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Title of submission: Designing a Multimedia Conversation Aid for Reminiscence Therapy in Dementia Care Environments

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Designing a Multimedia Conversation Aid for Reminiscence Therapy in Dementia Care Environments

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Abstract

As world populations grow older the incidence of Alzheimer's disease (AD) and other dementia related illnesses increases (approximately 18million sufferers worldwide). One particularly devastating effect of AD is the loss of short-term memory, which radically impairs the sufferer's ability to communicate. People with dementia, however, often retain a facility for long-term memory that can function strongly given appropriate stimulation.

Project CIRCA (Computer Interactive Reminiscence and Conversation Aid), utilizes interactive multimedia (including audio, video, animation and QuickTime VR environments) to stimulate long-term memory to prompt verbal and non-verbal communication. We will demonstrate how — through good design practice, interdisciplinary collaboration and a user-centred approach to design — we can invest reminiscence therapy with technology-led solutions to assist our participating test groups (30+ people with dementia and 40 carers) in conversational settings. We will demonstrate how this adaptable, expansive, immediate and engaging tool can contribute significantly to 'quality of life' in dementia care environments.

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Keywords

Animation, Benefit Analysis, Cognitive Psychology, Concept Design, Content Strategy & Creation, Graphic Design, Interaction Design, Multidisciplinary Design / Interdisciplinary Design, Participatory Design, User Experience, User Interface Design, User Research, User-Centered Design / Human-Centered Design, Visual Design, Visual Systems.

Industry/category

Healthcare, Dementia Care Therapy

The Problem

As human beings we pride ourselves, indeed we judge ourselves, and each other, on the power of our cognitive abilities and our communication skills. Through verbal and non-verbal communication we describe our individual personalities to the world, and the world at large depends on this social intercourse to understand us.

People with Alzheimer's Disease (AD) and other forms of dementia face the progressive, incurable degeneration of their cognitive powers and commonly experience a gradual and cumulative loss of short-term memory function. People with AD lose the ability to store new memories, this impacts very directly upon their ability to participate in, and contribute to, a normal conversation. A fundamental problem for people with dementia - and subsequently their carers and relatives - is the 'dehumanizing' effect engendered by this cognitive impairment.

It has been noted that cognitive under-functioning is commonplace in dementia and is often related to the 'devaluing, invalidating and dehumanizing aspects of

the social environment' (Kitwood, 1990 in Woods, 1994) [8]. It appears evident that this process can begin to effect people very quickly following diagnosis: *'You are not the confident, competent person you once were . . . Knowledgeable professionals begin to bypass you and give pertinent information and eye contact to your caregiver'* (Patient diagnosed with 'Mild Cognitive Impairment, Cummings in Kolata, 2002) [3].

Despite experiencing degeneration of short-term memory function, people with dementia (including individuals who are severely impaired) can very often retain a facility for long term memory that will function strongly given appropriate stimulation. 'Reminiscence Therapy/Intervention' is a proven means of stimulating long-term memory to prompt communication in people with AD and other forms of dementia. Current practice often relies upon physical props, e.g. old photo-albums, memorabilia, audio tapes/CDs, videos etc. Biographical painting, themed environments, music therapy, inter-cultural and inter-generational reminiscence and reminiscence theatre are just a few techniques currently being employed.

Quality of reminiscence therapy can vary enormously depending upon many variables e.g. availability of resources, location, type of care environment etc. A culture of good practice will often rely upon the inclination and goodwill of institutions or even individual care-givers. Traditional practice is time-consuming, requiring planning and organization, and elicits varying degrees of success. It can be repetitive and stressful for those involved e.g. the responsibility of stimulating conversation is often placed upon the non-impaired

persons, while people with dementia can sometimes feel as if they are being tested.

Reminiscence intervention, when observed in its most positive and successful incarnations, promotes shared positive human experience and supports people with dementia and caregivers in developing a mutually supportive caring relationship. By tapping into long-term memory to elicit communication we can come to understand that people with dementia are individuals who have life histories and personalities, they have knowledge, wisdom and humour, and all of the other finer sensibilities that combine to form the human character. Reminiscence sessions enable older people to socialise, to share *'past competencies and failures'* and encourage people to *'value their lives and achievements and to have their emotions and feelings validated by facilitators and other group members'* (Bass & Gregor, 1996; Brooker & Duce, 2000) [1]

*'What is meant by revealing the hidden humanity in dementia care?
In practice, this means we actively learn to open our thinking, our intuiting, our sensing and feeling from what we thought we knew, from what we have come to expect, from the known and the loved to the to the not-known and the unloved. We open ourselves to a different expression of our humanity. Maybe we can learn to meet the person as they are at this moment? As workers in dementia care, our hidden humanity is revealed. We gradually acquire an interest in that which is not known about a person. We become more curious, we learn to be more patient, more human.'*
(Coaten, 2002) [2]

Goal

'Multimedia is making possible much more advanced, adaptive technology for persons with disabilities. The presence of several different media, together with sophisticated input and output devices, makes it much simpler to provide viable alternative presentation and input mode through which people with disabilities can gain access to the information and entertainment applications on their computer. Concerns have been expressed that developers should make every effort to ensure that their materials are accessible to all users.'
(Tannenbaum, 1996) [7]

Our goal is to design a computer-based multimedia tool that can support reminiscence intervention by using contemporary technologies to provide an easy-start, intuitive, failure-free, uplifting and user-friendly alternative to traditional practice. By providing access to an expansive database of different media content through a touch-screen interface (designed specifically to prompt communication within our target demographic [see Figure 1]) we can provide an expansive, varied programme of activity which supports and prompts conversation and encourages good practice in dementia care.

One stated goal of CIRCA was to provide a facility to customize the system to allow users to input their own personal images e.g. family photographs or home video. This idea was commonly highlighted in meetings with various groups and appeared to be an obvious and logical approach to reminiscence intervention. One argument against personalization relates to privacy of information, e.g. would individual personal images need to be password protected in care institutions where there could be a large number of users. Equally, as

personal files grow in a database someone would then have to be responsible for the management/ house-keeping of the system e.g. removing files when residents pass on. There is one other significant consideration which supports the argument against personalization i.e. tests which we are currently engaged in point to the likelihood that a personal slant to reminiscence intervention may not be appropriate, if we wish to encourage a failure free experience. A significant number of our subjects in tests using personal photographs often fail to recognise close relatives e.g. siblings, spouses and offspring. On many occasions they will fail to recognise themselves e.g. in their wedding photographs. This can cause great emotional upset for both the person with dementia and their close relatives.

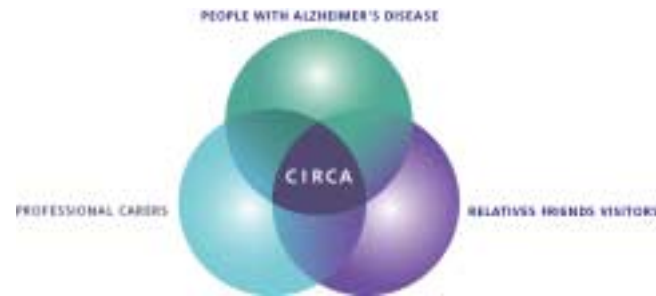


Figure 1. User Group Demographic

Team History and Context

Our plan was to approach the challenge from a multidisciplinary perspective, combining the skills of psychology (with particular emphasis on language function and dementia related research), graphic design (including interactive multimedia and interface design)

and software engineering (with research experience in design for communication difficulties in physically and cognitively impaired). It was clear from early discussions between our primary investigators, Norman Alm (Applied Computing), Arlene Astell (Psychology) and Gary Gowans (Design), that there was a keen mutual interest in pursuing collaborative work, and that there were definite areas of convergence and common interest in our individual disciplines. During preliminary meetings a number of project possibilities were discussed but one idea in particular fired the imagination of the team. The concept of an 'electronic scrapbook' to aid people with communication had been mentioned by Norman Alm as a possible avenue for investigation in very early discussions. It quickly became evident to us all that with our combination of skills and knowledge this was the ideal project to pursue.

Over a number of months we sketched out a concept for our device and formulated a bid to EPSRC (Engineering and Physical Sciences Research Council) for research funding. Our bid was successful and we were awarded funding for a three-year programme of research that runs from October 2001-04. This allowed us to expand the team to include a graphic/multimedia designer, to ensure quality of design in the look and intuitive navigation of the system; a psychologist who would be responsible for developing and maintaining links with potential user-associations and clinical professionals, for collecting and collating feedback on the system design and for carrying out formal evaluations; and a software developer with human-computer interaction expertise to design coding for the system structure and development of the authoring system. Interestingly all of the CIRCA team

researchers, including the three additions to the team have extensive professional and/or personal experience with dementia and a profound awareness of many of the problems experienced in dementia care environments.

An important feature of our proposal was the close collaboration with our prospective user-group throughout the development process. To facilitate this we made contact with various potential user-organisations to recruit a cohort of people with dementia, caregivers and families. A group of thirty caregivers and forty people with dementia volunteered their services as potential subjects for the testing and evaluation of our system. The Dundee Social Work Department and Alzheimer's Scotland Action on Dementia contribute to the project in an advisory/consultancy capacity.

Challenge

One small difficulty which we had not anticipated was the need to allay the suspicion of some individuals within care institution and to assure them that we would not be evaluating their performance or drawing comparisons with other practitioners. We also did not want to create an atmosphere wherein we were perceived as 'intruders'. It was important to create as natural and convivial an atmosphere as possible when conducting prototype tests with our participating user-groups and therefore essential for Maggie Ellis (the psychologist doing most of the 'hands-on' testing) to be seen as a familiar, friendly figure. Fortunately Maggie is an experienced voluntary helper with particular experience of assisting in dementia care and was able to offer voluntary help to some of our institutions prior to prototype testing. This arrangement was mutually

beneficial as it allowed Maggie to become familiar with residents and staff – while they could grow comfortable with her and receive the help of an enthusiastic volunteer at the same time.

First Stage Study

We started by conducting a study that examined the impact of Alzheimer's Disease on conversation and communication abilities, specifically looking at tapping into residual conversation skills using prompts. In the study twenty-one people with probable Alzheimer's Disease (pAD) were shown photographs of six different annual events. Each event was depicted by images of food, scenes or people and presented in both black & white and colour formats. The participants' level of cognitive impairment was divided into 'mild', 'moderate' and 'severe', based on their Mini Mental State Examination score. Participants were invited to discuss their memories of each event with the alternate use of 'specific' and 'general' prompts.

First Stage Findings

All six events in both black and white and colour and all image types were equally successful in eliciting recollections and exchanges. In terms of response types, more general memories and positive comments were produced when specific prompts were used as opposed to when general prompts were supplied. The moderate group produced significantly more general memories, specific memories and total output than the severe group and significantly less total output than the mild group - moreover, the moderate group employed 'conversational tactics' in an attempt to mask their conversational difficulties.

These findings suggest that even in the later stages of Alzheimer's Disease people can interact meaningfully when prompted specifically. Furthermore, output in the moderate stage is often characterised by 'cover-up' strategies, indicating both an awareness of conversational limitations and a desire to conceal them.

Design Process

Based on our knowledge of traditional reminiscence and awareness of the capabilities of interactive multimedia we began to formulate ideas for the content of our database and the design of the system.

CIRCA would need to be compact, easily transportable and easy to set-up. We decided to run the system using an Apple Macintosh 'Powerbook' laptop linked to a 20 inch touch-screen monitor, a combination which provides power and storage plus good scale and visibility. To design the system we use a combination of compatible software including, 'Macromedia Director' (interactive media authoring), 'Adobe Illustrator' (vector-based illustration), 'Adobe Photoshop' (digital imaging), Adobe Premier (video editing), InfiniD (3D wireframe modelling, animation and rendering), QuickTimeVR (3D interactive environments) and SoundEdit 16 (audio editing). This broad spectrum of software, allied to the designers' combined knowledge and expertise, allows us to exploit and explore many different media in our quest to provide engaging communication support for people with dementia.

Traditional perspectives regarding computer interface design have built up a series of do's and don'ts to formalise practice in developing intuitive navigational structures:

"Recognise Diversity - In order to recognise diversity, you, the designer, must take into account the type of user frequenting your system . . . Use the Eight Golden Rules of Interface Design: Strive for consistency; enable frequent users to use short-cuts; offer informative feedback; design dialogues to yield closure; offer error prevention and simple error handling; permit easy reversal of actions; support internal locus of control; reduce short term memory load . . . Prevent Errors . . . steps can be taken to design so that errors are less likely to occur, using methods such as organizing screens and menus functionally, designing screens to be distinctive and making it difficult for users to commit irreversible actions. Expect users to make errors, try to anticipate where they will go wrong and design with those actions in mind. (Schneiderman) [6]

Some established principles of interface design are pertinent to CIRCA; others are not. Providing short-cuts for experienced users becomes unnecessary since our user-group are not in a hurry to reach specific destinations. Preventing errors and fail-safe interaction however are crucial to our equation. Indeed, an important principal of CIRCA, which began to emerge and inform our thinking, was that we were not trying to guide people to specific locations. In essence the end-user could not get lost because wherever they were in the system was the right place to be or, perhaps more accurately, not the wrong place to be. The journey could be a non-linear, random experience and still function effectively in eliciting appropriate results. This is, we would suggest, an unusual situation in terms of traditional interface design and is informed by the specific nature of our end-users and by our particular criteria for successful engagement.

In team discussions and subsequent meetings with care managers and staff we debated possible content and the following media categories were suggested: Photographs, music, video/film, text, speech, computer generated environments and objects. In order to progress the prototype quickly we distilled this collection to three areas of media, namely, photographs, video and music.

Subject matter was also discussed and archive material would figure prominently. Highlighted amongst other themes were: public events, media/film news, local life, travel/holidays, occupations, fashions, hobbies & recreation, sport, house & home. Again this information was distilled for our initial development and was restricted to, Recreation, Entertainment and Local Life.

We then set about the task of collecting and categorizing archive material and developing initial concepts for the interface design. The database content was analyzed and a grid system was developed to structure particular information in regular and recognisable positions in order to promote continuity. We used a palette of muted pastel tones for the foundation of the interface to give contrast and strength to the photographic and video content. This palette also supports solid body text as well as 'reversals' (white text out of solid colour) that allows diversity in typographic handling and helps readability.

Consideration was also given to the duration of events - it was important to remember that we did not want to create a 'total immersion' experience and that our prime goal was to elicit memories to prompt and support reminiscence. We agreed that video should be selectively edited whereas with music it was decided

that it might be beneficial to retain whole songs as people may wish to join in.

In the music section we initially included an animated montage with some tracks e.g. with the old wartime favourite 'We'll Meet Again' by Vera Lynn a selection of period photographs were edited together in a series of transitions. Whilst this created a very aesthetic and highly enjoyable experience we felt that this encouraged people to watch the screen too intently, getting away from our intended goal of 'non-immersion' participation. We replaced the montage sequences with a selection of animated music players, drawn in 'vector-based' styling to compliment the graphic interface. These graphic illustrations of a 1930's radio, a 1950's record player (see illustration 1) and a 1960's reel-to-reel tape provide very simple movement (e.g. the record revolving), which not only signals that the system is active - 'Make it easy to evaluate the current state of the system', (Norman, 1996) [4] - but also provides an indication of where the music is coming from - an aspect which could be important with regard to orientation and perception in our cognitively impaired users. We also wrote a programme into the system to record user interaction e.g. time spent in particular subject areas or 'themes' and use of particular media.



Figure 2

We started using the prototype with our test subjects in late Spring/early Summer 2002. We used video to record these reminiscence sessions and all of the footage was transcribed to inform our findings. This was a very useful but time-consuming process and it was agreed that we should work with a combination of assessment techniques for measuring interaction e.g. coding sheets which would allow us to record specific characteristics of responses e.g. laughter, smiles, singing, talking, eye contact etc. allied to selective video analysis. A questionnaire was also developed to record and gauge the impressions of both family and professional carers with regard to the design and usability of the system.

The results from the questionnaire showed that all participants enjoyed interacting with the system and when asked could not identify anything they did not like. When care staff were asked what they particularly

liked, diversity and choice of material proved significant – it was also stated that the system got clients talking more than usual and that the interface was easy to use. When asked if there should be more text based information it was suggested this could be good for caregivers e.g. background information (see Figure 3). Issues relating to readability were raised i.e. contrast and point sizes and this would feed back into the design process.



Figure 3

Results July 2003

Following analysis and transcription of data from sessions (July 2003) we were pleased to discover that, despite designing CIRCA to be operated primarily by the non-impaired people in our user-group, many of our subjects with dementia (both male and female ranging from mildly to severely impaired) were willing

and able to interact with, and actually operate, the system themselves.

During CIRCA sessions caregivers asked less direct questions, which removed the pressure from the people with dementia to answer questions. Caregivers were empowered to offer the person with dementia more choice when selecting subjects and 'conversation routes' - subsequently people with dementia were able to make choices more often. CIRCA provides a clearly defined, easily understood framework to facilitate subject choices that are reinforced visually. This overcomes aspects of short-term memory deficit in people with dementia and is enhanced by the fact that people at varying stages of dementia can use the touch-screen themselves.

It was clear from our observations of a typical traditional one-to-one reminiscence session that responsibility was placed upon the caregiver to initiate conversation and to chain-link topics in a spontaneous way. This can often lead to a repetitive stream of conversation, often relying on familiar/safe territory, and a general feeling of artificiality (it should also be noted that the fact that the subjects were being recorded on video would no doubt contribute to this atmosphere).

Conversely, and perhaps surprisingly, CIRCA appears to promote a much more relaxed atmosphere. In a number of similarly recorded sessions many of the people with dementia - inclusive of mild, moderate and severe subjects - happily sang along with the audio tracks. This, in itself, proved successful in prompting conversation. It was also noted that the CIRCA sessions prompted a good degree of 'humorous banter' which

added to the fluidity of the experience and promoted a more natural atmosphere.

During traditional sessions, the more the person with dementia chose what to reminisce about after being offered a choice by a caregiver, the less he/she laughed. This suggests that the method of offering a choice of topics in traditional reminiscence is uncomfortable for the person with dementia. For example the carer may have offered a choice by asking, 'What do you want to talk about?' whereas during CIRCA sessions the carer might have asked, 'Would you like to choose photographs, video or music?' As our photograph study showed that the use of specific prompts providing cue words are helpful to people with dementia in producing memories, perhaps open-ended options put pressure on the person with dementia to suggest a topic. This result suggests that CIRCA provides a framework for choosing which is more easily accessible and therefore more enjoyable to the person with dementia than traditional reminiscence methods.

Perhaps the most significant outcomes were:

- (1) CIRCA prompted memories from a number of individuals that none of the caregivers had heard before.
- (2) Some people who normally react poorly to traditional reminiscence intervention were more involved and alert.
- (3) People with dementia enjoyed physically interacting with the system themselves.
- (4) CIRCA provided a more naturalistic conversation experience by removing pressure from the caregivers to continually prompt.

(5) CIRCA empowered the person with dementia to participate on a more equitable basis.

While the discovery that people with severe dementia with no experience of computers could interact with a computer system was a significant and very welcome finding, it did highlight a not-insignificant problem. When initially approaching the design challenge of providing user-friendly interaction with our system we did not consider the physical ergonomics of an interaction. We had originally anticipated that the non-cognitively impaired people (caregivers etc) in our user-groups would be the ones to physically interact with the touch-screen. They (being, usually, physically able) can manoeuvre to locate themselves into a comfortable position while operating CIRCA. It became evident, from viewing videos of early prototype testing, that when our people with dementia (often less physically able due to advanced age) inter-acted with the system, they experienced different degrees of physical effort during engagement with the screen, often due to variable seating positions and, therefore, variable proximity to the touch-screen.

To immediately alleviate part of this problem we decided to move all of our main controls for the interface to the bottom of the screen. This reduced some of the effort in reaching controls. We have subsequently secured extra funding to provide an adjustable, mobile stand to support the system that will now provide easy access and improved usability.

Recent Developments

People with dementia are often house/institution-bound and may rarely have the opportunity to experience environments and activities that they once enjoyed e.g.

a walk in the countryside or garden, a visit to an art gallery or to the pub. Recent developments of CIRCA have progressed early tests with QuickTimeVR (QTVR) to introduce interactive 360 degree environments.



Figure 4

Three computer environments have been developed (following consultation with our user-groups) and our users can now experience a 'walk' round the University Botanical Gardens by scrolling on screen (see Figure 4). 'Visitors' to the garden interact by means of 'hot-spots' which access detailed images of the flowers at a touch. Scrolling and touching other hot-spots in the environment accesses video of water features, goldfish in the lily pond and bees collecting pollen from the flowers. We also included a visit to the local Victorian Art Gallery where the paintings can be selected and viewed with some biographical information. Our third

environment differs from the others in that it was not developed using photographic techniques but created using 3D wireframe computer modeling. The modeled environment is a representation of a 1930's/40's style public bar (see Figure 5) wherein the patron can see details of the nostalgic ephemera (e.g. old beer bottles and packets of cigarettes and pub advertising), see a traditional pint of beer being poured from the pump, and view a game of dominoes being played. Early responses to our 'virtual spaces' have been very enthusiastic. The novelty aspect of the QTVR's alone seems to generate excitement across our user-group. Direct testing of this specific aspect of CIRCA is about to commence and will progress over the next few weeks (October 2003)



Figure 5

Projected Development

One successful aspect of traditional reminiscence that we always felt to be important is the generation of stimulation through the senses of touch and smell. Touching and experiencing the aroma of objects works well in reminiscence as these senses are commonly unimpaired in elderly people and have strong connections with memory function. Through our 'virtual environments' and 3D computer animations (CIRCA also contains realistic interactive 3D animations of a kettle boiling and toast being made in an electric toaster) we hope to give people with dementia something approaching a sensory experience of objects. We are also considering a means of introducing aroma (perhaps smelling cards or phials) that could be used in conjunction with some of our QTVR experiences - this might prove particularly effective, for example, in our botanical garden environment.

We know that the primary media content of CIRCA, i.e. digitized images, music and video, successfully stimulate communication in conversational settings and we are currently expanding our database to include more categories e.g. historical news events and a variety of music categories. If our QTVR's are found to generate positive results in our users, we then have unlimited scope to exploit virtual computer environments to assist people in dementia care to enjoy new and past experiences. We hope to progress the QTVR content of CIRCA to include an interactive garden. Users will be able to see plants being bedded and watered, view wildlife, perhaps see time-lapse video of plant growth and seasonal change. We are also considering the possibility of developing an interactive shopping experience. This could be designed as a contemporary or historical/reminiscence experience

e.g. with the ability to create 3D computer environments we can design interiors from any period in history, e.g. from a 1940's corner shop to a 1950's cafe.

CIRCA as a Cognitive Prosthesis

'Today's technology, especially that of the Personal Computer, is too complex. But the potential is enormous . . . They make the invisible visible, they permit play and exploration of even the most complex of topics, and they allow groups of people to interact constructively, even when separated by time or distance . . . The goal is a human-centred approach rather than today's technology-centred one. People's needs first, technology second. We need to get away from the tool – the computer – and focus on support for human activities. The computer needs to disappear from sight, to become embedded in task-specific devices.

The real impact of the converging technologies is in the combination of communication and computation that thereby impacts social interaction, access to knowledge, just-in-time learning, and enjoyment.'
(Norman D, A, 1998) [5]

The potential of computers to inform compensatory strategies against cognitive impairment has been noted since at least the early 1960's and the term 'cognitive prosthesis' has been used to describe such human/computer interaction. We believe that our studies with CIRCA demonstrate that a computer can perform as a cognitive prosthesis. In our prototype tests we have observed people with dementia interacting with a touch-screen pro-actively — participating in a dialogue with technology. When we

consider that our test subjects, who are cognitively impaired and range in age from 65-95 years of age, are being empowered to participate in conversation in a more equitable capacity through the intervention of a computer system, this, we suggest points to a very convincing argument that CIRCA can assume the role of a 'cognitive prosthesis' in dementia related healthcare.

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