Assisting People with Early Stage Dementia: Monitoring Wandering

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Abstract

Objective A symptom often associated with early stage dementia is the misunderstanding of context. This may be inability to match activities of daily living to time of day and can manifest by wandering behaviour, at dusk or during nighttime. This behaviour is certainly inconvenient to the carer, but can be dangerous should the person trip, misuse a domestic appliance (e.g. cooker) or leave the dwelling. Technology has been used to assist people with dementia. Commercial systems deploy sensors that can raise an alarm and allow a remote carer to intervene via an intercom, for example. In this work we seek to extend the technology to provide reassurance and guidance to the client. In this case the client can be the person with dementia, but the beneficiary may also be their carer.

Main Content A person may engage with wandering behaviour, possibly because they forget their intended goal. This is of course exacerbated by early stage dementia. Sensors such as movement detectors can trigger actuators to provide lighting guidance, for example. Reasoning systems use rules and utilize context to decide whether the recorded behaviour is intended and legitimate or unintended and potentially dangerous. The rules can be preset and supported by collected data. The decision on when and how to intervene in a particular situation is complex. In this case the reasoning system may need to utilize context to provide a reasonable result, and hence compensate for the misunderstanding by the individual.

Results In this study, which has been undertaken in the Nocturnal project, we discuss the use of software agents, which monitor 'restlessness' and 'wandering' to determine the rules for subsequent intervention. The intervention should be initially advisory, e.g. using lighting to guide a wandering person back to the bedroom during the hours of darkness. However there should be an in-built safety procedure, which alerts a carer, should the person ignore advice and potentially put himself or herself in a harmful situation. The guidance technology supports the carer, and seeks to assist the cared for person, in a beneficial manner.

Conclusion The technology to implement sensing and guidance is available. In order to utilize this technology for assistance with early stage dementia requires the development of supporting software (agents) and rules of engagement. In any case the necessity of back up assistance, a human carer, is still a requirement.

Keywords Dementia, Wandering, Guidance, Software Agents.

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Introduction

The prevalence of dementia is increasing, and this effect is exacerbated by an increasing proportion of people in the population over the age of 65. Knowledge for early diagnosis is increasing, with simple on-line cognitive tests becoming available [1] Treatment, including diet and drug, may be used to control and manage the condition more effectively. Technology also has a role to play to assist the person with dementia and their support network.

Research into the needs of people with dementia has produced solutions to support activities of daily living (ADL) using information and communication technologies (ICT). Projects include the ENABLE and COGKNOW projects. ENABLE assessed (Enabling Technologies for People with Dementia) the effect of assistive devices to support memory, to provide pleasure and comfort, and to facilitate communication. Issues with regard to their quality of life, and the burden on their carers were addressed [2]. COGKNOW developed a system to support people with remembering, maintaining social contacts, performing daily activities and feeling safe [3]. These projects focused on the needs of people with dementia, but primarily during the hours of daytime.

Nocturnal addresses the needs of people with dementia at night time, an equally important time [4]. People with dementia have irregular sleep patterns, often suffering from insomnia [5], and are more likely to 'wander' causing distress to themselves and their carers [6]. At night, most of the ADL activity should in the bedroom and bathroom. ICT and assistive technology has an important role in supporting the carer of a person with dementia during night time. This can be by providing an intervention that alleviates the burden enabling them to achieve better sleep, or by assisting the carer in supporting the person with dementia by automating some tasks.

The person with dementia may have a much more pronounced and immediate need for help and support as they awake in an unknown, dark environment. While not an emergency, the sensors and actuators are capable of quickly creating an intervention that moderates the anxiety of the person with dementia. During night the actuators can manage the lighting to provide illumination and lighted guidance to the bathroom and back. In addition to light, sound can play a more important role. In particular, the use of music as a therapeutic intervention has been shown to reduce anxiety [7]. Better lighting can also play an important role in reducing the risk of falls.

A Rowntree Foundation report [8] made recommendations for home management of older people. These recommendations were to ensure that, where appropriate, relevant technology should be used, for example, guidance around noise, light, safety, silent call system, as well as to ensure that systems are in place for night staff to have all the equipment and facilities required to provide good night time care.

1. The Nocturnal system

The Nocturnal system is focusing on the detection of restlessness, bed occupancy and wandering and therapeutic interventions. The system technological infrastructure is based on X10 technology, which provides deployment at an affordable price. The hardware components are available from companies such as Tunstall[2]. Pressure mats can be used for sensing bed occupancy, PIR sensors for detecting wandering and actuators to control the lighting comprise the hardware. The sensing and actuation platform is controlled by tablet PC (see Figure 1).
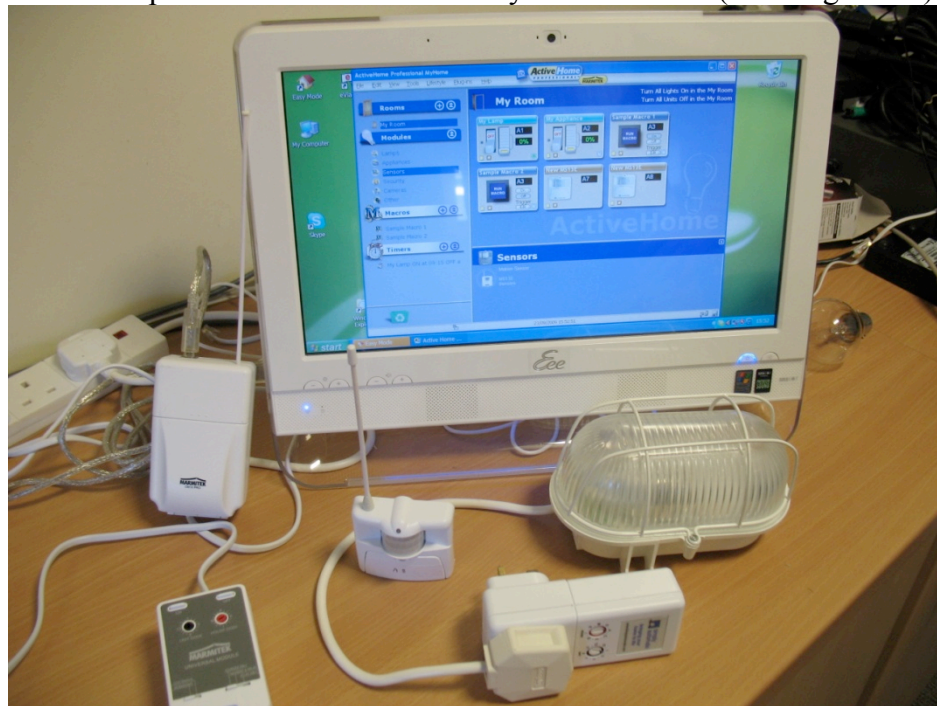

Figure 1. Nocturnal components comprising tablet PC, sensors and actuators.

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[2] www.tunstall.co.uk

The Nocturnal decision making process relies on the interaction of intelligent agents, summarized in Figure 2. Agents have been programmed for detecting bed occupancy, restlessness, and wandering under the control of a coordinating agent. The therapeutic and intervention agent can address the situation by turning on lights for guidance or music for calming, but it also has communication facilities to corers for an escalating situation.

The system tries to understand the environment through the data from the sensors. This data can be partially processed and acted upon through a local Decision Support System (DSS). The information is also uploaded to a server, where more complex Intelligent Data Analysis can be conducted. The result of that analysis can trigger actions of the system, such as contacting healthcare professionals, carers and the house occupants (including the person with dementia). Healthcare professionals and researchers can interrogate the database for more complex data retrieval [9], [10].
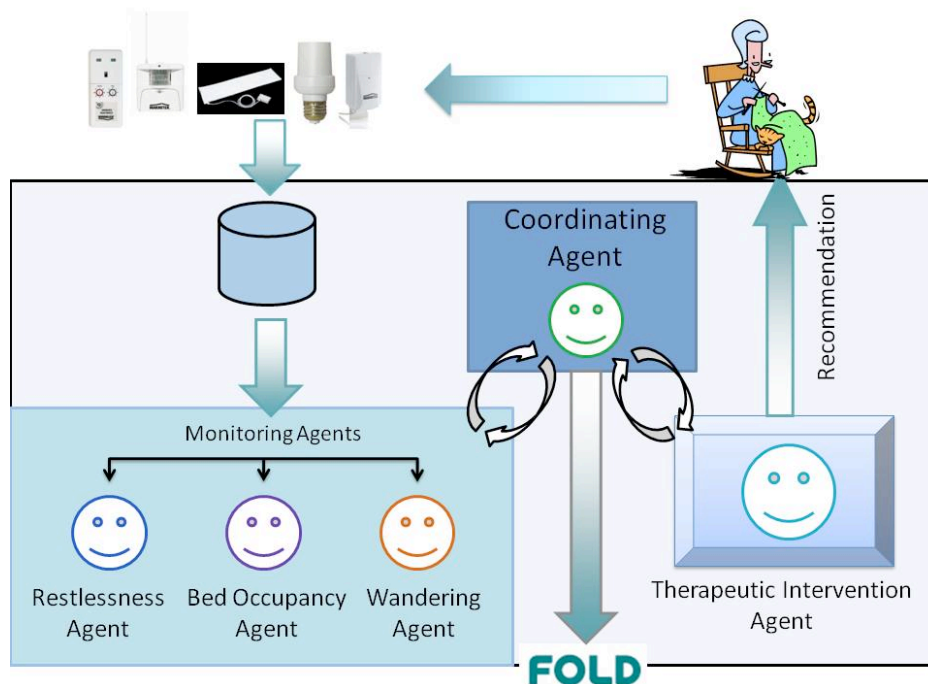

Fig. 2 Monitoring Agents associated with NOCTURNAL

Tracking the client within their home is one of the most important goals. Receiving data from any of the sensory equipment helps to pin

point the location of a client, which in turn will enable the system to serve the client better. One PIR is located in a corner of each room, positioned to ensure that each PIR will not detect the client's movements in any other room. Pressure strips, approximately 1m long by 5cm wide, are used as a bed sensor. Door contact sensors are located in the kitchen area to measure the opening and closing of the fridge, food cupboard and front and back doors. Voltage sensor adaptors can also be connected to plug-in appliances and are used to measure frequency of usage. Appliances currently being monitored are the kettle and microwave. All sensory equipment is attached to a Remote Call box, which collects the data (appliance identification, time and duration of use) in Comma Separated Variable format, for upload to a secure server. Whenever an emergency is triggered, the Call box puts out or receives a call from the healthcare team at FOLD Telecare [3], who provide current home healthcare to elderly people in Northern Ireland.

The aim of the completed network will be to have a sensor enriched environment, which will aid the client by introducing ambient control mechanisms throughout the house (e.g., using the X10 communication/automation protocol to control lighting). Whatever the client decides to do at night will be aided in a number of ways. The system supports the current setup, where the healthcare team (from FOLD) remotely monitor the status of sheltered dwellings and can respond to an emergency request or alerts (e.g., fall pendant alarm pressed) by telephone.

Additional features focus around providing greater guidance. Sensing will help to automatically control the lights in a number of beneficial ways, subject to conditions. Firstly it will ensure any areas the client wanders into lights up. Not only will the new room light up but it will also maintain an illuminated pathway back to the safety of where the client ought to be. More complicated lighting guidance algorithms will be developed to also encourage clients to follow a logical path when needed, for example lighting the way to the bathroom to ensure that the client is less likely to wander off to another location instead.

Whilst the system will react with real time solutions based on real time sensor input and short term recorded pattern deviations, it is possible that a tailored healthcare plan from professionals can be developed as a consequence of the sensory information gathered over much longer periods.

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[3] http://www.foldgroup.co.uk/

2. User acceptance

Nocturnal provides assistive technology, which aims at improving the quality of life of people with dementia, whilst at the same time preserving privacy. This could pose a threat to personal dignity as data on activities of daily living, e.g. duration of sleep, wandering and toileting van be sensed and evaluated with respect to what is 'normal'. An 'abnormal' activity will require the system to respond by alerting a carer, or possibly by the direct use of technology (lighting or audio prompt). A report to the Information Commissioner [11] provides the following commentary: "We live in a surveillance society. It is pointless to talk about surveillance society in the future tense. In all the rich countries of the world everyday life is suffused with surveillance encounters, not merely from dawn to dusk but 24/7."

When asked about 'quality of life' issues, older people's first preference is for "comfortable and secure homes" [12]. Whilst accepting the potential for intrusion, the ethical dilemma is to weigh up the pros and cons of such an intervention. A 2009 report from the Alzheimer's Society, addressing healthcare in hospitals, stated: "Keeping people with dementia at home for longer, is normally the preferred mode for the person with dementia and their carer. Poor hospital care also had a negative impact on the people's dementia and physical health. The majority of people with dementia leave hospital worse than when they arrive with a third having to enter a care home as they are unable to return home." It also argued the economic perspective. "At least £80 million a year and probably hundreds of millions could be saved if people with dementia are enabled to leave hospital one week earlier. Hospitals must commit to reducing the length of stay if we are to stop people with dementia deteriorating in hospital and lessen the chance of people being discharged to a care home"

However there is also a danger that by increasing the amount of technology that we could contribute to social isolation; by reducing the need for interaction with carer, and health care professionals. Nocturnal assistive technology and telecare can orientate the person that it is day time or night time, switch on the lights automatically if the person gets up at night, alert a carer or monitoring centre that the person needs assistance. This can potentially free carers to spend time with the person and it may enable a carer to get a good night rest, knowing that if the person gets up at night they will be alerted. Here technology can hopefully benefit the individual. However the Trent Dementia Services Development Centre [13] stated: *"If assistive technology does not meet*

the individual needs and preferences of the person it may be ineffective or may even cause additional confusion or distress. For example, assistive technology and telecare may not be the answer if the person switches off or unplugs the equipment, the person is confused or distressed by any alarm sounds or recorded messages, or if there are insufficient carers or care workers to respond to an alert."

Assistive technology on its own cannot provide human contact and personal care. Many older people experience loneliness and social isolation. Ideally technology should be provided as an addition to contact, not as a replacement. Potential for bad can be reduced by involving people with dementia, carers and healthcare professionals in the design process.

3. Conclusions

The Nocturnal system provides support for people with dementia at night. Previous developments in the area focused on isolated factors or dimensions of the problem, using only one sensor (e.g., pressure pad), considering only one area of the house (e.g., bed) or condition to be monitored (e.g. restlessness). Nocturnal aims to provide a more holistic approach with a combination of sensors and devices covering a whole house and several important situations of concern. The sensing component is based on off-the-shelf solutions [14]. The 'understanding' component is crucial to beneficial use, and linked to concepts of data analysis, data visualization, data mining and AmI [15]. One other important element of the system is the guidance offered in the way of warnings and alarms to the call centre but also in the form of reassurance and help through multimodal interaction (audio-visual reminders, advice, orientation, etc.) that helps the house occupant to stay safe at home. The development of the system is based on an intelligent multi-agent system, which associates agents with monitoring and intervention tasks.

Recent developments in the assistive technology industry have made available technology that can be used to deploy new applications closely related to the needs of people's daily lives. Policy makers in the healthcare system have been also gradually moving the focus of healthcare from the traditional hospital focus to the home. At the same time, our society have become accepting of technology (mobile phones, GPS technology in the car, computers and Internet at home) that can be used to assist our daily lives. These factors paved the way for the use of technology that can provide assistance at home to increase independence.

This is particularly meaningful for older people, especially if they are affected by chronic conditions, such as dementia.

Acknowledgments

References

[1] Daily Mail (online). 15-minute online test for dementia: DIY memory quiz detects early signs of Alzheimer's in people as young as 50, http://www.dailymail.co.uk/news/article-1386912/15-minute-online-test-dementia-DIY-memory-quiz-detects-early-signs-Alzheimers-people-young-50.html?ito=feeds-newsxml

[2] T. Adlam., R. Faulkner, R. Orpwood, K. Jones, J. Macijauskiene, A. Budraitiene. 2004. The installation and support of internationally distributed equipment for people with dementia. IEEE Transactions on Information Technology in Biomedicine 8(3): 253-7.

[3] R.J. Davies, C.D. Nugent, M. Donnelly, M. Hettinga, F. Meiland, F. Moelaert, M.D. Mulvenna, J.E. Bengtsson, D. Craig , R.M. Droes. 2009. A User-Driven Approach to Develop a Cognitive Prosthetic to Address Unmet Needs of People with Mild Dementia, Journal of Pervasive and Mobile Computing, 5(3):253-67.

[4] W. Carswell, P.J. McCullagh, J.C. Augusto, S. Martin, M.D. Mulvenna, H. Zheng, H.Y. Wang, J.G. Wallace, K. McSorley, B. Taylor, W.P. Jeffers, "A Review of the Role of Assistive Technology for People with Dementia in the Hours of Darkness". Technology and Health Care, Volume 17, Number 4, pp. 281-304. 2009. IOS Press.

[5] N. Wolkove, O. Elkholy, M. Baltzam, M. Palayew. 2007. Sleep and aging: 1. Sleep disorders commonly found in older people, CMAJ 176(9):1299–1304.

[6] D.G. Hermans, U.H. Htay, R. McShane R. 2007. Non-pharmacological interventions for wandering of people with dementia in the domestic setting. Cochrane Database System Review (1): CD005994.

[7] D. Aldridge,, 2000. Music Therapy in Dementia Care, Jessica Kingsley.

[8] D. Kerr., H. Wilkinson and C. Cunningham. 2008. Supporting older people in care homes at night, Joseph Rowntree Foundation.

[9] H. Zheng, W. Carswell, S. Martin, M. Mulvenna, P. McCullagh, P. Jeffers, J.. Augusto, J. Wallace, H. Wang, B. Taylor, K. McSorley. 2009. NOCTURNAL: Night Optimised Care Technology for UseRs Needing Assisted Lifestyles, Proceedings of eChallenges e-2009 Conference

[10] J.C Augusto. Design and Modelling of the Nocturnal AAL Care System. Proceedings 2nd International Symposium on Ambient Intelligence (ISAmI 2011). Series: Advances in Intelligent and Soft Computing, Vol. 92 Novais, Paulo; Preveneers, Davy; Corchado, Juan M. (Eds.)

[11] D. M. Wood. 2006. A Report on the Surveillance Society. For the Information Commissioner by the Surveillance Studies Network, www.ico.gov.uk, (accessed Nov 2009).

[12] H. Clark. and J. Crissel. 2006. Addressing what older people want? Policy context, Evidence submitted to the Older People's Inquiry into 'That Bit of Help', Edited by Norma Raynes, Heather Clark and Jennifer Beecham, Joseph Rowntree Foundation.

[13] Atdementia . 2009. Technology for people with dementia. http://www.atdementia.org.uk Information on Assistive (accessed May 2011).

[14] P.J. McCullagh, W. Carswell, M.D. Mulvenna, J.C. Augusto, H. Zheng, and W.P. Jeffers. "Nocturnal Sensing and Intervention for Assisted Living of People with Dementia.". In Healthcare Sensor Networks - Challenges Towards Practical Application. In D. Lai, R. Begg and M. Palaniswami (Eds.). Taylor and Francis/CRC Press. To appear in July 2011.

[15] J H. Wang, H. Zheng, J. C. Augusto, S. Martin, M. Mulvenna, W. Carswell, J. Wallace, P. Jeffers, B. Taylor, and K. McSorley. "Monitoring and Analysis of Sleep Pattern for People with Early Dementia". 1st Workshop on Knowledge Engineering, Discovery and Dissemination in Health (KEDDH'10), in Proceedings of 2010 IEEE International Conference on Bioinformatics and Biomedicine Workshops, 18-21 December 2010 (ISBN:978-1-4244-8302-0), Hong Kong, pp. 405 - 410, China.A.N. Author, *Book Title*, Publisher Name, Publisher Location, 1995.