

# Towards guidelines for a design which stimulates the involvement of the caregiver in the neuro-rehabilitation process.

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## ABSTRACT

In this paper guidelines for a design that involves caregivers into the geriatric rehabilitation process are made. This is done by a qualitative research that involves caregivers, nurses and therapists.

## Author Keywords

Geriatric rehabilitation, caregiver involvement, design guidelines

## INTRODUCTION

Neurological rehabilitation can be done in various ways, in a rehabilitation centre, at home or in a geriatric rehabilitation department of a nursing home. The way a person rehabilitates depends on the situation. In the rehabilitation centre there is a lot of time is focused on therapy sessions, in the geriatric rehabilitation and the patients own home there aren't so many sessions and resources for this. For this reason a lot of rehabilitation methods are set up in the last decade to implement technology to provide the patient with more support. But these do not take the partner or home situation into account. The implementation of technology in rehabilitation exercises is already used in former studies. In these studies, the writers are using, for instance, a Kinect, gamified task or wearable (Webster & Celik, 2014).

A lot of research is done towards implementing technology in the form of gamification of rehabilitation exercises. (bronnen), but a field that is not investigated yet is the relation between partner involvement during neurological disorder rehabilitation and the influence on the rehabilitation process. During medical specialist rehabilitation in a rehabilitation centre, with therapy sessions seven days a week multiple times a day, the caregiver is involved wherever needed. The patient is strong and young enough to handle the intensive treatment focused on full recovery of the same quality of life as before. The caregiver is very much involved in this process because the

patient will move back home at some point. In geriatric rehabilitation the patients are more vulnerable and old and even though the goal is to return to home as well, the quality of life will be very different. If it is possible the patient will return home, but still needs a lot of help from nurses and the caregiver. In other cases, the patient will move to a nursing home, to get 24-hour care. The struggle in the geriatric rehabilitation process is that the partner wants to help, but does not understand with what and how.

Additionally, within nursing homes, there is a need for independence, less staff and cost-reducing solutions (as stated by ZGE employee we spoke to). Involving the caregiver in such a way that he/she will be part of the coaching/motivational role of the therapists in an appropriate way will adhere to these requirements.

There is, however, little known about partner involvement and changing their role within the rehabilitation process. Therefore what first needs to be explored is the needs and requirements for partners, patients and therapists are which will be investigated in this paper. The question which will be focused on is: 'What are the guidelines for a design which stimulates the involvement of the caregiver in the neuro-rehabilitation process?'

First, the importance of partner involvement will be discussed. Secondly, the requirements and guidelines of the situation for a co-partner design will be investigated. Then imaginary studies will be created. Lastly, these guidelines and imaginary studies will be discussed in a focus group session, to create a final set of guidelines for caregiver involvement in the rehabilitation process.

## THEORETICAL BACKGROUND

In this paper the focus lies on geriatric, in other words low capacity, rehabilitation of people with a neurological

disorder. People with a neurological disorder can suffer from physical functioning limitations, cognitive impairments, behavioural problems and communication impairments (World Health Organization, 2006). During medical specialistic (medisch specialistisch), in other words high capacity, rehabilitation the caregivers are involved very much, however during geriatric rehabilitation they are not while a lot of studies mention that the patient benefits a lot from the involvement of the caregiver.

The way in which partner involvement can improve the rehabilitation process is by means of social support. (Rodakowski et al., 2012). In the study of Glass & Matchar “Impact of Social Support on Outcome in First Stroke” was found that higher levels of social support cause a more rapid rate of recovery and a greater amount of overall improvement in functioning. The study of Huijbregts et al points at this issue and suggests more involvement of the partner (Huijbregts et al, 2008). However, during the study of Cameron, Naglie, Silver, and Gignac it appeared that therapists had a hard time involving the caregivers: “HCPs [health care professional] highlighted the difficulty of engaging caregivers in therapy and education when they did not consistently come to the rehabilitation hospital during the clinicians work hours” (Cameron, Naglie, Silver, & Gignac, 2013, p.321). The caregivers who engaged mentioned that they benefited from this. On the other hand, the caregivers also mentioned that the amount of medical information was overwhelming, and that they did not have the opportunity to ask questions afterwards. The therapists mentioned that they did not know at what moment they had to provide the information (Cameron, Naglie, Silver, & Gignac, 2013).

As mentioned above, the influence of the family and caregiver in the rehabilitation could be a meaningful addition to the rehabilitation process of patients. Next, to the aspect of the involvement of the family, it is also important to look at the role the primary caregiver has in the current situation. According to Cameron, Naglie, Silver, and Gignac the current role of the caregiver is care-giving. Rehabilitation exercises are individual nowadays and this results into less involvement and therefore understanding of the caregiver during the rehabilitation process. Besides that, a lot of caregivers have to work and are not present the whole day (Cameron, Naglie, Silver, & Gignac, 2013).

## **RELATED WORK**

Social support from family can improve the rehabilitation process of a person with a neurological disorder (Rodakowski et al., 2012). However, most patients with a neurological disorder need to go to a rehabilitation centre in which they experience lower social interaction with their family (Gulick, 1994). This may affect rehabilitation. Social support is created by means of collaborative activities and

communication (Van den Hoogen, Ijsselsteijn, & De Kort, 2009). Several studies tried to change this by using a design that facilitates interaction. In the study, Role and Quality of Communication in Collaborative Training for Multiple Sclerosis Patients, this was done by supporting audio and/or video communication through a collaborative game. In the study, Interactive Therapy Gloves: Reconnecting partners after a stroke, they tried to foster acceptance of each partner’s contribution and to help them reconnect. This study focussed more on rehabilitation at home. By using a glove that would stimulate the partner to reconnect and help the patient (Hallam & Whiteley, 2011). Both studies are examples of involving the caregiver more in the rehabilitation process. However, in the field of rehabilitation for patients with a neurological disorder at rehabilitation centre studies on the involvement of the partner through design are scarce.

Multiple studies have been conducted using a device to enhance rehabilitation exercises for patients with a neurological disorder. A lot of these devices use gamification and track the movements of patients (Chatzitofis et al., 2015). The study, ARMStrokes: A Mobile App for Everyday Stroke Rehabilitation, used gamification to tackle the lack of motivation among stroke survivors. Many stroke survivors find daily rehabilitation exercises at home were quite boring (Shaughnessy, Resnick & Macko, 2006). This app motivated them to complete more exercises by using stimulating visuals (Guo et al., 2015). There are several rehabilitation systems that use Kinect to do this (Webster & Celik, 2014). However, these systems involve individual training and do not include the partner at all. Then there are also studies focussed on using a design that stimulates frequent motor training in daily activities. This was the goal of the study ReHappy – The House Elf that serves your Rehabilitation Exercises. In this study, ReHappy was designed. A device that monitors the daily activities of the user and logs what motor training is done by the user. Next, to this it also guides the user through the exercises. As mentioned above there is a wide range of methods to enhance rehabilitation exercises. With the knowledge gained from this study these methods can be improved by involving the caregiver of the patient.

Making prototypes and testing them is believed to be a crucial element of the design process (Ozenc et al., 2007). Prototypes are especially important to explore different settings or design decisions (Buchenau & Suri, 2000). However, when the means of prototypes are not just exploring but to stirrup a conversation. Then what kind of prototype will be made? That is where Design Fiction comes in. Bruce Sterling described Design Fiction as “a

creative act that puts the viewer into a different conceptual space — for a while” (Sterling, 2013). Design Fiction can be used to establish discursive spaces where the design will be situated, to specify concepts while retaining a certain level of ambiguity and lastly to consider multiple outcomes of a design by creating fictional findings from field studies (Blythe, 2014). Design Fiction is used in a lot of different ways, such as images (Blythe et al., 2015), objects (Tanenbaum, Tanenbaum & Wakkary, 2012) and texts (Schulte, Marshall & Cox, 2016). Using more than one mediums can help people to get a thorough understanding of the design fictions.

### **ORIENTATING INTERVIEWS**

To gain insights into the needs of the field of investigation interviews with multiple experts were conducted. The first experts that were interviewed were Richard Geers a medical technologist and Jule Elmanowski a physiotherapist from the rehabilitation centre Adelante (appendix x). They gave insights about how the partner is involved in a rehabilitation centre and the different kind of exercises patients with a neurological disorder need to do. The next expert that was interviewed is a nurse (appendix x) nurse and she confirmed that there is indeed need for improvement of the partner involvement. One of the other experts was Siete Sirag who works at Fontys as an educational designer and lecturer interprofessional collaboration and collaboration and orthopaedic technology. He also confirmed the need for improvement and introduced behaviour change (appendix x). Behaviour change is not the goal, but learning new behaviour will be a part of the impact that a design should provide. 3 fontys students who do an internship at the department of rehabilitation at the Tolburg hospital located in s Hertogenbosch were interviewed as well to further investigate the problem statement created.

### **METHODOLOGY**

#### **Participants**

The stakeholders involved in this study are caregivers, nurses and therapists. For this research 4 caregivers between the age of x and x were interviewed. Two caregivers have patients living at ‘De Zorgboog’ located in Helmond, the Netherlands. The other two caregivers have patients living at ‘ZGE (Zorggroep Elde)’ located in Boxtel, the Netherlands. The caregivers are selected by nurses from ZGE to be able to perform a basic interview and are willing to take part in this study. Three of the caregivers interviewed are children of the patients living in the nursing home. These children were mostly younger (between x and x years old) and were the main caregiver of their parents living in the nursing home. One caregiver was the partner of a patient living in a nursing home and had a elderly age of x

years old. A total of 7 experts were interviewed. Two occupational therapists, 2 physiotherapists, 2 nurses and 1 speech therapist took part in the study. These therapists were between x and x years old. Four therapists work at ‘De Zorgboog’ in Helmond (1 of each function). The other three work at ‘ZGE (Zorggroep Elde)’ in Boxtel. Here, no speech therapist had the time to be interviewed.

#### **Method**

The goal of this study is to create design guidelines for caregivers to take on an active role during the rehabilitation process. This study consists of three distinct parts in which design guidelines were created to increase caregiver activity in the rehabilitation process. Expert and caregiver interviews were conducted at first. From the results of all the interviews the first set of guidelines were made. From these guidelines two imaginary studies were created. At last a focus group session was held with a participant and two experts of the geriatric rehabilitation department. After the focus group the final guidelines were made.

A total of 7 interviews with experts were conducted. In these interviews, the questions were focussed on discovering the limitations, obstacles and opportunities concerning partner involvement and their role in the rehabilitation process. The questions asked were open and unstructured and the main goal of these interviews were to get insights into past experiences of experts regarding this topic.

With the results of these interviews in mind, interview questions for the caregivers were made. The questions of these interviews were more closed than the interviews with the experts, in order to find specific interests and preferences to create a design from. The conclusions of the interviews with the experts were proposed to the caregiver as well. Interviewees would report the challenges and opportunities that they encountered with these conclusions. Additionally, from this, a comparison in views on the topic between experts and caregivers could be made.

All interviews conducted were scheduled to last an half an hour to an hour in order to create an in-depth analysis. The transcribed interviews can be found in Appendix x.

For the second part of the study the first set of guidelines were made. This was done by doing two thematic analysis’ on as well as the expert interviews and the participant interviews. The thematic analysis was based on the paper from xxxxxx. From the first guidelines two imaginary studies were designed. These studies were based on two ‘imaginary’ designs made from the guidelines. The imaginary studies helped to understand the guidelines better.

For the third part of the study a focus group session was set up. The focus group session adhered to the method of

xxxxx. This session was set up to discuss at first the imaginary studies and after that the guidelines. Every participant of the session had given the time one by one to give his/her response towards the proposed guidelines and study.

In the final part of this study the focus group session was analyzed. The guidelines which the participants commented on, had been adjusted and the final set of guidelines were made.

## FINDINGS

After the interviews with the experts themes were found and printed so that subjects in the themes could be formed, see figure 1. After that, the interviews with the caregivers were conducted and grouped in themes as well. These themes were printed and added to the first groups. After this the subjects in different themes were grouped together, see figure 2. Within these subjects the general message was written down and from that the preliminary guidelines were made. From these guidelines the imaginary studies were constructed. After this, the focus group session was conducted with one caregiver, one nurse and the responsible of the rehabilitation center. During this session the imaginary studies and guidelines were discussed. From the insights of this session the final guidelines were constructed, these guidelines are explained in the next section.



Figure 1



Figure 2

## RESULTS

### Guidelines

After the groupings of the interviews, thematic analysis and focus group 6 guidelines were created to support a future design that stimulates the involvement of caregivers in the rehabilitation process situated in nursing homes. Each guideline is followed by an explanation which explains the reasoning behind it and the additions made to the guideline after the focus group session.

#### 1. Provide specific, unrepeated and case related knowledge to the caregiver:

Caregivers often mentioned that they were not informed enough, incorrectly or simply did not know how to handle in a specific situation. The design should, therefore, provide

information about the specific disorder and rehabilitation process in a clear and concise manner. This information would be tailored to the caregiver and provided by the therapists through means of a design. This guideline will aim to provide the right information at the right time. Caregivers want to be informed and want to help but how remains a question for many (quote). Using information resources that can be provided to caregivers such as links to useful websites or presentations will aim to give caregivers more knowledge. During our focus group session we recognized that, according to the caregiver: “(quote) More clarity will lead to less questions.”

During the interviews several therapists mentioned they would like to have as many contact hours with partners as possible to get them more involved in the rehabilitation process. Caregivers also feel like they can ask at any point in time for information if they don't know what to do. What happens in these cases is human to human contact and communication. When talking about the exercise folder, one caregiver explicitly mentioned that it felt impersonal (quote). He would've liked to get personal feedback from therapists themselves. According to this interviewee, the (quote, exercise folder is impersonal) and he would like to see more personality and a hands-on explanation on how to fulfil certain activities. According to experts this is already a possibility and happens quite a lot (quote?). A future design should take personality as a guideline by trying to make the experience as hands-on as possible. The caregivers should not feel like the same exercises are provided to them as any other case. As for instance mentioned by caregiver x (Quote, the same card was on the table as two weeks before).

#### 2. Set clear but adjustable expectations about the goals of the rehabilitation process for the caregiver:

During the interviews, we recognized that frustration for caregivers comes forward because of a lack in setting expectations for the caregivers. Experts in a rehabilitation centre inform caregivers but do not set expectations for the rehabilitation process. There is much to be gained when looking at the communication between the caregiver and the patient. However, the rehabilitation process and progress is often hard for therapists to predict as well. This was especially made clear during the focus group session where therapists indicated that: “(quote) expectation set in the future design should be adjustable and flexible in use”. As a result, caregivers indicated that only main goals and the progress of the rehabilitation process should be shown in the design.

And although, during earlier interviews, more specific expectations that weren't met seemed to cause a bigger loss in motivation: “Because, he himself says, yes I can stand up. I have to stand up and I have to cycle. So, I have an

expectation then, because I imagine cycling differently than what he has to do now.” An overview of the progress showing larger goals might also redeem expectations for situations as described above.

Taking part in a session is, however, an important part of involving caregivers into the rehabilitation process in the right way. During these sessions, caregivers can get tips from therapists. In an ideal situation, therapists even indicate that as much contact points with the caregiver is an endeavour. (Quote)

### **3. Two sided, low effort and non time-bound communication between experts and caregivers:**

As recognized by the interviews done with both therapists and caregivers, communication plays a central role in how the role of a caregiver is formed. Communication also forms a large problem within the environment of a nursing home and how caregivers fit into the nursing system. In the current situation, at both nursing homes visited, a folder was used where exercises or rehabilitation reports could be put in. According to partners, these folders were used very little during rehabilitation with caregivers (quote). The exercises in the folder are there, but there is no motivation into using the exercise folder (quote). This folder is a means of one one-sided communication.

We opt for a 2 sided communication system being used in a design that supports a low effort communication system between experts and caregivers. As said, caregivers, themselves often take on a supportive role in relation to the rehabilitation process. By means of 2 sided communication through design, questions can be asked in a low effort way and caregiver input can be given which has proven to be helpful for both therapists and caregivers. Example: “voorbeeld over extra input”. In this case, caregivers come up with their own plan to help during rehabilitation. During the focus group session, however, the low effort side of the communication was stressed by therapists: “(quote)”. Even so that it became clear that the communication from experts to caregivers should not be time-bound. We therefore opt a a communication system that is quick for caregivers to use but makes clear that experts can not respond immediately (which relates to guideline 7).

### **4. Motivational as well as withholding (depending on role and age of patient and caregiver):**

During the large scope of the interviews it was recognized that there is a large modality between the motivation of caregivers of patients rehabilitating in a nursing home. These modalities depend on the age of the patient, home situation and actual personality of the caregiver in charge. As mentioned by (paper die ik heb gevonden over rollen), caregivers can take on a variety of different roles ranging from very active and involved, to passive and not

motivated. As mentioned by almost all experts interviewed, caregivers can become too involved which may lead to negative effects on the rehabilitation process. Experts need to invest time and energy into sometimes involving and motivating partners but also into withholding them from helping too much during the process.

The balance between helping too much or too little is hard to find, however, if not there, influences important factors of a good rehabilitation process (making appointments, doing exercises at home, communication to experts, the motivation of patient, caregiver input etc.) In order for a design/interface to work for both caregivers and experts, the option must be available to either motivate the caregiver or withhold them from helping during rehabilitation. This makes the design application for a larger target group and in this way experts have more control over what a specific caregiver needs in terms of motivation.

### **5. Create awareness on the influence of a, non-committal, family centered role:**

A future design should let the family be family. The family members do not want to turn into full-time caregivers (quote). The design should, therefore, be of low effort and non-committal. This means that the design only casually tries to motivate it's users and also respects and motivates the way in which caregivers have fun with their loved ones. Caregivers especially indicated that seeing the joy of the patients when doing casual activities would give them motivation as well: “quote”. The exercises caregivers take part in are often low-key and easy to understand. One partner even mentioned that a lot of exercise with the patient is, in his eyes, done unconsciously (quote). We, therefore, opt to design the product/service so that caregivers become conscious of their unconscious exercises done. This, in a way, will show the potential of what caregivers can offer for their rehabilitating loved ones, which in a way will be a form of communication lacking in current rehabilitation processes (quote). The design should let the family role be central, not the caregiving role.

The creation of awareness was especially stressed during the focus group session (quote). The caregiver present mentioned that creating awareness for the caregiver about the fact that they unconsciously help the patient by doing activities should be regarded important. In the end all stakeholders agreed that a lesser aware caregiver could provide a lot from being aware of their contribution as family to the rehabilitation process (quote).

### **6. Low workload and easy to maintain for therapists:**

A large subject that came forward during the research was the fact that therapists often try their best to contact caregivers who are not motivated enough or should help more during the rehabilitation process (quote). We opt that



the design should therefore make sure as little extra work for therapists is added to make the product/service is actually usable in accordance with the busy working schedules therapists in nursing homes have. This therefore relates back to guideline 2 which states that a 2-sided communication system should not be time-bound. Experts indicated they would not want to feel the pressure of caregivers asking questions in which they felt would slow down their work (quote).

Especially during the focus group session therapists were in great favour of adding this guideline to the set of guidelines. Even so that therapists, but also the caregiver, mentioned that the system should use a system that curates information for the caregiver on its own and not by the therapists (quote). We therefore opt to try and design an advanced system that is not only a tool for therapists to communicate information but really functions on its own as a smart product that knows the needs and problems of caregivers with minimal input from therapists.

### Imaginary studies

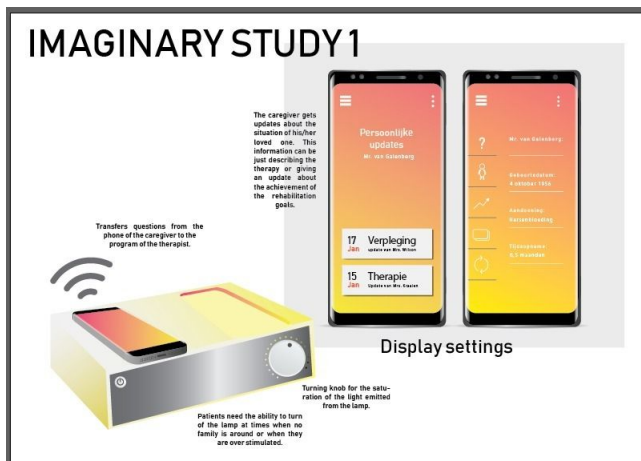


Figure 3

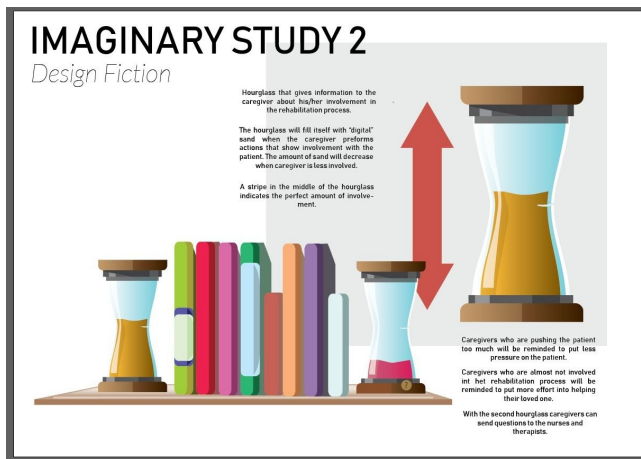


Figure 4

### DISCUSSION

Due to some time issues not yet able to write

### CONCLUSION

Due to some time issues not yet able to write

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