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Ethical Issues and Tagging in Dementia: a Survey

Julian C. Hughes MA MB ChB MRCPsych PhD
Consultant in old age psychiatry and honorary clinical senior lecturer, Northumbria Healthcare NHS Foundation Trust and Institute for Ageing and Health, Newcastle University, UK.

Jane Newby MBBS MRCPsych
Consultant in old age psychiatry, Centre for the Health of the Elderly, Newcastle General Hospital, Westgate Road, Newcastle upon Tyne, UK

Stephen J. Louw MB ChB, MD (UCT), FCP (SA), FRCP, FRCP (Edin),
Consultant Physician, Care of the Elderly Directorate, Freeman Hospital, High Heaton, Newcastle upon Tyne, UK.

Gill Campbell RMN RGN
Community Psychiatric Nurse, Centre for the Health of the Elderly, Newcastle General Hospital, Westgate Road, Newcastle upon Tyne, UK.

Jane L. Hutton PhD CStat
Professor of Medical Statistics, Departmen tof Statistics, University of Warwick, Coventry, UK.

ABSTRACT

A good deal of concern is generated when a person with dementia wanders. One putatively easy technological remedy is to consider electronic tagging. This possibility, however, raises a different set of ethical concerns. In this paper we report the results of a survey that was intended to elicit people's views about the ethical issues surrounding the topic of tagging in dementia. There was broad agreement in response to the scenario used in the survey that electronic tagging could be an ethically reasonable way to deal with wandering in people who are confused. It was seen as considerably better than locking doors as a way to maintain a person's safety. There were, however, concerns and uncertainties about principles relating to civil liberties, stigma and dignity. And there appeared to be some weight behind the view that electronic tagging of confused people who wander requires professional involvement, the nature of which would need to be decided. population in general.

Key Words: confusion, dementia, electronic tagging, ethics, wandering

Introduction

Electronic tagging as a means of restricting the liberty of criminals is often in the headlines, but increasingly there are demands for its use in people with dementia, including in the UK by government ministers (BBC, 2007). At the same time, the possibility of using electronic tagging for confused people who "wander" is becoming ever more feasible (Miskelly, 2004). Ethical concerns about the use of tagging and tracking devices in the context of dementia have been discussed for some years (McShane, Hope, & Wilkinson, 1994; Hughes & Louw, 2002; Hughes & Campbell, 2003). The concerns are rising because of the rising numbers of people with dementia as the population ages: the estimates are that 24 million people have dementia in the world and that this will increase to 81 million by 2040 (Ferri et al., 2005). And, since "wandering" is a common enough behaviour in dementia (McShane et al., 1998), many people wish that there might be an easy solution.

The issues are much the same as those that surround other forms of restraint. The conflict is often between, on the one hand, the concern to do good (beneficence) and prevent harm (non-maleficence) and, on the other, the need to allow people freedom to make their own decisions (autonomy). According to the literature (Hughes & Campbell, 2003), there are a number of advantages to electronic devices that tell us when someone has wandered. For instance, patients or residents generally are less restricted since locked doors are not required, the devices are unobtrusive, nurses

and carers do not have to worry so much, and harm might be prevented. There are also disadvantages. For example, tagging is seen as degrading, freedom is still curtailed, and the devices might distract organizations from the need to provide more staff and better training. So, on the good side, not only might electronic tagging allow us to do good and prevent harm, these devices might also extend the person's autonomy, by allowing more choice and by allowing people to take risks. Nevertheless, on the bad side, there is still the concern that tagging will encourage us to think of people as if they are objects, to restrict their liberty and deny them their civil rights. Those who have written about electronic tagging have argued that there is a need for agreed protocols, proper risk assessments, attention to issues of consent and a transparent and just review process (cf. Hughes & Campbell, 2003).

There is a need to see the electronic tagging debate in its broader context. For instance, it is important to recognize that the technology that might be used is diverse and developing. An electronic tag might be used in conjunction with a boundary-crossing alarm. So if a confused resident in a home crosses the boundary, for instance to the front door, the alarm would sound. An alternative is that the electronic tag can be used in conjunction with a tracking device, so that – if lost – the person might be found. Increasingly this might be possible using mobile phone systems. The point to note is that different systems would raise different practical and ethical problems. The practical problems would have an effect on the ethical issues. Thus, if the system involved a tracking device that did not work well in built-up areas, its ability to keep the person safe would be compromised and the argument based on the principles of beneficence and non-maleficence would to this extent be nullified. A very basic practical problem is that the electronic tag must be kept on the confused person. This is not always easy (McShane, Hope, & Wilkinson, 1994)!

The broader context also now involves various assistive technologies, including the possibility of 'smart homes' (Cash, 2003). Thus, technology allows most of the movements of a person in their own surroundings to be monitored. Again in the name of beneficence and non-maleficence it can be argued that this sort of monitoring helps to keep the confused person safe and, indeed, in the name of autonomy, might allow the person to maintain his or her independence for longer. The person's use of food, the temperature of the bath water and the person's location can all be monitored. If the person gets up at night, this can be observed and directions given if it looks like he or she might be intending to leave the building. Sudden movements, such as falls, can potentially be detected and help provided.

In many regards this seems like the perfect way to maintain an older confused person independently in the community. However, there is a cost in terms of the person's privacy. And it might be argued that this whole conception of how people might be monitored and managed is dehumanizing. One possible aim is to cut down on the need for personal intervention. Furthermore, it might be feared that, whilst pilot projects would emphasize the need and importance of human contact, once such systems were available on a wide scale, they might simply become another form of institutional care, albeit in the person's own home.

The ethical issues around smart homes are not the concern of this paper. The relevance of them, however, in terms of the broader picture should be obvious. From the ethical perspective, however, it is worth noting that, arguably, we have not reached a consensus on electronic tagging and yet we are now already being encouraged to consider ever more rigorous surveillance (with its concomitant risk of restricted liberty). The movement is not led, seemingly, by any clear ethical consensus or imperative, but by the advent of technological possibilities.[i] All the more reason then to reflect on the basic ethical issues that still surround the use of electronic tagging.

The need for broader public debate on electronic tagging is well recognized (Welsh, Hassiotis, O'Mahoney, & Deahl, 2003), but there has only been one reported survey, which has not appeared in a peer-reviewed journal (Nicole, 1998). We present the results of a survey concerning ethical issues surrounding the use of electronic tagging for confused people who wander.

Participants and Methods

The participants (n = 143) were recruited from convenience samples of main carers of younger people with dementia (n = 6), main carers of older people with dementia (n = 26), people attending a memory remediation group (n = 3), doctors (geriatricians (n = 17), old age psychiatrists (n = 16) and general practitioners (n = 15)), social workers (n = 4), community psychiatric nurses (CPNs) (n = 20), general nurses (n = 31) and occupational therapists (n = 5). The study had ethical approval from the local Research Ethics Committee and informed consent was obtained from participants.

A questionnaire was first piloted with 20 older people on a general medical ward. This was partly for convenience, but also allowed us to test the questionnaire amongst people who were potentially prone to the problems under discussion. The pilot study showed, however, that the patients in this setting found it difficult to engage with the nature of the questionnaire: it seemed difficult for them to contextualize the situation in which the question of tagging might arise. Hence, as well as simplifying some of the questions and reducing their number, an important innovation, in response to the pilot study, was that respondents were forced to choose between three possible strategies. To provide more context we used a case vignette, which described an older person with memory problems who wandered. It is noteworthy, from a methodological point of view, that the use of a vignette has been found to increase decision-making capacity seemingly by making the hypothetical questions more realistic (Vellinga et al., 2005). Following the vignette, the acceptability of electronic tagging was set against locking doors or constantly watching the person.

The questionnaire was distributed to the target groups (described below) in the North East of England and returned anonymously. It sought, first, to obtain respondents' attitudes to electronic tagging using the case vignette. The second part of the questionnaire comprised 10 statements concerning tagging, to which the participants were asked to indicate variable degrees of agreement or disagreement. Finally, there were spaces for further (qualitative) comments.

Terminology

On the grounds that our survey was to involve members of the public, we deliberately left some of the terminology vague in a way that we judged would reflect lay understandings. For example, the questionnaire was headed "Electronic tagging in people with memory problems". Having talked again of people "with memory problems" in the context of a vignette, we then used the term "confused" in our specific questions. We did not try to define the cause of the confusion any more precisely, but our impression was that the lay people had dementia in mind. "Confusion" might also refer to delirium, where the ethical issues might be similar, except that the longer-term nature of dementia raises particular issues that might not be so relevant in the acute situation.

Similarly, although not insensitive to concerns about the breadth of behaviours that might be termed "wandering", we have used the word in keeping with its everyday usage without prejudice to its broader meanings and the possibility that walking by people with dementia might have a variety of purposes (Hope et al., 1994). We have continued to use the term "wandering" in this paper to reflect usage in the survey and to avoid having to specify the types of walking in dementia that might raise the possibility of tagging (McShane et al., 1998). Finally, we are aware that there are various electronic devices, but for the sake of brevity we referred throughout the survey simply to electronic "tagging". The respondents did not seem perturbed by this simplification.

Results

A total of 143 responses were received, a response rate of approximately 67%. Two-thirds of the respondents were aged under 61 years, and 73% were women. Those older than 60 were carers or relatives. Of the 39 men, 72% (28) were doctors; 20 of the 104 women were doctors. Very few respondents (7%) thought that people should be free to wander regardless of risks.

As Table 1 shows, two-thirds of the respondents regarded electronic tagging as the most appropriate and only 8% thought it the least appropriate approach to wandering. Just over a fifth felt that constant watching was the most acceptable strategy. Locked doors were regarded as the least appropriate response by half the respondents. Almost all respondents were willing to be tagged themselves (93%) or to let a relative be tagged (92%). For the people attending the memory remediation group, along with the social workers and the occupational therapists, there was 100% agree-

ment with the idea of being tagged or having a relative tagged, but these were small groups (for all three groups n = 12). Otherwise, age, gender and experience affected the responses. Almost all of those opposed to tagging a relative were female professionals between 41-60 years old. The groups who objected the most to the idea of a relative or themselves being tagged were nurses, with the CPNs showing the biggest reluctance to tagging of a relative. There was a highly significant difference between CPNs and all other groups with respect to being willing to have a relative tagged ($\chi 2 = 11.342$, DF = 1, P < 0.001), with the CPNs being unwilling in 25% of cases, whereas for the others the figure was 4%. The one man who objected to a relative being tagged was also a nurse. For self-tagging, 80% of those opposed were women, and 9 were under 61 years. Again, there was a statistically significant difference between CPNs, who were much less inclined to be tagged themselves, and all other groups ($\chi 2 = 4.822$, DF = 1, P < 0.02). Those who opposed self-tagging were also those who were less inclined to worry about confused people wandering.

The results in Table 2 can be highlighted in three groups: (a) showing a good deal of agreement, arbitrarily defined as greater than 70%, (arranged as items [i] to [v] in Table 2); (b) showing mixed responses (items [vi] and [vii]); and (c) where the percentage – again arbitrarily determined – neither agreeing nor disagreeing was 20% or over, (items [viii] to [x]).

There was a good deal of agreement with the statements that locking doors was worse than tagging (73%), that tagging would benefit the confused person (80%) and the carer (83%), that it would help people to be looked after in their own homes (71%), but that decisions about tagging should only be made with the involvement of health and social care professionals (82%). Concerning the statement that tagging would be used to benefit carers, there was no strong disagreement (only 6% disagreement). Similarly, there was no strong disagreement with the statement that tagging would help people to remain at home. Although fewer carers (as opposed to professionals) agreed with the idea that professionals should be involved in the decision to tag someone, ignoring those who were undecided, this did not reach statistical significance ($\chi 2 = 1.866$, DF = 1, P < 0.10).

In the more mixed reactions, most (64%) were in agreement that tagging would increase the freedom of the person with confusion. Family carers certainly agreed with the idea, whilst most of the disagreement (which amounted to 15%) came from doctors and nurses. There was also ambivalence about whether tagging would mean less worry for carers: 45% agreed or strongly agreed and 41 % disagreed or strongly disagreed. Of those who strongly

TABLE 1: APPROPRIATENESS OF DIFFERENT RESPONSES TO WANDERING		
Response to wandering should be:	Most appropriate (%)	Least appropriate (%)
Watching the person	29 (21)	57 (40)
Locking doors	19 (14)	75 (52)
Electronic tagging	91 (65)	11 (8)
Totals	139 (100)	143 (100)

		Agree or strongly agree (%*)	Neither agree nor disagree (%*)	Disagree or strongly disagree (%*)	No response (%*)
TABLE 2: RESPONSES TO STATEMENTS ABOUT ELECTRONIC TAGGING WITH RESPECT TO CONFUSED PEOPLE WHO WANDER (N = 143)					
(i)	It would be used to benefit the carer	119 (83)	12 (8)	9 (6)	3 (2)
(ii)	Decisions regarding tagging should only be made with the involvement of health and social care professionals	117 (82)	8 (6)	17 (12)	1 (1)
(iii)	It would be used to benefit the confused person	114 (80)	14 (10)	12 (8)	3 (2)
(iv)	Locking doors is better	13 (9)	24 (17)	104 (73)	2 (1)
(v)	It would help people to continue to be looked after in their own homes	102 (71)	28 (20)	10 (7)	3 (2)
(vi)	It would increase freedom for the confused person	91 (64)	25 (17)	22 (15)	5 (4)
(vii)	It would mean less worry for carers	64 (45)	17 (12)	59 (41)	3 (2)
(viii)	It would be undignified	26 (18)	33 (23)	82 (57)	2 (1)
(ix)	It would result in stigma	26 (18)	32 (22)	32 (22)	3 (2)
(x)	It would improve overall quality of life	73 (51)	55 (38)	14 (10)	1 (1)
* Percentages rounded to whole numbers, so occasionally totals are above or below 100%.					

agreed (n = 14), 79% were family carers; of those who disagreed or strongly disagreed (n = 15), 75% were psychiatric nurses. If the respondent was opposed to tagging overall, 63% disagreed that it was a means of decreasing the worry for carers.

There were three statements with which more than 20% of the sample were unable to agree or disagree. Most people (57%) neither agreed that tagging was undignified nor that it would increase stigma. (In fact, no one strongly agreed that it would be undignified.) Of those who were opposed to tagging overall, 82% thought it would be undignified and 58% thought it stigmatizing. But in both cases, over 20% seemed to be neutral or could not make their minds up. Similarly, despite the marked agreement (71%) with the idea that tagging would facilitate independent living, 20% neither agreed nor disagreed. There was a more marked reticence about whether tagging would increase the quality of life for the confused person: 51% agreed or strongly agreed that it would, but 38% neither agreed nor disagreed.

Discussion

In developing the questionnaire we found that asking abstract questions about tagging led to ambiguous responses. The case vignette and the forced choice of management strategies proved helpful in rooting the questions in some sort of reality. At least in the context of a vignette about an older person who wanders, this survey suggests that, amongst professionals and carers, most people are not worried on ethical grounds about the use of electronic tagging as a way of looking after people with memory problems who wander. And yet, there is a strong inclination that such use needs to be monitored and there are obvious ethical concerns being voiced.

In general, as in an earlier survey across several European countries (Nicolle, 1998), people would be accepting of tagging for themselves as well as for others. Our survey demonstrates that carers of people with dementia are particularly in favour of the use of tagging. Concerns persist, however, with some people (about 6%) taking the libertarian view that wandering should not be restricted. There was also a view that tagging would not increase freedom; and it is noteworthy that worries about dignity and social stigma were evident in about 18% of respondents (with another 22-23% being unsure). Again this mirrors the earlier European survey (Nicolle, 1998). This reticence perhaps underlies the feeling (amongst 82% of the respondents) that health and social care workers need to be involved in some unspecified way in the use of electronic tagging, albeit this is not so popular with family carers.

The conclusions of the study are limited by the relatively small number in each of the samples, which precludes more detailed analysis. In particular, despite some effort, it was difficult to recruit many people with even mild memory problems. This deficiency would need to be addressed in any future similar study. Non-professionals are represented by the main (usually family) carers, who appear to focus more on issues of safety and less on the

arguments to do with civil liberties, no doubt reflecting their experiences. It could also be argued that professionals share the same concern with safety, although the tendency for CPNs to veer towards a more libertarian view is noticeable.

We have not explored the nature of this tendency. We could conjecture that it reflects a greater awareness of the requirements for person-centred care in dementia and for attention to be paid to issues of consent and to the needs of vulnerable adults. It may be that professionals are more aware that restrictions of liberty in those who cannot consent (but who might seem passively to assent) need to be justified. But then it is striking that there was a difference between the views of nurses, especially CPNs, compared to other professional groups. It is equally striking that family carers, who have often experienced the reality of the person they care for being lost (at least to them), were seemingly more inclined to favour tagging. The debate comparing issues of safety over against considerations of liberty and autonomy has recently been discussed following a broader literature review (Robinson, et al., 2007a).

That we have not explored the nature of this tendency reflects the nature of our survey. A larger qualitative study would be required to do so. Not only would this allow a greater understanding of the ethical issues, but it might also encourage further probing of the practical issues with their concomitant ethical implications. For instance, if some form of tagging were thought to increase safety (seen as ethically good), but as a result there was less surveillance, so that the confused person was in fact able to wander and be put in harm's way, the practical outcome would argue (at least to this extent), on the grounds of non-malfeasance, against the ethical use of tagging.

Some of the issues in this survey have been touched upon in a systematic review of the literature on wandering in dementia, which considered the ethical implications and acceptability of various non-pharmacological interventions (Robinson, et al., 2006; Robinson, et al., 2007b). It found that there was considerable ethical concern in the literature over the use of electronic tagging and tracking devices. However, the majority of the papers reviewed were discussion papers with little empirical evidence to support the arguments presented.

This survey demonstrates broad agreement that electronic tagging is an ethically reasonable way to deal with wandering in people with memory problems who are confused. However, there is a real sensitivity to wider concerns and principles relating to civil liberties, stigma and dignity. This suggests the use of electronic tagging is something that should be monitored and sanctioned in a formal way. Such formal procedures should, perhaps, be required in the light of legislation to do with consent, capacity, duties of care and rights to liberty. Further research might wish to study the specific circumstances under which electronic surveillance (by whatever means) is considered appropriate. The exact context is likely to determine the extent to which electronic tagging is ethically acceptable for any particular individual (Hughes & Baldwin, 2006).

Endnote

[i] However, it is interesting to note that E M Forster considered relevant ethical and social issues a century ago in "The Machine Stops", long before the advent of recent technological possibilities! See: http://brighton.ncsa.uiuc.edu/prajlich/forster.html

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Address for Correspondence: *Dr Julian C. Hughes, Ash Court, North Tyneside General Hospital, Rake Lane, North Shields, Tyne and Wear, NE29 8NH, UK. Tel: +44 (0)191 293 4057. Fax: +44 (0)191 293 2749 e-mail: j.c.hughes@ncl.ac.uk*