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Research Article

WanderRep: A reporting Tool for Caregivers of Wandering Persons with Dementia

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Abstract. Wandering behaviour is regarded as one of the most difficult to manage for Caregivers of Persons with Dementia. It also results in a lot of stress and burden for all caregivers involved, since this behaviour can result in injuries and getting lost. In this research we are proposing a tool which utilizes the currently available Smart Mobile Technologies to focus on the patients' wandering patterns whilst identifying any possible dangers pertaining to the patient. A number of findings have been collected from this research tool, through a number of studies with both formal and informal caregivers and patients at the St. Vincent de Paul Elderly Nursing Home. These findings primarily relate to: (1) The benefits which caregivers perceive when being alerted of danger relating to their patients and (2) the need for further understanding this research area through the collected data. Caregivers are also given the opportunity to give their feedback on a patient's exposure to danger, thus creating a cooperative environment between caregivers of the same patient. Preliminary tests have shown how this system achieves an 89 % specificity to danger rate, which defines the statistical performance of a binary classification test, together with showing how caregivers find this system as a positive way of reducing their burden when caring for wandering patients.

Keywords Dementia, Wandering, Burden, Smart Mobile Technology

1 Introduction

Due to the number of improvements being achieved in the areas of medicine and quality of life, amongst others, the age structure of societies worldwide is continuously changing with a constantly aging trend. As a matter of fact, the European old-age dependency ratio in 2010 amounted to 25.9 % while it is projected to grow to more than 34 % by 2025, as reported by Eurostat (n.d.). This indicates that by 2025, the European eligible work force (including people aged between 15 and 64) will consist of an average of 66 % of all the population, thus another 34 % are aged 65 and over. In the Maltese islands, this ratio is expected to reach 28 % of the population by 2050, according to Abela et al. (2007).

As a result of this increase in age, an increased frequency of age related deficiencies, such as physical and cognitive impairments, are continuously demanding a higher availability of health and social services. This is especially the case when the elder people suffer from conditions such as Dementia and Alzheimer's Disease, where they would be unable to keep on living independently in their own homes. Figures show how persons with dementia are expected to amount to 1.47 % of the whole Maltese population by 2015, while the same figure is expected to reach a staggering amount of 3.26 % by 2050 and 3.62 % by 2060, according to A. Scerri and C. Scerri (2012).

The term "successful ageing" is regarded as a fundamental goal that must be achieved to fight this ageing problem. Zhou et al. (2012) define successful ageing, which is also referred to as "ageing-in-place" by Patterson et al. (2002), across a number of elements, namely: reduced physical disability over the age of 75, good self-ratings and a greater length of a normal and independent life. Courtenay et al. (2010), however, detail two strategies that can be considered in achieving successful ageing at home:

Ageing-in-place Care provision is gradually adapted according to the user's needs inside the household;
In-Place Progression User moves within the service as his/her needs increase.

Considering the shortage in the current supply of professional care workers, helping patients achieve successful ageing has proved to be a stressful task for caregivers (both formal and informal) and family members of people with these types of cognitive impairments as Lauriks et al. (2007) and Wherton and Monk (2010) suggest. According to Hulme et al. (2010), this burden is largely due to the emotional and behavioural problems that the persons with dementia evidence, along with the decline in function and other symptoms such as aggression, depression and wandering.

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2 Dementia

Dementia can be divided into several types of conditions, which all include a degree of cognitive decline that influences a patient's ability to conduct activities of daily living. These include, amongst others: Alzheimer's disease, Vascular Dementia and Pick's Disease. Moreover, the condition can be divided into three main stages, each having different characteristics: Mild/Early which usually takes 2-4 years until the patient progresses to the next stage, Moderate which can take 2 up to 10 years and Severe which can endure 1 to 3 or more years (Alzheimer'sAssociation, 2011).

The caring of persons with dementia mainly involves the attending and supervision of everyday needs, together with the management of behavioural problems. The latter are in fact the most recurring issues when caring for a patient diagnosed with dementia, and require constant supervision since the person involved may end up disoriented, unable to express his/her feelings, and end up behaving disruptively. These behaviours can range from repeatedly asking the same questions to having more aggressive actions such as hitting, biting and screaming (WHO, 2012). Although not every person suffering with dementia resorts to these types of behaviours, all may face vulnerabilities to low frustration tolerance, impaired judgment, apathy and inability to initiate tasks as Zimmerman (2001) notes. On the other hand, Wherton and Monk (2010) note how persons with mild dementia face difficulties when conducting multi-step tasks due to memory impairment. Biswas et al. (2010) confirm this issue and state that conducting these daily tasks becomes problematic even though they are physically capable of doing them correctly. This matter is made worse when the patient is not capable of remembering the correct steps required in Activities of Daily Life (ADL), such as grooming, bathing, eating and taking medication on time. Mild dementia can also affect more complex activities, such as tidying, cooking and financial calculations. This concern raises the need for personal assistance and residential care in order to fight consequences such as diminished quality of life, poor self-esteem and anxiety (Hoey et al., 2011).

Apart from the several everyday activity functional deficiencies, Douglas et al. (2011) notice how cognitive decline also brings about a number of safety concerns this may cause persons with dementia, such as forgetting items on a stove and taking medication too frequently.

3 Wandering Behaviour

Research in the area of wandering has resulted into a number of definitions, most notably the one defined by Hermans et al. (2007), who explains Wandering as a set of issues related to people with dementia walking inside or away from home, with health risks related to injury, weight loss, early institutionalisation, decline of language skills, premature mortality and therefore higher caregiver burden. Another highly cited definition is given by Algase (2006) who describes the behaviour as one which incorporates, at a minimum, the amount of walking or wandering, spatial disorientation and eloping behaviour. The review by Algase also shows a relationship between agitation and wandering with these patients. Wandering can be considered as one of the most frequent and possibly hazardous behaviour malfunctions in persons with dementia, as illustrated by Vuong et al. (2011). This behaviour terminology combines a number of different complex actions without each having a reason in particular, as Faucounau et al. (2009) state. In accordance with this statement, Robinson et al. (2007) argue that there is no distinct definition for wandering, which is also dubbed as agitation or agitated behaviour and can be described according to geographical pattern, typology and neurocognitive deficits. Despite this claim, Algase (2006) reviewed literature in the area and came up with the most cited definition of wandering behaviour, as quoted below:

"*Wandering is a syndrome of dementia-related locomotion behaviour having a frequent, repetitive, temporally-disordered, and/or spatially disoriented nature that is manifested in lapping, random, and/or pacing patterns, some of which are associated with eloping, eloping attempts, or getting lost unless accompanied.*"

While wandering is still considered as dangerous and a source of distress for carers, its main consequences can also be beneficial for persons with dementia. In fact, wandering can be considered as a form of exercise which can help in the patient's blood circulation, amongst other benefits, as Robinson et al. (2007) suggest.

Despite these benefits, Faucounau et al. (2009) argue that caregivers (both formal and professional) find it very unsafe for their patients to wander on their own, since they will be more likely to stray outside, get physically hurt and even face deadly situations. On the other hand, Douglas et al. (2011) state that the prospect of injuries from wandering was found to be low as compared to the injuries suffered by the same types of patients in other situations, such as falls. Siders et al. (2004) explain how frequent wanderers face a considerably larger chance of falling, having hip fractures, facing home placement and making use of physical restraints.

The hazards from wandering can be further measured when compared to the likelihood of injury from fire and burns, where wandering behaviour was found to present a greater risk to the persons with dementia themselves. Douglas et al. (2011) also show how wandering behaviour is still reported as the most common safety problem by caregivers, whilst increased caregiver rigour is a direct result of increased patient wandering situations.

Although research has highlighted a number of hazards related to wandering, this research required further evidence of the problems which caregivers face in their day to day jobs. The section below introduces the research conducted with both caregivers and persons with dementia to achieve this goal.

4 Methodology

4.1 Participants and Instrumentation

For the purpose of this research, two main events were organised in order to gather the necessary data and elements required by this work. These events involved; (1) A

Workshop with Dementia Caregivers, and (2) Pilot Study with Dementia Patients.

The workshop was primarily organised to gather first hand insight into what care giving on a daily basis means. This helps in understanding the problems associated with patients with dementia , especially those with wandering behaviour. On the other hand, the aim of the Pilot Study was twofold: It provided the possibility of collecting wandering and movement data related to a Person with Dementia (PwD) inside the care home, as well as the opportunity to conduct interview and feedback sessions with Caregivers themselves who were given a demonstration of the final prototype and asked to evaluate the system.

The first workshop with Dementia Caregivers was organised in St. Julian's, Malta, and attracted a total of 16 formal and informal caregivers. The attendees were first given an overview of the current limitations found in research with regards to caring for dementia patients. During the second part of this workshop, attendees were offered the opportunity to contribute with their experiences and discuss ways in which their troubles might be alleviated through the use of technology.

The second event was conducted over a period of 5 days at the St. Vincent de Paul Residence in Marsa, Malta. A total of 5 Professional Caregivers participated in this study, where a prototype of the system was presented for their use. This proptotype utilised wandering pattern data collected from a Dementia Patient inside the ward during the same study. This data was collected by using indoor wireless signal Received Signal Strength (RSS) fingerprinting for indoor positioning, by using a Smartwatch device capable of recording location data relating to the patient. Caregivers were given examples of/how the system reacts to irregular wandering patterns displayed by the patients.

5 Smart mobile technology

With the utilisation of the latest smart technologies, Information and Communication Technology (ICT) can become a significant player in the creation of intelligent and automated home environments which help the elderly in their day-to-day lives while still sustaining their independence and self-sufficiency despite their ageing process.

Research has achieved the objective of ageing-in-place in a number of cases through Context Awareness, which forms part of the latest generation of computing, known as Ubiquitous Computing. This vision, otherwise known as pervasive computing, knows its foundation in research by Weiser (1991). He described this concept as one where technologies vanish into the structure of objects which people use for everyday tasks, in a way which makes it unnoticeable to its users. When this vision was published, the required technology wasn't available and eventually the vision did not materialise. However, with the advancing developments in computer hardware, sensors and their networking capabilities, Wieser's vision is becoming even more possible to emerge, as Satyanarayanan (2001) explains.

Pervasive computer systems need to continuously exploit information about the situation of their users, or the state of the actual system in order to make adaptations to their behaviour. These functions contribute to another concept of visions: those of context-aware systems, which according to Mark Wieser, will make the vision of pervasive computing possible. In fact, he describes it as a vision of personal computing through which future living environments are infused with non-interfering, seamlessly operating services which are readily available upon user's request (Weiser, 1991).

6 WanderRep

Given the highly stressful task of managing wandering dementia patients, WanderRep, as a tool, aims to help both the caregiver in managing a patient more effectively and the patient being safeguarded against possible dangers. This work utilises Mobile Computing to ultimately achieve the pre-determined objectives. In this type of model, where the computer in question is expected to be portable and transported with the user, a number of limitations arise. This is mainly due to the restricted nature of currently available mobile devices with regards to hardware specifications such as storage capacities and processing power. This work is thus basing its proposal on a general Client/Server Architecture, where different layers refer to particular functions within this eco-system which together work to overcome the limitations in current mobile devices while achieving the pre-set objectives. All components pertaining to each side will be analysed. These include: Patient Mobility Layer, Distributed Database Layer, Machine Learning Layer, Service Layer, Caregiver Mobility Layer and Client Database Layer. The overall architectural design is displayed in Figure 1.

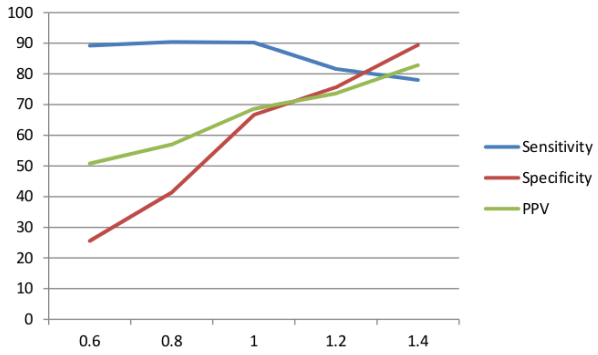

Figure 1: Technical Architecture

6.1 Server Side

This research extends the work of Vuong et al. (2011, 2011), who propose a wandering recognition process based on a less resource intensive smartphone. Given the lack of computing resources available, this method makes use of State Prediction techniques with adaptive confidence estimation in order to predict a patient's next location, which allows for a degree of certainty when predicting a future state. When it comes to analysing the user's actual patterns, Vuong et al. apply the definition introduced by Martino-Saltzman et al. (1991) in representing the user's

movement patterns as wandering or non-wandering patterns.

Assessment of a user's state is tackled through a different approach, taking machine learning methods as a solution. The wandering detection algorithm being proposed in this work involves the inclusion of the four main features, or attributes, which ultimately are involved in building the wandering profile of a patient. Based on the types of dangers to be deduced, the features chosen for this algorithm include Location, Travel Patterns, Temperature and Activity Level. All these will be coupled with their respective Time element. This structure aims to give maximum flexibility for the system to learn the user's main traits. These will be used to model the patient's profile for abnormal event detection capabilities.

The machine learning layer being proposed in this work has the objective of providing a level of intelligence capable of understanding a patient's behaviour and habits in order to be able to detect episodes whenever the patient's behaviour is considered aberrant. This work makes use of Unsupervised Learning algorithms to provide the system with a learning ability where the patient's normal behaviours are learnt, making it possible for the system to identify and detect events when the patient's behaviour does not conform to these habits. The choice falls on Unsupervised Learning since this involves a one-class approach to learning what is normal and can be used to detect what is abnormal in the user's whole presence dataset. Since anomalous data in these scenarios is highly difficult to gather, Unsupervised Learning fits in perfectly with the requirements of this project since a patient's behaviour will be assessed based on current and historical unlabelled data. Clustering and Anomaly Detection techniques are used in this case to provide for Unsupervised Learning of a patient's patterns and the discovery of abnormal data. This approach uses X-Means for clustering of data, together with Local Density Cluster-Based Outlier (LDCOF) for detection of anomalies in the patient's behaviour.

6.2 Client Side

This solution is implemented on a smart mobile device, whose main objectives are those of tracking a patient's indoor movements while being unobtrusive in the user's activities. Indoor positioning has proved to be a major research area in academia. In fact, one of the more widely accepted positioning techniques, the Global Positioning System (GPS), is efficiently used when outdoors. However, as Dale (2010) and Kamel et al. (2011) report, this system doesn't work inside homes and suffers from bad reception in areas with high buildings. For this reason, a system which makes use of a smart device and the available Wireless Local Area Networks (WLAN) was chosen to allow for indoor positioning. With the use of inexpensive and currently available WLAN access point location fingerprints, this implementation would be capable of detecting the location of a user by comparing the access point values with a fingerprint database of values related to particular predefined locations.

Given these requirements, the smart mobile device shall consist of a wearable smart watch which has the capability of scanning for WLAN access points and communicating these values wirelessly to a centralised server. This solution is ideal since it allows for indoor positioning to be realised while being less intrusive to the patients during the pilot study. The smartwatch should also be running on the Android platform, which allows for the developed solution to be used across a number of other devices. Android is an open source framework, mainly designed to be used in mobile devices, and is managed by Google. Android also provides a number of development tools which includes all the libraries needed to interface with the available hardware and to deploy the application effortlessly in the smartwatch and other compatible Android devices.

7 Results

The Caregiver Workshop provided positive outcomes as to what caregivers perceive from the use of technology in their area, especially when related to the problems and dangers caused by their patients' wandering behaviour. One of the most significant outcomes was that of caregivers considering this type of behaviour to be one of the most stressful from their daily challenges associated with caring for people suffering from dementia. This is reflected through the 100 % of results, implying that all attendees agree with this statement.

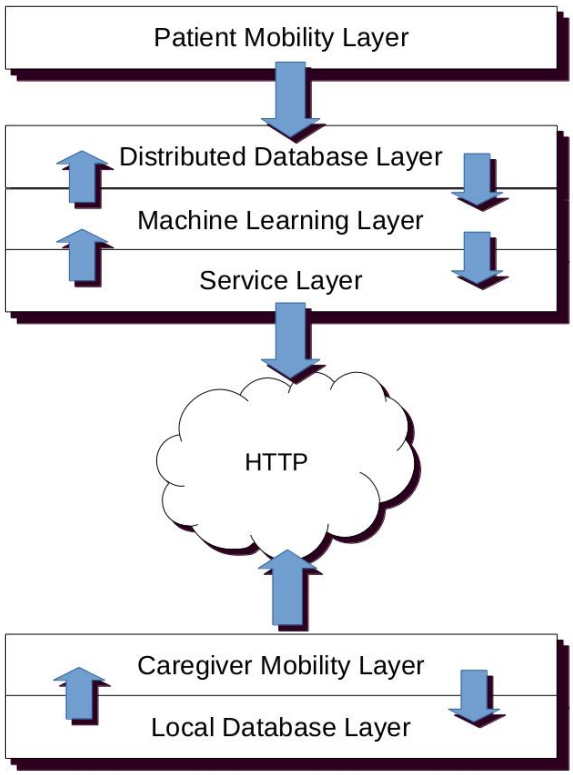

Figure 2: Sensitivity, Specificity and PPV results at the different levels of threshold

With regards to one of the major indicators of wandering

behaviour, that of tracking movement of patients, caregivers also showed positive feedback. In fact, more than 75 % of respondents state that deterioration in a patient's cognitive ability is reflected through a change in daily routines, although these routines are different according to the patient. Therefore, the tracking of changes in a patient's patterns can lead to a caregiver being alarmed of any substantial changes in a dementia patient's wandering routines. From the subsequent workshops, the features found in Table 1 were considered to be important for a Wandering Detection system to consider in order to identify danger associated with wandering.

Table 1: Features and Associated Dangers identified during Caregivers' Workshop

Feature	Danger
Location	Wandering Patterns
Temperature	Hypothermia, Sickness
Time	Sundowning, Associated time with movements
Activity Level	Fatigue, Chance of Wandering

The features identified as a result of the caregiver workshop were implemented into a proof of concept system which allowed formal caregivers to test a solution based on these outcomes. Moreover, five case scenarios were tested using the proof of concept, tackling the following patient situations: (a) Irregular Wandering Patterns, (b) Low Activity Levels, (c) High Activity Level, (d) Non-Compliance To Daily Activities, and (e) Irregular Ambient Temperatures. These case scenarios were tested for an indication of the Proof of Concept's success rate in determining dangers from a patient's wandering scenario. Three main values were identified in this case, namely Sensitivity and Specificity to Danger as a Binary Classification Test and a Positive Predictive Value as a precision value for true positive results. The following results listed in Table 2 were achieved across the five case studies.

Table 2: Case Studies Results

Sensitivity	78 %
Specificity	89 %
Positive Predictive Value	83 %

The results confirm that the five different case scenarios achieved a high specificity to danger rate at 89 %. Sensitivity reached high average scores at 78 %. This implies a high proportion of actual positives being identified as such. In this case, the system is providing high proportions when identifying real danger scenarios. This implies that fewer false alarms are generated by the system as the probability of normal activity being regarded as abnormal is lower. The precision rate in identifying dangerous scenarios, denoted as PPV, follows a similar average rate at 83 %. These results can be considered as positive due to the system's dependency on an Unsupervised Learning System for Danger Detection, as shall be explained in the following sections.

8 Conclusion

This paper describes in detail the framework used to conduct the work as part of this research. This work includes the design of a new wandering detection algorithm, its implementation through a technical architecture, together with its field evaluation together with experts in the area of Caregiving for Persons with Dementia.

8.1 Evaluation

The evaluation process involved in this work has included two main outlooks, namely: (i) the creation of five case studies each representing a particular dangerous scenario being exposed to the patient, as identified through literature and field research, and (ii) an interview session held with caregivers of Persons with Dementia at the St. Vincent de Paul residence for the elderly.

The major outcome from this evaluation involves a high percentage of accuracy when detecting dangers, as reflected by the 78 % sensitivity to danger rate shown in Figure 2. This figure can further be improved through time as extra learning data is applied to the model within the Unsupervised Learning System. These results imply the achievability of objectives such as ageing in place and in-place progression for older adults diagnosed with Dementia when utilising Smart Mobile technologies. On the other hand, caregivers' evaluation of the final prototype involves a number of positive elements with regards to the system's modelling and utilised user interface.

Despite these advantages, caregivers also suggest further improvements with the addition of further data related to the patient, such as blood pressure levels and sugar levels, together with ways of creating a suitable cooperation environment for all formal and informal caregivers caring for the same patient.

8.2 Future Research

This work utilises four main features for its learning model, namely: Temperature, Activity Level, Location and Time. These features are then modelled into the Patient Safety Wandering Profile. Given the rate by which Smart Technology is continuously progressing, increasing capabilities and sensors along the way, future research may include more features related to body sensors, such as tilt, blood pressure and body temperature. Moreover, security with regards to the sensitive nature of the data handled by these sensors also needs to be tackled in future work.

8.3 Constraints and Limitations

The major constraints in this research are related to the availability of resources, both human and technical. Apart from lacking the availability of both professional and formal caregivers. More accurate indoor positioning methods are also a limit on this research. A point of mention is also required for the difficulty encountered when conducting research with the vulnerable subjects specified in this work.

References

Abela, S., Mamo, J., Aquilina, C. and Scerri, C. (2007). Estimated prevalence of dementia in the Maltese Islands. *Malta Med. J.* 19(2), 23–26.

Algase, D. L. (2006). What's new about wandering behaviour? An assessment of recent studies. *Int J Older People Nurs* 1(4), 226–234.

Alzheimer'sAssociation. (2011). Understanding Dementia: Signs, Symptoms, Types, Causes and Treatment.

Biswas, J., Sim, K., Huang, W., Tolstikov, A., Aung, A., et al. (2010). Sensor based micro context for mild dementia assistance. *Proc. 3rd Int. Conf. PErvasive Technol. Relat. to Assist. Environ. - PETRA '10*.

Courtenay, K., Jokinen, N. S. and Strydom, A. (2010). Caregiving and Adults With Intellectual Disabilities Affected by Dementia. *J. Policy Pract. Intellect. Disabil.* 7(1), 26–33.

Dale, Ø. (2010). Usability and Usefulness of GPS Based Localization Technology Used in Dementia Care. *Lect. Notes Comput. Sci.* 300–307.

Douglas, A., Letts, L. and Richardson, J. (2011). A systematic review of accidental injury from fire, wandering and medication self-administration errors for older adults with and without dementia. *Arch. Gerontol. Geriatr.* 52(1), e1–e10.

Eurostat. (nodate). European old-age dependency ratio.

Faucounau, V., Riguet, M., Orvoen, G., Lacombe, A., Rialle, V., et al. (2009). Electronic tracking system and wandering in Alzheimer's disease: A case study. *Ann. Phys. Rehabil. Med.* 52(7-8), 579–587.

Hermans, D. G., Htay, U. H. and McShane, R. (2007). Non-pharmacological interventions for wandering of people with dementia in the domestic setting. *Cochrane database Syst. Rev.* (1), CD005994.

Hoey, J., Plötz, T., Jackson, D., Monk, A., Pham, C. and Olivier, P. (2011). Rapid specification and automated generation of prompting systems to assist people with dementia. *Pervasive Mob. Comput.* 7(3), 299–318.

Hulme, C., Wright, J., Crocker, T., Oluboyede, Y. and House, A. (2010). Non-pharmacological approaches for dementia that informal carers might try or access: a systematic review. *Int. J. Geriatr. Psychiatry* 25(7), 756–63.

Kamel, B. M. N., Athanasios, A., Evangelos, B. and Mary, P. (2011). Geo-enabled technologies for independent living: Examples from four European projects. *Technol. Disabil.* 23(1), 7–17.

Lauriks, S., Reinersmann, A., der Roest, H. G., Meiland, F. J. M., Davies, R. J., et al. (2007). Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Res. Rev.* 6(3), 223–246.

Martino-Saltzman, D., Blasch, B. B., Morris, R. D. and McNeal, L. W. (1991). Travel Behavior of Nursing Home Residents Perceived as Wanderers and Non-wanderers. *Gerontologist* 31(5), 666–672.

Patterson, D. J., Etzioni, O., Fox, D. and Kautz, H. (2002). Intelligent Ubiquitous Computing to Support Alzheimer's Patients: Enabling the Cognitively Disabled. In *Ubicog '02 first int. work. ubiquitous comput. cogn. aids*.

Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., et al. (2007). Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health. Risk Soc.* 9(4), 389–406.

Satyanarayanan, M. (2001). Pervasive computing: vision and challenges. *IEEE Pers. Commun.* 8(4), 10–17.

Scerri, A. and Scerri, C. (2012). Dementia in Malta : new prevalence estimates and projected trends. *Malta Med. J.* 24(3), 21–24.

Siders, C., Nelson, A., Brown, L. M., Joseph, I., Algase, D., et al. (2004). Evidence for implementing nonpharmacological interventions for wandering. *Rehabil. Nurs.* 29(6), 195–206.

Vuong, N. K., Chan, S., Lau, C. T. and Lau, K. M. (2011). Feasibility study of a real-time wandering detection algorithm for dementia patients. *Proc. First ACM MobiHoc Work. Pervasive Wirel. Healthc. - MobileHealth '11*.

Weiser, M. (1991). The Computer for the 21st Century. *Sci. Am.* 265(3), 94–104.

Wherton, J. P. and Monk, A. F. (2010). Problems people with dementia have with kitchen tasks: The challenge for pervasive computing. *Interact. Comput.* 22(4), 253–266.

WHO. (2012). *Dementia: A Public Health Priority*. World Health Organisation.

Zhou, J., Su, X., Ylianttila, M. and Riekki, J. (2012). Exploring Pervasive Service Computing Opportunities for Pursuing Successful Ageing. *Lect. Notes Comput. Sci.* 73–82.

Zimmerman, S. (2001). *Assisted living needs, practices, and policies in residential care for the elderly*. Baltimore: Johns Hopkins University Press.