Participatory Design with Aphasic Individuals

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Abstract

Aphasia is an acquired cognitive disorder that affects language abilities, while leaving intellect intact. The overall goal of the Aphasia Project is to investigate how technology can be designed to better support people with aphasia, contributing to the objective of universal usability. Through the design of a daily planner for a handheld device, we explore the issues that arise and modifications needed when including individuals with aphasia in the participatory design process.

Key words: Participatory design, universal usability, language deficits, aphasia.

1 Introduction

Aphasia is an acquired language disorder that affects over 100,000 people in Canada [1]. The overall goal of the Aphasia Project is to determine how technology can best be used to support people with aphasia, furthering the objective of universal usability. Within this, the project addresses the impact that communication deficits such as aphasia have on the participatory design process, and what modifications may need to be made to that process. Many issues arise with the evaluation of assistive technology, including the increased variability between participants, small sample size, and the lack of existing alternatives to be used as control [4].

Aphasia manifests in a range of language deficits, including reading, writing, listening, and speaking [2]. It is neurogenic, i.e, caused by damage to the brain. Most commonly this is the result of a stroke, but can also result from a tumour, infection, or head trauma. Individuals have fully developed language prior to onset; aphasia targets the ability to access and use that language. It is neither a sensory deficit, i.e., a deficit of vocalization or hearing, nor a deficit of the intellect; however, the ability to share thoughts and feelings through language is impaired.

During initial conversations, individuals with aphasia, as well as their families, stressed the importance of being able to manage one's own schedule. However, standard paper and electronic organizers require the user to read and write, something many people with aphasia are unable to do. A daily planner application using a combination of text, images and sound to represent appointment data could be used to support the user in a more independent lifestyle. Here, we present initial results from the design of the Daily Planner, and our analysis of participatory design involving people with aphasia.

2 Low Fidelity Prototyping

Low fidelity prototyping is often used in iterative design because of its ability to quickly bring together many ideas and uncover design flaws. Rettig [3] lists the following strengths of low fidelity prototyping:

- Many ideas are generated quickly by moving through several iterations in a short time span.
- Feedback is given on the big picture items: flow of control, terminology, expressiveness of the basic metaphor; rather than comments on the color and font choices.
- Encourages users to make big changes by giving them a prototype that appears rough and easy to change, rather than one that looks finished and final.

2.1 The Daily Planner Prototype

The Daily Planner is a high-level application to support individuals with aphasia in an everyday manner. As is typically the case with low fidelity prototyping, we produced a series of drawings that could be used to mock-up a scenario. The participant talks and gestures through the interactions, while a designer plays the role of the computer, responding to the actions of the user. Figure 1 shows the starting screen from the Daily Planner low fidelity prototype we tested.

2.2 Evaluation

Both language and physical abilities vary widely from one individual with aphasia to the next, so we initially evaluated the prototype with only one participant. The participant was an expert computer user prior to the onset of aphasia.

When presented with the prototype, the participant did not attempt to interact with the system or comment on high-level features such as interaction flow. When prompted further as to how she might interact with the

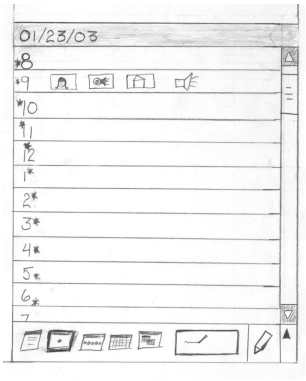

Figure 1: Example screen from the Daily Planner low fidelity prototype.

system, the participant was unable to provide feedback, stating, "I just dont know." This result was particularly surprising given the participant's technical background.

The breakdown in the interaction may be attributed to many factors. First, there were communication difficulties: it was difficult for us to communicate what we wanted; and it was difficult for the participant to communicate her actions. In addition, because the participant had only recently acquired aphasia, and her brain tumour was not stable, she had difficulty assessing what she could or could not do.

Given that brain functionality is not clearly compartmentalized, aphasia is often accompanied by other deficits, including visual or motor skill impairments. Drugs prescribed to treat the source ailment may also contribute to motor skill deficits. These can further reduce the participant's intuition about his or her own ability to interact with technology. Since predicting this interaction is a key element of participatory design, it is not surprising that the process is impeded when an individual has difficulty doing just that.

3 Analysis

It is clear that the design process must be adapted to accommodate the needs of participants with aphasia. Some of the more obvious changes include allowing extra time to ensure aphasic individuals have the opportunity to express themselves, and using alternative communication techniques such as drawing and gesturing to facilitate communication.

We also need to reduce the reliance on communication. A medium fidelity prototype consists of a computerized implementation of the application with functionality limited to just enough core features that a few example scenarios can be evaluated. With a medium fidelity prototype, the participant can show what they would do with the system, thus eliminating the need to explain what they are doing, and can demonstrate their physical limitations, thus removing the need to conjecture on their abilities. While it is harder to rapidly test different interface possibilities with a medium fidelity prototype, such a prototype is sufficiently flexible that fundamental changes, such as reorganizing the flow of control, can still be made.

4 Conclusion and Future Work

To summarize, the following guidelines emerged from our experience. These guidelines are not necessarily limited to participants with aphasia, and likely generalize to many situations where communication is hampered or where conjecturing on one's interaction abilities is not amenable:

- Allow ample time for communication to ensure mutual understanding of all parties.
- Place less emphasis on structured low fidelity prototyping, perhaps using only a few screen shots as a conversation starter.
- Prepare to spend more time on medium fidelity prototypes. Encourage participants to act out rather than describe their actions.

We are working on a medium fidelity prototype that will provide some limited functionality. We predict this method will be more useful for eliciting feedback since many of the problems with low fidelity prototyping will be addressed. For example, the inability to think aloud or verbalize actions would be dealt with because participants could demonstrate what they would do rather than describe what they would do. As well, physical limitations would become self-evident, relieving the participant from having to speculate on how they would interact.

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