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Involving older people with dementia and their carers in designing computer based support systems – some methodological considerations

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Abstract: Older people with dementia are a particularly challenging user group to involve in the process of designing interactive systems that could assist them. It may also be difficult to involve family caregivers of people with dementia as they are most likely to be older themselves and uncertain about technology. Paid care staff, whilst younger, may be unclear about the benefits of technology and may lack confidence in their ability to incorporate it into their work. Over the past five years we have worked closely with all three groups to develop and evaluate a multimedia computer system to support communication between people with dementia and caregivers. To achieve this we have addressed a number of user involvement issues ranging from legal and ethical considerations of working with people with dementia to the reluctance of hard-pressed staff to add to their workload for a research project. However, the central problem has been conducting evaluations and eliciting the views of people who have severe working (short term) memory impairment plus additional cognitive and social difficulties. We have developed a variety of approaches to tackle these issues, which are described in this paper, including familiarizing the whole team with the unique difficulties posed by dementia, continuous confirmation of participants' consent, and ways to measure enjoyment, engagement, and joint interaction using observation.

1. The growing prevalence of dementia

One effect of the demographic shift towards an ageing population is a growing number of people with dementia. Current estimates put the numbers of people worldwide with dementia at around 25 million, but this is predicted to rise to 114 million by 2050 [41]. In the UK at least 750,000 people are currently believed to have a diagnosis of dementia [3], which in turn affects at least the same number of family members who care for their relatives at home.

The majority of people with dementia are over 65 and most likely have Alzheimer's disease, cerebrovascular disease or a combination of both [26], although there are also other less common types of dementia (e.g. fronto-temporal dementia, Lewy Body dementia). Dementia is a clinical syndrome that is diagnosed on the basis of co-occurring symptoms. The most noticeable symptom in dementia due to Alzheimer's disease is deterioration in memory such that people have problems keeping track of ongoing activities (e.g. remembering they have put the kettle on to make a cup of tea) and making new memories (e.g. birth of a grandchild). This memory impairment progressively worsens until people with dementia become confused and disoriented about the current time and place. However their recollection of memories from earlier in their lives may be relatively unaffected [36]. In addition, other aspects of functioning are gradually implicated, such as concentration, social competence and self-care, until people with dementia come to rely on other people to care for them.

These combined difficulties mean that dementia makes a person exceptionally dependent on others in a physical and also a psychological sense [25]. Thus dementia disables people practically and also affects their well being and sense of self. Interventions to assist people with dementia to maintain their independence and make the most of their relatively unaffected skills for as long as possible are therefore highly desirable. Suitably designed technology has the potential for providing such interventions and addressing the needs of people with dementia and those who care for them.

2. How technology can help

The potential of technology to provide solutions to the problems faced by older people with dementia is increasingly being recognized. Developments to date fall mainly into addressing the three areas of safety, security and social needs of people with dementia [6]. For example, the serious issue of falls in the home is being addressed with systems which can automatically detect if a fall has taken place and notify a relative or other carer that they should check in to see if there is a problem [27]. Attempts are also being made to read a variety of sensors from all over the home in order to register the normal patterns of activity, and thus be able to detect possibly worrying departures from the usual patterns (for instance by noting that the living room has not been entered that day). Such systems might be able to detect a range of potentially dangerous situations and alert carers to them [20].

A further body of work is aiming to develop 'cognitive prostheses' to augment failing cognitive abilities in a number of ways [4,23]. Applications of this work could be memory prompts, communication support, and interactive entertainment for people with dementia. Such developments require a comprehensive profile of the cognitive difficulties to be addressed plus a clear understanding of the impact these have on behaviour. In addition, all interventions in dementia care must strike a balance between doing what is perceived to be for the best and preserving the personhood of people with dementia. This presents a constant challenge to develop technology *with* people with dementia rather than just *for* them [5].

3. User centred design

User centred design developed to ensure that designers took account of the actual characteristics of their user population [19,31,33,37]. This approach is not only useful in conventional software design, but also when designing for groups with unconventional needs, where usability must be defined in terms of each specific user group . However, traditional user centred design approaches do not provide a great

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deal of insight into how to design for older people, thus presenting a challenge of how to involve them in the development process. Innovative methods such as interactive theatre and painting are being developed to provide better ways of eliciting users' requirements and wishes for emerging technology [28,40]. Technologies to make older people safer through developing responsive environments have benefitted from close attention to user involvement in the design process [14,29,30]. Work is also ongoing in making sure that web design guidelines take into account the older population [38].

Important points which have emerged from this work include :

- (1) What is important to older people is the practical application of any technology, and what specific benefits it could bring, as opposed to being interested in the technology for its own sake [29,30].
- (2) Privacy and intrusiveness are important issues. Exploring attitudes to privacy can benefit from innovate ways to elicit users' honest views [28]. A potential technical solution to the problem of intrusiveness is technology which is effectively invisible, which assists without overwhelming [1].

These are issues which need to be addressed in developing technology for the older population in general. Older people who have dementia present a range of further challenges as potential users of assistive technology. If we are to involve people with dementia in designing the systems which will help them, we need to be innovative in creating ways to ensure that we keep their views and their needs at the forefront of the process.

Particular difficulties which arise in involving people with dementia in the design process are : obtaining informed consent, determining their requirements, eliciting their views and evaluating prototype systems. In addition, there are difficulties attached to including both family caregivers and professional care staff in the development process. Specifically, family carers are very often the spouse of the person with dementia, who are likely to be of a similar age and unlikely to be confident and knowledgeable about new technology. Professional caregivers are usually younger but may have limited training about dementia and how technology

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could be of benefit. In addition, many services are hard pressed and staff may have limited motivation to make time for research.

Over the past five years we have put together a multidisciplinary team comprising psychologists, software engineers and graphic designers, to develop technology for people with dementia. During the course of our research we have had to address all of these difficulties in involving people with dementia and their carers in our research programme and we present here a summary of our experience as encouragement to others thinking of engaging in this challenging but extremely rewarding endeavour.

4. Involving people with dementia and caregivers in research

4.1 Initial involvement

The CIRCA (Computer Interactive Reminiscence and Conversation Aid) project began in 2001. Our idea was to develop a computer system that could support people with dementia to participate in satisfying and meaningful social interactions with caregivers. We envisaged CIRCA as a multimedia system presented on a touch screen that people with dementia and caregivers could sit down and use together. We planned to use reminiscence content, in order to prompt long term memories, which are often well preserved relative to the working (short-term) memory problems of people with dementia.

We partnered with two dementia care providers - Alzheimer Scotland and the local Social Work Department. At the start of the project we ran an open session for all interested parties to explain our ideas and answer questions about the research. Approximately 75 people attended this session, representing a range of groups including people with dementia, families of people with dementia and dementia care services. This session served as an early stage in determining the user requirements of the target population of CIRCA.

From this session we identified a number of important issues for developing CIRCA. First that caregivers and people with dementia were positive about being involved in research and were excited about the project. Second, that all participants

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at the meeting welcomed the attention of the project on communication as this is often overlooked in the provision of health and personal care for people with dementia. Third, concerns were expressed about the suitability of a computer for people with dementia. Many caregivers felt that as they were not ‘computer-savvy’ themselves, a computer would be no use for people with dementia. We recognized this as an important obstacle for us to tackle in developing CIRCA.

Another important contribution to identifying user requirements has been the extensive experience of people with dementia among team members. The psychologists in the team have twenty years experience of working with people with dementia, their families and staff in care services between them and another member of the team has volunteered for seven years in a dementia day care service. In addition, over the course of the project every other member of the team has spent some time in dementia care settings.

This has been especially important for the software and design members of the team to get a feel for the difficulties people with dementia face. Designers are selected for their portfolio of previous work and software engineers for the programming skills. Neither is expected to have specialist knowledge of users with specific disabilities, although they may of course have some personal experience. However, we have found that encouraging all team members to spend time in our partner organizations, either on regular visits or as volunteers, has been a critical element in developing effective technology for people with dementia. Specifically the designer and software engineer have been able to see straight away how people with dementia react to the system and how they interact with the interface. They have also gained a first hand impression of people with dementia, which cannot be gleaned from books or second hand reporting.

We have involved family caregivers in the development process by inviting them along to sessions to try out the technology and by taking it into their homes. We recruited a number of couples comprising one person with a diagnosis of dementia plus their husband or wife who agreed to try out CIRCA prototypes at home. These couples had the system at home for varying amounts of time and fed back on all aspects of the system from the interface design to the contents. Such frank and

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thorough commentary have been of the utmost importance in developing the system to meet the specific needs of people with dementia and their families.

We also recognize the needs of staff in dementia care services and have encouraged them to feed into the development process at all stages. We approached this by meeting with managers and staff groups at the start of the project to inform them about the research and collect their views of what would benefit their relationships with the people they care for. In addition, we have looked to their expertise in delivering dementia care, particularly in the use of reminiscence, for developing the contents of CIRCA. In addition, the process of close involvement of dementia care staff has highlighted the need to develop a system that is user-friendly and takes the minimum effort to learn. Staff have little time for one-to-one activities and we recognised that CIRCA should be something a novice could sit down and use straight away.

4.2 Consent

From the outset, obtaining informed consent for participation in research is clearly a difficult issue for people with dementia. We have developed a two-stage consent procedure to recruit people with dementia in line with mental capacity legislation. First letters are sent out to people with dementia and their families in the partner organisations informing them of the study and asking if they are agreeable to the study team approaching them to take part. On receipt of agreement to be approached the study is explained again to individuals with dementia and they are then asked if they would like to take part. If they are agreeable they are asked to give written consent or verbal consent witnessed by a neutral third party.

All participants are informed that they are free to leave at any time. However, given the memory difficulties of people with dementia we thought it advisable to use a method of continuous consent checking. This involves the researcher checking at regular intervals that the person with dementia is still content to carry on with the session, and to let them know regularly that they are free to call a halt whenever they wish. If the participant appears to become uncomfortable or distressed at any point,

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the researcher will end a session whether or not the person with dementia expressly requests to stop.

This action was in fact taken when we were conducting sessions to determine whether personal photographic material might be included in the system. When looking through old photographs with a family member, participants with dementia would often become agitated and upset if they failed to recognise people in some of the photographs, and the family member continued to pressure them to try to remember. At least one incident of distress occurred in each session and we discontinued this line of investigation after working with five couples

These sessions also highlighted the expectation of family members that personal reminiscence items such as family photographs or artifacts should help people with dementia to remember more. If this does not happen, then family members often make ‘personal detractors’ [24] towards the person with dementia, such as belittling them or making negative comments to a third party. Sometimes family members interpret such memory failures (e.g. not remembering a photograph of a daughter’s wedding) as personally motivated and indicative of the ‘real’ feelings their relative has for them (‘mother never loved me as much as my brother’). These reactions contributed to our decision to avoid the use of personal stimuli in CIRCA.

4.3 Developing CIRCA

Our initial prototype comprised a database containing 113 items, including photographs, video and music recordings. The contents were presented on a touch screen with material organised into three themes and into three media types. In the interface each theme was associated with a colour, and when a theme was selected, the hue of the background and of all the buttons changed to reflect the hue of the selected theme. Muted colours were used so that each media item would be the most prominent element on the screen. An example of a photograph presented by the system is shown in Figure 1. Figure 2 shows a representation of a reel to reel tape recorder which ‘plays’ the song selected with an animated movement of the reels.

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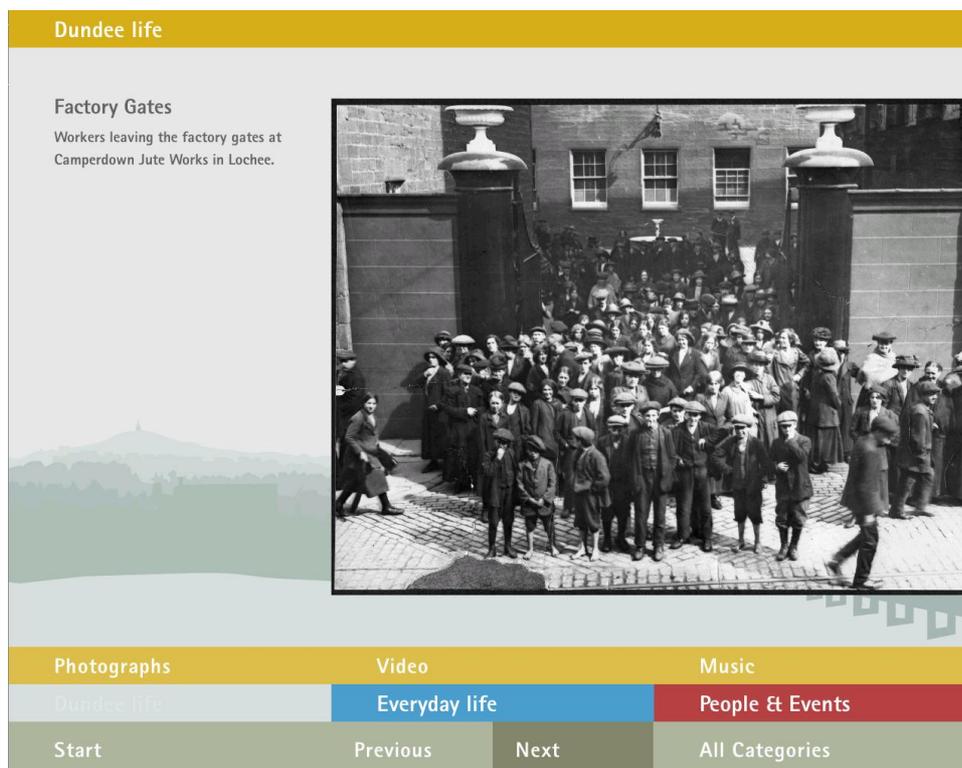


Figure 1 : Screenshot from the Photographs section of the Dundee Life theme in CIRCA. Navigation buttons are along the bottom to make them easier to reach

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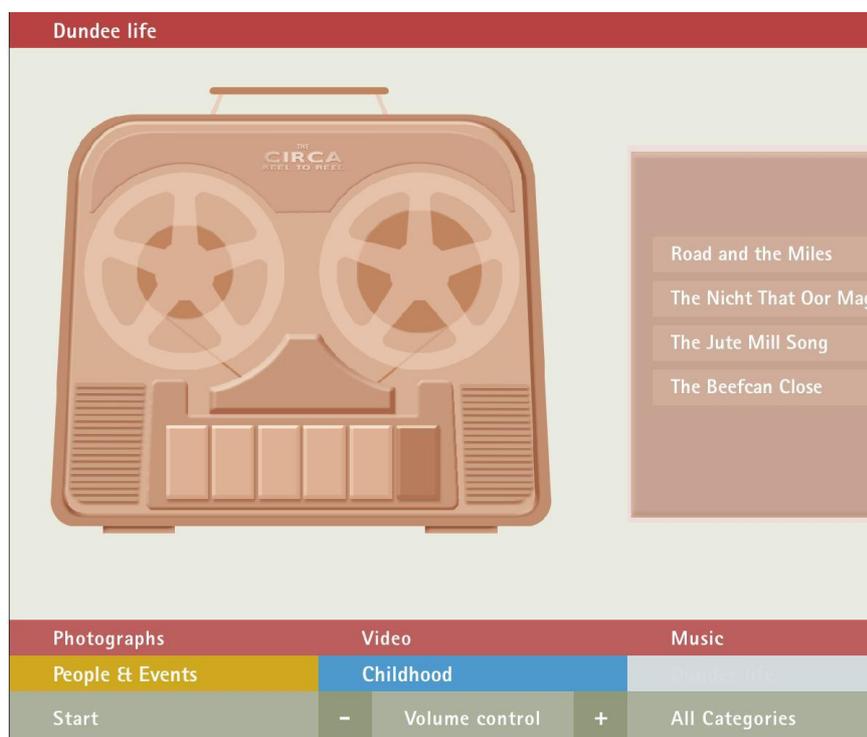


Figure 2 : Screenshot from the Music section of the Dundee Life theme. Songs are selected by touching the titles. The tape recorder is animated so the reels move realistically as the song plays.

We used an iterative design process with members of the team taking out each new development to our partner organizations and observing how people respond to it before we carried out formal evaluations. Thus we included people with dementia throughout the design process by directly sampling their responses and reactions to each iteration of the system. From this process we learnt a great deal about how to 'fine tune' the presentation of material to increase its impact. For example early on we identified that generic items can be used very successfully to prompt people to recall autobiographical memories [7]. The finding that personal items are not necessary has been very important in terms of developing the contents of CIRCA.

We also wanted to include panoramic 3D views of various environments, which the users could navigate around by touching the screen. At this point we had no idea how people with dementia would react to this unusual presentation. We took a selection of experimental interactive interfaces to a day care facility operated by one

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of our partner organisations. We were particularly interested in whether people with dementia could understand what such a display was showing them, and whether they were engaged by it and could interact with it. The environments were a garden, a museum and a pub. A screen shot from the garden environment is shown in Figure 3.

Clients at the day centre were invited to touch the screen and explore the environments. Their spontaneous comments when interacting with the touch screen and immediate reactions were recorded. This session provided very useful data on the appropriateness, appeal and navigability of the interfaces for the intended population. We found that the people with dementia who took part could indeed make sense of what they were seeing when presented with a 360 degree panorama on a flat screen. They immediately got involved in discussions about what they were seeing, and were intrigued by this form of presentation. Of the three environments the garden seemed to be the most universally popular.

One method of navigation that involved dragging a finger across the screen to move the view left or right was difficult for the people with dementia to use. They found it far easier to make use of an onscreen control with arrows to indicate the direction of travel.

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Figure 3. A 360 degree panoramic representation of a botanic garden, which the user can explore by using the touch screen to move around in the environment.. In this screen shot we have entered the greenhouse.

One incidental finding from these sessions was that this form of presentation could be a useful group activity. We demonstrated to a group and then had each member in turn come up and have a turn at navigating round the scene themselves. Our intention was to develop a system for individual use but clearly there would be potential for developing a similar presentation to be used for group enjoyment and comment [8].

Another useful finding related to the left to right order in which the selection buttons were displayed on the screen. We included a logging facility built-in to the system so we could see which items were selected and how long was spent looking at each item. From this we found that of the three themes which were presented to choose from at the start, one was much more popular than the other two. It appeared that the choice of this theme was due to it being the rightmost button and the carers

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normally read out the choices from left to right, and it was always the last choice offered. Given the working memory problems of people with dementia it was possible this was biasing their choice toward the last item on the list. This was important for informing our decision to randomize the presentation of the themes in the next version of CIRCA and as a result this effect disappeared.

Another reason for randomizing the contents arose from examining the interactions between staff and people with dementia when they were using CIRCA. We found that if the system was in use for an extended period, or if carers used it several times, they became familiar the contents and this resulted in them steering the person with dementia toward particular items. This had the effect of putting the carers in charge of using the system. However, in our initial sessions the people with dementia and caregivers had explored the contents together as equals. We concluded that an improved system would need much more material and on set-up should automatically make a random selection from a large pool of items, so that each time it was used it was a different and unpredictable experience for both partners.

One very positive finding from our work with carers was the enthusiasm with which they were willing to try out new technology. After the reservations expressed in the initial launch meeting (Section 4.1) we had expected at least a concern about feeling at a loss with new technology, and at worst a resistance to it as irrelevant and impersonal. However, the touch screen and well designed interface ensured that CIRCA could be used without any training, and caregivers responded very positively to this.

More importantly, we found that on the whole care staff felt frustrated at not being able to do a better job at communicating with people with dementia, Combined with pressures to provide a good level of safety, comfort and address everyday needs they did not have a great deal of time to try to overcome the barriers to communication with the people they worked with. All the staff who used CIRCA were very positive about it because it gave them an effortless way to communicate more meaningfully with people who they care for. One carer said of the person they were using CIRCA with : ‘After this one session I now know far more about him than I ever did in all this time. It’s great.’

5. Devising objectives measures of engagement and enjoyment

5.1 Verbal behaviour

CIRCA was intended to support communication for a person with dementia by prompting long-term memories and thus improve their engagement in a conversation and the quality of the interaction with another person. To evaluate this we set up communicative interactions between people with dementia and a carer, with and without the system being used. As CIRCA uses reminiscence contents to stimulate conversation, so the control condition uses standard reminiscence material to prompt and facilitate conversation. We carried out pre-and post-session assessments with caregivers and post-session interviews with both people with dementia and caregivers.

Given the difficulties people with dementia may have in communicating their views, we needed to devise objective measures for such aspects of the interaction as engagement, enjoyment, and the degree to which a satisfying interaction is taking place. We tackled this by video recording and coding all the sessions. We developed a set of coding techniques to describe both verbal and nonverbal behaviour that allowed us to focus on (i) the people with dementia, (ii) the carers and (iii) the relationship between the two. In particular, we have tried to determine if people with dementia can be supported to take the lead more in conversations, rather than the contents and course of the interactions being determined by the carers. This should have a beneficial effect on the quality of life of people with dementia as the provision of a positive interaction, at whatever level a person with dementia understands it, can be considered a successful intervention [45]. In addition, facilitating staff to engage in successful reminiscence activities has a positive impact on their attitudes towards the people they work with that continues beyond the activity sessions [11].

To measure the caregivers' role in the interaction we examined instances of prompting (Figure 4a). These are prompts given by the carer to the person with dementia to make a choice about what he/she wishes to talk about. For example, during sessions using traditional reminiscence materials the carer might ask, 'What

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would you like to talk about?’ During a CIRCA session, the carer might ask, ‘Would you like to look at photographs, music or video?’ We also looked at caregiver conversation maintenance activities. These are contributions from the carer that we classified as serving to maintain the conversation. For instance the carer might ask the person with dementia a question such as ‘Did you enjoy going to the pictures when you were younger?’ [9].



Figure 4a and 4b : Two stills from a CIRCA session showing the caregiver encouraging the person with dementia to make a choice (13a) and the person with dementia making a choice (3b).

To examine the role of the people with dementia in the interactions we looked first at instances of choosing after prompting (Figure 4b). Thus we counted the amount of times the person with dementia chose what they wanted to talk about/see/listen to in response to being offered a choice of stimuli by the carer. We also examined initiation by the people with dementia, which we defined as every time they made the first turn in a conversation or introduced a new topic [9].

Finally we examined the behaviour of the dyad - that is the interaction between the two partners in the interaction. We looked particularly at the use of humour, such as making a joke or an amusing comment, by either the person with dementia or the

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caregiver during the interactions. We also looked at the duration of laughter and whether it occurred jointly or was one person laughing alone.

5.2 Nonverbal behaviour

Alongside verbal behaviour we also examined both partners' nonverbal behaviour for indicators of joint attention and scaffolding behaviour. Joint attention is said to occur when two individuals attend to the same object, due to one person interpreting the attentional cues of the other [15]. It forms the basis for referential communication [12] involving shared understanding between individuals of an object or event [16]. Joint attention is pivotal in the development of communicative interactions between parents and infants [13] and is a key component of scaffolding behaviour that occurs in parent-infant relationships and other dyads of unequal status [43].

Scaffolding refers to the provision of structure, guidance and encouragement by the higher status partner in a relationship (e.g. parent, caregiver), which takes into consideration their partner's (e.g. infant, patient) abilities [22]. Successful scaffolding has three components [44]. First, 'intersubjectivity' [34] or joint attention must be established between the two parties. Second, the facilitator must offer a suitable level of guidance, which is sensitive to their partner's competencies [39]. Finally, the lower status partner must be encouraged to actively participate and 'take ownership of the situation' [18]. The most effective forms of guidance involve the lower status partner in decision-making processes regarding joint attention activities [35].

To examine joint attention and scaffolding in our reminiscence sessions we looked at the occurrence of pointing by one partner to draw the other partner's attention. The frequency of each participant's pointing behaviour was noted when there was clear intention to engage the partner's attention within the dyadic interaction (i.e. pointing at the screen or at an object). Alongside pointing we looked at the direction of eye gaze of both partners as another measure of the degree of involvement individuals invested in social situations [32]. Thus we examined how much time was spent looking at the computer screen or reminiscence object, how much at the interaction partner and how much looking elsewhere. Finally, we looked at the use of music during interactions and how the dyads responded to it. Specifically we looked at the

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use of music to prompt / aid conversation plus instances of moving to music and spontaneous singing by one or both partners.

The observational information allowed us to draw conclusions about the level and quality of participation of the people with dementia and of their partners in the interactions. We have identified clear differences both in the behaviour of the people with dementia and the caregivers in the two reminiscence situations [9]. Specifically we have shown that people with dementia can be supported by the sensitive use of technology to take greater control over the interaction and engage in a more equal relationship with the caregiver [2]. This finding is very important for furthering our aim of promoting the well-being of people with dementia and their identity as an individual with a life history before dementia. It is also an important outcome reported by caregivers in follow-up interviews.

5.3 Interviews

At the end of each session we immediately interviewed the person with dementia to find out their reaction. We used a brief set of questions about their enjoyment, what they liked and disliked, and what else they would like to do. The interview was semi-structured and there was scope for the people with dementia to make additional comments about the sessions they participated in. By interviewing people with dementia as soon as the session ends whilst they are still sitting in front of the screen we have been able to capture their immediate reactions to the sessions.

After interviewing the person with dementia, we interviewed the caregiver using a slightly longer set of questions, covering both the caregiver's response to the sessions and their perception of the person with dementia's response. The caregivers were also encouraged to comment on the contents of the sessions and any positive or negative aspects. They were asked what they liked and disliked and their views about the benefit for the people with dementia they work with.

To complement these semi-structured interviews we also used a range of formal measures both with participants with dementia and caregivers. For example, we routinely use the Mini-Mental State Examination [17] to provide a measure of the severity of the dementia of our participants. We may also ask staff to complete the

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Attitudes towards Dementia Scale [10] or the Holden Communication Scale [21] before the sessions and when they are finished. These measures provide information about the caregiver's perceptions of the abilities and difficulties experienced by the person they are working with in the sessions.

Creating a shared activity for people with dementia and caregivers has provided an opportunity for the care staff to get to know better the people they work with. This is important for the quality of life of the people with dementia and the quality of the work/care environment of the caregivers. Providing care for people with dementia can be demanding and exhausting and a distance often develops between the caregivers and those they care for. This 'dehumanisation' may serve a protective function for relatives or care staff of people with dementia as they struggle to cope with caring for a highly dependent person or group of people [24]. Therefore providing positive interactions where caregivers can interact with a person with dementia on an equal basis should not only improve the relationship between them but also the environment in which care is provided.

We have found that care staff may be reluctant to engage in research as they feel that their jobs are so demanding that they do not have time to take on something new. In some instances this is overlaid by a lack of confidence about using technology or sometimes lack of knowledge about dementia and how to interact with people [42]. However, we have found that when staff do participate in one-to-one sessions, they can be supported to provide a positive interaction using the computer system. This in turn boosts their feelings of competence and confidence in themselves as care providers.

Caregivers have tended to be enthusiastic about how the system benefits the people with dementia who they work with. For example, in post-session interviews of the first CIRCA prototype, all carers said that they enjoyed the session and that they thought the people with dementia also enjoyed it. They all reported that they found the session worthwhile for them as carers and for the people with dementia they were working with. When asked what they found the most enjoyable part of the session for them as a caregiver comments included: 'the client's reaction', 'the fact that the system is easy to use', and 'the client's interest in using CIRCA'. When asked what

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they thought was the most interesting or enjoyable part of the session for the people with dementia their responses included ‘using the touch screen’, ‘talking about memories’ and ‘all of it’.

6. Conclusion

When developing complex interactive systems, user involvement is essential throughout the entire design process. This does not rule out creativity and exploratory approaches, even ideas that may initially be technology led or design led. What is needed is a partnership between the designers of the technology and potential users that elicits the best contribution from both sides. Working with people with dementia has particular problems due to the cognitive difficulties they are coping with. Their memory impairments make many tasks difficult and can interfere with their ability to communicate their ideas and opinions. In addition, family and professional caregivers may not be comfortable with advanced technology, or may not see any value in taking part in research when they are already hard-pressed.

We have outlined some of the ways we have approached these challenges, which have proved successful in bringing into being an innovative system for helping people with dementia and caregivers to communicate more effectively and enjoyably. We have achieved this by paying attention to the special issues of consent when working with people with dementia, by building and maintaining long term relationships with people with dementia and care providers, and by ensuring that the entire multidisciplinary team is familiar with the specific needs of the target population. We have also developed a range of objective measures to evaluate the engagement and enjoyment of interactive systems by people with dementia.

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