

# The Ethnographically Informed Participatory Design of a PDA Application to Support Communication

Rhian Davies<sup>†</sup>, Skip Marcella, Joanna McGrenere<sup>†</sup>, and Barbara Purves<sup>\*</sup>

Department of Computer Science<sup>†</sup>  
School of Audiology and Speech Sciences<sup>\*</sup>  
University of British Columbia  
Vancouver, BC  
1 604 827 5201  
aphasia-ubc@cs.ubc.ca

## ABSTRACT

Aphasia is an acquired communication deficit that impacts the different language modalities. PDAs have a form factor and feature set that suggest they could be effective communication tools for people with aphasia. An ethnographic study was conducted with one participant both to learn about communication strategies used by people with aphasia, and to observe how a PDA is incorporated into those strategies. The most significant usability issues found were file access and organization. A participatory design phase followed, resulting in a paper prototype of a file management system that addressed the key usability issues identified. The participatory approach continued during the implementation of a high-fidelity prototype.

## Categories and 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, Experimentation

## Keywords

Assistive technology, augmentative alternative communication, universal usability, ethnography, participatory design, handheld devices, cognitive disabilities, aphasia

## 1. INTRODUCTION

Aphasia is an acquired language deficit which diminishes the capacity to communicate through language. Aphasia can impact any or all of the language modalities: speaking, writing, and written and spoken language comprehension.

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Handheld computers, or personal digital assistants (PDAs), are portable, have sound and image capability, and have significant and increasing storage capacity, all features that would seem to offer people with aphasia an effective tool when communicating with limited language. We wondered whether an off-the-shelf PDA would be sufficiently usable by computer-literate people with aphasia. More specifically, we asked how well it might fit into their existing communication strategies. We took an ethnographic approach to answer those questions, as well as to increase our ability to successfully communicate with, and learn the communication strategies of, people with aphasia.

An ethnographically informed participatory design methodology addresses the challenges faced when designing technology with and for people with aphasia. In human computer interaction (HCI), the participatory design methodology assumes communication can occur fluidly among all members of the design team. The ability to communicate with people with aphasia, however, is a skill that takes time to acquire; conducting an ethnographically informed study provides that required time. This methodology not only offers an opportunity to gain insight into the communication strategies of people with aphasia but allows us to gain a better understanding of the daily context within which those communication strategies are used. Our research is operating within a larger multi-disciplinary project, The Aphasia Project; the knowledge gained from using the ethnographic approach is intended to inform the research reported here and the larger body of projects being undertaken by our group [2].

Within a participatory design paradigm, there is a tension that exists between maintaining confidentiality and acknowledging contributions of the participant. Our research depended on the expertise and intimate knowledge of living with aphasia that SM, the participant in this study, brought to the project. Our balance is achieved by acknowledging SM by name and by thoroughly reviewing the paper with him, particularly those excerpts that refer to him, gaining his permission and getting his input and verification of the accuracy of the content.

The first phase of this research was a field study in which two of the authors, Marcella (SM) and Davies (RD), spent over 70 hours together. During this time, RD noted the communication strategies used by SM, who has lived with aphasia for over two years. We then identified and categorized key elements in SM's communication strategy. As part of the study, SM began using a PDA and the usability issues that arose were noted, particularly when they related to using the PDA as a communication tool.

In the second participatory design phase, we used the key usability issues of the PDA identified in the field study to motivate the design of an alternative file management facility. Usability problems included file access that was too demanding, both in time and attention, within the context of interactions, and file organization that was not adequately supported, particularly of multi-modal data. The loss of files due to battery failure identified the need for a feature that supported automatic archiving to the desktop of any directories supported by our file facility.

The iterative design process continued with the implementation of a high fidelity prototype, with RD and SM meeting weekly to ensure that SM's input was continuous throughout the research.

## 2. BACKGROUND

### 2.1 Aphasia and Assistive Technology

Aphasia is an acquired communication deficit [5]. It is the result of a brain trauma to the language centres of the brain, which are commonly situated in the left hemisphere [1]. The most common cause of this trauma is a stroke, although a number of other causes, such as brain tumours, infections, or injuries, can also cause aphasia. Because of the contra-lateral relationship that exists between the brain and the body, motor and visual deficits that co-occur with aphasia are seen on the right side of the body. Aphasia is neither the result of deficits in sensation nor of intellect; people with aphasia are able to hear what is said and are not intellectually impaired [2].

Few alternative and augmentative communication (AAC) devices have been designed to meet the needs of people who have acquired communication deficits as a result of cognitive disabilities [15]. Mollica suggests that one reason such devices have been under-utilized is that they are seen as a communication prosthesis, rather than as aids that can scaffold communication skills.

TalksBac is a text-based AAC device designed for people with aphasia who can recognize some words and short sentences. While the system enhanced some users' conversational abilities, one user who had developed his own strategies found those to be more effective than TalksBac. The demand on a support person to update the database was also found to be problematic [19].

A multimedia story telling service was developed for socially isolated seniors with speech or language impairments. The user created stories using images, video clips, and sound clips, and then retrieved these stories during social interactions. Using multi-modal data resulted in communication partners gaining a more accurate version of the story, and a stronger sense of the personality of the story teller [10]. Although this technology was not designed specifically for people with aphasia, and there are questions as to how people with aphasia might utilize such technology, it draws attention to the value of considering the integration of multimedia in communication.

A day planner that used triplets of sound, image, and text was developed for people with aphasia. The day planner was designed on a PDA for people with aphasia to allow them to independently manage their appointments. A controlled experiment revealed that subjects with aphasia could complete more tasks correctly with the multi-modal planner than with an equivalent text-only planner. Specific guidelines from this work include the need for inactive space near targets to allow for users with less dexterity [14]

### 2.2 Ethnography, Participatory Design, and HCI

Participatory design within HCI originated in Scandinavia in an attempt to increase workplace democracy by involving unionized workers in the design of the technology they were destined to work with [18]. Missing from participatory design is an in-depth analysis of current work practices, a problem that has led to the adoption of ethnographic techniques [6]. Envisioning future solutions requires that current solutions can be articulated [17]. Ethnography, with its emphasis on understanding activities where they occur, and its use of qualitative data gathering techniques rich in description [3], has the potential to ground participatory design in current practice. In the past few decades, ethnographic techniques have been increasingly adopted by practitioners in the area of computer supported collaborative work (CSCW) [11, 9] and HCI [3].

## 3. PHASE 1: FIELD STUDY

The field study offered an opportunity to observe how someone with aphasia, i.e., SM, incorporated a PDA into his communication strategies and to evaluate how usable and useful an off-the-shelf PDA was to him. RD and SM spent 70 hours together over the course of three months, beginning in May 2003. During that time their ability to communicate effectively increased greatly, thanks largely to SM's skill in teaching effective communication strategies. RD observed how SM communicated within the day-to-day context of his life and with people both experienced and inexperienced in interacting with people with aphasia.

The PDA used in this study was an HP iPAQ running Pocket PC 2002. In August 2003, SM was given an attachable camera, the Nexicam, a Nexian digital camera expansion pack for the iPAQ. It is an attachable camera that uses the iPAQ's memory for image storage and its display screen for a viewfinder.

### 3.1 Motivation

Prior to taking an ethnographic approach we attempted to conduct a more traditional field study. SM was interested in replacing his use of paper notes (as discussed later in this paper) with the *Notes* application of the iPAQ. First, SM recorded the number of note pads he used in conversation over a period of two weeks, to provide a baseline for comparison. Once the iPAQ was introduced, we met with SM once a week for a few weeks to discuss his use of the device, particularly his use of the *Notes* application. Technical and usability problems encountered by SM, however, largely prevented him from using the iPAQ at all. In addition, we lacked confidence in our ability to fully understand what he communicated to us. The ineffectiveness of this preliminary study prompted the ethnographic approach. Given the time commitment necessitated by this approach, we restricted the study to a single participant, with the expectation of including other participants in a future evaluation phase.

### 3.2 Participant

SM, the participant and co-researcher in this study, is a 52-year-old man with aphasia and apraxia of speech. Apraxia of speech is a deficit in the motor programming stage of the verbal production process. The small motor movements that are programmed prior to articulation are impacted, so that speech production is more impaired relative to other modalities, such as gesture or writing, than it might be in a person with aphasia only [7].

SM has limited ability to produce both verbal and written language, and therefore the process by which he communicates does not allow for direct quotes. Field notes, set off by italics, serve the same role as participant quotes, allowing SM's voice to come through more clearly, and to highlight the contextual grounding from which the conclusions have been drawn. As suggested by Suchman [16], the *situated* nature of these interactions is fundamental to their meaning. Including excerpts from the field notes makes the process by which communication occurs between RD and SM transparent.

At the time of the field study, SM [Skip] was two years post-onset. A motorcycle accident precipitated a stroke that resulted in the aphasia.

*Skip acted out biking, crouching, hands on handles.*

*RD: "You were riding on a motorbike?"*

*SM: "Yes." ... [omitted]*

*RD: "So you lost control and crashed?"*

*SM: "Yes..."*

*There's more, but I'm not sure what. Skip does a somersault in the grass.*

*RD: "You flipped? Head over tail?"*

*SM: "Yes."*

The impaired language modalities for SM are speech production, reading, and writing. Receptive language understanding has not been noticeably impacted, although miscommunication does occur, particularly within a group conversation, when abstract details (e.g., dates) are discussed, or when SM is tired.

Speech production is limited to a handful of words, most frequently common social expressions such as *OK*, *yes*, *no*, *holy cow*, *come on*, and *hi*. He can sometimes say content words, though typically with considerable effort. He says very few grammatical words as he rarely uses sentence constructs but rather speaks one or two words together.

Reading is difficult, although SM can pick out words, especially when they are seen in context.

*We stopped at the pizza place. Leaning on the counter, we both go over menus. They were colourful, with lots of pictures. Skip chose a special then said "no" pointing to the menu: after 9:00PM only.*

SM writes words on note pads to assist him in communicating. Although he is unable to write sentences, he is able to write almost any content word, or at least enough to communicate any thought, given enough time.

Spelling correctly or writing the name of something out of context is difficult for SM.

*Skip writes muff and says "motor". "Motorcycle?" I ask. Skip shakes his head and points to the note he's written. "Muffler?" "Yes"*

In addition to being very creative in combining all his available language abilities to communicate effectively, SM is very comfortable with technology and enjoys learning about and using computers and electronic devices. He is computer literate; he was a graphic designer and ran a desktop publishing business prior to his accident.

### 3.3 Methods

SM and RD live in the same neighbourhood, about an hour away from the university. Beginning in May 2003 they met at least twice a week, sometimes at coffee shops, at the home of SM or RD, or at local parks and restaurants, and they would sometimes ride the bus to the university together. Throughout June they continued to meet at least twice a week, with each meeting being from 2½ to 7 hours long. In July and August they spent less time together, but continued to meet approximately once a week.

SM was uncomfortable with RD taking notes unless she asked him a direct question and was recording the answer; therefore, only brief notes were taken when they were together. SM knew that RD wrote notes after every meeting, and gave his permission for her to make detailed notes about what transpired, with the knowledge that his permission would be obtained before making public any information that involved him.

The field notes written by RD after every meeting were the primary source of data for this study. Emails sent between SM and RD, the notes SM wrote during conversations, and the informal interviews and discussions between SM and RD were further sources of data. The interviews were open-ended questions posed to SM by RD to clarify observations she had made, and usually led to further discussion.

### 3.4 Findings

The focus of the field study was SM's communication strategies and how he incorporated the iPAQ into those strategies. His strategies span drawing on the ground with a stick to using text-to-speech software on both his desktop and iPAQ. SM combines strategies fluidly and continuously. These strategies are discussed according to the context in which they were primarily used, with the caveat that in daily life no clear boundaries between contexts exist.

#### 3.4.1 Daily Interactions

The primary way SM communicates is to express a thought which his communication partner tries to articulate for him. SM then either corrects or confirms what is said. This process is iterative, with the communication partner focusing on SM to pick up on any cues he is using in order to accurately articulate what it is SM wants to express.

During daily interactions with people SM relies heavily on the few words he can say without difficulty, and on articulating other content words with great effort. This is often done once a conversation has begun, with SM guiding his conversation partner to express his thought. When this method fails, or to start a new topic, he writes one or two words on a notepad or a small portable white board he carries with him for this purpose, or any available piece of paper. When SM first began using the iPAQ, he used the *Notes* application as an alternative writing surface. When he is caught without paper, or when mentioning something in passing, SM writes out words or symbols (e.g. numbers) with his finger in the air. Once, when SM was out walking, he used a stick to write a word in the dirt.

SM makes great use of gestures and props. For example, because SM often confuses the words *tomorrow* and *yesterday* and they are difficult for him to say, he often gestures when he says them. To reinforce his meaning he points behind him when he means *yesterday*, and points forward when he means *tomorrow*, while

articulating one of the words. He acts out scenarios to communicate and will incorporate props, pointing to street signs, improvising with household items, or using whatever is in the immediate environment, to get his message across. He sometimes uses reference materials, for example he pulled out a map and pointed to a start and end point when mentioning he went on a long walk the previous day.

SM writes autobiographical stories and shares them with people. The story of his accident is the primary autobiographical story he shares with new people in his life. This not only fills the role of increasing intimacy by sharing a significant event in his life, a common practice when getting to know someone, but also offers people a description of exactly what his deficit is, which helps to guide the communication strategies they use when interacting with him. He copies many of these stories into the iPAQ, and when he shares them he either asks those he is sharing with to read aloud or uses *iSpeak*, a text-to-speech application for the Pocket PC. SM visits people in hospital who have recently had a stroke and/or acquired aphasia. *iSpeak* is particularly useful when visiting people who have difficulty reading. When SM knows he will be interacting in a group, for example at a stroke retreat, he makes a recording on audio cassette of *ReadPlease* reading his stories. *ReadPlease* is a text-to-speech application for the desktop PC. He records the stories rather than relying on the iPAQ as its sound level is too low to be heard easily by more than two people at a time. During introductory rounds, an effective strategy SM uses is to get a few people to read out parts of his story in turn. The combination of voices succeeds in giving the story a great depth and power.

SM keeps a 3-ring binder that contains information about the events surrounding his accident. These include his autobiographical stories, stories and letters other people have written, and photographs. Significant artifacts, such as newspaper clippings about events connected to him, are kept and used in conversations. SM has a scanner at home, and uses it to access non-electronic written material. He first scans the paper and then, using optical character recognition, converts it to text which can then be processed by *ReadPlease*. Photographs are used by many people to share events with friends; SM relies on photographs to describe past events and to generally share his life. He copies photos into the iPAQ, and shares these photos to aid in communication. For example, the first day that SM began using the *Nexicam*, he took close up photographs of parts of his motorbike to aid in communicating with his mechanic.

### 3.4.2 Interactions with Strangers

When meeting people for the first time, SM offers them business cards that state:

*As a result of a stroke, I have aphasia .This means I have no speech.  
However, my intelligence is intact.*

People respond to him in a range of ways, some people not noticing, some quickly accommodating, and others becoming wary, apprehensive, or nervous. Some people mistake his difficulties with articulating words for drunkenness, and back away quickly. Others assume he cannot understand them, and talk exclusively to whoever is accompanying him. Some people raise their voices, or use telegraphic speech.

### 3.4.3 Personal Communication Supports

SM has a list of names, with each name paired with a memory cue. For example, if he had a friend Mary who had red hair, the listing for Mary would be *Mary red*. He keeps a list of emotion words to point to when having a conversation about feelings. Other lists contain words associated with common conversation topics, or frequently used words that he sometimes forgets.

SM uses day planners and wall calendars to not only remind himself of scheduled meetings and events, but to share past and future events with others in conversations.

### 3.4.4 Communication Strategies Using Desktop PC

SM uses his desktop PC extensively as a communication aid. *ReadPlease* allows him to listen to written material, and he uses it to assist him in writing. Prior to his accident, he had been editor of a newsletter, and so had a large database of previously written editorials. In writing new material, he searches through existing files, listens to each using *ReadPlease*, and then cuts and pastes selected sentences into the new document. He keeps a document of phrases culled from emails that have been sent to him and these phrases are another source of material when creating new documents. Once he has the document written, he then asks his partner or a friend to edit it, sending it via email. Once the edited document is returned, he again listens to it with *ReadPlease*, making sure the changes made do not change his intended meaning. This is a time consuming process. For example, a 20 minute speech took SM 10 hours to edit after he had copied in the major content from previously written documents.

SM uses email a great deal, both to exchange messages, but also as an alternative communication mode to augment conversation. For example, when parting company, if he remembers to mention something but the person he is addressing does not understand, he will say "email" and continue with saying good-bye. The ability to compile his thoughts before communicating them is a huge benefit to him. Email is preferred over phone calls, which are extremely one sided and a difficult medium for him to communicate what he wants to say.

### 3.4.5 iPAQ Usability Issues

In previous sections we have stated how SM incorporated the iPAQ into his communication strategies. He uses the *Notes*, *Day Planner* and *Pocket Word* applications, the sound recording/playback and image display features, and the digital camera attachment. Although the range of iPAQ features SM uses is a promising indicator that a PDA could be incorporated into the communication strategies of someone with aphasia, there were usability issues that significantly hindered its use as a communication tool. The biggest problem was finding files using *Pocket File Explorer*, the interface to the iPAQ file system. One confusing feature of that system is the mapping of files to their applications. If you know you have copied an image *a* into the same directory as *Pocket Word* document *b*, it is confusing to see a listing of a directory which includes *b* but not *a*. A directory system that displays files filtered by the applications to which they are mapped is unfamiliar to users of the desktop PC, and was a source of confusion.

Initially SM experienced difficulty consistently starting applications, as well as accessing files. The solution to this was surprisingly simple. A directory named *Skip* was made available from the *Start* menu, and shortcuts to applications SM started were placed in the

*Skip* directory. Additional directories for specific events were created in the top level *Skip* directory. For example, after SM attended the birthday of his mother-in-law RD and SM met for coffee. SM described this event to RD by drawing a picture of a boat, and playing a sound clip of people singing *Happy Birthday*. Later, he sent RD a photograph of a sailboat. They created a directory, called *Birthday* and placed both the sound clip and the photograph in it. The files in the *Birthday* directory helped SM talk about the event.

Creating the *Skip* directory may have helped for three reasons. First, when initially faced with the *Start* menu, SM can quickly identify his own name. Second, after opening the *Skip* directory, only the application shortcuts to those applications SM opens directly are visible, and therefore the search space is greatly reduced. Third, after opening a subdirectory, SM only sees files related by context, making it easier for SM to read the filenames. As noted earlier, reading in context, when words are surrounded by white space, is much easier for SM.

Moving files within the iPAQ relies more on text-based messages and dialog boxes than does the same operation on the desktop, where the user is able to drag and drop files. Because of this difference and the overview the larger screen real estate allows, SM manages files on his PC's *File Explorer* program, when the iPAQ is in its cradle.

Although SM finds *iSpeak* to be very useful, it takes a number of taps of the stylus to start. Only text that can be copied to the Clipboard (using *select* and *copy*) can be read by *iSpeak*. File and directory names cannot be read by *iSpeak*, a feature that would be useful to SM.

The attachable camera is useful and increases the size of the iPAQ only slightly; SM is still able to carry it around easily in a hip bag. Images can be viewed through *Nexicam* or accessed through *File Explorer*. *Nexicam* has options to show images as a slideshow, or scroll through thumbnails, but does not have a utility to rename the images. In *File Explorer*, images are shown by name only, but can be renamed and organized into different directories. Neither of these options suit SM's needs of quickly identifying a photograph and showing it to a communication partner and organizing easily identified images.

Poor screen visibility, the number of taps required, and the high-degree of dexterity required by the stylus militated against the *Notes* application replacing paper note pads. This was disappointing as *Notes* motivated SM's initial use of the device. SM only occasionally uses *Notes* when he does not have paper at hand.

The poor sound quality and limited volume of the sound recordings and playback in the iPAQ hindered the usefulness of this feature to SM. He only finds it useful when interacting with one other person.

PDA's seem to have a great deal of potential as communication tools. The ability of the iPAQ to store and display information in a variety of formats is used by SM to assist him in telling stories. Despite the potential of these devices, their ability to augment existing communication strategies does have limitations.

## 4. PHASE 11: PARTICIPATORY DESIGN

We began the design phase with a very informal and exploratory discussion that centred on the usability issues that impeded SM's use of the iPAQ. The outcome of this discussion was the decision to focus on an alternative file facility.

### 4.1 Method

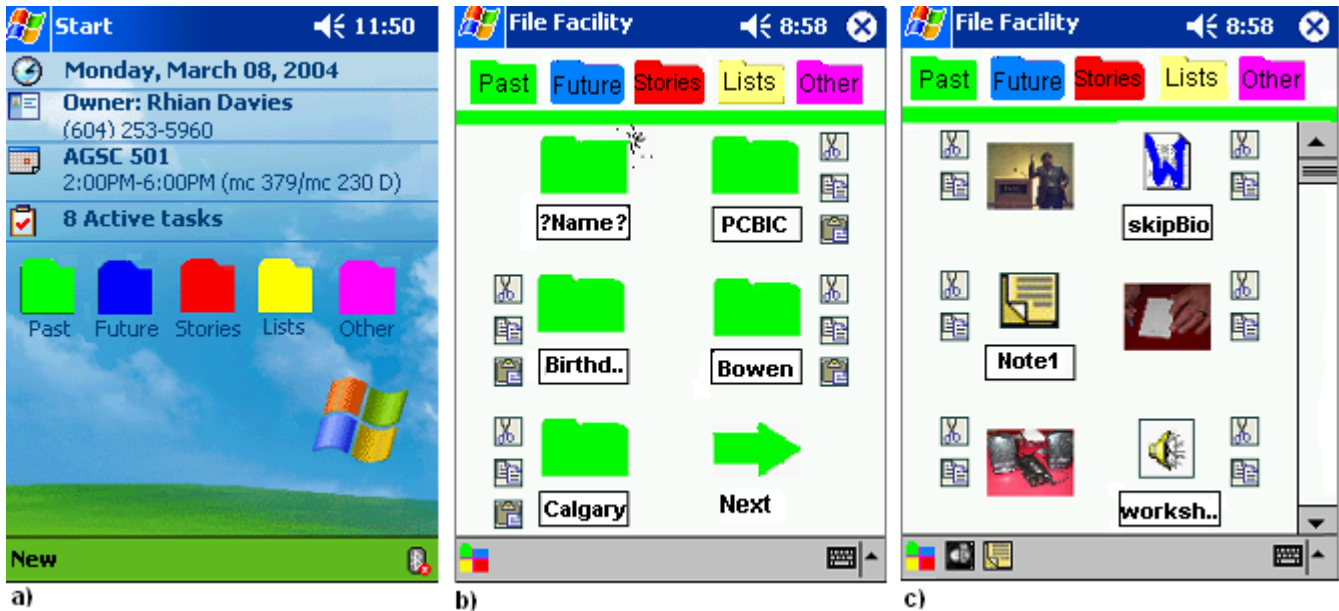
After identifying the problems that the file management facility would address, RD and SM agreed on the participatory design process they would use in forming a solution. Paper prototyping involves designing a prototype first on paper and then walking through the design with users to gain feedback and discover usability problems early in the project. Unlike traditional paper prototyping where the researcher creates the prototypes in advance of the participatory session, we continued as equal partners in the design process. Prior to a session, *both* SM and RD would think about possible design ideas and would participate in the creation of the paper prototypes.

This approach was adopted slowly in the first session. In retrospect, a better approach would have been to introduce paper prototyping towards the end of the field study, to allow SM to get comfortable with the technique.

In the first session, RD initially sketched out a design, asking for feedback as she went, with SM observing. He was quick to give positive feedback, but more reticent to criticise her ideas or suggest his own. In an attempt to move this first session into a more mutually participatory mode, RD began using a scale of 1 to 5, with 1 representing a terrible design, and 5 representing a perfect design. Using this scale, SM identified these initial sketches as being about a 4 on the scale. RD then requested he make a suggestion to move the design from a 4 to a 5 rating. This moved the session into a more mutually participatory one. Introducing both the techniques of prototyping and requesting design ideas in the same session proved to be exhausting. This first session was 1½ hours in duration; given the novel task that was being introduced, a shorter first session would have been more appropriate.

The subsequent sessions went more smoothly than the first, with SM participating much more fully. RD and SM continued to meet once a week throughout the fall of 2003, although these meetings were not always dedicated to paper prototyping. The sketches were very rough, with both SM and RD writing on the paper, discussing problems and strategies, and SM using the iPAQ as a prop to explain different design problems or solutions. When the paper prototypes had stabilized and implementation could start, SM and RD broke from the scheduled weekly meetings. At this point several design requirements had been identified:

- ◆ A subset of frequently used files should be accessible in 2-3 taps of the stylus.
- ◆ New files should be placed in a directory of choice.
- ◆ Files should be automatically archived when the iPAQ connects to the desktop, ensuring all files are backed up on the desktop. This frees SM to delete files and directories on the iPAQ that are no longer used in conversation. Archived files provide material for new autobiographical stories.



**Figure 1 (a):** The *Today Screen*, the home screen of the iPAQ that appears initially and when all applications are closed or minimized. The 5 top-level directories of the file management system are available from this screen.

**Figure 1 (b):** The *Directory Screen* for the *Past* top-level directory. New directories can be created by tapping on the icon at the top left.

**Figure 1 (c):** The *File Screen* for the *Past/PCBIC* folder (Pacific Coast Brain Injury Conference folder). Application shortcuts (*Nexicam*, *Notes*) are available on bottom command bar. From both the folder and file screens, a top level icon links to the top level screen (not shown).

- ◆ When a Pocket Word document opens, iSpeak should start automatically.
- ◆ There should be some simple way to accomplish directory management tasks (deleting and moving files) on the iPAQ, although it is assumed most directory management tasks will continue to be done when the iPAQ is connected to the desktop.
- ◆ There should not be multiple ways to accomplish one task, because this leads to confusion.
- ◆ A simple design which gives the user control is preferred over a complex design where things are done automatically (with archiving being the exception).
- ◆ Scrolling through many files and directories (shallow directory hierarchy) is preferred over many selection points (deep directory hierarchy).

Implicit in these requirements is the assumption that SM be able to accomplish the above tasks without assistance.

The design was implemented using C# in the .NET Compact Framework. When a partial implementation was complete, SM and RD began again meeting once a week. The bugs in the software did not prevent SM from stepping through the application; rather, they made it easier for him to give feedback on an obviously unfinished prototype. These regular meetings succeeded in catching design flaws.

## 4.2 Prototype Description

The file facility we designed and implemented acts as an alternative to, not a replacement for, the existing Pocket *File Explorer*.

Solutions to usability issues identified during the field study are offered, but to keep the interface as simple as possible, no extra functionality is added.

Our file facility is three levels deep. The top-level pre-defined directories are: *Past*, *Future*, *Stories*, and *Lists*. One extra directory, *Other*, was added to act as an “overflow bucket” which will allow us to determine how well our pre-defined directories match users’ needs. All top-level directories are accessible from the *Today Screen*, the screen that appears in the initial state when rebooting, or when minimizing or closing every application (see Figure 1a). Each top-level directory is colour coded and the line separating the navigation bar from the directory or file screen matches the colour code of the top-level directory in which it lies. A new directory can be created by tapping on the directory icon above the textbox labeled *?Name?*, as shown in the upper left of Figure 1b. Tapping on the textbox invokes a soft keyboard allowing the user to enter the new directory name. When the user creates his sixth directory in a top-level directory, an arrow, with the text *Next* underneath it, is placed on the screen, and the least-recently used directory icon is removed from the screen. Keeping the maximum icons displayed to six means that no scrolling is required on the first directory screen. If the directory wanted was not one of the last four accessed, the user will find it in the screen that opens when the *Next* icon is tapped. Files are found in the third layer of the hierarchy. This makes it possible to open a file in a recently accessed directory in three taps, the maximum number of taps SM considered acceptable during interactions.

As one would expect, tapping on a directory icon opens a screen with file icons representing all the files in that directory. From that screen, icons to start the *Notes* and *Nexicam* applications are accessible from the bottom command bar (see Figure 3c). Files

created when tapping on these icons will be placed in the directory the application icons were accessed from, which prevents the user from losing files. Images are represented as thumbnails and, when tapped, open in *Internet Explorer*. *Pocket Word* files, when tapped, open in *Pocket Word*, and initiate user simulated taps to copy the contents into the clipboard, which *iSpeak* then begins to read. All file icons, with the exception of image thumbnails, have the filename of the file placed below the icon; when tapped, *iSpeak* reads the name.

Each file and directory, except top-level directories, has a *cut* icon that, when tapped, deletes the file or directory. Only empty directories can be deleted. A *copy* icon exists beside each file and directory icon, with each directory icon also having a *paste* icon. Files and directories can be copied by tapping on their respective *copy* icons, and then selecting the destination directory by tapping its *paste* icon.

The file management facility has a shallow hierarchy of three levels, accessible through at most four screens. One might be concerned that large amounts of scrolling could be required in the screens where the files and least-used directories reside. We don't expect this to be the case, however, because SM clearly indicated that only a small set of regularly accessed files would reside on the PDA. All other files would be archived on his desktop PC.

## 5. DISCUSSION AND FUTURE WORK

Using an ethnographically informed methodology was critical in ensuring that SM had first class status as a member on our design team. Our approach was influenced by the work in community based action research (CBAR) in that the line between researcher and participant was blurred. One motivation for this approach is that researchers and professionals often have very different perspectives from the participants in their studies [4]. If the research is focused on assessing or addressing the needs of the participants without their input, this assessment can miss what the participants themselves perceive to be their needs [4]. The importance of avoiding a *colonial* relationship [8] has also been noted in disability research [20]. Krogh has noted that although there are examples of researchers expressing the importance of involving people with disabilities in the research process, there are few studies documenting a mutual research relationship with users [13].

One way to enhance communication is to establish a common context. Because the communicative partner must often make guesses when articulating for someone with aphasia, mutual trust is involved. It is very difficult to circumvent an issue. The person with aphasia must choose from the words they have access to, and these words may not be the most discreet, or carry the subtlety of their thoughts. Rather than offend a stranger, a thought may not be expressed. In an established relationship there is less concern over creating a wrong impression. As well, people with aphasia may question how well designers understand what aphasia is and how it is manifested. If trust has not been established, these queries may go unasked leaving a negative impression of the design process. For example, after a paper prototyping session with another project, SM asked RD if his brain injury had prompted the researcher to use paper prototypes. He questioned the researcher's understanding within an established relationship; he did not ask the other researcher directly. For a participatory session to meet its mandate an environment where the participants can communicate their concerns must be established.

We place a great deal of emphasis on social validity in our research, and generalizability has only been addressed through referring to literature in assistive technology and aphasia. For example, the value of colour coding has long been recognized in designing materials for people with aphasia [12]. We are currently addressing the generalizability of our design. In conjunction with a field evaluation in which SM is using the file management facility in his daily life, we are currently doing a usability evaluation which includes six people with aphasia, and six without, with the six pairs of participants matched on age, education, and computer use.

SM is a gifted and enthusiastic communicator. He is computer-literate and enjoys learning about novel technologies. We believe these characteristics made him an ideal initial participant for this research. He has made it very clear that aphasia is not a barrier to the use of technology, as long as the technology has an appropriate user interface. SM is clearly not a representative participant in his willingness to struggle with the PDA and to spend considerable time communicating with us about technology. However, we believe that his needs for a communication tool will generalize to other people with aphasia who have similar communication abilities to him.

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