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Words Are Not Enough: Empowering People With Aphasia In The Design Process

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ABSTRACT

This paper explores the issue of empowering participants in design when they do not have the language skills integral to many design methods. We describe the challenges, solutions reached and lessons learned whilst employing a participatory design (PD) approach in the development of a prototype computer therapy tool for people with aphasia, a communication disorder.

Our approach was workshop based. During a series of participatory workshop sessions, five people with aphasia, employed as consultants, took part in game-playing activities followed by hands-on interaction with a series of iterative prototypes. The challenges we faced arose primarily from the consultants' difficulties with the production and comprehension of language, both textual and verbal, and with the retention of information. The strategies and techniques we devised to cope with these challenges evolved over the course of the workshop sessions. We discuss these and how to involve and empower users with cognitive impairments, in the context of a broadening scope of PD practices.

Author Keywords

Aphasia, participatory design, participatory workshops

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Effective communication, founded upon the production and understanding of oral and written language, lies at the heart of most participatory and user-centred approaches to technology design. Our concern in this paper is with the substantial numbers of people for whom such communication is a challenge and who therefore face serious obstacles to participating in collaborative design activities.

By means of a case study, we explore the issue of empowering people in design when their communication skills are impaired. The case study examines how people with aphasia, a communication disorder, participated in a design project to develop a gesture therapy tool (Galliers et al, 2011). The tool, GeST, supports people with aphasia in independent practice of a set of communicative gestures. Five people with aphasia were recruited to work as consultants on the project. Their role was to help other members of the interdisciplinary team to understand the interaction needs of people with aphasia and to assist with the design of the therapy tool. The consultants' participation was accomplished through a series of participatory workshops where they initially took part in exploratory evaluations of a range of different technologies and then which they participated by working with a series of iterative prototypes of the tool.

One of the biggest challenges to involving people with aphasia in PD is how to facilitate participation and communication in the face of impaired language skills. In the following sections we firstly provide some background into aphasia. After this, we describe the methods employed by others in previous research; largely these involve caregivers or therapists acting as *proxies* who "speak for" the person with aphasia that they represent. One describes combining the features of individuals with aphasia into a single, composite *persona*. In contrast, our PD approach treated the five consultants as independent and varied individuals, each with a "voice" and sought to empower their individual contributions. We have found no similar work that has involved people with aphasia as consultants to the design process in this way.

We then present the participatory workshop method we adopted and use selected experiences from the workshop sessions to illustrate the challenges to participation that the consultants faced and how these challenges shaped our approach. We also consider more broadly the impact of a PD approach on the participants and conclude with some reflection on PD for people with language and communication difficulties.

BACKGROUND

Aphasia is a communication disorder resulting from damage to the areas of the brain that are responsible for language. In many cases, aphasia is a consequence of stroke: about one third of the people who survive a stroke will have aphasia. There are currently about one million people in the US, and about 250,000 people in the UK,

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living with aphasia. Aphasia affects all aspects of language use: speech, writing, reading and understanding. This has far-reaching consequences. Clearly, the particular consequence of concern here is the implications this has for participation in a design process.

Most participatory and user-centred design methods make fundamental assumptions about the communication skills of those who will participate. They are founded on the premise that participants will have the requisite skills, for example, to communicate orally, to understand and produce written text, to comply with instructions. Those who do not have these skills cannot readily participate.

A number of computer-based tools have been developed to assist people following a stroke. Most are aimed at improved motor function in stroke survivors generally, but a small number of specialist technologies have been designed to assist communication for people with aphasia. Of these, those that have incorporated a PD approach to design have mostly used proxies. In other words, either speech and language (S&L) professionals played the roles of the aphasic participant or the caregivers of aphasic participants provided feedback. For example, two S&L professionals were used as proxies for users in the development of PhotoTalk (Allen et al, 2007), an application that allows people with aphasia to capture and manage digital photographs to support face-to-face communication. Koppenol et al (2010) similarly designed an application that uses photographs to support communication and used therapists as proxies. Boyd-Graber et al (2006) used S&L pathologist proxies in the development of a system that enables aphasic users to combine images and sound on a desktop computer before downloading the "speech" to a mobile device.

Daeman et al (2007) additionally included the notion of a persona during the development of their storytelling application, to act as a specific instance of expressive aphasia and guide their design. The application enables the creation and sharing of stories from pictures the users have taken. Brainstorming sessions were held with speech and language therapists who also then acted as proxies for preliminary evaluations. Further evaluations involved four people with aphasia but included their primary caregivers to assist with communication. The aphasic participants themselves were observed for facial expressions and signs of confusion or enjoyment whilst using the prototype. They were also asked to rate 36 statements according to a scale of smiley faces (very smiley to very sad). Cards showing pictures or icons were used for ranking certain features.

Moffat et al, (2004) involved aphasic participants more directly in the design process for the ESI (Enhanced with Sound and Images) Planner which was aimed at enabling aphasic users to independently manage appointments on a mobile device. They based their design initially around meetings with one user or 'design member' who, "although she had difficulty finding words and was largely unable to read or write, she maintained relatively fluent speech". Unfortunately, this woman died before the preliminary design was completed after which they recruited three 'surrogates' to fill her role. The PD practices employed included brainstorming, low fidelity paper prototyping, and medium and high fidelity software prototyping. Such techniques were enabled presumably by their user's "relatively fluent speech". The potential for using these PD techniques with people with aphasia is discussed later in this paper. Finally, Al Mahmud and Martens (2008) designed an email tool for people with aphasia where they also had more direct contact, but this was limited to interviews.

Moffat et al (2004) offer general guidelines for working with special populations, such as people with aphasia, in the development of technology. They describe the main challenges as: interpreting data from a population with large individual differences, recruiting sufficient participants, addressing mobility and transportation issues, and communicating with participants. They suggest firstly assessing users' abilities through standardized speech and language assessment tests because many aphasic individuals have developed sufficient compensatory skills to mask the extent of their deficits; secondly, connecting with existing stroke and aphasia groups and organizations; and thirdly, gaining practical experience with the target population.

The case study that we present here concerned the development of a gesture therapy tool, GeST, for people with aphasia. When a person with aphasia has little spoken or written communication ability, S&L therapists often advocate the use of non-verbal communication strategies such as gestures instead (Rose, 2006). Indeed some people with aphasia use gestures very successfully, even in spontaneous communication (Goodwin, 2000). However, others show marked gesture impairments (Goldenberg et al, 2003). The ability of an individual to produce gestures may be enhanced by therapy, conventionally delivered face-to-face by a therapist (Marshall et al, in press). GeST was intended to offer an alternative: it is a computer-based therapy tool that supports people with aphasia in practising gestures for communication such as "tea", "money". A detailed account of GeST is outside the scope of this paper, but the central idea is that it presents a series of gestures to the user, inviting the user to emulate them. The user's gestures are detected and recognised using a computer vision-based gesture recogniser. A key innovation that distinguishes GeST from other therapy tools for people with aphasia is that it incorporates a 3D virtual world. In adopting a participatory approach, we sought not only to empower people with aphasia in the design of technology for their use but also to benefit from an improved understanding of how to design virtual worlds and effective interactive experiences for people with aphasia.

THE PARTICIPANTS

Rather than using proxies, we chose to give a direct voice to people with aphasia by recruiting five consultants to the project team. Each person's aphasia is different. For this reason, we begin the case study by introducing the participants and their individual characteristics.

The Consultants

The selection criteria for the five consultants were that they should be at least six months post stroke, physically

able, sufficiently independent to come into the University to attend the participatory workshops and that they should demonstrate moderate to severe expressive aphasia. They were referred by qualified speech therapists who had been working with them, a clinician's referral determining their suitability rather than a standardised assessment result. Additionally, they were screened at interview by one of the S&L therapists employed on the project. All signed their consent for use of their results, images and video clips in the dissemination of the research; an S&L researcher read the form to each individually, checking that they understood each point.

The two men and three women ranged in age from early twenties to early seventies and in their experience with technology. Notably, the two younger consultants were more experienced and confident with trying new technologies.

Tanya was in her thirties. She had a stroke 9 years previously. She spoke in short sentences and had some problems understanding exactly what people were saying when they spoke to her but could understand the gist of a conversation. She could no longer read text. She also had hemiparesis plus visual problems on the right side.

Sarah was in her twenties. She had a stroke three years previously. She used short sentences or one or two words at a time. She was able to understand what people were saying when they spoke to her. She could read individual words but not a whole book. She walked and managed independently but had right-sided hemiparesis.

Ann was in her sixties. She had a stroke many years previously. She talked using few single words. She found it easier to understand other people's speech than to produce words herself. She had limited understanding of text.

Tom was also in his sixties. He had a stroke three years previously. He showed evidence of some limb apraxia but could use both hands. He spoke a few single words but could follow and understand conversations. He could read text if it was clear. He drew to communicate ideas.

Martin was in his seventies. He had a stroke two and a half years previously. He also showed evidence of limb apraxia but could use both hands. He spoke one or two words at a time and found understanding what other people said easier than producing speech. His reading was limited. He also drew to assist communication.

The Researchers

Abi was in her thirties. She was an S&L researcher who had been working with people with aphasia for the three years prior to this project. She had previously researched a computer-delivered speech therapy programme for people with aphasia to use at home.

Julia was in her fifties. She was a human computer interaction (HCI) researcher whose research included innovative technologies in healthcare and communicative symbolic languages for people with cerebral palsy.

Sam was in his thirties. He was a technical researcher and software developer, experienced in gesture recognition, computer vision and machine learning.

THE APPROACH: PARTICIPATORY WORKSHOPS

The approach we adopted to enable the participation of the consultants was to run a series of participatory workshops. Twenty, two-hour workshops were held over a period of 10 months, giving the team time to get to know each other. In this section we focus firstly on the aims of the different participatory workshop sessions. This is followed by a more detailed discussion of the methods employed in the workshops.

The five consultants, three researchers and three project grantholders all attended the initial workshop session. Abi, the S&L researcher, briefly introduced everyone and the aims of the project before we paired off to engage in two communication exercises. These involved each consultant and each team member 'talking' for 5-10 minutes before swapping partners and talking again. Topics in the first exercise were: family, job, holiday, and computer use. For the second exercise, four photographs were used to stimulate discussion. These were: a popular TV programme, a current event, the royal family and the England football team's manager. The activities allowed the researchers and consultants to relate to each other individually. All the researchers later wrote up their impressions about what was said and how each consultant managed to 'say' it. An example: "To describe his own job as a teacher of Maths, Tom wrote the word 'Maths' at the head of a table with stick people around it. He added '15 – 20 yrs' to indicate the age of the students. Later he wrote 67 and said 'now' then wrote 63 and indicated with gesture a falling motion. I guessed: was that when you had your stroke? He indicated 'yes'."

The remaining workshops occurred in pairs, with two or three consultants and the three project researchers attending each workshop. Each pair of workshops had a specific objective; each was concerned with exploring critical design issues for the gesture therapy tool. The final workshop was a 'debriefing' session to elicit the consultants' views about the participatory process they had experienced and this was conducted by a different S&L researcher. All workshop sessions were videoed.

In the first pair of workshops, the consultants played a WiiSports tennis game and bowling game. This game context was used in part to enable everyone to get to know each other better and to observe the consultants' communication, both with the researchers and with each other. We also wanted to observe how the consultants managed the Wiimote and their understanding of instructions. After the games, we talked with each consultant individually about specific aspects of the session using a feedback sheet.

All remaining workshops began with a round-the-table gesturing game using cards. Workshop sessions 2 explored different gesture recognition technologies. Workshop sessions 3 focussed on different modes of presenting gesturing instructions. After that, the workshops involved the consultants individually interacting with a series of iterative prototypes of GeST, with a different emphasis for each session. For example, sessions 4 were a preliminary exploration of gesture therapy within 3D computer worlds. Sessions 5 explored

alternative modes of presenting feedback and offered the first taste of incorporating a 'story' into the gesturing game. Sessions 6 explored navigation. Subsequent sessions then offered increasingly refined versions of GeST with the emphasis on designing timing, support and feedback. The final sessions offered each consultant the opportunity to use GeST entirely on their own whilst the researchers watched through a two-way mirror. The intention was to emulate the context in which GeST would eventually be used in people's homes.

The Design Method

The workshops involved game playing, exploration of different technologies, and evaluations of a series of iterative software prototypes. Beyond these variations in content, we aimed for consistency in as many aspects of the workshops as possible.

Most of the workshops took place in a large meeting room that was part of the 'Interaction Lab' at the University. The room was set up so that several tables were pushed together for the round-the-table activity in one area. In another area, a computer was set up with a connection to an amplifier for additional volume (Tom in particular, found the computer's speakers too quiet). The consultants became familiar with this setting. Only the final pair of workshops, involving unsupported use of GeST, took place elsewhere.

Likewise, all workshops except for the final pair followed the same structure. Firstly, Abi handed out name badges and explained what was to happen that day. This was followed by an introductory round-the-table game. The purpose of the game was to re-introduce everyone, make them relaxed, and introduce or remind participants of the set of gestures to be used that day. It worked well.

The games generally involved pictures representing the day's gestures on cards. All games were repeated several times with everyone taking a turn at playing each role i.e. taking the 'lead' or responding to someone else's lead. 'Leads' might select a card and show it to the others who would need to perform the correct gesture. Alternatively, they might select a card but keep it hidden, then make the gesture for the others to name. Other round-the-table activities involved a set of pages each containing four pictures. The 'lead' would make the gesture and the others would select which of the four pictures was being gestured. This could be made more challenging by having four closely related items on a page. Finally, we played a Bingo game where the Bingo cards were made up of the pictures. The 'lead' would play the caller, selecting cards from a bag to gesture. The first player with a full Bingo card won the game. This was the most popular game.

After the round-the-table activity, the computer activity was introduced. This mostly involved the consultants individually (and sometimes collaboratively) interacting with a prototype version of the tool which comprised a 3D game environment, or elements of such an environment. There would be a specific goal for each session (see above). Whilst the first participant was taking their turn at the computer assisted by Abi, Julia (the HCI researcher) would ask the other consultant(s) to accompany her to the kitchen to help make tea for everyone. This served the purpose of removing the non-participating consultant(s) from the room, thus removing a potential distraction for the participating consultant. It also enabled some 'conversation' outside of the room at which participants could get to know each other better.

Each consultant talked individually to Abi as soon as they had finished the computer activity. This data supplemented observations of the consultants' activities with their own perceptions. These "interviews" were supported by the use of paper-based rating scales. Pictures and visual aids (such as the Wiimote controller itself) were used to aid recall. The consultants were also asked to rate various aspects of the game activities via rating scales that showed a thumbs-up sign at one end and a thumbs-down sign at the other. For example, they were asked to rate much fun they found the session or whether they found a particular aspect easy or hard. A scale of smiley to glum faces was used to rate enjoyment, or how using the prototype made the consultant feel.

The discussions were convened immediately to aid recall. They were also conducted at the computer so that Abi could navigate and/or point to particular features, thus providing the consultants with concrete visual aids for communication and recall purposes. Consultants' views were written by Abi onto a feedback sheet. As each comment was recorded, Abi would read it back to check that she had accurately recorded the consultant's views.

Because of the communication challenges, we designed the sessions so that consultants' contributions were, to a large extent, made via the "doing" of the activity rather than what they said about it afterwards. Hence, all activities i.e. round-the-table games, hands-on computer activities and interviews, were videoed for later analysis, yielding rich observational data. Two cameras were set up for the computer work and interviews – one focussed on the computer screen and the other on the consultant's face and hands. The session videos were reviewed afterwards and a detailed summary was written for each session. The quantitative data from the rating activities was summarized in the form of a table. Any communicative drawings produced by the consultants were kept along with the feedback sheets. Paper, pens and writing boards for this purpose were always available in the room.

Evolution of the method

This participatory design activity was a learning process for all concerned and all brought valuable expertise to the table. The HCI and technical researchers brought expertise in design methods, in creating interactive experiences and in technology; the S&L researchers brought expertise in communicating with people who have aphasia and in gesture technology and, most importantly, the consultants brought expertise regarding their aphasia. Various aspects of the method described above evolved as we discovered more about what worked and what did not. One such evolution was a change to the feedback sheets due to the problems people with aphasia have with abstract concepts. We had asked how the consultants felt they might have coped with some aspect of the session 'after they had first had their stroke,'

initially planning to ask this about each aspect of the session. When this did not work, we adapted the sheet for the next session to ask it as a single question. This idea was then also abandoned.

The time and place of the interview with Abi changed after the first couple of sessions. Initially, interviews were carried out after everyone had taken their turn at the computer and at a separate table. Screenshots on the feedback sheets and visual aids were used to aid recall. However, we found that conducting the interviews immediately and at the computer was much more effective. This change came about as the result of a recommendation from Tom.

At one session, one consultant used the current prototype of GeST whilst two others watched. There were interactions therefore, not only between the consultant who was 'driving' the tool and the tool, but between the others who were watching. Furthermore, much of this was not captured on video and the running of the session and analysis of observations was hugely more complex than when one consultant interacted with the computer at a time. We determined to only have one consultant at the computer at a time from then on.

CHALLENGES TO THE DESIGN PROCESS

Difficulties with comprehension and production of language, both verbal and textual

Aphasia is a communication disorder affecting not only the production, but also the comprehension, of language (Rosenbek et al, 1989). In participatory sessions, it is obviously important that the participants understand what is required of them. All the workshop sessions were run by Abi. As an experienced S&L researcher, she knew to speak slowly, use repetition, and speak sentences with only one phrase at a time. For example, asking, 'Would you like a tea or coffee?' is too difficult. 'Would you like tea?' Pause. 'Or would you like coffee?' allows for a response via a nod or a shake of the head in between questions. The same principle applied to the presentation of tasks: these were presented gradually, one at a time.

There were inevitably times when there was evidence of a lack of understanding on the part of one or more consultants. For example, each prototype of GeST prompted the user with a short video of Abi demonstrating a gesture and then saying, 'Now it's your turn', after which the user was expected to copy the gesture. The portion of the screen where the video had been would then go black, indicating that the gesture recognition component was ready and showing the user's gloved hand as they made the gesture. It took time for some of the consultants to understand that they needed to wait for, 'Now it's your turn' before making their own gesture. In one session Martin, for example, repeatedly gestured only whilst the video played and then stopped. Abi reminded him that the computer could not 'see' what he was doing until after the video had finished. In response, and presumably because he was still unsure when exactly he was supposed to gesture, he adopted the strategy of constantly repeating the gesture throughout Abi speaking and into the recognition phase. This worked well. But later in the same session, he made the same mistake again. (See the section on information retention).

In terms of production of language, some of the consultants were able to say a few words, but word finding difficulties (anomia) are very common. Mostly, the consultants used gestures, pointing, drawing, and facial expressions, with the researcher then speaking back to them what they thought was meant. For example, when Tom put his hand behind his ear and leaned towards the computer, Abi said, "You mean it's too quiet? You can't hear?" Obviously, there were times when this did not work. Sarah in particular would become embarrassed when her attempts at communicating failed, and she would shake her head and wave her hand as if to say, "It doesn't matter."

Difficulties with abstract information / concepts

People with aphasia find it harder to process abstract words and concepts than concrete ones (Franklin et al, 1994; 1995; Tyler et al, 1995). For example, when Tanya was asked about different modes of presenting gestures (e.g. presenting images within a standard video image or presenting gestures using a white outline against a black background), she found it impossible to separate the gesture itself from its mode of presentation. Her answers were consistently about the gesture itself, not the mode of presentation. This persisted regardless of however many ways she was asked the question.

When referring to an object, we also found that using a photograph or a model of that object was more likely to result in recognition and understanding than a more abstract representation such as a drawing. An early example of this was when we explored alternative ways of presenting instructions describing how to make a gesture. We were curious to know how the consultants might respond to a talking avatar of Abi versus videos of the real, live Abi. Would they, for example, find the avatar more 'fun?' The consultants managed to follow the instructions when delivered by avatar but they all said quite strongly that they preferred the videos of the real Abi. Tanya indicated that she needed to see the face and the lips moving whilst it was speaking the words. Tom said he found the avatar a distraction – he did not like it.

Finally, there was one 'abstraction' that we asked of the consultants that none of them could cope with. Because they had been living with aphasia for a number of years and had had time to adjust to the condition, we wondered if they might be able to suggest how "other people who have had a stroke more recently" might, for example, deal with using the Wiimote. The Wiimote was there to aid recall. We asked, 'When you first had your stroke, would you have found using this remote easy? Or would you have found using this remote hard?' using the five point rating scale showing a thumbs-up at one end and a thumbs-down at the other. Sarah was able to communicate that she was not able to think about other people. The other consultants were unable to answer at all. We dropped this type of enquiry from subsequent sessions.

It is worth noting that the inability to respond to such a speculative question is by no means universal in aphasia

and might not be due to the problems with abstractness. Studies have shown that at least some people with aphasia can perform 'theory of mind' tasks, which require speculation about the mind sets of others (Varley et al, 2001). It is possible that the consultants' reactions stemmed more from an awareness of the individual variation in aphasia, making them reluctant to judge the reactions and responses of others with the condition.

Difficulties with numbers

Other than as a part of a pictorial rating scale, we did not require the consultants to use numbers in any of the sessions but difficulties with numbers (dyscalculia) can also result as a consequence of stroke (Capelletti & Cipolotti, 2010).

Difficulties with information retention and retrieval

We encountered many different examples of memory problems. These impacted on both the activities of the workshops and their organisation.

Impaired word retrieval is almost universal in aphasia (Martin 2011). For example, Tanya had problems with people's names. This is not unusual, proper names being a particularly vulnerable category following brain injury (e.g. Saetti et al, 1999; Robson et al, 2004). Perhaps more unusually, she showed difficulty even with the comprehension and recognition of these names. We distributed name badges for everyone attending the workshop at the start of each and every session. When on a couple of occasions, reference was made to someone who was not there, Tanya said, 'Who's that?' She would remember when shown a picture.

Martin struggled to recall words. He spent a long time, going, 'Oh, Oh,' as if the word was on the tip of his tongue. Sometimes, he would ultimately find it. Other times, he would draw something or gesticulate. He struggled to recall the name of one of his children when talking about his family in the introductory session.

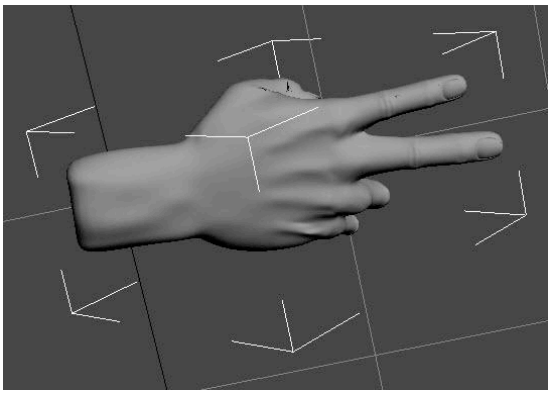

Figure 1: Scissors gesture

Recall of words was not the only problem faced by the consultants. Some also found it difficult to recall the taught gestures. Tom needed regular reminders how to make 'scissors' for example (Figure 1), which he initially made using his thumb and finger until it was pointed out that he should be using two fingers. Later, he forgot again. Ann sometimes forgot what to gesture when the picture of it had disappeared. These problems may stem from impairments to working memory, which frequently accompany aphasia (Harris Wright and Shisler, 2005). There were also two occasions when Tom forgot about workshops and rearrangements had to be made.

Difficulties with chains of reasoning

There is good evidence that people with aphasia are very sensitive to task demands, possibly because of concomitant problems with attention (Murray, 2002) or executive function (Purdy, 2002). Chains of reasoning present a huge cognitive challenge. For example, the round-table games generally involved a set of pictures on cards. These pictures represented the gestures for the day. In one game, Abi selected a card but kept the picture hidden from everyone else. She said the name of the object and everyone else made the appropriate gesture. Once this had happened with Abi selecting the cards, she would pass the cards over for someone else to 'take the lead'. A variation of this game involved selecting two cards together. Tanya, who was the most able to copy and remember gestures, interestingly, found it hard to take the lead and decide which card to show. This became noticeably much harder for her when she needed to select a pair of cards at one time.

In a session comparing the Wiimote as a means of making a gesture versus doing so with a gloved hand in front of a webcam, the latter method was much easier because it did not require actions to be performed simultaneously or in sequence. In contrast, the Wiimote required the making of the gesture with the Wiimote whilst simultaneously holding down a button. The button then needed to be released when the gesture was finished. Most of the consultants did manage to do this but needed reminders to press or to release the button. Tom needed reminding not to press any other buttons.

Distractions

People who have aphasia often present with attention deficits (Murray, 1999). We tried very hard to keep distractions to a minimum during the workshop sessions, such as avoiding having other conversations going on in the same room, or too much happening on the computer screen. The confusion caused by 'busy' screens was evident in the first session when we played WiiSports. Tom and Sarah were quite good at the tennis game and played against each other by taking turns with the single person game. Seeing how well they were doing, we tried the two-person game in which the court was represented using a split screen. Both demonstrated some difficulty in continuing with the task – we inferred that the complexity of the screen may have impaired their performance.

After we had introduced the 3D world into our prototypes, we noticed that Tanya and Sarah were able to respond very obviously and positively to the computer world they were in. Tanya commented on features, saying for example, "[I] like that" whilst pointing at 3D models of tables and chairs outside a cafe. Both she and Sarah stated preferences. For example, "[I] like [the] beach.' The other three consultants did not comment on the worlds until asked about them. We postulated that because Sarah and Tanya were more able at the gesturing tasks, they had greater cognitive capacity available to notice other things.

One design idea we implemented was to include on the screen a picture of a gloved hand in the correct configuration for the particular gesture being practised. Martin and Tom appeared to find this useful. Tanya, on the other hand, found it a distraction. "I don't like that one" (pointing to the shape in the corner) "but that one" (turning to Abi) "with your voice" (pointing at her mouth) "understanding the meaning, the telephone and then" (indicating the gesture for telephone). She was saying that she liked the video and the picture. Then she said, "but I prefer this" (as she puts on the glove) "you can see it." (She was referring to the image of her own hand). The shape in the corner: "don't do anything. It's stuck on it." Her comment was that the shape was static. Abi asked if she wanted it to move. But she indicated that she did not want too many bits of information at a time. Tanya repeated that she wanted Abi speaking, and then the gloved hand to appear.

Physical difficulties

It is common after stroke for the limbs on one side of the body to be weaker than the other (Bonita and Beaglehole, 1988). As said above, two of the consultants were unable to use their right arms and also had limited use of their right legs when walking. The others could use both hands, but their left hands were stronger. In addition, it is common for patients to have one sided visual field deficits after a stroke (Sterzi et al, 1993). This was the case for Tanya.

To cater for potential physical difficulties, we ensured that the workshops were held in rooms which were only a short distance from the lift. Consultants were also provided with swipe cards enabling independent access to the university building.

Personality and Emotional issues

Another challenging aspect of the workshop sessions was the different personalities of the consultants and their ability (or otherwise) to deal with the frustrations of not being able to communicate, or not fully understanding what was happening or was required of them. Disinhibition and other emotional changes are commonly observed following stroke, particularly when the frontal lobe is affected. There may also be an increase in the use of emotionally laden language, such as swearing (Gainotti 2003). Tom in particular, demonstrated this. For example, when working with one of the prototypes, he quickly picked up that he could press a button to move on but he did not understand that he needed to wait until the video was finished before he could gesture. This made him sigh and sometimes swear. He had the same response when gestures that he found difficult were not recognised by the gesture recogniser. However, his mood could also swing quite suddenly. So, he might be smiling and happy again barely moments after scowling angrily.

One personality "quirk" of Tom's that we never got to the bottom of was his refusal to respond when presented with a printed rating scale. The others were quite happy to use these as indicators of how much they liked or disliked certain features, or if a certain aspect was easy or hard. We never found out what Tom's objections were.

In general, Tanya and Tom were outgoing characters. Sarah, Ann and Martin were much more reserved and, certainly in the early days, would wait to be communicated with rather than volunteering information. Martin however, was very quietly persistent, doggedly trying alternative means of getting whatever he wanted to say across, whether by drawing on paper, or by gesticulating and pointing.

Practicalities

Many of the practicalities of organising and running PD workshop sessions are harder with people who have had strokes and people with aphasia. Arranging sessions over the phone can be difficult; largely we tried to make arrangements for the next session at the end of the previous session. Abi would write the dates and times down in the consultants' diaries. Illness was another factor. Some of the consultants went on a lot of holidays. Absence had to be worked around. They also needed help from Abi to negotiate interactions with Human Resources (HR) and to fill in their time sheets.

Representativeness

Each individual's aphasia is different, not only in its severity but also in terms of the different language modalities that are impaired (Goodglass et al, 2001). Depending on the site of the lesion in the brain, there can be other co-morbid problems, such as right visual field deficits or hemiparesis affecting the functioning of the right arm and leg.

This raises the issue of how representative the consultants were of potential users of the therapy tool. Of course, this is a general issue confronting PD and user-centred design. According to Muller et al (2001), there are alternative approaches to the problem which include statistical approaches such as considering an 'average' user or a stratified sample. Alternatively, as we have seen in other work, a 'persona' can be developed i.e. a fictitious but representative user, even an 'extreme' version, to fully challenge assumptions and expectations. In general however, PD approaches employ representative users and ideally in sufficient numbers to reflect the multiple perspectives of the different user types.

Involving people with aphasia in the numbers required to cover all manifestations of aphasia would be impossible. Finding even a few people who not only satisfy the requisite selection constraints but who are willing and able to commit significant amounts of time is very difficult. Offering payment is an inducement, not only in terms of the money but for the positive self-esteem effects of being in employment. However, many people with aphasia and other cognitive impairments are unable to work full time and claim benefits, so offering part-time payments can be just another problem for them to solve, and one that requires sophisticated communication skills.

Time is another limiting factor to the number of participatory users. People with aphasia inevitably require a lot of time; even making arrangements can be a difficult and lengthy process. For those without carers, it is often not as simple as making a quick phone call or sending an email. The sessions themselves also need sufficient time -

for conveying instructions and what are often, numerous communication attempts.

Then there is a limit to the number of people that can be included in a workshop session. People with aphasia are easily distracted by other people talking or other activities in the same room. Our sessions needed to be very focussed on the two, or an absolute maximum of three individuals, and with only a few specific goals for each session. This inevitably limited the number of consultants we could employ.

PARTICIPATORY WORKSHOPS: REFLECTIONS

At the heart of participatory design approaches is a commitment to the participation of the people who will be affected by the new technology. Originally employed in work-settings, the field has diversified not only to include non-work settings and the design of technologies that are increasingly becoming embedded within peoples' everyday lives, but also to accommodate a variety of approaches and views (Bodker and Pekkpla, 2010). One issue about which there is still some debate concerns the extent of the users' role (Winters and Mor, 2008) and the importance of mutual learning between designers and end-users (Beguin, 2003). Our approach has taken the perspective that mutual learning is essential when designing for users with cognitive impairments, a view endorsed by the participatory approach of Wu et al (2004) in their work on designing a memory aid for people with amnesia.

Tapping into the expertise that the consultants had about their own aphasia, and reflecting on our own experiences, led us to adapt our PD method to accommodate the challenges described above. Many of the workshop activities were grounded in concrete, hands-on activities. We used both paper-based and computer-based game-playing, and a succession of iterative prototypes, each including elements of a 3D game environment comprising a simple story. These high-fidelity prototypes took the place of low-fidelity prototypes, because people with aphasia find abstraction difficult. We made use of observations as well as creative and flexible means of communication involving paper and cards, gestures and symbols, such as the thumb-up or thumb-down. The observations and video recordings of all workshop activities supported later review and reflection, and were a mechanism for the consultants to contribute to the design activities, in part replacing the oral and written contributions that other PD techniques elicit from participants. We allowed lots and lots of time, holding twenty workshop sessions over a period of ten months. But most importantly, we rejected the notion of proxies or personas. Over the period of twenty weeks, Tom, Sarah, Tanya, Ann and Martin were empowered to "speak" for themselves. They were genuinely representative of the target user population and their diversity was one of their strengths.

EMPOWERMENT: BROADER IMPACTS

We have described the approach we used to facilitate the participation of people with aphasia in design. This successfully enabled the participation of five people with impaired language skills in shaping the design of a gesture therapy tool for other people with aphasia. However, the impact of participation extends beyond the production of technology: in particular, it has ramifications for the participants themselves. We wanted to know if there were any additional effects, benefits or drawbacks, for the participants themselves. How did the ten-month experience affect the five consultants and three researchers involved in the workshops?

The Consultants

The experience of each consultant was explored in an individual debriefing interview with an S&L researcher (a different individual to the S&L researcher who had been involved in the workshops). Again, the sessions were videoed and techniques of rating scales using thumbs-up or thumbs-down symbols or a range of smiley to glum faces were used to facilitate contributions. The following discussion draws on these interviews and our own observations over the 10 month workshop period.

Importantly, all the consultants agreed that they were listened to and that their opinions were taken into account.

The improvement in *Martin*'s confidence over the period of the participatory workshops had been evident; he contributed more and looked happier. In his interview, he was asked if his confidence had improved. He nodded. Then he stood up and pointed to each of the three windows in the room, saying, 'There, and there, and there.' He was confirming that he was more confident in the outside world. He agreed he would be happy to take part in another project and would recommend others with aphasia to do so too.

Ann indicated that she had enjoyed the sessions, particularly the gesturing and games. She felt her naming had improved a little; everything else – gesturing, confidence with computers was the same. She would take part in another project.

Tom said that coming to the University was good and he felt his naming and confidence had improved. However, he was negative about the gesturing and about the computer. He would not recommend anyone else take part in such a project, yet he would take part again himself. It should be noted that his emotional state during the interview was negative and this may have affected his responses. He has since returned to the University to attend a talk where GeST was being demonstrated, and appeared happy, interested and positive.

Sarah said her gesturing had improved. She had only used letters and numbers before the project. She found working with those consultants less able to communicate a bit frustrating but overall she enjoyed the experience and would participate in something similar again. She would also recommend others to do so. She liked helping people with aphasia and meeting others who have had a stroke (and having tea and biscuits).

Tanya used the rating scale to report that her confidence had increased - she now rated it as 1 on the 5-point scale whereas it had previously been at 2. We felt that she was proud of her contribution to the project, particularly her starring role in a number of video clips that were

incorporated into the therapy tool. Tanya liked the small sessions with 2 people. She liked having to practise speaking but with a speech therapist present who understood about aphasia. She would take part in another project if asked.

The Researchers

Debriefing interviews with the researchers revealed a number of interesting positive effects, as well as highlighting aspects of the participatory workshops that could be improved in the future. The S&L researcher felt she gained most from a change of perspective. This was a shift from the perspective of a clinician/patient relationship in which S&L therapy traditionally takes place, to a perspective where the consultants were her colleagues. "It helped me challenge some of my preconceptions about my role as facilitator in place of 'fixer'!" The HCI researcher said she had learned patience and flexibility: "Sometimes it just took time and it was important to sit quietly and wait."

The researchers found the participatory workshops tiring, "...but mostly uplifting, life-affirming." They all agreed that carrying the sessions out over a long period of time and developing relationships between consultants and other team members benefitted the flow and effectiveness of the sessions. The method itself also benefited from reflection. "The structure at the end was definitely a lot easier to manage than the methods employed at the start."

Suggestions for improvements mostly centred around practicalities. For example, the S&L researcher suggested that a possible improvement might have been having two rooms for parallel activities. "In the early sessions there were quite often two events carrying on simultaneously which made communication and session management difficult. Later sessions were improved by managing these situations so there was less overlap." One aspect of this management was the tea break; all agreed that this worked well.

Another area for potential improvement concerned the interviews. "It would be really good if we could establish an anonymous way of users giving feedback but I feel this is probably not practically possible given the amount of interaction needed to ascertain consultants' opinions with any certainty."

Another suggestion was about the arrangement of sessions. "I put quite a lot of effort into organising appointments with the consultants. e.g. phone calls, letters, diary checks etc. There were still some occasions where participants were late to attend or forgot the appointment altogether. On reflection, we may have benefitted from arranging sessions to fall on the same day and same time every other week so that consultants could fall back on routine." However, the consistent location, lift access, and giving the consultants swipe cards for access to the building as members of staff, were all seen as very positive.

CONCLUSIONS

We have reported a case study in which we confronted the challenge of empowering participants in the design of technology when they did not have access to the language skills integral to many design methods. The technology and all participants derived benefit from the involvement of representative users rather than proxies.

A language disorder such as aphasia need not be a barrier to participating in design. In fact, given the paucity of information regarding effective technology design for people with aphasia and other cognitive impairments, there is a greater imperative here to enable participation. As a community, we need to embrace this challenge and consider carefully how to facilitate effective participation. This requires setting aside some established design methods. The design of GeST certainly caused us to rethink how we enable people to contribute and, recognising that not everyone could contribute in the same way, to be flexible and responsive in the methods we adopted. The roles of participants (consultants and researchers) were undoubtedly more differentiated than we might expect in other design settings and the contributions made by the consultants were certainly not the same as might have been made by people who did not have aphasia.

The insights that we gained related both to the specific activities in the participatory workshops and to the overall organisation of the design process. As regards the former, there was significant value in asking the consultants to engage in hands-on activities, observing what they did, and grounding discussion in the activities. In terms of the process, we found considerable benefit in carrying out the participatory workshops over an extended period of time thus enabling valuable relationships to develop between all participants; in continually reflecting on the process and allowing it to evolve; in taking time in the participatory workshops, limiting the number of participants, limiting distractions; and in ensuring as much consistency in as many of the different aspects of the process as possible.

Some of the challenges we faced are not unique to aphasia but can be encountered in people with other cognitive impairments. In the context of an increasing penetration of technology and an increasingly broad scope of PD practices, we hope that other design projects will embrace the message that they can and should empower participants with cognitive impairments in design.

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