A Communication Support System for Older People with Dementia

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CIRCA lets those with short-term memory loss draw on reminiscences to converse with relatives and caregivers. The system, which software engineers, psychologists, and designers developed with caregiver input, features a touch screen that displays photos, music, video, text, and other materials to help those with dementia access long-term memory.

The short-term memory loss associated with dementia makes ordinary conversation difficult and eventually impossible. However, because long-term memory is often well-preserved, those with dementia can potentially hold conversations based on reminiscence. The Computer Interactive Reminiscence and Conversation Aid presents material from the past via a touch screen to stimulate long-term memories. A multidisciplinary team of software engineers, psychologists, and designers developed CIRCA with input throughout the design process from potential users, their families, and professional caregivers.

Dementia—the loss of cognitive abilities, particularly short-term memory—usually results from Alzheimer's disease or a stroke. It primarily affects older people, with its rate of occurrence rising steeply from about one in 10 persons over age 60 to one in two over age 90.[1]

Furthermore, dementia's incidence will likely increase as our population balance shifts toward the elderly. By 2030, the number of UK residents over age 60 is expected to increase by half.[2] According to the United Nations' latest population report, by 2050, more than one-fifth of the world's population will be over age 60, up from one-tenth in 2005.[3]

There's currently no way to check or reverse the physical causes of dementia. Consequently, until preventive measures are found, designing computer systems to support people with dementia will remain a growing priority.

EFFECTS OF DEMENTIA

The effects of dementia can be quite devastating for both the person with dementia and family members, as well as pose significant challenges to professional caregivers. Since effective participation in many social activities and interactions requires short-term memory, dealing with the effects of dementia becomes increasingly difficult as the condition progresses. As a result, people with dementia can become socially isolated and deprived of the range and variety of social interactions that characterize unimpaired people's everyday lives. This can have a profound effect on the person's sense of well-being, and put severe strains on family and caregivers.

Since dementia degrades the ability to communicate, finding ways to promote communication is vitally important. Communication is such a fundamental ability that people are treated as less than human when they can no longer communicate successfully. Sadly, this dehumanization is common in the treatment of people with dementia.[4]

Caring for someone with dementia is often frustrating and upsetting. When communication fails, caregivers

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are left to infer intention and meaning from behavior alone. This can have negative consequences, such as believing incorrectly that someone is deliberately being difficult.

The breakdown in communicative abilities in dementia has an uneven pattern. Thus, the apparent loss of some communicative abilities doesn't mean a person can no longer communicate at all. Working-memory impairments can make various aspects of conversation difficult and frustrating for the conversation partner. However, activities that don't require the person to keep a conversation topic active—for instance, looking at photographs—can provide a structure for meaningful interactions.

REMINISCENCE SESSIONS

Reminiscence sessions are a useful way to structure interaction to maximize the positive contribution that people with dementia can make.[5] Although the working memory of people with dementia is impaired, their long-term memory often still functions even at the latter stages of the disease.

Traditional sessions

Guiding and supporting people with dementia to take advantage of long-term memory helps them take a more active part in conversations. While valuable, traditional reminiscence activities involve prior planning and gathering of material, which is time-consuming for busy relatives and caregivers.

Also, conducting these sessions requires a great deal of effort. Although the person with dementia can find reminiscence sessions pleasurable and empowering, caregivers might find them far from a relaxed natural interaction.

Computer-based sessions

The computer-based system we developed to help persons with dementia communicate and reminisce assumes that they might need help accessing their preserved longer-term memory. CIRCA—which a person with dementia uses with a relative or caregiver—acts as a type of cognitive prosthesis to augment the user's ability to carry on a conversation.[6]

One obvious advantage of a computer-based system over traditional materials is that it can incorporate various media into one easily accessible device. CIRCA can also potentially mimic a conversation's natural movement from topic to topic.

To accomplish this, we developed a hypermedia structure for presenting the reminiscence material. The team's earlier work on communication support systems for physically disabled nonspeakers showed that this is a useful approach to modeling the way free-flowing conversation proceeds.[7] Research in conversation analysis has established that topic change in a casual conversation occurs in a stepwise fashion, a procedure we modeled previously with a hypertext structure.[8,9]

In addition to acting as a tool, we hoped the hypermedia structure would constitute an active third party, offering help and prompts to let both parties maintain a conversation with relative ease. At the same time, we required that users view the system as a conversation support rather than as an entertainment provider.

CIRCA acts as a type of cognitive prosthesis to augment the user's ability to carry on a conversation.

SYSTEM DESIGN AND DEVELOPMENT

The development team—consisting of members with expertise in design, software development, and the psychology of dementia—took a multidisciplinary approach to designing the system. The designers gave the interface an engaging and attractive look and made navigation easy and pleasurable. The software engineers designed the system's interactional elements and multimedia database, keeping the program code and data separate to allow users to easily update and change the material presented.

The psychologists linked with potential users, their families and caregivers, and user organizations to involve them throughout the design process. As we developed the prototypes, the psychologists also designed and carried out evaluations of the prototypes' effectiveness.

Touch screen

The touch screen proved essential for this application, since working-memory problems normally preclude people with dementia from acquiring new skills, such as using a mouse. Research that we and others have conducted established that people with dementia can almost always use touch screens. The direct sense of manipulation that touch screens provide seems to offer enough affordance so even people with fairly severe dementia can use them with encouragement and appropriate prompting.[10,11]

Interface design

Several dementia specialists recommended that the interface be as simple as possible while still appearing attractive and encouraging interaction. People with dementia are often unable to cope with too many items that compel attention. In this state, the user will often focus on and stay with one item, not being able to scan easily over the other possibilities.

To cope with this, we designed the background and navigation features with muted colors, as shown in

Figures 1 and 2. In most cases, the system only displayed one item of interest at a time. In this way, even a black-and-white photograph stood out clearly, drawing the user's attention.

However, users complained that they sometimes had difficulty reading the text because of the lack of contrast in the color scheme. We experimented with making the interface more colorful, while at the same time adding some navigation aids using simple animated titles. Users liked this new interface, and its slight increase in complexity didn't cause any problems.

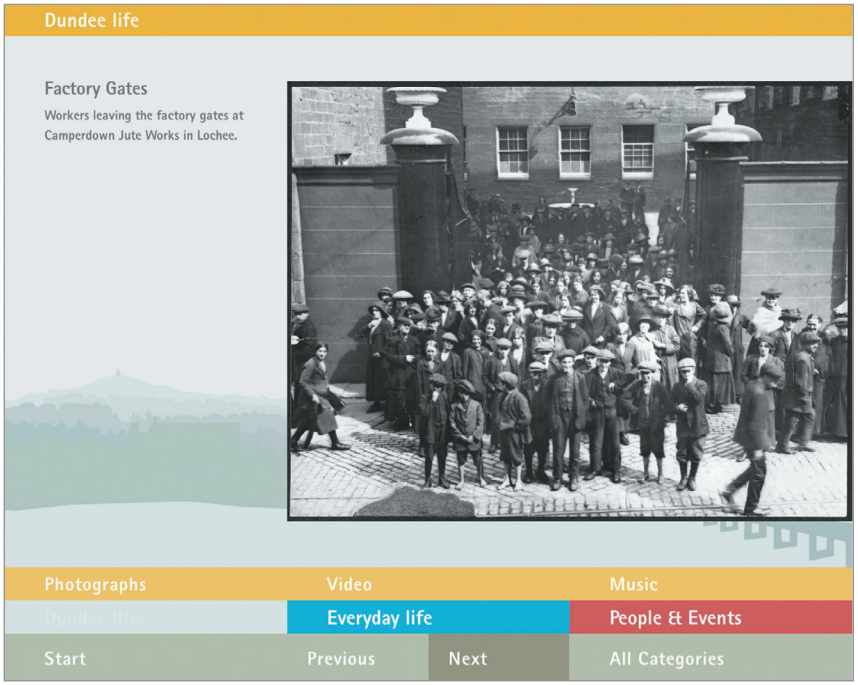

Figure 1. CIRCA interface. The interface provides a title and brief description to help the caregiver, who might not recognize what's being shown. CIRCA features three themes (the current theme label moves to the top), three media choices, and simple navigation buttons.

INITIAL PROTOTYPING WITH POTENTIAL USERS

We employed an iterative design approach to developing the first prototype. After presentations by the team to potential users and their families and caregivers, we identified 40 people with dementia who expressed an interest in helping develop and evaluate the system. In addition, 30 relatives and caregivers agreed to take part as advisors and evaluators. Working with people with dementia required careful attention to ethical aspects of this research. In addition to adhering to the required ethical approval procedures, we adopted the principle of regularly ensuring that everyone we worked with was happy to continue in any of the sessions.

Day-care demonstration

After trying to determine the most helpful multimedia aspects and presentation methods for such a reminiscence experience, we developed several prototype interfaces. Some of the interfaces attempted to represent a scrapbook-like appearance on the screen, and others simply presented the media choices as simply as possible. Representatives from the University of Dundee, the Dundee City Archives and Dundee City Library, and the Dundee Heritage Project helped collect the materials, which included text, photographs, videos, and songs from the city's past life.

We demonstrated the prototypes for staff and people with dementia at a day-care center. The evaluation sessions showed that we didn't need to duplicate the look of a paper scrapbook, since participants easily understood and used clearly and attractively presented material that didn't echo noncomputer presentation methods.

The multimedia presentation interested and motivated people with dementia, who preferred arrangement of materials by subject instead of type of media. Users could only strongly identify with videos when they triggered specific personal memories, whereas they widely appreciated photographs and music.

We didn't know how staff might react to the high-tech system invading their domain. In fact, they were keen to see the idea developed further, which isn't surprising, since participation in reminiscence activities also helps caregivers.

Theme selections

In total, the system contains 10 videos, 23 music items, and 80 photographs. To keep the navigation process simple, we stuck to three themes—recreation, entertainment, and Dundee life. Each theme is associated with a particular color scheme. When a user selects a theme, the background and button color reflect the selected theme, and the system offers the user a choice of photographs, videos, or music.

The recreation theme focuses on the UK, with an emphasis on Dundee and Scotland, and includes holidays, sports, and hobbies materials. The entertainment theme contains both US and UK music, film and TV extracts, and photos of famous entertainers. The Dundee life theme includes photos of past street scenes, videos of factories at work, and a selection of Dundee songs. Figure 1 shows a screen shot from the Dundee life photographs section.

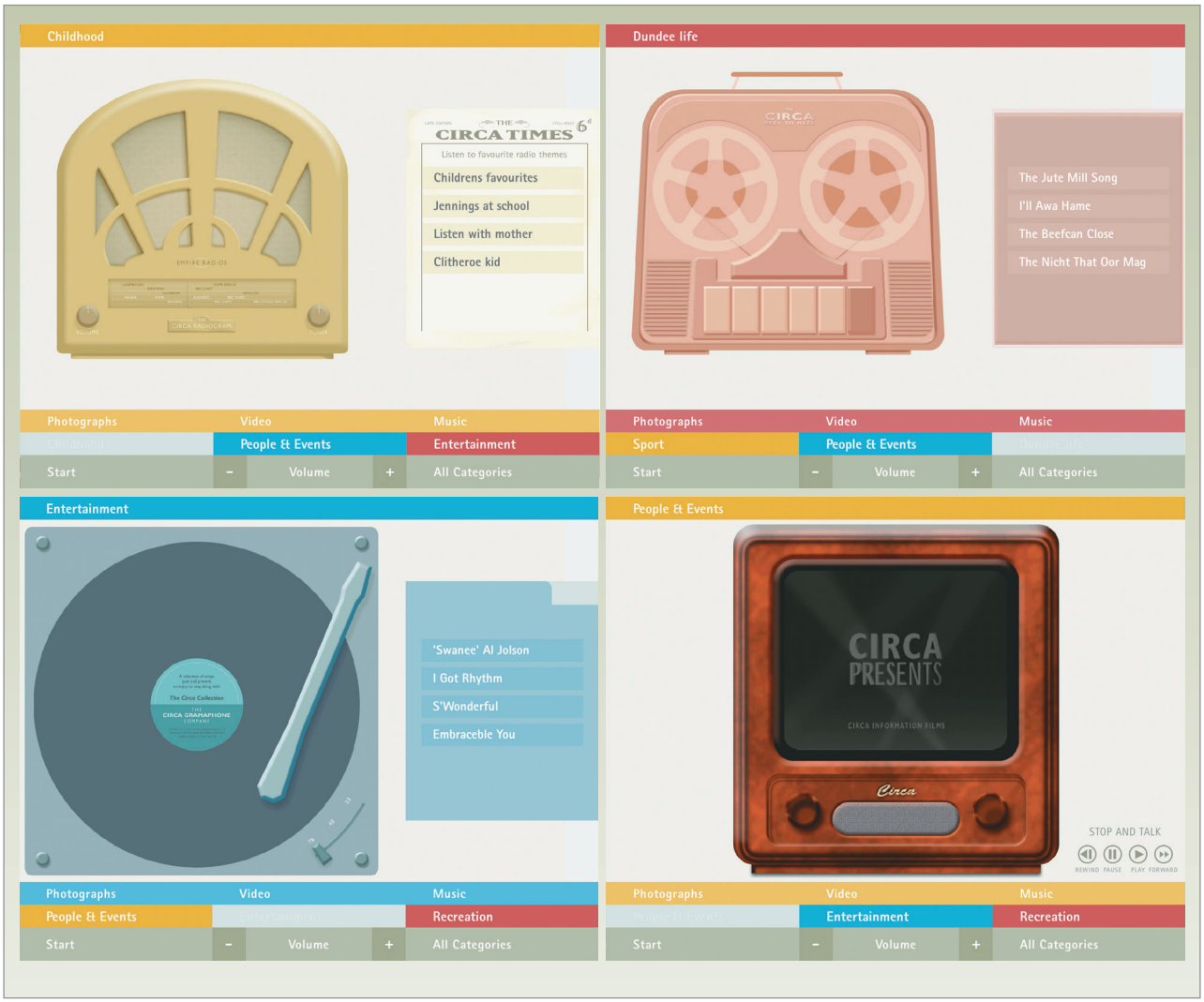

Figure 2. Device representations. Users access media through representations of the type of device that might have produced it. The record player and reel-to-reel tape recorder are animated to give the impression of working while the song is played.

Media selections

The system lets users choose and play video clips related to the selected theme. The video clips are short because working-memory problems might preclude people with dementia from being able to follow long clips. In addition, the clips are intended to act as conversation prompts and not be too immersive.

CIRCA also allows users to select and play music related to the theme. Rather than simply maintaining a static screen while music plays, the system displays an old record player, radio, reel-to-reel tape recorder, or TV set depending on which theme the user selects, as Figure 2 shows. The record player and reel-to-reel tape recorder are animated to simulate them actually producing the music. We found that the representation of these old devices could in itself act as a conversation prompt.

Both caregivers and people with dementia found CIRCA enjoyable and easy to use. People with dementia used the touch screen with encouragement, and professional caregivers thought the system got clients talking more than usual.

Our observations and their feedback gave us ideas about ways we could improve the interface. For example, the original design placed control buttons along the top of the touch screen, which led to older users quickly developing fatigue in their arms. Moving the buttons to the bottom of the screen worked much better.

COMPARISON WITH TRADITIONAL REMINISCENCE SESSIONS

Having informally evaluated the system, we set out to compare whether CIRCA offered any improvements over traditional reminiscence materials.

Caregivers appreciated the system's ease of setup and use. Because of the required preparation time, caregivers don't use traditional reminiscence sessions as often as they like. When they do use them, they

usually conduct sessions for an entire group, since it's difficult to justify the time investment for one person's benefit, given the many demands on care staff's time.

A system that can instantly produce a one-to-one reminiscence session would be a clear boon. However, we also wanted to know if CIRCA offered benefits that a traditional session couldn't provide. We thought the system could help maintain the session, and thus leave the caregiver free to interact in a more equal manner with the person with dementia.

Eighteen people with dementia (13 women and five men) from several day-care and residential facilities took part in the evaluation. We randomly assigned the participants to one of two groups—one using the prototype and the other carrying out traditional reminiscence. There was no significant difference between participants in the two groups in terms of age or degree of dementia. Participants were moderately to seriously affected.

All the caregivers reported positively on their experience with CIRCA.

We paired each of the 12 participating caregivers with a person with dementia for the study sessions. The caregivers were asked to choose their own generic materials for the traditional reminiscence sessions based on what they used in their normal course of work. We videotaped the sessions and logged items accessed using the prototype.

Observation protocol

We produced a coded transcript from the recordings and developed a protocol for observing and recording behavior during the sessions to identify the degree of participation, engagement, and enjoyment. We coded the following interaction features:

- the person with dementia choosing with and without prompt;
- the caregiver providing prompts and conversation maintenance; and
- both responding with memory, humor, laughter, or movement to music.

Some of our results were as follows: We used a between-subjects protocol (Mann Whitney test). All the caregivers reported positively on their experience with CIRCA. All the people with dementia participated fully with the system, and some remarked spontaneously that they enjoyed using it. The caregiver offered the person with dementia a choice of reminiscence subjects and materials more often when using CIRCA ($U = 1.50$, $p < 0.001$). The person with dementia chose reminiscence subjects and materials more often when prompted when using CIRCA ($U = 2.00$, $p < 0.001$).

The caregivers asked more direct questions when using traditional reminiscence methods ($U = 5.00$, $p = 0.01$). The more the caregiver offered the person with dementia a choice in reminiscence subject, the more information and memories the person with dementia shared ($r = 0.40$, $p < 0.05$).

We interviewed participants at the end of the sessions, beginning with those with dementia, followed by caregivers. We also asked caregivers to complete a questionnaire. As expected, the caregivers did most of the direct operation of the touch screen, but the person with dementia often prompted and directed them. With encouragement, several people with dementia also directly used the touch screen to make selections. Even when the caregiver was using the touch screen, it did seem that the direct and obvious cause and effect between their actions and the response of the system helped the person with dementia to remain engaged.

User comments

The participants with dementia made sense of the material the system presented and showed an understanding of how it worked. Some spontaneously commented several times that they enjoyed using CIRCA. Among the comments were: "It takes you back and refreshes your memory." "This covers everything." "Good thing, this." "It's good to remember things." and "That's entertainment."

One woman said she'd like to use CIRCA again, adding that she thoroughly enjoyed the system and found it very interesting and "something new." Another woman commented that she enjoyed using the touch screen herself.

CIRCA benefits

CIRCA offered people with dementia more choices of reminiscence subjects and materials. With CIRCA, they also chose reminiscence subjects and materials more often when prompted.

During the traditional sessions, caregivers typically asked questions that the person with dementia answered. The CIRCA sessions were more conversational, with each person contributing an equal amount and sharing control of conversational direction.

FURTHER TESTING AND ENHANCEMENT

We next left the system at a residential home for an extended period to determine how much the staff and residents would use it and how the system functioned in a real environment. All the staff liked the system, but some took a particular interest in using it with residents.

After becoming familiar with the system's contents, those staff members began steering residents toward sections they thought the residents would enjoy. This was

commendable, but worked against the system's intention of relieving the caregiver's conversational burden of responsibility and letting persons with dementia experience a more equal interaction.

The system's usage logs showed the repeated selection of one theme and one media type. This was explained when we observed the system in use and noticed caregivers characteristically reading out the choices for the person with dementia. If working-memory problems cause the person to have difficulty remembering items as they're named in a list, it will be natural to opt for the last item to be read out.

The system acts as a simple cognitive support, replacing working memory with a hypermedia display of material from the past.

Randomizing feature

Following CIRCA's long-term trial, we expanded its content and introduced a randomizing feature. The next version we wish to evaluate randomly selects three themes from a larger pool, and it does the same when setting up the various media items. In this way, the system is in a different configuration each time it's used.

We found that with a wide enough range of interesting items, the system stimulated people with dementia to recall memories no one had heard. We knew relatives could guide a person with dementia to tell a favorite story when they already knew it, but that didn't amount to a free-flowing conversation where each participant played an equal part.

On one occasion, a street-scene photograph prompted a woman in her 80s to tell a vivid, and to her, amusing story of foiling an attempted robbery at the shop where she worked at age 18. When the woman's daughter saw the videotape of this, she asked for a copy, partly because it was such a pleasure to see her mother talking so freely again, and partly because this was the first time she'd heard this story from her mother's girlhood.

Personal material

From the project's start, we wanted to include personal material in the system. We began by working with five people with dementia, each with a family caregiver. Relatives went through family photograph albums with the person with dementia. However, this led to distress, often to the point of tears.

It upset both parties that the person with dementia often couldn't remember accurately who was pictured or what the photo depicted. While many long-term memories are better preserved than working memory, the pattern is uneven and not all long-term memories are unaffected. The activity created expectations the person with dementia couldn't meet and violated a guiding principle that activities for people with dementia be *failure-free*.

This investigation highlighted the fact that CIRCA's hypermedia structure, where you're never in the wrong place, provided a failure-free environment. Because CIRCA can prompt personal memories with generic content, it doesn't need personal material to evoke personal memories.

Aesthetic usability

The system's appealing appearance seemed to invite engagement in a way that a worthy, but less aesthetically pleasing, interface might not. This relates to what some designers call the *aesthetic-usability effect*, the perception that aesthetic designs are easier to use than less-aesthetic designs.[12] This is an essential feature, since the system's aim is to engage the continued attention and involvement of people who have difficulty with such activities.

The CIRCA system represents one form of support for people with dementia. We're now working on Living in the Moment, a project that aims to produce an interactive entertainment system a person with dementia can use independently. We're also exploring ways that technology can help a person with dementia carry out satisfying creative activities. We believe technology has great potential to provide personal support for people with dementia, if it's innovatively designed and also enlists potential users in the development process.

Our system can partially restore the ability of a person with dementia to carry out a satisfying conversation with a relative, caregiver, or friend. The system acts as a simple cognitive support, replacing working memory with a hypermedia display of material from the past.

In evaluations, the system showed itself superior to traditional methods of organizing a reminiscence session. It helped the person with dementia take more control over the direction of the conversation, and relieved the caregiver of the burden of responsibility for keeping the conversation going.

To make CIRCA more widely usable, we need to feature generic materials that can still stimulate personal memories. We plan to create and test the effectiveness of a version that's suitable for the whole of Scotland. From there we'll move on to creating versions suitable for other populations. To support these developments, we're planning to produce a commercial version of CIRCA.

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