
Generalizability in Research with Cognitively Impaired Individuals

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ACM Classification Keywords

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Introduction

A major challenge in designing technology for users with cognitive impairments is achieving generalizable results. By design, controlled experiments—the gold standard of evaluation in HCI research—remove individual differences through statistical means. While this is appropriate in many situations, when working with special populations, individual differences are often very pronounced, and, generally, crucial to the success or failure of the design. Moreover, it has been noted that traditional user-centered design lacks the flexibility to accommodate user groups with large individual differences, resulting in a dearth of applicable design methodologies [7].

Custom-built systems, such as the cognitive prosthetics introduced by Elliot Cole [1], circumvent the problem of addressing diverse needs by creating individualized solutions tailored to the unique needs of each user.

However, a notable drawback to this approach is its limited ability to develop a broader, more generalized theory that can be used as the basis for future work. Thus, a tension exists between satisfying the need for customized solutions that address the immediate needs of users, and identifying generalizable results that can be used to achieve long-term research goals [8].

With regards to this tension, we have identified two questions that need to be addressed:

1. What methods provide a balance between identifying generalizable results and creating a custom solution that meets the unique needs of each user?
2. Given the wide variability of skills and needs inherent in cognitively impaired populations, how can we perform evaluations to unveil both generalizable aspects of the design and areas where customization is necessary?

In our research with individuals with aphasia¹, we have used two approaches to address these questions. The remainder of this paper is going to focus on these approaches:

- Designing in the small; Testing in the large
- Using detailed assessments of functional abilities

¹ Aphasia is an acquired communication impairment that is usually acquired as a result of stroke, brain tumor, or other brain injury. It results in an impairment of language, that is, an impairment to the production and/or comprehension of speech and/or written language.

While we have found these two approaches to be useful, they are by no means a complete solution to this problem. Our intention in presenting them is to open up further conversation that will hopefully unearth other approaches and ideas.

Designing in the small; Testing in the large

One approach we have taken to address the tension between meeting the needs of our specific users while identifying generalizable results has been to work with a small number of users initially, designing a system targeted to their needs, and subsequently evaluating the system with a broader group. The larger evaluation provides insight into which aspects of the designs generalize and which need to be customized.

To date, we have used this approach in three major subprojects [3, 6, 10], and have worked closely with two aphasic individuals: AB provided initial design requirements and feedback for a daily planner application and an electronic recipe book, while SM was involved in the participatory design of a file management system. In each of these projects, we performed evaluations with larger groups of target users. We have found this approach to be successful in giving us the desired balance.

For example, in developing the file management system, an ethnographically-informed participatory design approach was taken to ensure the resulting design would meet the needs of SM [2]. This approach proved successful as SM continued to use the system beyond the completion of the project. In addition, the subsequent evaluation of the system with six aphasic and six control participants revealed not only generalizable aspects of the design, but also many

points where design decisions that worked for SM were in conflict with the needs of the study participants.

Using Detailed Functional Assessments

A second approach that we have found useful in working with cognitively impaired individuals is to perform detailed functional assessments of each participant's abilities, a process which has also been emphasized by other researchers [4]. As part of the experimental evaluation methodology, we have used the Western Aphasia Battery (WAB) [5], a standardized speech and language assessment administered by a speech-language pathologist. We have found these assessments to be invaluable in interpreting study results and identifying underlying reasons for successes and failures.

While the use of standardized tests is a generally accepted and encouraged practice in HCI, the WAB was particularly important in our research when large individual differences complicated analysis of the results. For example, in our evaluation of a daily planner designed to support the needs of aphasic users [6], we would not have been able to infer the reasons for the diverse planner preferences expressed by our participants had data relevant to their language and communication skills not been available.

A more striking example, however, was in our evaluation of a visually enhanced recipe application (VERA) [10]. In this project, results were mixed: VERA was more effective than a paper-based text recipe for two aphasic participants, the text was more effective for one, and one showed no difference. We expected this difference to be reflected in the participants' reading assessments, but their overall reading scores

were relatively even. Only upon further analysis of the assessments did we discover differences in their abilities to follow written instructions—a skill which obviously impacts the ability to follow a written recipe—demonstrating the necessity of obtaining detailed assessments as the relevant level of detail will vary across situations.

It is important to note that these assessments provided more than mere confirmation of our informal intuition regarding participants' language skills. In many situations, we were surprised by the results of the assessment; many aphasic individuals develop sufficient compensatory skills to mask the extent of their deficits. As such, when working with diverse user populations, formal assessments should be used, whenever possible, to give an unbiased assessment of the abilities of each participant.

Conclusions

Generalizability remains a challenging goal with research involving cognitively impaired individuals. In working with aphasic individuals, we have found that designing for one individual or a small group, yet testing with a larger set of potential users can help us identify which characteristics of a design are generalizable and which will require customization. We have also found that detailed functional assessments of each participant's abilities can be beneficial in interpreting results when individual differences are pronounced. We note that these approaches are not a complete solution, but hope that in presenting them we can motivate further discussion on these issues.

Project Description and Author Bios

The Aphasia Project is a multi-disciplinary research project spanning computer science, psychology, and speech-language pathology, investigating how technology can be designed to support individuals with aphasia in their daily life. Our main goal is to gain a better understanding of alternative forms of communication, and to develop assistive technology that incorporates these alternative forms in ways that are sufficiently flexible to accommodate the needs of particular individuals with aphasia. In doing so, we intend to identify and demonstrate a process for developing assistive technology that can be adapted to meet the needs of a large number of people with aphasia, improving their communication capacity and their quality of life.

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