop conducted October 17, 2010 in Reykjavik, where 17 participants from almost as many different countries spent the morning on short presentations with initial discussions facilitated by posters, and the afternoon with broader discussions on issues common to the papers.

We want to thank all the participants and co-authors for contributing to the workshop. We also want to thank the organizers of NordiCHI 2010 for providing great facilities.

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Participatory Design of IT-support for Anxiety Therapy

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ABSTRACT

In this paper we discuss some of the challenges involved in developing mobile support for CBT based anxiety therapy together with phobics and therapists.

Keywords

Therapeutic strategies, Anxiety, Social phobia, Agoraphobia, Mobile tool.

INTRODUCTION

In this paper we report on early work in the MIKAT project, an ongoing research project aimed at developing IT-based tools, employing bio-sensors for cognitive behavioral therapy (CBT) based therapeutic action for and by people with phobia. The project is loosely based on earlier work by Bering (2008).

As a quite large part of the population suffers from anxiety and related conditions¹, the potentials for resource efficient therapeutic strategies supported by technology are enormous. In this project IT-researchers work together with psychologists, phobics, and bio-sensor engineers.

The course at Jysk Psykologcenter, a psychology clinic in Aarhus, offers a three-month therapeutic school program where clients suffering from phobia are taught about the mechanisms that maintain their phobias and ways to overcome them. Typically, they suffer from social phobia or agoraphobia.

The project has been taking off from the observation that anxiety develops quite fast, and that phobics will often be unaware of evolving attacks until they have developed so far that they cannot be controlled. Consequently, one idea would be to let phobics take control back by having a warning system that enables them to take appropriate measures in time. It is possible to have early indications of an anxiety attack by measuring a person's heart rate variability. Thus, it has been the idea of the project that this kind of measurement could invoke various therapeutic scripts (e.g. exercises or alternative thoughts) on the mobile device.

While the idea is simple, making usable measurements in the field is far from trivial. Calibrating a system alone is a challenge, and making continuous measurements that conform to the same baseline is difficult too. In addition, it seems that becoming aware of own reactions and developing a sense of the strength of anxiety is an

important part of the CBT based therapeutic strategy of the Jysk Psykologcenter.

In the rest of this paper we first report on an early design workshop with phobics and a therapist, then we discuss some themes emerging out of the workshop and subsequent design effort.

WORKSHOP WITH PEOPLE SUFFERING FROM ANXIETY

We have chosen to involve phobics actively in the design process to ensure that we follow a path to empowerment. Obviously, a Participatory Design (PD) process is complicated by the attendants suffering from social anxiety. Many PD processes are characterized by meetings and workshops in smaller or larger groups and are based on the participants' commitment to provide input to the process. A precondition for our process has thus been a fairly equal balancing in the amount of project people and people with different anxiety challenges.

Previously, there had been a startup workshop with approximately 10 people from the project, two therapists and 10 invited phobics. The invited phobics were all in the final stage of a three-month therapy program, and the therapist had approved that the phobics were prepared to join. However, only three of the 10 phobics turned up at the session. Two of the phobics had a social anxiety diagnosis, and interestingly - even though the situation must have been close to a "worst case scenario" for them, both of them made it through a group work prototyping session and the plenum discussions.



Figure 1: Situation from first workshop.

¹ <http://www.dr.dk/P1/Feature/Udsendelser/20090505104403.htm>

The application should be password-locked, to avoid someone accidentally getting access to their anxiety info.

Automatic encouragement

When the application opened they also wished to get a short encouraging sentence to remind them about the guidelines they have learned during the therapist sessions.

Simplicity and therapy focus

An interface was envisioned in which there were five choices when the application opened. “Remember”, “Before”, “Under”, “After” and “Challenges”. Regarding “Before-Under-After” the application should relate to the above mentioned. “Remember” should provide sentences with good advice written by the phobic. These should also be the sentences randomly displayed when the application opens. The “Challenges” should be a therapeutic application with a range of challenges that users should confront themselves with when they are ready to engage in them.

These design ideas were not brought into simulated situations during the workshop. Because the whole workshop was organized around a specific situation it was not realized how important a situation orientation was in the therapeutic strategy and how important situations were in the structuring of the interface. Thus, in the subsequent application design it was remembered that the anxiety situations were well defined, and the very center in therapy, and should be the basic units in the interface rather than the generic before, under, after. In retrospect, it seems like “situation” had been implicit during the workshop and thereby somehow forgotten.

Our subsequent design ideas maintained the simplicity from before, but now structured by “situations”. Also it has been realized that the individual phobics anxiety hierarchy would be important. With respect to “challenges”, we realized a need for posting reminders outside the application *per se*, e.g. by way of the calendar.

TESTING THE FIRST PROTOTYPE

The mobile application prototype, implemented as an iPhone application, is understood as an integrated part of the therapeutic strategy, supporting the transition from being at the course, over the loose consultation phase, to the “after therapy” situation (Fig 3).

We have planned a workshop where the phobics get the prototype and together with the therapist enter situation sentences, challenges, etc. into their respective instances of the prototype. In the future this would be done during the last phase of the therapy.

We have planned for a period where the phobics use the application in their day-to-day life. We have instructed them that the prototype should be considered a prototype (Mogensen 1992). This means that we have told the phobics that we do not expect this to be the final design, but that we see the potentials in it as something that can help us all learn more about the possible future. We could have used other ways of explaining the purpose of the prototype, but explaining that it was a prototype communicated very well.

DISCUSSION AND IMPLICATIONS

Empowerment

Empowering people with anxiety has been a basic motivation for the MIKAT project. However, already the first discussions revealed conflicting perspectives on what empowerment would mean. The idea that mechanized anxiety detection would empower phobics by enabling them to take action is in contrast with the therapeutic strategy employed at Jysk Psykologcenter, in which phobics are empowered by teaching them to know their anxiety. In the later perspective the mechanized approach would easily be seen as an alienating strategy. The open question is if there is room for mixed approaches.

Maintaining the therapeutic activity alone

Maintaining the therapeutic effort seems to be a problem



Fig 3: Screens from the first prototype.

for many phobics after the main part of the therapeutic program is concluded. Ideally, the phobics would like to have continued interaction with the therapist. This is, however, not possible because of obvious resource limitations, and it is not necessarily desirable because it could keep the phobic in a less powerful role. Using a mobile application as the central “gateway” for the phobics to work with material about their own anxiety could improve continued effort, because they could use idle times in busses etc. for reflecting or updating their anxiety hierarchy.

Two distinct active strategies seem possible to address this issue. The *tool-centric solutions* would use reminders, or even game like effects to encourage phobics to continue challenging themselves, reflecting, etc.

Alternatively, *social group based solutions* would be based on phobics being members of a group from the program. In many other contexts it has showed to be effective to embed self-care activities in a social group. It is not so easy to postpone a challenge if it has already been announced to the group. Seeing the other peers announcing how they have updated their anxiety hierarchy will be a strong encouragement to maintain that activity.

From application to toolbox

Even though the basic structure of the three-month therapeutic program at Jysk Psykologcenter is quite stable, our workshops also revealed that there is a great deal of variation across groups and therapists. Some activities make sense in some groups but not in other, and new activities are developed. Therapy is a phenomenon in development.

Therefore, to meet the therapeutic culture, it would make sense to develop the MIKAT application as an extensible toolbox with which therapists and phobics could tailor a suitable tool by a LEGO-bricklike combination of elements. Such an approach could be based on work from the Palcom project on therapist configurable environments for rehabilitation (Grönvall et al, 2006).

Phobics versus therapists as users

An underlying motivation for the phobics, for participating in the project, has been that they find it difficult to let go of the therapy. Participating in the project gave them a chance to stay in contact with the therapeutic milieu. This showed in various ways during the first workshops. Thus, the phobics’ motivation tends to contradict the therapeutic plan for enabling them to let go of the therapy.

Similarly, we saw quite some differences in enthusiasm, with respect to the idea of a bio-sensor-based system. The phobics saw it as prolonged safety to have externalized aids for rating and controlling anxiety, whereas the therapist more saw it as being irrelevant to the therapeutic regime.

The importance of the phobics point of view here is that they are not necessarily limited by a specific therapeutic strategy. They are engaged by the needs of their own specific situation. At the same time, the point of view of the therapist is needed for a more generalized perspective.

In our workshops we have seen an interesting kind of interaction and interdependence between the therapist and the phobics, where the phobics often want to have their design ideas approved by the therapist. E.g. a discussion of the possibility of some features being a possible sustainer of negative thinking.

The challenges in involving users with anxiety

Involving social phobics in participatory design has been a challenge, but not at all impossible. It has been possible for us because our design activities were thought of as part of the therapeutic program for the individual phobics. Until now we have worked with phobics that have finished the three-month program, but in future phases we will need to work with the prototype application in earlier phases of the therapeutic program, and in doing so we interfere with less robust people. Obviously, applying the application earlier in the program will be sane, but we still don’t know which requirements on application stability and evaluation strategy we will meet.

CONCLUSIONS

The MIKAT project is still in progress. The bio-sensor approach has not been central in the work presented in this paper, but may somehow come into play. We have instead focused on how to extend existing therapeutic strategies by means of IT based tool.

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Multiple perspectives on self-care: How can healthcare professionals and patients contribute to design?

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ABSTRACT

In this paper we describe the design process of a web-based healthcare tool for patients who have undergone weight-loss treatment. People who undergo such treatment need to implement extensive self-care to establish and maintain lifestyle changes. However, self-care is labor intensive, and compliance and long-term maintenance is difficult. Electronic healthcare tools have the potential to help establish and maintain lifestyle changes. By involving patients and healthcare professionals in a participatory design process of such a tool, we were able to identify barriers and solutions to self-care and further gain understanding about the most important aspects when designing a web-based healthcare tool.

Keywords

Participatory Design, self-care, obesity, patient, e-health.

INTRODUCTION

Since its infancy in the 1980s [1], the perspectives and techniques of Participatory Design (PD) have become part of state-of-the-art in systems development. As exemplified by Druin's work with children [2], certain user groups require modifications and adaptations to the existing PD methodologies. We will here report from a Participatory Design project with another non-standard user group: obesity patients. It is our hope that the lessons learned from co-designing with this patient group will apply to other patient groups.

With the increasing amount of people who suffer from severe obesity and with following diseases, weight-loss treatment is highly demanded. Weight-reduction can be achieved through pharmacotherapy, bariatric surgery or by lifestyle therapy. Regardless of what kind of weight-loss treatment people undergo, it requires some sort of lifestyle modification with focus on eating habits and physical activity. However, long-term maintenance is a challenge, and many people experience weight-regain after a period of

time [3,4]. Self-care management with self-monitoring is crucial for successful long-term weight maintenance, but compliance among the patients is difficult.

To be able to design a web-based healthcare tool for this patient group, an understanding of current challenges and barriers to self-care is needed. By involving patients and healthcare professionals, we aimed to get a better understanding of this. By means of this insight, we have implemented a web-based electronic healthcare (e-health) tool to support patients after treatment.

PARTICIPATORY DESIGN PROCESS

In this project we have conducted a series of participatory design workshops. Based on the findings from the future workshops, we started to develop a prototype web-based e-health tool. A final workshop was carried out to get feedback on the prototype and to validate the findings. The results were used for the continuing development process of the e-health tool, where also two phases with usability testing and redesign was included.

The study got approval from the regional Ethics Committee (Central Norway, Trondheim), and all participants provided written consent when enrolling to the study. The workshops and the usability tests were audio- and video recorded, and transcribed verbatim before analysis.

The Workshops

The workshops were moderated by 2 facilitators from the research team, and involved a combination of semi-structured interviews and group-based activities. In parts of the workshop, we created two smaller groups, where there was one facilitator present in each group. By creating smaller groups, we aimed to allow the participants more freely take part and discuss perspectives and challenges concerning the current issues. We also had in mind that participants might have similar experiences that might be fruitful to discuss in smaller groups. In the mini-groups the participants used artifacts such as post-it notes and posters during brainstorming activities and to create sketches.

Workshop 1: Involving healthcare professionals

The first workshop was conducted with healthcare professionals that currently were working with obesity treatment. The participants had background from nursing, medicine and clinical nutrition. The workshop involved

both semi-structured interviews and group-based activities. The tasks involved creating personas (one patient that goes through lifestyle therapy, and one going through surgery), describing the personas daily life before and after treatment, and describing the use of technology. Further the participants were to suggest technical solutions.

Lessons Learned

Personas are detailed fictional people created with the means of representing users need [5,6]. The objective of creating personas in this setting was to get the healthcare professionals to focus on the patients and their challenges, and to find out what they regarded as the needs of patients who undergo lifestyle therapy and surgery. This gave the professionals a basic concept to link the further discussion upon. They gave their persona a name, personal characteristics, described where they lived, talked about their family and about their work-situation. They described the lives of the personas in a concrete way, and included both psychosocial and psychological, as well as practical aspects that are relevant for the patients. This was of course from the healthcare professionals perspective, and they could tell about how *they* perceive the patients' barriers and challenges', but also about how they as healthcare providers experience challenges with patient education, (non)- compliance to recommended follow-up regime, diet, exercise etc. By creating personas, the participants were able to clarify the needs, barriers and solutions in a strategic way. When the participants were to suggest technological solutions, we experienced that they continued to work with the persona, and were able to implement technology in the fictional future of the patient, and they discussed problems and measures. Throughout the workshop the professionals uncovered that patients who undergo surgery experience differing challenges than patients that undergo lifestyle treatment, and thereby have differing needs and requirements concerning self-care management.

Workshop 2 & 3: Involving patients

The inclusion criteria for the patients were that they (1) had completed a weight-reduction program at the hospital, (2) were over 18 years, and (3) had basic proficiency in Norwegian language. We conducted two separate workshops with patients who had undergone two different weight-loss treatments; one group that had undergone lifestyle therapy, and one that had undergone bariatric surgery. The patient groups were to discuss their daily life before and after treatment, what tools (if any) they used after treatment, and suggestion on how technology could help in this situation. Further they suggested specific technology they considered to be important to support self-care.

Lessons Learned

The workshops including the patient groups validated what the healthcare professionals had suggested; that patients who undergo weight reduction through lifestyle therapy experience differing challenges and have other needs than

patients who undergo bariatric surgery, and hence have other requirements towards an e-health tool. The objective of conducting the task with describing their daily life before and after treatment was to illuminate the changes in daily life (if so), and use this as the basis when talking about future solutions. The setting provided an opportunity for the participants to see similarities and differences between each other's experiences. We observed that there were similarities between the two patient groups, e.g. regarding that both groups required information about food and nutrition, but the specific information they needed was differing. Patients who were operated required specific information regarding food to eat and food to avoid for preventing side-effects of the operation. While patients attending lifestyle therapy required general information about healthy food, and needed to learn about strategies to avoid using food as a coping mechanism. This implies that the provided information needs to be disease/treatment specific.

Workshop 4: Validating preliminary findings

To validate our findings from the previous workshops, we invited the participants to a final workshop. Not all participants were able to show up due to different reasons, but participants from the multiple groups were represented. The workshop involved a presentation of the web based e-health prototype, followed by feedback and discussion. The workshop also included a card-sorting session where the participants were to group together predefined functionalities. This was further used to link technical functionalities to aimed patients outcomes (that were created based on findings from the workshops).

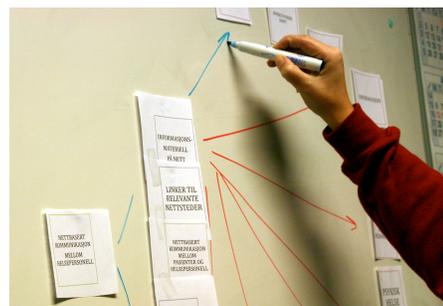


Figure 1. Participant connecting functions and outcomes.

Lessons Learned

By conducting the last workshop we could validate that we had understood the participants' requirements towards the system correct. The feedback on the prototype formed the basis of the further system development. With the card-sorting session, we got a prioritized list of functionalities that the multiple groups considered to be the most important. By linking functionalities to what they considered to be the outcome measures, they were able to change their priority list accordingly.

With the workshops we aimed to provide a setting in which to approach personal topics, including issues that some

participants might perceive as delicate subjects, such as eating habits, family routines, and other personal issues that may influence on these. We suspected that if we mixed participants from multiple interest groups, the presence of other group members would inhibit the creativity within the groups. By conducting the final workshop this assumption was confirmed, as we could observe that there were differences in perspectives and power that justified separating the groups.

Usability testing

The system development process included two phases of usability testing and redesign.

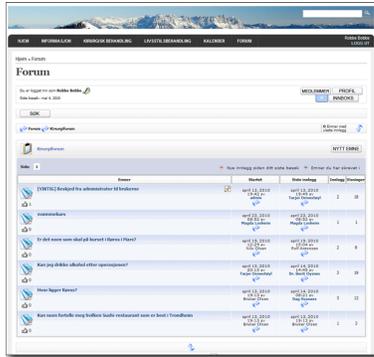


Figure 2. First version of system.

The system was developed based on open source modules (Figure 2). The usability testing involved standard procedure where users conducted tasks on a desktop computer, while they used the think-aloud technique explaining the interaction. A semi-structured post-test interview was conducted to elicit the interaction, and the System Usability Scale [7] was used to measure subjective satisfaction.

The Usability tests

The first usability test of the web-based e-health tool included normal weight participants that had not undergone weight-loss treatment. The objectives were to get feedback on early design and functionality, and to identify usability problems. The usability test led to a process with redesign before we conducted a second usability test that involved patients that had undergone weight-loss treatment.

Lessons Learned

The first usability test identified both critical, serious, and cosmetic usability problems. However, as the normal weight individuals do not have the experiential knowledge that real patients have, they could not provide feedback regarding if the functions in the system were as required. After a process of redesign and eliminating the major usability issue, we conducted a second usability test with real patients. They provided concrete information about which functionalities that were the most important, and thus needed to be enhanced, as well as providing information regarding if the system was as required.

RESULTS

The participatory design process pointed out three major findings. First, we got insight to the perceived barriers and

challenges that patients experience after weight-loss treatment. Second, we gained better understanding to the healthcare professionals perspective about treatment of obesity. Finally, we were able to identify what such a tool should contain of contents and functionality, and in what contexts such a tool can be of meaningful use. Through the PD process we identified four major barriers to self-care: Structural aspects, coping mechanisms, knowledge and social network. The most important suggested solutions and requirements were 1) Patient education/information, 2) Online communication among patients, and between patients and professionals. 3) Support for daily management: Patients need to learn how to structure their day, and need reminders to establish new routines.

DISCUSSION AND CONCLUSION

Patients and healthcare professionals have differing knowledge, perspectives and experiences. When designing an e-health support tool for use as part of a treatment process of a disease or illness, both perspectives are relevant and valuable. Traditionally healthcare professionals have been the provider of healthcare services, and healthcare has taken place in hospitals and healthcare institutions. Lately there has been a paradigm shift, and healthcare also takes place in the home environment of the patient. An understanding of this environment is crucial when implementing new technology. However, the professional knowledge and experience that healthcare personnel have gained over several years is invaluable during a development process, as they have knowledge about a whole group, and not only about one individual patient.

Patients hold on unique experiential knowledge, they provide insight to their daily life and about what their challenges and needs are. Their individual perceptions are important to understand, and only they can tell about the context of use. That the new tool fits into the daily routines of the individual patient is crucial if the tool should be adopted. In this project we also determined quite early that we were dealing with two distinct user groups: those undergoing surgery and the lifestyle group. The difference was not mainly concerning medical or social characteristic, but simply the fact they had different needs. Having undergone this kind of surgery leads to a number of specific needs that is irrelevant for the lifestyle group. Mixing the two would only lead to a lot of confusion, and underlines the importance of involving multiple user groups during the development process.

Through the participatory design process we revealed that system developers might lack crucial information if not involving the end-users during a system development process.

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We thank the participants for sharing their time, valuable experience and great ideas.

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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:

Lesley Axelrod, Eric Harris (University of Sussex); Ann-Marie Hughes, Jane Burrige (University of Southampton); Anna Wilkinson, Sue Mawson (Sheffield-Hallam University); Thomas Nind, Ian Ricketts (University of Dundee); Tom Rodden (Nottingham University); Nour

Position paper for:

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Shublaq, Penny Probert Smith (Oxford University); Zoe Robertson (Barnsley District General Hospital).

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:

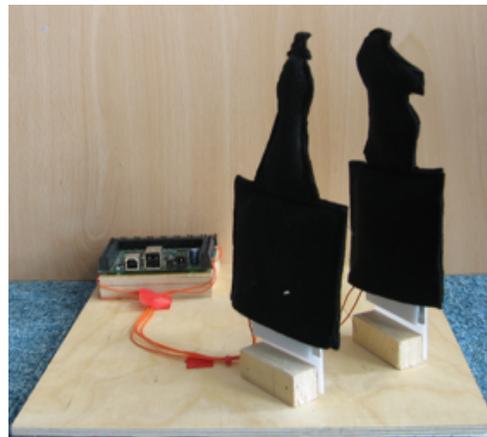
Ida and Eric – Rehab reader

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.

ACKNOWLEDGMENTS

We thank our participants who gave their time and effort and ideas to the project and who welcomed us into their homes. This work was funded by the UK EPSRC: Grant EP/F00382X/1.

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Co-Designing Personal HealthCare Solutions for the Treatment of Bipolar Disorder

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ABSTRACT

This position paper presents some initial thoughts on challenges and considerations for collaborations between designers, healthcare professionals and patients in the development of solutions for monitoring and treating bipolar disorder. We present our experiences on the MONARCA project, a cross-disciplinary and collaborative European project involving extensive participatory design.

Keywords

Personal Healthcare, Participatory Design, Mobile Healthcare, Feedback Technology.

INTRODUCTION

Bipolar Disorder is a common and severe form of mental illness characterized by repeated episodes of mania and depression. Treatment of bipolar disorder is typically based on a combination of pharmacotherapy and psychotherapy. In addition, a promising form of intervention is to help both doctors and patients to recognize and manage early warning signs (EWS) of mania or depression, to prevent the occurrence of critical episodes [6]. However, training patients to recognize their own EWS is difficult and time-intensive, and these efforts only prove successful with some patients. Ubiquitous, context-aware technologies have the potential to improve this intervention through early detection of patient behaviors and persuasive interfaces [3] to encourage healthy behaviors.

The goals of the MONARCA European Project¹ are to develop and validate solutions for multi-parametric, long term monitoring of behavioral-physiological information relevant to bipolar disorder (e.g., level of patient activity,

amount of social interaction or changes in daily routine; stress, pulse, quality of sleep, etc.). These solutions will be deployed through an appropriate healthcare platform providing a set of novel services for personalized management, treatment, and self-treatment of bipolar disorder.

For instance, the system will feature an appropriate user interface running on a smart phone and/or the home gateway, closely integrated with the monitoring system and the patient's health record. This mobile application should allow the patients to easily get support from the therapist and jointly view and analyze the system feedback.

THE MONARCA DESIGN PROCESS

For the design of MONARCA user interfaces we have adopted a human-centered, participatory design approach [4], including workshop activities, to develop ideas in close cooperation with a group of patients, their doctors and therapists. The design process is fed with results of ethnographic studies [5] about patients with bipolar disorder, reporting relevant patterns of their daily activities, ways of handling the disease, as well as the collaboration with doctors.

In these studies we focus on ambulatory patients in regular treatment. Based on the study findings, an iterative design process is initiated. The interaction design process will be based on a scenario-based approach [1] using mock-ups, as well as low-mid fidelity prototypes. During the design workshops, held at ITU and at the University Hospital (Denmark), typically 2-3 healthcare professionals (doctors and nurses) and 3-7 patients are involved. Patients are asked to role-play a series of scenarios and provide feedback on the ideas or prototypes presented (see Figure 1). The results of the workshops and interaction design phases are documented and shared within the project partners for subsequent implementation.

¹ <http://www.monarca-project.eu>

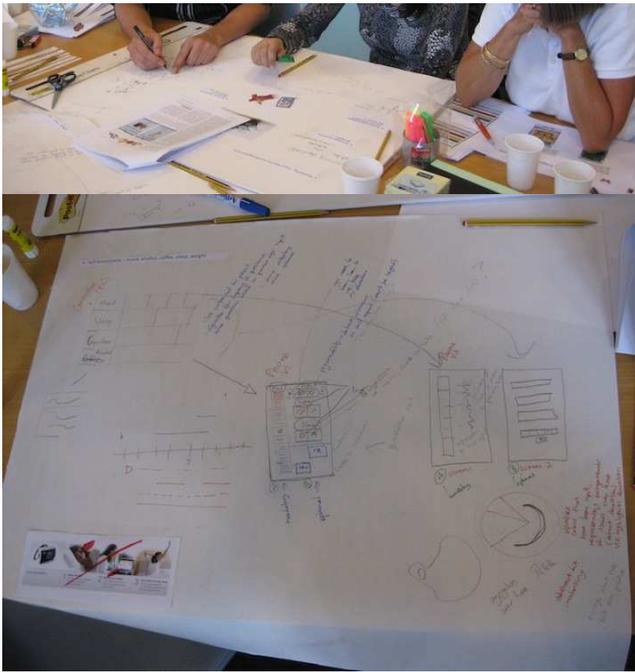


Figure 1. (top) A group consisting of a patient, designer, and HCP, working together on a design activity using a variety of materials. (bottom) A sample result of a design activity, including sketches of interface ideas, and notes on desired functionality.

KEY DESIGN CHALLENGES

In the following sections we report some key challenges met by the MONARCA design team in employing participatory design during the initial phases of the project. We also offer some lessons learned, effective strategies we used, and advice for other designers based on our experiences.

Involving Patients in the Design Process

There are a multitude of challenges and risks to involving patients in participatory design, and they affect the work of designers, the outcome of design efforts, and the wellbeing of the patient participants themselves. In this section we reveal some of the primary challenges we experienced during our process.

Limited Access to Patient Participants

Patients are more difficult to access than other kinds of participants. Patients are accessible and eligible if they have been diagnosed, are receiving treatment, and are relatively stable. Because it is difficult to recruit patients as participants, this challenge can result in both limited and biased participation.

For example, we were able to recruit several students with bipolar disorder from our own university. Due to the fact that we are at a technical university, these students are technically oriented. While we embraced the opportunity to increase our patient participation, this made our group of patient participants heavily oriented toward technical

backgrounds. Due to the difficulty of recruiting patients, we were unable to balance these participants with patients of other ages and backgrounds. Therefore, we had to deal with this limitation and be aware of the bias present in our set of participants.

We may be able to counteract this imbalance in future phases of the project. For now, we will have to find ways to deal with this limitation, or at least be aware of its influences, during our current design activities with the patients.

Another difficulty is being able to involve an acceptable number of bipolar patients representing a good sample of clinical symptoms (including their range of frequency and severity) that could allow us to find the best strategies for supporting effective interventions. In order to involve patients with different age/gender/cultural background, our workshops, pilots and trials will be carried out in two different European countries (Denmark and Austria).

Egocentric and Symptom-Produced Patient Bias

Patients bring perspectives and experiences that are invaluable to the design process, but their participation is of course biased. We observed two kinds of bias displayed by our participants: egocentric bias and symptom-produced bias.

Patients have an egocentric perspective of bipolar disorder and are likely to believe that their case is representative of the illness. In reality, bipolar disorder differs from patient to patient in symptoms, intensity, and experience. Individuals will also differ in the way they cope with the illness and respond to treatment. However, individuals only understand their own experience with the illness and will unknowingly display this bias.

Designers must be aware of this egocentric bias and realize that the perspective, opinions, and ideas of patients are only representative of their own experience with the illness. There are insights that patients will provide which may reflect a universal experience with bipolar disorder, while sometimes their experience may be somewhat unique. When working with patients, designers should utilize the rich data available within each patient experience, without allowing the work to be biased by any one patient perspective.

Designers can use several methods to maintain a neutral perspective and an understanding of the illness that is as generalizable as possible. Designers should get to know patient participants and try to understand their stories and personalities. Understanding patients' backgrounds and personalities allows a designer to interpret what they say and predict how they may be biased. When patients express opinions and ideas, it is also important for them to explain their basis and rationale. Finally, involving HealthCare Professionals (HCPs) can help reduce bias because they have a broader perspective of the illness from their experience with the illness and working with many patient

cases. While holding participatory design sessions with patients and HCPs together, we observed HCPs correcting claims that patients made and directly pointing out and correcting their bias.

In addition to inherent egocentrism, patients' symptoms may influence their participation in the design process. Patients may be outspoken, imaginative, and highly involved, or they may be quiet, contemplative, and not very involved.

One of our patient participants has put an extraordinary amount of effort into our design activities. He has read literature on his own time, documented his findings and thoughts, presented us with lengthy reports and graphs, and is very outspoken and involved during design sessions. His psychiatrist explained to us that this patient has a particularly complex illness, and his high level of thought and participation in our project is a reflection of the complexity of his mind. The example of this patient demonstrates an extreme to which patient participation can vary, and the way a patient's illness can influence participation.

Designers can approach this challenge by being aware of its possibility, and employing the bias-reducing strategies mentioned in this section. Designers can also act as a moderator for stakeholder conflict and bias, a role that we will discuss later.

Patients and Their Carers

It is evident that involving bipolar patients in the co-design of MONARCA prototypes and self-treatment interfaces is a delicate and complex matter that requires caution. An additional option, which is still an open issue in the project, is whether to also involve patients' relatives and carers (and to what extent) in the participatory design process.

A goal of MONARCA is to facilitate the collaboration of patients with their clinical team and carers during the treatment process. Data collected by the system can be shared with the people who typically play a role in monitoring a patient's progress and status: clinicians, significant others, family members, friends, and other carers. Notifications can alert these individuals of possible early warning signs, encouraging them to check in on a patient. The patient herself can also be encouraged and assisted in reaching out to clinicians when necessary.

The input of patients together with their carers would enable us to explore this kind of functionality and find the most appropriate, effective, and non-intrusive ways to implement it. Tradeoffs exist between privacy and awareness, autonomy and collaboration. The input and consensus of all parties is needed to find ways of involving carers that are minimally intrusive while having the maximum impact on patient outcome.

MONARCA also aims to support the preventative model of taking appropriate action in response to early warning signs that precede critical episodes. Prevention of critical

episodes may be achieved more successfully when carers are engaged in the treatment process, and therefore their involvement in the design process could have positive outcomes.

Stakeholder Conflicts

In addition to involving patients in the design process, it is also important to involve healthcare professionals for a clinical perspective. Co-designing with both of these groups, HCI designers therefore work as part of a team of very different people. Each of these three stakeholders in the design process has different motivations and approaches. In this section, we describe the differing stakeholder stances and how they can conflict with one another.

HealthCare Professionals and Designers

The involvement of HCPs in collecting the user requirements and performing initial design, raised two main types of obstacles: a) the risk of a power imbalance between the contributions to the design process provided by HCPs, and those provided by patients and designers [2], and b) the difficulty of fully exploring the innovation potential offered by new technologies to improve treatment of bipolar disorder, when there is the risk of exposing patients to new interventions whose benefits have not been possible to prove, yet. There is a strong need by HCPs to orient design decisions towards making the new technological solutions fully compliant with current protocols used in the medical practice for bipolar disorder. This is of course a legitimate stance, since HCPs are the first ones to respond for patients' healthcare and the success of any therapy proposed. However, this can also represent a limitation in the possibility of experimenting with new forms of therapy for bipolar disorder that, by being based on a richer set of physiological and behavioural data of patients, could turn out to be more objective and valid.

The key challenge in this participatory design context is to establish from the project start an open, cross disciplinary collaboration environment, as well as common language where the HCPs concerns, ethical policies and constraints can be shared and properly discussed with the other relevant stakeholders to balance and accommodate the different perspectives.

Evaluation Goals

While HCI researchers generally aim for system evaluations and user studies as an end goal for designing a system, HCPs may have clinical trials in mind. These disparate goals will cause each to approach the project in a different way.

It became apparent during our design workshops that the HCPs were approaching the design exercise with the goal of a clinical trial. We explained our approach as HCI researchers and clarified that our aims were instead evaluations of the use and impacts of the technology. This

changed the way the HCPs approached the design problem and put us all on the same page.

It is important for a discussion to take place early on about the goals for the work. Experts and researchers from different backgrounds may have disparate expectations and assumptions. Setting expectations helps avoid misunderstandings and unify the design team.

The Designer as Moderator of Stakeholder Conflicts

As a clinically neutral party, the designer can keep in mind the biases of HCPs and patients. HCPs will be influenced by a clinical way of thinking, and aim to meet their strictly clinical goals. Patients will communicate their own desires and perceived needs, which may not coincide with clinical significance or generalizability. At most, these two perspectives can be in conflict with one another. At least, they can multiply the number of design ideas and directions generated.

It is the role of the designer to moderate these stakeholder positions in order to direct design activities toward an effective solution. In the case of healthcare technology used by both HCPs and patients, the needs and desires of both stakeholders must be met in order for the technology to be accepted and used effectively. A system that does not match clinical requirements and standards will fail, and so will a system that patients do not accept.

The designer therefore has the difficult task of moderator, ensuring that the needs of all stakeholders are met. This includes moderating activities during the design process, so that all stakeholder voices are heard, and all stakeholders feel that their input is being incorporated, so that they remain actively involved in the process. Carried out effectively, this moderating task will produce a successful technology that will be accepted by all users and make an impact on their healthcare roles.

To fulfill this moderating role, designers can use the following strategies: question stakeholder requests to ensure a good understanding of their rationale; ask stakeholders to prioritize requests; pose another stakeholder's conflicting views or requests; propose compromises that may alleviate conflicts.

Designing for a Complicated Illness

Even when involving key stakeholders in the design process, it is still a challenging task to develop a system like MONARCA. One difficulty lies in the fact that even personalized solutions for self-coaching and therapy, developed with patients during the workshops, might turn out difficult for them to use over extended periods of time, especially during critical episodes of mania/depression.

Designing for Daily Long Term Use

Designing healthcare solutions means designing for daily long-term use when treatment is ongoing. Bipolar disorder requires consistent, ongoing management of symptoms and episodes. This means that any solution to be used as part of the treatment needs to fit into patients' daily lives and

possible symptoms they may experience. This kind of use is challenging to design for.

Our participatory design workshops have uncovered many details and considerations that help shape our understanding of the circumstances we are designing for. The high involvement of patients and HCPs in the design process has shown to be fruitful for tackling this design challenge. Designing together with the users and stakeholders enables us to learn about their daily lives, ask about limitations and challenges that threaten successful long term use, and propose possible solutions and prototypes to gauge their feasibility.

To get the most out of co-designing with patients and HCPs, designers should ask and encourage these participants to share their stories and experiences, provide input and opinions freely, and brainstorm creatively about possible solutions. The better that the creativity and involvement of participants is fostered, the more innovative and effective solutions will emerge from design activities. More importantly, perhaps, solutions will be more successfully integrated into the life, challenges, and treatment of a patient.

Acknowledgements

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The intrinsic fragility of elderly care networks: five challenges in Participatory Design practices

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ABSTRACT

Taking inspirations from a number of case studies and experiences, we herein propose and discuss five challenges related to users' participation in the design and development of assistive technologies for elderly people. We believe that it is important to extend participation in care-related Participatory Design (PD) processes to both include elderly people and other, professional and non professional stakeholders, namely the network of actors surrounding the patient. However, active participation of the network in design work is challenged by a number of circumstances that are mainly related to the intrinsic fragility and the vulnerability of social relations that is characterizing for many care settings. In particular, we will discuss the following five challenges: organizing participation; forms of participation; latent and emergent actors' motivations; managing heterogeneous expectations; and strategies to manage roles and conditions.

Author Keywords

Participatory Design, challenges, network of actors, assistive technology, elderly people, fragility, care setting

ACM Classification Keywords

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

INTRODUCTION

A shared view within the PD community is that it is important to involve all the stakeholders [7, 9]. In Health-care related PD processes this view can be challenged by a number of reasons. Furthermore, system development for healthcare related activities with a focus on PD, especially in a non-professional setting such as the patients' private home, is challenged in a wider perspective than the direct patient involvement. In this paper, we argue that it is important to extend participation in health related PD processes to include also other, non professional stakeholders, namely the network of actors surrounding the patient (see figure 1). This network of friends, neighbours, spouses, children etc can, and usually do perform articulated work related to the care or recovery of a patient, especially in a non-hospital setting. Furthermore, close family members will on many occasions live alongside the envisioned systems, mediate knowledge about them, control them and provide motivation and support for the (elderly) patient on a day to day basis.

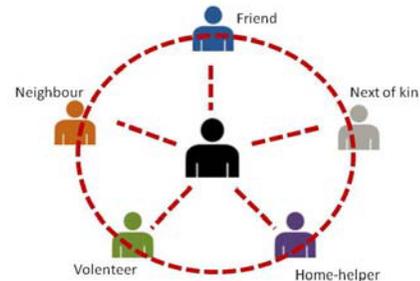


Figure 1: examples of actors surrounding a patient or a person subject to home help service.

However, the care networks active participation in design work is challenged by a number of circumstances. In contrast with workplace located participatory design projects, the care setting is characterized by a network of actors that is more heterogeneous, dynamic and with less defined boundaries; furthermore, the social context has an intrinsic fragility and vulnerability that is related to the often tragic and dramatic experience of weakness [5].

On the basis of the experience we have matured in the following projects: NETCARITY [14], MSN [13], CALCE [4] and BDSI [8] we have identified five challenges that specifically address the difficulties related to the involvement of the social care network surrounding an elderly patient in a PD process. What now follows is a walk-through of the five challenges highlighted in this paper as issues to consider when performing PD activities with elderly people in their own homes. Then, a discussion will follow to summarize this paper.

ORGANIZING PARTICIPATION

In the context of private care settings, organizing Participatory Design sessions could be complicated for different reasons. The first one is related to the definition of the stakeholders that have to be involved in the co-design activity. The care network can be very articulated and understanding who play a role in the life of elderly people is not easy; beyond relatives and caregivers there could be sets of people that may provide assistance on fairly regular bases and which are not easy to identify such as neighbours or friends. Another critical issue is related to the emergence of unexpected events; in care settings, unexpected events occur quite frequently because of the fragile conditions of the involved subjects: elderly people may feel tired or even get sick. On the other hand, care-

givers could have tight schedules and it is not easy to arrange meetings or rescheduling them. This situation could be very stressful for researcher trying to manage a PD process.

Furthermore, in order to participate in the PD sessions, elderly people need to trust the research team. And this is something that should be carefully considered in the organization of a PD process. In a recent study, a step-by-step process was adopted to progressively build a trust relationship with the elderly participants [6]. In this study, a comprehensive approach was adopted to motivate the participation of older people in the design team and to establish a long-term relationship with them. This approach is based on the work carried out by [11] in a different but related project and encompassed: (i) the endorsement by, and the direct involvement in the project of, local authorities and associations of older people with the role of mediators between researchers and participants and guarantors of the good intentions of the research; (ii) the establishment and nurturing of the sense of belonging to a pioneering group, with emphasis on the value of both individual and group contributions. Following these principles, a day centre for senior citizen was involved in one of our studies. During the years, the personnel at the centre have established a well-consolidated relationship with the attendants and this facilitated this specific project initiation and created a trusted atmosphere between participants and researchers. The first meetings were conducted on the premises of the day centre with the presence of attendance; only after some encounters, it was possible to organize meeting with the elderly people alone. And finally, some of them allowed the researchers to access their home for in-situ workshops. In another project, the involved physiotherapists mediated the first contact, allowing the researcher to meet the elderly people together with the physiotherapists at the hospital. From there, individual contacts and PD activities in the private homes could be initiated.

FORMS OF PARTICIPATION

The deeply personal nature of care or rehabilitation activities limits what can be investigated as well as how it can be investigated [5]. In certain situations, the direct participation of elderly people in a participatory design process can be inappropriate: discussing, sharing and negotiations can be frustrating and unaffordable tasks.

In order to minimise the risk associated with the application of inappropriate strategies for involving elderly, an opportunity is offered by the involvement of *cultural mediators' users* [10] a "hybrid" category of users that mediate the relationship between the design team and the final users. Being asked to consider both the final user and the design team viewpoints, the mediators' task consists in interpreting the behaviour of the final users according to the objectives and the perspective of the designers. A *mediator* is neither the simple executor of a task allocated by a designer, nor an informant of the process. *Mediators* are

active participants in the design cycle who bridge the roles of designers and final users, and in doing so favour a common view and understanding. In order to perform this activity, *mediators* should be involved as equal partners in the process, sharing objectives and tools with the design team. In the MSR project therapists and care-givers have supported the design team to obtain a thorough comprehension of how the different actors in the home care make sense of what happens, and how the continuous process of understanding is supported. They also played a fundamental role in facilitating the interpretation of the user requirements that emerged through fieldwork activities, and the adaptation of the concept to daily practice in the home care. Moreover, they rendered the sharing and evaluation of the concepts easy [12].

With a specific focus on roles and the division of work within a PD process, [15] discuss participation not in terms of mediators but what different roles different participants are capable of taking in PD activities and how these diverse roles complement each other. This work discussed the challenge of participation, involving elderly patients undergoing home-based rehabilitation in PD activities. In the reported study the patients' general condition, their medical problems and aspect such as available time (many of them has been reported to have a very busy schedule) challenged the participation. On the other hand, the study shows that the physiotherapists involved in the project, in contrast to the patients, could engage in the PD process as part of their work practice and hence, they did not challenge the design process in a negative manner. The paper continuous "While we to a large extent design with the physiotherapists, we to a larger extent design for the elderly." [15]. In contrast with traditional PD studies, participation was not equal and symmetric: the actors participate and contribute to the final system determination in a different way: while elderly patient mainly were involved in the requirement elicitation and validation, physiotherapist directly contribute to the design of the system. This is also exemplified by figure 2, from the same paper.

However, the introduction of mediators and different forms of participation in the PD process is challenging in many respects. It is fundamental to guarantee that all the actors' voices, even if to a different degree, have the possibility to contribute to the construction of a shared interpretation of the future system. Especially when involving elderly people with communication problems for example due to a stroke or other medical constrains, it is important to carefully consider the role played by mediator: their specific point of view, subjectivity and personal experience could be a bias in the understanding of the real needs and desires of these people. The involvement of different actors – and not only therapists or care-givers – such as relatives, friends, domain experts (such as gerontologists) could lead to a more distributed interpretation process that results in a more clear and reliable understanding of patients needs and desires.

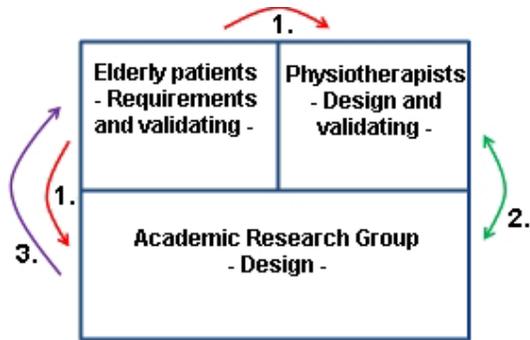


Figure 2: Roles and division of work occurring in parallel throughout the project; 1 = requirements and feedback, 2 = Iterative PD work, 3 = Concepts and prototypes for evaluation. From [15].

LATENT AND EMERGENT MOTIVATIONS

The engagement within a research project can be grounded on motivations whose nature should be taken into account when orchestrating network participation. On one hand, institutions and public organizations can be motivated by the opportunity to improve the quality of a service, enhance their public visibility, and benefit from being part of a local or international network. Within organizations, diverse and eventually conflicting views can exist if we consider the diverse professional roles involved (for instance hospital manager, nurses, therapists, etc.). On the other hand, single citizens motivations are more related to the satisfaction of expressive needs, such as self-esteem, self-actualization (doing something useful for future generations, feeling active within the local community, being protagonist within a innovative process), social needs (being part of a group, overcome loneliness or social isolation) or cultural needs (familiarizing with the world of technology and innovation). In the context of care technologies for elderly people, family members' motivations are often crucial, becoming the trigger to establish involvement among the elderly citizens. Mapping of the motivational aspects turn out to be a crucial aspect in PD projects, in particular when a long-term participation is required and the investigation of sensitive issues (sickness, loneliness) in private settings is at hand. An understanding of the motivational dimension of participation is hence a requirement to manage expectations of participants (and hence to avoid "frustrations"). We have observed that the motivation for the elderly participants were, often social, to develop new relationships and becoming a "protagonist" within a successful story. However, at the end of one study this turned out to be a methodological limit: the development of intimate and trusted relationships between the elderly and the researchers made it difficult to collect data and to conclude the study.

MANAGING HETEROGENOUS EXPECTATIONS

Expectations, especially the unfulfilled ones, can have a crucial impact on the outcome of the project. This is particularly true for specific fragile groups, as some elderly people, that tend to only focus on, and stick to, aspects of the projects that are relevant for them. For this reason researchers have to be very careful when providing information about the project especially at an early project

phase. In fact, the initial phase of the design process is usually explorative and analyzes the problem from different perspectives, touching various topics. If the explorative aim of this phase is not clearly explained there is the risk that older users stick to a relevant (for them but not for the research study) aspect and face the design process creating big expectations on that particular aspect. In one project for example [3], some participants were convinced that the prototype designed together with them could also be a device for care support and emergency assistance. This was a topic raised at the very preliminary stages of the project that apparently the users kept in mind throughout the whole design process. One of them even decided to drop out from the study when realizing that the prototype did not respect those expected features. Expectations developing within the network of actors around the elderly should also be carefully considered: in one of our example projects [14], the public service (a University) expected that the final prototype could improve the quality of their service while the project was focused on improving the independence of the elderly living at home.

The relatives emotional bound also impacts on the types of expectations that family members develop during the participatory process making prominent ethical and privacy issues [14]. Eventual anxieties and concerns of family members acting as mediators between the research team and the elderly should also be handled. In contrast to the researchers, who have a long-term perspective of the project's goals, family members are interested in results that can be applied as soon as possible to improve the lives of their loved one and have immediate benefits. In the Calce project for example [4] the perception of the usefulness of the monitoring technology was higher for family members than for the users themselves. In this regards, leveraging on family was a good strategy to convince the users that the system was useful. We argue that the network's expectations are in some cases much more important than the single, intended end-users ones; firstly, because they can spread among different actors without the researcher's control and, secondly, because they can have a profound impact on the involvement of the intended primarily end-users, namely the elderly people.

STRATEGIES TO MANAGE ROLES AND CONDITIONS

We live through different roles and mindsets in different settings. What is accepted in one setting might not be accepted in another. Indeed, the role of a patient tends to change as the patient moves between the hospital and the home. At the hospital, the patient is indeed there as an ill person, 'a patient', while at home, 'the patient' will also live other roles such as e.g. husband/wife, sportsman, and neighbour [1]. Studies have shown that people often prefer to hide, or keep invisible their health problems within the home [2]. This diversity between a hospital and a home setting can challenge not only the PD process but also a successful implementation of home-based healthcare applications [15]. Performing PD 'in the wild', in the private homes of patients, we as researchers can run the risk

to cross many invisible borders. For some people our home-based PD activities can be both tiresome and invasive. For example, we put focus on our subjects' sickness while being in their homes, a place not primarily perceived as a place for sickness and care. Furthermore, our visits might be preceded by cleaning, one dress up and feel the pressure to offer something to eat or drink as one would do when inviting other people at home for the first time. Indeed, tasks that can be both physically and mentally tiresome for an ill person undergoing treatment or rehabilitation at home. If the patient is not living alone, one must also consider how both our PD activities and the following development of assistive technologies influence the family members and their everyday lives.

DISCUSSION

Co-development of assistive technologies with elderly people can be challenging. This paper highlights five topics identified to be of importance when engaging in co-development processes with elderly people. They become especially important if the user is resource-weak due to illness. Hence, elderly people do not always have the resources to fully engage in PD activities such as technology explorations, Wizard of Oz and creative workshops; not due to hierarchical or power-structures but rather due to their capabilities. Still, the authors have identified a specific need to include this user-group as much as possible into the design process to align the outcomes with the end-users needs. An ongoing dialogue within the network of actors surrounding the elderly person can support the alignment of expectations and avoid unrealistic perspectives. An issue is how we can keep an open design process while still communicating an early vision that can provide the end-users with a fair picture of the project outcome. What will the users actually get out of the project and what are the expected results? It is rare that a research based PD project results in a working product that remain with the users in a working form after the project ends. Sharing a common vision and negotiating the work process become main goals whose fulfillment is challenged by the above mentioned potential problems. A deeper reflection is also required on the effect of visiting elderly people at home and establishing a trusted and intimate relationship with them can have: how does PD process influence our elderly co-developers? How can appropriate and ethical ways of closing the process be identified? We acknowledged in some projects the challenge to engage in a PD process with resource-weak people. Regarding this matter, we must understand not only how we can get as much as possible out of our PD process but also how our PD processes challenge and influence our users and the network of actors surrounding them.

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Designing for Stress Prevention from an Interactional Empowerment Stance: why and how?

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ABSTRACT

While stress is in part a socially induced problem, relating to work regulations and norms in the society, very few attempts have been made to treat the problem as a social, community-oriented problem. We aim to design ‘mirroring artifacts’ that can expose everyday behaviors linked to physiological stress reactions to whole communities. The aim is to empower users to identify, reflect on and attach value (negative or positive) to patterns in their behavior and thereby by empowered to alter what they see fit. But taking a social stance in a stress prevention tools, requires dealing with important issues of power, privacy, autonomy and identity. How can we do so in an ethically and value-based sound way?

Keywords

Stress prevention, participatory design, interactional empowerment, privacy, values

PARTICIPATORY DESIGN WHILE “IN USE”

As we move outside the work place into consumer markets, we are moving into a new problematic arena where power distribution between those who produce systems and those who get to consume them is quite different. In the work place, a participatory design process could rely on the workers and unions as possessing some power and being interested in influencing the values and needs of people in a longer perspective than a moment-for-moment consumism. In the consumer market, the only power at hand lies in whether we buy or not buy the products that are put out there for us. Some claim that our current culture is making us infantilized [2] – we consume without reflection, and do not engage in deep relationships with one-another or with the deeper more hard-gained values in life. Thus, people are lulled into being good consumers and buyers, believing that buying and owning is the key to happiness. Be that as it may, we are certainly competing for the buyers’ attention when we put out products on the consumer market. Products that require more from us as consumers, for example, encouraging us to reflect [14] and take an active stance, will have to make use of the same beautiful surface and seductive packaging in order to compete on this market. (Alternatively, we may reduce ourselves to producing systems for museums or art installations.)

In our view, the problem we need to solve is a design problem, and the powers now lie with the designers and those who employ them. The consumers do not have any powers over the products they are given – the powers are in the hands of the designers and what they decide to provide us with. We need to show that users will indeed like and buy systems where their own interpretation and appropriation of technology is a market advantage.

DESIGNING FOR APPROPRIATION

As we discussed in [6], participatory design makes (some) users part of the design process leading up to the launch of a system. Once the system is launched, the system design is typically seen as settled once and for all. One problem to this kind of system development perspective is that systems have to be maintained and might be changed in later development cycles. In those cycles, it is unclear when the changes to the interaction are so substantial that users should be brought in again. In a sense, the underlying design model is that of a waterfall design process, while in reality, many applications nowadays are launched and then altered while in use. A good example is Facebook that keeps changing with the small applications that are added to it by both its users and collaborations with various games companies.

In a sense, there is no guarantee that just because the design process was democratic and involved users, the end result will also be such a tool. The same problem arises with the Value-Sensitive Design (VSD) method [3]. In VSD various stakeholders, both direct and indirect, are brought into the early decision face putting their needs and priorities on the table. These ‘values’ are then balanced against one-another aiming to make the final solution, be it a software system or a city planning process, a well-balanced solution catering for everybody’s needs. This process is obviously invaluable and an important democratic tool, but it does not necessarily lead to a final solution that is un-biased and conveys the values intended.

In our work, we have therefore tried to work more directly with design that could allow for appropriation while the system is in use [1,6,7]. We have named our design approach *interactional empowerment*, as users become empowerment in and through the interaction as such. The

meaning of the system does not exist until users pick it up and start filling it with content – while interacting.

Here, we want to discuss a novel way of dealing with stress prevention building for social appropriation and support for one another to prevent stress. Our approach arises from the idea of letting stressed people learn more about their bodies and thereby be empowered to alter negative behavior patterns. But instead of making this an individual problem, as we have done through our previous design of e.g. the system Affective Health [13], we are interested in turning this into a social learning process.

THE STRESS PREVENTION DOMAIN

- Stress is a growing problem in the modern world and a major cause of disease and sickness absence. WHO goes as far as to consider it one of the major occupational health concerns [9]. The result of stress is apparent in cardiac diseases, depression, insomnia, diabetes and so-called burnout (or: exhaustion) syndrome [10]. In Sweden, sickness absence during the 1990s doubled, with the bulk being associated with stress-related diagnoses. There is considerable research available on ways of counteracting stress – apart from sedatives –, for example, on psychological treatment, stress management courses, preventive intervention in organizations. These approaches are costly and often applied after stress has produced adverse effects. Most individuals do not realize they are under stress until it is too late for an easy adjustment of lifestyle.

- Within stress research, we find very few investigations on which measurable indicators can be used to see potential stress-related problems before they have turned into illnesses. Most of the stress-prevention systems measure short-term stress as registered by HR(V), breathing patterns, GSR, or pulse. These only offer moment-by-moment stress treatment (e.g., breathing slowly [16] or taking a break). But there is no evidence that short-term stress necessarily leads to stress-related illnesses. Obviously, they are related, but some live with high levels of stress their whole life without getting ill. What is more interesting is to find indicators that can, very early on, indicate that the stress is affecting us in a bad way. Sleep patterns are of key importance in this respect as disturbed sleep quickly leads into a negative spiral where the body does not recover from the exposure to stress. Treating short-term stress through various bio-feedback loops, like e.g. paced breathing, is not necessarily getting at the roots of the problem. Often, a major shift in how we work and live our lives is needed – not short-term fixes of acute stress reactions.

- Investigating technology for stress prevention that employs a social, community-oriented approach is a unique stance, not done before. While stress obviously is in part a socially induced problem, relating to work regulations and norms in the society [18], very few attempts have been made to treat the problem as a social, community-oriented problem. In general, social support from family, friends,

and colleagues is a very strong buffer against the effect of stress [17]. Support or interest groups are widespread in a large number of areas in today's society and they are widely used in dealing with obesity, mental health, suicide prevention, cardiovascular rehabilitation, etc. [15]. Current applications of technology in stress prevention are limited to diagnostic tools for health professionals and very specific programs in the workplace. All technologies work on an individual basis; with an expert (-system) advising its non-expert user on how to control their moment-by-moment stress levels.

INTERACTIONAL EMPOWERMENT APPLIED TO PERSONAL STRESS MANAGEMENT

Stress is a form of emotional response, tightly coupled to subjective feelings of being able to cope (or not) with the demands that everyday life puts on us. A person who believes they have the resources necessary to deal with stressful demands will be better at doing so than someone who believes their resources are empty.

We applied our design approach, interactional empowerment, when we built a personal stress management system named Affective Health. An interactional view sees emotions as constructed in interaction, where the system supports people in understanding and experiencing their own emotions. An interactional perspective on design will not aim to detect a singular account of the 'right' or 'true' emotion of the user and tell them about it, but rather make emotional experiences available for reflection. That is, to create a representation that incorporates people's everyday experiences that they can later reflect on. Users' own, richer interpretation guarantees that it will be a more 'true' account of what they are experiencing.

In this sense, an interactional approach to stress management could work really well. In short, the Affective Health system works as follows. The system uses skin conductance, heart rate and accelerometer sensors that transmit data to the users' mobile phones in real-time. The user interface, on the mobile, shows the current bodily state relative to a history of previous states. Users can enter a biofeedback loop by interacting with the system, e.g. taking a deep breath and seeing the effect in real-time, but mainly our aim is to provide a tool for reflection through the history provided by the system. By finding patterns in their own behavior, users can start figuring out both what stresses them and how to cope.

The interface of Affective Health, shown in Figure 1, explores a circular perspective of time allowing users to view their activities separated from standard units. One example of cyclic time is the ecclesiastical (church) year that is not a year of moving forward, it is rather an eternal repetition of certain qualities of time: expectation, sorrow, and sacred hope. In this interface the big centre sphere shows data in real-time. This data is then translated into the history that grows outwards in a spiral. With this interface, it is easy to compare different states over time since they

are shown in parallel cycles: data from the previous seconds, minutes, hours, or days are placed in the spiral (with a maximum of three cycles in the spiral). By doing so, users can start comparing and finding patterns in different parts of their data. They can squeeze the data to condense it (compress data), or stretch it to see more detailed information.



Figure 1 Affective Health interface showing how can users scroll through history and discover trends

Our last study of Affective Health, not yet published, involved ten social workers that wore the system for two days each. The study is not yet published, but in short, we found that users did not only find negative patterns in their own daily, quite stressful work life. Two of them commented on how they had also found moments of relaxation – much to their own surprise. They wanted to emphasize those moments more, reminding themselves that there were these possibilities to recover in the midst of their busy work life.

INTERACTIVE EMPOWERMENT APPLIED TO COMMUNITY-BASED STRESS MANAGEMENT

But still, the Affective Health system is a *personal* stress prevention system. It does not really portray the social aspects of why we get stressed, nor how we could help one-another to find less stressful behaviors at work and at home.

What if we could collect similar bio-data, but from whole communities, extracting patterns in how groups of users behave? By community, we mean both workplace groups, but also less easily accessible groups such as friends or families.



Figure 2 Affective Health in use - sometimes sharing personal data with others.

In workplaces, there are some attempts to find stress-inflicted subgroups through self-report methods. Research has shown that bad leaders in organizations can inflict damage on their employees [11]. Therefore, it is important to identify such groups. But also, in general, to identify groups that may be under pressure because of deadlines or bad work processes.

Similar to how we have shown that rather than trying to diagnose stress, it is better to mirror short- and long-term stress reactions back to users, inviting their interpretations and reflections [12], we would like to do the same for this community, group-oriented system. The system, in a sense, becomes a mirror of the communities everyday behaviors linked to their physiological stress reactions. It empowers users to identify, reflect on and attach value (negative or positive) to patterns in their behavior and thereby by empowered to alter what they see fit. A *social interactional empowerment* design stance – as it gives users power to change their lifestyle over time through the interaction with the tools. The design will be shaped to invite and even provoke reflection, similar to individual stress-prevention tool Affective Health.

Obviously, such an idea poses a range of challenges. Let us outline some of the issues that we would like to discuss at the workshop. Some of them relate to the problem of how to involve stakeholders in the design process.

What is a relevant pattern?

Let us say that we manage to collect biosensordata (sleep behavior as well as daytime, short-term stress reactions in GSR, HR and similar), combined with subjective measurements of stress levels, from whole groups of users, perhaps at a workplace or from a group of friend. And let us furthermore assume that we can find patterns in that data that signifies that something is happening in terms of subjective stress experience. How can we ‘name’ such patterns and expose them back to the users in a form that makes sense to them? Similar to how we cannot know whether a stressful behavior by an individual is good or bad for them (some stress is good for us – too much stress paired with a subjective feeling of not being able to cope is detrimental), it will be equally hard to know whether these patterns are negative or positive for the group or for the individual. Occasionally, in a workplace or in a group of friends, engaging, stressing deadlines or joint activities, are good for us. It engages us, makes us produce together and have fun. But to some, and in some situations, it is detrimental.

How do we balance different values, power, and what do we want to share?

Given that we give up aspects of our privacy and share very personal bio-data and subjective measurements of our stress levels, how can we then mirror those patterns back to users without revealing their individual identity? Or can we involve users in helping one-another if we find good design solutions that allows them to choose whom to share with?

As pointed out in the MSR-foresight work “HCI 2020: Being Human” [5], any design that infers with our everyday life needs consider tradeoffs between different values. Stress relief needs to be balanced against privacy sacrifices. If we do so, we could imagine design concepts such as:

Healthy company processes

Many companies aim to provide a healthy, sustainable work environment and they already make use of subjective stress measurements to identify problem areas, but through more systematic, mobile, bio-sensor-based solution, a better mapping could be achieved. “Heat map” illustrations showing how different groups in a company over time develop good or bad patterns can be used to show both managers and employees what is going on. But do we want to share our personal data with our employers?

Ambient stress indicators

To increase awareness of stress patterns, it might be interesting to ambiently show stress levels of groups of people in aesthetically evocative forms. For example, a frame around the exit door of a public (office) building that illustrates (e.g., by color coding) today’s jointly experienced stress level of all that have passed the door. We may become aware of differences between Mondays and Fridays or effects of upcoming deadlines. But, again, this would also be seen by our employer who has substantial power over our everyday life. Do we want to create a tool that would allow our employer to perhaps try and increase the pressure if we seem to be too relaxed?

Stress buddies

At work, we may be willing to share data with a few colleagues. Graphically expressive displays, perhaps in unusual forms, such as a re-configurable statue on your desk [ref], can alert the stressed person, but also her peers helping to take some of the burden off the persons’ shoulders. But who do we trust? Can we really share our data with someone who might be gossiping about our failures as perfect machines in the machinery of our company?

Inspirational lifestyle patterns

Through seeing bio-data of how others organize their daily life, how long they sleep, how often they exercise, or how frequently they take a break, we can perhaps inspire one another to a more healthy behavior (or if things go wrong, inspire bad behaviors as can be seen between e.g. anorectics sharing advice on the net on how to loose even more weight). Or perhaps find negative patterns that make it clear that we are not alone in experiencing too much pressure – in turn potentially empowering us to question the lifestyle we have adopted together. In a sense, this becomes an activist tool. We can start putting pressure on employers and politicians to form policies and work routines that are people-friendly. The problem is that we are very different. Some life style patterns may fit really well to certain groups of people, in a certain stage of their life, with certain needs, but not at all for others.

Participatory/Activist involvement

Coming back to the issue of participatory design and how to involve end-users in the design process of therapeutic applications there are some interesting issues arising from the design direction we are proposing here. As discussed in the introduction, participative design can happen when an application is in use, rather than only during the early design phases before the system exists. In that sense, we see in particular the last concept, *Inspirational Lifestyle Patterns*, as an idea that we should elaborate further. Similar to how Eric Paulos and colleagues try to involve activists in improving their city environment by placing sensors around the city [8], we could involve citizens in reflecting on and combating the norms that make people ill from stress. But our problem is different from theirs in that stress illnesses and bio-data from our own bodies are more sensitive data than collecting information about the amount of noise in the street outside my window.

How do we evaluate such systems?

As indicated above, stress is not only hard to diagnose and treat using only moment-by-moment information, but also notoriously hard to study as individuals have very different reactions and illness symptoms. It requires that we put our designs to the test ‘in the wild’, in real use with real users, in longitudinal studies. But how do we “measure” whether people have started to become more aware of the norms and regulations that are forcing them into a lifestyle that hurts them? And how can we involve users that might be close to illness in a study that might do them no good but instead harm them? What are our obligations as designers here?

DISCUSSION

What we outline above may seem quite naïve design ideas accompanied with serious design problems to do with privacy, values and empowerment. On the other hand, we would like to emphasize that stress is an increasing, almost plague-like, disease. Unless we find ways of dealing with stress, we will see way too many of our colleagues and friends – or even ourselves! – become ill with permanent damages. Our society needs to arrive at better life styles for everyone. And our ICT-tools bear some of the blame for the way we stress one-another. They also carry certain values with them already – values of efficiency and task performance. ICT tools are not innocent, blank, valueless, passive objects in our environment; they are actively shaping our behaviors. In that sense, we need to find both tools for everyday work and leisure that enforces ‘slow computing’ ideas [4], as well as specific tools that can help alert people to the risks they expose themselves to.

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Co-Designing with People suffering from Aphasia

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ABSTRACT

This paper briefly presents my interest in co-designing with people with communication disabilities. The point of departure is experiences and findings from my former work and research as a speech therapist working with people with aphasia concerning development of new rehabilitation methods with ICT and virtual environments performed at The Institute of Language, Speech and Brain Disorders, The County of North Denmark. On the basis of the findings, this paper presents my ongoing PhD project, *Cognitive Fitness in 3D immersive virtual worlds (IVW) - designing a virtual community-centered learning environment for people with aphasia*, and the needs, ideas and challenges in co-designing with a user group with communication disabilities.

Keywords

Aphasia, communication rehabilitation, virtual learning environment, co-designing

INTRODUCTION

Over the last 9 years The Institute of Language, Speech and Brain Disorder, Region Nordjylland have had practical experiences with rehabilitation of people with aphasia, facilitated in a web based

virtual communication- and learning environments. The overall idea has been to integrate functions such as email, assignments and communication forums in an easily accessible, flexible and individually tailored user interface, and to create a virtual community where people with aphasia learn through interaction and communication with a speech therapist and peers.

In 2004 Groubee¹ developed a special version of the LMS Basecube, Ansigt til Ansigt (ATA)², for aphasiac, and this environment has since been further designed in close collaboration with people suffering from aphasia and speech therapists.

Research findings - conducted by RECIT Aalborg University (AAU)³ - are that the virtual environment offers possibilities in addition to the formalized face- to-face teaching as it provides various options of communication methods e.g. being able to communicate and learn via various forms of perception, being able to use preferred learning- and communication strategies, meeting people of the same standing, opportunity for self-reflection and self-presentation via profiles and weblogs. The virtual learning environment offers people with aphasia new strategies to develop their communication and options for acting

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¹ www.Groubee.com

² in English Face-to-Face

³ RECIT – Aalborg University, Denmark (Rådgivning og Evaluerings Center for IT-omstilling/ Consulting and Evaluation Centre for IT conversion)

independent. The virtual linguistic possibilities can replace parts of the lost communication ability. The driving force in the rehabilitation process is the possibility to assert oneself communicatively and participate in communities. (Petersen et al 2004)

Social media

People with severe expressive and impressive communication disorders due to diseases like aphasia, Alzheimer, Parkinson etc., are increasingly being isolated from participating in the social activities and networks that take place through modern communicative services such as text messaging, internet portals, public administration digital services and social networking sites. The new social media though offer great opportunities for a group of participants who potentially are marginalized in the communication- and learning society, both in the rehabilitation of people with aphasia disorders and in the broader sense of personal and social mastering (Konnerup and Schmidt 2006).

The design of the virtual environment

The virtual learning environment, ATA⁴, has been designed in close collaboration between the web-design company Groubee, speech therapists and people with aphasia. Initially the user group was mainly involved through user surveys and usability tests (Pettersson 2004). Later, through ongoing discussions and exchanges of experiences in an online forum in ATA. In addition to the online debates one annual physical meeting with all stakeholders has been held.

Involving the user group in developing in solutions to their rehabilitation has provided a unique access to the aphasiacs expertise *in having aphasia*. The collaboration has often led to unexpected development and design. Over the years the involved group has mastered the ICT tools they have been offered more and more to express themselves and to make demands on their

needs for both tools and design of the learning environment.

Related to the design some of our experiences are:

- The interface, content, symbols and pictures **MUST** be on an *adult level*. You can simplify it but not make it childish.
- Aphasiac themselves put a greater emphasis on being able to *give themselves communicative force* in family and society than to achieve a correct language as they had before the language through verbal language training
- The content must fulfil their intellectual needs and interest from post onset (e.g. an easy way to follow the stock exchange listing has been one demand (Konnerup & Schmith)

Taking these experiences into account it is necessary to involve users both in the initial design phase, but also sustaining in the adaptation and further development of the virtual learning environment. We must do it out of deference for their expertise but also with the aim to design the best possible learning environment right from the outset - an environment, where users want to act, communicate and learn.

Thus convinced, I am committed to involving the users in my ongoing PhD project. The design phase set to proceed in the fall 2010/spring 2011. Knowing the challenges in communicating with this specific user group, it is interesting to discuss and frame co-designing with people with communication disabilities with a broader group of researchers.

As communication is fundamental for collaboration, I will in the following describe the characteristics of aphasia. To give the readers insights into my research field and design challenges, I will subsequently present my PhD project and my preliminary considerations and criteria on the design process.

⁴ www.ata.dk

APHASIA

Aphasia is an impairment of the language function as a result of a brain injury. The injury is due to a.o. Apoplexy⁵ or other injuries where the blood vessels of the brain are damaged⁶ Aphasia takes many forms depending on which centers of the brain have been injured and how deeply the patient has been affected. Aphasia leads to communication difficulties in a varying degree. A total loss of the ability to communicate is, however, rare. Aphasia influences a person's ability to produce and understand speech/language. In addition, the ability to read, write, spell and calculate is affected. The patient may experience problems of recognizing the correct use of judgment terms (e.g. yes/no), and of recognizing and applying words to certain objects. Aphasia may be accompanied by other disorders such as paralysis, impairment of memory, and lack of concentration. The person with aphasia often exists in a world of chaos and confusion using language and interplaying with the surrounding environment is shattered.

Aphasia may occur in persons of any sex, age or social status and the risk increases with age. Often long term, communication rehabilitation is required (Luria et al 1969)

In Denmark, Aphasia affects 2,500 to 3,000 people every year.⁷

Communication as an essential element of social cohesion.

Communication is a broad term but is often connected to speech, hearing, reading, writing and understanding. As we define ourselves as individuals through social interactions a loss or impairment of these functions often leads to a

⁵ Common designation for cerebral hemorrhage or embolism in the brain

⁶ Head trauma (Accidents – road, work or violence), Illness (tumors, infections)

⁷ Hjernesagen: Orientering om sproglige vanskeligheder efter en blodprop eller blødning i hjernen- Afasi (2004) (*Orientation on communication disorders after embolisms or haemorrhages in the brain*)

reduced quality of life. Aphasia makes it difficult to communicate with the surroundings, thus the opportunity to express his/her ideas and opinions are impaired.

Based on the fundamental considerations about the link between language and mental activity, it is believed that the aphasia also will affect the victims' self-understanding and have implications for the identity. Furthermore, the ability to maintain individual thoughts and opinions thereby thought processes are complicated. A person with language difficulties will experience a change in external methods to deal with and react to - it is seen as someone with a different identity (Vestberg 2002)

DESIGNING A LEARNING ENVIRONMENT FOR PEOPLE WITH APHASIA – NEW HYPOTHESES

Inspired by the results of former projects, particularly how training in web based communities both heightens motivation and develop communicative skills, my current PhD project focuses on web based community-centered learning in 3D IVW and discusses how community based learning, perceptions and emotional impacts in the 3D IVW affect actions, socialization and communication. Acting in IVW open up for bodily immersion and interacting through avatar mediation. Related to the target group, this dimension has a particular interest since many have physically or/and cognitive difficulties. The project is based on an assumption that the involvement of body and nonverbal activities will affect the brain and result in re-establishing process positively and promote cognitive and communicative functions. IVW provide the opportunity for use of multiple sensory stimuli, and for the promotion and development of the nervous lanes in the brain. Moreover, experiences and action on a conceptual level might stimulate nerve cells.

The project will explore the possibilities for strengthening the neural network, communication and recounting identity. Brain research has shown that nerve cells can proliferate throughout life, and that the damaged nerve cells can form

new ramifications and that new neurons are developing on the basis of stem cells and that the nerve cells can divide, if they are stimulated. If the nervous system is challenged and senses and emotions are affected positively, the neuroplasticity will enable people to learn throughout their lives - even after a brain injury. By challenges the brain develops; and context and feedback play a key role in the ability to learn. (Bjarkam, 2004, Goldberg, 2005).

Design process

The designing processes are not the main focus in my PhD project. My research and knowledge fields are learning, communication and developing new rehabilitation- and learning methods. However, doing that the design of the learning environment is nevertheless crucial. Trying to get an overview of *how* to involve the users in the design process and to explicate what kind of user involvement that will be useful in this coherence. My first step in my design phase has been to play a board game, developed by associate professor at Aalborg University, Anne Marie Kanstrup. It is called *User Innovation Management*⁸ and helps the researcher to plan and reflect on how to perform the user-driven innovation. A facilitator is required for the game and 1 or 2 discussion partners are recommended. The game has 6 steps 1) *Select*: who, where, how and why regarding the selection of the users. 2) *Plan*: specific planning how many meetings, where, who, how often and finally: what are the outcome of the meetings supposed to be? 3) *Insight*: What, whose insight do you need, how to get them and what is the outcome supposed to be. 4) *Visions*. What and who and how to explore 5) *Sketch*: What, how, who and again the supposed outcome. 6) *Present*: What, how, where and outcome.

In the initial research phase it can be difficult to answer all the questions, but the game can help you to get an idea of how to select the users, give

an overview of the time consuming, and finally you have to explicate and elaborate to your co-gamers what insight you need and what visions you have. Besides the facilitator both my supervisors participated in my game and gave the following outcome:

1. Select:

Core users are people with aphasia but in addition to that I want to involve their relatives, speech therapists trainers, social workers, designers, programmers and researcher. The core users is supposed to be strongly motivated to participate, as they really have something to gain – rebuilding their communicative ability. I have contact with the The Institute of Language, Speech and Brain Disorders, so the users are easy to recruit for the project.

2. Plan

I need to gather as much expertise as possible and we need at least one workshop where all stakeholders listening to one another in words, actions and pictures. Before that I am planning to get to know the users and their families by visiting them in their home. Doing that I will also get to learn about their injury and their specific disabilities.

3. Insights

We need to know something about the aphasiac and their relative' communication problems. Some of the often-used activities in user driven innovation requires undisturbed communication ability. Furthermore, some activity and cultural probes might seem childish and might offend a newly brain injured person by sending a signal: "your intellect is not like it used to be". We therefore need to rethink and adjusted the why we are getting the insights.

4. Vision

The vision is to design tools – more specific a learning environment in a 3D immersive world - that makes people with aphasia to communicate and regain their full independence in actions

5. Sketch

⁸ still under development, the website will be www.uim.aau.dk.

The objective is that the involved programmers and designers (in this case students for Mediologi at AAU) to sketch a 3D virtual environment.

6. Present

In the first place try the environment out in a pilot course for a group of people with aphasia.

Conclusions

Designing with and for people with aphasia is a challenge first and foremost due to the user group's communication problems. But it is also a challenge because we are dealing with a group of people who has been affected by a severe illness. They are very vulnerable to being regarded as unintelligent. Some might have understanding and cognitive problems that question whether they really understand what is wanted from them. Nevertheless I have experienced the importance of getting access to the expertise *in not being able to communicate* and what is needed to regain the communication ability and am convinced that we will be able to design better tools and environment if we co-design with the user group. The workshop in Iceland could be a fantastic opportunity to discuss the challenges, refine and innovate new and new ideas.

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Participatory Interaction in Therapeutical Strategies

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ABSTRACT

Involving users in innovation processes is important in order to produce sustainable, usable and useful applications and products. However, when working with physically and mentally challenged users, complexity rises to a challenging degree. The approach introduced in this paper, defines the user as a relationship between the staff and the resident of the institution for mentally and physically challenged. The relationship between staff and resident is important in the daily work of the therapists. We show through an example how their work informs our way of understanding an interactive application designed for the Village of Sølund, an residential home for mentally and physically disabled.

Author Keywords

Participatory design, interaction design, therapeutic strategies.

INTRODUCTION

The main scope of the HandiVision project is to develop new methods to involve people with disabilities in the development of better assistive technologies in a cross-disciplinary design process. The project is a 3 year project, supported by the Danish Enterprise and Construction Authority and Central Denmark Region. The project is divided into 4 subprojects, each with their specific focus. This paper is concerned with the work taking place in the first subproject of HandiVision, known as the Sølund project.

At Sølund we are working on the making of an interactive sensory environment which can be transformed seamlessly from being a solely sensing experience, into a special gaming environment for two player action between the disabled resident and the related staff person. The work is done in a multidisciplinary cooperation between staff, residents, architects and designers, innovation specialists,

and physiotherapists, a music therapist and two companies specialized in interactive technology.



Figur 1: A resident at the village of Sølund interacting with an interactive application developed by Personics - a participating company in the HandiVision projekt

In the following we introduce the process and methods we have used in our work, and describe how work done by the music therapist has informed our understanding of the interactive environment we are currently establishing.

THE RESIDENTS AT THE VILLAGE OF SØLUND

The methodological perspective in the HandiVision project addresses the development of methods for engaging users in participatory design processes. As mentioned above the unambiguous focus of the ‘resident-user’ understood as an independent participant with the full ability to express needs, ideas and judgments in innovation processes became somewhat meaningless as this notion failed to grasp the core of the methodological problem in the project.

The majority of the residents have severely physically and mentally challenges. The residents can thus not express their opinions on matters including general or imaginative thinking and reasoning. Many residents do not have the cognitive ability to keep attention focused on a given subject matter for a longer period of time. The main methodological question is therefore centered on the problem of how to engage the residents as ‘participating users’ in the innovation process as opposed to simply being represented by the professional staff and their relatives

Giving the high degree of resident reliance on and orientation towards the staff, it has become quite clear that the focus of attention should rather be on the meaningful *relationship* and interplay between the resident and staffmembers. An approach, that turned the scope of innovation away from an individual user perspective (roughly speaking) to the question of *how to enhance or*

innovate a relationship between resident-user and staff-user. Therapist and pedagogues were interested in inventing new tools for developing their professional practice. In this respect they became users as well with professional and personal needs and requirements of their own. This is something very different from only expressing needs on behalf of the residents.

At the same time this shift of focus allowed us to bridge the ongoing professional theories and discussions among the professionals at Sølund. Most prominent was the theory of ‘Gentle Teaching’ and the ‘Snoezelen practise’. Gentle Teaching is, in very short terms, a practice striving to encourage the residents to develop their own individual life-potentials rather than to practice the disciplines of ‘normal’ behavior. Snoezelen is a therapeutic practice using multi sensory environment to create experiences for the residents. Both theories spring from practice and experiences with resident users.

What characterizes the residents at Sølund is the high degree of individual differences in regard to their physical and mental handicaps. It is in fact impossible to speak of an average resident or even place them on a scale comparing them to children. Some groupings do exist such as the deaf blinds or the sentenced patients placed under 24/24 surveillance. Other residents do have a higher degree of mental, physical and social capabilities including verbalization, however they do not represent the majority of the residents. Many residents have no diagnosis because of the rarity of their conditions or it is complicated by the fact that physical and mental handicaps are often accompanied by a psychiatric diagnosis as well. This challenge made it almost impossible to discuss problems and design with reference to some well-defined group with clear characteristics or to infer from individual preferences and capabilities to other users without actually testing it. And it made it difficult to generalize design solutions to encompass larger groups. Nevertheless, we could use a theory developed by a local music therapist which turned out useful. Not by making a generic profile based on individual characteristics, but by using her theoretical framework to describe and understand the different levels of contact *between* the therapist and the resident. This work is described in the following.

5 LEVELS OF CONTACT

Through our participatory design approach [1], [2] an essential question has been: Which kind of users are we making concepts for? During year 1 and 2 of the project, we had done videoprototyping, ethnographic design work and experimental sessions exploring use of existing technology together with staff and residents. Well into the project as we got to know the staff and residents better, we would ask the staff questions such as; “would this be useful for Peter”, or “is it realistic to assume that Mary could do this” in order to

get an understanding of the complexity of a concept in relation to the abilities of the resident. However, this communication was based on our common references on an individual basis, and thus not useful in more generic terms to for example make an interactive environment suitable for all of the residents at Sølund.



Figur 2: A videoprototyping session, based on an ethnographic design study by an interaction design student.

In the work of the music therapist, the key issue is not a specific profile of the resident, based on generic terms. Rather, the work is based on the establishment of the contact between the therapist and the resident through communication by music and sounds. The degree of this communication she has described through a theory called “The Five Levels of Contact.”



Figur 3: The music therapist at Sølund (contact level 1)

Basically the contact level 1, can not be compared with a relationship between a person and a child in normal development. Reactions and actions seem random and the relationship is primarily based on the assumption that the person is aware of the presence of the therapist. Level 2,3 and 4, are levels that can be compared to the relationship between a person and children in their early development

stages. Level 5 is a way of unfolding oneself in the music. It is a kind of music therapy which can be used in many connections regarding both children (from approx. two and a half years old) and grown ups. The theory is meant to support the different professionals working with disabled people, in understanding how to establish contact and to stimulate and evolve the communication between therapist and the disabled person.

The Butterflygame and the “Five Levels of Contact.”

In the following we use the five levels of contact to show how it has been used as a framework to design an interactive application “The Butterfly Game”, that can be used not only by “Peter and Mary”, but by all the residents at the Village of Sølund.

How it works

The “Butterflygame” application is still work in progress, but is based on the creation of an interactive application that can be used by the residents together with a helper. The application can be used within the five levels of contact, and can furthermore shift seamlessly between a simple sensing experience into a two player “game” based on the movements of the resident and the helper in the room. The application is very simple and consists of a butterfly on



Figur 4: One of the residents at Sølund interacting with the “Butterflygame”

a projected screen. When a “player” moves forward in the room, the butterfly will “fly” away from the player. If the player moves back, the butterfly will move towards the player. If he moves left or right the butterfly will move correspondingly. The projected background can be changed by the staff, so the landscape the butterfly is flying in, is recognized by the resident, for example by showing a picture from the residents’ housing unit.

Interaction in relation to the “Five levels of contact”

We have used the 5 levels of contact as an inspiration in our work with the “Butterflygame.”

At contact level 1, the contact between the resident and the therapist is really weak. The reaction of the resident is barely visible or hearable when music is played for him or her. The basic relationship between resident and therapist is in this case a “feeling” of connection described as “when I sense being sensed by you, I assume that you experience being sensed by me” [3]. *At this level the Butterfly Game functions solely as a sensory experience consisting of visual and auditive stimulation.*

At contact level 2, there are clear reactions on the contact by the therapist. There are reactions which are significant for the specific person, and there is a beginning understanding of the persons self, and maybe especially of the surrounding environment. *The Butterfly Game can be experienced as a response to movements by the resident. When the resident stands still, nothing happens in the application, when s/he moves the “butterfly” reacts. As such, the application contributes to improve the residents consciousness of hers/his expressions related to bodily movement.*

At contact level 3, there are very significant and visible reactions on the approach by the therapist. A person at level 3 is very conscious about his/her own ability to make something happen and to get the attention of the surroundings, but does not understand the basic communication rule of my turn/your turn. *At this level, the Butterfly Game supports the resident in his/her ability to take initiatives and to interact with other people, and it stimulates the understanding of action/reaction.*

At contact level 4, the interplay is a conscious act by the resident. The therapist and the client can take turns making sounds and listening. The client is conscious of the basic rule in communication – taking turns. *In the Butterfly Game application, this level is addressed by the possibility of the therapist to introduce his or her own “butterfly” in the game and thus “fly” together with the resident. In this mode, the application supports the relation between the resident and the therapist in a direct way somewhat similar to musical dialogues.*

At contact level 5, the resident has a clear understanding of him/herself in interplay with the surroundings. Often there is a (limited) verbal communication. However it can be whatsoever short and abrupt. *At this level it is possible for the therapist and the resident to game together, for example by playing “follow the leader” or similar games.*

Contact level	Sensory experience	Single interaction	Two – player interaction
1	X		(X)
2	X	X	(X)
3	X	X	(X)
4	X	X	X
5	X	X	X

Table 1. Relationship between contact levels and interaction. The parenthesis around X “(X)” indicates that at contact level 1-3 the therapist/helper can use the two-player interaction mode as sensory input and stimulation, but not to “game” together with the resident.

CONCLUSION

To involve users in designing interactive environments is a complex task when the end-users are mentally and physically disabled. The process addresses both practical and ethical issues. If the end-user lacks the ability to express even simple needs and wishes in common language, there is a need for careful interpretation by the surroundings. The daily helpers and therapists are naturally the best to do this. However it is important to state, that the residents at Sølund have a language. Even at what the music therapist Anne Steen Møller defines as contact level 1, it seems meaningful to state that there are glimpses of communication.

In the Sølund project, we have tried to involve the users, as individuals participating in relations with their helpers/therapists. The helpers/ therapists are the interpreters/advocates for the resident in the process. We have tried to involve users directly by using “off the shelf” interaction devices such as e.g. the Nintendo Wii and the Personics System. Also, we have worked with functional prototypes as the e-tracker in order to get direct response from the users.

A major concern from the involved companies has been the wish for having 3-5 user profiles, from which we then could define and produce a final application with them in mind. However, in this process we have found it much more useful to utilize the resources and reflections available. Thus using the work done by the local music therapist, together with workshops, field studies and visits together

with staff at Sølund, provided a framework which has led to an application that can be used within the therapeutical structure already in use.

The collaboration with the helpers and therapists and the insight obtained in their daily work highlights personalization and flexibility as key issues in their contact with the residents at Sølund.

In other words there are basically 3 lessons to be learned:

- 1) Prototyping is essential for involving users in therapeutic contexts due to the low abstraction level of mentally challenged. The concrete and socially engaging approach is simply the only way to gain first hand knowledge of the residents.
- 2) The residents at Sølund are highly individual users, indicating that typical user profiles are difficult to put into use. Attunement to practical and theoretical assumption and ongoing discussion in the field has been crucial. But most importantly is the rich resource of the personal relationship between residents and caregivers
- 3) Flexibility and personalization reflects the relation between therapists and residents. It should be build into the design of interactive applications as to enhance personal appeal for the residents and give the therapist the professional means for bringing variations into their practice.

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Home Care Nurses and a Development of a Home Care Service Information System – Observations from the Field

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ABSTRACT

In this paper we discuss about the preliminary findings and observations made during the pilot testing of a home care service information system on a field. During the field observations the main findings have related to the various gaps between the stakeholder groups. These gaps are connected to the language, knowledge, and expectations about the work and the information systems. As a preliminary finding we will discuss about the expectations gap, how it is manifested and how it might affect the nurses' and clients and the views of the different stakeholders during and after the field testing about the piloted information system.

Keywords

User centered design, home care, field observations, stakeholder gaps.

INTRODUCTION

The traditional way of the home care nurses' work already includes the usage of information systems. These systems are used with workstation on the office premises before and/or after the work rounds. With these systems the home care nurses record how they spend their time during the daily route; these recordings are done per client and per task basis.

Also the changes on the state of the clients are recorded regularly, and once a year they have to fill the Resident Assessment Instrument (RAI) about the state of every client. These are important part of the home care nurses duties, as majority of their clients are elderly people living alone. Changes in the clients' state are utilized when home care nurses have to make decisions about the clients and also when they have meetings with the relatives of the clients. Minor tasks with provided information systems include reading emails, checking the changes in the medications for which their clients have recipes, and so on.

On the field the home care nurses are working on a tight schedule, and in many cases they are working on minute to minute schedule trying to complete their tasks so that they can move on to the next client. These tasks include cleaning, changing bandages, cooking, and distributing medication. Constraints on recourses and time can be seen in the fact that they barely have a time for these necessary

tasks, anything extra will cause overtime and problems with next patients, etc. But despite the lack of time they also try to discuss with their clients while doing their chores. This interaction with the home care nurse might be the only interaction with other people to some of the clients, so they see it as an important part of their work.

The new information system which is currently being piloted with the home care nurses attempts to change the work processes by moving some of the tasks from office computer to be performed with a palmtop computer the home care nurses carry on with them on the field. The "company A", which is developing the information system, can be described as an SME specialized in the health care and wellness technology. This company will be referred as a vendor on this paper.

The development project for this information system has taken several years so far, it started with a feasibility study, in which for example user needs were gathered. During development the vendor has also co-operated with home care nurses by doing SUS evaluations, experimentations with paper prototypes, and has carried out some usability tests and field tests. They have had three separate pilot tests with home care nurses on different regions around Finland. During these pilots the representatives of the vendor have been on the field with the home care nurses. These representatives include people from the marketing, support and development positions. From the observations made during these sessions, designers have made adjustments based on what they have seen and on the feedback that have been received from the home care nurses. This is also done during the current pilot test where new versions with improvements and changes already have been introduced to the piloted system.

Our part as researchers has been to observe the training sessions and daily work routines of the home care nurses with and without the mobile device by going to the field with them. We also have had the opportunity to conduct interviews with some of the nurses, during which we have collected their ideas and opinions about variety of subjects related to the pilot. Other interviewees were the developers, and the people on the charge of the operations of the home care unit.

On this paper we will first describe how the home care nurses carry out their work without the new device and software, and how it seems that they perceive their work. Then, we will discuss how the vendor understands these same topics. These views of the same work are then discussed further. We will also discuss about the effect the new system might have on the clients, and how the different stakeholder groups see these changes.

OVERVIEW OF THE RELATED WORK

From the viewpoint of process improvement, which is one of the goals of the new information system, there is a wide body of a literature available about different kind of health care related projects. One of the most comprehensive reviews of projects and research done about them in recent years is the work of Orwat et al. [5] in the area of health care including the home care. Some studies that are conducted after their review include Alasalmi et al. [1] for the recent study about the usage of wireless ICT solutions to improve the processes in hospital settings.

ISO 13407 standard [3], Human-centred design processes for interactive systems, offers guidance for designing usability. It identifies four general principles that characterize user-centered design in development cycle. [4] Two of those principles; an active involvement of users throughout the project (in some communities known as participatory design), and iteration of design solutions [2] have both been prominent in our pilot project. Vendor does not have an official usability engineer, and multi-disciplinary design does not seem to be reached in this case.

User participation is an important way of improving software quality and increasing user satisfaction and acceptance. At the same time, it can have a negative effect on project performance by making project longer and more complex [6].

METHODOLOGY

The present research is conducted as a qualitative field study done during the pilot of the new information system on a county center Sotkamo in the sparsely populated Kainuu region of Finland. Empirical data combines the data collected during the observations on the field with the interviews of the different stakeholder group members.

This study has four clearly defined stakeholder groups. First one is the vendor developing the mobile software system for the home care market. Second group is the home care nurses, who are the end-users for this software. Third group is the local county administrators, who have the responsibility of arranging the home care services, and in this case, to decide if the piloted system will be introduced to the operational use. Fourth group are the clients, as in the end the way how the work of the home care nurses is arranged, and done, affects their quality of life.

As researchers we have had access to all of these stakeholders, but we have chosen not to involve the clients as interviewing them could be difficult, because many of

them have also memory related problems. Some of the managers from the local county organization have been interviewed for the wider perspective of the framework wherein the home care work is done.

First observations about the representatives of the vendor and home care nurses were done during the training sessions that were arranged before the beginning of the piloting on the field. The first round of preliminary interviews was also conducted before the field pilot to find out the thoughts and expectations of the home care nurses.

Data has been collected during the time period of the April 2010 to the August 2010. We are still collecting more data as observations are going on, and the second round of the interviews with home care nurses will be done during the autumn of 2010 when the pilot software and device are more familiar to them.

PRELIMINARY FINDINGS

As a preliminary result we will discuss about the expectations gap that we have observed and how this gap is manifested. Related subject of how it might affect the clients and the views of the different stakeholders during and after the field testing is then debated.

Some of the observations might have been affected by the fact that during this pilot, home care nurses are doing double work with the record keeping. They still have to enter the data to the information system in the office too, as there is no interface from the mobile device to the information system used at the health care center. This limitation is related to the larger ICT change project going on at the health center as they are changing their backbone system during next year. This double work might hide some of the positive effects of the new system from the home care nurses.

Expectations gap

During the training session observations before the pilot, we have found out that despite the long collaboration between the vendor and the home care organization(s) they still have various gaps between them in different subjects. Some of these gaps are related to the language used by the different groups, and on the understanding on how the other group does their work, or how they can do it.

From the viewpoint of the user involvement in designing information system for the home care field, the interesting gap has emerged in a form of differing views of the work practices of the home care nurses and expectations related to the usage of the new information system.

From the perspective of the vendor the new system is something that will radically change the way how nurses allocate their time between nursing duties with clients and clerical tasks with computers on the office premises. Their expectation is that by doing some of the current bottleneck tasks on the field with mobile device instead of the office, the home care nurses can save time from 15 minutes to hour per day, waiting times to the computers included. Thereupon this time could be transferred from the clerical

tasks to the nursing duties, e.g. they could have more time for the clients in the field.

Viewpoint of the home care nurses to this problem is more practice oriented and widespread. Their general opinion seems to be that the piloted system will indeed move the work from office to the field, but the opinions about where this time will go is not so unanimous.

Previously the home care nurses have used pen and notebook to mark up times spend on doing tasks with clients, changes in state of the clients, or the metrics like blood pressure. These are then been recorded on the information systems in the office, if there is computer available from them. Depending on how often they can use the computer the transfer of data takes anything from 10 to 30 minutes. For many of them the tasks done on the office computers are cumbersome, but mostly because they don't have enough computers for everybody. In their current situation, all the on-duty home care nurses share only three computers, and one work shift might have eight nurses on it trying to record their data after the work rounds.

With the new mobile information system most of these office tasks are transferred to the field and the paper phase is removed. Effects of these moves are not seen just as a time saving effects by them like the vendor sees it. In vendors vision the device is always with the home care nurses while they do their tasks with the clients, and the nurses can do the data entry during and between the subtasks they perform for the client.

In practice many of the nurses do not take the mobile device with them to the client's apartment, as in some cases they do not want to confuse or disturb the clients with technological gadget that they would be twiddling with every now and then. In some cases the nurses start the markings in their car, and leave the device there so that they do not have to carry it around the client's apartment and they finish the markings based on the pen and paper notes when they return. There are also at least two other ways of doing the markings outside the clients' apartment, which both affect heavily on the statistical information related to the length of the visits.

Second observed reason for this behavior is that the device is seen as too big and bulky to be carried with them when they do their tasks, e.g. cleaning, cooking, and washing of the clients on the bathroom. There is also a third reason which is the continuation of the second reason. In this pilot phase the nurses still have separate mobile phones with them as the phone capabilities of the new device are not yet utilized. Some nurses suspect that if the device is left on e.g. to the counter, and they get an emergency call to go to some other client's apartment immediately, they might forget the device to the first client's apartment.

Minor issues

Beside the introduced gap and other mentioned gaps, that are not discussed here, we can also see some ethical issues in this case that could be interesting to study on the side.

The new software updates the information about nurse's location when nurse starts or ends the visit to the client to the information system at the health center. This feature is used to track the whereabouts of the nurses, so that if some other nurse needs help, or some client needs to be moved from one nurse to another, the manager can send the closest nurse to the new destination.

But, this same feature can also been seen as a surveillance tool of how and where the nurses spend their time in almost real-time. Of course they have to report their usage of time anyway, but this surveillance capability might raise some questions about the employer's right to follow the employees on the field. But then, this has not been an issue during the pilot nor have the nurses raised it up during the training sessions.

Previously home care nurses have reported the state of the client's health and general well-being by filling the evaluation forms in the information system used on the office, and some more immediate info has been transferred and circulated by the mouth to mouth method and by the famous small yellow paper slips which are stored in their common room at the local county health center.

In the pilot this same information is saved on the new information system before it is copied to the patient information system at the health center. There is also a new more formalized and mandatory feature where home care nurses have to evaluate the state of the client every time they are visiting them, replacing the previous method of mouth to mouth and paper slips.

This data has been collected before, but now the same data is stored and accessible more widely, and even outside the health center with the mobile devices. Question is, does it raise new issues with data confidentiality or does it solve the previous potential confidentiality problems?

BASIS FOR THE DISCUSSION

Currently the main question for the researchers in this case is to study how the new information system might affect the work processes of the home care nurses; e.g. does it make some aspects of their work more efficient or does it have some other unexpected results. For this we still need more data which we are already collecting and it is outside of the scope of this paper, so we will now present ideas generated by the data so far.

Based on the data we have collected, the most interesting thing is the expectation gap which relates to the perception gap reported in the recent literature [6]. Combining our findings with the prior results could be the future direction for us. With this we could help the decision makers on identifying these gaps, and finding solutions for the bridging or understanding the reasons why and how these gaps form, and especially how they affect the outcome of the projects.

This gap also affects the administrative staff's work, since they use the pilot as a testing platform for the potential new system. After the pilot they have to make a decision if this

system should be bought for active use in wider scale. This decision is based on their views of the success of the piloted system, and this view is constructed from the observations about the system and the potential future users. In this case, this decision affects the work of approximately 300 home care nurses.

The gap on expectations and views of the work between the optimism of vendor and reality of the home care nurses is one of the main points in our data. To find out the reasons why this kind of differences on expectations and views of the current situation during the pilot exists could be interesting to find out. Especially as this is not the first time these same stakeholders are doing piloting together, or in general.

Some of the problems and gaps might also stem from the fact that nurses have different kind of habits to use the system as described earlier. Also, during the pilot they have to record the data twice, or even three times if they also record it on the paper form as they did before the pilot. This causes differences on the usage patterns, what features they use from the new system, and how they perceive the benefits and problems of the new system. These differences are one thing that might benefit from a formalization of the work processes that has not yet been done so far in this pilot. But it might be that in this case and on this domain the formalization is not even a feasible goal because of the dynamic nature of it.

Another possibility for this research is to focus on the effects of the technology that is used by the home care nurses to the quality of life of the clients. Both focus groups of our research have their own way of trying to ensure that the client's quality of life would either stay the same level or get better by the home care service.

Vendor tries to minimize the time spend on the non-caring tasks, and main method for the home care nurses based on the observations and interviews seem to be interaction with the clients while they do their other tasks. This is seen as especially important part of their job with clients who do not have relatives or friends who visit them, or they have disability that prevents them from leaving their home when they so wish.

Potential subject for this research could be the new digital "worrymeter" on the new mobile system. This part of the new information system is aimed to replace the previous method of passing the information from the immediate state of the clients. Traditional counterpart for this has been the RAI forms, notes of the home care nurses about the clients, and what has been passed on at the common room.

With the new information system the home care nurses have to mark up the state of the client every time they are leaving their apartment on a scale from one to five, five

being the most severe case. Then all the evaluations done by the home care nurses are collected, formalized and visualized to show off the general trend in individual client's state. This information can be seen in real-time at the offices, and used immediately as a basis for further actions.

As far as we know, most of the studies about the effects of the technology in health care are aimed on the products that are used by the clients themselves at their homes, or at the hospitals by the doctors or the patients.

The empirical data that has been produced during this field study needs to be analyzed more thoroughly after we have finished the data collection. But even at this point we are positive that our research can help to generate better understanding about involving the users on the development work of the (mobile) information systems for the health care field.

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Sharing Sensitive Health Matters Online – Design Challenges for Participation and Polyvocality

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ABSTRACT

Online communities for patients and their families complement health care therapeutic regimes of care and treatment. We present how we have addressed challenges to establish a community applying a collaborative design process where participants providing quite heterogeneous perspectives took part. The process draws from participatory design and agile approach to development; extensively using design workshops and iterative prototyping. In the process several challenges and requirements surfaced. For this contribution we highlight two design challenges related to sharing sensitive health matters online; design for participation and design for polyvocality. The outcome was a new net-based service supporting challenges of “living well” with a rare, chronic disorder.

Keywords

Peer-support, sensitivity in design, empowerment social software, Web 2.0, collaborative knowledge construction, rare conditions

INTRODUCTION

Patients and their relatives increasingly use online forums to collect information, and to share knowledge and experiences related to their personal health. The inherent opportunities and current use of social media promote and cultivate patient communities.

There is a growing expectation to find and communicate with health providers online, e.g. direct and secure communication with the GP or other providers, and to be able to read the electronic patient record (EPR). At the same time complex privacy issues and specific professional challenges for the health providers to meet expectations for online participation [1].

As health care migrates from professional practices and organized care settings, e.g., hospitals, outpatient clinics,

care-centers or doctor's offices, to the home dwelling, new practices emerge and demand timely access to health-related knowledge and experiences of daily living [2].

Social media and web 2.0 applications offers opportunities to augment health care therapeutics by opening up for exchange of experiences between different groups, such as patients, relatives, and health providers, and accommodate for a richer dialog about complex health matters. For patient groups social media can be a new, refreshing arena to present and express health concerns [3]. Sometimes these health concerns can be of an intimidating character and inhibit open communication. This points to complex privacy issues that present specific challenges to accommodate users when the health matters are felt as sensitive.

We report from a design-oriented study where we explored conditions for use to understand how net-based services may empower patients, specifically focusing on:

- resources that are relevant and meaningful for the work of "living well", engaging in activities for self-care and coping.
- arenas that augment dialogue between various groups constituted of peers and formal and informal providers.
- required privacy, confidentiality, and security supported by authentication mechanisms and institutional support.

In this contribution we briefly present our case, design methods and research approach with some illustrative findings and conclude with two major design challenges illuminated in this study.

The Case

Our clinical case focus on challenges to “live well” with a relatively rare, congenital malformation: anorectal anomaly. The malformation represents different degrees of severity, and present a variety of challenges to daily living. "Living well" with this condition is largely experienced as a trial-error exercise for the individual and their family, on a physical, psychosocial, as well as emotional level [4]. Sharing experiences from trial-error exercises can contribute to independence and self-care. This can be valuable support and sources for empowerment.

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Centre for Rare Disorders at Oslo University Hospital is a national center set up to serve people with rare disorders. They consult and offer information and educational material, support community building, and help out to coordinate medical and social welfare units involved in treatment, care and service provision to people with rare conditions. They mediate general, medical information and patient reported experiences and solutions in their daily living. The Centre approached us to lead a project with the goal to establish a net-based service to distribute information and educational material, accumulate experiences, and support knowledge creation.

DESIGN METHODS AND RESEARCH APPROACH

We applied a participatory design approach to learn firsthand about the everyday living and challenges of daily living well with a rare condition. These insights pointed out challenges and underlined importance to create a new configuration using social software to bridge professional health providers and patients and their families.

We arranged two cycles of workshops; 4 workshops in the first cycle and 6 workshops in the second cycle. Altogether 50 persons contributed. In the workshops the participants contributed and discussed insights, experiences, strategies, and knowledge. The findings from the workshops provided suggestions for design.

Presenting mock-ups illustrating possible webs of interactions among and between peers, formal and informal providers, pointed us to special considerations in two essential aspects. The first aspect was to accommodate a lifecycle, quite heterogeneous perspectives [6]. The other aspect was to carefully design a social media site that account for and catered to the sensitive nature of a disorder [7].

Experiences and insights from discussion of different prototypes pointed towards a resource providing support beyond the traditional 'one to one' interaction in consultation, and 'one to many' interactions found in most net-based services. We exploited available social software functionalities to stimulate participants to take part in 'many to many' interactions to create, share and accumulate knowledge, experiences and practical strategies.

FINDINGS

We proposed a social software or web 2.0 solution. Requirements are reported in [5]. The net-based service is offered as a service accessed through the hospital's patient portal to account for user requirements related to the complex privacy issues. The solution contains collaborative elements and ample opportunity for involvement that support interactions, discourse-types and knowledge production processes in new and novel ways. The processes transcend time and space, and provide arenas where different voices and perspectives can co-evolve.

To elaborate this further we zoom in on two related, tensions that challenged the design of this service; design for participation and design for polyvocality.

Design for Participation

The collaborative elements and user-generated content offer affordances to shift from discussion forums to collective creation of resources where experiences, practical doing and a wide variety of knowledge and expertise are shared and accumulating.

Participants' agency shape new practices of accumulating experiences and reconstructing knowledge in social media spaces. The iterative process with design workshops organized around mock-ups and prototypes turned out quite helpful. The artifacts provided shared objects of reference to facilitate different discussions. These discussions span from a participatory approach aimed to empower the patients and their informal care givers to "live well" with the rare condition to an organizational development approach centered around questions about the formal providers' roles, communication, and changes in division of work. The ongoing pilot should help us to reach a more comprehensive understanding of these important questions related to design for participation.

Design for Polyvocality

A finding from the workshops is that content; knowledge, accumulated experiences as well as practical strategies are of equal value and contribute to meet different challenges to the work of "living well" with a rare condition. Further, the perspectives of patients, informal and formal care providers are important to co-create an evolving resource. Therefore, multiple voices will contribute the richness and growth. Opening for polyvocality contributes to a heterogeneous resource that augments dialogue and appreciates exchanges where groups constituted of peers and formal and informal providers may engage.

However, participants suggested that content was marked or tagged according to the contributor's role, i.e., health personnel, patient, that opportunities to edit text should be controlled, and that different types of contributions should be related to each other as topics rather than as co-written written. From the perspective of polyvocality, we regard these tensions as examples of multiple needs, difference in expressiveness, and variety of expertise and authority held by the various groups.

Designing for polyvocality can be a strategy to find how to balance perspectives and design for meaning potentials [8]. In our case the relationships are asymmetric and it is an unresolved challenge to find appropriate forms to accommodate to this asymmetry.

DISCUSSION

Patient portals can provide services for direct and secure communication with health personnel and secure access to EPRs and meet growing expectation from patients to find and communicate with health providers and health care online [1]. Our design-oriented study led to challenging processes in terms of balancing control and innovation. Hence, we regard the field as under-researched and this project needed to set up a large number of workshops to understand the complexity of the situation, and come up

with rich and engaging designs that mixed the various voices in meaningful and understandable ways.

Our experiences point to new forms of participation and opportunities to share sensitive health matters. In the emerging community patients and their family members become experts in their own health experience related to “living will” with this rare condition, and the health providers are experts in clinical signs and symptoms, and they know about available treatment strategies. Designing solutions for a community like this can in sum contribute to accumulation of distributed and ill-systematized experiences to expand on the existing body of knowledge. How the community evolves need further study.

Another aspect that comes to the fore in design projects offering opportunities to share sensitive health matters online is the many responsibilities as participants. A community like this allows for and depends on the trust relationships that participants engage in and depend on. Expressiveness relates to articulation of requirements but equally important the participants subjectivities, their assumptions and motives. How the subjectivities are resources for participation and polyvocality needs further scrutiny as important feature of resources opening for sharing health matters online over time.

CONCLUSIONS

Our design-oriented project point to arenas for knowledge creation in the interplay of subject matter and content, design, and use of functionalities in modern social media, integrating wikis, blogs and semantic linking. Participatory, web-based environments can encourage accumulation of experiences, practicalities, and personal expertise to empower users in their efforts to “live well” and find peer-support.

To include social media based services in therapeutic approaches, there are important issues to further elaborate. Patients request a space where they feel secure to discuss and present their health matters and areas of concern. Equally important there have to be a critical mass of content, submissions and other patients, and the health providers’ are challenged to rethink and understand their roles when participating in such a medium.

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Design of a Wearable System for Personalized Monitoring and Therapeutic Interventions in Bipolar Disorder

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ABSTRACT

The increasing prevalence of bipolar disorder (BD) makes it a focal point of healthcare services research. It is a condition characterised by occurrences of manic and/or depressive behaviour throughout the patient's lifetime that it is estimated will in the future affect around 2% of the EU population. Currently, management of the wellbeing of BD patients is based primarily on questionnaires and interviews. This paper considers the design of a wearable personalised ambient monitoring (PAM) system that uses ubiquitous mobile computing and communication technologies to facilitate continuous, real-time monitoring of the state of a patient and provision of personalised therapeutic interventions. First a patient scenario is introduced that illustrates how the condition may manifest itself in daily life. Based upon this scenario, we enumerate design implications for monitoring (i.e. the 'sensing') component and non-clinical interventions (i.e. the 'actuating') component of the PAM. In addition concepts for the algorithms that would be at the core of the PAM system are also discussed.

Author Keywords health telemonitoring, wearable systems, bipolar disorder, therapeutic intervention, early diagnosis, mobile psychiatry.

ACM Classification Keywords H.5.2. User Interfaces – Input devices and strategies; B.4.2 Input/Output Devices – Channels and controllers.

General Terms Design, Human Factors, Measurement, Performance, Reliability, Security.

INTRODUCTION

Bipolar disorder (BD) affects almost 2% of the European population [1]. During their lifetime, sufferers of this condition will typically go through several episodes of manic and / or depressive behaviour, often resulting in lifestyle changes, that can last days or even weeks [2][3]. Commonly, there are two main types of BD classified depending upon the magnitude and length of the episodes; with Type I being the most severe [3].

The behavioural changes related to bipolar episodes can lead to potentially serious consequences resulting in the patient requiring long periods of carefully managed clinical care that obviously impacts significantly upon their quality of life. Such changes, however, can be mitigated by

appropriate therapeutic interventions. Significantly many BD patients are self-aware and hence these interventions may be initiated by the patient's themselves rather than solely by their psychiatrists. Consequently, a well-developed self-awareness can be an important factor in the management of this condition with the early recognition of emergent symptoms being particularly important [4].

Currently, this monitoring process is performed via questionnaires and mood diaries; often implemented using mobile computing devices [4]. The personalised ambient monitoring (PAM) concept is to utilise a personalised, unobtrusive set of sensor and actuator technologies to enhance the patient's self-awareness (as illustrated in Figure 1). Much of the PAM apparatus could be deployed on the patient's phone (or similar mobile device) and therefore carried around anytime-anywhere so acting as a ubiquitous prosthetic. In principle such a system would help patients to monitor their own behaviour and daily life activities; that are linked to mental state [2][5]. PAM would be able to alert the patient and their clinician to an upcoming episode as well as providing advice regarding therapeutic interventions; for example by prompting the patient towards appropriate actions that may mitigate the possible deleterious consequences of a bipolar episode.

Personalisation of the system is a key feature with the involvement of the patient and use of their feedback to customise the final configuration an essential component.

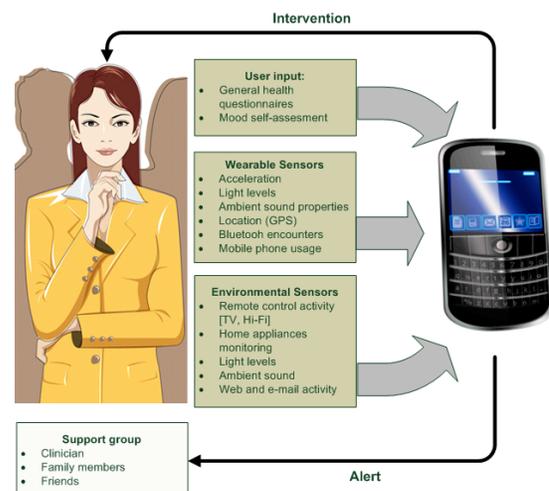


Figure 1: A concept of PAM for BD monitoring and therapeutic interventions

The PAM system could also provide a patient's support network (e.g. family and friends) with accurate and informative data about their state, this being importantly, at a mutually agreed level of detail since there will clearly be data privacy issues with such an arrangement [6][7].

This paper presents a possible user scenario that is used to inform design concepts for a PAM system that could facilitate the process of monitoring, and ideally predicting, the health trajectory of BD patients as well as providing therapy via basic interventions with the potential to improve patients' quality of life. The research presented in this paper has arisen from a *Personalised Ambient Monitoring* project conducted in collaboration with the University of Southampton and the University of Stirling (both in the UK) [6][7].

USER SCENARIO

Anne, aged 35, lives by herself in Birmingham, UK and suffers from Type I BD. Consequently at any point in the future she is likely to undergo several episodes of manic behaviour as well as periods of major depression. She works as an architect for a large international studio.

Recently, Anne was due to finish a major project necessitating long hours at work. A lack of sleep together with major changes in her usual routine were instrumental in the onset of a manic episode causing her to feel energized and full of ideas. She therefore still took little sleep, convinced that she did not need to rest. Rather, she visited different entertainment venues every evening to 'unwind' as her regular haunts seemed too quiet and calm. If she stayed at home she felt restless and nervous. Her friends have noticed that her behaviour changed radically in a short time and that she spoke both more loudly and faster and was easily excitable.

A resultant lack of focus meant she was unable to complete the project but her new found 'creativity' led her to decide to develop new several business ideas of her own. All were abandoned within a couple of days after significant personal financial investment that included a very large phone bill.

A few weeks later Anne has returned to a more stable routine. She was sleeping better, no longer experienced the regular flights of ideas and regretted the financial outlay on what were misguided business ideas. Her friends noticed that she was much less talkative and irritable appearing both more relaxed and calm.

Several months later Anne experienced a period of significant depression. Gradually she stopped going out, began to suffer from insomnia, lost her appetite and hence started to lose weight. Invitations to social events were declined and contact with most friends and relatives lost. Sporadically Anna did visit her close family and best friend telling them about her anxiety and sadness; that sometimes helped improve her mood. Her moves were slow and she was irritated when faced with lengthy tasks. Her supervisor

noticed that her efficiency had decreased and she felt personally responsible every time a problem arose.

Within a few weeks Anne recovered from the depression and proceeds to live her non-symptomatic healthy lifestyle. She attempts to monitor her mood and actions in order to detect the early warning signs of upcoming episodes as her psychiatrist whom she consults regularly has suggested. She has no wish to suffer episodes as severe as the previous ones; not least because she is afraid it will mean she loses the job that she enjoys so much

PAM MONITORING - DESIGN IMPLICATIONS

In this section the requirements for a personalised monitoring and therapeutic intervention system that would enable a patient and their support group to receive warnings, and take appropriate action, upon the detection of symptoms of upcoming (or already occurring) debilitating episodes are discussed.

Syndromes and sensors

It is proposed that common bipolar episode syndromes can be detected via monitoring of a patient's behaviour using appropriate sensors. These PAM sensors may be personal, either carried or worn by the patient, or deployed in a patient's home, or possibly their workspace, to monitor the environment they create for themselves.

A. Manic episodes

As imagined in the above scenario for Anne, a manic episode is connected typically with elevated mood, euphoric behaviour and a lack of concentration [2]. Related syndromes and possible sensing mechanisms include:

- *Changes in sleep patterns* via bed occupancy sensors and light detectors installed in the patient's home plus body worn accelerometers.
- *Flights of ideas, increased goal oriented activity and euphoria* may be indicated by communication activities, in terms of both the frequency and correspondents, via phone, social media and personal interaction. Monitoring the usage of keyboards and household remote controls may also be of value since data entry is likely to be faster.
- *Psychomotor agitation and rapid movements* will be noticeable from body worn accelerometers.
- *Increased (excessive) social activity* will be observable from geospatial and temporal patterns. During a manic episode a patient is more likely to visit new (probably lively) locations and meet previously unknown people. This could be monitored via location (e.g. GPS-based) tracking. The identification of crowded places is possible via both the audio landscape and scanning for the number of mobile devices present.
- *Talkativeness* via body worn microphones and suitable speech analysis.

B. Depressive episodes

As imagined in Anne's scenario, patients are more likely to be self-aware of a depressive than a manic episode [2][3]. Low mood, negative thoughts and a lack of interest in their normal activities characterise a depressive episode manifesting themselves in syndromes such as:

- *Insomnia* that can be monitored in the way described above.

- *Inability to concentrate and indecisiveness* with most activities work related and inefficient that may be monitored by slowed interactions with computing and communications devices.

- *Slow movements due to psychomotor retardation*; the inverse of the corresponding manic syndrome

- *Lack of interest in social and other activities* resulting in simpler geospatial location patterns and less social encounters [7].

- *Diminished appetite leading to loss of weight*: Regular weight measurements could be automated and basic usage of kitchen appliances monitored.

Triggers and Types of Therapeutic Interventions

Using sensing technology to monitor and evaluate daily patterns from BD patients may be of a greater value than simply detecting the early signs of an episode since evidence suggests that disruptions to daily rhythms not caused by a bipolar episode may trigger an onset [4]. Therefore the proposed system should ideally detect and classify any changes in a patient's lifestyle as either an indication of an occurring episode or a change due to other factors, such as a heavy workload in Anne's scenario, that may trigger an onset of a (most likely manic) episode in the near future.

Based on the type of trigger different therapeutic interventions would be appropriate such as offering suggestions as to how best accommodate external factors through to managing the assistance of a clinician.

ALGORITHMS

At the core of a successful PAM system deployment and operation would be a set of data processing algorithms able to accurately, and in a timely manner, translate a large volume of input data into a set of alerts concerning significant changes in a patient's lifestyle and behaviour considered to be linked to their mental state.

Of course any system aiming to monitor behaviour and lifestyle will involve data that is potentially sensitive. Therefore all inputs should be processed to extract, as early as possible after data capture in the processing pathway, only the information that has clinical value.

Rules and thresholds

The PAM system must reliably and accurately determine whether changes to patient's lifestyle are due to an occurring episode or simply benign factors, which may of

course trigger an episode. Figure 2 illustrates the different ways that changes in daily lifestyle patterns may be accounted for. Intersecting areas in the figure indicate key variables regarding the accurate recognition of the true cause of an occurring lifestyle change.

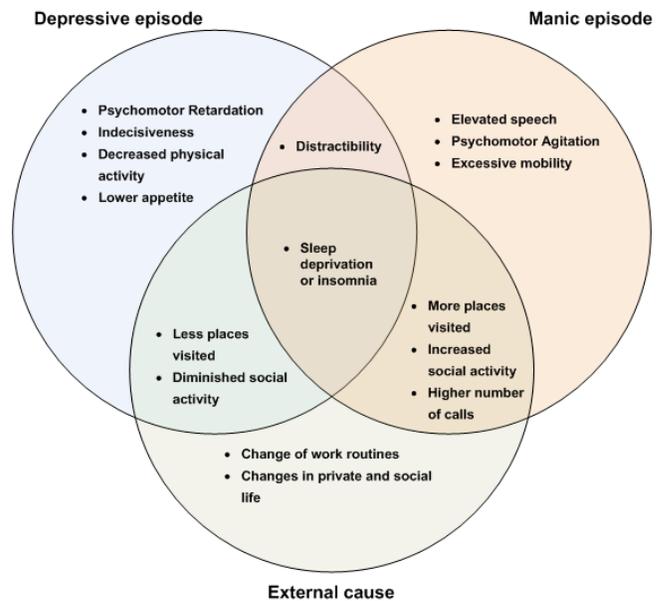


Figure 2. BD patients' behavioural changes and their causes

The figure suggests factors that may be used to quantify a patient's lifestyle although obviously exact thresholds for all of these variables will exhibit inter patient dependence. This is why personalisation is a key factor in the proposed PAM system with input from patients and their therapist and/or psychiatrist vital in PAM design.

PAM Personalisation

Hence generic PAM apparatus deployed on patients' mobile devices must be truly personalised. An appropriate strategy would be to collect data when patients are free from a manic or a depressive episode (euthymic) for around a month to permit representative modelling of their regular behaviour and lifestyle. Explicit user feedback would be important for patterns to be 'learnt' with the Experience Sampling Method [8] used to label usual places visited and encounters.

During the personalisation stage it is conceivable that, despite accepting the general concept of PAM, the patient may not feel comfortable with certain elements of the system (e.g. its usability or wearability). This raises the important research question as to what would constitute a minimal set of input devices and sensors from which the information necessary for a successful PAM implementation could be extracted. This of course is likely to vary from patient to patient. This issue would need to be addressed during the month long euthymic monitoring by discussions between the patient, their clinical team, carers and friends and the PAM developers.

PAM INTERVENTIONS – DESIGN IMPLICATIONS

In this section we discuss the requirements, and implications, for the design of a personalised feedback system that would enable simple non-clinical interventions and the issuing of alerts for the patient's support group and clinicians.

PAM therapeutic interventions could include:

- Immediately contacting of a practitioner or support group member in the case of a serious change in the patient's state considered to require immediate attention.

- Prompting the user to take prescribed medication. As with many chronic conditions adherence to therapy is an important component of BD management.

Possible interventions as a result of a manic episode are:

- Prompting the patient to try to get sufficient rest and, quality, sleep and avoid overstimulation. Such a prompt may be triggered if an abnormal amount of time is spent in noisy, 'bright' environments.

- The managed blocking of 'risky' websites and activities (e.g. in Anne's scenarios business related websites).

Upon the detection of depressive episodes appropriate interventions could include:

- Prompting the user to go out and socialise when a lack of mobility is detected.

- Prompt the patient to call a member of his support group

- Suggest physical activities and exercises (that were known to have been undertaken by the patient in the past).

- Suggestions to help maintain a healthy and regular eating regime.

And to avoid consequences of changes in daily routine:

- To provide time-management tools for work-related tasks.

The therapeutic intervention spectrum will of course need to be personalised for each patient especially since most BD sufferers usually have a good understanding of the trajectory of their condition. Each patient must be able to select appropriate interventions from a given set, that they will have been instrumental in creating. Once any intervention is applied, the patient should also be able to provide feedback to the system on their subjective view as to its effectiveness. This data would be invaluable in the dynamical remodeling of the whole system that will be used over multiple BD episodes or cycles.

CONCLUSIONS

In this paper a design concept of personalised monitoring to facilitate the management of BD patients has been postulated. How such a system, potentially using a mobile computing device as its core component, could benefit the

patient's well-being by performing basic monitoring and facilitating therapeutic interventions has been described. The key concept is to aid BD patients obtain quasi-objective measures of self-awareness that would aid greatly the efficient and effective management of this debilitating condition.

Obviously for such a system to be adopted issues of patients' privacy and comfort is crucial. This means sensors should be unobtrusive and comfortable with potentially sensitive data translated at early stage into clinically relevant, but relatively non-sensitive, data to be further processed in order to issue simple alerts and prompts for the patient and/or their support group (previously defined by the patient). Our current work includes an implementation and deployment of a PAM system that is being evaluated with BD patients

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Use of an exploratory pilot to facilitate the involvement of COPD patients early in the design process

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ABSTRACT

The forthcoming growth in the elderly population implies a need for new solutions to be developed. It is a complex task to find such solutions that are suitable for all stakeholders. This becomes even more complicated when some of the end-users are severely ill. There are both ethical and practical difficulties with involving these users in an innovation process. New design practices are thus required [1]. Several authors have pointed out that there is a need for an emphasis on user-centered approaches at the fuzzy front end of innovation to cope with new complexity. [2-4]. In this paper we describe an attempt to overcome these challenges, by designing an early pilot prototype. This prototype enabled the designers to study the needs of COPD patients without putting much pressure on them.

Keywords

Participatory design, patient involvement, pilot study, exploratory prototype

INTRODUCTION

The number of elderly citizens in industrialized countries is growing rapidly. By 2050 the population of 80-year-olds and older will grow by 154 percent, while the population as a whole will grow by 34 percent [5]. To meet the continuing rising demand for new solutions, we need to form new solutions based on new products, procedures, services and forms of organization. This is a complex challenge, with an extended time-frame, open-ended opportunities and a broader scope than traditional development [6].

Based on these new demands, there is a shift from simply designing products to designing solutions for people's more tacit and latent needs and experiences and for societal needs [6]. This is particularly difficult when the users are patients. Even in participatory design projects, the real user group (the patients) is often omitted because of ethical and practical constraints [1]. Participation may be exhausting for this group. Interviews with care personnel, and final

tests therefore often represent the only involvement of patients. Exploratory prototypes, for example, have been tried out on patients with aphasia [7] and in eHealth [8] to facilitate participation. In this paper we will use COPD as a case study to describe our use of an exploratory prototype that involves both patients and other stakeholders at the fuzzy leading edge of a complex innovation project.

Chronic obstructive pulmonary disease (COPD) is a collective term for conditions in which the chronic constriction or collapse of minor airways produces increased resistance in the airways. Sufferers from this condition have difficulty in breathing even at rest. Patients with COPD at an advanced stage may suffer from four to six acute exacerbations a year [9]. During these attacks, the patients become seriously ill and must be hospitalized immediately for advanced medical treatment. The repeated deteriorations with repeated long stays in hospital seriously affect their quality of life. This project was performed in collaboration between the Department of Pulmonary Diseases at St. Olavs Hospital in Norway, Trondheim Municipality in Norway, InnoMed and SINTEF.

METHODS

The project has had a participatory design approach [10], in that it attempted to involve all the different stakeholders at appropriate phases throughout the project.

Different stakeholders were brought in to answer initial questions. The following methods were tried out:

COPD patients	Semi-structured interviews with patients and next of kin Direct observations of Cultural probes, that allows COPD patient themselves to document their needs Drama workshop, where nurses played the patient role in a scenario with nurse-assisted monitoring at home
Home care nurse	Semi-structured interviews with home care nurse, Direct observations of nurse-assisted monitoring at home Drama workshop, role-playing the nurse-assisted monitoring at home
Secondary specialists	Semi-structured interviews, one by one and groups with nurses at the hospital

The process has been iterative, but has mainly followed three main steps, each involving an “understand” activity and a “create” activity. The three main steps were Opportunity Selection, Need exploration and Concept development.

Opportunity Identification

In the opportunity identification phase, a participatory steering group decided to carry out a pilot study from a general point of departure regarding COPD. The initial open-ended question was “How to improve the situation for COPD patients”. This wide scope was selected because the needs related to COPD patients were assumed to be both complex and interrelated. Their needs forming their everyday life, and should be approached as they are and not as unattached needs which would probably lead to incompatible solutions. Since the topic is extensive, there was a need to prioritize one or several main challenges for further development.

In order to answer the initial question, individual users were asked to tell about their lives (COPD patients) and their work with COPD patients (professionals). Their stories were told through semi-structured interviews and observations. In addition, literature reviews were performed. The information from the data collection was sorted in groups belonging to different phases in a defined patient flow, ranging from prevention of COPD to home situation. Based on this information, several possible project ideas were discussed, and three were selected as being most promising. In this case study we further describe the methods used in one of these selected projects, entitled “COPD Home”

Need exploration and pilot development

The principle objective of COPD Home was to increase COPD patients’ quality of life, by improving home-based treatment, and thereby hopefully reducing their frequent hospitalizations. The target for the idea exploration activity was to identify the most important needs related to monitoring the patients at home.

As in the Opportunity Identification phase, data were gathered through literature reviews, interviews and observations, but this time more in-depth and on a narrower topic. The interviews were semi-structured and included a wide selection of COPD patients, home-care nurses and hospital specialists (i.e. primary users). Interviews with next of kin and friends (secondary users) were also carried out.

The needs and questions based on the data collection were then identified in workshops with the secondary specialists. This exercise resulted in two main needs regarding the project’s overall objective, and several important questions regarding how these might be met. The COPD patients should be observed, but how frequently, with which parameters, by whom and with which technology. Since there was no existing solution in Norway for COPD patients living at home, these questions could not be answered

through interviews, observations or workshops. We therefore had to design a brand-new system instead of making improvements in an existing product or service. Both the stakeholders and the project group found it difficult to envision detailed needs relevant to future solutions. In addition, since the target COPD patients were severely ill, both workshop participation and thorough observations were difficult to accomplish.

The answers to the questions were identified as being crucial to the development of solution, while a premature educated guess might take the project in a wrong direction. At this early point in the project it was important to discover needs without making any definitive decisions regarding a future solution. The method selected was to develop a pilot scheme with a simple prototype for home-based treatment, involving just some of the main stakeholders and only the main needs identified.

The first step in the pilot development was thus to select stakeholder groups that would most easily be able to ensure that the two main needs were met. The home care nurses were assigned this responsibility. Based on this selection, the list of main needs *for the pilot* could be slightly detailed. Since the nurses would perform the monitoring, their needs related to this task were in focus at this time (before the needs of the COPD patients and the secondary specialists). These needs were explored in a workshop with representatives from the home care sector. By studying the home-care nurses monitoring the COPD patients, we hoped to learn more about the needs for monitoring.

The needs discovered in the workshop led to the selection of a pilot design which included the training of home care nurses, a paper form for registration and instructions about treatment for use at home. This was developed in a co-design process with the designers and the secondary specialists with COPD expertise. The physicians had the final word as regards which symptoms needed to be registered, and how the instructions should be set out. The nurses were responsible for carrying out the training, the form and instructions with high professional quality and making them understandable for their colleagues in the home-care services.

Concept Development

The objective in the Concept Development activity was to develop a viable follow-up and treatment system for COPD patients at home. This development was based on needs discovered by exploring the pilot scheme. The needs were identified among patients and at various levels in the health-care sector, through a new series of interviews and observations. The information gathered was transcribed, analysed using language processing, and sorted related to activity topics. On the basis of this overview, different scenarios were outlined in order to create a solution that would be suitable for all stakeholders. The scenarios varied as regards the self-reliability of COPD patients, the stakeholders involved and the technology needed. In order

to evaluate those scenarios, a COPD home working group was established with representatives of the various stakeholders. The working group organised individual workshops with each group of stakeholders, in order to investigate in detail their unaffected point of view regarding the proposed scenarios.

RESULTS

Opportunity Identification

The interviews, observations and literature review pointed out several project initiatives. The most promising were: preventive health measures, early COPD diagnosis, oxygen treatment at home and home-based treatments. The need for new solutions for home-based treatments turned into the project called COPD Home, which will be used as a further case-study in this paper.

Need exploration and pilot development

In-depth investigation of the topic “reduce the number of hospitalizations for patients with COPD” revealed two main needs: A) Early discovery of a relapse, and B) Effective treatment when a relapse is discovered.

The early research activities revealed more questions than answers and evident needs, and a pilot prototype was needed to explore these questions. COPD patients, home-care nurses and specialists were identified as primary stakeholders. The specialists were assigned responsibility for the expert COPD advisory service and treatment plan, while the home care nurses were responsible for monitoring the patients and activating treatment.

The selection of home care nurses as the responsible partner in meeting the main needs in the patients’ homes led to some additional pilot-related needs: knowledge of COPD, easy registration of symptoms and progress, easy access to a patient’s treatment description and easy access to expertise. On the basis of the main needs identified, the pilot project established the following solution:

Main needs	Detailed needs	Pilot solution
Symptoms of relapse should be discovered early	Knowledge of COPD	A COPD school held by the secondary specialists, developed to give home-care nursing staff training in diagnosing the progress of COPD
	Easy registration of symptoms and progress	A COPD-book with a paper form for registering the progress of the disease. The book is kept at home, and used by the nurses
Effective treatment system when a relapse is discovered	Easy access to patient’s treatment description	Guidance: detailed instructions in the COPD book about the disease, the patient and treatment
	Easy access to expertise	A COPD-centre: a reception apparatus set up at the hospital

In the pilot scheme, the local authority’s home care service visits the COPD patients regularly in order to follow up the progress of the disease, which is recorded in the COPD book. In the event of relapse, the central is contacted by

mobile telephone, and the center decides which extra measures need to be set in motion. After a treatment, the family doctor is informed.

Concept Development

The major needs from the use of the pilot prototype were:

- *Daily* registration, to intercept alterations in state of health
- Discreet presentation of medical values; the registration may make the patients anxious, because they are irreversibly getting worse
- Differentiated solutions for COPD patients. COPD patients differ in their physical and social condition, self-reliability, and access to support from next of kin. Some patients may carry out the registration themselves, some needs assistance
- A solution that encourages social contact
- A continuity in care personnel who are familiar with the actual patient, and have access to knowledge about the disease
- Monitoring guidance
- Access to medical information and treatment plan for all responsible stakeholders
- A limited range of external equipment for measurements

Based on those major needs, a scenario matrix was developed, showing several possible solutions:

- a) COPD patients measure themselves and use a PDA or a stationary unit to communicate with COPD expertise at the hospital, within the community, or at a regional or national alarm central
- b) Home-care service assists COPD patients in measurements and uses a PDA or a stationary unit to communicate with COPD expertise at the hospital, within the community, or at a regional or national alarm central
- c) A combination of A and B, where the home-care services observe patients several times a week

This scenario matrix has formed the basis for discussion and evaluation in workshops for the established COPD Home working group. Several iterations have been carried out, ending with a final solution to be proposed to the steering group in COPD Home:

A system that assists patient to be self-aware of their condition. Daily measures in the beginning, may be replaced with a “yes, I am OK today”, when the patient has learned more about their disease.
A CALL Centre as a consulting body for patients and care personnel.
A secured portal for monitoring and transmission of medical data, to which COPD patients at home, CALL Centre, next of kin, home care services, family doctor and hospital have access.
Use of video conferences between patients and CALL Centre. Real-life picture will reduce the need for additional measurements.

DISCUSSION

This paper provides an overview of the methodological findings, working with COPD as a case study to describe attempts to involve patients at the “fuzzy leading edge of innovation”. The project started with a wide scope, focused on reducing the number of hospitalizations, and used an exploratory prototype to identify the stakeholders’ needs. Our major findings were:

(1) It is useful to start out with a wide scope at the beginning of an innovation process, with input from a wide range of informants. Even though the focus is narrowed during the project period, the team members acquire wide knowledge of the disease and its challenges. The solution eventually developed is thus adapted to a wider setting, and they will be able to incorporate other relevant needs into a solution.

(2) Semi-structured interviews, even though they may be time-consuming, were satisfactory in all phases, and became a useful way of involving all kinds of users. Conducting interviews may still place a heavy burden on COPD patients, who also found it difficult to envision needs related to new solutions.

(3) By making an exploratory prototype early in the process, the users were given an idea of what the solution could be, and the subsequent interviews revealed new and surprising information. However, only the secondary specialists were involved in a co-design process. The patients and home-care nurses were included merely as informants before the pilot was developed, and as evaluators of the pilot in use. The home-care nurses might well be more heavily involved in a new project, while the COPD patients in the target group were severely ill. We thus saw a need for better means of involving patients and understanding their latent needs without “disturbing” them. The use of a pilot prototype was a useful approach; an improvement might be to invite healthier COPD patients to act on behalf of them in the development of the pilot.

(4) The prototype we developed was made as simple as possible, in order to learn about the needs without making any definitive decisions regarding a future solution at this early point in the project. This enabled us to explore emerging opportunities. The stakeholders involved in the prototype turned out not to be the main stakeholders in a new version, and while some measurements were assumed to be necessary, patients’ self-awareness became more important. If we had developed a more sophisticated prototype, the resulting improvements might have been at an excessively detailed level, possibly improving the wrong scenario.

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Patient-user involvement for designing a self-help tool for Type 2 diabetes

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ABSTRACT

The importance of user involvement from an early phase of the design and development cycle is becoming pervasive in the field of eHealth and health care, but effective patient-user involvement is still a great challenge. The authors have actively and iteratively involved patients in the development of a mobile terminal-based self-help tool for people with Type 2 diabetes. The patients were highly motivated to participate in the process, and many decisions on user interface design were made as a result of their input. On the other hand, there were certain difficulties in implementing all the inputs provided by the patients. Thus, a new question arose from the long-term field testing of the developed prototype: Which factors need to be taken into account for effective patient-user involvement? In this position paper, we discuss this question based on our experiences and related work.

Keywords

Patient user, user involvement, diabetes, mobile terminal

INTRODUCTION

Type 2 diabetes is one of the most prevalent chronic diseases in the world, and it is important that patients with Type 2 diabetes conduct self-management in a proper manner to prevent secondary diseases that cause immense personal suffering, as well as social and economic burdens. In recent years, a number of studies and development projects have been conducted with regard to self-management tools for people with diabetes. The number of tools is rapidly increasing along with the evolution of ICT, especially the emergence of Smartphones [16], but the effectiveness of interventions using such tools is not yet statistically clear in terms of the clinical outcomes [7,17]. Low or decreasing utilization of the tools during the interventions in studies is often reported, and this might indicate low usability of the tools provided [14,16], which could have been improved by user involvement in the design and development processes [1]. Reflecting these issues, the importance of human factors engineering approaches and user involvement from an early stage of the design and development process has been recently recognized in the field of eHealth [2,3]. Patient involvement in health care for service creation and policy making is also deemed important, but there has been no clear evidence of the effects of such patient involvement on the quality of care or patient satisfaction [6,13]. The vague and unclear definition of patient involvement is also pointed out as a background problem [5,8]. While user involvement is recognized as the most important issue in designing ICT products and services in order to enhance their usability, it is a great challenge to establish effective methods of patient-user involvement for designing tools for

eHealth services.

Below, we present our experience from design and development processes involving patients, and raise a question about effective patient-user involvement in the design process for a tool whose ultimate goal is to let users manage their diabetes by conducting proper self-management activities. Finally, we discuss this question and look at related studies.

CASE: INVOLVEMENT OF PATIENTS

In our research and development processes related to mobile terminal-based self-help tools for people with Type 2 diabetes, 12-15 patients have been involved from the idea phase, through design requirements, to long-term field testing providing feedback of the prototype, since early 2007 to date [18,20,21]. The form of involvement includes various methods inspired by HCI disciplines [19]. The developed system referred to as “the Few Touch application” consists of the software application “Diabetes Diary”, which runs on a Smartphone, a blood glucose system and a step counter with automatic wireless data transmission to the Diabetes Diary. Examples of user interface designs of the Smartphone software are shown in Figure 1. Using the Diabetes Diary, users can view a graph of their daily steps in relation to their personal goal, manually record and view food habits, set goals for food habits and steps, view lists and graphs of their blood glucose levels, read daily tips about diabetes self-management, and access the ordinary functions of the Smartphone. The main concept of the application is ease of use: to require as few touches as possible, so that it can replace paper-based diaries for recording self-management activities. The patients involved were highly motivated to participate in the process of gathering design requirements, and the user-interface designs were mostly decided by their input. Long-term testing of the Few Touch application in real life settings was initially conducted for six months by 12 of the pa-



Figure 1. Examples of user-interface design of the Diabetes Diary. Feedback for: Steps (left), food habits (center), and blood glucose measurements (right).

tients who were involved in the design process [19]. The users have continued to use the application, and it has been iteratively improved on the basis of their feedback. There were no drop-outs due to low or decreased interest in the process. The patients are still using the application, two years after the field study started. The results at the six month point of the study are summarized in [20], showing that the patients were mostly satisfied with the Few Touch application, and its usability also scored high (SUS score of 84 out of 100). However, the usage of the application is quite different among the patients. Currently the authors are analyzing qualitative data in detail together with the log data and answers to questionnaires obtained from this long-term testing, in order to obtain more insight into usage, perception, and impact of the application on their self-management of diabetes. The differences found in these three factors among the patients indicate the need to take certain factors into account in the design of mobile disease specific tools.

DISCUSSION

The research question “how patient-users should be involved in the design process for a self-help tool for people with Type 2 diabetes” is raised for the purpose of making the designed solution most effective. By “effective” we mean that the patient-users will be able to improve their management of their diabetes by using the tool, and eventually achieve ideal values of clinical outcome measures, such as HbA1c. In order to reach this ultimate goal, such tools should be designed for changing behaviors of the patient-users [9]. According to a systematic review [15], a high proportion of targeted- and tailored-intervention studies showed statistically significant or improved outcomes. It has also been shown to be important to tailor intervention based on the patient’s stage in terms of health behavioral theories, barriers and facilitators [10,12]. Recent study in persuasive technology shows that there is a notable difference in perception of persuasive strategies for health-promoting mobile applications among people with different personalities [11]. These related studies would suggest the factors to be incorporated in patient-user involvement, such as barriers, personalities, and psychological status in terms of health behavior theories.

The discussion of this paper at “Therapeutic Strategies- a Challenge for User Involvement in Design Workshop”, 17th October 2010 at NordiCHI 2010 raised many important themes. Heterogeneity was one of the five summarized themes. Regarding this study, the important implication for design process is to accept heterogeneity among patients and to build a design solution that accommodates the heterogeneity. One of the participants in the workshop explained the heterogeneity she experienced from interviewing patients with Type 2 diabetes, and the difficulty to get common design needs from them. Another participant indicated the importance that a tool is designed in a way patients are able to find their own “patterns” by using the tool, and the interpretation should be done by each patient because the patterns are different between individuals [4]. To conclude, effective patient-user involvement would be achieved by taking into account heterogeneity among patients in terms of the factors described above, and by seeking for a design solution that can be used by various types of patients in their own way.

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