Investigating the Opportunities for Technologies to Enhance QoL with Stroke Survivors and their Families

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ABSTRACT

There are over 80 million stroke survivors globally, making it the main cause of long-term disability worldwide. Not only do the challenges associated with stroke affect the quality of life (QoL) of survivors, but also of their families. To explore these challenges and define design opportunities for technologies to improve the QoL of both stakeholders, we conducted semi-structured interviews with 10 survivors and one of their family members. We uncovered three major interlinked themes: strategies to cope with technological barriers, the (in)adequacy of assistive technologies, and limitations of the rehabilitation process. Findings highlight multiple design opportunities, including the need for meaningful patient-centered tools and methods to improve rehabilitation effectiveness, emotion-aware computing for family emotional support, and re-thinking the nature of assistive technologies to consider the perception of transitory stroke-related disabilities. We thus argue for a new class of dual-purpose technologies that fit survivors' abilities while promoting the regain of function.

Author Keywords

Stroke Rehabilitation; Quality of Life; Assistive Technologies

CCS Concepts

•Human-centered computing → Accessibility; Empirical studies in accessibility; User studies;

INTRODUCTION

Stroke is a condition caused by a disturbance of blood supply to the brain, which results in the death of a localized area of brain cells. Such an event can have a significant impact on cognitive and motor abilities, which affect the quality of life (QoL) of survivors [13, 22]. There are over 80 million stroke survivors globally, making it the main cause of long-term disability worldwide [17, 25, 44, 48]. The number of people affected by stroke has increased across the globe in both men and women of all ages [17] and its incidence is expected to increase due to an aging population and lifestyle changes [21].

Stroke impacts primarily one side of the body (e.g. hemiparesis), while leaving the other side mostly unaffected. Approximately 80% of stroke survivors never fully recover from motor impairments [33] and nearly 50% have to rely on assistance to carry out activities of daily living [42]. Although suffering a stroke affects many aspects of the survivor's QoL, it also often leads to the dependence of others [22, 58]. A majority of stroke survivors reside at home with family members and the resulting adjustments in family dynamics can be significant (e.g. role changes, routines, and emotional reactions) [16]. Nevertheless, there is little doubt that families play a major role in the lifestyle changes associated with a stroke, namely in care, socialization, recovery, and wellbeing of survivors.

Rehabilitation is a crucial process that aims to improve both function and independence in daily activities. Many technological solutions have been explored for physical rehabilitation, including robotics [49], virtual reality [26, 52, 57], games [2, 12, 28, 40, 54], tangibles [34], and mixed reality [12, 35]. These approaches provide engaging activities and appear to be successful in encouraging sensorimotor integration, promoting motor learning, and developing confidence. Mainstream technologies have also been used to improve speech [60], enable patient-professional communication [32], support creative writing [45], explore social identities [15], and support caregivers [39, 10]. Still, while rehabilitation is often effective in improving functioning over time, there are still gaps (*e.g.,* activity limitation, reduced participation) in QoL where stroke survivors are dissatisfied with life [13, 22].

It has been shown that the use of mainstream technologies (*e.g.,* smartphones, computers) can provide a sense of independence and safety to stroke survivors [19, 36, 41, 64], even though accessibility barriers exist (*e.g.,* handling, finding functions) [14, 27]. Still, research on Assistive Technologies (ATs)[1] has

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[1] ATs can be defined as technologies to support people with disabilities in performing tasks they were unable (or inefficient) to complete otherwise, by decreasing interaction barriers [8, 46]

been largely limited to rehabilitation, and little is known about the opportunities of mainstream technologies to improve QoL of stroke survivors. Also, despite their crucial role, even less attention has been paid to the views and opinions of families.

In this paper, we explore the potential of mainstream technologies to enhance the QoL for stroke survivors. Key questions include: What is the impact of stroke on QoL of survivors and family members? How are they using mainstream technologies (e.g., mobile devices, computers)? What are their accessibility challenges? What are the main benefits and drives of using mainstream technologies? What are the design opportunities for future technologies? To address these questions, we conducted semi-structured interviews with 10 stroke survivors and 10 family members. We discussed the effects of the stroke on aspects of wellness [43, 59] and family dynamics along with the (non-)technological solutions they employ.

The contributions of this paper are: 1) an analysis of the themes that emerged from interviews with stroke survivors and caregivers, emphasizing the impact of stroke both on QoL and on technology use; 2) a set of design opportunities to inform the design of mainstream technologies and of ATs for stroke-related disabilities; 3) a new paradigm of Dual-Purpose Technologies that fit survivors' abilities while promoting the regain of function. This work will be of interest to accessibility researchers, and designers of AT and Rehabilitation Technologies, who should consider the current use and perception of technology of stroke survivors (and their families).

METHODOLOGY

We conducted semi-structured interviews to assess how the stroke affected QoL of stroke survivors and caregivers and the role of mainstream (and assistive) technologies on their everyday life. Moreover, it allowed us to inquire about changes in family dynamics, having a perspective of both stakeholders.

Participants

We recruited 11 stroke survivors who experienced a stroke within the last 10 years. Participants were recruited through both a local support organization for stroke survivors and local rehabilitation centers. Inclusion criteria was participants who had a stroke that affected their QoL within the last 10 years. Exclusion criteria included people with severe cognitive or communication impairments, which would prevent them from fully participating in the interview. This assessment was conducted by experienced physiotherapists as part of the research team. One of the survivors had to be excluded from the study as he had severe communication impairments, resulting in a total of 10 stroke survivors (6 females). All participants were Portuguese and their ages ranged from 33 to 68 (M=51, SD=11) years old. All survivors scored at least 62.5% on the Lawton Instrumental Activities of Daily Living Scale [18] (M=84%, SD=11%), showing some level of autonomy in performing activities of daily living (Table 1).

In addition to the interviews with stroke survivors, we conducted interviews with their primary caregiver. Although their relationship was not a criterion, all caregivers were either spouses or partners. Caregivers' age ranged from 40 to 65 (M=51, SD=9) years old. We could not conduct the interview with S5's primary caregiver, as they were divorced at the time.

Procedure

This study was approved by the Ethics Committee of Instituto Superior Técnico, University of Lisbon. Interviews inquired about how the stroke affected participants' QoL along eight dimensions of wellness that are frequently used in the literature: physical, spiritual, occupational, environment, intellectual, financial, emotional, and social [3, 20, 43, 59]. Questions were about the role of mainstream technologies along each of the wellness dimensions, including but not limited to the use of computing devices, online services, ATs or built-environment adaptations. We also inquired whether they have or had experienced accessibility barriers using those technologies and what were their coping strategies; and how the stroke affected the use of technology. Finally, we prompted participants to envision novel technologies that could improve their QoL.

Interviews with family members covered the same topics and were similar in structure; however, these interviews focused on the family members' experience and views while supporting their relatives in the post-stroke period. Interviews with both stroke survivors and family members were conducted individually and separately. All participants signed a consent form. Each interview took approximately one hour and each pair was compensated for their time (20€).

Analysis

We audio recorded and transcribed the interviews. For the data analysis, we followed an iterative coding process [23]. Two researchers independently created a codebook from a set of four interviews (two with stroke survivors; two with caregivers) using an inductive approach; the codebook was subsequently refined and merged. After reaching a consensus on the codebook, another researcher reviewed their work. The two researchers then coded a randomly selected subset of 20 questions from the entire dataset, followed by two iterations (with 10 questions each) of refinement and comparison. Finally, Cohen's kappa was computed to assess interrater reliability. The average kappa score across all codes was 0.81 (SD=0.19, range 0.55 to 1.00). Each of the two researchers then coded a subset of the remaining interviews, independently.

FINDINGS

Interviews with stroke survivors **(S)** and caregivers **(C)** uncovered challenges that affect their QoL and the rehabilitation process, individually and as a whole. In this section, we highlight the more relevant challenges for the pair *survivor-caregiver* **(SC)** including coping with emotional burden **[F1]**, adaptations to mainstream technology **[F2]**, perceptions on ATs **[F3]** and the barriers found in the rehabilitation process **[F4]**. S and C perspectives are also discussed highlighting the value of an effective *survivor-caregiver* team **[F5]**.

"We Had a Stroke" [F1]

It is well documented in the literature that stroke has a detrimental impact on the survivor's life, visible in the decline of the survivor's physical, cognitive and motor abilities [25, 44, 48]. However, the survivors' professional activities, hobbies,

S ID	S/C Age	S/C Gender	Stroke Onset (years)	Type of Stroke	Lawton & Brody score (%)	Impairment	Relationship
S1	55 / 65	F / M	1	Hemorrhagic	62,5	Hemiparesis Right Side, Mild Dysarthria	Partner
S2	- / 43	M / F	1	Ischemic	-	-	Spouse
S3	45 / 46	F / M	9	Hemorrhagic	87,5	Hemiparesis Left Side	Spouse
S4	68 / 66	M / F	2	Ischemic	80	Hemiparesis Right Side, Ataxia	Spouse
S5	33 / -	F / -	2	Ischemic	100	Hemiparesis Left Side	Partner
S6	55 / 55	M / F	2	Ischemic	80	Hemiparesis Right Side, Mild Dysarthria	Spouse
S7	64 / 45	M / F	7	Ischemic	100	Hemiparesis Left Side	Partner
S8	43 / 45	F / M	8	Ischemic	75	Hemiparesis Left Side	Spouse
S9	35 / 40	F / M	4	Hemorrhagic	87,5	Hemiparesis Left Side, Neglect	Spouse
S10	51 / 52	F / M	6	Hemorrhagic	87,5	Hemiparesis Right Side	Spouse
S11	60 / 57	M / F	10	Ischemic	80	Hemiparesis Left Side	Spouse

Table 1. Demographic information about participants. S - Survivor, C - Caregiver, F - Female, M - Male.

activities of daily living, perception of self-image and group activities suffer negative transformations [13, 17, 21, 22, 25, 44, 48] that can lead to the deterioration of one's emotional health. This has repercussions on their QoL, social networks (losing or weakening friendships) and close family, who have to cope with abrupt changes in their own lives. As a caregiver claimed (C6): "*The whole family had a stroke. This did not mess with him alone, we were all affected*".

Impact on our Emotional Health **[F1a]**

The *survivor-caregiver duo* can "make or break" the rehabilitation success and for that reason, the recovery process should include the two. One caregiver points out "*Rehabilitation involves the family, it is not only the survivor recovering*" (C6). It is noted that little attention is given to the emotional health of each individual separately and to them as a duo, disregarding how much that impacts recovery. S9 highlighted that *"A major flaw I think exists in stroke rehabilitation is psychological support. There is none"*. S4, C4 and S9 ended up looking for private health professionals for such purpose.

Impact on our Motivation **[F1b]**

All participants mentioned that family and close friends were the cornerstones of their rehabilitation process, adding value as their extrinsic motivation. Other critical assets in the rehabilitation process are social groups dedicated to support stroke survivors. These groups offer support and motivation, allow sharing of knowledge, and help people find others with similar experiences. As mentioned by S8, stroke survivors "*need to feel that they are not the only ones going through it*".

Another necessary ingredient to manage emotional health (not accessible to all) is intrinsic motivation. Setting self-directed goals has a major impact on their motivation [4]. For instance, C6 mentioned that S6 "*has not given up on getting back on his motorcycle*", while S4 said: "*I will not buy an adapted car, I will not be without my car"*, which worked as an incentive to recover the functions required to drive again. See also **[F4]**.

Survivors (often) Adapt to Technology [F2]

Survivors' impairments resultant from stroke affect how they interact with technology. For this reason, they find new strategies to cope with the increased accessibility challenges.

Quit or Switch Technologies **[F2a]**

Although most stroke survivors ended up adapting to technologies, two (S2, S8) have chosen to stop using a particular technology (the computer) due to the increased barriers they faced, as described by C2: *"He liked to go to the computer to check out heavy machinery [related to his work] for sale" but "stopped using it. (...) I think it is because he cannot write, does not want to, or is not encouraged"*.

Another strategy used by stroke survivors is to switch technologies, making use of devices that are more accessible to them. Both S6 (who still uses the computer but less often) and S8 started using a smartphone for many of their tasks. S8 commented: *"I stopped using the computer... but I am very connected to the phone. I do everything on the phone (...) [because] it is practical. It is always with me. I can easily get on it and see what I need to do"*.

Adapt How to Interact with Technology **[F2b]**

One of the main strategies of stroke survivors when interacting with devices such as computers or smartphones was to use only their unaffected hand. Still, some survivors (S3-S6) tried to gradually incorporate their impaired hand in the interaction with such technologies, which also worked as an incentive to regain function. For instance, S4 said: *"I used to write every day on the computer (...) At the time, it was just with my left hand. I used to take a very long time to finish one page. But then, slowly, I started pressing Shift with my right hand for uppercase characters, inputting numbers on the keypad (...) so I could move the [right] hand because I wanted to [use it]"*.

Another strategy concerns handling the smartphone in a different way, but still making use of both hands. Both S1 and S6 started using their affected hand to interact with the touchscreen, by keeping it still with the index finger sticking out and moving the smartphone with their other hand for the usual tapping gesture. S7 and S9, on the other hand, made use of low tech such as pop sockets (removable grips for smartphones) or a headset to ease how they handle the smartphone. S9 mentioned that "*Now I have something great that is a pocket [pop] socket (...) I could not take pictures with my left hand, and now I can because these fingers are holding it and I can tap with the thumb (...) I could not hold [the smartphone] and take a selfie (...) if I am doing something with the right [hand]*".

New Applications of Technology **[F2c]**

The physical and/or cognitive impact of stroke has also resulted in participants finding new applications that meet the current needs of survivors and caregivers. Several participants mentioned examples of strategies for solving specific issues in their lives, such as medication control (S7), reminders (S8 and S9), or fitness (for walking) applications (S9). In addition, C3 mentioned that their family has a "*a shared mobile phone calendar in which we [they] invite each other*", in order to better coordinate family activities.

Asking for Help **[F2d]**

Besides finding their own coping mechanisms to interact with technology, some participants resorted to others when needing help. S6, who uses his personal computer for work, sometimes *"hits keys without noticing it"*, but feels comfortable to ask his co-workers for help: *"when someone has difficulties (...) asks for help"*. S1, on the other hand, reported some discomfort asking for help when using the computer at a local library: *"The mouse is difficult to use. I do not have a personal computer, and therefore I go to the library. The man [librarian] does not have the patience to help me anymore... because my fingers are no longer the same. He says I have to practice"*.

The (in)Adequacy of Assistive Technologies [F3]

All participants presented severe impairments earlier in their recovery and despite significant improvements in their motor or cognitive abilities, they still have difficulties performing some of their daily living activities. ATs were extremely important in the rehabilitation process, in particular, to support daily activities such as mobility and cooking. For instance, all stroke survivors, except S1, referred to using a manual wheelchair, four switched to a car with automatic gears and some adaptations, and three used specialized kitchenware. However, most stroke survivors do not use any kind of AT to interact with their technological devices such as smartphones or computers, despite having difficulties interacting with them.

Unawareness **[F3a]**

Stroke survivors found strategies to interact with technology **[F2b]**, mostly by adapting themselves instead of the opposite. The lack of use of specialized AT can be explained in part by people's unawareness of existing AT. S10 commented: "*People who suffered [the stroke] recently, they need a lot [of help] because they can't use the mouse nor the computer, they can't go.. they can't cut, they need help for everything. (...) I have tried to adapt to what already existed. Actually, there are few adapted things. Either we adapt to what exists or there is nothing that adapts to what we need.*" This view is shared with caregivers who ask for more adaptability through technology, as described by C6: "*I think it has to be as much adapted [as possible], and more and more, because it does not make much sense to me, in the era we are in with so much technology, not adapting what is possible (...) I think everywhere, at home, at work, and starting eventually at the hospital.*"

The Perception of Transitory Disabilities (and ATs) **[F3b]**

The main factor in AT rejection by stroke survivors is their perception that their disabilities are temporary. This perception is shared with therapists involved in the rehabilitation process. S9 commented: "*I try not to do [any adaptation] because as they say in Occupational Therapy, and I think it makes sense, this does not have to be forever, right? It is recoverable (...) so it is something that I need to force [myself to do]*". S4 had the same opinion on the use of motorized wheelchairs: "*It was manual because it didn't make sense to invest in a motorized wheelchair, because I didn't want to stay in the wheelchair.* ".

By perceiving their disabilities as transitory, some survivors believe that the use of ATs hurts the rehabilitation process as it dramatically lowers the interaction barriers, which as a consequence has a negative impact on their ability to recover function. S6 stated: "*No, I did not look [for ATs]. In my perspective it was also a transition, right? Because it was not definitive (...). I was always worried about evolving, always doing more instead of settling. (...) I give the [an] example (...) I always tried to use the TV remote with the right hand, which is the affected one (...). It was a stimulus to get better"*.

Low Usability **[F3c]**

Despite the little use of ATs, there were a few occasions where survivors tried solutions that could ease their interaction with technology. One example is text input; most survivors continued to use the same method they used before the stroke, but C9 refers to a colleague of S9 (who also had a stroke) using speech input: "*There is a colleague of hers who also wrote a book (...) and she had difficulty writing by hand, so she wrote a whole spoken book. She used an application, used Facebook or Google..*". S9 – who does not have speech impairments – referred to the same colleague, but also to the low usability of current speech input technologies that prevented her from doing the same: "*She dictated and that [the system] transcribed (...) But I do not think it is very good. Or I speak badly. Because that [the system] understands everything wrongly"*.

The Limitations of the Rehabilitation Process [F4]

Rehabilitation is seen by most stroke survivors and their caregivers as a central aspect of improving QoL. Still, as with the lack of emotional support **[F1a]**, participants also noted the need to improve some aspects of rehabilitation procedures.

Dependence of In-Situ Therapy **[F4a]**

Due to the continuous nature of stroke rehabilitation, most participants are still enrolled in physiotherapy sessions despite being in recovery for several years (five survivors suffered their stroke more than five years ago). Still, stroke survivors' desire to be continuously enrolled in physiotherapy is often interrupted (e.g., two to four weeks between sets of sessions – S4, S10 and S11) or delayed due to bureaucracy in the public healthcare system. C4 commented on the wait for admission in a rehabilitation center: "*Because it is a very long waiting* *time for those who have a stroke. Waiting three, four, or five months to enter the rehabilitation center. You can not imagine, it is despair, crying everyday. Because we only see one thing, rehabilitation. There is only one cure for this, rehabilitation.*"

C4 went on to say "*and then the support they have at home is none*", which was a common belief among participants. While some families have the financial means to partially cover these interruptions (through private institutions), this is not generalized. Overall, participants were enthusiastic about taking rehabilitation home, but not without raising relevant concerns that need to be addressed in order to make it possible. First, physiotherapists are often reluctant to prescribe rehabilitation exercises, as performing them incorrectly can be harmful due to the introduction of compensatory movements (C8, S9). Potential solutions suggested by participants included the use of technology to validate their exercises [1], as mentioned by S6: "*If there was a technology relatively simple that could replace the physiotherapist, some video camera that could see, analyze... 'It's 10% out of the correct pattern', and then warn the person about what is incorrect*". Still, most participants referred to the importance of including physiotherapists in the whole process. Second, although physiotherapists sometimes specify a few simple exercises that stroke survivors can do at home, it can be hard for survivors to keep motivated to follow the plan and perform the required exercises (C9, S9, S10, C11). Finally, the tools used in rehabilitation centers (including specific games or apps) are not available at home, as highlighted by S9: "*No, at home I do not do much (...) because those kind of things [the tools] are not available... not accessible to people, to the average person*".

Progress is Central, but Slow or Invisible **[F4b]**

All stroke survivors and caregivers were able to positively identify recovery of specific functions, showing how important it is to be aware of progress even when only small changes occur. Overall, participants were highly aware of the progress they have made between their early recovery stages and now. An exception is S11, as shown by C11's comment: "*What he got on his mind was... This [physiotherapy] does not do anything to me [S11], Because my arm does not move. What does physiotherapy give me if my arm does not move*?"

Lack of information and control can affect how individuals see the benefits of certain activities. A perception of stagnation may result from small relapses (S1, S5, S11), but is mainly justified by the very hard and slow nature of stroke rehabilitation. C9 describes his strategy to make S9's progress more clear: "*One thing that I think would be very useful (...) [would be] to have a kind of tracking of what they are doing... For them to register their progress (...) I made the effort of trying to register by taking photos. With the conversations that exist in everyday life, unintentionally there is a good record as well (...) Because the steps are so, so small, with such a big effort (...) That's why it is so important that they look back after three months and see.. 'Wait, it was step-by-step but I have progressed this much*"'. In this case, C9 used the means he had available (smartphone camera) to track progress and motivate S9. S5 adds: "*I think progress has always been going slowly, but we don't even know what contributed to such progress*".

The Lack of Personalization **[F4c]**

C4 commented that stroke survivors require a different kind of rehabilitation when compared to other patients. Yet, time available for treatment ends up being similar among patients. Moreover, a recurrent topic in the interviews that was noted by C8 is that "*all strokes are different and for that reason, there has to be a larger differentiation of its consequences*". C8 goes further and comments on the need for personalization: "*I think there has to be an adaptation.. First of all, age is very important (...) Age groups, mobility, knowing which side.. S8 moves the right side and there are people who do not move the left side.. Or others who do not speak. I mean, the level.. what are we talking about? Catching balls with baskets? Come on, for us, it is so childish (...) Seeing adult men and women catching balls with a joystick and not even making it*".

The need for adaptation in rehabilitation was often mentioned in terms of activities that are important or motivating for stroke survivors. For instance, S9 would like to follow a plan prepared by her therapist, eventually taking it to a gym. Yet, she notes that the "*problem is that there are no technologies [referring to exercising apps] with all the details that are absolutely 100% personalizable*". C8 on the other hand, referred to playing games that could involve the whole family on the Wii. In addition, C6 commented on using intellectual stimuli to make S6 more physically active: "*Everything that can make him tired.. to move, it is difficult. It had to be something that really stimulates him intellectually (...) forcing him through the intellectual part to get him to physically move*".

Perspectives of Survivors and Caregivers [F5]

The interviews with stroke survivors and their caregivers provided different perspectives on the impact of stroke. While there are many findings that are supported by both stakeholders, we also found contrasting opinions between pairs, and novel or supplemental information provided by one of them.

Contrasting Perspectives **[F5a]**

Although the *survivor-caregiver* pair shares points-of-view, it is common to obtain information at different levels of granularity, as well as role-specific perspectives. We also found contrasting arguments between pairs and explicit statements of disagreement. For instance, S6 and C6 had contrasting opinions regarding the involvement of caregivers in the rehabilitation process at home. S6 commented: "*It does not work (...) because this is physical therapy (...) I do not believe most [caregivers] would know if the exercise is well done or not*"; and that *"caregivers have other things to do (...) It may be an asset in some cases, but I do not think it is a solution"*. In contrast, C6 thinks that they should be "*increasingly more involved in the rehabilitation process [at home]. (...) Caregivers need to be empowered with more professional skills"*. Another difference concerns the pair's attitude towards the consequences of stroke. For instance, S4 is very motivated to recover to the full extent including traveling as he used to do, but C4 is afraid of taking trips that are far away from home.

Contrasting perspectives were also disclosed just by one of the elements. For instance, C11 stated: *"He thinks he did not improve [with physiotherapy], but he did. Of course, he did"*, which was not shared to the researchers by S11.

New and Complementary Perspectives [F5b]

Caregivers provided more details than survivors either because survivors forgot to mention them or were uncomfortable to discuss specific subjects. A few examples include the need to ask for psychological support (C4), survivor starting to have risk behaviours (*e.g.,* drinking, smoking) post-stroke (C6), the effect of stroke on sexual activity (C7), interaction with health professionals during hospitalization (C8) and even specific hobbies of the survivors (C9).

The interviews show the need of an effective *survivor-caregiver* team **[F1a]** where a balance between protection and opportunity allows the survivor to gain back independence and autonomy (SC1, SC3, SC4, SC7-SC9). When over-protection exists, it can break the *survivor-caregiver* link because it limits personal freedom. S9 stated: "*There is a very thin line between being a caregiver and promoting autonomy. I have met many perfect caregivers (...) and then the survivor thinks, why would I [get up]? He is going to get the glass of water for me. (...) Actually, C9 often says that to me 'you get up and go get it'*".

DESIGN OPPORTUNITIES

Mainstream technologies have the potential to support the *survivor-caregiver* pair in several of the challenges that emerged in the interviews. In this section, we discuss a set of design opportunities **[DO]** aimed at improving the *survivor-caregiver* QoL and support their rehabilitation process, in line with the findings (**[F1-5]**) previously described.

Emotion-Aware Computing [DO1]

Stroke impacts both survivor and caregiver, but rehabilitation is focused mainly on the survivors' physical and/or cognitive recovery. The lack of support of the *survivor-caregiver* emotional health was reported as a major flaw in the rehabilitation process **[F1a]**. This limitation brings novel design opportunities for detection, prevention and intervention mechanisms for emotional health in areas such as *affective computing* [50].

Voice user interfaces (VUIs) (e.g. Amazon Echo, Google Assistant), for instance, are becoming ubiquitous and part of the social fabric at home [51]. Although VUIs can hardly be considered conversational, the fact that they are somehow integrated into a family dynamics makes them promising tools for rendering valuable and more holistic information to professional healthcare about the individual [51]. Moreover, these devices can be the scaffold for more complex designs intended to increase the necessary synergy between *survivor-caregiver* for effective rehabilitation, including emotional health assistance. This type of approach draws a parallel with conversational agents (CA), either virtual or robotic, designed to support the user in a myriad of scenarios including healthcare [5], companions for the elderly [55, 63], couples therapy [61], coaching[29], and support for mental health issues [11].

CAs attempt to overcome barriers that usually prevent people from seeking help in each of the aforementioned topics, while offering objective measures of the user's behaviour to support healthcare providers. For instance, *Ellie* [11] is a virtual therapist that follows a protocol to identify markers of depression, anxiety and post-traumatic stress disorder. Similar technologies could be applied to stroke given its impact on emotional stability. However, *Ellie* faces challenges in managing dialogue and its perception system relies on technology that is not available to all for the analysis of non-verbal behavior. Not to mention that this technology is focused on the individual and not on the pair *survivor-caregiver* as a whole **[F1a]**.

A challenge exists in creating multi-modal technology that allows to elicit utterances from the user in a plausible and coherent dialogue while collecting voice and social features - in the wild - to monitor *survivor-caregiver* affective impairments. Additionally, VUIs ability to sense the environment could act as a mechanism to improve the relationship between *survivor-caregiver* towards more effective *teams* **[F5a, F5b]**. Still, the potential of such technologies can be reduced in case of communication disabilities – e.g., aphasia, severe dysarthria.

Dual-Purpose (Assistive) Technologies [DO2]

There are many Assistive Technologies (ATs) that can potentially help stroke survivors performing their daily tasks or interacting with mainstream technologies, by lowering the interaction barriers. A representative example – especially because all participants had upper-limb impairments – of the availability of ATs is text input, where one-handed keyboards or speech input can be used to ease and speed up interaction. However, despite the impairments resultant from stroke (either cognitive or physical), survivors reported limited use of ATs to interact with their devices, preferring to limit their use and functionality [36] or to adapt themselves to the technology **[F2]**. This is derived not only from the unawareness of ATs, but from many participants' perception that their disabilities are transitory **[F3b]**. As a consequence, the current paradigm of ATs, which aims to lower the interaction barriers, was seen as restrictive and as slowing down their ability to recover. For example, survivors rejected a one-handed keyboard since they would stop using their affected hand.

We argue for the need of a paradigm shift: the design of *dual-purpose* technologies that consider the survivors' perception of transitory stroke-related disabilities while contributing to the rehabilitation process **[F3b, F3c]**. When building such technology, it is essential to dynamically consider the trade-off between easing users interaction with technology and creating challenging situations that can be compatible simultaneously with their disabilities and with their rehabilitation objectives **[F1b, F5b]**. Revisiting the keyboard example, a dual-purpose soft-keyboard could split the keyboard in two, assigning different roles to each hand based on current hand function, promoting the use of the affected hand.

ATs researchers can draw parallels with disciplines such as Tutoring Systems and Game Design [53], where the challenges placed on the learner/player are adjusted to their performance and motivation level. In (Serious) Game Design, the concept of offline and online adaptability emerge along with engagement and learning outcomes [62]. The former refers to adjusting the game obstacles to the user's current level of proficiency before interaction. The latter dynamically balances challenges' difficulty as the user's proficiency increases over time during task execution. The central idea is to make things simpler for underachieving users, but keep them interesting enough so that it does not undermines engagement. Such game design principles that have been applied to other disciplines (e.g. fitness apps [6]) over the years can also be explored to build dual-purpose technologies for stroke survivors. Online adaptation, for instance, could support device interactions to help users make small steps over time while taking into account their performance and current emotional state (for instance, by monitoring frustration and overall motivation) **[F4c]**. The importance of these mechanisms is salient in the context of stroke recovery where improvements are often slow despite survivors' enormous effort, requiring minimal barriers and step-by-step progress for extended engagement **[F4b]**.

Other parallels can be drawn with research on Situationally-Induced Impairments and Disabilities (SIID), which uses ATs in temporary scenarios to ease users' interaction with technology when their abilities are negatively impacted by contextual factors [65]. The distinctive factor of stroke survivors' perspective is that by decreasing the interaction barriers, ATs can, in turn, hurt the rehabilitation process. Such paradigm shift and striking a dynamic balance between interaction barriers and regain of function opens a new topic of research.

We argue that considering survivors' perception of transitory disabilities is crucial in the design of technologies for this user group. Still, it is relevant to note that this transition may not lead to a full recovery and that health professionals should be involved both in the design of technology and in determining which technologies are appropriate for each survivor and their specific disabilities. It is then key to design personalizable, dynamic solutions that adapt to the abilities (and rehab plan) of survivors in order to motivate, but not frustrate them. Also, AT designers and health professionals should consider that some survivors may perceive their disabilities as permanent, in which case an existing AT could be more appropriate.

Self-directed Rehabilitation & Progress Awareness [DO3]

Stroke survivors usually need to regain physical, cognitive or language function. More importantly, they aim to reclaim back their independence, old routines, and QoL. We verified that survivors develop their own health outcomes to cope with their *mundane* challenges [47]. For instance, ride a motorcycle again, or get dressed on their own (*performance goals*) **[F1b]**.

In educational literature, it has been argued that learning in contexts with practical utility and with links to one's everyday interests strengthens the individual intrinsic motivation for learning [9]. This represents the key idea of self-directed rehabilitation: recovery centered and adapted to the intrinsic needs of the patient **[F1b, F4c]**. Current technological solutions [1, 24, 56] offer support for the execution of exercises prescribed by the therapist, which may be abstract and decontextualized. In line with educational learning, this results in a decrease in motivation due to the lack of understanding of the direct utility of the exercise and not because of the level of abstraction in and of itself. Technological solutions that illustrate the benefits between exercise and performance goal, would give information and control to the individual, and potentially heighten their motivation to master a goal-relevant behavior.

Self-directed rehabilitation is certainly affected by progress awareness, as stagnation and slow progress affect the individuals' motivation and raises doubts about the benefits of their therapeutical activities. People feel that they need more information and control over their rehabilitation **[F4b]** and technology can be key to bring awareness to survivors.

Systems that assist during the execution of rehabilitation exercises (in clinical centers or at home) are data centers of one's progress [56]. A challenge exists in making this technology more accessible using mainstream sensors, such as RGB cameras or wearable sensors (e.g., activity trackers) and convey that data to people. Advances in computer vision and activity detection (with technologies such as OpenPose [7]) can use data captured with webcams or smartphones [37] to assess one's level of mobility over time or identify critical progress milestones reflected in *mundane* activities (previously set as *goals* **[F1b]**): know when the user started walking, cooking or having a shower on their own. These milestones are certainly small steps towards self-directed achievements and worth to keep track **[F4b]**. Still, information should be conveyed in a meaningful way to the *survivor-caregiver* pair and therapists.

Digital diaries are a result of this continuous logging of one's activities and represent a personal and meaningful way to store information about one's achievements. It is also a means to express inner thoughts and re-experience past events [38]. The *Affective Diary* [38], for instance, invites reflection and interpretation of abstract visualizations of one's emotions throughout the day. We envision that monitoring progress through a combination of automatically collected and user generated content **[F4b]** that reflects meaningful activities to the survivor's QoL, will have a positive effect on rehabilitation.

Despite the potential of technologies for rehabilitation, designers should consider that individual differences such as age may have an impact on rehabilitation and technology adoption, influenced by lack of trust, usability or due to anxiety [30]. Age, in particular, is relevant because the risk of stroke is higher for older adults, even though it may occur at any age.

Caregivers in the Design Loop [DO4]

A stroke episode causes significant changes in the survivors' daily living while affecting the caregivers' routines and responsibilities as they usually take on new roles [31] **[F1]**. Throughout the interviews, the caregiver emerges as a fundamental piece in rehabilitation effectiveness.

Because primary carers are individuals that are constantly involved in the survivor's care, they can offer unique perspectives for the design of novel technologies that are compatible with their care practices and their family routines – as shown by the new, complementary and contrasting perspectives of each survivor-caregiver pair **[F5]**. Their participation in the design process can also reduce resistance to adoption [47], as they can approach technology as a collaborative element to enhance QoL of stroke survivor and caregiver alike.

Contrasting perspectives **[F5a]** need to be carefully analyzed to design solutions that are accepted by all stakeholders. For instance, further including the caregiver in the rehabilitation process should consider their willingness to do so, but also survivors' perception that caregivers are already overloaded. In another example, S5 and S10 found that over-protection was detrimental to their rehabilitation and wellbeing, while C4, C6, and C10 thought monitoring would be beneficial. Monitoring approaches would then benefit from providing enough information to caregivers to reduce their fears and concerns, but only if maintaining survivors' autonomy.

Perspectives from caregivers **[F5b]** can bring attention to outcomes that survivors feel uncomfortable to share, meaning that designers need to consider privacy when addressing them. Also, further formative studies – anonymized or subject-specific – may be more appropriate to collect sensitive data.

LIMITATIONS AND FUTURE WORK

We interviewed stroke survivors who were relatively diverse in attributes such as age, current disabilities, and experiences in the rehabilitation process. Also, including both survivors and their caregivers provided us an holistic view of the pair dynamics. However, we did not interview survivors with severe cognitive or communication impairments due to communication challenges. Although our findings and design implications can be applied to stroke in general, including survivors with such characteristics would provide a broader view of the impact of stroke – and of technology – on survivors' QoL. We aim to broaden this investigation, by including children who are stroke survivors (and their parents) in the process. We note however that conducting this research with children requires a different study design than the one presented herein. Moreover, including health professionals in the process will be key to design technologies that are both adopted and effective in improving the QoL of stroke survivors and their families.

CONCLUSION

We presented the findings of interviews with stroke survivors and their primary caregiver, aiming at uncovering the impact of stroke on the pair's QoL and the opportunities for mainstream technology to improve the rehabilitation process and QoL. We found that the *survivor-caregiver* dynamics has a key role on the recovery – including emotional – and on the regain of autonomy of stroke survivors **[F1, F5]**. In addition, we found three major inter-linked themes related to the use of and interaction with technologies: the current strategies to cope with technological barriers **[F2]**, the inadequacy of ATs **[F3]**, and the limitations of the rehabilitation process **[F4]**.

Based on these findings, we contributed with a set of design opportunities to leverage mainstream technologies to improve both the rehabilitation process and the QoL of stroke survivors and their families. Namely, we envision opportunities in the design of: emotion-aware computing for family emotional support **[DO1]**; self-directed rehabilitation that considers survivors' mundane challenges and the support of progress awareness to overcome the difficulties in perceiving the slow – and sometimes invisible – recovery of function **[DO3]**.

In addition, we argue for a paradigm shift to the design of *dual-purpose technologies* **[DO2]** that ease the interaction with mainstream devices, while contributing to the rehabilitation process. The goal of ATs is to lower interaction barriers, which survivors consider an obstacle in their rehabilitation. Dual-purpose technologies ask for a thought design of ATs that dynamically increase barriers as users show improvements.

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