

Giving Voice to Stroke Survivors and Caregivers: Co-designing Technologies for Rehabilitation Activities

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Abstract

Nowadays, 5 million people per year are left permanently disabled and with affected independence due to a stroke. For these survivors, the physical rehabilitation that follows a stroke is critical. Often, this rehabilitation is performed at home, after hospital discharge. There are countless technological solutions to facilitate home rehabilitation. However, currently available technologies miss the opportunity to leverage the role of caregivers. In this work, we engaged in a co-design process with both stroke survivors and caregivers to create a novel home-based rehabilitation system. We started by performing interviews where we disclosed the caregivers' roles during the rehabilitation process, the emotional state and motivation of each person in the pair, the activities they do (family and rehabilitation activities) at home and in-clinic and the impact and role of technology in the rehabilitation and their lives. After, we conducted co-design workshops that led us to design implications such as the need to design for mobile phones and the need to include features to share their goals and conquests. With those, two versions of a high-fidelity prototype were designed - one with high caregiver involvement and another with low involvement. The proposed design concept consists in embedding daily life activities in the rehabilitation process through gamification features. Both stakeholders evaluated the prototypes. The results were overall positive and the participants preferred the version with low caregiver involvement. Possible improvements were mentioned but we concluded that involving the stakeholders in the design process helps design a solution that fits their needs.

Keywords: Home-based Rehabilitation, Stroke Rehabilitation, Informal caregiver, Co-design

1. INTRODUCTION

Stroke is the sudden death of brain cells due to lack of oxygen when the blood flow to the brain is lost by blockage or rupture of an artery¹. Nowadays, 5 million people per year are left permanently disabled, limiting physical activity and affecting independence due to a stroke [10]. The focus of our work is the motor impairments and the physical rehabilitation that follows a stroke which is critical in order to recover the survivors' functionalities [1].

Due to the escalating cost of healthcare and shortage of healthcare providers, post-stroke patients often perform rehabilitation exercises at home¹. Home-based rehabilitation has multiple benefits to offer, such as providing a sense of control over the rehabilitation process.

Besides rehabilitation, when stroke survivors are discharged home from the hospital, they need assistance with basic activities of daily living. This help is mostly given by a caregiver, who should have an important role in the rehabilitation process

since there is evidence to believe that the active involvement of the family in rehabilitation can be determinant in the degree of recovery [4].

Furthermore, the involvement of caregivers in the recovery process can have numerous advantages including for the caregiver himself. By being a part of this process, the caregiver feels useful and does not have a perception of not being prepared and engaged to participate in rehabilitation after discharge from hospital [5]. Despite having positive aspects, the involvement of the caregiver in the rehabilitation process can also lead to tensions between the dyad. The caregiver can feel burdened [11] and we should be careful when including them in the rehabilitation.

Nowadays, there are countless technological solutions to facilitate home-based rehabilitation either for stroke survivors or for other health problems [6]. **However, none of the currently available technologies for stroke survivors take into consideration the role of the caregiver.**

Moreover, most of the current solutions do not

¹www.stroke.org

consider the impact that involving caregivers might have in the recovery of survivors. The reason for this could be that only a few of the solutions include either stakeholder in the design, which can decrease the efficacy of meeting their needs.

The approach of this work will be based on co-designing with stroke survivors and their caregivers to develop a platform for home-based rehabilitation. This platform aims to meet their needs and considers the role of the caregiver in rehabilitation. We will make sure that both stakeholders' voice is heard during the design process, allowing them to participate and define research priorities. Therefore, our contributions with this work are: 1) Understand the role of caregivers in the life and rehabilitation process of stroke survivors and how it could be improved with new technology; 2) Co-design of a home-based rehabilitation platform with the cooperation of survivors and caregivers, taking in mind the role of the caregiver that we pretend to enhance; 3) A high-fidelity prototype of a home-based rehabilitation platform.

2. BACKGROUND

After being discharged home, stroke survivors rely on their caregivers - who are typically a spouse, son of the stroke survivor or other family member - to monitor their health conditions, oversee and support their rehabilitation activities, provide emotional support and assist in daily activities [13].

As we explored the relationship between the survivor-caregiver dyad, we discovered caregiver-mediated exercises which are exercises in which caregivers are actively involved in rehabilitation training and can be a promising and cost-effective way to augment daily practice intensity [14] so its importance should be considered. Since it can be performed at home, the therapy based on caregiver-mediated exercises can help eliminate the need for patients to commute for rehabilitation. Besides that, the patient and the caregiver can practice rehabilitating skills in a familiar and comfortable environment.

The fact that caregivers can identify needs that the survivor, a designer or a therapist cannot [9] is also a factor that should be taken into account when considering home-based rehabilitation.

3. RELATED WORK

Besides the technologies and systems that explore existing solutions such as tablets, telerehabilitation, virtual environments and games, there is the possibility to design specifically for the survivor. A study by Balaam et al. [3] presented the experience of building systems that motivate people to engage in rehabilitation exercise after a stroke. Each of the four survivors was interviewed, and it was found what was their main motivator and a rehabilitation

method/activity was built around that. Solutions like this should be taken into consideration since they motivate the patients.

None of the reviewed solutions for home-based rehabilitation platforms for stroke survivors involved caregivers. Nevertheless, there is some work performed around technological solutions regarding health conditions, other than stroke, where the caregiver has a vital role.

An approach of solutions that assist the caregiver in their role is e-health tools. The previously discussed caregiver-mediated can, sometimes, be complemented with these e-health tools by having an app with videos with a voice-over explaining and demonstrating the caregiver-mediated exercises [14]. Despite existing few examples, there are studies that give us a base on how the caregiver can be included in the rehabilitation technology design process and how, after, they can participate in the exercises [2].

With this, we understand the absence of numerous solutions for stroke rehabilitation that give the caregiver an active role and the stakeholders involved in the design process. Consequently, this will be the direction of our work.

4. CO-DESIGN METHODOLOGY

In a participatory methodology, the researchers design **with** people rather than **for** the people. The collaborative approach that is participatory design is important when designing for people with disabilities such as stroke survivors because nobody completely understands their needs like themselves [12]. Therefore, the methodology used in this study to design a high-fidelity prototype combined research methods and had a couple of steps. The first was to conduct semi-structured interviews and, the second was to organize and conduct co-design workshops. They were conducted via Zoom due to the ongoing Covid-19 pandemic.

Exploratory Interviews

The interviews helped disclose the caregiver role in the rehabilitation process and life of the survivor and the potential of technology.

Methodology: We conducted semi-structured interviews to disclose the perspective of both participants on the caregiver's role in the rehabilitation and the survivor's life.

Participants: We recruited 6 stroke survivors and their main caregivers (if existent). The participants were Portuguese between 37 to 71 years old. Although the dyad's relationship was not a criterion, all caregivers were spouses/partners.

Procedure: There were questions among four main topics: generic, rehabilitation and physical

impact, relationships and occupations and hobbies. With these interviews, we also disclosed how comfortable using technology they are and how frequently they use it.

Analysis: We audio-recorded and transcribed the interviews using Google Doc speech-to-text feature. For the data analysis, we followed an iterative coding process [8]. One researcher independently created a codebook from a subset of interviews (two with stroke survivors and one with caregivers). Then, another researcher coded the same interviews until reaching a consensus on the codebook. To achieve a consensus, between the two researchers, on the codebook, we used Cohen's kappa. The average kappa score across all codes was 0.98. After the consensus on the codebook, the two researchers coded an equal subset of the remaining interviews.

Findings: Interviews with pairs (P) of stroke survivors (S) and caregivers (C) uncovered their perspectives on the caregiver experience during the rehabilitation process and the role of technology in that process.

We highlighted the most relevant findings, including the caregivers' roles after the stroke and during the rehabilitation process [F1], emotional state and motivation of each person [F2], activities including family activities and rehabilitation activities at home and in-clinic [F3], role of technology in the rehabilitation process and their lives [F4].

F1: "Where Do I Stand?"

It is known that having a stroke affects the survivor both on a physical and psychological level. To increase their quality of life, they need different types of therapy. However, participants showed concerns about where caregivers stand in all of this recovery process.

If we think about the rehabilitation process, we understand it is a process that can consume a lot of a person's time and energy. In this case, the main role of the caregiver was taking care of everything else in their life so that the survivor could focus only on the recovery.

The survivor-caregiver dyad has the power to determine the rehabilitation's success. To take on this role, the caregiver must have some knowledge about the rehabilitation process and furthermore about the exercises themselves. Most participants mentioned the presence of the caregiver in the rehabilitation sessions. S2 even pointed out that her caregiver had specific days to watch over the session and that he was taught some things in those sessions.

Three caregivers felt that their role as a caregiver was also to help with the emotional part of the post-stroke life. As a caregiver C2 said *"a caregiver is*

always the one who puts the motivational part on top, this is the caregiver". Other caregivers can also exist like children who can also help with rehabilitation and motivation. They can be important motivators as the survivors want to be able to, for example, do activities with their children and so feel the urge to recover fast.

F2: Emotions and Motivation Divided by Two

In the previous finding (F1) it was possible to understand how the caregiver can have an impact on the survivor's emotional state and motivation. However, the dyad's emotional state is differently affected after a stroke when we look at the caregiver and the survivor separately.

Survivors' motivation is the most important point for a favourable recovery. They mentioned two main ways to find motivation for their recovery. The first is defining little steps and achievements. The second channel where motivation comes from is something all participants mentioned and it is the importance of sharing and the sense of community. In addition and as previously mentioned, most survivors mentioned the great impact the caregivers have on their motivation.

The dominant feeling the caregivers share is the lack of power, most of them disclosed they feel powerless most of the time. The dyad's emotional state works as a cycle since when the caregiver is in a good state they help the survivors gain motivation and therefore progress in their recovery. Then, when the caregivers notice this progress their emotional state is well and the cycle begins again. With this, we can perceive that even though each member of the duo has their own motivation and emotional state, they work together as a whole to reach a successful recovery and a happy household.

F3: Post-Stroke Activities

After a stroke the most important thing is to not stay still, the more the survivor moves around the easier is the recovery. For an effective recuperation three important components were mentioned: the rehabilitation in a clinic or at the hospital mainly in the beginning (occupational therapy where most played games, physical therapy where most did exercises to recover mobility and cognitive/psychological therapy), the rehabilitation exercises learnt from a therapist and reproduced at home (few or none did these classic/usual home-based rehabilitation activities because they lacked motivation) and the family activities that help the survivor not be inactive (all the interviewed participants played some sort of game with their family and/or did some sort of activity like walking or watching movies).

From the mentioned activities, some were acknowledged as activities that influenced the survivor's recovery. From these family activities

that can be considered rehabilitation activities, we can summarize the most mentioned ones: Hikes, Puzzles, Dance, Yoga, Paint, Traditional Games (board or others, such as Pictionary, word games like Scrabble and mimic games), Wii/Playstation Games, Daily Life Activities (such as hair wash, change diapers, cook, put on shoes, dress/undress and play with children).

F4: The Power of Technology

Technology can help enhance the recovery of a stroke survivor and can help in many other aspects of a person's life, especially since nowadays almost none of us lives without technology.

They all use some sort of technology in their day-to-day life and clarified they are comfortable with technology and all have smartphones and computers. They all also mentioned they are comfortable with social networks.

Most of the participants used some kind of technology in their rehabilitation sessions in a clinic or at the hospital. Especially in occupational therapy, they all used technology.

In terms of technology, the most common disadvantage addressed by the participants was the fear of doing something wrong when using technology.

Creative Workshops

In the creative co-design workshops, with the aid of the activity performed, design opportunities are found. The idea for the activity was created with the findings from the interviews.

Methodology: We conducted co-design workshops to discover the design opportunities by generating and discussing a wide range of ideas. An activity of creativity and idea generation was used to encourage discussion among the participants.

Participants: For the workshops, two of the previously recruited participants had to be excluded from the study, resulting in 4 survivors and their respectively 4 caregivers. The exclusions happened because one had no mild or severe physical impairments and therefore never experienced physical rehabilitation and the other one did not have a caregiver.

Procedure: Each caregiver/survivor pair did a design workshop separately. Initially, each pair aimed to find an analogy or a way to adapt a daily activity/hobby to their home rehabilitation using technology and including the two participants. To help, cards from different categories were created. These cards were created taking in mind what was disclosed with the interviews. The categories chosen were: Devices, Sensors, Features and Activities. All the different categories and respective cards are shown in Figure 1. In each cat-

egory, there are also blank cards with a question mark for the participants to create their own new cards.

The goal of this activity and the purpose of the cards is for the participants to join one or more cards from each category in order to find a solution. They were asked to think out loud when choosing the cards for the combinations so we can then analyse their choices. With the intention to facilitate the flow of ideas from the participants, two examples were shown so they could understand better what was expected.

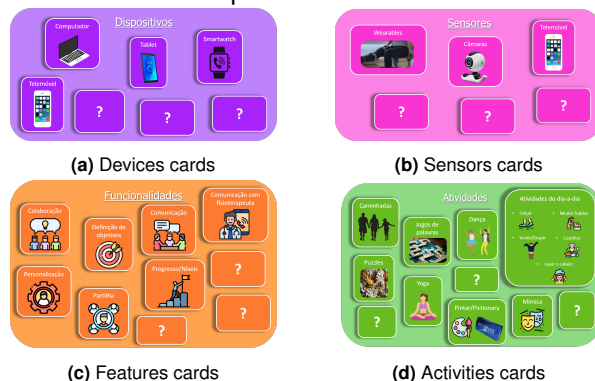


Figure 1: Set of cards from each category used to assist in the design workshop

Analysis: Just like the interviews, all the workshops were recorded. One of the researchers that created the codebook for the interviews created a codebook for the workshops as well, using an inductive approach. Then, that researcher coded the set of workshops. In addition, we also performed a quantitative analysis. For that, we quantified the most used cards.

Quantitative Results: In the devices category, the "Mobile Phone" card was the most used by far. The sensors category was overall not much used since it was not mandatory to include sensors cards. Despite that, the most common included card sensor was "Cameras". In terms of features, the most used and was "Sharing" followed by "Progress/Levels" and "Collaboration". When it comes to the activities, the only card activity used by all the participants was the "Daily Life Activities".

Findings: Co-design workshops helped disclose what are the things they value the most when constructing a technological solution for rehabilitation activities. We highlighted the more relevant findings: preferred and most used devices [F1], understanding sensors usefulness [F2], important features that lead to interesting conversations [F3], activities that attract the participants [F4] and overall discoveries [F5].

F1: "Everyone Owns a Mobile Phone"

Nowadays it is almost impossible to know someone who does not own a smartphone since this kind of device is a big part of our day-to-day life.

When given different options, inevitably people often chose the one they are more comfortable with and/or the most familiar one. Most participants opted to include a Mobile Phone in many of the solutions they constructed because they were familiar with its operation and features.

To see information on the screen, the participants prefer the screen where they can see everything more clearly, therefore, the biggest screen available and that is the Computer screen.

One of the most important things disclosed with the choices of devices by the participants was how much they value the device's portability.

F2: Sensors' Usefulness

Understanding the usefulness of sensors was the hardest part of the workshops for the participants. As mentioned earlier, participants find it easier to understand the things they already know. Given that, the sensors are what they have the least knowledge of and therefore they have more difficulty in choosing one to include in their ideas of solutions. The most chosen sensor was the camera because it is included in devices they use daily.

With the difficulties seen in this category and with their choices, we understood that to include a sensor in a solution it is important that it is hidden or included in a device they are familiar with.

F3: Features as Conversation Starters

The features category triggered several conversations which always led to the same conclusions.

For the survivors, one of their main sources of motivation is the recognition of their progress. When they have levels they understand that they are getting better as they reach the more advanced levels. In addition to that, it is essential to set goals. About setting goals, some participants believed the best would be to have a therapist set them but a caregiver (C4) stated that she could be the one to set the goals for her husband and he agreed.

During the workshops, several examples of how the caregiver can collaborate were given. Collaboration was found to be an important feature since it helps in making the survivors feel less alone. Also, most of the time including other people such as family or other survivors can help make activities more light and fun.

One of the most significant discoveries made with the workshops was how much survivors value the community and the feeling of not being alone. In all the workshops most of the constructed ideas included sharing as a feature and when talking about its importance all participants had a lot to say. As C4 said *"Sharing is good for encouraging others and mostly for fighting isolation"*.

F4: "If I Do It Then I am Interested"

The participants disclosed that the activities they could choose from were very different because

they tackled distinct aspects of rehabilitation and could be divided into two big groups: more related to physical rehabilitation or cognitive recovery.

In activities to move the body and recover physically, participants mostly chose Hiking because this activity was something they already did. Also because it is an activity where other things can be integrated. Activities such as Paint, Word Games, Mimic or Puzzles were chosen by the participants considering they are a sort of occupational therapy and are popular games in their households. They find these activities vital, especially because sometimes in in-clinic rehabilitation this part of their recovery is forgotten.

The fact that stroke survivors value personalization was proved when choosing activities for their ideas of solutions. Some participants decided to include specific activities they like to do such as Photography, driving, reading, taking care of plants or watching video conferences.

All the activities mentioned until now depend on people's tastes and people are only willing to do what they like. When it comes to Daily Life Activities it is impossible to escape, everyone does them on a daily basis. So a solution that includes this type of activity does not exclude anyone because of specific tastes.

F5: The Bigger Picture

With the workshops, we also disclosed common combinations from different categories. The first found pattern in combinations was the use of the Daily Life Activities card with the Sharing card from features. All participants constructed one solution using these two cards combined. In their solutions, the main idea was to share the way to do certain daily life activities. In most of these solutions, participants also used the Mobile Phone as a device. One important finding is the fact that all participants did one example with Daily Life Activities and they were all very similar.

Even though the caregiver involvement in the solution has advantages most of the time, some survivors pointed out that it is crucial for the caregiver to be less and less involved so they can feel independent.

Design Implications

We can say that the device the participants prefer is the mobile phone because it is the one they know best and because it is mobile, i.e., they can take it anywhere. Designing for a mobile phone can mean that the users will use the designed solution since they do not need to buy anything new or learn to use new technology.

When designing for the users, it is preferable to not include a sensor or if it is needed it should be covered in another technology they already know.

Sharing is one of the most important things to have in mind when designing for the stroke community. The survivors need to feel like they have conquests to share so it is important to design a solution that includes levels and progress. This way they feel motivated because they see their evolution and can share it with the rest of the community.

The participants believe it is almost impossible to have one activity to recover cognitively and physically at the same time. With that in mind, we should design for only one, either something to do with other people and where the progress can be seen or games or something they already know. The possible importance of daily life activities should be considered as it is an exception since it can help in both recoveries and also it does not take into account the preferences of people because everyone is forced to do them to live.

As we know since the start of this study, the active role of a caregiver in the rehabilitation process can be crucial [7], but it can also bring some tensions in the dyad's relationship as discovered during the interviews and workshops. Given this, the caregiver-survivor relationship should be considered as something important but with which we should be careful. The caregiver should have an active role at least as a motivator but the survivor can not feel too dependent. It should be a balanced involvement from the caregiver in the survivor's recovery journey.

5. PROTOTYPE - HomeGame

Taking in mind the related work previously discussed, the findings from the exploratory interviews and the creative workshops and the design implications, we constructed a prototype. This high-fidelity prototype is a possible solution of a technology for rehabilitation activities. All the ideas to develop this prototype emerged from the stroke survivors and their caregivers.

Approach

The approach followed was based on the design implications previously pointed and consisted in designing a prototype where the major theme was the gamification of daily life activities.

We chose to develop a solution based on daily life activities taking in mind that it is an activity that can help both recoveries - cognitive and physical. By taking this path, we can guarantee that we are not giving importance to particular preferences because this activity is not about preferences but about something they are forced to do every day.

The gamification elements used in the followed approach are points, levels and progress. We decided to divide the daily life activities into areas, for example, cooking or gardening, and in each area,

the user has a progress bar. This means that for each area of activities the user is at a certain level and can gain points to reach the next level. To gain points he must do a task in that area. Different tasks have different points. After the user reaches a certain amount of points he passes to the next level of that area where he will find new activities. With these gamification elements, the survivors can understand their progress, set small goals and achieve conquests.

One of the most important things the participants mentioned was the need to not feel alone and the benefits of having a community with whom to share the conquests and frustrations. The best way to reproduce this into a solution is by having a sharing feature. We decided that an important feature to include was sharing videos of the survivors doing their daily life activities. This video share is important because it helps survivors to feel motivated. They can also share some tricks to do particular tasks and that motivates others.

Because caregiver involvement is one of the most significant parts of this study, we should consider it when developing a solution. Since there was a drawback disclosed when analysing the workshops, we consider it could be interesting if we tested two versions of the prototype solution with the participants. The idea is to develop one version where the caregiver has a very active role and another where his role is almost insignificant. The importance of caregiver inclusion was one of the main focuses of this work and therefore it was deepened here as what differentiated the two versions was this level of inclusion.

In the first version, the caregiver does not have an application for himself. The caregiver can film the activities and help the survivor perform them if he needs. Here his role is more of a motivator and support for the specific tasks. In the second, the caregiver has a version of the app for himself. Here, it is the caregiver who defines how many points each task is worth. In the workshops it was found that this could be good motivation because the points would be personalized and given by someone who knows and believes in them. Besides this, the caregiver needs to approve the submission of tasks done by the survivor. This way, the survivors will not skip rehabilitation activities and the progress they see in the app will be the real one since they will not be able to cheat.

We believe that with two versions it is easier for the participants to describe why they like one more than the other and the different aspects they prefer in each version which can help us understand how important is the caregiver involvement after all and if the roles we previously disclosed are the correct.

System

We developed a solution called "HomeGame", which is a system to gamify daily life activities for stroke survivors. This system is composed of one or two applications, depending on the version. In the version where there are two applications, one is for the survivor and the other for his caregiver. In this case, they depend on each other to fully function as they are co-dependent.

After the initial sketch, the final prototypes were designed in a tool named Proto.io². There are many things in common between the two versions which are explained below, the specifics of each version are explained afterwards.

The first common thing is the survivor's sign up. The survivor can choose if their profile is private (only their friends can see the videos they publish) or public. They are also requested to choose their areas of interest. In the version with high caregiver involvement, the caregiver email is also requested to connect the two applications.

After this sign up, the home page with the areas of interest chosen is shown as seen in Figure 2. In the version with high caregiver involvement, on the home page, we can see the different areas and some are available and others are still waiting for the caregiver to give points. In the version with low involvement, seen in the Figure 2 on the right, the home page has all areas of interest available since the points are given automatically by the app.

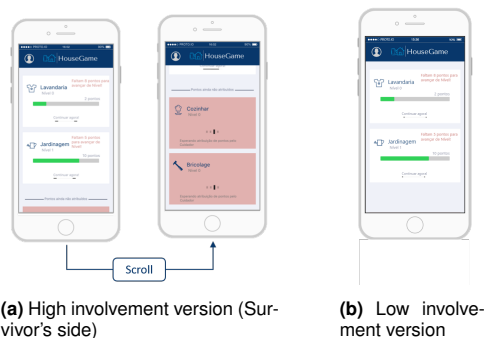


Figure 2: Home page screens

The user's profile screen and features is also the same in both versions. On this profile page, the survivor can see his friends, his friends requests and his published videos. He can also edit his profile. From the profile page when looking at the friends it is possible to access the profile page of a specific person. On that page, it is possible to then see their friends, their published videos from any task from any area and their levels on each of their areas. If the survivor wants to access the videos of a specific task instead of a specific person he should choose the task in its area screen and then choose to see the videos.

²www.proto.io

Version with Low Caregiver Involvement: In this version, the caregiver has only the role of helping in the specific tasks if the survivor needs or wants. This help makes them gain one less point. The caregiver can also film the videos of the survivor doing a task that he can then publish. Since this



Figure 3: Submit task

version is more simple, most of it is explained previously. The only part left to explain is the submission of a task done, which can be seen in Figure 3. After the survivor accesses the specific task page by pressing it in the specific area screen, he can choose to submit a video of himself doing that task and can choose if he did the task alone or with help. Then he can submit this task as done that task will appear green and together with the other already done tasks as seen Figure 3. Besides that, the points will increase as seen on the top of the screen in the progress bar.

Version with High Caregiver Involvement: In this version of the solution, there are two versions of the app, one for the survivor and another for the caregiver. On the caregiver's side, he does not need an account. He should enter the app with a link received on his email, which was previously provided by the survivor in the sign up.



Figure 4: Caregiver's home page screens

In this version, the caregiver has two main chores: give the points to the different tasks in each of the survivor's areas of interest (he can also delete tasks and add new ones) and approve the tasks the survivor does. The caregiver's home page can be seen in Figure 4.

In this version, the survivor can only do tasks of areas where the points were already given by the caregiver. If the caregiver did not define the points then that area will appear unavailable to the survivor and he will not be able to see the specific tasks until the caregiver gives the points.

On the caregiver's side, on his home page, he

can see the areas that are still missing the definition of points and below he can see areas where the points were already given. To define the points of a specific area the caregiver must choose that area and then he will see a slider for each task (between 1 and 10 points). After he defines the points for each task he can submit. After that submission, on the survivor's side, he will see that area as available. Besides this, the caregiver can also delete or add new tasks to an area.

On the survivor's side, everything is already explained except the way to submit the tasks done. In this version, the way to access the task is the same but after submitting the task as done it does not become green, i.e. done, as previously. In this case, the task becomes yellow and the survivor must wait for the approval from the caregiver. On the caregiver's side, he receives a notification and can approve the submission of the specific task. After that approval the survivor can see the task green, meaning it is done and approved.

Then, the two versions were evaluated by survivors and caregivers.

6. EVALUATION

After revisiting the objectives of our study, we constructed three research questions based on two dimensions: the involvement of the caregiver in the rehabilitation process and the motivation to do rehabilitation exercises at home with the help of technology. From these dimensions, we get our **three research questions** that we intend to answer through our study:

- **RQ1:** Is the caregiver involvement in the rehabilitation process valuable?
- **RQ2:** Is the approach of using daily activities to do rehabilitation appropriate?
- **RQ3:** Does the gamification approach of an activity give motivation for rehabilitation at home?

Methodology: We conducted evaluation workshops to get feedback about both versions of the developed solution for home-based rehabilitation and have a clear insight regarding the defined research questions. This evaluation was conducted via Zoom due to the ongoing Covid-19 pandemic.

Participants: The recruited participants were the same as the ones from the design workshops. For these evaluation workshops we did random combinations to join more than one caregiver and one survivor. The first group was composed of P1 and P2 and the second by P4 and P5.

Procedure: Initially, the version where the caregiver involvement is low was demonstrated. After, a whiteboard was presented to them to write the positive and negative aspects and the possible improvements. Each pair was asked to participate in turn. This peer sharing helped to streamline the

sharing of feedback on that version of the developed solution. For the other version of the application, the procedure was the same. At the end of this activity, all participants were asked to fill in a small form about the two versions of the prototype and choose their preferred version.

Analysis: The evaluations were recorded and one of the researchers that created the previous codebooks created a codebook for this activity and then coded the set. In addition, an analysis was also performed with the answers to the form.

Results

We gathered results from the coded workshop records, from the whiteboard and from the form responses (all answered except one caregiver).

From the participants' responses, we disclosed that the participants considered the overall idea of the prototype (using daily life activities for rehab, having levels and points and the sharing feature) good and innovative as most of them chose 5 (from 1 to 5) as seen on the graph in Figure 5. The responses from the survivors and caregivers are mostly equivalent and the majority is above 3.

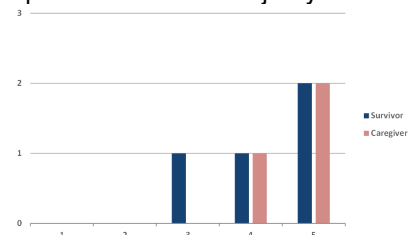


Figure 5: Overall evaluation of the idea

The majority of the participants (3 survivors and 2 caregivers) choose the version with low caregiver involvement as their favourite. This is due to the fact that they felt too dependent on the caregiver to make any progress on the other version. As quoted by S5 *"This always leaves us dependent on someone and we also need to move forward alone."*

From the workshops' findings, we believed there could be benefits from being the caregiver who defined the levels and goals for the survivor. Now, throughout these sessions, this was revealed to have unfavourable implications: friction in the relationship or the probability that the caregiver does not understand the true effort of a certain task and therefore will be unfair when giving the points.

They all agreed that the caregiver giving the points might be unfair and that is why, most participants, preferred the version with low caregiver involvement. Although this happened, the participants are also not fully satisfied with the idea of automatic points since it could also be unfair as they would be the same for every user and all users have different sequels.

After these generic questions, the participants had to answer three questions about both versions.

The majority of participants believe this application could have an impact on the rehabilitation process since their answers are above 8 and there are no answers below 5 (on a scale of 1 to 10) on this question. The results were the same for both versions as the participants believe the help this application can have is not influenced by the caregiver participation and involvement.

Afterwards, they were asked to evaluate each version on a scale of 1 to 10 (1 indicating that the caregiver involvement was incorrect, 10 indicating that it was correct). In the version with high caregiver involvement, most caregivers think their involvement is correct as they answered above 8. However, half of the survivors' answers are below 3. In the version with low caregiver involvement, there are no answers below 5. Therefore, in this version, all participants agree that the involvement is, at least, minimally correct.

Lastly, the participants answered if they would use this application on a daily basis. In both versions, the majority of the evaluations were 7 or above, however, in the version with low involvement there were answers below 5.

It was difficult to gather specific feedback on the whiteboards from each version as participants would give feedback that could be applicable to both versions. The feedback from two versions and the two workshops is presented joined.

Positive Aspects - Application easy to understand; Seeing videos is motivational; Points and levels motivate the users and helps them recognize their progress; Feeling of achievement from small goals when doing a task.

Negative Aspects - Only hemiparesis is considered; Only focused on domestic chores; Caregiver might not comprehend the difficulty of some chores and there is a possibility he finds it boring (only related to the high involvement version)

Possible Improvements - Include more activities (outside the house and for other sequels); Community gives points after seeing the shared video; Caregiver side of the app also include activities similar to the survivor but with different points.

As seen in the negative aspects of the whiteboard results, the participants believe that daily life activities can not be resumed to domestic chores as they are boring and an obligation. They suggested it would be more fun to include other activities that, for example, entail leaving the house.

As it was perceived with the whiteboard results, the majority of positive aspects are about gamification elements such as points and levels or about the sharing of videos. Therefore, the chosen features for this solution with the knowledge from the workshops were correct. The idea of sharing videos was well received by the participants and

corroborated our idea that sharing is important. The points and levels were also features whose importance was proved with these sessions. The value of these features was mentioned by C2, *"(...) with points you have achievements and personal recognition, that is good. I mean, the person herself, having this information, gives her self realization."*

Discussion

From the evaluation workshops, we understood that we have some possible improvements for our developed solution and some new ideas emerged. As viable improvements, we have the inclusion of other sequels and activities to help rehabilitate them. In addition, another improvement is adding more fun activities and activities people can do in a group, with that the users would be more satisfied with the developed solution.

The first new idea that emerged consisted of having the community vote for the points a task was worth for a specific person after seeing their video. This way the survivors would see this dependence as part of the game as there would be other people depending on them too. It would mean fewer unfair scores as they are given by vote and not dependent on one person's opinion. The other idea, consisted in changing the caregiver's side of the app so he would also have tasks to do. C5 gave this idea, *"(...) use the same application with the same tasks (...) but the caregiver's score would always be half that of the survivor for the same task."* This way the caregiver would be less probable to lose interest and the survivor would not feel dependent. The two ideas could be joined and be an upgrade from our developed solution.

When analysing the results of our system regarding its main objective, which is providing a solution to home-based rehabilitation including the caregiver where the stakeholders have an active voice, we believe the results are positive as seen in the graph in Figure 5. To corroborate this, we can disclose that the average evaluation of the idea was high (≈ 4.43) and the median was the highest possible (5). This means the participants felt their ideas were well represented with this idea.

Most participants believe the caregiver involvement is more correct in the version where his participation is low and choose the version with low involvement as their favourite. To answer our first research question (RQ1), this does not mean their involvement has no value it just means that we were not able to fully capture their ideal caregiver involvement in our solution. Considering the second proposed research question (RQ2), we can answer that the daily life activities approach was correct but incomplete. The participants found the idea over-

all good, therefore the main idea was correct. The critics made to the idea were all to make improvements and include more activities but it was never shown that the participants were unsatisfied with this idea. The third research question (RQ3) also had a positive answer. This is proven by the fact that most of the registered positive aspects were related to the gamification features.

Overall, this idea was well accepted by our sample from stroke survivors and their caregivers and we hope that with the upgrades and improvements mentioned it could satisfy even more people in this community. Quoting S1 "Yes, for a lot of people this can be very important and can help."

7. CONCLUSION

Nowadays, strokes affect many people, and it is expected to affect even more over the years. For the survivors, rehabilitation is essential in helping patients as it can help bring back some mobility and overall quality of life.

Frequently, the rehabilitation is performed at home after hospital discharge because of its convenience and comfort. Although there are many developed and explored technologies that target rehabilitation at home for stroke or other health conditions there are very few that consider the role that the caregiver might have in the rehabilitation process even fewer that consider involving the stakeholders in the design process. The approach used in this work can be extremely important because it is guaranteed that the needs and requirements are fulfilled perfectly. The major contribution of this work is the co-design process with the cooperation of survivors and caregivers that led to a home-based rehabilitation (HomeGame) high-fidelity prototype.

With this study, we heard the stroke survivors and caregivers voices and a group idea was developed. This idea can help stroke survivors recover faster at home with the contribution of their caregivers. Moreover, it can improve the quality of life for stroke survivors and their caregivers.

Our study's primary limitation is the small number of participants. Although a higher participant number would be advantageous, this number of participants still provided a relevant analysis of several trends in our results. The other main limitation was the ongoing pandemic Covid-19 that forced us to conduct our co-design method through an online platform instead of in person.

Future work for this study involves including the stakeholders in the development of the fully functional prototype for, for example, to give ideas for the areas of interest so they meet their preferences. Lastly, in the future, this solution application can be fully developed with the mentioned improve-

ments and a functional prototype can be tested to investigate its true usability and feasibility.

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