A user centred approach to supporting people with cognitive dysfunction

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Abstract
A number of themes are very apparent in the papers in this workshop, which have been excellently addressed by the authors. This keynote paper brings together some of the views suggested in the papers, and also suggests some challenges in research and development into technology to support people with cognitive dysfunction which have received less attention from the authors

Keywords
Cognitive dysfunction, user centred design.

Models of Disability
There are two models of disability: the "medical model" and the "social model". Similarly there are two approaches to the design of equipment for people with disabilities. Although they have many similar characteristics, rehabilitation engineering operates in clinical settings, where the major focus is on curing people who are sick. In contrast, assistive technology takes the view that it is primarily concerned with supporting disabled people with technology rather than "curing" them of their disability. The majority of my group's research does not involve clinical settings (we do not consider day centres or sheltered housing to be primarily a clinical setting), and, for this and other reasons, we have tended to follow the social model of disability. The consequence is that our focus is on attempting to exploit the abilities of users and how these can be utilised to compensate for reduced or lack of functionality in our user population. Details of the research at Applied Computing at Dundee University can be found the HCI overview paper in CHI 2006 [6]

User Centred Approaches

Like many authors in this workshop, my group believe that we need to interact closely with users. There are a range of approaches to achieve this which have been developed for main stream design. These include user centred design, participatory design, cultural probes, future workshops, ethnography, and co-design. All of these methods have been developed with the aim of ensuring that users are active participants in the design processes. There are, however, some important distinctions between traditional User Centred Design with able-bodied users, and the approach needed when the user group either contains, or is exclusively made up of, people with cognitive dysfunction. These include:

- Much greater variety of user characteristics and functionality, hence difficulty in finding and recruiting 'representative users'.
- The need to specify exactly the characteristics and functionality of the user group.
- Conflicts of interest between user groups, including temporarily able-bodied.
- The users may not be able to communicate their thoughts, or even may be 'incompetent' in a legal sense.
- Ethical issues, of what types of interaction are appropriate and also the difficulties of obtaining informed consent from some users. (Recent legislation in the Scotland, for example, has meant ethical approval for work with anyone who cannot give informed consent has to be obtained from a central Scottish organisation via a system which is more appropriate to medical interventions than technologically based ones).

There can be particularly difficult ethical problems when involving users with cognitive disabilities in the design process. Even with these problems, however, it is not impossible to include users with cognitive dysfunction sensitively in the design process. This discussed in more detail in [5]. It is also worth considering other ways of obtaining insights, for example, we have arranged for staff members to attend day centres as volunteers on a regular basis, and also to combine experiment sessions with social gathering so that the users and the designer can meet very informally.

Another way of facilitating interaction with users is the use of dramatic techniques and theatre. This could provide a particularly valuable methodology for the design process when the target users have cognitive impairment and thus may not be appropriate for including within standard user centred design methodologies. The Experience Report in CHI 2006 [7] discusses the various ways in which actors and theatre can play a part in the design process for human computer interfaces.

Variability of Users

The extreme variability of users, not only makes evaluation methodologies very difficult, but also has a major effect on the design process. Compared with the user groups for the vast majority of HCI research and development, users with cognitive dysfunction have a very much wider range of variability, both in type and extent of their cognitive functioning. This is addressed in [3] and in many of the papers in this session, and authors have suggested ways in which this variability needs to be factored into the design process. In addition, however, it must be remembered that cognitive abilities of any human being change with time. Significant changes can occur over a period of minutes, days and weeks. It has thus been suggested

that this be drawn particularly to the attention of designers by introducing the concept of Designing for Dynamic Diversity[2]. This process entails a recognition that peoples' abilities are diverse at any given age and that as they grow older the diversity grows dynamically; it also involves a recognition that even any given individual's abilities will vary according to factors such as mood, fatigue, and blood sugar levels. Current software design typically produces an artefact which is static and which has no, or very limited, means of adapting to the changing needs of users as their abilities change. Most user-centred paradigms look typically at concerns such as representative user groups, without regard for the fact that the user is not a static entity. It is thus important not only to be aware of the diverse characteristics of people with cognitive dysfunction, but also the dynamic aspects of their abilities.

Older users

There is a tendency in much assistive technology research and development to focus on a particular disability, and, in the past, also a tendency to concentrate on young motivated people with a single disability. This also occurs in developments for people with cognitive dysfunction, although the high occurrence of dementia in older people. has meant that there is an increasing focus on supporting people with this disability. This research can also be useful to other age groups, as, in many ways the user-requirements of 'slow learners' are equivalent to those of many elderly people. In addition some forms of dementia simply exaggerate the relatively mild effects of 'normal' aging on the cognitive system, and thus support systems appropriate to people with mild dementia can be useful for older people without any clinical signs of dementia.

In contrast to young people with cognitive dysfunction, however, older people rarely only have a single cognitive disability. The range and type of cognitive dysfunction is very large compared with other sections of the population, and the changes and rates of change of cognitive functioning are much larger than in younger groups. Ogozalec [8] comments that: "It is difficult to categorise and draw conclusions about 'the elderly', since they comprise such a diverse and heterogeneous population". This diversity, particularly of cognitive function, ought to be taken into account if we are to make software and the internet available to as large a percentage of the population as possible.

Older people with cognitive dysfunction can roughly be divided into three groups

- Fit older people, who will not consider themselves disabled, but whose cognitive functioning is less than it was when they were younger, and who also will have multiple minor motor and sensory impairments.
- Older people with multiple minor disabilities, who also have a major cognitive dysfunction
- People with a long term cognitive dysfunction, who have grown old, and therefore beginning to have other dysfunctions associated with older age.

The other characteristic, which is particularly important when considering cognitive dysfunction, not only for all ages, but for people with all levels of cognitive ability, is the concept of cognitive overload. All people "suffer" from cognitive overload, when they are in the position where the environment has higher requirements for

cognition than they have available. This applies to a fighter pilot, to a person being required to work faster than is appropriate, from doing too many things at once, or failing to cope with information overload or to person suffering from exhaustion or the effects of (legal or illegal) drugs.

One way in which cognitive overload can occur is when the task must be done under externally imposed time constraints whether actual or simply inferred by the user . Salthouse [9] comments that "A key aspect of any intellectual task , in regard to interactive technology for people with mild or moderate 'global' cognitive impairment, is speed" . That is, whatever level of performance a person can achieve in any given situation, it will be made worse if the task has to be done quickly. This resonates with the social model of disability in which the rhetoric is not that the wheel chair users is disabled because he is in a wheel chair, but it is the steps which disabled the person. There are other ways in which people can be cognitively disabled by the environments within which they have to operate. The human machine interaction problems of an able bodied (ordinary) person operating in an high work load, high stress or environmentally extreme (i.e. extra-ordinary) environment has very close parallels with a disabled (extra-ordinary) person, operating in an ordinary situation [4].

We can thus support people with cognitive impairments either by supporting their cognitive capacity, or by reducing the cognitive demands on them - two different approaches to essentially the same challenge.

Other characteristics effecting cognitive performance

The ability for a person to cope with the cognitive demands of a task are not only down to their cognitive ability. Virtually all aspects of cognitive processing are shaped by attention, and, regardless of impairment, while we all have some control over attention, attention can also have some control over us. The efficiency of selective attention is markedly diminished in most forms of cognitive impairment. In addition the effects of depression in later life can closely mimic those of dementia, and can be easy to confuse the two causes.

There is also marked deterioration of visuo-spatial and verbal abilities in older people, which can directly affect the way they use interactive systems. Decline in visuo-spatial abilities can cause difficulty with 'de-coding' layouts and utilising any inherent organisation, and a deterioration in iconic memory can be due to the graphical nature of many interfaces, as can limitations in verbal ability, the diminution of vocabulary and the lack of familiarity with technological vocabulary. Abstract and metaphorical phrases can also provide a challenge with a tendency for older people to take them literally. Individuals with congenital language and/or intellectual disabilities (e.g. congenital aphasia and Down's syndrome) may never become literate, and dyslexia may substantially reduce the ability to understand written messages.

Another key concept related to interface design for older people and people with cognitive impairment is 'complexity'. This is a particular challenge provided by for older people by many commercial computing systems (e.g. an out of the box version of Outlook

Express contains 250 functions on its first page, and using Yahoo one can have over 300 active functions available on one page!) For older people the challenge of complex interfaces can be due to age related declines, particularly in hearing and vision, rather than cognitive impairment per se, but, where there is significant cognitive impairment, complexity also needs to avoided and the use of language given careful consideration with the syntax and vocabulary being straightforward and 'everyday' as the context allows.

High work loads, and the stress levels to which this can lead, often reduce the cognitive performance of the human operator. For example, not only can a very noisy environment create a similar situation to hearing or speech impairment, but it can also create stress, which can reduce cognitive performance.

The importance of research and development taking into account the full diversity of the potential user population was addressed by Newell in his keynote address to InterCHI '93, and is further discussed in [4]

Evaluation

It is clearly important to evaluate the results of research and development of support systems for people with cognitive dysfunction to provide evidence of the success (or failure) of our devices/systems. Both the medical, and mainstream HCI evaluation methods, however, can be less than ideal. Evidence based medicine, although very appropriate in certain circumstances, is dominated by the needs of evaluating pharmaceutical interventions. This requires large numbers of patients, carefully organised control groups, who receive identical treatment except for the pharmaceutical intervention, and, usually, double blind trials – where neither the patient or the researcher are aware which users have received the intervention and which the placebo. HCI practitioners recommend carefully controlled studies with large numbers of users to give results representative of the population. These approaches are rarely completely suitable for research and development of systems to support people, who have cognitive dysfunction. The only "intervention" in drug trials is whether a particular chemical is contained in the pill, whereas technological intervention is substantially more complex and also there is usually a great amount of variability in the experience of using technology which cannot possibly be controlled for. Calls for a narrow definition of "scientific evidence" can thus make traditional evaluations worse than useless (I once took part in a discussion about the evaluation of a PDA based memory aid in which it was said that there had to be a control group using pencil and paper, and that exactly the same time had to be spent training the control group to use pencil and paper as the intervention group! In this particular study the training time for the intervention group was significantly reduced because it was thought inappropriate to have an overlong period training the control group to use pencil and paper – thus meaning that the intervention group did not have sufficiently long training on the PDA).

We need to develop evaluation methodologies appropriate to the context of our research, which suit our own purpose and are valid within our own context, rather than try to ape the approaches of either medicine or HCI, and be apologetic about our evaluation methodologies. One such very thorough evaluation methodology for a conversational support system is reported in [1].

Aesthetics

Finally developers should remember that people with cognitive dysfunction do not automatically have reduced appreciation of aesthetics, and this aspect of design should have a high priority. An example of this is that a visual designer being part of the CIRCA project [6] was a significant factor in its success.

Conclusions

It is vital that designers are fully aware of the range of diversity which can be expected with people with cognitive impairment, and also the changing nature of the cognitive functioning of people. They should also be aware that cognitive dysfunction often co-exists with sensory and motor dysfunction, particularly for older people, and thus those developing systems for people with cognitive dysfunction need to take account of other potential disabilities. It is important to evaluate the systems we produce, but such evaluations should be fair and not unnecessarily disadvantage the potentially useful systems we have developed. We need to put more effort into developing new evaluation methodologies and justifying their efficacy.

References

The references provided by the authors of the papers submitted to this workshop are very extensive and cover the field excellently. The reference below are mainly the work of this author and complement the personal statements made in this paper.

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