Designing for Stroke Patients

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Abstract
The motor and speech impairments of many stroke patients make interacting with screen interfaces a challenging activity. Consequently, they might be excluded of the possibilities of social contact and entertainment provided by technology. Inspired by the movie ”The Diving Bell and the Butterfly”, in which a man has his life completely changed after losing all body movementswe designed ”The Tavern”. Our goal was to help them by giving new interactive ways to enjoy positive social experiences during their recovery, however we faced many challenges, as described on this paper.

Author Keywords
assistive technology; gesture based interaction; speech based interaction; social games.

Introduction
We worked on a designing and building a prototype to help stroke patients during recovery. We wanted to help them to rediscover the joy of living by creating a social space for patients to talk with each other and play games together, the way it was in the traditional taverns. We envisioned this concept to be displayed on a screen equipped with Kinect sensors, so that they could use gesture or speech interaction and to indirectly help them in the rehabilitation.

However, we found out that reaching these patients and

understanding their actual needs is not an easy task. We faced many challenges during each phase of the design process, which will be described further. As much as we wanted to involve the patients on the ideation and evaluation, we had to overcome many obstacles to have a chance to interact with them. Therefore, a design team willing to create an product for stroke patients must be aware of that.

Background

Around 15 million people suffer a stroke worldwide each year [15]. A stroke is caused when blood supply with oxygen and nutrients cannot reach to parts of the brain because it was suddenly cut off. When the victim does not die, it can affect speech, vision, bowel control, spatial awareness and movement coordination.For these reasons, the life of the stroke patients who survive is not easy. It is estimated that one third of stroke survivors develop post-stroke depression, whilst 73% of them lack confidence and 56% feel friends and family treat them differently [15].

Industry has worked on applications aimed to help stroke patients. Most of them are used during speech and movement rehabilitation, by proposing exercises and displaying daily progress. An example is the app Constant Therapy [14]. In addition, there are application focused on helping patients to communicate during day to day activities, by translating text to voice messages for small talk situation [13]. Moreover, some robust applications were published by researchers, using augmented and virtual reality for rehabilitation [1, 9, 12].

Our approach differs from these ones as we focus on the social insecurities of stroke patients who report feelings of loneliness, anxiety and fear [16]. The phase of recovery is especially delicate as it might involve permanent changes on their lifestyles and some patients do not feel motivated to continue the recover process [10]. For this reason, we want to help patients to rediscover the joy of sharing moments with others by creating the social space called ”The Tavern”.

Design Process

Our design process consisted in four phases, one per week: brainstorming, building personas and scenarios, creating sketches and prototypes, then evaluating a prototype.

Exploration

On our first meetings, we had many brainstorming sessions. We mainly used the Six Thinking Hats method [7] and bodystorming [11]. At some point, we were particularly inspired by the movie ”The Diving Bell and the Butterfly” [2] in which a locked-in syndrome patient felt trapped in his own condition. We wanted to find a way to help paralyzed patients to not feel excluded from the life around them.

However, we needed to reach these patients in order to found out their needs[3]. This was when we faced the first challenges to get direct access to them. First of all, we needed to establish a contact with a doctor before talking with patients. Then, at stroke associations meetings most of the attendees were family members, not actual patients. Given that we had the time constraint of one week to finish the exploration phase, we decided to use secondary data gathering techniques such as surveys on online communities and interviews with subject matter experts [6].

Using the data collected we built a persona, called Frank[6]: a patient recovering from a stroke he had 4 years ago, mainly supported by his wife, living at home (as stated by 78% on the survey) and felling incapable of fulfilling his needs for social contact (61% of respondents). A scenario [5] in which Frank would use our device would be: Frank is at home, wishing he could play cards with his friends.

Then he turns on the television to navigate through the ”The Tavern”. He sees that another stroke patient is online and they start playing a card game. Frank uses mainly hand gestures to control the game, because he still has trouble to speak. As a bonus, he notices that the game also helps with his rehab exercises.

Composition
Based on the artifacts of the previous phase we developed sketches, and later on an interactive prototype to be used for evaluation. As already mentioned by [8], choosing the right prototype for a design phase is not a trivial process, because it has to reflect its main purpose. Since we had not been able to actually interview patients in Stockholm, we wanted to focus on how the idea would be received by our users and if the styles of interaction were usable. To answer these design questions, we thought that a MS PowerPoint prototype, with a representation of the look and feel of the main functions would be enough, with no need for actual implementation now. In summary, the first prototype had a welcome screen (menu); a help page; card games, like âĂIJGin RummyâĂİ and a window for a chat.

Evaluation
After building the interactive prototype, we were ready for the evaluation. We wanted a participatory-based method, with on-site tests interviews [3]. However, we again had issues with the time constraints and the complexity of interviewing them in the hospitals. Our way out of this was to conduct our evaluations in other contexts: we tested it with a stroke nurse and two patients from Germany.

The evaluation methods used were semi-structured Interviews followed by the participant-based Usability Testing. The interviews were structured by the guidelines described on [4]. During the interviews, we asked about how the daily life of a stroke patient is, how they interact with other people, how the experience in the hospital was and what difficulties they face. We were also interested in how the patients felt when socializing with others and what activities they usually do to entertain themselves.

We interview the stroke nurse in a hospital in Stockholm, using a Macbook 13âĂŹ and we controlled the prototype using a Wizard-of-Oz technique [3]. During the testing she confirmed our findings that most of the patients struggle while spending a lot of time alone and she liked the idea of chatting because some patients feel embarrassed to speak in real life. For the remote evaluations, the setup was a shared screen video by Skype. The subjects stated that it was very useful to have different interaction styles (speech and gesture), and they suggested features to improve playability such as customized gestures and more game options and competitions between users. All these features seem to be technically feasible, so we will consider them for the next iterations.

Conclusions
This project showed us it is extremely challenging to reach stroke patients in the spam of four weeks. We did not have contacts to stroke patients where we are living at the moment and performing remote evaluations was not ideal. For this reason we have the following recommendations for designers willing to work with any group of patients. First, the schedule must allow enough time to go through the process of contacting doctors, arranging interviews and getting permission to visit visit patients. Second, knowing patients personally can help skipping the formal process of getting authorization from doctors. Another recommendation is to choose subjects that are not in too delicate conditions and cannot be in activities for too long.

The journey a stroke patient has many moments of struggle, anxiety, pain and loneliness. Our goal was to find a give them the chance to feel part of a community of people who do not only play together but also care about each other. We were glad to see that the users liked the idea and we also received a very positive feedback. Just like these patients, there are many other user groups that could be immensely helped by Assistive Technologies. Therefore, we sincerely hope more designers feel called to be engaged in such projects, even though it is a challenging field to explore. And that these contributions can add more meaning and joy to other patients' lives.

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