Lessons Learned from Developing Cognitive Support for Communication, Entertainment, and Creativity for Older People with Dementia

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Abstract. We have developed cognitive support for people with dementia in three areas of activity: communication, entertainment and creativity. In each case the cognitive support was intended to in some way replace an effective working memory. With all three projects our findings have been a mix of expected results and surprises. We are still working out the implications of some of the surprising results. In this paper we set out some key findings from each of these projects, and the lessons learned.

Keywords: Dementia, cognitive prostheses, assistive technology, multimedia, multidisciplinary working.

1 Introduction

The increase in the numbers of people who have dementia is tied to the remarkable demographic shift which is taking place in most places in the world, with the proportion of older people in the population increasing at such a rate that the 'population pyramid' is in the process of inverting. The incidence of dementia increases from about 2% of those in their 60s to 33% or more of those in their 90s [1]. Dementia in older people involves the loss of cognitive abilities, in particular the use of working (short-term) memory. Without an operating working memory, many activities become problematic, including conversation, entertainment, and being creative. A cure for dementia still seems a considerable distance in the future. Until a way to reverse the effects of dementia can be found it is essential to maximise the quality of life of those who have the condition. The treatment of people with dementia has increasingly focused on keeping the personhood those who have dementia in the foreground, emphasising their positive capacities and looking for non-pharmacological approaches to helping them [2,3].

We have developed a number of computer-based systems to provide cognitive support for older people with dementia. Developing these systems has produced a number

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of findings, some of which were more or less expected, and a number of which were quite unexpected results.

2 A System to Support Communication

We have recently completed the development and evaluation of a computer-based communication support system which can assist older people with dementia to carry out conversations. Without an effective working memory, ordinary conversation becomes impossible. Long-term memory, however, can remain relatively well-preserved, so conversations based on reminiscence are possible, if long term memories can be prompted

Our system, called CIRCA, stimulates long term memories by providing the person with dementia and a carer with a touchscreen based hypermedia presentation of material from the past: photos, music, video clips, graphics and text, all accessible in a flexible and engaging manner. Using this system allows people with dementia to once again have a conversation on a more equal basis with relatives and carers. In evaluations the system was acceptable, and positively received by both staff and people with dementia, and people with dementia were able to take more control of the interaction than they could in reminiscence sessions run in the traditional way [4,5].

The system was developed a multidisciplinary team of software engineers, psychologists, and designers. Potential users and their families and professional carers were involved throughout the design process.

A number of design features have emerged from this work which are particularly important in systems which are to be used by people with dementia. Touchscreens are usable by this population, despite their unfamiliarity, whereas other forms of computer input would not be suitable. The interface was simple and uncluttered enough so as not to overwhelm the person with too much detail, while remaining interesting and engaging. Aesthetic considerations in the interface design were very important, in order to achieve engagement from a group with whom this can be problematic. If there is a rich enough selection of media items, we have found that long-term memories can be stimulated which are new to relatives and carers, and which might have remained unavailable without the prompting of a system such as this.

Some of the lessons learned from this project:

1. The importance of multidisciplinary working

It took equal contributions from all three disciplines: software engineering, psychology, and design to make this project a success. It was also important that such a disparate team worked cohesively. One practice that strengthened this was that contributions about all aspects of the project were welcomed from all members of the team, regardless of their home discipline. Given this approach, all team members learned a great deal throughout the project about the other aspects of the problem we were working on.

2. The key effect of aesthetics in interface design

We knew from the start that it would be important to engage and hold the attention of people with dementia, and the aesthetic aspect of he design was an important contributor to this. In addition the motivation to take part from the carers was

increased by the feeling that a great deal of thought and expertise had obviously gone into the interface they worked with.

3. The discovery that there was no need for personal material to trigger personal recollections

We had originally intended to create both a generic and personalised versions of CIRCA, but we found that the general version did an excellent job of eliciting personal recollections. In fact recounting personal recollections was all that the person with dementia could do. Also, we found that if the material was varied and rich enough, memories were triggered which none of the carers or relatives had heard before, which was a surprising and welcome bonus.

3 An Interactive Entertainment System

Finding ways to engage people with dementia in stimulating but safe activities on their own would be beneficial both to them and to their caregivers. The CIRCA project demonstrated that a simple but carefully designed computer-based touch screen interface can capture and hold the attention of people with dementia who are normally difficult to engage. With CIRCA, people with dementia used the system together with a caregiver to provide a shared activity. We are now developing a similar hypermedia system to be used alone by a person with dementia without caregiver assistance. The system is intended to focus on the 'living in the moment' state of people with dementia and make the most of their preserved skills. At the same time, the system will compensate for diminished abilities, such as working memory. We have piloted a number of virtual environments and activities and reported the results of this work [6,7].

Evaluation of three initial virtual reality environments by a group of dementia care professionals and a group of people with a diagnosis of dementia was positive and provided useful feedback for the initial development of the project. Of particular interest were the comments relating to the engaging properties of the stimuli. The dementia care professionals directly commented on the way the system captured attention and provided an engaging experience. These observations were further supported by the comments of the users with a diagnosis of dementia, who were able to imagine themselves in the environments, for example sitting on a bench in the botanic garden or having a pint of beer in the pub environment.

We then developed a wide range of virtual activities to try out with potential users. These included:

- 1. Short video clip presentations of activities, e.g. playing with a dog
- 2. Exploring environments, e.g. the Botanical Gardens
- 3. Creative activities, e.g. painting a virtual pot
- 4. Sport activities, e.g. bowling
- 5. Fair ground activities, e.g. coconut shy
- 6. Amusement arcade type games, e.g. pinball

We experimented with prompting methods, including spoken prompts with synthetic speech and real speech and text boxes.

Some of the lessons learned from this project :

1. Engagement is achieved through interactivity and not just passive appreciation We had expected that some very beautiful and interesting virtual environments to explore would have been positively received. As a group activity and as a demo carried out by a researcher, these worked, but as a single unsupported activity, the users soon lost the thread of what they were supposed to be doing. Just 'having a look around' did not have enough structure to keep them engaged. On the other hand we were surprised at the impact that some very simple games had, as long as they required constant interaction. In this way the interaction itself acted as a kind of prompt.

2. Minimal prompting was needed

We planned to provide a range of prompts, from simple text boxes and voice prompts to having an avatar on the screen to guide the user. We discovered that spoken prompts and text boxes worked very well, and there was no need for the possible intrusive presence of an avatar. One unresolved issue was how best to deploy the text boxes, in particular how long to wait with the user not doing anything before prompting them. This will need further experimentation.

3. Having a 'mastery' aspect to activities was helpful even for people with working memory problems

This is one finding that was quite puzzling, and which definitely merits more investigation. We found that users would stick at a task that required mastery (e.g. the coconut shy game), trying very hard, and succeeding, in getting better at it, over a surprisingly long period of time (20 minutes or so). This seemed to require a degree of working memory usage that was surprising, given their condition. We speculate that the game may be helping them in some way to access procedural memory, which can be more persistent. But this requires a closer look.

4 System to Promote Creativity

Supporting communication and entertainment for people with dementia has involved considerable challenges. An even more ambitious aim would be to help people with dementia to be creative. We have begun to explore this possibility, beginning with a system to support the creation of original music.

It has been known for some time that music can be experienced and enjoyed by people with dementia, and recent research suggests this is evident even in the latter stages of the condition [8]. However, without a specialist music therapist present musical activities provided by caregivers tend to be passive, i.e. listening to music or to others singing. Where music therapists are available to provide active music making sessions for people with dementia, therapists often opt for simple percussion instruments for basic rhythm making [9]. This is because the use of traditional musical instruments for this group would be impractical: the symptoms of the condition make it difficult to learn to play such an instrument, and playing musical instruments successfully requires considerable prior training. Thus, although there are recognised

benefits associated with the provision of musical activities, caregivers lack resources for them to support active music making sessions for people with dementia.

This project explored developing a system that could enable people with dementia to be creative with music-making, whether their skills were pre-existing or not. The system was intended to provide an engaging and enjoyable activity for those participating, with the added potential to increase social interactions if used in pairs or groups.

We have now developed a touchscreen based system called ExpressPlay that addresses the following requirements:

- Is easy and intuitive to use
- Plays music instantly, i.e. providing one-touch feedback
- Allows users to express themselves creatively
- Can be used on a one-to-one basis with a carer, or alone
- Does not require a prior knowledge of music

Music making is a pastime generally limited to people who have mastered playing an instrument. However, it is possible to use chords as a means of playing pleasant-sounding music regardless of prior musical knowledge. A chord is a set of three or more notes that are played simultaneously, and are usually the first, third and fifth notes taken from a musical scale. Any chord can follow another and usually sound reasonable. In Western culture we use chords that are split into two categories – major and minor - and this is an important way of giving an emotional effect to any music. Major chords are generally used to portray a happy, active mood, and minor chords, a melancholy or sad mood. This portrayal of emotion is recognisable within the culture regardless of musical training. Given the above, it would seem plausible that the system could be developed for people with dementia to not only do creative music making, but also as a way for them to express emotion.

We therefore decided to develop an initial system that could allow people with dementia to play music specific to three moods (happy, contemplative and angry). The design has an uncomplicated navigation system with a simple interface. Music is produced by the user dragging their finger around the touchscreen. Choices are kept to a minimum in order that users not become confused. Visual feedback is provided instantly during music play to help individuals with severe short-term memory loss to remain engaged while using the system [10].

Some of the lessons learned from this project:

- 1. Engagement was achieved to a high degree
 - Users engaged for long periods of time with the system, whether the output they were creating was simple or complex. We were intrigued in particular to see users who were in fact producing very simple, minimal patterns locked in concentration for extended periods.
- 2. The system facilitated very individualized expression
 We logged the usage of the system and tracked all the finger movements on the touchscreen. The patterns of movement around the screen varied considerably from person to person, leaving a visual record that each person had an identifiable 'signature style' in expression.

Next we need to try other sound outputs to create more 'failure free' aesthetically pleasing results

The initial prototype had three different sound themes, which we intended to roughly suggest happy, contemplative, and angry moods. The 'angry tool' consisted of discords, and while a number of users enjoyed banging these out, most did not like it. Having established that we can achieve engagement and individual expression, we would like to experiment further to find ways that the system could always be relied on to produce aesthetically pleasing output as well.

5 Conclusions

Our work to provide cognitive support for people with dementia has thus far covered three areas of activity: communication, entertainment and creativity. In each case the cognitive support was intended to in some way replace an effective working memory. In the communication system, the system took over the executive function of guiding the user towards their relatively intact long-term memories. With the entertainment and creativity systems, the system supplied a visual and auditory scaffolding to prompt the user through the activity. We have focused on activities which relate to the social and expressive aspects of life, and hope this work can complement research into ways of supporting daily routines, in order to achieve a better quality of life for people with dementia, and their carers. The work is still in a relatively new area, and the findings so far have been a mixture of expected results and surprises, as is the nature of exploratory research. We plan to take all these projects further, and to follow up what seem to be the successful pathways towards supporting people with dementia and their carers in enjoying themselves, in addition to carrying out daily tasks.

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