
Designing a Prompting System to Facilitate the Rehabilitation of People with Acquired Brain Injury

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Abstract

Assistive Technologies (AT) in the form of prompting systems can help people with Acquired Brain Injury (ABI) cope with cognitive impairments and executive dysfunction. Studies, however, show several factors that impact the uptake and effectiveness of AT, indicating there is room for better design. To gather requirements for the development of such a system in a user-centred way, we held 2 focus groups with people with ABI who follow a rehabilitation programme (n=13), and 1 focus group with the professionals running the rehabilitation programme (n=7). We examined the common injury-induced difficulties in everyday life, the standard rehabilitation practices in the field, and the use of external aids by people with ABI. Based on the findings, we outline some initial guidelines for the design of prompting systems to improve daily functioning of people with ABI.

Author Keywords

Acquired brain injury; assistive technology; cognitive rehabilitation; focus group

ACM Classification Keywords

H.5.2 Information interfaces and presentation: User Interfaces (User Centered Design).

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Figure 1: Focus group 1 – People with ABI (Ages: 25-57)



Figure 2: Focus group 2 – People with ABI (Ages: 25-51)



Figure 3: Focus group 3 – Neuropsychologists / Rehabilitation Experts

Introduction

Acquired Brain Injury (ABI) can cause cognitive impairments and executive dysfunction [11, 4]. These effects reduce the independence of the ABI survivor, who may have to rely on regular support from others. This, in turn, can result in withdrawal and psychological stress both for the person with the ABI and the person providing the support [2]. Cognitive rehabilitation aims to ameliorate or alleviate deficits caused by a brain injury [13]. External aids are also used to support remembering in people with ABI, in various contexts. These can be paper-based tools (e.g. calendars) [5], or Assistive Technologies (AT), i.e. technology-based tools usually in the form of prompting systems [12, 6, 10]. However, studies show that the uptake of AT by people with ABI is rather low [8] and there are barriers that can prevent the use and uptake of AT [1,7]. Furthermore, the progress in the implementation of AT in cognitive rehabilitation is limited [3]. By applying a user-centred approach, we aim to gather stakeholder requirements and lay the groundwork for the improved design of such AT.

We conducted 3 focus groups with people involved in the Brain Injury Neuropsychological Rehabilitation Unit, at ELEPAP, an NGO for people with disabilities in Athens, Greece, to acquire information regarding the common difficulties induced by a brain injury, the standard rehabilitation practices, and the use and effectiveness of external aids in a cognitive rehabilitation context. In this paper, we report the findings and discuss a set of attributes for an AT prompting system to facilitate the everyday functioning of people with ABI.

Research Process

Focus Groups

We conducted 2 focus groups with people who follow an ABI rehabilitation programme (n=13, 1 female), and 1

group with neuropsychologists who run the programme (n=7, 5 female). In the first two groups, the participants were adults with ABI (mean age=38, range 25 - 57), able to provide informed consent. They introduced themselves and talked about their injury and rehabilitation. Then followed a semi-structured group interview. The third session (therapists) was similarly structured: participants talked in turns about their experiences of the common symptoms of ABI, and the rehabilitation practices they apply. Then there was a discussion about the use and design of AT. We used Thematic Analysis on the data gathered from the focus groups, to identify elements most relevant to the design of prompting AT, which we present below.

Key Findings

Cognitive Effects

For most of the participants with ABI (10/13) memory was reported to be the biggest problem. Some of them (4/13) said that their memory had improved over time. but they also mentioned having difficulties remembering to do things they considered important, even many years after their injury. Another issue was the lack of self-awareness. As therapists reported, most people do not realize their deficits when joining the programme. That could also be concluded from some of the answers given by the people with ABI; e.g. when discussing the use of a diary as a memory aid, one participant said: "I used to take it with me. But when I was informed about something I would have to do, I took it for granted that I would remember it, and didn't even consider noting it down. And then I would forget it".

Executive Dysfunction

Besides memory problems, another issue that was very frequently brought up was the lack of initiation. People

Figure 4: Quotes by people with ABI (Focus groups 1-2)

"I'm supposed to look at [my calendar], but sometimes I forget. My carer reminds me to do that. I don't have just a problem with starting things, but also completing things. That's very important. I used to be very active. Now I need prompting to continue."
(Male, 57)

"I used to set a reminder saying 'I have to do this, at that time'. And I would see the reminder and say 'I'll do it in a minute', and then I would forget it. And I would get the reminder maybe the next day, and still wouldn't do it."
(Male, 25)

I could ask you how to go somewhere, and you could tell me. Then I will think 'it was that simple, why did I have to ask? What will the other person think of me?'"
(Male, 25)

"I want to become independent, and be able to live by myself"
(Female, 46)

reported a tendency to stay inactive and sedentary after an ABI, avoiding or neglecting even basic activities, like taking care of their personal hygiene, even if they remember (or are reminded) to do so (Figure 4). According to the therapists, this is often interpreted as a symptom of depression, but it can be a direct result of the brain damage. Problems with organization and scheduling were also mentioned. Typical issues included difficulty creating / following a plan, breaking a task into steps, and deciding what to do in unfamiliar situations. Moreover, lack of concentration or attention, and extreme cognitive fatigue seemed to be serious for some people (e.g. getting distracted easily and losing track of what one is doing or saying). These issues were presented as obstacles that can prevent completion of tasks, and even effective use of memory aids, like calendars and alarms.

Behaviour and Mental Health

One of the primary obstacles in rehabilitation according to the therapists is the client's behaviour and disposition. This is often exacerbated by not receiving any treatment for several years after their injury (erratic manners become solid habits that are very difficult to break) and lack of self-awareness: "Sometimes I don't realize that I'm talking abruptly, but others do. Then I misunderstand how they respond, and I might become rude". Depression and anxiety disorders were reported as some of the most frequent mental health issues after an ABI. Anxiety (often enhanced by fear or lack of self-esteem) is particularly intense when people find themselves in unfamiliar contexts, or having to deal with a lot of information. The therapists were of the conviction that cognitive performance and social functioning were usually affected by the person's mental health, and *vice versa*.

Rehabilitation methods

According to participants in all three groups, rehabilitation goals are individualised and so vary greatly from one person to the other. Therapists indicated that these goals can be short or long term, but they ought to be feasible and practical. They are set together by the therapists and their clients, and often with the participation of the client's family. The goals reported were usually focused on restoring (or compensating for) cognitive dysfunction, helping people with ABI become aware of their deficits and adapt to new conditions, and helping them modify their behaviour to become more active and socially functional.

To assess rehabilitation progress, the combination of two methods was reported: standard psychometric tests and regular communication with the person's "significant others" (i.e. family members, caregivers, etc.). Ultimately, the elements that determine the rehabilitation's success are: the completion of the rehabilitation goals, the enhancement of cognitive functions, and the overall improvement of wellbeing and social life. To increase people's activeness, the main strategy described was the application of a repetitive routine of day-to-day activities, mainly through the continuous prompting from the person's caregiver. The manner in which the prompt is given, as well as the trust towards the person giving it, were reported to be essential to the prompt's effectiveness (Figure 5).

Motivation and Reward

According to the therapists, people's biggest motivation during rehabilitation was involvement in social activities. Indicative answers which participants gave when asked about their expectations from the rehabilitation included: being more independent/not being taken care of, being able to participate in conversations, being

Figure 5: Quotes by neuro-psychologists
(Focus group 3)

“They will forget to write what they have in mind. They will think that ‘I need to make a note about tomorrow’s appointment’, but after 10 minutes, when they’re supposed to write the note, they will forget it. Also, possibly because they get distracted.”

“A prompt does not always have the same effect. It depends on the person’s situation, who gives the prompt and what is the person’s relationship with the one giving the prompt.”

“If the person is not aware that they have problems with memory, they believe they [the aids] are not important.”

“I believe that technological aids should be about prompting/reminding, and cues for self-control. What to do, and what not to do.”

perceived as “normal”, and re-join society. Receiving positive feedback from their peers was also mentioned as an important factor for motivation to pursue rehabilitation goals. Regarding what people perceived as an indication of success in rehabilitation, self-monitoring was important for some participants (e.g. “What really helps me is writing down what we do here. I read them and realize that I get better, and that’s good for me”). According to the therapists, the realization of accomplishing one’s goal is its own reward.

External Aids

The people with ABI reported using paper diaries to help them with memory and scheduling. They also reported using them to note their rehabilitation goals, as well as their therapists’ advice regarding how to control their behaviour and how to cope with common difficulties. Regarding their effectiveness, they admitted not always carrying their diary with them, even if they were supposed to, for practical reasons (Figure 4). Some also expressed concerns about being seen by others and perceived as “not normal”. The use of external aids seemed to be directly affected by the person’s awareness of his/her impairment (Figure 4). This is consistent with the findings of Wong *et al.* [14] regarding use of smartphones as cognitive aids. Only 2 people reported using technology (i.e. smartphones) as memory aids, but did not mention any difficulties or issues related to their effectiveness.

Discussion

Our findings from the focus groups regarding the cognitive effects of ABI are in accordance with existing literature [4,1]. Moreover, some of the themes that emerged regarding prompting and use of external aids are consistent with those from other studies [7,9]. Regarding the usability of existing AT, the data gathered

from this study is not adequate to allow safe conclusions. However, we suggest some attributes that a prompting system should have to address the points outlined in our findings. In particular, to facilitate the rehabilitation of people with ABI, a prompting system should aim to:

- Support memory and initiation, by providing timely reminders to prompt action;
- Help users concentrate on the task at hand, until its completion;
- Provide a goal-oriented sense of achievement and self-monitoring, to increase motivation;
- Remind users of their behaviour issues and how to control them.

Additionally, to be effective, the system should be:

- Personalisable, to support users with different goals and with an appropriate manner of prompting;
- Customizable to support change or improvement of cognitive skills during rehabilitation;
- Simple and straightforward, to address users with limited communication skills;
- Friendly/Intimate, to give prompts in a familiar and trustworthy manner;
- Discreet, so that it does not become annoying or draw the attention of others;
- Autonomous, so that it does not have to rely on the user’s input.
- Finally, the prompting system should incorporate the participation of the end user’s therapist and/or family members, who should be able to create and modify the content of prompts and rehabilitation goals.

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TEAM Project's Webpage:
<http://www.team-itn.eu>

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