

Insights from the Aphasia Project: Designing Technology For and With People who have Aphasia

Joanna McGrenere[†], Rhian Davies[†], Leah Findlater[†], Peter Graf[‡], Maria Klawe[‡],
Karyn Moffatt[†], Barbara Purves^{*}, Sarah Yang[†]

aphasia-ubc@cs.ubc.ca

Department of Computer Science[†]
Department of Psychology‡
School of Audiology and Speech Sciences*
University of British Columbia
Vancouver, B.C., Canada

Engineering and Applied Science[‡]
Princeton University
Princeton, NJ
USA

ABSTRACT

This paper explores a number of HCI research issues in the context of the Aphasia Project, a recently established project on the design of assistive technology for aphasic individuals. Key issues include the problems of achieving effective design and evaluation for a user population with an extremely high degree of variance, and user-centered design for a user population with significant communication impairments. We describe the Aphasia Project and our initial approaches to dealing with these issues. Similar issues arise in many areas of assistive technology, so we expect our paper to be of general interest to the research community.

Categories & Subject Descriptors

K.4.2 [Computers and Society]: Social Issues - *Assistive technologies for persons with disabilities*; H.5.2 [Information Interfaces and Presentation]: User Interfaces - *Evaluation/methodology, graphical user interfaces, prototyping, user-centered design*

General Terms

Design, human factors

Keywords

Cognitive disabilities, participatory design, iterative design, mobile handheld technology, multi-disciplinary research

1. INTRODUCTION

The HCI community recognized long ago that it should play a role in the design, implementation and evaluation of technology for users with cognitive disabilities. For example, there was a panel at CHI '86 on *Human Interface and the Handicapped User* [2], and CHI has repeatedly offered the tutorial *Designing for Users with Special Needs* [6]. Yet, to date there has been relatively little HCI research done with this population of users. For instance, a search for “cognitive impairments” (or cognitive

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disabilities, disorders, or dysfunction) in hcibib.org yields remarkably few publications. While there are some significant challenges to working with users who have cognitive disabilities, there has never been a more opportune time to embrace those challenges. Advances in computer technology, including the prevalence of low-cost handheld devices, combined with the increasing likelihood that individuals with acquired cognitive disabilities were computer-literate prior to acquiring the disability, suggest new opportunities for assistive technology to support these individuals in their daily activities.

The Aphasia Project is an exciting new multi-disciplinary research project investigating how technology can be designed to support individuals with aphasia in their daily life. Aphasia is a cognitive disorder, usually acquired as a result of stroke, brain tumor, or other brain injury, that results in an impairment of language, affecting the production and/or comprehension of speech and/or written language. Over 100,000 people suffer from aphasia in Canada, and the number exceeds 1,000,000 in the United States [1]. There is great variability of language abilities and impairments across individuals with aphasia, although some impairments are commonly encountered. For example, a common symptom of aphasia is anomia, which is an inability to retrieve the names of the objects one wishes to speak about. However, even with this symptom there is variability. Some individuals may be able to describe a desired object but not produce its name. Some are able to use alternative forms of communication such as writing the names of desired objects while others use gesturing or pointing. Others may convey a sense of knowing what they want to say but fail to recognize the target word even if it is provided for them.

The use of alternative modes of communication suggests the potential for electronic assistive technology, yet the number of reports of successful applications remains quite limited. This may be in part because rehabilitation efforts have tended to focus on using alternative or augmentative communication (AAC) systems only when efforts to regain natural speech have failed, so that the user population has tended to be individuals with severe or profound aphasia [7].

Aphasic individuals usually retain their ability to recognize image-based representations of objects, and portable systems have been developed that allow users to search through a symbol-based collection to retrieve desired items. The words are formed by a triplet representation of symbols, sound, and text. Once the symbol is selected, the text is displayed and audio produced,

thereby allowing the individual to communicate with others. There are a number of custom dedicated handheld communication systems that have been developed such as Dynamo and Dynamyte (www.dynavoxsys.com) and Vantage (www.prentrom.com). One serious disadvantage of such systems, however, is that the combination of custom hardware and software makes the systems very expensive and out of reach for many individuals. In addition, these systems are limited to communication through the selection of symbols. While this may be appropriate for individuals who have no other communication modalities, it can be far too slow for many aphasic individuals who have retained a partial ability to talk, write, draw, and gesture. In fact few AAC systems have been designed specifically for people with acquired language impairments [11]. In addition, some individuals exhibit competence when using these systems in structured situations, but this is seldom observed outside the therapeutic setting [11]. We speculate that it is because the systems are too limited for many aphasic individuals.

The face of personal computing has changed dramatically in recent years. We now see many everyday users of mobile handheld technology such as the Pocket PC and Palm PDA. Many of these systems are intended to provide more functionality than simply a mobile desktop computer – for example, they provide mobile communication through wireless email and text messaging and the ability to make handwritten notes. A small number of AAC vendors have begun to port their software to these mobile platforms; for example, the GUS Communicator software (www.gusinc.com) and Impact Series software (www.enkidu.net) are available for the Pocket PC. This has had the positive impact of substantially reducing the cost of these communication systems and therefore making them affordable to more aphasic individuals. However, the software remains limited to communication through symbol selection and has not yet taken advantage of the additional power that the mobile technology provides. The affordability and power of these mobile devices presents an opportunity to expand support for communication and other daily activities to a larger portion of the aphasic population.

The great majority of individuals with aphasia acquire it at middle age or older, as the risk of stroke – the most common etiology for aphasia – increases with age [9]. While even ten years ago this meant that most individuals were not computer-literate prior to the onset of aphasia, the demographics have now changed. Information technology has become pervasive, both in the workplace and at home, and so it is more often the case that individuals have at least basic computer literacy prior to the onset of aphasia. This means that using computer technology is no longer a barrier to working with an assistive device. More and more aphasic individuals are open to using specialized software, given that the devices themselves are familiar.

1.1 Multidisciplinary Approach

Like many other HCI research initiatives, achieving the goals of the Aphasia Project requires expertise from several areas in addition to HCI. Our project includes research faculty from the departments of Computer Science, Psychology, and Audiology and Speech Sciences. The computer scientists bring the technical know-how, and expertise in prototype development and evaluation. Our psychologist brings expertise in memory and cognition, and has developed specialized methods and instruments for the assessment of high-level cognitive functions in healthy normal individuals as well as in cognitively impaired persons. Our speech and language pathologist brings the essential domain

expertise as well as practical skills such as the ability to communicate with aphasic individuals. We have also created a working partnership with the Assistive Technology Centre at a local rehabilitation centre, namely GF Strong in Vancouver, Canada.

1.2 General Research Challenges

Designing technology so that it has a proper “fit” with the individuals who are expected to use it is the fundamental challenge in HCI research. Achieving this fit is even more challenging when dealing with individuals who have cognitive disorders. Newell et al. have done an excellent job of listing the difficulties in working with this population [10]. We will not repeat their list here. Rather, we select two key difficulties to illustrate that they are not all absolute:

1. participants’ ability to communicate their thoughts and to understand instructions is diminished, often quite substantially
2. lack of a truly representative user group

The first difficulty is one that is inherent in the population of users. This can be mitigated by including people on the design team who are skilled at communicating with the target population and by modifying the methodology in various ways, including when and how user feedback is obtained. We discuss our approaches to this later, but the issue remains a challenging one.

The second difficulty is one that, at least to a certain extent, the HCI community has imposed on itself and we challenge it here. HCI as a discipline emerged out of the fields of Computer Science and Psychology (although it has since embraced other fields). One of Psychology’s contributions to HCI is that of formal empirical evaluation, in particular, the controlled experiment, which remains to this day the gold standard of evaluation in HCI research. Controlled experiments, by design, remove individual differences through statistical means. While this is appropriate in many evaluation situations, it is not appropriate when working with a population that is distinctive in its exceptionally large variation of individual differences. As a research community we need to be more accepting of case-based research in such situations. Moreover, we should use methods that allow both the detection of generalizable design principles, and the detection of instances where the design must allow for substantial customization to meet the needs of specific individuals. We present our initial steps in this direction later in the paper.

1.3 Goals and Objectives

The main goal of our project is to gain a better understanding of alternative forms of communication, and to develop assistive technology that incorporates them 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.

There is little existing research on assistive technologies for aphasic individuals, so our first step is a number of preliminary studies. We are taking a three-pronged approach: evaluating existing assistive technologies, designing and evaluating new technologies based on our own investigations, and evaluating the usefulness and usability of out-of-the-box technology. In the next

section we describe our first three sub-projects exemplifying the three approaches.

2. THREE SUB-PROJECTS

In this section we outline our goals, hypotheses, methodology, and progress to date for each of our sub-projects.

2.1 Preliminary Evaluations of Existing Assistive Technology

Goals:

The goal is to understand the strengths and limitations of commercial assistive devices. We will identify what features of currently available assistive communication technologies/systems affect (increase or decrease) their usability. We will assess the specific motor, attentional, perceptual and cognitive demands of such systems, and identify where (how and why) they exceed the cognitive capacities of particular individuals with aphasia and whether they can be adapted to accommodate those capacities.

Hypotheses:

We hypothesize that a significant reason for the lack of success of currently available communication systems is that they make excessive attentional, perceptual, cognitive and perhaps even motor demands on people with aphasia. We further hypothesize that the available technologies/systems are rejected because they cannot be tailored easily to meet the specific communication needs of individuals with aphasia.

Research Methods:

We plan to investigate the GUS Pocket Communicator which runs on a Pocket PC. From the instruction manual available for each device, we will adapt (simplify) the instructions for a number of basic system operation and maintenance tasks: turning the system on and off, changing batteries and navigating the device interface. We will also create a series of communication tasks or assignments (e.g., find the visual representation for various objects, use the voice feature of GUS to sound out a specific target word) that will require participants to use the various communication features of the device/technology. In one-on-one interviews, each participant will be asked to perform each of these tasks to the best of their ability. They will also be asked to perform a number of standardized attention, perception and language tasks to obtain a fuller characterization of their cognitive skills. If a participant has problems with any aspects of any task, the interviewer will explore them (by means of questions, by means of standardized tests, and by offering hints and alternative solutions) in an attempt to identify precisely why the problem is occurring and to determine various means to overcome it. All interview sessions will be video-recorded for further off-line data analysis.

Our first explorations will involve non-aphasic control participants. Insights we gain from these participants will help us to fine-tune each assessment component; they will also help us anticipate where problems might occur and to prepare more effective problem coping strategies. By this route, our approach will also serve to minimize the discomfort that might arise when an aphasic individual is unable to perform one of the assigned tasks.

Progress to Date:

We are still in the early stages of planning this study. We are currently identifying the specific system-operations and communications tasks to be performed by participants and pilot testing instructions. The first group of participants will be evaluated in August, 2003.

2.2 Design & Evaluation of High-Level Prototypes

In this subproject we move beyond specialized communication software to higher-level applications that are designed to be usable by aphasic individuals.

Goals:

The goal is to identify specific needs that could be met by new application software and to create that software. In addition, we will explore adaptations of participatory design methodologies to accommodate a user population with communication impairments and a high degree of individual variability.

Hypotheses:

We hypothesize that through a participatory design process we will be able to create software applications that are usable by aphasic individuals and thereby improve their quality of life. Further, we expect that these applications will have to be highly customizable in order to accommodate the large individual differences inherent in the population of users with aphasia.

Research Methods:

Our general research approach in this subproject is participatory. This design process is fundamental to the field of HCI and espouses early and continual participation in the design of technology by the intended users. The advantages of a participatory design process over a non-participatory one are that the resulting technology often better meets the needs of the intended individuals. In addition, the building of relationships between the research and user communities can lead to better design and the development of future technologies.

In this subproject we identify the specific needs of particular aphasic individuals, which may or may not draw on existing technology. These needs are identified through informal interviews with the participants. Our research team then brainstorms possible design solutions that match a participant's need. We then iteratively evaluate the possible solutions, starting with low-fidelity paper prototypes and progressing to higher fidelity software-based prototypes. The participant-focused approach is based on – guided or informed by – participants' comments, insights, and suggestions. Participants' feedback is used to design new prototypes, to improve on them, and finally to implement them in an effective user-adapted technology.

More specifically, we will initially work with two or three aphasic individuals to identify potentially useful applications. We will build preliminary prototypes of these applications which we will iteratively refine and evaluate with the original participants. At each stage we will identify both general improvements that are required and also look for places where the design needs to incorporate significant customizability. We will specifically note the degree to which the requirements vary among the participants. In this way, we may end up working on two or three different *versions* of the prototype, one for each of the participants. We expect the design, on a per participant basis, to stabilize after a

small number of iterations (3 or 4). At that point we will introduce our prototype versions to two or three new participants for a single one-hour session to assess usability with prescribed tasks. The goal in this last stage is to evaluate the prototype with a broader audience, again looking to see the extent to which the design(s) generalize.

Progress to Date:

Our research began with one aphasic individual, Anita Borg¹ (AB) who was not only a participant in this project but one of the conceptual founders of the project. She had been suffering from a brain tumor (grade 4 glioma) for two and a half years. AB was a highly computer-literate middle-aged female. She maintained relatively fluent speech but had significant difficulty retrieving words, particularly nouns, so that she relied heavily on circumlocution. Her auditory comprehension was good. She had a severely limited ability to read text but no difficulty in reading numbers. Through informal initial interviews we identified two applications that would improve her quality of life, namely, an electronic daily planner and an interactive electronic recipe book.

A daily planner is an application that allows one to set events (appointments, meetings, social functions, etc.) into one's schedule. Many people currently use paper-based booklets for their daily planning – these booklets come in a variety of sizes and formats to accommodate different preferences. Electronic daily planners such as the one bundled in the Palm Pilot or Microsoft Outlook on the Pocket PC are becoming increasingly popular. Aphasic individuals like AB, who have great difficulty reading and writing, are often unable to use text-based planners, whether electronic or paper. We envision an electronic planner that instead of relying solely on text is based on triplets of information: images, sounds, and text. When a user enters an appointment, the entry will consist of any or all of the three components. A database of these triplets will be built up over time², allowing the user to select an image rather than enter the text. For example, if one wanted to schedule lunch with one's friend Sally at Milestones, one would simply click on the appropriate time and date, and then select the images of Sally and Milestones from a pop-up dialog box.

Figure 1 shows one of our first low-fidelity paper prototypes of the daily planner that was evaluated with AB.

Based on the evaluation of the paper prototypes we have created a first medium-fidelity software-based prototype on an iPAQ Pocket PC. An image of this prototype is shown in Figure 2. When a user clicks on an image that image is enlarged and the text is output in synthesized speech. Our prototype is designed to run on top of the Microsoft Outlook engine so that we will be able to take advantage of scheduling modules and extend them to include images.

¹ Unfortunately, Anita passed away recently. Her impact on the project's direction and the implications of including terminally ill participants on the design team are discussed in the *Lessons Learned* component of this section.

² At first glance it might seem unrealistic to assume that an aphasic individual or his/her caregiver would be able to construct such a database. We believe that the technology is here (e.g., digital cameras that attach to PDAs), although some usability work is still required to ensure the easy capture and management of images, and coordination with text and sound.



Figure 1: low-fidelity paper prototype of the electronic daily planner application that uses images and sound to mark a scheduled event.

The goal of the interactive electronic recipe book is to address the difficulty that many aphasic individuals have in processing large chunks of text. For these individuals, text needs to be broken down into short phrases with substantial white space surrounding each phrase. AB particularly enjoyed cooking and had the motor and cognitive skills to continue to do so. The problem was that she could not read traditional recipes that included a long list of ingredients followed by two or three paragraphs of dense text describing the process of combining the ingredients. AB thought that if the cooking process were broken down into its elementary steps, with each step being described in simple language and identifying the requisite ingredients through pictographs, she would be able to follow a recipe once again. Figure 3 shows our first medium-fidelity prototype of the interactive electronic recipe book.

We are following the same iterative participatory protocol with the recipe book as with the daily planner. We will identify 2 to 3 participants who will participate in the iterative design and evaluation of the recipe application. Once the design stabilizes we will assess the application with a larger group of aphasic individuals.

Technical Challenges:

Creating images that can be recognized at thumbnail size has proven difficult. This is particularly the case with ingredients in the recipe book application. We expect that enabling the user to enlarge the images and to hear the text spoken aloud will significantly improve recognizability.

The small screen display, although ideal for portability, is a constraint. For example, with respect to the recipe book application, it is not clear whether users will be able to follow a recipe given such a limit on the number of instructions that can be seen at once. In addition, many recipes do not follow a strictly

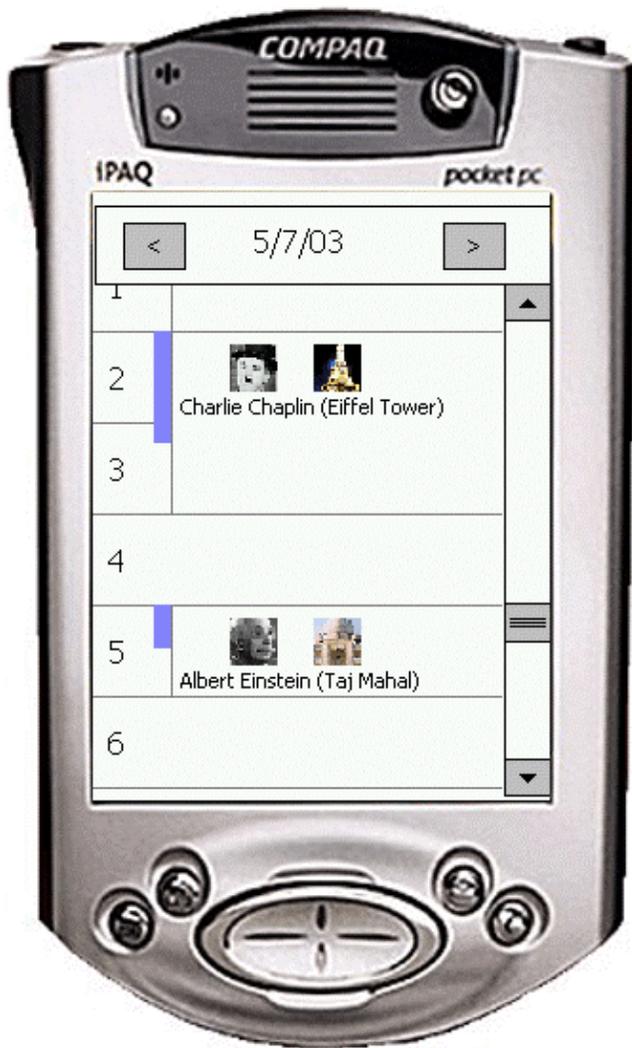


Figure 2: medium-fidelity prototype of the electronic daily planner that uses images, sound, and text to denote a scheduled event.

linear order. Often the execution branches into sub-routines and then returns. The small screen size makes navigating such instruction sequences more difficult.

Lessons Learned:

Despite the fact that AB had quite fluent speech and was technically literate, the exercise of evaluating low-fidelity paper prototypes provided only a limited amount of information. When prompted as to how she would interact with the “system” AB often responded that she did not know. It was difficult (perhaps impossible) to fully determine whether she did not understand our instructions, whether she could not express what she was thinking, or whether our design was just not the right one.

In order to reduce the reliance on the user’s ability to communicate precisely, we plan to concentrate on medium-fidelity prototypes. 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

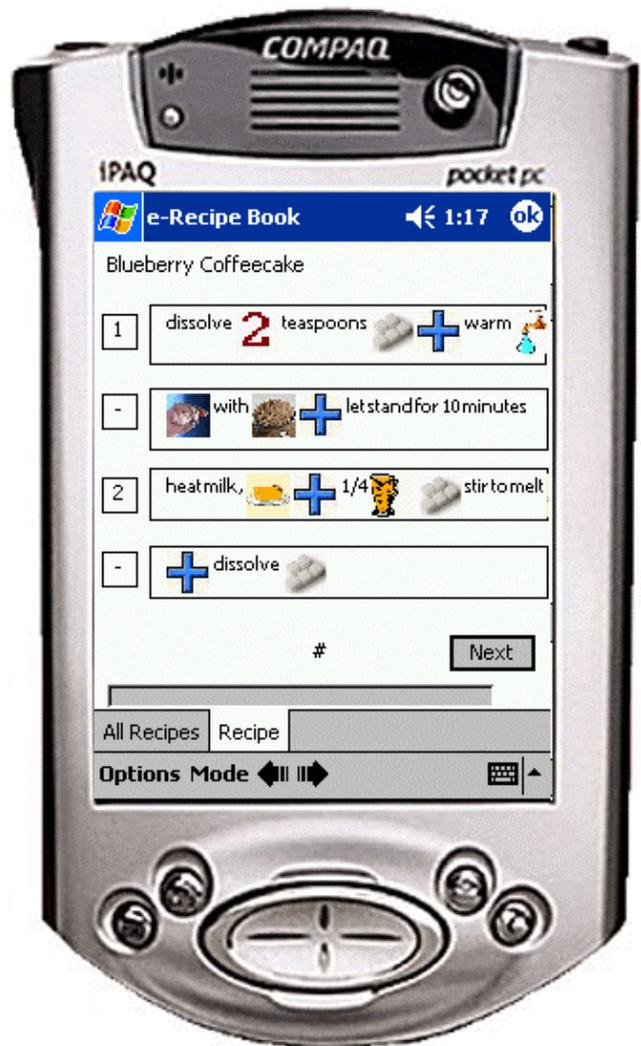


Figure 3: medium-fidelity prototype of the electronic recipe book.

prototype, participants can show what they would do with the system, thus eliminating the need to explain what they are doing. In addition participants can demonstrate physical limitations, thus removing the need to conjecture about such issues. Thus participants can *show* rather than *tell*. 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. The prototypes shown in Figures 2 and 3 are medium-fidelity prototypes.

Regrettably our participant AB passed away recently as a result of her brain tumor. It was extraordinarily motivating to work with AB, because her participation in this project gave her tremendous joy and that joy was infectious. However, in order for our research to make progress, we will initially need to focus on aphasic individuals whose condition is stable, for example individuals who have suffered from a stroke or brain injury and are at least one-year post onset. We are currently working with a second participant who meets these requirements.

2.3 In-context Evaluation of Existing PDAs

Goals:

The goal is to evaluate the use of a commercial Personal Digital Assistant (PDA) by individuals with aphasia. We will provide aphasic individuals with PDAs and examine the usefulness, usability, and impact of such devices on these individuals.

Hypotheses:

We hypothesize that the iPAQ PDA will enhance communication for aphasic individuals who are technology literate. For individuals who communicate with others partially by pen and pad notes, the PDA will be an effective replacement for some of the notes. PDAs have a certain cachet and as such, we believe that using a PDA may improve the self-esteem of aphasic individuals.

Research Methods:

The methodology for this subproject will consist primarily of qualitative analysis, informed by some quantitative measures. The general protocol will include three stages: (1) qualitative and quantitative observations of how a participant communicates, including all modalities; (2) introduce PDA to participant and observe how the participant is able to incorporate the device into his/her daily activities and any impact the device is having; and (3) identify customizations that would make the device more useful/usable and develop prototypes that include those customizations.

Progress to Date:

We are in the early stages of working with an aphasic participant, KM, who is technology literate, but who has lost most of his speech. He communicates predominantly through gesture and extensive notes. He carries small notepads that he uses throughout the day. For one-on-one meetings (for example, with his therapist) he uses larger 8½ by 11 notepads and at home and in group meetings he sometimes uses a small, portable whiteboard as well as notepads to communicate. In addition to free-form notes, this participant carries a small number of printed note cards and information sheets that explain his condition and that contain memory cues to assist with name and word retrieval. When he meets a new person he uses the information sheets and cards to inform the person that, although he cannot speak, he can understand and can communicate in alternate ways. KM has a high degree of computer literacy. In addition to using email on a daily basis, assisted by applications supporting word-prediction and text-to-speech, he designs websites.

We are following the three-stage protocol outlined above. We collected quantitative data on KM's note making and card usage prior to introducing the PDA. In particular we counted the number of notepads he used over a two-week period, and how often he showed his information cards to other people. The second stage has recently begun – we have provided our participant with a PDA for up to three months to use as he sees fit. We expect that he will use the notepad software on the PDA to write his short notes and also to store the information from his printed note cards. We expect to meet with him at regular intervals throughout the three months and conduct in-depth interviews to assess his use of the device, to ascertain the usability of the device, and to gain an understanding of the impact the device is having on him with particular attention to the issue of self-esteem. We will also record the number of paper notepads he continues to use as well as the number of times he shows his printed note cards. We expect that

over time he will rely more and more on the PDA, and thus the number of notepads and use of note cards will diminish. We also plan to record any usability problems encountered. In the third stage we will analyze the usability problems and determine whether there are customizations that we could make to the device to address those problems, or prototypes that we could build.

Although we are only part way through the research protocol, one potential application already seems evident. The iPAQ PDA has native software for creating free form notes, word processing software for storing frequently accessed text (like KM's notecard information), and the ability to load a symbol system (e.g., that of the GUSInc software), however, there is no application that integrates this functionality into a seamless application. Such an application would likely provide significant support for individuals like KM who use multiple methods and modalities for communication.

This sub-project is similar to the first subproject in that we are assessing the use of a Pocket PC. However, here we are conducting a longitudinal study in the field, rather than prescribing tasks in a shorter laboratory study. Another difference is that we are assessing native software that is shipped with the Pocket PC, rather than assistive software such as GUS Communicator.

3. RELATED WORK

Elliot Cole has been working in the area of cognitive prosthetics for well over a decade. A cognitive prosthesis is a form of treatment that supports individuals in functional activities; it uses computer technology; and it is designed specifically for rehabilitation purposes, such as the creation of a customized check-writing application that allows a particular aphasic individual to pay her bills. (See [4,5] and also [8], for review.)

Research has also been undertaken to understand how assistive technology can be designed to support individuals with developmental cognitive disorders, such as downs syndrome. The Cognitive Lever Project (CLever) at the University of Colorado at Boulder is working with this population of users. For example, they are designing a prompting system that can be tailored to guide a particular individual in his/her everyday activities. One possible scenario is assisting an individual to navigate to and from her local community center. In that scenario, the system incorporates many details such as reminders to bring her house keys and backpack, as well information about which bus to take and where to get on and off the bus [3].

Waller et al. performed a longitudinal evaluation of a computer-based communication system called "TalksBac" with four nonfluent adults with aphasia [11]. That system was word-based and was designed so as to leverage aphasic individuals' abilities to recognize familiar words and phrases. A caregiver would enter relevant words and stories into the system, and the aphasic individual would then be able to use those words and stories in conversation with other people. The evaluation showed that the conversational abilities of two out of four of the participants improved with the use of TalksBac. Waller et al. noted that one of the participants had developed his own nonverbal strategies which he found to be more effective. Although the authors do not elaborate about his nonverbal strategies, we speculate note making was used.

Although there is much to learn from the research endeavors described above, our research can be distinguished from that work in three important ways: (1) our goal is not to rehabilitate aphasic

individuals, but rather to provide computer technology to support and enhance their existing abilities; (2) we are focusing on individuals who had normal cognitive functions and were computer literate prior to the onset of aphasia and can therefore leverage those skills in the design of our assistive technology; and (3) we are also focusing on individuals who are able to communicate somewhat verbally and nonverbally, who would not be limited to communicating through an assistive device alone.

4. SUMMARY

The Aphasia Project takes a multi-disciplinary approach, including researchers from Computer Science, Psychology, and Audiology and Speech Sciences, to explore the use of technology to support everyday activities for people with aphasia. Although many symbol-based communicative aids have been developed, there have been few reported successes. We suspect that this is because few systems have been developed specifically for individuals with acquired language impairments, and thus none of these systems take advantage of the partially retained abilities of many aphasic individuals to talk, write, draw, and gesture.

Within three subprojects we are exploring how these abilities can be leveraged in new technology – we are evaluating existing assistive technologies, designing and evaluating new technologies based on our own investigations, and evaluating the usefulness and usability of out-of-the-box technology. The first and the third subprojects both evaluate existing technology. The first consists of a set of controlled laboratory experiments to evaluate the effectiveness of existing assistive technology. The third is a longitudinal field study to assess the capabilities of native Pocket PC software in meeting communicative needs of individuals with aphasia. The second subproject involves taking a participatory design approach to creating highly customizable software applications that are usable by aphasic individuals.

Although our research project is young, progress has been made in each of our subprojects. We've iterated through low-fidelity prototypes and have created our first medium-fidelity prototypes. Methodologically, we've learned that low-fidelity prototypes are challenging to evaluate with individuals who have cognitive disorders and we are therefore focusing on medium-fidelity prototypes. We are also employing methodology that will identify where personalization is necessary, and where generalizability is possible. A small number of aphasic individuals have been involved as participants in our project, and we have identified at least a dozen additional technology-literate aphasic individuals who are eager to join the project. This serves as an early indicator that there is indeed a niche to be filled.

The Aphasia Project is ongoing, and we will present our most recent findings at the CUU 2003 conference.

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