REAFF - A framework for developing technology to address the needs of people with dementia

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Abstract

As the number of older people with a diagnosis of dementia continues to grow, the potential for developing technological solutions to the problems they face is increasingly being recognised. This paper describes the REAFF framework, a set of principles to guide the development of technology to support people with dementia. The framework has evolved from experience developing computerised technology to address psychosocial needs but the principles have broader application across all areas of technological development to support people living with a diagnosis of dementia.

1. Introduction

Dementia is an irreversible, progressive neurological condition that gradually interferes with all aspects of a person's life. Alzheimer's disease (AD) is the most common cause of dementia, accounting for approximately 42% of cases (Brunnström, Gustafson, Passant & Englund, 2009) although vascular dementia (VaD; 23.7%) and mixed AD and VaD (21.6%) are also common (Brunnström, et al., 2009). The greatest risk factor for developing any sort of dementia is age (Alzheimer's Association, 2009).

The early clinical signs of dementia due to AD are characterised by memory problems and failure to learn new information (McKhann, et al., 1984). Over time, all aspects of cognitive function are affected which in turn impacts on a person's ability to carry out everyday activities and participate in social situations. As dementia advances, people find themselves increasingly in need of support and assistance in all aspects of their lives.

Living with dementia presents a range of challenges ripe for creative applications of technology. These tend to fall broadly into addressing the safety, security and social challenges of living with dementia (Astell, 2005). Safety issues are those relating to aspects of dementia that can put people at risk such as going out and getting lost. Security refers to the challenges of keeping people functioning in their own homes for as long as possible. Social deals with the aspects of a person's life concerned with engaging with other people and participating in enjoyable and meaningful activities (Astell, 2006).

Some of the developments to date have been technology-lead, such as the application of GPS systems as personal locators and tracking devices for people with dementia and other cognitive impairments (e.g. Miskelly, 2005). However, there is also potential to develop tailored solutions for people with dementia that reflect the patterns of spared and impaired processes they experience. The REAFF framework has been devised to inform and support the development of technology to address the broad range of challenges faced by people with dementia. It emerged from experience developing technological solutions to meet social and

psychological needs of people with dementia. However, the principles have broad application across to all areas of technological development for people with dementia.

2. REAFF Framework

This framework has developed over a number of years and contains four principles for guiding development of technological solutions to address the needs of people with dementia (Table 1). These are Responding, Enabling, Augmenting and Failure-free (REAFF).

Table 1. The REAFF framework

Principle	Definition
Responding	Technological solutions must be responsive to the needs of people with dementia
Enabling	Technological solutions must enhance the life of the person with dementia and not disable them in any way
Augmenting	Technological solutions must build on and extend the retained abilities and skills of people with dementia
Failure-free	Technological solutions must be intuitive and accessible and not undermine the confidence of a person with dementia

2.1. Responding

The principle goal of technological solutions should be to respond to the needs of people with a diagnosis of dementia. Their needs fall into the following domains: (i) *cognitive* – memory is the primary aspect of cognition affected, with other domains such as naming, attention and concentration all likely to deteriorate; (ii) *social* – cognitive changes impact on a person's ability to initiate and maintain conversations and interactions with other people. However, their need and desire for these social contacts is undiminished as dementia progresses (Astell & Ellis, 2006); (iii) *environmental* – this refers to the needs of people with dementia for active participation in their environment as opposed to being passive recipients of things being 'done for' and often 'done to' them (Astell, 2006).

Technological solutions can address the needs of people with dementia in one cognitive domain for example Memojog (Szymkowiak, et al., 2003), which provides prompts to jog a person's memory. Alternately, solutions can be developed to meet people's needs across a range of cognitive or other functions, such as the Picture Gramophone (Päivi, et al., 2004), which was developed to support reminiscence and promote social interaction through music.

It is important to be aware that developing technology to meet the needs of people with dementia must be balanced with the needs of family and professional caregivers, which may not be the same, either as each other or as people with dementia's. For example, family caregivers prioritised the safety of their relative and their own peace of mind in respect of endorsing the use of GPS to track people with dementia (Landau, Werner, Auslander, Shoval & Heinik, 2009). By contrast professional caregivers were less supportive of the use of GPS technology and expressed more concerns about the autonomy of the person with dementia (Landau, et al., 2009). Additionally, people with dementia may have different views again such as concerns about invasion of their privacy (Miskelly, 2005).

2.2. Enabling

Enabling embodies the principle that interventions should "help people with dementia maintain their independence and dignity" (Alzheimer's Society (AS), 2004). This means that enabling people with dementia to do as much as possible for as long as possible should be at the forefront of technological developments. Unfortunately many solutions and interventions offered to people with dementia are disabling rather than enabling. For example, disconnecting the gas is often applied as a solution to a person with dementia forgetting to light the gas on the stove (REF). However, the application of a cooker usage monitor can support people with dementia to keep using the stove to prepare food for themselves (Gibbs, Adlam, Faulkner & Orpwood, 2003).

"Excess disability" (Kahn, 1965; cited in Brody, Kleban, Lawton & Silverman, 1971) is also a major problem for people with dementia. This refers to a mismatch between a person's actual impairment and the level of incapacity they experience. People with dementia are excessively disabled by the environment as caregivers often find it easier to do something themselves than to support the person with dementia to do it, e.g. getting dressed (Rogers, et al., 2000). Additionally, caregivers may view people with dementia as incapable and therefore underestimate what they are still able to do (Sabat, 2006).

Yet, if people are supported and prompted appropriately, they can continue to carry out activities and maintain their independence as far as possible (Rogers, et al., 2000), which is why technological solutions must aim to be enabling. The challenge is therefore to provide technological solutions that are responsive and enabling and that do not disable people with dementia, which is not without its problems. For example, electronic tagging has been used in a similar way to GPS to locate people with dementia when they go out and prevent them from getting lost.

Bail (2003) argued that this approach provided "more freedom of movement and personhood" (Bail, 2003, p281) for people with dementia who would otherwise be kept behind locked doors. However, objections to tagging include how able people with dementia are to agree to the tagging; how the benefit to people with dementia is evaluated; and the weight given to caregiver's views about the benefits of tagging (Hughes & Louwe, 2002). The complexity of balancing these positions is highlighted by two position papers produced by the Alzheimer's Society, where in 2004 they were broadly opposed to tagging but in 2007 came out in support of tagging re-branded as "safe walking technology".

2.3. Augmenting

Technological solutions for people with dementia should aim to minimise the cognitive problems that characterise dementia and maximise people's retained skills. Thus technological solutions should be a form of cognitive prosthetics, which are "computational systems that leverage and extend human intellectual capacities… systems that fit the human and machine components together in ways that synergistically exploit their respective strengths and mitigate their respective weaknesses" (Ford, 2001). This principle requires a good understanding of the profile of cognitive changes experienced by people with dementia to identify which ones to circumvent and which are available for exploitation in the development of technological solutions.

2.4. Failure-free

As stated above, people with dementia experience excess disability through negative perceptions and expectations of caregivers, both formal and informal. They are confronted on a daily basis with multiple situations, such as shopping, taking medication, etc., in which they can fail due to their cognitive impairments. It is therefore paramount that interventions for people with dementia avoid "devaluing, invalidating and dehumanizing" (Kitwood, 1990) them further.

Technological solutions must therefore aim to be as 'failure-free' or 'user-friendly' as possible. That is they should be intuitive and accessible for the users, require minimal effort and not feel like a chore. To achieve this technology must be designed to recognise and take account of potential problems. For example any technological solution designed to support people with dementia must not have a high memory load to learn and operate as potential users will be disadvantaged from the outset by their reduced capacity for learning new information.

Equally important, technological solutions must not feel like a test or evaluation of a person with dementia. Given the multiple daily failures people with dementia already experience, their confidence in their own abilities is easily undermined and should not be shaken further by technology that is intended to help.

These four principles – Responding, Enabling, Augmenting and Failure-Free - provide a touchstone for developing technological solutions to meet the challenges of living with dementia. They have evolved over the past nine years from a research programme creating computerised systems to meet the social and psychological needs of people with dementia. The Computer Interactive Reminiscence and Conversation Aid (CIRCA) project is an example of the work being carried out in this area and is described below to illustrate the four REAFF principles.

3. CIRCA

Executive functions are those aspects of cognition responsible for planning, initiating and monitoring activities. People with AD have an early problem with executive function (Carlson, Xue, Zhou & Fried, 2009), especially the working memory component, which makes it difficult for them to keep track of the turns and contents of a conversation. Thus conversations between people with AD and caregivers are very difficult.

CIRCA (Astell, et al., 2008) is an interactive computer system designed to facilitate communication between people with dementia and caregivers. CIRCA contains a multimedia database of generic photographs, music and video clips to prompt and support conversation through reminiscence (Astell, et al., 2004). CIRCA was developed to minimise the working memory problems of people with dementia by not requiring them to keep track of the conversation – whatever is on the screen is the current topic of conversation. Equally, the CIRCA contents were designed to make the most of the retained knowledge and skills of people with dementia, especially in regard to their well-preserved memories from the past. The system uses a touch screen, does not involve a mouse or keyboard and requires no previous computing experience (see Figure 1).

Figure 1: CIRCA interface showing People & Events video

For people with dementia CIRCA provides the opportunity to make choices and engage as an equal partner in a one-to-one conversation with a caregiver (Astell, et al., 2008). As CIRCA requires no preparation or practice, it is easy for caregivers to conduct one-to-one or group sessions with people with dementia. Evaluation of CIRCA identified three major outcomes for care staff: 1) staff saw the people with dementia in a new light; 2) staff re-evaluated their perceptions and expectations of their interactions with people with dementia; and 3) using the computer to run one-to-one sessions improved staff feelings of competence as caregivers (Astell, et al., 2007).

4. CIRCA and the REAFF framework

The four principles of the REAFF framework are illustrated by the development and evaluation of CIRCA as follows. **Responding** – CIRCA was developed to address a specific cognitive need, i.e. the working memory problem that people with AD-type dementia experience that makes it difficult to hold a conversation. However, CIRCA also addresses people's needs for social interaction and active participation in their environment. **Enabling** – CIRCA supports people with dementia to participate equally in interactions with caregivers. Using CIRCA was judged by caregivers to be an enjoyable activity for both parties, as opposed to being viewed as a caregiving task. Seeing people with dementia in a different light also enabled caregivers to revise their perceptions and expectations about what the people they care for are capable of (Astell, et al., 2007), an important step in reducing the excess disability experienced by people with dementia. **Augmenting** – alongside minimising the working memory problems of people with dementia, CIRCA was developed to maximise their retained cognitive abilities, particularly long-term memory and responsiveness to social interaction. The CIRCA contents were selected to prompt reminiscence, which led to situations where people with dementia were the experts on certain topics (e.g. 1940's movie stars) relative to young caregivers. **Failure-free** – CIRCA was developed to provide a failure-free activity for people with dementia. The use of generic contents avoids CIRCA seeming like a memory test, as there are no right or wrong memories in response to the stimuli. Designing the interface to be easily accessible for people with no previous computer experience enabled people with dementia to use it successfully.

In conclusion the REAFF framework encompasses four simple, general principles to guide the development of technological solutions to support people living with a diagnosis of dementia. Their application should facilitate the production of sensitively designed person-centred technological solutions for people with dementia.

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