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

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To my mother, who was also an engineer
and would have been so proud of this accomplishment

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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

Resumo

Hoje em dia, 5 milhões de pessoas por ano ficam incapacitadas e com independência afetada devido a AVCs. Para esses sobreviventes, a reabilitação física é fundamental. Frequentemente, essa reabilitação é realizada em casa, após a alta hospitalar. São inúmeras as soluções tecnológicas para facilitar a reabilitação domiciliária. No entanto, as tecnologias atualmente disponíveis não reconhecem a oportunidade de impulsionar o papel dos cuidadores. Este trabalho consistiu num processo de co-design com sobreviventes de AVC e cuidadores para criar um novo sistema de reabilitação domiciliária. Começámos por realizar entrevistas onde revelámos os papéis dos cuidadores durante o processo de reabilitação, o estado emocional e a motivação de cada pessoa, as atividades que realizam (em família e de reabilitação) em casa e na clínica e o impacto e papel da tecnologia na reabilitação e nas suas vidas. Depois, conduzimos workshops de co-design que nos levaram a implicações de desenho como a necessidade de desenhar para telemóveis e de incluir funcionalidades para partilhar objetivos e conquistas. Com estas, duas versões de um protótipo de alta fidelidade foram projetadas - uma com alto envolvimento do cuidador e outra com baixo envolvimento. O conceito proposto consiste em gamificar as atividades diárias e incorporá-las no processo de reabilitação. Os sobreviventes e cuidadores avaliaram estas duas versões. Globalmente, os resultados foram positivos e os participantes preferiram a versão com baixo envolvimento. Foram mencionadas possíveis melhorias, mas concluímos que envolver os stakeholders no processo de desenho ajuda a projetar uma solução que se adapta melhor às suas necessidades.

Palavras Chave

Reabilitação Domiciliária, Reabilitação de AVC, Cuidador Informal, Co-design

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Acronyms

AT	Assistive technologies
CME	Caregiver-mediated exercises
CHI	Caregiver-mediated home-based intervention
CRSS	Collaborative Rehabilitation Support System
IMU	Inertial Measurement Units
VE	Virtual Environments
VR	Virtual Reality

1

Introduction

Contents

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 artery [1]. The number of stroke survivors has increased worldwide in all ages, and it is expected to increase even more due to an ageing population and lifestyle changes [2]. Nowadays, strokes affect approximately 15 million people per year, and of those, 5 million die and 5 million are left permanently disabled, limiting physical activity and affecting independence and quality of life [3].

1.1 Motivation

Stroke survivors often suffer from cognitive deficits (short-term memory loss, dementia, or aphasia) and/or impairments (visual field cuts or hemiparesis) that sometimes require lifelong medical intervention[1].

The focus of our work is the motor impairments and the physical rehabilitation that follows a stroke. This rehabilitation is considered critical in order to recover the survivors' functionalities and improve their quality of life. Evidence suggests that post-stroke rehabilitation exercises if repeated often, and with sufficient quality of movement, can lead to increased mobility [4].

Due to the escalating cost of healthcare and shortage of healthcare providers, post-stroke patients are often resigned to performing rehabilitation exercises at home[1]. Home-based rehabilitation has multiple benefits to offer, such as the possibility to do the exercises anytime. This approach gives the patients some freedom and provides a sense of control over the rehabilitation process. Moreover, the use of technology in this rehabilitation method is a major contribution to the success of patients' motor skills improvements, resulting in similar rehabilitation quality as conventional therapies by enhancing patients' activities of daily living [5].

Besides rehabilitation, when stroke survivors are discharged home from the hospital, they need assistance with basic and instrumental activities of daily living. This help is mostly given by an informal caregiver, which can be a family member or a friend. This caregiver 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. In addition to that, under some conditions, family-supported rehabilitation can achieve better outcomes than direct clinician-delivered rehabilitation [6].

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 [7]. Moreover, if the caregiver is involved there is a higher probability of the survivor having

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[1] www.stroke.org

a better utilization of poststroke formal care [8]. Despite having positive aspects, the involvement of the caregiver in the rehabilitation process can also lead to tensions between the dyad. Caregiver burden is a term used to describe the weight or load carried by caregivers as a result of adopting the caregiving role [9]. The caregiver can feel unease and we should be careful when including him in the rehabilitation.

1.2 Problem

Nowadays, there are countless technological solutions to facilitate home-based rehabilitation either for stroke survivors or for other health problems and disabilities [5]. **However, none of the currently available technologies for stroke survivors take into consideration the role of the caregiver and gives the stakeholders an active voice in the design process.** There is a major flaw with the available solutions: there is no consistent approach to support or involve the caregivers in the rehabilitation process [10].

Moreover, most of the current solutions do not 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.

1.3 Approach

Our approach was 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. By using user-centred and co-design methods, we will be able to understand the stakeholders' concerns and adapt the design of the technologies to suit their needs [11]. We will need to understand what is the caregivers' role in the rehabilitation process of the patients. Furthermore, we will make sure that both stakeholders' voice is heard during the design process, allowing them to participate and define priorities.

1.4 Expected Contributions

In this work, we understand the role of stroke caregivers in the rehabilitation process and how it could change the use and design of home rehabilitation technologies. We also intend to achieve a solution that can contribute to stroke survivors' rehabilitation and, at the same time, engage the caregiver in the rehabilitation process. Therefore, our contributions are:

- Understand the role of caregivers in the life and rehabilitation process of stroke survivors and how it could be improved with new technology

- 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
- A high-fidelity prototype of a home-based rehabilitation platform

1.5 Document Structure

This document is structured into seven chapters. The first chapter is the Introduction. Chapter 2 is the background, where we explore the caregiver-survivor relationship after a stroke. We explain the importance of a caregiver in the survivors' life and the important role that the caregiver can have in rehabilitation and motivation process. In chapter 3, we explore all the related work conducted around home-based rehabilitation technologies. We close this section with a discussion and a reviewed work analysis. Chapter 4 is where it is explained all the co-design methods used and the different steps needed to reach a grounded idea of a solution for rehabilitation at home. With this idea that came from the survivors and the caregivers themselves, a prototype was constructed and it is deconstructed in chapter 5. After, a final workshop to evaluate the prototype was conducted as explained in chapter 6. Finally, we close this document with the conclusion in chapter 7. In this chapter we also mentioned the our limitations and the possible future work that can arise from this work.

2

Background

Post-stroke Caregiver

An informal caregiver is typically a spouse, son of the stroke survivor or other family member. As we can recognize, caregivers can be very different in terms of background or even age [12]. These factors can affect how they carry on the role of caregiving. For example, when it comes to age, younger caregivers tend to focus on informational support while older feel that too much information is overwhelming. On a different note, older caregivers are more likely to focus on keeping a positive attitude to cope with the difficult times [10].

After being discharged home, stroke survivors rely on their caregivers to monitor their health conditions, oversee and support their rehabilitation activities, provide emotional support and assist in daily activities [13]. Although the caregivers appear to take on a more passive role post-discharge and usually are not present in the physical therapy sessions as recommended, most of the survivors describe caregiver involvement as high. When they have a more active role, the survivors often describe their activities as driving them to the hospital or calling 911, coordinating medical appointments and monitoring recovery [14].

Considering that a stroke cannot be predicted, in most cases, the caregiver is not ready for his role, which could be why they take a more passive-role post-discharge. So, assessing caregiver readiness during the inpatient stay and providing immediate follow-up at home to assist caregivers is critical [15]. Using a structured program of activities under professional supervision during inpatient rehabilitation may also empower informal caregivers in their future roles by teaching them appropriate skills [16]. Otherwise, the caregiver might not assist and support the survivor on his needs in the best way possible.

The caregivers summarize these various needs regarding rehabilitation and care under the following domains: body functional needs, activity and participatory needs and environmental needs [17]. The fact that the caregivers can identify several needs that perhaps the survivor, a designer or a therapist cannot, shows the importance of including them in the rehabilitation process.

The importance of their inclusion can also be perceived after a study developed by Haley et al. [12]. In this study, they concluded that in about 25% of cases, stroke survivors and caregivers agreed that caregiver engagement led to major improvements in stroke survivor care.

Caregivers in Different Health Conditions

The importance of caregiver involvement can also be seen when exploring studies about different health conditions where we always get the same outcome: the caregiver's support is crucial.

For example, considering traumatic brain injury, Foster et al. [18] state that it is highly recommended that family members be actively engaged in the patient's rehabilitation process since evidence suggests that this is associated with better outcomes. They also provide a description of practical examples demonstrating the attempt to improve families' support: through early engagement, meeting cultural needs, actively listening, active involvement, education, skills training, and support for community integration. This exploration of how to engage the families is important because it can improve the rehabilitation process.

Considering other health conditions such as dementia, a theory emerges that collaborative training has more positive effects due to its social nature. The caregiver may be regarded as a human support system offering the person with dementia a more socially engaged lifestyle. With the results from the study carried by Neely [19], it is shown that active participation of the caregiver matters in cognitive dementia rehabilitation and perhaps it can matter in all types of rehabilitation.

Older people's and their supporting family members' experiences of home rehabilitation is different. For them, rehabilitation is an ongoing process, considering bodily capability and a striving for well-being. We also need to consider that they feel dependent and struggle to carry on. Nevertheless, family support is perceived to be necessary for older peoples' rehabilitation [20].

Caregiver-Mediated Exercises

As we explored the relationship between the survivor-caregiver dyad, we discovered that caregivers have a significant role in the rehabilitation and daily life of survivors. Since caregiver or family mediated exercises in-home rehabilitation are efficacious and cost-effective in improving stroke survivors' functional recovery [16] its importance should be considered.

Caregiver-mediated exercises (CME) 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 [21]. These exercises are a safe way of improving the degree of independence, ambulation status, dynamic and static balance, trunk function, and concerns about post-stroke falls of stroke survivor [22].

Several studies show how CME can improve rehabilitation and be a sustainable alternative to conventional approaches. Among them is a controlled trial that examined the impact of additional family-mediated exercise therapy on outcome after acute stroke [23]. The results from the trial suggest statistically significant differences in favour of the group of patients who received the family-mediated exercises intervention in comparison to the group that received physiotherapy in rehabilitation units. Participants who received family-mediated exercises were also significantly more integrated into their community at follow-up. Their improvement in mobility is perhaps one of the factors that helped in the integration.

Since it can be performed at home, the therapy based on CME 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. A study developed in Taiwan demonstrated that a Caregiver-mediated home-based intervention (CHI) could improve physical functioning and social participation in chronic stroke patients [24].

The discussed importance of the caregiver-survivor relationship and the relevance the caregiver can have in the rehabilitation process, with CME and CHI as example, are factors that should be taken into account when considering home-based rehabilitation.

3

Related Work

Contents

Much work has been done to study the feasibility of technologies for home-based rehabilitation or present new solutions. In this section, we explore the description of the Frameworks for Rehabilitation Technologies and after, we also categorize previous work in Stroke Home-based Rehabilitation Technologies and Technologies Including Caregivers.

3.1 Frameworks for Home-based Rehabilitation

Design frameworks are useful when understanding and designing a system for stroke rehabilitation because they summarize the requirements and needs for developing such system/technology.

When dealing with scalability and personalization of support systems, Balaam et al. [25] establish the following themes around the key lessons and guidelines: (1) Helping people articulate what motivates them: what they say initially and what would motivate them over time might be different; (2) Balancing work, duty and fun: how much exercise can be added to an activity before the exercise overwhelms the activity; (3) Supporting motivation over time: input devices need to be easily extended or narrowed as an individual's physical ability improves or deteriorates over time and (4) Understanding the wider social context: any device needs to be acceptable both to the recovering individual and other members within the family. A support system's main requirements can be summarized as a diverse range of activities, autonomy over the level of exercise and easily configurable and changeable. In addition to that, the design of these systems must take into account the social and spatial context of where the rehabilitation will take place.

Egglestone et al. [26], developed a framework for home-based stroke rehabilitation. This framework was developed using data collected in a series of workshops with people living with stroke and professionals who learned about the social context around stroke care. The key themes and requirements for home-based stroke rehabilitation technologies discovered after the workshops are divided into two big themes: (1) Designing for the wider social context of strokes: for example, the system should be cheap and personalized, the system should stand without outside support, the system should take in consideration the difficulty for participants who may have impairments and (2) Specific technology features: for example, the system should change to meet new interests or abilities and the system could respond to poor quality movements and give feedback that could be used by therapists to monitor progress.

Bagalkot and Sokoler [27] suggested how to embrace the difference between the clinic and home environments in designing tools for physical rehabilitation. Usually, home rehabilitation is only used to complement the clinic rehabilitation but rehabilitation tools, prescriptions and routines can be boxed and shipped from clinic to home and be adapted. The embodied actions taken into account here are *self-monitoring* by recording and measuring progress and *self-articulation* by sharing self-monitored data. The patients can articulate how the treatment went and *social scaffolding* by sharing data with peers and using it as motivation. With this exploration by Bagalkot and Sokoler, it was concluded that are three ways in which technology can be designed to support the three kinds of embodied actions: turning already ongoing activities into legitimate rehabilitation exercises, strengthening the already engaged social relations as an encouragement to exercise at home and turning familiar physical artefacts into resources for complying with the treatment. In order to use these design ideas, different types of technologies can be used.

The types of technologies used for home-based rehabilitation after stroke and the design requirements for such technologies are explained by Chen et al. [5]. These technologies are games, telerehabilitation, robotic devices, Virtual Reality (VR), sensors and tablets. For a better design of home-based rehabilitation technology, it is required to consider the internal and external factors, such as motivation and time management, respectively. With this, we also understand that designing for motivation and home environment are important requirements for home-based stroke rehabilitation technologies.

When designing home-based rehabilitation technologies, it is extremely important to design considering the home environment. Axelrod et al. [28], make clear that technologies need to be designed to consider ‘real’ homes and ‘real’ lives of the people who have had a stroke. With that said, we need to design options that fit current realities instead of designing for futuristic ‘smart-homes’. With house visits, a major theme in this project by Axelrod et al. was also discovered: the need to personalise approaches and treatments to the individual’s needs at multiple levels (each house is very specific so we must design different things to motivate different people).

3.2 Stroke Home-based Rehabilitation Technologies

As stated before, there are many different technologies for home-based rehabilitation after stroke.

Tablets

One of these technologies is the use of tablets. A feasibility study using tablets was conducted by White et al. [29]. In this study, clinicians selected and installed a range of apps addressing speech/language, visual/cognitive processing, mood and physical function. Then, stroke survivors used an iPad with those apps for three months after hospital discharge. With this, we discover that tablet technology provides a platform to increase the variety and intensity of therapy. Also, the quality and intensity of patient care can be increased, time travel to clinics can be reduced, and the survivors are given the ability to self-manage their health conditions. White et al. also discover that the iPad was non-burdensome and its use was a positive and beneficial experience.

Besides feasibility studies, there are also some review studies of tablet use for rehabilitation. For example, Ameer and Ali [30], analysed the use of iPad in stroke rehabilitation and explored the different apps that can be used in rehabilitation. Such apps can facilitate social interaction (e.g., Skype), have recreational use (e.g., gaming applications) or be educational and provide stroke survivors with up-to-date and on-demand health information. It is given an overall look at the studies done before with iPads and stroke survivors. Therefore, we get the information that iPad technologies might be useful to rehabilitation since it helps survivors fight boredom, social isolation and disengagement.

Telerehabilitation

Another technology used for home-based rehabilitation is telerehabilitation. Piron et al. [31] evaluated the effects of a telerehabilitation system on arm motor impairments therapy due to a stroke. Five subjects used the telerehabilitation system for four weeks. This system consisted of two PC workstations - one at the patient's home and another at the rehabilitation hospital. It also had video-conferencing which allowed telemonitoring of the therapeutic sessions. The workstation was equipped with a 3D motion tracking system to record arm movements. The patients did virtual tasks conducted by the therapist at the remote workstation. During the performance, the patient could see his movement and the correct trajectory, as prerecorded by the therapist. At the same time, the therapist provided feedback through the video-conferencing. With this study, we can conclude that telerehabilitation may represent a valid method in addition to conventional home-based therapy, which can be realized by the tele-interaction between the patient and the therapist. Telerehabilitation hence may provide a low-cost solution to a set of patients because these procedures do not require any displacement of the users from their natural location.

Virtual Environments

It is also possible to use Virtual Environments (VE) for rehabilitation. In the study developed by Holden et al. [32] VE are joined with telerehabilitation to test the feasibility of deploying a system in a home-based environment. The system combined video conferencing and a real-time VE software which provided a rich interactive training system. The training was designed to improve four categories of movement control: reaching movements, hand body movements, repeated reciprocal movements and control of the hand. These categories were measured using clinical standard tests four times: pre-training, post-15 sessions, post-30 sessions, and four months follow-up. Overall it shows that this novel VE and telerehabilitation system appears to be effective in improving motor control and functional performance in subjects with chronic stroke.

Combined Technologies

Sensors can also be combined with telerehabilitation as it happens in the study developed by Palmcrantz et al. [33]. In this study, an interactive distance solution - DISKO tool - was developed to enable home-based motor training after stroke. Its feasibility and safety were explored in different rehabilitation phases. The study involved 15 patients who participated in 15 training sessions. The DISKO tool integrated a video communication system, remote patient monitoring and evaluation of stroke-specific individualized movement - controlled exercises. The tool included six exercises that could be selected to perform. Follow-up sessions with therapists were done to provide real-time feedback, adjust the difficulty level, and provide follow-ups to unsupervised previous training sessions. When interviewed, the patients stated difficulty in selecting a place for training and training itself, having, sometimes, to seek help from caregivers. They also often had trouble finding the right level of training. With this study, the DISKO tool was found to be useful and safe by patients and physiotherapists. Palmcrantz et al. also guide further development and testing of interactive distance technology for home rehabilitation.

There are other possible combinations of the technologies already explored, for instance, Wittmann et al. [34] joined VR to a sensor and gaming. They developed a study to understand this solution's feasibility for unsupervised arm therapy for self-directed rehabilitation therapy in patients' homes. The patients used the ArmeSenso system in their homes for six weeks. This system consists of a VR arm rehabilitation platform based on wearable Inertial Measurement Units (IMU) to detect compensatory movements. In each rehabilitation session where the system was used, there was a guided start, an assessment and a game. In this therapy game, the patient trained reaching velocity, arm coordination, and arm pointing precision by integrating a virtual arm that matched the patient's arm's movement. The wireless IMU captured such movement. Elderly patients and patients without gaming experience were able to use this system. This study proved that self-directed home therapy with an IMU-based home therapy system is safe and can provide a high dose of rehabilitative therapy.

Games

Games can also be used to conduct rehabilitation without any other technology, as shown by Tang et al. [35]. They proposed a Collaborative Rehabilitation Support System (CRSS), where mobile-based interactive games are included. With this, they expand in-home rehabilitation to self-rehabilitation, which allows users to perform rehab anywhere and anytime. This study proposes a CRSS system with a mobile application to provide stroke survivors with an easily accessible and interactive rehabilitation approach to improve their upper extremity function. There are two methods to access this system: through an app or the web. To perform rehab exercises, the user uses the app with games, but the therapist uses web access to see the rehab records and make new plans. In this system, rehab exercises are integrated with interactive games to improve the engagement and motivation of stroke survivors. In the games, users control the animated figures through different rehabilitation exercises (e.g., forearm rotation), and then feedback is provided. Stroke users are very happy with this solution since it is an alternative approach to rehab practice.

User-Centered Technologies

Besides these technologies and systems that explore existing solutions, there is the possibility to design specifically for the survivor. Balaam et al. [25] presented the experience of building systems that motivate people to engage in upper limb rehabilitation exercise after stroke. So far, most technologies for home-based rehabilitation are not focused on the motivations of the survivors. As a solution, in this experiment, the design was made bottom-up. Each of the four survivors was interviewed, and it was found what was their main motivator. After some alterations, all of them experienced the prototypes, and after a few weeks, it was evaluated how good these prototypes were. For example [4], through conversation with one of the survivors, it was perceived that he liked playing chess and had a lack of fine control in the fingers of his left hand. Knowing this, a chess game that helped rehabilitation was built, as seen in Figure 3.1. Each chess piece was a card with a pressure sensor, and the chess game was played on the computer. When playing the game, the survivor cannot select any pawns without first squeezing the card representing that same pawn.

(a) Tangible chess board **(b)** Grasping a chess piece **(c)** A chess game in progress

Figure 3.1: Chess game for rehab in which the patient is controlling pawns with the sensor input device

Other solutions like this were developed, such as, the Rehab Reader, which motivated rehabilitation through reading: squeezing a switch caused the text to advance by one line. The Ball Funnel was another of the solutions deployed. This solution consisted of a game where the patient plays with her son, throwing a ball at each other. Social interaction and family closeness was the main motivator for this patient. Solutions like this should be taken into consideration since it helps in motivating the patients.

3.3 Technologies Including Caregivers

As seen in the previous sub-section, numerous technologies and solutions can be applied when developing a home-based rehabilitation platform for stroke survivors. However, none of the reviewed solutions involved caregivers or considered them for an active role in rehabilitation.

Nevertheless, there is some work performed around technological solutions regarding health conditions, other than stroke, where the caregiver has a vital role. The caregiver can also be the main subject of the solutions, or the solution can work as a replacement for the caregiver. This issue can happen due to technology being increasingly either occupying or sharing the role traditionally occupied by humans.

Assistive Care Systems

Systems that assist in care are outlined by Haigh [36] as: (1) Smart Home Technologies: systems that have sensors that monitor the occupants, communicate with each other and support the occupants in their daily activities; (2) Targeted Assistance: projects that target specific problems within the more general category of supporting people in their homes; (3) Broad-based Assistance: systems that address numerous issues for supporting people in their homes; (4) Assistive Robotics: robots to assist people with personal care and assistance; (5) Electronic Travel Aids: systems to assist in compensating for the patient's lack of sight; (6) Robotic Wheelchairs: seeks to address issues such as safe navigation. These systems can remind people to take medicine, monitor the health and safety of people who live alone or help them move around.

Assistive technologies (AT) are examples of a solution created to replace the caregiver or take some of the burdens off them. According to Madara Marasinghe [37], AT assist caregivers by reducing assistance and energy put towards caregiving, anxiety and fear, task difficulty, safety risk (particularly for physical assistance), and increasing independence of the user.

Some studies have been elaborated in this area, such as the one published by Mortenson et al. [38]. In this study, an investigation was conducted to determine if a caregiver-inclusive AT intervention improved older care recipients' functional autonomy and decreased their family caregivers' burden compared to regular care. Dyads comprising a care recipient and family caregiver were randomly assigned to either a caregiver-inclusive experimental group (N= 44) or a customary-care comparison group (N=46). Similar caregiver involvement was evident and caregivers' activity-specific and overall burden decreased significantly in both groups. This research suggests that there may be beneficial effects on AT that involve caregivers.

The intelligent COACH system is one of many smart home technologies, which can also be beneficial. This system was elaborated by Hwang et al. [39] in co-design sessions with informal caregivers of older adults with dementia. They explore the participatory design approach and the tensions that challenge the system's user interface design, which assists with daily living activities in the home. The study was conducted with six participants who were part of two 90-minute group participatory design sessions. In the first session, participants were asked to reflect on the discussion and write or sketch ideas, scenarios or designs on their envisioned interaction with COACH. The second session aimed to gather participants' feedback and design recommendations on preliminary UI designs. The second UI design iteration was developing a paper prototype, as we can see in Figure 3.2, for usability testing on five tasks. Following the usability test sessions, a list of suggested prototype revisions, user recommendations, and design considerations was gathered.

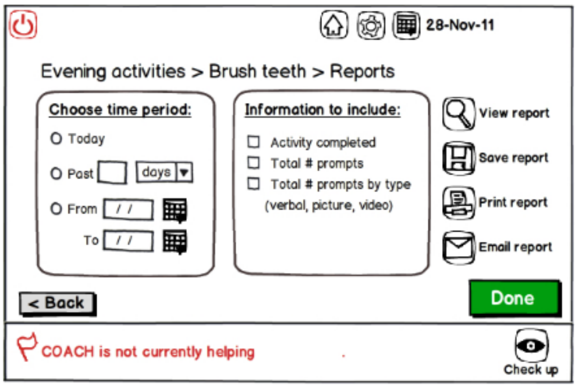


Figure 3.2: Paper prototype used for obtaining a report from COACH

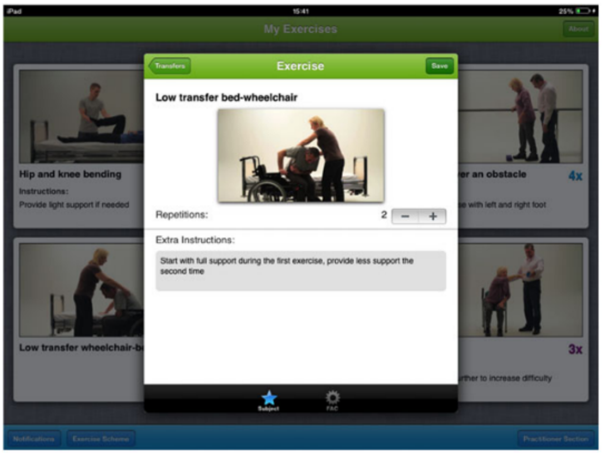
Another approach of solutions that assist the caregiver in the job of caregiving is e-health tools. There are different paths to take when addressing assistance and e-health tools can help in various ways.

Giroux et al. [40] developed an investigation in partnership with community organizations, health professionals and caregivers. This research explored an e-health tool that promotes the early identification of the needs of older people and the optimal use of available resources. This tool is meant to help caregivers optimize their process of seeking help and prepare for the disease's trajectory. The tool was developed using a co-design approach with eight sessions, ensuring that the tool met the user needs. In the sessions, the needs and requirements were identified, a low fidelity prototype and Web mock-ups were developed. With this initiative, caregivers can have more control over the various situations as they will be better equipped to deal with them. Besides that, the patient can count on quality help from a better-equipped caregiver.

Cristancho-Lacroix et al. [41] also made a user-centred design approach when developing a web-based psycho-educational program called Diapason. In this case, the tool was developed for caregivers of people with Alzheimer's disease and aimed to reduce their stress. It consisted of the following tools: disease information in 12 weekly sessions, relaxation guidelines with training videos, caregivers' testimonials, and stimulation activities for the relatives. The design process included three parts: project team workshops, proof of concept and two usability tests. The design approach used provided valuable guidelines for the program and improved website usability. With this, we understand that the implementation of web-based programs requires the adaptation of the system to match the needs of target populations, in this case, to match the needs and requirements of caregivers.

Despite having previously discussed the importance of caregiver-mediated exercises in rehabilitation after stroke, there is yet a topic that has not been touched. These exercises are sometimes complemented with e-health tools.

The CARE4STROKE program developed by Vloothuis et al. [21] is an appropriate example of this combination. The caregiver-mediated exercises and repetitions are chosen by the therapist, taking into consideration the patient's needs and goals. These exercises and repetitions can be adapted to meet the new patient's ability. On top of that, new exercises were always practised in therapy sessions. These exercises are under five domains: lying, sitting, transfers, standing and walking. Some examples are stair climbing, hip flexion or low transfer from bed to a wheelchair, as seen in Figure 3.3. The e-health tool used in this program is an app that consists of videos with a voice-over explaining and demonstrating the exercises. On the application's therapist side, he can tailor the exercise program, for instance, choose the exercises and number of repetitions. The selected videos and repetitions are displayed on the patient side, reminders to exercise can be set and there is a diary to record exercise adherence. This process is a good rehabilitation method as it gives the patient freedom (and caregiver, since the exercises are caregiver-mediated) to decide when to do the exercises. It is also good because of its adaptability to the new patients' abilities.



Low transfer bed-wheelchair

Repetitions: 2

Extra Instructions:

Start with full support during the first exercise, provide less support the second time

Instructions:
Provide light support if needed

e with left and right foot

rther to increase difficulty

Figure 3.3: Exercise video from the CARE4STROKE app

Another example of a similar approach is the trial conducted by Van Den Berg et al. [42]. In this proof-of-concept trial, the effects of caregiver-mediated exercises combined with telerehabilitation services on patient's mobility and caregiver burden were investigated. The intervention consisted of a caregiver-mediated training program with support using a customized exercise tablet app. Telerehabilitation services through a video conferencing app to provide access to the treating therapists was also used. This combined solution proved to be promising as it augmented the intensity of practice resulting in improved daily living activities from the patient. In addition to that, caregiver levels of fatigue decreased and feelings of self-efficacy increased.

In rural China, Yan et al. [43] developed and implemented a simplified stroke rehabilitation program where nurses and family caregivers were used for service delivery and combined it with an app. Nurses were trained by rehabilitation specialists and in turn trained the family caregivers in the intervention group. The intervention, follow-up care, and evaluation were guided by the RECOVER mobile phone app specifically designed for this study. This app substantially decreased the nurses and family caregivers workload and enhanced their efficiency to manage and help patients. As the ones previously discussed, this solution also has the potential to improve the health and function of stroke patients while also relieving the caregiver burden.

These solutions suggest that CME with e-health support is a safe way to augment the intensity of practice at home.

In addition to e-health tools, other interesting approaches exist to help caregivers, such as video coaching tools. In that case, the tool aims to help the caregiver learn about therapy and/or cope with daily life activities. Alabdulqader et al. [44] explore the coaching needs for mothers of children with cerebral palsy and a video coaching tool's feasibility. Video coaching has been explored to address the challenges of home therapy delivery. This tool was developed in workshops with the mothers and therapists and consisted of parents sharing a video recording of the parent-child interaction annotated with their comments. They would then get the needed feedback from the therapist. Therapists would equally annotate the recording with comments and engage in coaching discussions via their smartphones. The recorded videos of the mother-child interaction work as leverage for the therapists as they understand the real context and interactions patterns, something that cannot be accomplished during a home visit. With this, video coaching technologies were perceived as having the potential to offer valuable support to caregivers and therapists.

Therapy Systems

All of the solutions presented before are not rehabilitation technologies as they are more technologies that aim to assist the patient or the caregiver. In terms of therapy, there are very few studies that explore solutions where the caregiver is included. Bagalkot and Sokoler [27] presented one of the scarce studies that are developed around this area. They present three in-situ design explorations for three different and specific patients. The first design was ”MagicMirror” which consisted of a platform with pre-recorded videos of exercises to help recreate them at home and has the option to add notes to give to the therapist. Another design developed was ”Reswing” which incorporated a mat and led lights that lit up whenever the patient uses the swing to do the rehabilitation. This solution used an activity already done by the patient and involved her husband that saw the lights gain colour and gave feedback. These factors gave the patient motivation. The last design developed was ”Reexercise”, which consisted of a mat and led lights and used motivation through religion and his wife's help. The light in a religious figure would light up if the rehabilitation exercises done with the help of his wife were correct.

As perceivable only in two of these solutions, the caregiver plays an active role and participates in the design and the therapy itself. Despite existing few examples, it still gives us a base on how the caregiver

Figure 3.4: Patient exercising with the ReExercise mat connected to the LED on a religious figure

can be included in the rehabilitation technology design process and how, after, they can participate in the exercises.

On another note not deeply explored here, the caregivers can be formal, such as clinical staff, instead of informal as observed in the studies considered before. RehabMaster is an example of that approach. It is a technology developed by Seo et al. [45] based on a serious games approach to rehabilitation. This platform uses games as a major home therapy session to motivate outpatients while training at home. RehabMaster was designed to address stroke patients' motivation and the feedback and feedforward of rehabilitation information for the clinical staff. The patients are given a training set from 36 types of exercises defined by the therapist. Dynamic difficulty adjustment is applied to suit the different types of patients and their skills. The performance and training data gathered by the platform is made available to the therapists (feedback). Based on this knowledge about the patients, therapists can prescribe the rehabilitation therapy for the patient recommended by the platform (feedforward). This platform was designed considering that all the stakeholders should be considered for a rehabilitation program to be effective. In this case, the clinical staff participated in the interviews to understand how stroke patients' rehabilitation process works. Clinical and usability tests were carried out. The results suggest that serious games and motion-based rehabilitation programs like RehabMaster can contribute to a patient's upper limb motor function improvement.

Although they are a good foundation, none of the studies discussed here, presenting different rehabilitation technologies solutions, faces the major issue we found - that the caregiver is not included in the rehabilitation process after a stroke.

This way, it is important to understand how caregivers can be included in a patient's life and how technology can help in this process.

3.4 Discussion

To gather the conclusions about the work previously done and reviewed in this section, we compare them in different categories as presented in Table 3.1. The domains for this categorization are the following:

Rehab Target: Gives us information about the rehabilitation audience, whether stroke rehabilitation patients or patients with other health problems. At this moment, we can perceive what has been done in our field of work. We can also recognize what has been done in other fields and that, perhaps, can be adapted to fit our area of interest.

Stakeholder Involved in Design Process: There are several ways of involving the stakeholders in technology's design process. To illustrate that, we categorized this involvement as high, low or none. We should keep in mind that the developments made without any participation of the stakeholder(s) may end up not including their needs and requirements, which can be a disadvantage. We categorized as low involvement from the stakeholders the solutions that require efficacy or feasibility tests from them. There are usually about one dozen patients in these solutions who use the technology developed for a few days or months. This situation happens after hospital discharge, and then conclusions are gathered. These studies aim to explore the feasibility and safety of using the technology developed. Since the stakeholders are needed for the tests but do not participate in any other step of the design process, we can consider their involvement low. In order to engage the stakeholders in the design process and therefore consider their involvement as high, different approaches can be carried out. As developed in different studies [27] [25], interviews can be conducted to understand the problems, the needs and preferences of the stakeholders and afterwards include them in the solution's design. Another form of high involvement in the design process is by conducting design workshops where participants are asked, for example, to sketch ideas, scenarios, or designs on their envisioned interaction with the system that was being developed [39]. These workshops can also identify the requirements, brainstorm on the paper prototypes and then test the final one [40]. We can conclude that engaging the stakeholders in the design process may have numerous advantages, such as informing caregivers on the technology's potential in development and acknowledging and overcoming deferential attitudes.

Main Stakeholder: With this category, we can separate the main stakeholder of each explored solution. In most of the work reviewed involving stroke care and rehabilitation, the main stakeholder is the survivor/patient himself. Regarding other health problems, the main stakeholder is usually the caregiver as these solutions often offer help to the caregiver in his caregiving job. Only a few studies and technologies tackle both the patient and the caregiver. Given the caregiver's importance in the patient's recovery, we believe that these are important studies. This shared role of the main stakeholder can be carried out in various ways. The caregiver can be involved in the rehabilitation exercises and have an e-health tool to help him [21]. Another way is to involve the caregiver in the AT instead of replacing him, making the patient and the caregiver the main stakeholders [38]. The caregiver can also be involved in the feedback process in addition to helping with the exercises [27].

Caregiver Involved in Rehab: Usually, the involvement of the caregivers is regarding the help the patients need to perform the rehabilitation exercises and provide them feedback [44] [27] [21]. Often, this involvement can also include technology to support the caregiver, and it can be an e-health tool or a video-coaching tool. We categorize this involvement as ’Yes’. In most of the work reviewed, the caregivers have no involvement in the rehabilitation process, so their involvement is categorized as ’No’. They do not have any active role during the rehabilitation exercises or after when they do not provide and are not asked to give feedback or help.

Table 3.1: Categorization of the work reviewed in this section

	Rehab Target	**Stakeholder Involved in Design Process**	**Main Stakeholder**	**Caregiver Involved in Rehab**
Ameer and Ali [30]	Stroke	None	Patient	No
Balaam et al. [25]	Stroke	High	Patient	No
Holden et al. [32]	Stroke	Low	Patient	No
Palmcrantz et al. [33]	Stroke	Low	Patient	No
Piron et al. [31]	Stroke	Low	Patient	No
Tang et al. [35]	Stroke	Low	Patient	No
White et al. [29]	Stroke	Low	Patient	No
Wittmann et al. [34]	Stroke	Low	Patient	No
Alabdulqader et al. [44]	Other	High	Caregiver	Yes
Bagalkot and Sokoler [27]	Stroke/Other	High	Patient/Caregiver	Yes
Cristancho-Lacroix et al. [41]	Other	High	Caregiver	-
Giroux et al. [40]	Other	High	Caregiver	-
Hwang et al. [39]	Other	High	Caregiver	-
Mortenson et al. [38]	Other	None	Patient/Caregiver	-
Vloothuis et al. [21]	Stroke	None	Patient/Caregiver	Yes

Lastly, we can close this section by accomplishing the knowledge gathered from previous studies and their comparison. We can, therefore, comprehend the lack of solutions where the caregiver is involved in rehabilitation. We consider the stakeholder’s involvement in the design process important, and so when focusing on only those studies regarding stroke, the scarcity is even more obvious. Only the work of Bagalkot and Sokoler [27] and the work of Vloothuis et al. [21] fill the requirements of having the stakeholders engaged in the design process and having the caregiver involved in the rehabilitation. In the first one, the solution is not perfect as the rehabilitation is done using an activity the patient already did, so the rehabilitation exercises may be incorrect. The caregiver is either only helping with the exercises, having no interaction with the technology, or only providing feedback based on the interpretation of such technology's feedback. In the second one, the technology developed does not help in the rehabilitation exercises themselves. It just helps the caregivers make sure the exercises are correct by following the videos provided. 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

Contents

As mentioned previously, involving the stakeholders in the design process can lead to a better solution that fits their needs. Below is an explanation of the used co-design process, followed by a description of the several steps that we took.

4.1 Methodology Overview

Technology designers need to consider that the fundamental paradigms they design around might not be the ones the users need. Given that, participatory and co-design have been gaining more value through the years.

In health informatics, many technologies fail to be adopted by the intended users. However, participatory design methods that involve target users in the development process can help. This method can be seen in studies like the one carried out by Sjoberg et al. [46] or by Nasr et al. [47]. These studies found that it is critical to connect with potential users before developing technology to determine user requirements and then design system requirements based on users' perspectives.

In a participatory methodology, the researchers' design **with** people rather than **for** the people. They see the people as the true experts in domains of experience such as living, learning, and working [48]. In participatory design methods, users are active members of design teams. Design researchers see them as co-creators in the design process [48]. This happens because they help develop the prototypes and make decisions alongside designers. By having the presence of users, this approach gives them the power to represent their own needs, constraints, goals, and priorities instead of relying on designers to understand and represent them. This presence also results in better technology and a better understanding of the technology by the users [49].

The participatory design also boosts mutual learning, where users learn from designers and designers learn from users [49]. The designers gain knowledge of the work context, and therefore the new technology will explicitly incorporate the work system's values, history and context [50].

Additionally, Sanders [51] believes that the participatory experience is a mindset and attitude toward people, not just a method or set of methodologies. It is the belief that everyone can contribute to the design process and that when given the right tools to express themselves, they can be both articulate and creative.

Participatory design is an approach that attempts to actively involve those who will become the "users" through the design process to help ensure that the designed product/service meets their needs. [48]

Creating together entails more than merely drawing on the personal knowledge of internal and external stakeholders. It is about uncovering their distinct and collective perspectives on the systems in which people exist, and this is why collaboration is essential.

The collaborative approach that is participatory design is important when designing for people with disabilities such as stroke survivors. Knowing that they made adaptations to their lives, we can say that nobody completely understands their needs like themselves.

Nasr et al. [47] understood that to design home-based rehabilitation technologies, survivors need to make sense of their experiences of living with stroke.

Moreover, if we want the solution to be viable and have an impact on their lives they need to be involved in the development process. A technology that reflects user priorities and preferences can only be achieved by involving users in the design process [49], and that is what we aim to obtain with this work. More specifically, linking stroke survivors' goals, motivations, behaviour, feelings, and attitude to user requirements before technology development has significantly improved the design of such technology [47].

That is why for this study, the methodology used to design a high-fidelity prototype combined multiple research methods and had a couple of steps. The first was to conduct semi-structured exploratory interviews and, the second was to organize and conduct co-design creative workshops. The interviews helped disclose the caregiver role in the rehabilitation process and life of the survivor and the potential of technology. Then, an idea for a design activity to do in the workshops was created with the findings from the interviews. In these workshops, with the aid of the activity performed, design opportunities are found.

The Ethics Committee of Instituto Superior Técnico, University of Lisbon approved this study. The respective form and approval are in the Appendix A.

4.2 Exploratory Interviews

The exploratory interviews were a base to answer our first research questions. These key questions include: What roles do caregivers play during the survivors' rehab process? What is the emotional state of the pair and how that affects the rehabilitation process? What are the current rehabilitation activities practised? What benefits and concerns do survivors/caregivers perceive from current rehab technologies? To address these questions, we executed interviews with 6 stroke survivors and 5 caregivers.

4.2.1 Methodology

We conducted semi-structured interviews to disclose the caregiver's role in the rehabilitation process and in the survivor's life. Moreover, the interviews allowed us to inquire about family dynamics after the stroke, having a perspective of both participants. These interviews were conducted online via Zoom due to the ongoing Covid-19 pandemic.

4.2.1.1 Participants

We recruited 6 stroke survivors and their informal and main caregivers (if existent). Participants were recruited through a local support organization for stroke survivors named ”Portugal AVC”. Exclusion criteria for the recruitment included people with severe cognitive or communication impairments, which would prevent them from fully participating in the interview. All participants were Portuguese and their ages ranged from 37 to 71 years old. Although the dyad’s relationship was not a criterion, all caregivers were spouses or partners. This and other demographic information about the participants can be seen in Table 4.1.

Table 4.1: Demographic information about participants
(F - Female, M - Male)

Pair ID	Stroke Onset	Type of Stroke	Impairments	Relationship	Survivor/ Caregiver (ID)	Age	Gender
P1	5 years	Ischemic/ Hemorrhagic	Hemiparesis Left Side, Neglect	Spouse	Survivor (S1)	37	F
					Caregiver (C1)	-	M
P2	9 years	Ischemic	Hemiparesis Left Side, Hypotonia	Spouse	Survivor (S2)	44	F
					Caregiver (C2)	-	M
P3	14 years	Ischemic	Aphasia, Dexterity Issues	Spouse	Survivor (S3)	62	M
					Caregiver (C3)	57	F
P4	8 years	-	Hemiparesis Left Side	Spouse	Survivor (S4)	71	M
					Caregiver (C4)	66	F
P5	3 years	Hemorrhagic	Hemiparesis Left Side	Partner	Survivor (S5)	39	F
					Caregiver (C5)	34	M
P6	3 years	-	Hemiparesis Left Side, Ataxia	x	Survivor (S6)	58	F
					x	x	x

4.2.1.2 Procedure

There were questions among four main topics in the semi-structured interviews: generic, rehabilitation and physical impact, relationships, and occupations and hobbies. The first topic gave us insight into the general life after stroke, which helped us understand the context of the stakeholders’ lives. The second gave us knowledge about their rehabilitation process. The last ones functioned as a base to understand the participants’ hobbies and the relationship between the dyad, which helped us design the solution. This structure and the questions asked to the survivor, and the caregiver can be seen in Appendix A. With these interviews, we also disclosed how comfortable using technology they are and how frequently they use it.

Interviews with both stroke survivors and their primary caregivers were preferably conducted individually and separately, however, we gave the participants the option to do the interview together to make them feel more comfortable.

All participants signed a consent form, present in Appendix A, and each person was interviewed approximately for half an hour.

4.2.1.3 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 [52]. One researcher independently created a codebook from a subset of interviews (two with stroke survivors and one with caregivers), using an inductive approach. 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. Each researcher coded two interviews of stroke survivors and two interviews of caregivers independently.

4.2.2 Findings

Interviews with 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.

In this section, we highlight the more relevant findings, including the caregivers' roles after the stroke and during the rehabilitation process [F1], emotional state and motivation of each person in the pair (and other family members) [F2], activities including family activities and rehabilitation activities at home and in-clinic [F3], impact and 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.

Caregiving on Daily Life **[F1a]**

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. That is mentioned by survivor S5, who says, *"my husband took care of our son and I focused more on recovering for two months"*. 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. It is common for the caregiver to adopt this role of taking over on many of the survivor's daily activities. For example, another survivor pointed out that her husband started to be a better cook after her stroke, *"that is why he started to get a grip, so if this had not happened to me, he would probably never have tried it, nowadays he cooks many times and cooks well"* (S2). This meant that he took care of daily activities such as cooking and she would have more energy and time for her rehabilitation.

Together with this, another important thing that can be very helpful for the survivor if the caregiver is present is their help communicating with the doctors. It is something that can consume energy from the survivor and it can be avoided because when the caregiver knows the survivor it is easy to be helpful when communicating with the doctors, C4 said *"It was always me who communicated between the doctors and him, so it was always me who set the tone or tried to better frame his situation with the doctor or how he was or how he was reacting, which I interpreted better"*.

In addition and to help the caregivers carry on this role, it is important to plan. C2 mentioned he had to plan everything for when the survivor came home from the hospital. Without this planning, it is possible that when the survivor comes home the conditions for a good life are not met, for example, a bedroom whose only access is by stairs or corridors too small for wheelchairs. So C2 felt that he needed to take on the role of planner and change everything that needed to be changed in their house.

Two Party Rehabilitation **[F1b]**

The survivor-caregiver dyad has the power to determine the rehabilitation's success. As previously discovered in the Background (Chapter 2), the caregiver can have a great impact on the success of a rehabilitation process. Taking this into account, C2 believes the caregivers have an active role in the different processes of at-home rehabilitation. As mentioned by him *"That is why the caregiver will always serve to help or assist in these exercise application processes"*.

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, *"There are specific days when the family is called to go there, but any day my husband always had the doors open to attend the treatments and he was also taught some things"*. This is an agreement between more participants, S4 also mentioned that his caregiver *"watched and sometimes they gave her some recommendations for her to help me with the exercises at home"*. We can then disclose that this concern of including the caregiver also came from the therapists.

Nevertheless, we cannot forget the caregivers' concern of not doing the right thing, as confirmed by a caregiver that has *"talked to a bunch of them (...) and they say to me "she better do this", "she better do that" and they tell her and we're trying to be careful but I'm not a physiotherapist"*. But, even though he had that concern, S1 said that her therapist told her *"the only solution you have is to never stay still and ask C1 to give an eye because an outsider will always notice"*. So regardless of that fear, the caregiver was always motivated and encouraged to be involved, especially at home.

Emotional and Motivational Force **[F1c]**

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"*. Most of them believe that their presence has an important impact on the survivors' emotional state.

Besides that, survivors acknowledge that the caregivers are there to accompany and motivate them through different activities, whether they are direct rehabilitation activities or exercises or even daily life activities. This acknowledgement can be seen when S4 mentioned about his caregiver that *"Yes yes, walking yes, it is true. She accompanies me and pushes and motivates me (...) she accompanies me in this and in the exercises and encourages me to do the exercises and supports me"*.

Other caregivers can also exist like children who can also help with rehabilitation and motivation. Changing diapers is good occupational therapy or playing games with children. In this case, these other family caregivers have the role of participating in activities that can help with the recovery of the survivor. Furthermore, 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.

Survivor's Panorama **[F2a]**

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. By doing this they feel like they are succeeding in the small things, they are able to see their progress and it gives them the power to judge for themselves if they are getting better. They use all sorts of measures to evaluate their progress, for example, S6 mentioned she used a door to measure her strength. In the beginning, when she left the hospital, she could not open the door with her sequels side's arm and as time went by she began to be able to open and hold the door longer and longer. S6 was able to understand her own progress with such a simple activity as opening a door. Another survivor (S5) also shared this interest in acknowledging her own progress as she said *”But now I play these games and I think it’s so easy and it’s cute because they help me to see the evolution and also understand my difficulty at the time.”*

The second channel where motivation comes from is something all participants mentioned and it is the importance of sharing and the sense of community. They felt it was very important to share their achievements and fears with people that were going through the same recovery process (Organizations like ”Portugal AVC”) or just friends and family that push them to be better and help them. They all highlighted the importance of having a community of people to confide in and where everybody motivates one another.

For the right motivation to exist, the survivors need to be in the right emotional state. In addition and as previously mentioned, most survivors mentioned the great impact the caregivers have on their motivation and how without them they could not be in such a good emotional state.

Caregiver’s Panorama **[F2b]**

The dominant feeling the caregivers share is the lack of power, most of them disclosed they feel powerless most of the time especially at the beginning of the recovery process. They mostly feel like this when the survivors are demotivated, frustrated or feel down. The caregivers believe they exist to take those feelings out of the survivors and give them motivation.

The dyad’s emotional state works as a cycle since when the caregiver is in a good state he helps the survivor gain motivation and therefore progress in their recovery. Then, when the caregiver notices 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. As a caregiver noted *”When you are at home, you have a family, you have a household, a group of people, and you have to have your own motivation since you wake up until you go to sleep. That is, you either have a household or a colleague or friend, boyfriend, girlfriend, whatever, with whom under that roof you have to be okay, in partnership, because that’s not “It is you and me” no, it’s the group”* (C2)

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, the rehabilitation exercises learnt from a therapist and reproduced at home and the family activities that help the survivor not be inactive.

Classic Rehabilitation **[F3a]**

The classic rehabilitation is the one every participant mentioned, it is the rehabilitation performed in a clinic or at a hospital by a therapist. This type of rehabilitation was prescribed by a doctor to all the survivors. They all had various types of rehabilitation: occupational therapy, physical therapy and cognitive/psychological therapy. Besides this, some mentioned speech therapy.

In occupational therapy, most of the survivors did some games to help with memory and some hand movements. For example, S1 played a game in occupational therapy to help her recover from her neglect impairment - a disorder of attention where patients fail to orientate, report or respond to stimuli located on the affected side of the stroke. She explained it in this manner *”So because of that, in occupational therapy, I did something that was very interesting, it was like I was an airport security and there were several screens, one screen showed the suitcase mat, another screen showed an automatic door (...) and then every time the carpet jammed or the automatic door jammed I had to press the enter key.”*

In physical therapy most did exercises to recovery mobility or even learned how to walk again. They all mentioned the importance of this physiotherapy and that without it, nowadays, they would not have a good quality of life. The participants also understand that physical therapy should be a continuous practice because when they stop they get worse. Especially now, due to the ongoing covid-19 pandemic, some that used to have regular sessions stopped going to physiotherapy and noticed differences.

Rehabilitation at Home **[F3b]**

When it comes to rehabilitation at home, some physiotherapists recommended exercises for survivors to perform at home which were taught during the in-clinic sessions. Despite this fact, few or none did these classic/usual home-based rehabilitation activities because they lacked motivation. Moreover, they mostly never did exercises where the caregiver is included.

However, some examples were mentioned by the participants. C2 commented that he sometimes did physical exercises with his spouse but the survivor did adaptations of those exercises. Another caregiver (C5) sometimes told S5 to stretch. The most obvious example was given by the only dyad where the survivor did rehabilitation exercises at home with the help of his caregiver. This caregiver (C4) mentioned she helped with some movements in the rehabilitation exercises the survivor saw and copied from a ”Portugal AVC”’s platform with videos.

Family Activities **[F3c]**

As previously described few or none of the survivors do rehabilitation at home but, on the contrary, all the interviewed participants played some sort of game with their family and/or did some sort of activity like walking or watching movies. This happens because the motivation to play a game including the whole family is bigger than the motivation to do doctor prescribed exercises.

From these mentioned activities, some were acknowledged as activities that influenced the survivor's recovery. As an example, a caregiver even mentioned *"she had OT which is occupational therapy to develop the arm and the best OT she has had so far was our son, I mean, changing diapers, dressing, undressing, he is alive"* (C2). 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).

Another activity most mentioned when asked about hobbies and what they usually do in their free time was socializing with friends and/or stroke communities. This community support was already noted as an important part of the motivation for the recovery and was mentioned here too as one of their favourite hobbies. As C1 stated *"We get together with people, with family, with friends, very often, fortunately, that's more our hobby, our hobby is more like this"*.

F4: The Power of Technology

Technology is all around us and in stroke survivors and their caregivers it is not different. 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.

Technology All Around **[F4a]**

They all use some sort of technology in their day-to-day life, although some mentioned they only started using technology and platforms like Zoom during the pandemic. It is also because of the ongoing pandemic that some of them discovered and acknowledged the advantages of technology. As survivor commented *"The technology only if it is really to help in periods when we are actually at home or we are more stationary at home like this phase of confinement that no one counted on 2 years ago but maybe it helps."* (S4) In general, they all clarified they are comfortable with technology and all have smartphones and computers. They all also mentioned they are comfortable with social networks.

When social media was mentioned some talked about sharing groups and how social media can help people be in touch and talk even when they are distant. This is a great advantage for the sense of community mentioned before by them because talking to a doctor is not the same as talking to someone who is going through the same thing.

Besides the technology used daily, a survivor also used technology for rehabilitation at home, he saw videos of exercises from a platform and copied them with the help of his caregiver, as previously disclosed.

In-Clinic Rehabilitation Technology **[F4b]**

Most of the participants used some kind of technology in their rehabilitation sessions in a clinic or at the hospital.

Many different examples were given, between them, the examples given for the recovery of the lower members were a bicycle used to recover the motion of the legs mentioned by S4 and S5. Another example was given by S2 who used Locomate, which consisted of a vest and a variation of a crane to help the survivors walk. This same survivor also used sensors to measure pressure done by each foot when walking and perceive her progress in the recovery.

In terms of occupational therapy, it was where they all used technology. For this type of technology, the therapists usually give the patients games for them to play. A survivor (S5) said she did some memory games in the clinic and installed some game apps during the rehabilitation process to help with her cognitive part and help exercise her memory. Some mentioned games using a joystick which helped with the movement of the sequels side's hand. S2 specified the games she played as going to the supermarket and she had to use the joystick to put things on the shopping cart. Besides the joystick, S1 said she played games with a computer mouse and the purpose of those games was to gain perception of what was happening in her left side (the side of her sequels) and at the same time the purpose was the same as the ones with the joystick, gain hand movement.

In addition to this, S1 mentioned she was well impressed with the use of technology for people with aphasia. She explained that tablets had pre-constructed phrases for the survivors to communicate, she said *"They had those Tablets with simple things like going to the bathroom "yes" or "no", "My name is. . . " and then it was set to default with the speech therapist and I really think this is technology in favour of people"*.

Technology: Booster For New Ideas **[F4c]**

In conversation with the participants, some conjectured new ideas for the use of technology in rehabilitation. A survivor purposed a mirror to help her with the exercises prescribed by the therapist at home. She explained how a mirror with technology could correct a person doing the exercises in real-time and how that could help her because she usually did not do the exercises since she was afraid of doing them wrong. Another survivor said it would be a great help if there was a technology that could help her with basic daily life chores like putting the hair up, washing the hair or cooking. Lastly, one survivor said that a Playstation or Wii game could help her do exercises and moreover it would be something she would do with her spouse and therefore involve the caregiver.

These are just some ideas that were disclosed during the interviews but they show how the participants are able to understand what they are missing and create new solutions for their lives which is very important for this work.

The Other Side of the Coin **[F4d]**

Just like anything it is impossible for technology to have only advantages. The most common disadvantage addressed by the participants was the fear of doing something wrong. Besides that, some mention the problems aggravated by the ongoing pandemic and the difficulty in learning or explaining new technologies at distance.

4.3 Creative Workshops

After disclosing insights from the interviews, the creative workshops were a base to answer our second research questions. With these workshops, we intended to discover: What are the technologies the stakeholders are more conformable using? What are the activities they can adapt into rehabilitation? How can the caregiver be included in those activities? To address these questions, we executed workshops with 4 stroke survivors and 4 caregivers.

4.3.1 Methodology

We conducted co-design workshops to discover the design opportunities and understand the mind of the participants about new ideas and solutions for home-based rehabilitation. The purpose of this design workshop was to generate and discuss a wide range of ideas, for which an activity of creativity and idea generation was used to encourage discussion among the different participants. Just like the interviews, these workshops were conducted via Zoom due to the ongoing Covid-19 pandemic.

4.3.1.1 Participants

The recruited participants were the same as the ones from the interviews. For the workshops, from those participants 2 of them had to be excluded from the study, resulting in 4 survivors and their respectively 4 caregivers. The exclusions happened due to the fact that one had no mild or severe physical impairments and therefore never experienced physical rehabilitation and the other one did not have an informal caregiver as she always provided the help she needed for herself. Even though their testimony was important for the interviews, for this activity we decided that their participation would not be valuable. Given this, the workshop participants are pointed out in Table 4.2.

Table 4.2: Demographic information about workshop participants
(F - Female, M - Male)

Pair ID	Relationship	Survivor/ Caregiver (ID)	Age	Gender
P1	Spouse	Survivor (S1)	37	F
		Caregiver (C1)	-	M
P2	Spouse	Survivor (S2)	44	F
		Caregiver (C2)	-	M
P4	Spouse	Survivor (S4)	71	M
		Caregiver (C4)	66	F
P5	Partner	Survivor (S5)	39	F
		Caregiver (C5)	34	M

4.3.1.2 Procedure

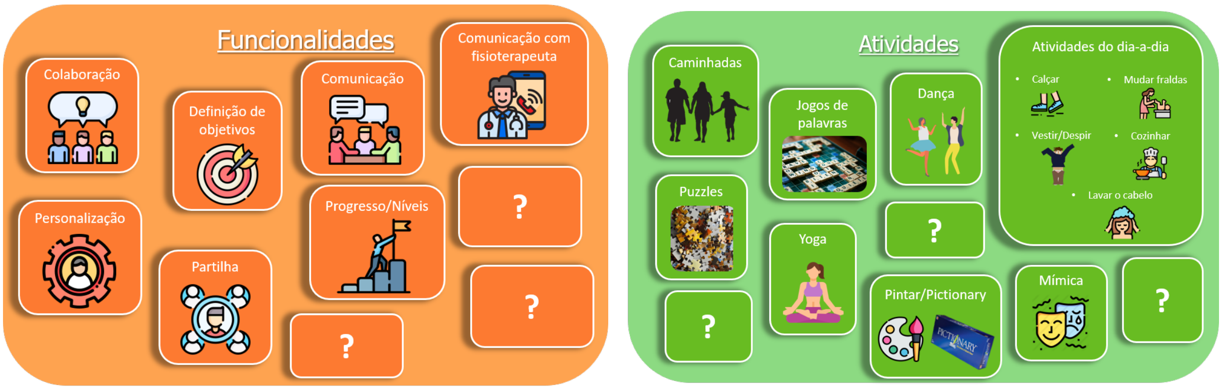
Eight people participated in these workshops, four pairs of survivors/caregivers. Each pair did a design workshop separately. Initially, each pair of participants (survivor and caregiver) aimed to find an analogy or a way to adapt a daily activity/hobby to their home rehabilitation using technology and including the two participants. For this, and to help, cards from different categories were created. These cards were created taking in mind what was disclosed with the previously performed interviews. The categories chosen were: Devices, Sensors, Features and Activities. All the cards that form the categories Features and Activities were built from what was exposed during the interviews, i.e., all that is in the cards was mentioned by the participants as activities they did or important things that could be features in a solution. All the different categories and respective cards are shown in Figure 4.1. In each category there are also blank cards with a question mark representing them. These cards exist to give the participants the space to create their own new cards. The followed protocol can be fully seen in the Appendix A.

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 ideally come up with three or more combinations. After the combinations were created, they were asked what was their favourite and why. In addition to this, 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.

The first example explained to them, started with the choice of an activity card, “Dance” in this case. People would have a mobile phone in their hand and use it as a motion sensor and do dance steps that they would see on a computer screen. This combination also has features like “Sharing”, if these dance

(a) Devices cards **(b)** Sensors cards



(c) Features cards **(d)** Activities cards

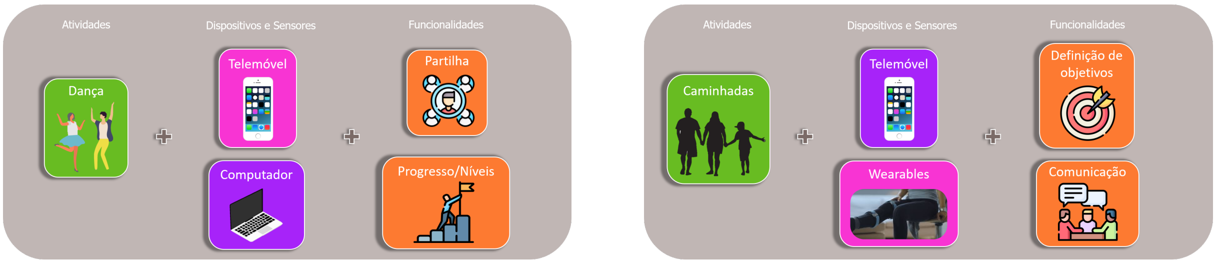
Figure 4.1: Set of cards from each category used to assist in the design workshop

steps are done with other people at the same time or if the results and points gained are shared with the community. These points would be gained from doing the dance moves correctly. It could also have a “Progress/Levels” feature if there are different levels of dancing and use that to see progress, as they would realize they would already manage to dance at a more advanced level.

The second example was built around the activity ”Hikes”. The hiking experience can be amplified by joining this activity with wearable sensors. So, this example had the card ”Hikes” from the activities category and the cards ”Wearable” and ”Phone” from the sensors and devices categories, respectively. This could be a good combination as with a sensor people can monitor, for example, how many kilometres they walk. The feature cards added here were ”Communication” and ”Setting Goals”. These features would work with the aim of the mobile phone and the communication should be with a therapist that would help them define the goals.

These examples were carefully explained in detail and displayed to the participants as seen in Figure 4.2

After the explanation of the activity and the examples presentation, the participants started the brainstorm and the construction of their own combinations. For that, they were asked to fill in a template as shown in Figure 4.3, which was also the one used for the explanation of the examples. This template



(a) Dance example **(b)** Hiking example

Figure 4.2: Examples of card combinations used to explain better the purpose of the design workshop

begins with the choice of an activity since we believe it was the easiest choice as they should just choose an activity they do or would enjoy doing. Although the template was built like this the participants were given the liberty of starting with whatever they felt more comfortable and following the order of choices they preferred.

Figure 4.3: Template for the participants to fill

At the end of all the ideas being exposed, that is, at the end of all the workshops, we had information to arrive at a common idea that satisfied everyone's needs and tastes.

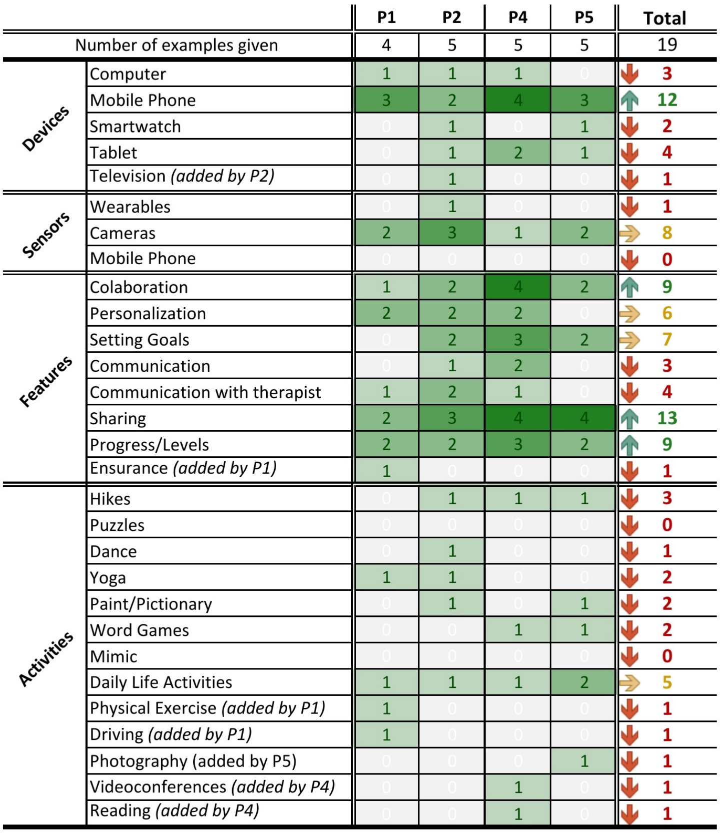
4.3.1.3 Analysis

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. By analysing those coded workshops we disclosed important findings, explained in 4.3.3.

In addition to this analysis that helped disclose the findings, we also performed a quantitative analysis. For that, we quantified the most used cards and the cards used in their favourite combinations. These quantitative results can be seen in 4.3.2

4.3.2 Quantitative Results

To execute a quantitative analysis, we found what were the most used cards which can be seen in detail in Figure 4.4.

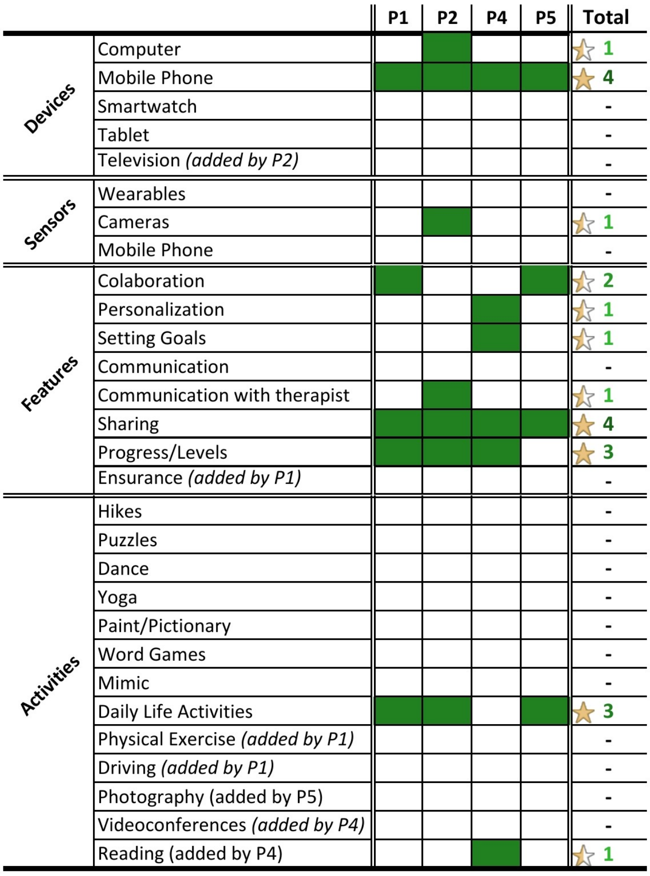


		P1	P2	P4	P5	Total
Number of examples given		4	5	5	5	19
Devices	Computer	1	1	1	0	↓ 3
	Mobile Phone	3	2	4	3	↑ 12
	Smartwatch	0	1	0	1	↓ 2
	Tablet	0	1	2	1	↓ 4
	Television *(added by P2)*	0	1	0	0	↓ 1
Sensors	Wearables	0	1	0	0	↓ 1
	Cameras	2	3	1	2	→ 8
	Mobile Phone	0	0	0	0	↓ 0
Features	Colaboration	1	2	4	2	↑ 9
	Personalization	2	2	2	0	→ 6
	Setting Goals	0	2	3	2	→ 7
	Communication	0	1	2	0	↓ 3
	Communication with therapist	1	2	1	0	↓ 4
	Sharing	2	3	4	4	↑ 13
	Progress/Levels	2	2	3	2	↑ 9
	Ensurance *(added by P1)*	1	0	0	0	↓ 1
Activities	Hikes	0	1	1	1	↓ 3
	Puzzles	0	0	0	0	↓ 0
	Dance	0	1	0	0	↓ 1
	Yoga	1	1	0	0	↓ 2
	Paint/Pictionary	0	1	0	1	↓ 2
	Word Games	0	0	1	1	↓ 2
	Mimic	0	0	0	0	↓ 0
	Daily Life Activities	1	1	1	2	→ 5
	Physical Exercise *(added by P1)*	1	0	0	0	↓ 1
	Driving *(added by P1)*	1	0	0	0	↓ 1
	Photography (added by P5)	0	0	0	1	↓ 1
	Videoconferences *(added by P4)*	0	0	1	0	↓ 1
	Reading *(added by P4)*	0	0	1	0	↓ 1

Figure 4.4: Quantitative analysis of cards usage

Firstly, with this, we can acknowledge that the workshop was understood by the participants and engaging. This can be concluded since they were asked to give three or more examples and all of them presented at least four. Therefore we were left with 19 examples to analyse. From those, we can easily perceive what were the most used cards. 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 to fill the template. Despite that, the most common included card sensor was the ”Cameras”. In terms of features, the most used and was ”Sharing” followed by ”Progress/Levels” and ”Collaboration”. This is foreseeable as one of the main themes in the interviews was the importance of sharing their progress with a community. The collaboration card being used so much helps support our foundation for this work that the collaboration between the survivor and the caregiver is valuable. When it comes to the activities, the cards seem little used but it is only because each example usually only uses one of these cards. Given that we can notice that the only card activity used by all the participants was the ”Daily Life Activities”.

Beyond this quantitative analysis, we can also analyse the chosen favourites from the participants as they were asked to select a favourite example between the ones they gave. These choices can be seen in Figure 4.5



		P1	P2	P4	P5	Total
Devices	Computer		🟩			☆ 1
	Mobile Phone	🟩	🟩	🟩	🟩	★ 4
	Smartwatch					-
	Tablet					-
	Television *(added by P2)*					-
Sensors	Wearables					-
	Cameras		🟩			☆ 1
	Mobile Phone					-
Features	Colaboration	🟩			🟩	☆ 2
	Personalization			🟩		☆ 1
	Setting Goals			🟩		☆ 1
	Communication					-
	Communication with therapist		🟩			☆ 1
	Sharing	🟩	🟩	🟩	🟩	★ 4
	Progress/Levels	🟩	🟩	🟩		★ 3
	Ensurance *(added by P1)*					-
Activities	Hikes					-
	Puzzles					-
	Dance					-
	Yoga					-
	Paint/Pictionary					-
	Word Games					-
	Mimic					-
	Daily Life Activities	🟩	🟩		🟩	★ 3
	Physical Exercise *(added by P1)*					-
	Driving *(added by P1)*					-
	Photography (added by P5)					-
	Videoconferences *(added by P4)*					-
	Reading (added by P4)			🟩		☆ 1

Figure 4.5: Cards from favorite solution

In this analysis, we can perceive that the cards from chosen favourites almost perfectly match the most used cards. In the devices category, the common card in all the chosen favourites is the ”Mobile Phone” and in the sensors category, there is only one solution that used a sensor and it is the ”Cameras” card. The most used features cards in the favourites are also ”Sharing”, ”Progress/Levels” and ”Collaboration”. The activities category is not surprising as well since the card most used in the favourites is the same as the most used in general.

4.3.3 Findings

Co-design workshops with stroke survivors and their caregivers helped disclose what are the things they value the most when constructing a technological solution for rehabilitation activities.

In this section, we highlight the more relevant findings, including the 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. Given this, most of the participants knew at least one device. There was an exception when in a workshop S4 said *”We do not use devices, we have not used”* but it was easily resolved as they were told it could be hypothetical and they could just imagine how the device worked despite not owning it. Therefore they chose to take equally into account all the options and picked those that they imagined themselves to use the most.

Preference for the Known **[F1a]**

When given different options, inevitably people often chose the one they are more comfortable with and/or the most familiar one. This can help explain the device choices made by the participants in the workshops. Most participants opted to include a Mobile Phone in many of the solutions they constructed because they were familiar with its operation and features. For example, they know a smartphone can work as a camera and as a timer and it can also facilitate sharing content with others and communication. The fact that the participants have more information about this device than about others, makes them appreciate Mobile Phones the most and think it is better.

For the same reason, Computers are the most picked option after the Mobile Phones. Most participants own a computer and therefore are comfortable using one and they understand its advantages and features.

As a result of these choices, Smartwatches and Tablets are not often selected by the participants when constructing a solution. Tablets are sometimes chosen as a second option for a Mobile Phone or a Computer. Participants chose both to implement in an idea that could use either one. As C4 said about a solution constructed in the workshop *”The Mobile Phone will show us or the Tablet will show us the evolution, the progress, the levels”*.

The Bigger the Better **[F1b]**

The main reason for the participants to choose the Computer as a device for their ideas is to see information on the screen. For this, they prefer the screen where they can see everything more clearly, therefore, the biggest screen available and that is the Computer screen. They consider it is easier to see information on that screen than on a Tablet or a Mobile Phone.

With this need for a big screen in mind, a caregiver (C2) in his workshop decided to fill in a blank card in the devices category with a Television. He also mentioned that *”one of the features can be to share for the whole family”*, so a big screen can have many advantages. Another pair (S5 and C5) also used the Television as a device for one of their ideas so perhaps it is something that should be considered.

The Importance of Mobile **[F1c]**

One of the most important things disclosed with the choices of devices by the participants was how much they value the device's portability. The main reason for them to select Mobile Phones so often was already exposed but the advantage of a device that can be carried anywhere is also important. The fact that a person can have a device wherever she is makes the Mobile Phone and the Tablet more preferred options.

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. This discomfort in choosing a sensor was also augmented by the fact that none of the participants ever consciously used any of these technologies in their daily life and as a result, feel like it is something too technologically advanced for them.

Taking this into account, often the participants chose the sensors to include in their ideas without understanding they were doing it. They were capable of understanding that for example a camera could be useful but included it using a device such as a Mobile Phone which has a camera. Moreover, they comprehend the advantages of a sensor and want to include them but do not understand that those can be incorporated in the solution by including the sensor itself.

With the difficulties pointed out with this category and with the choices made, 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.

Why Cameras? **[F2a]**

The most chosen sensor was the camera and there are multiple reasons for that.

The first and already mentioned one is the fact that a camera is included in most of the devices they use daily. It is easy to choose a camera because it is incorporated in a mobile phone, for example, which is something the participants are comfortable with the way it works.

The other reason to pick the camera over the other options is the importance of seeing themselves. As S5 mentioned *"It is good for the survivor to see what he is doing right and what he is wrong because and it is only after seeing the video he has that ability."* and after she also pointed out that *"We are aware that we were not using correctly (the sequel side) when viewing the video."*. This importance of seeing themselves was also corroborated when S1 and S4 mentioned they used a mirror to see if they were doing some movements correctly. Furthermore, they mentioned the mirror was not a solution because it was difficult or impossible to transport and so the camera could be a solution.

Given these two facts, the choice to integrate a camera in the solutions can also be made because it is a way to include the caregiver. Taking into account the importance of seeing themselves, the caregiver can film the specific movements or activities for survivors to watch later or share with other people from the stroke community. In all the workshops this was mentioned in at least one solution where the camera was included and the caregiver would be some sort of cameraman.

F3: Features as Conversation Starters

The features category triggered several conversations which always led to the same conclusions. Regardless of the constructed idea itself or the other cards used from different categories, when talking about important features to include all participants mentioned the same ones. For them, the most important thing is to not feel alone and at the same time feel useful and independent. Additionally, they want to enjoy things that are specifically made for them. This happens because *"there are not two equal strokes*, as spoken by S1 who also mentioned about already existing solutions *"There are already these apps but they are not for me"*. Besides this, they also feel the need to understand their evolution and acknowledge they are making progress in their recovery.

Finding Motivation in Progress **[F3a]**

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. There is also another problem pointed out by C2: *"We do not value what we do and we are always waiting for the others to tell us"* and added that *"we always have to give that [medals by levels] to people because that way they feel valued."*. This confirms the importance of having levels.

In addition, it is essential to set goals. Having levels is a part of this as each level is essentially a small goal for them to achieve. This idea that setting goals is powerful was corroborated by most participants, for example, a survivor mentioned in her workshop *"Wanting to reach a goal, wanting to do something until the end is very important"* (S5). Furthermore, in another workshop, C2 said *"There is no better pleasure than victory and a victory is the achievement of a goal that the person has created within himself, so telling a person that the goal is fulfilled and they passed a level is very motivational"*.

About setting goals, it was also questioned who would set them. Some participants believe the best would be to have a therapist set their goals but in one of the workshops, there was another idea. The caregiver (C4) stated that she could be the one to set the goals for her husband, *"I can be the one to define the goals, it should be me because the person is on the defence with herself"*. She considers her husband to be very pessimistic about his recovery and if she was the one to set the goals she would be realistic but much more optimistic and that could help him.

Importance of Collaboration Partners **[F3b]**

The caregiver role can be to help set the goals for the survivor as seen previously but the caregiver can also be a collaboration partner.

During the workshops, several examples of how the caregiver can collaborate were given. Between them, S2 mentioned how a caregiver can participate in an activity like Yoga, *"The caregiver can also intervene in certain ways to help with specific yoga positions or even do partner yoga"*. About games, several participants mentioned different ways to have the caregiver or even the whole family collaborating. For instance, it was mentioned how children collaborate with their parents when doing a puzzle or how in word games people can collaborate to find certain words. As C5 mentioned *"Collaborate with someone to help find the word. Imagine that you can't find a word, you ask someone for help and that is collaboration"*.

Along with this, most participants mentioned collaboration as the caregiver or other survivors giving recommendations, information, suggestions or even guidance. *"Collaboration is about caregiver or other survivors giving advice"*, as spoken by S5.

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.

No One Wants to Feel Alone **[F3c]**

One of the most significant discoveries made with the workshops was how much survivors value the community and the feeling of having other people going through the same. The stroke community that includes survivors and sometimes even their caregivers is important because it is a place to share their frustrations and challenges but also their conquests and victories with other people that are feeling those same things.

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. A survivor said *"I honestly think that the most positive thing about all of this is not the rehabilitation exercises but the community itself"* (S4), proving the value of this feature and the interest in including it in a solution. She also added that *"Going to those meetings made a lot of difference to me and I think an application that had this component could be very very good"*.

The power of sharing was explained by C4 when she said *"The sharing helps make the survivor feel less alone, less like he is the only one with the problem, more like he is accompanied, more like he has a chance because others have triumphed and succeeded, so why not us? And that's good"*. The survivor in the same workshop also added that *"Sharing is good for encouraging others and mostly for fighting isolation"*.

In addition to this, S2 and S5 mentioned that another noteworthy part of sharing is making others do what you did and shared. S2 already shares videos on social media of her strategies to do daily activities and she said that her goal is achieved when she sees other people apply those strategies in their own lives. She stated that *"The goal is to show that it is possible to have a life after a stroke and do things, we have to come up with strategies to do them"*. S5 also believes that *"'Look, next week, we could go do what they did' is the real sharing"*.

Given this, the power of sharing and how it makes the survivors and caregivers feel should be taken into consideration when designing a solution for them. The fact that this feature was one of the most talked-about themes in all the workshops can not go unnoticed.

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

Amongst all the activities the participants could choose from, some they did not do, others they did not like, or, furthermore, they did not understand how it could be rehabilitation. Nevertheless, all the participants easily chose one of the possible activities but preferably those they already knew or did.

Some participants disclosed that the activities were very different because they tackled distinct aspects of rehabilitation. For that reason, they could be divided into two big groups taking into account what they related to the most. These activities could be more related to physical rehabilitation or cognitive recovery. Despite that, the participants chose the activities considering only what they like, would like to do or already did.

"Moving the Body" Favorite Activities **[F4a]**

In activities to move the body and recover physically, participants mostly chose Hiking for several reasons. The first was because this activity was something they already do. It is also an activity where other things can be integrated, like in the idea from a survivor (S5) where Hiking was joined with Photography. Besides including other activities, Hiking can also easily include the caregiver or other people in general since it can be done accompanied. In addition to this, Hiking is an activity where setting goals and sharing conquests is easy and as seen previously this is an important thing for the participants.

Other physically-oriented activities were also chosen such as Dance. S2 and her caregiver talked about how Dance could be a good rehabilitation activity as it could include the caregiver if it was partner dance. This activity could also certainly include sharing with the rest of the community, either the specific dance moves or just the conquests. Given that, Dance can also easily have levels and small goals to achieve. Another survivor also mentioned this (S1) when she said that she saw other people dance on social media and would like to be able to do the same. She believes that slowly and with levels she could dance like that and, moreover, she considers that the sharing from other people motivates her.

Yoga was also chosen by some participants for their ideas (S1/C1 and S2/C2). But it was disclosed that it would be difficult to make it a fun activity for rehabilitation when including the caregiver because he would probably be just checking if the survivor was doing the right positions. Another idea to include the caregiver would be to do Partner Yoga but none of the participants that chose this activity for an idea seemed too happy with this.

Cognitive Recovery Activities **[F4b]**

Activities such as Paint, Word Games, Mimic or Puzzles were chosen by the participants considering they are a sort of occupational therapy. They find these activities vital, especially because sometimes in in-clinic rehabilitation this part of their recovery is forgotten. As S4 said *"There is a concern for our functionality, for the limb recovery and they often forget about the rest, the cognitive part"*.

The most chosen activities of this genre were Paint and Word Games, mainly because they are the most popular games in their households. As a survivor said about these games *"We sometimes play as a family and it is all laughs"* (S2). So, besides the cognitive recovery, there is also an important part from these activities that is the fun they bring along and the inclusion of the caregiver and/or other family members which is important. Furthermore, C2 pointed out that *"Pictionary is a game that can be enjoyed by people of all ages and different generations because it has arts, creativity and imagination and at the same time it can all add up to knowledge. So where do you classify this within therapies? Obviously, this is the cognitive part but you can also train the fine motor skills"*.

With the workshops, we can conclude that participants value activities that are fun but also activities that help with cognitive recovery because the physical gets more attention from the therapists.

Specially Tailored Activities **[F4c]**

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.

Photography was mentioned by S5 as an activity that could be joined to Hiking and that way it would be an activity that specifically matched her preferences. In this activity the participant would have to take photographs of the route taken and for S5 that would motivate to hike more difficult or longer routes.

Driving was mentioned by C1 as something S1 wished she could do but nobody ever helped her gain back the skills to do it. The same thing applies to the reading mentioned by C4. These activities and situations are very specific for a particular survivor. But the fact that they talked about them proves they think about specially tailored activities for themselves.

Taking care of plants was mentioned by S5 but this was so distinct and peculiar that she included this activity in the Daily Life Activities and used that card for the construction of her idea. Even though she incorporated a specific idea of an activity in a more general one she still thought it was important to mention it as a possible activity for her particular rehabilitation.

Watching video conferences was referenced by C4 *”The two of us together see a lot of online conferences”*, and this specific activity shows how much they value sharing and viewing other people’s shares as mentioned beforehand.

With these activities choices, we can understand that each person is motivated by different and specific things but in the end they all value the same things in terms of features (sharing and personalization).

The Activities We Can Not Escape **[F4d]**

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. As pointed out by S2 *”While in dance there can always be someone who says they don’t like to dance or in Pictionary there will always be someone who identifies flaws, or on hikes ’Oh I have calluses’... Here, there is no way to escape in the daily life, we have to get dressed, we have to cook...”*.

Some people may have some difficulty in some of these daily activities but other people can share their way of doing them, the tricks they use. This way everyone in the community can help and be helped. Voiced by S2 *”So if you have difficulty doing certain things, sometimes watching other people do it can help you in that way”*.

Another important feature that can be expressive in this activity is setting goals and levels. S5 said, specifically about cooking, *”But this was in stages, at first I could not even hold the knife well and now I can cut things thinner every day. In the beginning, I couldn’t even make soup”*. So these kinds of activities can also help survivors see their progress by achieving small goals. Additionally, C2 also explained that these activities can be separated in different levels as there are ones more difficult than others *”They are won stages like I can get dressed now but I still can not tie the shoelaces. These activities could even be different levels because there are activities more difficult than others”*.

Ultimately, the fact that all the participants did at least one solution with this activity should be taken into account. It is an activity that everyone does but the fact that they can construct an idea with it means they believe it could also be a rehabilitation activity and not only a daily life obligation.

F5: The Bigger Picture

With the workshops, we gathered knowledge on individual preferences in each category. We also disclosed common combinations from different categories. These patterns can be interesting to understand the things participants join and if those junctions have the same justifications between different participants.

Common Patterns **[F5a]**

After all the workshops were analysed some interesting patterns were found. These patterns were found taking into account the choices made by the participants and the most common combinations of cards made.

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 and sometimes the computer since these devices enable sharing in social media and others.

The second found combination pattern was exactly this, every time the participants used the Sharing card they also used the Mobile Phone card.

Figure 4.6 shows a combination made by P2. It is a perfect example of these common patterns. The Daily Life Activities card is joined with the Sharing card. In addition, the Sharing card is joined with the Mobile Phone card.

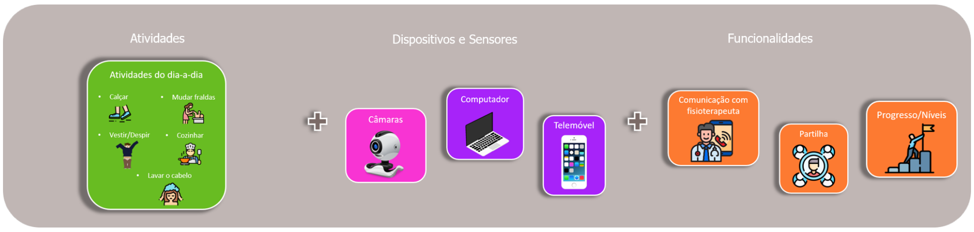


Figure 4.6: Combination made by P2 that shows common patterns

In terms of used cards, all participants have Mobile Phone, Camera and Sharing as the most used ones. In terms of activities, they all did just one example for each chosen activity so they do not have one activity card they used more.

One important finding is the fact that all participants did one example with Daily Life Activities and the reason for this was previously explained. But an interesting fact is that with other activities participants constructed very different ideas but with the Daily Life Activities they all constructed very similar solutions.

In the end, the most talked-about theme was the importance of sharing progress and conquests but also the difficulties they all go through. The importance of having a community of other survivors and caregivers that does not let them feel alone.

Caregiver Involvement Drawback **[F5b]**

Even though the caregiver involvement in the solution has advantages most of the time, some participants pointed out an important fact. Some survivors find it crucial for the caregiver to be less and less involved so they can feel independent. As spoken by S1 about a solution that could have a point system *"You can even earn points as the caregiver is being less included, that is, the person should earn more points as the caregiver is demoted from his role as caregiver because the goal is to be autonomous"*. Furthermore, she explained that this could also help the survivor acknowledge his progress, *"there is a phase in which the caregiver has to do it, the survivor has to delegate to the caregiver and then there is another phase in which the caregiver progressively delegates to the survivor and the survivor feels like he can do it alone and acknowledges the progress made"*.

Given this problem, the goal should be to design a solution that involves the caregiver but also allows the survivor to feel independent and understand his progress.

4.4 Design Implications

As a result of our design methodology, we were able to determine several design implications that we wish to take into min during the design and development of our solution system.

Mobile Devices: When it comes to devices, we disclosed that the survivors and the caregivers prefer what they know since they are more comfortable with the technology they already use. This can have advantages when designing a solution because 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. After the workshops, we can say that the device they prefer because, as said before, is the one they know best, is the mobile phone. Additionally, it is the participants favourite because it is mobile, i.e., they can take it anywhere.

Not Scary Sensors: When choosing sensors, the participants choose the ones that are included in something they already used. They preferred cameras that are in mobile phones so they are familiar with them. They also preferred other sensors like motion sensors that are included in other technologies. The participants only used sensors if it was really necessary since they are scared of unknown technologies. When designing for these people, it is preferable to not include a sensor or at least not include a sensor that can be seen for itself. If it is needed it should be covered in another technology they already know so they do not get scared and do not need to learn to use a new thing.

Sharing Goals and Conquests: Sharing is one of the most important things to have in mind when designing for the stroke community. The stroke 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. This evolution can also be measured by setting goals and achieving them, which is something that can also be included when designing a solution to help them with the rehabilitation process. Besides sharing the conquests, the survivors also want to feel like they are not alone when they struggle and sharing frustrations can help them feel motivated. In addition to this, survivors like the community but also like personalized things because each survivor is different and has different sequels and therefore a different recovery path.

Cognitive or Physical Activities: All the participants believe there are two types of rehabilitation activities for different recoveries (cognitively and physically) and it is almost impossible to have one activity to recover these two at the same time. With that in mind, to recover physically the chosen activity for the solution should be something to do with other people and where the progress can be seen. One of the activities where this is more obvious is hiking which was one of the most chosen in the workshops. In the cognitive area, participants chose games. This makes sense according to the fact previously pointed out that participants tend to choose things they already do and that should be taken in mind when constructing the solution for them. 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.

Caregiver Role: The caregiver role is an important implication when designing for stroke survivors. As we know since the start of this study, the active role of a caregiver in the rehabilitation process can be crucial [12], 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

Contents

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 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.

In this chapter, we start by describing the approach that we took, which was based on the design implications pointed out before the development. Afterwards, we provide a detailed description of our prototype system, including the different variations designed and all its features.

5.1 Approach

The approach followed was designing a prototype where the major theme was the gamification of daily life activities.

5.1.1 Daily Life Activities

We chose to develop a solution based on daily life activities taking in mind everything that was said previously about these activities. Firstly, it is an activity that can help both recoveries - cognitive and physical. It is also almost the only activity that everyone does since to live people need to do them. 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 which has the potential to be more fun and motivational for their recovery. The choice of these daily life activities as the base of our work was an important step to start working on the prototype solution. The participants said they would use a solution with these activities because of the reasons pointed out before and with this, we will be able to understand if it is true.

5.1.2 Gamification

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.

5.1.3 Sharing Videos

One of the most important things the participants mentioned all the time 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. In this approach, we decided that an important feature to include was sharing videos of the survivors doing their daily life activities. With this sharing, they can show their conquests to the community when they can do the tasks but also share their frustrations since they share videos of them doing the tasks with the help of the caregiver. This video share is also important because it helps survivors to feel motivated as they do not feel alone. They can see others that are going through the same and can do certain tasks so they feel like they can also do them themselves. With the videos, they can also share some tricks to do particular tasks and once again that motivates the others seeing the videos.

5.1.4 Caregiver Involvement

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.

In the first version, the caregiver does not have an application for himself, it is a solution designed for the survivor. 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. His role is much more active as the survivor needs the caregiver to fully give use to the solution. 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 role of supervising the tasks done by the survivor comes from the thought that this could motivate him. This way, the survivor will not skip rehabilitation activities and the progress he will 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. Moreover, we will be able to understand how important is the caregiver involvement after all and if the roles we previously disclosed are the correct.

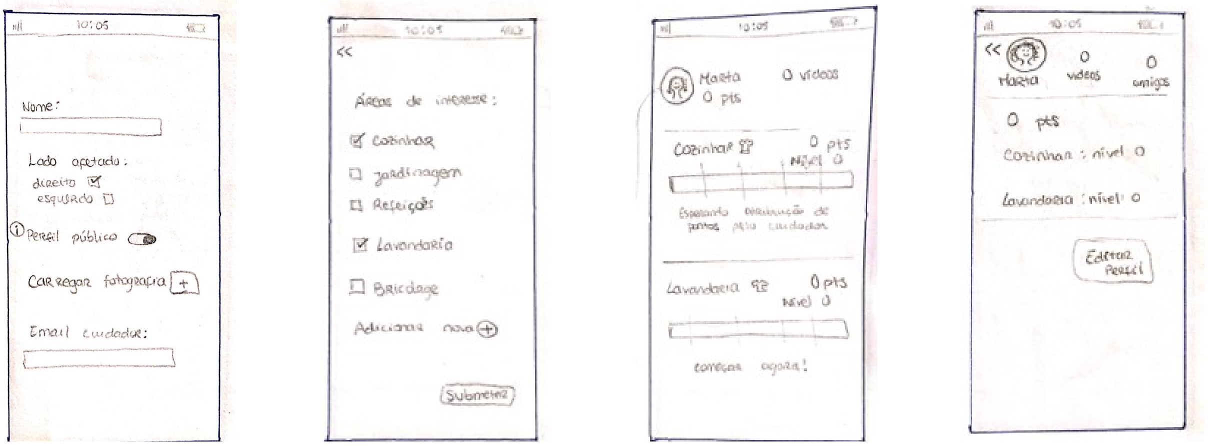
5.2 System

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 main caregiver. In this case, they depend on each other to fully function as they are co-dependent.

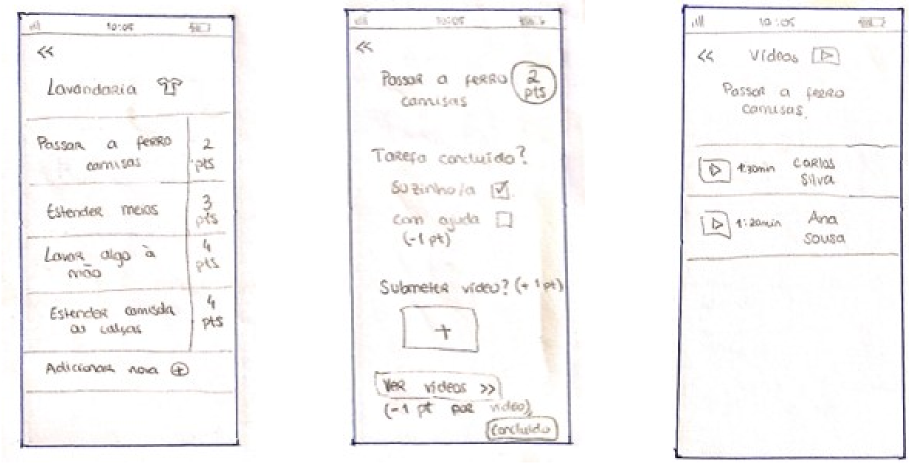
After the concept was developed, we constructed the two versions. The importance of caregiver inclusion was one of the main focuses of this work and therefore it was deepened here as what differentiated the two versions was this level of inclusion. It is also important to explore this since in the workshops' findings we discovered a drawback of including the caregivers. The two versions with high and low levels of inclusion are explained in detail, afterwards, in Sections 5.2.2.1 and 5.2.2.2, respectively.

5.2.1 Initial Design

The initial sketch was made for the version where the caregiver involvement is high. The initial sketch for the survivor's version of the application is illustrated in Figure 5.1. In this sketch, we can see the possible sign up of the application where it is asked the caregiver's email to connect the two applications. The idea is that the caregiver will receive an invitation for his version of the application on his email. After he accepts, then the two applications are connected. It is also requested to fill the areas of interest to then build the home page. The home page can also be seen in the sketch from there we can go to the edit profile screen or the specific area screen. From the specific area screen, we can go to the specific task screen if we select a task and from there to the video screen to see the feed of videos from that task from other people.



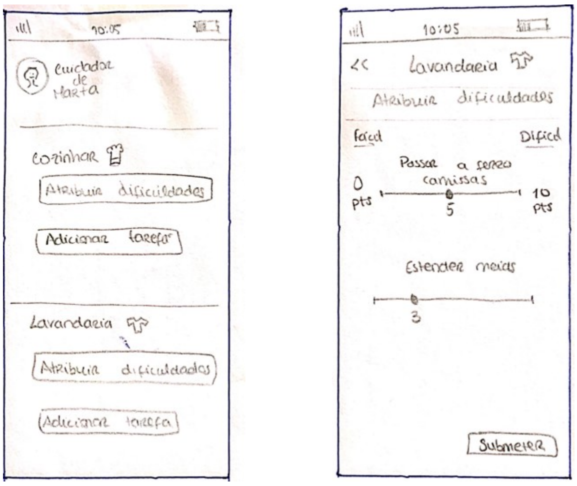
(a) Sign up screen **(b)** Sign up screen 2 **(c)** Home page **(d)** Edit profile screen



(e) Specif area screen **(f)** Specific task screen **(g)** Videos screen

Figure 5.1: First sketch of the survivor's side of the app

The initial sketch for the caregiver's version of the application is illustrated in Figure 5.2. As we can see this application has fewer screens than the survivor's one because this one is supposed to be much more simple. In the sketch, we can see the home page and from there we can go to the specific area screen to give points for the specific tasks the survivor will have to do.



(a) Home page **(b)** Specific area screen

Figure 5.2: First sketch of the caregiver's side of the app

5.2.2 Final Prototype

The final prototypes were designed in a tool named Proto.io[1]. Three final prototypes were constructed, two with high caregiver involvement (one for the survivor and another for the caregiver) and another with low involvement. There are many things in common between the two versions which are explained below, the specifics of each version are explained afterwards.

Survivor's Sign Up and Home Page

Beginning with the survivor version or the only version in the low involvement case, the initial page can be seen in Figure 5.3.

Figure 5.3: Initial screen of the survivor's side of the app

The sign up can be done as seen in Figure 5.4, with this sign up the survivor can choose if their profile is private or public and it is explained to them that a private profile means only their friends can see the videos they publish. They are also requested to choose their areas of interest. In the version

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[1] www.proto.io

with high caregiver involvement, the caregiver email is also requested to connect the two applications as explained previously.

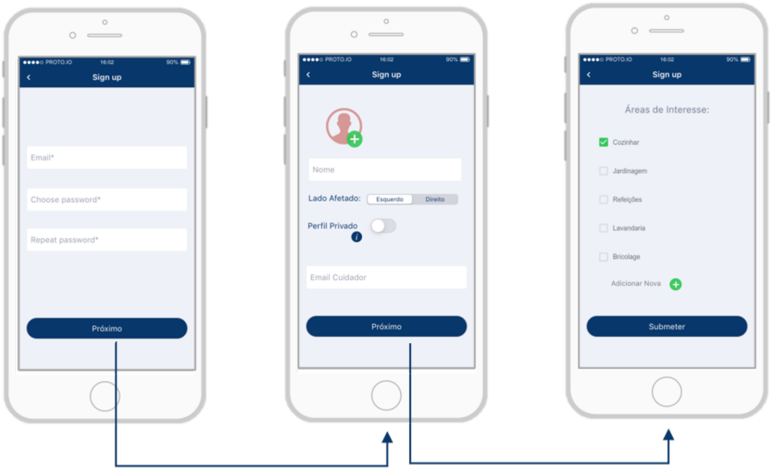
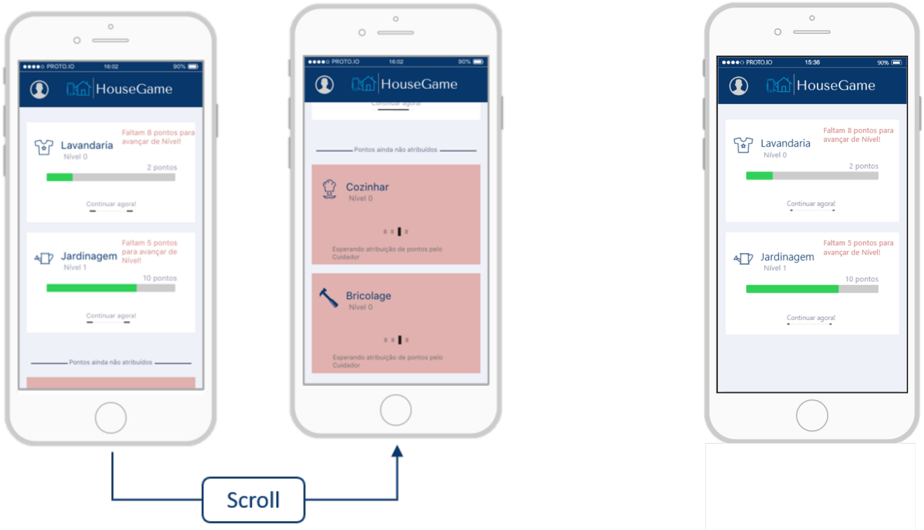


Figure 5.4: Survivor's sign up screens

After this sign up, the home page with the areas of interest chosen is shown as seen in Figure 5.5. 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 to the tasks. If the survivor wants to continue the tasks from a specific area where the points were already given he can do it by pressing that area. In the version with low involvement, seen in the Figure 5.5 on the right, the home page has the areas of interest but since the points are automatically given by the app all the areas are available and the way to choose them is the same - by pressing that area.



(a) Survivor's home page screens from high involvement version

(b) Home page screen from low involvement version

Figure 5.5: Home page screens

For example, if he presses the ”Lavandaria” area he will be directed to the screen seen in the left figure of Figure 5.6 where the different tasks for the specific area and level are shown with the respective points. The way the survivor chooses to see a specific task is by pressing its rectangle as shown in Figure 5.6. Then the screen on the right will be shown and the way to do a specific task will be explained in detail after since it is different in each version.

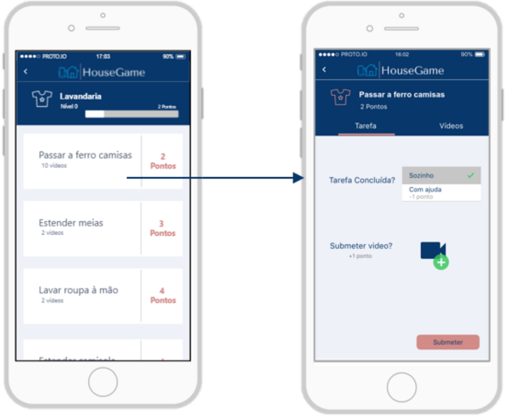


Figure 5.6: Survivor’s specific area and task Screen

Survivor’s Profile and Friends

The user’s profile screen and features is the same in both versions. To access the profile page, the user should press the profile icon and then the profile screen will appear as explained in Figure 5.7.

Figure 5.7: Access survivor’s profile page

On this profile page, the survivor can see his friends, his friends requests and his published videos. To access these features he should swipe right or left as explained in Figure 5.8. The features available here are: remove a friendship, accept or decline a friend request and edit the profile. After choosing edit profile, the survivor will be redirected to a page similar to the sign up where he will be able to change all the things he filled in those sign up pages previously including the areas of interest.

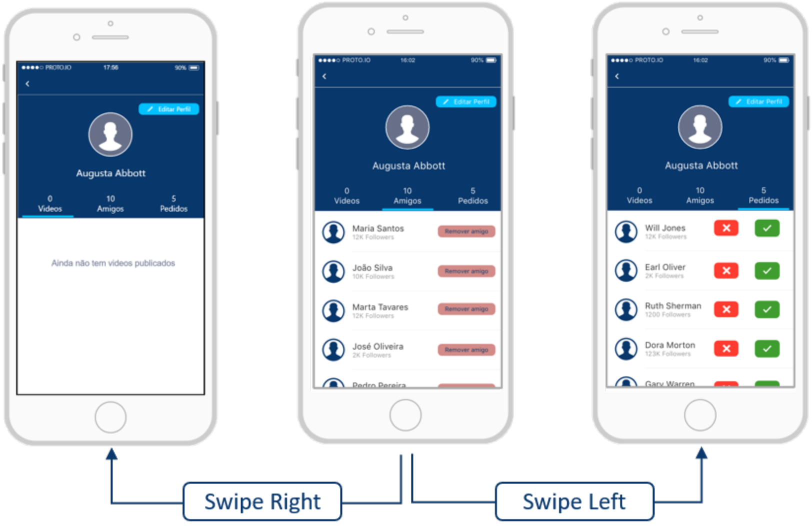


Figure 5.8: Survivor's profile pages

From the profile page, when looking at the friends, it is possible to access the profile page of a specific person. For that, the user should choose the person by pressing her name. The next screen will be the profile page of that person. On that page, it is possible to see their friends, their published videos and their levels in each of their areas. This can be seen in Figure 5.9.

Figure 5.9: Friend profile page

Videos Feed

Another thing both versions have in common is the way to access the videos of other survivors doing a specific task. There are two roads to reach the videos, the survivor can see the videos of a specific person or of a specific task. To reach the videos of a specific task he should go through that task, meaning he should choose the task by pressing it in its area screen. Then, he should choose to see the videos on the top of the page or swipe left. Then the videos of that task will be accessible as seen in Figure 5.10.

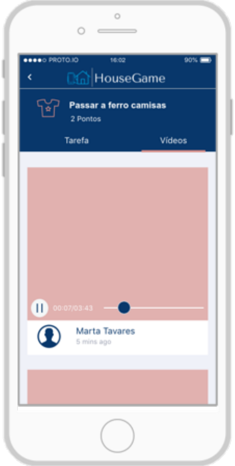


Figure 5.10: Specific task video feed

To access the videos of another particular survivor the way to do it is through his profile. It was explained before how a user can access their friend profile and after accessing it the survivor can see the videos published by that friend in their profile as seen previously in Figure 5.9. When accessing this page, the survivor can see the published videos by this specific person of any task from any area.

5.2.2.1 Version with Low Involvement from Caregiver

In this version, there is only one application used by the survivor. 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 specific task that he can then publish.

Since this version is more simple, most of it is explained with the common things previously. The only part left to explain is the submission of a task done, which can be seen in Figure 5.11. 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 and the specific area screen will be different as seen on the right of the Figure 5.11 as the task done will appear green and together with the other already done tasks. Besides that, the points will increase as seen on the top of the screen in the progress bar.

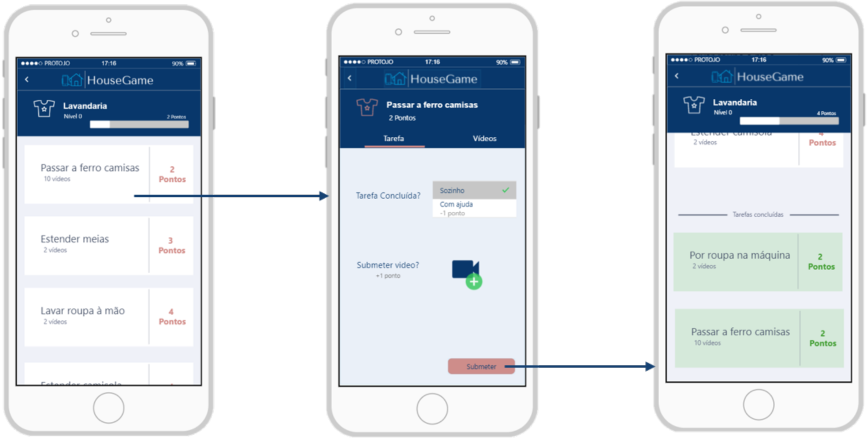


Figure 5.11: Submit task

5.2.2.2 Version with High Involvement from Caregiver

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. This email was previously provided by the survivor in the sign up. These two apps are co-dependent and this way they are connected. In this version, the caregiver has two main chores. He should 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. The other main chore is approving the tasks the survivor does.

The caregiver's home page can be seen in Figure 5.12.

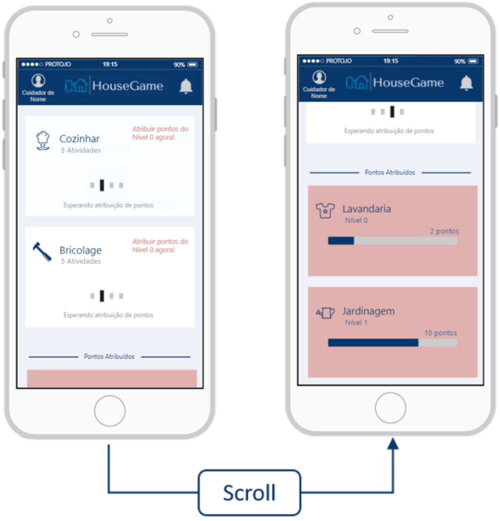


Figure 5.12: Caregiver's home page screens

Definition of Points for Tasks

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 red to the survivor and he will not be able to see the specific tasks of that area until the caregiver does his part and 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 in red where the points were already given. In those last ones, the survivor has already made some tasks and therefore some progress and so the caregiver can not change the points anymore.

To define the points of a specific area the caregiver must press that area and then will see the screens on the right of Figure 5.13. In the case of this Figure, the caregiver is giving the points for the "Cozinhar" area. To define the points he has 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 to start the tasks.

Figure 5.13: Caregiver's definition of points in specific area

Besides this, the caregiver can also delete or add new tasks to a certain area. To delete a task he must simply swipe left the rectangle of that task and then press the bin icon. After confirming the verification pop up that task will disappear. The screens of this operation can be seen in Figure 5.14.

Tem a certeza que pretende eliminar a tarefa "Cortar legumes"?

Figure 5.14: Delete specific task

Additionally, the caregiver can also add new tasks, as explained in Figure 5.15. For that, we should press the ”+” icon at the end of the list of tasks and new write the name of the new task and press ”OK”

Figure 5.15: Add new task

Submitting and Approving Tasks

On the survivor's side, once again, everything is 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 and it is only after that approval that the survivor can see the task green, meaning it is done and approved. This process from the survivor and caregiver perspectives can be seen in the Figures 5.16 and 5.17, respectively.

Figure 5.16: Survivor's submission of task with approval from caregiver

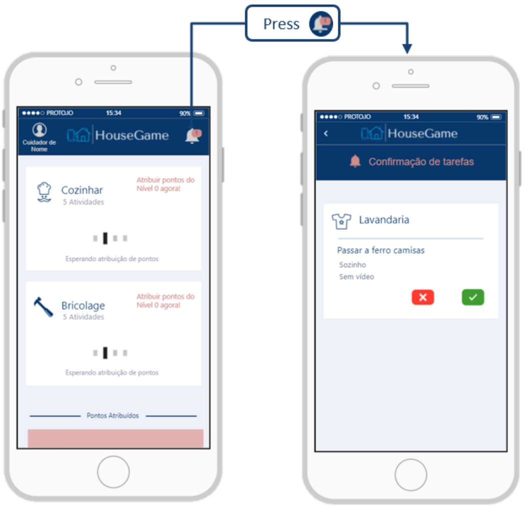


Figure 5.17: Caregiver's approval of specific task

So, the major difference from the other version in terms of caregiver inclusion is the fact that the points of the tasks are given by them and the survivor needs their approval for a task to be considered done.

6

Evaluation

Contents

The general idea of the developed solution and the two versions were evaluated by survivors and caregivers as it is described in this chapter.

6.1 Research Questions

After revisiting the objectives of our study, we constructed three research questions based on two dimensions. These dimensions are the involvement of the caregiver in the rehabilitation process and the motivation to do rehabilitation exercises at home with the help of technology. From both these dimensions, we can derive 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?

6.2 Methodology

We conducted evaluation workshops to disclose feedback and understand the opinions of the participants about both versions of the developed solution for home-based rehabilitation. Moreover, we wanted to have a clear insight regarding the defined research questions. Just like the interviews and the design workshops, this evaluation was conducted via Zoom due to the ongoing Covid-19 pandemic.

6.2.1 Participants

The recruited participants were the same as the ones from the design workshops. Given this, the evaluation workshop participants are pointed out in the previously shown Table 4.2. For these evaluation workshops we decided to join more than one caregiver and one survivor and they were two groups. These random combinations happened only due to availability. Given that, the first group was composed of P1 and P2 and the second by P4 and P5.

6.2.2 Procedure

As previously said, in these workshops we joined two dyads and therefore there were two different workshops for the eight participants. The activity performed in these evaluation workshops is an adaption of ”Think-Pair-Share” [1].

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[1] https://www.readingrockets.org/strategies/think-pair-share

Initially, the general idea was explained to the participants. Then, there was a demonstration of the first version of the application developed, the one where the caregiver involvement is low. Meanwhile, it was asked for each participant to think about the positive and negative aspects and the possible improvements for that version. This is the Think-Pair-Share "Think" phase. After that, a whiteboard was presented to them where the positive aspects would be written on the right side and the negative aspects on the left side. Below this division, there was be a space to write improvements. The whiteboard used can be seen in Figure 6.1. In the Figure, the whiteboard is still empty but it was later filled with post-its by the participants. Each pair was asked to participate and fill a post-it in turn. This peer sharing helped to streamline the sharing of feedback on that version of the developed solution.

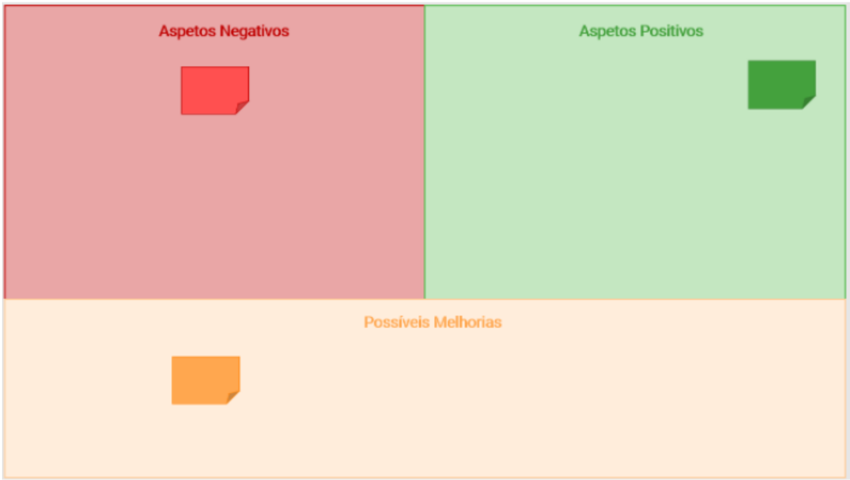


Figure 6.1: Whiteboard for the prototype evaluation workshop

For the other version of the application, the procedure was the same. Firstly, the participants saw a demonstration and then they filled the whiteboard with positive and negative aspects and possible improvements.

At the end of this activity, all participants were asked to fill in a small form about the two versions of the prototype. The form can be seen in Appendix A. In that form, they also had to choose their preferred version of the solution.

The followed protocol for this evaluation activity can be fully seen in Appendix A.

6.2.3 Analysis

Just like the interviews and the workshops, this activity was also recorded. One of the researchers that created the codebook for the interviews and the workshops created a codebook for this activity as well, using an inductive approach. Then, that researcher coded the set.

In addition to this analysis that helped disclose the findings, a parallel analysis was also performed by analysing the answers to the form the participants filled.

6.3 Results

As said before, we were able to gather results from the workshop itself, with what the participants said and with the filling of the whiteboard, and also from the form responses.

Form Quantitative Results

We collected the form responses from all participants except one caregiver who did not fill the form with his answers. From the participants' responses we got, we were able to gather information. Firstly, we disclosed that the overall idea of the prototype (using daily life activities to see progress, having levels and points and the sharing feature) was well accepted by the participants. When asked if overall, this idea is good and innovative, most of them chose 5 on a scale from 1 to 5. It can be seen on the graph in Figure 6.2, the responses from the survivors and caregivers are mostly equivalent and the majority is above 3.

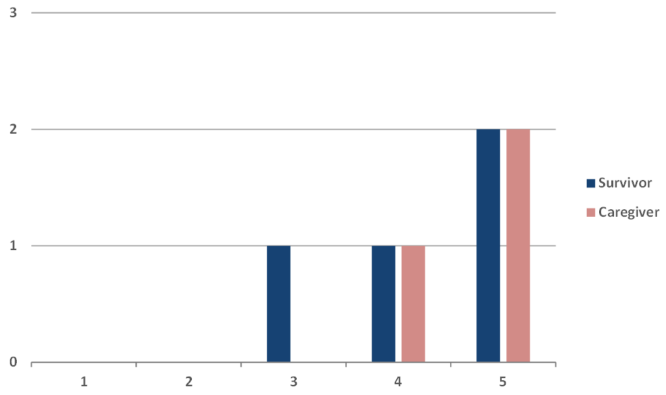


Figure 6.2: Overall evaluation of the idea

When asked to choose their preferred version, the results are as shown in Figure 6.3. Again, the results from survivors and caregivers are equivalent - the majority choose the version described previously in 5.2.2.1, which has low caregiver involvement. The reason for this choice can be later understood in Section 6.3.1.

After these generic questions, the participants had to answer three questions about both versions. The results are presented on the graphs in the Figures below. In the Figures, on the left are the results from the version with high caregiver involvement and on the right are the answers from the version with low caregiver involvement. This way, with the responses side to side it is easier to compare the differences.

The participants began by evaluating how much this application could help in the rehabilitation process. The results can be seen in Figure 6.4. In this question, the results are the same for both versions as the participants believe that the help this application could have is not influenced by the caregiver

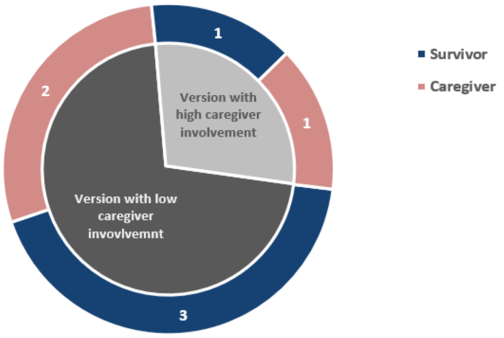
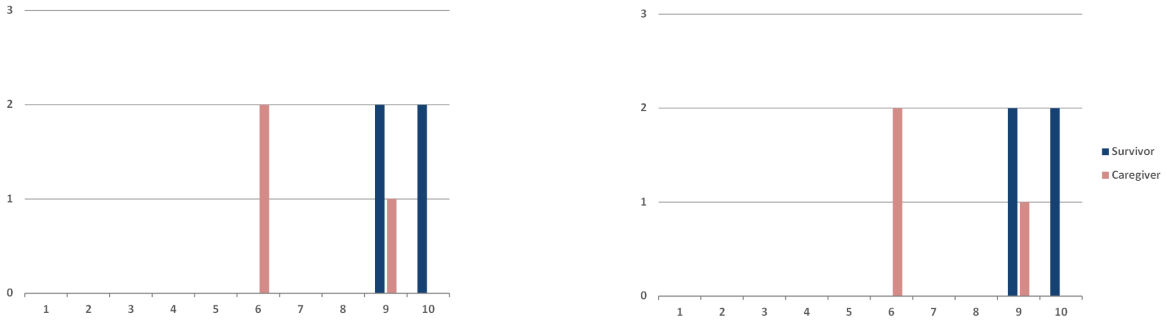


Figure 6.3: Survivors and caregivers version preference

participation and involvement. All the participants agreed that this application helps with the rehabilitation as all the answers are above 5, on a scale of 1 to 10. Moreover, the majority of the participants answered above 8, which means they believe this application could have an impact on the rehabilitation process. The two participants who answered below 8 are caregivers and therefore people who probably understand less how this application could help a survivor.



(a) Answers for high involvement version

(b) Answers for low involvement version

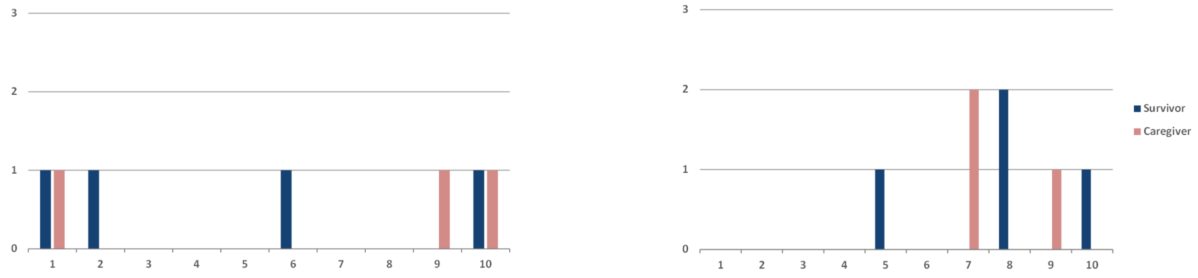
Figure 6.4: "This application helps in rehabilitation"
(1 - Totally disagree, 10 - Totally agree)

Afterwards, the participants had to evaluate the caregiver involvement in each version. Again, this evaluation was done on a scale of 1 to 10, with 1 indicating that the involvement was incorrect and 10 indicating that the involvement was correct. In this question, the answers were different, as expected, since the involvement is different in the different versions. The graph that summarizes the response is in Figure 6.5.

Overall, in the version with high caregiver involvement, the answers are in the extremes. However, as we can see, most caregivers think their involvement is correct as they answered above 8. The survivors' answers are more scattered and although there is one that believes the caregiver involvement is correct, half of the responses are below 3.

On the other hand, 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. The caregivers believe their involvement is correct more than the survivors. All caregivers answered above 6 and there is one survivor that chose 5. Other than that, the dyad's responses are mostly equivalent.

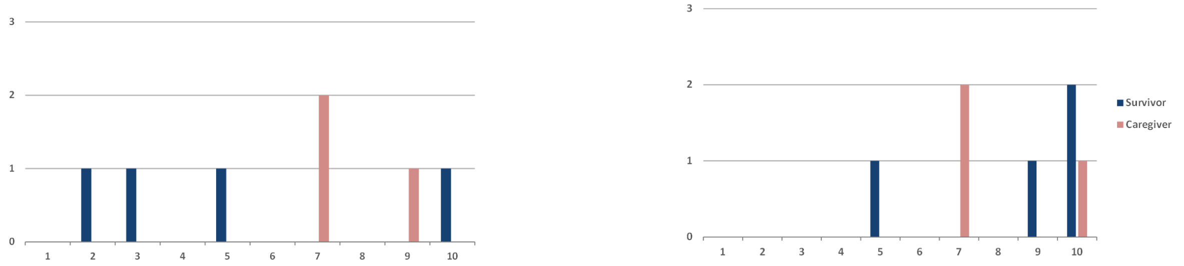


(a) Answers for high involvement version

(b) Answers for low involvement version

Figure 6.5: "The caregiver involvement is correct"
(1 - Totally disagree, 10 - Totally agree)

Lastly, the participants answered if they would use this application on a daily basis. The answers for the different versions have some disparities as we can see in Figure 6.6. On the version with high caregiver involvement, there are answers below 5 and in the other version that is not true. More specifically, only survivors evaluated the usability of the application with 5 or below. On the version with low involvement the lowest response was actually only one survivor who evaluated with 5, so, in general, the survivors evaluated this version better. The caregivers, generally, also evaluated the version with low involvement better. However, in both versions, the majority of the evaluations were 7 or above. And in the specific case of the caregivers, it was more than the majority as none evaluated below 7.



(a) Answers for high involvement version

(b) Answers for low involvement version

Figure 6.6: "Would you use this application on a daily basis?"
(1 - Would never use, 10 - Would use frequently)

Whiteboard Outcomes

At the end of the evaluation workshops, we gathered information in four whiteboards - one for version in each workshop. The positive and negative aspects and the possible improvements are shown below. It was difficult to gather specific feedback from each version as participants would give feedback that could be applicable to both versions. Therefore, they are presented grouped as the feedback from the different versions of the application and the different workshops were joined. The feedback that was given to a specific version and is not applicable to the other is pointed out. After this, in the following Sections 6.3.1, 6.3.2 and 6.3.3 these aspects and improvements are explained.

Positive Aspects: Application is intuitive and easy to understand and use; Seeing videos is motivational and can be used to get ideas on how to perform a task; Application is ludic; Points and levels motivate the users and helps them recognize their progress; Feeling of achievement from small goals when performing a task.

Negative Aspects: Other sequels are not considered, only hemiparesis; Only focused on domestic chores and not fun activities; Caregiver might not comprehend the difficulty of some chores and there is a possibility he loses patience since it can be boring for him (only related to the high involvement version)

Possible Improvements: Include activities to rehabilitate other sequels like aphasia; Feature to share the conquest with friends; Weekly or daily surprise task; Feature to do tasks in a group; Instead of being the caregiver, other people should give points after seeing the shared video; Include new areas of interest with more fun and diverse activities, including activities outside the house such as going shopping or dancing; Caregiver side of the app also include activities similar to the survivor but with different points since these activities are easier for the caregiver.

6.3.1 High or Low Caregiver Involvement

With the form responses, we disclosed that most of the participants preferred the version of the application where the caregiver had low involvement and participation. This is due to the fact that they felt too dependent on the caregiver to make any progress on the version with high caregiver involvement. As quoted by S5 *"Being dependent on the caregiver, dependent on his/her evaluation, if he does not evaluate, it remains pending. Depending on someone else is terrible."*, she also added that *"(...) this always leaves us dependent on someone and we also need to move forward alone. Although we have to have the caregiver on our side we have to struggle to do things alone so I prefer an application to rate me than the caregiver"*. Her caregiver agreed and noted that an evaluation made automatically by the application would be fairer.

The feature we included that consisted of the caregiver giving the points to the tasks was not received as well as expected. From the workshops' findings, we disclosed that the survivors are pessimists and that there could be benefits from being the caregiver who defined the levels and goals for the respective survivor. Now, throughout these sessions, this was revealed as a trait with a variety of unfavourable implications. Those implications were pointed out by the participants in both sessions. For example, S1 said *"And there may be friction because, for example, the survivor may be making a huge effort to do something and the caregiver later may find it very easy."*. The participants consider there is a high probability that the caregiver does not understand the true effort of a certain task and therefore will be unfair when giving the points. As it was mentioned in the other session *"(...) because she may think it was worth two points and we only give one because we are not aware of the sacrifice involved in doing a task. Cutting vegetables is commonplace for me, but for her to cut the same vegetables she can take twice as long as I do. For a simple thing, I could give one point and she could think it is unfair."* (C5).

They all came to this conclusion that the caregiver giving the points might be unfair and that is why, as seen previously in the graph in Figure 6.3, 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. These could also be unfair as they would be the same for every user and all users are different because their sequels can be very different. As S5 said *"The points would be automatic but I don't know what would be the parameters to evaluate, that is difficult."*.

With these outcomes from the sessions, an idea emerged in one of them. Since they were not satisfied with any of the ways to give/receive points C2 suggested a new idea. It consisted of a group vote, meaning that the survivor would do a task without any points and then submit a video. With that video, other people who had the application could vote for how many points that task was worth for that person. In his words *"I think that there could be a system for the assessment not only by the caregiver but also by various users through voting. Because being only the caregiver to assess can be extremely indelicate, it can depend on his mood and disposition, which is not always the same. The entire community could work on this. It would appear something like "Do you want to give a score to Mary or to Joseph?", it would make the application interactive."*. C1 added *"Meaning, a person would see a video and then give a score."*. With this idea, the caregivers could also give points but not only them. This way the survivors would feel less dependent on that specific person and would see this dependence as part of the game as there would be other people depending on them. It would also mean fewer unfair scores as they are given by vote and not dependent on one person's opinion.

6.3.2 Activities Approach

As seen in the negative aspects of the whiteboard results, the participants pointed out in the evaluation workshop, they believe that daily life activities can not be resumed to housework and domestic chores. They consider those activities boring and an obligation. They suggested it would be more fun to include other activities that, for example, entail leaving the house. This means that what we disclosed earlier is not entirely true. Although daily life activities are the most likely common activity among all of them, as we determined via this evaluation, they can be uninteresting. This should be taken into account as it makes the solution usability high since it is something that can be used daily but users can easily lose interest if other more fun activities are not included. Quoting S5, *"I think it is a shame to be only dealing with tasks in the house."* and S4 added *"The tasks are restricted."*. Afterwards, in the workshop, it emerged the idea to add new activities as C5 said *"Yes, but we can add new tasks in the possible improvements. You can, for example, go shopping. Shopping is something that costs her (S5) so much and for it would be a task outside home."* and C4 joined and mentioned that for S4 would also be better than some domestic chores. Some other examples were added such as recycling, *"which needs washing, separating, you have to make the effort with your arm to put it in the recycling bin"* (S5).

6.3.3 Points, Levels and Sharing Videos

All the gamification elements used to design this solution were the most complimented part. With this evaluation, we were able to confirm the fact that recognizing their progress and achieving goals is important in the recovery process. 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. During the session, S4 stated *"My hemiparesis does not allow me to hang clothes or iron but the objective is really that. Is to someday be able to do it, is to see other people's videos doing the task because there are people who have tricks to do lots of things so that is really the goal, to help you learn from them and recover."*. His caregiver added *"I think the videos are a very good idea because sometimes we don't remember to film or watch them and so we have an easy way to remember and see other people's videos."*. In the other session, the videos were also mentioned, S1 said *"There is also that idea of community and mutual help so no one will have any problems sharing the videos."*.

The points and levels were also features whose importance was proved with these sessions. Besides being pointed out as positive aspects it was also a topic in the evaluation workshops. Receiving points and upgrading level was proven to give motivation to users which is one of our main goals. As S5 mentioned in her session *"I think this can push people, S4 for example, can be motivated to do it. Then there is that mischief with colleagues and friends who can and also have hemiparesis or something."*. In the other session, the value of these features was also mentioned, *"(...) with points you have achievements and personal recognition, that is good. I mean, the person herself, having this information, gives her self realization."* (C2).

Our choice of features for the designed solution was proper as no participant pointed possible improvements that included new or refined features. All the perceptions we gathered from the co-design methodology with the exploratory interviews and the creative workshops were accurate.

6.4 Discussion

In this section, we gather information to draw conclusions from the work performed in this study which culminated in the evaluation of the developed prototype.

From the evaluation workshops, we understood that we have some possible improvements for our developed solution but also some new ideas similar to the developed one that emerged. As viable improvements, we have the inclusion of other sequels and activities to help rehabilitate them. As C2 mentioned *”Including other sequels is very important because there are people who, for example, are super normal but then have immense difficulty reading. I know someone like that who uses lots of applications to help him.”*. This could be included with different areas of interest which included activities that demand speaking or reading. Other improvements were also about including new areas of interest and activities. If we included activities outside the house, more fun activities and activities people can do in a group the users would be more satisfied with the developed solution. We came to this conclusion given the fact that these suggestions were given on the whiteboard in both evaluation sessions. As seen in Section 6.3.2 the participants missed the inclusion of activities where they have fun and therefore feel less like an obligation to the housework and also to rehabilitation. Another interesting idea suggested was to include daily or weekly surprise tasks to earn more points. This proves that the participants give value to the gamification of the solution and would not mind amplifying it by adding this feature.

In terms of the new ideas that emerged, they could be merged and be an upgrade from our designed solution. The suggestions given were all related to caregiver involvement. In both ideas, the participants want to take the power to give points from the caregiver. The first idea emerged in the first workshop, explained earlier in Section 6.3.1, and consisted of having the community vote for the points a task was worth for a specific person after seeing their video. This shows that stroke survivors and their caregivers believe a lot in the power and importance of the community. They trust more in the community’s judgment than in the caregiver’s by himself. This idea also showed how scared the caregivers and survivors are of frictions between them and prefer that the caregivers do not get too much involved. The other idea, which can be joined with this one, emerged in the second workshop and consisted in changing the caregiver’s side of the app to match the survivor’s side. This means that the caregiver would also have tasks to do. C5 gave this idea, *”It’s not possible, for example, to make an application for S5 and me to use the same application with the same tasks, but the score for, for example, washing dishes for S5 would be 2 points and for me, it would be 1 point? At the weekend we could even talk about the application and we would see how many points each had. The caregiver’s score would always be half that of the survivor for the same task.”*. His wife agreed with him and added that *”Otherwise my husband says to me “you have to go do the laundry to earn more points” and all week I do the laundry and my husband never does the laundry.”*. So, as we can perceive, this idea can have many advantages and could be an upgrade from our presented solution. This way the caregiver would be less probable to lose interest and the survivor would not feel dependent or obligated to be the only one to do housework. The participants in both workshops found these ideas good improvements.

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 6.2. To corroborate this, with these results from a scale of 1 to 5, 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 and wishes were well represented with this idea.

The results conclusions helped us answer the first research question (RQ1). As seen in the graphs in Figure 6.5 the participants believe the caregiver involvement is more correct in the version where his participation is low. Also, most of the participants choose the version with low caregiver involvement as their favourite. 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 overall 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. Besides this, the average and median punctuation from the usability of the application was high for their preferred version (≈ 6.14 and 7) but it was also positive in the other version (≈ 8.28 and 9). We believe that if they would use this application daily, then they are satisfied with the idea behind it.

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. The participants mentioned that the several gamification features would give them motivation.

Overall, this idea was well accepted by our sample of 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 C2 *”You have to promise me that you’re going to take this to investors because as you’ve already realized this can be a very big asset for many people.”* and S1 added *”Yes, for a lot of people this can be very important and can help.”*.

7

Conclusion

Contents

Nowadays, strokes affect many people, and it is expected to affect even more over the years. When it does not result in death, the survivors are left permanently disabled. In that case, rehabilitation is an essential step in helping patients as it can help bring back some mobility and overall quality of life.

Caregivers have an important role in the survivors' life as they become less independent after the stroke. In most cases, caregivers help with daily activities, but their essential role in the survivor's life is not well explored and we tackled this in our study.

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. Furthermore, there are 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 application (HomeGame) high-fidelity prototype, taking in mind the role of the caregiver that we also disclosed in this study.

Involving the stakeholders in the design process helps design a solution that best fits their needs. With this in mind, a solution that they helped design is also more likely to be used by them because it meets their wishes. With this study, we heard their voices and a group idea was developed. We believe that the developed 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.

7.1 Limitations

Our study's primary limitation is the small number of participants. Although a higher participant number would be advantageous in better understanding the impacts on the research subjects described above, this number of participants still provided a relevant analysis of several trends in our results.

The other main limitation of our work was the obstacle of the ongoing pandemic Covid-19. This forced us to perform the interviews and workshops through an online platform instead of in person. This withholds the personal contact with the materials in the workshops and also between the researchers and the participants. Without this limitation, the participants could have tried themselves the developed solution instead of just seeing a demonstration and perhaps would have more opinions. In the workshops, there was a major adaptation to perform it online since in the first idea it was needed for the participants to try technologies and do some of their hobbies in front of the researchers.

7.2 Future Work

Future work involves feedback from more participants. Our user sample was very limited and if there were more participants we could have gathered more knowledge and more precise information. Including more people from the stroke community can provide for a more appropriate representation of the target audience for this category of technologies. The stakeholders can also be involved in the development of the fully functional prototype for, for example, to give ideas for the areas of interest and tasks so they meet their preferences.

In addition to this, for future work, physical therapists can be involved as stakeholders as they help when choosing rehabilitation activities. They can also provide information on a variety of critical topics that survivors and caregivers may not be aware of, such as the importance of specific motions or tasks. They can also help perceive the feasibility of this solution.

Lastly, in the future, this solution application can be fully developed and a functional prototype can be tested to investigate its true usability and feasibility. The previously mentioned improvements could also be included such as including more inclusive activities. In addition to that, the mentioned upgrade with the new ideas can also be developed and tested.

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A

Appendix

Approval of the IST Ethics Committee

TÉCNICO
LISBOA

Ethics Committee (EC-IST)

Ref. n.º 6/2021 (CE-IST)
Date: 15/03/2021

Name of IR: Hugo Miguel Aleixo Albuquerque Nicolau
Name of the project: Co-Designing a Home-based Physical Rehabilitation Platform

Prof. Hugo Miguel Aleixo Albuquerque Nicolau

The Ethics Committee of Instituto Superior Técnico (EC-IST) reviewed your application to obtain ethical assessment for the above mentioned project. The following documents have been reviewed:

Ref.	Documents	Version & date
# 980060	[NOVO] Consentimento Informado v3.pdf [NOVO] Formulario_COMISSAO DE ETICA IST.pdf	19-02-2021

The following members of the EC-IST participated in the ethical assessment:

Name	Role in Ethics Committee	Qualification	Gender	Affiliation to IST (Yes/No)
Mário Gaspar da Silva	Presidente	Professor	M	Y
António Pinheiro	Member	Professor	M	Y
Isabel Trancoso	Membro	Professor	F	Y
Isabel Sá Correia	Member	Professor	F	Y
Rui Medeiros	Member	Professor	M	N

This EC-IST is working accordance to ICH-GCP, Schedule Y and ICMR guidelines, the EC-IST regulation and other applicable regulation.

None of the researchers participating in this study took part in the decision making and voting procedure for this assessment.

Based on the review of the above mentioned documents, the EC-IST states a an unanimous favourable ethical opinion about the request / trial as submitted.

The EC-IST expects to be informed about the progress of the study, any Serious Adverse Events occurring in the course of the study, any revision in the protocol and in the participants' information/informed consent, and requests to be provided a copy of the final report.

Prof. Mário Gaspar da Silva
President of Ethics Committee of
Instituto Superior Técnico (CE-IST)

Informed Consent to Participate in the Study

Consentimento Informado

Co-Designing a Home-based Physical Rehabilitation Platform

Somos uma equipa de investigação do Instituto Superior Técnico da Universidade de Lisboa que está a conduzir um trabalho de investigação no qual temos como objetivo criar novas tecnologias que possam ajudar na reabilitação após um Acidente Vascular Cerebral (AVC). Pedimos que faça parte deste estudo porque se voluntariou e vai de acordo com o perfil que procuramos. Pedimos que leia este documento cuidadosamente e pergunte esclareça quaisquer questões que tenha antes de aceitar fazer parte do estudo.

O que é o estudo?
Este estudo está englobado num projeto de maior dimensão cujo principal objetivo é criar novas tecnologias que possam melhorar a qualidade de vida de um indivíduo após Acidente Vascular Cerebral (AVC).

Neste trabalho em particular, temos o principal objetivo de recolher informação sobre a experiência de vida pré- e pós-AVC (Acidente Vascular Cerebral) e qual o papel que a tecnologia tem (ou poderá ter) no dia-a-dia e na reabilitação de sobreviventes de AVC e nos seus cuidadores. Com esta informação, iremos desenhar com os cuidadores e os sobreviventes uma plataforma de reabilitação física para uso domiciliário. Nesta plataforma, o papel do cuidador no processo de reabilitação será tido em conta.

O que vamos pedir que faça
Se aceitar fazer parte deste estudo, vamos recolher informação sobre a sua experiência de vida pré- e pós-AVC e qual o papel que a tecnologia tem (ou poderá ter) no dia-a-dia e na reabilitação de sobreviventes de AVC e nos seus cuidadores. De forma a conseguir recolher todas as informações necessárias para o nosso estudo, será realizada uma entrevista individual, via Zoom, com duração aproximada de trinta minutos. Posteriormente será realizada uma sessão em grupo com duração aproximada de uma hora. Para facilitar, posteriormente, a análise da informação recolhida, a sessão irá ser gravada.

Riscos e benefícios
Não existe nenhum potencial risco nem benefício para os participantes.

Compensação
Todos os participantes serão recompensados pelo seu tempo com um vale de oferta de 20€.

Confidencialidade dos dados
O Investigador Responsável pelo projeto, o Prof. Hugo Nicolau, será também o responsável pelo tratamento de dados. Todos os dados recolhidos serão mantidos em sigilo e serão analisados, exclusivamente, pelos investigadores deste projeto. Os dados poderão também ser utilizados para apresentação ou exibição de resultados, devidamente anonimizados, em publicações

científicas, conferências ou eventos semelhantes. Após cinco anos todos os dados serão destruídos.

Caso necessite de entrar em contacto com o Encarregado de Proteção de Dados do INESC-ID, poderá fazê-lo através de comunicação escrita dirigida a: Encarregado de Proteção de Dados (DPO, Data Protection Officer), INESC-ID, para Rua Alves Redol, n.º 9, 1000-029 Lisboa, Portugal ou via dpo@inesc-id.pt. Como participante tem direito a solicitar a este responsável acesso aos dados pessoais que lhe digam respeito. Tem também os direitos de retificação, remoção, limitação e oposição do tratamento, incluindo o direito de retirar consentimento em qualquer altura, sem prejuízo da licitude do tratamento eventual e previamente consentido. Para além disto, tem também o direito de apresentar reclamação à Comissão Nacional de Proteção de Dados.

A sua participação é voluntária e poderá sempre optar por não responder ou mesmo desistir a qualquer momento sem qualquer penalização ou consequência.

Declaração de consentimento: Li a informação acima e recebi resposta a todas as questões que coloquei. Eu concordo em participar no estudo.

Adicionalmente a concordar em participar, também aceito a gravção do estudo.

O/A participante ____ Data ______/______/2021

Investigador condutor do estudo ____________________________ Data ______/______/2021

Investigador Responsável e Responsável pelo Tratamento de Dados:
Hugo Nicolau
Professor Auxiliar do Departamento de Eng. Informática do Instituto Superior Técnico, Universidade de Lisboa
Investigador do INESC-ID
http://web.tecnico.ulisboa.pt/hugo.nicolau/
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Encarregado de Proteção de Dados:
INESC-ID
Rua Alves Redol, n.º 9, 1000-029 Lisboa, Portugal
dpo@inesc-id.pt

Este documento será guardado pelo investigador por pelo menos três anos após o final do estudo.

Entrevista ao Doente pós-AVC

Bom dia, antes de mais gostaria de agradecer a sua disponibilidade para falar connosco. O meu nome é Marta Ambrósio e faço parte de uma equipa de investigação da Universidade de Lisboa cujo objetivo é criar novas tecnologias que possam ajudar na reabilitação após um Acidente Vascular Cerebral (AVC). Em particular, hoje o que gostávamos de fazer era ter uma pequena conversa consigo, de cerca de 30 minutos, acerca da experiência de vida como uma pessoa que sofreu um AVC, tanto na perspetiva pré- e pós-AVC, e qual o papel que a tecnologia tem (ou poderá ter) no vosso dia-a-dia e na reabilitação.

[**Não esquecer consentimento informado**]

Caso não se sinta à vontade com alguma das perguntas que lhe vamos fazer, por favor, avise-nos. Está sempre à vontade para dizer que prefere não responder. Não existem respostas certas ou erradas, apenas a sua opinião.

Até agora, alguma questão?

Podemos **gravar esta conversa para posterior análise**?

Dados demográficos:
- Perguntar nome, data de nascimento

Perguntas Genéricas

- Há quanto tempo teve o AVC?
- De que forma é que o AVC afetou o seu dia-a-dia?
    - Quais as maiores barreiras de acessibilidade que encontrou e que estratégias utilizou para as ultrapassar?
- Existe algum tipo de tecnologia que tenha deixado de utilizar após ter sofrido o AVC? Ou que tenha passado a usar de forma diferente?
- Está familiarizado com tecnologias touch (tablets, smartphones, etc)?
    - Se sim, usa? Quão à vontade está?

Reabilitação e Impacto físico

- Qual o maior impacto em termos físicos do AVC? Como lida com isso no seu dia-a-dia, consegue dar exemplos?
    - Poderia dar exemplos concretos.
- Como faz reabilitação física atualmente?
    - Usa algum tipo de tecnologia ou dispositivo? Se sim, qual e como?
        - Quais acha que são os benefícios e as limitações?
- Durante a pandemia utilizou mais ou começou a utilizar dispositivos tecnológicos novos para reabilitação física em casa?
    - Se sim, quais?
- Utiliza dispositivos tecnológicos que indiretamente ajudam na reabilitação física em casa? (Por exemplo, o telemóvel para contactar com o fisioterapeuta)

- Qual a sua opinião sobre a integração de novas tecnologias e dispositivos tecnológicos no processo de reabilitação?
    - Quais são as suas expectativas? (O que gostava ver incluído)
    - Consegue encontrar vantagens? E desvantagens?
- Na sua opinião, qual o potencial da tecnologia na reabilitação física em casa?
- Acha que novas tecnologias podem melhorar a sua reabilitação em casa?
    - Se sim, dê exemplos de situações de reabilitação em casa que poderiam ser melhoradas

Relacionamentos

- Necessita de algum tipo de ajuda por parte do cuidador para atividades do dia-a -dia? (ex. cozinhar, higiene pessoal, ...)
    - Utiliza algum tipo de tecnologia nestas atividades?
- Na sua opinião, o AVC teve impacto na dinâmica familiar?
    - Qual? Como?
- Na sua opinião, qual o papel da família e amigos na recuperação e no dia-a-dia do paciente?
    - O que acha da integração da família no processo de reabilitação?
    - Pode dar exemplos desse papel da família na reabilitação?
- Qual acha que podia/devia ser esse papel no papel no futuro?
- Alguma vez sentiu falta de ter o cuidador mais integrado na reabilitação?
- Como se sentiria se o cuidador estivesse mais integrado na reabilitação?
- Existe mais alguém que esteja envolvido na reabilitação que faz em casa sem ser o cuidador?
    - Se sim, pode dar exemplos do que essa(s) pessoa(s) faz(em)
- Necessita, ou necessitou de apoio dos seus familiares ou amigos para interagir com tecnologia?
    - Se sim, de que forma?
- Existem dispositivos tecnológicos ou aplicações que utilize que permitam a interação entre a família e amigos?

Ocupações e Hobbies

- Em termos ocupacionais, tinha algum hobby/passatempo?
    - Se sim, esse hobby/passatempo envolvia a utilização de algum equipamento tecnológico?
    - Continua a realizar esses hobbies/passatempos?
        - Se sim, pratica-o da mesma forma?
- Tem novos hobbies?
    - O que ele gosta mais acerca deles?
- Está familiarizado com jogos tradicionais/de tabuleiro?
    - Se sim, costuma jogar? Prefere jogos colaborativos ou de confronto? Usa algum tipo de equipamento tecnológico para jogar?
    - Se sim, prefere jogos individuais (ex. solitário) ou de grupo?
        - Se em grupo, que pessoas são (família, amigos, conhecidos, …)?
    - Se sim, tem algum jogo em particular que goste?
- Tem alguma atividade/hobby que realize com o cuidador em conjunto?

Caregiver’s Interview

Entrevista ao Cuidador do Doente pós-AVC

Bom dia, antes de mais gostaria de agradecer a sua disponibilidade para falar connosco. O meu nome é Marta Ambrósio e faço parte de uma equipa de investigação da Universidade de Lisboa cujo objetivo é criar novas tecnologias que possam ajudar na reabilitação após um Acidente Vascular Cerebral (AVC). Em particular, hoje o que gostávamos de fazer era ter uma pequena conversa consigo, de cerca de 30 minutos, acerca da experiência de vida como cuidador de uma pessoa que sofreu um AVC, tanto na perspetiva pré- e pós-AVC, e qual o papel que a tecnologia tem (ou poderá ter) no vosso dia-a-dia e na reabilitação.

[**Não esquecer consentimento informado**]

Caso não se sinta à vontade com alguma das perguntas que lhe vamos fazer, por favor, avise-nos. Está sempre à vontade para dizer que prefere não responder. Não existem respostas certas ou erradas, apenas a sua opinião.

Até agora, alguma questão?

Podemos **gravar esta conversa para posterior análise**?

Dados demográficos:
- Perguntar nome, data de nascimento

Perguntas Genéricas

- Há quanto tempo (é cuidador)/(o doente sofreu o AVC)?
- De que forma é que o facto de se ter tornado cuidador de uma pessoa que sofreu um AVC afetou o seu dia-a-dia?
    - Quais as maiores barreiras de acessibilidade que o paciente encontrou e que estratégias utilizou para o ajudar a ultrapassá-las?
- Existe algum tipo de tecnologia que o paciente tenha deixado de utilizar após ter sofrido o AVC? Ou que tenha passado a usar de forma diferente? (tentar perceber se teve de prestar algum tipo de auxílio diferenciado para o doente conseguir ficar mais à vontade com o uso de tecnologias)
- Está familiarizado com tecnologias touch (tablets, smartphones, etc)?
    - Se sim, usa? Quão à vontade está?

Reabilitação e Impacto Físico

- Do seu ponto de vista, qual é o maior impacto em termos físicos para o paciente? Como lida, no seu dia-a-dia, para ajudar nessa incapacidade?
    - Poderia dar exemplos concretos.
- Como faz o paciente reabilitação física atualmente?
    - Usa algum tipo de tecnologia ou dispositivo? Se sim, qual e como?
        - Quais acha que são os benefícios e as limitações?

- Durante a pandemia utilizou mais ou começou a utilizar dispositivos tecnológicos novos para ajudar com a reabilitação física em casa?
    - Se sim, quais?
- Utiliza dispositivos tecnológicos que indiretamente ajudam na reabilitação física em casa? (Por exemplo, o telemóvel para contactar com o fisioterapeuta)
- Qual a sua opinião sobre a integração de novas tecnologias e dispositivos tecnológicos no processo de reabilitação?
    - Quais são as suas expectativas? (O que gostava ver incluído)
    - Consegue encontrar vantagens? E desvantagens?
- Na sua opinião, qual o potencial da tecnologia na reabilitação física em casa?
- Acha que novas tecnologias podem melhorar a sua reabilitação em casa?
    - Se sim, dê exemplos de situações de reabilitação em casa que poderiam ser melhoradas

Relacionamentos

- Necessita de dar algum tipo de ajuda ao paciente para atividades do dia-a -dia? (ex. cozinhar, higiene pessoal, ...)
    - Utiliza algum tipo de tecnologia para ajudar nestas atividades?
- Na sua opinião, o AVC teve impacto na dinâmica familiar?
    - Qual? Como?
- Na sua opinião, qual o papel da família e amigos na recuperação e no dia-a-dia do paciente?
    - O que acha da integração da família no processo de reabilitação?
    - Pode dar exemplos desse papel da família na reabilitação?
    - Pode dar exemplos do seu papel específico na reabilitação?
- Qual acha que podia/devia ser esse papel no papel no futuro?
- Quanto se sente integrado na reabilitação?
- Costuma assistir/ir às sessões de reabilitação?
- Existe mais alguém que esteja envolvido na reabilitação que faz em casa sem ser o cuidador?
    - Se sim, pode dar exemplos do que essa(s) pessoa(s) faz(em)
- Existem dispositivos tecnológicos ou aplicações que o paciente utilize que permitam a interação entre a família e amigos?
    - Se sim, há alguma que use em conjunto com o paciente?
- Utiliza alguma tecnologia que considere importante no seu papel de cuidador, familiar, ou amigo do paciente?

Ocupações e Hobbies

- Em termos ocupacionais, o paciente tinha algum hobby/passatempo?
    - Se sim, esse hobby/passatempo envolvia a utilização de algum equipamento tecnológico?
    - O paciente continua a realizar esses hobbies/passatempos?
        - Se sim, como cuidador, motiva-o e ajuda-o a realizar esses mesmos hobbies/passatempos?
- O paciente tem novos hobbies?
    - O que ele gosta mais acerca deles?
- Está familiarizado com jogos tradicionais/de tabuleiro?

Co-design Workshop's Protocol

Protocolo para Design Workshop

Marta Ambrósio | Instituto Superior Técnico | marta.ambrosio@tecnico.ulisboa.pt

PROPOSTA

Este estudo está englobado num projeto de maior dimensão cujo principal objetivo é criar novas tecnologias que possam melhorar a qualidade de vida de um indivíduo após Acidente Vascular Cerebral (AVC).
Neste trabalho em particular, temos o principal objetivo de recolher informação sobre a experiência de vida pré- e pós-AVC (Acidente Vascular Cerebral) e qual o papel que a tecnologia tem (ou poderá ter) no dia-a-dia e na reabilitação de sobreviventes de AVC e nos seus cuidadores. Com esta informação, iremos desenhar em conjunto os cuidadores e os sobreviventes uma plataforma de reabilitação física para utilizarem em casa. Nesta plataforma, o papel do cuidador no processo de reabilitação será tido em conta.

O objetivo deste design workshop é gerar e discutir um amplo conjunto de ideias, para isso vai ser utilizada uma atividade de criatividade e geração de ideias para incentivar a discussão entre os diferentes participantes.

SELEÇÃO DE UTILIZADORES

Os utilizadores para a realização do workshop são os mesmos que foram recrutados previamente para as entrevistas já realizadas no âmbito deste estudo. Estes participantes foram recrutados através dos procedimentos padrão, que inclui anúncios nas redes sociais e através de pedido direto a pessoas. Os participantes são sobreviventes de AVC que façam fisioterapia e os respetivos cuidadores interessados em participar neste estudo. A cada participante será pedido que assine um formulário de consentimento onde permite a recolha dos seus dados.

APPARATUS

Local de realização dos testes
O workshop será realizado em casa de cada um dos participantes.

Equipamento
A interação com os participantes e entre eles próprios será realizada através dos seus computadores pessoais ou outro dispositivo tecnológico que tenha acesso à plataforma Zoom.

PROCEDIMENTO

A atividade realizada neste workshop é uma adaptação de algo chamado “Forced Analogy”[1].
Neste workshop vão participar 8 pessoas, 4 pares de sobreviventes/cuidadores, cada par fará um workshop separadamente. Inicialmente cada par de participantes (sobrevivente e cuidador) tem como objetivo arranjar uma analogia ou uma forma de adaptar uma atividade à sua reabilitação em casa usando tecnologia e incluindo os dois participantes. Para isso, e como ajuda, existem cartas das seguintes categorias:

- Dispositivos
    - Telemóvel
    - Computador
    - Mesa digitalizadora
    - Tablet
- Sensores
    - Wearable
    - Câmaras
- Features
    - Colaboração
    - Comunicação
    - Definição de objetivos
    - Personalização
    - Partilha
    - Progresso/Níveis
- Atividades
    - Caminhadas
    - Jogos de palavras
    - Dança
    - Yoga
    - Puzzles
    - Pintar/Pictionary
    - Mímica
    - Atividades do dia-a-dia
        - Calçar
        - Mudar fraldas
        - Vestir/Despir
        - Cozinhar
        - Lavar o cabelo

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[1] https://www.thedesignexchange.org/design_methods/123

Prototype Evaluation Workshop's Protocol

Protocolo para Workshop de Avaliação

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PROPOSTA

Este estudo está englobado num projeto de maior dimensão cujo principal objetivo é criar novas tecnologias que possam melhorar a qualidade de vida de um indivíduo após Acidente Vascular Cerebral (AVC).
Neste trabalho em particular, temos o principal objetivo de recolher informação sobre a experiência de vida pré- e pós-AVC (Acidente Vascular Cerebral) e qual o papel que a tecnologia tem (ou poderá ter) no dia-a-dia e na reabilitação de sobreviventes de AVC e nos seus cuidadores. Com esta informação, iremos desenhar em conjunto os cuidadores e os sobreviventes uma plataforma de reabilitação física para utilizarem em casa. Nesta plataforma, o papel do cuidador no processo de reabilitação será tido em conta.

O objetivo deste workshop de avaliação é gerar e discutir um amplo conjunto de feedback, para isso vai ser feita uma demo de diferentes versões da solução desenvolvida e de seguida será feita uma atividade de feedback.

SELEÇÃO DE UTILIZADORES

Os utilizadores para a realização do workshop de avaliação são os mesmos que foram recrutados previamente para as entrevistas e para os design workshops já realizadas no âmbito deste estudo. Estes participantes foram recrutados através dos procedimentos padrão, que inclui anúncios nas redes sociais e através de pedido direto a pessoas. Os participantes são sobreviventes de AVC que façam fisioterapia e os respetivos cuidadores interessados em participar neste estudo. A cada participante foi pedido que assinasse um formulário de consentimento onde permitiu a recolha dos seus dados.

APPARATUS

Local de realização dos testes

O workshop será realizado em casa de cada um dos participantes.

Equipamento

A interação com os participantes e entre eles próprios será realizada através dos seus computadores pessoais ou outro dispositivo tecnológico que tenha acesso à plataforma Zoom.

PROCEDIMENTO

A atividade realizada neste workshop é uma adaptação de algo chamado “Think-Pair-Share”[1]. Neste workshop vão participar 8 pessoas, 4 pares de sobreviventes/cuidadores, cada dois pares fará um workshop separadamente.

Inicialmente irá ser feita uma demonstração da primeira versão da aplicação desenvovida e cada participante vai pensando nos aspetos positivos e negativos e quais as possíveis melhorias. Esta é a fase do “Think” do Think-Pair-Share.
Depois disto, terão um quadro branco onde irão ser escritos do lado direito os aspetos positivos e do lado esquerdo os aspetos negativos. Por baixo desta divisão haverá um espaço para escrever as melhorias. Irá ser pedido para cada par participar à vez. Esta parte de partilha entre os pares irá ajudar a dinamizar a partilha de feedback sobre aquela versão da solução desenvolvida. Para a outra versão da aplicação o procedimento será o mesmo.

No final desta atividade, todos os participantes terão de preencher um pequeno formulário sobre as duas versões do protótipo e onde terão também de escolher qual a sua versão preferida da solução..

Posteriormente, todos os dados e ideias e respetivo feedback retirados deste workshop serão analisados.

COMPENSAÇÃO

Os utilizadores foram previamente compensados pela participação neste estudo com um vale oferta de 50€ por cada dupla (sobrevivente e cuidador).

RISCOS E BENEFÍCIOS

Não existe nenhum potencial risco nem benefício para os participantes.

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[1] https://www.readingrockets.org/strategies/think-pair-share

Prototype Evaluation Form

23/09/21, 17:33 Avaliação Protótipo

Avaliação Protótipo

Este pequeno questionário serve para complementar a atividade de avaliação ao protótipo desenvolvido feita no âmbito do estudo cujo objetivo é criar novas tecnologias que possam ajudar na reabilitação após um Acidente Vascular Cerebral (AVC).

*Obrigatório

1. *

Marcar apenas uma oval.

○ Sobrevivente
○ Cuidador

2. No geral, esta ideia é boa e inovadora *

Marcar apenas uma oval.

	1	2	3	4	5	
Discordo totalmente	○	○	○	○	○	Concordo totalmente

3. Qual das versões é a melhor? (Se não estiver satisfeito com nenhuma pode descrever sucintamente uma melhor solução na opção "Outra") *

Marcar apenas uma oval.

○ Versão com envolvimento mínimo do cuidador (apenas ajuda nas tarefas e filma vídeos)
○ Versão com envolvimento significativo do cuidador (dá pontos às tarefas e aprova as submissões do sobrevivente)
○ Outra: ____________________

4. Justifique a escolha à pergunta anterior *

Protótipo I - Baixo envolvimento do cuidador	Nesta versão da aplicação a participação do cuidador é mínima. O cuidador apenas pode ajudar a fazer as tarefas e filmar o vídeo para o sobrevivente depois publicar

https://docs.google.com/forms/d/1KW3qna89h-ANmLhr0j9hMgQzHF6DRPLWdDZ9FI3TtJI/edit 1/3

5. Esta aplicação ajuda na reabilitação *

Marcar apenas uma oval.

	1	2	3	4	5	6	7	8	9	10	
Discordo totalmente	○	○	○	○	○	○	○	○	○	○	Concordo totalmente

6. O envolvimento do cuidador é o correto *

Marcar apenas uma oval.

	1	2	3	4	5	6	7	8	9	10	
Discordo totalmente	○	○	○	○	○	○	○	○	○	○	Concordo totalmente

7. Usaria esta aplicação no dia a dia? *

Marcar apenas uma oval.

	1	2	3	4	5	6	7	8	9	10	
Nunca usaria	○	○	○	○	○	○	○	○	○	○	Usaria frequentemente

8. Se respondeu que não usaria a aplicação no dia a dia (entre 1 e 5 na pergunta anterior) explique porquê

9. Comentários adicionais a esta versão do protótipo

Protótipo II - Alto envolvimento do cuidador

Nesta versão da aplicação a participação do cuidador é significativa. O cuidador tem uma versão própria da aplicação e para além de poder ajudar a fazer as tarefas e filmar o vídeo para o sobrevivente depois publicar, o cuidador também dá os pontos às tarefas e aprova se o sobrevivente fez as tarefas.

10. Esta aplicação ajuda na reabilitação *

Marcar apenas uma oval.

	1	2	3	4	5	6	7	8	9	10	
Discordo totalmente	○	○	○	○	○	○	○	○	○	○	Concordo totalmente

11. O envolvimento do cuidador é o correto *

Marcar apenas uma oval.

	1	2	3	4	5	6	7	8	9	10	
Discordo totalmente	○	○	○	○	○	○	○	○	○	○	Concordo totalmente

12. Usaria esta aplicação no dia a dia? *

Marcar apenas uma oval.

	1	2	3	4	5	6	7	8	9	10	
Nunca usaria	○	○	○	○	○	○	○	○	○	○	Usaria frequentemente

13. Se respondeu que não usaria a aplicação no dia a dia (entre 1 e 5 na pergunta anterior) explique porquê

14. Comentários adicionais a esta versão do protótipo