Computing Technologies for Reflective and Creative Care for People with Dementia

Neil Maiden, Sonali D'Souza, Sara Jones, Lars Muller, Lucia Panesse, Kristine Pitts, Michael Prilla, Kevin Pudney, Malcolm Rose, Ian Turner, Konstantinos Zachos

Abstract

Digital technologies have much to offer the care for people with dementia. However, their uptake so far has been slow. In this article, we report the introduction of sensor and mobile technologies and applications to support carers of people with dementia in residential homes to be more reflective and creative. Results revealed that carers can and want to use these technologies, but more effective app alignment with different dementia care strategies will be needed to achieve widespread technology take-up.

1. Residential Care for People with Dementia

Dementia is a condition related to ageing. Symptoms range from memory loss to decreased reasoning and communication skills [Graham & Warner 2009]. The number of people with dementia worldwide is estimated at 35 million, a figure expected to double in the next 20 years [Wimo & Prince 2010]. People with dementia in economies where attaining great age has become the norm are increasingly cared for in residential homes by paid carers – typically busy women, often mothers and housewives, not highly paid, practical, and under-pressure to balance care and administrative duties [Help The Aged, 2006 p.33]. Their work is often afforded low social status, which contributes to high staff turnover and numbers of inexperienced carers [All-Party Parliamentary Group on Dementia, 2009]. Increasing the quality of care given in such constraining environments has become a pressing issue [Department of Health 2012].

In residential homes, digital technologies have the potential to improve the quality of the care given, reduce paperwork and raise the social standing of care work. Currently, however, most care homes have just one or two desktop computers with which to manage their finances and resident records. Wireless networks remain uncommon, and residents themselves rarely have access to email or social media. Indeed, technologies sometimes have been perceived to place additional pressures on carers [SCIE, 2010]. Moreover, managers have often lacked the skills needed to introduce and advocate digital technologies [SCIE 2010], although the situation is changing as Internet and mobile computing have become commonplace. Recent initiatives such as the UK Government's Get Connected programme have further increased the technological readiness of homes. For the first time, the foundations for the use of digital technologies in dementia care in residential homes are in place.

2. Digital Technologies for More Reflective, Person-Centred Care

In particular, digital technologies have the potential to support the care sector's move to more person-centred care. Person-centred care is an individualized

approach to care that recognizes the uniqueness of each resident, seeks to understand the world from the perspective of each resident, and provides a social environment that supports psychological needs [Brooker 2007]. The sector now recognizes that digital technologies have the potential to provide the right information about the right resident at right time, as well as deliver more cost-effective training to new carers.

Digital technologies have already been introduced to support people with dementia maintain a sense of self. For example, Hanson et al. [2007] report positive results with a digital support service for people with early dementia as long as core usability problems are resolved. Wallace et al. [2012] report the use of digital devices designed as furniture pieces to provide notions of home, intimacy and possessions with which to develop a sense of personhood. Whilst evidence suggests that these digital pieces have led to improved communications between carers and residents, we believe that digital technologies designed primarily to support carers in their work can more effectively deliver the person-centred care that is required.

Electronic care systems already provide carers with direct access to resident data, however this does not necessarily guarantee that carers can understand the world from each resident's perspective. Indeed, learning something new about a resident can be triggered by obscure resident behaviours that a carer observes then reflects on with respect to a resident's past to discover possible explanations [Stokes 2008]. A carer must often return to the care experience to re-evaluate it, attend to feelings about it, then generate new perspectives on the experience in order to change the care to be given. Such behaviour is consistent with established general models of reflective learning [Boud et al. 1985]. Although digital technologies can support such event-driven reflective learning, there has been little research – until now.

The EU-funded Mirror Integrated Project [Mirror 2012] has been investigating new forms of digital technologies to enable reflective learning about residents. In this article, we report how these technologies are intended to bridge the current gap between the increasing volume of digital data about each resident that is available and the learning that carers need to achieve to deliver more person-centred care.

3. Digital Technologies in Care Homes

The successful uptake of digital technologies in residential homes has proved challenging. Muller et al. [2012], for example, report that parachuting in existing technologies into residential homes is unlikely to be effective. Instead, new designs need to be framed by important socio-technical themes such as sociality and trust. To discover the socio-technical themes relevant to dementia care in residential homes, we observed and interviewed carers then led co-design activities at pilot homes in the United Kingdom.

The observations and interviews revealed that most dementia care is mobile and physical. Carers used paper documents to record access information about residents. Indeed, these documents were often used as workarounds to obstacles posed by existing digital technologies. For example, carers often supplemented their

observations with written notes on information sheets located next to desktop computers that they used to enter more detailed notes into the electronic care systems later on. However, the resulting delays to recording care notes, exacerbated by queuing with other carers to use the computers, led to poor recorded data quality.

Therefore, as part of the co-design activity, we facilitated carers in one pilot home to role play care activities with different mobile objects. Outcomes revealed that mobile computing has the potential to:

- Provide more effective support for carers than for residents whose interactions with mobile devices are often impeded by physical and cognitive impairments;
- Deliver a single source of information about residents: carers often struggle to retrieve and communicate information about residents' from disparate paper sources;
- Reduce the distance between personalized care and information**:** care work was event-driven and frequently interrupted, and carers often need to access to update resident information at unpredictable times;
- Reduce memory load on carers**:** carers often had to rely on memorized information to deliver individual care: mobile solutions can reduce the amount of information about residents and care tasks to be remembered;
- Coordinate collaborative work using shared external representations of it: social interactions alone were insufficient, and external representations of this work on mobile technologies have the potential to enhance coordination of care work;
- Moreover, reducing the volume of information to be memorized during care work might free up the cognitive resources needed for effective reflective learning, and more immediate access to resident data can both trigger and enable that reflection.

Therefore, in the Mirror project, we investigated new mobile digital technologies with which to support person-centered care and reflective learning about people with dementia. These solutions are made available to carers through the *Dementia App Sphere*, a collection of inter-operable mobile apps that support dementia care and reflective learning in residential homes.

4. Mobile Computing Solutions to Support Dementia Care

The apps in the *Dementia App Sphere* are depicted in Figure 1.

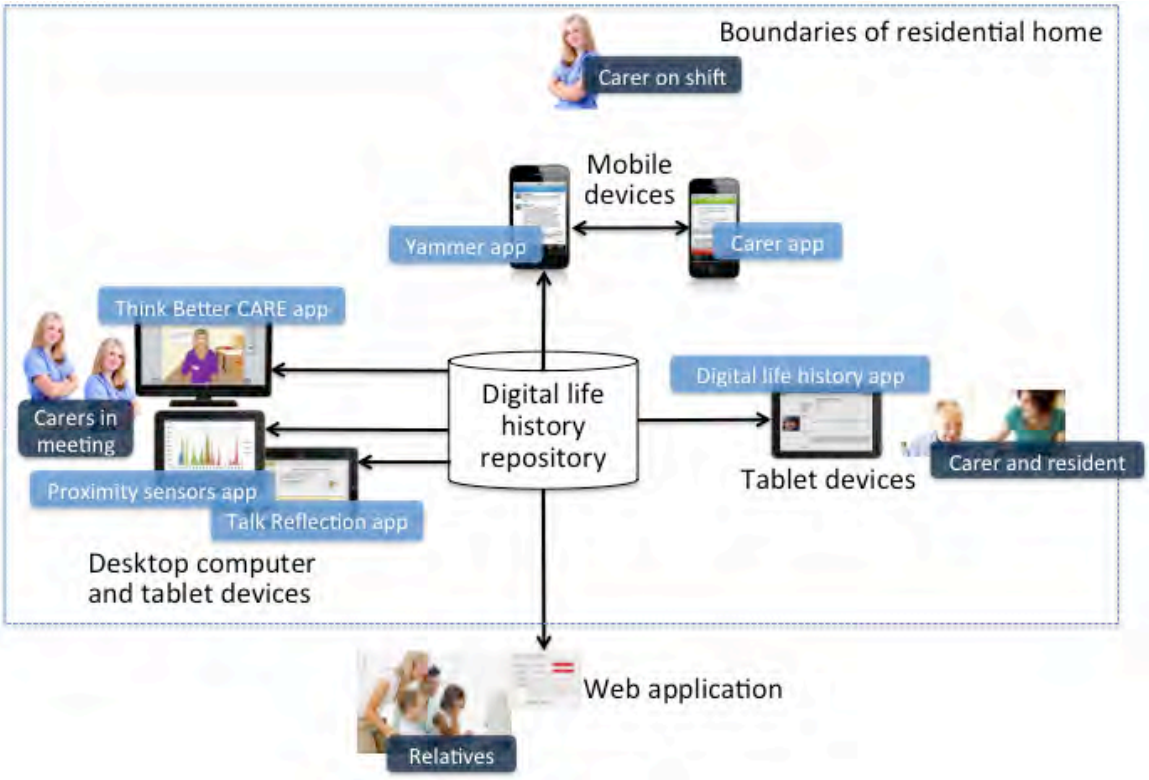

Figure 1: The architecture of the Mirror Dementia *App Sphere.*

Some of the apps communicate with a digital life history repository that makes all available data about each resident accessible to carers using mobile devices. The history contains not only data about each resident's past but also data directly recorded and captured from the other apps in the *App Sphere,* such as about social contact with carers. A separate bespoke web application enables relatives to upload information about a resident's past from a range of devices, differentiating the *Digital Life History* app from equivalent others [e.g. Webster et al. 2011].

During care work on shift, a carer can use two apps on personal mobile devices carried throughout the shift. Earlier pilot studies revealed that, in spite of sector concerns, carers were willing to carry and interact with mobile iPod Touch devices to capture and share observations about residents [Karlsen et al. 2011]. The first app is an adapted version of the micro-blogging *Yammer app* client. It provides a single source of information about each resident's behaviour, health and wellbeing that, when used, can reduce each carer's memory load and enable more personalized care through reflective learning. A second app that it interoperates with is called *Carer*. If a carer encounters challenging behaviour during the shift, it can be invoked to help to resolve challenging resident situations during the care work through creative and reflective thinking. The *Carer* app and its evaluations in 2 residential homes are reported in more detail later.

During team meetings, carers can use other apps to support reflection about resident reminiscing [Damianakis et al. 2009], behaviour and the care given. They

can reflect together about the observed behaviour of residents using the portable *Digital Life History* app that is a digital equivalent to physical scrapbooks that use photographs and written notes, see Figure 2. Whilst immersing digital content in familiar artefacts such as televisions [Wallace et al. 2012] and shoebox and timecard devices [Banks et al. 2012] have been shown to improve interaction with residents, these resident-facing pieces do not explicitly support the reflective learning needed by carers to personalize care to individual residents over time. Our tablet-based app is deliberately designed to support collaborative explorations of past life events by a carer and resident, and subsequent learning about the resident by the carer through reflections about the collaboration.

Carers can use a second app to reflect about their own care patterns based on data from proximity sensors that capture interactions between themselves and residents, for example to explore reasons about unusually long contacts with a resident. The use of sensors to provide information about dementia care is not new [Carswell et al. 2009] but our sensor design, inspired by the SocioMetric Badge [Olguin et al. 2009], is smaller and consumes less power to allow daily use. It is embedded in wristwatches worn by each resident and carer, see Figure 2, and broadcasts a unique ID over a 1.5m radius to capture close carer contact with residents.

Carers can also use a third app called *Talk Reflection* that allows them to work together to learn through reflection about distressing conversations that can impact negatively on a carer's emotional state. This app and its evaluation are also described in more detail later.

During training, less-experienced carers can train in a desktop-based 3D app called *Think Better CARE* to resolve and reflect on dementia care scenarios in a virtual and hence safe environment. During each session, the carers receive tutorial guidance from a virtual learning companion, called *Maria,* to reflect on the strengths, weaknesses and effectiveness of the care given to each individual. The design of the companion is based on Vygotsky's social learning theory (1978). Interactions with Think Better Care are depicted in Figure 2.

Figure 2: A selection of the apps from left to right: the *Digital Life History* app, a proximity sensor that captures care data to reflect on, and *Think Better Care* app

Moreover, to address ethical constraints on resident data use, the *AppSphere* enables privacy through the anonymity and encryption of important resident information. In some apps, such as *Yammer* and *Carer*, identifiers known only to carers in a residential home are used to document information about individual residents. In others, such as *Proximity Sensors*, the source of resident data is simply not recorded. That said, effective reflective learning about individual residents necessitates the recording and sharing of resident information, and the residential homes that participated in co-design of the apps prioritised information recording and use over privacy of resident information.

In the remainder of the article, we describe two of these apps in more detail and report results from their evaluation in residential homes.

5. The Carer App

Carers often encounter challenging behaviour from residents. Examples include the refusal of food and medication, and physical and verbal aggression. Diagnosing and resolving such behaviours are difficult for carers. No two residents are the same, and a resolution effective for one resident will often not be effective or the next. The resulting need for person-centred care often means that effective resolutions are new to a resident and the people caring for him or her. As such, carers need to exhibit some creative and reflective thinking to generate new resolutions. Therefore, we developed a new app to support creative thinking with similarity-based techniques based on studies of the effectiveness of such creativity techniques with carers [Zachos et al. 2013], and reflective learning based on new areas about care.

The iOS app, called Carer, retrieves resolutions of cases of challenging behaviour in both dementia care and analogical domains such as policing, schooling and parenting. It automatically retrieves the previous cases from a server-side XML database using different services in response to natural language entries typed and/or spoken by a carer into the app. One supports case-based reasoning with literally similar cases based on information retrieval techniques, similar to strategies applied to people with chronic diseases [Houts et al. 1996]. A second supports analogical reasoning with cases from different domains based on a computational model of analogical matching [Falkenhainer et al. 1989]. A third support the other worlds technique more generally by recommending other domains to resolve the challenging behaviour [Innovation Story 2002]. A fourth service automatically generates creativity prompts from retrieved case content. A carer can then record new ideas resulting from creative thinking in audio form, then reflect on them by playing them back to change them, generate further ideas, compose them into a care plan and share the plan with other carers. Some of these features are depicted in Figure 3.

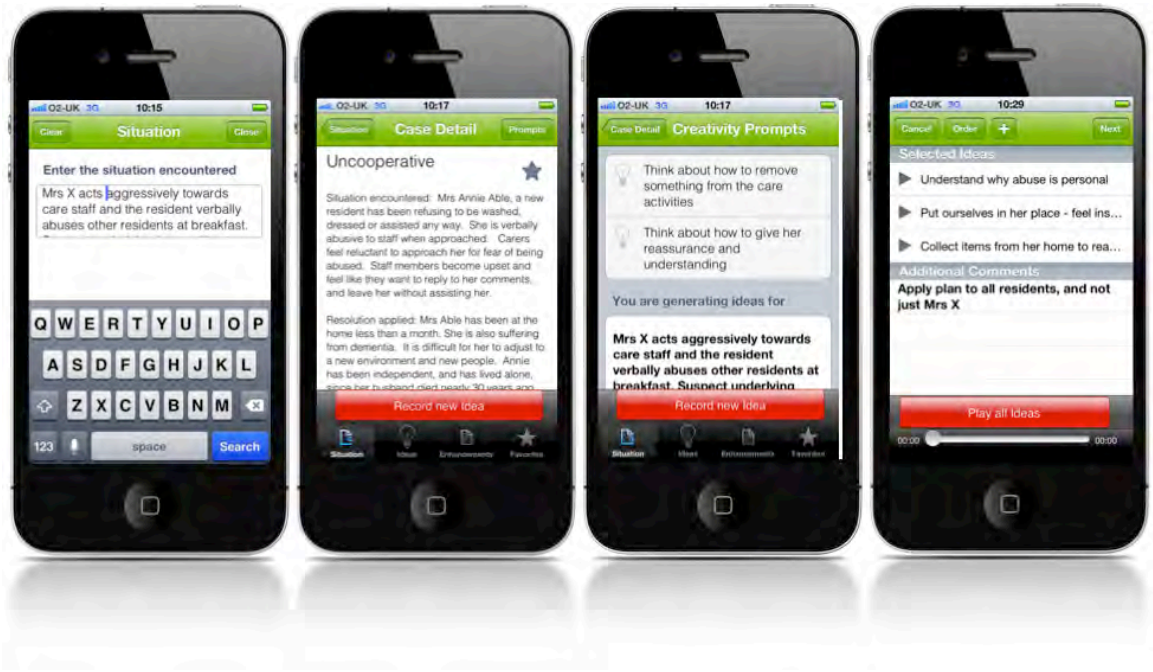

Figure 3 – Different features of the Carer app to record a challenging behaviour, browse retrieved cases, view creativity prompts and generate a care plan enhancement.

The *Carer* app was trialled in 2 different unconnected residential homes, A and B, of different types in the United Kingdom. Carers in each were provided with individual iPod Touches running the *Carer* app and *Yammer* app reported in Section 4. Seven carers in home A had the devices for 28 consecutive days, and 8 carers in home B had the devices for 42 consecutive days. All received face-to-face training in how to use the app and the creativity techniques that it supports. Evaluation data was collected from 2 main sources. The first was a data log implemented in the apps that automatically recorded the date and time that each app feature on each device was used. The second was a focus group with carers in each home held at the end of the evaluation period that was audio recorded, transcribed and analysed in-depth using predefined themes.

All 7 carers at home A carried their devices throughout their shifts, and successfully used *Carer* to generate new care enhancement plans. Each individual carer undertook an average of between 6 and 23 separate app feature uses (e.g. *retrieve past cases*, *request new creativity prompts*) during each 7-day period. Most used 2 app services, the case-based reasoning with previous cases of good practice in dementia care, and the creativity prompts automatically generated from them, to create a total of 10 separate new care enhancement plans for their residents. The implementation of at least one of these 10 plans was used to increase the quality of life of one resident to reduce her violence during medical treatment based on the novel idea of having 2 carers present during essential care to provide reassurance. We considered this to be a successful outcome of a first 28-day trial.

Analysis of app log data revealed that over 70% of app feature use occurred outside shifts. The focus group revealed that most carers only had the time needed to create and reflect on new care ideas outside of their shifts. App use in shifts was also reduced by a short-lived technical network problem that disproportionately affected carer confidence in it because the carers incorrectly took responsibility for app errors when the network was unavailable.

Although the carers did not use the *Carer* app each day, the frequency of app use needs to be understood in the context of home A, which did not specialise in dementia care, but would care for existing residents who developed dementia. As a consequence, dementia-based challenging behaviour was occasional and not well understood by the carers, and the app's guidance led them to resolve unfamiliar challenging behaviours in new ways in the absence of a prescriptive care strategy. Even so, the evaluation revealed obstacles to this creative and reflective thinking. The home's workflow needed to be redesigned to allow more in-shift time for creativity and reflection, as well as more systematic support for it outside of carer shifts, and carers needed more effective training in both creativity techniques and the mobile technologies being used.

In contrast, home B was an acknowledged quality provider specialising in dementia care. Seven of their 8 carers carried their devices throughout their shifts and successfully used the *Yammer* app throughout, but stopped using the *Carer* app after just 9 days of the trial. One reason identified during the focus group was that the app's support for creative thinking to generate new knowledge about residents did not align with the home's strategy to provide specialist dementia care at different stages of the condition based on carers in-depth knowledge of the characteristics and needs of each individual resident [Stokes 2008]. Not only did the app fail to stratify its support by the stages of dementia, but it also did not provide knowledge about individual residents. As a consequence, the carers rejected the app due to a lack of perceived benefits, a decision reinforced by an *in-principle* stance because of the personalisation theme pursued at the home. In hindsight, rolling out the *Digital Life History* app exchanging data with *Carer* might have led to greater app acceptance.

The rejection of the *Carer* app in home B revealed the need for app support for creativity and reflective learning to align with a home's dementia care strategy, which was not an obstacle to app use in home A. Successful app use also appeared to require more flexible care working practices and training in new techniques and technologies.

6. The Talk Reflection App

The *Talk Reflection* tablet-based app supports carers to share then reflect on strategies for holding difficult conversations with residents and for managing their emotional responses to these conversations. It can be used in different work settings to allow carers to document, share and give feedback on conversations during a shift, after work or in meetings, online or offline. The app is connected to a central repository of sharable documented conversations that can be user-

commented with notes and the outcomes of previous reflection sessions to facilitate sharing. Conversation assessments are presented in different visual forms such as the spider graph, shown in Figure 4, to enable quick browsing. Furthermore, the app offers simple creativity techniques to carers to discover new ways of holding difficult conversations, as also depicted in Figure 4. Each documented conversation can also be linked to the relevant resident in the digital life history so that other carers are made aware of difficult conversations associated with that resident.

Figure 4 – Features of the Talk Reflection App including carer self-assessment of emotions during talks, and sharing documented conversations with others

The *Talk Reflection* app was also trialled in a different residential home in the United Kingdom. The manager and 5 carers used 2 iPads running the *Talk Reflection* app for 33 days. Data for evaluation includes log files from app usage, pre and post questionnaires and feedback given in a workshop.

All 5 carers and the manager used *Talk Reflection* on 62 separate occasions to document difficult conversations and situations to view a total of 99 documents, create 19 ones and comment on existing ones on 20 occasions, although only 5 of these comments were made on documents that another carer had previously authored. Both the documentation of difficult conversations and use of tablet technologies were new to the carers, therefore we considered this level of app use a

success. However, although its use did trigger reflection by carers, as only 3 reflective outcomes were documented using the app. The workshop revealed that, most of the time the carers communicated and discussed the comments verbally during their shifts, as this was faster and more beneficial. The obvious downside was that insufficient numbers of difficult conversation comments and outcomes were documented to share in the *Talk Reflection* app.

On the other hand, the carers reported that use of the *Talk Reflection* app had improved both their wellbeing and handling of difficult situations. One example was a difficult conversation with relatives requesting their resident go to hospital, contrary to the view of the carers. The deterioration of the resident's condition in hospital led them to reflect and agree changes to similar future conversations.

However, as in the previous evaluation, the carers did report technical and organizational obstacles to app use during their shifts. A wireless network was not available in all resident rooms because of the home's concrete walls. The home's manager restricted the times available to use the app so that its use would not intrude on care duties, even though the carers explicitly asked for more time to use it to discuss difficult conversations. And some residents' relatives complained about app use on shift – use of such technologies in residential homes is still rare, and the relatives erroneously assumed that the carers were playing rather than working.

These obstacles again revealed the need to adapt care workflows, this time to mandate the recording of and reflection about difficult conversations and provide sufficient resources for this to happen during and outside of shifts. As in home A, they reveal the need to align the app with each home's prevailing care strategy to motivate app use as an integral part of care. In addition, more needs to be done to acquire approval for app use. Simple changes now being considered include a poster campaign to inform residents about the roles of new technologies and the use of white tablet covers with blue crosses to indicate medical care work.

7. Conclusions

Our development of new types of mobile app to support the reflective and creative thinking needed by carers who deliver person-centred care to older people with dementia contrasts with current use of digital technologies to retrieve information for carers and trigger reminiscing by residents. Whilst the reported evaluations have revealed the potential of such apps, realising this potential will necessitate overcoming some significant obstacles. Key amongst these is the need to align app use with the range of different care strategies adopted by residential homes. Not only do homes support residents with and without dementia differently, but also different and inconsistent care strategies are implemented across homes. For example, person-centred care that rejects the disease model [e.g. Stokes 2008] differs from support for best practice care themes such as a positive culture [e.g. My Home Life 2013]. Rolling out even one app needs to be sensitive to these differences. We believe that new technologies will need to be mixed and adapted to different care models. Whilst our *AppSphere* provides a baseline for mixing

technologies, our next step will be to configure them to different care models as a starting point for more effective future uptake.

Acknowledgements

The research reported in this paper is supported by the EU-funded MIRROR integrated project 257617, 2010-1.

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