



Designing & Evaluating a Cognitive Prosthetic for People with Mild Dementia

Mulvenna, M., Moelaert, F., Meiland, F., Sävenstedt, S., Hettinga, M., Craig, D., Bengtsson, J., Dröes, R.-M., & Martin, S. (2010). Designing & Evaluating a Cognitive Prosthetic for People with Mild Dementia. In W.-P. Brinkman, & M. Neerincx (Eds.), *Caring Technology for the Future: Proceedings of the European Conference on Cognitive Ergonomics* (pp. 11-18). Springer.

[Link to publication record in Ulster University Research Portal](#)

Published in:

Caring Technology for the Future: Proceedings of the European Conference on Cognitive Ergonomics

Publication Status:

Published (in print/issue): 24/08/2010

Document Version

Author Accepted version

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ABSTRACT

Motivation – Develop a portable, mobile information and communication device with specific applications that meet the identified needs of people with mild dementia.

Research approach – A qualitative study with a user centred design was applied: Three iterative development cycles of one year each were performed, in which around 15 persons with mild dementia and their carers participated in each cycle of development to attune the functions and form of the cognitive prosthetic to their needs and wishes. A mixed methods approach of qualitative interviews and standardised tools were used for the evaluations that were performed by formulating research questions and assigning appropriate methods for data collection before, during and after the field tests at the end of each development cycle.

Findings/Design – The COGKNOW Day Navigator consists of a touch screen, a mobile device, sensors, a home hub and a central server. Several features such as colours and icons, can be adjusted to personal preferences, which was much appreciated by users. The functions to support people in their daily activities were overall appreciated, though there were individual differences in preferences and abilities to use them.

Research limitations/Implications – It was recommended to perform an impact study within the target group for a longer period of time when the system is considered stable and to make use of a randomised controlled design in a larger study population.

Originality/Value – The research built upon previous evidence of needs of people with mild dementia and the

findings are valuable in directing further research and innovation. However, it was found that this technology can be complex to implement in a manner that ensures good quality of service delivery during field tests.

Take away message – The work has shown the value of designing an analysis framework for development of assistive technology that gives a strong voice to people with dementia and their carers.

KEYWORDS

Mild dementia, cognitive prosthetic, user-centred design,

INTRODUCTION

The aim of the COGKNOW project was to achieve a breakthrough with research that not only addressed the needs of persons with dementia but also included them in the study cycles. Specifically COGKNOW focused on those people living with mild dementia in community settings in Europe – literally helping these people navigate through their day (COGKNOW, 2010). In the project, the focus of the intervention was on cognitive reinforcement in the four key areas of helping people to remember, helping to maintain social contact, helping with performing daily life and recreational activities, and providing enhanced feelings of safety. The overarching research questions focused on the applicability and usability of the resultant COGKNOW solution, as instantiated in these four intervention areas. Is it possible to use user-centered methods in the design of solutions for people with dementia? If so, what is the best way to involve users, including the carers of people with dementia?

The COGKNOW analysis of the state of the art found that previous research has delivered devices and services which have had mixed or little success when applied to actual living conditions among ageing people with dementia (Lauriks et al 2007). However, they have proven useful in highlighting where gaps in service and autonomy may be filled. The COGKNOW advances on the state of the art are focused on addressing these gaps and on delivering an integrated service and technology that makes a difference in actual living conditions.

THE SCALE OF THE PROBLEM

Dementia is a progressive, chronic disease affecting 10% of all persons above 65 and over 40% of people over the age of 90. In Europe by 2050, it is estimated that one-third of Europe's population will be over 60. The number of 'oldest old' aged 80+ is expected to grow by 180% (Eurostat 2002). For example, in 1951, there were 300 people aged 100 and over in the UK. By the year 2031, it is estimated that this figure could boom to 36,000 (BBC 2007). Life expectancy has been rising on average by 2.5 years per decade in Europe. There are 10 million cases of dementia in Europe and more new cases per year (ADI 2009). Dementia has been called the 'plague of the 21st century'. There is currently no cure for this disease, however prevention and early diagnosis may play a significant role in delaying the onset of severe disease and offering people timely care and support. Medicines are available but the positive effects are limited, side effects are reported and medicines are often viewed as too expensive.

Besides formal costs associated with ageing, a lot of pressure is put on informal carers. 65-80% of older people are cared for by their relatives, who – as a consequence of caring - may experience changes in physical and mental health themselves (Burns 2000). To be able to provide sufficient care in the future, formal care and welfare resources as well as help from informal carers will be needed. However, alternative strategies will also have to be found to be able to account for the needs of the growing number of ageing people. One of these strategies can be the development and application of integrated cognitive prosthetics.

STATE OF THE ART IN COGNITIVE PROSTHETICS

While there is some research and development in cognitive prosthetics, there are very few relevant tools, solutions or technologies specifically for people with mild dementia. It is important to note that there exists no one solution in the market or research laboratories that proffers a solution in line with the technological objectives of COGKNOW. However, if the state of the art is divided into four areas of remotely configurable reminding functionality; communication and interaction functionality; supportive technology for performing daily life activities; and safety or anomaly detection, then there are solutions and tools that address to a greater or lesser extent each one of these areas.

In the area of reminding, the EU project Technology, Ethics and Dementia (TED) under the EU programme Biomedicine and Health (and the Enable project – see below) has produced some devices for reminding and reinforcing – including the Forget-Me-Not device (Hagen 1998), which is an electronic calendar to aid persons suffering from memory problems or cognitive impairment. The researchers found that the calendar could be useful for persons who are confused about day and date.

In the area of communication, mobile phones with one button have been developed for elderly persons with cognitive disabilities to allow direct contact with a family member or carer. Only a few small-scale studies were carried out with mobile phones for people with dementia. Kort (2005) reported on the positive social experiences and positive effect on self-esteem of some people with dementia using a "Mobile TeleCoach", which answers automatically and has just one button for calling, to keep in contact with the informal carer. The users were not very satisfied with the design of that particular mobile phone.

In the area of daily activities, the multi-national ENABLE (Enabling Technologies for People with Dementia) project assessed the effect of assistive devices to support memory, to provide pleasure and comfort, and to facilitate communication (calendar, medicine reminder, lamp, locator, gas cooker monitor and picture phone) among people with dementia, regarding their quality of life and the burden on their carers (Adlam 2004).

Finally, in the area of safety, several detection devices have been used in different diagnostic groups and alarm systems in the home used for people with dementia. However, only a small number of scientific studies investigating the results of these applications in people with dementia have been found. Miskelly (2004) investigated electronic tagging (bracelet and monitoring station) in patients with dementia in residential homes and found it to be reliable and successful in detecting external wandering and argues for using the system also for people living in the community with a relative.

THE APPROPRIATENESS OF USER-CENTRED DESIGN

One of the main goals in the care of persons with chronic diseases such as dementia is enhancing the autonomy in their daily life by providing compensation for their disabilities. In the last decade another important goal in caring for these persons has been recognized: enhancement of their quality of life. In the case of persons with dementia this has led to an increased interest in the way they experience their disease and how to optimize their quality of life (Markova et al 2005; Clare 2003, 2005; Dröes 2007). This has in turn led to the development of emotion-oriented care for persons with dementia (Finnema et al 2000), and also to another perspective on care ethics

that pays more attention to the experience of the sufferers themselves (Kitwood and Bredin 1992).

It is important to know what determines the person's feeling of quality of life; in other words, to know what they themselves find to be important domains of quality of life (Dröes et al 2006). This has led to a new field of knowledge in dementia care: the uncovering of the experience of persons with dementia (de Boer et al 2007). Several studies demonstrate that a collaborative and person-centred approach is feasible for people with early-stage dementia (Orpwood et al 2003; Freeman et al 2005).

Within development of innovative products, user-centred design (ISO13407 1990) is seen as an empirical research and product development orientation that utilises end-user information for making better and thus more commercially successful products. This is achieved by involving the end-user throughout the product development process in order to create applications which provide added value to the intended users and that are easy to use. Especially in healthcare this process is of vital importance.

User centred design (UCD) cannot be encapsulated in one stage of product design but needs to be applied through the whole process of design. Rubin (1994) outlined several aspects to consider for UCD. To start with, UCD is a phased approach where user input is needed at all critical decision points. This ensures that user needs are well translated to appropriate product specifications. User centricity is more likely to take place in multidisciplinary teams. In COGKNOW, it was noticed that the gap between an expressed user need and its mapping to functional requirements and design specifications is sometimes difficult to achieve in a single step, for the simple reason that expressed user needs can have many interpretations. Several iterations between needs analysts and system designers were therefore needed before the prototype development could progress. Users and user testing are sources of uncertainty, which should be tolerated and is indeed beneficial for the outcome. In UCD there exists no one single process description but rather a range of methods and tools that can be implemented flexibly, case-by-case. The choice of methods and tools depends on the application to be built and on the target group. Furthermore, user centricity and usability are highly context-dependent, and therefore processes, requirements, guidelines and lists are interpreted and redefined for the purpose and preferences of each individual. In the case of the COGKNOW project, it was noticed that between the three project locations (Amsterdam, Luleå and Belfast) as well as between the individual persons, differences existed in many aspects, such as living situation (alone or together with a spouse or family caregiver), specific disabilities, social network, the willingness to openly discuss needs within group workshops or individual interviews, the habit to use

mobile phones, preferences for reminders, and also their attitudes towards the design of the stationary and mobile devices.

PROJECT OBJECTIVES AND METHOD

In the COGKNOW project, people with mild dementia were the primary target group and they were seen as active collaborators in the process to develop a system that aims to support them in different aspects of their daily life (remembering, maintaining social contacts, performing daily life activities and feeling safe) (Meiland et al 2007). These support areas were identified in the literature as areas in which community dwelling persons with dementia experience unmet needs most frequently (Van der Roest et al 2009). Three iterative development cycles of one year each were performed, in which persons (12 to 16 per cycle) with mild dementia (GDS 3-5 or MMSE 15-25) and their carers participated. The cycles consisted of user needs workshops, interviews, formulation of functional requirements, incremental improvements of the COGKNOW prototype and evaluation during a field test. During the Field Test (FT), the COGKNOW prototype was installed in the participants' homes. The duration of the FT was one or more days for FT#1 and one to two weeks for FT#2 and three to eight weeks for FT#3. These cycles of development were carried out with a maximum of sixteen people with dementia and their carers (six dyads per test site) in Belfast, UK; Lulea, Sweden and Amsterdam, the Netherlands. The user needs workshops and interviews were conducted with persons with dementia and carers separately, according to pre-defined guidelines (Meiland et al 2010). Two presentations (one with slides of the different time frames and activities during the day, and one with possible ICT solutions) were used to help people express their needs, wants and demands in daily life as well as their preferences for possible ICT solutions. During the field tests, the developed COGKNOW devices were installed in the participants' homes, and evaluated by means of semi-structured interviews/observations, in-situ measurement (logging) and diaries/problem checklists.

The first development phase in 2007 and the second in 2008 focused on user friendliness and usefulness for supporting memory, social contacts, daily activities, and enhance feelings of safety. The third development phase in 2009 focused also on the impact of the full COGKNOW solution on daily life. After each test phase, human factors analysis, test reports and results from business workshops were synthesised into an overall evaluation from user, technology and business perspectives.

One goal of the project was to evaluate whether or not the COGKNOW services, devices and platform met the stated project objectives and fulfilled the functional and technical requirements identified during the project. In particular, the aim of the evaluation was to improve the

design and integration of applications that help people with dementia to navigate through their day in the four COGKNOW support areas of memory, social contact, daily activities and feelings of safety; to identify the complex circumstances under which people with dementia operate; to obtain a better understanding of how people with dementia understand, interpret, and use technology; and to assess the overall impact on their actual and perceived autonomy and quality of life.

THE COGKNOW DAY NAVIGATOR

The four main components that were designed within the system, called COGKNOW Day Navigator (CDN), from a technical perspective include the:

- COGKNOW Home Hub (CHH), which provides services for the person with dementia within their own home. The CHH, a commercially available tablet computer with custom COGKNOW software, also acts as the hub for the sensors in the person's home. During the field tests, sensors on doors (front door, refrigerator) and bed/chair sensors were tested.
- COGKNOW Cognitive Assistant (CCA), which is a commercially available handheld device with telephony and location-finding capabilities and custom COGKNOW software.
- COGKNOW Server (CS). CS stores all information relating to users and manages detailed service settings, such as for reminders. Information stored on the server is also synchronised with the CHH and CCA.

From the user perspective, the COGKNOW Day Navigator consists of a touch screen in the home linked to sensors and computer-mediated controls, and a mobile device to bring along when going out. Both devices offer multiple very easy-to-use functions in validated top priority needs areas: memory support, support to manage activities of daily life, support to maintain social contacts, and to enhance feelings of safety. The COGKNOW Day Navigator has been carefully designed to provide multimodal interfaces that are highly adaptable to the cognitive support needs and any perception disabilities of different persons, and as those needs and disabilities change over time. The ability to adjust service settings remotely enables family and professional carers to support persons with dementia from any location. Figure 1 illustrates the schematic architecture of the CDN.

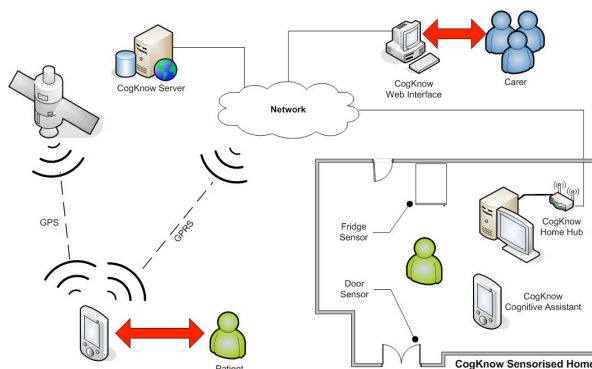


Figure 1 - Overall System Architecture of COGKNOW Day Navigator

There were significant technical challenges to be overcome, mainly to provide a reliable, scalable platform that guaranteed a high level of service delivery quality. In COGKNOW, commercially available off-the-shelf equipment was chosen where possible, and the state of the art was advanced by adding new software components for integrated service delivery to persons with dementia. This provided a potential for a reliable platform, and offered opportunities for experimentation with service provision and functionality. The project used this platform to advance the state-of-the-art in the areas of mobile and home based delivery of reminding services; context aware services and ubiquitous computing within the realms of mild dementia.

EVALUATION RESULTS

The CDN was evaluated by 16 persons with dementia and their carers in the first field test, 14 couples in the second field test and 12 in the final field test. In general the developed prototype was perceived as a user-friendly and potentially useful aid to support persons with mild dementia living in the community (see Figure 2 and 3).

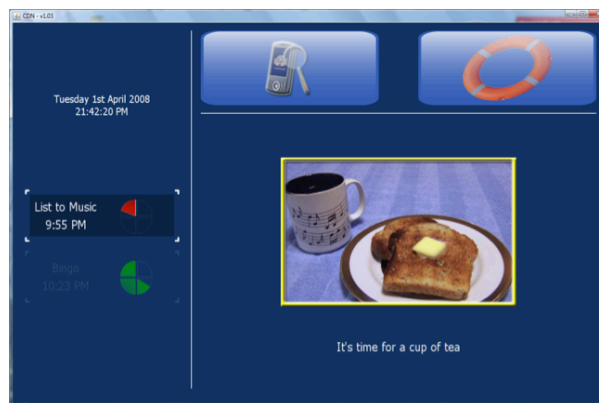


Figure 2 - CDN and Activities of Daily Living

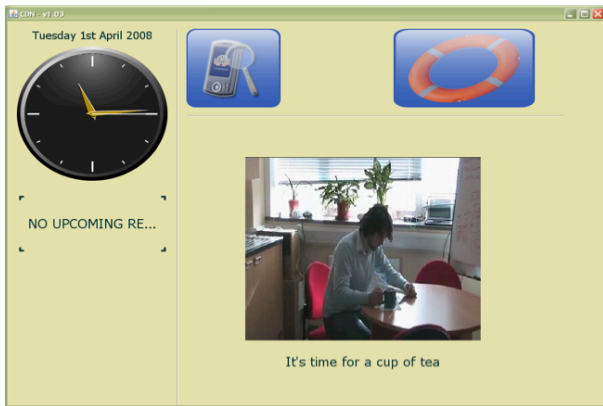


Figure 3 - CDN showing personalised interface

The memory support (day and time indication, reminders), picture dialling and the radio control were especially perceived as helpful by the persons with dementia. Also, the mobile device (CCA – see Figure 4) was valued positively.



Figure 4 - CCA showing a reminder

The carers considered the reminders, radio control and music playback the most helpful. The usefulness of the different functions appeared to be related to the personal preferences and needs of the persons with dementia. In the final field test, also the impact of using the CDN in daily life on (experienced) autonomy and quality of life was assessed, but no significant effects were found. This is probably explained by the relatively short period of testing due to technical instability of the prototype. From a technical point of view, the results showed that although the prototype suffered from a number of instabilities in some services, the system deployed provided the ability to gain an insight into its utility. In addition, a number of advanced components were developed although not fully integrated within the final version of the system. The CDN has the potential to be improved and to become more stable and secure, and with more voice prompts and other ways of multi-modal interaction (see Table 1 for a list of functionalities in the final prototype). There is also the potential to improve the capabilities of the system to configure and personalise COGKNOW services remotely. Special

attention needs to be paid to the audio quality of media and phones.

Table 1 - Functionalities in the final COGKNOW prototype

General
Languages: English, Dutch, Swedish
Selectable services
Selectable icons, text captions, font sizes, CHH voice prompts
Support in Reminding
Date & weekday & time indication: analogue or digital, 24-hour or am/pm, possibility to suppress the seconds indicator
Pop-up reminders: remotely configurable, one-time or daily, user-defined text/image/audio/repetition
Agenda & Quarter Hour Clock
Appointment Reminders
Find Mobile Device
Item Locator
Forgotten Keys Warning
Support social contact
Picture Dialling: priority, photos, landline prefix, using existing phone or voice modem with handset
Internet-based telephony (SIP)
Support daily activities
Radio/lamp control using actuators
Music/story player: Selectable music
Activity assistant: stepwise video or image+voice instructions for daily activities
Automatic music during lunch (MotivateToEat)
Enhance feelings of safety
Help/emergency: personalised contact/help icon
Pop-up safety warnings: doors, household appliances
Sensorised night light (NightLight)
Navigation when outdoors (TakeMeHome)

Key functional areas for improvement that have been identified during the COGKNOW project are reminders, outdoors navigation and daily activity assistance.

DISCUSSION

Our experiences in this study were that persons with dementia and carers were able to participate actively in a research project on development and evaluation of ICT services. User-driven or user-participatory design methods are advocated to enhance the chances of developing an ICT device that is user-friendly, useful and will be accepted by users (Sixsmith et al 2007). From a recent literature review we know that many ICT solutions aimed to support elderly persons are developed (Lauriks et al 2007) and in some studies the ICT solutions were also tested with persons with dementia in real life situations (Woolham 2005; Gilliard et al 2004; Ager et al 2001; Wilson et al 2001). However, many researchers did not (yet) test the

applications involving persons with dementia. In a recent review (Nijhof et al 2009) the first results of ICT solutions for persons with dementia are promising. For instance the fall incidences of persons with dementia decreased and their quality of life improved (Lauriks et al 2008). However, Nijhof concludes that the actual effects of ICT solutions for the care of persons with dementia (and informal and professional carers) are not well known. It is therefore important that more studies are undertaken to evaluate the effects of ICT solutions in the target group.

The preferred ICT solutions that persons with dementia and carers brought forward during workshop interviews in our study correspond partly with other studies among persons with dementia (Lauriks et al 2007), e.g. aids for reminding appointments of activities like NeuroPage (Hersh et al 1994), Electronic Memory Aids (EMA) (Inglis et al 2003; Wilson et al 2001), an Electronic agenda (Zanetti et al 2000) or calendar (Holthe et al 1998), and aids to find items (Gilliard et al 2004). To enhance communication, simple photo phones (Sixsmith et al 2007a), videophones (Savenstedt et al 2003) or mobile phones were proposed and tested (Gilliard et al 2004; Ager et al 2001). Technological support for leisure activities was recommended by Sixsmith (et al 2007b) and Wherton (et al 2008), and amongst others an activity guidance system with music and sung messages (Yasuda et al., 2006) and a picture gramophone were tested (Gilliard et al 2004). To enhance feelings of safety, several Global Positioning Systems to locate elderly persons with cognitive impairments were developed, such as GPS Columba and Keruve. Also, monitoring systems inside and outside the house were tested in which alarm messages are forwarded in case of potentially dangerous behaviour of the person with dementia (Masuda et al 2002; Lin et al 2006). When persons with dementia accept such solutions, these may enhance their experienced autonomy, help them to keep in contact with family and friends, help them in engaging in useful activities and enhance their feelings of safety. All of these domains are considered important determinants of quality of life for people with dementia (Dröes et al 2006). Our impression based on this study is that persons with dementia and carers are willing to accept assistive technology, provided that they can trust the reliability of the system.

CONCLUSION

As discussed earlier, the broad objectives to be taken on board when designing solutions for people with dementia are to seek to support their autonomy by supporting and compensating for their cognitive disability, and indeed to seek to enhance their quality of life, however this is measured. The research questions addressed in the work have explored how user-centred design can be facilitated for people with dementia and their carers, without exposing them unnecessarily to

unreliable technology and equipment. Specifically, the research questions explored how to support people cognitively to remember, to maintain social contact, to perform daily life and recreational activities, and to provide enhanced feelings of safety.

The work undertaken has shown that the CDN can support people with dementia to become more autonomous in terms of memory, maintaining social contact and daily activities. The memory support - day and time indication together with reminders - stimulate people with dementia to use the CDN, whereas for the domain of safety it is felt that more research is needed; where, perhaps the functionality could be broadened, for instance it was a wish of people with dementia and carers to have an opportunity to trace the people with dementia when outdoors by means of GPS. The fact that people with dementia might be less dependent on others because they are reminded about appointments and are able to engage in social contacts and activities more easily, may enhance their feelings of self-esteem and thus their feelings of quality of life. The advantage of the CDN is that it is not only a care service, helping people with cognitive impairments, but also a well-being service, supporting people in performing enjoyable activities. This well-being aspect could be more elaborated, for instance by adding a capability to play games such as chess. If the functionalities in the CDN are extended, it may be possible to make use of the CDN from early stages of dementia to more severe stages of dementia. People with dementia and carers should be able to select those functionalities that could help them with their unmet needs, and to de-select or deactivate functionalities that have become less useful for them.

For the carers the CDN is also considered potentially supportive. It might diminish the burden of carers because people with dementia are reminded by the system to undertake activities, such as having lunch. Even though carers may have to motivate the people with dementia sometimes, for instance to make a phone call, the people with dementia are able to perform the phone call themselves with the aid of the CDN. The carers may also feel more at ease knowing that the people with dementia takes the mobile along when leaving the home and is supported by the CDN to find the way back home when lost or to make a phone call in case of trouble.

In the COGKNOW project a user-driven design method was employed to develop and evaluate an ICT device to support persons with dementia in their daily life. The persons with dementia and carers in the project were willing to participate in this research and they provided the researchers with lots of comments regarding their experiences and advice for improving the system. There were frequent issues with technology not performing correctly and sometimes failing to perform in the field tests. In future research the persons with dementia

should be more protected against inadequate stability and other technical issues through thorough lab tests prior to field tests at the persons' homes.

ACKNOWLEDGMENTS

COGKNOW researchers would like to acknowledge all the persons with dementia and their carers who participated in the field tests in Amsterdam, Belfast and Luleå. The COGKNOW project was supported by the European Commission's Information Society Technologies (IST) programme under grant 034025.

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