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Developing a Digital Platform for Telerehabilitation of Patients Treated with External Fixation Device after Complex Tibia Fractures

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Abstract
In Denmark, more than 500 patients are treated yearly with external fixation device after complex tibia fracture and this affects the lives of patients and relatives physically, mentally and socially. The aim of this study was to develop a digital platform prototype for telerehabilitation of patients treated with external fixation device at Aalborg University Hospital based upon participatory design. In order to identify challenges for the patients and develop a prototype, an iterative process took place in collaboration with patients (n=8), relatives (n= 4) and healthcare professionals (n=6). The following data collection techniques were used: cultural probes, observation in patients' homes, qualitative interviews (n= 18) and workshops (n=3). The prototype was evaluated with focus on design, content and relevance. The users found that the prototype was easily manageable, and the content supported their needs in the rehabilitation context. The prototype has to be tested on a larger scale.

Keywords
Complex tibial fracture, external fixation device, participatory design, telerehabilitation, qualitative evaluation.

1 INTRODUCTION

The treatment of complex tibia fractures is challenging and requires specialized orthopedic surgery [1,2]. In Denmark 503 treatments with external fixation device (EFD) were registered in 2018 (Figure 1) [3]. Regardless of the treatment method, the complication rate is high [1,4], and the long-term outcome is often associated with a risk of knee pain, malalignment and persistent articular damage with an increased risk of post-traumatic osteoarthritis [1,2,5]. Operative treatment with EFD has significant benefits, including the fact that patients can put stress on the leg during the treatment period [1,4,6–8]. At the same time, it is possible to restore misalignment both during and after surgery, and gain easy access to observation of the skin, which may be necessary for larger skin lesions following trauma [4,6].

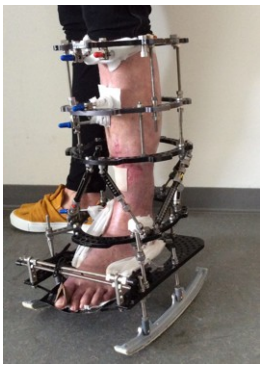

Figure 1 shows an image of EFD attached to the lower leg of one of the users in the study.

However, the treatment with EFD is long-lasting (8-87 weeks), complex and burdens both the healthcare system, patients and relatives [1,4,6–8]. In Denmark patients are continuously monitored at the outpatient clinic at the nearest hospital specializing in treatment with EFD.

A minimum of once a week the nurses in the municipality will have to do pin site care, and up to three times a week, the patients will go to specialized rehabilitation at the hospital [9]. In addition, the patients must also handle the activities that belong to sick leave, insurance, etc. Treatment with EFD is based on a highly specialized and evidence-based approach, and due to the long treatment period, the process must be coordinated across sectors. The patients account for a smaller group of the orthopedic surgical patients, which means that healthcare professionals (HP) outside the hospital specializing in EFD do not get much experience with patient care.

The most frequent complication of EFD treatment is superficial pin site infection. Studies report that up to 70% of patients will experience some degree of infection during treatment [10,11]. Several studies indicate that patients also experience a high level of mental and social stress, including anxiety, depression, and reduced quality of life, both during treatment and after removal of EFD [2,4,6–8,10,12,13]. Therefore, treatment requires a high degree of mental strength and ability to self-care in patients [1,7,12]. There is a need to systematize counseling and knowledge sharing across sectors to achieve quality, continuity and patient safety. This is why we want to develop a digital platform for telerehabilitation.

The aim of this study was to:

1. Identify challenges in a rehabilitation context for patients treated with EFD
2. To design a digital platform prototype for telerehabilitation of patients treated with EFD
3. To test and evaluate the digital platform prototype for telerehabilitation of patients treated with EFD

2 METHODS

The study was inspired by participatory design (PD), in which user are involved in the development and design of technological solutions in order to ensure usability and inclusion of relevant functionalities [14,18].

2.1 Setting and sample

The study was conducted in collaboration with the Department of Orthopedic Surgery, Aalborg University Hospital, specializing in EFD, and Home Nursing, Aalborg Municipality. HPs, patients and relatives were involved in the process and recruited through the Orthopedic Surgical Ambulatory and Orthopedic Surgical Ward, Department of Orthopedic Surgery, Aalborg UH.

2.2 Ethical considerations

We contacted the local Ethics Committee and the study did not have to be reported. An agreement on handling personal data was obtained. The study followed the Helsinki Declaration and all participants signed an informed consent.

2.3 Theoretical frame of reference

To develop the concept, we were inspired by Aaron Antonovsky's theory, Sense Of Coherence [15], because it can contribute perspectives on mental health and coping, which is an area where the patients are challenged [5,7,12,16]. In addition, theory of inter-organizational networks helped to provide perspectives on the organizational challenges that arise in patient care, where many parties are involved and tasks cross sectors, as is the case with EFD [17].

2.4 Phases in the study

The study was divided into three iterative phases:

1. Identifying needs
2. Idea generation
3. Design, test and evaluation

Phase 1: Identifying needs

The aim of this phase was to identify the user's needs. We conducted interviews with patients (n=8), relatives (n=4) and HPs (n=6) (Table 1), did observations in the home of the patients and used cultural probes. Criteria for selection of patients and relatives were: 1. Patients treated with EFD after complex tibia fracture in North Jutland, Denmark, 2. Patients must have EFD or had EFD removed maximum four weeks ago, 3. Patients have given consent that contact can be made by telephone in order to participate in the study. Criteria for the HPs were in-depth knowledge of the treatment with EFD. The interviews were conducted as respectively individual interviews and group interviews (e.g. patient and relative).

Baseline data for patients
P1 (M), age 36, Butcher
P2 (F), age 37, Flex job
P3 (F), age 56, Account assistant
P4 (F), age 38, Work at a farm
P5 (F), age 60, Early retirement
P6 (M), age 65, State pension
P7 (M), age 42, Biblical archaeologist
P8 (M), age 48, Window cleaner
Baseline data for relatives
R1 (M), Parent of P4
R2 (F), Parent of P4
R3 (F), Parent of P2
R4 (F), Wife of P8
Baseline data for HP
HP1 (M), Orthopaedic chief doctor, clinical lecturer
HP2 (M), Physiotherapist and PhD
HP3 (F), Nurse, Orthopaedic Ambulatory
HP4 (F), Nurse, Orthopaedic Surgical Ward
HP5 (F), Home Care Nurse specialized in wounds
HP6 (F), Home Care Nurse specialized in wounds
Baseline data for researchers
Researcher1 (F), KVT student, Nurse
Researcher2 (F), KVT student, Physiotherapist

Table 1 shows baseline data for the users and researchers.

An interview guide was developed based upon the following themes: context, challenges and collaboration across sectors. All interviews were recorded, transcribed and analyzed following the process described by Kvale [19] and using NVivo [20] in the following steps: coded into central themes, condensed into descriptive statements and in the end interpreted. In order to achieve inter subjectivity in data processing and analysis, we coded the interviews that we did not perform ourselves. During the coding, we noted definitions and thoughts on the codes used along the way to create transparency and to increase the reliability of data [19].

Phase 2: Idea generation

The aim of this phase was to gain mutual understanding and collaborate to create, reflect, and evaluate ideas for a digital solution that can meet these needs through workshops. Three workshops were held with the users and took place at Aalborg UH. The workshops lasted on average 2-3 hours, and tools like cards of inspiration, graphical scenario and future workshop were used for generating ideas [21].

Phase 3: Design, test and evaluation

The aim of this phase was to design and evaluate the digital platform prototype. The prototype was developed based on identification of needs and idea generation in Phase 1-2 and designed using interactive mockups in the prototype tool Justinmind Prototypes (25). The prototype was the first iteration of the platform and served primarily to contextualize the capabilities that a digital platform can provide. The platform was tested on five users in three steps, providing a first view of the prototype's functionality (content) and ease of use (design and structure). The approach was inspired by Jakob Nielsen's perspectives on development and design [22]. The three steps of evaluation were: 1. Orientation in platform, 2. Questionnaire designed as Likert scale and 3. Open questions.

3 FINDINGS

Physical, mental and social challenges and challenges related to collaboration and knowledge sharing across sectors were found and led to the development of a digital platform prototype, which was tested and evaluated.

3.1 Challenges in a rehabilitation context

The users in this study describes challenges related to physical, mental and social aspects in treatment with EFD and how these challenges affect each other (Table 2).

Physical challenges	P	HP
Limited in daily activities	X	X
Infection	X	X
Edema	X	X
Pain	X	X
Bad sleep	X	
Psychological challenges		
Stress	X	X
Depression and mood swings	X	X
Concern of complications	X	
Impotence	X	
Insecure and lack of control	X	
A lot of information/lack of overview	X	X
A lot of appointments and transport	X	X
Social challenges		
Social Isolation	X	X
Lack of community	X	X
Dependency on relative	X	X

Table 2 shows challenges described by users. P: Patients, HP: Health professionals. X indicates if the challenge was described by the patient (P) or HP.

Patients are temporarily physically limited and largely dependent on their relatives. In addition, there are mental challenges, where mood swings, feelings of impotence, lack of control over one's own life and concern about complications are periodically dominant. As a result of the physical and mental challenges, patients' social activities are affected with mental deficit and an experience of social isolation.

'There have also been days when I could barely manage it - especially remembering all the things I have to do'

The users also describe challenges regarding collaboration and knowledge sharing across sectors and HPs as listed in Table 3.

Challenges of collaboration and knowledge sharing across sectors	P	HP
Knowledge of treatment	X	X
Knowledge of training	X	
Knowledge of painkillers	X	
Knowledge of help supplies and clothes	X	X
Knowledge/experience in pin site care	X	
Sick leave/activities in the municipality	X	X
General knowledge sharing	X	

Table 3 shows challenges described by users.

Patients and relatives experience a lack of overview, knowledge and milestones in the process, which result in a feeling of lack of control over their own lives. All users point out that the knowledge that exists at Aalborg UH is not sufficient in the patients' local areas, including local hospitals, Home Nursing and the municipality, because the HPs in the municipalities do not continuously gain experience with patients with EFD.

'They [the Home Care nurses] seem insecure, and it [pin site care] seems to be a bigger task than they are used to'

3.2 The digital platform

The platform had two parts: one for the patient and relative, and one for the HPs that could provide various services for each part.

The overall features for the patients' user interface were:

- Overview of appointments
- Rehabilitation
- Pin site care
- Information
- Social forum
- Information for relatives

The overall features for the HPs user interface were:

- Pin site care
- Rehabilitation
- Information
- Access to the Electronic Health Record (EHR)

We integrated the possibility of video communication between the two parts in order to target the challenges of knowledge sharing across sectors and e.g. to support patients who do pin site care themselves. The platform is based on individualized treatments, so the HPs were able to set up the system according to the patients' individual needs by a management function.

Pin site care

We selected one focus area from the list of features to base the design upon and to serve as an example of the platform's function and design: Pin site care. The following features were designed to meet the needs of patients and HP's in relation to pin site care:

- Individual set-up of the patient (management function) regarding who, where and when pin site care is performed. This results in individual information being made available to the patient.
- Assessment of the pin sites and action instructions for the Home Care nurses (Figure 2) to share knowledge and ensure quality and patient safety in relation to pin site care.
- An overview for the patient with milestones (Figure 3) gives the patient and relatives opportunity to follow the development, e.g. in relation to the progress of pin site infections.

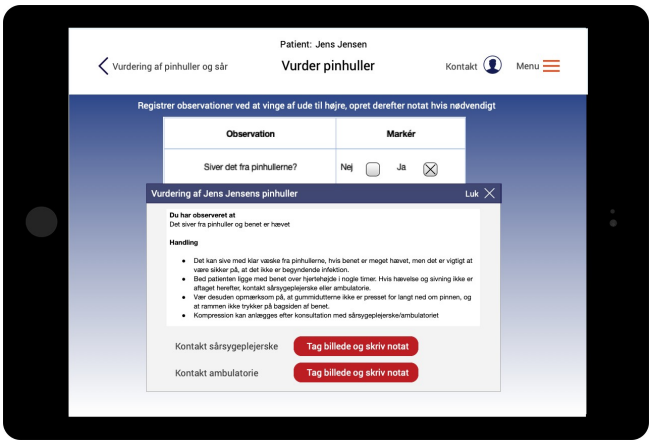

Figure 2 shows the feature "Pin site assessment", which is an action guide for the Home Care nurse (user interface for HPs).

Figure 3 shows "Pictures and notes" regarding progress in infection in a fictitious patient, which is used to display milestones for the patient (user interface for patients).

3.3 Test and evaluation

Figure 4 shows an overview of how the users evaluated the prototype.

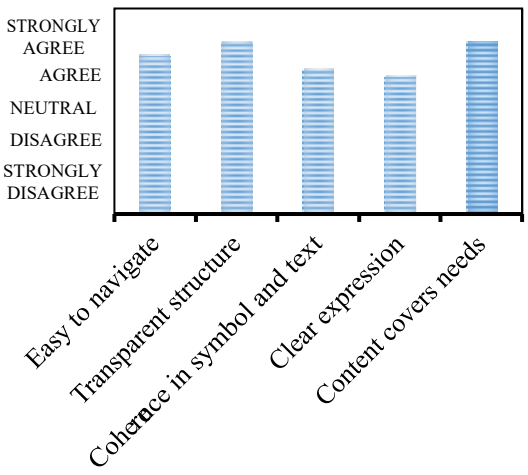

Figure 4 shows the average of user responses in the questions using Likert scale in evaluation of the platform.

The patients' evaluation was predominantly positive. As one of the patients stated:

'These are just the things we needed access to.'

At the same time, the HPs highlighted an immature prototype that will require many changes and tests by several users before a final version of the platform can be designed. Some of the improvements that were pointed out by the HPs were 1) The platform would require extra workflows for them 2) Risk of double documentation.

4 DISCUSSION

In this study, the challenges in a rehabilitation context for patients treated with EFD have been identified through a PD process: physical, mental and social challenges as well as challenges related to cross-sectoral collaboration. We designed, tested and evaluated a digital platform prototype for telerehabilitation. The users evaluated the platform in an overall positive way, but several adjustments remain necessary.

4.1 Challenges

The users in this study report on both physical, mental and social challenges, which affect each other and put a massive strain on periods of the treatment (Section 3.1, Table 2). Previous studies have shown that the patients experience a high level of mental and social stress [4,5,7,10,12,13] in which changes and unpredictability, together with reduced control of their own lives, dominate, and this has been found to contribute to symptoms of anxiety and depression [10]. Concern of complications, including pin site infection, is described by patients in this study. This is supported by Krappinger et al. (2013), who points out that fear of complications is mentally stressful for both patients and their relatives [7]. As the complication rate for fracture types where EFD is used as treatment is relatively high this fear is well-founded. Pin site infection is the most frequent complication in relation to treatment with EFD, in most cases, however, it will be a local problem and irrelevant to the clinical outcome [7,11]. To address the fear this information is important to communicate to both patients and relatives [11]. Modin et al. (2009) also report a degree of physical and mental impact 2 and 4 weeks postoperatively but conclude that physical limitations are minimized over time [12]. Bashera et al. (2014) finds that patients 10 years after surgery with EFD are satisfied with the treatment and that they would undergo the same treatment again if needed [4].

Modin et al. (2009) points out that some of the challenges experienced by patients and some of the causes associated with impaired patient compliance could be related to inadequate information and understanding of the treatment [12]. Findings in this study support this, and further adds that it is complicated by the fact that the knowledge at Aalborg UH does not find its way across sectors. Santy et al. (2009) emphasize that there is a need for the knowledge provided to be structured and located where it can be found when the need is there, while the information is accurate and easy to understand [23]. In addition, Modin et al. (2009) and Limb

et al. (2006), points out that psychological adjustment to treatment i.a. can be supported by setting milestones for the patients along the way, as this helps them to cope with the situation [5,12]. A need for clear milestones is also described by the patients in this study and integrated in the design of the digital platform prototype.

4.2 Design

Telerehabilitation has proven promising in achieving improvements in some of the areas where the patients with EFD are challenged: quality of life, anxiety and depression [24,25]. Personalization of Health Care is described as a key element in the development of new tele health solutions [26]. In this study, patients also express the need for individualized milestones, and a key feature of the platform was the HPs' management function, so that information for the patient appears tailored to the individual, e.g. regarding pin site care, training, etc.

We have not identified other studies in which telerehabilitation has been developed for patients with EFD, but similar telerehabilitation programs including digital platforms have been developed for patients after knee [27] and hip surgery [28]. Naeemabadi et al. (2019) designed and developed a sensor-based telerehabilitation program for knee patients as an alternative solution for conventional rehabilitation [27]. Jensen et al. (2018) investigated whether a telehealth solution (app) can assist hip patients in their recovery and found that patient information and education could be supported by the app [28]. Our prototype differs from the above-mentioned solutions because of a personalized holistic-oriented solution where both information, rehabilitation and pin site care for patient, relatives and HPs across sectors are a part of a shared digital platform.

4.3 Test and evaluation

The test and evaluation of the prototype showed a general satisfaction with the selected functionalities and the simple design. The patients and relatives were particularly pleased, but the evaluation also showed that the HPs expressed concerns about extra workflows and risk of double documentation. In developing and implementing technologies, it is essential that HPs see benefits before restrictions [26]. It is well known that technological developments are taking place at a faster pace than development of clinical workflows and their concern is important to take seriously as the technology in the end is only as good as its use in practice.

In conclusion, the digital platform prototype developed in this study has to be tested in several clinical test. If results from clinical tests show promising results, the system can be further developed and implemented. It will be important that the system is able to integrate with other IT systems in healthcare that the HPs are using in their daily work with patients.

5 LIMITATIONS

This study has several limitations. The study included a total of 18 users, eight of whom are patients, four are relatives and six are HPs. The number is not enough to generalize but can indicate whether there is a potential for change. Key elements of the findings are also supported by other studies [1,2,12,23], but future research is required. The digital platform prototype has only been tested by five users and already after the first design iteration. The prototype needs to be further developed, tested and evaluated in more clinical trials.

6 ACKNOWLEDGEMENT

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