Monitoring people with dementia – controlling or liberating?

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Abstract

In the increasing discussion about electronic assistive technology, the most emotive reactions are provoked when it is suggested that technology is used to monitor older people with dementia. The words associated with monitoring are rather negative – surveillance, 'big brother', intrusive, controlling.

For the past two years care practitioners in local authorities and NHS mental health trusts have been using the Just Checking activity monitoring system to assess people with dementia, living alone in their own homes. Small, wireless movement sensors placed in the key rooms of the house, are triggered as the person goes about their daily life, and the data are represented as a line on a 24-hour chart. There are no cameras. The chart is accessed via a password controlled website.

The charts give care professionals and family carers a much clearer 'picture' of how a person with dementia is acting in their own home. The information is used to devise a care package that is appropriate, and will support them to continue to live independently.

Case study names have been changed.

Case study 1: Mrs Bowler

Mrs Bowler lives in a private retirement flat where she moved seven years ago when she was widowed. She has moderate dementia and doesn't always recognise her daughter, Elaine, who calls a couple of times a week in her lunch hour. Elaine works a few minutes' drive from her mother's house. She organises the shopping and housekeeping. Elaine is keen to help her mother stay in her own home, where she has made it clear she wishes to be.

Mrs Bowler has two homecare calls a day, at breakfast and teatime. A hairdresser visits once a week and other members of the family call in from time to time.

Mrs Bowler is a very private person, and she finds the homecare visits quite intrusive. She often asks the home carer to leave as soon as she has arrived.

The home carers were reporting that Mrs Bowler was not eating when they went in. The social worker was considering putting in a third home care visit at lunchtime.

The daughter often found her mother asleep in the chair in the lounge when she called at lunchtime, and she wondered if she was up for much of the night and therefore tired in the day. The social worker and daughter agreed that it was in Mrs Bowler's best interest to try and establish what she was

doing for herself before adding further homecare visits, which she did not want. The activity monitoring system was installed.

The system showed a regular daily pattern. Mrs Bowler got up between 7–8.00am, used the bathroom, went into the lounge and then into the kitchen where she spent some considerable time – about half an hour or so. The visit to the kitchen was repeated at lunchtime, and again in the evening, and the same pattern emerged each day, at around mealtimes.

By the time the homecare call came in at 8.30am, Mrs Bowler had already had breakfast and didn't want to eat again. Typically, in the evening she was choosing to eat after the homecare call. Regular visits to the bathroom verify that Mrs Bowler is eating and drinking. The chart showed periods of activity and periods of quiet, and there was usually a period of quiet after lunchtime, when Mrs Bowler snoozed in the chair. This was exactly the time that her daughter came in. Elaine was surprised at how active her mother was; she thought she sat in a chair all day.

Mrs Bowler went to bed at around 9.00pm. Throughout the night there was brief movement in the bedroom and bathroom as Mrs Bowler got up to go to the toilet, but she always returned to bed – she was not using any other rooms in the house.

The system also highlighted that at the weekend, the door was not used at all, and Mrs Bowler did not receive a visit from homecare. The home carer claimed to have made the calls and to have the timesheets signed by the client. The system provided objective information about the time and duration of the homecare calls, which the social worker found valuable in her discussion with the care agency.

Overall Mrs Bowler's pattern of activity was much better than expected, and the social worker and the daughter changed their view of Mrs Bowler's capabilities and the prospect of her being able to remain at home.

As a result, the social worker, in agreement with Elaine, decided to reduce the homecare visits from two to one a day, giving Mrs Bowler more independence, and reducing the cost of homecare by £2,500 per annum. The homecare visit was also refocused on encouraging Mrs Bowler to shower and change her clothes two or three times a week, something she was sometimes forgetting to do.

There is great sensitivity about reducing homecare visits, which are seen as social contact. But for many people with dementia, a stranger entering your house three or four times a day for only a few minutes, can be very intrusive and of little social value. Homecare visits tend to based around tasks, such as help with meals, or with getting up and washing, but if a person can manage this themselves, it might be better to arrange a less frequent, but longer social visit; some local authorities have service level agreements with befriending services. The £2,500 saving on Mrs Bowler's home care could be used in a more creative way to satisfy a social need.

Relatives can see that rather than dashing in every day (often on the way to work or on the way home again, mainly to reassure themselves that all is well) it might be better to visit less frequently but for longer, spending time having a meal or going out together. The short 'checking' visit can be replaced by logging on to the system. Another family carer pointed out that, with the monitoring system in place, he rang his mother less often: *'That may sound terrible, but actually, I was ringing her three or four times a day to reassure myself, and sometimes she was confused about why I was ringing. Now I ring her once a day, at a certain time and we have a more meaningful chat.'*

Case study 2: Mrs Bailey

Mrs Bailey, 85, has a formal diagnosis of vascular dementia. She continues to live in the house that has been her home for 30 years, with the support of daily homecare calls and her daughter, Caroline, who lives 10 miles away. Caroline works throughout the week, but spends Wednesday afternoons with her mother, taking her out to the hairdresser or shopping. On a Friday Mrs Bailey is picked up for a lunch club. On Saturday Caroline and her husband go over to Mrs Bailey's house to help with housework and gardening. On a Sunday Caroline picks up her mother and takes her back to her own house for the day.

Recently, Mrs Bailey walked to the local shops, which she has done for 30 years, and then forgot how to get home again. A kindly passerby helped her back, and knocked on the neighbour's door to check that he had brought

Mrs Bailey back to the right house. The neighbour rang up the daughter in anger, claiming Mrs Bailey was wandering and suggesting that Mrs Bailey *'should be in a home'*.

Caroline thought this might be *'the beginning of the end'*. She didn't want to discourage her mother from going out for a walk, which she enjoys, but she was worried that her mother's mental condition had reached a stage where she might not be able to continue living independently. The activity monitoring system was put in to establish how often Mrs Bailey was going out and for how long.

The system showed that Mrs Bailey had a clear and regular daily routine. She got herself up every morning at around 8.00am, before the homecare call, and took herself off to bed at around 8.00pm. Caroline was surprised that her mother went to bed so early. Mrs Bailey slept soundly. Over an initial three-month period Mrs Bailey went out every two or three days, but returned within three-quarters of an hour, about the time it takes to walk to the local shops buy a few things and walk back. At this stage, Caroline was reassured that arrangements could continue as they were.

Marshall and Allan (2006) point out the paradox that walking is normal and healthy, but when people with dementia do it, it is pathological and labelled 'wandering'. Marshall suggests that the notion that wandering is an inevitable consequence of dementia is widely accepted, and that we use the term as a shorthand way of describing walking behaviour in people with dementia, because we believe people with dementia are different from the rest of us. We pathologise the normal behaviour of walking because we are over-concerned about risk and the possibility of vulnerable people coming to harm.

Rather than jumping to the conclusion that Mrs Bailey would now need residential care because she is beginning to 'wander', her family can look at the activity monitoring data to make an informed judgement about Mrs Bailey's excursions. So far it looks as if it was a one-off incident when Mrs Bailey forgot how to get home. If in the future, she is frequently out for prolonged periods they may need to think of other strategies, but they will be able to make judgements based on the overall picture of activity, and concentrating on her capabilities.

Case study 3: Mrs Reynolds

Mrs Reynolds lives in a spacious two-bedroom bungalow, which has been her home for more than 15 years. She has moderate dementia, but continues to live independently with the support of homecare and her recently retired son who lives locally. Recently she had been admitted to hospital with an infection. While in hospital, she was very confused and her son was doubting if it would be feasible for his mother to continue to live at home. He was persuaded by an occupational therapist in the community mental health team that they would have a trial period in which Mrs Reynolds would return home, the activity monitoring system would be put in, and the homecare support would be reinstated, together with the support he was able to provide. The son was sceptical but agreed it was worth a try.

When Mrs Reynolds first returned home she was up for extended periods in the night, moving between the bedroom and bathroom, but within two days this settled down to a much clearer day and night-time routine. The system helped the mental health team to decide on the best times for the homecare calls, to fit in with Mrs Reynolds' routines, particularly the timing of the first morning call when she needed help with a urostomy bag. After 15 months Mrs Reynolds was still in her own home.

Occupational therapists know that people with dementia function better at home, and psychological theories offer an explanation of why that should be so. *'Situated cognition'* (Seely Brown *et al,* 1989) suggests that people adapt themselves to their world and adapt their world to themselves over their lifespan. Habits and routines, the structure of a room and what is in it – help to build memories, and then reinforce memories and the skills that are associated with them. Nowhere is this stronger than in one's own home. The ability to continue to prepare meals is reinforced by habit and the familiarity of the kitchen where a person has prepared meals for many years.

In the majority of cases in which this activity system has been used for assessment, it has shown that people with dementia are maintaining daily activities, contrary to initial

concerns and expectations. Far from being intrusive, the system provides a means for the person with dementia to communicate their capabilities in their own home, where they are orientated and at ease, and this encourages families and professionals to step back and see what the person is capable of, and avoid intrusive and inappropriate interventions.

Wey (2006) reminds us that people exist within a social, cultural and historical context and their memories, skills and personhood do not exist in themselves but in their relationship with this lived context. Practitioners need to observe people as they function in their own settings, what they do with their living space and time, how they approach activities, and what is meaningful and habitual to them.

This is difficult in many health settings. Assessments are carried out in an unfamiliar institution or by piecing together anecdotes from relatives and neighbours with short visits to a person's home where the very act of visiting will have an effect on the person. It is our observation that many people with dementia are often passive when they are visited by family members or professionals, possibly not wishing to show their vulnerability, and getting things wrong in front of others. But once the visitors have gone, they are back in charge and their activity charts show that they are active and purposeful when left to their own devices.

Now, activity monitoring systems can show us objectively that it is the case that people function best in their own home. Fears that monitoring will lead to a loss of control have proved to be the contrary. Activity monitoring can put the person with dementia back in control, allowing those who care for them to adopt a light touch, and to be clearer about the capabilities of the person that are still in place.

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A Just Checking chart