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Abstract. Augmentative and alternative communication (AAC) methods are used to support people who have communication problems. Attempts have been made to apply AAC to assist the communication of people with cognitive impairments, including people with dementia. Two systems, CIRCA and Talking Mats, took as their starting points different types of communication situation which are problematic with dementia. Both systems have proved to be of benefit to user populations, encouraging further exploration in the field. Such exploration is likely to be gradual and incremental, given the nature of the challenges involved, building on retained capabilities of persons with dementia. There are implications for approaches to system design and development, including the software engineering of new systems.

Keywords: AAC, augmentative communication, dementia, older people

1   The rise of dementia

Dementia is a progressive neurological deterioration that at present cannot be prevented or reversed. It is a condition associated primarily with ageing. As the population of older adults grows worldwide, the number of people with dementia will increase proportionally. This number is predicted to rise from 25 million in 2000 to 63 million by 2030 and to 114 million by 2050 [26].

Dementia's most characteristic result is degradation of working (short-term) memory. This creates difficulty in recalling and discussing recent events. However, memories of events from earlier in the person's life, especially childhood and early adulthood, can still be relatively intact. As the illness progresses, all aspects of cognitive function are involved, including language production, judgment and problem solving [8]. This progressive deterioration means that people with dementia become increasingly reliant on family or professional caregivers for meeting all of their needs.

2   The potential of ICT support for people with dementia

While pharmacological treatments for dementia are being developed, their impact is limited so far, and there is an urgent need for non-pharmacological treatments to meet the social and emotional needs of people with dementia and their carers [22], [25].

Developments must take account of the needs, abilities and desires of the intended users, especially in respect of the cognitive impairments of people with dementia, which can interfere both with their ability to participate in the development process and their ability to use new technology once it is created [4].

One particularly challenging aspect of coping with dementia is the deterioration in the ability to communicate. This can be frustrating and disempowering for people with dementia and distressing for family and carers they are trying to communicate with. Developing interventions to support communication and maintain relationships between people with the cognitive disability of dementia and those who care for them is a growing social and healthcare priority.

3   Applying existing AAC structures to support communication in dementia

Augmentative and alternative communication (AAC) as a field has, for many years, been developing both technological and non-technological systems to support the communication of people who have communication problems [7], [23]. AAC users with physical impairments include people with cerebral palsy from birth and people with acquired conditions such as motor neurone disease. Some attempts have been made to apply AAC systems for people with cognitive impairments, such as aphasia [14], and interactional difficulties such as autism [18]. Attempts have also been made to apply some of the techniques and technologies of AAC to try to assist the communication of people with dementia.

Egan et al. [12] conducted a systematic review of studies on techniques to improve communications between caregivers and persons with dementia and found that the strongest support was for the use of memory aids combined with caregiver training. The field was said to need more thorough investigation through high-quality randomized controlled trials (RCTs), existing trials being relatively uncommon. An RCT by Bourgeois et al. [9] found that participants with dementia using memory aids made significantly more utterances and had more informative interactions with their caregivers, where the caregivers had first been given relevant communication training.

Bourgeois et al. [10] reported that non-electronic or low-tech AAC approaches have been used by speech–language pathologists to support communication and social interaction for people with dementia. Elsewhere it was reported that verbal conversation could be improved with AAC communication boards if relevant training was first given to participants [16]. High-tech AAC can be problematic however; it was found [15] for example that pre-programmed digital voice output in devices proved distracting to participants with moderate dementia and reduced their conversational performance compared to devices without digital voice output. Fried-Oken et al. [17] also reviewed AAC-supported communication for patients with neurodegenerative disease, including Alzheimer's disease (AD), observing that "Communication supports, including high-tech, low-tech, and no-tech approaches, should be tailored to the specific needs and abilities of each person, and should be modified throughout disease progression".

Ekström et al. [13] described a single-case study of a person with dementia using a personalized AAC application on a tablet computer during interaction with her husband. She required considerable support from her husband in using the tablet and while there was more interaction occurring when the tablet was in use, there was no evidence of the tablet supporting communicative initiatives for the person with dementia. The study concluded that a personalized communication application on a tablet may encourage communication for people with dementia, but pointed also to a need for further investigation.

Efforts to apply existing AAC methods and technologies to the problem of communication for people with dementia which assume that relatively simple adaptations may be sufficient could be underestimating the magnitude of the cognitive challenges that a system appropriate for dementia must address.

4 Developing new structures based on the experience of dementia

In addition to investigating ways in which existing AAC systems might be adapted to help people with dementia, research has also been undertaken into focussing on specific communication problem areas with dementia, and devising ways of ameliorating these specific difficulties. The hope here is that eventually, a large suite of such tools might be able to offer people with dementia a much fuller communication experience than they currently have. Two systems which have hitherto been developed took as their starting points two different types of communication situation which are problematic with dementia: free-flowing conversation and expressing an opinion. In each case the developers devised a scaffolding for the communication based on what the person with dementia was still capable of.

5 Supporting free-flowing conversation through reminiscence

CIRCA is a multimedia computer system developed to make possible again free-flowing conversation between people with dementia and caregivers [1-5]. The system is based on presenting reminiscence materials from a wide range of archives. Reminiscence provides an opportunity for people with dementia to speak about memories from earlier in their lives, which are often well-preserved, despite the lack of working (short-term) memory. Engaging in reminiscence is considered to contribute to well-being and to provide a positive activity for people with dementia [11].

5.1 Flexibility and dynamic linking with hypermedia

CIRCA uses reminiscence materials in a hypermedia format to address the memory and conversation maintenance problems experienced by people with dementia. Two features of hypermedia make it particularly suitable for people with dementia. First is its inherent flexibility. Users of the computer have the freedom to move between in-

terconnected but individual items as they choose. This is beneficial for people with memory loss as it does not put any penalty on 'losing the place' in the system. Whatever place the user is in is the right place to be, and exploring and 'getting lost' are actively encouraged as strategies to enjoy experiencing the material. Secondly, hypermedia provides the opportunity to link items from a range of media in a dynamic way. Text, photographs, graphics, sound recordings and film recordings can be seamlessly intertwined to present an inviting and lively activity for people with dementia and caregivers to explore and discuss together (Fig. 1).
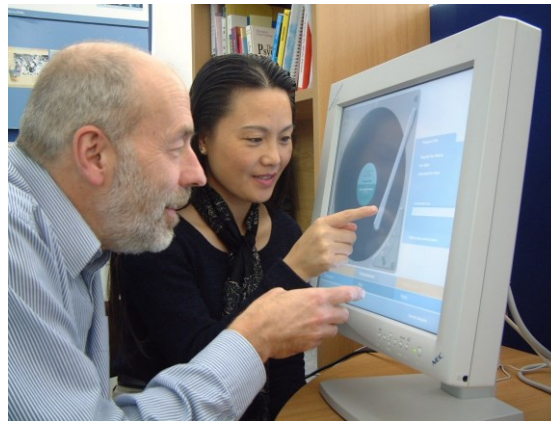

Fig. 1. CIRCA prompting discussion through the display of generic reminiscence material

5.2   Outcomes with CIRCA

In controlled trials CIRCA was shown to support an engaging conversation maintenance activity which was not replicated in traditional reminiscence sessions. There were notable differences between the two session types in the verbal and nonverbal behaviour of both parties. In traditional reminiscence sessions the caregivers worked very hard to keep the interaction going, particularly by asking lots of questions. These were typically closed questions (e.g. "Did you used to do that?" "Do you remember those?"), which did not encourage either initiation or choosing by people with dementia. Caregivers reported in interviews after the two reminiscence activities that they found the traditional sessions much more demanding and that twenty minutes felt like a long time. By contrast they found it relatively easy to facilitate a shared interaction using CIRCA [5].

Lower levels of initiation were recorded for people with dementia in the traditional sessions compared to CIRCA sessions. Measures of non-verbal behaviour such as attention to the task and mutual laughter showed similar results, with sessions with CIRCA being more effective than traditional reminiscence sessions.

The success of CIRCA for people with dementia may reflect that it focusses on one cognitive task that they can still perform: using their long-term memory to tell stories based on events from their past. An interesting aspect of CIRCA is that it prompts these memories by means of generic reminiscence material. It was found that using

personal material was not necessary [6]. The sheer size of the collection of generic material ensured that there was always something to talk about.

6   Supporting the expression of opinions and views

Talking Mats is a communication framework which can help people with dementia (and other communication difficulties) to express their views and opinions [19,20,21]. The system uses a mat, such as a doormat or carpet tile, to which symbols and pictures can be attached by hook and loop tape. A touch-screen tablet-based version is also available. Symbols representing emotions are placed along the top to form a visual rating scale. The emotions can be as simple as 'positive', 'neutral' and 'negative' or more detailed, depending on the user. A relevant topic is discussed and a symbol representing it is placed at the bottom of the mat. As the session progresses the user expresses their views by placing pictures representing various aspects of the topic on the mat, grouping them underneath the appropriate rating symbols. The process is engaging and empowering, and the result is a vivid pictorial representation, in some detail, of the person's views (Fig. 2).
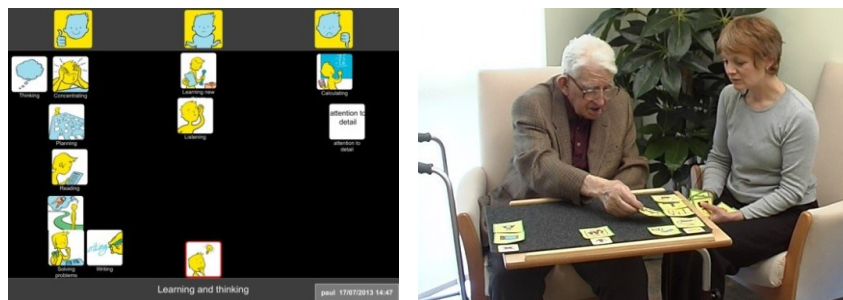

Fig. 2. An example of a Talking Mat (left) and one under construction (right)
(Symbols © Adam Murphy and owned by Talking Mats Ltd)

6.1   Outcomes with Talking Mats

Talking Mats has been found to be successful in a number of ways with people who have dementia. The quality of communication was analysed with Talking Mats compared to structured and unstructured conversation [20]. Sessions were recorded and studied for evidence of effectiveness, perseveration, and distractibility. Conversations using Talking Mats lasted longer than ordinary conversations; they were more effective for people with dementia than both unstructured (ordinary) or structured conversations. Improvements were evident in the participants' understanding, engagement, and ability to keep on track and make their views understood. The reliability of information provided was enhanced. The amount of time spent 'on-task' – e.g. making eye contact and engaging actively in conversation – increased when using Talking Mats, and participants were less frequently distracted. Instances of repetitive behaviour such as repeating words, phrases, ideas or actions were reduced.

Although people with dementia and their family carers both felt more involved in discussions when using Talking Mats, the increased feeling of involvement was significantly higher for the family carers, who repeatedly reported feeling 'listened to' by the person with dementia and felt that their loved one could actually 'see' their point of view. One carer said: "It never seems like he is listening to me. With this I can make him sit down and look at symbols and get him to understand what I am trying to say."

The success of Talking Mats for people with dementia may be that it 'externalises' cognitive processes in a simple and easy to understand way. The layout of pictures in front of the person acts both as a reminder of what the person has already said and an emerging easy-to-read picture of what their views and opinions are.

7 Discussion

7.1 Further exploration of AAC in dementia

Developing communication support systems for people with dementia is an important priority. So far, some low-tech AAC systems have proved to be of benefit, but high-tech AAC systems seem to be too confusing for people with dementia to understand and to operate. The best way forward may be to start with the capabilities of the person with dementia, and build from there, always keeping in mind that the user-interface to any communication system will need to be extremely simple, however complex the functioning is 'behind the scenes'. The CIRCA system was built on the ability of the person with dementia still to draw on their long-term memory. The Talking Mats approach provides them with a simple and easy to understand layout, and a procedure that does not require their working memory to be employed. It is noteworthy that both CIRCA and Talking Mats involve the other person in the conversation (conversation partner) actually helping to sustain it, but with considerably less effort than is normally required. The structure which the two systems offer takes much of the burden from the conversation partner, and allows them to join in a mutually satisfying interaction where the control of the person with dementia is maximised.

A strategy for further exploration of AAC in dementia would thus be to build on the capabilities retained by persons with dementia, using AAC methods and technologies to gradually augment these capabilities, while focussing carefully on the user experiences of the persons with dementia and their conversation partners. Progress is likely to be gradual and incremental as the challenges are great, but some encouragement can be taken from previous outcomes.

7.2 Implications for Software Engineering of AAC systems for dementia

From the standpoint of Software Engineering, a particularly challenging aspect for new developments in this field is eliciting requirements. Standard practice is to derive user requirements from conversations and structured interactions, such as questionnaires, with potential users. In the case of people with dementia this is likely to be of limited assistance. Deriving requirements from carers is possible, both as surrogate

users and as participants themselves in communications with the person who has dementia. Projects, however, can be built on an evidence base derived not from interviews or questionnaires, but from direct observation of users interacting with an evolving series of prototypes. Where necessary, this can involve video-recording, transcribing, and coding sessions to enable a very fine-grained analysis of the interaction [2], [4]. It is widely accepted that user involvement in the design process and understanding the user is highly desirable [24]. In the case of people with dementia, for reasons set out above, we would say it is essential.

8   Conclusion

Supporting communication for people with dementia is a growing priority, given the increasing number of people so affected. Applying existing AAC systems with some modification may not be sufficient to meet the challenges inherent with the users' lack of short-term memory and other cognitive challenges. Developing new systems which build on their remaining cognitive abilities may be a more fruitful approach.

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