Electronic tracking for people with dementia who get lost outside the home: a study of the experience of familial carers

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Key words:
Dementia, GPS tracking, wandering.

Purpose: The study aimed to elicit a description of GPS (global positioning system) tracking use in the care of people with dementia in domestic settings and to generate hypotheses about impact.

Procedures: Users were recruited through a commercial provider. Qualitative interviews with 10 carers were completed to generate an in-depth description of how the devices were used and the perceived impact. A questionnaire was administered to ascertain sample characteristics.

Findings: Most carers preferred to use tracking as a back-up to other strategies of management, particularly supervision by a carer and locked doors. In cases where the carers perceived the risk of harm from getting lost to be low, tracking was used to preserve the independence of the person with dementia. The carers reported that tracking gave them reassurance and also enhanced the sense of independence both for themselves and for the person with dementia. The poor reliability of the device was identified as a substantial limitation.

Conclusion: Larger studies are needed to assess the safety and clinical value of GPS tracking. These should explore the views of people with dementia. Assessment tools are needed to assess suitability. Occupational therapy can play a pivotal role in this process of intervention design, assessment and evaluation.

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Introduction

Approximately 40% of people with dementia wander from their homes and become lost on at least one occasion and 5% repeatedly get lost (McShane et al 1998a, Hope et al 2001). GPS (global positioning system) tracking provides a possible means of locating the lost person with dementia, but there are few published studies that have examined the actual usage of this technology outside the home. The intervention throws up several ethical issues. For example, the possibility of locating someone might be an invasion of privacy, GPS tracking might be stigmatising and the autonomy of the person with dementia might be threatened (Robinson et al 2007). This small study sought to elicit a description of how tracking is used by familial carers of people with dementia in domestic settings and to generate hypotheses about usage and impact. In so doing, the purpose of the study was to inform the design and direction of future research on this novel intervention.

Literature review

Wandering and getting lost

Wandering is a common behavioural symptom of dementia, which encompasses a broad range of walking behaviours and can result in the person becoming lost (Algase et al 2007). 'Getting lost' can be defined as becoming spatially disorientated and, as a result, being unable to find one's way (Rowe and Pe Benito 2007). Substantial risks for people with dementia are associated with becoming lost, including mortality, injury, dehydration and hypothermia (Koester and Stooksbury 1995, Rowe and Glover 2001, Rowe and Bennett 2003).

McShane et al (1998a), in a 5-year prospective study of 104 people with dementia, found that approximately 40% were locked into their homes because of carer concerns about getting lost. Importantly, admission to permanent institutional care was significantly more common in those who tended to get lost (77%) than in those who did not (31%), a finding that has recently been replicated in a larger United States sample (Scarmeas et al 2007). This may be related to carer burden, a risk factor for institutionalisation (Ballard et al 2000). Miyamoto et al (2002) observed higher levels of carer subjective burden in the carers of people with dementia who wandered when compared with those where wandering was not observed in the index person (0.24, $p<0.0001$, $n = 379$). A review of studies examining the impact of behavioural and psychological symptoms of dementia on carer burden also found an association between wandering and carer burden (Ballard et al 2000). If tracking is effective in enhancing the safety of people who wander, it is conceivable that it could reduce the level of objective burden experienced by carers and, in so doing, lower levels of subjective burden.

On the other hand, it is likely that wandering, where the person does not get lost, affords benefits to people with dementia by providing a form of exercise and an enhanced subjective sense of independence (Robinson et al 2006). Moving away from traditional medical models of dementia care, more positive approaches to dementia have been developed, in particular the concept of personhood (Kitwood 1997) and, more recently, citizenship (Innes 2009). These perspectives promote a more positive, holistic and active construction of living with dementia. This has shifted the perceptions of what people can do away from disability towards an explicit recognition of ability, particularly in the early stages of dementia. Interventions for wandering behaviour need to take account of these developments and to preserve independence and the positive aspects of wandering.

The intervention

Psychosocial and technological interventions to date have focused largely on either reducing wandering behaviour (music therapy, behavioural therapy and aromatherapy, for example); preventing wandering outside (door alarms, electronic tagging and subjective barriers, for example); or promoting safer walking (exercise and walking groups, for example). Currently, the evidence base for the effectiveness of psychosocial interventions is very limited, as highlighted in two recent systematic reviews (Robinson et al 2006, Hermans et al 2007).

GPS tracking differs from electronic tagging, which solely alerts a third person to a boundary transgression, such as exiting a building. GPS tracking provides a means of locating the user at any given moment by locating the device through satellite and sending the information via the mobile-phone network to a personal computer, a call centre or a mobile phone (Kearns and Fozard 2007). Although radio-frequency identification devices have been used in the past (for example, McShane et al 1998b), GPS tracking appears to be far more accurate, with accuracy ranging from 5 to 100 metres (Shimizu et al 2000, Miskelly 2005). There are also calls for a two-way function design, whereby a device not only allows a third party to locate the person but also acts as a navigational guide to the person with dementia through verbal directional cues (Kearns and Fozard 2007, Robinson et al 2009). A single case study evaluating such a prototype design is outlined by Rasquin et al (2007), but larger, robust studies evaluating these devices have not been undertaken.

Tracking focuses on retrieval and, as such, is an intervention aimed at promoting safer walking rather than reducing wandering or restricting physical freedom. In this sense, it fits within a more positive, enabling paradigm of dementia care (Moniz-Cook and Vernooij-Dassen 2006). Despite the ethical issues associated with use (Landau et al 2009), tracking technology may have the potential to sit comfortably within an enabling paradigm. By facilitating people with navigational difficulties to continue to go out alone, it may support independence and enable people to participate in meaningful activities enjoyed throughout the life course, such as walking, shopping or visiting friends. As such, it is important that further research examines users' experiences of this technology in order to inform intervention studies that examine effectiveness.

Research evidence

Currently, there is little evidence to support the use of GPS tracking in either institutional or domestic settings. Two recent systematic reviews of interventions for wandering behaviour, Robinson et al (2006) and Hermans et al (2007), did not identify any randomised controlled trial of electronic tracking systems for wandering behaviour.

A pilot study (Miskelly 2005) tested GPS tracking in a sample of 11 people with dementia living in a domestic setting. Five participants discontinued use due to difficulties with usage or discomfort. A failure to carry the device was reported to explain most location request failures. The study found that the carers who used it successfully felt reassured.

Although the topic of GPS tracking in dementia has received considerable attention in the media, there is no published description of the opinions and experiences of carers who have actually used such a system. This small observational study sought to address this and, in so doing, yield hypotheses that could then be formally addressed in larger studies of effectiveness.

Method

The study was primarily qualitative, comprising face-to-face interviews with carers, but also included a questionnaire to collate background characteristics. The questionnaire was derived from an earlier telephone survey (McShane et al 1998b)

Table 1. Summary of participants

Pseudonym	Age	Gender	Participant's relationship to index person	Index person: domicile (all lived in a domestic setting)	Additional methods of managing wandering
Philip	47	Male	Adult child	Alone	Door alarms
Martin	57	Male	Adult child	Son	Door alarms
Ben	44	Male	Adult child	Partner	Carer supervision
Pamela	45	Female	Adult child	Alone	None
Alice	70	Female	Partner	Partner	None
Sarah	58	Female	Partner	Partner	None
Sharon	59	Female	Partner	Partner	Carer calls his mobile phone
Caroline	70	Female	Partner	Partner	None
Edith	73	Female	Partner	Partner	Locked doors, carer supervision
David	73	Male	Partner	Partner	Locked doors, carer supervision

and a carer burden questionnaire, the Machin Carer Strain Scale (Modified) (Gilleard et al 1984, Gilleard 1987).

Ten qualitative interviews were carried out to generate an in-depth description of the experience of using tracking and its perceived impact. The focus of grounded theory on theory generation and subjective experience (Creswell 2007) was deemed appropriate towards eliciting a picture of how carers used this novel intervention. The interview schedule was derived from a literature review as well as from unstructured discussions with professionals and a carer support group. The interviews focused on carers' experience of the problem, their use of the system, their perceptions of its impact, their views about its acceptability and the process of deciding to use tracking. The interviews were conducted in a flexible manner to maximise carer-led responses. The interview schedule was piloted with carers and relevant health professionals. The interviews were audio-taped and transcribed, then thematically analysed with reference to the coding framework developed by Corbin and Strauss (1990). The data were managed using QSR NVivo8 software to award transparency to the coding process (di Gregorio 2003).

The sample was recruited from a single commercial provider. The users had either bought the device through the website or availed themselves of a free trial offered by the service provider. A website showing the location of the device could potentially be accessed either through a personal computer or an internet-enabled mobile phone or by phoning staff at a call centre who would track on behalf of the carer. The tracking request was sent via the mobile-phone network (GPRS or SMS) to the device. Its location was then determined by the GPS and sent back to the website via the mobile-phone network and appeared on the website map within 2 minutes.

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. The sample size was dictated by the small number of participants available through the service provider, limiting attempts to implement theoretical sampling through data saturation.

A decision not to include people with dementia as participants in the study was made on ethical grounds. As recruitment was carried out in a non-clinical forum, information about competency to make decisions about involvement in research was not available. The perspectives of people with dementia should be included in future studies of tracking. As a small qualitative study of carers' perspectives, it is not possible to draw conclusions about the use of tracking devices in subgroups, such as by age group or severity of dementia. Information about dementia could not be obtained because of recruitment from a non-clinical sample. However, the advantage of this recruitment strategy was that it provided a naturalistic setting in which to capture the experience of usage and, arguably, the absence of selection criteria in terms of the index person was likely to have yielded a more generalisable sample.

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

Findings

Sample background

Seven of the people with dementia lived with a spouse or partner. Two lived alone. Nine had got lost in the last 6 months. Six had got lost at least three times in that period. Four carers had not utilised any other strategy for managing wandering prior to starting to use the GPS device. Six had used a combination of constant supervision by a carer (n = 4), and/or locked doors (n = 2) and/or door sensor alarms (n = 2); carers continued to use these methods after starting to use the device.

Carers were either a partner (n = 6) or an adult child (n = 4) of the index person. The average age of the adult-children carer group was 48 years and, of note, the partner-carer group was relatively young, averaging 67 years. Six were female and four male. Carers presented with moderate levels of carer strain (22.4) on the Machin Carer Strain Scale (Modified) (Gilleard et al 1984, Gilleard 1987), but there was considerable variation between carers (13-29).

Summary of main themes about usage

The carers' informal assessment of the index person's safety precipitated a decision to use tracking. Safety concerns appeared to be shaped not only by the wandering behaviour but also by the carers' value systems. All the carers attributed primacy to the protection of the person from harm, over and above issues of autonomy or privacy. Personality and relationship factors, as well as the usability of the tracking technology, acted as mediators, influencing the specific way in which tracking was used. Carer perceptions about impact included carer reassurance and enhanced independence for both the carer and the person with dementia. The carers' accounts suggested that safety concerns were constantly reassessed on the basis of their experience of the tracking system and changes to the wandering behaviour.

Decision to use tracking

Assessing safety

Typically, the carers associated getting lost with 'danger' (Sharon). Yet, there was considerable individual variation in the carers' safety concerns and the levels of risk tolerated by the carers. Variation in safety concerns appeared to be attributable to the carers' informal assessment of risk and protective factors, the availability of alternative strategies for managing the problem, concerns about the consequences of inaction and beliefs about the impact of GPS tracking.

Road safety awareness was identified by two carers as a protective factor and by five as a risk factor: 'They're going to get themselves run over' (David). Neighbourhood safety and community support were also identified as protective factors; for example, neighbours who helped in 'keeping an eye on' the person (Philip). When the neighbourhood was perceived as dangerous (Ben) or the neighbours as unsupportive, it was considered a risk factor (Caroline). Predicting wandering incidences, such as verbal cues (Philip) or a set geographical pattern of wandering (David), was perceived to reduce risk. Conversely, the absence of a predictable pattern of wandering was viewed as increasing risk (Ben) and prolonged the time until retrieval.

Concerns for the psychological wellbeing of the person with dementia were taken into account by one person (Pamela), who reported her mother as being 'very distressed' by getting lost. However, eight believed that the person with dementia viewed wandering as unproblematic, posing challenges to carer attempts to manage the problem. Alice described the response typical of her partner after an incident of being lost overnight as: 'What on earth is all the fuss about; you must have known I'd find my way back.' Carer concerns about their own psychological wellbeing were more common, with three carers reporting using tracking to reduce a feeling of being 'anxious' (Sarah) if the person had not returned home at the expected time.

Opinions about alternative methods of managing the problem influenced a decision to use tracking. Carer supervision was identified as inadequate: 'They [carers] don't have eyes in the back of their heads' (David). Locking doors was perceived as socially undesirable: 'I don't like locking doors but it's necessary' (Caroline). The risk of institutionalisation appeared to be a concern for two carers. Ben and Philip briefly described concerns about the negative impact of institutionalisation:

> The worst scenario is basically they live in a hospital locked up and they're only going to go down [hill] (Ben).

The carers associated getting lost with accidents, harm and mortality: 'They're going to cause harm to themselves' (David). Similarly, Sharon justified tracking because 'It could save their life'.

Safety as paramount

Nine carers (n = 10) awarded primacy to safety over privacy and civil liberty:

> The fact that they value their freedom has to be balanced against the fact that they're putting themselves in danger (Sharon).
>
> Safety is the most important thing (Ben).

Four carers thought all people with dementia 'should have a tracking device' (David) and Martin attributed such importance to it that it justified invasive modes of attachment:

> I think they should chip people like they do animals … for their own safety.

Although acknowledging privacy as important (n = 5), the carers prioritised safety needs. Three accounts suggested a belief that the use of tracking in dementia care could only be benign:

> 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 (Philip).

Personality and relationship context

The accounts of seven carers suggested that the acceptability of tracking was mediated through personality factors. Sharon believed that her husband accepted it because he is not 'foolhardy' and Sarah because her husband was open about the dementia diagnosis: 'The openness has been actually really helpful.' Caroline partially attributed her husband's intolerance of the device to personality, describing him as 'intolerant about many things'. Alice considered carefully the process of introducing it to her partner because she felt it potentially to be 'quite emasculating'.

The relationship between the carer and the person with dementia also appeared to be a mediating factor in six carer accounts. Caroline described feeling burdened, 'a lot going on', which prevented her from persisting with tracking after her husband refused it initially. 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.

Edith described her relationship with her husband 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 in which she used tracking, as a back-up to monitoring her husband herself.

Accessibility and acceptability

The accessibility and acceptability of the technology to both the carer and the person with dementia also appeared to influence usage. Most (n = 7) thought the technology was accessible. 'Most would get used to using it if they're prepared to use a computer' (Alice). Sarah thought it needed 'simpler instructions' and 'a voice at the end of the phone' in the initial stages.

The device's physical form also appeared to influence acceptability, with seven carers thinking it either uncomfortable or too large (dimensions 9.5cm x 4.5cm). Caroline thought tolerance would be improved if it was an object familiar to the person, such as a watch. Gender also played a role. David thought it should be a 'pretty brooch or bracelet' for women. Alice and Philip believed it better suited to women who carry handbags. Edith's opinion was that its mobile-phone appearance was 'in keeping' with men's attire. Attachment was also an issue, with eight carers preferring a device that could be attached securely to the person, viewing it as 'very losable' (Pamela). Four carers believed that the mobile-phone appearance made the person vulnerable to theft.

Usage

Tracking as a secondary intervention

Four carers used tracking as a back-up to constant supervision by a family member:

> It's like keeping him on a short lead instead of a long lead … the tracker is a back-up, I feel better … I wouldn't allow that [her husband to go out without her] now because I wouldn't take that chance anymore (Edith).

Martin and Philip described using it as a back-up to door sensor alarms. Philip also relied on formal carers. Three carers described using it as a back-up to locked doors; this appeared to be linked to their safety concerns and a high value placed on safety. For example, Edith's account suggested that she thought her husband at high risk of becoming lost and associated getting lost with harm. She awarded primacy to safety. Their relationship was historically characterised by large amounts of time spent together. Constant carer supervision as the front-line intervention is consistent with these factors.

Tracking as a primary intervention

Three carers used tracking as a front-line intervention. None of these people with dementia had *a priori* restrictions in place. Alice linked using it as a primary intervention to her relatively low safety concerns. She believed her partner was physically strong and not 'very confused' and the neighbourhood safe with supportive neighbours. Sharon described relying solely on the device when her husband went for long walks alone. She believed that it could only be used in this way in the early stages of dementia. Although Sharon had awarded primacy to safety in her account, it is likely that her assessment of him as at a low risk of becoming lost enabled her to use tracking to maintain 'freedom and independence for as long as possible'.

Perceived impact

Reassurance

Nine (n = 10) carers believed that tracking awarded the carer 'peace of mind'. Edith repeatedly reported feeling 'reassured', despite never having formally searched for him in the 8 months of usage:

> It's just constantly keeping an eye on him, but if I've got this tracker attached to him I feel more comfortable (Edith).

Contradicting this, Alice and David pointed out that managing the device adds to the list of things a carer must do. Philip thought it afforded only a small measure of reassurance because wandering is 'one of many' worries when caring for a person with dementia.

Only one carer, Sharon, described tracking as affording reassurance to the person with dementia:

> He doesn't know when he's going to get confused, so it's reassurance for him but it's also reassurance for me (Sharon).

Independence and freedom

Three carers aspired to enhance the independence of the person with dementia, but felt unable to do so because of the perceived risks: 'We would ideally prefer him to have his independence, but … it's too difficult' (Ben). Three carers thought it maintained the freedom of the person they cared for:

> This has been another tool that keeps that independence for him (Sarah).

Edith thought tracking enabled them to continue to do 'normal' things together, such as gardening.

Three carers thought it maintained the freedom of the carer. Ben described how they initially used tracking to allow his father to go out alone, giving familial carers '5 or 6 hours where they don't have to worry about him' (Ben). Sarah made a link between using tracking, reduced carer anxiety and a knock-on effect of enhanced freedom for both the person with dementia 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 (Sarah).

Re-evaluation of safety concerns

Safety concerns appeared to be re-evaluated constantly. Caroline, whose husband did not tolerate the device, appeared to reassess how she managed wandering and introduced locked doors. Similarly, David continued to lock doors after ceasing to use the device because of his wife's discomfort with it. The carers appeared to reconsider the person's safety in the light of their experience of tracking. Ben's account was the most explicit. He changed from using it as a front-line intervention to a back-up. He described how he was 'too dependent' on it initially, using it to enable his father to go out alone and tracking him if he did not return in the evening. He explained how the battery had not been charged on one occasion and subsequently went flat, meaning that he was unable to locate his father. He reported that his father was found after 'about two days' following an admission to hospital. Ben repeatedly described the device as 'dangerous' because 'it is not 100% reliable'.

Reliability and limitations of tracking

Although Ben's account is paradigmatic, trust in the tracking system varied across the sample. This was related to personal experience with its limitations. Martin reported that he did not intend to continue with tracking on grounds of unreliability, reporting episodes of inaccurate locations: 'It was giving false information.' Substantial limitations of the technology were identified. Nine carers thought the battery-life inadequate:

> You're running against the battery, the battery life. If that battery life goes down, you're done for (Ben).

Furthermore, Ben expressed concern about its vulnerability to 'human error' and, in particular, the need for a carer to remember to charge the device and switch it on. This was mirrored in comments by seven other carers. The level of support from the tracking service was also thought deficient by Ben and Martin, particularly the lack of out-of-hours technical support, 'By 5 o'clock they've gone home' (Ben).

Discussion

Assessment

The study elicited a number of risk and protective factors that the carers considered when making decisions about managing wandering and when choosing electronic tracking. The carers took account of individual, familial and community-level or environmental factors in the decision-making process. Assessment instruments to date have focused on identifying and categorising the wandering behaviour; for example, the Neuro-Psychiatric Inventory (Aberrant Motor Activity Dimension) (Cummings et al 1994); the Present Behavioural Index (Wandering Dimension) (Hope and Fairburn 1992); and the Revised Algase Wandering Scale (Algase et al 2001). As such, the instruments do not evaluate the risk of harm from the wandering behaviour, nor do they lead directly to the identification of intervention goals.

Some progress in this area is being made. Algase (2007) and Moore et al (2009) have outlined a promising structured interview, the WING-AP, which aims to identify possible adverse outcomes of wandering and to identify suitable interventions. The factors highlighted by the carers in this sample largely concurred with this model. Further research is needed to adapt the instruments used to assess relevant risk factors, such as the falls risk, and to develop specific instruments for assessing suitability for electronic tracking.

Occupational therapy is well placed to undertake and develop this assessment role. Occupational therapy operates within an enabling paradigm that emphasises ability, wellbeing and quality of life (Moniz-Cook and Vernooij-Dassen 2006, Mountain 2006). This approach may provide a necessary balance to the focus of carers, evident in this study, on risk reduction and safety. Furthermore, as a technology that holds the potential to maintain independence, tracking may be congruent with a self-management approach (Mountain 2006), particularly for use in the early stages of dementia. Devices with a navigational cue function for the user may fit particularly well within a self-management approach. The focus of self-management on including the person with dementia in the assessment process and of valuing his or her perception of need (Mountain 2006) is important in view of the considerable ethical implications associated with tracking technology.

Usage and intervention end-points

This study has highlighted how carers use tracking as either a stand-alone intervention or in conjunction with other measures. Research that specifically examines subgroup differences, such as stage of dementia, comorbidities and age, is needed to identify who can benefit from tracking. This would help to guide decisions about the need for additional supports in managing the wandering behaviour. In addition, research needs to examine the potential for risk compensation: the possible adverse implications of any changes to the management of wandering made by the carer in the light of the new technology. This also highlights the role of professionals in educating carers around appropriate usage.

This carer study has sought to generate hypotheses about impact for intervention studies. An additional study is needed to capture the views of people with dementia in order to identify meaningful outcomes for them; for example, whether tracking affords the person with dementia a sense of confidence or reassurance. An intervention study could assess for changes to what Algase (2007) referred to as immediate (such as injuries) and cumulative (such as institutionalisation) outcomes. This study has sought to identify the less visible end-points from the perspectives of carers. Reassurance as a meaningful outcome for carers could be evaluated through a carer burden scale (for example, Zarit Caregiver Burden Interview, Zarit et al 1980) or through cortisol salivary tests (Kirschbaum and Hellhammer 1989).

In order to avoid focusing solely on adverse events, intervention studies also need to capture qualitative changes in terms of quality of life. Electronic monitoring systems have been advocated on the basis of their potential for enhanced freedom and independence (McShane et al 1994, Bail et al 2003). However, independence holds subjective meaning and cannot be quantifiable in terms of time spent alone, nor would it appear from this small sample to be a universally realistic or desirable outcome. Thus, it may be more meaningful to focus on quality of life in dementia; for example, through the DEMQOL instrument (Smith et al 2005). With the strengths perspective intrinsic to occupational therapy's approach to assessment, the profession can play an important role in the design of intervention studies in order to ensure that outcomes are not focused solely on risk minimisation.

Technology: limitations and support requirements

Substantial technical limitations and vulnerability to human error were identified by the carers, which furthers the case for intervention research. There is a case for greater collaboration between those that design technology and the key stakeholders, including professionals and the users of technology, to ensure that prototypes are designed with the end-user in mind. A clear example of this user-centred approach in the context of electronic tracking is the recent *Keeping In Touch Everyday* project, in which people with dementia participated in the design process of an electronic tracking device (Robinson et al 2009). The approach served the purpose of creating prototypes for devices that were both acceptable and appropriate to the needs of end-users.

The different modes of access to the tracking system used by carers in this study suggests that carers need varying degrees of support in accessing tracking technology. It must be noted that the sample was relatively young, with the average age of the partner group being 67 years. However, age may not be a significant factor in the successful adoption of new technology. A study by McCreadie and Tinker (2005) found that older people were likely to adopt assistive technology if there was felt to be a need for it and the technology was accessible, reliable and straightforward to use. Addressing issues of accessibility and acceptability in the design stage through partnership approaches is likely to be an important factor in developing electronic tracking as a worthwhile intervention for use in this population.

Study limitations

The novelty of the technology has had a substantial impact on research design and conduct. Access to a sample, which was in itself limited to recruitment from one company, was dependent on sales of the device, which were far lower than anticipated. The direct consequence of this for the study was a small sample size (n = 10). This study did not involve people with dementia as participants and, as such, has not captured at first hand the experience of usage among this group. Although challenging to conduct, a study is needed to highlight the perspectives of people with dementia. It is also possible that the findings were influenced by whether participants had bought the device or had availed themselves of a free trial. However, reports of tracking within this small sample did not appear to differ on this basis.

The small sample size, indicative of researching novel technology, limited data saturation of the qualitative themes. Further sampling is needed to verify the findings. As an exploratory study, it did not measure whether tracking actually reduced the time taken until the lost person with dementia was found. However, the study provides a prerequisite step to such intervention studies by generating hypotheses about the possible impact of tracking and by identifying meaningful intervention end-points.

Conclusion

GPS tracking provides a novel means of locating people with dementia who get lost; however, the evidence to support its use in dementia care to date is limited. This exploratory study sought to elicit a description of how GPS tracking is used and to generate hypotheses about its impact for future intervention studies. The study found that the decision to use tracking was informed by the carer's informal assessment of safety. Assessment tools and occupational therapy support could assist carers in decisions about suitability and usage. Tracking was most commonly used as a back-up to other strategies of management (particularly carer supervision), but for a minority it was used to enable the person to continue to go out alone. Carer perceptions about impact centred on enhanced carer reassurance and enhanced independence for both the carer and the person with dementia.

Future intervention studies should incorporate these subjective variables as meaningful outcomes for carers in addition to assessing whether tracking reduces the time until the person is found. Studies also need to assess possible unintended consequences, particularly risk compensation arising from a false sense of security conferred on carers. This also points to the need for professional support and education around usage. Further research is needed to elicit the experience of people with dementia and their views about its impact. In view of its use in real life settings, intervention studies of GPS tracking are urgently required.

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Conflict of interests: At the time of this study, EBW was paid a small fee by the Oxfordshire and Buckinghamshire Mental Health NHS Foundation Trust to disseminate information about the tracking service and was reimbursed for attendance at conferences to present the results of this study. No other potential conflict to declare.

At the time of this study, RMcS's employer (Oxfordshire and Buckinghamshire Mental Health NHS Foundation Trust) stood to recoup a very small amount of money (<£100) for each device sold. No other potential conflict to declare.

Key findings

- Tracking was most commonly used as a back-up.
- A minority used it to enable the person to go out alone.
- Carer perceptions about impact included reassurance and enhanced independence.

What the study has added

The study has generated hypotheses about how GPS tracking is used in the care of people with dementia and about impact in a domestic setting, necessary for future intervention studies.

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