

LEARNING FROM PEOPLE WITH DEMENTIA TO DEVELOP RESEARCH METHODS FOR OLDER PEOPLE

Nada Savitch and Panayiotis Zaphiris
Centre for HCI Design
City University
London EC1V OHB
Email hf208@soc.city.ac.uk

ABSTRACT

Much of the research into HCI and the older population has concentrated on physical problems associated with older age, such as visual and motor problems. Cognitive decline is associated with older age, and in many older people cognitive impairment develops into dementia.

This paper describes how people with dementia are too often an overlooked minority and how the HCI design community might learn from them to develop research methods and computer interfaces which are of benefit to older people in general.

Keywords

Older people, dementia, participatory design, person centred research, inclusive design

1. WHAT IS DEMENTIA?

Dementia is predominantly a disorder of later life, with its prevalence and incidence rising sharply with advancing age [12]. About 750,000 people in the UK have dementia; only around 18,000 are under the age of 65. One in five people over the age of 80 has dementia [3].

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 [17]. Many of the impairments caused by dementia are also associated with old age. 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 is more difficult [13].

2. PEOPLE WITH DEMENTIA AND COMPUTERS

Historically, people with dementia, in common with the majority of older people, have been seen as passive consumers of computer applications, rather than being involved in their development.

Computers have been used as tools in diagnosis and assessment [4]. There are various projects developing computer applications to aid independent living, eg sensors, detectors and tracking devices [5]. Some work has been carried out on memory aid applications [9] and the use of computers for rehabilitation [11] and reminiscence [2].

However, people with dementia can enjoy using computers, profit from a sense of achievement and be involved in evaluation of web-based systems [11, 3 and see also poster at this conference].

3. PERSON-CENTRED APPROACH

Tom Kitwood pioneered the idea of person-centred dementia care and urges researchers to take into account the uniqueness of each individual and use an array of methods to build up a total picture of their experience [15]. Researchers are increasingly recognising the importance of the person with dementia and their experience, rights and perspective [7].

The views, preferences and choices of people with dementia have often been disregarded or treated as irrational or unreliable [14], but people with dementia can be included in the design and evaluation of the services they use [1].

4. FINDING A SUITABLE DESIGN METHODOLOGY

A 'holistic' approach, where the user is involved from the start of the design process, has been identified as important when designing for older users. This is because the designer can examine the context of the application in the user's life: how the user learns to use the technology, what support might be needed and how the user experiences and perceives it [6].

Lines and Hone have described their experience of using focus groups with older people and the difficulty of retaining the attention of the whole group [16]. Attention is a problem in dementia, however, lessons from person centred care have shown that there are many ways in which people with dementia can communicate and that time and patience are very important [1].

Participatory design techniques, have been used successfully with older people. Participatory design focuses on collaborating with the users throughout the design and development process. Ellis and Kuriawan have described the importance of building a relationship based on trust with the participants in the design project and the advantage of using a flexible and easily modified HTML based system for cooperative prototyping [8].

Researchers at the University of Dundee have put forward a new methodology that they called user sensitive inclusive

design, which addresses the great variety of user characteristics shown by people with dementia and promotes the development of tailored, personalisable and adaptive interfaces [10].

5. PROPOSED RESEARCH

We plan to investigate the possibility of developing a unified methodology that combines the participatory and sensitive inclusion design approaches from HCI with person-centred support from dementia research to develop and validate design techniques with and for people with dementia.

The project aims to work with people with dementia themselves to identify what aspects of computer interface design may act as a barrier to access, and to establish new ways of working with people with dementia to design computer interfaces

The limited work carried out so far has shown that people with dementia will need support both to use computers and to express their views. In order for the research to be truly 'person-centred' the participants will need to see the benefits for them in the work being carried out.

Ethnographic studies of groups of people with dementia using computers are the first stage in identifying their needs, capabilities, limitations and views; and in developing an appropriate methodology for involving people with dementia and older people in general.

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