

**Using GPS technologies with People with Dementia: A systematic review of the evidence and recommendations for future practice**

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**Abstract (300 words)**

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## Introduction

Dementia is a disability that affects a person's ability to navigate. Early findings from the PREVENT Dementia Program – a prospective study of the adult children of persons with dementia - are that losing your navigation skills or getting lost may provide some of the initial indicators of Alzheimer's disease (Ritchie, et al, 2017). It is estimated that 40% of people diagnosed with a dementia will get lost at some point, and 5% of these people will get lost repeatedly; sometimes with fatal consequences. Often the police or search and rescue teams are called out to search for people with dementia who go missing, causing distress for the individuals and families concerned and a financial burden for the services involved (Cole, 2012). Some family carers lock the person indoors to avoid the possibility of the person going out and getting lost; even though this in itself could potentially harm a person's physical and psychological well-being. For people with dementia who live on their own, getting lost may lead to institutionalisation. If it were possible to prevent people with dementia from getting lost when they went outdoors, the distress and human costs associated with impaired navigation skills could be avoided.

Over the last decade, the police and care services have been providing Global Positioning System (GPS) or location technologies, to support people with dementia and their family carers with navigation. GPS is a satellite based navigation system that can be used by anyone who needs to keep track of where he or she is, to find his or her way to a specified location, or know what direction and how fast he or she is going. With the exception of locations where it is not possible to obtain a signal, such as underground car parks, shopping malls, and railway tunnels, the system can locate a person wherever they are outside. Individuals and families affected by dementia are being offered devices which combine GPS with activity monitoring to help locate the wearer and support their family carer. Such devices include wristbands, bracelets and shoes equipped with GPS; other prototype technologies (such as GPS armbands) may also be developed in the future as we discover more about what works for people with dementia (Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009). Clearly, GPS technologies have a potential role in supporting people with dementia and their carers to overcome the challenges of navigation. Plus, such technologies have the potential to transform care in the community for people with dementia by protecting a person's right to social inclusion and mobility. However, it is unclear how and when such technologies should be used, or whether they are effective in providing navigation support and preventing a person from getting lost.

GPS is a worldwide system that spans the globe. As such there is a burgeoning investment and interest in using GPS technologies with people with dementia and their family carers amongst international companies and researchers. This is evidenced by the rising number of patents for new devices (Garner, Giroux, Gomez, Hyatt, Ingerson, Shi), as well as the development of prototypes involving people with dementia themselves (McCabe and Innes, 2013). However, current scientific knowledge regarding the use of GPS technologies by people with dementia and their family carers is limited and lacking the perspective of people with dementia themselves. Furthermore, the topic is typically discussed in a medicalised way in terms of 'a treatment for wandering' and to 'relieve caregiver burden' rather than a

potentially effective measure for supporting navigation and preventing harm. Therefore, we undertook a systematic review to examine all the current evidence regarding the use of GPS technologies by people with dementia and their family carers. The review was conducted by an international team of social scientists and an engineer; we examined the topic through a citizenry lens and in terms of having transformative potential.

This paper presents preliminary findings of a systematic review of research papers on using Global Positioning System technologies with people with dementia. The range of factors encompassed in this review represents those deemed most significant and relevant for public officials, care professionals, and researchers. Within the care sector, the use of GPS technologies by people with dementia has been regarded as ethically controversial and divides opinion, particularly amongst medical professionals. Some see it as an infringement of a person's civil liberties (O'Neill, 2013); whereas others consider it an effective means of maintaining a persons' safety (McShane, 2013). At the heart of the issue are tensions between concerns for autonomy, privacy, civil liberties, and human rights on the one hand, and concerns for welfare, safety, and carers on the other (Robinson et al., 2007). Other research confirms that attitudinal issues, ethical concerns, as well as a lack of training and information, are the main barriers to nurses and other care professionals providing and monitoring the use of GPS technology more routinely (Clark & Mcgee-lennon, 2006). This research has led to the development of guidance for nurses and healthcare staff to 'manage wandering behaviour' (see for example, Futrell, 2010), and calls for more robust evidence on the effectiveness of using these technologies (Milne and McKinstry, 2012). The aim of this paper is to provide fresh insights into using GPS technologies with individuals and families affected by dementia, and to offer recommendations about future practice and research on this topic.

## **2. Methods**

### **2.1 Search strategy**

A Health Librarian at the University of Southampton worked with the researchers on the search strategies. The initial search strategy was tested for specificity using an ESBSO Medline search and selected references from the researchers. Once amended to include more keywords, the search was performed on the following six databases using the same keywords and amending the Subject Heading as appropriate. Medline, EMBASE, CINAHL, PsychINFO. Web of Science and Scopus. (Individual search strategies are in Appendix 1) The searching took place between the 29/04/2016 and the 15/6/2016. There were no language or publication status restrictions.

A list of references compiled by the researchers (RB, TB) over a period of time were also combined into the search, these had been gathered from a variety of resources. These references were de-duplicated against the key database searches. Total **1765** Additional searching took place using the Internet to find published material not included in academic databases. The following keywords were used "dementia, cognitive impair\*, walk\*, GPS, track\*, wander\*, "Global positioning", Alzheimer\* where only simple searches could be undertaken. This was undertaken between the 20/06/2016 and the 25/07/2016, and twenty seven additional resources were identified (List of websites in Appendix 2).

## **2.2. Study selection**

### **2.2.1 Eligibility criteria**

All study designs were suitable for inclusion. Empirical studies involving people with dementia and/or their family carers living at home and using Global Positioning Technology were eligible for inclusion. Only articles with sufficient details about the study sample and data collection methods were included in the review. We excluded studies not published in English and were only available in abstract form.

### **Data extraction**

Two reviewers (RB, PB) independently selected studies, based on title and abstracts according to inclusion and exclusion criteria. Disagreements were resolved in discussion with a third reviewer (PT). A data extraction table was created jointly, which included study characteristics, aims and duration of the study, description of the device, population and data collection methods, outcome and main results; and distributed to each reviewer with a sample of identified papers to review.

### **Results**

Initially, 7230 research papers were found, plus 27 pieces not in research databases. Duplicate and irrelevant publications were removed, which left 54 potentially relevant publications. After reviewing the title and abstracts for relevance based on the inclusion criteria, the number of publications was reduced to 47. These papers were then read in their entirety and a further 25 were excluded because they did not fit our eligibility criteria. A total of 22 papers were deemed to meet the inclusion criteria and were retained for the final review.

The earliest studies on the use of GPS technologies with people with dementia were reported in 2007, with the most recent in 2016. Four papers pertained to the same study, which was a three year Senior-Tracking (SenTra) bi-national study between Germany and Israel, completed in 2011. The largest study, conducted in Norway, recruited 208 persons living with dementia, all of whom were supplied with a GPS device. The smallest study reported on just one dyad case – a man with dementia and his wife.

Results from these papers are organised by reviewing the benefits and drawbacks of using GPS technologies with people with dementia and their families. Some studies included results pertaining to other technologies (such as radio frequency transmitters) or other groups (such as medical staff and engineers). These results were not analysed and are therefore not reported in this paper.

### **Benefits of using GPS technologies**

There is growing evidence on the benefits of using GPS technologies with people with dementia. In this review, we found that benefits were seen either from the perspective of the person with dementia, a family carer, healthcare professional, or a researcher.

One major benefit noted by people with dementia and their carers was the freedom it provided; freedom to continue outdoor activities and increased autonomy. For example, one

small-scale experimental study involving three men with dementia found that the use of GPS technologies led to an ‘increased frequency of independent outdoor activities’ in all three cases. Another small-scale field experiment involving four people with dementia using navigation support to walk familiar routes, concluded that such systems could prevent unsafe situations (Hettinga, et al, 2009). Significantly, one participant in another study stated that there comes a time when ‘safety becomes more important than privacy’ (Oderud, et. Al. 2015). Safety is a critical concern for people with dementia, particularly in outdoor environments (Lin et al, 2015). These researchers suggest that the use of GPS technologies by a person with dementia can provide respite to carers because they know of person’s whereabouts.

A number of the papers focused on the carers’ perspective. A survey of carers’ attitudes found that the main benefit it brings is ‘protection of life (Landau, 2010, 413). The large Norwegian study found that family caregivers liked the increased sense of safety and freedom brought about by using GPS technologies (Oderud, 2015, et al). One carer stated how it made her life easier. Another study was a very small-scale study involving a single dyad case using a GPS system for one day; here the carer was given the authority by her husband who had dementia to decide about using GPS. This carer, like those in a study by Landau et al (2010) gave preference to a person’s safety rather than autonomy when they are responsible for that person (p.409). Interestingly this study, which included a focus group with six female caregivers being asked their thoughts on ‘wandering technologies’ and the functions it should have, found that GPS technologies were favoured because they afford caregivers with a high degree of control over the person with dementia.

Another benefit is the speed with which someone with dementia can be found if they are using GPS technologies. One study compared a radio transmitter with GPS system and found the latter to be highly reliable in providing a position as soon as it was requested (Bulat, 2016).

A number of the papers reported the perspective of health care professionals. Perhaps unsurprisingly, one survey involving this group found that ‘electronic tagging’ was considered to be the most appropriate response to ‘wandering’ by health care professionals (Hughes, et al, 2008). It was concluded that the decision to use ‘electronic tagging’ should only be made with the involvement of a health care professional.

Another major benefit of using GPS technologies identified in the review was a methodological one. Five papers reported on how data provided through GPS technologies can provide researchers with real-time, accurate information about a person’s spatial behaviour and walking trips. For example, in one study, computer scientists in China used the GPS trajectories of ten people with dementia to develop an ‘isolation-based disorientation detection model’ (iBDD) (Lin, et al, 2015). The iBDD is an algorithmic model, which can determine with 95% accuracy whether or not someone’s walking trajectory is normal for that person or a possible instance of disorientation or ‘wandering’. The researchers defined wandering as ‘traveling to semantic places or along old routes with a different sequence

inside the historical traces’ – so whenever a person makes lots of direction changes, which they have never made, and visits a place, which they have never visited before. A convincing case is made for when it is warranted to use the term ‘wandering’ (Lin, et al, 2015: 74).

The four papers from the SenTra study focused upon the value of using GPS technologies as a research tool to collect objective geographic data on the outdoor mobility of people with dementia (Oswald, et al, 2010; Shoval, et, al, 2010, Wettstein et al, 2015, Isaacson, et al, 2016). The SenTra study recruited 35 people with Alzheimer’s disease, 76 with Mild Cognitive Impairment and 146 healthy adults. All participants were issued with a GPS tracking kit and instructions concerning its use, which they used for four weeks. The conclusion drawn in all these papers is that using GPS technologies with people with dementia can provide researchers with high quality time-space data, that is much more than objective than verbal reports from family members or health care staff.

### **Drawbacks of using GPS technologies**

There are several drawbacks to using GPS technologies with people with dementia. One mentioned in several papers involving people with dementia and their families had to do with the physicality and functionality of a GPS device. Some devices are quite bulky and people do not want to carry them around. The small-scale study involving just one dyad ended after just one day for this reason. In another study, some functions were found to be unhelpful (such as warning sounds) (Hettinga, et al, 2009). People have to remember to take them with them too.

Another drawback with using GPS technologies is that it can raise concerns about harm to human rights. Such technologies are associated with ‘tagging’ and monitoring and may therefore not be seen as a viable care option for people with dementia. For this reason, one study found that health professionals are reluctant to intervene and recommend this service (Landau, et al, 2000). In other study, it was reported that health care workers said that they not know how to broach the subject of using technologies, as it can sound like monitoring. A number of studies focused on the negative connations and ethical issues of using GPS ‘tagging systems with people with dementia.

### **Discussion**

This paper has reported on a systematic review of using GPS technologies with people with dementia. It has addressed a gap in the literature by synthesising the research evidence and reviewing studies through a citizenship lens. This has meant analysing the use of GPS technologies in terms of a potentially effective measure for promoting a person’s right to live in the community. Health and social care professionals are in a position to recommend and support the use of GPS technologies with individuals and families affected by dementia. The small-scale studies reported in this review. Given the lack of large-scale intervention studies.

Using GPS technologies cannot prevent all forms of harm; crossing the street, for example, is still a potentially dangerous activity. However, it can help in terms of reducing the time it takes to discover a person. Indeed, some researchers have suggested that ‘time spent



searching and days spent until long term admission are useful outcome measures' (Milne, et al, 2012)

This review contributes to the literature in several ways. It has found that in certain circumstances it is warranted to use the term 'wandering' to describe a person's walking behaviour. At such times, the information provided by GPS systems is invaluable.

It is striking how none of the research on the use of GPS technologies by people with dementia takes into account the other health related problems a person is likely to have, such as hearing loss and physical disabilities. One study referred to a participant with dementia needing to walk with a walking aid, but otherwise there was no reference to physical health status. In addition, the effects of ageing were Increasing age is associated with reduced spatial activity (Shoval, et al, 2010: 6116). As other researchers have pointed out, 'the heterogeneity of caregiving contexts means solutions must be flexible and creative' (Wan, et al 2014). Not everyone with dementia will need or want a full scale GPS-enabled care system that involves call centre support.

Given the growing availability and acceptability of using GPS to locate yourself and other people, some of this work already seems dated. With more and more GPS-enabled devices on the market, some of which are targeted at people with Alzheimer's disease (e.g. key fobs), it no longer seems reasonable to expect that a health professional should be involved in the decision about whether to use one or not.

This systematic review was undertaken by an interdisciplinary team of researchers, with the expert assistance of a health librarian. All available evidence pertaining to the use of GPS technologies by people with dementia was located and critically reviewed by the research team using a data extraction sheet and interpretative synthesis.

### **Limitations and recommendations for future research**

A few limitations should be noted. First, the studies identified varied greatly in quality. Most of the studies were relatively small-scale and some provided very little information about the system being trialled. This review only found non-trial evidence. The suggestion to evaluate the use of technologies using a randomised control trial has been made (Milne and McKinstry, 2012). Unless and until trial evidence is available, there is unlikely to be wholesale prescription or uptake of GPS technologies for safer walking.

Second, the next tranche of work on this topic should take the perspective of people with dementia themselves. It is striking how much of the available evidence is from the perspective of family carers and health and social care professionals, rather than from those actually using the device. For this to happen, researchers need to develop and hone more creative methods of data collection. Standard tools are usually not appropriate to use with people with severe cognitive impairments. Indeed, in one study the intention was to interview people with dementia but it was deemed inappropriate due to the severity of the condition (Dale, 2010). Such a shift in mindset and language could make a huge difference to the lives of people living with a dementia, and our understanding of how GPS technologies can be used to promote the social inclusion and mobility of people with dementia.

Finally, the emphasis in previous work has been on the prevention of ‘wandering’, ‘lost seeking’, and alleviating ‘caregiver burden’. It has been medically biased and from the perspective of carers. This study has been the first to examine the topic through a citizenry lens, which has meant focusing on the value of using such technologies to promote a person’s rights and social inclusion. Future studies should investigate the use of GPS technologies through a citizenry lens and consider the effectiveness of using such technologies to prevent harm to a person with dementia in the broadest sense of the term.