

**Exploring the requirements for technology to
support people with dementia in the home**

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Abstract

This thesis explores the requirements of technology to support people with dementia in the home. More specifically, it aims to establish design requirements for systems that prompt people with mild to moderate dementia through multi-step tasks.

Chapter 1 presents existing literature that is relevant to the development of cognitive prostheses for people with dementia. The review describes patterns of cognitive decline in dementia, the impact of these deficits on everyday tasks, and technological and non-technological methods of support.

Chapter 2 presents the problems of dementia in the home from a professional carer perspective. Nine interviews and one focus group were conducted with 22 occupational therapists and professional carers. The transcripts were analysed using Grounded Theory Analysis (GTA), in accordance with Strauss and Corbin (1990). The analysis revealed three main themes: 'Problems in the home' (daily activities, risks, and interpersonal interaction), 'underlying deficits' (sequencing, memory/orientations, and learning), and 'consequences' for the person with dementia (physical wellbeing and control) and the informal caregiver (relationship and care demands). The implications of these themes for the design of assistive technology are discussed.

Chapter 3 presents the problems of dementia from a patient-caregiver perspective. Eight home visits and two individual interviews were conducted with people with mild to moderate dementia and informal caregivers. GTA revealed four main themes: 'Problems in the home' (daily activities, domestic tasks, leisure, and interpersonal interaction), 'underlying deficits' (sequencing and memory/orientation), 'consequences' for the person with dementia (physical wellbeing and control), and the informal caregiver (relationship and care demands), and 'situated factors' (verbal cues, visual cues, and familiarity). The perspective is compared to the professional carer perspective, and the design implications are discussed.

Chapter 4 describes the types of problems people with dementia experience when performing kitchen tasks. Six people with mild to moderate dementia were video recorded performing activities in their own kitchen. These included making a cup of tea/coffee, a bowl of soup, beans on toast, and tea/coffee with toast. Twenty-two video recordings were transcribed and analysed. Errors that prevented task accomplishment were recorded and grouped to form error classifications. Eight error types were identified with four main themes: ‘Sequencing’ (intrusion, omission, and repetition), ‘orientation’ (locating and identifying), ‘operation’ of appliances, and ‘incoherence’ (toying and inactivity). The error types are discussed in relation to cognitive theory and the implications for designing prompting systems.

Chapter 5 describes an experiment embedded in a real activity, designed to evaluate the effect of a novel cueing method. Eight participants with moderate dementia carried out real cooking activities (making porridge with syrup and chocolate cornflake cakes) with a care worker. At certain points, the participants were required to turn on/off the cooker. Correct control selection was scored under three different cueing conditions that represented the association between hotplates and controls. Condition 1 used the original design (symbols), condition 2 used verbal (written) cues, and condition 3 used a lighting effect (hotplate and corresponding control would light up). The implications of the experiment for the design and evaluation of technological prompts are discussed.

Chapter 6 describes future steps that should be taken to develop prompting systems for people with dementia. This includes a review of recent developments in pervasive computing that match the design requirements for prompting systems, and an interactive design framework that should be used to guide the design of prompting systems for domestic settings.

Chapter 7 provides a summary of the thesis. This includes an overview of requirements for technology to support people with dementia at home. The methodological contributions of the thesis are also discussed.

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Author's Declaration

I declare that all of the material presented in this thesis is based on my own work. Prior to submitting the PhD thesis, some of the work has been published in conference papers and a journal:

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Chapter One

Literature review

1. Introduction

Dementia refers to a collection of symptoms, including impaired memory, reasoning, and communication skills. These impairments result in a gradual decline in ability to perform daily activities. One in five people over the age of 80, and one in 20 over the age of 65 have a form of dementia (Knapp & Prince, 2007). With the increase in the aging population, formal care costs will inevitably rise, making it more difficult to provide support for persons with dementia who wish to live at home (McNamee, Bond & Buck, 2001). There are currently around 700,00 people with dementia in the UK, which is forecast to increase to over 940,000 in 2021, and 1,735,000 by 2051 (Knapp & Prince, 2007).

It is estimated that 63.5% of people with dementia live in private households, and 36.5% live in care homes. The financial cost of dementia in the UK is over £14 billion a year. The contribution made by informal caregivers saves the taxpayer £5 billion a year. The largest component of cost relates to care home accommodation, which totals almost £6 billion a year (House of Commons Committee of Public Accounts, 2008).

The progressive decline in functional status of people with dementia is emotionally and financially exhausting for caregivers. Their role changes with time, starting with assistance with relatively complex tasks, through dealing with personality changes and behavioural disturbances, to helping with more fundamental activities of daily living (Burns & Rabins, 2000). The burden on the carer contributes to levels of stress and depression, which often leads to perceived inability to cope. For the person with dementia, social dependence leads to depression, learned helplessness and loss of identity.

Decline in cognitive abilities severely disrupts abilities to carry out everyday tasks. Rehabilitative and compensatory strategies have been developed to improve functional abilities. Some of these include the use of external aids, or ‘cognitive prostheses’, in order to reduce demand on impaired cognitive processes. Recent developments in pervasive computing have provided new opportunities for supporting people with dementia in their own homes. Developments in activity monitoring through sensor and vision data, and advances in artificial intelligence have created the possibility for supporting people with dementia through multi-step tasks. The aim of this thesis is to explore the requirements for such technology so that it is useful and appropriate for the users.

This chapter will review existing literature on dementia and methods of overcoming the associated cognitive deficits. Sections 2 and 3 describe the cognitive processes that are impaired in dementia. Section 4 looks at how these cognitive impairments disrupt everyday tasks. Section 5 describes non-technological and technological strategies that have already been developed for people with dementia.

2. The human memory system

The human memory is not a unitary system. It consists of various sub-systems responsible for different memory processes. The first main distinction is that of short- and long-term memory. Short-term memory, also known as working memory, involves temporary activation patterns within the neural architecture. Long-term memory is represented by synaptic strengthening between neurones, and holds information for a longer, or permanent, period. All memory systems require three processing stages. Firstly, information is *encoded*, whereby it is registered within the system. The level of encoding usually depends on the nature of the material presented (e.g. processing the meaning of a word is encoded more effectively than the visual characteristics). Second, information is *stored*, whereby it is retained within the system. Finally, information is *retrieved*, in which the required information is accessed from storage. Retrieval capability can be manipulated by altering the cues available that reduce retrieval demands (e.g. recognition of remembered information is easier than free recall).

2.1 Working memory

Working memory is responsible for temporarily holding information that is required to perform a range of cognitive tasks, including learning, reasoning and comprehension. This system is responsible for processing incoming information into long-term memory as well as selecting and organising knowledge required for a given task. It possesses two 'slave systems' that serve a central control component (Baddeley & Hitch, 1974). The *visuo-spatial sketchpad* holds visual and spatial information, and the *phonological loop* holds verbal and audio material. Although storage capacity only lasts a few seconds, information can be mentally rehearsed, retaining it for longer. This is particularly effective in the phonological loop system, which generates a sub-vocal rehearsal of verbal material known as 'articulatory rehearsal'. The central component that controls these systems is the *central executive system* (CES). This coordinates the operations of various executive function processes such as planning, sequencing and attentional control, which are all required to achieve goal-directed behaviour in a flexible manner (Lezak, 1995).

2.2 Long-term memory

Working memory transfers information to long-term memory, and retrieves it when required. Long-term memory has a number of systems that are responsible for holding different types of information. These systems can be classified into two main forms, declarative and non-declarative (Squire, 1992).

There are two declarative systems, *episodic* and *semantic memory* (Tulving, 1972). Episodic memories are isolated events that are personally experienced (e.g. what you had for breakfast). Semantic memory includes general knowledge regarding facts and concepts about the world (e.g. the capital of France is Paris).

Declarative memory can also be classified according to its temporal direction. *Retrospective memory* refers to information from past events, whereas *prospective memory* relates to future intentions, and is concerned with when something should be remembered. It is likely that these two concepts overlap. After all, prospective memory would hold a retrospective element with regards to plans and intentions.

However, evidence suggests that these processes are distinct. For example, performance on retrospective and prospective memory tasks is not necessarily correlated. A person with a good verbal recall may be less successful at remembering to perform planned activities (Wilkins and Baddeley, 1978). The two processes demand distinct cognitive processes. Retrospective memory holds a higher degree of content than that of prospective memory (e.g. remembering a conversation with a friend involves greater memory capacity than remembering to meet a friend for lunch). However, prospective memory requires the person to remember the content at the appropriate time, and remember the appropriate action to be performed. Prospective memories are often self-initiated, and so are sensitive to the context of the to-be-remembered event. Ellis (1988) makes a distinction between *pulses* and *steps*. Pulses refer to a specific time (e.g. appointment with the doctor at 10am), whereas steps involve remembering to perform something on a broader time scale (e.g. remembering to book a doctor's appointment). Ellis (1988) found that people tend to be more effective in remembering pulse events, which tended to be remembered either at the specific time or over the course of the day. Steps, on the other hand, were remembered from time to time during the day and considered less important, contributing to a higher likelihood of forgetting.

Non-declarative, or implicit, memory refers to the accumulation of information without any conscious reference. Prior exposure to particular stimuli or events can facilitate certain responses or operations without any conscious recollection of learning. Processes involving implicit memory include: *priming*, in which exposure to one stimulus facilitates a particular response to a proceeding stimulus (e.g. naming the word 'doctor' is more rapid if it is preceded by the word 'nurse'); *conditioning*, whereby particular behaviours or responses become associated with specific events (e.g. when a particular event becomes associated with a physiological response, such as fear); and *procedural*, which includes both perceptual-motor (e.g. riding a bicycle) and cognitive (e.g. reading) processes.

Various memory and problem solving tasks have been used to explore the functioning of each subsystem in human memory. The next section will describe how these tests have been used to devise a cognitive model of dementia. We will focus on studies conducted on the two main types of dementia, which are

Alzheimer's disease (AD) and vascular dementia (VaD), during the early to middle stages of decline.

3. Cognitive deficits of dementia

During the early and middle stages of dementia, pathology tends to remain localised within particular brain regions, affecting specific cognitive modalities. Patterns of cognitive decline vary between different types of dementia. AD is the most common form, constituting 62% of all dementia cases in the UK (Knapp & Prince, 2007). AD involves high concentrations of neurofibrillary tangles and neuritic plaques in specific regions, causing a gradual deterioration of intracellular connections between neurones (Braak & Braak, 1995; Khachaturian, 1985). VaD is the second most common form of dementia, which accounts for around 27% of all cases (Knapp & Prince, 2007). VaD results from ischemic and hemorrhagic brain lesions due to cerebrovascular insufficiencies (Erkinjuntti, 1999). Unlike the gradual decline in AD, VaD tends to be stepwise, increasing in severity after each stroke episode. Despite the contrast in etiology between AD and VaD, the same brain regions tend to be affected during the early to middle stages. Consequently, the patients show a similar pattern in cognitive decline. For this reason, the literature reviewed in this thesis will be based on work carried-out with people with both AD and VaD.

3.1 Memory loss in dementia

Memory loss is the deficit most commonly associated with dementia. Although all aspects of memory are eventually affected, during the early to middle stages it is episodic memory that is most profoundly impaired. Experimental studies have consistently demonstrated poor performance in recall and recognition tasks involving verbal and non-verbal material from the onset of dementia (Delis et al., 1991; Graham, Emery, & Hodges, 2004; Green, Baddeley & Hodges, 1996).

Evidence suggests that the memory loss results from impaired learning, as opposed to poor retrieval processing (Morris, 1986; Morris & Kopelman, 1986). For example,

recognition tasks demand less retrieval effort than free recall, and so it is expected that performance would be improved as long as the information is available in long-term memory. However, people with dementia show little difference in score between recognition and free recall, indicating that the information is not available (Green, Baddeley, & Hodges, 1996). Flat learning curves also indicate deficits during the early stages of memory processing. For example, people with dementia show a minimised primacy effect, where much of the recalled material comes from working memory (Burkart, Heun, & Benkert, 1998). Forgetting rates also indicate that memory loss occurs during the transfer of material into long-term memory. Although people with dementia show normal rates of forgetting between immediate and delayed recall, they show severe memory loss between figure copy and immediate recall (Becker, Boller, Saxton, & McGonigle-Gibson, 1987). This evidence suggests that the learning deficit arises from impaired encoding, as opposed to problems in consolidation or retrieval of encoded information.

People with dementia also perform poorly on experimental tests demanding prospective memory (Huppert, Johnson, & Nickson, 2000; Maylor, Smith, Della & Logie, 2002). Maylor et al. (2002) asked participants to watch a film and respond every 3 minutes (time-based prospective memory) and whenever they saw an animal (event-based prospective memory). Additionally, in a separate experiment, participants were required to reset a clock every time they saw a clock (related cue) or an animal (unrelated cue) in the film. Participants with dementia were significantly impaired in all these tasks compared to controls, despite remembering task instructions.

The breakdown in semantic memory is far less striking than episodic memory impairment. People with dementia are usually able to recall knowledge and appear to remember the meaning of words. However, research has identified subtle deficits (Bayles & Tomoeda, 1983; Graham et al., 2004; Martin & Fedio, 1983). For example, people with dementia may be capable of classifying and identifying an item (e.g. a carrot as a vegetable), but show difficulty in actually naming the item. This indicates a breakdown in the semantic network, which consequently leads to a blurring of category boundaries and difficulty naming particular items (Martin & Fedio, 1983).

Non-declarative memory appears to be the most robust memory system. People with dementia show normal priming effects on word naming and lexical decisions (Morris, Wheatley, & Britton, 1983; Nebes, Brady, & Huff, 1989; Nebes, Martin, & Horn, 1984) and show evidence of learning through conditioning (Ankus & Quarrington, 1972). People with dementia have also shown normal learning curves on procedural tasks when matched with age controls. For example, they have normal learning rates on pursuit-rotor tasks that require the participant to maintain a stylus in contact with a small rotating target on a screen (Eslinger & Damasio, 1986).

3.2 Executive control deficits in dementia

Impairment to the CES (Central Executive System) gives rise to a collection of cognitive deficits, in planning, sequencing, reasoning, and attentional control. Deficits have been identified using a variety of tasks, including the Wisconsin Card Sorting Test (WCST) (Graham et al., 2004; Kramer, Reed, Mungas, Weiner, & Chui, 2002), verbal fluency (Graham, et al., 2004; Voss & Bullock, 2004), and the Clock Drawing Test (Kitabayashi et al., 2001; Rouleau, Salmon, Butters, Kennedy, & McGuire, 1992; Royal, Cordes, & Polk, 1998). The WCST involves a set of cards that differ in colour, size and shape. The participant is required to arrange and group these cards a number of times according to various rules (e.g. by colour, size, and shape). Similarly, verbal fluency tests require participants to list a set of words that follow a specific rule (e.g. animals beginning with 's'). The Clock Drawing Test requires participants to draw a clock face that represents a particular time. Performance on the test is scored by the number of errors made on each feature of the drawing. People with dementia tend to perform poorly on these tests because it requires them to plan and initiate a set of operations to achieve a nested goal, as well as monitor their progress through the activity.

Impairment to the CES also results in poor performance on tasks that require divided attention (Baddeley, Baddeley, Bucks, & Wilcock, 2001; Baddeley, Logie, Bressi, Della Salla, & Spinnler, 1986), selective attention (Baddeley et al., 2001; Graham et al., 2004) and attention shifting (Tales, Butler, Fossey, GilChrist, & Troscianko, 2002; Tales, Muir, Jones, Bayer, & Snowden, 2004). Divided attention refers to the ability to attend to several events concurrently. Baddeley et al. (1986) compared the

performance of people with dementia and age-matched controls on the performance of two concurrent tasks (tracking a visual stimulus and digit span). The participants carried out the two tasks separately in order to identify stable levels of performance. When the two tasks were carried out simultaneously, people with dementia showed a marked decline in performance compared to controls.

Selective attention refers to the ability to attend to a particular stimulus whilst inhibiting interference from other 'distracter' stimuli. Deficits in early stage AD and VaD have been shown using visual attention tasks, such as the Stroop test. This involves the presentation of a verb representing a colour (e.g. 'green'), but with the text written in a conflicting colour (e.g. red). The participants are required to state the verb, whilst ignoring the colour of the text. People with dementia tend to perform poorly on this task compared to controls because of difficulty in focusing attention on the target stimuli (the verbs) whilst inhibiting interference from the distracting factor (the colour) (Kramer et al., 2002; Graham et al., 2004)

Deficits in shifting attention have also been demonstrated using visual search tasks (Tales et al., 2002; Tales et al., 2004). Visual search requires participants to detect the presence of a target element (e.g. a vertical 'T'), which is displayed among numerous non-target, or distracter, elements (e.g. horizontal 'T's). Studies have shown that targets can be identified with no interference from distracters, particularly if the target has a feature that distinguishes it from all the distracters (e.g. the target is a *green* T, whilst the distracters are *red* Ts). This is also known as the 'pop out effect'. Other searches can take longer if the target shares features with different types of distracter items (e.g. the target is a *green* T, whilst the distracters include *red* Ts, and *green* Ss). In these instances, the person must conduct a 'serial visual search' by shifting attention across the display. Consequently, serial visual search is affected by the number of distracters, which is known as the 'display size effect'. People with dementia show a marked decrease in performance on serial search compared with matched controls. This suggests difficulty in shifting attention between items in the visual array, and inhibiting irrelevant stimulation.

4. The Impact of dementia on everyday activities

Experimental work has provided a model of cognitive decline during the early to middle stages of dementia. Performance on cognitive tests has been found to correlate with measures of functional status (Baum, Edwards, Yonan, & Storandt, 1996; Bell-McGinty, Podell, Franzen, Baird, & Williams, 2002; Boyle, Cohen, Paul, Moser, & Gordon, 2002; Boyle et al., 2003). What is less clear is the manner in which the episodic memory and executive function deficits affect daily activities. Tests in the laboratory are very different from everyday events, and so it is difficult to reliably deduce the problems that may be experienced in the home. Some studies have explored the impact of cognitive impairment on abilities to perform everyday tasks. These studies have mainly focused on the action disorders resulting from deficits in executive control. In this section we will describe the observational methods used to record action errors in clinical groups, and discuss the finding in relation to cognitive theory on action control. This issue will be explored further in Chapter 4, and so will only be briefly discussed here.

4.1 Studies using naturalistic observations

Observational studies have explored action disorders in people with damage to the frontal lobe region of the brain, resulting from stroke or trauma (Humphreys & Forde, 1998; Schwartz, Mayer, Fitzpatrick-DeSalme, & Montgomery, 1993; Schwartz et al., 1995). These studies have used activities, such as making a hot beverage or packing a lunchbox, to establish the types and frequencies of errors made during everyday tasks. Errors identified across these studies include ‘place substitutions’ (e.g. coffee granules in oatmeal), ‘object substitutions’ (e.g. orange juice added to the cup of coffee), ‘drinking anticipation’ (sipping coffee before it has been fully prepared), ‘omission errors’ (e.g. failure to open the bottle before pouring), ‘instrumental substitutions’ (e.g. stirring coffee with a fork), ‘faulty execution’ (e.g. partial opening of a sugar packet), ‘perseveration’ (e.g. adding milk to coffee more than once), ‘quality’ (e.g. filling the cup to the point of overflow), and ‘spatial’ (e.g. missing the cup and pouring the tea onto the table).

A similar approach has also been used to study people with dementia (Feyereisen, Gendron, & Seron, 1999; Giovannetti, Libon, Buxbaum, & Schwartz, 2002; Rusted & Sheppard, 2002). Feyereisen et al. (1999) observed 26 people with AD getting dressed. People with mild impairment frequently showed problems with choice of clothing and unsatisfactory executions of basic actions. Those with more severe impairment had problems of passivity, in which they showed a 'mental block' or inability to initiate the next step. Giovannetti et al. (2002) studied 51 people with dementia on a standardised action test, which requires participants to perform three short tasks (prepare toast with coffee, wrap a gift and pack a school bag). They scored the frequency of errors within a taxonomy of error types. It was found that the most common type of error was omission, in which the participant would miss out an action. Other frequently occurring errors were sequence errors, object substitutions, and action additions.

These studies are primarily interested in the role of executive function processes during everyday actions. One influential model for describing the occurrence of action disorder is the Norman and Shallice (1986) model of attention. A component of this model includes an executive control process, which is required for planning, sequencing and regulating actions during everyday tasks. As this cognitive process is severely impaired in dementia, it is thought that many of the problems experienced during everyday tasks originate from this deficit.

4.2 The origin of action errors

Schneider and Shiffrin (1977) make a distinction between *automatic* and *controlled* processes. Automatic processes involve the actions required to perform regular or routine activities (e.g. washing in the morning or walking to work), and so require little attention to perform. In contrast, controlled processes are needed to carry out less regular or novel procedures (e.g. writing a letter or packing a suitcase) that require greater cognitive effort.

According to the Norman and Shallice (1986) model of attention, these two types of procedures are controlled by two different systems. They propose that action schemas for routine procedures are stored in a hierarchical network. The schemas are

activated through a selection mechanism, known as contention scheduling (CS). During familiar routines, the action schemas are selected automatically through bottom-up activations. This includes internal activation from associated actions (e.g. closing the door triggers the action of locking it), and external cues from the environment (e.g. seeing the door open triggers the action of pulling it closed). These processes are habitual and so little conscious effort is required to accomplish them.

For non-routine activities, there are no stored schema networks that can be automatically activated to achieve the end goal. Such activities require input from a second source, known as the supervisory attentional system (SAS). The SAS is required to formulate subordinate goals, and activate required action schemas. This top-down activation requires greater conscious effort than the habitual routine procedures.

Although routine activities are largely automatic, the SAS is required to oversee that the actions selected match the intended goal. In many instances, the bottom-up process might trigger incorrect action schemas. The SAS is therefore required to inhibit the effect of associated actions, or habits, and distracting aspects of the environment. Overload or weakening of the SAS (e.g. distraction from another task) can result in an inappropriate schema becoming selected, which is when an error or action slip occurs.

The SAS is considered to be an executive function process, and is thought to take place within the prefrontal cortex. Pathological weakening of the SAS means that people with dementia have difficulty carrying out novel or unfamiliar procedures, but have relatively preserved ability on familiar routines (Jorm, 1986). However, the unregulated activation of the CS still poses problems in executing routine tasks correctly. It is this deficit that has been the focus of naturalistic observations of clinical groups during everyday tasks. People with acquired pathology to the frontal lobes are less able to inhibit activation from associated schemas and task-irrelevant aspects of the environment. The outcomes of the observational studies will be discussed further in Chapter 4.

5. Cognitive support for people with dementia

So far this literature review has focused on the cognitive deficits of dementia and how these deficits can impact performance on everyday tasks. This section of the review will focus on existing strategies for assisting people with dementia. Cognitive models of mild to moderate dementia provide a basis for devising appropriate training methods and compensatory strategies. These approaches intend to support impaired processes or direct cognitive effort towards more preserved functions. In this section we will explore the various technological and non-technological methods used to support people with dementia in everyday tasks.

5.1. Cognitive rehabilitation

Knowledge about the patterns of cognitive impairments and preserved processes in dementia allow appropriate training strategies to be developed. As episodic memory deficits largely result from a limited ability to encode new information, learning can be improved when substantial support is provided at this stage of processing. Facilitation of encoding has been achieved through multi-modal representations (Lipinska & Backman, 1997), imagery (Downes et al., 1997; Kalla, Downes, & van de Broek, 2001) and enactment of target words (Moore, Sandman, McGrady, & Kesslak, 2001). In addition, retrieval support may include recall cues that are compatible with conditions at encoding (Bird & Kinsella, 1996; Lipinska & Backman, 1997).

In establishing alternative learning methods, therapists exploit the implicit memory processes. For example, preserved priming effects enable people with dementia to learn through the expanding rehearsal techniques, also known as *spaced retrieval* (Landauer & Bjork, 1978). This involves the person repeatedly recalling information between gradually increasing intervals (e.g. 5s, 10s, 20s, and so on). When the patient correctly recalls a target word, the time interval is doubled. If their recall is incorrect, the interval is halved. When information is successfully retrieved after a 15 minute-1 hour interval, then long-term storage has been achieved (Camp, Bird, & Cherry, 2000). This strategy has been used to support face-name recognition (Camp

& Foss, 1997) and object naming (Camp et al., 2000). A similar approach is to use *vanishing cues*, in which the recall of a target word is supported by giving as many letter cues as required. As the person improves, letters are removed from the word presentation. For example, when learning a name, a letter will be removed from each presentation until they can retrieve the word without any letter cues. Using this procedure, Glisky and Schacter (1989) taught a severely amnesic patient over 250 pieces of information relating to the rules and procedures for performing a data entry task on a computer. De Vreese (1999) also demonstrated that this strategy could assist people with dementia to learn factual knowledge, such as addresses, phone numbers and recognition of indoor objects.

Preserved ability in procedural learning has provided opportunities to train people with dementia to learn activities of daily living (Zanetti et al., 2001). The method aims to stimulate sensory-motor skills related to procedures required to accomplish a task. Zanetti et al. (2001) trained 11 people with dementia to perform 13 instrumental activities of daily living (e.g. personal hygiene, using the telephone and dressing). They underwent individual sessions for three consecutive weeks (one hour/day; five days/week). Occupational therapists conducted the training by prompting and informing them about each task. The participants were invited to execute each element of the task, and were assisted by verbal cues and modelling. The training group showed a significant reduction in the number of cues required, and the time taken to perform activities compared favourably to control and baseline scores.

5.2 Non-technological prostheses

The role of the environment in determining functional capabilities in dementia is widely acknowledged. Lawton and Nahemow's (1973) ecological model of ageing emphasises the need to match the demands of the environment with the capabilities of the individual. As the person decreases in cognitive ability, the cognitive demands of an activity should be reduced. This environmentally deterministic approach has led to a number of strategies used to optimise levels of functioning. These have generally been used and tested in care facilities, but could potentially be used in home settings.

5.2.1 Non-tech memory aids

Portable items and aspects of the local environment have been used to aid memory. Visual cues, such as flowcharts and calendars have been used to help people with dementia follow scheduled activities, remember appointments, and remember likely places to find lost objects (Camp et al., 1996). Hanley and Lusty (1984) tested the efficacy of a diary and watch in supporting appointment keeping. They used an ABCBA single case design over seven weeks with a person with dementia, Miss S, who was a resident in a care home. Miss S was set different appointments at specific times during the week (e.g. meeting with a care staff member). Without the memory aid (phase A) she did not make any of the appointments. With the diary and watch introduced (phase B), there was only a small improvement. With the aids introduced in conjunction with 5 minutes training each day (phase C), there was marked improvement; she met nearly half of the appointments.

5.2.2 Non-tech orientation supports

Reality orientation therapy is a technique used to compensate for memory loss and time-space disorientation. There are two components to reality orientation. One part includes sessions, or classes, in which groups of people with dementia and staff meet regularly during the week. Activities and materials are used during these sessions to engage attendees with their surroundings and the wider world. The other component, known as 24-hour reality orientation, involves presenting information about the day, time, and date throughout the environment using calendars, clocks, and whiteboards. Signs are also used to assist people with dementia in locating rooms. It is frequently implemented in institutionalised setting to minimise anxiety and behavioural problems, such as incontinence and wandering. The use of large signposts, in conjunction with training sessions, has been found to minimise spatial disorientation and incontinence for care home residences with severe dementia (Hanley 1981; Hanley, 1986). Hanley (1986) reports a case study in which a person with dementia, Miss M, suffered from incontinence. The problem was thought to be that she could not find the toilet. To address this, signposts were placed around the care home, and Miss M was prompted to go to the toilet every hour. Minimum support was given in guiding her to the toilet, but after she had been there she was given a tour of the

other rooms. After two weeks her incontinence had stopped, and in a one-year follow-up she continued to show no problems.

5.2.3 Non-tech communication aids

Language deficits and memory loss result in problems with communication, including word finding, repetition, and topic maintenance. The most established approach in facilitating communication is reminiscence therapy. As people with dementia have relatively well preserved memories of remote experiences, focusing on past events is a useful way of establishing points of conversation. Reminiscence therapy is usually assisted with cues such as photographs, videos and music to stimulate particular memories. Despite its popularity in the field of dementia care, there is little evidence so suggest that it can improve cognition in the long-term. However, it does increase interaction between persons with dementia and their caregivers, and so is considered to be an effective method for engaging them in meaningful conversations (Woods & McKiernan, 1995).

Bourgeois (1992) explored the effect of a prosthetic memory aid on conversational content between people with dementia and their carer. The 'memory wallet' consisted of five cards containing 30 pictures and short sentences about familiar persons, places and events that each participant had difficulty remembering. Six people with moderate dementia received initial training with the memory wallets before using them to converse with familiar conversation partners. Analysis of the conversation showed that when using the wallet, people with dementia showed an increase in elaboration of topics and statements of fact, and a decrease in repetitiveness and ambiguous utterances.

5.2.4 Non-tech activity assistance

Strategies in supporting performance on multi-step tasks often include the use of proximal cues (visual cues and signs) combined with verbal prompts from a carer. Josephsson et al. (1993) attempted to support everyday activities (such as preparing a drink or snack) for four people with dementia. Each participant carried out a different task that they were motivated to do and had problems in performing. The

external guidance included signs on drawers and cupboards, and organisation of objects needed. The activities were performed in the care facility, and performance was measured using the Assessment of Motor and Process Skills (AMPS, Fisher, 1990). It was found that three of the four participants benefited from the intervention. The other participant became anxious and agitated during the activity sessions and so no improvement was observed.

Beck, Heacock, Rapp and Mercer (1993) also emphasise the role of environmental guides for sequential tasks. They state the need for 'stimulus control', in which carers should manipulate the environment (e.g. place clothes on the bed) and draw the person's attention to relevant items (e.g. point at the soap during washing). Management of environmental cues is widely used in dementia care practises. Common approaches found to be useful include the minimising of clutter and organisation of task-relevant objects so that they are more visible (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Gitlin et al., 2003; Gitlin et al., 2002).

5.3 Technological prostheses

Technological supports have also been applied to problems of memory, orientation, communication and task sequencing. Here we will describe existing prototypes designed for the purpose of supporting people with dementia.

5.3.1 Hi-tech memory aids

There are a number of technological devices available that are designed to support prospective memory. Gillard (2004) evaluated a medication reminder that provides an audio cue when the medicine should be taken, and only dispenses the tablets required for that particular time. The device contains various compartments that hold tablets, and is set by the pharmacist who can also monitor adherence by recording the number of pills left in the device. The added advantage is that it minimises the need to recall required dosage so that the person with dementia does not take two sets of medication at one time.

Technology can also be used to support retrospective memory. For example, Gillard (2004) describes the Object Locator to help people with dementia, or their caregivers, to find items that frequently get misplaced. The system includes a device that can be mounted on a wall and contains a series of buttons that correspond to the objects (e.g. keys or glasses). Tags are placed on these items, which make a loud sound when the user presses the corresponding button on the device.

Sensor technology has also been used to minimise risk in the home. Sensors have been used to detect heat, gas and smoke, in order to cue the user when the cooker has been left on. If the audio cue does not work, then the cooker can be automatically shut off at the mains. Safety devices have also been developed to prevent baths and sinks from overflowing. For example, Orpwood, Bjerneby, Hagen and Maki (2004) designed a tap that is controlled by an electric switch, but is operated much like a regular tap. This means that when the water is overflowing, the electrical switch can turn off the tap rather than shutting off the water supply. This allows the user to easily operate the tap when they want to use it again.

5.3.2 Hi-tech orientation supports

Some researchers have explored ways to orientate people with dementia to time and place. With regard to temporal orientation, the approach has been to display information, such as time, day, month and year, on computer screens located in prominent areas of the house (Baruch, Downs, Baldwin, & Bruce 2004; Gillard, 2004). Baruch et al. (2004) describe a case in which a lady with dementia lived alone, and often became confused in the night. She would wander around the house and continually phone her family for reassurance. To overcome this, they presented temporal information on a computer screen, which was located near her bed. The information included the date, time, time-of-day, and a picture representing the time (e.g. a moon on a dark background). It also included a short message (e.g. “it is night time you need to go to bed”). They reported that the technology reduced her wandering behaviour and she made fewer phone calls in the night.

Kautz, Fox, Etzioni, Borriella and Amstein (2000) developed a portable orientation aid, the Activity Compass, designed to guide people with dementia both outdoors

and indoors. The Activity Compass is a PDA device presenting a large digital compass on the interface. When outdoors, GPS is used to detect the location of the user, and algorithms detect when they appear to be lost (e.g. approaching unfamiliar locations). In such incidences, the device provides the user with a verbal prompt to go back home, and uses the compass arrow to show them which direction to walk. Indoors, the Activity Compass uses sensors to track their movements and directs them when necessary. For example, if mealtime is overdue the device cues them to go into the kitchen so that they may become encouraged to make something to eat. Although the system was designed for people with dementia, it has not yet been tested with this population and so it is difficult to know how they would respond to this type of technology.

5.3.3 Hi-tech communication aids

Technology has been used to improve reminiscence communication. Alm et al. (2004) developed CIRCA (Computer Interactive Reminiscence and Conversation Aid), which is a multimedia design package for facilitating communication between people with dementia and carers. The system includes a 20-inch touch screen interface that allows the users to navigate their way around different reminiscence themes (e.g. recreation, entertainment and local history). Each theme includes different media types (photographs, video and music). The interface maximises simplicity and mutes colours so as to not to distract the user from the media presented. This technology was found to have some advantages over the traditional reminiscence approach. The person with dementia tended to participate more in the conversation, and take direction of reminiscence topics. The care workers also offered significantly more choice to the person with dementia regarding conversation topics (Alm et al., 2004; Alm et al., 2007).

Microsoft Research developed a wearable still camera, called the SenseCam, to capture a digital record of the wearer's day. It is believed that reviewing these images will help recall aspects of earlier experiences. The camera has a wide-angle lens and is triggered to take a picture when there are significant changes in sensor readings (e.g. changes in light level or body heat). These changes indicate a meaningful event (e.g. going outside or meeting somebody in the street), which can

then be recorded and viewed with another person. Case trials with amnesic patients show that SenseCam led to significantly better recall of everyday events compared to using a diary. This facilitates the communication and allows the user to recall day-to-day events with other people (Berry et al., 2007; Hodges et al., 2006).

5.3.4 Hi-tech activity assistance

Developments in artificial intelligence have allowed researchers to explore ways in which technology can compensate for deficits in planning and sequencing of actions required to perform everyday tasks. Levinson (1997) developed the Planning and Execution Assistant and Trainer (PEAT) to assist patients with impaired executive function processes, including people with dementia. The system includes a handheld device, which can be customised to cue the user at different times of the day, and guide them through the steps required to accomplish activities. The software allows the sequence to be personalised in order to match the needs of the user. The interface offers voice recordings, sounds and pictures. The software is capable of branching into error correcting procedures if the user becomes confused. There are no reports of how people with dementia respond to this system. In order to track performance on the task, the device does require the user to press a button on the interface after every action has been completed. The need for manual input would require the person to be trained with the system.

However, recent advances in activity monitoring have allowed the development of systems that do not require manual input. Mihailidis, Barbenel and Fernie (2004) developed the COACH (Cognitive Orthosis for Assisting Activities in the Home), which is designed to assist dementia sufferers through the process of washing their hands. The system uses computer vision to track the movements of the hands and objects. If an error is detected, or an action is not initiated, a pre-recorded prompt is presented through speakers located above the sink. The specificity of the prompt depends on the user's response. For example, an initial prompt would be provided for a step in the task (e.g. 'turn off the tap'). If the person failed to respond, then the prompt would address the user by name, or provide more specific instruction (e.g. 'turn off the tap in front of you').

The COACH was evaluated at a care facility with ten people with moderate dementia. The whole task was broken into 6 component steps (turn on tap, pick-up soap, and so on). Participants were scored on how many steps they could accomplish without assistance from a care worker. Overall, it was found that participants performed 25% more steps with the intervention compared to baseline performance. The implications of this study for designing prompting systems for people with dementia will be discussed further in Chapter 4.

Others have used Radio Frequency Identification (RFID) technology to track task performance. Dishman (2004) describes a system for assisting people with dementia when making a cup of tea. The prototype involved attaching RFID tags to objects (cup, teapot etc), and an RFID reader attached to a glove worn by the user. The system tracked task progress based on the interaction with objects. Video clips of required action steps were then presented on a television screen located on the worktop. Although the system could track task progress, there was no test to evaluate the suitability of these prompts for people with dementia.

A different approach to supporting multi-step tasks has been to provide performed actions rather than to-be-performed actions. Tran, Calcaterra and Mynatt (2005) devised the Cooks Collage, a Wizard of Oz prototype that guides the user through a cooking activity. The system includes a single screen located on the kitchen cupboard, which presents a series of close-up hand shots of previous actions performed during the activity. The design intends to reduce cognitive load by providing a reminder of actions already performed. The system was evaluated in an experiment in which the 22 participants had to carry out a cooking activity. As the system was a Wizard of Oz simulation, the researcher took the images manually. All of the participants were healthy adults, and so were required to perform a dual task to simulate impaired working memory. This involved performing the cooking activity (preparing punch) and carrying out a language learning task (learning how to count to ten in a foreign language) at the same time. Participants reported positive feedback on the assistance provided by the system. It was also found that 45% of the participants performed better on the learning task, which suggests that the aid reduced cognitive load on the cooking task.

6. Conclusion

The increasing prevalence of dementia creates the need to develop systems that enable people to remain in their own homes for longer. Independent living not only reduces strain on care services, but also means a better quality of life for the person with dementia and their caregiver. There has been extensive research to understand the patterns of cognitive decline in people with AD and VaD. These studies have been instrumental in guiding the development of cognitive rehabilitation strategies and cognitive prostheses. Recent developments in tracking technology and artificial intelligence provide new possibilities for guiding people with dementia through multi-step tasks. Despite advances in the technology, little work has been done to establish how these systems should be designed so that they are compatible with the needs and abilities of people with dementia.

The aim of this thesis is to explore the design requirements of technology to support people with dementia in their own homes. More specifically, it is intended to contribute to the design of prompting systems capable of guiding people with mild to moderate dementia through multi-step tasks. It is important to base the design on an understanding of the problems of dementia, and how these relate to cognitive theory. In Chapters 2 and 3, we explore the experiences of professional carers, family caregivers and people with dementia. This will provide a broad insight into the types of problems that need to be addressed in the home setting. In Chapter 4 we focus on one aspect of daily living (kitchen tasks) to provide a detailed account of the types of problems that occur during such activities. The study involved naturalistic observations of people with mild to moderate dementia carrying out activities of their choice in their own homes. In Chapter 5 we report an experiment designed to evaluate a novel cueing method to assist people with dementia on a real task (operating the cooker). Finally, in Chapter 6 we discuss future steps for designing prompting systems for people with dementia in home settings. This bottom-up approach will provide further insight into how technology can support people with dementia in real domestic settings.

Chapter Two

Exploring the problems of dementia in the home:

A professional carer perspective

Abstract

Nine interviews and one focus group were conducted with 20 occupational therapists and care assistants who specialise in the care of people with dementia. The transcripts were analysed using Grounded Theory Analysis, revealing ten main categories grouped into three themes: *Problems in the home* (daily activities, risks and interpersonal interaction), *underlying deficits* (sequencing, learning and memory/orientation) and *consequences* for the person with dementia (physical and control) and the informal caregiver (relationship and care demands). The implications of these themes for designing technology for people with dementia are discussed.

1. Introduction

1.1 Describing the problems of dementia

As discussed in Chapter 1, despite the technological advances of cognitive prostheses, little work has been done to direct research efforts towards aspects of daily living that are important to support. Some work has been done to prioritise the needs of older adults. Brownsell, Aldred and Hawley (2005) described opportunities for designing telecare systems that address the ‘trigger factors’ that reduce independence of older adults. Their taxonomy was based on a literature review and a focus group with care professionals. A total of 36 factors were prioritised, which relate to quality of life in different ways. This includes issues such as domestic activities (e.g. housework), health (e.g. dealing with illness or mobility problems), frailty (e.g. fear of falling), nutrition (e.g. cooking), and personal hygiene (e.g. washing).

Similar work needs to be carried out to identify the needs of people with dementia. In particular, it is important to identify the problems that contribute to the decisions to move people with dementia from their home to residential care settings. Capturing the nature of such problems would also provide designers with the detailed insight necessary to hypothesise strategies of support.

1.2 The present study

This study focuses on the problems of dementia in the home. The analysis is based on the views of occupational therapists and care assistants in order to identify problems related to increased social dependence or decisions to move into residential care settings. The analysis will involve a bottom-up approach using Grounded Theory Analysis (GTA, Strauss and Corbin, 1990) to summarise the nature of the problems from the perspectives of our informants. By describing the accounts in accordance with cognitive theory, it is intended to propose design requirements that are suitable for people with dementia.

2. Method

2.1 Participants

Nine interviews and one focus group were conducted with occupational therapists (OTs) and care assistants that specialise in the care of people with dementia. They were recruited from the UK National Health Service (NHS). In total there were 20 informants. Ten participants took part in the interviews and 11 took part in the focus group (one of the focus group participants also took part in an individual interview). Table 2.1 lists the transcripts and participant profiles.

The role of an OT is to assess the cognitive and functional status of clients, either in their own homes or in clinical settings. Based on these assessments the OT recommends methods of support and identifies risks. For this reason they were considered to be a very suitable group for this study. The care assistants were based in a care facility for people with dementia and/or provided domiciliary care to people with dementia living in their own homes.

Table 2.1: Professional carer profiles

Transcript	Participants	Description
1 Interview	Professional Carer	Care assistant at care home for elderly mentally infirm and domiciliary
2 Interview	Professional Carer	Nurse at care home for elderly mentally infirm.
3 Interview	Professional Carer	Care assistant at care home for elderly mentally infirm and domiciliary
	Professional Carer	Care assistant care home for elderly mentally infirm and domiciliary
4 Interview	Professional Carer	Care assistant at care home for elderly mentally infirm.
5 Interview	Professional Carer	Care assistant conducting domiciliary.
6 Interview	OT	Assesses functional capability and risks at home
7 Interview	OT	Assess functional capability and risks at home
8 Interview	OT	Assesses functional capability and risks at home
9 Interview	Project Manager for Care Services	Previously worked as an OT before becoming project manager for research into dementia care services.
10 Focus Group	11 OTs	A Team of OTs that assesses functional capability and risk at home

2.2 Procedure

2.2.1 Interviews

The interviews were semi-structured (see Appendix A for the interview structure). The focus was on the informants' experiences with clients. This included problems in accomplishing activities, the impact of dementia on daily living, important activities to support, concerns around daily living and reasons for moving into permanent care settings.

Interviews were conducted in an office at the care home where the professional carer or OT was based. Before the interview started, the interviewer described the research objectives and explained the purpose of the interview. The interviews were audio recorded, and each lasted approximately one hour.

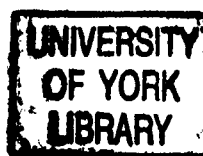
2.2.2 Focus group

The focus group took place at the University of York, UK. Participants were first given a tour around the Responsive Home on the university campus. The Responsive Home is a purpose built house for researching and demonstrating assistive technology. The tour was intended to introduce the aims of the project and facilitate the focus group discussion. The meeting was audio recorded, and lasted one hour.

2.3 Analysis

Audio material from the interviews and focus group was transcribed. The transcripts were analysed using GTA (Strauss and Corbin, 1990). The method of analysis involves three main stages. The first stage (open coding) involves reading the material and identifying component concepts of what participants talk about.

The second phase of the analysis (axial coding) involves grouping related concepts together to form categories. The naming of these categories is based on the language used by the informants to express these issues. Related categories were further grouped into main categories.



The third stage of analysis (selected coding) involves grouping the main categories into broader themes, and identifying how the themes relate to each other.

3. Results

The analysis revealed three themes that summarise the problems of dementia in the home, as perceived by our informants. The core theme represents 'problems in the home', which had three main categories: *Daily activities, risks* and *interpersonal interaction*. The second theme relates to the 'underlying deficits' of these problems, which was composed of three main categories: *Sequencing, memory and orientation*, and *learning*. The third theme represents the 'consequences' of the problems for people with dementia and informal caregivers. The main categories for patient consequences were *physical wellbeing* and *control*. The main categories for caregiver consequences were *relationship* with person with dementia and *care demands*. Figure 2.1 depicts the three themes and their category components.

The main categories were composed of 29 subcategories in total. This level of coding derives from the initial phase of the axial coding and so the category terms used reflect those used by our informants (e.g. 'initiating actions'). Not all of the subcategories will be discussed in detail here. However, they are listed in Table 2.2 with an extract from the transcripts (the *instances* present the frequency in which the category was mentioned and the *groups* represent the number of transcripts in which the category occurred).

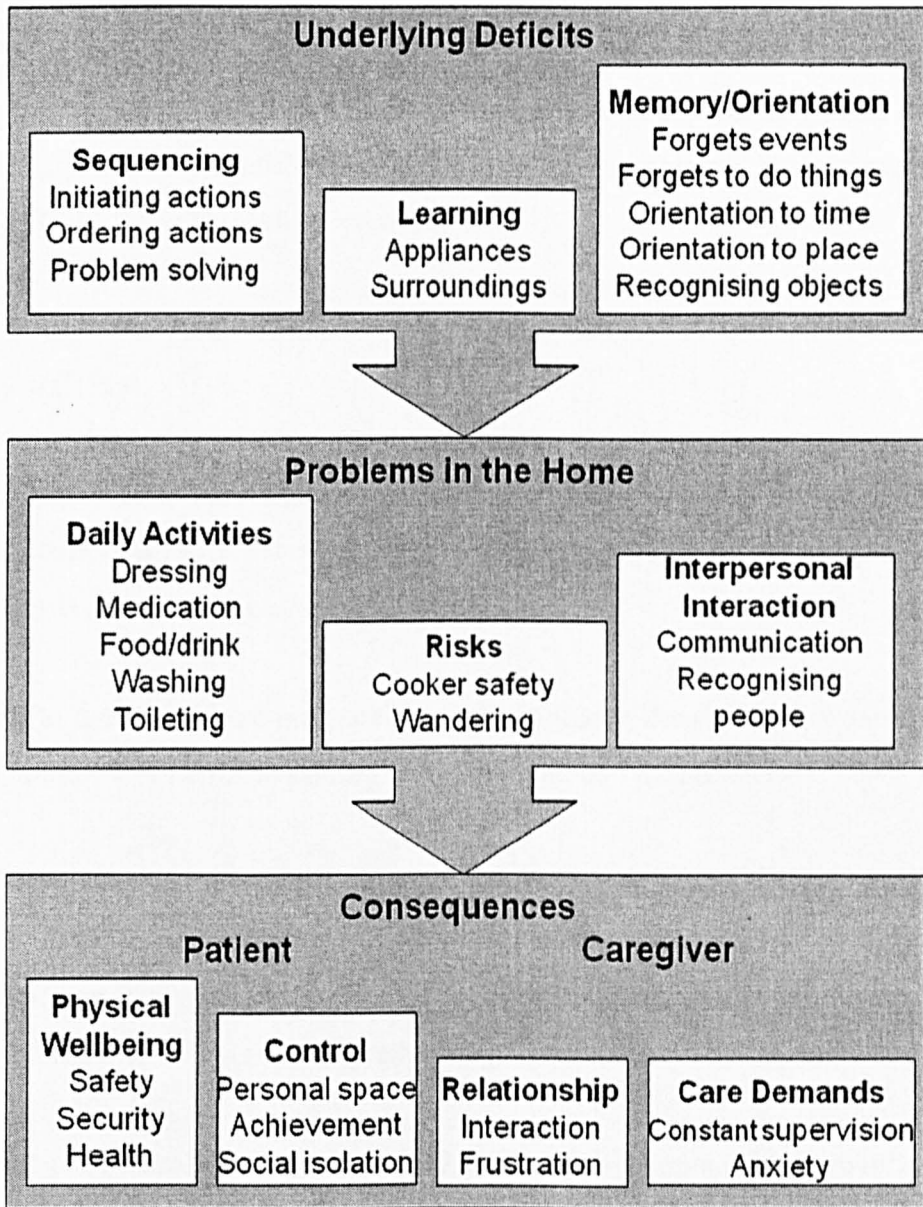


Figure 2.1: A summary of the problems of dementia in the home, as perceived by professional carers

3.1 Problems in the home

The core theme relates to the types of problems that occur in the home. Three separate categories were identified that summarise these problems. These were daily activities, risks and interpersonal interaction.

3.1.1 Daily activities

The participants reported five main activities that people with dementia find difficult to achieve independently. These were *dressing, taking medication, preparing food or drink (usually a cup of tea), washing and toileting.*

With regard to dressing, there are problems of orientating the clothing, wearing the appropriate number of items, or putting them on in the correct order:

“You put their clothes there in the right order, but they still don’t put it on in the right order... And they may put on more than one item of the same thing. You know, they may have three petticoats or two vests.” (Transcript 3)

Management of medication was considered difficult as people with dementia are required to follow and monitor a specific schedule. They may forget to take medication at appropriate times or forget it altogether. Some do use a ‘medibox’ (a plastic box that holds the tablets in separate compartments indicating the day and time the medicine should be taken) but these often turn out to be insufficient:

“We’ve got one lady, she has a medibox. She’ll take her morning pills, but forget her evening pills. Or she’ll take her morning and evening pills all together, even with her medibox”
(Transcript 4)

Difficulty in preparing food or drinks was the most frequently reported issue. These tasks were considered to be too complex to accomplish successfully, as it requires

the appropriate use of various items and appliances. This places major restrictions on daily living, as the person would become dependent on short scheduled visits by the care worker:

“People do all sorts of things with a kettle and a tea pot. They may put tea bags in the kettle, they may put tea bags in the fridge, they may do all sorts of variations on how they would actually structure the tasks” (Transcript 6)

Problems with toileting would occur for different reasons. Although in many cases this relates to incontinence, some problems also result from difficulties in locating the toilet or performing components of the actual task (e.g. wiping, flushing or washing their hands):

“If we could get people to find the toilet quickly, or remember where it is, you can reduce incontinence that way. Its not that they're physically incapable of being continent, but that they don't know where to go” (Transcript 1)

3.1.2 Risks

Categories relating to risks reflect our informants' concerns about safety that often lead to the person being moved into residential care settings. The two main concerns were cooker safety and wandering

When using the cooker, it might be left on or the gas could be turned on without lighting it:

“On two occasions when Home Care went in, the house was flooded with gas fumes because she'd switched something on and not lit it.” (Transcript 6)

"We've had somebody burn the dinner, then wake up at 3 in the morning with the alarms going. They started doing a task, walked away...and the next thing alarms going off, holes in saucepans."

(Transcript 8)

As well as memory lapses in lighting the gas or switching the cooker off, problems also result from difficulties in actually operating the appliance:

"She cannot read the plates...she doesn't know which hob is affected by which dial." (Transcript 7)

"Problems with the cooker, it really is a battlefield. If you can't operate your cooker or you fiddle with the switches and you can't turn it off properly, or you turn it on too much, that is quite dangerous...just talking about peoples' cognitive abilities to look at the dials, understanding simple concepts of what's right and what's left, what's on, what's off." (Transcript 7)

With regard to wandering, the main concerns are leaving the house, particularly during the night. Participants reported that such behaviour often resulted from misperception of time or a false belief that they need to leave the house for a particular purpose (e.g. going to work or going home):

"Wandering is a big one...If someone goes out, they may forget their stick, not put on a coat, vulnerable depending on where they live...Leave the door open...getting lost...and that is often the final straw, and you end up going in a care home."

(Transcript 6)

"They go out willy-nilly at any hour of the night or day. They get lost. We have people brought back by the police. They even become unaware that that is even their own home." (Transcript 3)

3.1.3 Interpersonal interaction

Social interaction becomes disrupted due to communication difficulties or inability to recognise family, friends or carers. Our informants also report a breakdown in communication because of problems in following what is being said to them, as well as remembering what they had said themselves:

“So they have memory problems, and they repeat themselves and don’t get anywhere.” (Transcript 4)

“The person has hardly any insight into their memory problems. And they make the same repetitive comments. And carers often feel very guilty because they get very stressed out with them.”
(Transcript 8)

Problems in recognising people would clearly disrupt communication further, but also raises difficulties in reassuring the person with dementia or gaining their trust:

“One day they get on with the carer really well, the next day they come round and its like ‘who are you’. And then they get upset because someone is in their house and they don’t know who it is, or sometimes don’t let them in.” (Transcript 4)

3.2 Underlying deficits

The second theme represents what our informants perceived to be the deficits underlying the problems in the home. The three areas identified were sequencing, memory and orientation, and learning.

3.2.1 Sequencing

Sequencing refers to difficulties in correctly executing a series of actions that constitute an activity. Our informants reported problems of initiating actions, ordering actions and problem solving.

The problem of initiating action refers to the inability to begin an activity or cease actions during the task:

“Big problems with initiating...there is that problem of thinking ‘I’m hungry, got to go to the fridge and get the food out.’”
(Transcript 6)

“Sequential stages are dreadfully difficult...doing a cup of tea...the milk is probably in the fridge and that the cups are probably in the cupboard...and although you probably tell a person that they are there, they may not logically think it out. They fail, and they fail because they can’t link up all the tasks.”
(Transcript 7)

It was reported that people with dementia would perform actions in the wrong order:

“Actually knowing how to do something in the right order. Somebody might put their trousers on first, then their underpants. Might put a shirt on then their bra.” (Transcript 6)

Limited ability in problem solving was also associated with problems in the home. It was also reported that people with dementia struggle to resolve a problem that breaks the task sequence:

“If a saucepan of milk is boiling, and it’s going up and up the saucepan and it is about to spill over, we would immediately turn it down. A person with dementia won’t know what to do.”

(Transcript 7)

3.2.2 Memory and orientation

Problems in memory and orientation made it difficult for people with dementia to monitor their day-to-day activities. Our informants described five types of deficits: Forgetting events, forgetting to do things, orientation to time, orientation to place, and recognising objects.

It was reported that people with dementia often forget to perform scheduled tasks and have poor recall of recent events. This makes it difficult to follow daily routines:

“Putting something on the stove, which is part of the sequence, then stopping that sequence of events to do something else, such as dusting the lounge – so broken into another activity...We would be fine, to do several things, but people with dementia will often forget they were cooking.” (Transcript 6)

“It is the memory, short-term memory. Most of the time they can’t remember where they put the ingredients, or can’t remember that they put the chicken in the fridge rather than in the cupboard, or in the bin.” (Transcript 2)

Problems may also arise in carrying out scheduled tasks because they cannot remember activities that need to be performed:

“You might have a care package where a carer goes in...then makes them a sandwich. The sandwich is put in the fridge but when someone comes back at tea time, they hadn’t eaten the sandwich.” (Transcript 10)

Orientation to time was also associated with problems in carrying out scheduled activities (e.g. medication and meals) and also contributed to the problem of wandering out at night:

“Knowing what time of day, it can be very difficult. At winter time when it gets dark early, people will think it’s night time...also remembering what time of the week it is, and if it is the weekend, or during the week.” (Transcript 7)

“Often patients lose a lot of weight because they’re forgetting to eat because they don’t know what time of day it is...And also going to bed and things like sleep patterns become disturbed because they’re not orientated to time.” (Transcript 8)

“Not knowing the time, so going out in the middle of the night.” (Transcript 7)

Wandering behaviour was also associated with problems of orientation to place. In some cases, people with dementia do not recognise their own home, which is why they leave the house:

“They believe they are not in their own home and try to get out and find their own home...Obviously you can’t lock them in, in case of a fire risk or something like that.” (Transcript 4)

Errors made when performing daily activities, such as preparing food and drinks, were often associated with inability to recognise objects:

“She went into the cupboard to get the cup out. There was a jug in there and she got the jug out and used it instead of a cup.”
(Transcript 6)

3.2.3 Learning

Problems in learning new information were considered to be a cause for many problems in the home. It was reported that people with dementia have difficulty adapting to new appliances:

“Relatives make the mistake of buying new equipment, and then they’re worried because ‘mum can’t operate a new cooker that she’s never seen before.’” (Transcript 6)

Problems in accomplishing daily tasks were also disrupted if the person were required to adapt to new settings or re-orientate themselves to their own home after being away:

“If somebody was to go into hospital for a couple of weeks and then come back home, it can really disorientate them. If we have people come to respite in these units, sometime when they go back they are worse for a while because they’ve got to get back to understanding their environment.” (Transcript 7)

3.3 Consequences

Categories under the consequences theme reflect the impact of dementia on the lives of the patient and the informal caregiver (e.g. spouse). For the person with dementia, our informants' concerns were physical well being and sense of control over their lives. For the informal caregiver, the concerns focused on the relationship with the person with dementia and the care demands placed on them.

3.3.1 Consequence for patients: Physical wellbeing

The main concerns regarding physical well being were safety, security and health. Concerns around safety are a common reason for referral into residential care settings.

"If some people are too dangerous to go home...and if you did not try and find better care, it would be negligent for you to keep them there." (Transcript 7)

Security refers to the threat of others who target older adults. Problems of wandering and difficulty in recognising others make people with dementia particularly vulnerable:

"In terms of their own safety, they could open the door, and leave it open all night." (Transcript 5)

"He had been receiving a lot of unknown visitors. It ended up him being admitted. He carried large amounts of cash and let anyone in who knocked on the door." (Transcript 9)

"Security in their own homes, they may be being exploited by anyone coming in. That's a growing problem. People try and get money off them." (Transcript 7)

Health was considered important as poor nutrition or medication management would have a negative impact on their cognitive ability, worsening the problems further:

“Not getting the physical health needed, that’s going to affect their memory even more.” (Transcript 2)

“They try and cook a meal, but still have frozen meals, and try and eat them, which is quite bad” (Transcript 1)

3.3.2 Consequence for patients: Loss of control

Another consequence for people with dementia is the sense that they have lost control over their lives. Our informants report a loss of control with regard to personal space, sense of achievement and social isolation.

Dependence on others means that people with dementia lose their personal space. This was reported to be particularly the case with dressing, washing and going to the toilet.

“If you’ve got a man with difficulty with personal care, but is a proud man, he might not want his wife to give him a bath or get him dressed.” (Transcript 7)

“I think it’s hard with washing and cleanliness. The client doesn’t like that. Because it’s not right for their children to clean them...it’s intruding for the client.” (Transcript 4)

Loss of a sense of achievement results from inability to perform activities independently. This can result in a loss of self-esteem and also takes away the level of flexibility in their daily lives:

“Being able to do simple things like making a cup of tea. A lot of them when you go and visit them are very hospitable and

want to be able to do these things. They don't want their identity taken away from them. They don't want to be labelled, they want to be able to be 'I can still do these things'"
(Transcript 7)

"Preparing food, I think they miss that, especially if the family are around and they can't cook for them." (Transcript 2)

"To lose your skill is bad enough, if you take away from the person with dementia the few things they can do, that's even harder...It is when your worth as a human being and your living starts to disappear out the window that you start breaking down emotionally and socially" (Transcript 7)

Problems of social interaction result in social isolation. It was also reported that loneliness is a major reason for people deciding for themselves to move into a residential care setting:

"They may make the decision to come to a care home themselves. Perhaps they have been very lonely and coming here they have a certain degree of friendships." (Transcript 7)

"Lots of people talk about being lonely, and many people find interacting with people with dementia very difficult and hard."
(Transcript 5)

3.3.3 Consequence for the caregiver: Patient-caregiver relationship

Our informants reported that some of the problems in the home disrupt the relationship between the person with dementia and the family caregiver, such as their spouse. The relationship is affected by problems in interaction and the frustration for the caregiver.

Problems in communication can distance the person with dementia and the caregiver. Memory loss means that they cannot talk about shared experiences:

“They have very poor recall that they were ever married, or recognise their children. If that’s happening at home, and you’re looking after this old lady, day after day, and she doesn’t know that that’s her husband, or even who he is...his value in himself really goes. I think that’s the hardest thing in being a carer.” (Transcript 8)

Daily life can be frustrating for the caregiver who has to assist the person with dementia, which can put a strain on the relationship. It is particularly difficult if the person with dementia resists assistance.

“He may not want his wife to get him dressed. And then resist her getting involved. That can put a strain on the relationship.” (Interview 5)

“We often find the biggest thing is when you start to see somebody go downhill they find it very frustrating because that person has hardly any insight into their memory problems...And carers often feel very guilty because they get very stressed out with the patient. Patients can get quite aggressive towards the carers as well.” (Transcript 8)

3.3.4 Consequence for the caregiver: Care demands

The second consequence for the caregiver is the strain of the care demands. This includes the need to provide constant supervision and having little time to themselves:

“Doing the job of actually watching them go to the toilet. Whether it goes right or wrong, they have to be there to check that it has been done right.” (Transcript 1)

“I think what carers find hard are things like ‘I can’t turn my back for a minute’ because X will go and do this. Those kinds of things require frequent or constant supervision.”
(Transcript 5)

Caregivers have problems sleeping when the person with dementia wanders during the night:

“They sometimes get up in the night, and carers often say they are very light sleepers. And they have to be if the patient is up all the time. And they get dressed at 2 o’clock in the morning. And then finally get into bed. And then at 4 o’clock they get up again thinking they’ve got to get to work. Sometimes that can be a big problem.” (Transcript 1)

Anxiety is increased when the caregiver is unable to provide supervision. This disrupts sleep and also means that they cannot relax when leaving the person with dementia alone at home:

“It’s a strain really...the whole time you’re awake you’ve got anxiety. And even when you’re asleep, you’ve got anxiety.”
(Transcript 8)

“People get worried they’re going to fall, so they sleep with one eye open.” (Transcript 7)

“They have to leave their loved one at home and rush the shopping.” (Transcript 9)

Table 2.2: Ranked list of sub-categories from the professional carer perspective, with example extracts from the transcripts. The number of 'instances' shows the number of times the item was mentioned, the number of 'groups' shows how many transcripts it appeared in.

Category	Instances	Groups (10)	Sample Extract
Food/drink	32	9	"People do all sorts of things with a kettle and a teapot. They may put tea bags in the kettle, they may put tea bags in the fridge, they may do all sorts of variations on how they would actually structure the tasks"
Cooker safety	22	10	"Once someone left the gas on, went out the house, and when they came back the house was full of gas"
Wandering	19	7	"So she walks down to the house next door, and doesn't know where she is. Wanders two houses down the road, and could go on the main road"
Forgetting events	13	8	"A memory lapse can lead to a disaster most days really. They could leave the cooker on, or turn on the gas and forget to light it"
Medication	13	4	"We've got one lady, she has a medibox. She'll take her morning pills, but forget her evening pills. Or she'll take her morning and evening pills all together, even with her medibox"
Constant supervision	10	5	"I think that what carers find hard are things like 'I can't turn my back for a minute because he or she will go and do this'. Those kind of things require frequent or constant supervision"
Safety	10	5	"The problems tend to be around things like safety. Because there isn't anybody on hand to make something safe"
Washing	9	5	"I think a lot of them find it hard with washing and cleanliness"
Achievement	9	4	"I think they miss that [cooking], especially if the family are round and they can't cook for them"
Orientation to place	8	7	"See there are things to do with continence, which aren't really to do with continence. Maybe the person couldn't find the toilet in time, or doesn't know where the toilet is...It's not that they're physically incapable of being continent, but that they don't know where to go...one man used to go into the airing cupboard and wee in there instead."
Social isolation	8	7	"Lots of people talk about being lonely, and many people find interacting with people with dementia very difficult"
Dressing	8	6	"Somebody might put their trousers on first, then their underpants. Might put a shirt on then their bra"
Security	8	5	"He had also been receiving a lot of unknown visitors. It ended up him being admitted because of his safety. He carried large amounts of cash and let anyone in who knocked on the door"
Forget to do things	7	5	"I suppose the main problem is memory. Anything that requires memory, whatever that might be. So remembering to have meals"
Interaction	7	5	"There are issues of communication with families and between people with dementia"
Recognising people	7	4	"They may not recognise a person, their husband or wife. They think of themselves as younger, wondering who this old man or women is...And in some case they won't recognise themselves in the mirror as well"
Communication	6	5	"They don't understand what you're saying to them...they forget what you asked them"

Personal space	6	5	"The hardest thing is personal care because you're doing something that people do not like. And you're invading their space"
Appliances	6	3	"Relatives make the mistake of buying new equipment, and then they're worried because 'mum can't operate a new cooker that she's never seen before'
Ordering actions	5	4	"You put their clothes there in the right order, but they still don't put it on in the right order"
Health	5	4	"Some of them, they try and cook a meal, but still have frozen meals, and try and eat them, which is quite bad"
Frustration	5	3	"We often find the biggest thing is when you start to see somebody go downhill they find it very frustrating because that person has hardly any insight into their memory problems. And they make the same repetitive comments. And carers often feel very guilty because they get very stressed out with the patient".
Initiating actions	5	3	"If you've got somebody who can't plan tasks, can't sequence tasks...can't remember what they did a minute ago, you're going to find that that is a big problem"
Toileting	5	3	"Going to the toilet, remembering where the toilet is. What you actually do in the toilet, and how you finish the job"
Surroundings	5	3	"If somebody was to go into hospital for a couple of weeks and then come back to the home, it can really disorientate them"
Problem solving	5	2	"For example, a saucepan of milk, and its boiling and it's going up and up the saucepan and it's about to spill over. We would immediately turn it down. A person with dementia won't know what to do"
Anxiety	4	3	"They have to leave their loved one at home and rush the shopping"
Orientation to time	3	2	"Knowing what time of day it is can be very difficult. At winter time when it gets dark early, people will think it's night time...also remembering what time of the week it is, if it is the weekend, or during the week"
Recognising objects	3	2	"She went into the cupboard to get the cup. There was a jug in there and she got the jug out and used it instead of a cup"

4. Discussion

Below is a summary of the problems of dementia in the home from the perspective of OTs and care assistants. The analysis revealed three themes that address separate issues with regard to assistive technology design. The core theme, 'problems in the home', covers activities to be supported. The 'underlying deficits' theme provides further detail regarding the nature of these problems and how the activity needs to be supported. The 'consequences' highlight what the technology should aim to achieve in order to enable people with dementia to remain at home for longer.

4.1 Problems to address in the home

The core theme, 'problems in the home', lists daily activities that are considered important to support. This could help direct research towards aspects of daily living that technology should address. Some of these activities are already being addressed by technology, and so we will discuss the issues in relation to existing concepts and prototypes.

4.1.1 Activities in the home

Preparing food and drinks was frequently reported as a problem. This activity presents obvious health implications, but also contributes to a sense of control and self-esteem. Some of the technological prototypes discussed in Chapter 1 had focused on supporting kitchen tasks. Dishman (2004) reported the development of a prototype that uses RFID technology to track progress when making a cup of tea, and provides step-by-step instructions on a video screen. The Cooks Collage used a Wizard of Oz prototype to explore how cooking activities could be supported using a retrospective memory aid. The design involved photographic hand shots of performed actions on a computer screen located on the kitchen cupboard. This was intended to assist the user in following their own task progress so that they would not get confused about what actions need to be performed (Tran et al., 2005).

The high frequency of reports about food and drink by our informants suggests that such research should continue to develop solutions for this area of daily living. The complexity of the activity means that further work is needed to develop tracking and artificial intelligence algorithms capable of dealing with these types of tasks.

Medication management was the second most reported daily activity. This problem is more relevant to people who live alone as there is no caregiver available to remind them during the day. Medication adherence is clearly an important issue, and so there are many devices available to provide reminders when medication should be taken. It is evident from our informants that the problem is not only about remembering to take the tablets, but also remembering that they have taken the tablets. The medication reminder described by Gillard (2004) was designed specifically for people with dementia. It only dispenses the medication that should be taken at that particular time in order to reduce such problems. However, if the person forgets that the medication has been taken, and so wishes to take the medication again, they may become confused. Providing clear information to reassure the person with dementia that the medication has been taken could help minimise this.

Being able to wash and dress yourself is closely linked to a sense of independence and also affects how others perceive you. Failure in accomplishing these routines could therefore increase problems of social isolation and loss of self-esteem. The COACH system (Mihailidis et al., 2004) described in Chapter 1 is designed to support people with dementia when washing their hands. The system uses vision-based tracking using a camera located above the sink, which can monitor object and hand movements to identify errors and provide audio cues (e.g. 'pick-up the soap'). Similar methods could be used to support other aspects of personal care such as a face wash and brushing teeth. Dressing poses more of a problem for designers. With the use of RFID technology, it would be possible to track whether a clothing item was picked. However, it would be difficult to know if the item has been put on correctly. More work is needed to develop sensor- or vision-based technology to identify these problems.

As with other morning routines, assistance with going to the toilet affects the

person's sense of dignity and personal space. The Friendly Rest Room (FRR) project focused on designing technology to assist people with physical, sensory or cognitive impairment when going to the toilet. The system uses RFID technology to recognise users and mechanically adjust the customised seat height and angle. In addition, it includes a prompting functionality, which provides an audio message referring to the step just taken and the steps that will follow. This could be used to prompt the person with dementia so that they complete all the steps in the sequence (Panek et al., 2005). Systems should also be designed to orientate the person where the toilet is. Non-technological approaches have reduced incontinence in care home settings by providing reminders every hour and using orientation aids (signposts) around the environment (Hanley, 1986). Technology could be designed to provide similar methods of assistance in domestic settings.

4.1.2 Risks

Problems with cooker safety and wandering were considered to be common reasons for moving a person with dementia into a residential care setting. There are safety devices available to detect when the electrical cooker has been left on or the gas is left open (Adlam & Orpwood, 2004). These systems provide an audio prompt to warn the user that the cooker has been left on. If there is no response then it will cut off the power or gas supply. According to our informants, accidents are not only the result of forgetting the cooker is left on, but also because of difficulties operating the cooker. This means that a risk still remains despite the person remembering they need to turn it off.

Wandering is a difficult issue to address because people do this for different reasons. In some cases, the person with dementia does not know the time, and so might get out of bed or leave the house at night. The orientation aids discussed in Chapter 1 would go some way in addressing this problem (Baruch et al., 2004; Gillard, 2004). These systems present the date, time, and time of day. This would help resolve wandering behaviour resulting from disorientation about time. However, many people leave the home because they believe they need to do something (e.g. go to work or find somebody). Although there are systems that can inform carers when a person leaves the house, more work is needed to reassure the person with dementia

in order to prevent them from leaving. For example, sensors could be used to detect when they are approaching the door, and audio messages could be presented to distract them or reassure them that there is no need to leave the house.

4.1.3 Interpersonal interaction

Loneliness was reported to be the main reason for people with dementia deciding for themselves to move into permanent care settings. Difficulties in communication cause problems in sustaining relationships with family and friends. In Chapter 1 a number of technological tools were described that facilitate communication. The CIRCA project adopts the reminiscence approach to support social interaction (Alm et al., 2004; Alm et al., 2007). The system involves the presentation of reminiscence material on a computer touch screen, which allows the person with dementia to select various themes (e.g. recreation, entertainment and local history), each having three media types available (photographs, video or music). This system engaged the person with dementia more effectively than other methods (e.g. photograph albums) and was more effective in cueing recall of remote memories. Similarly, the SenseCam is a wearable camera that takes pictures of meaningful events by sensing significant changes in the environment (e.g. light and body heat). The device was found to support people with amnesia when telling another person about their day (Berry et al., 2007; Hodges et al., 2006). Being able to recall personal events to others can enhance a sense of self worth and minimise withdrawal from the outside world (Feil, 1982). Improving the quality of the communication would also improve the experience of the other person, and so they would be likely to engage in conversation more often. Communication supports should be explored further in the home context to see how it affects the relationships within the household. Such work would reveal additional features that would support their interaction. For example, the technology could allow the family caregiver to easily include reminiscence material related to their shared interests or experiences, and talk about current events that would be of particular interest to the person with dementia.

4.2 Underlying deficits and design implications

Categories relating to the ‘underlying deficits’ (sequencing, memory/orientation and learning) describe the causes of the problems in the home, as perceived by the professional carers. For cognitive prostheses to be effective it is necessary to understand the nature of the problem being addressed. In this section we will discuss how the perspectives of our informants relate to cognitive theory on dementia.

4.2.1 Sequencing actions in multi-step tasks

Many of the problems reported were associated with an inability to sequence component actions within a task. This is consistent with previous studies that have explored executive control deficits in dementia. Studies using problem solving tests have demonstrated that people with dementia have difficulties formulating subordinate goals and monitoring their own performance on a task (Kramer, Reed, Mungas, Weiner, & Chui, 2002; Voss & Bullock, 2004).

In order to design effective methods of prompting people with dementia, it is necessary to understand the nature of these problems and how they relate to the cognitive impairments. Developments in tracking and artificial intelligence have shown potential in using technology to support people with dementia through sequential tasks (Dishman, 2004; Mihailidis et al., 2004). Our informants provide some insight into the nature of these problems experienced in the home. However, more work is needed to identify the types of errors that occur and communicate these problems to designers. In Chapter 1 we described the Norman and Shallice (1986) model of attention, which has been an influential model in understanding the origin of action errors during everyday tasks. This model will be instrumental in designing cognitive prostheses that meet the underlying causes of the problem. This will be discussed further in Chapter 4, in which the action errors presented by people with dementia will be related to cognitive theory on action control.

4.2.2 Memory and orientation in the home

Consistent with existing cognitive models of dementia, professional carers highlighted problems in prospective memory ('remembering to do things') and retrospective memory ('remembering events'). Reminder devices are generally geared towards supporting prospective memory. However, as people with dementia easily forget recent events, it is equally important that the device provides feedback to the user on what actions have been performed.

This problem is not only relevant to performance of scheduled tasks, but is also important for accomplishment action sequences. Our informants reported that problems also occurred during everyday tasks due to impaired memory as well as sequencing deficits. Existing prototypes on task assistance have focused on the planning and execution of actions. However, such technology must also compensate for memory deficits that disrupt task performance. More work is needed to understand the nature of action errors resulting from impaired memory in order to design prompting systems that address all aspects of the task.

4.2.3 Adapting to new environments and appliances

According to our informants, people with dementia have great difficulty in adapting to new surroundings and household appliances. It is widely acknowledged that people with dementia respond negatively to unfamiliar situations and settings. Studies have shown that people with dementia have limited abilities in acquiring new information (Morris, 1986; Morris & Kopelman, 1986). Impaired executive control also means that they present severe limitation in attending to unfamiliar procedures. In contrast, activities with familiar procedures require little conscious effort and so they show relatively preserved abilities (Jorm, 1986).

Problems dealing with unfamiliar appliances and environments present potential constraints for the development of cognitive prostheses. Any technology that transforms a person's ability to perform everyday tasks will require some degree of novelty. More work is needed to explore the extent to which deficits in learning

restrict possibilities for designing cognitive supports. This issue will be explored further in Chapter 5.

4.3 Promoting independence in the home

The ‘consequences’ theme describes how dementia impacts independence. As would be expected, the informants reported the need to address physical (safety, security and health), as well as psychosocial (sense of accomplishment, personal space and social well being) issues. Importantly, the informants also focused on the needs of the caregiver. Most technology addresses the problems faced by the person with dementia. However, our informants reported a need to also assist the caregiver. This would involve supporting the relationship within the household and minimising the demand for constant supervision. Previous studies have shown that caregivers’ levels of stress is a strong predictor for patient referral into institutionalised settings (Hope, Keene, Gedling, Fairburn, & Jacoby, 1998), and so addressing caregiver consequences also plays an important role in helping people with dementia to remain at home for longer. Remote alerts and monitoring systems could allow the caregiver to remain away from the house for longer (e.g. when shopping), which would reduce their level of stress and anxiety. The main design issue to be addressed is the ethical problem of privacy. Our analysis highlights the need to improve the sense of personal space for the person being cared for, and so such systems must reduce caregiver anxiety, but also provide the other person with a sense of control and privacy.

4.4 A professional carer perspective

It is important to remember that the present study draws from the perspectives of OTs and care assistants. All participants specialised in the care of people with dementia, and so were well suited for the objectives of this study. However, it is likely that training and care practise models have helped shape their knowledge and perspectives. Despite this, they would have had a broad experience of different households and good insight into the types of problems that prevent people with dementia from remaining in their own homes. They are therefore a valuable source for guiding research efforts in designing cognitive prostheses.

The present study shows the value of including care professionals in the design process at the earliest stages of designing assistive technology. The study provides a broad insight into the nature of the problems to help direct research towards activities that are considered to be important by carers. This highlights areas that should be the focus of future work. In particular, more work is needed to understand the nature of sequencing and memory/orientation errors during everyday activities. Additionally, the barrier of learning deficits needs to be investigated so that technology can be easily adopted and used.

4.5 Limitations

The findings summarise the perspectives of our informants, and so it should not be interpreted as an absolute account of dementia in the home. The ‘underlying deficits’ theme is important as for any intervention to work it is necessary to understand the cause of the problem being addressed. Naturalistic observations would provide further insight into how these problems occur.

The thesis focuses on the design of cognitive prostheses to support activities in the home. This meant that the interview structure was restricted to problems in home settings. It should be noted that there are other activities outside the home that may also be important, such as shopping and transport.

The combined role of OTs and care assistants is to assess functional ability, identify risks and provide personal care. Their views might be shaped by previous training and formal roles, and so more subtle issues may not have been reported. It is possible that the perspectives of people with dementia and informal caregivers would present some differences.

5. Conclusion

The present study describes the problems of dementia in the home, from the perspective of OTs and care assistants. The analysis revealed areas of daily living that should be addressed with assistive technology. These issues were presented in relation to the perceived deficits and consequences. The 'underlying deficits' theme relates the experience of our informants to cognitive theory. The 'consequences' theme describes how independence should be promoted. These factors are important in designing technology that addresses the real problems faced by people with dementia.

This chapter has demonstrated the importance of including care professionals in the design process in order to develop technology that is useful and appropriate for the users. It will also be important to explore the perspectives of people with dementia and their family caregivers. This issue will be covered in Chapter 3.

Chapter Three

Exploring the problems of dementia in the home: A patient-caregiver perspective

Abstract

Home visits were conducted with eight people with mild to moderate dementia and ten family caregivers. Grounded theory analysis revealed 13 main categories, described under four themes: *Problems in the home* (daily activities, domestic tasks, leisure and interpersonal interaction), *underlying deficits* (sequencing and memory/orientation), *consequences* for the person with dementia (physical and control) and the caregiver (relationship and care demands), and *situated factors* (verbal cues, visual cues and familiarity). The perspective is compared to that of the professional carers described in Chapter 2. Implications of the themes for assistive technology design are also discussed.

1. Introduction

Chapter 2 summarised the problems of dementia in the home, as perceived by professional carers. This revealed three separate themes. Firstly, ‘problems in the home’ presented areas of daily living that need to be addressed. These problems related to daily activities, risks and interpersonal interaction. Second, ‘underlying deficits’ described perceived causes of these problems, which included sequencing, memory/orientation and learning. Third, the ‘consequences’ of these problems for the person with dementia and their caregiver were identified. For the person with dementia, this included physical well being and control. For the caregiver it included relationships and care demands.

Drawing from the experiences of professional carers is useful for designing technology that is appropriate for the users. However, it is important to recognise that the perspective of professional carers might be different to that of people with dementia and family caregivers. The day-to-day experience of dementia could be different from the limited periods of formal care and assessment. This study explores the experiences of dementia within the household drawing on the perspectives of people with dementia and the informal caregivers.

1.1 Living with dementia

Previous work has been done to explore the personal experience of dementia. These have mainly focused on the subjective accounts, including depression, loss of identity and privacy (Bender & Cheston, 1997). They have also provided insight into the burden for caregivers and reasons for requesting support, highlighting the difficulties in dealing with behavioural problems, aggression and incontinence (Burns & Ranins, 2000; Chenoweth & Spencer, 1986). Chenoweth and Spencer (1986) prioritised the concerns of informal caregivers, which included issues of complete physical care and supervision, strain on emotional health, financial cost of care, wandering, incontinence, feeding difficulties and irregular sleep patterns. Thomas et al. (2002) recorded the frequency of complaints from caregivers. Common complaints included withdrawal or loss of motivation, sadness, anxiety,

passiveness and sleep disorders. More work is needed to understand the day-to-day problems experienced by people with dementia and how this impacts their lives and the lives of their caregiver. This will help direct research efforts in assistive technology design.

1.2 The present study

This study explores the problems of dementia from the perspective of patients and family caregivers. The study includes a home visit methodology, in which the researcher visits the participants' homes to discuss everyday problems. This involves a tour of their home during the interview, as well as the use of a whiteboard for participants to record thoughts and events over the course of one week. The purpose of this approach is to facilitate the discussions and cue recall of events. We expect that many of the issues raised will confirm those discussed in Chapter 2. However, we also expect the methodology to reveal additional themes that have more subtle effects on daily living, but are still important to address.

2. Method

2.1 Participants

2.1.1 Recruiting

Participants were contacted through the UK National Health Service (NHS) Primary Care Trust (PCT). The occupational therapists (OTs) identified clients who they thought to be suitable for the study. They made initial contact with the client and explained the nature of the study. Clients who expressed interest were then introduced to the researcher. The researcher would make an initial visit to their home with the OT to explain the study and ask if they wish to take part. This initial visit is described in *Section 2.3*.

2.1.2 Participant profiles

There were 18 participants in total. Table 3.1 presents the profiles of the participants. Ten participants took part in the ‘home visits’, and two participants took part in the ‘individual interviews’. The home visits included eight couples (a person with dementia and their spouse) living together in their own homes. The most recent Mini Mental State Examination (MMSE) score was taken from the clients’ records. In all cases the MMSE was recorded within 6 months of home visits. The MMSE is a measure of cognitive status. It includes 30 questions on memory and orientation. A score between 21 and 28 indicates mild dementia. A score between 11 and 20 indicates moderate stages of dementia. A score of 10 or below indicates severe dementia. In the present study, the clients’ scores ranged from 11 to 28.

The two participants who took part in the individual interviews were both spouses of a person with dementia. In both cases the person with dementia and caregiver lived together in their own home.

Table 3.1: Participant profiles: There were eight persons with dementia (PwD) and ten caregivers.

Transcript	Participants	Description of person with dementia
1 Home Visit	PwD <i>and</i> <i>Caregiver</i>	JF has Alzheimer’s disease (MMSE = 19, Age = 80). She lives a house with her husband.
2 Home Visit	PwD <i>and</i> <i>Caregiver</i>	RG has Alzheimer’s disease (MMSE = 12, Age = 76). She lives in a bungalow with her husband.
3 Home Visit	PwD <i>and</i> <i>Caregiver</i>	PW has Alzheimer’s disease (MMSE = 19, Age = 75). He lives in a house with his wife.
4 Home Visit	PwD <i>and</i> <i>Caregiver</i>	PL has Alzheimer’s disease (MMSE = 11, Age = 75). He lives in a house with his wife.
5 Home Visit	PwD <i>and</i> <i>Caregiver</i>	SG has Alzheimer’s disease (MMSE = 28, Age = 77). He lives in a house with his wife.
6 Home Visit	PwD <i>and</i> <i>Caregiver</i>	DA has Alzheimer’s disease (MMSE = 17, Age = 80). He lives in house with his wife.
7 Home Visit	PwD <i>and</i> <i>Caregiver</i>	FA has Alzheimer’s disease (MMSE = 23, Age = 74). She lives in bungalow with her husband
8 Home Visit	PwD <i>and</i> <i>Caregiver</i>	TM has Alzheimer’s disease (MMSE = 25, Age = 76). He lives in bungalow with his wife.
9 Interview	<i>Caregiver</i>	Wife of a person with moderate vascular dementia. They live together sheltered accommodation.
10 Interview	<i>Caregiver</i>	Wife of person with moderate vascular dementia. They live together in a house.

2.1.3 Ethical considerations

Ethical approval was obtained through the NHS Research Ethics Committee. The OTs identified clients who they felt would be interested in taking part. The OT described the research to their clients. If the client expressed an interest in taking part, the OT introduced them to the researcher for an initial visit to the participants' home. During the visit, the researcher explained the purpose of the study. An information sheet was left with them, which gave details of the study. It was emphasised that there was no obligation to take part, and that they could withdraw at any time. Consent was obtained from the person with dementia, the informal caregiver, and the OT (see Appendix B for the information sheet and consent form).

2.3 Procedure

2.3.1 Home visits

The home visit procedure involved three separate visits to each household. In the initial visit the OT introduced the participants to the researcher. The researcher explained the purpose of the study and asked them to take part. An information sheet was also left with them at the end of the visit that provided further details regarding the procedure of the following visits.

On the second visit (Visit 1) an interview and 'home tour' was conducted with both participants at the same time. The meeting began in the lounge or dining room area. During the interview the participants would show other areas of the home (e.g. kitchen, bathroom and bedrooms). All interviews were audio recorded and lasted for approximately one hour. The interview was semi-structured, covering problems experienced, concerns and activities that were important to them (see Appendix C for the interview structure). Photographs were taken of tools, utensils and appliances that were talked about in the interview. At the end of the visit, the participants were given a new information sheet that explained the purpose and format of the next visit (Visit 2). The researcher also left a whiteboard (36cm x 56cm) with them. The board was divided into four sections: 'Likes', 'Dislikes', 'Problems' and 'Reminders'. Participants were asked to fill in the various sections during the week to note down

activities that, for example, the person with dementia likes to do, or that the caregiver and person with dementia like doing together. The reminders section was to be used as a memory aid.

On the third visit (Visit 2), the researcher sat with both participants for a second interview. The researcher raised issues that were discussed in the first interview. They then discussed notes taken on the whiteboard. The visit was audio recorded and lasted approximately one hour.

2.3.2 Individual interviews

The individual interview involved one interview in the lounge or dining room area of the participant's home. The researcher introduced the study and the purpose of the visit. The interview was semi-structured, following the same format as that used in the home visits. The interview was audio recorded and lasted approximately one hour.

2.4 Analysis

Audio material from the interviews and focus group were transcribed. The transcripts were analysed using Grounded Theory Analysis (GTA), as developed by Strauss and Corbin (1990). This method of analysis involves three main stages. The first stage (open coding) involves identifying component concepts in the text.

The second phase of the analysis (axial coding) involved relating concepts together to form categories. The terms of these categories reflected the terms used by our informants. Related categories were then further grouped into main categories.

The third stage of analysis (selected coding) involved grouping the main categories into broader themes and identifying how the themes related to each other.

3. Results

The analysis revealed four themes that summarise the problems of dementia in the home, as perceived by people with dementia and their informal caregivers. The core theme represents 'problems in the home', which had four main categories: *Daily activities*, *domestic tasks*, *leisure* and *interpersonal interaction*. The second theme relates to the 'underlying deficits' of these problems, which is composed of two main categories: *Sequencing and memory/orientation*. The third theme represents the 'consequences' of the problems for the people with dementia and their caregivers. The main consequences for people with dementia were *physical well being* and *control*. The main categories for caregiver consequences were *relationship* with the person with dementia and *care demands*. The fourth theme describes 'situated factors', which relate to aspects of the environment that have a bearing on the ability to perform daily tasks. This had three main categories: *Verbal cues*, *visual cues* and *familiarity*. Figure 3.1 depicts the four themes and the category components.

The main categories were composed of 38 subcategories in total. Not all of the subcategories will be discussed in detail here. However, they are listed in Table 3.2 with an extract from the transcripts (the *instances* present the frequency in which the category was mentioned, and the *groups* represent the number of transcripts in which the category occurred).

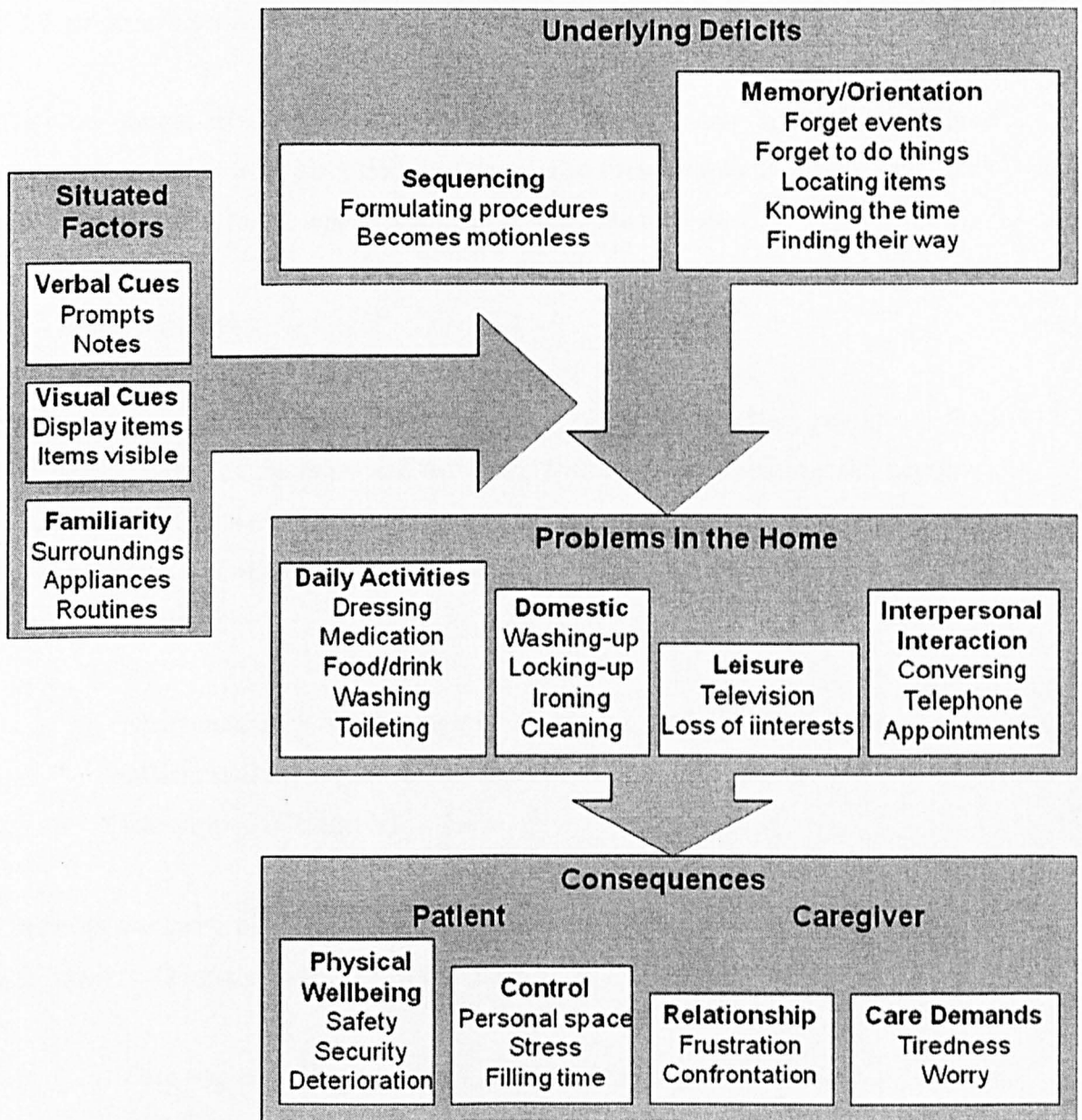


Figure 3.1: A summary of the problems of dementia in the home, as perceived by people with dementia and informal caregivers

3.1 Problems in the home

The core theme relates to the types of problems that occur in the home. Three separate categories were identified that summarise these problems. These were daily activities, domestic tasks, leisure and interpersonal interaction.

3.1.1 Daily activities

Participants reported difficulties with *dressing, taking medication, preparing food and drinks, going to the toilet and washing*. With regard to dressing, the caregiver would need to provide support in terms of deciding what to wear and finding clothing items. Prompts from the caregiver were usually required when clothing items were omitted:

“She would pick her trousers or shorts up, and I’d say, what’s missing, and she would realise that she had no underclothes on.”

(Transcript 2: Caregiver)

Dressing was particularly difficult if the items had to be obtained from cupboards and drawers. Often the caregiver would place items on the bed to overcome this:

“Dressing is a slight problem. You tend to forget where clothes are.” (Transcript 2: Caregiver)

“She would say I’ve put everything out on the bed for you. So I know exactly where I’ve got to find it, and it’s no problem really.”

(Transcript 4: PwD)

The caregivers usually managed the medication. They would remind them when to take the medication and store it away so that it would not be taken at the wrong time.

“Well I put them there every morning as part of the routine. At breakfast I put them all out for him.” (Transcript 3: Caregiver)

Preparation of food and drinks was generally carried-out by the caregiver, as it was considered too complex for the person with dementia to achieve alone, and too time consuming for them to do together.

“I do invariably make breakfast, if she comes out and I’m in the middle of porridge or something. If I leave it all ready, the plate, bread in the toaster, the wall switched on. All she has to do is press the lever down and the toast automatically jumps out. But to have to prepare it, get the bread out of the bread bin, and put it in the toaster, put the switch on, I think she’d have a problem.” (Transcript 1: Caregiver)

Problems in toileting generally centred on issues of hygiene, in which the person may forget elements of the task, such as wiping themselves, flushing the toilet or washing their hands:

“He would forget to wipe himself, and I need to sit there to remind him, and he can do it.” (Transcript 10: Caregiver)

Washing includes many aspects of personal hygiene, including washing, shaving and brushing teeth. Often the caregiver would need to remind them each morning, as well as provide particular prompts during the activity:

“I have to put his razor out. And I put it on there [side of sink]. And I have to put all these things out. And I say ‘don’t forget to put water in here. Don’t forget to put on aftershave. Deodorant’.” (Transcript 3: Caregiver)

“I tell him when he has to shave. And I think really he’s got so out of doing it he cannot remember how to do it. So I sort of help him now.” (Transcript 4: Caregiver)

3.1.2 Domestic tasks

There were four domestic tasks reported. These include *washing-up*, *locking-up*, *ironing* and *cleaning*. Participants reported that when doing the washing-up and ironing, the main problems occurred when they were required to store or acquire items, as opposed to actually performing the activity:

“She will wash up, but she cannot remember where the pots and cutlery goes. But otherwise I say ‘leave them out,’ and I put them where they’ve got to go.” (Transcript 1: Caregiver)

“And emptying the dishwasher. You sometimes put things away in the wrong places.” (Transcript 7: Caregiver)

“Having just ironed, nowadays she’d put all clothes away or she would bring them in and she’d plonk them on the bed. She’d not put them away. I would say ‘where do the towels go, in the airing cupboard’. But she’ll have a problem thinking ‘where’s the airing cupboard’, and then she would put them in the fridge.”
(Transcript 2: Caregiver)

One household in particular reported concerns around locking-up at night. When prompted, the person knew where the keys were kept and could lock the door. However, her husband was concerned that she would never remember to do it if he was not there to remind her. Participants were also put off using burglar alarms as they could never remember the code.

“He came down with the burglar alarm one morning. And he couldn’t put in the numbers and it went off. And he’s never done it since.” (Transcript 6: Caregiver)

3.1.3 Leisure

There were two topics related to leisure. These were loss of interests and problems in using the television. With regard to loss of interests, it was often reported that people with dementia showed a decline in personal interests (e.g. reading, gardening, music and flower arranging), and caregivers found it difficult to motivate them to adopt recreational activities. Although the person with dementia would be aware of the problem they still had little interest in engaging in such activity:

“You used to play the organ all the time. You got a lot of pleasure out of it. With the grandchildren some time ago – they used to come down and sing together with her playing the organ. But she can’t be bothered now.” (Transcript 1: Caregiver)

“I’m not interested now, you know. I used to do quite a lot. But I don’t now.” (Transcript 1: PwD)

“I think keeping an interest for her is important because, the days are long...just finding what to keep her interested in, rather than sitting in the corner of the room.” (Transcript 1: PwD)

With regard to watching television, those who wanted to watch it had difficulty operating the remote control and remembering the programmes scheduled. It was also difficult to follow the television programme:

“And she has a television in the other room. And she doesn’t even know how to switch that on.” (Transcript 1: Caregiver)

“It’s a problem because we have two or three remote controls for different things and he can’t use them. I think the only reason he can’t use those is because I’ve done it. That’s the DVD one, couldn’t train him to use that.” (Transcript 6: Caregiver)

"I know if I am going to try and use it, I'm going to make a fool of myself." (Transcript 4: PwD)

"Things he used to be interested in. and if they get a bit complicated you get bored don't you. If you're watching a film and it's a little bit hard to understand you get a bit bored with it." (Transcript 6: Caregiver)

3.1.4 Interpersonal interaction

There were three issues related to social interaction. These were conversing with others, using the telephone and keeping appointments. Participants reported that communication is often frustrating for the caregiver because of repetitive questions throughout the day. For the person with dementia, they lose confidence in conversing with family and friends, and so rely on the caregiver to remain in contact with other people:

"I find it very hard talking to people...my sons are very nice to me. They're quite good. If I speak to them it would be 'could you do that', and it is like 'oh yes', and so it wouldn't be like a chat or anything... I just collapse. Bit stupid isn't it. I sort of say so much and then that's all I can say." (Transcript 1: PwD)

"Just can't get the words out. It is like on the tip of your tongue." (Transcript 4: PwD)

"If you were to say 'what did you discuss this morning'. I would say, 'I can't remember'." (Transcript 8: PwD)

"She doesn't retain anything at all. Well apparently she doesn't. I can say something to her and within a matter of seconds, what I said has gone." (Transcript 1: Caregiver)

A second problem with interpersonal activity is that the people with dementia rarely use the telephone. This is partly related to lack of confidence in conversing with others, although it is further amplified when answering because they cannot work out who is on the other end of the line. Difficulty also arises in actually operating the phone with regards to remembering phone numbers:

"Yeah that is a problem. Not being able to use a phone, in this day and age is a serious problem."(Transcript 2: Caregiver)

With regard to keeping appointments, people with dementia may forget that they are getting visitors, or forget when people have been visiting. They tend to rely on the caregiver to remind them about who is visiting and when, which can further frustrate the caregiver:

"She's asked me ten times, what time you were coming today. And as soon as I tell her, it's gone, and she'll come back again."
(Transcript 1: Caregiver)

"On Saturday she went off twice to get ready and dressed for people who were coming to pick her up. But they don't come until Tuesday. But she was persistent on telling me. But she didn't know what day it was really. So that's a problem for her, and a problem for me, purely because she will argue with me."
(Transcript 1: Caregiver)

"I know that my son and daughter-in-law are coming but I don't know when." (Transcript 8: PwD)

3.2 Underlying deficits

The underlying deficits theme represents what the participants perceived to be the causes for problems. The main categories are sequencing and memory/orientation.

3.2.1 Sequencing

Sequencing refers to problems with the execution of multi-step tasks. This includes problems in 'formulating procedures' and instances when they 'become motionless' during certain points in the task. With regard to formulating procedures, it was reported that they had difficulty planning component actions. Activities involving repetitive actions (e.g. brushing teeth) caused fewer problems than more complex activities (such as cooking), which require a degree of planning:

"Meals are the biggest problems. For some reason you just can't. If it's a repetition thing, it can be done. If it's when you have to use your initiative to formulate a meal, such as toast and cheese, you're useless on it." (Transcript 2: Caregiver)

"There's another side of that sort of problem. And that is processes or procedures. Things I know that were second nature to you years ago, like being able to make custard. And you got in such a tangle with it." (Transcript 7: Caregiver)

"You would need to actually do it, before you knew what it was all about. You couldn't just say well you do so and so. I wouldn't even know what you meant. It is one thing, if you could see it, and you knew about it, that's when you might start to remember how to do it." (Transcript 1: PwD)

Tendency to become motionless refers to instances where the person with dementia fails to initiate component actions within the sequence. At certain points of the task the caregiver needs to prompt them to perform a required action:

“Gets the kettle, fills it, switches it on...But then you’ll stand there, and I’ll say, ‘what you doing now?’ and I’ve jogged her memory again. And generally speaking you get the coffee out. And she’ll take the top off the jar. And she’ll look at it and think, ‘well what am I taking this off for?’ And I would say, ‘well we’re having a cup of coffee.’” (Transcript 2: Caregiver)

“For some reason he fills the hand basin and he stands looking at the hand basin.” (Transcript 9: Caregiver)

3.2.2 Memory and orientation

Participants also reported that memory loss and disorientation to time and place contributed to problems in the home. Problems include remembering events, remembering things to do, locating items, knowing the time and finding their way around. Forgetting to do things or forgetting recent events, lead to difficulties in following scheduled activities:

“It’s difficult to do anything, you’ve got to have a memory.”
(Transcript 5: PwD)

“He says ‘Have I had my breakfast?’ And I say ‘Yes you have.’ And he say ‘Have I had me dinner?’ And I say ‘Yes you have.” (Transcript 3: Caregiver)

“Well I can’t remember full-stop, you know, it is just ‘puff.’”
(Transcript 1: PwD)

Remote memories were more preserved than more recent events:

“I can remember the park across the road. It had a statue, a tree that had sap come out, like a rubber tree. I can remember when I had to go to school. My memory is a strange thing... I

could go into the town I was born, where I left 60 or 70 years ago. And what happened the day before yesterday, I probably can't remember." (Transcript 5: PwD)

Performance on everyday tasks can also be disrupted by difficulties in finding items. This includes problems in identifying stored items (e.g. locating kitchen utensils), as well as problems in locating lost items (e.g. glasses or handbag):

"The biggest problem is that she is continually losing things. That causes a lot of upset. I don't know where to look. But it's to do with her handbag mainly, and her make-up. Handkerchiefs are a bother with her. We even lost the box of tissues, a big blue box. I spent ages looking for it. She loses her glasses, and gets in such a panic." (Transcript 1: Caregiver)

Problems of orientation centred on difficulties in 'knowing the time' and 'finding their way'. People with dementia rarely had insight into the time of day or week, and so relied on the caregiver to tell them:

"I do get a bit panicky, but I never know what the time is, which day it is, you know, this is my problem." (Transcript 1: PwD)

Finding their way around tended to be less of a problem in their own home as it is a familiar setting. However, problems did arise when memories of previous settings overlap with memories of existing residences:

"He goes up to the...bathroom and actually it's down here... We've lived here two years... And the toilet was upstairs in our old house. So its not immediate memory, it's more remote. He remembers things from the past." (Transcript 4: Caregiver)

Problems also occurred if they had been away from the home (e.g. on holiday):

“When we go abroad, the light switches are in different places. All the light switches in the bathrooms are on the outside, and eventually she gets use to doing them. And when we come back from holiday she’s looking for the light outside.” (Transcript 2: Caregiver)

3.3 Consequences

The ‘consequences’ reflect the impact that dementia has on the lives of the person with dementia and the family caregiver. Consequences for the person with dementia include effects on physical well being and control over their lives. Consequences for the family caregiver include effects on relationships and care demands:

3.3.1 Consequence for the patient: Physical wellbeing

With regard to the physical well being, concerns were mainly over ‘safety’, ‘security’ and ‘deterioration’. Safety relates to dangers in the home. This is the major reason why caregivers feel they have to stay with them throughout the day:

“You’ve twice made tea in the kettle, and the second time it fused the kettle. You know and we had to have a new kettle. So really that why he’s never made a cup of tea, just safety really.”
(Transcript 4: Caregiver)

Security relates to concerns over threats from others, either because the house is left unlocked or letting strangers into the house:

“There’s one thing that really worries me, and that is...unawareness of people...I’ve been aware of never letting strangers in the house. I never give my address or the telephone, or internet. Now he is the most trusting person. I get a delivery, and

most of these firms that are mail order don't have their own system, they have firms taking their goods, and he will ask them to come in and have a cup of tea or something. You've never met that person."

(Transcript 5: Caregiver)

Deterioration relates to concerns over the person's decline in health, including personal hygiene (e.g. brushing teeth) and medication management:

"And in that short period of time, she only had one pill. And from not taking those pills in that period, I noticed a distinct deterioration in her." (Transcript 2: Caregiver)

3.3.2 Consequence for the patient: Control

People with dementia lose a sense of control over their lives. This includes problems around personal space, stress and filling time. Personal space refers to the loss of privacy due to social dependence in personal care (e.g. washing and toileting):

"I would like him to be able to use the toilet mostly, because that's a personal thing."(Transcript 10: Caregiver)

Stress relates to a tendency for the person with dementia to become anxious or frustrated as a result of becoming disoriented or unable to accomplish daily tasks. The caregiver tends to address this by reassuring or re-orientating them:

"When I go to the supermarket and I do a week's shop, my daughter comes and sits with him, because he gets stressed otherwise."

(Transcript 3: Caregiver)

"I am getting frustrated that I cannot do what I have been doing in the past." (Transcript 7: PwD)

Problems in 'filling time' relates to loss of interests in hobbies or recreational activities (e.g. gardening, listening to music and reading). Caregivers' attempts to resolve this (e.g. introducing puzzles, painting etc) tend to have little result, even though the person with dementia had various interests in the past:

"I think he should incorporate some sort of interests because the day must be so long. I mean I've always got something to do, so I can fill my day. But the days must be so long. And you keep looking at your watch, don't you." (Transcript 4: Caregiver)

3.3.3 Consequence for the caregiver: Relationship

The relationship can be affected by the caregiver's increasing frustration and incidences of confrontation. Caregivers frequently become frustrated by the problems that occur during simple everyday tasks:

"She frustrates me sometimes. The stupidity of what she does, and an inability to do what to me is so common." (Transcript 2: Caregiver)

They may also become irritated by the need to provide constant reassurance:

"I can tell her, she has asked me once, she has asked me ten times, what time you were coming today. And a soon as I tell her, it is gone. And she'll come back again. And I find that...I get irritant... you are forever asking a repetitive question, time and time again." (Transcript 1: Caregiver)

"He's always asking, 'where's my car'. We've sold it.' 'Where's the money' I get that every ten minutes, all day long. It does my head in." (Transcript 3: Caregiver)

Caregivers reported that they often try to avoid confrontation. However, caregiver frustration and distress in the person with dementia can often lead to conflict:

“A problem for her, and a problem for me, purely because she will argue with me. Everything she loses, it’s my fault. She’s lost a rubber, she puts it away in peculiar places, I don’t know how you can resolve this. She blames me for it.” (Transcript 1: Caregiver)

“And he can be really nasty if I don’t answer him, I get fed-up with it all.” (Transcript 3: Caregiver)

3.3.4 Consequences for the caregiver: Care demands

Issues related to care demands include ‘tiredness’ and ‘worry’. Tiredness relates to the need to provide ongoing assistance and supervision. Caregivers need to be on-hand to help the person with dementia through daily activities, as well as provide reassurance:

“It’s terribly bad. I think I’m going mad myself with it all. He’s always asking about the car and money. And I’m saying ‘it is alright we’re comfortable’. But he wants me to tell him, all day long.” (Transcript 3: Caregiver)

At times when the caregiver is unable to supervise them (e.g. night time or when they leave the house) they become worried. This often disrupts their sleep at night and restricts opportunities to leave the house:

“And I worry, well I have problems getting her to bed at times at night. Cus I like her to get there and then I know, hopefully, she’s settled. But I’m never sure because she gets up and wanders around at times.” (Transcript 1: Caregiver)

3.4 Situated Factors

The fourth theme, 'situated factors', describes external factors that determine the affect of the underlying deficits on everyday tasks. Informants reported three main aspects of the environment or situation that influenced task performance. These were verbal cues, visual cues and familiarity.

3.4.1 Verbal Cues

It was reported that task performance is supported by prompts from the caregiver and written notes. Verbal prompts are used to remind the person with dementia and guide them through activities. The prompts need to be given at appropriate times and with the correct level of content so that they will not be forgotten:

"As I say, it's gone in one ear and out of the other. And that's it, just as quickly as that." (Transcript 1: Caregiver)

"I can't ask him to do two things together. He'll do one, but the second thing is gone... he'll just do the first thing." (Transcript 4: Caregiver)

Notes and diaries are often used as an external memory aid:

"I write things down. And knowing where you've written it down is important. No point having paper all over the place... If it's something that matters and I actually need to know, then I have to write it down. What I'm doing tomorrow, I have to look in the book." (Transcript 8: PwD)

Most of the households used lists located around the home or diaries that they refer to throughout the day. In one case, PL, written cues were used to reassure him when his wife left the house. He often became anxious when she left as he did not know where she was, or when she would be back. His wife decided to place a whiteboard in a prominent location in the kitchen, which she would write on before she left the

house (e.g. “gone shopping, will be back at 5pm”). Her husband knew that he just had to look at the board to find out where she was (see photograph in Figure 3.2).

Written cues are also used to make sense of appliances. In one case, SG, written cues were used to help him use the cooker and oven. He did not recognise the meaning of the symbolic cues indicating the different functions of the appliances, so his wife drew the symbols on a piece of paper and wrote the meaning next to it (e.g. ‘grill’). The paper was then stuck above the cooker (see photograph in Figure 3.2).

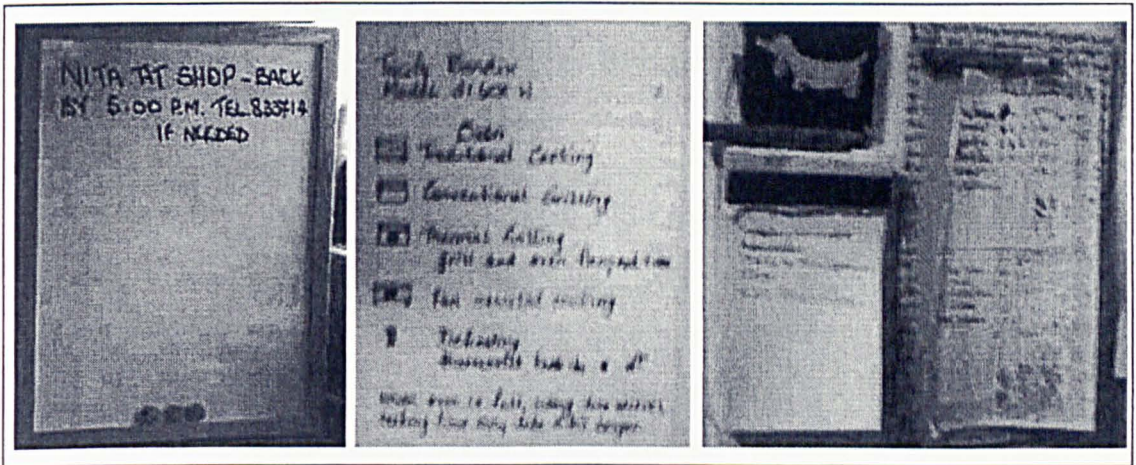


Fig. 3.2 Photographs of verbal cues used in the home. A white board used by the caregiver to remind her husband where she had gone when she leaves the house (left); A list of cooker/oven icons and the meaning written in text next to them (middle); A reminder list located in the kitchen used to remember tasks that need to be done (right).

3.4.2 Visual Cues

Visual cues were also used to support task performance. This included the strategy of deliberately displaying items in a certain way so that they were immediately visible. Participants often reported that objects, such as those needed to make a cup of tea, would be placed on the worktop. In one case, JF, the items for making tea and coffee were stored together on a tray on the worktop. It was believed that this helped her to make drinks independently (see photograph in Figure 3.3). A similar approach was used when getting washed and dressed, in which items would be placed on top of the sink or clothes placed on the bed:

“In the morning, organising your clothes, where they are. If she sees them, there’s no problem.” (Transcript 2: Caregiver)

Medication management was also supported by placing the pills in prominent locations in the home where they would be seen during the daily routine:

“Well every morning I make those into two bottles. Because if I don’t put them out and make those, she’d never take her pills...Providing I put that one bottle out, I wouldn’t put two because she’d take them both.” (Transcript 1: Caregiver)

People with dementia also formulated their own strategies to support memory. In one case, SG, it was important that he could blend his own coffee and did this everyday. He arranged the jars of the different coffee types in a specific order with one jar on the left, two in the middle and one on the right. He then remembered the number sequence 2-4-2, which meant that he needed two spoonfuls from the left coffee jar, four from the middle two, and two from the right jar. This way he could make his favourite blend without having to remember the exact ingredients of coffee types (see photograph in Figure 3.3).

Participants were also aware that performance depended on the structure of the task, and cues were often inherent in the activity. Certain stages of an activity are easier to accomplish because the relevant items are visible.

“Kettle on, no problem, and that’s when the problem starts, because she thinks ‘what comes next’ she can see the kettle, the kettle’s not invisible, but if you look around, there’s nothing there.” (Transcript 2: Caregiver)

It was reported that some devices, such as remote controls, only posed problems because there were too many buttons (see photograph Figure 3.3). In one case, RG, the person with dementia could not locate the control on the vacuum cleaner and so

the caregiver attempted to make it more salient by sticking an arrow next to it (see photograph in Figure 3.3).

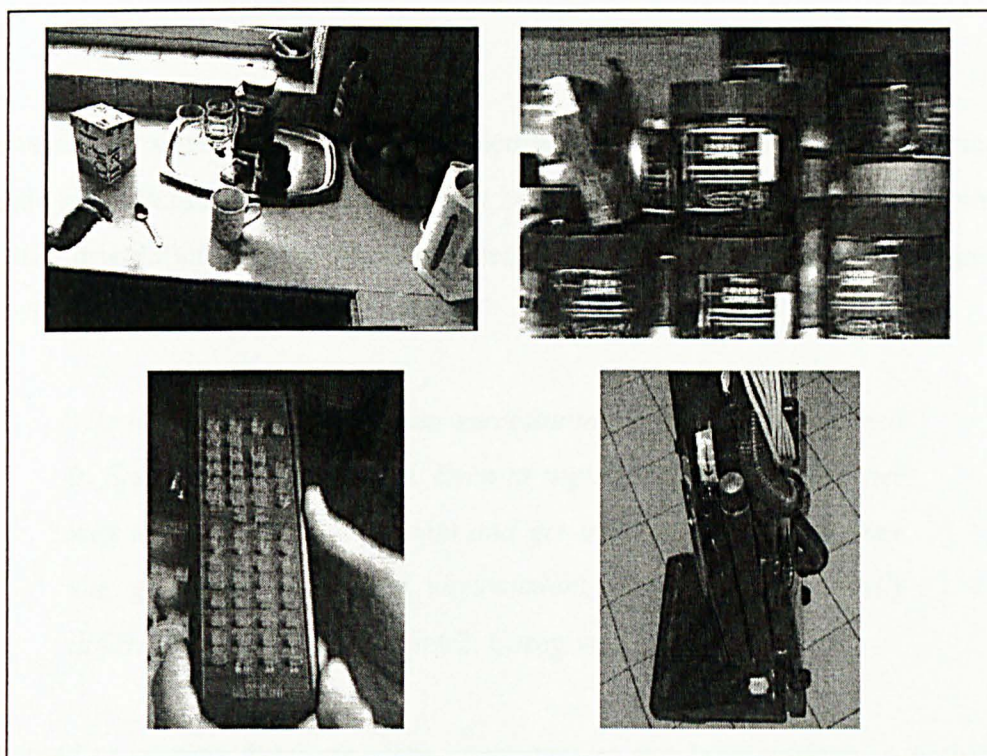


Figure 3.3: Photographs of visual cues in the home. Tea making items are placed on a tray located on the worktop to support task performance (top-left). Coffee bean jars arranged to support the memory for correct measurements (top-right). The person with dementia remembered the sequence 2-4-2 (two spoons from the left jar, four from the middle jars, and two from the right jar). A typical TV remote control that people with dementia find difficult use due to the numerous buttons (bottom-left); The caregiver stuck an arrow on the side of the vacuum cleaner to help locate the on/off switch (bottom-right).

3.4.3 Familiarity

It was reported that problems in performing daily activities were more likely to occur when faced with unfamiliar surroundings, appliances and routines. With regard to appliances, people with dementia have difficulty with completely new devices (e.g. microwaves) and devices that are perceptually different to the one previously owned (e.g. a new vacuum cleaner):

“He wanted to use the vacuum cleaner, but when I handed it over he didn't know what to do with it. And this is from a man who understands mechanical things...He was looking at it. It

was a new machine that I bought when he was in hospital. I got a lighter weight machine and he wasn't accustomed to the machine. And he was interested at looking at it, but couldn't use it." (Transcript 9: Caregiver)

In terms of surroundings, people with dementia are more likely to experience difficulties in unfamiliar settings (e.g. new house or a public place). They reported that spatial orientation tends to be better when they are in their own home as opposed to other settings:

"As long as she is in familiar surroundings, she does rather well in finding her way around. Even at night. She can still find her way to the toilet or bathroom and get into bed again. But once she gets into a strange environment, then that's a totally different matter." (Transcript 2: Caregiver)

With regard to routine, they are more competent at regularly performed activities (e.g. morning routine). However, if it is changed (e.g. preparing to go on holiday) then problems start to occur. To minimise problems they try to maintain a familiar routine:

"If you have a strict enough routine, you don't have to remember, because one thing leads onto the other. I wake up in the morning, I know I must go to the bathroom, I know I must urinate, I know that I must do something with my face, or my head, comb my hair, have a bath, whatever it may be, it follows one from the other...Any break in the routine, excuse the language, buggers up the routine for the rest of the day."(Transcript 5: PwD)

It was also considered important to keep routines going. If they stop performing an activity it becomes very difficult to return to it without experiencing problems:

“Like for instance, laying the table. If I was to do the table each and every time, I wouldn’t have to think, ‘Where does that go? Where does that go?’ I would just do it. But now I don’t do it, so I’ve got to really stand there now and think ‘Where does that go’. If you do something regularly, you can do it no problem. You don’t even have to think about it. But if you stop doing it, you’ve got to start thinking. And you can’t always think...If you can do something without using your brainpower you can pick things up and put it down. That’s easy. But when it is switched over to your mind, you find that’s hard going.” (Transcript 7: PwD)

Table 3.2: Sub-categories from the patient-caregiver perspective, with example extracts from the transcripts. The number of 'instances' shows the number of times the item was mentioned, the number of 'groups' shows the number of transcripts it appeared in.

Category	Instances	Groups (10)	Sample Extract
Food/drink	27	8	"She couldn't cook now. She couldn't even turn the oven on I don't think"
Forget events	24	8	"He says, 'Have I had my breakfast' and I say 'yes you have' and he says 'have I had my dinner' and I say 'yes you have'"
Display items	20	7	"We tried a moment before, get all the essentials there, cup, water, coffee, and if she's got them all there where she can see them, no problem"
Locating items	17	5	"You tend to forget where your clothes are"
Prompts	16	7	"You just sort of say 'brush your teeth', then that's enough"
Medication	15	5	"Well every morning I make those into two bottles. Because if I don't put them out and make those, she'd never take her pills"
Loss of interests	15	4	"I'm not interested now, you know. I used to do quite a lot, but I don't now"
Formulate procedures	14	5	"If it's when you have to use your initiative to formulate a meal, such as toast and cheese, you're useless at it"
Conversing with people	13	6	"If I speak to people, it would be 'could you do that' and it's like 'oh yes', and so on. It wouldn't be like a chat or anything"
Notes	13	5	"It's just if I go out, and I leave him in [the house] which isn't very often... I put a note for him, and what time I'll be home"
Routine	12	6	"If you have a strict enough routine, you don't have to remember. Because one thing leads on to the other. I wake-up in the morning. I know I must go to the bathroom. I know I must urinate. I know that I must do something with my face, or my head, comb my hair. Have a bath. Whatever it may be, it follows one from the other"
Stress	11	5	"I do get a bit panicky, but I never know what the time is, or what day it is"
Forget to do things	11	7	"Well there's so much she needs reminding about"
Confrontation	9	5	"I try to avoid confrontation, but there are times when I have to deal with that"
Television	9	5	"And she has a television in the other room. And she doesn't even know how to switch that on"
Appointments	9	4	"On Sunday or Saturday she went off twice to get ready and dressed for the people who come to pick her up, and they don't come until Tuesday. But she was persistent on telling me, but she didn't know what day it was really"
Finding their way	8	5	"You tend to think the bathroom is upstairs and it isn't, its downstairs"
Dressing	8	4	"Dressing is a slight problem. You tend to forget where your clothes are"
Toileting	8	3	"It would be nice if he sat down and wiped his own bottom without me having to sit there and drop everything... It's either that, or have a mess everywhere"
Tiredness	7	4	"He's always asking, 'Where's my car' ... 'where's the money'. I get that every ten minutes, all day long. It does my head in"

Washing	7	4	"I have to put his razor out. And I put it on there [side of sink]. And I have to put all these things out. And say 'don't forget to put water in here. Don't forget to put on aftershave, deodorant'"
Ironing	7	2	"I've just ironed, and nowadays she'd put all clothes away or she would bring them in and she'd plonk them on the bed. She'd not put them away. Id say where does that go...She'll have a problem thinking where the airing cupboard is, then she'd put them in the fridge"
Frustration	6	5	"I can tell her, she's asked me once, she's asked me ten times, what time you were coming today. And a soon as I tell her, it's gone, and she'll come back again. And I find that...I get irritant"
Cleaning	6	4	"Well he doesn't do anything really. If you give him the bin to through something out, he forgets why he has it, and what he's doing"
Surroundings	6	4	"As long as she is in familiar surroundings, she does rather well in finding her way around. Even at night, she can still find her way to the toilet or bathroom and get into bed again. But once she gets into a strange environment, then that's a totally different matter"
Become motionless	6	2	"If I leave her on her own, she'll put the kettle on, and then she'll stand there waiting...and she must think to herself, 'why am I here' motionless"
Locking-up	6	2	"And if someone tells you to do something repeatedly 'have you locked the door?' – she knows where the keys are, and she knows how to lock the door"
Knowing the time	5	2	"You were up at two o'clock in the morning ready to go, when the people come for you at half past nine"
Washing-up	4	4	"She will wash-up, but she cannot remember where the pots and cutlery goes, sometimes she can. But otherwise I say leave them out and I put them where they've got to go"
Items visible	4	3	"The kettle's not invisible, but if you look around, there's nothing there"
Safety	4	3	"He comes out with me. Feel its safest that way"
Filling time	4	2	"It is difficult because there are so many things I've been used to, and you miss it completely"
Personal space	4	2	"I would like him to be able to use the toilet mostly, because that's a personal thing"
Using the Telephone	4	2	"I think it's a dislike to doing it. But if she's on her own, it has to be done. She wouldn't answer it if I was here, 'No I cant do it' she'd say"
Worry	4	2	"And I worry, well I have problems getting her to bed at times at night. I like her to get there and that I know, hopefully she's settled, but I'm never sure because she gets up and wanders around at times"
Appliances	3	3	"He wanted to use the vacuum cleaner, but when I handed it over he didn't know what to do with it. It was a new machine I bought when he was in hospital. I got a lighter weight machine and he wasn't accustomed to the machine."
Deterioration	3	2	"And from not taking those pills in that period, I noticed a distinct deterioration in her"
Security	3	2	"And he will ask them to come in and have a cup of tea or something, and he's never met that person"

4. Discussion

The present study describes the problems of dementia in the home from the perspective of people with dementia and informal caregivers. Many of the views and experiences are consistent with those of professional carers. The present study reiterated the same high level themes that summarised the professional carer perspective ('problems in the home', 'underlying deficits' and 'consequences'). At category and sub-category level, the present study revealed additional problems that did not occur in Chapter 2. Table 3.3 presents the three themes across the two perspectives. The present study also revealed the additional theme of 'situated factors', which describes how factors in the environment or situation affect task performance. This provides further detail about dementia in the context of the home. This section will focus on the additional issues raised in the present study, and the implications they present for cognitive prostheses design.

4.1 Problems to address in the home

The issue of risk did not emerge as a theme in the present study, but occurred frequently in the professional carer perspective. This reflects the formal role of an OT, which is to identify risks in the homes. Furthermore, whereas the OTs would be reporting problems with people who live alone, the present study only included those who live as a couple. Therefore, cooker safety and wandering may be less of a concern.

However, additional categories did emerge in the core theme. Firstly, our informants talked about problems with domestic tasks (washing-up, locking-up, ironing and cleaning) and leisure (loss of interests and television). Second, they present two new categories relating to interpersonal interaction (using the telephone and appointments).

4.1.1 Domestic tasks

In addition to the concerns around personal care, our informants discussed activities related to the maintenance of the home. Activities such as washing-up and cleaning have not been the focus of assistive technology. This is probably because it does not have a direct or immediate impact on physical well being. Such activities do not need to be accomplished at specific times of the day, and can be easily resolved by visitors or home help services. Furthermore, assistance on these activities is less invasive than personal care, and so would be of less concern to professional carers. However, from the accounts of our informants in the present study, it does appear that such activities do have meaning to people with dementia. Such activities fill the day, and they find it difficult to find other things to do to replace them. It is therefore an important part of maintaining a sense of continuity, which is important for self-esteem and self-identity. The tracking technology and artificial intelligence required would be much the same as those used for prompting systems to support other types of activities (Dishman, 2004; Mihailidis et al., 2004). However, many of the problems on these tasks related to locating items and putting them away, rather than actually accomplishing the activity sequence. This means that the prompting technology should aid orientation as opposed to cueing the initiation of action steps.

4.1.2 Leisure

Loss of interest in recreational activities also increased a sense of boredom during the day. This problem relates to a 'loss of interest' rather than inability to do the activities. To overcome such apathy, technology could be used to make leisure activities more engaging. The reminiscence media used in the CIRCA (Computer Interactive Reminiscence and Conversation Aid) was found to engage people with dementia more effectively than traditional methods of reminiscence, such as photograph albums (Alm et al., 2004; Alm et al., 2007). Similar technology could be developed to encourage engagement in other recreational activities, such as puzzles or games.

People with dementia may also become more engaged in an activity if they believe it would have some long-term benefit. For example, Morris, Lundell and Dishman

(2004) developed the 'social memory aid' for people with dementia to practise face recognition. The user selects photographs, which are linked to a database containing information about the picture via RFID tags. Questions about the person in the photo are then presented on a TV screen and the user can practise remembering relevant details about friends and family members. This would allow the person with dementia to enjoy their pastime whilst also gaining a sense of achievement and progress.

A related issue is watching television. Problems in operating the television may be resolved by simplifying the interface needed to operate it. For example, it is possible to get remote controls with only a few buttons to operate the main functions. However, our informants also reported problems of following the programme, which quickly leads to a loss of interest. More work is needed to develop media that requires minimal cognitive effort but is still engaging and relaxing to watch.

4.1.3 Interpersonal interaction: Using the phone and keeping track of appointments

Problems with operating the telephone and carrying out the procedures required to call somebody (e.g. find number in phone book, retain number to dial, and so on) are already known. Some have addressed this using 'picture phones' that present images of people you want to call, so you simply have to press the image to call them. However, our informants also expressed anxieties around speaking with people on the phone due to difficulties in communicating. More work is needed to maintain a sense of social connectedness without placing too high a demand on communication skills.

With regard to making appointments, the person with dementia needs to be reminded as to who is meeting them, and when. Unlike other scheduled activities, such as medication, the person needs to be orientated as to when the person is due to arrive. Even though they know someone is visiting, they might repeatedly ask the caregiver what time they would be arriving. Furthermore, the person needs to prepare for the appointment (e.g. get dressed), and so need to know in advance. Visual representations could be used to represent who is visiting, and how long they have until the appointment.

4.2 Underlying deficits and design implications

The sub-categories represent the language used by our informants. Therefore terms used to describe underlying deficits are less technically expressed in the present study than those used by the professional carers. For example, in Chapter 2 professional carers used terms such as 'orientation to place', whereas in the present study it was expressed as 'finding their way'. The two perspectives appear consistent with regards to sequencing and memory/orientation. However, in contrast to the professional carer perspective, the present study did not reveal categories related to learning. An equivalent category did emerge, but was referred to as an external factor, in which they discussed the need for familiar appliances, settings and routines. This was categorised under the 'situated factors' theme, which will be discussed later in this chapter.

4.3 Consequences for the patient and caregiver

There is little difference between the professional carer and patient-caregiver perspectives with regards to consequences. The main difference is the language used to express these issues. For example, informal caregivers talked about 'tiredness' whereas professional carers referred to a need for 'constant supervision'. The main additions to this theme are the problems of stress experienced by the people with dementia due to disorientation and the problems of filling time.

Table 3.3: Comparison of categories across the three themes ('problems in the home', 'underlying deficits' and 'consequences') from the professional carer and patient-caregiver perspectives.

Themes	Professional Carer Perspective		Patient-Caregiver Perspective		
	Categories	Instances	Categories	Instances	
Problems in Home	Daily Activities		Daily Activities		
	<i>Dressing</i>	8 (6)	<i>Dressing</i>	8 (4)	
	<i>Medication</i>	13 (4)	<i>Medication</i>	15 (5)	
	<i>Food/Drink</i>	32 (9)	<i>Food/Drink</i>	27 (8)	
	<i>Toileting</i>	5 (3)	<i>Toileting</i>	8 (3)	
	<i>Washing</i>	9 (5)	<i>Washing</i>	7 (4)	
	Risks				
	<i>Cooker Safety</i>	22 (10)			
	<i>Wandering</i>	19 (7)			
			Domestic Tasks		
			<i>Washing-up</i>	4 (4)	
			<i>Locking-up</i>	6 (2)	
			<i>Ironing</i>	7 (2)	
			<i>Cleaning</i>	6 (4)	
			Leisure		
		<i>Watching Television</i>	9 (5)		
		<i>Loss of Interests</i>	15 (4)		
	Interpersonal Interaction		Interpersonal Interaction		
	<i>Communication</i>	6 (5)	<i>Conversing</i>	12 (5)	
	<i>Recognising people</i>	7 (4)	<i>Telephone Use</i>	4 (2)	
			<i>Appointments</i>	9 (4)	
Underlying Deficits	Sequencing		Sequencing		
	<i>Initiating actions</i>	5 (3)	<i>Formulate procedures</i>	14 (5)	
	<i>Ordering actions</i>	5 (4)	<i>Becomes motionless</i>	6 (2)	
	<i>Problem solving</i>	5 (2)			
	Memory/Orientation		Memory/Orientation		
	<i>Forget events</i>	13 (8)	<i>Forgets events</i>	24 (8)	
	<i>Forget to do things</i>	7 (5)	<i>Forget to do things</i>	11 (7)	
	<i>Orientation to time</i>	3 (2)	<i>Locating items</i>	17 (5)	
	<i>Orientation to place</i>	8 (7)	<i>Knowing the time</i>	5 (2)	
	<i>Recognising Objects</i>	3 (2)	<i>Finding their way</i>	8 (5)	
	Learning				
	<i>Appliances</i>	6 (3)			
<i>Surroundings</i>	5 (3)				
Consequences	Patient	Physical		Physical	
		<i>Safety</i>	10 (5)	<i>Safety</i>	4 (3)
		<i>Security</i>	8 (5)	<i>Security</i>	3 (2)
		<i>Health</i>	5 (4)	<i>Deterioration</i>	3 (2)
		Control		Control	
		<i>Personal Space</i>	6 (5)	<i>Personal Space</i>	4 (2)
	<i>Achievement</i>	9 (4)	<i>Stress</i>	11 (5)	
	<i>Social Isolation</i>	8 (7)	<i>Filling time</i>	4 (2)	
	Caregiver	Relationship		Relationship	
		<i>Frustration</i>	5 (3)	<i>Frustration</i>	6 (5)
		<i>Interaction</i>	7 (5)	<i>Confrontation</i>	9 (5)
		Care Demands		Care Demands	
		<i>Constant Supervision</i>	10 (5)	<i>Tiredness</i>	7 (4)
	<i>Anxiety</i>	4 (3)	<i>Worry</i>	4 (2)	

4.4 *Situated factors in the home setting*

4.4.1 Verbal and visual representations

The home visit methodology provided a detailed account of the living spaces of our informants, which led to further insight into the role of the environment. The most obvious level of support is explicit representations (e.g. prompts, notes and diaries). The caregivers highlighted the need to represent instructions in a form that is compatible with the person's knowledge and cognitive capabilities (e.g. not giving more than one instruction). Prompts must also be presented at the appropriate time so that they are not forgotten before performing the task. Prompts are generally used to cue the person with dementia to do something. In contrast, written cues orientate them (e.g. whiteboard informing the person about where his wife has gone), and re-represent information in the environment (e.g. using words to translate the meaning of cooker and oven symbols). People with dementia show a relatively preserved ability to read (Noble, Glosser, and Grossman, 2000) and so this demonstrates how information in the environment can be re-represented in a form that is compatible with the cognitive capabilities of the person with dementia.

Another influence on abilities to carry out daily tasks is the implicit representations of visual cues. Objects would be deliberately positioned to cue certain activities or trigger actions during multi-step tasks. This also demonstrates how the environment can be deliberately re-represented to compensate for cognitive deficits. Such behaviour has been observed in other settings. Kirsh (1995) refers to the use of 'complementary strategies' to shape the environment in order to reduce cognitive load. In an office setting, Kirsh (2001) describes the role of 'entry points' that are objects in the environment that invite certain actions. The entry points have different properties that vary along a number of dimensions, including *intrusiveness* (how much attention it attracts), *richness in metadata* (how much it conveys), *visibility* (how distinct or unobstructed it is), *freshness* (how recently it was presented), *importance* (priority of the associated activity) and *relevance* (how useful it is to a current activity).

Managing the location and visibility of objects is well acknowledged in dementia care. Lawton and Nahemow's (1973) ecological model of ageing describes the need to match the demands of the environment with the competences of the individual. As the person decreases in cognitive capabilities, the cognitive demands of an activity should be reduced. Occupational therapy has often involved the management of home environments by minimising clutter in kitchens and placing items in prominent locations (Beck et al., 1993; Corcoran & Gitlin, 1992; Corcoran, Gitlin, Levy, Eckardt, & Vause, 2002; Gitlin et al., 2001, Gitlin et al., 2003). Not all of the visual cues were deliberate. Often the nature of the task would inherently present situational triggers for action.

The effect of visual cues on activity performance is important for the designing of technological prompts. More work is needed to better understand how features of the home environment affect task performance. In Chapter 4 we explore this issue more closely in relation to the cognitive deficits of dementia.

4.4.2 Learning and familiarity

In Chapter 2, the professional carer perspective highlighted that deficits in learning prevent the accomplishment of activities involving new settings and appliances. In the present study, our informants refer to a similar issue. However, they attribute this problem to the situation, by describing problems of unfamiliar appliances, settings, and procedures.

In Chapter 1 we described existing theory on action control, which makes a distinction between 'controlled' and 'automatic' processes (Schneider & Shiffrin, 1977). Automatic actions involve familiar or routine activities (e.g. grooming and walking to work), and so require little attentional resources. In contrast, controlled processes involve novel or less familiar tasks (e.g. packing a suitcase and writing a letter) that require greater cognitive effort. According to the Norman and Shallice (1986) model of attention, action involves two separate cognitive processes. Routine is generally controlled by an automatic activation of stored action schemas, known as the contention scheduling (CS) system. Unfamiliar procedures require an executive control process, known as the supervisory attentional system (SAS), which

formulates sub-goals before activating required action schemas. Impairment to the SAS in dementia results in problems in dealing with unfamiliar procedures or situations (Jorm, 1986).

This issue presents important implications for assistive technology design as any device aimed at improving abilities on everyday tasks will involve some degree of novelty. This issue will be explored more closely in Chapter 5.

4.5 Using the patient-caregiver perspective

Previous studies have demonstrated the importance of including people with dementia and their caregivers in the process of designing assistive technology (Orpwood et al., 2004). Participatory design has generally taken place after the system has been developed in order to evaluate and improve the technology. The present study illustrates the importance of including the users at the earliest stages in the design process. This guides research efforts towards what people actually want, and ensures that the system being developed is useful and appropriate.

In Chapter 2, the professional carer accounts provided a broad insight into the problems of dementia in the home. Their views were drawn from experiences with numerous clients at different stages of dementia. Importantly, their role as OTs and care assistants meant that they had good knowledge of the common reasons for moving people with dementia into care facilities. To some degree their perspective would have been shaped by their formal role and the purpose of the visits to clients' homes (e.g. assessment). The present study presents the views of people who live with dementia day-to-day. This revealed more subtle problems that were not discussed in Chapter 2. For example, problems around domestic tasks and loss of interests are important to address. More personal issues resulting from these problems (e.g. filling time) highlight the need to think beyond physical and social well being.

The home visit methodology also revealed the role of situated factors, which has important implications for designing technological supports. The whiteboard that was left with the informants at the end of Visit 1 was an effective probing tool. It

provided insight into problems that were not directly related to independence in the home. For example, in the 'dislikes' section, one person with dementia reported that she did not like being 'bossed about'. This led to a conversation about how she does not like it when her husband is prompting and reminding her about things she needs to do.

Both perspectives are important for assistive technology design. The broad insight and knowledge of OTs and care assistants highlight the aspects of daily living that are considered necessary to allow people to live at home for longer. The accounts of people with dementia and their caregivers reveal more subtle issues that impact the experience of living at home. Together these accounts could help guide efforts in developing technology towards aspects of daily living that are important to the users.

In both Chapter 2 and the present study, our informants described what they perceive to be the underlying deficits (sequencing, learning and memory/orientation). It is important to acknowledge that these accounts are the interpretations of our informants, and so caution should be taken in drawing conclusions from them. However, the theme does provide some insight into how the problems relate to existing cognitive theory. This is important for the hypothesising of effective prompting systems. More work is needed to explore this theme and to understand the nature of the problem for specific activities. In Chapter 4 we will focus on this issue using an observational approach in real home settings.

4.6 Limitations

It should be noted that all informants in the present study were couples who lived together. This means that the analysis does not include problems that might be specific to people who live alone. This may explain the absence of certain issues, such as social isolation and risks, which occurred in the professional carer perspective.

One problem with interviewing caregivers and people with dementia together is that the input is not always equal. In social situations the person with dementia might rely on the caregiver to do all the communicating. The relationship between the caregiver and person with dementia may have also been a factor. Some caregivers may take the opportunity to complain about the habits or behaviours of their spouse, and so problems that frustrate them the most could have dominated the discussion.

As was the case in Chapter 2, the structure of the interview focused on problems within the home. Other problems outside of the home would have been overlooked. Similar work should be conducted to explore problems for tasks outside the home, such as shopping, going for walks and transport.

5. Conclusion

The present study summarises the problems of dementia in the home, from the perspective of people with dementia and informal caregivers. The analysis presents activities in the home that should be supported with technology. The nature of such problems is described in relation to the consequences, underlying deficits and the situated factors. These themes present different implications for the design. The accounts in the present study provide additional issues that were not revealed in the professional carer accounts. The findings show subtle differences in experience and perspective. The home visit methodology also provided a more contextual account of everyday problems. This highlights the benefits of using different elicitation methods

and sources of information to obtain a more complete understanding of the real problems to be addressed.

Further work is needed to understand how the cognitive deficits of dementia disrupt everyday tasks. Chapter 4 will explore this issue more closely using observational methods to identify the types of problems faced by people with dementia when carrying out tasks in a specific context.

Chapter Four

Video analysis of kitchen tasks

Abstract

Six people with mild to moderate dementia were video recorded performing activities in their own homes. In total there were 22 video recordings. Activities included making a cup of tea or coffee, a bowl of soup, beans on toast, or coffee with toast. The video recordings were transcribed using an adapted version of the Action Coding System devised by Schwartz et al. (1991). Problems that prevented the participants from accomplishing the task were recorded. These incidences were grouped into categories based on behavioural features. This revealed eight error types that were further grouped under four main themes: *Sequencing* (intrusion, omission and repetition), *Orientation* (locating and identifying), *Operation* of appliances, and *Incoherence* (toying and inactivity). The implications of this error taxonomy for the design of prompting systems for people with dementia are discussed.

1. Introduction

Chapters 2 and 3 described the problems of dementia in the home from the perspective of professional carers, informal caregivers and people with dementia. The core theme, 'problems in the home', summarised our informants' views on what activities are important to support. A related theme, 'underlying deficits', described their perspective on the nature of these problems, which include difficulties in sequencing action, memory/orientation and learning.

For any intervention to work it is necessary to understand how cognitive deficits disrupt the activity. Non-technological approaches in neuropsychological rehabilitation are based on an understanding of the role of impaired cognitive processes. This allows the demands of a task to be transformed so that it matches the cognitive capabilities of the patient. Similarly, cognitive prosthesis design should be based on an understanding of how the underlying deficits disrupt task performance. This ensures that the technology is being directed towards the cognitive capabilities of the users. In order to design technology to support people in the home it is important to understand in the context in which the activities are performed.

This chapter reports the findings from observations of six people with mild to moderate dementia performing daily activities in their own homes. Cooking and preparing hot drinks were selected as the activities to focus on. Based on the findings described in Chapters 2 and 3, the kitchen environment was considered a good starting point. Firstly, such activities are important to people, not only because of the obvious health implications, but also because it related to self-esteem and sense of control. Second, due to the complexity of most cooking tasks, problems were frequently reported. Therefore, this context should reveal a number of different types of problems.

It was decided that the activities should be performed in the participants' own kitchens, and that they should choose what activities to perform. This would provide insight into the types of problems that occur in real situations where people are

performing task in familiar environments and with activities that are meaningful to them. This is important if the technology is to assist people in real settings.

Before describing the study it is necessary to consider relevant literature. Firstly, as the present study aims to guide the design of prompting systems, it is necessary to describe existing designs. In Chapter 1 we briefly described the few existing prototypes that are designed to assist people with dementia through multi-step tasks. This chapter will discuss the prompting methods of these prototypes, as well as other prompting systems designed for other types of cognitive impairment. Second, as the present study uses an observational method to identify problems that need to be addressed, it is necessary to review the methods and outcomes of previous studies that have looked at action disorders. In Chapter 1 we described previous work that used naturalistic observations with clinical groups. Here we will focus on the methodologies for recording behaviour and the outcomes in relation to cognitive theory.

1.1 Methods of prompting people with cognitive disabilities

In Chapter 1 we described some of the concepts and prototypes that are designed to guide people with dementia through a task sequence. At present, evaluations of these systems have focused on the reliability of the activity monitoring and the algorithms used to predict appropriate prompts. Less work has been conducted to evaluate the appropriateness of these prompts for people with dementia. There are a number of ways in which information could be represented to the users. However, little work has been done to establish which method is appropriate for people with dementia.

The only work to test such technology on people with dementia was an evaluation of the COACH (Cognitive Orthotic for Activities in the Home) conducted by Mihailidis et al. (2004). The design is described in Chapter 1 and so will not be presented here. However, it is worth describing the evaluation with regard to the efficacy of the audio prompts in guiding users through the task of washing their hands. They tested the COACH system with ten people with moderate to severe dementia. They evaluated efficacy of the prompts based on the number of task steps accomplished independently. They divided the whole task (washing hands) into six component

steps: 1) Turn the cold water on, 2) perform initial rinsing of the hands, 3) use the soap dispenser, 4) rinse the soap off the hands, 5) turn water off, and 6) use a towel to dry the hands. Audio cues for the step were provided (e.g. "Turn off tap"). If the person did not respond or performed the wrong action, then a more specific cue would be provided (e.g. addressing the user by name). Overall, the users performed 25% more steps with the technological intervention. However, improvement between participants varied greatly, from 10% to 45%. It was reported that one participant ignored prompts, spoke back insisting that he had completed the steps or became agitated. Another participant responded to the prompts but could not accomplish the action, such as using the soap dispenser.

The evaluation of the COACH system is the only work to date that has studied the efficacy of technological prompts for people with dementia. However, some work has been done using computerised prompts with other types of cognitive impairment. Despite difference in target group it would be useful to review their approach and outcomes.

Similar to the method used by Mihailidis et al. (2004), these studies have selected a task and broken it into subordinate steps. The evaluation is based on how many steps are accomplished without assistance from another person. Sigafos et al. (2005) tested the efficacy of video prompting to guide three adults with learning difficulties through the task of making popcorn in a microwave. The activity consisted of ten steps (e.g. "close door of the microwave"). When each step was performed the carer would direct the participant's attention to a screen presenting a video recording of the next step, along with an audio cue. If the person failed to respond, or performed the action incorrectly, then they were shown the clip again. The baseline score of the action steps ranged from 0 to 20%. With the technological support all three participants were able to accomplish 100% of the steps after 10 weeks of training.

Lancioni et al. (1999) also tested the efficacy of a computer system in prompting adults with learning difficulties. They tested a system providing pictorial representations on four people during eight activities (six were food preparation and two table setting tasks). The number of steps for each task ranged from 25-31. The study compared performance between two strategies: A card control condition

(pictures represented on separate cards), and a technological prompt that presented pictorial representations. The technology required the user to press a switch to view the next pictorial instruction. After 20 training sessions, participants were able to perform 15-33 more steps with the computer-aided system across the eight tasks.

These studies suggest that technological prompts are effective for people with learning difficulties in guiding actions through multi-step tasks. However, more work is needed to see how people with dementia respond to such cues, and what methods of prompting are most appropriate. The current prototypes present similar approaches for supporting everyday tasks. They all adopt a single prompting strategy (e.g. audio cues or videos) and then attempt to assist the user with through the whole task sequence. Furthermore, they all provide explicit representations (e.g. verbal, pictorial or video) to cue actions.

This is a top-down approach in that a prompting method is selected and then tested on the whole task sequence. More work is needed to better understand how the cognitive deficits of dementia impact performance of activities in the home. This requires detailed observations of activities in real contexts, and an understanding of these problems in accordance with cognitive theory. This approach will allow effective prompting methods to be hypothesised. The present study adopts a bottom-up approach to the designing of technological prompts for people with dementia. This involves conducting naturalistic observations, recording action errors, and communicating these problems to designers. Drawing from cognitive theory it should be possible to propose strategies for providing effective interventions to these problems.

At present, no observational work has been done with the purpose of communicating the problems of dementia to designers of prompting systems. However, others have conducted observations of action disorder in people with dementia and other cognitive deficits with the objective of developing assessment tools and gaining theoretical insight into action control. Some of this work has already been mentioned in Chapter 1. For the purposes of this section it will be useful to focus on their methodologies and outcomes.

1.2 Methods of analysing action disorders during everyday tasks

Descriptions of action errors in healthy volunteers have been based on self reports. This provided useful material in developing theories of action control for everyday activities (Norman, 1981; Reason & Mycielska, 1982). Norman (1981) analysed a corpus of error accounts to form error categories. These included three main themes. Firstly, he describes problems in the *formation of intention*. This includes 'mode errors' (e.g. going to remove glasses, then realising they are not being worn) and 'insufficient specificity' (e.g. putting the sugar lid onto the coffee jar). Second, he describes *faulty activation*. This includes 'capture slips' (triggered by habits), 'external activation' (triggered by visible objects), associated schemas (related intentions) and loss of activation (due to decay or interference). Finally, *faulty triggering* may result in the blending of actions or sentences (e.g. combining the words 'lose' and 'shut' into the response 'clut').

Naturalistic observations in clinical settings have been used to identify error types. This has involved video recording the volunteer on set activities and identifying points where they make a mistake or require assistance from the researcher or care worker. Gendron and Levesque (1993) developed an instrument called OPTIMAGE to evaluate the functional autonomy of patients with Alzheimer's type dementia. The instrument was developed through observations of 13 people living in a care facility performing four activities (getting dressed, getting washed, eating and going to the toilet). Each resident was observed on two or three occasions for each activity. When they performed an incorrect action, or failed to initiate an action, then assistance was provided. Three levels of prompting were used. Firstly, verbal instructions of the action would be given. If the verbal prompt did not work, then miming the action or pointing to the relevant object would be used. If the patient still failed to act, physical assistance would be provided. The observations revealed 19 'blocking' behaviours that hindered performance. These behaviours were incorporated into the OPTIMAGE instrument for assessing functional ability (see Table 4.1):

Table 4.1: List of ‘blocking’ behaviours used in the OPTIMAGE assessment instrument (Gendron & Levesque, 1993)

1. Unsatisfactory execution	11. Perseveration
2. Request for information	12. Motor resistance
3. Verbal resistance	13. Avowal resistance
4. Scattered gestures	14. Avowal of inability without trying
5. Request for help without attempting	15. Verbal monologue
6. Request for help after attempting	16. Verbal dialogue
7. Stop	17. Motor dispersal intra-area
8. Omission	18. Motor dispersal extra-area
9. Repetition	19. Retrogression
10. Passivity	20. Other

Others have conducted naturalistic observations to better understand the origin of the problems. Schwartz et al. (1991, 1995) devised the Action Coding System (ACS) to analyse action disorders during everyday tasks (e.g. coffee making and brushing teeth). The system required the transcription of individual actions, termed ‘action units’ (e.g. picking up a bottle of milk). This provided a script at the action level (A1). The A1 scripts were recorded using a semi-formal notation to describe four different types of action: *MOVE*, *ALTER*, *TAKE* and *GIVE*.

MOVE refers to the moving of an item from one location to the other in a single action (e.g. moving the sugar from a jar to a cup). *ALTER* refers to actions that change the state of the environment (e.g. open a cupboard). *TAKE* refers to the taking of a possession from a location (e.g. taking a jar from a cupboard). *GIVE* refers to the relinquishing of an item to a location (e.g. putting the jar in the cupboard). The A1 scripts allowed errors to be identified and recorded at specific points in the task sequence.

The ACS also involved grouping A1 scripts into sub-procedures (e.g. sugaring the tea), which were termed A2 scripts. The purpose of A2 scripts was to identify problems with the transition between sub-goals. For example, difficulties in initiating actions occurred at the beginning, rather than during, the sub-goal. The A2 script also allowed the flow to be analysed, such as the degree of overlap between different sub-goals.

Schwartz et al. (1991, 1995) used the ACS to observe two stroke patients (HH and JK) performing tasks such as making a cup of coffee or brushing their teeth. Across a number of video recordings they recognised a range of error types. These included 'place substitutions' (e.g. coffee granules in oatmeal), 'object substitutions' (e.g. orange juice added to the cup of coffee), 'drinking anticipation' (sipping coffee before it has been fully prepared), 'omission errors' (e.g. failure to open bottle before pouring), 'instrumental substitutions' (e.g. stirring with a fork), and 'faulty execution' (e.g. partial opening of a sugar packet). Also observed were incoherent actions, including 'independent acts' (picking an item up and putting it down again) and 'toying' behaviour, in which the patient would make gestures with objects without any apparent goal.

Humphreys and Forde (1998) adopted the ACS to record action disorders among three brain-injured patients. The observations were conducted in controlled settings so that the presence of task-irrelevant objects, or 'distracter items', could be manipulated. They grouped the errors into eight categories, similar to those described by Schwartz et al. (1991, 1993, 1995), with the addition of 'persistence' (e.g. adding milk to coffee more than once), 'quality' (e.g. filling the cup to the point of overflow) and 'spatial' (e.g. missing the cup and pouring the tea onto the table).

These studies have led to the development of standardised methods of observing action disorders. The Multi Level Action Test (MLAT, Schwartz et al., 1998) is an observational method for scoring error occurrence on three set tasks (making a slice of toast with butter and jam, wrapping a present, and packing a lunchbox). Participants perform these tasks under four conditions that range in difficulty: *Solo basic* (only materials needed are presented in the array), *solo-distracters* (functionally related items are also presented), *dual-basic* (the primary task with another specific task, such as wrapping a present and preparing a letter) and *dual-search* (some of the materials are located in a closed drawer with other task-irrelevant items). Participants perform the test in a lab setting, seated at a 'U' shaped table upon which the items are located in standardised positions.

Performance on the MLAT was scored according to an error taxonomy: (i) *omission* (e.g. fail to add cream to coffee), (ii) *sequence*, which includes anticipation-omission

(close lunchbox before packing), reversal (stir mug, then add coffee granules) and perservation (e.g. make two sandwiches instead of one), (iii) *object substitution* (stir coffee with fork), (iv) *action addition* (pack extraneous items in the lunch box), (v) *gesture substitution* (spoon rather than pour milk into cup), (vi) *grasp-spatial misorientation* (e.g. hold wrong end of scissors), (vii) *spatial misorientation* (e.g. cut paper too small to wrap around present), (viii) *tool omission* (e.g. spread jam with finger) and (ix) *quality* (e.g. fill cup to point of overflow). In a shortened version of the MLAT, often referred to as the Naturalistic Action Test (NAT), three of the MLAT items are administered: Prepare toast with butter and jam and prepare coffee with cream and sugar (item 1), wrap gift with related distracter objects in the array (item 2), and pack lunch box and school bag with objects a stored away in a drawer, in the presence of task-irrelevant objects (item 3).

The MLAT and NAT have been used with different clinical groups, including dementia (Giovannetti et al., 2002), closed head injury (Schwartz et al., 1998), and stroke (Schwartz, et al., 1998). Across these studies, the clinical groups had error rates that were at least five time that of age-matched controls. Interestingly the proportions of error types were very similar between different patient groups and controls. Omissions were found to be most frequent. This was followed by sequence errors. For all groups, the presence of distracter objects increased the occurrence of omission errors. For people with dementia, omission errors and substitution errors occurred more frequently when distracters objects were present (Giovannetti et al., 2002). It was concluded that the uniformity of results across patients indicates that the different error types result from an impairment to a single cognitive process responsible for goal directed behaviour. This conclusion is discussed further in the next section.

Feyereisen et al., (1999) combined the OPTIMAGE and ACS methods to study dressing performance in Alzheimer's patients. They video recorded 26 residents of a nursing home during the morning routine. The action level (A1) included five basic steps for each piece of clothing: Choosing, orienting, putting on, adjusting and fastening (when necessary). The second level (A2) referred to the particular clothing items (underwear, first sock etc). Performance was measured at both levels.

The study found that the mean rate of success for A1 units was 56%, with no significant difference across the five action types. The rate of successful transitions between A1 units was 62%. At the A2 level, the mean rate of success was 39% whereas smooth transitions were 61%. The analysis at the A2 level revealed that performance was highly dependent on the clothing factor. For example, the most difficult basic action for putting on an undershirt was orientating, whereas for underwear, errors most often occurred during putting on and adjusting.

The analysis also looked at possible causes for errors. In the mildly impaired the most common errors were incorrect choice of clothing and 'unsatisfactory executions' of basic actions. For the more severely impaired the most common problem was passivity, in which they showed a 'mental block' or inability to initiate the next step.

Rusted and Sheppard (2002) studied nine people with Alzheimer's disease making a cup of tea. The analysis was intended to identify changes in performance over four years, and compare the occurrence of problems in familiar settings (own kitchens) and unfamiliar settings (lounge/dining room). Errors were classified under four types: 'Omitted steps', 'action repeats', 'semantic errors' (inappropriate use of objects or blending actions) and 'intrusions' (e.g. actions from a different routine).

Participants failed to accomplish the task on only 12% of recorded attempts. Action repeats, semantic errors and intrusions were infrequent. Intrusions errors occurred on only four occasions in 260 recordings. In all cases this involved the participant making coffee instead of tea. This tended to occur when the coffee jar was located near the tea caddy. There were three semantic errors recorded. On two occasions teabags were added to the kettle instead of the teapot, and on one occasion the teapot was used to fill the kettle. Omission errors were more frequently observed, occurring on 12% of the video recordings. These occurred across all three sub-goals: Boiling the kettle (16%), adding water or tealeaves (56%), and pouring the tea (28%). It was found that performance was better in familiar settings than the unfamiliar settings. Removing participants from their own kitchens increased the likelihood of making omission and repetition errors.

The objective of these studies was either to develop assessment tools of functional status or provide theoretical insight into action control. However, a contribution to assistive technology design is limited. Firstly, the studies focused on action control, and so the analysis only included problems of action execution. Other aspects of the task may be affected due to other attention and memory deficits associated with dementia.

Second, the studies tend to focus on the frequency of action errors, and so the activities and environments are often standardised and conducted in clinical settings. Such controls limit the opportunities for errors that might occur in real settings. Being in an unfamiliar environment could also distort performance. A further problem with standardisation is that the tasks had to be pre-set. Some of the tasks may be meaningless to the participants (e.g. packing a schoolbag) and often require specific objectives (e.g. toast must have jam). These outcomes do not necessarily reflect performance on tasks that are meaningful to the participants.

Third, although these studies provide proportions of error occurrences, there is little description regarding the nature of these errors and the context surrounding them. Designers of prompting systems would benefit from detailed account of real situations, so that solutions to real problems could be proposed.

Finally, these studies include all types of errors within the analysis, irrespective of whether they prevented task accomplishment. For example, action repeats have theoretical importance, but may have no detrimental effect on task accomplishment. In designing assistive technology, only those errors that prevent task accomplishment are of interest.

Despite these limitations, these studies demonstrate how performance on daily activities can be documented and analysed to categorise error types into meaningful groups. Designers of prompting systems would benefit from such accounts. With the objective of designing cognitive supports, it is also necessary to understand the nature of the problems in accordance with cognitive theory. Therefore, the theoretical conclusions drawn from the naturalistic observations will also be useful in explaining some of the problems observed in the present study.

1.3 The origins of action errors

The Norman and Shallice (1986) model of attention has been influential in understanding action disorder. This model was described in Chapter 1. It is claimed that pathological weakening of top-down activation from the supervisory attentional system (SAS) means that the contention scheduling (CS) system selects action schemas in a less regulated fashion. Consequently, bottom-up activation from internal (associated action schemas) and external (environment) triggers often result in actions that do not follow the intended goal.

This highlights the role of situated factors in guiding actions of people with impaired executive control. Schwartz et al., (1991, 1993, 1995) point out that, despite the variety of action errors presented by people with frontal lobe pathology, action disorder actually results from a unified deficit. They describe this as ‘limited capacity’ in top-down activation. This unified deficit also applies to omission errors and incoherent behaviour (e.g. toying). In these instances, competing action schemas fail to become activated in the face of different situational cues (Schwartz et al., 1991) stated that:

“When intentions direct the perception-action cycle, task-relevant affordances or objects become more salient relative to the many other, irrelevant affordances that the context provide. On the other hand, when intentions are pathologically weakened or poorly sustained, irrelevant objects and/or affordances may exert greater influence” (pp. 409-410)

Consistent with this claim it has been found that reduced capacity of sustained attention explains the frequent occurrence of action errors in traumatic brain injured patients (Robertson, Manly, Andrade, Baddeley, & Yiend, 1997). Studies on eye movement have also shown that attention is continually deployed to task-relevant locations and objects during routine tasks. Land, Mennie and Rusted’s (1999) analysis of three typical adults performing a tea-making task found that the eyes rarely moved to task irrelevant objects despite numerous distracters. This led them to

conclude that in real tasks eyes are driven by intended goals through top-down activation.

Cooper and Shallice (2000) used an artificial neural network to simulate the CS system. They built models for activities such as making a cup of coffee (Cooper & Shallice, 2000) and packing a lunch box (Cooper, Schwartz, Yule, & Shallice, 2005). The architecture included the hierarchical structure of action schemas, which received both top-down and bottom-up activation. The implemented models further emphasised the role of the environment with the inclusion of a separate network for 'object representations'. The action schemas interact directly with the object representations, responding to the 'post-conditions' and 'pre-conditions' of the environment. The model also makes a distinction between objects that are 'sources' (e.g. sugar bowl) and 'targets' (e.g. cup). These features provided the model with some degree of flexibility, which is seen in real behaviour. For example, if the milk bottle is open then the action of opening it is not performed. The network connections were manipulated to simulate the pathological weakening of top-down activation flow. This revealed behaviours that closely resembled the action errors observed in the naturalistic observation studies that used the MLAT and NAT with stroke patients.

As people with dementia present symptoms of frontal lobe pathology, the theoretical conclusions from previous studies on action disorder will be useful for the understanding of some of the problems observed in the present study. An important point that can be drawn from these conclusions is the role of the environment. With impaired executive control, situational cues play a greater role in guiding actions. Knowledge about the interaction between cognitive deficits and real environments will be an important part of understanding how technology can support performance on multi-step tasks.

1.4 The present study

The objective of this study is different from previous work that has used naturalistic observations. The studies conducted to date have been mainly theoretically based. In contrast, the present study intends to contribute to the development of cognitive prostheses that enable people with dementia to accomplish everyday tasks. It is therefore necessary to analyse what people do in familiar environments, and on tasks that are meaningful to them. Most naturalistic observations conducted so far have been set in an unfamiliar clinic or lab setting. They have often used pre-selected tasks that may not have much relevance to the participant's everyday life (e.g. packing a school bag), with specific task objectives (e.g. items to include in the lunch box). These factors limit the degree to which error types identified could be generalised to real situations. Controlled settings also limit opportunities for error that might occur in real settings. Even under the 'distracter' condition within the MLAT the environment is not as complex or cognitively demanding as real home environment.

In this study, naturalistic observations will be conducted in the participants' own kitchens. There will be no standardisation of items in the kitchen, so that the method is sensitive to errors that would occur in real situations. This setting will contain real situated factors and the analysis will be sensitive to error types that fall outside the topic of action control. The activities will be the chosen by the participants so that they understand what they are expected to do and are motivated to accomplish the task.

As the objective is to communicate the problems to designer of prompting systems, the method of analysis will also be different from those previously used. Most importantly, the analysis takes a minimum set approach to errors that prevent task completion. In contributing to theoretical insights, previous work has included all types of errors as important, irrespective of the impact it had on accomplishing the end goal. The present study will only report those errors that stop the person from being able to complete the task.

It is expected that the methodology and analysis used in the present study will reveal a different collection of errors than those from previous observations. Conducting the activities in natural settings will allow identification of problems, in addition to action disorder, that need to be considered in designing cognitive prostheses. Coding only the errors that prevent task accomplishment will highlight the problems that need to be supported. A taxonomy based on these criteria will be better suited for prompting systems for people with dementia in the home.

1.5 A 'grounded' method of analysis

Given that the objective of the present study is different to previous observational studies, it is necessary to develop classifications without any expectations or assumptions about the error types that will emerge. This can be achieved through a bottom-up method of categorising error incidences from the raw material similar to earlier approaches exploring action errors (Norman, 1981; Reason & Mycielska, 1972). In developing these categories, the ACS devised by Schwartz et al. (1991, 1995) will be a useful method of transcribing the video material to facilitate analysis.

Although a bottom-up approach to the analysis will be used, it is likely that some of the incidences recorded will confirm those previously identified. Where relevant the same terms will be used to describe similar types of errors.

2. Method

The purpose of the study is to communicate the problems people with dementia experience when performing activities in their own home. It was important that the situation appeared natural and the activities were meaningful to our participants. In order to achieve this, the observations were conducted in the participants' own kitchens, and they could choose what activities to perform. The procedure was designed to be as natural as possible, and so controls and standardisation were kept to a minimum.

2.1 Participants

2.1.1 Participant profiles

Six people with dementia were recruited through the UK National Health Service (NHS) Primary Care Trust. The observations were conducted as part of the home visit ethnography reported in Chapter 3, and so all participants reported in this study also took part in the home visit interviews. They all lived with a spouse in their own home, were physically mobile and had no other physical or sensory impairment that prevented them from completing activities in the home. An occupational therapist (OT) recorded the Mini Mental State Examination (MMSE) scores within six months of the study. These ranged from 11 to 25. A score between 24 and 28 indicates mild dementia. A score between 10 and 23 indicates moderate dementia. A score below 10 indicates severe dementia. Therefore, all participants were in the range of having mild or moderate dementia. Table 4.2 gives a summary of the participant profiles.

Table 4.2: Participant profiles for the naturalistic observations

Case	Description	MMSE
RG	Female (age = 76) with dementia of the Alzheimer's type. Lives in a bungalow with her husband. Her husband performs all kitchen related tasks, but says that she can perform them with his assistance. Other activities (dressing, cleaning the house) they do together. They lived in the house before the onset of dementia.	12
PL	Male (age = 75) with dementia of the Alzheimer's type. Lives in a house with his wife. His wife does all the kitchen tasks. He can make himself a cup of tea as long as she boils the water for him. The water is left out in a flask for him when she is not available. They lived in the same house before the onset of dementia, but the cooker was new after he was diagnosed.	11
JF	Female (age = 80) with dementia of the Alzheimer's type. Lives in bungalow with her husband. Her husband does all the cooking. They store tea and coffee making items on a tray on the worktop. They believe this helps her when making hot drinks for herself. She can do other tasks alone (dressing, cleaning). They lived at the bungalow before the onset of dementia, and she used to do all the kitchen tasks.	19
TM	Male (age = 76) with dementia of the Alzheimer's type. He lives in a bungalow with his wife. The wife does all cooking tasks, and he does occasionally make a cup of tea. Other daily tasks he does independently. They lived in the bungalow before the onset of dementia.	25
FA	Female (age = 74) with dementia of the Alzheimer's type. Lives with her husband in a bungalow. He does all cooking tasks. She can make them both tea/coffee but it takes a long time, and she often forgets to do certain parts of the task. She has a hearing aid, which wears all day. They moved to the bungalow after the onset of dementia.	23
DA	Male (age = 80) with dementia of the Alzheimer's type. Lives with his wife in a house. She does all cooking and tea/coffee making. They lived at the house before the onset of dementia. He rarely did cooking before he had dementia.	17

2.1.2 Ethical considerations

The NHS Research Ethics Committee approved the procedure. The OTs selected clients who they felt were appropriate for the study. The purpose of the study and the procedure was explained to the participant and their caregiver. An information sheet was also left with each household explaining the study. It was emphasised that they could withdraw at anytime. Consent was obtained from the participant, their spouse and the OT (see Appendix D for information sheets and consent forms).

Although the participant was asked to carry out the activities on their own the researcher informed them that they would help when necessary. The participant was also given some choice on what activities they wanted to do. This was discussed between the researcher, participant and their caregiver. Activities were chosen that

stretched the participant's abilities but were not too uncomfortable or confusing for them to perform. For example, those who felt making a cup of tea was too easy would perform a more demanding task, such as beans on toast, or coffee with toast. Allowing them to choose the activity also meant that it was meaningful to them and they were motivated to perform the task.

If the participant appeared uncomfortable or distressed at any stage, the researcher would assist them. The researcher also intervened at any point where the participants were at risk of harming themselves.

2.2 Procedure

2.2.1 Activities performed

Before carrying out the tasks, the researcher and participants would agree on what activities to perform. This made the situation more natural for the participant, and also meant that they had a good understanding of what was required from them. Across all participants these tasks included making a cup of tea or coffee, bowl of soup, beans on toast, and tea or coffee with toast. Table 4.3 presents the tasks performed by the six participants. Note that some of them performed the same task twice. In total, 22 activities were performed.

Table 4.3: Kitchen task performed by six the participants

Activity	Participants that performed this activity	No. of times performed
Cup of tea/coffee	RG	1
	PL	1
	JF	2
	FA	2
Bowl of soup	RG	1
	PL	1
	JF	2
	FA	2
Beans on toast	FA	2
	DA	2
Tea/coffee with toast	JF	2
	TM	2
	FA	2

2.2.2 Location

All the activities were performed in the participants' own kitchens. Only the researcher and participant were present in the kitchen throughout the task. The session was recorded using a handheld camcorder. All items and ingredients belonged to the household, with the exception of two food items (tin of soup and tin of beans). The researcher brought these items because some households did not have these stored. The kitchen environment was left exactly as it was before the researcher arrived, with the state and location of items unchanged. The participants would perform a maximum of three tasks in one day.

The reason for using participants' own kitchens and minimizing any changes to the environment was so that the performance on the task reflected that of a real situation. Changing these factors could potentially change the cognitive demand of the task. Furthermore, the familiar context would feel more natural. An unfamiliar or clinical setting could potentially increase anxiety or confusion, which would affect the validity of the findings. Representing problems that would occur in real situations is important for designing technology that is to be implemented into people's homes.

2.2.3 Instructions for the participant

The researcher would explain to the participant what to do (e.g. 'I want you to make a cup of tea for yourself'). This was also presented to the participant on a piece of paper (e.g. 'make one cup of tea') in large text (using Arial 72-point). The researcher explained that they should attempt the task on their own, but also told them that assistance would be provided when needed. Although the researcher familiarised himself with the environment, the participant was not briefed (e.g. location of items, how to operate appliances) before the task. This was with the exception of items brought in by the researcher (tin of soup and tin of beans), which were placed on the worktop. The task ended once the participant had accomplished the end goal.

2.2.4 Assisting the participant

Participants were assisted when they ceased to perform any action (after 5 seconds) or presented problems that would prevent them from accomplishing the end goal. The level of assistance was hierarchical so that the minimum level of support needed was given. Based on existing approaches used to optimise independence among people with dementia (Beck et al., 1993; Gendron & Levesque, 1993), five levels of support were provided: (i) a verbal prompt of the end goal, (ii) a verbal prompt of the sub-goal, (iii) a verbal prompt of the action, (iv) a verbal prompt of the action and pointing, and (v) physical (performing the action for them).

For example, when making a cup of tea, the researcher would initially cue them by stating the end goal ('make one cup of tea'). The researcher would say this twice. If the participant did not respond, then the researcher would state the next subordinate goal (e.g. "boil the water"). The subordinate goals were predetermined by a generic task analysis of the activities (see Figure 4.1 for example). Each sub-goal would be stated twice. If the sub-goal did not initiate the appropriate action then the required action would be cued (e.g. "pick-up the kettle"). If the participant still failed to respond to this level of cue, then the researcher would say the action cue whilst pointing to the relevant item. The researcher would eventually perform the action for the participant if they still failed to respond.

To avoid distracting the participant from the task, some flexibility was allowed with regard to the end goal. There was no intervention if they made *minor deviations* from the main goal (e.g. making two cups of tea instead of the initially set goal of one cup of tea). However, participants were corrected if they showed *major deviations* from what was required (e.g. making just toast instead of beans on toast).

More immediate interventions were made if the participant showed physical difficulty (e.g. opening a jar) or the researcher recognised a potential risk.

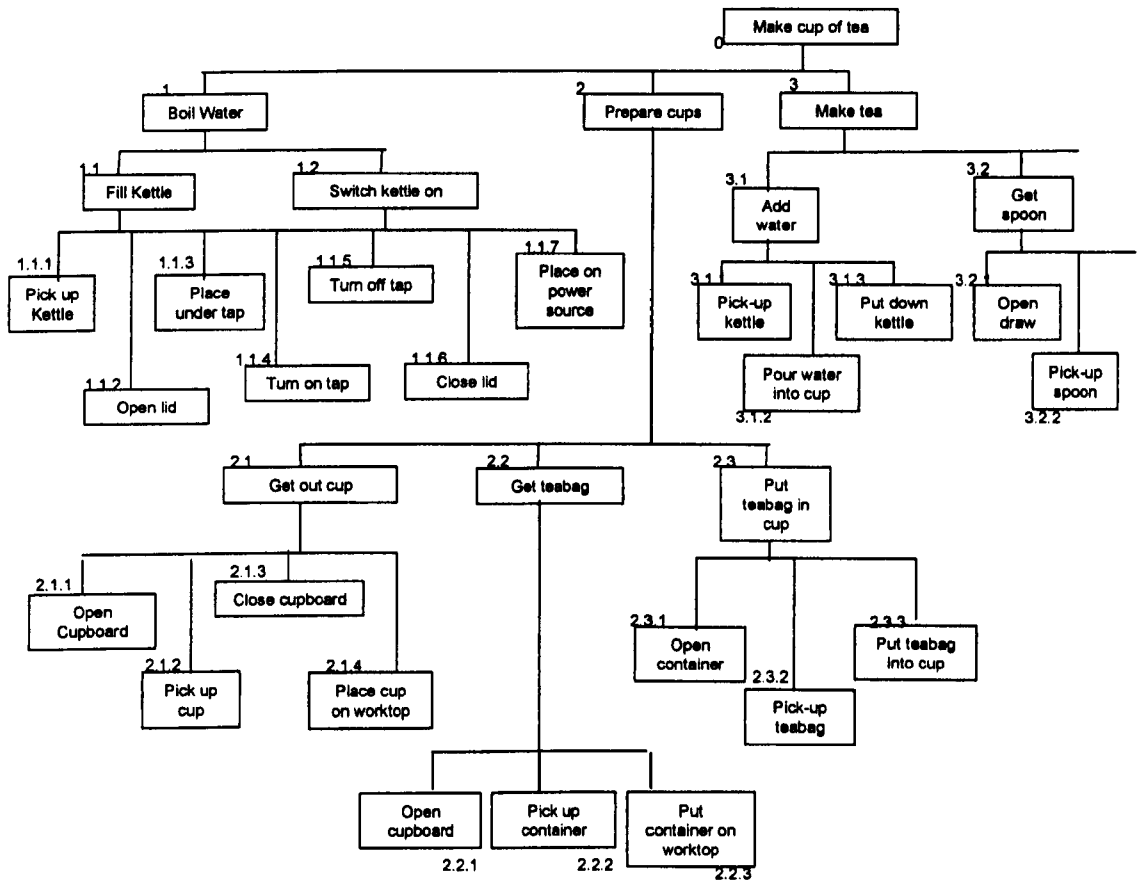


Figure 4.1: Example prompts for making a cup of tea, with lower goal prompts (e.g. fill kettle) and action prompts (e.g. pick-up kettle).

2.3 Transcribing the video recordings

2.3.1 Representing actions

Twenty-two video recordings were transcribed at the 'action unit level' described by Schwartz et al. (1991). Figure 2 shows an example section of the transcripts used. Each action unit is defined by an event in which the environment or an object is manipulated or moved. For uniformity, the semi-formal notation developed by Schwartz et al. (1991) was used to describe four action types: MOVE, ALTER, TAKE and GIVE.

MOVE refers to when something has been moved from one location to another and is written as:

MOVE (*x*) to (*location*) using (*instrument*) by (*manner*)

For example, using this notation to explain the action of pouring water into the cup would be represented as:

MOVE *water* to *cup* using *kettle* by *pouring*

ALTER refers to when the state of an item has been changed (e.g. on/off or open/closed) and is written as:

ALTER (*x*) to (*state*) using (*instrument*) by (*manner*)

For example, opening a coffee jar would be recorded as:

ALTER *coffee jar* to *open* using *lid* by *turning*

TAKE refers to when an item has been picked-up or taken from another location and is written as:

TAKE (*x*) (i.e. take possessions of object *x*) using (*instrument*)

Taking a cup from a cupboard would be written as:

TAKE cup from cupboard

GIVE refers to when a possession has been relinquished and is written as:

GIVE (*x*) (i.e. relinquish possession of *x*)

For example, putting a cup into a cupboard would be recorded as:

GIVE cup to cupboard

If more than one event occurred at once (e.g. closing a cupboard and stirring the tea) then the action that was initiated first would be coded as occurring before the other action. However, if more than one item was moved at exactly same time, this would be coded as one action unit. For example, moving the coffee and sugar containers to the worktop would be coded as:

MOVE *coffee jar* and *sugar container* from *cupboard* to *worktop*

In some cases, an item might be picked up and put down again in the same place. In such cases this was coded as a single action:

TAKE/GIVE (*item*) on (*location*)

If an item was moved from one location to another in a single action, such as from a cupboard to the worktop, it would be represented as:

MOVE coffee jar from cupboard to worktop

However, if an intermediate action occurred when moving the item (e.g. closing the cupboard door) then the action would be coded as three separate units:

TAKE coffee jar from cupboard

ALTER cupboard to closed using door by pushing

GIVE coffee jar to worktop

The action definitions provide a formal method of transcribing the actions in detail. To some degree the terms are arbitrary and two different series of terms could be used to describe one event. However, this was not of concern for the present study as it merely provides a basis to describe a series of actions in a manageable and unambiguous way.

2.3.2 Representing speech

Narrative between the participant and researcher during the task was recorded on the transcript. In Figure 4.2 this is presented to the left of the action units. This provided further information in understanding the context in which problems occurred. Only speech that was relevant to the task was transcribed. The participant's speech was transcribed in **bold** text and the researcher's speech was represented in *italics*. The verbal content is presented on the same row as the action it preceded. For example, Figure 4.2 shows that the participant switched on the cooker (action unit 42) after the researcher prompted her to do so.

Verbal transcript	Action units
	36 Move soup to saucepan from container by pouring
	37 Give soup container to worktop
	38 GIVE saucepan to burner 1
	39 TAKE saucepan from burner 1
I have to get the heat	40 GIVE saucepan to burner 2
You have to get the heat don't you	41 TAKE spoon from worktop
So you want to turn on the cooker	42 ALTER burner 2 to on using control by turning

Figure 4.2: Example task transcript: The participant was cued to turn on the cooker.

2.4 Analysis of errors

2.4.1 Coding errors

The transcripts and video recordings were used together to identify error incidences. The action error would be marked on the transcript at the point, or action unit, where it occurred. A more detailed description of the error was written at the end of the transcript.

As this study focuses on problems that prevent the accomplishment of the task, errors were only included for analysis if they prevented the participant from reaching the end goal. Therefore, errors were excluded if they did not prevent task accomplishment. Examples of excluded errors included instances of immediate recovery (e.g. selecting the wrong cooking items, then putting it back and obtaining the correct item), use of substitute items that still accomplished the intend function (e.g. stirring soup with a knife instead of a spoon), and action repeats that did not disrupt the activity (e.g. adding milk to the cup twice). If the participant did not initiate actions, then this was included as an error. However, if the researcher intervened too early then this was excluded. It was decided that five seconds should be left before the researcher intervened. If inactivity led to a potential risk (e.g. leaving the gas running on the cooker) then this was included as an error despite immediate intervention by the researcher.

2.4.2 Forming error types

Errors included for analysis were recorded with a brief description of the circumstances surrounding it. The incidences were then grouped together based on behavioural features to form categories. Categories believed to be similar in nature were then grouped together to form broader themes.

2.5 *Inter-rater reliability*

2.5.1 Selecting video recordings for inter rater-reliability testing

The study reports the analysis conducted by the author on all 22 video recordings. A subset of 12 (out of the 22) recordings was selected for a second rater. Three one-minute clips were selected for the second rater to transcribe and identify errors. This meant that the second rater analysed a total of 36 one-minute clips.

The procedure was designed so that the rater had to first identify errors to include in the analysis, and then classify them within the taxonomy that emerged from the analysis. Based on the original analysis, the subset contained 25 errors. They were selected so that the clips covered the whole range of error types. Additionally, across the subset were 11 excluded errors. Nine of the clips contained no error incidences.

2.5.2 Procedure for inter-rater reliability testing

The second rater was an MSc student within the psychology department at the University of York. He had been trained to use the transcription method used in this study and was introduced to the error types that emerged from the analysis. In addition to training he was given an instruction manual that provided details about the transcription method and definitions of the error types.

For each video recording, the rater was required to watch the whole recording of a complete activity. He then had to transcribe the three selected clips. Using his transcript and the video recording he was then required to identify error incidences

and code them according to the error taxonomy. He was also asked to report any errors that he believed did not fit into the existing taxonomy.

2.5.3 Scoring inter-rater reliability

The raters analysis of the subset was compared to that of the author. A Cohen's Kappa (k) was used to measure the rate of agreement between them. Comparisons were made with regard to the classification of the errors within the taxonomy. If the rater excluded an error, or did not identify an error, then this was classified as a 'non-error'.

Agreement was scored when: (i) both raters identified the same error and coded it under the same classification, (ii) both raters coded an 'excluded error' (classified as a 'non-error'), (iii) one rater coded an 'excluded error' and the other did not code the error (classified as 'non-error'), or (iv) both raters coded a whole clip as containing no error (classified as a 'non-error'). Disagreement was scored when: (i) both raters identified an error but coded them under different classifications, (ii) one rater identified and coded an error, but the other excluded it from analysis (coded as 'non-error'), or (iii) one rater coded an error, but the other rater did not identify the error (coded as 'non-error').

3. Results

3.1 A summary of the error classifications

Across the 22 video recordings 62 errors were included for analysis. These were classified into eight error types, which formed four main themes: *Sequencing* (intrusion, omission and repetition), *orientation* (locating and identifying), *operation* of appliances and *incoherence* (toying and inactivity). Table 4.4 summarises the four themes and the constituent categories. More detailed descriptions of these classifications are presented in Section 3.3. Accounts of all included error incidents are shown in the Appendix E.

Table 4.4: Error types during kitchen tasks

Error type	Description
Sequencing	
<i>Intrusion</i>	Performs an action from a different activity that is not appropriate for the task
<i>Omission</i>	Misses an action that is required to accomplish the end goal
<i>Repetition</i>	Repeats an appropriate action unnecessarily
Orientation	
<i>Locating</i>	Requires assistance in finding items that are out of view (i.e. stored in cupboards/drawers)
<i>Identifying</i>	Requires assistance in selecting items in view
Operation	Problems in using appliances (cooker, kettle, toaster)
Incoherence	
<i>Toying</i>	Performs gestures with items without any apparent goal
<i>Inactivity</i>	Does not perform any action

3.2. Inter-rater reliability

The Cohen's Kappa (k) showed an agreement rate of 84%. Table 4.5 presents the agreement scores across the different error types. Rater 1 (author) coded 25 errors and Rater 2 coded 27 errors. The disagreements related to decisions regarding the presence or absence of an error (i.e. one rater coded the occurrence of an error whilst the other did not). This type of disagreement occurred twice for omission, identifying and inactivity errors.

Table 4.5: Inter-rater reliability scores: The matrix shows frequency of agreement (highlighted in the grey boxes). Disagreements are highlighted in **bold**.

		RATER 1 (author)									
		Intr	Rep	Om	Op	Loc	Ident	Toy	Inact	None	Total
RATER 2	Intr	4	0	0	0	0	0	0	0	0	4
	Rep	0	2	0	0	0	0	0	0	0	2
	Om	0	0	1	0	0	0	0	0	1	2
	Op	0	0	0	5	0	0	0	0	0	5
	Loc	0	0	0	0	2	0	0	0	0	2
	Ident	0	0	0	0	0	1	0	0	2	3
	Toy	0	0	0	0	0	0	3	0	0	3
	Inact	0	0	0	0	0	0	0	5	1	6
	None	0	0	1	0	0	0	0	1	25	27
	Total	4	2	2	5	2	1	3	6	29	54

3.3 Characteristics of the error classifications

3.3.1 Sequencing

There were three types of errors related to the incorrect execution of an action in the task sequence. These were intrusion, omission and repetition.

Intrusion: A total of eight intrusion errors were identified. These included instances where actions from an alternative activity were performed. This included the intrusion of an item (e.g. selecting the coffee jar instead of the teabags), as well as intrusion of actions (e.g. opening the teabag and pouring the content into the cup).

Figure 4.3 presents an example of an action intrusion, in which PL opened a teabag and poured the content into the cup, instead of placing the whole teabag into the cup.

Verbal	Action
<i>You want to put the teabag into the cup</i>	26 ALTER teabag 1 to open by tearing
	27 MOVE tealeaves to cup by pouring
<i>Not to open it though; Not to open it?; Yeah so put the teabag into the cup; Oh I see</i>	28 GIVE teabag 1 to worktop
	29 MOVE teabag 2 from worktop to cup 2

Figure 4.3: PL intrusion error when making a cup of tea

Omission: Five omission errors were identified. These included incidents when an action required for the end goal were missed out. TM added milk and water to a cup and then indicated that he had finished without adding the coffee granules. Similarly, FA added water to the teapot but did not add any teabags.

Others made omission errors in relation to the end goal. For example, when making beans on toast, FA made the toast but did not heat any beans. Similarly, when JF was making coffee with toast, she prepared the coffee but did not initiate the toast making part.

Some omission errors also posed a risk. DA did not turn off the gas cooker once the beans had been heated. As there was little space available on the worktop, he then rested the plate on the burner to serve the beans. The researcher immediately intervened and cued him to switch off the cooker (see Figure 4.4).

Verbal	Action
That should be alright, its bubbling	32 TAKE saucepan from burner 1
	33 MOVE plate 1 from shelf to hob 1
<i>Turn that off first. Oh yeah</i>	34 TAKE plate 1 from burner 1
There we go. It'll be alright now	35 GIVE plate 1 to worktop
	36 GIVE plate 1 to burner 1
	37 MOVE beans from saucepan to plate 1 by pouring

Figure 4.4: DA omitting the action of turning off the gas cooker

Repetition: Seven repetitions were identified. These involved incidents where the participant would repeat an action unnecessarily and subsequently require assistance from the researcher to initiate the next step. These were only included when the participant continued to repeat the action, or failed to initiate any action, after the repetition. PL made the most repetition errors, committing six of the eight identified. These included repeating the action of switching on the kettle, heating or stirring the soup and obtaining cooking items from the cupboards.

When making a bowl of soup, PL repeated the action of heating the soup at two points in the task. After heating the soup he was cued to obtain a bowl from the

cupboard. After getting the bowl he went back to the cooker and reheated the soup. He turned the cooker off and brought the bowl closer to the saucepan. However, instead of serving the soup he heated it again. The researcher had to cue him towards the next action.

Figure 4.5 describes RG performing a similar repetition. After heating the soup and switching off the cooker she was cued to serve the soup. However, after obtaining the bowl from the cupboard she went back to stirring the soup.

Verbal	Action
<i>Now you want to serve the soup. So you want to get out a bowl.</i>	26 MOVE saucepan from burner 1 to burner 2
<i>You want to get out a bowl. You want to get out a bowl to serve the soup. So open this cupboard.</i>	29 ALTER cupboard to open using door by pulling
	30 MOVE bowl from cupboard to worktop
	31 TAKE spoon from saucepan
<i>So you want to serve the soup. You want to put the soup into the bowl</i>	32 ALTER soup to stirred using spoon
<i>Put the soup into the bowl</i>	33 GIVE spoon to worktop
<i>Put the soup into the bowl</i>	34 MOVE soup to bowl using saucepan by pouring

Figure 4.5: RG committing a repetition error when making soup

3.3.2 Orientation

Orientation refers to problems in finding items in the kitchen. This includes problems in *locating* and *identifying* objects. Classification of orientation errors was based on the visibility of the items.

Locating: Locating errors include occasions when the participant had difficulty finding items that were concealed in compartments, cupboards or drawers. When the participant searched for an item in more than two locations, or requested assistance, they would be directed to the correct location by the researcher. Seven of these errors were identified.

Figure 4.6 shows how this type of error would have looked in the transcript. In this case PL searched through two drawers and one cupboard before the researcher cued him towards the correct drawer.

Verbal	Action
<i>So you want to get out a spoon; spoon: That's what I'm looking for.</i>	51 ALTER cupboard 1 to closed using door by pushing
There we are, that's it	52 ALTER drawer 1 to open using drawer by pulling
No it isn't	53 TAKE/GIVE tea towel in drawer
	54 ALTER drawer 1 to closed by pushing
	55 ALTER drawer 2 to open by pulling
	56 ALTER drawer 2 to closed by pushing
	57 ALTER cupboard 2 to open using door by pulling
	58 ALTER cupboard 2 to closed using door by pushing
<i>That's it here [points at drawer 3]; That's it</i>	59 ALTER drawer 3 to open by pulling
	60 TAKE spoon from drawer 3

Figure 4.6: PL searching for a teaspoon when making a cup of tea

Identifying: Problems in searching for items that were not concealed (e.g. located on the worktop or in an open cupboard) were coded as identifying errors. Five such incidents were recorded. On one occasion, FA could not locate the toaster, which was clearly visible on the worktop. On three occasions, participants opened the correct cupboard or drawer but then would not find the item, which was visible. For example, when making beans on toast, FA was looking for the bread knife. She opened the correct drawer, but did not see the knife and continued to look through other drawers (Figure 4.7).

Verbal	Action
Right, beans on toast, I need a large knife	1 ALTER drawer 1 to open by pulling
	2 ALTER drawer 1 to closed by pushing
	3 ALTER drawer 2 to open by pulling
	4 TAKE/GIVE scissors in drawer
	5 ALTER drawer 2 to closed by pushing
I don't know where the large knife is <i>I just saw it in the other drawer [pointing at drawer 1]</i>	6 ALTER drawer 3 to open by pulling
Oh yes it is here.	7 ALTER drawer 1 open by pulling
	8 TAKE bread knife from drawer 1
	9 ALTER drawer 1 to closed by pushing
	10 ALTER drawer 3 to closed by pushing

Figure 4.7: FA searching for a large knife when making beans on toast

3.3.3 Operation

The operation theme relates to problems experienced when using kitchen appliances. There were seven operation errors identified. Four of these involved the cooker. On two occasions, FA selected the wrong control on the cooker, which meant that the wrong hotplate was switched on. Similarly, PL placed the saucepan on the cooker and then selected the control for the oven (Figure 4.8). In another instance involving the cooker, RG selected the correct control when turning off the gas cooker, but she turned it in the wrong direction. This meant that the cooker was set on a low setting instead of being completely off.

Verbal	Action
We haven't got any heat on there have we? There's no heat on here is there?	36 GIVE saucepan to burner 4
	37 TAKE saucepan from burner 4
	TAKE/GIVE teabag on worktop
	38 GIVE saucepan to worktop
So how do we make that into a bowl of soup <i>So you want to turn on the hob</i> <i>So you want to use these controls here (point)</i>	39 TAKE saucepan form worktop
	40 ALTER oven to on using control by turning
	41 GIVE saucepan to worktop
	42 ALTER burner to on using control by turning

Figure 4.8: PL selecting the oven control instead of the correct cooker control

On three occasions, participants required assistance when using the toaster. For example, FA placed the bread into the toaster but could not understand why it was

not heating up. She looked around the toaster for a switch, and then pulled out the crumbs tray. She was then cued to push the lever down to turn it on (Figure 4.9).

Verbal	Action
	18 TAKE give toaster to worktop
	19 ALTER toaster mains to on using switch by pressing
	20 GIVE bread to toaster
	21 ALTER crumbs tray to out by pulling
<i>That should be coming on</i>	22 ALTER crumbs tray to in by pushing
Just need to push that [point to lever]; Oh thanks	23 ALTER toaster to on using lever by pushing

Figure 4.9: FA being assisted to turn on the toaster

There were two occasions when participants had problems using the kettle. For example, Figure 4.10 describes JF taking the kettle from the power stand and filling it with water. She placed the kettle on the worktop instead of back onto the power stand, and so could not understand why it was not heating up after she switched it on. The researcher then cued her to put the kettle onto the power stand.

Verbal	Action
	19 ALTER tap to on using control by turning
	20 GIVE kettle to worktop
	21 ALTER kettle to closed using lid by pushing
	22 TAKE/GIVE glass on worktop
Now then your going in this one aren't you;	
<i>You want to make a cup of tea</i>	
Well I am, you have to get the heat	23 ALTER kettle to open using lid by lifting
Yes you have to get the heat don't you	24 ALTER kettle switch to on position by pressing
<i>So you want to put the kettle onto there [pointing at power stand]</i>	
You have to wait, I mean it will work without going on there won't it. Oh it needs to go on there?	25 MOVE kettle from worktop to power stand
	26 TAKE/GIVE tea towel on worktop

Figure 4.10: JF making an operation error with the kettle

3.3.4 Incoherence

Incoherence refers to occasions when the participants showed no goal-directed behaviour. There were two types of incoherence, which were *toying* and *inactivity*.

Toying: Actions that appeared to show no apparent goal were coded as ‘toying’. This involved repeatedly picking up and putting down items, and making gestures with objects without any purpose. This behaviour occurred ten times across two cases (PL and RG). Figure 4.11 presents a transcript extract presenting toying behaviour. In this case, PL was cued to get a spoon to remove the teabag from the cup. He opened the drawer and repeatedly took out and put back cutlery items. He then later repeated the action of picking-up and putting down the cups.

Verbal	Action
Which one do you want, this?	36 TAKE spoon 2 from drawer 1
<i>Use which ever one you think</i>	37 TAKE spoon 3 from drawer 1
	38 GIVE spoon 2 to drawer 1
	39 GIVE spoon 3 to drawer 1
These are saucers	40 TAKE knife 1, 2, and 3 from drawer 1
	41 GIVE knives to drawer
	42 GIVE spoon to worktop
	43 TAKE seven table spoon
That’s the other type of spoons that we’ve got; So you want to get one of these spoons (points) Yes	44 TAKE out teaspoon 2
<i>You want to take the teabag out of the cup</i>	45 TAKE teaspoon 3
	46 GIVE spoons to worktop near cup
	47 TAKE/GIVE cup 1
	48 TAKE/GIVE cup 2
<i>You want to take the teabag out of the cup; Yes</i>	49 TAKE/GIVE kettle
	50 TAKE/GIVE cup 1
	51 TAKE/GIVE cup 2

Figure 4.11: Operation error with the kettle: RG does not put the kettle on the power stand

Inactivity: When participants ceased to perform any action, then this was coded as ‘inactivity’. This was only included if it persisted for longer than five seconds, at which point the researcher would cue them. Inactivity was excluded if it appeared appropriate for that stage of the task (e.g. waiting for the kettle to boil). The inactivity was noted on the transcript as a single action unit, indicating the length of time before the participant was cued (see Figure 4.12). There were 13 occasions when participants showed inactivity, 12 of which occurred across two cases (PL and RG).

when participants showed inactivity, 12 of which occurred across two cases (PL and RG).

Verbal	Action
<i>So you want one cup. One cup of tea</i>	16 MOVE cup to worktop
	17 [5]
<i>So now</i>	18 TAKE coffee container 1 from worktop
<i>You want to get out a teabag</i>	19 GIVE coffee container 1 to worktop
<i>Get out a teabag, there [pointing at teabag container]</i>	20 TAKE coffee container 2 from cupboard 1
<i>Get out a teabag (pointing at teabag)</i>	21 MOVE teabag container from cupboard 1 to worktop

Figure 4.12: Inactivity error committed by RG when making a cup of tea

4. Discussion

The aim of this study was to communicate to designers the problems faced by people with dementia when performing activities in the kitchen. Six people with mild to moderated dementia were observed carrying-out activities of their choice in their own kitchens. The study was designed so that the problems identified reflect those that could occur in real situations. As the focus is on designing assistive technology, we took a minimum set approach to the analysis to describe errors that actually prevent accomplishment of the task.

In contrast, previous work using naturalistic observations often required participants to carry out tasks in clinic or lab settings, and involved pre-selected activities with specific sub-goals that may not have personal relevance to the participant. These studies focused on action disorder, rather than other broader problems that prevent task accomplishment. Furthermore, their analysis included all errors, irrespective of whether they prevented or simply hindered accomplishment of the task.

In this discussion we will compare the outcomes of the present study with existing error taxonomies, and relate the findings to cognitive theory. We will then discuss

the implications of the finding for the designing of prompting systems for people with dementia.

4.1 Relating the errors to existing taxonomies and cognitive theory

Difference in methodology and analysis means that the collection of problems reported in this study is different to that of existing error taxonomies from clinical groups. In the present study, observations were conducted with participants with different cognitive capabilities, in a variation of physical contexts, and on different tasks that they chose. This led to additional categories that could not be revealed under controlled settings with standardized procedures. The minimum set approach to taking errors that prevent task completion meant that classifications included in previous taxonomies were not included in the present study.

In this section, we will describe the error types that emerged from the present study in relation to existing taxonomies and cognitive theory. Knowledge about the underlying cognitive deficits will be important for designing prompting systems that are appropriate for people with dementia.

4.1.1 Sequencing:

It is well documented that executive function deficits in dementia disrupt performance on tests that require planning and initiation of actions required to achieve a nested goal (Graham et al., 2004; Kitabayashi et al., 2001; Kramer et al., 2002; Rainville et al., 2002; Rouleau et al., 1992; Royal et al., 1998). The sequencing errors identified in the present study confirm previous observations of action disorder seen in clinical groups with frontal lobe pathology. Despite the variety of sequence errors, they are considered to originate from a unified deficit, in which top-down processes are pathologically weakened. This limits the ability to suppress situational triggers from the environment and activation from associated schemas, resulting in actions that do not follow intended goals. This view will be discussed in relation to the three types of sequence errors identified in the present study.

Intrusion: Earlier studies with healthy and clinical groups have reported problems of using inappropriate items or actions. Norman (1981) describes people's accounts of 'capture slips' and 'external activation' in which an intended action is disrupted by activation from task-irrelevant objects of associated action schemas. These have been categorised more specifically with clinical groups. Schwartz et al. (1991, 1995) describe 'object substitution' (e.g. orange juice added to the cup of coffee), 'place substitution' (e.g. coffee granules in oatmeal) and 'instrument substitution' (e.g. stirring coffee with a fork). The taxonomy used in the MLAT also included 'object substitution', 'action addition' (e.g. pack extraneous items in the lunch box), and 'gesture substitution' (spoon milk into cup, rather than pour).

Therefore, it appears that intrusion errors are well documented, and have been categorised with greater specificity. The intrusions identified in the present study could have been placed under the more specific categories. For example, PL added tea leaves to the saucepan instead of the soup, which could be termed as 'object substitution'. JF placed a bowl of soup on the toaster to heat it, which could be described as a 'place substitution'. However, distinctions between intrusion errors at such a level appear too arbitrary for the purposes of this study. With the small number of cases and error incidences, dividing the themes further would risk losing any meaningful classifications.

A further reason for not using the existing definitions is that such errors were excluded from analysis because they did not prevent task accomplishment. For example, RG used a knife to stir the soup. On another occasion she removed a teabag from a cup of tea with her fingers. These errors would be regarded as 'object substitution' and 'object omission' respectively in previous studies. However, as neither prevented accomplishment of the end goal, they were not the focus of this study.

The intrusion of inappropriate actions and objects is said to result from an inability to suppress stimulation from task-irrelevant objects or affordances. The top-down processes that sustain intended goals become overridden by bottom-up activation. In dementia patients the top-down processes are pathologically weakened and so are prone to such errors. This is consistent with the circumstances surrounding the

intrusions reported, as inappropriate objects selected tended to be visually present on the worktop, or in close proximity to the relevant item. For example, when PL poured the content of the teabag into a saucepan (instead of adding the soup), the teabag was directly in front of him on the worktop. Similarly, Rusted and Sheppard (2002) found that during the tea-making activity, dementia patients would mistakenly select a coffee jar because it was located next to the tea caddy.

It could also be argued that intrusion errors resulted from deterioration in semantic memory. Evidence has shown that from the onset of dementia, patients show subtle decline in semantic memory (Bayles & Tomoeda, 1983; Graham et al., 2004; Martin & Fedio, 1983) resulting in a blurring of object categories. Therefore, participants could confuse coffee with teabag. As the kitchen contains numerous items that are in some way semantically related, they would be sensitive to this impairment. Semantic memory deficits may play a particularly important role when the participant responds to verbal prompts from the researcher. However, in the absence of proper controls it was not possible to explore whether our participants made intrusion errors as a result of impaired attentional control or decline in semantic memory.

Repetition: Previous studies have included perseveration and ‘action repeats’ in the error taxonomy. Repetitions reported in the present study are different in the sense that only the repetitions that persisted or lead to inactivity were included. Nevertheless our participants presented similar errors to those observed by Shallice and Burgess (1993), in which they get ‘stuck in a set’ because of strong situational triggers.

In Cooper and Shallice’s (2000) implemented model of the CS, the ‘object representation’ network included ‘pre-conditions’ and ‘post-conditions’ of the environment. This assumes that visual feedback guides action sequences. Rusted and Sheppard (2002) found that dementia patients performed more action repeats when conducting a routine activity in unfamiliar settings, which also suggests an important role of the environment in triggering such errors.

In the present study, two participants (PL and RG) repeated the goal of heating the soup on the cooker when they were actually required to serve the soup. It is possible

that seeing the soup on the cooker was a situational trigger for heating it. Impaired episodic memory would increase the influence of such cues, as they would need to recall what activities had already been performed in the absence of visual feedback.

Repetition errors were committed by the two participants with the lowest recorded MMSE (PL and RG). Action repeats did occur among the other participants, but were eliminated because they had little impact on continuation of the task sequence.

Omission: Previous studies found that action omissions were the most frequently occurring errors among clinical groups. The omissions reported here are limited in comparison as they were only coded if they prevented accomplishment of the end goal. For example, JF opened a pot of sugar but never added sugar to the cup. As this was not detrimental to the task, it was excluded. The method also allowed for some flexibility with regard to the goal, which also meant that omission errors were less likely. Other observational approaches (e.g. MLAT) involved specific goals (e.g. toast with jam), and so omission errors are more likely to occur.

One explanation for the omissions committed by our participant is that they had forgotten what goals were set. For example, when making beans on toast, some participants made the toast and forgot to prepare the beans. Problems in coping with the dual element of this task reflect executive control deficits demonstrated in experimental studies with AD patients (Baddeley et al., 2001).

Previous studies on the omission of actions in routine sequences have mainly been attributed to faulty activation of the CS due to impaired top-down control processes. Some omissions did appear to reflect anticipation for the subsequent step. For example, adding water and milk without coffee granules (TM), switching on a kettle without water (FA), and sipping the tea without removing the teabag (RG).

Schwartz et al. (1991, 1995) also coded actions as omissions if they discontinued the task, resulting in omission of the remaining procedure. This type of behaviour was observed among our participants but was coded as 'inactivity', which will be discussed later in this section.

4.1.2 Orientation

Problems of orientation are not included in existing taxonomies. This is probably because most observations have been conducted in laboratory conditions, in which the concealment of items and presence of distractors is limited, compared to real settings. However, in occupational therapy orientation in the environment is addressed to improve functional ability. The practise includes minimising clutter on worktops, and placing required items in prominent locations (Corcoran et al., 2002; Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Gitlin et al., 2003; Gitlin et al., 2002). For the purposes of the present study, orientation in the environment is equally important as action control.

Locating: Difficulties for our participants in finding items concealed in cupboards, drawers and compartments is not particularly surprising, especially considering that they rely on their spouse to carry-out many kitchen related tasks. Impaired episodic memory means that people with dementia would have difficulty recalling the location of stored items. Searching strategies were often ineffective, as some would look in the same place twice or forget what they were looking for. Therefore, this problem has a major impact on task performance.

Identifying: Although participants showed difficulties in locating items out of view, finding items that were visible also posed a problem. Eye tracking studies have been conducted with healthy adults when making a cup of tea in a kitchen setting. Eye movement showed that for 95% of the time the eye fixated on the task-relevant objects. They concluded that top-down processes drive eye motions during everyday activities (Land et al., 1999). Limited top-down control in dementia would reduce the salience of task relevant items, thus relying on serial visual search strategies, which is impaired in dementia. Experimental studies have shown that people with early onset dementia have profound difficulty conducting a visual search for target items that are among perceptually similar distractors (Tales et al., 2002; Tales et al., 2004). Deficits in attention shifting and suppression of task-irrelevant stimulation would hinder ability to locate required items in the visual array.

It could also be argued that deterioration in semantic memory could contribute to problems with locating objects in the environment. The person with dementia may have forgotten what an item looks like, making it more difficult to identify an object among perceptually similar items.

4.1.3 Operation

Operation is another error type that has not been considered in previous studies. This is because the controlled settings have not included the use of domestic appliances. These errors centre on problems with using kitchen appliances (cooker, kettle and toaster). Unlike sequence errors, these instances reflect difficulties in understanding how the appliance operates as opposed to action control.

It is important to note that this theme relates use of appliances, and does not include object use. Our participants were competent in using objects and utensils. This confirms studies that have focused on object use in people with dementia (Bozeat, Lambon Ralph, Patterson, & Hodges, 2002b; Buxbaum, Schwartz, & Carew, 1997; Giovannetti et al., 2006; Hodges, Bozeat, Lambon Ralph, Patterson, & Spatt, 2000; Hodges, Spatt, & Patterson, 1999a). They found that despite loss of conceptual knowledge regarding an object, patients were still able to use it correctly. They concluded that this was due to a preserved ability to respond to the visual/tactile features of objects. Hodges, Spatt and Patterson (1999) describe two processes that guide interaction with objects. Firstly, they refer to the concept of affordance, which involves an automatic response to the physical structure in order to understand the purpose of the object and information about how to hold, orientate and move it. It is likely that this process guided our participants' actions when using familiar utensils (such as a cup, spoon or knife).

The second process relies on 'deliberate reasoning' about an object based on the physical characteristics. This is often referred to as 'mechanical problem solving' and is capable of guiding actions with novel tools. Our participants' incorrect use of appliances suggests that the operation was not familiar enough to be cued automatically, and offered insufficient affordance to reason about how it functions.

This theme is important with regards to the design and implementation of assistive technology, and so will be explored further in Chapter 5.

4.1.4 Incoherence

Incoherence refers to the absence of goal-directed behaviour. The flow, or transitions, between actions has been an important issue in other naturalistic observations. The term, 'incoherence', was used by Schwartz et al. (1991, 1995) to describe disturbances in the action sequence. These included 'independent acts' such as picking up and putting down an item, or overlap between different sub-procedures within the activity. The term also relates to 'toying' behaviour (e.g. performing gestures with objects without any purpose). Gendron and Levesque (1993) also reported such behaviour among people with AD, in which they presented 'scattered gestures', which hindered performance on daily activities.

Toying and inactivity were the two types of incoherence that required assistance from the researcher. The two participants with the lowest MMSE (PL and RG) committed nearly all of the incoherence errors recorded.

Toying: When the participants interacted with items without any apparent goal for more than five seconds it was coded as 'toying'. For example, they repeatedly picked something up and then put it down, or moved an object without any apparent purpose. Schwartz et al. (1991, 1995) proposed that the cause for such errors was the same as for other error types, which is the weakening of top-down activation. Toying occurs because competing schemas fail to become fully activated. Therefore, such behaviour occurs due to weak top-down control, and insufficient elaboration in the environment.

Inactivity: Inactivity refers to when participants ceased to perform any action. Other studies have observed similar behaviour in people with dementia. The OPTIMAGE taxonomy includes 'stopping' as a blocking behavior. Feyereisen (1999) also describes problems of 'passivity' as the main problem for people in the severe stages of cognitive decline. Inactivity also reflects a failure to select an action schema. This

could either be due to failure to select competing schemas or compromised memory regarding the actions that need to be performed. In some cases, inactivity was resolved by providing verbal prompts towards the sub-goals. This would suggest problems resulting from impaired memory. In other instances, further support was required using cues to action in conjunction with pointing to relevant objects and locations. This demand for assistance suggests a failure to attend to task-relevant cues. Although a combined deficit seems likely, the methodology does not allow for reliable distinctions across the different errors.

4.2 Design implications

The purpose of the present study is to communicate the problems faced by people with dementia to designers. The classifications highlight the types of problems that need to be resolved. The detailed descriptions also provide a context for designers to propose technological solutions. How these problems relate to current developments in pervasive computing will be discussed further in Chapter 6. However, there are two broad themes to discuss here, which present important implications for designing prompting systems for people with dementia. The first relates to the need for situated assistance in order to overcome the limitations of current methods of prompting. The second relates to the methodological approach of developing and testing prompts for people with dementia.

4.2.1 Situated assistance for people with dementia

In Chapter 3, our informants described how they would manipulate the local environment to support daily activities (e.g. placing items out on the worktop). Consistent with these accounts, practises in dementia care often uses methods of ‘stimulus control’ such as reducing clutter, placing items in visible locations and pointing to support independent behaviour (Beck, Heacock, and Rapp, 1993; Gitlin et al., 2001; Cocoran et al., 2002).

The existing approach to designing technological prompts for people with dementia has been to use explicit cues, either with voice prompts or video footage of required actions (Dishman, 2004; Mihaildis et al., 2004). Although this addresses deficits in planning and problem solving, it does not match the cognitive demands of real environments. The problems reported in this study highlight three main limitations for using explicit cues alone in real home settings.

Firstly, there is the effect of situational triggers due to impaired attentional control. The sequencing and incoherence errors recorded in this study confirm the outcomes of previous observations. As discussed in the introduction, these type of action errors result from a limited ability to suppress stimulation from task-irrelevant cues, due to pathological weakening of top-down activation from the SAS. Therefore, a person might acquire the correct goal (e.g. “put soup in saucepan”), but execute the wrong action in response to salient representations of irrelevant objects (e.g. pouring the content of the teabag that was located on the worktop into the saucepan). Similarly, incoherence errors are said to result from competing schemas due to the absence of a salient trigger. To overcome these problems, the technology should be capable of increasing the salience of task-relevant objects in conjunction with verbal cues, in order to compensate for the attentional control deficit. Drawing attention to the object or location should increase the efficacy of the audio prompt.

The second limitation is the cognitive load required to comprehend explicit prompts. Explicit cues are directed towards goals and actions. However, the present study highlights that in real environments many of the problems experienced were not goal related. Problems of operation and orientation would be difficult to address through verbal cues alone. It is unlikely that a person with dementia could follow instructions to a correct cupboard or object. The operation of an appliance (e.g. what control to press) would also be difficult to verbally describe to a person with dementia. In order to design technological prompts for real environments, efforts must be made to design methods of implicitly guiding the person’s attention so that they are easily orientated within the environment and can operate appliances.

Thirdly, explicit cues cannot support object recognition. It is possible that deterioration in semantic memory contributed to the occurrence of intrusions (e.g.

selecting the wrong items) and identifying errors (e.g. searching for an item). The methodology does not allow us to distinguish errors based on the cognitive impairment, but as evidence suggests that semantic categories become blurred in dementia (Bayles & Tomoeda, 1983; Graham et al., 2004; Martin & Fedio, 1983), it is possible that the action errors resulted from incorrect object recognition. The kitchen environment presents numerous items that are semantically related in different ways. Explicit cues require the person with dementia to first recognise the meaning of a word (e.g. 'cup') and relate that to the object in the environment. Methods of directing attention to the relevant object would allow them to perceive the object visually in conjunction with the prompt, placing less demand on conceptual knowledge for kitchen items.

These limitations demonstrate that explicit prompts alone are not sufficient for supporting people with dementia in real home environments. A more implicit approach is necessary to compensate for deficits in attentional control, problems of orientation and subtle deterioration of conceptual knowledge. Advances in pervasive technology show potential in addressing these problems. Work has been done to explore how ambient cues can be implemented into home environments. For example, Bonanni, Lee and Selker (2005) developed the 'augmented reality kitchen', which includes light projections on worktops to provide recipes, and illuminating drawer handles to guide users to the location of utensils. Although these prototypes are designed to support typical users, such technology could be developed for people with dementia. In Chapter 6 we will discuss possible approaches to designing such technology for people with dementia.

In theory, situated cues (e.g. using light projections) should minimise cognitive load. However, such representations are unfamiliar to people with dementia, and little is known about how they would respond to such novel representations. Chapters 2 and 3 described our informants' negative experiences of introducing unfamiliar situations and procedures to people with dementia. Therefore, further work is needed to explore the limitations of implementing novel methods of cueing. This issue will be explored in Chapter 5.

4.2.2 Courses for horses

Existing approaches to developing technological prompts for people with dementia have treated the activity as a whole. A single method of prompting is selected (e.g. audio cues or video clips) to support the person through the whole task sequence. This top-down approach is also reflected in the methods of evaluation in which the task is broken into component sub-goals, and the efficacy of the intervention is measured by the number of steps completed by the users. For example, evaluation of the COACH system involved breaking the task of washing hands in separate steps (turning on tap, using the soap dispenser, and so on) and then scoring performance based on the number of step accomplished independently.

The present study demonstrates that in real situations, sequential tasks present different types of problems at different stages. It is likely that different types of problems will require different methods of prompting, and so the activity should not be treated as a whole. Instead research should focus on specific problems and develop prompting strategies that overcome them. This phase would involve an experimental approach to test specific types of assistance for different types of problems related to sequencing, orientation, operations and incoherence. For example, researchers should explore how cueing methods could be designed to support initiation of actions when the object is located in the cupboard or on the worktop. This is a bottom-up approach to designing prompting systems for multi-step tasks, which is more suitable for the issue being addressed. Prompts for different aspects of the task can be pieced together to establish the task sequence. What the present study provides is a meaningful classification of the types of problems that need to be addressed and detailed descriptions of these problems in a real context.

In Chapter 5 we will take one example problem (operating the cooker) and use an experimental approach to test a novel cueing strategy to assist people with moderate dementia.

4.3 Limitations

4.3.1 Conducting observations in real homes

The benefit in using naturalistic observations is that material analysed closely reflects real situations. The disadvantage is that controls cannot be easily applied. Participants performed different tasks in different environments, and so the opportunities for errors were not the same throughout. This is particularly the case with regards to the location of items. In one kitchen, an item would be visible on a shelf, whilst in another it may be concealed in a cupboard. The MLAT and NAT standardise the items used, as well as its visibility and location. This allowed the frequency of errors to be scored and compared across different groups of people. However, the analysis in this study focused less on error frequencies, and more on the nature of the problems. Therefore, the variability across people, activities and environments was useful in capturing different scenarios.

The method is naturalistic in the sense that the activities are meaningful to the participants and are conducted in their own homes. However, it should be acknowledged that all of the participants lived with a spouse who would perform many kitchen related tasks for them. Furthermore, the observations only take a snapshot of functional ability across people with different stages of cognitive decline. Ideally, assistive technology would be implemented at the early stages of dementia, with increasing levels of support being integrated over time. Further work is needed to understand the changes in activity performance longitudinally in order to devise systems that can be introduced at the early stages of dementia.

4.3.2 Forming error categories.

The problems reported in the present study confirm all error types described in previous observations of people with dementia. This is with the exception of problems with orientating items correctly. Feyeriesen et al. (1999) found that people with dementia had difficulty orientating clothing items when getting dressed. In the present study, participants showed no such problems when using items in the

kitchen. This highlights the point that the analysis focused on one context. It is possible that other contexts (e.g. getting dressed and washing) would have posed other problems for our participants.

There is a degree of arbitrariness between some error types. For example, one could argue that forgetting to turn off the cooker is as much an operation error as an omission error. This problem is unavoidable and can only be minimised by forming clear definitions of error types.

The high rate of inter-rater agreement ($k = 0.84$) indicates that the definitions are meaningful. Disagreements centered on the decision to include an error, as opposed to its classification. On six occasions, one of the raters identified and classified an error, whilst the other excluded or missed it out. This highlights some of the difficulty in interpreting participants' intentions based on observational material alone.

Disagreements about the inclusion of errors occurred with omission, identifying and inactivity errors. These three error types, by definition, involve the absence of any action. The other error types, on the other hand, involve the commission of an error or some interaction with the environment for it to be coded. The absence of action could be the reason why decisions for their inclusion were less consistent. For example, an omission disagreement occurred for a situation when the researcher assisted a participant because she transferred the soup from the container into the bowl without heating it. One rater included this as an omission error (omitting the act of heating the soup). However, the other rater thought she poured the soup into the bowl in order to heat it in the microwave, and so excluded it from the analysis. Without being able to observe her next action step (e.g. placing the soup in the microwave), it was not possible to confidently conclude between these two possibilities. Ambiguity with regards to identification occurred when the participant indicated to the researcher that they could not find an item but then managed to locate it themselves. One rater considered this to be a significant error, as the participant had expressed some difficulty. However, the other rater did not include it because the researcher did not provide any assistance. Inclusion of inactivity presented a similar problem for the raters. The participant would indicate that they

were confused as to what to do next and paused to think about the task. They maintained a dialogue with the researcher, expressing that they were confused, but then realized what they needed to do without any assistance. This disrupted the flow of the task, but did not prevent them from accomplishing it. However, it did cause some disagreement between raters.

4.3.3 Transcribing activities

The semi-formal notation adopted from the action coding system (Schwartz et al., 1991) provided a useful way of recording performance at the action level. This method allowed the researcher to analyse the activity in detail, and note errors along the task sequence. Comparisons between the author and second rater showed a consistent use of the notations, which suggests that the rules for describing actions are clearly defined. The limitation to the transcript is that it depends on interaction with the environment. This means that no information is provided with regard to the person's location in the kitchen. This meant that that it was still necessary to observe the video recording to confidently identify errors. Furthermore, the transcript did not include actions that did not result in the movement or manipulation of objects and the environment. This meant that gestures with items could not be coded (e.g. shaking or tilting), which caused some difficulty in transcribing toying behaviors.

A further limitation is that the transcript does not allow the state of the environment to be recorded. Although it gives ongoing account of the person's interaction with the local environment (e.g. switching the kettle on), it does not represent current states of the environment (e.g. kettle on), or how these states are represented (e.g. red light on). Cognitive theory suggests that situational factors play an important part in guiding actions. For example, the representations of pre- and post-action conditions of the environment are an essential part of the implemented CS model developed by Cooper and Shallice (2000). The present study confirms the view that visual cues play an important part in action initiation, object locating and operation of appliances. Incorporating the perceivable representations into the transcript would be instrumental in better understanding the occurrences of errors and designing situated methods of assistance. We will return to this issue in Chapter 6 where we explore

how an interactive design framework could be used to capture changes in the environment.

5. Conclusion

The present study describes the problems seen when six people with mild to moderate dementia were asked to do simple kitchen activities. Eight error types were identified that prevent task accomplishment. This highlights the problems that need to be addressed by prompting systems to enable people with dementia to accomplish multi-step tasks. Some of the problems identified confirm the findings of previous observations. Issues around sequencing (intrusions, omission and repetition) and incoherence (toying and inactivity) have been well documented. However, additional themes that were not provided were also identified, including orientation (locating and identifying) and operation errors. This more complete taxonomy was made possible due to the naturalistic procedures and settings, in which participants conducted activities of their choice in their own kitchens. In contrast, previous studies have tended to conduct observations in controlled settings and on pre-set tasks with specific objectives. Conducting the observations in participants' own homes, and on meaningful tasks, allows more confident conclusions to be drawn about the nature of the problems faced by people with dementia in real settings. Unlike previous studies, we took a minimum set approach to analysing errors that prevented task accomplishment. These factors would suggest that error classifications described here are more appropriate for communicating problems to designers of prompting systems than error taxonomies currently available.

Providing a detailed account of error incidences provides a context for designers to propose technological solutions. Understanding the problems in accordance with cognitive theory also guides the design of effective prompting strategies that are compatible with the cognitive capabilities of people with dementia. One important requirement is the need for situated assistance, to guide attention to task-relevant objects and locations in the local environment. With advances in pervasive technology and ambient cueing, such methods would be possible. However, more

work is needed to better understand how people with dementia would respond to these unfamiliar cues.

Finally, the error classifications described in this study demonstrate that the cognitive deficits of dementia cause different types of problems at different stages of the task. In order to design prompting systems that are effective, it is necessary to address these problems separately. Existing approaches to developing computerised prompts have been top-down, in which a mode of representing cues is selected and then evaluate by testing performance on the whole task sequence. The present study has shown that different aspects of the task will require different methods of support. This indicates a need for a more bottom-up approach to addressing specific sub-goals, and specific types of problems associated with them.

In Chapter 5 we describe an experiment addressing a specific problem (operating of the cooker) with people with moderate dementia. The solution to the prompting involves a visual cueing method that would be unfamiliar to the users, and so it should provide some insight into how people with dementia respond to the novel representations provided by situated cueing method.

Chapter Five

Choosing the right knob

Abstract

Eight people with moderate dementia conducted an experiment embedded in two cooking activities (porridge with syrup and chocolate cornflake cakes). At specific points in the task, the participants were required to operate the cooker. They were scored on how many times they selected the correct control to switch on/off specific hotplates. Each participant performed the activities under three conditions that used different cueing methods to associate hotplates with controls. In Condition 1 (original) symbols often used on conventional cookers were used. Condition 2 (verbal) used written words (e.g. TOP LEFT, BOTTOM RIGHT). Condition 3 (lights) used a Wizard of Oz prototype, in which the hotplate and corresponding control illuminated at the same time. In addition there was a control condition, in which only one hotplate and the corresponding control were visible. The predicted ceiling effect under the control condition indicated that all participants understood the task. A 2 x 3 within-subjects ANOVA revealed a significant difference with regards to operation type (turning the cooker on or off), but no significant difference with regards to cueing condition. The implications for designing prompting systems for people with dementia are discussed.

1. Introduction

It is often reported that novel situations have a negative impact on people with dementia. In Chapters 2 and 3 we described our informants' concerns about problems in learning and dealing with unfamiliar settings, procedures and domestic appliances.

The suggestion that novelty should be avoided constrains possibilities for design. Any intervention aimed at transforming functional ability will inevitably require some level of novelty. In Chapter 4 we suggested the use of situated methods of cueing (e.g. light projections on task-relevant objects) to improve the efficacy of prompting systems for people with dementia. However, such cues would be unfamiliar, and so could potentially worsen performance or cause confusion.

More work is needed to explore the issue of novelty so that the constraints on design are properly understood. It is necessary to draw from cognitive theory so that the negative effects of novelty can be minimised. The study presented in this chapter focuses on a specific problem identified in Chapter 4.

1.1 Operating appliances

In Chapter 4 we discussed the need for a bottom-up approach to designing cognitive prostheses that assist people with dementia through multi-step tasks. It was highlighted that existing prototypes have selected a single method of prompting (e.g. audio instructions or videos of required actions), which would then be tested on performance of the whole task sequence. The error types described in Chapter 4 indicate the need to address components of the task sequence separately using an experimental approach to evaluate different methods of cueing. This chapter demonstrates this approach by addressing the problem of operating the cooker.

The 'operation' errors presented in Chapter 4 describe how people with dementia experience problems when using kitchen appliances (kettle, cooker and toaster). Use of utensils relied on automatic responses to physical features and so posed no

problem for our participants. However, use of domestic appliances caused more problems. With regard to using the cooker a common problem was associating a hotplate with its control. It was observed that the saucepan would be placed on a hotplate and then the wrong control would be selected to turn it on or off.

All of the kitchen settings in Chapter 4 had a conventional cooker, which included four hotplates (two at the front and two at the back) and four controls in a straight line (running horizontally or vertically along the side). As with most cooker designs, the association between hotplates and controls was made using either symbolic or verbal representations. The symbols include a map of the hotplate arrangement with one part of the symbol blocked out to indicate the hotplate affected (see Figure 5.1 for example). Other cookers might use written cues next to the control (e.g. TOP-LEFT, BOTTOM-RIGHT) to indicate the hotplate affected.

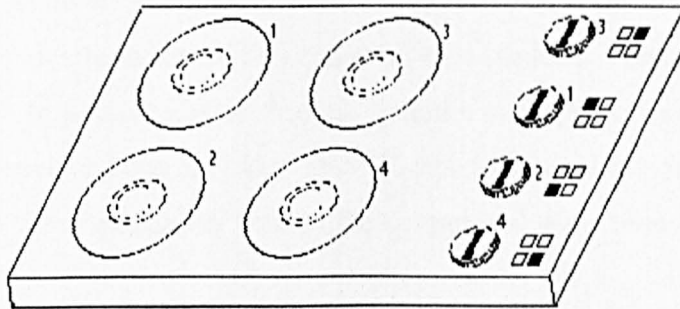


Figure 5.1: An example cooker that uses symbolic cues to associate controls with hotplate

The observations suggest that these representations were not sufficient in guiding the actions of our participants. This could have been due to lack of conceptual knowledge of what the cues represent. Alternatively, problems could have resulted from demand on executive control, in which they were required to observe the cue and relate that to the spatial arrangement of the hotplates.

1.2 Dealing with novelty

It is widely acknowledged that people with dementia respond negatively to novel procedures and settings, and that it is important to maintain a sense of familiarity. This suggests that novel methods of support should be avoided, and efforts should be made to design technology so that it appears familiar. This requirement has already been highlighted by others (Orpwood, Gibbs, Adlam, Faulkner, & Meegahawatte, 2005). Such requirement places a major constraint on design, and raises potential problems for using situated methods of cueing.

However, contrary to this premise that familiarity is required, previous work has shown that people with dementia can respond positively to unfamiliar technology. For example, the COACH (Cognitive Orthosis for Assisting Activities in the Home) system developed by Mihailidis et al. (2004) uses audio prompts to guide people with moderate to severe dementia through the task of washing their hands. The prompts led to some improvement on the task, despite the unfamiliar situation of hearing a disembodied voice. Alm et al. (2004, 2007) also demonstrated positive responses to a novel reminiscence tool that facilitated communication between people with moderate to severe dementia and care workers. The technology involved a touch screen to navigate users through a media package containing music, photos and videos. Touch screens are likely to be completely novel to people with dementia. However, the users responded well to the design and were able to interact with the screen.

Any intervention that improves functional ability is likely to require some level of novelty. It is important to better understand the importance of familiarity, and the extent to which novel cueing methods can be introduced.

Novel technology places a demand on two cognitive processes that are severely impaired in dementia. Firstly, memory impairment limits their ability to acquire conceptual knowledge about the technology. Evidence suggests that the memory deficit in dementia is a result of impaired encoding, as opposed to storage or retrieval of information (Morris, 1986; Morris and Kopelman, 1986). This means that despite preservation of knowledge acquired before the onset of dementia, patients have great

difficulty in learning new information. This poses a problem as the user must be able to recall how the technology functions or recognise representations and cues. Secondly, novel procedures place demand on executive control processes. According to the Norman and Shallice (1986) model of attention, which is described in Chapter 1, familiar routines can be executed automatically through the contention scheduling (CS) system with little need for top-down control from the supervisory attentional system (SAS). However, responding to new technology will require activation from the SAS, which is severely weakened in dementia.

Relating the problems of novelty with cognitive theory is important for establishing how technology might be designed to be compatible for people with dementia. Much of the work on object use provides further insight around the issue of familiarity and dementia. Studies have shown an advantage of 'personal familiarity', in which people with dementia respond better to their own items. Giovannetti et al. (2006) tested the influence of personal familiarity on object naming, knowledge and use. Sixteen people with mild to moderate dementia were presented with 12-15 personal household objects, and a different version of the same object. With each pair of items (personal and laboratory) participants were tested on *naming*, *gesture* (using item), *personal object decision* (recognising their own object) and *script generation* (state where, when and how each object would be used). They found a significant personal object advantage for script generation and gesture.

Bozeat et al. (2002) conducted a similar study with two people (JH and BW) who had semantic dementia. Unlike most forms of dementia, semantic dementia includes a profound degradation of conceptual knowledge, including the use of objects. The study required the participants to demonstrate the use of 15 single objects that they were using at home. Performance on these items was compared with use of 'perceptually similar' and 'perceptually different' exemplars of the same object. Perceptual similarity was categorised based on size, shape and colour. For example, one participant's own hairdryer was the standard 'L' shape, large and red. The perceptually similar one was black, slightly smaller, but still 'L' shaped. The perceptually different one was small, yellow, and was a travel hairdryer that folded up and was 'squarer' in shape. It was found that JH showed significantly better use of her own and perceptually similar objects than the other objects. BW showed

significantly better use of her own objects, with no advantage for perceptually similar objects relative to perceptually different exemplars.

These studies demonstrate the advantage of 'personally familiar', or at least 'perceptually similar' objects. However, studies have shown that people with semantic dementia who have lost conceptual knowledge about an object (e.g. naming it and describing what it is used for) are still able to demonstrate correct use of the object (e.g. hold, orientation and movement). This has led to the conclusion that object use is guided by the physical properties of the object, rather than semantic knowledge about how it should be used (Bozeat, Lambon Ralph, Patterson, & Hodges, 2002b; Buxbaum, Schwartz, & Carew, 1997; Hodges, Bozeat, Lambon Ralph, Patterson, & Spatt, 2000; Hodges, Spatt, & Patterson, 1999a). These studies describe two separate mechanisms in which object use is guided by visual or tactile features.

The first mechanism refers to an automatic process in which information about hold, orientation, movement and purpose are related to the physical structure (e.g. a handle is for holding, and a sharp edge is for cutting). This relates closely to Gibson's (1977) concept of affordance, in which representations in the environment can be perceived and acted upon directly. At this level, features and functions are associated frequently and consistently, and so become strongly encoded. Response to these visual and tactile cues are therefore automatic and requires minimum cognitive effort

The second mechanism relates to problem-solving or deliberate reasoning about the object on the basis of the visual or tactile characteristics (e.g. the hammer is used to hit the nail into the wood). Also referred to as 'mechanical problem-solving', this process allows users to infer correct use of novel tools. This has been demonstrated using the 'novel tool test' (Goldenberg & Hagmann, 1998), in which a set of six cylinders and six tools are presented in front of the participant. Each cylinder has a part to which only one of the tools fit. The task is to select the correct tool to lift one of the cylinders. Participants are scored on tool selection and tool use (inserting it and lifting the cylinder). Importantly, it has been found that people with impairment to executive function processes are still competent at this task, showing no

significant difference to that of controls. Therefore, this type of non-routine task differs from other types of non-routine and problem-solving tasks, as performance is not disrupted by deficits in executive control. (Bozeat et al., 2002; Goldenberg & Hagmann, 1998).

These studies involved simple objects and only required the participant to perform very basic actions. However, they do demonstrate how external visual or tactile representations can be used to guide actions and bypass demand on impaired cognitive processes.

Norman (1990) popularised the concept of affordance in design. He also makes a distinction between different levels of support. He refers to 'physical constraints' to describe the restriction of action possibilities, which is often automatic and requires minimal cognitive effort. He also describes the role of 'logical constraints', in which the perceived properties of the object or interface provide 'clues' that supports reasoning about how it is used. He uses the cooker as an example to demonstrate the role of logical constraints in reducing demand on conceptual knowledge and attentional control. In this example (see Figures 5.2) the natural mapping between the controls and hotplates are intuitive to the user, and so there is little need for the explicit representations (symbols or words).

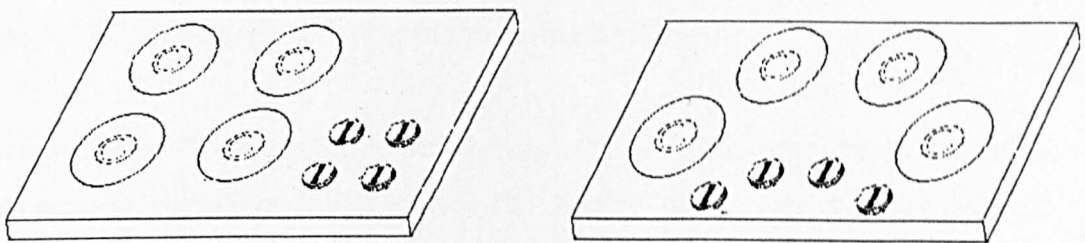


Figure 5.2: Suggested cooker designs (Norman, 1990) using 'natural mapping' of controls and hotplates.

More work is needed to explore how novel representations could be designed to be compatible with the cognitive capabilities of people with dementia. Ability to deal with novelty often requires acquisition of new information and places demand on attentional processes. However, the negative impact of novelty could be reduced if

enough affordance is provided. More work is needed to explore how people with dementia respond to novel methods of cueing, and how the technology could be designed so that it is compatible with their cognitive capabilities. The present study explores this issue by using a novel representation to address a real problem experienced by people with dementia.

1.3 The present study

The present study explores the problem of novelty for people with dementia. Continuing with the cooker theme, participants were required to operate the appliance under three cueing conditions and a control condition. The methods of cueing varied in degrees of novelty and cognitive demand. In Condition 1 (original) the cooker design included symbols to represent the association between control and hotplates. In Condition 2 (verbal) written words were used (e.g. TOP-LEFT, BOTTOM-RIGHT). In Condition 3 a Wizard of Oz prototype was used in which the hotplate and corresponding control would light up to represent their association. In the control condition, three hotplates were covered, and the corresponding controls removed, leaving only one hotplate and control exposed. Under each condition, participants were required to operate the cooker eight times (four times switching on, and four times switching off). They were scored on how many times (out of 8) they selected the correct control to operate it. Under the control condition, only one hotplate was available and so they were not required to make any selection. See Figure 5.7 for photographs of some of the cueing conditions.

Eight people with moderate dementia took part in the experiment. Individual differences in cognitive decline across the sample meant that a within-subjects design was most appropriate. A Latin square randomisation was used to control for order effects. The experiment was designed to be appropriate for people with moderate dementia. People with dementia may have difficulty understanding the procedures of an experiment, lose interest, or become confused and agitated. The experiment procedure was designed to overcome these problems by embedding it in a real cooking activity. This involved two short tasks, making porridge with syrup and making chocolate cornflake cakes. Both of these tasks were conducted under all conditions and were structured so that the participants were required to operate the

cooker four times for each task (8 times per condition). This made the situation more natural, meaningful and engaging for the participants. Each condition was carried out on separate days. To avoid fatigue or loss of interest, each activity was short (5-10 minutes) and there was a one-hour gap between the two tasks.

The activity sequence was scripted so that it was the same throughout the whole study. The script included a distracter task (e.g. placing paper cake cups on a tray) between each operation. This meant that the participant's attention was taken away from the cooker before and after each operation.

The experiment was conducted at a care facility for people with dementia. Three participants conducted the experiment in their own flats within the facility, and five in the day centre kitchen. A care worker based at the care facility, and was familiar to the participants, carried out the cooking activity with them. Conducting the experiment in a familiar setting and with a familiar person helped minimise anxiety experienced by the participants, which could potentially affect the validity of the results.

This experiment explores the issue of novelty in order to better understand the extent to which assistive technology should be constrained by the need for familiarity. Comparing scores on control selection across the three conditions provides insight into how people with dementia respond to novel representations that are designed to reduce cognitive demand.

It is hypothesised that scores for correct control selection will be higher under the light condition than the original and verbal conditions. Although unfamiliar to the participants, the visual representation reduces cognitive demand. The original and verbal conditions require the participant to observe the explicit representations (symbols or words) and relate them to the spatial arrangement of the hotplates. This places demand on attentional control. In contrast, the light representations can be perceived directly, and so less attentional control is required. The novel design presents a 'logical constraint' (Norman, 1990), which should be intuitive enough for participants to respond correctly without conceptual knowledge about what the light cues represent. Therefore, participants will not be briefed about the novel design.

2. Method

2.1 Design

The experiment was embedded in a real cooking activity with a care worker who was familiar to the participants. This involved two cooking tasks: (i) porridge with syrup, and (ii) chocolate cornflake cakes. At certain points in the task the participants were required to operate the cooker by turning the hotplates on or off. There were four operations for both tasks, which meant that there were a total of eight operations across the two activities. Participants were required to select the correct control.

The design was repeated measures. The independent variables were condition (4 levels) and request (on and off). The dependent variable was the number of correct responses out of 8.

There were three cueing conditions and one control condition. Condition 1 (original) used symbolic representations to associate the control with the hotplate (Figure 5.3). Condition 2 (verbal) used words to associate controls with hotplates (e.g. TOP-LEFT, BOTTOM-RIGHT, see Figure 5.4). In Condition 3 (lights) the hotplate and corresponding control would light up in order to indicate the association (Figure 5.5). In the control condition (cover) only one hotplate (bottom-right) and the corresponding control were exposed (Figure 5.6). This condition was used to establish whether the participant understood the task. As there was only one control to select we expect to find a ceiling effect. Failure to select the control under this condition would indicate that the participant did not understand what was expected from them.

2.2 Participants

2.2.1 Recruiting

Eight people with moderate dementia were recruited from a care facility in Leeds, which was run by the Methodist Housing Association (MHA). The facility had residential flats and a day centre. Three of the participants were residents within the housing complex. The other five participants lived in their own homes and attended the day centre three or four days a week. Six of the participants were female and two were male. Table 5.2 summarises the profiles of the eight participants.

2.2.2 Cognitive profiles

Cognitive status was measured using the Abbreviated Mental Test (AMT, Hodkinson, 1972) at the end of the experiment. The AMT is a short test of memory and orientation. It includes 10 questions and takes around two minutes to complete (see Table 5.1 for the questions asked). The AMT score has been found to correlate with longer assessment tools such as the Mini Mental State Examination (MMSE). Jitapunkul, Pillay and Ebrahim (1991) provide a useful formula for predicting MMSE score based on the known AMT score:

$$\text{MMSE score} = 7.06 + (1.94 \times \text{AMT score})$$

The predicted MMSE score for the participants is included in Table 5.2. Using the shorter assessment tool as opposed to more in depth measures was at the request of the care managers who wanted to avoid making participants feel that they were being examined.

Table 5.1: Abbreviated Mental Test (Hodkinson, 1972)

Items of the AMT	
1	Age
2	Time to the nearest hour
3	Show them an address and ask them to repeat it back
4	Year
5	Name of institution
6	Recognition
7	Date of birth
8	Date of a significant event (e.g. World War II started)
9	Name of monarch
10	Count 20 to 1

Table 5.2: Profiles of the eight participants in the cooker experiment

Case	Sex	Age	Description	AMT	Predicted MMSE
BF	Male	81	Day centre attendee	4	15
CS	Female	76	Resident	5	17
JM	Female	75	Resident	3	13
LF	Female	80	Resident	3	13
NI	Female	75	Day centre attendee	2	11
GW	Female	78	Day centre attendee	5	17
LL	Female	76	Day centre attendee	6	19
CL	Male	73	Day centre attendee	5	17

2.2.3 Ethical considerations

For each participant, consent was provided from the participant, care home manager or day centre manager, and a family member. Participants and family members were given a one-page information sheet to explain the experiment. It was emphasised that the participant or family member could withdraw at any time (see Appendix F for information sheet and consent form).

It was important that the participants felt comfortable when taking part. A care worker at the day centre, who was a familiar face to all the participants, would assist them through the task. Before each cooking activity the care worker would explain to the participant what they were going to do, and asked if they were willing to take part.

2.3 Location

The sheltered housing complex is an extra-care facility for older adults and people with dementia. Three of the eight participants lived in the complex. They had their own flat with a kitchen area. For these cases the experiment was conducted in their own kitchen. The remaining five visited the day centre during the week. The day centre is run specifically for people with dementia. Activities done during the day include music, baking and reminiscence. The centre is open every day and around 10 to 15 people attend on a given day. In the main part of the day centre building is a kitchen where attendees and staff would carry out baking activities. It is in this kitchen that the experiment was conducted with the five participants who attended the day centre. The same cooker design was used in the flats and the day centre.

2.4 Materials

The flats in the housing complex and the day centre had the same cooker design installed, and so the hotplate and control arrangement remained the same throughout the experiment. It was an electric cooker. The four hotplates were arranged in a square formation (two at the front and two at the back). The controls were arranged from left to right (Figure 5.3 shows the control and hotplate arrangement). The first (far left) control corresponded to the top-left hotplate, the second control operated the bottom-left, the third control operated the bottom-right, and the fourth (far right) operated the top-right hotplate.

Located on the far right was a red light that came on when one or more of the hotplates were switched on. The control was in the 'off' position when pointing upwards. The controls could be turned in either direction to click into six levels. It was, therefore, easy to see when the control had been turned (see photographs of the cookers in Figure 5.7)

2.4.1 Condition 1: Original

For condition 1 (original) the design of the cooker was not changed. This meant that the symbolic representations were used to represent the association between the control and hotplates. This design is often used on conventional cookers. The symbol next to the control represented a map of the four hotplates (e.g. four squares) with the corresponding hotplate blocked out (see Figure 5.3).

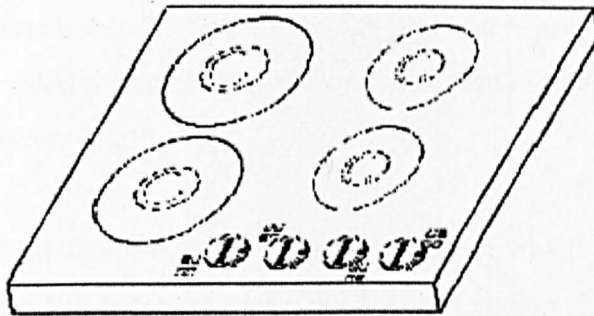


Figure 5.3: Hotplate-control alignment and symbol cues in Condition 1

2.4.2 Condition 2: Verbal

For condition 2 (verbal) the symbols were covered with text (e.g. TOP-RIGHT, BOTTOM-LEFT) in the MS Word Arial font size 20 (see Figure 5.4).

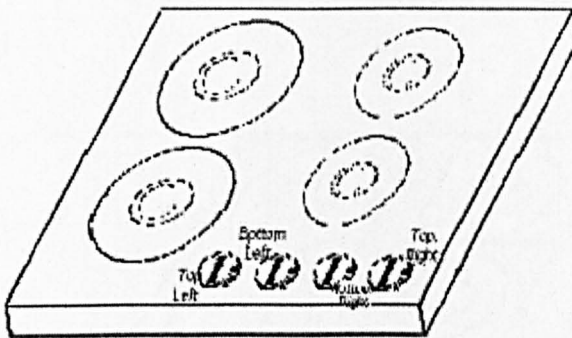


Figure 5.4: Hotplate-control alignment and verbal cues in Condition 2

2.4.3 Condition 3: Lights

Condition 3 (lights) used a lighting effect to associate the hotplate with the corresponding control. The lighting effect was created using electroluminescent wire that was fitted around the hotplate and controls. The lighting for each wire was controlled using separate switches powered by a battery. The wire was placed on the cooker top in separate squares. Four rings were made to fit around the separate controls (Figure 5.5 shows the cooker with the arrangement of the electroluminescent wire). The lights for the four hotplates and corresponding controls were different colours: Red (top-right), blue (bottom-left) green (top-right) and yellow (bottom-right).

This condition used a Wizard of Oz simulation, in which the researcher controlled the lights. When the saucepan was placed on the cooker the researcher would press the switch that controlled the hotplate and the switch that controlled the corresponding control. The light around the hotplate would remain still, whilst the light around the control would flash. When the control was turned (to switch the cooker on) the researcher pressed the switch a second time, at which point the light around the control would become still. When the control was turned to switch the cooker off, the researcher would press the switches so that light around the hotplate and control would go out. Only one saucepan was placed on the cooker at any one time during the experiment, and so only one hotplate and control would be illuminated.

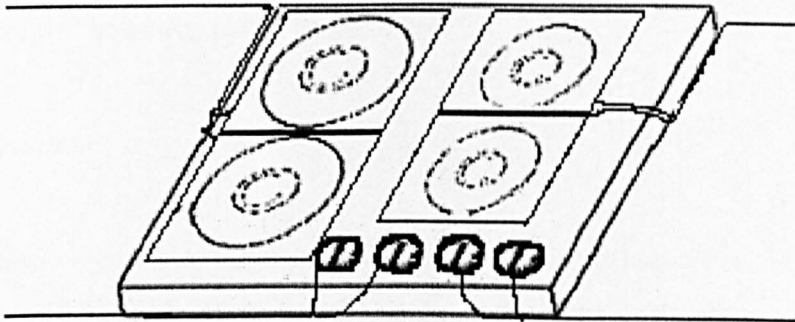


Figure 5.5: Hotplate-control alignment with electroluminescent wire in Condition 3. Four squares of electroluminescent wire are fitted around the four hotplates. Four rings of electroluminescent wire fitted around the four controls. Each square/ring is attached to a wire so that it can be controlled by a switch as part of the Wizard of Oz simulation.

2.4.4 Control condition: Cover

In the control condition (cover) a metal cover was fitted on top of the cooker, covering three of the four hotplates. Only the bottom-right hotplate was exposed. The three controls corresponding to the covered hotplates were also removed, leaving just the relevant control (Figure 5.6). The same hotplate (bottom-right) was used for all activities in this condition

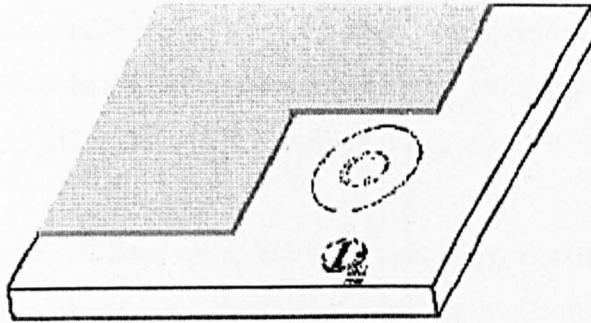


Figure 5.6: Hotplate-control alignment and cover in the control condition

All the utensils belonged to the day centre. Items for the porridge with syrup task included two saucepans, one tablespoon, one breakfast bowl, instant porridge oats, milk, and syrup. Items for the chocolate cornflake cakes included two saucepans, one baking tray, 12 paper cake cups, two mixing bowls, a tablespoon, white and brown chocolate, and cornflakes. The milk and chocolate were also heated before the experiment. This was because in condition 3 (lights) the cooker was switched off at the mains, because the wires controlling the lights were affected by the heat of the cooker. A digital video camera was positioned on the worktop, overlooking the cooker so that control selection could be recorded.

2.5 Procedure

Before the experiment, the care worker asked the participant if they would like to take part in the cooking activity. When the participant agreed they were taken to the kitchen area. Before every task the care worker would introduce the participant to the researcher. Participants were not briefed about the cooker designs (e.g. what the lights represented).

2.5.1 Activity scripts

The participant was required to carry out two cooking activities. These were porridge with syrup and chocolate cornflake cakes. Both activities took approximately ten minutes to complete. The participants were assisted throughout the task by the care worker. At certain points during the activity, the researcher would place a saucepan on one of the hotplates and ask the participant to turn the hotplate on (pointing at hotplate with the saucepan). Both activities were structured so that there were four operations of the cooker. Therefore, across both activities there were eight operations in total. All four hotplates were used with the exception of the control condition (cover) in which the bottom-right hotplate was used for all operations.

Between operations there were distracter tasks (e.g. transferring cornflakes into the mixing bowl). This was to draw the participant's attention away from the cooker after each operation. The activity sequence was kept the same for each condition. Table 5.3 and Table 5.4 present the activity script for the two activities. See Figure 5.7 for photographs from the video recordings.

Table 5.3: Activity 1 script: Making porridge with syrup

Step 1	Carer asks participant to pour milk into saucepan 1. The carer places saucepan 1 onto the top-left hotplate (bottom-right in condition 4)	START
Step 2	The researcher asks the participant to turn on the hotplate (pointing at the saucepan)	Operation 1
Step 3	The carer asks the participant to spoon four tablespoons of porridge oats into a jug add them to saucepan 1	Distracter 1
Step 4	The researcher asks the participant to turn off the cooker (pointing at the saucepan 1)	Operation 2
Step 5	The carer asks the participant to pour syrup into saucepan 2. The carer places saucepan 2 on the bottom-right hotplate.	Distracter 2
Step 6	The researcher asks the participant to turn on the cooker (pointing at saucepan 2)	Operation 3
Step 7	The carer asks the participant to pour porridge from saucepan 1 into a bowl	Distracter 3
Step 8	The researcher asks the participant to turn off the cooker (pointing at saucepan 2)	Operation 4
Step 9	The carer asks the participant to pour the syrup from saucepan 2 into the bowl of porridge	END

Table 5.4 Activity 2 script: Brown and white chocolate cornflake cakes

Step 1	Carer asks participant to add brown chocolate into the saucepan 1. The carer places saucepan 1 onto the top-right hotplate (bottom-right in condition 4)	START
Step 2	Researcher asks the participant to turn on the cooker (pointing at saucepan 1)	Operation 1
Step 3	The carer asks the participant to add four tablespoons of cornflakes into two mixing bowls	Distracter 1
Step 4	Researcher asks participant to turn off the cooker (pointing at saucepan 1)	Operation 2
Step 5	Carer asks participant to pour chocolate from saucepan 1 into one bowl of cornflakes and mix them together. Carer then asks the participant to put white chocolate into saucepan 2 and places it on the bottom-left hotplate (bottom-right in condition 4)	Distracter 2
Step 6	Researcher asks the participant to turn on the cooker (pointing at saucepan 2)	Operation 3
Step 7	Carer asks the participant to place paper cake cups onto baking tray	Distracter 3
Step 8	Researcher asks participant to turn off cooker (pointing to saucepan 2)	Operation 4
Step 9	Carer asks participant to pour white chocolate from saucepan 2 to second bowl of cornflakes and mix them together. The chocolate cornflake mix are then transferred to the paper cake cups.	END

Activity 1 and Activity 2 were conducted on the same day with a one-hour break between them. The same activity sequence (Activity 1 and then Activity 2) was used for all four conditions. Each condition was conducted on a separate day. Two Latin squares were used to counterbalance the order of conditions experienced by each participant.



Figure 5.7: Images of the cooker taken by the video camera during the experiment. Images include 'original' condition (top-left) and verbal condition (top right), the 'light condition' (middle images), and the 'cover condition' (bottom images).

2.5.2 Assistance

The participant performed the main part of the task with the carer, and so assistance was provided throughout. The only part of the activity that the participant was required to perform alone was the operation of the cooker. If they selected the correct control then the activity would proceed to the next step. If they selected the wrong control, then the researcher would indicate the correct control. Once they turned the correct control the activity would continue.

If the participant turned more than one control, the first to be turned was counted as the selected one. The control would have to be turned for it to be scored. If the participant held one control before turning another, the control turned was scored as the chosen control. The cooker was designed so that the controls clicked into six different levels. When switching the cooker off, they were only required to turn the control to another position for it to be scored as correct (i.e. they were not required to orientate the control to the correct 'off' position).

If the participant requested assistance with regard to selection of the control, the researcher would give a neutral response ("*choose the one you think it is*").

3. Results

3.1 Overall scores for control selection

Table 5.5 presents the means and standard deviations for correct control selection. This includes the scores for all operations (out of 8), as well as separate scores for turning the cooker on (out of 4) and turning the cooker off (out of 4).

For the control condition ('cover') nearly all participants reached the maximum score. When turning the cooker on, there were only two occasions when the correct control was not selected. The scores for the control condition will not be considered for the significance tests because of the predicted ceiling effect.

Table 5.5: Mean scores and standard deviations for control selection

Condition	Turning on (out of 4)		Turning off (out of 4)		Total (out of 8)	
	Mean	SD	Mean	SD	Mean	SD
Original	1.13	0.64	3.00	1.51	4.13	1.55
Verbal	2.00	0.93	2.75	1.04	4.75	1.49
Lights	2.50	1.31	3.00	1.31	5.50	2.45
Cover	3.75	0.46	4.00	0.00	7.75	0.46

Figure 5.8 presents the overall mean score of correct control selection across the three cueing conditions (original, verbal and light) and the cover condition. Participants scored higher with the light condition than the original and verbal conditions, and higher in the verbal condition than the original condition.

Control selection score for three cueing conditions and control

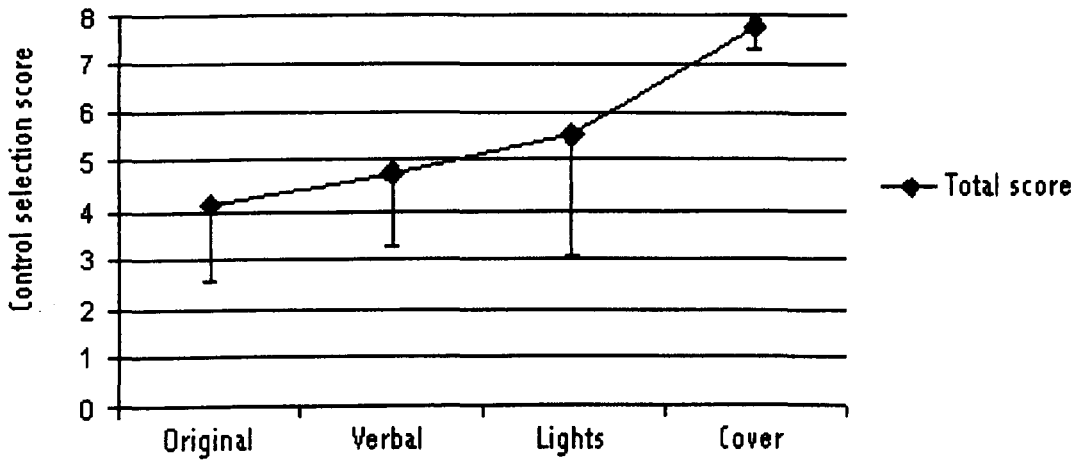


Figure 5.8: Overall control selection score (out of 8) for the three cueing conditions and control condition

Figure 5.9 presents the scores for control selection under the three conditions (original, verbal and light) and the two different operation requests (on and off). Mean score was higher when turning the cooker off, than when turning the cooker on. When turning the cooker on, the light condition scored higher than the original and verbal conditions, and the verbal condition scored higher than the original condition. When turning the cooker off, the light condition and original condition were equal, both scoring higher than the verbal condition.

Control selection score for switching the cooker on and off

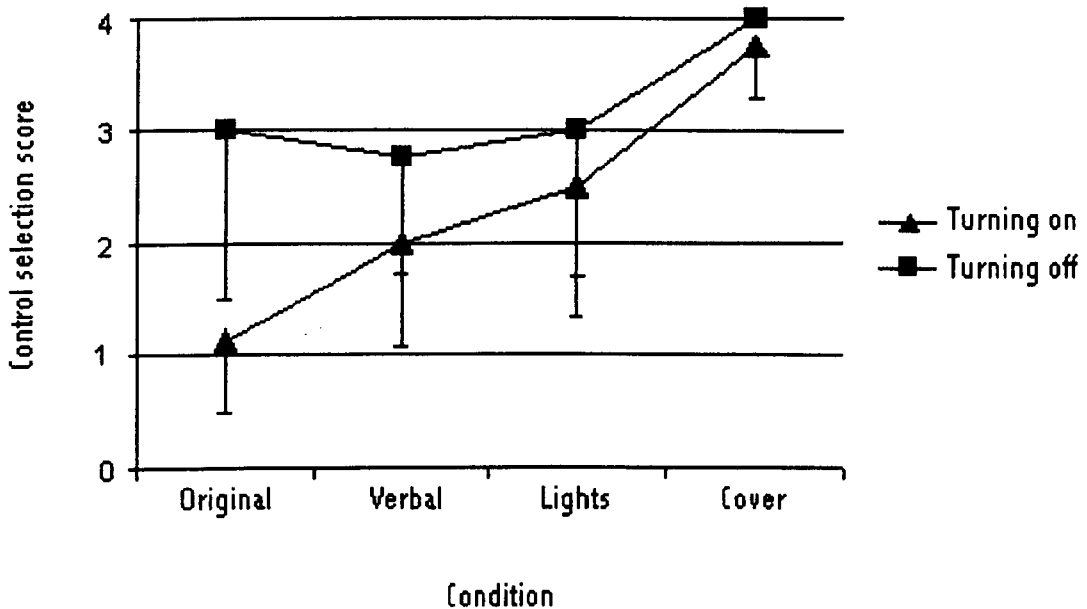


Figure 5.9: Control selection score (out of 4) for the two types of operation (on and off)

A 2 x 3 within subjects ANOVA revealed a significant main effect of request, in which control selection scores were lower when turning the cooker on than when turning the cooker off, $F(1,7) = 14.83, p < .01$. However, there was no significant main effect of cueing condition, $F(2,14) = 1.27, p = .31$.

The key comparisons were for the turning on condition, as in the turning off condition there was already a cue to which to turn (orientation of the control). When turning the cooker on, there was no significant difference in score between the original condition and light condition, $t(7) = -2.20, p = .06$. There was also no significant difference between the verbal condition and light condition, $t(7) = -.94, p = .38$.

3.2 Individual scores

In six of the eight cases (BF, CS, JM, GW, LL, and CL) scores for the light condition were higher than scores for the original design. Of these cases, five had a score for the lights condition that was higher or equal to the score for the verbal condition. Two participants (LF and NI) scored lower for the lights condition than for the original and verbal conditions. For the cover condition, all participants scored higher than the other condition, or equal to the lights condition. Figure 5.10 presents the total score for each participant under the three cueing conditions and control condition. Table 5.6 breaks the scores of individual cases to account for the two types of operation (turning on and off).

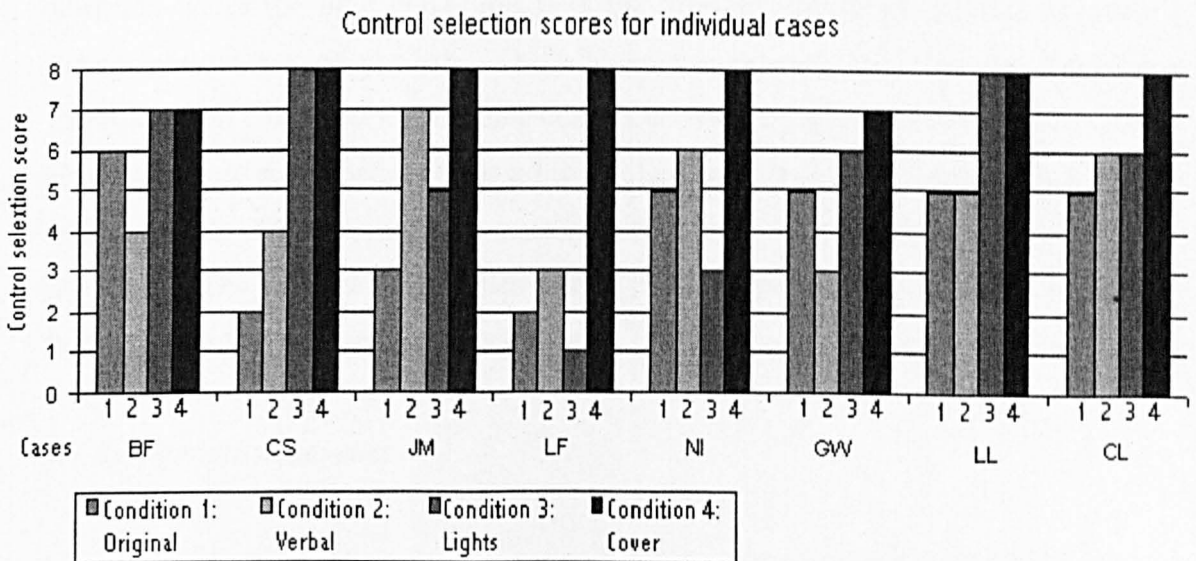


Figure 5.10: Control selection scores for the eight individual cases (out of 8)

Table 5.6: Individual scores for control selection

	Cueing Condition											
	Original			Verbal			Lights			Cover		
	On	Off	Total	On	Off	Total	On	Off	Total	On	Off	Total
BF	2	4	6	1	3	4	3	4	7	3	4	7
CS	0	2	2	2	2	4	4	4	8	4	4	8
JM	1	2	3	4	3	7	2	3	5	4	4	8
LF	2	0	2	1	2	3	0	1	1	4	4	8
NI	1	4	5	2	4	6	2	1	3	4	4	8
GW	1	4	5	2	1	3	3	3	6	3	4	7
LL	1	4	5	2	3	5	4	4	8	4	4	8
CL	1	4	5	2	4	6	2	4	6	4	4	8

4. Discussion

It was hypothesized that the participants would have a higher score for control selection under the light conditions than the original and verbal conditions when turning the cooker on and off. Overall, the means were higher under the light condition than the verbal and original conditions when turning the cooker on and off. However, these scores were not found to be significant ($p > .05$). Despite this, we are encouraged to see that the light condition was as good, or better, than the other conditions. The experiment provides insight into how people with dementia respond to novel cues that reduce cognitive demand.

4.1 Response to novel cues

In order to draw conclusions about participants' responses to the different cueing conditions, it was important to know whether they actually understood the task. To test this the control condition (cover) was used. In this condition, only one hotplate and the control were visible, and so participants did not need to make a selection. Nearly every participant reached the maximum score in this condition. This indicates that they did understand the task. There were only two occasions when the incorrect control was chosen. Both times the participants were distracted by the location where the other controls had been removed. Although three of the controls were detached, the sockets that joined them to the cooker were still visible. This was enough to

distract BF and NI when switching the cooker on. If these were not visible it is likely that they would also have reached maximum score.

Overall, the participants scored higher with the novel light cues than the more familiar original and verbal cues. Although the difference was not found to be significant, it demonstrates that technology should not be constrained by a need for familiarity. The light condition presented a larger standard deviation, which suggests reactions were more varied under this condition. With such a small sample, the data was sensitive to individual responses to the cueing method. Looking at scores across individuals, it can be seen that LF and NI were the only participants that responded worse under the lights condition. LF scored low on all conditions, apart from the cover, which acted as a control. This suggests she had some difficulty understanding how the cooker worked. In fact, on nearly every occasion LF operated the cooker by turning all of the controls instead of selecting one. NI shows a slightly different picture, as her scores in conditions 1 and 2 were on par with the other participants, but scored noticeably lower for the lights condition.

Examining the remaining six participants indicates a positive response to the novel light cues. It is also important to note that participants were not briefed about the different cueing methods. They were not told, for example, what the lights represented in condition 3. Therefore, their selection of controls was based on their own reasoning in response to the novel representation.

4.2 Interfaces for people with dementia

The light condition offers a 'logical constraint' (Norman, 1990) that supports deliberate reasoning about the functioning of the appliance. The original cooker design was not compatible with the cognitive capabilities of people with dementia. Firstly, it required them to recognise the symbolic representations to associate controls and hotplates. Second, the interface demands attentional control to map the explicit representations with the hotplate arrangement. The implicit representation reduces demand on these processes. The affordance of the illuminated hotplate and corresponding control provides a 'logical constraint' that can be immediately perceived. Participants were not briefed about the novel representation, which also

suggests that for some participants, the representation did not require conceptual knowledge. This is consistent with previous studies on object use, which has found that visual and tactile features of objects can guide its use (Bozeat, Lambon Ralph, Patterson, & Hodges, 2002b; Buxbaum, Schwartz, & Carew, 1997; Giovannetti et al., 2006; Hodges, Bozeat, Lambon Ralph, Patterson, & Spatt, 2000; Hodges, Spatt, & Patterson, 1999a). Many have referred to ‘mechanical problem solving’ to describe correct use of novel tools in response to physical features. Studies have used the novel tool test to demonstrate that non-routine problem solving tasks can be performed independently of executive control processes when there is sufficient affordance to guide actions (Goldenberg & Hagmann, 1998). Similarly, the present study demonstrates that reducing demand on executive control can reduce the negative impact of novelty.

This experiment was the first attempt at using lights to increase the usability of the cooker. No preliminary tests had been conducted to develop or improve the design. Although the design used seemed most logical, other features could have been implemented. For example, the use of arrows to link controls and hotplates or the additional use of audio cues could have further improved performance. An iterative process of re-design and testing would be necessary to establish the most effective cueing method, especially for the population being addressed. The present study only goes as far as describing the first step in this process.

The approach taken highlights the role of cognitive theory in making technology usable for people with dementia. At face value the ethnography described in Chapters 2 and 3 would suggest that technology needs to appear familiar if it is to be used by people with dementia. However, research into related cognitive processes raise possibilities of implementing novel technology that is still compatible with the cognitive capabilities of people with dementia.

4.3 Methodological contributions

The present study includes two important features that should be considered when designing technological prompts for people with dementia. Firstly, the experiment was designed to be compatible for people with dementia and captures response that would occur in real situations. Second, it focuses on a solution to a specific problem, rather than treating the task sequence as a whole. Given the population being addressed and the complexity of everyday tasks in the home, these two features are necessary for designing effective prompting methods. Both issues will be discussed here.

4.3.1 Naturalistic experiment

The experiment was embedded in a semi-natural context. This reduced potential for participants to become agitated, disinterested or confused. The tasks were meaningful to the participants, and so avoided the anxiety of feeling as though they were being assessed. Conducting the activities in real kitchens with real appliances and items meant that participants understood what was happening and little explanation was required.

A problem with using real tasks is that some control would be lost. The task scripts were used to minimise this. This meant that the same sequence of steps was used throughout the experiment. The distracter tasks between operations also meant that the participant's attention would be drawn away from the cooker between operations. This was to reduce the chances that they could remember what control had been turned or use strategies (e.g. staring at the cooker or holding onto the control) that would have assisted them.

All participants responded well to the methodology and remained interested in the task. This was helped by the fact that they were in a familiar environment and in the presence of a familiar care worker.

4.3.2 Solutions to specific problems within a task

The present study illustrates how ethnographic material can be explored in more detail through an experimental approach. Solutions to other aspects of a task sequence that pose problems for people with dementia could be tested with a similar methodology. Existing work to designing prompting systems for dementia have taken a top-down approach, in which a cueing method is selected and then used to test performance on the activity as a whole. Chapter 4 demonstrated that activities in real settings pose different types of problems at different stages of the task sequence. Different types of problems may require different methods of support, and so they need to be addressed separately. This experiment demonstrates the value of breaking the task down into different cognitive components when designing technology to support multi-step tasks.

5. Conclusion

This chapter describes an experiment embedded in a semi-natural situation to test three different cueing methods to assist eight people with moderate dementia when operating a cooker. The purpose was to explore the importance of familiarity over novel methods designed to reduce cognitive demand. Overall, participants responded better with the novel cues, which used lights to indicate association between cooker hotplates and controls. Although the improved performance was not found to be significant, we are encouraged to see that the highly novel cue was at least as good as the familiar designs. Participants were not briefed about the new design. This means that correct control selection was based on deliberate reasoning of the novel representation.

The methodology was designed to be compatible for people with dementia. The predicted ceiling effect under the control condition demonstrates that they understood the task. The activity was designed to be fun and engaging for the participants so that they responded in the experiment as they would in a real situation. A similar approach could be used for other stages in a task sequence.

The methodology reflects a bottom-up approach to designing technology for people with dementia. Existing methods of evaluating technology have treated the task sequence as a whole. These studies assume that a single method of prompting is appropriate for the whole task sequence (e.g. audio prompts or video recordings). The method of evaluating the efficacy of these prompts has also involved the whole task, in which they score the number of steps accomplished independently. The present study demonstrates how solutions to specific problems can be hypothesized and tested in a natural way. This approach is better suited to designing prompting systems for people with dementia. Given the complexity of activities in real settings, and the different types of problems faced by people with dementia, designers should focus on developing and evaluating cues for specific task components.

Chapter Six

Future steps towards designing prompting systems for people with dementia

1. Introduction

Developments in tracking technology and artificial intelligence provide new possibilities for supporting people with dementia through multi-step tasks. Current approaches in designing prompting systems for people with dementia have used explicit cues (audio instructions or videos) to support the user through the whole activity. This approach overlooks the complexity of daily activities in real settings, and how different cognitive deficits disrupt task performance. This point was highlighted in Chapter 4, which described different error types that were identified when observing people with dementia perform activities in their own kitchens. Understanding these problems in the context of cognitive theory pointed to the need for situated cues, in addition to explicit prompts. Directing the user's attention to task-relevant objects and locations within the environment would be necessary for prompting systems that compensate for the cognitive deficits of dementia.

This chapter focuses on the next steps required to develop situated supports for real homes. In the first part we will discuss recent developments in pervasive computing that match the need for situated prompting systems. In the second part we will explore how an interactive design framework could be applied to design situated cues.

2. Building situated supports

2.1. Relevant developments in pervasive computing

In Chapter 5 we discussed the need to provide situated cues, in which the attention of the user is directed to task-relevant aspects of the environment in order to make prompting systems more effective for people with dementia. This requires the technology to increase the salience of objects and locations. One method could be to illuminate the object, either using devices attached to them, or by deflecting light onto it using light projectors. There are a number of projects currently looking at how information displays can be augmented within real settings. The Everywhere Display Projector (ED-projector) developed by IBM Research allows information to be projected onto any surface in a room. The LCD projector uses a mirror to deflect the image onto work surfaces, walls or the floor. A camera on the projector can track hand movements so that the user is also able to interact with the display (Pinhanez, 2001).

Bonanni, Lee, and Selker (2004) demonstrated how ambient displays could be used in a kitchen context. They used the projected displays to present step-by-step recipes on the worktop or cupboards. Using a remote infrared thermometer, the system can measure the surface temperature of food in pans, and then project temperature level and required cooking times onto the cookware. Drawer and cupboard handles can also light up to assist in locating items. This is achieved using translucent handles with LEDs embedded inside them, which light up when required.

These methods of assistance were designed with typical users in mind. However, it does demonstrate how situated cues could be augmented into real homes to support people with dementia. Devices such as the ED-projector could be used to deflect light onto required objects and locations in order to increase their salience. LED based devices could also be augmented onto existing objects, cupboards and appliances.

For systems such as the ED-projector to work, it must be possible to accurately position the location of objects within a home environment, such as the kitchen. Many objects during everyday tasks are moved around to different locations. Radio Frequency Identification (RFID) technology would be capable of tracking whether an object was placed in, or taken out, of a compartments (e.g. cupboard, drawer or fridge). However, locating items that are moved around the worktop would be more difficult.

There are a number of methods for indoor object positioning that are being explored. RFID and infrared signals have been used to estimate object positions indoors. These systems can use multiple distance and angle measurements from known points (triangulation) or distance to known sets of points (proximity) to predict location of tagged objects. For example, the Active Bat location system uses ultrasound time-of-flight techniques to locate the position of tags that can be attached to everyday objects. This is capable of locating objects within 9cm of the true position for 95% of measurements (Harter et al., 1999). Another approach has been to use vision-based systems. For example, the TRIP (Target Recognition using Image Processing) uses cameras located around the room to identify circular barcode tags ('ring codes') that are attached to objects. The accuracy of the system depends on the distance between the barcode and the camera. It was found that error in estimating position ranged from 2-6 cm when the camera was 190cm away from the object (Lopez de Ipina, et al., 2002). More work is needed to increase the accuracy of these systems. It is likely that sensor fusion will be used, in which different locating systems are used simultaneously to improve the accuracy (Hightower & Borriello, 2001).

Developments in augmented reality and object positioning systems illustrate the possibilities for developing situated cueing methods. However, these systems have not been developed with the objective of supporting people with dementia, and so more work is needed to explore how such technology might be used to guide actions during multi-step tasks. A project has recently been launched with this objective in mind. The project involves the Ambient Kitchen to explore different methods of tracking behaviour and providing situated cues at appropriate times in the task sequence.

2.2 The Ambient Kitchen

The Ambient Kitchen (www.culturelab.ncl.ac.uk) at Newcastle University, UK, has been built to explore how pervasive computing can be used to support activities in the kitchen. This work was initiated by Steve Lindsay who used early versions of Chapter 4 to determine the kinds of prompting and sensing methods that might be necessary for people with dementia.

The technology is integrated into the physical environment, and so it retains the appearance of a conventional kitchen (see Figure 6.1 for a photograph of the kitchen and integrated technology). Elements of the physical environment and appliances are instrumented with sensors and displays to track activities and provide useful information to the person performing the task. Sensors are embedded in the floor, worktop, cupboards, appliances and food containers so that the system is aware of how items are being used. RFID tags attached to objects and food items, with readers embedded in the worktop, allows the system to track movement of items. Accelerometers are also embedded in objects and appliances so that the system can track how they have been manipulated (e.g. tipping) in order to infer actions being performed. Integrated into the worktops are projectors that can provide ambient displays. These are positioned to project information onto the wall, but could potentially be located to deflect light onto objects and cupboards.

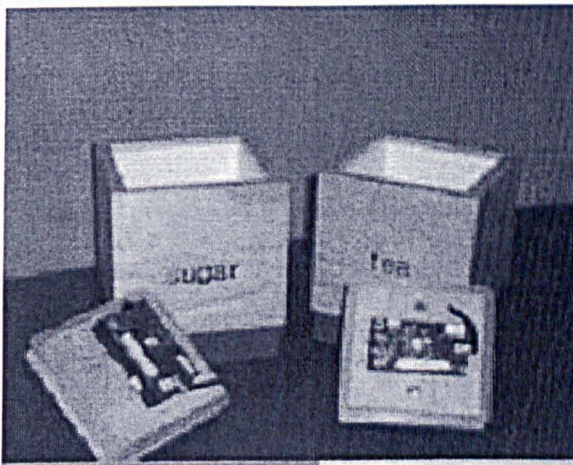
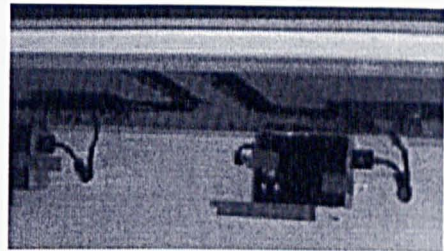
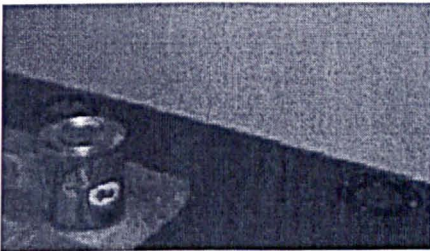


Figure 6.1: Ambient Kitchen technology: The Ambient Kitchen with a recipe projected onto the wall (top); Gap in the worktop for the projected image to pass through (middle-left); Projector underneath the worktop (middle-right); Sensors attached to sugar and tea containers (bottom-left); Kettle with accelerometer attached below the handle (bottom-right).

Photographs taken from the Culture Lab, Newcastle University, UK (www.culturelab.ncl.ac.uk)

By integrating this technology throughout the physical environment, the Ambient Kitchen provides a platform to explore how pervasive technology can be used to resolve problems faced by people with dementia, such as those described in Chapter 4. The setting also allows different methods of activity recognition to be explored, and improve the capabilities of wireless technology in monitoring domestic activity sequences and identifying action errors.

This project shows potential for developing technology that can provide situated assistance for people with dementia. The aim of using a purpose built kitchen is that it allows all possibilities of tracking and support to be explored. Methods found to be effective could then be transferred into real homes.

3. Designing situated prompts for the home

3.1 Syndetic models for interactive systems

In human-computer interaction (HCI) it is useful to describe behaviour as an iterative process, involving the user and the system. Behaviour should be considered as a series of steps in which goals, actions and environments are integrated. An evaluation of the environment leads to a new goal, which then leads to an action. The action results in a change in the environment, which subsequently leads to a new goal, action and so on. Syndetic models provide an integrated description of the user and the system (Duke, Barnard, Duce & May, 1998). This allows aspects of the user and system to be specified so that the compatibility between cognitive resources and device functionality can be explored. Monk (1998, 1999) proposes a 'cyclic' model of interaction that represents actions as a series of 'state-transitions' with regard to the physical environment (external) and the user's goals (internal). Being able to communicate this interaction between user and environment helps designers understand what goals the user must generate to accomplish a task, and what needs to be perceived to formulate these goals. This makes it possible to specify points in the interaction when the environment could lead to inappropriate goals or actions

Ryu and Monk (2005) applied the cyclic interaction framework for evaluating and improving interface design. The method uses a scenario approach to specify how the user should interact with the system and to identify stages in the interaction where information in the environment fails to trigger appropriate goals or actions. The model represents the cyclic interaction between the user and environment at each component step within the task procedure, termed 'interaction units' (IU). The environment part includes 'most recent changes' resulting from the user's actions. It also presents 'other information' in the environment, which includes any aspect of the environment that the user must recognise to accomplish the task. The user part includes the 'current goals' and 'changes to goal' as a result of the state-transitions in the environment. Also represented are the processes through which features of the environment affect changes in the user's goals. These processes include *recognition*, *recall*, and *affordance*. Recognition refers to the user's understanding of the meaning of an object in the environment. Recall refers to the user's memory of a procedure or event, which is necessary if the relevant information cannot be perceived. Affordance refers to the features of objects in the environment that guide the user's expectations of what actions should be performed on them, and what effect these actions will have. Finally, the model describes the user's actions that result from the goals and cognitive processes.

The model makes explicit how goals and actions result from representations in the environment. This is useful for designers of interactive systems as it reveals what assumptions are being made with regard to their existing goals and knowledge of the system. This makes it possible to specify points in the task sequence where the representation of the environment is not compatible with the internal state of the user. The advantage of using a scenario approach also allows designers to think about how alternative designs may affect the user.

This approach is suited to the objective of designing situated supports for people with dementia for two reasons. Firstly it allows researchers to look more closely at the types of problems people with dementia have on everyday tasks and make predictions about the effect of different cueing methods. Second, it can be used to capture the representations of different environments so that prompting systems can be tailored to the needs of the individual users. In the next section we will

demonstrate the applicability of the IU model for these separate phases of designing situated cues for the home.

3.2 Using interaction units to design situated prompts

In this section we will demonstrate the use of IU models in designing situated supports for the home. There are two main parts in the design process in which the IU method should be used. The first relates to the general design of situated prompting systems for people with dementia. Previous work has selected a single prompting method (audio) and then evaluated this method on the whole task sequence (Mihailidis et al., 2004). However, in Chapter 4 we discussed the need to address specific types of problems rather than treat the activity as a whole. This is because real activities involve different types of problems, which require different methods of support. In Chapter 5 we described how naturalistic experiments could be conducted to evaluate a solution to a specific problem (e.g. operating the cooker). In this section we will use this problem as an example to demonstrate how the IU framework can be applied to explore action errors and propose situated prompting methods.

The second phase of design in which IU analysis should be applied is the implementation of prompting systems into real homes. In real contexts people present individual differences with regards to chosen activities, environments and cognitive ability. The IU methodology can capture the representation of any environment, required goals, actions and cognitive processes. This provides a useful way of devising prompting systems that are tailored to the user. We will explore this issue with two different people, JF and FA, who took part in the naturalistic observations described in Chapter 4.

3.2.1 Making predictions about situated cues

Table 6.1 presents the IUs involved in choosing the correct knob when using the original cooker in the experiment described in Chapter 5. Each IU presents the state of the environment, and the user's goals, cognitive processes and actions. Each IU should be read from the left to right. On the left is the state of the environment. This

includes 'most recent changes' that resulted from the previous action, as well as 'other information' relevant to the task that the user can perceive.

The user part includes 'current goals' and 'changes to the current goal'. On the far right are the user's actions, which subsequently cause changes in the environment. The cognitive processes include *recognition*, *recall* and *affordance*, which trigger changes in goal and actions.

Figure 6.2 presents the hotplate and control arrangement on the original cooker design, which uses symbols to associate hotplates and controls. For the purpose of describing the IU model, the figure includes codes to indicate hotplates being referred. For example, the bottom-right hotplate is referred to as *p4*, and the corresponding knob is *k4*.

It can be seen in Table 6.1 that the user has the goal of switching on the hotplate that holds the saucepan. The task starts with saucepan located on the bottom-right hotplate (*p4*). The main goal of the user is to '*turn on p4*'. It can be seen under 'other information' in IU₁ that the four knobs (*k1*, *k2*, *k3*, *k4*) are visible to the user. The user section of IU₁ shows us that they must recognise the knobs (*recognise: k1, k2, k3, k4*). This leads to the new goal to '*find knob for p4*', and subsequently the action of looking at one of the knobs (*k3*).

The next step, IU₂, begins with the user focusing on *k3*. The user section shows us that they recognise the symbol for *k3* as not corresponding to *p1*. This means that there is no change to the current goal, and they perform the action of looking at different knob (*k4*).

In IU₃ the user recognises that the symbol of *k4* corresponds with *p4*. This means that the goal to '*find knob for p4*' is dropped. It can also be seen that the user understands the affordance that turning *k4* will lead to *p4* being switched on. This leads to the action of turning *k4*.

In IU₄ it can be seen in the 'most recent changes' that the red light on the cooker comes on. The user recognises this as indicating that the cooker is on, and so drops the goal to *'switch on pl'*.

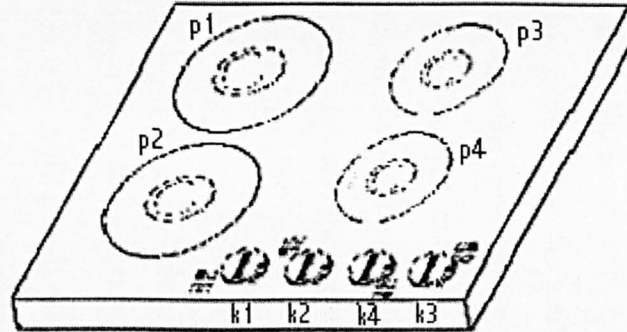


Figure 6.2: Original cooker design

Table 6.1: Interaction units for using the original cooker design

	Environment		User Activity			
			Mental Process			Behavior
	Most Recent Changes	Other Information	Current Goal	Recognition/Recall/Affordance	Change to Current Goal	Action
IU ₀			Switch on p4			
IU ₁	[START] Saucepan on p4	k1, k2, k3, k4 Red light off	Switch on p4	Recognise k1, k2, k3, k4	(+) Find knob for p4	Look at k3.
IU ₂	k3 focus of attention	k1, k2, k3, k4 Red light off	Switch on p4 Find knob for p4	Recognise icon not p4		Look at k4
IU ₃	k4 focus of attention	k1, k2, k3, k4 Red light off	Switch on p4 Find knob for p4	Recognise icon is P4; Affordance turn k4 -> p4 on	(-) Find knob for p4	Turn k4
IU ₄	Red light on	k1, k2, k3, k4	Switch on p4	Recognize p1 on, when red light on.	(-) Switch on p4.	[END]

People with dementia often show problems in selecting the correct control on this task. In Table 6.1, problems in control selection relate to IU₂ and IU₃, in which the designer assumes that the user will recognise the symbols. This means that demand to recognise symbolic cues need to be removed. Table 6.1 is the same model for the verbal condition described in Chapter 5. This condition achieves its advantage because written labels are easier to recognise than symbolic icons.

Table 6.2 presents the model for the light condition, which uses an implicit representation to reduce demand for recognition and elimination of the sub-goal 'find k4'. At IU₁, it can be seen that hotplate (*p4*) lights up when the saucepan is placed onto it. At the same time, the corresponding knob (*k4*) flashes. The user section of the model assumes that the association is immediately perceived through the affordance, and so they do not generate the goal to look for the control. Instead they immediately select the correct control. In the experiment described in Chapter 5, some of the participants responded to this situational trigger. For others the affordance was not strong enough and the presence of the other knobs in the 'other information' triggered this sub-goal.

The control condition described in Chapter 5 was more effective in guiding actions. Table 6.3 presents the IU model for the control condition, in which only one knob was visible. According to IU₁ in this example, the availability of only one knob provided enough affordance to make the association. During the experiment described in Chapter 5, there were two occasions when the participant did not select *k4* under the control condition. Instead they attempted to push down on the areas where the other knobs had been attached to the cooker. These distracting stimuli could be represented as 'other information' within IU model. Increasing the salience of the control, may have increased the affordance and overcome the distracting effect.

Table 6.2: Interaction units for cooker with light cues

	<i>Environment</i>		<i>User Activity</i>			
			<i>Mental Process</i>			<i>Behavior</i>
	Most Recent Changes	Other Information	Current Goal	Recognition/Recall/Affordance	Change to Current Goal	Action
IU ₀			Switch on p with pan on it			
IU ₁	[START] Saucepan on p4 <u>p4 with flashing light and k4 with flashing light; when pan on p4</u>	k1, k2, k3, k4	Switch on p4	Affordance turn k with flashing light -> p with flashing light On.		Turn k4.
IU ₂	k4 with steady light	k1, k2, k3, k4	Switch on p4	Recognize p4 on when k with light steady	(-) Switch on p4.	[END]

Table 6.3: Interaction units for cooker in the control condition (one hotplate and control)

	<i>Environment</i>		<i>User Activity</i>			
			<i>Mental Process</i>			<i>Behavior</i>
	Most Recent Changes	Other Information	Current Goal	Recognition/Recall/Affordance	Change to Current Goal	Action
IU ₀			Switch on p with pan on it			
IU ₁	[START] Saucepan on p4	k4	Switch on p1	Affordance turn k4 -> p4 on		Turn k4.
IU ₂	Red light on		Switch on p1	Recognize p4 on when red light on	(-) Switch on p4.	[END]

The example used here demonstrates how the IU scenarios can be used to think about the types of problems people with dementia experience during everyday tasks, and make predictions about the effect of situational triggers. Representing the interaction between environment, goals and actions allows designers to explore these connections and specify how cues could be integrated at an action level.

Based on the IU analysis it would be possible to test these predictions in naturalistic experiments, such as the one described in Chapter 5. Research settings, such as the Ambient Kitchen, provide a platform to explore how some of the proposed solutions might be developed and augmented into domestic settings.

However, the development of effective prompting systems requires a separate phase in the design process. This involves capturing the activity structure of individual users so that the technology can be implemented appropriately. This is an important phase, as the more information gathered about the user and their environment, the easier it is to retrofit the technology into existing environments and minimise disruption to existing living spaces. The IU framework is suited to this phase of the design, as it provides information about the activity and environment at an action level. This offers the information necessary to transfer technology from the research context into the home setting.

3.2.2 Designing for real homes

A major requirement for prompting systems is the ability to tailor such technology to the users and their environments. Designers must take into account the individual differences with regard to cognitive abilities and tasks chosen to perform. Furthermore, home environments, such as kitchens, include different structures, layouts and appliances. It is therefore, necessary to capture the user's environment and activity structure so that the technology can be augmented appropriately. The IU method of analysis can be conducted in the user's home so that opportunities for situated assistance can be specified at each stage of the task. The scenario approach also allows designers to propose methods of support that can be integrated into the task structure before the system is implemented.

In this section we will use the IU methodology to propose situated supports for two participants, JF and FA, who took part in the naturalistic observations described in Chapter 4. The analysis will focus on the process of boiling water in the kettle. We will first provide an IU model of the activity being performed in the kitchen of JF. The model will be used to propose a situated prompt to address an error she made during the activity. We will then describe the same activity for FA to demonstrate how IU analysis can be used to specify where the demand of the environment can be reduced to minimise the likelihood for error.

In the kitchen of JF: The IU model for using the kettle in the kitchen of JF is presented in Table 6.4. The task begins with the goal to *'boil water'*. It can be seen under 'other information' in IU₁ that the water level is visible when looking at the kettle. This is because there is a transparent section at the side of the kettle. The user generates the goal *'check water level'*, which leads to the action of looking at the transparent window. In IU₂ the user must *'recognise kettle empty'*, to generate the goal to *'fill kettle'*. This leads to the action *'move kettle to under tap'*.

In IU₃ the kettle is being held under the tap. It can be seen that she must recognise that the kettle is closed and understand the affordance that pressing one of the switches (*switch 1*) will open the lid. It can be seen that IU₄ begins with the kettle open. The

user recognises that the tap is off, which triggers the goal to turn it on. It also shows us that the user must understand the affordance that turning the tap will switch it on.

It can be seen in IU₅ that the user recognises the tap is on and that the kettle is becoming full. The user also understands the affordance that turning the tap will switch it off. This leads to them dropping the goal '*turn tap on*'.

In IU₆ the user recognises that the kettle lid is open and understands the affordance that pushing the lid down will close it. In IU₇ the user must recognise the power stand and understand the affordance that placing the kettle onto it will connect it to a power source.

In IU₈ the kettle is located on the power stand. It can be seen in 'other information' that the red light on the kettle is off. The user must recognise the red light as indicating the kettle is off, and generate the goal '*turn kettle on*'. It is assumed that the user understands the affordance that pressing switch 2 will turn the kettle on.

In IU₉ the 'recent changes' indicate that the red light has come on. Upon recognising this, the user drops the goal '*turn on kettle*' and the main goal to '*boil water*'.

Table 6.4: Interaction units for JF using the kettle

	Environment		User Activity			
			Mental Process		Behaviour	
	Most Recent Changes	Other Information	Current Goal	Recognition/Recall/Affordance	Change to Current Goal	Action
IU ₀			Boil water			
IU ₁	[START]	<i>Kettle closed, on power stand, empty; Red light off; Tap off; Switch 1; Switch 2</i>	Boil water	Recognise kettle	+ Check water level	Look at transparent window
IU ₂	Transparent window focus of attention	<i>Kettle closed, on power stand, empty; Red light off; Tap off; Switch 1; Switch 2</i>	Boil water; Check water level	Recognise kettle <u>empty</u>	- Check water level + Fill kettle	Move kettle from power stand to tap
IU ₃	<i>Kettle under tap</i>	<i>Kettle closed, empty; Red light off; Tap off; Power stand available; Switch 1; Switch 2;</i>	Boil water; Fill kettle	Recognise kettle <u>closed</u> ; Affordance: Press <i>switch 1</i> -> kettle <u>open</u>	+ Open lid	Press kettle switch 1
IU ₄	<i>Kettle open</i>	<i>Kettle empty; Red light off; Tap off; Power stand available; Switch 1; Switch 2;</i>	Boil water; Fill kettle; Open lid	Recognise kettle <u>open</u> ; Recognise tap <u>off</u> ; Affordance: turn tap -> tap <u>on</u>	- Open lid + Turn on tap	Turn tap on
IU ₅	<i>Tap on; Kettle full</i>	<i>Kettle open; Red light off; Power stand available; Switch 1; Switch 2;</i>	Boil water; Fill kettle; Turn on tap	Recognise kettle <u>full</u> ; Recognise tap <u>on</u> ; Affordance: turn tap -> tap <u>off</u>	- Turn on tap - Fill kettle	Turn tap off
IU ₆	<i>Tap off</i>	<i>Kettle open, full; Red light, off; Power stand available; Switch 1; Switch 2;</i>	Boil water;	Recognise kettle <u>open</u> ; Affordance: Push down lid -> kettle <u>closed</u>	+ Close lid	Push down lid
IU ₇	<i>Kettle closed</i>	<i>Kettle full; Red light off; Tap off; Power stand available; Switch 1; Switch 2;</i>	Boil water; Close lid	Recognise kettle not on power stand; Affordance kettle <u>on power stand</u> -> connected to power supply	- Close lid + Connect kettle to power	Put kettle on power stand
IU ₈	<i>Kettle on power stand</i>	<i>Kettle closed, full; Red light off; Tap off; Switch 1; Switch 2;</i>	Boil water; Connect kettle to power	Recognise kettle <u>off</u> ; Affordance: Press <i>switch 2</i> -> Kettle <u>on</u>	- Connect kettle to power + Turn kettle on	Press kettle switch 2
IU ₉	<i>Kettle with red light on</i>	<i>Kettle closed, full; Tap off; Switch 1; Switch 2;</i>	Boil water; Turn kettle on	Recognise kettle <u>on</u> ; when red light on	- Turn kettle on - Boil water	[End]

An analysis of this might suggest IUs that are more or less vulnerable to disruption in dementia. IU₂, IU₄, and IU₅ might be well learned, but IU₃ and IU₇ involve novel operations and might well cause problems. This was in fact the case. During the naturalistic observations described in Chapter 4, JF committed an operation error when boiling water in the kettle. After filling the kettle she did not place the kettle onto the power stand, and placed it on the worktop instead. She pressed the switch to turn the kettle on and was confused as to why it did not work. This error relates to IU₇ in Table 6.4. Here it specifies that the user must recognise the power stand and the affordance that placing the kettle onto it would connect it to a power source. This suggests that the salience of the power stand should be increased, and the affordance indicating that the kettle should be placed onto it should be made stronger.

In Table 6.5 we present the same scenario but with a situated cue. An implicit cue is used, much like the novel cue used to support the operation of the cooker in Chapter 5. The cue is integrated into the sequence at IU₃. Here it can be seen under 'most recent changes' that the power stand flashes when the kettle is lifted off it. At the same time, the base of the kettle flashes the same colour. The flashing remains until IU₈ when the user places the kettle back onto the power stand. It can be seen in IU₇ that the flashing power stand and flashing kettle should offer affordance to place the kettle onto the power stand.

6.5 Interaction units for JF using the kettle with situated cues

	<i>Environment</i>		<i>User Activity</i>			
			<i>Mental Process</i>			<i>Behavior</i>
	Most Recent Changes	Other Information	Current Goal	Recognition/Recall/Affordance	Change to Current Goal	Action
IU ₀			Boil water			
IU ₁	[START]	<i>Kettle closed, on power stand, empty; Red light off; Tap off; Switch 1; Switch 2</i>	Boil water	Recognise kettle	+ Check water level	Look at transparent window
IU ₂	Transparent window focus of attention	<i>Kettle closed, on power stand, empty; Red light off; Tap off; Switch 1; Switch 2</i>	Boil water; Check water level	Recognise <i>kettle empty</i>	- Check water level + Fill kettle	Move kettle from power stand to tap
IU ₃	<i>Power stand with light flashing and kettle with light flashing; Kettle under tap</i>	<i>Kettle closed, empty; Red light off; Tap off; Switch 1; Switch 2;</i>	Boil water; Fill kettle	Recognise <i>kettle closed</i> ; Affordance: Press switch 1 -> <i>kettle open</i>	+ Open lid	Press kettle switch 1
IU ₄	<i>Kettle open</i>	<i>Kettle with base flashing, empty; Red light off; Tap off; Power stand flashing; Switch 1; Switch 2;</i>	Boil water; Fill kettle; Open lid	Recognise <i>kettle open</i> ; Recognise <i>tap off</i> ; Affordance: turn <i>tap</i> -> <i>tap on</i>	- Open lid + Turn on tap	Turn tap on
IU ₅	<i>Tap on;</i> <i>Kettle full</i>	<i>Kettle with base flashing, open; Red light off; Power stand flashing; Switch 1; Switch 2;</i>	Boil water; Fill kettle; Turn tap on	Recognise <i>kettle full</i> ; Recognise <i>tap on</i> ; Affordance: turn <i>tap</i> -> <i>tap off</i>	- Turn on tap - Fill kettle	Turn tap off
IU ₆	<i>Tap off</i>	<i>Kettle with base flashing, open, full; Red light off; Power stand flashing; Switch 1; Switch 2;</i>	Boil water;	Recognise <i>kettle open</i> ; Affordance Push down <i>lid</i> -> <i>kettle closed</i>	+ Close lid	Push down lid
IU ₇	<i>Kettle closed</i>	<i>Kettle with base flashing, full; Red light off; Tap off; Power stand flashing; Switch 1; Switch 2;</i>	Boil water; Close lid	Affordance <i>kettle with flashing light on power stand with flashing light</i> -> <i>kettle connected to power supply</i>	- Close lid + Connect kettle to power	Put kettle on power stand
IU ₈	<i>Kettle on power stand; Power stand with light off and kettle with light off</i>	<i>Kettle closed, full; Red light off; Tap off; Switch 1; Switch 2;</i>	Boil water; Connect kettle to power	Recognise <i>kettle off</i> ; Affordance Press <i>switch 2</i> -> <i>Kettle on</i>	- Connect kettle to power + Turn kettle on	Press kettle switch 2
IU ₉	<i>Kettle with red light on</i>	<i>Kettle closed, full; Tap off; Switch 1, Switch 2</i>	Boil water: Turn kettle on	Recognise <i>kettle on</i> ; when red light on	- Turn kettle on - Boil water	[End]

In the kitchen of FA: The IU model for the same activity with a different participant (FA) is presented in Table 6.6. The IU model is almost the same as the one previously described. However, there are subtle differences in task demand. For example, in IU₁ of Table 6.6, the water level is not presented in the 'other information'. This is because there is no transparent window at the side of the kettle. In IU₂, the user is required to open the kettle in order to check the water level. Similarly, in Table 6.5 it can be seen that the user must distinguish between two separate switches (one for the lid and one for the power) where as in Table 6.6 only one switch is present (for the power).

Although FA did not have any difficulty operating the kettle, the IU model allows designers to specify where there are weak connections between the state of the environment and user's goals. For example, in IU₇ of Table 6.6 the user must switch the kettle on. The goal '*switch kettle on*' is generated in the absence of any situational trigger in the 'recent changes' of the environment. Instead, the only information available is the '*red light off*' in the 'other information'. A more salient cue could be integrated into the 'recent changes' part of IU₇. In Table 6.7 a cue is integrated in the task at IU₇, in which the switch flashes once the kettle has been placed back onto the power stand. This provides a salient cue at the time when the action is required.

Table 6.6: Interaction units for FA using the kettle

	Environment		User Activity			
			Mental Process			Behavior
	Most Recent Changes	Other Information	Current Goal	Recognition/Recall/Affordance	Change to Current Goal	Action
IU ₀			Boil water			
IU ₁	[START]	<i>Kettle closed, on power stand; Red light off; Tap off; Switch;</i>	Boil water	Recognise <i>kettle closed</i> ; Affordance: Lift lid -> <i>kettle open</i>	+ Check water level + Open lid	Lift lid
IU ₂	<i>Kettle open</i>	<i>Kettle empty; Red light off; Tap off; Power stand available; Switch;</i>	Boil water; Check water level; Open lid	Recognise kettle open Recognise <i>kettle empty</i> ; Recognise <i>tap</i>	- Check water level - Open lid + Fill kettle	Move kettle to tap
IU ₃	<i>Kettle under tap</i>	<i>Kettle empty; Red light off; Tap off; Power stand available; Lid available; Switch;</i>	Boil water; Fill kettle	Recognise <i>tap off</i> ; Affordance: turn <i>tap</i> -> <i>tap on</i>	+ Turn on tap	Turn tap on
IU ₄	<i>Tap on;</i> <i>Kettle full</i>	<i>Kettle open; Red light off; Power stand available; Lid available; Switch;</i>	Boil water; Fill kettle; Turn tap on	Recognise <i>kettle full</i> ; Recognise <i>tap on</i> ; Affordance: turn <i>tap</i> -> <i>tap off</i>	- Turn on tap - Fill kettle	Turn tap off
IU ₅	<i>Tap off</i>	<i>Kettle open, full; Red light off; Power stand available; Lid available; Switch;</i>	Boil water	Recognise <i>kettle open</i> ; Affordance place <i>lid</i> on <i>kettle</i> -> <i>lid closed</i>	+ Close lid	Place lid on kettle
IU ₆	<i>Kettle closed</i>	<i>Red light off; Tap off; Power stand available; Switch;</i>	Boil water; Close lid	Recognise <i>kettle power stand</i> ; Affordance <i>kettle on power stand</i> -> <i>kettle connected to power</i>	- Close lid + Connect kettle to power	Put kettle on power stand
IU ₇	<i>Kettle on power stand</i>	<i>Kettle closed; Red light off; Tap off; Switch;</i>	Boil water; Connect kettle to power	Recognise <i>kettle off</i> ; when <i>red light off</i> Affordance: Press <i>switch</i> -> <i>kettle on</i>	- Connect kettle to power + Turn kettle on	Press kettle switch
IU ₈	<i>Kettle with red light on</i>	<i>Kettle closed; Tap off; Switch;</i>	Boil water; Turn kettle on	Recognise <i>kettle on</i> ; when <i>red light on</i>	- Turn kettle on - Boil water	[End]

Table 6.7: Interaction units for FA using the kettle with situated cues

	Environment		User Activity			
			Mental Process			Behavior
	Most Recent Changes	Other Information	Current Goal	Recognition/Recall/Affordance	Change to Current Goal	Action
IU ₀			Boil water			
IU ₁	[START]	Kettle closed, on power stand; Red light off; Tap off; Switch;	Boil water	Recognise kettle closed; Affordance: Lift lid -> kettle open	+ Check water level + Open lid	Lift lid
IU ₂	Kettle open	Kettle empty; Red light off; Tap off; Power stand available; Switch;	Boil water; Check water level; Open lid	Recognise kettle open Recognise kettle empty; Recognise tap	- Check water level - Open lid + Fill kettle	Move kettle to tap
IU ₃	Kettle under tap	Kettle empty; Red light off; Tap off; Power stand available; Lid available; Switch;	Boil water; Fill kettle	Recognise tap off; Affordance: turn tap -> tap on	+ Turn on tap	Turn tap on
IU ₄	Tap on; Kettle full	Kettle open; Red light off; Power stand available; Lid available; Switch;	Boil water; Fill kettle; Turn tap on	Recognise kettle full; Recognise tap on; Affordance: turn tap -> tap off	- Turn on tap - Fill kettle	Turn tap off
IU ₅	Tap off	Kettle open, full; Red light off; Power stand available; Lid available; Switch;	Boil water	Recognise kettle open; Affordance place lid on kettle -> lid closed	+ Close lid	Place lid on kettle
IU ₆	Kettle closed	Red light off; Tap off; Power stand available Switch	Boil water; Close lid	Recognise kettle power stand; Affordance: kettle on power stand -> kettle connected to power	- Close lid + Connect kettle to power	Put kettle on power stand
IU ₇	Kettle on power stand; Kettle with switch light flashing	Kettle closed, Red light off Tap off.	Boil water; Connect kettle to power	Recognise kettle off; when red light off Affordance: Press switch with light flashing -> kettle on	- Connect kettle to power + Turn kettle on	Press kettle switch
IU ₈	Kettle with switch light still Kettle with red light on	Kettle closed; Tap off.	Boil water: Turn kettle on	Recognise kettle on; when red light on	- Turn kettle on - Boil water	[End]

These examples demonstrate how IU models can be used to design situated supports that match the needs of the users in domestic settings. Breaking action sequences into component steps allow designers to specify points where situated cues are required to transform the cognitive demand of the task. The example scenario used (boiling water in a kettle) is only a short section of an everyday task. However, it is still possible to identify moments in the task where situated supports could be implemented to guide the user. Comparisons between JF and FA also highlight subtle differences that could affect task performance.

3.2.3 Comparing the IU model and the ACS transcription method

In Chapter 4 we described a method of transcribing video material, which was based on the action coding system (ACS) devised by Schwartz et al. (1991). The method used a semi-formal notation to represent each action component. The action components were defined by a change in the state of the environment, and included four types of person-environment interaction: ALTER, MOVE, TAKE and GIVE. ALTER refers to changes in the state of an object of environment (e.g. ALTER cupboard to open), MOVE refers to changes in location of objects (e.g. MOVE cup from cupboard to worktop), TAKE refers to the obtaining of an object (e.g. TAKE kettle from power stand) and GIVE refers to the relinquishing of an item (e.g. GIVE spoon to worktop). This transcription method was useful for breaking down activity sequences into component steps in order to specify points in the task where the participants experienced problems. The purpose of the transcription was to identify and classify action errors. The analysis of transcripts was conducted in conjunction with video recordings, and so details about the environment were not necessary.

However, for the purpose of designing situated cues it is necessary to capture changes in the environment, and how these might interact with the person's goals and cognitive processes. The IU model allows designers to think about situated cues that would alter the representation of the environment to reduce cognitive demand and support the generation of appropriate goals.

The ACS was used to describe what participants actually did. In contrast, the IU method is used to describe what the person is required to do. For this reason the detail

in the action part of the transcription is slightly different. For example, in Chapter 4 transcription was restricted to interactions with the environment (ALTER, MOVE, TAKE and GIVE). It did not include other information such as '*look at control*'. This type of information was not possible to capture from the videos, although other studies have used eye tracking methods to study focuses of attention in healthy adults during everyday activities (Land, Mennie & Rusted, 1999). Furthermore, such information was not necessary to establish whether an action error had been committed. However, we know that this action is necessary when operating the cooker, and so for the purposes of design it is included in the IU model.

Another difference is the type of language used to describe the actions. The semi-formal notation used in the ACS was used to avoid conventional language. The four action types meant that transcription included each action component. However, it was not necessary to record the manner in which each action component was achieved. The outcome was the information required to record an error. For example, the notation 'ALTER kettle to open' was sufficient in documenting whether a required action had been achieved. For the purposes of designing situated cues, more detail is required regarding these actions. For example, 'lift kettle lid' may require a different type of cue than 'press switch' to activate the lid.

The ACS is an effective method for documenting action components for the purpose of identifying and classifying action errors that prevent task performance. In Chapter 4 an adapted version of this method was used to understand action errors. It was a useful approach for recording what participants actually did during kitchen tasks and identifying problems during the task sequence. Future research should use this method to explore error types for other activities in the home. The IU framework is instrumental in proposing solutions to such problems. This method describes what actions and processes are required to accomplish an activity, and how these relate to cues and representations in the environment. It provides a method for proposing situated supports and how they could be successfully integrated into an activity.

4. Conclusion

This chapter has described current work that is relevant to the development of situated prompting systems. An important part of the design process is the building of such technology. Recent developments in pervasive computing are compatible with the requirement for situated cues. Developments in augmented reality and object positioning show potential for the development of prompting systems capable of compensating for problems in attentional control, orientation and object recognition. More work is needed to develop such systems specifically for people with dementia, and explore how situated cues could be retrofitted into existing living spaces. The Ambient Kitchen project is addressing these issues.

Another part of the design process is the development of cueing methods, and the implementation of such methods into real homes. In Chapter 4 we highlighted the need to design prompts for specific aspects of the task sequence, rather than treating the activity as a whole. The IU framework is well suited to this approach. The method of analysis captures interactions between the user's environment, goals and actions at each step in the task. This information is necessary for the designing and implementation of situated cues for everyday activities. This chapter has applied the framework to a specific step in an activity. Future work should apply the IU framework to other procedures in domestic settings and make predictions about appropriate methods of support.

Chapter seven

Summary and conclusions

1. Introduction

The aim of the thesis was to explore the design requirements for technology to support people with mild to moderate dementia in their own homes. It was proposed that a bottom-up approach should be taken to understand the problems being addressed in accordance with cognitive theory. This chapter will first summarise the thesis and discuss the implications of the outcomes for design. The methodological contributions will then be discussed, focusing on the bottom-up approach and the use of natural contexts. Finally the requirements for technology to support people with dementia and future research directions will be presented.

2. Thesis Summary

Chapter 1 described existing literature on the cognitive deficits of dementia. Studies have shown that the most profound impairments in mild to moderate dementia occur in episodic memory (memory of experienced events) and executive function processes necessary for planning, sequencing and attentional control. As the severity of the cognitive impairment progresses, the person with dementia loses the ability to carryout everyday tasks. The literature has demonstrated how the impact of dementia can be reduced using rehabilitative and compensatory strategies. One approach is to use cognitive prostheses to bypass demand on the impaired processes, and exploit preserved functions. Such strategies have been used to support memory, orientation, communication and execution of multi-step tasks. Advances in pervasive computing provide further opportunities to guide users through everyday tasks independently. Although research has shown developments in technological capabilities, little work has been done to understand how such technology should be designed for people with dementia.

In Chapters 2 and 3 the thesis explored areas of daily living that should be addressed. Chapter 2 provides the professional perspective, which includes three main themes. The core theme, 'problems in the home', highlights areas of daily living that need to be addressed. The second theme, 'underlying deficits', describes the perceived causes of these problems that need to be overcome. The third theme describes the 'consequences' of these problems, which indicates what the technology should aim to achieve. In Chapter 3, home visits were conducted with persons with dementia and informal caregivers. This provided further insight into the nature of the problems, and highlighted more subtle aspects of daily living that should be supported. In addition, it provided an account of 'situated factors', which refers to aspects of the environment or situation that effect abilities to perform everyday tasks. This provided further insight into how people with dementia respond to their local environment, which has important implications for how technology should be designed to support them.

Chapter 4 focused on a specific area of daily living (kitchen tasks) to identify the types of problems that prompting system would need to address. People with mild to moderate dementia were video recorded performing activities of their choice in their own kitchens. A grounded approach to the analysis revealed eight error types, which were described under four main themes: Sequencing (intrusion, omission and repetition), orientation (locating and identifying), operation of appliances, and incoherence (toying and inactivity). Drawing from cognitive theory, it was concluded that explicit cues were not sufficient in compensating for the deficits of dementia. Prompting systems would require situated cues that can draw the person's attention to objects and locations in the environment. This would overcome deficits in attentional control, orientation and object recognition.

Chapter 5 presented an experiment embedded in a real activity. The study explored the issue of familiarity, in which a novel situated cue was provided to assist people with dementia when using a cooker. The experiment required participants to carry out a cooking task with the help of a care worker. At certain points in the task they were required to select the control that switched on/off a specific hotplate. Scores were compared across three methods of representing the association between

controls and hotplates. These were original (symbols), verbal (written words) and lights (hotplate and correct control light up). A control condition (one control and one hotplate) showed that all participants understood the task. Although the difference was not significant, we were encouraged to see that the novel light condition scores were higher, or equal to, the original cooker design.

Chapter 6 presented possible future steps towards designing situated supports for people with dementia. Research has shown that the technological capabilities match the requirements for situated methods of assistance. The applicability of an HCI framework, interaction unit (IU) analysis, for designing situated prompts was also presented.

3. Methodology

3.1 A bottom-up approach

In order to design effective interventions it is necessary to understand the problems being addressed. The literature has demonstrated the technological possibilities for supporting people with dementia. However, less work has been done to establish what areas of daily living require support and the nature of the problems to be addressed. The thesis presents a bottom-up approach to establish design requirements. In Chapters 2 and 3 we described the perspectives of professional carers, family caregivers and people with dementia. This highlighted areas of daily living where research efforts should be directed. The interviews were semi-structured and analysed using grounded theory analysis (GTA), according to Strauss and Corbin (1990). This allowed for the emergence of themes that were not influenced by existing assumptions about what activities should be supported. The value of this approach is reflected in the subtle differences between the professional carer perspective and the patient-caregiver perspective. For example, the people with dementia and their caregivers talked about issues that are not directly related to independence (e.g. watching television and ‘filling time’). Furthermore, the method allowed the emergence of themes that were not considered before the study, such as

the impact of dementia on the family caregiver. These outcomes highlight the need to involve the users at the early stages of the design process.

When designing a prompting system it is necessary to understand the nature of the problems being addressed and how these relate to cognitive theory. Existing prototypes have taken a top-down approach to design, which overlooks how the cognitive deficits of dementia disrupt task performance in real settings. Current designs use an explicit cueing method (e.g. audio or video) to guide the user through the sub-goals of a whole task sequence. In Chapter 4, we conducted observation of people with dementia performing activities in their own kitchens. The analysis highlighted that different aspects of the task present different types of problems, which would require different methods of support. Therefore, designers of prompting systems should not treat an activity as a whole, but should design cueing methods for specific problems. Furthermore, describing the problems in accordance with cognitive theory revealed the need to provide situated cues, as well as explicit prompts, to support people with dementia through multi-step tasks. This illustrates the need to understand the problems in accordance with cognitive theory before considering technological solutions.

3.2 Using real contexts

As the aim of the thesis was to explore requirements for technology in the home, it was important that the problems of dementia were understood in real contexts. In Chapter 3, we described home visits conducted with people with dementia and their caregivers. Interviews were conducted in their own homes, which provided a context to understand the day-to-day experiences of our informants. It also provided insight into the role of the environment. This led to the emergence of 'situated factors' theme, to better understand the role of the environment or situation when performing daily tasks.

In Chapter 4, naturalistic observations were conducted in the participants' own kitchens, and on tasks that they chose to carryout. This provided insight into the types of problems that occur in real situations. The findings confirmed previous work conducted in more controlled settings. The method also allowed the emergence

of new error types that need to be addressed, including problems of orientation and operation of appliances.

In Chapter 5, an experiment was embedded in a real activity. People with moderate dementia were required to operate a stove during real cooking tasks (making porridge with syrup and chocolate cornflake cakes). The experiment was designed to provide insight into how people with dementia respond to novel cues during real activities. The procedure included an activity script for both tasks. The care worker followed this script and assisted the participant until the critical point of operating the cooker. Providing assistance in this way allowed greater control over task demand, but also retained a natural context that was meaningful to the participant. Furthermore, as the operation of the cooker was the only step to be performed independently, the experiment allowed for people with different levels of ability to participate. The purpose of using a semi-natural context was so that the task was fun and engaging for the participant so that they would not become anxious, confused or agitated. It also meant that performance reflected that of real situations. It was found that participants responded well to this procedure, and so a future work should take a similar approach to evaluating the efficacy of situated cues.

4. Requirements for technology

4.1. Opportunities for technological support

In Chapter 1 we presented existing literature on the development of technology for people with mild to moderate dementia. The review highlighted the broad possibilities for support, including reminders, communication aids and prompting systems for multi-step tasks. This thesis focused on the design of prompting systems for multi-step task. Developments in this area are important as such technology would reduce social dependence for instrumental activities, such as washing or preparing meals. However, improving functional status is just one area of daily living where technology could help, and so it is important to point out other opportunities for technology. In Chapters 2 and 3 we broadly described other ways in

which technology could provide support. Table 7.1 lists some technological opportunities beyond the supporting of actions steps through instrumental tasks.

Table 7.1: Technological opportunities to support people with dementia in the home

Opportunities	Description
Domestic tasks	In Chapter 3, people with dementia and informal caregivers highlighted the importance of being able to perform domestic tasks (such as ironing and cleaning the house). Although such activities do not have a direct impact on physical wellbeing, they play an important part in maintaining a sense of continuity and self-identity. Failure to engage in such tasks also contributes to a sense of boredom during the day.
Engagement in leisure	In Chapter 3, people with dementia and informal caregivers reported that a lack of motivation is the major barrier for engagement in recreational activities. Technology should not only support instrumental tasks, but should also provide opportunities for fun and entertainment at home. Games that require mental and physical effort could provide users with a sense of achievement and progress.
Social interaction	In Chapters 2 and 3, our informants described the strain placed on the relationship between the person with dementia and the informal caregiver. Problems in communication contributed to sense of frustration and confrontation. Designers should consider how technology could be designed to support face to face interaction with family and friends in the home setting.
Reassurance	In Chapter 3, we described how people with dementia experience distress and anxiety due to disorientation (e.g. what time people are visiting, when will their spouse be home). This disorientation also caused problems for the caregiver as the person with dementia would continually ask questions. More work should be done to provide a means for people with dementia to access information to reduce anxiety.
Retrospective memory	Many reminder devices have been designed to cue action at a specific time (e.g. to take medication). In Chapter 2 and 3 it was highlighted that people with dementia also forget what has been performed. In order to reduce confusion for people with dementia, designers should explore how memory aids could also be designed to support retrospective memory.
Caregiver respite	In Chapter 2 and 3 it was emphasised that dementia can severely restrict the lives of the caregiver. The need to provide constant supervision means that they get little time

	to themselves, and rarely get the chance to leave the house. Designers should explore how communication or monitoring technology could be developed to provide greater freedom to the caregiver. Work is needed to explore how this technology could be used without compromising the privacy or personal space of the person with dementia.
Prevent wandering	Chapters 2 and 3 highlighted the point that people with dementia wander from the house for different reason. This includes not knowing the time, not recognising the house, or thinking that they have a specific thing to do (e.g. go to work). This means that there will not be a single solution to preventing wandering behaviour. Prompts should be designed to orientate them (e.g. what time it is, that they are at home), as well as discourage them from leaving the house at inappropriate times (e.g. at night).

4.2 Designing effective prompting systems

Existing prototypes have demonstrated the technological capabilities of tracking actions during everyday tasks and providing prompts at correct times in the sequence. Despite these developments little work has been done to compare different methods of prompting people with dementia. To date, such prototypes assume that an explicit method of prompting is sufficient for people with dementia. The COACH (Cognitive Orthosis for Assisting Activities in the Home) system developed by Mihailidis et al. (2004) used audio prompts to instruct users when they miss an action when washing their hands. Similarly, Dishman (2004) describes a prototype that uses video clips and audio instructions of required action steps when making a cup of tea. This thesis identified key requirements for these systems that need to be included in order to support people with dementia in their own homes. These are summarised in Table 7.2.

Table 7.2: Key requirements for prompting systems

Requirement	Description
Situated cues	<p>Visual cues should be provided to direct the user's attention to task relevant objects and locations. This will overcome problems in attentional control, orientation and object recognition. As discussed in Chapter 4, explicit cues alone (e.g. audio and video recordings) would not be sufficient for people with dementia in real settings. In Chapter 6 we described existing methods of ambient cueing. This includes the use of light projections and LEDs attached to objects. Using these cues in conjunction with audio prompts would help address problems in sequencing, orientation, operation and incoherence.</p>
Affordance	<p>Designers should not be constrained by the need for familiarity. Instead work should be done to establish how novel cues could be designed so that they minimise demand for conceptual knowledge and attentional control. In Chapter 5 we demonstrated the potential for using a completely novel cueing method to support people with moderate dementia when using the cooker.</p>
Design for components steps	<p>The existing prototypes for prompting multi-step tasks treat the activity sequence as a whole. A single method of cueing is chosen, and then evaluated across the whole tasks sequence. In Chapter 4, we found that people with dementia show different types of problems, which would require different methods of support. This means that prompting systems should be designed for specific task components (e.g. operating the cooker, finding a stored item). Chapter 5 demonstrated how cueing methods for a specific action (operating the cooker) could be evaluated in a semi-natural context. A similar approach could be used for other task components.</p>
Tailored to users	<p>People with dementia show individual difference with regard to abilities, environments and activities chosen to perform. It must be possible to design prompting systems that can be augmented into existing routines and living spaces. In Chapter 6 we demonstrated how IU analysis could be applied to guide the implementation of situated prompting systems in real settings.</p>

5. Future work

5.1 Designing cues for different error types

In Chapter 4, we presented the types of problems people with dementia face when performing activities in the kitchen. In Chapter 5 we described a naturalistic experiment that evaluated the efficacy of a novel cueing method to address one of the problems (operating the cooker). A similar approach should be used to evaluate cueing methods for other errors types described in Chapter 4. For example, work is needed to establish how situated cues could be designed to support orientation. This problem included difficulties in locating concealed objects (e.g. stored in a cupboard) as well as items located on the worktop. A naturalistic experiment, such as that described in Chapter 5, could be used to test the effect of visual cues to support orientation. This would require the participant to obtain an object at a certain point in the task sequence. The novel cueing method should be designed to direct their attention to the relevant item using light projections or LEDs.

Other error types included sequencing (initiation, repetition and omission) and incoherence (toying and inactivity). In order to address these problems explicit prompts (e.g. audio) would be needed to indicate the required sub-goal. Future work should be conducted to explore how the efficacy of these verbal prompts could be improved with the addition of situational triggers. For example, when prompted to perform an action, the relevant object could be illuminated in order to direct the person's attention.

Such work will provide further insight into how situational cues could be developed to assist people with dementia at different stages of a task. The overall aim should be to establish visual representations that are most effective for people with dementia. However, further work will be needed to establish a methodology for transferring such technology into real home settings.

5.2 Transferring technology into the home

Methods of augmenting situated cues and tracking technology into domestic setting could be explored in a lab, such as the Ambient Kitchen described in Chapter 6. However, research is also needed to develop a methodology for transferring such technology into real homes. This thesis points out the need to tailor technology to the match the individual's ability, chosen activities and environment. In Chapter 6 we demonstrated how IU analysis could be used to capture the state of the user and environment at different stages of the task sequence in order to integrate situated supports. Future work should use this framework as a tool for predicting how technology might be retrofitted into real living spaces. In order to further develop this methodology it would best to work with individual cases and evaluate the effect of the installed technology on functional ability on their chosen task.

5.3 Addressing problems outside kitchen

This thesis has focused on supporting people with dementia in the kitchen. Future work should explore how prompting systems should be designed for activities beyond this context. In Chapters 2 and 3, our informants highlighted other activities that are important to support. This included daily activities (e.g. washing and dressing), as well as domestic tasks (washing-up and ironing). Naturalistic observations should be conducted to identify the types of problems faced by people with dementia when performing these tasks. In Chapter 4 we described an observational method for identifying error types during kitchen tasks. A similar approach should be taken for the other activities of daily living. These observations should be conducted in the participants' own home settings, and should include items and tasks that are relevant to them. Such work may reveal additional errors that were not evident in the kitchen setting. For example, orientation and fastening of clothing items may present new challenges for designing technological supports.

6. Conclusion

The outcomes of the thesis have emerged from a bottom-up approach to design, in which the problems of dementia were explored before considering technological solutions. This process included the involvement of users at the earliest stage so that the technology being designed would be useful and appropriate. This phase provided a broad insight into the problems of dementia in the home and highlighted opportunities for technology. The bottom-up approach also required existing cognitive theory in order to understand the problems and propose effective strategies of support. This allowed conclusions to be drawn about the design requirements for prompting systems in real settings.

Future work should further explore how situated cues could be designed to be compatible with the cognitive capabilities of people with dementia. These studies should focus on the component parts of the task sequence, rather than addressing the activity as a whole. Further work should also be conducted to develop a methodology for transferring such technology into real living spaces. The IU framework is suited to this approach as it captures the interactions between the user's environment, goals and actions at each stage in the sequence.

This thesis demonstrates the need to ground the design an understanding of the real problems and how these relate to cognitive theory. This process is necessary for the development of technology that is capable of enabling people with dementia to live at home for longer.

Appendices

Appendix A: Professional carer semi-structured interview

Living with a carer in own home

- (i) What ADLs do person with dementia need most help with?
- (ii) What problems are hardest for carers to help with?
- (iii) What problems are most expensive?
- (iv) Examples of incidences

Living Alone

- (i) What ADLs do present most problems with?
- (ii) What problems most likely to prevent them living independently?
- (iii) Examples of incidents leading to being classified “at risk” – perhaps being forced to leave their homes.

Informal caregivers

- (i) What ADLs are important for them to support?
- (ii) What ADLs do they find hardest to support?

Formal care givers

- (i) What ADLs are important for them to support
- (ii) What ADLs do they find hardest to support?

Clients

- (i) What ADLs would be important for them to achieve
- (ii) What particular ADLs do people with dementia find most difficult to achieve independently?

Move from home to care home

- (i) What usually triggers this?
- (ii) What effect does moving to a care home have on the person with dementia?
- (iii) Could people stay longer?
- (iv) Should they?
- (v) What barriers prevent them from staying longer?

Appendix B: Information sheets and consent forms for home visits

Information for participants in their home

We would very much like you to help us with our research. This will involve talking to us about your day-to-day activities around the home. The information you give us will help us to invent new ways that technology can help people to live independently in their homes. This sheet is for you to read before you decide to take part. It explains a bit more about what we are doing. Please ask if there is anything which is unclear or if you need more information.

Why we are talking to you, and other people like you? We are trying to invent new ways that technology can help people who have memory problems in the home. For this reason, we need to know about your experiences and opinions. We are talking to people in the York area and Katie Barker (Head Occupational Therapist at Peppermill Court, York) is sending these invitations out to those who may be interested in taking part.

Do you have to take part? No, not if you don't want to. If you do agree to take part, you will be asked to sign a consent form. If you feel that you no longer wish to take part at anytime after signing the form just say so and we will stop and destroy all records of what you have said. Taking part is entirely voluntary and your decision not to take part, or to withdraw at any time, will not affect the standard of care you receive.

What will you be asked to do? The researcher would like to talk with you, at your home, on two separate days. The two visits will be about one week apart. Each visit will last for about 1 hour during which he will ask you about your day-to-day activities in the home. You are free to talk about issues that are important to you, and will not be expected to provide any information that you do not wish to.

Visit 1: You will be asked to show the researcher around some of the rooms in your home, and to talk about the things you do there and the types of problems that occur. If there are any rooms you are not comfortable showing us that is fine. A note pad will also be left for you to record any other issues you think of during the week.

Visit 2: The researcher will visit to talk further about the issues that came up in the previous interview. This may include video recording you carrying out one of the daily tasks mentioned in the first interview. Please note that you are not obliged to carry out the video recording session, and are free to miss out this section of the visit if you wish.

Who is carrying out the research? The interviewer is Joe Wherton. Joe is a Psychology PhD student at the University of York. His research is focusing on the design of household technology to support memory. Joe's work is being supervised by Prof. Andrew Monk, at the University of York.

How will you benefit from this study? You will not benefit directly from the findings of the study, though we hope that future generations will do. We acknowledge the major contribution that your information will provide. For this reason, we would like you to accept a £20 Marks and Spencer gift voucher.

Will anyone else be told what was said during the interview? No, everything discussed will be confidential. Participants' names will not be used when recording the interview or when writing the project. The researchers will not discuss what participants said with anyone else. Although the interviews will be recorded, all information will be stored anonymously. No one apart from Joe and the OT will know what you said.

What happens next? If you are interested in taking part, sign the consent form and we can arrange a convenient time for me to visit. Remember, signing the form does not commit you to taking part. If you change your mind at anytime, you are free to withdraw.

Consent form for home visits

- Q1) Have you read the information sheet for 'participants in their home'?
Yes No
- Q2) Do you understand what the project will involve?.....
Yes No
- Q3) Do you understand that you can change you mind about talking to me at
anytime?

Yes No
- Q4) Do you understand that everything will be kept confidentially?
.....
Yes No
- Q5) Do you want to take part in the project?
Yes No
- Q6) Is it okay by you if I tape-record the interview?.....
Yes No

Appendix C: Home-visit semi-structured interview

Daily routines

- (i) What does the caregiver do for the person with dementia?
- (ii) What does person with dementia do independently?
- (iii) What do the caregiver and person with dementia do together?
- (iv) What activities are important for the person with dementia to do themselves?

Problem tasks

- (i) What tasks are difficult for the people with dementia to do independently?
- (ii) Can you think of any reoccurring or ongoing problems?
- (iii) Can you think of any specific incidences?
- (iv) What tasks/activities do you think would be most important to support?
- (v) What household appliances are problematic?
- (vi) What are your concerns for the consequences of these problems?

Appendix D: Information sheet and consent forms for video analysis

Information for Participants in Their Home: Visit 3

Thank you for taking part in the first meeting. We would like to visit again in about one week's time. At that time, we would also like to video record you doing a household task that was mentioned in the first interview. This sheet will explain what the filming will involve. After reading the information, if you are willing to be video recorded, please sign the consent form attached to this sheet.

Why are we filming you? The filming will be very useful in understanding how you carryout day-to-day activities in the home.

What will you need to do? The researcher will identify tasks to perform that arose from the previous interview. You can choose to do one or more of these tasks. However, if there is a task you would prefer to do, which is not on the list, you can choose to do that instead. When the camera is set up, we would like you to carryout the task as you would on any other day.

Using the Video Recording at Conferences It would be useful if the video recording could be used to present the findings at research conferences. However, this will not be done without gaining your consent before hand. You do not have to decide at this stage whether you are willing for the recording to be used at a conference. If at some time in the future, we wish to use it as part of a conference presentation, we will contact you and ask for your consent.

What happens next? If you would like to be filmed doing a task, please sign the consent form attached to this sheet. Joe will collect it on arrival. Signing the consent

form does not commit you to filming. If you change your mind at any time, you are free to withdraw. Taking part in the filming is entirely voluntary. Your decision not to take part, or to withdraw at any time, will not affect the standard of care you receive.

Consent form for video recording

- Q1) Have you read the information sheet for 'Visit 3'?.....
Yes No
- Q2) Do you understand what the video recording will involve?
Yes No
- Q3) Do you understand that you can change you mind about being filmed at any
time?.....
Yes No
- Q4) Can we video record you doing a task during visit 3?.....
Yes No
- Q5) Can we use the video recording for conference presentations?.....
Yes No

Appendix E: Error incidences during kitchen tasks

Classification	Case	Activity	Description	
Sequencing <i>Intrusion</i>	FA	Cup of coffee	She opens the cupboard where the coffee is stored, but she takes the drinking chocolate instead of the coffee.	
	JF	Cup of tea	She repeatedly asks whether she needs to use the coffee, which is located next to the teabags on the worktop.	
	JF	Bowl of soup	She puts the soup from the container into the bowl, and then goes to place the bowl on top of the toaster to heat it up	
	PL	Bowl of soup	When instructed to make a bowl of soup, he opens one of the cupboards and gets out the teabag container, he opens the container and takes out a teabag	
	PL	Bowl of soup	The saucepan and soup are located on the worktop. When cued to put the soup into the saucepan, he picks up a teabag (also located on the worktop) and tears it open. He then goes to pour the content of the teabag into the saucepan.	
	PL	Cup of tea	The teabag is located on the worktop next to the cup. When cued to put the teabag into the cup, he picks up the teabag and tears it open. He then pours the content of the teabag into the cup.	
	RG	Cup of tea	The kettle was boiled, and the researcher cued her to get a cup. She opened one of the cupboards, which contained the coffee, teabags, and sugar. She took the coffee jar instead of getting the teabags (or cups).	
	RG	Cup of tea	She was cued to get the teabags out of the cupboard, which was already open. She took out the coffee jar instead of the teabags.	
	<i>Omission</i>	TM	Tea with toast	He had two cups in front of him. He boiled the water in the kettle and put coffee granules into one cup, and put a teabag into the teapot. He then added the hot water and milk to both cups. He did not add hot water to the teapot, and so one cup contained only hot water and milk.
		DA	Beans on toast	He heats the beans on the cooker, and then takes the saucepan away from the (gas) cooker. He does not turn off the burner on the cooker. He then gets a plate and places it on the burner that is left on. He then goes to serve the beans on the plate, but the researcher first intervenes by telling him to turn the cooker off.
FA		Beans on toast	She makes the toast, and serves it on a plate. She then indicates that she has finished. The researcher reminds her that she needs to make the beans.	
FA		Cup of coffee	She puts the coffee granules into a cup. She picks up the kettle from the power stand and goes to add the water to the cup. The researcher cues her to boil the water	
RG		Cup of tea	She mashes the tea, and then picks it up and sips it without actually removing the teabag or adding milk.	
<i>Repetition</i>	PL	Bowl of soup	After heating the soup, he was instructed to get a bowl to serve it, but he repeated the action of getting a saucepan from the rack.	
	PL	Bowl of soup	After heating the soup and turning off the cooker, he was cued to serve the soup in the bowl located on the worktop. He went over to the cooker, leaving the bowl at the other end of the kitchen, and repeated the action of heating the soup by switching the cooker on.	
	PL	Bowl of soup	After heating the soup for a second time, he was cued to put the soup into the bowls. He took the bowls closer the saucepan but then repeated the action of heating the soup again.	
	PL	Cup of tea	He had boiled the water in the kettle. After putting the teabag into the cup he was cued to pour the hot water into the cup. He	

			went over to the kettle and felt the side saying 'this is hot'. He then switched the kettle on again, instead of pouring the hot water into the cup.
	PL	Cup of tea	He was required to mash the tea, so was cued to get out a teaspoon. Instead of getting a teaspoon from the draw, he went over to the cupboard that contained the cups, plates, saucers etc. and repeated the action of getting out a cup.
	RG	Bowl of soup	She had heated the soup and switched off the cooker. She was cued to get out a bowl, which she did. When cued to serve the soup, she went back over to the saucepan located on the cooker, and carried on stirring it, as if it was being heated up.
	RG	Cup of tea	She had two cups, and placed a teabag in each one. She was then cued to add the hot water, but instead she took two more teabags from the container and added them to one of the cups.
Orientation			
<i>Locating</i>			
	JF	Coffee and toast	She looks around for worktop for the bread. But the bread is located in the breadbin, which was closed. She asks for assistance to find the bread.
	DA	Beans on toast	He looks around for the saucepan, and then asks for assistance in locating it. It was stored in one of the cupboards
	FA	Beans on toast	She looks around for the saucepan, and searches in three cupboards. The saucepan was located in a large draw that she had not opened.
	JF	Bowl of soup	She looks around the worktop for a bowl, and then requests assistance to locate where the bowls are stored.
	PL	Bowl of soup	He was cued to get a spoon. He searched for a spoon, opening two draws and one cupboard. He then went and looked in the fridge. The researcher cued him to look for a spoon, which he said he was looking for. The researcher then cued him to the correct draw containing the spoons.
	PL	Cup of tea	He was cued to get out a teaspoon. He searched through a cupboard containing the cups, bowls, plates etc. He then searched through a draw containing the tea towels. The researcher cued him to the correct draw containing the spoons.
	RG	Bowl of soup	When cued to get out a saucepan, she opened and searched in two cupboards located below the worktop. The researcher then points her towards the correct cupboard, which was located below the sink.
<i>Identifying</i>			
	FA	Beans on toast	She was looking for a bread knife to slice the bread. She initially opened the wrong draw, but then opened the correct draw. However, she did not see, so closed the draw and carried on searching. The researcher cued her to open the draw again and pointed out the knife.
	JF	Coffee and toast	She tells the researcher she is looking for the butter. She opens the fridge and looks in. The butter was visible in the fridge, but she tells the researcher she cannot see it. The researcher points out the butter to her.
	PL	Bowl of soup	He opened the fridge and looked for the soup container. He picked up the soup container and put it back, continuing to look. The researcher cued him saying that that was the correct item.
	RG	Bowl of soup	She was cued to get the soup from the fridge. She opened the fridge and looked inside, but did not take out the soup. The researcher was required to point out the soup
	FA	Beans on toast	She looked around for the toaster. She told the researcher that she could not find the toast. The toaster was located on the worktop. The researcher pointed out to her where the toaster was located. She misunderstood the researcher, and went over to the bread-making machine (located next to the toaster). She looked at it for a while and then realised it was not the toaster.

			The researcher cued her again to the toaster, which she then recognised.
Operation	FA	Beans on toast	She put the bread in the toaster and switched it on at the mains. She had not pushed down the lever that switches the toaster on. She couldn't understand why it was not heating up. She pulled out the crumbs tray, and then pushed it back in. She placed her hand above the toaster to feel the heat, but it wasn't on. Then she checked that it was switched on at the mains. The researcher then cued her that she needed to press the lever down to switch it on, which she then did
	FA	Beans on toast	When turning the cooker off, she selects the wrong control, which turns a different hotplate on. She does not realise so the researcher tells her which control to turn off.
	FA	Bowl of soup	She turns on the cooker. She places the saucepan on the correct hot plate (bottom right) but then moves it to the other hotplate (top right). The researcher tells her that the original (bottom right) hot plate is the correct one.
	JF	Cup of tea	She fills the kettle at the sink, and then places it on the worktop. She closes the lid, and presses the switch to turn it on. She notices that the water is not boiling, but does not realise that she needs to place it on the power stand. She opens the kettle to see if it is heated up, and presses the switch to turn it off and then on again. She then expresses <i>she doesn't understand</i> why the water was not boiling. The researcher tells her to <i>put it on the power stand</i> . She then states that she didn't realise it had to go on the power stand.
	PL	Bowl of soup	He was holding the saucepan, which contained the soup He was cued to heat the soup, so he went over to the cooker. He then asked how to heat the soup on the cooker. He was told to turn on the cooker on using the controls. He turns the control for the oven, which are located below the cooker. The researcher pointed to the cooker controls to cue him. He turns one of the controls, and then places the saucepan on the burner that is lit.
	PL	Cup of tea	He picks up the kettle to pour water into the cup. He tilts the kettle the wrong way, as if to pour the water from the back of the kettle (where the switch was protruding). The research points at the spout and tells him to turn the kettle around.
	RG	Bowl of soup	She put the saucepan on the cooker. She was cued to turn the cooker on. She turned the control that started the gas, but did not press the spark switch to light the gas. The researcher cued her to press the spark switch, which she did.
Incoherence <i>Toying</i>	FA	Cup of tea	She boils the water for the tea making task. When she goes to the fridge to get the milk, she starts taking various things out of the fridge and talking about them. After a period of time she apologised and said she does not know what he needs to do next. The researcher tells her to make the cup of tea.
	PL	Bowl of soup	The researcher cued him to make the soup. He repeatedly picked-up and put down the saucepan. The researcher cued him to get a bowl
	PL	Bowl of soup	The researcher cued him to make the soup. He again repeatedly picked-up and put down the saucepan. The researcher cued him to get a bowl
	PL	Bowl of soup	When cued to put soup in the bowl he repeatedly picked-up and put-down the bowls. The research cues him to perform the next action
	PL	Bowl of soup	When told to put soup in the bowl he again repeatedly picked-up and put-down the bowls for over
	PL	Bowl of soup	When cued to put the soup into the bowl he picked-up and put down the teabag container. Then he picked-up and put down the

			saucepan. The researcher reminded him to put the soup into the bowl
	PL	Bowl of soup	When getting out a spoon, he took out 3 spoons and passed them through his hands. Then he took the knives and passed them through his hands. He then took the spoons to the worktop. The researcher cued him to take the spoon. He took all the spoons to the worktop
	PL	Cup of tea	When getting out a spoon, he picks-up three spoons and searches through them in his hands, then picks-up the knives. When cued to remove the teabag with one of the spoons, he takes all of the spoons to the worktop
	PL	Cup of tea	When prompted to remove the teabag from the cup, he toyed with the cups
	PL	Cup of tea	When prompted to mash the tea, he lifts and toys with both cups, which were located on the worktop in front of him
<i>Inactivity</i>	PL	Bowl of soup	He takes the soup from the fridge and holds it to the camera. After five seconds the researcher cues to make a bowl of soup. He then puts the soup onto the worktop and looks in the fridge. The researcher then cues him to get a saucepan
	PL	Bowl of soup	He puts the saucepan on the worktop and stops. After 7 seconds he asks what to do next
	PL	Cup of tea	The kettle was boiled, and the switch clicked off. However, he stood still and waited. After five seconds the researcher cued him to perform the next step
	RG	Bowl of soup	The researcher asks her to make one bowl of soup. She does nothing for five seconds and so the researcher tells her to get soup from the fridge
	RG	Bowl of soup	She places the saucepan onto the burner. She stops for 8 seconds. The researcher cues her to heat the soup. She doesn't respond and so the researcher tells her to turn on the hob. She then switches the gas on the hob.
	RG	Bowl of soup	She puts the soup into the saucepan and then stops. The researcher cues her to make one bowl of soup. She then takes the saucepan to the cooker
	RG	Bowl of soup	When cued to get out a bowl, she leaves the kitchen and goes into the lounge. The researcher cues her to come back into the kitchen
	RG	Cup of tea	Researcher prompts her to make a cup of tea. She does not initiate any action, so he cues her to get the kettle and put water in it.
	RG	Cup of tea	Once the kettle boils she does nothing. The researcher cues her to make a cup of tea but gets no response, the researcher then cues her to get out the cups.
	RG	Cup of tea	She takes the cups from the cupboard and places them on the worktop. She then stands still. After five seconds the researcher cues her to get a teabag
	RG	Cup of tea	Once she puts the teabags into the cups, she stops. After five seconds the researcher prompts her to make a cup of tea. He then prompts her to add water to the cup
	RG	Cup of tea	She adds the hot water to the cup, and puts the kettle on the power stand. She then stops. After five seconds the researcher cues her to mash the tea. She does not respond so the researcher tells her to get a teaspoon
	FA	Beans on toast	She opened the tin of beans, and got the saucepan from the cupboard. She then stops, and states that she does not know what to do next. The researcher tells her she needs to heat up the beans.

Appendix F: Information sheet and consent form for the cooker experiment

Information sheet for participants

We would very much like you to help us with our research. This will involve us visiting you on four occasions. This sheet is for you to read before you decide to take part. It explains a bit more about what we are doing. Please ask if there is anything which is unclear or if you need more information.

Why are we visiting you, and other people like you? We are trying to invent new ways that technology can be designed to support memory. We are exploring ways to make the cooker more usable, and would like you to test our designs in an experiment.

Do you have to take part? No, it is entirely voluntary. If you do agree to take part, you will be asked to sign a consent form. If you feel that you no longer wish to take part at any time after signing the form just say so and we will stop and destroy all records. The decision not to take part, or to withdraw at any time, will not affect the standard of care you receive.

Who is carrying out the research? Joe Wherton is a Psychology PhD student at the University of York. His research is focusing on the design of household technology to support memory. Joe's work is being supervised by Prof. Andrew Monk, at the University of York.

What will you be asked to do? The researcher would like to visit you at on four occasions over (each visit lasting about 30 minutes). Each time you will be asked to operate a cooker (turning on different hotplates).

What will be recorded? A video camera will be positioned above the cooker to record which controls were used. All information will be anonymised and only people involved in the research will see the recordings.

What happens next? If you are interested in taking part, sign the consent form and we can arrange a convenient time for me to visit. Remember, signing the form does not commit you to taking part. If you change your mind at anytime, you are free to withdraw.

Consent form for participants

Q1) Have you read the information sheet for 'Tenants at Moor Allerton Care Centre'

.....

Yes No

Q2) Do you understand what the project will involve?.....

Yes No

Q3) Do you understand that you can withdraw from the project at any time?

.....

Yes No

Q4) Do you understand that all information gathered during the project will remain confidential?.....

Yes No

Q5) Do you want to take part in the project?

Yes No

Q6) Is it okay if we record each session using a video camera? (All data will be anonymised)

Yes No

Glossary of Terms

ACS	Action Coding System
AD	Alzheimer's disease
AT	Assistive technology
CES	Central Executive System
CIRCA	Computer Interactive Reminiscence and Conversation Aid
COACH	Cognitive Orthosis for Assisting Activities in the Home
CS	Contention Scheduling
GTA	Grounded Theory Analysis
HCI	Human-Computer Interaction
IU	Interaction Unit
MLAT	Multi-Level Action Test
NAT	Naturalistic Action Test
OT	Occupational Therapist
PDA	Personal Digital Assistant
PwD	Person with dementia
RFID	Radio Frequency Identification
SAS	Supervisory Attentional System
VaD	Vascular dementia

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