FINDING CALM IN A PERFECT STORM

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ABSTRACT

This paper presents insights from an exploratory study into the experience of orthopaedic rehabilitation that sought to support patients in self-care. In a research-through-design study, rough prototypes were generated and patient needs elicited. The project was a collaboration between an academic designer, a design agency, and an orthopaedic surgeon, and included perspectives from hand therapists and patients themselves. The study showed that patients greatly appreciate data support of hand rehabilitation exercises, because it helps them adjust and pace their perspective and experience of getting better. From a reflection on the prototypes in relation to the patient experience we also concluded that the prototypes do not fully help patients with one thing yet: not doing anything and staying calm. This yielded a new research goal and thus a new sub-program of research.

INTRODUCTION

This paper reports on the results from an exploratory project between academic designers, a design agency, and a hospital represented by an orthopaedic surgeon. In addition, hand therapists and patients were consulted. The project addressed orthopaedic revalidation in patients' own living environment. The background of the project is the challenge to develop answers in the general context of the rise of non-communicable diseases and the ageing of European (and global) citizens. They mean that health systems cannot sustain their quality of service (Matheson et al, 2013). Currently many applications proposed to support health systems are based on an individualized behaviour change paradigm. However, shortcomings of this paradigm are starting to be recognized (Blue et al, 2016). For example, combined conditions such as orthopaedic problems as well as obesity or Diabetes Type 2 can be associated with depression, low self-efficacy and low action control which hamper the needed sustained lifestyle management (Kenter et al, 2014). It is a well-known problem in orthopaedics that patients do not carry out the daily exercises they need to do to get better. A life practices-based perspective called ‘possible self’, informed by social and health psychology as well as anthropology (Kenter et al, 2014; Trost et al, 2014; Blue et al, 2016; Markus and Nurius, 1986; Szaniawski, Boess, Kraan & Goossens, 2015), proposes to promote context-appropriate and life-course related positive experiences to empower patients.

Our research interest is: how can data-enabled devices help support patients in their own social and physical environment – which, according to the ‘possible self’ theory, is good for motivation, while on the other hand the absence of the care of the hand therapist leaves patients unsupported in a situation of low self-efficacy.

The research serves shared and also different goals for the partners in the collaboration: an orthopaedic surgeon's goal is to support the patients' hand rehabilitation and adherence better than through frequent patient visits to hand therapists. Surgeon and physiotherapist are interested in monitoring progress remotely, while the patient may benefit from data-enabled rehabilitation in a familiar home or local context. The design agency sought to enrich their portfolio of expertise in designing for motivation with a case study on data-supported rehabilitation. The design researcher to contribute to design research, by seeing the project as a research program (Binder and Redström, 2006): a set of explorations pursuing a research interest. The design researcher has long been more broadly interested in the quality of research-through-design and how to describe it (Boess, 2009). The design researcher wanted to explore how the prototyping would affect and contribute to the program of seeking to support patients' 'possible self' through data-enabled devices in their own environment. In earlier studies, we had found that video, generated by patients themselves or scripted, can help them understand their health state (Boess, 2018). These studies showed that these tools support patients in developing a concept of their current state and achievable future states. However, they were not yet combined with a specific rehabilitation intervention.

In this study, the prototypes served to elicit needs, including on data privacy and ethics, and to define the aspects to be researched further in order to connect eHealth interventions with local social and physical surroundings.

THE STUDY

The study took a research-through-design approach in which "Designers / researchers (were) directly involved in establishing connections and shaping their research object." (Jonas, 2007). Initial consultations with the orthopaedic surgeon, hand therapists and patients revealed as a key theme that wrist instability rehabilitation is a lengthy process.

INITIAL RESULTS

Three patients agreed to participate for an in-depth interview and an evaluation of three of the prototypes. Key insights from patients, mainly from the interviews about their rehabilitation experience, were that:

- It takes a long time to see some progress. "If you are in the middle, it seems to have no end."
- It is difficult to find a moment to do the exercises. "My days are not the same every day, so it is not that easy to take three minutes every day."
- Patients have issues with trust in the recovery. "It helped that the doctor told me that 95% of patients with this issue are cured with physiotherapy alone. I'm always reminding myself of this, because I am not patient."
- Progress takes a long time to achieve, and setbacks can wreck progress at any unexpected moment. "I once achieved freedom from pain, through exercise. Then one day I walked my dog, the dog pulled on the leash and my wrist was back to bad. It was devastating."
- Learning what they can and cannot do with their wrist is a fraught process. "I tried to be careful but became very depressed because I could not do anything. I locked myself up all day and watched Netflix."

Figure 1: The patient journey in orthopaedic wrist rehabilitation from a medical perspective

Patients do not easily see progress. There is a fragile shifting between states of no pain, then exerting and overexerting the wrists, recovery pain, and unexpected pain events that throw the patient back in their progress and reintroduce a level of pain in which the wrist can only be immobilized in a brace and no longer used. When this state occurs, the patient has to wait until pain recedes and they can consider rehabilitation exercises again, on the advice of the hand therapist. Figure 1 below shows the flow of this process in the medical context.

The design partners in the project then collaborated to create four low-fidelity prototypes in a research-through-design approach. In this they also collaborated with a small number of local patients (e.g., 3-5) in the patient's social and physical context.

Following these initial insights, we conceived as the design challenge to support the patients' motivation to do the exercises actively. Providing data feedback could potentially increase trust and help along the long stretch of time over which patients do the exercises.

PROTOTYPING

With the initial insights, the main design principles for initial concepts, to be prototyped, were:

- Give feedback
- Show progress
- Provide link with patient's personal life
- Facilitate planning the exercises.

Three ideas were quickly conceptualised and realised as prototypes. The idea of this fast step was mainly to learn from these prototypes, rather than to drive concept development.

Prototype 1: my pyramid

Prototype 1 (Figure 2) consisted of a pyramid to be placed on the table, with a stand on top on which a patient could attach a photo of a personal goal (e.g. playing tennis, carrying own shopping) that they could agree to work towards with their hand therapist. The concept shows the patient if they are holding their pulse in the right (straight) position for the exercise as well as directing the speed at which the exercises are carried out. The prototype is intended as a decorative object (pyramid) for the home, in which the glove one wears during exercise can be stored.

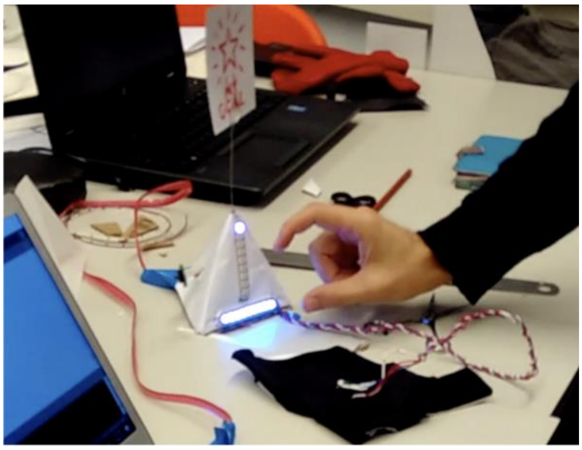

Figure 2: prototype 1, a pyramid on the table, attached to the computer, with light feedback and an attached glove to measure your wrist movement

Prototype 2: my dumbbells

Prototype 2 (Figure 3) consisted of: an armband around your wrist and an element to hold in your fist, since the exercises should be done with a relaxed but closed fist. A software application runs on a phone or computer screen. The visuals of the software teach the patient how to perform the exercises in a playful way by showing a wavy line to follow, as the patient lifts and lowers their lower arm (that is the exercise). Over time the patient can see how well and how often they did the exercises.

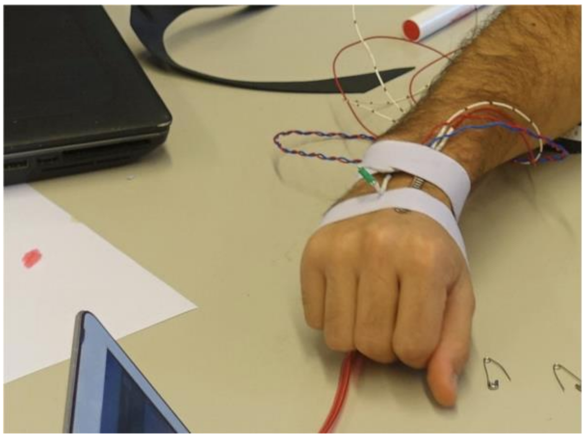

Figure 3: protoype 2, my 'dumbbells', an entirely wearable prototype with no fixed place in the home. An element on your wrist is connected to an element in your lightly closed fist. Software application not shown.

Prototype 3: my tracker

Prototype 3 (Figure 4) consisted of a glove, similarly to prototype 1, and additionally a screen that communicated to the patient the percentage of exercises completed as well as via a colour feedback whether the posture of the wrist was correct.

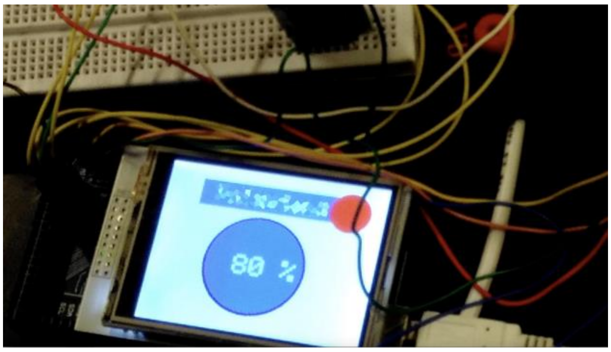

Figure 4: prototype 3, 'my tracker', a glove (not shown) with a display. Shown: percentage of daily exercise achieved, and (colour dot on top) indication of wrist posture. Here, the posture is not straight, which results in a red feedback.

EVALUATION

The three patients whose interview insights were presented above, also evaluated these prototypes. They met with a researcher who demonstrated the entire functioning of the prototype to them. This encounter included an informal interview with the patient in which they reflected on how the use of the prototypes would affect their daily life and how they reflected on their life and rehabilitation in general. To date, one of the patients also took the prototypes home with them and reflected on their experience of it for a few days. This included reflecting on where they would use the prototypes in their own environment, where they would keep them and how they felt about others in their personal environment encountering the prototypes. The other patients may yet do the same. However, we can already share insights from the data collected so far that shift our thinking in the main goal a rehabilitation support should achieve, and hence our research program.

EVALUATION RESULTS

Personal goal. A goal is very personal, and they would not want to share it with everyone. Regarding prototype 1: "A photo is going to be counterproductive. I do not want others to see it. It is o.k, if I get asked about it one time, but I do not want to talk about it thirty times. So I would never display a photo in my personal environment where someone else can see it." There is an additional problem with the photo: "If I keep seeing it, I will stop doing the exercises because I know it is not achievable."

Fixed object. The fixed object in one's environment was, however, something patients appreciated: "It helps me to remind me about the exercises. You might forget it during the day (at work), but you can also do it in the evening, before you go to sleep." One patient also commented that they appreciated that Prototype 2 was physically connected to the computer, although this was merely a prototype effect: “For people like me, who spend long periods of time on the computer, this is ideal.”

Immediate feedback. In all three prototypes, patients greatly appreciated the immediate feedback on the effectiveness of the exercises, in that they corrected a wrong wrist posture, indicated the range and speed of the exercises and counted along with them. In wrist instability rehabilitation, as we saw earlier, patients experience a lot of fatigue and frustration, because progress is invisible over a long time, whereas setbacks are frequent. “It is really motivating, because then you know whether you should tweak how you do it or whether you are doing it well.”

Building up trust. Patients also appreciated the overview of days and how many exercises they had done. Rather than motivating them to look ahead and gauge how far they still had to go, it was valuable to them to look back and see how much they had (or had not) done, so that they could get an idea of how successful they actually were at sticking to the exercise regimen. This led them to build up trust: “you develop trust that you are doing it well.” “I become more aware of whether I am actually doing the exercises or not.”

All these findings were to be expected and are well-known benefits of feedback devices, confirming that the functions of the prototypes were useful. However, a last finding provided us with a new aspect to the topic:

A perfect storm. During the research encounter, the patients started to focus on their wrists. They started to talk in detail about what it is they thought was wrong with their wrists. It started to transpire that their relationship with their wrists had become fraught. As one patient put it: “Although my wrists are currently in good shape, I can still feel that deep down, it is still in there.” While saying this, they pointed at points in their wrist (Figure 5). It began to become apparent that patients lacked trust in their wrist, and had a negative attitude towards it.

Figure 5: patient pointing at specific points in their wrist (photo of researcher’s hands, simulating the patient’s action)

Once we recognised this negative aspect, more insights emerged for us. During the interview, the patients were focusing intensely on their wrists, looking at them while talking and describing experiences that had very strong impacts on their lives (Figure 6). Their wrists got them caught up in a perfect storm. They described experiences whereby they had to give up, one by one, several activities they enjoyed and partly depended on for their livelihoods. In addition to this, they impatiently rubbed their affected wrist.

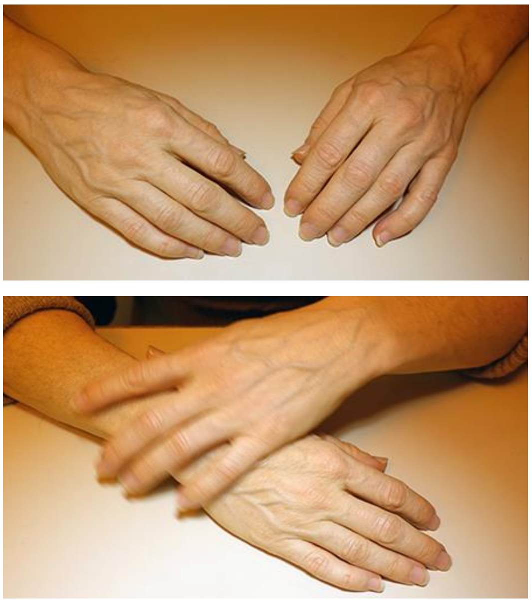

Figure 6, top: patients looking intensely down at their passive hands before them. Bottom: rubbing impatiently. (Photos of researcher’s hands, simulating the patient’s action)

REFLECTION

The last findings, about the patients’ relationship with their hands, particularly led us to an insight on how we would need to adapt our goal and perspective on data-enabled supports for orthopaedic wrist rehabilitation. It led to a new sub-program in our research-through-design program. While before, our design goal had been to activate patients to perform the exercises actively, we now understood a function that the prototypes had for the patients, which was at the same time still a deficiency in the prototypes. For the patients, their wrist injury condemned them to inactivity. At the same time, the exercises are so light and minimal, and can only be done if there is no pain (if there is, they have to stop and wear a brace again), that the patients experienced impatience for which there was no outlet. Nothing that they could do could speed up their lengthy recovery process – any impatience, any unwise move could only lengthen it. All of the patients filled their lives with business so as not to think about their wrists, just like anyone who does not have wrist problems would hardly ever consciously reflect on their wrists. We interpret that they were trying to think the problem away, or ‘unthink’ the problem.

An additional thing that a data-enabled rehabilitation support would have to provide, therefore, which was now not present in the prototypes, is to direct patients’ attention in a mindful and accepting way towards their wrists: to find calm. Rather than a discipline problem, not doing the exercises here seemed to be an avoidance problem. A new design goal would have to be: “support patients in orthopaedic rehabilitation to become calm and mindful of their wrists, and positive towards them, so that they can perform the exercises”.

DISCUSSION

This exploratory study identified several criteria for design of data-enabled devices, such as that rehabilitation supports need to respect patients’ need for privacy, provide direct feedback in order to experience effectiveness, give patients a possibility to look back rather than forward on progress, and support patients’ calm and positive mindfulness of their affected body part. With that, our findings respond to Blue et al’s (2016) challenge to engage with the specific circumstances of health. We identified how our prototypes, inadvertently, reinforced an idea that people are inert which is somehow their fault, and need to be activated for their own good. However, we also found that another component could add a valuable perspective for patients: that of accepting a part of themselves in order to find the calm to engage with it. With that, we contribute an example of how a research-through-design exploration can yield a new sub-program in a program of inquiry as envisaged by Binder and Redström (2006). The contribution is to provide an example of theory being sub-divided.

Our findings also add nuance to the application of the ‘possible self’ concept (Kenter et al, 2014) in rehabilitation. The goal, the future that a patient could imagine of themselves, is not so much about an end-point that a patient may or may not ever reach (again). Rather, the possibility needs to be close, within the shifting (and sometimes receding) scope of what the patient can achieve within a relatively short term. We found this similarly in a previous study (Szaniawski, Boess, Kraan and Goossens, 2015.) which focused on visualising achieving next steps in rehabilitation.

This has been an exploratory study which concludes at this point. Our next steps will be to explore the new program aspect that was discovered through this research-through-design study, and tie it in more thoroughly with literature on emotional and culturally appropriate approaches to supporting patients.

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REFERENCES

Binder, T. and Redström, J. (2006). Exemplary design research. In Proceedings of Wonderground, the International conference of the Design Research Society.

Blue, S., Shove, E., Carmona, C., & Kelly, M. P. (2016). Theories of practice and public health: understanding (un) healthy practices. Critical Public Health, 26(1), 36-50.

Boess, S. (2009). Designing in research: Characteristics and criteria. In Proceedings of IASDR, Rigor and relevance in design.

Boess, S. (2018). Video tools to support patient empowerment in orthopaedic revalidation. In Proceedings of the 5th Participatory Innovation Conference.

Jonas, W. (2007). Design Research and its Meaning to the Methodological Development of the Discipline. In R. Michel (Ed.) Design Research Now. Birkhäuser. Pps 187-206.

Kenter, E.J., Gebhardt, W.A., Lottman, I., van Rossum, M., Bekedam, M. and Crone, M.R. (2014). The influence of life events on physical activity patterns of Dutch older adults: A life history method. Psychology & Health, 6, 1-44.

Markus, H. and Nurius, P. (1986). Possible selves. American Psychologist 41, 9, 954-969.

Matheson, G. O., Klügl, M., Engebretsen, L., Bendiksen, F., Blair, S. N., Börjesson, M., ... & Ljungqvist, A. (2013). Prevention and management of non-communicable disease: the IOC consensus statement, Lausanne 2013. British journal of sports medicine, 47(16), 1003-1011.

Szaniawski, M., Boess, S., Kraan, G. and Goossens, R., (2015). Enhancing engagement with motor rehabilitation therapy through gamified rehabilitation interactions. In Proceedings of the 3rd European Conference on Design4Health.

Trost, S. G., Blair, S. N., & Khan, K. M. (2014). Physical inactivity remains the greatest public health problem of the 21st century: evidence, improved methods and solutions using the ‘7 investments that work’as a framework. British journal of sports medicine, 48(3), 169-170.