# Cognitive Support for Dementia: Submitted to the CHI2006 Workshop on Designing Technology for People with Cognitive Impairments

**Joe Wherton and Andrew Monk**
Centre for Usable Home Technology (CUHTec),
Department of Psychology, University of York
York YO10 5DD, UK
j.wherton@psych.york.ac.uk
a.monk@psych.york.ac.uk

## Abstract
The perspective developed here grounds the design of cognitive prostheses in a thorough understanding of the problems that patients have in their activities of daily living. To this end two studies were carried out exploring the requirements of assistive technology that can support people with dementia in the home. This is the first phase of the design process, in which the problems of dementia are understood from the perspectives of professional carers, patients and informal caregivers. Interview data across the two studies revealed four themes (Problems in the Home, Underlying Deficits, Consequences, and Situated Factors) that help direct research efforts in designing cognitive support systems. Problems relating to cooking activities were frequently reported, and so subsequent work will focus on supporting this task.


CHI 2006, April 22–27, 2006, Montreal, Canada.
ACM 1-xxxxxxxxxxxxxxxxx.

## Keywords
Dementia, Assistive Technology, Grounded Theory Analysis, Episodic Memory, Executive Functions

## Introduction
Dementia refers to a collection of neuropsychological symptoms that are sufficient to disrupt activities of daily living. During the early to middle stages, cognitive decline is most profound in episodic memory (memories of personally experienced events) and executive functions (planning, sequencing, and attentional control) [1,2]. Executive functions are essential for goal-directed behaviour, and recent neuropsychological studies emphasis their role in daily functioning [3].

Existing concepts for supporting executive functions involve systems that monitor task progress and provide prompts when necessary. For example, Mihaildis et al. [4] devised the Cognitive Orthosis for Assisting

Activities in the Home (COACH), which is designed to prompt patients when washing their hands. The system provides audio prompts when the patient fails to initiate an action or performs an action out of sequence. Similarly, Dishman [5] devised a Wizard of OZ prototype that monitors task progress during tea making and provides video clips of the to-be-performed actions on a monitor located on the work-top.

This paper summarises the initial phase of a PhD project that aims to inform the design of cognitive support systems that address executive function deficits. The project is being conducted at the Centre of Usable Home Technology (CUHTec), at the University of York. Much of CUHTec's research focuses on designing technology for the home that can enable older people to live more independently. It is considered that the designing of any cognitive support system needs to be based on an inductive account of everyday problems in conjunction with cognitive models of the underlying deficits. This paper describes two studies that cover this phase of the design process, focusing on the problems of dementia in the home from the perspective of professional carers, patients and their informal caregivers. This approach provides an ecological account of dementia that guides hypotheses on effective designs.

## Study 1: Professional Carer Perspective

*Method*

Nine interviews and one focus group were conducted with 20 professional carers and Occupational Therapists (OTs). Transcripts were analysed using Grounded Theory Analysis [6].

*Results*

The analysis revealed three themes that summarise the problems of dementia in the home, from the perspective of professional carer and OTs. These were 'Problems in the Home', 'Underlying Deficits', and 'Consequences for Patient and Caregiver'. The themes consisted of ten main categories, and 28 sub-categories. Figure 1 depicts the three themes with their constituent main categories and sub-categories

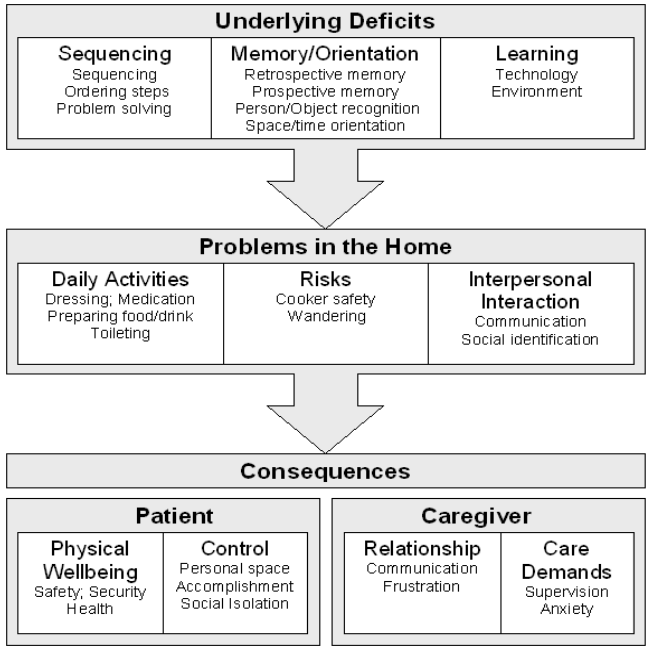


**figure 1:** A summary of the problems in the home, as perceived by professional carers and OTs.

## Study 2: Patient-Caregiver Perspective

*Method*

Interviews were conducted with five mild-moderate dementia patients and seven informal caregivers in their own home. Transcripts were analysed using Grounded Theory Analysis [6].

*Results*

Four themes summarise the problems of dementia from the perspective of patients and informal caregivers. The themes composed of 13 main categories and 37 subcategories. Figure 2 depicts the four themes and their categories.

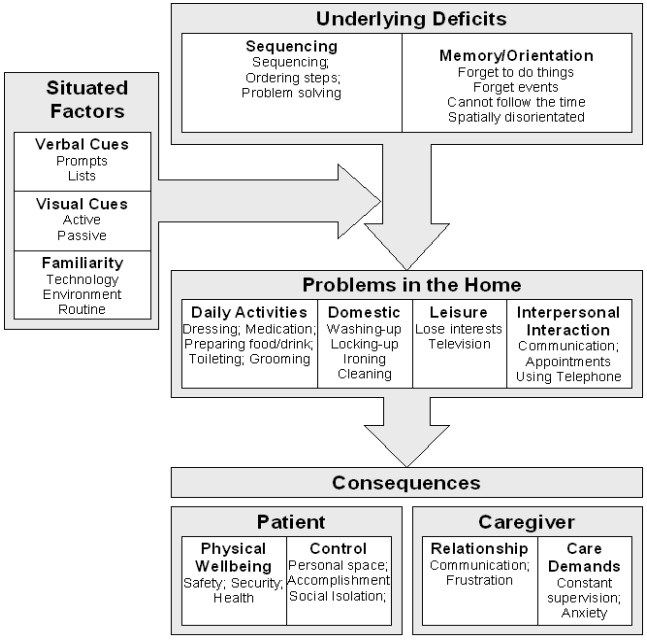


**figure 2:** A summary of the problems in the home, as perceived by patients and caregivers.

Three themes covered similar issues raised in Study 1 (Problems in the Home, Underlying Deficits, and Consequences for Patient and Caregiver). The fourth theme covers 'Situated Factors' that influence the impact of the underlying deficits on patients' functional status.

## Discussion

The two studies provide an account of dementia in the context of the home. The two perspectives are largely similar. However, clear discrepancies can be seen with regards to Problems in the Home (e.g. the professional carer perspective includes risk concerns, whereas the patient-caregiver perspective includes leisure and domestic tasks), as well as an awareness of Situated Factors. Each theme presents implications for designing assistive technologies that are useful and appropriate for the users.

## Next Stage

The next phase of the research focuses on particular problems reported by the participants. Concerns over cooking and cooker safety occurred frequently in both studies. Patients had difficulty operating the cooker controls (e.g. associating hob-burners with appropriate controls), and reported problems in sequencing all the necessary actions. Therefore, this project will focus on supporting mild-moderate dementia patients through a simple cooking activity. This will involve minimising executive functioning demands by re-representing the cooker interface and devising appropriate prompting methods. In subsequent work, participants were video recorded performing tasks in the kitchen. Analysis of the videos presented details of action errors that occur,

providing further support in proposing designs that can be empirically tested.

## Related Questions

1. What perspective should take priority when designing technology for people with cognitive impairments (e.g. patient concerns regarding leisure and control vs. caregiver concerns over care demands vs. professional carer concerns over risks)?

2. How should we augment existing domestic appliances given dementia patients' need for familiarity?

## Biographical Sketch

Joe Wherton is in his second year of the PhD project described in this paper he has presented the work at two international conferences and two external talks.

Andrew Monk is Joe's PhD supervisor and director of the Centre of Usable Home Technology (CUHTec). He has published widely on: HCI; mediated communication, and technology for the home.

CUHTec is a collaboration of researchers in Psychology, Computer Science and Electronics at York University UK to articulate user requirements for the next generation of home technologies. Key themes for our current research include: telecare and the needs of older people who wish to live independently; designing for user experience; empirical studies of leisure time activities such as viewing films and sharing photos. (See www.cuhtec.org.uk)

## References

[1] Graham, N. L., Emery, T., and Hodges, J. R. Distinctive Cognitive Profiles in Alzheimer's Disease and Subcortical Vascular Dementia. *Journal of Neurology, Neurosurgery, and Psychiatry, 75,* (2004), 61-71.

[2] Voss, S. E., and Bullock, R. A. Executive Function: The Core Feature of Dementia? *Dementia and Geriatric Cognitive Disorders, 18,* (2004), 207-216.

[3] Bell-McGinty, S., Podell, K., Franzen, M., Baird, A. D., and Williams, M. J. Standard measures of executive function in predicting instrumental activities of daily living in older adults. *International Journal of Geriatric Psychiatry, 17,* (2002), 828-834.

[4] Mihaildis, A., Barbenel, J. C., and Fernie, G. The Efficacy of an Intelligent Cognitive Orthosis to facilitate Hand-washing by Persons with Moderate to Sever Dementia. *Neuropsychological Rehabilitation*, *14,* 1/2, (2004), 135-171.

[5] Dishman, E. Inventing Wellness Systems for Aging in Place. *Computer, 37*, 5, (2004), 34-41.

[6] Strauss, A. L., and Corbin, J. *Basics in Qualitative Research: Grounded Theory Procedures and Techniques.* Sage Publications: Newbury Park, California, 1990.