Monitoring and Detection of Agitation in Dementia

Towards Real-Time and Big-Data Solutions

Philip Moore
Faculty of Technology, Engineering and the Environment
School of Computing. Telecommunications & Networks.
Computing. Telecommunications & Networks.
Birmingham City University, Birmingham, UK.
ptmbcu@gmail.com

Leonard Barolli
Department of Information and Communication Engineering.
Faculty of Information Engineering.
Fukuoka Institute of Technology (FIT), Japan.
barolli@fit.ac.jp

Fatos Xhafa
Technical University of Catalonia,
C. Jordi Girona, 1-3, 08034,
Barcelona, Spain.
fatos@lsi.upc.edu

Andrew Thomas
Wales Centre For Behaviour Change
Adeilad Brigantia, Ffordd Penrallt,
Bangor, Gwynedd, Wales.
andrew@geocomputing.co.uk

***Abstract*—The changing demographic profile of the population has potentially challenging social, geopolitical, and financial consequences for individuals, families, the wider society, and governments globally. The demographic change will result in a rapidly growing elderly population with healthcare implications including Alzheimer type conditions (a leading cause of dementia). Dementia requires long term care to manage the negative behavioral symptoms which are primarily exhibited in terms of agitation and aggression. This paper considers the nature of dementia along with the issues and challenges implicit in its management. The Behavioral and Psychological Symptoms of Dementia (BPSD) are introduced with factors (precursors) to the onset of agitation and aggression. Independent living is considered, health monitoring and implementation in context-aware decision-support systems is discussed with consideration of data analytics. We postulate that the challenges lie in the effective realization of independent assisted living, achieving this remains an open research question.**

Keywords*—dementia, real-time health monitoring, assisted living; intelligent context-aware systems, big data.

I. BACKGROUND

There is a demographic time bomb that has potentially challenging social geopolitical and financial consequences for individuals, families, the wider society, and governments globally. The demographic change will result in a rapidly growing elderly population with healthcare implications including Alzheimer type diseases (a leading cause of dementia) [1]. Dementia requires long term care to manage the negative behavioral symptoms which are primarily exhibited in terms of agitation and aggression. Caring for patients with Alzheimer's disease and related disorders (ADRD) is estimated to cost 80 to 100 billion dollars annually [1].

In considering the prevalence of dementia there is a direct correlation between the demographic changes alluded to and the incidence of dementia [2]. The results of BPSD are manifested in suffering, premature institutionalization, increased costs of care, and significant loss of quality-of-life for the patient and h/her family and carers [2]. This brief overview identifies the scale of the problem and the issues around ADRD and dementia and demonstrates the correlation between an ageing population and dementia. To address the issues and challenges identified and provide for an increase in the *Quality of Life* (QoL) for patients and carers, while mitigating the burgeoning costs in managing patients with dementia and ADRD related conditions.

This paper considers the nature and management of dementia, introduces BPSD and identifies the precursors to the onset of agitation and aggression in patients with dementia. *Independent Assisted Living* (IAL) with e-Health monitoring to manage the BPSD using intelligent context-aware systems incorporating decision-support is discussed wit a discussion around data analytics. Finally the paper closes with conclusions and directions for future research.

II. DEMENTIA

Dementia is a degenerative condition [3] and is a progressive cognitive disabling disease which effects around 5% of people over 65 and in excess of 40% of people aged over 90. Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke. Typical symptoms include: (1) memory loss, (2) speech impediments, (3) deteriorating thought processes, and (4) impaired perception and reasoning [4].

Additionally, changes in personality, behaviour, and mood, which include: depressive symptoms, apathy, agitation, and aggression [4]. Alzheimer's disease (AD) is a leading cause of dementia and characterised by progressive cognitive impairment with neuropsychiatric symptoms such as anomalous motor behaviour, depression, anxiety, weight loss, irritability and agitation. The stages dementia have been modelled in [5] based on the *Behavioral and Psychological Symptoms of Dementia* (BPSD) [2]. The BPSD has gained acceptance from health care practitioners and in computer science research; seminal work being conducted by, for example, Cohen-Mansfield *et al*, see [6].

A 7 tiered conceptual model [5] sets out a graphical representation of BPSD in which patients with dementia are classified according to the severity of symptoms and their need for different levels of health care services, the seven tiered model is constructed as follows. The prevalence % are estimates; for tier 7 prevalence is the estimated percentage of people with dementia who fall into this category and for tiers 5 and 6 estimates are based on clinical observations in, for example, [7].

- Tier 1: No dementia. Management: universal prevention, although specific strategies to prevent dementia remain unproven
- Tier 2: Dementia with no BPSD. Prevalence 40%. Management: by selective prevention, though preventive or delaying interventions (not widely researched)
- Tier 3: Dementia with mild BPSD – e.g., night time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing. Prevalence 30%. Management: by primary care workers.
- Tier 4: Dementia with moderate BPSD – e.g., major depression, verbal aggression, psychoses, sexual inhibition, wandering. Prevalence 20%. Management: by specialist consultant in primary care.
- Tier 5: Dementia with severe BPS – e.g., severe depression, psychoses, screaming, severe agitation. Prevalence 10%Management: in dementia specific nursing homes or by case management under a specialist team.
- Tier 6: Dementia with very severe BPSD – e.g., physical aggression, severe depression, suicidal tendencies. Prevalence <1%. Management: in psychogeriatric or neurobehavioral units.
- Tier 7: Dementia with extreme BPSD – e.g., physical violence. Prevalence rare. Management: in intensive specialist care unit.

In considering ***tier 1***, this can be managed by regular consultations with healthcare professionals where diagnosis and management can implemented however while management of the condition can be achieved through universal prevention, specific strategies to prevent dementia remain unclear [5].

Tiers 6 and ***7*** require institutionalisation and retention of a domestic living arrangement is impractical and potentially dangerous for both patients and carers. ***Tier 5*** is more problematic as management [of the patient] may be in: "dementia specific nursing homes or by case management under a specialist team.

Thus, for ***tier 5*** patients the spectrum of BPSD severity varies; as such there may be patients within ***tier 5*** who display symptoms and behaviours closely related to ***tier 4*** behaviours who may be capable of remaining in a domestic environment while monitored. For a patient classified as ***tier 5*** IAL is patient specific and whilst there may be a case made for retention of IAL arrangement the likelihood is that institutional care is the sensible option. In considering ***tiers 2, 3***, and ***4*** the status'(s) classified under these tiers offer the optimal scope for retention of IAL supported by 24/7 remote monitoring using sensor technologies with mobile technologies.

Based on this analysis retention of IAL for domestic settings can be restricted to ***tiers 2, 3***, and ***4*** with possible ***tier 5*** patients displaying behaviours closely related to tier 4 patients as set out in the 7 tier model. This conclusion is supported by the observations in [5]; from a dementia management perspective the estimated prevalence of BPSD in dementia patients in specific tiers is: 40% for ***tier 2***, 30% for ***tier 3***, 20% for ***tier 4***, 10% for ***tier 5***, and 1% for ***tier 6***. The incidence in ***tier 7*** is noted as 'rare'. In practice the clear demarcation between the tiers is not realistic as the boundaries are fuzzy however the conclusions drawn from the analysis remain valid.

From this analysis it can be seen that the manageable tiers from an IAL perspective (tiers 2, 3, and 4) represent 90% of the population of patients with dementia and retention of IAL for these cases (plus the identified cases in tier 5) present opportunities to improve the QoL for patients and carers while realising significant financial savings for all stakeholders in the management of ADRD and dementia.

There is a large body of documented research addressing Alzheimer type conditions in general and dementia in particular [5][6][7]; the literature reviewed has focused on agitation and aggression as these behaviors relate to dementia. Agitated behavior is one of the most frequent reasons that patients with dementia are placed in long-term care settings. These behaviors are indicators of distress and are associated with increased risk of injury to the patients and their caregivers [8]. Biswas *et al* [9] have noted that Agitated behavior is common in patients with dementia and represents a challenge for all stakeholders in dementia management. There is a consensus in the literature that for dementia agitation and aggression represent not only a serious problem but is also frequently a tangible manifestation of other negative behavioral issues.

III. The Precursors to the Onset of Agitation

The symptoms and behaviors identified as they relate to BPSD are addressed in [3] and are classified under 6 neuropsychiatric symptoms: (1) anomalous motor behaviour, (2) depression, (3) anxiety, (4) weight loss, (5) irritability, and (6) agitation. These classifications provide realistic headings under which the precursors to manifestation of the BPSD can be modelled for use in implementing IAL.

Firstly, symptoms of dementia which Pugh *et al* [3] consider are not amenable to monitoring in smart and assisted living environments. These symptoms relate to depressive states; we would argue that the monitoring of such states is possible as discussed by Peng *et al* [10]; therefore we will include the precursors to depressive states in the list of precursors discussed in this paper. The 6 neuropsychiatric symptoms [3] represent classifications of precursors which are potentially amenable to automated sensor-based monitoring in IAL if suitable non-invasive sensor-based monitoring and data capture in a machine processable formalism can be identified and implemented. This is discussed in subsequent sections of the paper.

A. Anomalous motor behaviour

Anomalous motor behavior (AMB) can be viewed as physical movement including location-based behaviours such as wandering as discussed in the literature review. Additionally, verbal behaviours as identified can be viewed as motor behaviours. Such behaviours are amenable to monitoring using a range of sensor technologies including blind video monitoring and non-medical grade sensors.

B. Depression and Weight loss

Changes in a dementia patients weight (generally weight loss however weight gain may be an indicative factor) is a significant precursor of dements behaviour driven by: failure to eat a good diet (often patients forget to eat a prepared meal) or anomalous motor behaviour in terms of anomalous behaviour relating to either excessive movement (a precursor of agitation, aggression, mania, or general restlessness) or alternatively too little movement which may be an indicator of a depressive state which has a reported frequency in a patient population of 80% in the BPSD scale [2][6].

Two potential sensing approaches are possible: (1) regular weighing using smart scales, and (2) sensor technologies to measure the levels of movement. Research conducted by James Levine *et al* [11] addresses the measurement of movement as it relates to obesity. Whereas in dementia the measurement (generally) relates to excessive motor behaviour (i.e., weight loss is an indicator) Levine *et al* targets the lack of exercise (resulting in weight gain). Notwithstanding the differing focus of the research the approach adopted by Levine *et al* may be useful in monitoring the motor behaviours in dementia patients (both for weigh loss and weight gain). In their original work the energy generated by sensors located in clothing was intended to measure a lack of exercise; the converse can be applied to dementia patients to measure excessive exercise.

C. Anxiety / Irritability / Agitation

This is perhaps the most important category of demented behaviour is agitation; irritability and anxiety are arguably related to agitation and may share many of the symptoms. Such symptoms and behaviours have been shown to lead to aggression which is an issue for patients and carers alike. Agitation, anxiety, and irritability may be monitored using blind video monitoring and non-medical grade sensors; there is however a potential need to include physiological measurements such as [12]: Galvanic Skin Response (GSR), Blood Volume Pressure (BVP), Heart Beat (HB), respiration, EEG, ECG, etc.

IV. IMPLEMENTING INDEPENDENT ASSISTED LIVING

Having considered the relevant metrics that relate to agitation and aggression in dementia and identified the precursors (data points in computational terms) to the onset of agitation and aggression we now turn to the challenge of implementing IAL using the precursors to trigger graduated interventions. From a practical perspective implementation of IAL essentially relies on three components: (1) the data structure used for *in memory* and *persistent* storage of data (contextual information), *computational modelling*, (2) data capture using sensor networks realized using ‘smart spaces’ with wireless networked and / or mobile communication technologies with interfaces to the software (context middleware) defining the appropriate data types and format, and (3) context middleware to process the captured contextual information (sensor derived data) with visualization in an appropriate format.

A. The Data Structure (Computational Modelling)

Identifying the precursors demands the modelling of the domain of interest (context modelling); this has been addressed in [13][14] where O*ntology Based Modelling* (OBM) has been identified as the optimal approach. OBM provides a generic, non-hierarchical, and readily extensible structure capable of adaptation to suit the domain specific nature of context with the capability to define the metadata, the context properties, and the literal values used in the context-matching process. Additionally, while the approach presented in this paper does not currently use inference and reasoning (which generally applies subsumption and entailment).

Context modelling is designed to enable the mapping of context properties and their literal values with a comparative analysis of data points (such as environmental parameters), proximate information (social parameters), and motion (spatio-temporal parameters). Motion is reflected in movement and position (e.g., vertical or horizontal) in space and time. OBM implemented using Semantic Web technologies (e.g., OWL) [17] implemented using the Jena API [18]provides the basis upon which data storage with accessing and updating to be used in the comparative analyses.

In considering dementia the modelling of BPSD has been investigations by Hurley *et al* [15] have resulted in the development of the SOAPD ontology. A number of implementations of systems designed to model dementia use the SOAPD ontology including [16] to enable the development of sophisticated systems that facilitates caregiving and clinical assessment of dementia patients. The SOAPD ontology [15] addresses the domain specific BPSD parameters thus enabling the implementation of current states (contexts) with updating over time in ‘real-time’ with ‘Big Data’ solutions as discussed in this paper.

B. Sensors and data capture

The nature of the data required to identify and measure the data points (the precursors) relate to the 6 neuropsychiatric symptoms identified in [3]. It is apparent from the discussion on precursors and symptoms that progression of dementia through the seven tiers is characterised by significant changes in behaviour. The most appropriate changes for use with sensing appear to be based around location, motion and sound. For instance, in terms of sound, it is possible to diagnose conditions such as Parkinson's Disease through an analysis of spoken words, even in the early stages (see e.g. www.parkinsonsvoice.org). Figure 1 shows an android app designed to monitor trembling in Parkinson's patients, this has a synergy with dementia where monitoring of a patients changing 'state' in 'real-world' e-health monitoring situations is concerned.

Fig. 1. Measuring hand trembling using an Android smartphone.

Sound can also be used as part of systems for emotion recognition as discussed in [19], this may help to inform diagnosis at Tier 3 and above. More significant verbal outbursts above Tier 3 (and even repetition at lower tiers) are obvious candidates for use of microphone-based sensors which, especially when worn on the body, need not provide any privacy concerns as actual voice data need not be recorded. It is also apparent that pitch and amplitude data, from microphones, can provide significant monitoring data in the detection of verbal aggression and screaming in tiers 4 and above.

As far as motion is concerned, monitoring behaviour changes through video is likely to be considered highly intrusive, although to a reducing extent as a patient moves toward the higher tiers. So, in Tiers 6 and 7, where violence (to oneself and others) is a real risk, it is likely to be an expected form of monitoring (e.g. CCTV in a care home). Therefore, it is that perception of intrusion that is likely to, at least in part, dictate the sensing techniques that can be used. So, where computer vision is considered appropriate it also has the advantage of being able to provide more information than simple motion-related data. For instance, a significant problem in older people is ensuring adequate nutrition, especially where patients may forget to eat. In that scenario, CCTV can be used to monitor body-mass changes [20].

Shadow data from cameras is likely to be more appropriate for lower tiers, however, where systems such as those of [21] can provide information on gait using the Microsoft Kinect sensor. For both CCTV and shadow data, it is possible to detect the problem of wandering (e.g. Tier 3/4 and above) and unattended exit, the Kinect in particular having the advantage of simpler three-dimensional location estimation. Similarly, location-contexts are likely to provide significant behaviour data and can be measured also through proximity switches and radio-module signal strength measurement (e.g. Bluetooth, WiFi, Zigbee, and suchlike). In some contexts night-time wandering can be dangerous, and so monitoring systems such as those discussed in [22] can help reduce risk. It has been suggested that temperature perception alters for dementia sufferers, and associated discontent can be expressed through problematic behaviour [23]. Also, analysis of light levels and spectral components within a care environment can provide useful clues in terms of sleep problems, see e.g., [24]. It is therefore possible that monitoring of dementia sufferers environment, comfort level and any adjustments they make to heating/cooling controls, could add to longitudinal data for diagnosis. In fact, a wide variety of links have been suggested between environment sensor data and medical conditions such as dementia, a fuller discussion being available in [25].

Finally, it should be noted that many of the above factors can be monitored through Smartphone use, as well as static and body-mounted monitoring systems. Smartphones are likely to be used by sufferers through many tiers of dementia, and include sensors such as accelerometers, gyroscopes and microphones suitable for event detection and longitudinal data collection. For carers and clinicians they can also be used for logging of symptoms, problematic-events and emotion data that can enhance longitudinal analysis of sensor data (i.e. humans as sensors into their own, and others, states).

V. Data Processing

The processing of the captured data into useful information can be viewed under two headings: (1) in 'real-time' data processing in e-health monitoring, and (2) the processing of data in 'big-data' solutions in which data is mining is applied to realise long-term prognoses.

The goal of 'real-time' data processing in a health monitoring scenario is to measure a patients current state at time t0 and the changed state a time t1 (the time intervals between t0 and {t1 … tn} will be defined by the clinician and will be patient and condition dependent). The current *high end* Smartphone's offer the prospect of implementing local data processing with decision support thus enabling remote health monitoring. Health monitoring clearly involved a very large volume of data. The requirement in 'real-time' health monitoring is for health monitoring applications which can run on low-powered devices (such as high-end mobile phones) and can process the sensor derived data to reach instant decisions relating to a patients dynamic state at times {t0 .. tn}. Ideally, health monitoring systems will only communicate current patients state if there is an issue or problem (see the brief illustrative scenario later in this article). Where there is no change the system will not react. Clearly there is a requirement for any number of reasons for the patient monitoring information to be sent at periodic intervals for logging and possibly further analysis. The intervals at which such uploading of the collected data is made is again a clinical decision. The analysis of the data from multiple patients can be viewed as a big-data challenge.

'Big-Data' (it has been observed that the term is a 'buzz-word' and has formerly been known as data mining amongst other similar terms) relates to a scenario in which very large volumes of data are gathered and processed to identify (in the case of health monitoring systems) trends in the data and potential prognoses based on the data collected and results obtained from multiple patients. Clearly, big-data solutions require massive data storage and computing power (as opposed to the 'real-time' data processing). An exemplar of a big-data analysis can be seen in the brief illustrative scenario later in this article.

Central in the proposed approach to data processing is the processing of captured data (contextual information); the posited approach uses a *Context Processing Algorithm* (CPA) [13] which provides a basis upon which contextual information can be processed while with constraint satisfaction and *predictable* decision support (an essential consideration in, for example, health monitoring which whilst arguably fuzzy in nature must result in clearly defined decisions relating to a patients current and changing state / prognosis. Essentially, the context-matching process is one of reaching a Boolean decision as to the suitability of a specific individual based on context [13]. Given that a perfect match is highly unlikely the CM algorithm must accommodate the PM issue along with a number of related issues as discussed in [13]. In CM the probability of a perfect match is remote therefore *Partial Matching* (PM) must be accommodated.

The CPA is predicated on the *Event:Condition:Action* (ECA) rules concept, the <condition> component employing the IF-THEN logic structure [13] which relates to the notion of <action> where the IF component evaluates the rule <condition> resulting in an <action>. The <action> in the proposed approach can be either: (1) a Boolean decision, or (2) the firing of another rule.

To address the PM issue the CPA applies the principles identified in fuzzy logic and fuzzy sets with a defined membership function which is predicated of the use of decision boundary(s) (thresholds) [26] as discussed in [13]. The membership function provides an effective basis upon which predictable decision support can be realized using both single and multiple thresholds to increase the granularity of the autonomous decision making process. Conventional logic is generally characterized using notions based on a clear numerical bound (the crisp case); i.e., an element is (or alternatively is not) defined as a member of a set in binary terms according to a bivalent condition expressed as numerical parameters {1, 0} [27]. Fuzzy set theory enables a continuous measure of membership of a set based on normalized values in the range [0.0…1.0]; these mapping assumptions are central to the CPA [13]. The processing of contextual information in context-aware systems imposes issues similar to those encountered in decision support under uncertainty, which is possibly the most important category of decision problem [28] and represents a fundamental issue for decision-support. In summary, the CPA provides a basis upon which decisions under uncertainty with high levels of predictability can be realised. A discussion on the CPA, rule strategies, and the related conditional relationships for intelligent context-aware systems with example implementations and a dataset evaluation can be found in [13].

VI. Conclusion

This paper has introduced the background and motivation for the growing concern regarding Alzheimer type conditions in general and dementia in particular. The BPSD has been discussed and the 7 tier model [5] has been presented with conclusions drawn on the appropriate stages of dementia which can be addressed using health monitoring techniques in IAL in a computerized system. The overall conclusions are that behaviors tiers 2, 3, 4, and possibly 5 may be monitored with the aim of enabling a demented patient to remain in a domestic environment for longer with benefits for the patients QoL, family, the healthcare system, and the wider society.

Consideration has been given to the precursors to the detection of the onset of agitation and aggression in patients with dementia along with references to sensor technologies. In data intensive context-aware systems the basic component technologies exist are all currently available and widely researched . Such technologies include: mobile systems and the related infrastructures, sensors, smart appliances, wireless mesh architectures, cloud services, and data brokerage/processing. While there is a need for the development of non-invasive sensor technologies (as discussed in subsequent sections of this paper) the basic sensor and communications technologies are generally well developed. The challenges lie While there is a need for the development of non-invasive sensor technologies (as identified in this paper) the basic sensor and communications technologies are generally well developed [29]. The challenge lies in the development of intelligent context-aware systems software capable of processing the sensor derived data in context-aware decision-support systems capable of implementing enhanced levels of computational intelligence.

Health monitoring for patients with dementia has been discussed and agitation and aggression identified as a major problem. Agitation may be viewed in terms of an emotional response to a range of stimuli [30]. This is addressed in [30] where the nature of knowledge is considered along with cognitive conceptual models and semiotics [31][32][33]; the use of these approaches to tacit and explicit knowledge representation including the use of *valence* [30][34][35] offers exiting potential opportunities to model agitation (stress) in patients with dementia to enable graduated interventions. This however currently represents an open research question.

While the research discussed in this paper has begun to resolve a number of issues relating to the processing of contextual information, including potentially the data that relates to emotional response, a number of challenges identified remain as open research questions. Such questions relate to: (1) the identification of the data (knowledge) that identifies emotional responses, (2) the development of a [non-invasive] approach to data capture of such information, (3) the development of a suitable Semiotic grammar and valence measurement system for emotion, and (4) representing the knowledge (data) in a suitable data structure. Currently OBM represents the optimal solution to the storage of a context; it is however recognized as an effective but sub-optimal solution. For a discussion on the issues and challenges identified in the research with consideration of potential solutions see [13].

The health monitoring introduced in this paper, while focusing on ADRD and dementia has the potential to generalise to a range of conditions where IAL forms a desirable aim (e.g., post-operative care in a patients own home). The potential is very exciting and represents a potentially profitable direction for research with benefits for all stakeholders in health care.

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