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Enabling technologies for inclusion in health, support, care and education

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Pavilion

Celia Price
Just Checking Ltd



Evaluation of an activity monitoring system for people with dementia

Abstract

The aim of this evaluation was to carry out an evaluation of the Just Checking activity monitoring system, which supports people with dementia in their own homes. The study was carried out with Warwickshire County Council's social services, and a number of their service users. The system was installed in the homes of six people with dementia, and used by their family carers and care professionals, whose experiences were gathered in semi-structured interviews. In total 15 people took part in interviews, including two of the people with dementia.

The system gave family carers and professionals a better insight into the activities of the person with dementia, and how they were managing in their own homes. The majority of users were surprised at the consistency of the daily pattern of activity of the person with dementia and, as a result, their view of the capabilities of the person changed. The data from the system reassured family carers and proved a useful assessment tool for professionals on which to plan care.

Contrary to expectations, the monitoring system gave people with dementia more control of their lives by providing a means by which they could communicate their capabilities in their home environment.

Key words

Assistive technology; people with dementia; home.

Within the UK's ageing population, the number of very old people (aged 85 and over) is rising. In this very old age group the prevalence of dementia rises to one in five people: there are currently 680,000 people with dementia, forecast to rise to 940,000 by 2021 (Kings College London & London School of Economics, 2007). Over the past two decades there has been a shift in the balance of care for people with dementia, from institutional care towards community-based care, and a realisation that many people with dementia may be able to remain in their own home for much longer, with appropriate prompts and support.

This study focuses on an assistive technology system that helps to support people with dementia in their own home.

The activity monitoring system

The activity monitoring system used in this study

records the daily activities of people with dementia who live in their own homes. Small wireless movement sensors around the home enable activity to be mapped on a chart, which is made available via a password-protected website. A family carer or professional can log on and see when the person:

- got up and went to bed and whether they had a disturbed night
- visited the kitchen
- left the house and for how long
- received visitors and how long they stayed.

For health and social care professionals, the system provides objective information on the activities of a person who may be unable to communicate reliably, and this helps with the planning of care. For example, it will show: if the person with dementia is visiting the kitchen at mealtimes, or whether meals have to be

initiated by a visitor; if the person gets themselves up or whether a homecare call is essential to start the day. It can also be used for troubleshooting. For example, neighbours might claim that Mrs X is 'often wandering at night'. The system can help establish how often this is happening and whether there is a pattern that can be managed with prompts or reminders.

Family carers face continuous worry about how a person with dementia is managing on their own. Some try to visit every day to reassure themselves that all is well, squeezing in a visit for just a few minutes on the way to or from work. It can be argued that this type of contact has little social value to the person with dementia and can be stressful for the carer. The activity monitoring system aims to provide daily reassurance for carers and will help them to plan productive social visits.

The trial

Warwickshire County Council Social Services agreed to pilot the system with staff who are responsible for the care of people with dementia. The authority invited the South Warwickshire branch of the Alzheimer's Society, and the South Warwickshire Carers' Support Service to be involved in the trial.

1. Aim

The overall aim of the trial was to carry out an evaluation of the system. The objectives of the trial are listed below.

- To record and evaluate the experiences of using the system by two groups of users:
 - professional staff (social workers, community psychiatric nurses)
 - informal carers/family members.
- To identify user experiences which demonstrate the system had value to:
 - informal carers
 - the promotion of independence, and support for the wish to remain in the community
 - the assessment of need, care planning and review
 - risk assessment processes.
- To identify tangible outcomes which help meet the preventative agenda (preventing or delaying admission to residential or nursing care or hospital).

2. Method

Activity monitoring is a new technology, and this study

Figure 1 An Example of a chart from the Just Checking activity monitoring system

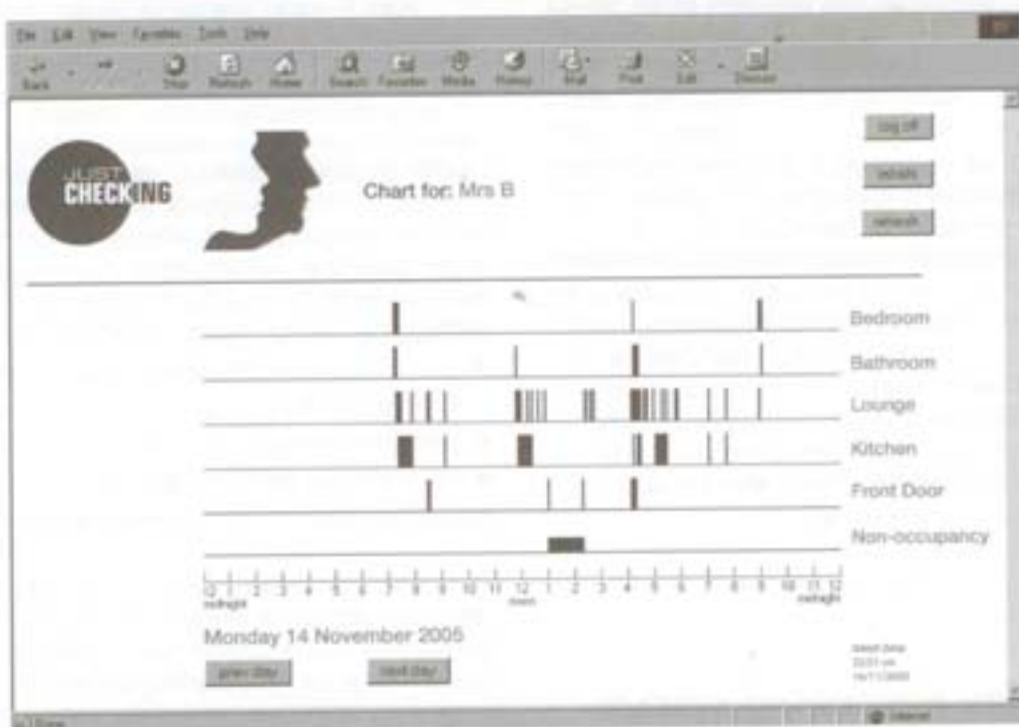
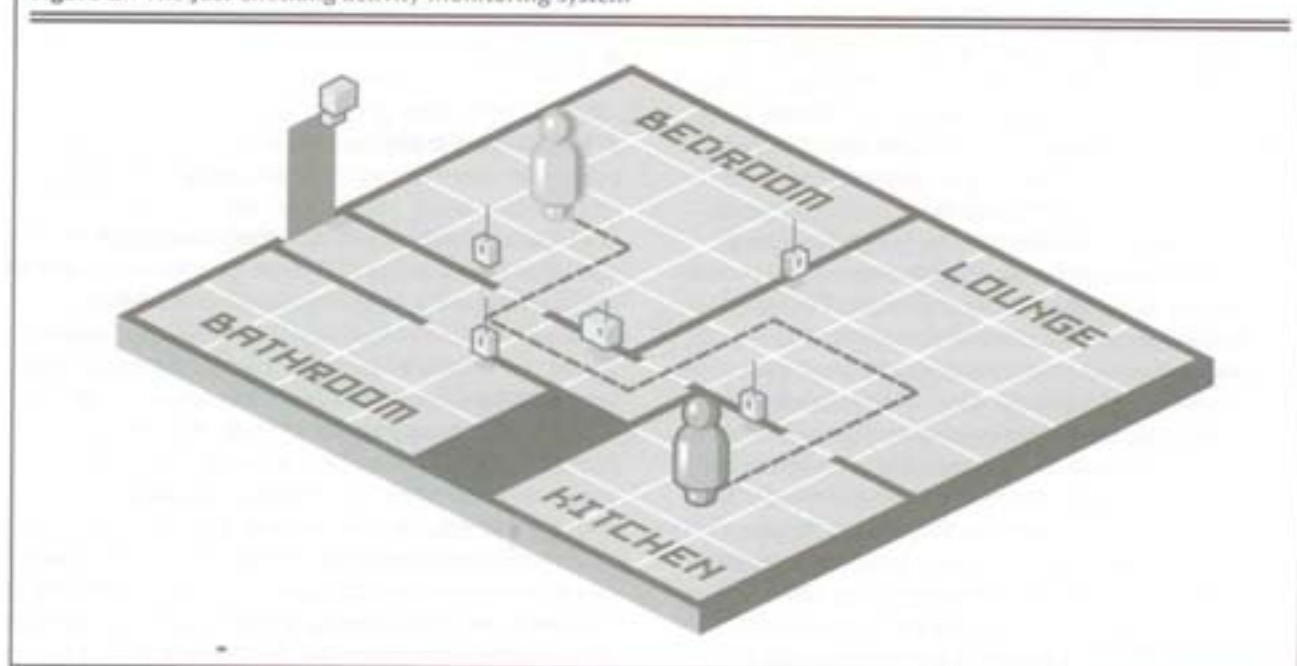


Figure 2 The Just Checking activity monitoring system



was the first structured trial of this. The methodology needed to allow for open expression of ideas and experiences of users. It was important not to miss clues about the use of, or differences that the new technology brings. To give an analogy, mobile phone companies did not anticipate the interest by younger people in the text facility. The SMS (short message service) was originally a means of communication for engineers working on the telecommunications infrastructure. Because the technology was new, the approach was to record the views and experiences of users in semi-structured interviews, and analyse the comments for common themes.

Three of Warwickshire's Older Persons Community Care Service teams identified, in the normal course of their work, clients for whom there would be a sound reason for trialling the system. In each case there was **some concern** about the service user. The inclusion criteria were:

- the person in whose home the system was installed had symptoms (or a formal diagnosis) of dementia
- the person with dementia lived alone, or spent significant periods of time alone eg. when a carer goes out to work
- informal carers/family members were supportive of enabling the person to continue to live in the community
- there was the potential for the service user and/or

carer to derive positive benefits from the use of the equipment as part of their care package

- the person would benefit from an ongoing period of assessment of needs or risks, and the equipment could contribute to this
- there were no contra-indications about the use of the equipment eg. increased paranoia.

Exclusion criteria:

- families whose members were without access to the internet/a computer

2.1 Consent and ethics

A decision was taken by the care manager, in conjunction with the family, about whether the person with dementia had the capacity to consent to the system being installed in their home. A simplified explanation of the system was provided verbally and in writing. Warwickshire County Council staff followed the authority's existing protocols in deciding if the person had capacity to consent and, if not, in using the four ethical principles of non-maleficence, beneficence, respect for autonomy and justice (Beauchamp & Childress, 2001) to guide them in making a decision that is in the person's best interest.

Two European projects, Technology, Ethics and Dementia (TED: Bjorneby *et al.* 1999) and ASTRID (Marshall, 2000) produced a guide for professionals

in the use of assistive technology for people with dementia, and the four basic ethical principles are re-iterated in these guides. The staff also needed to be satisfied that the installation of the Just Checking system had a potential benefit for the person with dementia, and an assessment checklist was completed. Approval to proceed with the referral was made by the experienced team leader.

The system was installed in the homes of a total of six people with dementia (and a pilot user, an elderly man who did not have dementia), for 12 weeks. One person with dementia was able to give consent, and to talk about her experience of having the system in her home. In the other five cases the system was discussed with the person with dementia, and each gave a verbal agreement for the system to be installed. However, the decision to go ahead was made jointly by the social worker and family, following best interest principles, because it was felt that the person with dementia would not remember enough about the system to consent. Only those cases where all parties were in agreement went ahead. There were four additional referrals where family members were unsure whether to proceed, and these were not pursued. At the end of the 12 weeks, family carers and professionals who had used the system were interviewed.

2.2 Interviews

Each care professional and family carer who made use of the system was interviewed, face to face, using a semi-structured format. The person with dementia was also invited to take part in this interview if the family carer thought it would be appropriate, and would not cause the person distress. Interviews were conducted with:

- five professional staff (four care managers and one CPN)
- seven family carers of people with dementia
- one family carer of a person who did not have dementia (the pilot)
- one person with dementia (early stage), plus one person with dementia who was present in an interview with her family carer, but did not make much contribution.

Interviews were audio-taped, transcribed and examined for recurring comments and phrases that could be grouped to form theme headings.

3. Results

Four main themes emerged:

- a better insight

- reassurance
- helping people with dementia to stay at home
- intrusiveness.

3.1 A better insight

Every user commented on the fact that the system gave them a better insight into day and night activity of the person with dementia. The information reassures family carers and helps care professionals with care planning. The majority of users were surprised at the consistency of the daily (and nightly) pattern of activity of the person with dementia. Most family carers commented that the person was more active than they had appreciated. If there were concerns about activity, family carers could see how often something was happening, gauge how important it was, and act accordingly. Two family carers had been concerned about their relative going out on their own. In one case the system showed this happened very infrequently. In the second, the person with dementia went out (to the local shops) and returned every morning at a regular time.

Professional staff found the information useful in planning care packages. Of the four cases that were referred by a care manager the following adaptations were consequently made to care plans.

- Two made changes to the care package as a result of the information; one reduced the number of daily homecare visits from two to one and changed the tasks from meal preparation (which was not needed) to encouraging the service user to shower and change her clothes (which she was not doing); the other increased daily homecare visits from three to four, to ensure that the main door, which was being left open at night, was closed. This possibly could have been tackled in a different way.
- Two were reassured that current arrangements for the person with dementia (neither of whom received homecare) were adequate. In one of these cases some further support for the carer was organised.

3.2 Reassurance

Every one of the family carers referred to the reassurance that the monitoring data provided. 'Peace of mind' was a phrase used by most carers. In all cases the person with dementia had a more consistent pattern of activity than the family carers had expected. Concerns about what happened at night were allayed.

Visits by home care staff, or activities such as a weekly trip out to a luncheon club could be identified, and families found it reassuring to see

that all was going to plan. In one case the system showed that home care staff were not visiting at weekends and action was taken to correct this. Professional staff were also reassured that the person appeared to be managing well, often better than expected, and that this had relieved some of the worry for family carers.

3.3 Helping people with dementia to stay at home

Three of the family carers thought that the system would help to keep someone at home. One family carer has a brother who lives in New Zealand, who also now logs on each day to view the chart for their mother. The carer feels that the system has helped to 'share the load' with her brother, that it gives him more to talk about when he phones her, and this supports her in her onerous caring role. Furthermore, if and when her mother's mental health deteriorates to a point that means she can no longer remain at home, the system will show this objectively and she and her brother will be able to make a decision jointly about this.

Three out of four of the care managers thought that the system could help a person with dementia to stay at home, and that it would have a role in deciding if and when a person would need to move to residential care.

3.4 Intrusiveness/acceptability

Two of the installations were in the homes of people who could answer questions about the system. One was the pilot, an elderly man who did not have dementia. The second was a woman in the early stages of dementia. Both users said that they did not find the system intrusive.

In three cases the system controller was hidden out of view. Family carers reported that they thought that the person with dementia was not really aware of the system. In two cases, it was difficult to hide the system controller. One service user initially switched off the system several times (which she was convinced was a lamp); this system was eventually moved out of sight and was no longer tampered with. The second was distressed by the system, which was taken out after two weeks.

Family carers took the view that it was better if the system was 'out of sight out of mind', and that their relative's lack of insight might make it difficult for them to understand and accept the system.

Care managers compared possible intrusiveness with the intrusiveness of other devices or increased care packages.

4. Discussion

4.1 Value to the family carers

The trial provided strong evidence that family carers found the system of value. They found the information that it provides reassuring and supportive in their caring role. In all cases, the person with dementia had a more consistent pattern of activity and they were more active than expected by the family carers.

These findings could indicate that carers sometimes worry unnecessarily. Because they have witnessed a deterioration in the mental health of their relative, they may fear that things are worse than they actually are. Anecdotes from neighbours ('she is always out at night') may be exaggerated because people feel that something should be done. The behaviour of the person with dementia may be quite different when a family carer is at the house; they may be passive, allowing others to do things for them for fear of getting it wrong (Jolley, 2005). With the monitoring system, carers can see that the person is more active when they are not there, and they are reassured by the patterns they see. The system gives a fuller, objective picture of activity and this is important for the family carer's peace of mind.

Supporting carers is a key factor in keeping older people at home and independent for longer. Local authorities undertaking carer assessments have to consider if the caring role is sustainable. The load on a carer is physical and emotional (Mountain, 2005). The physical workload can be relieved by deploying home care visits, befriending services, day centre visits etc. This study suggests that monitoring systems, which give the carer more information, may help to reduce the emotional load (they are managing, I don't need to worry).

While it is essential that family carers are not overloaded, there is evidence from the interviews that the family carers who are willing to take substantial responsibility for their relative are receptive to tools that enable them to do this. In organising social care we need to make the most of family support if it is being offered, and provide carers with the tools that can help them in their caring role.

4.2 Promotion of independence and remaining in the community

Information from the system gave a greater insight to carers and professionals about the daily activities of a person with dementia, and changed their views about that person's capabilities.

In one case, the person with dementia was unable to recognise her daughter, who visits her several times a week. Nevertheless, she was maintaining a very well-defined day and night time pattern, got

herself up and went to bed, and prepared meals regularly, regardless of when home care visits were made. According to her daughter, this person has always made it clear that she wants to remain in her own home. Although she now has severe memory problems, the data from the system shows that she is maintaining patterns of daily living, which may be deeply ingrained and, for the time being, she is able to stay in her own home.

The trial demonstrated that this type of telecare system has a role in allowing people to remain independent and more in control of their own lives without too many intrusive visits from health and social care. This is a key aim in the government's drive to reform community services (DH, 2006). Furthermore, this type of system has a role in supporting a person's wish to remain in the community. Most people want to stay in their own home for as long as possible. For someone with dementia, their home is familiar and full of things that help to remind and orientate them. Most major risks in the home can be managed, some using assistive technology (such as a cooker cut-off device if the gas is left on). This monitoring system provides a 24-hour picture of how the person is managing, and allows family carers and professionals to be assured on a daily basis that the person can remain at home.

4.3 Assessment of need, care planning and review

For the six selected users, the system proved to be a valuable tool for assessment. It provided objective information that allowed professional staff to make more evidence-based decisions about care needs. In particular, it influenced decisions to both reduce and increase home care visits.

The extra information provided by the system creates an opportunity to meet needs with a wider range of responses. Importantly, it offers the potential of reducing the reliance on home care, in which there is a shortage of staff.

4.4 Risk assessment process

The monitoring system demonstrated that it has a role in risk assessment. In the trial the system was installed because there was a particular concern, related to a perceived risk, in particular going out or night-time activity. The system shows how often something is happening, and provides an objective measurement on which to assess risk. It may indicate that a further assistive technology device would be helpful, eg. a device is available that plays a message, recorded by a familiar voice, to remind a person to return to bed, if the door is opened in the night hours.

4.5 Preventing or delaying admission to residential care

The majority of family carers and professionals who took part in the trial thought that the system would have a role in postponing residential care. Familiar surroundings help to orientate people with memory problems. Furthermore, the system will show objectively when a higher degree of care is needed, if patterns of behaviour change. The data can be compared with activity patterns from some months beforehand.

4.6 A new perspective

The trial provided a very different perspective of the person with dementia, and consequently altered the views of the family carers and care professionals about the person and how well they were managing in their own home. Patterns of daily living were generally better and more consistent than expected. This challenges some of our assumptions about dementia and its disabling effect on daily living. It suggests the possibility that some activities of daily living are deeply ingrained and may remain intact even when short-term memory is severely compromised. The new perspective enabled carers to 'back off', and care packages to be amended to suit the person with dementia, effectively giving them more control, enabling them to continue living as they wish without too much interference, and making the care more 'person-centred' (Kitwood, 1997).

The study also makes us re-examine current work-practice. For example, it is common practice to provide support for people with dementia in the form of several home care visits a day. But with clearer information about how a person is managing at home, we could consider a more diverse range of services for people with dementia, and home care visits might be intrusive and unnecessary in some cases.

In conclusion, the author proposes that, far from being controlling (Welsh *et al.*, 2003), this monitoring system **enables** the person with dementia. The system provides a means for a person with dementia to 'communicate' what they are doing for themselves in their normal home setting and to have more control of their lives.

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Address for correspondence

Celia Price
Just Checking Ltd
Appledore Lodge
Blind Lane
Tanworth-in-Arden
Works B94 5HT
UK

Email: celia.price@justchecking.co.uk

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