

Accessible Websites for People with Dementia: a Preliminary Investigation into Information Architecture

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People with dementia have not traditionally been seen as a user group for website development. This paper describes the first attempts to discover some of navigation design needs when developing an information-based website for people with dementia. A card sorting methodology is described using existing information that is provided for people with dementia about their condition. Some participants with dementia found it difficult to group concepts together. This could have a profound affect on the design of good websites.

Introduction

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 2006). There are however maybe 18,000 people under the age of 65 in the UK with dementia (Alzheimer's Society 2006).

People with dementia have not traditionally been seen as a user group for website development. However, due to the availability of drug treatments that slow the progression of the disease and patterns of increasing early diagnosis the numbers of people in the early stages of dementia are increasing. Involvement of people with dementia in voluntary organisations such as the UK Alzheimer's Society is also increasing (Litherland 2004). Websites of organisations for people with dementia now have sections specifically targeted at this user group. However, there is little evidence that the design of these websites takes into account any special needs people with dementia may have when using the web (Savitch and Zaphiris 2005).

Dementia has been defined as a syndrome characterised by the development of multiple cognitive deficits (Cummings and Khachaturian, 1999). Causes of dementia include Alzheimer's disease, vascular dementia and dementia with Lewy bodies (Alzheimer's Society, 2006). The cognitive domain which is impaired first and foremost in Alzheimer's disease is memory (Kertesz and Mohs 1999). Topographical disorientation, ie difficulty in orienting to, navigating through and feeling familiar with one's surroundings is also seen in Alzheimer's disease (Pai and Jacobs 2004). Most people with Alzheimer's disease show language changes with naming

disturbances being especially prominent (Henderson 1996). In tests where participants were asked to generate examples of words in a particular category, people with mild and moderate Alzheimer's disease produced many fewer exemplars than normal elders. People with mild dementia may remember a given concept and explain its meaning, whereas people with in the moderate stages could not (Bayles 2003). People with Alzheimer's disease may also retain knowledge of low-dominant attributes, ie properties not central to the word's meaning (Nebes and Halligan 1996).

These problems with language are likely to affect the way people with dementia use websites where navigation is heavily based on language and the need to associate the content of a page with a word or phrase used as a menu item or button label. This paper describes the first attempts to discover some of the navigation design needs when developing an information-based website for people with dementia.

Involving People with Dementia in Research

Until recently, assumptions were often made that people with dementia do not have views about their condition and are unable to express their own history (Allen et al 2003). However, there is growing recognition that people in the early stages of dementia are able to provide accurate and valid reports of the experience of services provided for them, such as community care (Bamford and Bruce 2000).

When working with people with dementia, appropriate research methodologies are vital. In both the areas of dementia care and dementia research a more person-centred approach has been adopted (Kitwood 1997). A collaborative style is appropriate when carrying out research with this population. In such research the person with dementia, carers and researchers explore difficulties and options for their resolution together (Blackman et al 2003). In the HCI community, it is recognised that new techniques might be needed when working with older or disabled people (Newell and Gregor 2004). Older people in general encompass an incredibly diverse group of users. For this reason, Gregor et al (2002) have put forward the concept of user-sensitive inclusive design rather than user-centred.

People with Dementia and Computers

Some people with dementia, however, are actively using computers and the internet (DASNI 2005; Alzheimer's Forum, 2005). Alzheimer's Forum is a website for people with dementia that is run by a small group of people with dementia at the West Kent branch of the Alzheimer's Society. There are also a number of websites offering information about the condition and ways of coping. However, although the content of these websites is written for people with dementia there is no evidence that they have been designed specifically for this user group (Savitch and Zaphiris 2005).

The aim of the follow-up study, reported in this paper, is to investigate how people with dementia view the information that is available to them in terms of any mental models they may have of how this information should be arranged and organised.

Information Architecture and Website Design

Information architecture has been defined as the process of creating an underlying organization system for information (Kuniavsky 2003). In website design, it especially refers to how the different pages of the site relate to one another, and involves such issues as content analysis and planning, organisation of the pages, providing cues to help users to orient themselves, labelling and navigation design (Brinck et al 2002). Navigation is a major part of the user experience on a website and careful attention needs to be paid to designing appropriate and usable navigation that allows users to get to where they want to go (Lazar, 2003).

Kuniavsky (2003) has identified the need to establish who the audience is, how they think, what words they use and whether the existing information architecture makes sense to them. Most websites are designed in some sort of top down hierarchy. Usually there is a top page where the user enters the site, middlemen page for topical areas or different user audiences and content pages (Lazar, 2003). Appropriate terminology is important as words can be ambiguous and easily misunderstood and their comprehension by the website user group is critical (Kuniavsky 2003).

The user's mental model of a particular website – ie how people understand the topic, the picture they have developed of how the information is organised, and the names and relationship of the terms they use (Kuniavsky 2003) is investigated in this study using a card sorting technique.

Methods

Ten people with dementia were asked to take part in the study. They were all in contact with the UK Alzheimer's Society for support and/or advice and recommended by staff working at the Society. The participants consisted of eight men and two women. Participants were not expected to have any prior knowledge of computers or websites. For comparison the study was also undertaken with eight people who are employed by the Society in various roles to give out information about dementia. This group consisted of six women and two men. This group was chosen because they are instrumental in providing information for people with dementia. Assumptions are often made that this group will have insight into how people with dementia think.

The topics used in this study were taken from existing printed publications produced by the UK Alzheimer's Society. The information provided and the language used has been extensively researched by the Alzheimer's Society 'Living with dementia' programme to produce a booklet entitled 'I'm told I have dementia' and a series of information sheets for people with dementia. This information has been used to produce a section of the UK Alzheimer's Society's website (Table 1). The website section was developed by the Society's website manager using a 'bottom-up' approach (Brinck et al 2002) using the text and titles of the sheets and booklet chapters. It has been established that the existing navigation is not particularly easy for people with dementia to use (Savitch and Zaphiris 2005).

Card Sorting

The card sorting technique is a useful approach to understanding what natural categories people have for the domain, and is appropriate when the designer is not a domain expert and needs the insight of users (Brinck et al 2002). The card sorting technique was chosen for this study because it is a simple technique that is not threatening to the participant. Card sorting has successfully been used to investigate web health information architecture for older users (Kurniawan and Zaphiris 2003).

The titles of the sheets/booklet chapters were cut out and pasted onto cards. Participants were asked to 'sort' the cards into groups in any way that made sense to them. It was made clear to all participants that there was no right or wrong answer, and that the groups could be made up of any number of cards and that not all the cards need to be grouped. Once the cards were sorted, participants were asked to provide a suitable overall title for each group. Participants were encouraged to talk through their decisions throughout. The results were then analysed using 'eyeballing' and cluster analysis techniques (Martin 1999).

Table 1: Existing website design

Website heading	Card topic
After the diagnosis	Living with dementia
Types of dementia	What is dementia? What is Alzheimer's disease? What is vascular dementia? What is dementia with Lewy bodies? What is fronto-temporal dementia?
Treatments	Aricept – a drug for Alzheimer's disease Reminyl – a drug for Alzheimer's disease Exelon – a drug for Alzheimer's disease Ebixa – a drug for Alzheimer's disease
Where can I get support?	Where can I get support? How can the GP help? How can social services help?
Planning for the future	Sorting out your money Working Will I still be able to drive? Writing a will
Ideas for looking after yourself	Everyday tips Making everyday life easier Ideas for keeping healthy
Family and friends	Telling other people Will my family get Alzheimer's disease?

An additional card – 'Having a brain scan' was also used.

Results

Three of the ten participants with dementia did not group the cards at all. They were happy to talk about the individual topics raised, but did not find any associations between the topics. All three participants could read the topics and clearly understood the meaning of the word or phrases. They appeared however to sometimes be confused especially if the phrase on the card appear in the form of a question. This would often prompt the participant to answer the question or state that they knew the answer.

The results of the card sort for the remaining seven participants with dementia and the eight information workers were analysed with the IBM's EZSort software. The results can be seen in Figure 1. The average algorithm was used. This gives a balance between two algorithms - single linkage algorithm, which emphasises more on similarities and the complete linkage algorithm, which emphasises more on differences.

The analysis of the card sorts shows that all participants in the study have grouped the drugs for Alzheimer's disease together and the various causes of dementia together. From Figure 1, it is clear that there is more agreement in associations within the group of information workers than within the group of people with dementia. The results from the people with dementia are less uniform than those of the information workers.

Areas of Most Difference Between the Sets of Participants

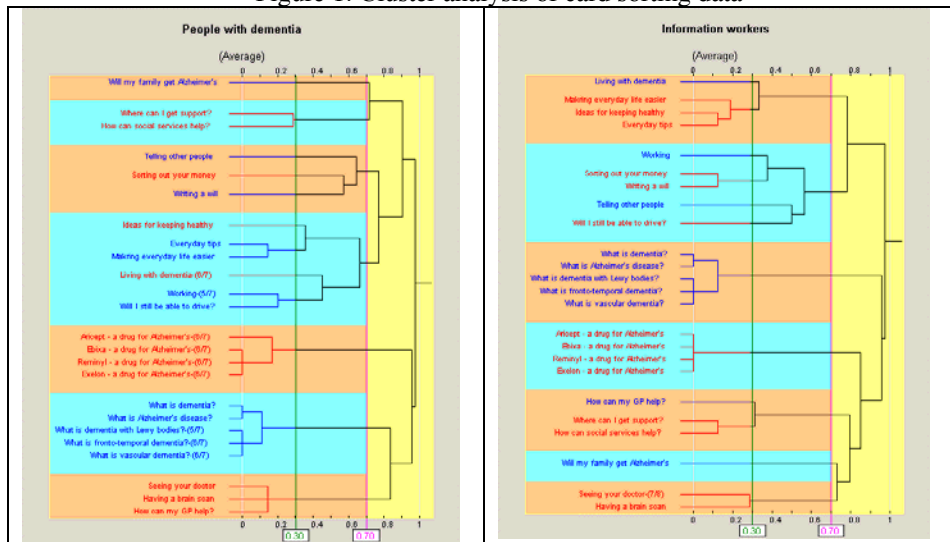
The topics that showed the most difference between the two sets of participants were: 'Telling other people', 'How can my GP help?' and 'Living with dementia'. The participants with dementia generally kept 'Telling other people' as a topic on its own. Many of the participants highlighted this subject as being very important to them. The information workers were more likely to group this card with others. The topic 'How can my GP help?' was treated differently by the two sets of participants. The information workers tended to see this topic as completely separate from the 'Seeing your doctor' topic and tended to associate it with the general 'How do I get support' topic and the 'How can social services help?' topic. However, the participants with dementia generally kept the two topics 'Seeing your doctor' and 'How can my GP help?' together. Presumably because they did not differentiate between the two statements in the same way as the information workers did. The 'Living with dementia' topic was also viewed differently between the two groups. The information workers tended to see this as a general topic covering everyday life for someone with dementia. Whereas the people with dementia themselves seem to associate it more with the more practical and pressing issues such as driving and working.

Areas of Most Agreement Between the Sets of Participants

The two areas where there was most agreement between the two sets of participants were the groups of topics associated with drug treatments and the group of topics associated with the different causes of dementia. Both sets of participants also tended to keep the 'Will my family get Alzheimer's' topic on its own. The information workers were more likely to name the drugs group of cards 'Treatments' (4/8 participants), whereas the people with dementia were more likely to call the group 'Drugs' or 'Medicines' (4/7 participants). The existing website uses the word 'Treatments'. The participants with dementia each called the causes of dementia group a different title, eg what is dementia, types of dementia, forms of dementia, kinds of dementia, whereas four of the eight information workers chose the title 'Types of dementia'. Again, 'Types of dementia' is the phrase used on the existing website. The 'Will my family get Alzheimer's' card was classed as a topic on its own by three of the seven people with dementia, and two of the eight information workers. One person with dementia and two out of eight information workers grouped it with

other ‘medical’ cards. Two of the information workers grouped the card with the ‘Telling other people’ card. Again, this might reflect their previous knowledge of the existing website.

Figure 1: Cluster analysis of card sorting data



Number, Size and Names of Groups

The information workers seem to have sorted the cards into fewer groups – 4-11 groups whereas the people with dementia had 5-9. People with dementia tended to have more groups consisting of only one card (14) than the information workers (12). Only three out of the eight information workers had any groups with only one card, whereas six out of seven people with dementia chose to have at least one group consisting of a single card. Although both the controls and the group of people with dementia found it difficult to give names to the groups, the people with dementia found it more difficult. Often the names of the groups given by people with dementia were longer and more complicated than those given by the control group. The group names given by people with dementia had a mean of 3.8 words per title compared with 3.0 words for the information workers.

Carrying out the Task

Way in which the task was carried out was very similar. All participants tended to pick out the cards about drug treatments and the types of dementia first. Some participants with dementia were put off by terms that they didn't understand, eg some seemed confused about drug names or the causes of dementia. Most of the participants with dementia were keen to give their opinions about the topics but were easily distracted – especially in the topic was given in the form of a question.

Conclusions and Discussion

The finding that three of the ten participants with dementia did not group the cards at all is interesting. Although it could be that the participants did not understand the task that was being asked of them. The fact that people with dementia found it difficult to group concepts together could have a profound affect on the design of good websites. It could be argued that people in a stage of dementia that hinders them from thinking hierarchically would not be able to use the world wide web. However, the authors believe that future generations of people with dementia will turn to the web for information and support. It is the role of web designers to make the website as easy to use as possible. It might be that traditional website design based on menus hierarchies is not suitable for people with dementia. However, it is too early in the research to make generalizations about website design.

The fact that three of the participants had problems understanding the task raises the issue that the card sorting technique used may not be suitable for use with people with dementia. It might be tempting to dismiss the views of the three participants who did not group the cards because there might be an assumption that these people would not be able to use websites. However, there is no evidence that the participants could not use a computer or that they would not be interested in the information provided by the Alzheimer's Society website. More work is needed to establish how people with dementia do find information they are looking for.

The interviews with people with dementia were generally longer than those with the information workers. All the people with dementia were keen to discuss the topics on the cards and their experiences. This was especially true when the topic was written as a question.

The fact that all participants grouped the cards relating to drug treatments and the causes of dementia may be due to the topics but may also be because the terminology used is very similar. For example, all the cards about drug treatments are written 'Drug name – a drug for Alzheimer's' and all the cards on the topic of causes of dementia are written in the style 'What is xxx?'. Terminology appears to be important – the information workers clearly see a difference between the phrase 'seeing your doctor' and the phrase 'how can my GP help?', whereas the group of people with dementia linked these two cards together more. The issue of the use of questions as headings was also raised. One of the information workers was initially drawn to grouping the cards as 'questions' and others. One of the participants with dementia specifically highlighted the issue of whether the 'reader' was 'you' or 'me'.

Further research is need. It is proposed that a website be devised based on the grouping identified by people with dementia and tested by people with dementia. The terminology used in website design also needs to be investigated further. Navigation systems are clearly important for people with dementia. The idea of a flat structure needs to be investigated further and compared with other navigation systems. It is clear that traditional HCI methodologies need to be adapted when designing for people with dementia.

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