

LEARNING FROM PEOPLE WITH DEMENTIA TO IMPROVE ACCESSIBILITY OF WEBSITE INTERFACES

Nada Savitch
Centre for HCI Design
City University
Northampton Square
London EC1V 0HB
nsavitch@alzheimers.org.uk

Ed Freeman and Linda Clare
University College London
Gower Street
London WC1E 6BT

Panayiotis Zaphiris
Centre for HCI Design
City University
Northampton Square
London EC1V 0HB

ABSTRACT

Computers could play an important part in improving the quality of life for people with dementia: for information seeking, communication and leisure. Computers and the Internet offer a special tool that could help people to maintain and learn new skills, develop hobbies and communicate with others in new ways. However, the design of interfaces often acts as a barrier to people with cognitive difficulties. Computer applications have been developed as tools in the diagnosis of dementia and the potential for using computers for activities in care settings is being recognised. However, very little research has been done into what people with dementia themselves need from computer interface design. This poster explores the attitude of people with dementia towards computers and the feasibility of involving them in the development of website design.

Keywords

Dementia disability participatory design

1. INTRODUCTION

Dementia is a progressive neurodegenerative disorder caused by many different diseases, the most common being Alzheimer's disease. People with dementia typically have problems with language, memory and visuospatial processing [9].

There are about 750,000 people in the UK with dementia. Although mainly older people are effected, there are 18,000 people in the UK under the age of 65 who have dementia [2]. Dementia is a progressive and debilitating disease. However, earlier diagnosis and advances in drug treatments that arrest progression of the disease, have highlighted the needs and abilities of people in the early stages.

2. COMPUTER USE BY PEOPLE WITH DEMENTIA

People with dementia are often passive consumers of computer applications. Computers are increasingly being used as tools in diagnosis [11]. There are various projects developing computer applications to aid independent living, eg sensors, detectors and tracking devices [3]. Some work has been carried out on memory aid applications and the use of computers for rehabilitation and reminiscence [8,1].

However, people with dementia are also using computers to improve their own quality of life. At a day centre run by the Alzheimer's Society in West Kent, the clients use computer applications to find new ways to communicate, pursue interests, and have fun. Participants have developed a website, which they maintain with the assistance of a support worker [12]. There is already at least one internet-based self-help group for people with dementia [5].

3. INVOLVEMENT IN RESEARCH

A person-centred approach to research is being widely adopted in the field of dementia research. Many researchers believe that people with dementia should be included in research as participants and not as subjects or objects. Increasingly people with dementia are being included in the design, development and evaluation of the services they use. However, there is debate about the level to which this can be achieved while not cognitively and emotionally out-pacing the person with dementia [6]. It will be important to consider the feasibility of some of the methods involved in classic participatory design, such as storyboarding for involving people with dementia.

The design of services for people with dementia should focus on abilities and residual interests rather than the deficits caused by the dementia [10].

4. IMPROVING ACCESSIBILITY OF WEBSITES

The feasibility study described here is the first stage of a larger research project which aims to develop website design guidelines in collaboration with people with dementia. A key principle underpinning the study was that

the needs of the participants be seen as the primary goal both in terms of the outcomes and of the research process.

4.1 Feasibility of people with dementia using computers

The ability of people with dementia who have used computers routinely may be preserved as research has shown that procedural memory for carrying out everyday tasks is relatively spared [13]. It has also been shown that people with dementia can learn new skills [4] and computers may be an ideal medium for this if interfaces are designed well.

Computer interfaces can and should be designed in a way that maximises their accessibility and enables people with early-stage dementia to benefit from this enabling technology should they wish to do so.

4.2 First phase study of website design

A small-scale, preliminary study, with a collaborative and person-centred approach has been undertaken [7]. Five men with probable Alzheimer's disease in the early stages participated in the study.

The participants were asked to compare two different website designs offering the same content. The original design was compared with a second website adapted to take into account some problems that people with dementia might have with respect to attention and language. The design of the second website was less cluttered than the original, made greater use of colour and icons, and had fewer links per page.

Six issues to be addressed in the future were identified from the study: scrolling difficulties, information hidden below the 'fold', becoming lost on the page, clicking on the wrong link, clicking on text which was not a link and becoming worried or upset.

However, the most important finding of the study was that people with early-stage dementia are interested in using the internet and that it is feasible to involve them as collaborators in the development of web-based resources. The study also showed that people with early-stage dementia who have little prior experience of using computers or the internet can be successfully introduced to this activity.

5. ONGOING RESEARCH

In the future people in the early stages of dementia will increasingly require access to the same electronic resources and information as the rest of the population. This research focuses on website interfaces because they are flexible to design and because the Internet is one of the main ways in which people with dementia are using computers.

The only way to understand the needs of people with dementia is to involve them in the design process. To

achieve this, a methodology for developing a truly participatory design approach for a website for people with dementia will be developed. Lessons learnt from the design process will be extrapolated to develop general website design guidelines, which will make a real difference to the experience of people with dementia using the world wide web.

6. REFERENCES

- [1] Alm N. and O'Mara D. (2001). Having fun with dementia, *Interfaces*, 46, Spring 2001, 6.
- [2] Alzheimer's Society website.
www.alzheimers.org.uk
- [3] Chapman A. (2001). There's no place like a smart home, *Journal of Dementia Care*, 9(1), 28-31.
- [4] Clare L. et al (2000). Intervening with everyday memory problems in dementia of Alzheimer type: an errorless learning approach, *Journal of Clinical and Experimental Neuropsychology*, 22 (1), 132-146
- [5] DASN international website
<http://www.dasninternational.org/>
- [6] Dewing J. (2002). From ritual to relationship. A person-centred approach to consent in qualitative research with older people who have a dementia, *Dementia*, 1(2), 157-171.
- [7] Freeman E., Clare L., Savitch N., Royan L., Litherland R., Lindsay M. (2004). Improving the accessibility of internet-based information resources for people with early-stage dementia: a collaborative approach. Submitted to *Aging and Mental Health*, 2004.
- [8] Hoffman M. et al (1996). Interactive computer-based cognitive training with patients with Alzheimer's disease, *Journal Psychiatric Research*, 30(6), 493-501.
- [9] Mendez M.F and Cummings J.L (eds) (2003). *Dementia: A clinical approach* 3rd edition (2003). Butterworth Heinemann.
- [10] Nolan M. et al (2002). Towards a more inclusive vision of dementia care practice and research, *Dementia*, 1(2), 193-211.
- [11] Swainson R. et al (2001). Early detection and differential diagnosis of Alzheimer's disease and depression with neuropsychological tasks, *Dementia and Geriatric Cognitive Disorders*, 12, 265-280.
- [12] West Kent branch of the Alzheimer's Society website
www.alzheimers.org.uk/WestKent
- [13] Zanetti O. et al (2001). Effectiveness of procedural memory stimulation in mild Alzheimer's disease patients: a controlled study, *Neuropsychological Rehabilitation*, 11(3/4), 263-272.