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# Stroke and Universal Design

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**Abstract.** Universal Design (UD) is usually stated to be “for all ages and abilities”. Given that stroke is a major source of disability, it is important that UD recommendations take stroke-specific problems into account. Within the framework of EU project STARR, we have investigated user requirements of stroke survivors. In this project we have used a mix of interviews, focus groups, design workshops and technology tests to come up with a set of design recommendations, which we present as a first step towards universal design recommendations which are inclusive for stroke survivors. Our general recommendations are: make it fun, do not make people fail, empower and encourage. The technology needs to be highly adaptable to different sets of abilities. Safety, but also aesthetics and simplicity is important, but it is pointed out that designs should not be “childish” – this can be felt to be degrading. It is important to be able to see and follow your progress and win small victories often. Consider social applications and activities –being able to connect to others in the same situation can enable discussions and provide peer support. More stroke consequence specific recommendations are to design to allow one-sided use (hemiplegia), avoid sensory and activity overload (fatigue), complement speech with images (aphasia), limit demand on memory, support learning and avoid errors (memory problems), and include multiple modalities in your design (reduced vision or hearing).

**Keywords.** Stroke, design, recommendations, universal design

## 1. Introduction

In 2013, stroke was the second most common cause of death, and the third most common cause of disability. Globally, there were almost 25.7 million stroke survivors (10.3 million new strokes). Stroke should not be considered a disease of the elderly, two thirds of all strokes occur among persons < 70 years of age [1]. Stroke is thus a major societal challenge, and common consequences of stroke needs to be considered in Universal Design. In this text we report from a series of user studies done within the context of the STARR EU project. Although this project specifically targets ICT solutions for the self-management of stroke, we suggest many of our findings are applicable in a wider context.

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## 2. Co-designing With Stroke Survivors

Current work on co-design has largely focused fully able-bodied people, and it can be difficult to involve persons who are disabled and/or elderly in this process. Björkquist, Ramsdal et al. [2] found that it can be difficult to involve older senior users in focus groups due to lack of information about different services. There is also the challenge of adapting activities to suit the prospective users. A person with memory problems or aphasia will find the use of scenarios, a common technique in co-design, hard to use, since these typically are fairly long stories that must be remembered by the participant during the discussion. The physical and cognitive ailments of ageing can add even more challenges to a co-design process [3]. Technology to be tested needs to be either very robust – or the activity well supported by persons able to cover up technology prototype imperfections [4].

Hendriks et. al. [5] identified seven challenges in doing co-design with people with dementia. These challenges seem to come down to 3 fundamental concerns that can apply also to co-design with stroke survivors: 1) the lack of approach for co-designing with these users – the number of works involving stroke survivors in co-designing is limited and few go beyond single case studies; 2) the over appreciation of the visual and the verbal – stroke survivors might lack the ability to communicate well verbally, or have a hard time to work in a visual manner; and 3) the perception of participatory design/co-design – which normally assumes that partners of (relatively) equal cognitive and physical abilities participate in the design process. Although persons with dementia are a different user group, these points are worth consideration also when designing for stroke survivors.

An example from the NavMem AAL project illustrates how one can adapt a common design technique, the scenario, to work better for stroke survivors. In this project comic like strips were seen to be useful in focus groups with persons who had had a stroke [6], and physical objects and props have been found to be a useful tool when involving persons with speech impairments in a design process [7].

One solution when designing for persons with stroke, is to engage in long term, in-situ, with stroke survivors [8]. Such an approach does not scale easily, and in order to make it practical, [8] suggest a toolkit approach.

Studies in the ActivABLES project [9], made use of a video prototype to illustrate unfamiliar technology to participants. The ActivABLES work also resulted in a set of design requirements when designing tangible interaction for stroke survivors. These requirements have been refined, extended and elaborated in the STARR project.

## 3. User Studies in STARR

The aim of the initial user studies in STARR was to gather initial input for the design process. The initial user studies in the project involved in total 116 stroke survivors (8 persons under the age of 45, 21 persons 45-59, 36 persons 60-69, 34 persons 70-79 and 17 persons 80+). We have strived to gather information to both inspire and direct our design work, as well as to involve different stakeholder groups in our work right from the very start. Thus we have made use of a variety of methods (semi structured interviews, focus groups and a co-design workshop). The work has mainly been performed at four locations: France (CEA and Hopale), Spain (Osakidetza) and in Sweden (Lund university) and the UK (The Stroke Association). Since there are differences between the sites (different health care systems, different culture, different segments of the user population, different methodological approaches and backgrounds in the research teams) we have had to deal with the question of how much should be the same, and what could be done differently in our studies. Our solution was to use a common questionnaire template that served as the backbone in a set of interview studies, and then complemented this with additional local studies with additional interviews, focus groups and a co-design workshop, reported in [10]. The stroke survivors and family members/informal carers have been recruited through health care organisations in France (Hopale) and Spain (Osakidetza), while for the user studies in Sweden and the UK participants have been recruited through the respective stroke associations. All studies have passed ethical approvals, and participants have signed informed consents. Below we summarize the recommendations resulting from these studies.

## 4. General Recommendations

Despite the differences between the sites involved, similar themes emerge in the studies. Motivation and empowerment are seen as important. Solutions should be simple and encouraging, but not childish. Social aspects are important, and it is recommended that social applications are included in the development – being able to connect to others in the same situation can enable discussions and provide peer support.

Another common theme is that people are different. Abilities vary, but also interests (including the interest in technology) and competitiveness (interest in gaming). Thus, we recommend avoiding “one size fits all” solutions, and suggest a range of solutions to allow flexibility and personalization to varying abilities, interests and situations. We need to have meaningful activities (not exercises) that are fun and/or useful as our primary focus. Games can be one way of providing both fun and meaning, but not everyone enjoys games, and we need to cater also to persons not interested in games.

Despite this, there are some factors common to many stroke survivors. Fatigue is an important factor for a large number of stroke survivors. Thus, all designs need to take fatigue into account; provide enough time to rest and also avoid sensory overload. Limited fine motor skills in one hand/arm as well as aphasia are also common in the population and needs to be considered.

Knowledge is important. Some stroke survivors/family members are reported to lack knowledge about stroke risk factors (or may not be aware of their lack of knowledge). It would also be useful if the system can provide information about related risk factors (e.g. hypertension, diabetes) and complications (e.g. pain, spasticity, dysphagia).

Data sharing needs to be considered carefully. Sharing with health care personnel and relatives appears accepted, but participants seem to reject the general sharing of video images (or audio recordings). Place, time, activity and sensor data, on the other hand, were more acceptable – as was abstract video where you are represented as a stick figure. In the end this is something which needs to be evaluated in the context of an application – what you are willing to share depends on what the information is used for and how useful you find the results of the sharing to be.

We see that progression is important, but we need to be careful with how progress is monitored and displayed in order to support and encourage, and avoid that users experience failures.

Many of these recommendations are true also for carers or heath care personnel. Health care personnel are often stressed, and do not have time to deal with complicated interfaces. Furthermore, they already have to deal with existing systems, and do not appreciate having to deal with additional systems. Ease of use, as well as smooth integration into existing practices is important. Many carers are elderly, and cannot be expected to be early adopters/advanced users of technical systems.

Thus, simplicity is needed not only for many stroke survivors and their relatives, but also for interfaces to be used by health care professionals. This also involves speed – all technology needs to be possible to adjust to speed suited for different end users.

Aesthetics, finally, is also important. We should aim for attractive designs that a person would be happy to use and show to others (aim for inclusion, avoid stigmatization).

To sum up – our overall recommendations are: make it fun, do not make people fail, empower and encourage. The technology needs to be highly adaptable to different sets of abilities. Safety, but also aesthetics and simplicity are important, but it is pointed out that designs should not be "childish" – this can be felt to be degrading. It is important to be able to see and follow your progress and win small victories often. Consider social applications and activities –being able to connect to others in the same situation can enable discussions and provide peer support.

Our findings elaborate the findings in [9] and are well in line with [11] as well as [12], and we consider that our mix of methods and participants has provided us with a good starting point for the design within STARR. Our findings generally fit well with the principles for Universal Design:

- solutions should be simple (Simple and intuitive use), but not childish (Equitable use)
- it is recommended that social applications are included in the development (Equitable use)
- designs need to take fatigue into account (Low physical effort)
- avoid sensory overload (Perceptible information)
- allow personalization to varying abilities, interests and situations (Flexibility in use)
- meaningful activities (Equitable use)
- aesthetics (Equitable use)
- avoid that users experience failures (Tolerance for error)
- easy to follow progress (Simple and intuitive use)
- limit demand on memory (Simple and intuitive use)
- support learning (Simple and intuitive use)
- include multiple modalities (Perceptible information)

It should be noted that although the specific diagnosis is important for rehabilitation and evaluation of health care effects, the aim of the current studies was to understand how to make a system that can be used by stroke survivors. Thus, we have focused on the consequences of the stroke in daily life, not on medical diagnoses in our initial user studies.

## 5. Stroke Specific Recommendations

Stroke is complicated. Not only the severity of the stroke, but also the location impacts on the result (as well as the care you got, and your general health before the stroke). Of those who experience a stroke, 40% have moderate to severe impairments that require special care. Nearly 25% of the strokes occur in someone who has previously had a stroke. A more detailed list of medical consequences is available in [13].

Globally, approximately 90% of the stroke burden can be attributed to modifiable risk factors (smoking, poor diet and low physical activity) [14]. It is a goal of the STARR project to support stroke survivors making changes to their lifestyle that reduce the risk for a second stroke. Since the STARR project is aimed at supporting self-management of stroke risk factors, persons who are in need of continuous care and who are permanent residents at care institutions are not part of the user group. The STARR user is a person who is able to self-manage (if needed with some additional support) and who is expected to be able to live more or less independently at home, although they may be in need of support in order to do so.

Among our users we find persons with a variety of remaining symptoms after the stroke. As was stated initially, different locations of the stroke cause different results [13]. A stroke on the right side of the brain can lead to:

- Paralysis on the left side of the body
- Vision problems (and spatial unawareness – “hemispatial neglect”)
- Quick, inquisitive behavioral style (including denial/unawareness)
- Memory loss
- Sensory loss

A left sided stroke, on the other hand, may lead to:

- Paralysis on the right side of the body
- Speech/language problems (aphasia)
- Slow, cautious behavioral style (the stroke survivor is aware of the problems)
- Memory loss
- Sensory loss
- Depression

Fatigue is not listed above, but is a common problem after all brain injuries. In our studies we have taken care to involve stroke survivors with a range of different problems. In the studies performed at/together with care institutions we have had access to detailed diagnosis, while in the studies done with stroke survivor organizations we have observed mobility aids (wheelchairs, walkers) and also asked participants about the difficulties they encounter after their stroke. The persons involved in the studies at/with care institutions generally presented more severe disabilities, while the persons recruited from stroke organizations were generally more independent. Given the variability of our user group, on the overall level a general recommendation is that designs need to be possible to personalize. We gather more specific recommendations in the table 1.

**Table 1.** Stroke specific recommendations

| Impairment | Consequences | Recommendations |
|---|---|---|
| Hemiparesis/hemiplegia | - Difficulty handling things with 2 hands or one hand<br>- Difficulty or inability to walk. Balance problems<br>- Contractures, swelling, pain | Interaction should allow for one-handed operation.<br>Activities and monitoring needs to work also for persons with impaired walking ability or wheelchair users.<br>Avoid designs that may trigger contractors (e.g. stimulate extending muscles, not contracting ones).<br>Avoid positions where the spastic muscle can be shortened<br>Use orthosis or technical aids when needed<br>Encourage the use of the affected limb(s) |
| Aphasia | Problems with understanding, speaking, reading, calculating and visual recognition | Design information so that it is available through multiple channels (text, images, sound, speech, vibration, etc.).<br>Give information in a sequenced way, not all the information together. Leave time to process the information and to answer. |
| Fatigue | Need to rest. Time of activity can be limited | Avoid long and very vigorous exercises or activities. Support the person in splitting activities into suitable "chunks". Promote breaks. Always allow pauses in activities, and design to encourage appropriate pausing.<br>Avoid too much simultaneous information (keep the interfaces "clean"). |
| Impaired vision or hearing | Difficulty perceiving and/or processing visual or auditory information | Design information so that it is available through multiple channels (text, images, sound, speech, vibration, etc.).<br>Make visual information clear and large enough, make it possible to adjust sizes and colors and make it possible to adjust sound volume. |
| Heminegligence | Complications such as falls, fractures, dysphagia, pneumonia… | Support users with appropriate reminders to think of and use the side that is forgotten about<br>Make them aware of the situation |
| Ataxia, coordination problem (same for sensitivity deficit) | - Balance problem<br>- Dexterity problem | Promote a secure gait, transfers<br>Avoid inactivity if waking ability<br>Propose coordination and dexterity exercises |
| Memory problems, apraxia, inattention, abulia (mutism) | Difficulty to start, follow and remember instructions and sequences | Support users with appropriate reminders.<br>Include instructions, do not rely on users learning the interaction.<br>Make help available throughout the interaction.<br>Avoid long sequences (where the user has to remember the initial steps).<br>Perform only one activity at a time |

## 6. Conclusion: Stroke and Universal Design

Given the number of stroke survivors, we argue it is important this group is considered explicitly in Universal Design. The principles for Universal Design are wide in scope, and artefacts and environments designed following these principles can in general work well also for stroke survivors. Equitable use, Flexibility in use, Simple and intuitive use, Perceptible information, Tolerance for error, Low physical effort and Size and Space for Approach and Use do indeed cover many of the requirements also for stroke survivors. Some specific requirements still need to be kept in mind: hemiparesis/hemiplegia (motoric problems involving only one side of the body) should be considered explicitly. When exemplifying a mobility impairment, a wheelchair is often considered as a "reference", but if we want to include stroke survivors, we need to think also about one-handed use and walking/balance difficulties. Brain Fatigue, which is common not only after a stroke, but after all brain injuries, puts the focus on cognitive/perceptual effort, not just physical effort. It is not just enough with low physical effort; enough time to rest and avoiding sensory overload is important when it comes to preventing fatigue. Aphasia, finally, stresses the importance of complementing speech with images.

Three of our recommendations: make it fun, empower and encourage, less obviously fit the Universal Design principles. Fun could be thought of as equitable use, since fun is a major part of many mainstream designs, and it is actually a question if fun should not be brought more explicitly into Universal Design. Empowerment and encouragement are a consequence of the application area (self management) and it is an open question if they should be part of Universal Design. Finally, since the project deals with ICT and interaction design, we note that we do not yet have any recommendations for size and space for approach and use. When our solutions are implemented into physical settings, this is something we will need to consider.

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