Dementia and social sustainability: challenges for software engineering

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***Abstract*— Dementia is a serious threat to social sustainability. As life expectancy increases, more people are developing dementia. At the same time, demographic change is reducing the economically active part of the population. Care of people with dementia imposes great emotional and financial strain on sufferers, their families and society at large. In response, significant research resources are being focused on dementia. One research thread is focused on using computer technology to monitor people in at-risk groups to improve rates of early diagnosis. In this paper we provide an overview of dementia monitoring research and identify a set of scientific challenges for the engineering of dementia-monitoring software, with implications for other mental health self-management systems.**

***Index Terms*—Software engineering, Dementia, Social sustainability.**

I. Introduction

In this short paper we argue that mental health problems in ageing populations are a threat to social sustainability, that software has a role to play in mitigating this threat and that developing such software poses a set of distinct challenges to software engineering (SE).

Across most of the world, life expectancy is increasing. In the developed world, this is a trend that has continued with few breaks, other than for major wars or pandemics, since the 19th century [1]. In the UK, by no means the healthiest of developed countries, the current average life expectancy of males and females has risen from 50 to 79 and from 53 to 83 (respectively) since 1911 [2]. This trend has serious implications for nations' economic sustainability, e.g. with respect to funding pension schemes. However, a wider societal challenge, one that includes but goes beyond a purely economic challenge, is that as more people live into old age, more people are developing age-related diseases. Ensuring they receive adequate care is imposing strain on them, their caregivers and health services.

Among the age-related diseases is dementia, a fatal condition caused by a range of diseases including the most common, Alzheimer's Disease (AD), but also fronto-temporal dementia, vascular dementia, lewy body dementia and others [3].

Software has a role to play in combatting dementia. However, dementia confronts software engineers with a particular combination of challenges. We concentrate on dementia in this paper because it is the focus of our own research, and because of the severity of the challenge it poses to social sustainability. However, the challenges dementia poses SE are the same or similar to those of a range of other mental health disorders. We explore these challenges to propose a research agenda for SE.

II. Background

Dementia is common in older people, affecting around one in six people at the age of 80. Taking the UK as an example, dementia currently costs £26.3b annually and the number of people living with the condition is predicted to increase from the current 850,000 to over 2m by 2051 [3]. In many countries demographic change is reducing the number of economically productive people, both as a proportion of the overall population and (due to declining birth rates) as an absolute number. Through their taxes, this economically active group funds the public health systems that provide for dementia sufferers' care. The group is further depleted by people surrendering jobs in order to care for elderly parents and relatives, including those with dementia.

Thus dementia poses a serious economic and human capital threat to social sustainability and this was reflected by the December 2013 G8 Dementia Summit [4]. Governmental concern is being turned into action, including increased spending on research, with software increasingly seen as part of the solution. For example, the UK's research funding council for ICT (EPSRC) recently launched a c. £5m Sensing and Imaging for Diagnosis of Dementias programme.

One of the goals of current research is to find ways to detect dementia when it is still at an early stage. Early diagnosis can help improve quality of life by treating debilitating side effects, such as depression. In the longer term, improved therapies will become available, but these will have to be administered early before the damage to the brain becomes so severe as to render the therapy ineffective.

To help achieve the goal of early diagnosis, software solutions are being sought to assist with the non-invasive detection of dementia biomarkers and indicators of cognitive health (cognitive indicators – CIs). Many diagnostic tools are designed for a clinical setting, such as those using MRI scanners. Such techniques presuppose that someone is referred for investigation. However, one of the reasons why so many people with dementia go undiagnosed (over 50% of those dying of dementia in the UK [3]) is that they never report their symptoms to their doctor. To counter this problem, a newly emergent thread of research is to find ways to monitor at-risk groups (e.g. people over 65 years). Our own research falls into this category [23].

III. Related Work on Monitoring for Dementia

At present, clinicians use tests (sometimes called *cognitive batteries*) such as the Mini Mental State Examination to assess patients' cognitive health for signs of dementia or its harbinger Mild Cognitive Impairment (MCI). Most of these are pencil-and-paper tests, but a number of on-line tests have also been developed, such as Cognitive Testing on Computer (C-TOC). However, tests are vulnerable to sampling errors because they take place only infrequently. The tests also have poor ecological validity because they take the subject out of their normal routine, perhaps inducing anxiety that can affect the results. Finally, the tests rely on a person presenting themselves for examination by their doctor.

Mobile computing offers the opportunity to address the sampling error problem and improve ecological validity by enabling Ecological Momentary Assessment (EMA) [5]. EMA has been used to study the dynamics of behaviour in real-world settings, including the monitoring of stress in dementia caregivers [6]. A major motivation for EMA is the elimination of recall bias and a common mode of use for EMA is to prompt subjects to record (e.g.) their actions or emotions on a smartphone app in real time during the day.

A different approach to achieving good ecological validity and low sampling errors is to use monitoring, where rather than requiring subjects to consciously engage with a task, data is collected as subjects go about their normal business. A good example in the dementia domain is the work of Jimison et al. [7] who monitored activity using mobile phone location sensors. In a longitudinal study of healthy and MCI cohorts, individual traces of activity were analysed. Exception patterns emerged that showed that the MCI cohort had lower levels of activity and more idiosyncratic patterns [8].

Monitoring has also been a major theme of assisted living environments in which data is collected from sensors in a specially instrumented domestic environment. One variant of this is Cognitive Assistive Technology (CAT), which specifically seeks to aid people with cognitive deficits. A good example is COACH [9], which is aimed at people whose decline in executive function makes it hard for them to complete everyday tasks, such as dressing or washing. COACH collects data from video and sensor data monitoring, and uses Hidden Markov Models to infer actions and user capabilities. It uses this information to select feedback messages to motivate behaviour change.

Increasing numbers of older people are computer users [10], and this presents an opportunity to monitor their interaction with a computer to infer cognitive deficits. Many websites offer cognitive ability and training games. Tong et al. describe a game that measures reaction time and uses the results to evaluate the CIs attention, executive function, perception and motor abilities, and provides calibration against a normal range of performance [11].

Hagler et al. developed a join-the-dots game based on a paper trail marking test to record latency, mouse moves, and task completion time [12]. A limited cognitive model of executive function proposed a three-phase process of recall target (number/letter), search (depends on distracters), and motor movement time using Fitts Law. Another game-based (pontoon, 21s) evaluation uses card choice as a surrogate for the attention CI, with different game board layouts [13].

The relationship between performance in a game and the cognitive functions used to play the game is much less developed than that between performance in a cognitive battery test and the CI(s) needed to complete the test. However computer games can be designed, or existing games instrumented, to collect data that is suggestive of particular cognitive functions and there are results that suggest that significant indicators of cognitive health can be obtained. Jimison et al. [14] are perhaps the most advanced in this area, and have developed a framework of computer-based measures for games-based interaction linked to CIs.

A disadvantage of using games to collect assessment data is that the health assessment function of the game is more-or-less explicit; it is clear to the subject that by playing the game, they are undergoing a form of examination. This is fine for people who enjoy playing the game. They will generate monitoring data for as long as the game retains its appeal. A further group, e.g. the so-called "worried well", may engage with the game because they *want* to have their health assessed. Since this group is primarily motivated by health concerns, it arguably doesn't need the health monitoring function to be disguised behind a game-laying façade. Such users would be better simply taking a test at periodic intervals. Critically, many people will neither play the game for fun nor want to have their health assessed explicitly. Perhaps they don't worry about their health, or perhaps they *do* worry about their health but fear diagnosis. For this group, an alternative is to use passive monitoring. Here, people do not perform tasks designed to generate monitoring data. Rather, monitoring data is collected as users perform tasks they want or need to do. For example, Jimison et al. use the computer keyboard and mouse for monitoring and collecting data on (e.g.) events and durations [7]. Deviations from smooth mouse movements were analysed from data collected from cohorts of healthy people and people with MCI, showing showed reliable differences over time.

Our own research in the SAMS project [23] also focuses on passive, opportunistic monitoring of computer use, collecting data at a number of levels. These range from low-level event data from the keyboard and mouse, to data about task performance, both generic (e.g. menu selection) and application-specific (e.g. composing an email). We also capture text written by the subject to look for the language deficits such as low idea density [15] that are characteristic of how linguistic ability declines in dementia. In the MODEM project, we also take a passive data collection approach, but this time using ambient eye-tracking. Eye movement and cognitive health are closely linked and there is growing evidence that eye movements are robust indicators of dementia [16].

IV. Challenges

Software support for dementia care poses a range of challenges. These are partly computational challenges where a solution is needed to derive results from sparse and noisy data, and partly process challenges where how software in this space is specified and validated needs a tailored but as yet unknown mix of techniques. While some of these challenges have partial progress towards a solution, others are unexplored.

A. Diagnostic Models

With passive monitoring the everyday tasks performed by the subjects will seldom map cleanly onto the CIs we wish to measure. A large gap currently exists between the clinical understanding of the cognitive deficits that result from dementia and how these can be measured from data collected opportunistically. As yet there is no diagnostic model of dementia that can be exploited.

It is worth contrasting how cognitive batteries have evolved and contrast these with the goal of assessment by passive monitoring. It has long been known that deficits in working memory (to pick on one CI) are characteristic of dementia, so paper tests were devised to exercise working memory directly, such as asking the subject to recall a list of numbers given to them a little earlier. Similar tests were designed for other CIs. These tests for different CIs can be combined in a cognitive battery and a score computed that serves as a measure of cognitive health. With passive monitoring by contrast, we may know that certain tasks, such as finding an application command contained in a pull-down menu bar, require the exercise of working memory. We may therefore instrument the application with a monitor to detect when someone has to hunt for the command. However, we cannot be sure that increased frequency of hunting is due to a memory deficit. There may be learning effects that distort the subject's actual performance. Similarly, infrequent use of the command will yield data that is only sparse and therefore unreliable. Some monitored actions will involve more than one CI. For example, tasks commonly involve a combination of executive function, working memory and attention so errors observed in these actions may be suggestive that something is wrong but hard to interpret or know how much evidential weight to ascribe.

Given this uncertainty, a diagnostic model will have to be induced from hypothesis-driven data-mining of monitored data, that seeks to link the observations to the CIs, and which presents the results to expert clinicians for validation – probably in a set of scenarios. If this works, there is a further scientific challenge to operationalize the induced model. Machine learning techniques will be needed to combine partial sources of evidence to derive a robust diagnostic result. These scientific challenges come with two engineering challenges. First, large-scale controlled trials of the pilot software monitors will be necessary for validation. Second, agreement will be needed on the acceptable sensitivity of the software. What levels of recall and precision can be tolerated as a trade-off between failure to diagnose genuine problems and minimising the anxiety caused by false positives?

B. Self-Adaptation

To be effective, dementia monitoring software would have to be widely deployed across a subset of the at-risk population. This population is likely to have a wide range of habits, inhabit different domestic environments and use computers and devices with different configurations and running different applications. Configuration of the monitoring software would be needed at installation but the software would also need to adapt to change over time. This change could encompass change to the monitor's physical and computational environment and change in the users themselves. Users' cognitive health might decline but even if it didn't, they might do different things, adopt different habits and change their patterns of computer use. All this means the software would need to be capable of dynamically adapting, where this adaptation might involve changing the data collected, its sampling rate, the weights given to partial bits of evidence and so on. Dementia monitoring software is therefore likely to have to be self-adaptive, using mechanisms such as awareness requirements to drive adaptation [17].

C. Technology Acceptance

Use of dementia monitoring software is discretionary, so technology acceptance is a key factor in the software's requirements. Conventionally, technology acceptance is thought to be determined by perceived usefulness and ease-of-use [18]. It is strongly affected by user personality factors; positively by (e.g.) a predisposition towards innovative technology [19], or negatively by (e.g.) anxiety and mistrust, particularly relevant in the healthcare domain.

In the wider healthcare systems literature, Garde and Knaup [20] argued for a grounded theory approach to RE in healthcare to deal with the complexity of the domain and socio-political issues. Cysenieros [21] suggested that technique combination might be most effective for healthcare RE. Technique combination (scenarios, prototypes and linguistic corpus analysis) was successfully applied to a healthcare decision support system [22], and adapted to SAMS [23] where we combined conventional workshops and scenarios with a follow-up thematic analysis of requirements issues, reactions to designs, emotional, ethical, security and privacy concerns. The privacy concerns were essentially about who should have access to the monitored data and any inferred assessment of the user's health. A key result was that most of the subjects didn't want their family doctor to have access to the data. Consequently, if a problem is inferred, the system needs to issue an alert encouraging the user to take a follow-up on-line test or visit their family doctor.

There are two implications of this. First, more work is needed on technology acceptance for affect-loaded discretionary use systems, like dementia monitoring systems. More understanding is needed of how peoples' values, motivations and emotions [24] can be discovered and what their impact is on systems' design. Second, more research is needed on how to motivate someone to do something they perhaps would rather not. This is a live issue with (e.g.) applications to encourage people to give up smoking or exercise more, but it also applies to dementia monitoring systems that may need to encourage users to admit to themselves that something is wrong and present themselves for clinical examination.

V. CONCLUSIONS

We have described a set of challenges posed by an emerging class of Dementia monitoring systems. These challenges are not necessarily unique to dementia monitoring, as (e.g.) mobile devices and ambient systems are increasingly being investigated for monitoring, behaviour change and even medical interventions for a wide range of health conditions such as depression and obesity. However, the scale of the dementia problem, and the threat that dementia poses to social sustainability, makes it pertinent to address the dementia-monitoring challenges now, some of which are in any case likely to be common to other kinds of healthcare technologies.

The key commonalities between the challenges we have identified are that they require new ways of working, whether inducing the relationship between the data collected from instrumenting user tasks or understanding what causes a user to adopt and keep using a monitoring technology or reject it, outright or stop using it after a period of use.

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