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Balancing rights and risks – conflicting perspectives in the management of wandering in dementia

Short title

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Abstract

Current Government recommendations in England suggest a national approach to risk management but in an increasingly litigious society, how do professional carers balance risk management with the promotion of a person-centred approach in dementia care? Wandering behaviour can be both beneficial and harmful to a person with dementia and generate considerable emotional distress in their carers. This study combined a systematic review and qualitative research methods to explore the perspectives of different stakeholders in the management of wandering in dementia. A major theme for carers was the conflict between the prevention of harm and the facilitation of a person's right to autonomy. Such tensions also impacted on carers' abilities to provide person-centred care. This dilemma was highlighted through the use of assistive technologies such as electronic tracking devices. Interestingly, people with dementia felt that the use of such technology placed them at greater risk i.e. as a target to theft, than the process of wandering itself. They spoke of their need for independence and their concern over carer surveillance and the identity of "big brother". There is a need to develop practical tools for managing risk within dementia care which allow all perspectives to be captured and risk management to be negotiated.

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Introduction

Recent policy initiatives in England have highlighted the need to facilitate autonomy and independent living for older people (Department of Health 2001; Department of Health 2006a; Healthcare Commission 2006). One way in which this may be achieved is through the development of assistive technologies, such as personal and social alarms, monitoring devices, and environmental adaptations and aids (Audit Commission 2004; Department of Health 2006a). However a report from the House of Lords Select Committee on science and technology identified that the potential of assistive technology to improve the quality of older peoples' lives is not being realised (House of Lords Select Committee on Science and Technology 2005; Phillips & Diwan 2003). Assistive technologies potentially offer important benefits in supporting older people to live independently (Woolham 2005). Such technologies can enhance the personal safety of older people by alerting carers to potential dangers or adverse events that might threaten an individual's health and safety. For people who require assistance to live independently, assistive technologies can offer reassurance and peace of mind. Despite the potential benefits, however, older people are rarely involved in the development of assistive technologies; especially those with dementia, and user acceptability is routinely assessed via proxy carer report (Robinson *et al.* 2006).

Understanding the acceptability of assistive technologies from the perspectives of older people and their carers is essential, because they are likely to have important impacts not only on the safety and wellbeing of individuals, but on their feelings of independence and sense of self. The possibility of their use becomes a factor in

making judgements about the risk and safety of a person living independently or in relatively autonomous surroundings, and thus impacts on decisions about how to manage the care of such people. In particular, such judgements can directly determine decisions about if, and when, an older person who would prefer to live at home should go into institutional care. It is therefore important to gain a better understanding of how the risks and benefits of new approaches to supporting the independent living of older people are understood by different stakeholder groups.

The idea of risk has attracted considerable attention in both the academic and professional literature (Adams 2001). Furthermore the notion of risk has increasingly become a focus of social policy. Within health and social services there is considerable attention to 'risk management' (Taylor & Donnelly 2006). In England, the recent White paper 'Our health, our care, our say' (Department of Health 2006b) stipulated its commitment to developing a national approach to risk management in social care. Furthermore a Controls Assurance Framework (Department of Health 2003) overviews issues surrounding risk and is being used to develop policies specifically focusing on risk management and practices of health and social services.

Historically the notion of risk was recognised as being either something 'good' or 'bad' which could involve loss or gain (Lupton 1999). However, in modern society the meaning of risk has been transformed from being seen as a neutral term into something that is entirely negative and dangerous (Douglas 1990). "High risk means a lot of danger" in our modern western culture (Douglas 1990)); furthermore inherent in this notion of risk is the probability of an adverse effect.

A discourse of risk has evolved with a particular application to health issues (Lupton 2005), which links in with the cultural individualism discussed by Douglas (1990), with

a focus on 'lifestyle', health choices and individual needs assessment. The dominant view in healthcare is one in which risk is seen as something dangerous, it is something that needs to be managed and avoided where possible. Kemshall (2000), drawing on Hugman's work (1998), argues that social care, health and probation practice are embedded within a managerialist discourse whereby technical competence is valued over professional judgement. Therefore the discourse that underpins health policy and guidance views risk as something real and objective that can be measured and acted upon. However a second approach challenges this notion of risk and highlights its socially constructed nature whereby risk identification is not objective but value-laden and is mediated through social and cultural processes (Lupton 2005). Risk assessment procedures based within one theoretical stance challenge the risk knowledge of practitioners in their daily practice of risk. Thus creating 'knowledge divides' between managers and workers as risk regulation procedures are introduced (Kemshall 2000). Through practice and policy guidance, professional carers are encouraged to identify, manage and reduce risk.

In the case of people with dementia, risk is often associated with harm and their perceived vulnerability to harm (Manthorpe 2003). With this in mind it is imperative that the push for assistive technologies and enabling technologies of older people evaluates what is perceived as 'risky', from the perspectives of all stakeholders and in particular older people (users) themselves (Alaszewski & Manthorpe 2000). Furthermore policy and research need to critically and theoretically investigate the meaning of risk to individuals in contemporary society (Lupton 2005; Lupton 1999). The challenge for policy-makers and managers therefore lies in "integrating differing, and at times competing knowledges of risk into a negotiated and effective collaborationist system of risk management" (Kemshall 2000).

This paper focuses on one particular behaviour in people with dementia to explore how risk is managed by all relevant stakeholders and through doing so highlights the plural constructions of risk and how these are balanced. Wandering is common in people with dementia (Chan *et al.* 2003; Klein *et al.* 1999). More recently the term has been replaced with 'walking' in recognition that it can be beneficial for people with dementia (Cohen-Mansfield *et al.* 1991; Marshall & Allen 2006). It encompasses a range of behaviours, which have been categorised in a variety of ways (Algase 1999; Hope *et al.* 1994) and which are often aggregated within the term agitation or agitated behaviour (Cohen-Mansfield 1986). It may be beneficial to people with dementia providing a form of exercise (Cohen-Mansfield *et al.* 1991) but can also be associated with earlier institutionalisation (Balestreri *et al.* 2000; Phillips & Diwan 2003), physical harm (Rowe & Glover 2001) emotional distress (O'Connor *et al.* 1990) and mortality (Koester & Stooksbury 1995). For the families of people with dementia, the risk of wandering causes great anxiety, although around one third of people are located within one mile of their homes and another 50% between one and five miles (Rowe & Glover 2001).

In terms of the degree of risk wandering poses to people with dementia, the incidence of significant injury has been shown to be around 5% (Rowe & Glover 2001). In a USA-based study evaluating a Safe Return Programme for people with dementia who have become lost, discovery details were complete for 615 incidents of lost people over a 13 month period. Four deaths occurred (3 from hypothermia, one from a train accident) and 30 people sustained significant injuries (20 skin injuries, five head injuries, four cases of dehydration and one of hypothermia (Rowe & Glover 2001)). Walking/wandering thus represents an area of dementia care where the perspectives of relevant stakeholders on risk assessment and management need to be explored in greater depth.

The aim of this paper is to explore different stakeholder perspectives in the management of people with dementia who wander, in particular the use of assistive technologies, through a literature review and qualitative methods. In this paper, we use the term 'assistive technologies' to refer only to hard technologies and technical devices that are intended to assist the older person in living safely and independently, and do not include technologies *of practice* (for example behavioural interventions). Our analysis focuses on the ways in which different stakeholders assess and balance rights against risks to older persons in relation to different assistive technology interventions.

Methods

This paper reports part of a larger project which incorporated both a systematic review and a qualitative study (Robinson *et al.* 2006). The aims of the systematic review were to ascertain the clinical and cost effectiveness of non- pharmacological interventions to reduce wandering behaviour in people with dementia and to determine their acceptability and the ethical implications associated with their use. A wide range of interventions were included:-

- physical barriers (for example locks);
- physical restraints (for example tethers, Buxton Chair);
- warning and tracking devices (for example alarm electric tagging and tracking devices, sensory pads);
- behavioural interventions (for example cognitive behavioural therapy);
- distraction activities (for example music therapy, exercise);
- alternative therapies (for example homeopathy);
- sensory therapies (for example aromatherapy, multi-sensory environment, massage/touch) and
- carer interventions.

The qualitative study drew directly on the findings of the systematic review to explore in greater depth:- the views of relevant stakeholders (people with dementia, family and formal carers) on the management of wandering in dementia, the management strategies they used and their views on the use of non- pharmacological interventions, particularly the use of warning devices, such as alarms and tracking and tagging devices.

This paper presents the results of the qualitative study and the second part of the systematic review; the first part of that review, the effectiveness study has already been published (Robinson *et al.* 2007). A variety of methods for incorporating the findings of qualitative studies into systematic reviews have been suggested (Dixon-Woods *et al.* 2004;Thomas *et al.* 2004). However this process is not common in practice and most systematic reviews, especially Cochrane reviews, focus exclusively on efficacy studies. This study used a narrative summary in order for the qualitative data to be interpreted and to allow systematic integration with the quantitative data analysis (Dixon-Woods *et al.* 2004).

i) Systematic review

A detailed account of the methodology of the full systematic review and the search strategy used has been published (Robinson *et al.* 2006;Robinson *et al.* 2007). A list of the main electronic databases and additional literature sources searched, and the search terms, is provided in Appendix 1.

Twenty seven papers successfully met the inclusion criteria for the review of acceptability and ethical issues of interventions for managing wandering (see Appendix 1 for full details of papers included). The findings of these papers were analysed in two ways. The first approach, consistent with the full systematic review,

involved applying a data extraction instrument to the set of papers to be included. This instrument allowed papers to be separated into one of two groups either empirical research, for which relevant quality criteria were assessed according to the type of study (Robinson *et al.* 2006), or review/discussion papers. For the first group of papers (n=10), a set of summary results for empirical studies that assessed questions of acceptability and/or ethics were produced. The second group of papers (n=17) that did not report empirical findings were deemed important to understanding the issues raised by the interventions that were studied and the implications of such issues for the practical management of wandering behaviour.

A second approach to understanding this literature was thus undertaken. These papers were analysed as 'original text transcripts' and coded thematically as such for themes relating to the acceptability and ethical considerations of the interventions. Initially two papers were coded in detail by members of the project team (D Hutchings, T Finch, J Hughes, L Corner, L Robinson), who then met to discuss codes and develop the initial coding frame. This provided the opportunity to discuss any discrepancies in interpretation and ensured the development of an analysis strategy based on shared understanding across the project team. The coding frame was piloted on a further two papers and refined accordingly. The remaining papers were then coded following the agreed coding frame. Coded papers were imported into the Non-numeric Unstructured Data Index Searching and Theorising (NUD*IST) software programme for the organisation and comparison of qualitative data. A cumulative comparative analysis was carried out to determine the main themes regardless of focus (ethics or acceptability) or intervention. Coding (and cross-coding) was compared across all of the papers and categories were collapsed and merged, until distinct but inter-related themes emerged. This was followed by a constant comparative analysis to examine any differences or commonalities within the main themes between the interventions (May *et al.* 2004).

ii. Qualitative study

Four focus groups were held (n = 19); two with health and social care professionals and nursing home staff (n = 10); one with family carers (n = 3) and one with an established group of people with mild dementia (n = 6). The discussion groups with carers used task group methodology (Mort & Finch 2005).

A task group provides a focus group forum that enables relevant stakeholders to contribute to discussion about services and policies that may affect them (Mort & Finch 2005). They are designed to provide the opportunity for stakeholders to engage in informed debate about a particular issue from their own perspectives, usually with the aim of arriving at a decision or recommendation after a process of deliberation. Three task groups were carried out with carers and facilitated by Deborah Hutchings, Tracy Finch and Louise Robinson. The groups included the following participants:

- a) Health and social care professionals including a clinical psychologist, an old age psychiatrist, an occupational therapist and a social worker. (n = 4)
- b) Carers including residential and nursing home managers, nursing home staff and inpatient ward managers (old age psychiatry services). (n = 6)
- c) Family carers, with experience of relatives with dementia who wandered, (n = 3) including two spouses (co-resident) and one daughter (non-resident).

Family carers were recruited via several sources. i) voluntary agencies such as Alzheimer's Society and ii) via health care professionals who identified known patients with dementia who demonstrated wandering behaviour.

The aim of the task groups was to ascertain relevant stakeholders' views on the management of wandering in dementia and the use of assistive technologies. For the latter, the three carer groups were presented with a summary of the key findings of the full systematic review with respect to assistive technologies and asked to consider the following study questions:

1. What principles would you wish to see considered in the management of wandering in dementia?
2. How useful and acceptable are the different types of approaches currently in use?
3. What are the ethical problems of the different approaches?

For the focus group with people with mild dementia, because of the cognitive impairment of the participants, it was agreed that this group would be less structured and shorter in duration than the task groups with carers. The group, facilitated by Lynne Corner, therefore consisted of a general discussion around their personal views about wandering in dementia (i.e. benefits and risks) and their views on one type of intervention only (tracking/tagging devices).

All discussion groups were taped and transcribed in full. One transcript was coded in detail by Deborah Hutchings and Louise Robinson to develop an initial coding frame. Discrepancies in interpretation were discussed and the coding frame refined through project team discussion. Anonymised transcripts were imported into the NUD*IST qualitative software programme for the organisation of data and application of the coding frame using a constant comparison approach. Analysis was conducted using the thematic framework approach (Ritchie & Spencer 1994), which is both deductive (a 'top-down' approach informed by the aims of the research and the study questions) and inductive (a 'bottom-up' approach grounded in the responses of the

participants). Thus analysis of both data sets, from the systematic review and the discussion group transcripts, followed a similar approach. All data was coded openly by more than one member of the team; the team then met to agree the coding frame which was applied to all papers/transcripts.

This study was approved by Newcastle and North Tyneside Local Research Ethics Committee and registered with the appropriate Newcastle, North Tyneside and Northumberland Mental Health NHS Trust in accordance with Research Governance procedure.

Results

Twenty seven papers were included in the review (see Appendix 1 for details). The most common intervention discussed (14 papers) was the use of assistive technologies, such as electronic tracking and tagging devices. The presentation of the results is organised round the main themes identified in the study:-

- Conflicting perspectives on the management of wandering in dementia;
 - i) Carer perspectives - balancing rights and risks.
 - ii) Perspectives of people with dementia - 'enjoying the fresh air'.
- Conflicting perspectives on the process of risk assessment and management in wandering;
- The use of electronic devices – conflict between autonomy and liberty and safety and security.

There was considerable consensus between the themes identified in the systematic review and the focus groups. For each main theme, the results from the systematic review are presented first followed by the qualitative data.

- Conflicting perspectives on the management of wandering in dementia

i) Carer perspectives:- balancing rights and risks

From the carer perspective, the most important theme was the prevention or reduction of harm to the person with dementia; all were mindful of the need to balance a person with dementia's right to autonomy and independence with a duty to minimise harm to themselves and to others.

From the systematic review, a number of factors were identified which influenced this balance (Box 1, Figure 1). All carer groups were mindful of their responsibility within society to act in the "best interests" of the person with dementia (beneficence).

However, the main argument around the principle of beneficence concerned whose "best interests" were being considered. From the health and social care professionals' perspective, best interests were most often discussed in terms of protection from harm (non-maleficence) both for the person who wandered and other residents who may be harmed by them (McShane *et al.* 1994; Moss & La Puma 1991; Welsh *et al.* 2003). However, one paper noted that although the present social climate favours individual autonomy, professional carers are more likely to favour "*the rights to safety over the rights to freedom*" (The Lancet (Anon.) 1994). Nursing philosophy incorporates the promotion of safety and protection from harm (Dawkins 1998); however responsibility for the person's safety in situations when movement cannot legally be restricted (i.e. residents who have voluntary status and are not detained under the Mental Health Act) led to nursing dilemmas (Kitwood 1997).

Box 1 here

The focus groups allowed this balance between an individual's rights and potential risks they were exposed to, to be explored in more depth between the different carer

groups. There was considerable awareness amongst the health and social care professionals of Kitwood's theory on personhood in dementia (Kitwood 1997) and the need to facilitate person-centred care, as recommended in the National Service Framework for Older People (Department of Health 2001). However for health professionals and nursing home staff, the overwhelming factor influencing this balance in favour of risk management was the fear of litigation, (Box 2, figure 1) although no evidence of this was discovered in the literature reviewed (Coleman 1993). All participants felt society would regard them as negligent if they didn't operate a locked door policy in nursing homes and on hospital wards. Medical and nursing professionals also spoke of the philosophies underpinning their training and professional values i.e. Hippocratic oath and their duty as health professionals to ensure the safety of all their patients/clients, and not just those with dementia.

Box 2 here

Family carers in their focus group favoured quality of life and independence for the person with dementia above the potential risks (Box 2, Figure 2). They commented upon the fact that they felt people with dementia were overprotected by health professionals and highlighted the difficulties they faced in challenging professionals' decisions on risk management. What was often viewed as an acceptable risk by family carers was considered unacceptable and potentially dangerous by professional carers.

ii) Perspectives of people with dementia – 'Enjoying the fresh air'

The views of people with dementia on the management of wandering and the variety of interventions available could not be determined from the literature as the included papers only contained carers' views.

However, the small number of people with dementia who participated in the discussion group felt that walking was enjoyable, kept them fit, relieved tension and facilitated independence. They did not use the term wandering.

“Sometimes we just go out ... haven’t any idea where I am going ... just enjoy the fresh air.”

Person with dementia 1

“I want to feel as if I’ve got a bit of independence and while I can I just go out”.

Person with dementia 2

- Conflicting perspectives on the process of risk assessment and management of wandering

The literature review highlighted how the process of risk assessment and management differed between carer groups. Whilst formal carers stressed the need for a team approach and joint decision-making involving all relevant parties (Cantes & Rigby 1997; Richter *et al.* 1995), family carers tended to make their own decisions based on personal experience of what worked (Dodds 1994). Sometimes family carers found it difficult to contest such decisions when they were made by professional carers (Coleman 1993). Informed consent was a particular issue in the papers on tagging and tracking, physical barriers and restraints. Most noted that informed consent should be obtained either from the person who wanders or a reliable proxy, as tagging without informed consent is illegal and may constitute an assault (Mapp 1994). Physical barriers such as locked doors were sometimes justified as a means of allowing the person with dementia to wander within a secure area (Coleman 1993; Gaze 1989). The use of restraints could be considered justified if serious harm was prevented, thus overriding the person’s right to refuse (Moss & La Puma 1991). There was also some discussion about capacity to consent and

whether or not the person with dementia really understood what they were agreeing to (McShane *et al.* 1998;Wilber & Machemer 1999).

In the focus groups, all carers felt that an individualised person-centred approach should be adopted in the management of risk for people with dementia who wandered. Some health professionals discussed the ABC approach (i.e. determining the antecedents, behaviour and consequences of wandering) and stressed the importance of getting to know the person and their personal history to help understand and manage the behaviour. A blanket approach was not recommended (e.g. everyone being tagged), rather approaches should be matched to the person. Furthermore it was felt that any decision should be fluid, regularly reviewed and able to change as the person or the situation changes.

“I think an individualised multi-disciplinary approach, including relatives and perhaps the users themselves and maybe raising the issues with the people before they become or in the early stages of dementia about how they want to be treated in the future”.

Health professional 2

“Why do they go out when they do and where do they go and a fair amount of detail on that, you know what happens beforehand, what are they doing, what the consequences are. I would probably do that and I certainly have done that with several people. And very much looking at past behaviours so is the wandering actually purposeless or is it actually something they’ve always done”.

Health professional 3

Nursing home staff sometimes felt that they failed to deliver person – centred care and utilised risk as a means of illustrating difficulties within their system.

“The gardens are there but you can’t go out because it’s too wet or too cold or we can’t spare the staff because you might fall.”

Nursing home manager 3

In the discussion group for people with dementia participants felt that they were placed at greater risk by carrying a mobile phone (i.e. as a victim for crime) than from the process of wandering. They were not familiar with using new technologies such as mobile phones (some of which have recently been developed to incorporate tracking devices), and said they would find the use of such technology confusing, difficult to learn and distracting.

“It would be more confusing when you’re walking along and this thing it would be more distracting you (all agree).”

Person with dementia 1

The theme of balancing a person’s rights with potential risk in the management of wandering in dementia was particularly highlighted in the papers on assistive technologies, especially electronic tagging and tracking devices. The process of risk management is discussed in detail with particular reference to the use of these interventions.

- The use of electronic tagging/tracking devices – conflict between autonomy and liberty and safety and security.

In the literature reviewed, this conflict between the person’s right to autonomy and liberty and the need for safety or security was emphasised most in papers related to the use of i.e. tagging and tracking devices. Some health professionals argued that

the person's right to autonomy should be balanced against the risk of harm both to themselves and to others (McShane *et al.* 1994;Mort & Finch 2005;Welsh *et al.* 2003). The tension between the use of surveillance through the use of tracking devices, and the person's right to privacy was also paramount, with some arguing that it was a breach of privacy (Dawkins 1998;Department of Health 2001) and others arguing that this was only the case if the person was trying to hide (Coleman 1993). There were also differing views with the respect to the impact of electronic devices on the dignity of the person. The stigma attached to tagging, as applied to its use in the criminal justice system, may equally apply if such devices are used for people with dementia (Marr 1989). However, it was also stated that the use of such devices is neither 'degrading nor dehumanizing' (Coleman 1993). Concerns that the use of electronic devices would reduce staffing levels or interaction with residents in nursing homes were cited in some papers (Mapp 1994;Marr 1989).

From the literature review, family carers were reported to have a positive response to the use of tagging and/or tracking devices, either in principle (Melillo & Futrell 1998;Nicolle 1998) or based on their experience from taking part in a research study (Altus *et al.* 2000;Blackburn 1988;McShane *et al.* 1998;Miskelly 2004;Thompson 1998). A survey of both formal and family carers reported that only 18% of respondents thought that the use of tagging or tracking devices would reduce a person's dignity' (Nicolle 1998). Interestingly in one study, none of the family carers who had experience of using electronic tracking devices felt they gave their relative more freedom. Rather than using the justification that the device would maximise the person's autonomy, it was used to reduce the time until their relative was found (McShane *et al.* 1998). The main benefits of using such devices were felt to be increased confidence and peace of mind for family carers (Altus *et al.* 2000;Melillo & Futrell 1998;Miskelly 2004), and a reduction in stress and release of time for other duties for nursing home staff (Nicolle 1998). The main benefit cited with regard to the

person with cognitive impairment was that they would be located more quickly and more easily and so reduce their risk from harm (Altus *et al.* 2000; Melillo & Futrell 1998; Nicolle 1998). The response to use of the devices by people with dementia who wandered was reported to be variable; some objected to wearing the transmitter whilst others were said not to mind (Altus *et al.* 2000; Blackburn 1988).

In the literature review family carers identified the following problems with the use of tracking and tagging devices:- cost (Altus *et al.* 2000) (although some carers would be willing to pay for such a device (Melillo & Futrell 1998)), the extensive training and technical support required (Kinney *et al.* 2004), technical problems (Kinney *et al.* 2004), the size of the device (McShane *et al.* 1998), difficulties fitting and remembering to test batteries (Altus *et al.* 2000), and the increased demand on family carers in terms of using the equipment, monitoring and searching for their relative, especially if the carer was also elderly (McShane *et al.* 1998). For nursing home staff there was the increased demand on staff time when they had to accompany residents who wanted to leave the building (Thompson 1998). In addition, some felt the devices gave a false sense of security, allowing people to go out when they were not safe; in effect the devices did not abolish risk (Mapp 1994; McShane *et al.* 1998; Nicolle 1998).

In the focus groups, none of the participants had direct experience of using electronic tagging and tracking devices. However family carers felt methods of surveillance (technical or otherwise), such as Closed Circuit Television (CCTV) and community watch groups, were commonly used and accepted in society in general. Confirming the carer views identified in the literature, all carer groups agreed that electronic tagging and tracking devices would be most useful in community settings for people who had a carer available, as they would give peace of mind to carers and reduce the time to locate a lost relative. However they expressed concerns about the effect

on a person with dementia's autonomy and privacy and the association of the use of tagging devices with criminal offenders.

"When my father wandered off and was brought back I thought it would have been ideal if he'd had something in his pocket that I could have phoned up and got the co-ordinates exactly where he was. I'd have just got in the car and gone off and picked him up."

Family carer 2

"I think tagging would be extremely useful but its more useful for those with carers than without"

Family carer 1

"In terms of being ethical, I don't want to be in a situation where big brother is watching me all the time and I don't think I should put other people in that situation. I'm not comfortable with it."

Health professional 3

It was also felt that electronic tagging would be useful in hospital settings, so that patients could not wander out of wards undetected. However, such devices were not felt to be as useful in nursing or residential homes with people with more severe dementia; problems were anticipated if there were insufficient staff available to answer the alarm. Health professionals also expressed concern about the over-use of such devices at the expense of other (more personal) approaches to care, simply because the technology was available. This had been experienced with the introduction of door intercom systems which were installed for many people but which they could not or did not actually use.

In the discussion group with people with dementia, there were mixed responses to the use of electronic tracking devices.

"I am not in the need of it but I wouldn't mind wearing one, I think it would be sensible."

Person with dementia 5

"No! I don't feel the need".

Person with dementia 6

People with dementia also expressed concern that tracking devices could be embarrassing if they omitted a noise when they were out in public, and that mobile phones used as tracking devices could be stolen from them. Familiarity of use of the intervention was of paramount importance to this group. For example, participants felt they would be happy to carry identity cards because they were used to carrying them during the second world war.

"I mean during the first world war we had identity cards and never thought anything about them".

Person with dementia 4

"I carry a form of identity and stick it in my pocket – I'm happy with that."

Person with dementia 3

In terms of managing risk, people with dementia said they would not want to be monitored all of the time, although this depended to some extent on who was doing the monitoring (e.g. spouse or social services). They also felt it should be the choice of the person with dementia whether or not they used such devices.

“I don’t want to feel as though my family are looking after me just through a mobile phone”.

Person with dementia 2

“If someone was keeping an eye on you it would depend who it was. If it was your partner you might feel alright about it but you might not. You might not want your partner always to know where you were. It’s the relationship you’ve got with the person who is keeping an eye on you.”

Person with dementia 3

Discussion

There was considerable consensus between the findings of the review and the qualitative study with respect to the main themes identified. The most important theme identified by all carer groups was the concept of risk assessment and risk management, with both family and formal carers mindful of the need to balance a person with dementia’s right to autonomy with their duty to minimise harm. Family carers exhibited greater tolerance of risk, with professional carers favouring patient safety over autonomy due to a fear of litigation; this appeared to affect the provision of person – centred care. The perspectives of people with dementia, as reported by themselves could not be determined from the literature review as the included papers contained only proxy reports from carers. However the small number of people with dementia who participated in the qualitative study felt that walking kept them fit relieved tension and was an enjoyable activity. They stressed the importance of maintaining their independence and felt that the use of interventions, such as mobile telephones and tracking devices, placed them at greater risk than wandering.

The findings of this study concerning differences in risk appraisal are supported by the developing literature that deals with the concept of risk and how it has become a central cultural concept (Carter 1995; Douglas 1996; Lupton 1999). The notions of risk and danger have become interchangeable and the power to make the distinction between safety and danger has been placed in the hands of the risk assessor (Carter 1995). This study has highlighted the plural constructions of risk in the management of wandering in dementia care. On the one hand it could be viewed as something 'risky' and dangerous and therefore is something that needs to be managed primarily through emphasis on *prevention*, hence the proliferation of different technologies and behavioural practices to prevent 'unsafe' (unrestrained or undetected) wandering. On the other hand it could be seen as something more positive in terms of the physical benefits from exercise, but perhaps more importantly, as a means of retaining a certain level of autonomy and independence and thus some preservation of the person's sense of self-identity. As this study has illustrated, these contrasting perspectives can lead to conflict in decision-making about management about the person with dementia who wanders. Previous research has found that, although, all carer groups strive to achieve a balance between maintaining personal autonomy and preventing/reducing risk (Alaszewski 1998; Alaszewski & Manthorpe 2000; Clarke 1995; Clarke 2000; Clarke & Heyman 1998); professional carers are more cautious than family carers about allowing people with dementia to take risks (Clarke 2000). In-depth studies of the process of risk appraisal by carers of people with dementia reveal that professional carers focus management strategies on the future (Clarke 1995), emphasising the physical domain of risk for example, falling (Alaszewski 1998) whereas family carers focus on the present (Clarke 1995) and the interpersonal domain of risk eg loss of the partnership role (Alaszewski 1998). People with dementia appear most concerned with the biographical domain of risk ie the loss of self identity (Alaszewski 1998).

In one such study exploring how situations in dementia care are constructed as a risk by community psychiatric nurses and family carers, detailed analysis of the discursive processes revealed a number of stages. Initially nurses encourage relatives to explore potential at risk situations (“fishing”), moving finally to a process of negotiation (Adams 2001). Discussion with family carers regarding the degree of individual risk and negotiation of a shared agreement regarding supervision is supported by the findings of this study. However our findings show that decision-making regarding the use of assistive technology is complex and associated with considerable ethical conflict. The process should include securing valid consent from the person with dementia (or a reliable proxy), multidisciplinary involvement including family carers and where possible the person with dementia, and a considered assessment of the balance between the benefits and the risks of using the intervention.

A number of limitations of the present study must be considered. The full review was guided by the principles for undertaking a systematic review (Khan *et al.* 2001), and therefore it could be argued that selection criteria applied using this approach may have restricted the breadth of papers that could be included in the analysis . However, although stringent criteria were applied to the review of efficacy of interventions included in the study, a more narrative approach was taken to the review of acceptability and ethics, which allowed the inclusion of papers reporting qualitative studies, pilot projects and surveys. Our approach to this part of the review was thus necessarily pragmatic, as the majority of papers addressing ethical issues were opinion-based discussion papers that would not normally be considered to meet the quality standards of a systematic review but which provided essential data for the study. Our approach to analysing and integrating quantitative and qualitative data within a systematic review, similar to that of others (Thomas *et al.* 2004), has thus demonstrated benefits in both addressing gaps in the literature and in facilitating the

interpretation of quantitative findings. In terms of the qualitative study, the findings are limited by the small number of participants included. We experienced great difficulty in recruiting family carers with experience of relatives with dementia who were presently wandering and in fact two withdrew from the focus group at the last minute due to problems in arranging replacement care. Unfortunately data collection was limited by time/funding constraints and not determined by data saturation. Despite this limitation, our findings begin to address a major gap in the research literature by providing some insight into the personal views of people with dementia concerning the use of technological and other interventions for the management of their safety, and the ways in which their views might differ from those of carers or other decision-makers.

During the last decade, there has been increasing recognition that walking/wandering may have beneficial effects for people with dementia (Marshall & Allen 2006) providing exercise and improving circulation, and promoting more regular sleep patterns (Taft *et al.* 1993); although the evidence is not strong (Lai & Arthur 2003). This is corroborated by the findings of our qualitative study. This shift towards a more person-centred approach to the management of wandering is increasingly reflected in nursing and therapy practice. Screening for wandering behaviour has been suggested and if detected, a structured, observational assessment of both the individual and the environment is recommended (Dewing J, personal communication 2006). For the former, a detailed account of the person's history, antecedents and consequences of their wandering behaviour is necessary. Research unravelling the complexities and aetiology of wandering (Hope *et al.* 2001) and the development of wandering specific assessment tools, such as the Algase Wandering Scale (Algase *et al.* 2001; Algase *et al.* 2004) will facilitate this. Attention to the environment, including location of exits, presence of alarms and the creation of safe, conducive areas for people to walk in, is essential. Such a shift towards a more person-centred

approach in the management of wandering (Marshall & Allen 2006) should also be reflected in future research studies and the outcome measures selected to evaluate the effectiveness of new strategies/interventions. Outcome measures which are more meaningful to people with dementia and their carers, such as quality of life, physical and emotional wellbeing and serious adverse events should be selected instead of attempting to measure actual behaviour.

Future research around wandering in dementia should explore what constitutes an acceptable risk to individual stakeholders, ie people with dementia, family carers and formal carers, and how such conflicting perspectives can be practically managed in order to promote person-centred care (Alaszewski & Manthorpe 2000). There remains a need to create a practical risk assessment tool which is “not just a ticky box” (Manthorpe 2003) but one which allows all relevant perspectives to be documented and negotiated. Assistive technologies have great potential to promote autonomy for people with dementia (Woolham 2005). However as their rapid development allows for a more diverse and sensitive range of electronic devices to be created, users’ views on their acceptability should precede complex quantitative studies to evaluate their effectiveness (Medical Research Council 2000).

In conclusion, the management of risk within the context of wandering in dementia, requires processes which allow all stakeholder perspectives to be captured and risk management negotiated.

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Appendix 1 Summary of search strategy and paper included in the review

Search strategy – databases and search terms

Cochrane Library, Medline, Embase, Science Citation Index, Social Science Citation Index, CINAHL, PsychINFO, HHEP, ADEAR, National Research Register, ETHX, Bioethics WEB.

Grey literature/conference proceedings were reviewed.

Search terms were focused on the identification of acceptability and ethical issues in the management of wandering in people with dementia and included:-

- i) “cognitive function”, “dementia” and related terms;
- ii) “wandering”, “walking” and related terms
- iii) intervention specific terms (e.g. exercise, music, aromatherapy, massage and touch, tracking/tagging devices, physical restraints, physical barriers, environmental modifications, carer strategies, behaviour, therapy);
- iv) ethical terms (e.g. dignity, rights, autonomy, beneficence, malfeasance).

Papers included in the review

Assistive technology (including tagging and tracking devices)

ALTUS, D. E., MATHEWS, R. M., XAVERIUS, P. K., ENGELMAN, K. K., & NOLAN, B. A. D. 2000, Evaluating an electronic monitoring system for people who wander, **American Journal of Alzheimer's Disease**, vol. 15, no. 2, pp. 121-125.

BLACKBURN, P. 1988, Freedom to wander, **Nursing Times**, vol. 84, no. 49, pp. 54-55.

HUGHES, J. C. & LOUW, S. J. 2002, Electronic tagging of people with dementia who wander: ethical considerations are possibly more important than practical benefits, **British Medical Journal**, vol. 325, no. 7369, pp. 847-848.

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MOSS, R. J. & LA PUMA, J. 1991, The ethics of mechanical restraints, **Hastings Centre Report**, vol. January/February, pp. 22-25.

THOMPSON, M. 1998, How 'bracelets' can open doors, **Care Plan**, vol. September, pp. 21-23.

MISKELLY, F. G. 2005, Electronic tracking of patients with dementia and wandering using mobile phone technology. **Age and Ageing**, vol. 34, pp.497-499.

MCSHANE, R., GEDLING, K., KENWARD, B., KENWARD, R., HOPE, T., & JACOBY, R. 1998, The feasibility of electronic tracking devices in dementia: a telephone survey and case series, **International Journal of Geriatric Psychiatry**, vol. 13, pp. 556-563.

NICOLLE, C. 1998, Issues in the use of tagging for people who wander: a European perspective, **[Proceedings of the conference working with vulnerable adults: innovative practice and technology in risk management] Belfast** pp. 10-22.

WELSH, S., HASSIOTIS, A., O'MAHONEY, G., & DEAHL, M. 2003, Big brother is watching you-the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties, **Ageing and Mental Health**, vol. 7, no. 5, pp. 372-375.

THE LANCET (ANON.) 1994, Wondering about the wanderers, **The Lancet**, vol. 343, no. 8908, pp. 1237-1238.

Physical restraints

COLEMAN, E. A. 1993, Physical restraint use in nursing home patients with dementia, **Journal of the American Medical Association**, vol. 270, no. 17, pp. 2114-2115.

DAWKINS, V. H. 1998, Restraints and the elderly with mental illness: ethical issues and moral reasoning, **Journal of Psychosocial Nursing**, vol. 36, no. 10, pp. 22-27.

MOSS, R. J. & LA PUMA, J. 1991, The ethics of mechanical restraints, **Hastings Centre Report**, vol. January/February, pp. 22-25.

Physical barriers

WILBER, K. H. & MACHEMER, J. 1999, Balancing the competing values of freedom and safety in long-term dementia care: the Secured Perimeter Program, **Journal of Ethics, Law and Aging**, vol. 5, no. 2, pp. 121-130.

Planned walking

HOLMBERG, S. K. 1997, A walking program for wanderers: volunteer training and development of an evening walker's group, **Geriatric Nursing**, vol. 18, no. 4, pp. 160-165.

Massage

KILSTOFF, K. & CHENOWETH, L. 1998, New approaches to health and well-being for dementia day-care clients, family carers and day-care staff, **International Journal of Nursing Practice**, vol. 4, no. 2, pp. 70-83.

Environmental design

MORGAN, D. G. & STEWART, N. J. 1999, The physical environment of special care units: needs of residents with dementia from the perspective of staff and family caregivers, **Qualitative Health Research**, vol. 9, no. 1, pp. 105-118.

Multiple interventions included

DODDS, P. 1994, Wandering: A short report on coping strategies adopted by informal carers, **International Journal of Geriatric Psychiatry**, vol. 9, no. 9, pp. 751-756.

RICHTER, J. M., ROBERTO, K. A., & BOTTENBERG, D. J. 1995, Communicating with persons with Alzheimer's disease: experiences of family and formal caregivers, **Archives of Psychiatric Nursing**, vol. 9, no. 5, pp. 279-285.

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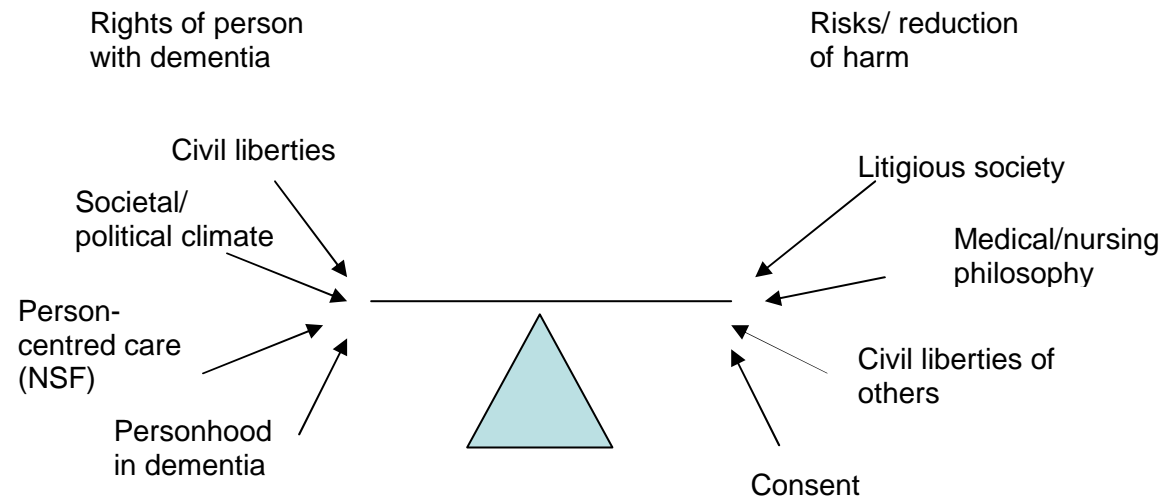
SMITH-JONES, S. M. & FRANCIS, G. M. 1992, Disruptive, institutionalized elderly: a cost-effective intervention, **Journal of Psychosocial Nursing**, vol. 30, no. 10, pp. 17-20.

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KINNEY, J. M., KART, C. S., MURDOCH, L. D., & CONLEY, C. J. 2004, Striving to provide safety assistance for families of elders, **Dementia**, vol. 3, no. 3, pp. 351-370.

Box 1

Figure 1 Factors affecting the balance between risks and rights



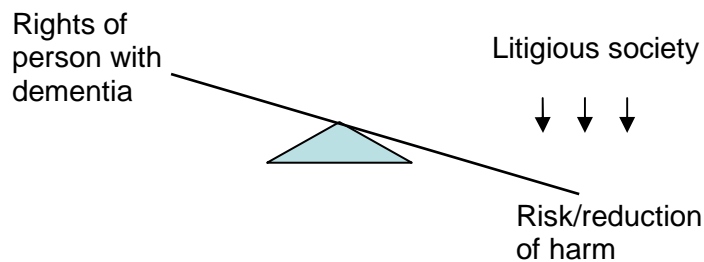
"I think one of the main dilemmas about caring for people with dementia is always bringing up the safety aspects and yet giving them some sort of freedom....walking might be the only thing they can do independently when they have lost nearly everything else". **Family carer 1**

"Locked doors prevent other people from entering and keep patients safe ... but might make them feel imprisoned and they might get more agitated." **Family carer 4**

"It is a constant compromise between what's best for the individual but what you have to do to protect yourself within the organisation you work for". **Health professional 3**

Box 2 Different perspectives of formal and family carers on risk management

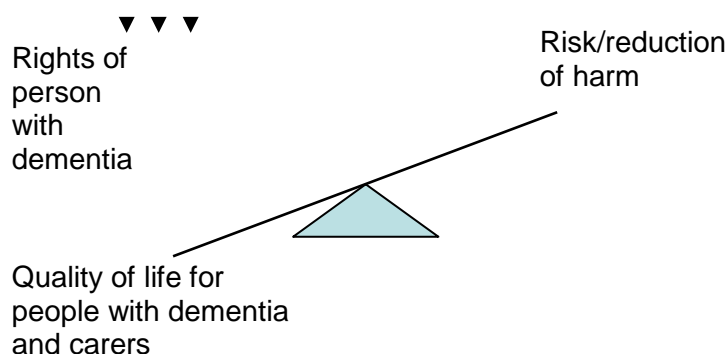
Figure 1 Formal carers' perspectives – “Favour rights to safety over individual freedom”



“One of the other things that we haven’t mentioned is the affect of wanderers on other residents in a home. If you’ve got one person who wants to be on the go all the time, how that affects everybody else.”
Health professional 3

We’re in an ideal situation....they can walk round a huge area but we had to do a risk assessment. Because there were too many untoward incidents happening, some were physical attacks, some were sexual, we had to block it off. Its about making a risk assessments. **Nursing home carer 6**

Figure 2 Family carers' perspectives – “People with dementia are over protected”



"When we were looking for a home, one thing we wanted....they would allow him to go out and walk because he enjoys his walking so much...its his main activity and it keeps him healthy but a lot of the homes wouldn't allow it and we didn't want to restrict him in that way...I would make it clear to the nursing staff that I was prepared to take a risk...I'd even put it in writing". **Family carer 2**

“He used to take the dog in the morning and at tea time and this was another example of him wandering and getting lost. Once he’d probably been away about half and hour...and he hadn’t come back. I couldn’t see him anywhere so I rang the police...before they came he wandered back with the dog, whether the dog brought him back, I don’t know”. **Family carer 3**

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