

Using GPS technologies with People with Dementia: A synthesising review and recommendations for future practice

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Abstract

In Norway and other Nordic countries, there is a policy emphasis on using welfare technologies to support people to live at home. For example, Global Positioning Systems (GPS) or 'location technologies' are used to support people with dementia and their next of kin with wayfinding. However, the research evidence has not been synthesised, and so the opportunities and challenges presented when using GPS technologies are not clear. This synthesising review examined all available empirical evidence on the use of GPS technologies by people with dementia and their family carers, through a critical disability lens – that is, in terms of protecting a person's right to live in the community and taking the standpoint of the person with dementia (rather than a caregiver or health professional). Employing this lens meant that we engaged with the literature in a more critical way than standard reviews, and consciously looked for evidence of marginalisation. A search of six major English language databases in 2016 identified 23 studies that met the inclusion criteria. Synthesis of the findings led to the identification of three overarching themes: using GPS to stay safe, taking control and the value of GPS data. The review revealed a growing interest in the use of GPS technologies by people with dementia, which indicates that policy implementation is effective. Future work should take a disability-rights approach and focus on the value of using GPS technologies from the perspective of the person with dementia, as the opinions of this group are often overlooked in discussions about welfare technologies.

Dementia, navigation, GPS technologies, telecare; systematic review;

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 getting lost or losing your navigation skills 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 (Carr et al., 2010). 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 (Robinson et al., 2007); even though this in itself is potentially harmful to a person's well-being or have fatal consequences if there were a fire. For people with dementia who live on their own, a behaviour like getting lost may lead to institutionalisation (Banerjee et al., 2003). If the anxiety and risks associated with getting lost were preventable, a person with dementia could continue living a full life at home.

Over the last decade, in Norway, and other western countries, there has been a policy emphasis on using welfare technologies to support people with dementia at home. One such device is a Global Positioning System (GPS) or 'location technology. 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. While GPS is not a navigation aid, it can be used to locate the wearer, so individuals and families living with dementia are being offered devices which

combine GPS with activity monitoring. Such devices include wristbands, bracelets and shoes equipped with GPS other prototype technologies (such as ‘smart canes’) (McCoogan, 2017). Clearly, GPS technologies have a potential role in preventing harm and promoting well-being for people with dementia. However, the evidence has not been fully synthesised or discussed and so the role of location technologies in care is unclear.

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 formal requests to develop and sell new GPS-enabled inventions (e.g. US2014090213-A1, 2016), and studies which seek the opinion of people with dementia themselves about how they should be designed (e.g. 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 remedial way in terms of ‘a treatment for wandering’ rather than a care intervention (e.g. Kearns et al., 2007). Possibly because it has been introduced too late in the ‘dementia journey’ and is less effective anyway. Therefore, this synthesising review aims to examine all available evidence regarding the use of GPS technologies by people with dementia and their family carers, through a critical disability lens – that is, in terms of protecting a person’s right to live in the community, and taking the standpoint of the person with dementia (rather than a caregiver or health professional).

Employing this lens meant that we engaged with the literature in a more critical way than standard reviews, and consciously looked for evidence of marginalisation. A defining feature of a critical disability approach is to examine power relations and external barriers to people getting the help they need, so this is what we did when analysing the studies. To our

knowledge, no other studies have reviewed and analysed the evidence on the use of GPS by people with dementia in this way.

This article presents a systematic review of all the available evidence on using Global Positioning System technologies with people with dementia living at home. The range of factors encompassed in this review represents those deemed most significant and relevant for public officials and care workers, particularly those with a responsibility for promoting disability rights. The use of GPS technologies by people with dementia and their next of kin can divide opinion among health care professionals, including physicians. For example, O'Neill (2013) sees it as an infringement of a person's civil liberties, whereas McShane (2013) considers it an effective means of maintaining a persons' safety. 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 and Melillo, 2014), and calls for more robust evidence on the effectiveness of using these technologies (Milne & McKinstry, 2012). The aim of this article is to provide a synthesis of existing evidence on using GPS technologies with people living with dementia, and to offer recommendations about future practice and research on this topic, in the context of a critical disability approach.

2. Methods

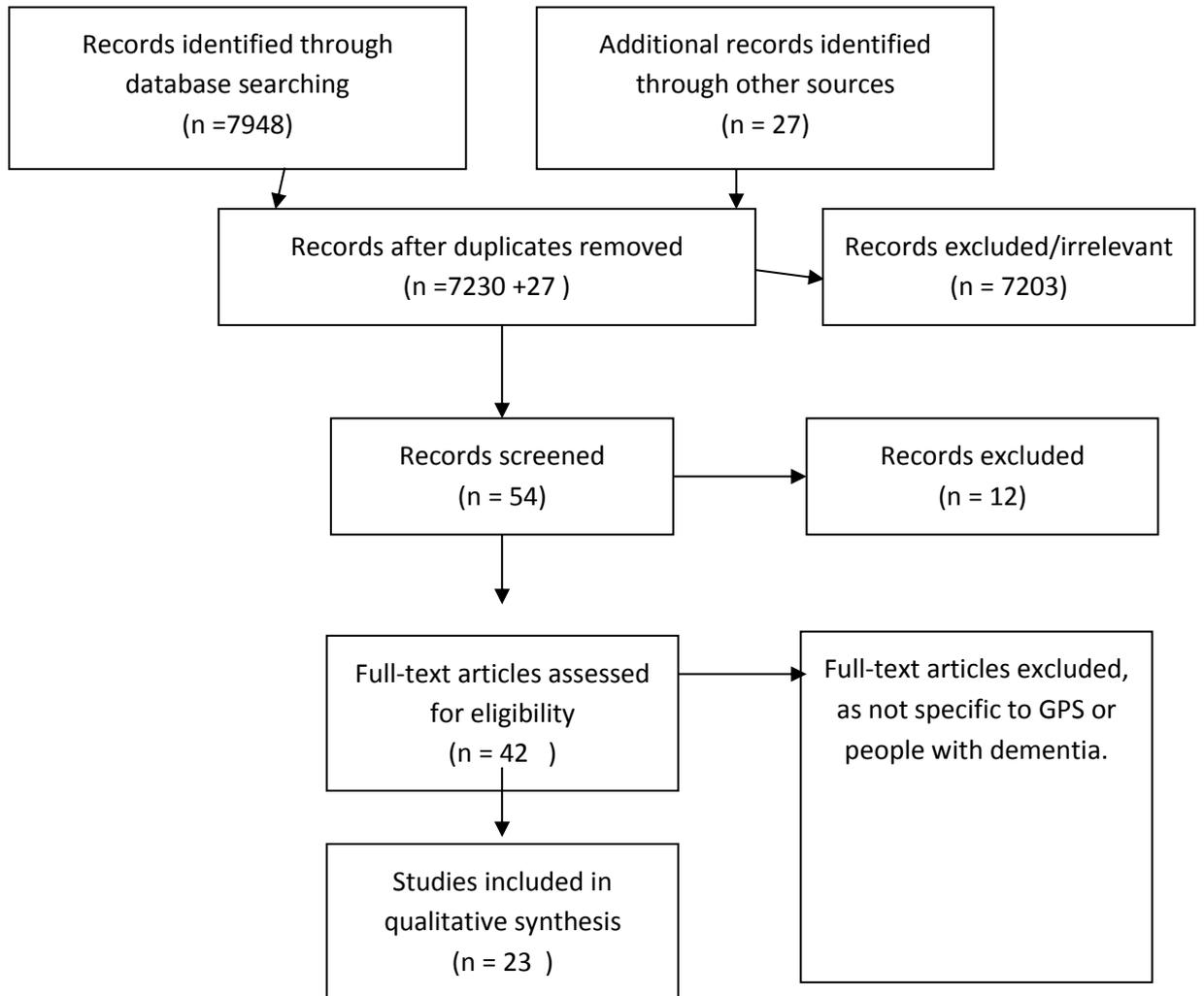
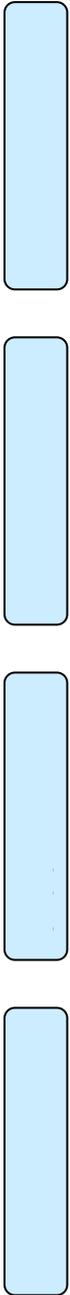
2.1 Search strategy

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. 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 can be provided by contacting the corresponding author).



PRISMA 2009 Flow Diagram



2.2. Study selection

2.2.1 Eligibility criteria

All study designs were suitable for inclusion. Empirical studies of people with dementia and/or their family carers using Global Positioning Technology were included. We excluded studies that only assessed electronic tracking or radio transmitter systems as these are completely different technologies from GPS-enabled devices. We also excluded studies not published in English and were only available in abstract form.

Data extraction

Studies were eligible if they focused on the use of GPS by individuals and families affected by dementia living at home. Where studies examined multiple settings (such as care homes) only results specific to participants living at home were extracted. 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, 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. All papers included in this review were read to synthesise overarching themes.

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 42. These papers were then read in their entirety and a further were excluded. A total of 23 papers were deemed to meet the inclusion criteria and were retained for the final review.

Findings

Methods, participants and technologies

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 (Oderud). The smallest study reported on one dyad case – a man with dementia and his wife (Faucounau et al., 2009). Of the 23 papers, fourteen involved people with dementia as research participants.

Eight of the studies involving people with dementia as research participants were pilot or exploratory studies designed to assess the feasibility of using a particular GPS system with people with dementia. Three reported on single-case studies, one was an interview study, and two used mixed methods combining field experiments and interviews. The large Norwegian study monitored peoples' usage of GPS for two years between 2012 and 2014 using interview and observational techniques. All studies included people with mild to moderate dementia.

One research study had planned to interview people with dementia but considered it inappropriate due to the severity of cognitive impairment (Dale, 2010).

Nine papers involved family and/or professional carers only. Four of them were interview studies, two used mixed methods and three were surveys.

Some studies included results pertaining to other technologies (such as radio frequency transmitters and assistive technologies more generally) or other groups (such as engineers).

These results were not synthesised and are therefore not reported in this review.

Data were synthesised across common themes found, which were:

1. Using GPS to prevent harm and promote wellbeing
2. Taking control
3. Value of GPS data

Using GPS to prevent harm and promote wellbeing

Most of the articles reviewed found that using GPS technologies prevented harm and promoted wellbeing (Milne et al., 2014)Wan, Landau, Olsson). Thygesen, H; Moser, I; Oderud, 2013). These were intervention studies, which had 'safer walking' - defined as walking independently by managing perceived risks (Milne et al., 2014) - and wellbeing for the person with dementia and/or their spouse as outcome measures (Hettinga, Boer, Goldberg, & Moelaert, 2009) Olsson, Engström, Asenlöf, Skovdahl, & Lampic, 2014).Pot, Willemse, & Horjus, 2012. Rasquin, Williams, deVlieger, Geers, & Soede, 2007). Evidence suggests that physical harm is prevented because a person can be found more quickly when they are wearing a GPS device than when they are not wearing anything (Milne et al., 2014). One study compared a radio transmitter with GPS system and found the latter to be more reliable in providing a position as soon as it was requested (Bulat et al., 2016). Additionally, the audio function can be used to warn the person about something and thus prevent an unsafe situation (Hettinga et al., 2009; Rasquin et al., 2007).

Safety is a critical concern for people with dementia, particularly in outdoor environments (Lin et al, 2015). There is strong evidence from people with dementia, as well as carers that staying safe is considered more important than protecting autonomy (White & Montgomery, 2014) or privacy (Oderud, et. al. 2015: 5). A clear example of how using GPS can save a person's life was found in the grey literature, in a report on a two-year trial to test a GPS

tracking device, and involving twenty patients from the Thames Valley and Somerset areas in the UK. One of the participants said:

“Our home is surrounded by fields so before we used the tracker it was very difficult to find where Peter had gone if he was late coming home. But using the tracker I found it gave very accurate results and told me exactly where he was and even which way he was heading!”

The idea that GPS use can provide ‘protection of life’ is highlighted in the study conducted in Israel (Landau, Auslander, Werner, Shoval, & Heinik, 2010a: 413). Even though, a person needs to be wearing a device for it to ensure their safety; a point that is raised in these and other studies.

One paper focused on compliance rates in GPS studies, and concluded, based on a sample of 39 healthy older adults, and 39 older adults in cognitive decline, that both groups are generally compliant when it comes to using GPS devices (Isaacson, Shoval, Wahl, Oswald, & Auslander, 2016). However, some functions (such as warning sounds) are considered unhelpful by participants (Hettinga, et al, 2009). In which case someone is likely to take the device off, or not want to wear it, which is what happened in a study where participants were not meant to take a watch off at night but they did (Isaacson et al., 2016). The physicality of a GPS device can be perceived negatively too; so poor design can cause harm. For example, in one study the plan was to test the GPS device with a married couple for one month but it only lasted one day because the couple found the device too big and ‘ugly’ (Faucounau et al., 2009). In another study, carers said the weight of the device was a problem (Chen & Leung, 2012). GPS is not therefore a completely effective option for staying safe. From a critical disability perspective, it is noteworthy that none of these studies referred to a person’s right to

access public spaces. Although, some attention was paid to how people with dementia feel about using GPS technologies.

Recent studies have begun to highlight how the use of GPS promotes the psychological wellbeing of people with dementia. Knowing you can be located means a person can go out without worrying as much. In one small-scale experimental study involving three Swedish men with dementia, it was found that the use of GPS technologies led to an ‘increased frequency of independent outdoor activities’ in all three cases (Olsson, 2015). Another pilot study conducted in the Netherlands found that people with dementia experienced a greater ‘sense of freedom’ when using GPS (Pot, Willemse, & Horjus, 2012: 131). According to the Norwegian study, families may need to consult with professionals about how to use GPS in the ‘least intrusive’ way, otherwise there is a risk of damaging rather than promoting psychological wellbeing (Oderud et, al, 2015: 6).

Taking Control

From a critical disability perspective, ‘independence is not about doing everything for oneself but about having control over how help is provided’ (Morris, 2001: 17). The question about who should take control and make the decision about using GPS technologies is emphasised in several papers. One survey study involving 296 respondents found that the spouse of the person with dementia was considered to be the most appropriate person to decide (Landau, Auslander, Werner, Shoval, & Heinik, 2011). Elsewhere, the same researchers suggested that GPS technologies were favoured because they afforded caregivers a high degree of control over the person with dementia (Landau, Auslander, Werner, Shoval, & Heinik, 2010b). How

a carer might assert control was highlighted in another case-study, which described a son hiding the GPS device in his mother's handbag (White & Montgomery, 2014). In addition, in the single dyad case study, it was reported that the person with dementia was happy to relinquish control to his carer (wife) who assumed the authority to decide about using GPS (Faucounau et al., 2009). These data suggest that GPS technologies afford control to carers (rather than the person with dementia), which raises questions about whether the opinions and rights of people with dementia are recognised enough.

In common with people with other disabilities, people with dementia need help and support to use technologies. Such assistance should be reliable and competent and grounded in respect for the disabled person (Morris, 2001). In this review, we found that the involvement of health professional was regarded as essential (Hughes, Newby, Louw, Campbell and Hutton, 2008). However, in another study, researchers found that clinicians are reluctant to intervene and recommend GPS technologies as it can sound like monitoring (Landau, et al, 2000). In other work, researchers have found that family carers play an important role in relation to implementation of GPS (Thygesen, Moser and Oderud, 2013) and value being able to consult with other family members when making a decision (Milne & McKinstry, 2012) or healthcare professionals (White & Montgomery, 2014). Clearly, assistance is not reliable, and why a focus on disability rights and self-advocacy is so important in the context of persons with dementia (Shakespeare, Zeilig and Mittler, 2017).

A critical disability approach means looking at the barriers to people receiving the assistance they need. Based on this review, it would seem that access to GPS technologies is not easy or universal. For example, in a study conducted in Norway, it was highlighted that there is no single service provider and so 'it is somewhat arbitrary what sort of equipment is obtained'

(Dale, 2010: 304). Similarly, a study conducted in Scotland found that only 20 devices were offered to clients over an eight month period, when social care staff expected the number to be more in the region of 50 given the number of people on the caseload (Milne & McKinstry, 2012). Although no studies examined the provision of GPS devices by local authorities, one paper highlighted how the ‘mixed economy’ landscape means that formal service provision does vary and is supplemented by ‘off the shelf’ technologies (such as GPS-enabled key fobs and smartphones) (Gibson, Dickinson, Brittain, & Robinson, 2015:1). These findings suggest that there are economic and attitudinal barriers to people with dementia accessing GPS technologies.

Value of GPS data

Digital information is potentially useful in a disability rights sense, as it can provide different people with valuable and reliable information. This is especially important in the context of dementia, as due to the nature of the impairment, people with this disability are often not seen as reliable informants (Bartlett, Balmer and Brannelly, 2016). Five papers reported on how data provided through GPS technologies can provide valuable real-time, accurate information about a person’s spatial behaviour and walking trips (Isaacson et al., 2016) Shoval et al., 2010) (Lin et al., 2015) . These papers focused on the use of GPS to investigate out-of-home behaviour by people with dementia. In one of the studies, 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’. Wandering was defined in this study as ‘traveling to semantic places or along old routes with a different sequence inside the historical traces’ (Lin, et al, 2015: 74) – so whenever a person makes a lot of direction

changes, which they have never made before, and visits a place, which they have never visited before. Such information pinpoints the moment when someone is technically ‘wandering’ and at risk of getting lost. This is potentially valuable data for not only researchers but also people with dementia themselves, as well as health care professionals.

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 (Isaacson, et al, 2016; Oswald et al., 2010; Shoval, et, al, 2010; Wettstein et al., 2012). 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 objective than verbal reports from family members or health care staff. From a critical disability perspective, such data could assist people with dementia to self-advocate, as they would have reliable knowledge about their lives.

Discussion

This review of 23 papers was undertaken to identify gaps in current understanding about the use of GPS technologies by people with dementia living at home. With increasing numbers of people with dementia living at home and increasing acceptance and usage of digital devices, the use of GPS technologies (amongst others) is likely to expand rapidly. Overall, evidence is strongest about the use of GPS technologies for averting harm and promoting wellbeing. It has been the first systematic review to analyse the use of GPS by people with dementia through a critical disability lens. Hence, the perspective of people with dementia

has been centralised and **disability rights and self-advocacy** have been highlighted. 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. However, the current review found no evidence that GPS technologies were conceptualised as, or provided to protect a person's right to live in the community.

Taking the perspective of people with dementia

The review has highlighted how the perspective of people with dementia is not routinely taken, and when it is taken, it is not contextualised within broader barriers. Many of the studies reviewed prioritised the feelings and opinions of either family carers or health professionals, instead of people with dementia themselves. The same bias was found in a previous review of the literature on use of assistive technologies (Topo, 2009). This is problematic; as it means our understanding of GPS use is informed by those without dementia. Evidence is still weak about the value of using GPS technologies from the perspective of people with dementia. This presents challenges for those in the industry who are manufacturing devices, as while caregivers may find devices simple to use, a person with dementia may not (Gibson et al., 2015). The next tranche of work on this topic should take the perspective of people with dementia themselves.

Lack of definitive evidence

This review only found non-trial evidence. There is a lack of large-scale intervention studies. The suggestion to evaluate the use of GPS technologies using a randomised experiment has already been made (Milne and McKinstry, 2012). Unless and until trial evidence is available,

there is unlikely to be wholesale prescription of GPS technologies by clinicians or service providers. However, people are increasingly using ‘off the shelf’ technologies (Gibson et al., 2016), as the market is awash with GPS-enabled location devices and not everyone with dementia will need or want a full scale GPS-enabled care system that involves call centre support. As other researchers have pointed out, ‘the heterogeneity of caregiving contexts means solutions must be flexible and creative’ (Wan, Müller, Wulf, & Randall, 2014). Therefore, any future large-scale studies need to take account of the range of GPS technologies that are available and the informal arrangements that individuals and families may already have in place.

Potential value of GPS data to improve care practice

The review has highlighted the potential value of using GPS data to improve care practice and assist people with dementia to take control of their lives. We have found evidence that GPS data is valuable for researchers, but the accuracy of information provided by GPS systems (such as walking speed and distances) could be useful for care providers as well. For example, we know that the mobility and nutrition needs of people with dementia often go unmet in the community (Eichler et al., 2016); possibly because care providers lack the information they need (about mobility and energy levels) to determine what a person’s needs might be. GPS data could be used to provide this.

Limitations of the studies reviewed

A few limitations should be noted. First, due to the exclusion criteria, some relevant information may have been missed. Second, the studies identified varied greatly in scope and quality. Most of the studies were small-scale and some provided very little information about the system being trialled.

Conclusion

Our systematic review revealed a growing interest in the use of GPS technologies by people with dementia. Earlier studies focused on the ethics of using such technologies to reduce ‘wandering’. However, we found no evidence to suggest that the rationale for using GPS technologies has ever simply been about monitoring the whereabouts of a person with dementia. More recent studies - those published from 2014 onwards - focused on the use of GPS technologies as a practical intervention for supporting people with dementia to live at home. People with dementia have a right to live in the community, and there is a proliferation of GPS-enabled technologies (such as Smartphones and watches), indicates a possible need for more research into how people with dementia and their families are using and integrating GPS-enabled technologies into their everyday lives. Future work should take an enabling approach and focus on the value of using GPS technologies from the perspective of the person with dementia. Moreover, attention should be paid to the relational aspects of upholding rights and promoting self-advocacy, as dementia is a progressive disability that affects cognition. As such, the power dynamics between family members, health professionals and people with dementia are important to understand during the inclusion process. Finally, the lack of definitive evidence that GPS technologies saves lives presents a challenge to clinicians and service providers, looking for guidance on service rationing and commissioning.

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