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An investigation into the accessibility of web-based information for people with dementia

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Abstract
People with dementia have problems with memory, attention, language and orientation. Designers in the physical environment have started to consider the needs of people with dementia, but research into the use of computers by people with dementia has not been widespread. The large English-speaking Alzheimer's associations around the world are all committed to providing information for people with dementia via their websites. However, analysis of the websites indicates that the pages may not have been designed specifically for people with memory and language problems in mind. A small scale preliminary evaluation of four Alzheimer's association websites from across the world demonstrated that people with dementia can contribute to the design of websites. The location of the link from the home page to information specifically for people with dementia is of particular importance.

1 Introduction

1.1 Dementia
Dementia has been defined as a syndrome characterised by the development of multiple cognitive deficits including as least one of the following: aphasia, apraxia, agnosia or a disturbance of executive functioning (Cummings and Khachaturian, 1999). Currently there are an estimated 18 million people worldwide with dementia. Dementia primarily affects older people. The chance of having the condition rises with age to 1 person in 20 over the age of 65, and 1 person in 5 over the age of 80 (ADI 2004). There are many causes of dementia including Alzheimer's disease, vascular dementia and dementia with Lewy bodies (Alzheimer's Society, 2005).

Alzheimer's disease is a progressive neurodengenerative disorder with characteristic clinical and pathological features. Clinical variations are common, including differences in age at onset, rate of progression, pattern of neuropsychological deficits and occurrence of non-cognitive neuropsychiatric symptoms (Cummings and Khachaturian 1999). Alzheimer's disease is the most common cause of dementia in the elderly. However, Alzheimer's disease often co-exists with vascular dementia or parkinsonism (Pryse-Phillips and Galasko 1999). Dementia with Lewy bodies is a form of dementia that shares characteristics with both Alzheimer's and Parkinson's disease (Alzheimer's Society 2005). The criteria for diagnosis of vascular dementia include uneven impairment of cognitive function, focal neurological signs, preservation of insight and judgement, abrupt onset and stepwise deterioration (Cummings and Khachuturian 1999).

1.1.1 Symptoms of dementia
The cognitive domain which is impaired first and foremost in Alzheimer's disease is memory (Kertesz and Mohs 1999). The distinction between severe dementia and normal ageing is obvious but establishing the difference between early, mild Alzheimer's disease and age-related cognitive loss can be more difficult (Jones and Ferris 1999). Working memory, such as the immediate recall of a newly learned telephone number is retained in old age, but may be lost in dementia. However, the patchy progression of dementia pathology means that people with severe dementia may retain early learning and access to long laid down memories (McIntosh 1999). Perhaps the most substantial deficits in people with Alzheimer's disease are found on short-term memory tasks that require divided attention (Morris 1994). Alzheimer's disease is also associated with deficits in various aspects of semantic memory functioning, eg categorical organisation (Backman 1998). However, procedural memories are relatively spared in Alzheimer's disease (Zanetti 2001).

Subtle language impairment is usually detectable early in the course of Alzheimer's disease. Impairments may include difficulties with word finding and circumlocations (Kertesz and Mohs 1999). Virtually all people with Alzheimer's disease show language changes with problems with naming being especially prominent (Henderson 1996). People with Alzheimer's disease have been shown to be impaired in their appreciation of the relationship between a word and its attributes (Grossman et al 1996).

Dementia often leads to deterioration in functional abilities of daily life that has a major impact on quality of life. The condition also has an emotional impact. For example, feelings of incompetence and loss of control are often expressed by people with dementia (Gelinas and Auer 1999).

The symptoms of dementia are not uniform. People with Alzheimer's disease may experience different symptoms at different times and some people may have a relatively greater impairment in one area of cognitive function than in other areas, especially in the early stages (Kertesz and Mohs 1999).

1.2 Computers and people with dementia

People with dementia are increasingly being exposed to computer technology for diagnosis and to aid daily living. Computers have been used in diagnostic and other assessment tests of people with dementia. The computer permits consistent presentation of the task, easy and accurate recording of the results and rapid data analysis. Personal computers are used because they are easily portable and require no special environment (Sano 1988). Various sensor and detector systems have been developed or are being developed for use in the care of people with dementia. For example, sensors which can be put under a mattress to alert care staff when someone moves to get out of bed or more sophisticated sensor systems that alert staff only if a particular person does something outside their normal routine (Marshall 1999).

There has also been some research into memory aids (Grandmaison and Simard 2003; Goodman et al 2002) and prothesis ware (Chute and Bliss 1994) but the application of these technologies for people with dementia is not clear.

The non-judgemental nature, user friendliness, repetitive capabilities, and adaptivity of computers have been described as making them suitable for helping residents in nursing homes with moderate memory loss. However, most studies tend to exclude people with dementia (Sherer 1996; Sherer 1997). Alm et al (2004) have described a multimedia reminiscence 'scrapbook' including text, photographs, videos and songs arranged by subject with a simple screen display. This multimedia presentation has produced a great deal of interest and motivation from people with dementia themselves and has been successfully used as an effective support for satisfying conversation for people with dementia with the emphasis on failure-free reminiscence activities. Some researchers have observed that people with dementia like using computers and seem to profit from a sense of achievement which was 'quite different from the feeling of getting worse in every other aspect of life' (Hofmann et al 1996). It has been acknowledged that older people benefit from computer use for communication and social interaction, access to information, entertainment and learning, healthcare and to assist them to remain independent and in control (Ryan and Heaven, 1986). However, this principle does not appear to have been widely extended to people with dementia. Some people with dementia, however, are actively using computers and the internet (DASNI 2005; Alzheimer's Forum, 2005).

1.3 Designing for people with dementia

Although there are many different causes of dementia, most research into design has presumed that the differences in symptoms are not as important as the similarities (Burton and Mitchell 2003). Overall, dementia is associated with progressively decreasing abilities to plan a route, to remember or try different options, to recall previous mistakes and to remember to use mental maps, spatial information and signs (Blackman et al 2003). Orientation has been identified as one of the main design considerations for people with dementia (Day et al 2000). Burton and Mitchell (2003) have concluded that designers should aim to create places for people with dementia that are: familiar, legible, distinctive, physically accessible, comfortable and safe. The first three of these concepts have direct relevance to designing computer interfaces. Cues should be used that are familiar and easily understood (Burton and Mitchell 2003). People with dementia are most likely to become disorientated at decision points, it has

therefore been recommended that designers enable people with dementia to go from one decision point to the next without having to plan for future decisions (Mitchell et al 2003).

1.4 Involving people with dementia in research

Although people with dementia are a sizeable group, it is still not uncommon for them to be excluded from a range of research. However, there is growing recognition that people with dementia should be included in research as participants and not as subjects or objects (Dewing 2002). When asked, people with dementia have often expressed a willingness to participate in research as they perceive it to be doing something worthwhile (Robinson 2002). However, research methodologies themselves can be a barrier to the inclusion of people with dementia into research. Some researchers believe that challenging methodology is an important part of encouraging research to be more inclusive of people with dementia. Methods need to be designed that focus on the strengths of the participants' abilities (Pratt 2002). For example, questions themselves can be threatening to someone with cognitive impairment (Stakler et al 1999). Dementia research calls for a collaborative style in which the person with dementia, carers and researchers explore difficulties and options for their resolution together (Blackman et al 2003). One of the most significant developments in the field of dementia care has been the focus on personhood (Kitwood 1997). It is now widely accepted that the goals of care should move beyond maintenance and focus instead on the abilities and residual interests rather than the deficits of the person with dementia (Nolan et al 2002). Research into the views of people with dementia has shown the importance that people with dementia place on autonomy and being in control (Bamford and Bruce 2000).

1.5 Alzheimer's Associations

Alzheimer's associations bring people with Alzheimer's disease and other dementias, their caregivers and family members, health and social care professionals, researchers, scientists and politicians together through shared concern for people with dementia. These associations are dedicated to providing support to people with dementia and their caregivers through:

- Practical and emotional help such as help lines and support groups
- Information and advice
- Advocacy to governments
- Training for caregivers and professionals (ADI 2005)

Alzheimer's organisations and charities have historically catered for the information needs of people who care for people with dementia. However, in recent years more people have been diagnosed with dementia at an early stage and drugs have been developed that can temporarily slow down the progression of the symptoms of Alzheimer's disease. Therefore, the focus of these organizations has shifted from solely caregivers to also involving people with dementia (Litherland 2004).

The websites of Alzheimer's organizations around the world reflect this changing emphasis in information provision. Some of the websites have dedicated sections that are clearly aimed at people with dementia.

1.6 Accessibility of web-based information for people with dementia

Although web-based information exists that is aimed at people with dementia, there is no evidence that the websites have been designed specifically for people with dementia. This paper describes a preliminary study to investigate the design issues for web-based information for people with dementia. The websites of four English language Alzheimer's associations around the world were chosen as these organisations are specifically targeting information for people with dementia. The paper uses review-based guidelines for older people (Zaphriris et al 2005) in an attempt to investigate whether these general guidelines can be used to design websites for people with dementia. The same websites are then evaluated by a small group of people with dementia in order to determine any special design features that may help people with dementia to access information on websites.

2 Methods

Four websites were chosen for evaluation. These websites were chosen because they were in the English language and had dedicated sections for people with dementia.
The sites chosen for comparison were:

- www.alzheimers.org.uk - the website of the UK Alzheimer's Society
- www.alz.org – the website of the US Alzheimer's Association

- www.alzheimers.org.au – the website of Alzheimer's Australia
- www.alzheimer.ca/english – the website of the Canadian Alzheimer's Society

2.1 Website comparison

The four websites were compared for structure and depth of information.

2.2 Evaluation against existing website design criteria for older people

As dementia rarely affects anyone under the age of 40, the websites will be evaluated against existing guidelines for designing interfaces for older people. These guidelines were selected from a literature review (Zaphiris et al 2005).

2.3 User evaluation of websites

Five people with dementia were asked to give their opinions about the four websites. Four of the five people with dementia attended a day centre run by the Alzheimer's Society in the UK and the fifth is also involved with the Society.

The participants consisted of three men and two women. Ages ranged from 55 to 72. Education ranged from leaving school at 15 to having a research degree. Only one participant described himself as happy with computers. Two participants were not familiar with computers at all (and asked for a care worker to support them when using the mouse), and the remaining two were reasonably happy using computers. All the participants had a computer in their homes, but only one considered the computer as his. Three of the participants stated that they had never used any of the test websites. One had visited them all at some time and another had visited the UK site only.

A co-operative evaluation method was used (Monk et al 1993). Co-operative evaluation is based on traditional talk aloud protocols but involves more intervention and the participant is encouraged to see himself as a collaborator in the evaluation and not an experimental subject. This method was thought to be appropriate for use with people with dementia because it enables the participant to be part of the research process and to concentrate on the strengths of the individual rather than highlight their impairments. The researchers felt that more quantitative methods would inhibit the participants and contribute to feelings of failure.

The participants were asked to perform the following tasks and explain their actions and thoughts aloud:

- Find the section of each website dedicated to people with dementia from the website home page
- Find information about driving and dementia
- Find advice about telling other people or sharing the experience of having dementia.

The tasks were chosen to reflect realistic information needs of people with dementia and because all the websites to be evaluated contained information on these topics. The order in which the tasks were given and the websites evaluated varied for each participant.

The co-operative evaluation method enabled the researchers to ask questions and clarify points with the participants during the tasks. This was felt to be especially useful when working with people with language and memory problems.

The screen text size was increased for most sessions and a support worker was present at the interviews with all the members of the Society branch.

3 Results

3.1 Website structure comparison

The different section for people with dementia from the Alzheimer's association websites varied in complexity from 9 pages of information to 41. Table 1 outlines the navigation structures used in the different sites. All the websites used traditional menus on the left hand side of the screen. The navigation systems used varied from expandable menus, to links in the body text to extra menu systems.

Table 1: Comparison of structure of dedicated website sections for people with dementia

Website	Relationship with main site	Number of menu items	Total number of pages	Menu alignment	Menu type
www.alzheimers.org.uk	Separate mini-website with special link from top of home page – *I have dementia*	9	29	Vertical menu on left hand side. Same pattern as main site.	Expandable menu to one more level.
www.alz.org	Integrated sub-section with special link from top of home page – *Persons with memory loss*	6	9	Vertical menu on left hand side. Main site menu horizontal.	5/6 menu items produce one page of information with jump links from top to different sections 1/6 had expanded menu.
www.alzheimers.org.au	Fully integrated section of main site. Link in main horizontal menu – *I have dementia*	11	27 plus 11 PDF files	Vertical menu on left hand side. Main menu for site is horizontal.	5/11 topics have text on one page with jump-links at top 6/11 contain summaries of deeper topics with subheadings as links. Linked to either HTML page or PDF files. PDF files clearly labelled with icons. HTML sub-heading pages have drop-down menus.
www.alzheimer.ca	Fully integrated subsection of main site. Link from main vertical menu on left hand side – *I have Alz. Disease*	13	41	Vertical menu on left hand side as part of an expanded menu for the entire site. Separate vertical menu on right hand side used for some sections.	8/13 utilised additional menu for deeper links. Text used to link to other sections of the website. One page links to message board. One page links to audio files.

The US site appears to be the simplest site in terms of content and structure. Therefore, it might be expected to be the easiest to navigate around.

3.2 Evaluation against existing website design criteria for older people

A preliminary simple check list of design features recommended in the literature for older people was used to try to predict the usability of the websites for people with dementia. Table 2 shows the results of this evaluation.

Table 2: Check box for guidelines for interface design for older people

	alzheimers.org.uk	alz.org	alzheimers.org.au	alzheimer.ca
Information should be grouped into meaningful categories (Czaja 1997)	Yes	Yes	Yes	Yes
Links should not be tightly clustered (Nielson 2002)	Yes	Yes	Yes	Yes
Screen layout should be simple, clear and consistent (Hawthorn 2000)	Yes	Yes	Yes	Partially satisfied
Links should be in a bulleted list (Benard 2003)	Yes	Yes	Yes	Yes
Clear navigation should be provided (Bernard 2003)	Yes	Yes	Yes	Yes
Links should be clearly named (W3 1999)	Yes	Yes	Yes	Yes
Information should be concentrated mainly in the centre (Cerella 1985)	Partially satisfied	Yes	Yes	Yes
Do not have a deep hierarchy (Benard 2003)	Yes	Yes	Yes	Yes
Language should be simple and clear (W3 1999)	Yes	Yes	Yes	Yes
Provide large target (Hawthorn 2000)	No	No	No	No
Provide fewer choices to the user (Vercruyyssen 1996)	Partially satisfied	Partially satisfied	No	No
Avoid pull down menus (Hodes and Lindeberg 2001)	Yes	No	No	Yes
Consistent layout should be present (Shneiderman 1998)	Yes	Yes	No	No
Text should have clear large headings (Hartley 1994)	No	Yes	Yes	No
Extra and bolder search cues should be provided (Hawthorn 2000)	No	No	No	No
Coloured text on coloured background should be avoided (Charness and Bossman 1990)	Yes	No	Yes	No
Important information should be highlighted (Czaja 1997).	No	No	No	No

None of the websites scored perfectly against the checklist. On the basis of this checklist the Canadian website might have been considered to be slightly less user-friendly for older people than the other sites.

3.3 User evaluation of websites

All the participants were keen to take part in the research. Even if they were not very familiar with websites they understood the importance of design for making information accessible.

Four of the five participants had no problem understanding the tasks. One participant was obviously having difficulty with the concept of how websites are organised and the tasks involved. Therefore the interview was stopped after only two sites (US and UK) had been evaluated. Another participant became tired before the final task was completed.

3.3.1 Task A: finding the section for people with dementia

When the link for the section specifically for people with dementia was not part of the main menu, all the participants had problems finding it. In contrast, none of the participants had a problem locating the section when it was part of the main menu and the menu was on the left hand side.

Participants found finding the link on the UK site was particularly difficult. On the UK site, none of the participants found the link without prompting. All the participants found the US site 'confusing' or became distracted. None of the participants found the link on the US site easily, and 3/5 needed prompting. Two participants found the *I have dementia* link on the Australian site easily, but the other two needed prompting to see the blue bar as a menu. All four participants who evaluated the Canadian site found the link (in the main menu) very easily.

There were mixed feelings about the terminology used. The use of the phrase 'I have dementia' was thought to indicate 'case studies' by one participant. The same participant liked the phrase 'Persons with memory loss', but another thought it misleading. Only one of the participants mentioned the abbreviation for the word Alzheimer's used on the Canadian site. Three of the participants were drawn to the word 'About' when used on the various websites (none of which was specifically for people with dementia). One participant pointed out that the whole website should be for people with dementia.

3.3.2 Task B: finding information about driving and dementia

The information about driving and dementia were found easily by all the participants only on the website where the word driving appeared as a main menu link. All participants initially looked for the word driving.

The participants who described themselves as less happy with computers needed prompting or teaching about the idea of menu categories and information being 'hidden behind' headings.

The category heading 'Planning for the future' used on the UK site was not immediately associated with driving by any of the participants. 'Living with the disease' (used on the Canadian site) and 'Coping with change' (on the US site) seemed to be more appropriate category headings.

The expandable menu used on the UK site was not intuitive to people who were not familiar with computers. But the use of secondary menus (eg on the right hand side on the Canadian site) did not appear to present any difficulties.
One participant had problems grasping the concept of headings and subheadings or categorising information, and so the session was stopped after looking at the US and UK sites.

3.3.3 Task C: finding advice about telling other people or sharing the experience

As with the driving information task, all the participants found the easiest website to use was the Australian one, where the link was part of the main menu.

Family and friends (UK) or *Helping family and friends* (US) seemed to be appropriate main category headings for advice about telling other people. Participants did not have as much difficulty with this task as with the categories used by the website designers for information about driving.

The Canadian site had two possible correct outcomes. 2/4 participants used the main menu list in the central body text rather than the menu. Use of a right hand menu did not appear to cause any problems.

4 Discussion and conclusions

The large English speaking Alzheimer's associations around the world are all committed to providing information for people with dementia via their websites. The four associations looked at have all produced a special section of their website dedicated to providing information direct to people with dementia. One comment from a participant should also not be overlooked by the associations. The participant stated that all of an Alzheimer's association website should be for people with dementia, not just a specialist section.

None of the sites or sections that were targeted at people with dementia are structured differently from the rest of the site. This indicates that the pages may not have been designed specifically for people with memory and language problems in mind.

Two of the four sites did not include the link to the specialist section on the main menu. This had the effect of making it difficult for people to find the section. This limited study suggests that placing the link in the main menu is the best way of alerting people to the presence of a special section. If a special section exists it should be worth considering making design adjustments that may help people with dementia to use the information they provide. This may include simplified menus and larger, simplified text.

Preliminary analysis of the sites suggested that the US section for people with dementia was the simplest. However, in tests by people with dementia themselves, this proved not to be the case. The structure of the main US site is complex and this was distracting to some of the participants.

The design guidelines for older people also suggested that the Canadian site might be less easy to use. However, some of the guidelines are vague. For example, the use of the phrase 'meaningful categories' is ambiguous. The designer needs to think meaningful to whom. This preliminary study has shown that the terminology and phrases used when designing for people with dementia are extremely important – possibly more so than for the average web-user. There are also inconsistencies between the guidelines. For example, one guideline states that fewer choices should be presented to older people, while another recommends avoiding deep hierarchies. There needs to be a balance between these two ideas if a wide variety of information is to be presented. This study suggests that a longer list of menu items may be preferable to grouping information into abstract categories. However, further study will be needed to investigate the optimum number of headings that is possible without causing confusion.

This paper describes a very preliminary study into the navigation design needs for people with dementia using websites. The sample size was very small so it is difficult to draw lasting conclusions. However, as a pilot study it shows that it is both possible and desirable to involve people with dementia in website design. It also indicates that, although each individual is different, it may be possible to elicit some general information about what makes a site easy to use for people with dementia. More research is certainly justified and needed in this area.

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