

THE FEASIBILITY OF ELECTRONIC TRACKING DEVICES IN DEMENTIA: A TELEPHONE SURVEY AND CASE SERIES

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SUMMARY

Background. Patients with dementia who go out unaccompanied are at risk of accidents or getting lost. It is not known whether they could benefit from electronic tracking devices or whether such devices are practically feasible.

Method. The likely demand for an electronic tracking device was assessed by means of a telephone survey of a convenience sample of 99 carers. The practical feasibility of a tracking system was assessed in 24 patients with dementia.

Results. The telephone survey suggested that 20% of patients were at continuing risk of traffic accidents and 45% were at continuing risk of getting lost. About 7% could have benefited from using the device at the time of survey and a further 11% could have benefited at an earlier point in their illness. In the feasibility study, only nine patients consistently used the device. In two patients, it was successfully used in a search. One patient was injured by a passing vehicle when he had got lost out of range of the device. A major barrier to using the device was recognizing the risk of getting lost before it happened.

Conclusion. Significant numbers of patients are at risk. Electronic tracking devices may occasionally be useful in carefully selected cases. © 1998 John Wiley & Sons, Ltd.

KEY WORDS—Alzheimer's disease; dementia; behaviour; disorientation; electronic; wandering

Approximately 40% of patients with dementia get lost at some point in their illness, and 5% get lost repeatedly over many months (McShane *et al.*, 1998; Ballard *et al.*, 1991). Patients with dementia who get lost are vulnerable to serious accidents and knowledge of these risks puts a considerable strain on carers. Getting lost is also a major cause of institutionalization. In a prospective study, we found that 77% of those who got lost were admitted to institutions, compared to 31% of those who did not (OR = 7.3; 95% CI: 3.0–17.8) (McShane *et al.*, 1998). There is no published quantitative information about the risks of

pedestrians with dementia having accidents and no available data about the extent to which patients with dementia go out unaccompanied.

There is anecdotal evidence to suggest that electronic tracking devices can be helpful in the search for patients with dementia. Some organizations have raised ethical objections to electronic 'tagging' (Cayton, 1994; Counsel and Care, 1993). However, carers of sufferers with dementia may be less likely to have ethical objections (Cayton, 1994; Editorials, 1994a,b). In an analysis of the ethical issues, we have argued that the reassurance that tracking devices afford might result in patients being given more freedom, or that such devices might increase safety by allowing those who had got lost to be found more quickly (McShane *et al.*, 1994). However, the debate about the role of such technology has not, so far, been informed by any systematic examination of its use.

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Contract grant sponsor: Charles Wolfson Charitable Trust.

The aim of the first of this pair of studies was therefore to establish an estimate of the proportion of patients who might potentially benefit from the use of tracking technologies by means of a telephone survey of informants. The practical feasibility of using such devices was then examined.

TELEPHONE SURVEY

Method

Informants. Community psychiatric nurses and other members of old age psychiatry teams in Oxfordshire provided the names of all patients with dementia who were currently on their lists and for whom there was an informant who could give a good account of the patient's behaviour (both before and after admission to an institution where appropriate). Although they were aware of the purpose of the project, care was taken to avoid biasing the sample towards those in whom getting lost or wandering was a problem. Letters were then sent to 120 informants to ask if they had any objections to participating in the interview. A further 36 informants were recruited from among patients in another study.

Informants of 15 of the 156 subjects declined to participate, 20 were uncontactable despite repeated attempts and 16 were not able to give sufficiently detailed information. Six of the patients had died or did not have dementia. The questionnaire was administered over the telephone by one of us (KG) to 99 informants, the large majority (90%) of whom were members of the patient's family: spouse (41), daughter (31), other relative (18), friend (six), professional carer (three). Sixty-six patients were female and 75 were still living at home.

Questionnaire. The information sought by the questionnaire included details about the patient's walking behaviour, road safety, episodes when the patient had been lost and home circumstances. The questionnaire referred to the period before admission to any institution. A patient was regarded as having got lost if someone had brought them home, if they had been gone for substantially longer than expected, or if someone had been sufficiently worried to search for them. The carers of patients who had got lost, or who had had to be dissuaded or prevented from leaving, were then given a general description of an electronic tracking system followed by some hypothetical questions about its use. The questions examined whether the

carer would in theory use a device and whether they would give the patient any more freedom as a result. Potential practical barriers to its use, such as whether the patient would be likely to tolerate the device and whether there would be anyone to ensure it remained in place, were then examined.

Results

Patient behaviour. A total of 43 (43%) patients had got lost at some point. Twelve patients had been lost on more than five occasions and six had been lost for 6 or more hours on at least one occasion. The period over which patients got lost was greater than 4 months in 26 cases and a year or more in 15 cases. The police were involved in searching for 14 cases. In eight cases the patient had been found by chance by passers-by who had recognized their vulnerability.

Forty-five patients were still going out on their own, 20 (44%) of whom were thought by carers to be unsafe in crossing roads. Twenty-four (53%) cases were venturing no further than a local shop, 11 (24%) patients were walking more widely in the locality and 10 (22%) were regularly going substantially further afield. Fifteen (33%) lived alone.

Of the 99 patients, six were known to have had accidents or 'near misses'. One had been knocked down by a car but had not sustained serious injuries. Five subjects had stepped out into traffic and nearly been hit; one of them had been walking down the middle of a dual carriageway. One of the six was still going out alone at the time of the survey. She had apparently stepped out into traffic on one occasion because her poor eyesight prevented her from seeing danger, but was now only going infrequently to the shop over the road.

Carers' views. Forty-three carers of patients who had got lost at some point were asked about their views on tracking devices. Only two said they would give the patient more freedom if they could be sure of finding them if they got lost. The remainder were evenly divided between those who would not give the patient more freedom and cases where the freedom of the patient could not be enhanced because it was not restricted in any way. However, 23 (54%) of the carers thought an electronic tracking system would reduce their anxiety about the patient. When asked what the proposed tracking system reminded them of, 18 (42%) referred to the tagging of prisoners and 13 (30%) said that they had heard of the possible

use of the system for patients with dementia. Although specifically prompted to do so, none of the informants cited ethical objections.

Practical utility in patients currently at risk. The carers of 11 of the 18 patients who had got lost and were still going out alone said they would have used an electronic tracking device if one had been available. The main reason for rejecting the use of the device was that the carer thought the risk of the patient getting lost was too small because they only walked in the immediate locality. Two of the 11 patients lived on their own and two would not have tolerated wearing the transmitter, whatever the mode of attachment. Three carers were insufficiently mobile to actively search for the patient, but there were other practical barriers in all three of these cases. Thus, in seven cases where patients continued to be at risk the carer said they would have used the device and there would have been no obvious barriers to its use.

Practical utility in patients previously at risk. A further 25 patients had got lost previously, but were no longer going out alone. The carers of 16 of these said they would have used an electronic tracking device if one had been available at the time of risk. However, five of these 16 patients lived alone. In these cases, there would have been no-one who could readily recognize that the patient was lost. Two carers were insufficiently mobile to search, but in both cases the patient was living alone anyway. Thus, the device would have had potential for use in a further 11 patients who had got lost in the past but were no longer at risk of getting lost.

FEASIBILITY STUDY

Method

Psychogeriatricians and community psychiatric nurses were invited to refer patients with dementia who were living at home for consideration for the use of an electronic tracking device. We explained that we did not wish to restrict the study to those who had already got lost and asked clinicians to have a low threshold for referral. We specifically wished to gain experience of problems which militated against the use of the device. The decision whether or not to include a referred patient and their carer in the study was taken as part of a multidisciplinary process. As part of that process, consideration was given to the use of a guardian-

ship order. The study received ethical approval from the Oxfordshire Psychiatric Research Ethics Committee.

The tracking system

The tracking system we used was adapted from its widespread employment in animal research (Kenward, 1987). It consisted of a small transmitter (Fig. 1) which was carried by the patient and a direction-finding receiver which was used by the person who was looking for them (Fig. 2). The radio signal from the transmitter was detected by a hand-held receiver and converted to an audible bleep which was loudest when the receiver was being pointed directly towards the transmitter and the patient was nearby. Once carers realized that the person with dementia was lost, they could search by walking or driving in the direction indicated by the strongest signal. It was recognized from the outset that some training of carers was necessary. For example, if a signal was not initially detected, considerable persistence was required since the carer would have to travel in a circular route centred on the point where the patient was last seen.

The transmitter was about the size of a small match-box and had a 6-inch aerial. The battery life for continuous use of the transmitter was about 6 months. A variety of methods of attaching the transmitter to the patient were tried: belt attachments, wristwatches, necklaces, sewing it into clothing. The equipment was tested in urban and rural environments. In rural settings the device had a range of 5 miles. This was substantially reduced in built-up areas to a maximum of half a mile in the centre of a town, where signal detection was less reliable.

Results

Twenty-four patients were assessed, of whom 17 were male. Five had never actually been lost but were nevertheless thought to be at risk of getting lost, 14 had been lost on up to five occasions and five had been lost on many occasions. After assessment, the transmitter was worn by 13 patients, of whom eight were living at home. There were three main reasons for the 11 exclusions. First, the 'window' during which the patient was at risk had passed because the patient had stopped walking or going out (nine cases). Second, there was no carer who was willing and able to use the receiving device



Fig. 1. Different forms of transmitter

(seven cases). Third, the carer thought it unlikely that the patient would tolerate wearing a transmitter without trying to remove it (six cases). In most excluded cases more than one of these reasons applied.

The transmitter was worn for no more than a few days in four cases, for up to 3 months in a further three cases and for 3–8 months in six cases. The main reason for rapid abandonment of the transmitter was that it was not tolerated by the patient.

The device was deployed in a search in four cases, in two of which the patient was successfully found using the device. In the other two cases, the direction of the patient had been established but passers-by found the patient before the person searching for them.

Those carers who needed least training used it most successfully. The receiving equipment (Fig. 2) was too large for easy use by seven of the 27 carers who were originally assessed. Careful and persistent listening to find the direction of maximum signal strength was required. Nevertheless, two of

the four carers who used the device in a search were elderly women. Since the searching process was an active one, in which the searcher had to follow on foot or by car, getting out of the car to use the device, the carers needed to be reasonably mobile. However, one carer with painful arthritis used the device successfully and said that she would have been more reluctant to undertake a potentially prolonged search if she had no idea where to look.

Illustrative vignettes

Case one. An 82-year-old man regularly left his flat to go to his allotment. He had been lost on three occasions and had been brought back by the police on two. He would become aggressive if his wife tried to stop him. She recognized that his traffic sense was 'appalling'. Her anxiety about the financial implications of nursing home care and the wish to nurse him for as long as possible delayed plans for placement. She rapidly understood the equipment and successfully used it on two occasions to find him when he failed to return



Fig. 2. Receiving device

for lunch. When asked by passers-by what she was doing, she said that she was searching for squirrels. Sedative medication was subsequently given because of his aggression at night. He sustained a fall and head injury and stopped going out.

Case two. A 49-year-old man with presenile dementia, whose job had involved regular, long expeditions on foot, continued to forcefully insist on going out regularly for long walks and cycle rides. On one occasion he was lost for 15 hours having walked 18 miles. He regularly showed off the device to others and explained why he was wearing it. Despite high levels of vigilance by the staff of the rural nursing home where he was subsequently placed, his speed of walking meant that he evaded them and got lost. Using the device, he was successfully found on two occasions. On a third occasion when he went missing, the frequency setting on the receiving device had not been tuned accurately and the device was functioning sub-optimally. The staff and police had been looking for him for 6 hours when they heard that he had been hit by a lorry as he walked down a country

road 10 miles away. He sustained a fractured arm but was fortunately otherwise uninjured. Following his return to the nursing home, the device was used on several occasions to establish which direction he had taken. This was sufficient to enable him to be found quickly. Subsequent placements in locked facilities have been associated with major frustration and outbursts of aggression.

Case three. A man had been admitted to hospital having been found walking on a motorway by the police. Initially, the clinical team considered the possibility that his son, who worked in the same town, would be able to use the receiving equipment if his father got lost after returning home. The patient therefore started to wear a belt with the transmitter attached while in hospital. On one occasion he used the belt to secure his suitcase which he had packed, saying he wished to go home. It became apparent that the frequency with which he left the house and the difficulty in persuading him to return once he was found would not have been alleviated through the use of the system. Furthermore, his son could not guarantee to be

available to look for him. It was recognized that decisions about his placement had to be made independently of whether or not the equipment was used.

DISCUSSION

The extent of the problem

This survey highlights the substantial degree of risk to people with dementia that is tolerated. Road safety was thought to be poor in 44% of those who were going out alone. Many (42%) of those who had already got lost continued to go out unaccompanied. The main reason that these risks were tolerated was probably because most (78%) of these patients did not stray too far from the locality. An electronic tracking device could have helped to reduce the risks in 7% of this sample who were currently at risk, and might have been useful in a further 11% in whom the period of high risk had passed.

Barriers to the use of tracking devices

Technical barriers. There are four techniques which could be used to indicate the location of an elderly patient. Boundary crossing alarms and movement-monitoring devices may have a role inside buildings. Once the subject has left the building, however, triangulation-based technologies (geo-stationary satellites or cellular phone relay stations) or direction-finding equipment are required. We have used a direction-finding system, which has been widely employed for tracking animals in the wild.

Although the device was simpler to use than programming a video-recorder, some degree of training was necessary. The receiving device was too large for some carers to use and signal strength was dependent on local topography. In urban settings it was most reliably used over short ranges to determine the direction of someone who was known to have recently left the house.

Risk assessment. Cases 2 and 3 graphically illustrate the point that electronic tracking devices do not abolish risk and cannot be a substitute for appropriate placement. The experience of case 2, who sustained an accident when lost for a long time but not when he was rapidly retrieved, suggests that the use of the device might have been instrumental in averting further accidents. However, it is also

theoretically possible that the use of an electronic system contributed to a false sense of security and resulted in subjects being allowed to go out when they were too unsafe. Although it was not formally assessed, it was our impression that the resolve of the carers not to let the patient get lost was *increased*, rather than decreased by the focus which the study put on the risks of getting lost. As the experience of case 1 suggests, there may be no practical alternative to accepting the risk that the patient might get lost again and have, or cause, an accident.

Workload. Looking after people with dementia is labour-intensive. It is tempting to think that this form of electronic device would enable people to be kept at home who would otherwise require institutional care. Our experience suggests otherwise. Not only does someone have to ensure that the patient is wearing the device, but the recognition that someone has left their home or has not returned when expected also requires someone 'on the ground'. Furthermore, someone needs to do the searching. Elderly spouses are sometimes too frail to do this themselves. Asking the police to conduct a search continues to be a final option. It is unlikely that any existing organization would have the resources to take on the role of routinely searching for the large numbers potentially involved.

Ethical barriers. The cooperation of patients in the use of the device was variable, although an expressed agreement to participate was a prerequisite for initiating it. One patient initially said he was happy to wear the transmitter, but subsequently rejected it saying he 'did not want to be kept on a lead'. Another spontaneously drew an analogy between the transmitter and a cow-bell, but was quite happy to use the device and whenever its purpose was explained was pleased by the security it afforded. The severity of dementia of patients who might use tracking devices is such that it will often not be safe to regard their consent as informed. While the 'best interests' test should be applied for the ethical treatment of such patients, our experience was that intolerance of the device was, in any case, a practical bar to its continuing use.

Since very few carers questioned in the survey said they would give patients more freedom if they had a device, and since none of the subjects who actually used the device was given more freedom as a result, the ethical justification of maximizing autonomy was shown not to be

relevant. A more relevant ethical justification was that the device had the capacity to reduce the length of time that someone was lost, thereby lessening the chances that they would sustain or cause an accident.

If a tracking device is to be used as part of a care package, the decision is probably best taken as part of a multidisciplinary consideration of alternatives. This helps to ensure that the 'best interests' of the patient are adequately considered before a device which some might regard as restrictive is used by a care organization. However, none of the informal carers we interviewed thought there were ethical problems with using the device and individuals may feel happy to buy and use tracking equipment independently of any involvement of psychiatric or social services.

Case 3 illustrates that decisions about whether or not the patient needs institutional care should not be influenced by the use of experimental tracking equipment. Guardianship orders were used in three cases where the patient was in an institution. The process of setting up the guardianship order helped to confirm that all parties involved were in agreement with its use. The continuing use of the device was formally reviewed and alternatives considered. The legitimacy of returning the patient to the home was reinforced.

Potential utility

If we make conservative assumptions: first, that our psychiatric services were only aware of the most difficult 20% of cases with dementia, second, that our figure of 7% for the proportion of these difficult patients who might at any one time benefit from a tracking system is double that which really exists, and third, that the prevalence of dementia is 650 000 in the UK, then the number of people in the UK who might potentially benefit is of the order of 10 000. It is possible that the enthusiasm of informants for electronic tracking equipment would not have been matched by the take-up rate, even where there were no practical barriers to its use. Predicting the take-up of new technologies is not easy, since such factors as risk perception, consumer education, social acceptability, user-friendliness, availability and cost can all influence the demand.

Methodological issues

A number of caveats must be applied to any generalization of our findings. The telephone survey

was conducted among carers of those who were known to psychiatric services and may therefore over-represent the extent of the problem in patients with dementia. However, there are no epidemiological studies with which to compare. Second, the questionnaire used had not been formally validated. Although the face validity of the questions was good, it is possible that carers underrated the traffic sense of the patients because they were acutely aware of their vulnerability. It is safest to assume that the figures derived from this survey are an upper estimate for the potential use of electronic devices.

The future

Refinements of the device we used or the application of different technologies could increase the usefulness of these devices for certain groups of carers. Specifically, a device which allowed the patient to be accurately located with little active searching from a carer would be useful for many frail carers. Such a system, while technically possible, would require a large and expensive infrastructure. For more mobile carers who recognize within minutes that the patient has left and need to know quickly which way he or she went, a smaller direction-finding receiving device with a short range would be an advance.

Patients who live alone and still go out alone are at the greatest risk because of the length of time before their absence is noted. For such patients, regular home visits, together with a transmitting device which remained attached semi-permanently, on a wristwatch strap for example, coupled with a locating system which did not require active searching would be required. A system of sensors within the home which could alert a distant carer to a change in the pattern of someone's activities might be useful to provide early warning of the patient's absence.

There are barriers to the use of tracking devices which no amount of technological innovation will resolve. Someone needs to recognize that the patient is at risk, and both informal and professional carers may need educating about this. Someone will always need to ensure that the device is attached to the patient and go and fetch them. The use of electronic tracking devices is warranted for carefully selected patients with dementia. Technical developments may yet allow more patients to benefit. However, continuing research will help to

temper excessive enthusiasm for a technical solution to a social problem.

ACKNOWLEDGEMENTS

We are grateful to all the carers and patients who participated and to the CPNs and medical staff involved. Sean Walls provided valuable technical advice. This work was supported by a grant from the Charles Wolfson Charitable Trust.

Conflict of interest

Bridget Kenward is a director of the company which manufactures the equipment which was used in this study, and both she and Robert Kenward own shares. The other authors have no conflict of interest.

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