Electronic tracking for people with dementia: An exploratory study of the ethical issues experienced by carers in making decisions about usage

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Abstract
Electronic tracking through GPS (global positioning system) is being used to monitor and locate people with dementia who are vulnerable to becoming lost. Through a review of the literature and an original study, this article examined ethical issues associated with use in a domestic setting. The qualitative study consisted of in-depth interviews with 10 carers who were using electronic tracking. The study explored the values, beliefs and contextual factors that motivated carers to use electronic tracking. It examined the extent of involvement of the person with dementia in decision-making and it explored the various ethical dilemmas encountered by carers when introducing the tracking system. As an issue that emerged from the interviews, specific attention was paid to exploring covert usage. From the study findings, recommendations have been made for research and practice about the use of electronic tracking in dementia care.

Keywords
dementia, ethical acceptability, electronic tracking, wandering

Introduction
Electronic tracking through GPS (global positioning system) is being used to monitor the whereabouts of people with dementia who are vulnerable to becoming lost. Its use in dementia care has attracted much debate about ethical acceptability. This article has
summarised key themes in the debate and has made an original contribution through an exploratory qualitative study that examined the ethical issues experienced by familial carers who were using electronic tracking in the care of a person with dementia in a domestic setting. The study has specifically shed light on the process of deciding to use electronic tracking in terms of the values and contextual factors underpinning decisions about usage; the extent of involvement of the person with dementia in the decision; and the strategies employed by carers to negotiate ethical issues encountered through use.

**Background**

Wandering is a common behavioural symptom of dementia that encompasses a broad range of walking behaviours and can result in the person ‘eloping’ from one’s dwelling and getting lost (Algase, Moore, Vandeweerd, & Gavin-Dreschnack, 2007; Hermans, Htay, & Cooley, 2007). The reasons for getting lost are likely to be multifaceted, emanating from cognitive deficits, environmental and psychosocial factors (Lai & Arthur, 2003). Studies have suggested substantial risks are posed by getting lost including death, injury, dehydration, and hypothermia (Koester & Stooksbury, 1995; Rowe & Bennett, 2003; Rowe & Glover, 2001). Becoming lost has also been associated with reduced freedom for the person with dementia, in particular, being locked into one’s home and higher rates of admission to care-homes (McShane, 1998a; Scarmeas et al., 2007). For carers, wandering has been associated with higher levels of carer subjective burden (Ballard, Lowery, Powell, O’Brien, & James, 2000; Miyamoto, Ito, Otsuka, & Kurita, 2002).

Electronic tracking through GPS can locate a person at any given moment by positioning the device through satellite technology and sending the information via the mobile phone network to a personal computer, a call-centre or a mobile phone (Kearns & Fozard, 2007). Accuracy of GPS tracking ranges from 5–100 metres (Miskelly, 2004; Shimizu, Kawamura, & Yamamoto, 2000). GPS tracking does not prevent the person from wandering or getting lost but enables a carer to locate the person with dementia at any given moment. Some systems have, however, been designed to include a boundary-alarm function wherein a carer is notified of a boundary transgression beyond a pre-defined area, a function commonly referred to as electronic tagging. Reflecting the novelty of the technology, few intervention studies of GPS tracking have been carried out in dementia care. Two systematic reviews of interventions for wandering behaviour, Robinson et al. (2006) and Hermans et al. (2007), did not find any randomised controlled trials of electronic tracking and concluded that there was insufficient research evidence to make recommendations about its use.

Electronic tracking has incurred considerable ethical debate (Robinson et al., 2006). A report published by The Alzheimer’s Society (2007) concluded that electronic tracking holds potential to enhance the freedom of people with dementia whilst minimising risks to them. Yet, the report also highlighted important ethical concerns surrounding its use and the contested nature of the debate. Much of the literature to date has been dominated by professional opinion rather than studies that have explored the perspectives and experiences of people with dementia and their carers. This over-representation of professionals within the debate may be significant because a recent survey found professionals appear to hold greater reservations about electronic tracking than carers (Landau, Werner, Auslander, Shoval, & Heinik, 2009). In view of the novelty of the technology, there is a lack of research about the ethical issues that is grounded in actual experience of usage. Debate about the ethical acceptability of electronic tracking has largely centred on the following
Rights and risks

Central to the debate is the challenge of balancing the potential safety gains afforded by electronic monitoring with the potential infringement of civil liberty resulting from its use (Hughes, Hope, Reader, & Rice, 2002; McShane, Hope, & Wilkinson, 1994; Robinson et al., 2006, 2007; Welsh, Hassiotis, O’Mahoney, & Deahl, 2003). From the perspective of consequentialism, the use of electronic tracking could be justified on the grounds of maximising liberty if it prevents institutionalisation and enables the person to remain at home (Hughes & Baldwin, 2006). McShane et al. (1994) proposed that electronic tagging (technology preceding tracking) could enhance freedom by reducing carer concerns for their safety. However, a later study of electronic tracking did not corroborate this. McShane (1998b), in a survey of 43 carers, found only two carers who planned to use electronic tracking to enable the person with dementia to have additional freedom, and none of the 13 carers who actually used it awarded the person additional freedom.

Further research is warranted to assess whether carers, when anticipating the consequences of getting lost, have a heightened awareness of the risks posed by getting lost relative to the risks posed by the technology to a person’s liberty. In balancing safety with liberty, there are challenges inherent to the assessment of risk in dementia. Robinson et al. (2007) drew attention to the socially constructed aspects of risk associated with wandering, and more broadly, the construction of people with dementia as vulnerable. Hughes and Louw (2002) emphasised the role of social norms in defining an acceptable level of risk in relation to the management of wandering. These issues highlight the need to examine how carers construct risk and how this informs a decision to use electronic tracking. A key recommendation of the recent report by the Nuffield Council on Bioethics (2009) was that risk–benefit assessment should be developed in lieu of risk assessment. This would enhance recognition of the potential losses arising from restricting a specific behaviour or activity. Specifically, the report highlighted how the risks of walking outside the home should be weighed against the risks of being kept in the home and enduring boredom, frustration and lack of exercise.

Privacy

Article eight of the European Convention for the Protection of Human Rights and Fundamental Freedoms (1950) outlined the right to private life, which has been adopted into law in many jurisdictions. Electronic tracking by its very nature infringes on the privacy of the person with dementia by enabling another person to check their whereabouts at any given moment. This is most problematic for devices attached to the person in a way that prevents them from removing it.

Comparison with alternative courses of action has been used to justify the infringement of privacy caused by electronic tracking and tagging technology. Surveillance by a carer, normatively deemed appropriate, could also be experienced as an intrusion on privacy (McShane et al., 1994). As an explicit form of surveillance, monitoring by a carer might be experienced qualitatively as more invasive than electronic tracking. McShane et al. (1994)
justified the infringement of privacy by narrowly defining the concept of privacy. They argued that an infringement of privacy can only occur if the person under surveillance wishes to hide. Concern for privacy is then minimal if the person freely consents to being monitored. However, Hughes and Louw (2002) have proposed that some people in certain circumstances may want to hide, and that reducing privacy in this manner could have the consequence that infringement of privacy is accepted without due consideration taken of a person’s rights. In the absence of mental capacity, the ‘best interests’ principle would need to take account of the person’s past and present views about privacy, for example whether it was highly valued by the person. If privacy were to be restricted, decisions about access to an electronic tracking system would need to take account of who would likely be most acceptable to the person with dementia to have such access to monitoring his/her whereabouts.

Mental capacity, consent and best-interests

Consent in the context of cognitive impairment adds complexity to use of electronic tracking in dementia care. The right of a competent person to make decisions has been afforded protection across legal systems in Western Europe and North America. While legislation on capacity exists in most jurisdictions, it was beyond the scope of this article to review the diversity of legislative models. This article has briefly examined consent with reference to the Mental Capacity Act 2005 (England & Wales). It is likely that many of the themes discussed in this context resonate with the challenges encountered in other jurisdictions. Under this Act, mental capacity is presumed unless otherwise proven; is specific to the decision in question; can fluctuate and be temporarily diminished; and decisions that appear irrational or unreasonable cannot be considered proof of incapacity. The act protects the presumption of capacity and dictates that every effort should be made to facilitate informed decision-making. Incapacity is only declared if the person is unable to understand the information given, retain it, weigh it up and communicate the decision (Hughes & Baldwin, 2006). Under the Act, in the absence of capacity, decisions can be made on behalf of the person if based on judgements about ‘best interests.’ These include objective ‘best interests’ such as enhancing safety but should also incorporate a subjective element that takes account of the person’s life-history, beliefs, values, past and present wishes, and the views of anyone nominated by the person involved in their care (Hughes & Baldwin, 2006).

Cases where the person with dementia fully understands the implications of electronic tracking and readily consents to use are unproblematic. However, this may not typically be the case. Wandering appears to be most common in the moderate–severe stages of dementia (Hope et al., 2001). At this stage, capacity to make decisions is likely to be diminished and to fluctuate over time. This calls into question difficulties associated with borderline capacity (Nuffield Council on Bioethics, 2009). Borderline capacity does not sit comfortably in a legal framework that constructs capacity as dichotomous, present or absent. In response to this challenge, the Nuffield Council on Bioethics (2009) proposed a joint decision-making model, involving trusted family members, as an interim measure for when the person is not fully able to make decisions but is not yet at a stage where a system of total proxy decision-making is required. Their report made specific recommendations about decision-making in relation to assistive technology. It proposed that account is taken of the need to support people with dementia in order to enhance both well-being and autonomy, and the need to consider the interests of other relevant parties, particularly carers. Drawing on ‘best practice’
principles, this involves taking account of a person’s past and present views and wishes; the actual benefit which is likely to be afforded by the technology; and the extent to which carers’ interests may be affected.

When considering the practice of informed consent, it is also important to take account of the role of carers in decision-making and the extent to which information about electronic tracking is communicated. A qualitative study, Hughes and Baldwin (2006) (not specific to managing wandering), found carers frequently withheld information from the person with dementia that was important to the decision-making process. It is also conceivable that where the carer/cared-for relationship is markedly unequal, it may be more difficult for the person with dementia to express their preferences with regard to usage. Another qualitative study by Hughes et al. (2002) found carers often used substituted judgements, which were directed by their perception of the decision the person would have made had they not been cognitively impaired. However, they documented instances where such decisions placed the person at risk of harm because the decision did not take account of their present situation and potential vulnerabilities. This has implications for the weighting given to the past wishes of the person when invoking the ‘best interests’ principle in decision-making.

**Person-centred care**

Personhood is premised on ‘being with’ rather than ‘doing to’ the person with dementia. It follows then that the process of decision-making, in this case use of electronic tracking, should seek to understand the perspective of the person with dementia and those significant to them, and involve them as far as is possible in this process (Hughes & Baldwin, 2006). The concept of personhood does not preclude the use of tracking technology but raises important issues for the process of implementation. This perspective makes it an ethical imperative to consider not only what is done to the person but also the means by which it is carried out (Hughes & Baldwin, 2006). It calls into question the process of consent: how electronic tracking technology is introduced to and received by the person with dementia. From this perspective, enhanced safety as an outcome does not provide in itself a satisfactory ethical justification if, for example, the means involved strong persuasion or coercion.

Robinson et al. (2007) highlighted how a tension between preventing harm and promoting autonomy can challenge carers’ ability to provide person-centred care. Kitwood (1997) theorised that poor quality of care was detrimental to a person’s wellbeing and compounded cognitive decline. Person-centred care implies a need to ensure electronic tracking is not used in a reductive manner, for example as a means to reduce the need for supervision by carers, which would diminish opportunities for interaction with others. Hughes and Louw (2002) have highlighted the potential for electronic tracking to be used as a quick fix, without due consideration of the reasons why people wander, for example as a response to unmet need.

**Stigma**

Stigma can compound depersonalisation of the individual (Innes, 2009). A small qualitative study by Robinson et al. (2007) found people with dementia associated electronic tracking with surveillance and as having overtones of the ‘big brother’. Association with use in the
criminal justice system has periodically been mooted in the media debate about electronic tracking (Alzheimer’s Society, 2007). However, stigma does not emanate from the technology itself but from social constructions of the meaning of its use. Drawing on this, McShane et al. (1994) pointed out that electronic tagging is not intrinsically ‘degrading or dehumanising’ but rather that these associations arise from the circumstances that it is used in. Furthermore, Hughes and Louw have illustrated how electronic tracking might actually reduce stigma by preventing the experience of ‘being lost and half dressed on a motorway’ (2002, pp. 848).

The experience of stigma may be compounded by the negative public images of dementia, which have frequently been associated with the loss of ability, being a physical burden and a source of emotional stress for those that care (Innes, 2009). Such is the strength of these negative constructions of dementia that a study found stigma was associated with delayed diagnosis of dementia in eight European countries (Vernooij-Dassen, 2005 in Innes, 2009). This may mean paying careful attention to the visibility of electronic tracking devices, and involving people with dementia in the design of such devices (for example, Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009).

Carers and caring

Wandering behaviour has been associated with carer strain (Ballard et al., 2000; Miyamoto et al., 2002). Thus, a decision to use electronic tracking also needs to take account of carers. Hope and Oppenheimer (1997) outlined three reasons why it is important to consider the needs of carers. Carers have needs in their own right, including a need to have an identity that is separate from the caring role. The person with dementia would likely have felt concern for the carer if they did not have dementia. The relationship is symbiotic, involving mutually dependent familial relationships. A difficult balance then ensues between respecting the person’s autonomy and alleviating the burden experienced by carers, which can be compounded by wandering. Hope and Oppenheimer (1997) pointed out that restricting damaging behaviour could in certain circumstances be justified if the behaviour harms the person or others. The challenges associated with this stance are two-fold: firstly, assessing the risk of harm to the person and others; and secondly, deciding upon the form and extent of restrictions placed on the person.

Hope and Oppenheimer (1997) also highlighted how carer burden is heightened by the language of morality associated with illness and vulnerability. They highlighted how the act of caring invokes a wide variety of culturally-specific, normative values which often include a sense of duty to care that defines caring as an imperative rather than a choice. If caring is conceived as an imperative, research is needed to understand qualitatively how carers balance the needs of the ‘vulnerable’ person with their own needs, and what normative standards inform their management of wandering. McShane et al. (1994) proposed that electronic tagging may have an indirect effect of enhancing freedom for people with dementia by having a direct effect of enhancing reassurance for carers. Opinion surveys by Rasquin, Willems, de Villegar, Geers, & Soede (2007) and Altus, Mathews, Xaverius, Engelman, & Nolan (2000) reported carers believed electronic tracking would offer reassurance to them through knowledge that the person with dementia would be safer. These findings have suggested that carers prioritise the safety needs of the person over other welfare concerns. In doing so, there may be additional benefits by way of enhanced reassurance for carers. Research is needed to examine the normative values informing a
carer’s decision to use electronic tracking and the extent to which a carer takes account of their own needs.

Methods

The primary study aimed to explore carers’ experiences of using electronic tracking. Specifically, the study sought to elicit the values, beliefs and contextual factors that motivated carers to use electronic tracking. The study aimed to explore the extent of the involvement of the person with dementia in decision-making and identify the ethical dilemmas encountered by carers through usage. In view of the exploratory nature of the study, grounded theory informed the conduct and analysis of the qualitative interviews conducted with 10 carers in this study (Corbin & Strauss, 1990). The focus of grounded theory on theory-generation and subjective experience was integral to exploring carers’ experiences about usage (Creswell, 2007). The carers were recruited through a GPS tracking service provider. The sample size was dictated by feasibility, the numbers available to participate, and in view of the novelty of the technology at the time of the study, the uptake of the technology was quite slow. The interview process was characterised by flexibility in order to facilitate carer-led responses. Five open-ended questions, which were developed from the literature review and based on methodology proposed by Corbin and Strauss (1990), were used in the interview schedule and refined as themes emerged at interview. Each interview was recorded with audio equipment and transcribed. Interviews were thematically analysed with reference to the coding framework of Corbin and Strauss (1990) and data was managed using NVivo8 software. Carers were included in the study if they were a familial, informal carer to a person with dementia who lived in a domestic setting. Professional carers were excluded from the study.

Ethical approval for this study was granted from the University of Oxford Social Sciences and Humanities Inter-divisional Research Ethics Committee (IDREC) in January 2008. All data has been anonymised and pseudonyms ascribed to participants.

Sample

The sample of 10 carers had either bought the device through the service provider’s web-site or availed themselves of a free trial offered by the service-provider. The system involved the person with dementia carrying a device the size of a mobile phone, typically in a pocket, handbag or mobile phone holder. A website showing the location of the device could be accessed by the carer either through a computer, an internet-enabled mobile phone or by telephoning staff at a call-centre who would track on their behalf.

The sampling strategy elicited a sample of 10 carers. A short questionnaire was administered before interview to elicit the following sample profile. The relationship to the person with dementia for six of the carers was as a partner and for four was as an adult-child. Seven of the people with dementia lived with a partner, two lived alone and one with an adult-child. Nine of the carers reported the person had got lost in the last six months. Carers used a range of other methods of managing wandering, including constant supervision by a carer (N=4) and locked doors or door sensor alarms (N=4). Carers had used electronic tracking on average for 10 weeks prior to interview (range one–seven months).
Findings

Carers explored the process by which they came to make a decision, describing the extent of involvement of the person with dementia in the decision. A decision to use electronic tracking appeared to reflect the dominance of protecting the safety of the person with dementia within carers’ value-systems. Contextual factors relating to personality and the relationship between the person with dementia and the carer seemed to have a significant influence on whether electronic tracking was considered an appropriate option, and on the ways in which it was subsequently used. Covert usage emerged as a theme in carers’ accounts and one person described using it in this manner. Related issues highlighted the complexity of covert usage, particularly carers’ preferences for more discreet devices to enhance tolerance, and carers’ responses to circumstances in which the person was unable to understand the purpose of electronic tracking.

Values informing decision-making

Protecting the person from harm was a dominant theme within carers’ approaches to the wandering behaviour. Protection from harm was described as an imperative, largely taking precedence over protecting the privacy of the person and in some cases, justifying restrictions on autonomy and liberty. Although such restrictions were in some circumstances deemed necessary by carers, preserving the freedom of the person with dementia was not considered unimportant. Carers frequently referred implicitly and explicitly to freedom and independence as important to the quality of life of both the person with dementia and the carer. For a minority of carers, their choice of intervention for managing the wandering behaviour reflected a desire to preserve the freedom of the person to leave home alone.

The primacy of safety. Nine carers awarded primacy to safety even at a cost to privacy and civil liberty.

‘Sometimes people’s quality of life has to be diminished because of the safety factor . . . the fact that they value their freedom has to be balanced against the fact that they’re putting themselves in danger.’ (Sharon)

Her comments resonated with others, for example: ‘keeping him safe’ (Edith); ‘safety is the most important thing’ (Ben); and ‘security of the person’ (David). The primacy of protection from harm was evident in their pursuit of technological solutions to their safety concerns. A belief in the ideal of a technological solution for some carers was so strong that electronic tracking was awarded universal application: ‘a good thing for children, adults with any illness of any kind’ (Edith). David thought all people with dementia ‘should have a tagging [tracking] device.’ Underlying this perspective, carers appeared to equate dementia with vulnerability. Martin attributed such importance to safety that it justified invasive modes of attachment:

I think they should chip people like they do animals . . . for their own safety, the quickness that they could be found and they wouldn’t hopefully bring too much harm to themselves in the short period of time that they are out.

While the tone of such comments may be read as in some way dehumanising, their accounts did not appear to consciously reflect a belief system that placed people with dementia as of less
value. Rather, these comments reflected a prioritisation of the need to secure objective physical safety even if at cost to the subjective needs of independence, autonomy, freedom or identity. Few carers considered the potential for stigma that may arise from ‘chip [chipping] people like they do animals.’ Only one carer considered the technology to be potentially stigmatising. She described it as ‘big brotherish’ and ‘emasculating’ and while believing it necessary on grounds of safety, thought it socially undesirable. In general, carers’ concerns about the visibility of devices centred on a belief that they made the person vulnerable to theft rather than a concern that their visibility was stigmatising.

Safety was predominantly prioritised over privacy. Whilst five carers explicitly acknowledged that electronic tracking diminished privacy, it was seen as preferable to exposing the person to harm. One carer drew attention to the subjective experience of this loss of privacy. Pamela thought that most people would not experience it as an unwelcome intrusion but some may do so if they ‘have a deep mistrust of people and things.’ Three accounts suggested that, unlike the use of surveillance in other groups, the use of tracking technology in dementia care could only be benign. Philip was most explicit in summing this perspective up:

I mean anything that can stop harm coming to someone…is a good idea. There’s only one problem…you can monitor it, so you can effectively spy on people…I think being able to listen in to see if they are in danger is a good thing…I think the safety aspects outweigh almost anything. I really can’t think of any situation where you could be monitoring on someone with dementia to spy on them in an inappropriate way.

The case supporting its use in dementia care was set against a tacit acknowledgement that it may be misused in other contexts, for example in intimate relationships: ‘people will use it inappropriately…I mean for their partners’ (Ben). This viewpoint may have reflected a form of paternalism; that people with dementia were more vulnerable than other groups and in need of protection. It may also have been considered more socially acceptable to intervene to protect this group of people on the grounds that people with dementia were already considered less autonomous on the basis of their cognitive decline.

Some might feel it’s an intrusion into the person’s privacy but…you have to override that and make the decision for them, because they’re not in the right frame of mind…I think that it’s a valid means of looking after someone, it’s part of caring for them. (Caroline)

Another factor that may have influenced this perspective was a sense that the privacy of people with dementia was already compromised through carer supervision: ‘constantly keeping an eye on him.’ (Edith)

**Independence and freedom.** Despite a belief that the adverse risks posed by wandering outside of the home necessitated some form of intervention, carers’ accounts suggested that independence and freedom were valued as significant to quality of life. Three carers described how they aspired to enhancing independence for the person with dementia but felt unable to do so, due to the perceived risks: ‘we would ideally prefer him to have his independence, but…it’s too difficult’ (Ben). Three other carers thought electronic tracking was a means of preserving the person’s freedom: ‘This has been another tool that keeps that independence for him’ (Sarah). Many of the carers described how their choice of electronic tracking not only reflected a motivation to protect the person from harm, but also a desire to enable the person to continue to go out alone and enjoy lifelong interests. For example,
Sharon’s husband used electronic tracking to continue to go out on long walks alone through rural canal tow-paths. While Edith described how she would not leave her husband on his own, she described how electronic tracking gave her the confidence to continue to do ‘normal’ things together such as gardening and shopping.

Preserving the independence and freedom of carers was also discussed by some carers as a motivating factor for use. Ben described how his family initially used electronic tracking to enable his father to go out alone and in so doing, give them ‘five or six hours where they don’t have to worry about him’ (Ben). Within this, carers frequently referred to the constant worry of caring for somebody with dementia and the added concerns for their welfare brought about by wandering. One of the reasons Sarah used electronic tracking was: ‘at the back of my mind is that not only maybe has he not got home that possibly he’s had an accident’ (Sarah). Sarah recognised that her worry for the safety of her husband made her act in a way that restricted his freedom to go out alone, and in so doing, her own time out from the caring role. She viewed electronic tracking as a means of reducing her anxiety and as a means of enhancing freedom for both the person and the carer:

That helps reduce my anxiety about him being out by himself and also, that if he can be out by himself safely then I get a bit of space for myself.

**Context of decision-making**

**Personality and relationship factors.** Deciding to use electronic tracking also appeared to reflect the carer’s assessment of how well it would be received by the person with dementia which, in turn, reflected personality factors. Caroline, whose partner did not tolerate the device, described him as ‘very independent’ and ‘intolerant about many things.’ Sharon thought electronic tracking as an intervention was viable because her husband was not ‘foolhardy’ and recognised a need for support. Alice described her partner thus: ‘he thinks he’s invincible,’ which influenced how she decided to present the idea of electronic tracking to him. She thought she would need to justify it in terms of her own needs because ‘somebody more pliable could be persuaded.’ Personality also seemed to rule out other options of managing wandering. David described a friend with dementia as ‘very dominant,’ and believed electronic tracking would assist his partner who had difficulty dissuading him from leaving the house alone. Two of the carers suggested that the person’s attitude towards dementia influenced the extent to which carers could introduce interventions for associated issues. Sarah thought her partner’s openness about his dementia enabled him to be more receptive to electronic tracking: ‘the openness has been actually really helpful.’

The relationship between the carer and person with dementia appeared to be significant to the decision to use electronic tracking. The relationship also seemed to influence the way in which the carer decided to use electronic tracking. Edith described their relationship as:

we’re always together anyway, we’ve always been like that, we go out shopping together, go walking together.

This may have influenced the way she used electronic tracking, as a back-up to monitoring her partner herself. Maintaining space between the carer and the person with dementia was identified as a reason for usage by Sarah: ‘if he can be out by himself safely then I get a bit of
space for myself to do things I need to do that perhaps are easier without him.’ This was illustrative of electronic tracking being used to assist carers in balancing their own needs with those of the person with dementia. It also suggests that there is an inherent tension between the need for carers to have time out and their ability to provide person-centred care. Caroline described how her partner did not agree to use electronic tracking. Her sense of feeling burdened – ‘a lot going on’ – prevented her from encouraging her husband to use it. More generally, she described the burden placed on their relationship by the constant demands of caring which was heightened by a sense of being unable to maintain independence from one another:

although we’re married, we had our separate areas, you know, friends and things we did.

The potential for creating such space may have been an incentive for usage for Caroline. Martin described his relationship with his mother as strained, and partially attributed her wandering behaviour to this:

she’s always phoning up constantly and threatening saying I’m leaving, I’m going out of the house.

It is plausible that their relationship acted as a context to the covert manner in which he used electronic tracking.

Decision-making

The role of the person with dementia in decision-making. There was considerable variation in approaches to and the value placed on ascertaining the informed consent of the person with dementia before using electronic tracking. Some took a passive approach. David believed consent was implied if the person with dementia complied by wearing it:

if the sufferer is prepared to wear it, I can’t see that there’s any problem.

Alice, whose partner had initially agreed to wear the device, thought his continued consent was implied by ‘the fact that he is prepared to carry’ it.

Sharon described feeling most comfortable with its use in early-stage dementia, in part due to the person’s ability to actively give informed consent to usage. Sharon described the decision to use electronic tracking as one of partnership in which they came to a joint decision following much discussion. She suggested that their mutual concern for the risks associated with getting lost facilitated this process. However, most carers suggested that the person with dementia did not recognise getting lost as a problem and were often unaware that they had got lost. For example, Alice described how her partner, when brought back by police said: ‘what on earth is all the fuss about; you must have known I’d find my way back.’ Martin believed the consent of the person with dementia should be bypassed if it protected the person from harm:

There’d be a lot who would adhere to their wishes, but myself, I would think of other ways around putting it on the person so they wouldn’t even know they were carrying it, because I think them carrying it is essential.
This reflected his prioritisation of safety even if at a cost to autonomy

In cases of mental incapacity, three thought others should make decisions on behalf of the person. Ben identified the family as best placed to make such decisions: ‘you’ve [the family] got to make the decision for them.’ Most of the carers felt challenged by making a decision on behalf of a family member and seemed to seek support in the form of professional involvement or guidelines. Pamela expressed discomfort in making proxy decisions, particularly with identifying the stage at which the person becomes incapable, stating a preference for an objective measure with a ‘cut-off point.’ Alice thought that the gravity of limiting autonomy warranted wide consultation: ‘a joint decision, several members of the family and maybe the family doctor or whoever was involved with the care of that person.’

**Process of decision-making.** Most carers described discussions they had had about electronic tracking with the person with dementia. However, it is possible that this reflected the influence of social desirability on interview responses because most were specifically asked about it. Sharon and Sarah described detailed discussions they had had with their partners and considered the decision to be a joint one. Alice and Caroline illustrated how they had justified it to the person in terms of their own need for reassurance. On that basis, the person had agreed to use it: ‘I’m sure you’re absolutely fine but we all worry about you’ (Alice). Alice also reported choosing this approach because: ‘that keeps his self-esteem up... it’s not people thinking that he’s completely hopeless... but that we worry long before he does and it isn’t fair’ (Alice). Some used humour as a strategy to aid acceptance: ‘a humorous joke, “oh,” he say, “I can’t get away.” I say, “no you can’t.”’ (Edith).

The aim of some of the discussions described by carers appeared to be about informing the person rather than offering choice, with little space given for the person to voice their opinion: ‘You have to accept it... I just stress to him you don’t take that off’ (Edith). This approach may have been influenced by the perceived imperative to protect the person from harm. It may have been a response to the different perceptions of risk associated with the problem between the perspective of the carer and the person with dementia, for example: ‘her saying: oh I don’t really get lost...So I just told her that I wanted her to keep it with her...and she’s always been compliant’ (Philip). This approach may have reflected a belief that the person would not be able to retain the information and would forget what the device was for (Edith). The inability to retain information appeared to affect whether the person agreed to carry it. Caroline’s husband ‘thought it was a good idea’ but then: ‘he’d forgotten the previous conversation, although it was only minutes before.’

**The case of covert usage.** There was some discussion in carers’ accounts about the extent to which the person with dementia was made aware that a tracking device was being used. Of note, one carer described using it covertly: ‘I’ve got it in a little bag, always concealed in a little black bag and just put it in her handbag’ (Martin). He reported initially telling her he was ‘tagging her’ but believes she did not retain the information. He expressed concern that:

> ‘If she knew it was in there there’s a possibility she would take it out because she wouldn’t know what it was’.

This was consistent with his consequentialist view that the perceived enhancement of safety justified the action. It may also have reflected the strained communication which appeared to have characterised their relationship. A broader understanding of covert use,
beyond the activity of intentionally hiding a device, may also be warranted. For example: ‘I think she doesn’t know what it is, so tolerance doesn’t really come into it . . . she doesn’t really question it’ (Philip). Philip’s comment highlighted his mother’s lack of understanding of electronic tracking rather than covert usage. Yet, his comments opened up the possibility that even where a device is not concealed from the person, its purpose might be.

Caroline, whose husband did not tolerate the device, expressed a preference for a device that could be used covertly: ‘slim enough to put in behind a watch.’ This highlighted the blurred line between seeking a discreet device in order to enhance tolerance and covert usage. Despite placing a high value on consent in the case of her husband, Sharon thought covert use justifiable in the case of a relative because ‘the benefit outweighs the subterfuge.’ This inconsistency may have reflected her belief that covert use ‘couldn’t possibly do them any harm.’ Alice discussed covert use in general terms, thinking it justifiable ‘if the risks outweighed the insult’ but reported being ‘uneasy’ about it. The acceptability of covert use appeared to emanate from a value system that prioritised safety over privacy and autonomy. It also appeared to reflect a practical response to the person not retaining information about the purpose of the device and efforts to ensure it was tolerated. It may also have reflected a belief that, unlike use with other groups, use of electronic tracking in dementia care reflected benign motivations.

**Discussion**

The study shed light on the factors that motivated carers to use electronic tracking; it examined the extent of involvement of the person with dementia in the process; and explored the ethical dilemmas encountered by carers through usage. The study suggested that the carers in the sample drew upon consequentialism to justify usage on the grounds of enhanced safety. Predominantly, safety was prioritised over liberty and autonomy, although carers did appear to place importance on these. The study did not evaluate the accuracy of carers’ safety concerns in terms of the risks posed to the person in question. It did not conceptualise the totality of risk such as the incorporation of road safety. In view of the socially constructed aspects of risk associated with wandering (Robinson et al., 2007), it is possible that carers had an inflated sense of the risks posed by getting lost relative to the actual presenting issue. Assessment processes with professional support may assist carers in evaluating the risks and in making decisions about management. As recommended in the report of the Nuffield Council on Bioethics (2009), the process could be constructed as a risk–benefit assessment to take account of the gains and losses afforded by being able to leave the home, albeit with an electronic tracking device.

Furthermore, such assessments would be enhanced by taking account of the needs of carers and their concerns for the person getting lost. The study suggested that a decision to use electronic tracking partly reflected a need for carers to have reassurance, space from the person, and time out from the caring role. This raises questions about who the technology is for. Careful consideration is warranted of how it may be used in a way that reflects the best interests of the person with dementia as well as the needs of the carer. An assessment process could take account of the dyadic relationship in which the needs of the carer and person with dementia are inter-dependent.

The perceived safety gains afforded by the technology were prioritised over the infringement of privacy brought about by usage. One carer acknowledged that this
restriction of privacy might be challenging for people who have difficulty trusting others, which resonates with Hughes and Louw’s (2002) observation that some people may want to hide from others. Interestingly, most of the accounts suggested carers thought surveillance technology in dementia care could only be used to benefit people. This may have reflected a form of paternalism and the social acceptability of intervening with this group, even at a cost to privacy. In thinking about privacy, carers appeared to make comparisons with alternatives, viewing it as less intrusive than constant supervision by a carer. While wider sampling would need to explore carers’ value systems in greater detail, such an uncritical stance towards the consequences for privacy warrants a careful consideration of the issues when making decisions based on ‘best interests.’ Drawing on the UK legal context, best interests decisions under the Mental Capacity Act 2005 (England & Wales) would need to take account of the person’s past and present views about privacy. If privacy was restricted through electronic tracking, access to a monitoring system would need to reflect the person’s wishes around the preferred person(s) to take on this role. It should not be assumed that the family is always the preferred forum for such a role.

There are broader issues for policy relating to third-party access (for example, a carer) to an electronic tracking system and the protection of privacy. Guidelines could be developed to aid the process of identifying people who can be granted access to a tracking system and in defining the extent of that access, to ensure it is appropriate and proportionate. It may also be necessary to develop mechanisms within which third-party access to a system could be withdrawn and to consider the grounds for such a withdrawal. The emergence of data protection legislation in many countries may provide a framework within which to develop such protocols.

In general, the carers in this study did not suggest that electronic tracking was stigmatising and did not make negative associations with its use in other contexts, for example prisoner populations. This may reflect the argument proposed by McShane et al. (1994) that the technology is not intrinsically stigmatising but that stigma arises from the way in which it is used. The carers in this sample predominantly viewed electronic tracking as affording benefit to the person with dementia, most importantly as a means of securing safety. Carers also seemed to view electronic tracking as a tool of enablement and independence, allowing a person and his/her carer to continue with activities enjoyed throughout the life course.

The study identified varied approaches to informed consent ranging from full involvement in decision-making to persuasion, insistence and covert usage. Some accounts suggested that where the person consented to use, it was unlikely that their consent was informed on the grounds that the person would not have been able to understand or retain the information discussed. The relationship between the carer and person with dementia appeared to be relevant to negotiating use and may have been a contributing factor in one case where the device was used covertly. Covert usage also seemed to reflect a prioritisation of objective best interests, securing the person’s safety, over and above subjective best interests, consideration of their wishes and preferences. The variation in approaches to consent raise questions for person-centred care and the protection of autonomy. It also exposes the difficulties carers face in balancing safety with autonomy. Person-centred care recognises the significance to well-being of the manner in which something is done. As such the perceived consequence, enhanced safety, may not in itself provide satisfactory justification for using electronic tracking if the manner in which it is used is not person-centred.

Carers made useful suggestions about decision-making in cases of mental incapacity, including wide consultation with family members and those involved in the person’s care.
Their accounts suggested a need for carers to be supported through the decision-making process, which would help to protect the rights and welfare of the person with dementia. Furthermore, support and guidance for carers through a decision-making process that aims to maximise the participation of people with dementia within the process, are in keeping with the principles of person-centred care. Recommendations by the Nuffield Council on Bioethics (2009) for a joint decision-making model in cases of borderline capacity, involving trusted family members, may be a useful approach to decisions about electronic tracking. Guidance in the form of information booklets may also be a resource for carers.

A range of legal facilities for decision-making may also be useful. While these examples draw on a specific context, the facilities under the Mental Capacity Act 2005 (England & Wales) may resemble similar legal mechanisms in other countries. Proxy decisions about personal welfare can be arranged by the person prior to the loss of capacity through a Lasting Power of Attorney (Section Nine). Another facility that may be of use to decisions about electronic tracking could be the Advanced Decision facility wherein a competent person can outline a wish to refuse a specific treatment prior to the loss of capacity (Section Twenty-four). However, both of these require early planning. In order to plan, people with dementia need clear information about both the possible consequences of their diagnosis and prognosis and the legal options available to them, including the timing of such options.

The study has a number of limitations. Findings were exploratory and need verification through wider sampling. The unanticipated small sample size \((N=10)\) arising from poor uptake of the technology prevented implementation of the principle of data saturation in which sampling continues until all the themes and relationships between themes have been fully developed (Creswell, 2007). Furthermore, because the sample had self-selected to use electronic tracking, the sample could not be considered representative of all carers to people with dementia. Carers who had invested financially in the technology may have been more favourable to it. More diverse sampling would generate an understanding of the perspectives of carers who choose not to use electronic tracking. Of note, the views and experiences of people with dementia were not elicited in this study which solely explored carers’ experiences. A further study is needed to elicit independently the views and experiences of people with dementia using electronic tracking. This would enhance debate about the ethical acceptability of the technology.

This study has explored at first hand the experiences and views of carers who made a decision to use electronic tracking. Further research with carers and people with dementia would develop the exploratory findings presented in this study. In view of the dominance of professional opinion in the debate about the ethical acceptability of electronic tracking to date (Robinson et al., 2006), research into the perspectives, experiences and opinions of people with dementia and their carers who have actual experience of usage is overdue.

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References


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