

Presentation of the author

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Realising disability-rights in dementia care: Using location technologies as an example

Summary

As the number of people living with dementia grows across the world, finding solutions to complex situations is becoming more and more urgent. One such situation is supporting people with dementia to walk outdoors even though the condition can affect way-finding and communication abilities. In clinical discourse this situation is typically framed in terms of people with dementia ‘wandering’ and solutions are aimed at caregivers, rather than the individual with dementia. In this paper I argue for a disability rights perspective, where the citizenship of the person with dementia is central and particular care arrangements are situated within a broader socio-political context. Such a shift involves acknowledging a person’s rights to mobility and social inclusion and understanding relations between individuals and between individuals and service providers. In my view it is only by making this shift that the full potential and parameters of location technologies in the care of citizens with dementia can be researched and realised.

Realising disability-rights in dementia care

The number of people diagnosed with dementia in 2015 worldwide is estimated at 46.8 million, reaching over 74 million by 2030 and 131 million in 2050 (Alzheimer's Disease International, 2015). Dementia is commonly seen as an individual medical problem and those living with the condition are regarded as 'patients'; however, dementia is also a disability and individuals are citizens with rights, as well as care needs. For example: people with dementia are protected by the UN Convention on the Rights of Persons with Disabilities, which came into force in 2008; a Charter of Rights for People with Dementia and their Carers in Scotland has been developed by Alzheimer's Scotland; and there is currently a campaign led by Alzheimer's Europe to establish a European Charter for the Rights of People with Dementia. Moreover, the World Health Organisation has long held that the key to reducing discriminatory practices in this area is recognition of the rights of people with dementia and their caregivers. The importance of rights in dementia care has thus been established and the desire to realise these is growing. Nevertheless, disability rights are not routinely referenced or utilised in everyday healthcare practice; where the focus is invariably on managing individual problems and alleviating the 'burden' of caregiving.

That said the discourse of rights does enter into dementia care discourse; most notably those arenas where ethical and legal concerns are most apparent. Like, for example, the use of Global Positioning Systems (GPS) or location technologies, sometimes (perhaps unhelpfully) called 'tracking devices'¹. GPS with people with dementia is ethically controversial and divides opinion, particularly amongst the medical profession. Some see it as an infringement of a person's civil liberties (O'Neill, 2013); whereas others consider it an

¹ Location technologies use 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 subterranean or underwater locations, a GPS system can locate a person wherever they are.

effective means of maintaining a persons' safety (McShane, 2013). Others have suggested that the use of GPS in dementia care 'raises more than a few human rights concerns' (Eltis, 2006: 393). The use of location technologies makes for a useful exemplifier then, when discussing the topic of realising disability rights in dementia care.

Use of location technologies in dementia care

Walking outdoors and 'getting out and about' is a common and valued activity for people with dementia. Evidence suggests that walking outdoors is beneficial for people with dementia, because it can engender a sense of self-worth within individuals (Olsson, Lampic, Skovdahl, & Engström, 2013) and help to extend the period of quality life for families (Duggan, Blackman, Martyr, & Van Schaik, 2008). However, dementia can affect a person's way-finding abilities and so leaving the house to walk outside is not without its risks for individuals with this condition.

Of the estimated 500,000 people with dementia in the UK who live in their own homes, 40% may get lost at some point, and about 5% (25,000) may get lost repeatedly, doubling their risk of admission to expensive long term care (McShane, et al. 1998). Half of all people with dementia who go missing for more than 24 hours die or are seriously injured; increasingly the police are called out to search for people with dementia who go missing, causing distress for the families concerned and a financial burden for the police force involved. In the UK, it has been estimated to cost between £1325 and £2415 for an average missing persons investigation (Greene & Pakes, 2012).

Location technologies are increasingly used to mitigate the risks and costs associated with walking outside for people with dementia. Products such as the EASE bracelet, which combines GPS with activity monitoring, and buddi technology, which can locate the wearer, are being issued to individuals and families affected by dementia by police forces and local authorities. 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. However, GPS systems are expensive and evidence is weak as to their effectiveness for promoting safer walking, defined as ‘walking outdoors unaccompanied by a caregiver with minimal risk of becoming lost or experiencing anxiety’ for people with dementia (Lindsay et al., 2012). Moreover, as more and more products flood the market, deciding which one to use is likely to become increasingly complex, especially as there is no single source of practical guidance available to guide either families or professionals in the decision-making process.

As well as practical and financial considerations, individuals and organisations are using technologies amid the ‘ethical controversy’, which in itself can be stigmatising (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). The issuing of technologies for safer walking by statutory agencies raises even more moral questions, particularly in relation to the legitimate scope of regulation, and regarding the essence of claims about civil liberties in the first place (Coggon, 2011). This is a significant point, as family members’ possession of personal information (e.g. where someone is), is a distinctly different matter to statutory agencies’ access to the same.

Research on the topic of location technologies is burgeoning but it invariably takes a biomedical perspective. Thus the emphasis is on how the GPS technology can help to manage clinical problems and reduce ‘caregiver burden’. For example, researchers report that GPS systems can be used in dementia care settings to ‘manage wandering behaviour’ (Kearns et al., 2007), reassure caregivers (White, Montgomery, & McShane, 2010), and mitigate the risks associated with getting lost (Plastow, 2006). In other words, the technology is seen as a potential way of managing individual patients rather than realising a person’s rights or

overcoming societal barriers to inclusion (such as a lack of signage). Evidence of its value for realising a person's rights is extremely limited.

Another feature of the GPS dementia research is that it tends to take the perspective of family and professional caregivers (e.g. Landau, Werner, Auslander, Shoval, & Heinik, 2009). The voice of the person with dementia using the system is noticeably absent. For example, the study by Landau et al. (2009) sought to examine the ethical aspects of using GPS technology for people with dementia by exploring the attitudes of family and professional caregivers towards this technology. They conducted four focus groups; one comprising of experienced group facilitators of the Israel Alzheimer's Society ($n = 20$); another included health and social care professionals from a psychogeriatric team ($n = 12$), and two family care-giver groups ($n = 22$ and $n = 14$). They found, with one exception, that family caregivers did not have an ethical problem with using GPS if it protected a person from harm; however, professionals were 'reluctant to intervene' and recommend GPS on the grounds that it invades a person's right to privacy (p. 16). Similarly, a small-scale qualitative project by White, Montgomery, & McShane (2010) examined the views of family caregivers about using GPS to locate a person with dementia. For this project, 10 carers were interviewed and the researchers found that people 'preferred to use GPS as a back-up to other strategies' (p 152); however, professionals reported feeling uncomfortable and ill-equipped to educate individuals and families around appropriate usage (p. 157). Other research confirms that attitudinal issues, ethical concerns, as well as a lack of training and information, are the main barriers to professionals prescribing technology that may be needed and desired by individuals living with ill-health in the community.

More recent research has involved people with dementia and found that location technologies are used in different ways by different people (McCabe and Innes, 2013). This finding is backed up by a number of small-scale pilot projects undertaken by various

organisations, exploring the use of location technologies with people with dementia. For example, Fife Council in Scotland trialled the use of GPS with people with dementia and their carers, and found it enabled the person with dementia to walk independently outdoors and reduced carer stress and anxiety when the person did so. Similarly, the Dementia Friendly Communities Project in rural Scotland evaluated the use of GPS with two families, both of whom found it beneficial as it gave them the ‘freedom to roam’. There is some evidence, then, that GPS technologies can be helpful for people with dementia and their families.

Investigating the use of location technologies through a disability-rights lens

As discussed previously a disability-rights lens is rapidly becoming part of the improving dementia care agenda. With location technologies this means examining the system from the perspective of the person with dementia, and situating care arrangements within a broader socio-political context. So, rather than pathologising a situation, the emphasis is on whether a device can mitigate impairment effects, uphold a person’s rights, and help overcome societal barriers. When researchers have taken the perspective of people with dementia they have found that people want to see and comment on devices to aid with design development (McCabe and Innes, 2013). However, no research to date has systematically and explicitly explored the use of location technologies through a disability-rights lens.

Such an approach involves not only acknowledging a person’s rights to mobility and social inclusion, but also understanding relations between individuals and between individuals and service providers. It recognises the crucial role of relationships and networks in realising disability-rights.

Conclusion

Location technologies have a role to play in dementia care. Evidence is mounting as to the value of GPS for promoting independence and improving familial relations. In this article I

have argued that further research should adopt a disability-rights lens so the barriers in society to safer walking can be identified and ethical and legal concerns can be unravelled and resolved.

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