

Title: Is Big Brother Watching You? Responding to Tagging and Tracking in Dementia Care

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The increased availability of assistive technologies, particularly tagging and tracking technology, raises questions for occupational therapists working in dementia care. As experts in environmental adaptation to support participation, occupational therapists need to be clear about what technologies are available to address wandering behaviour, how emerging technologies will be used in their practice, and how they will proactively respond to the ethical issues involved in these technologies. Their use within ethical, person-centred practice will ensure that big brother is not watching, but rather supporting independent functioning in the person's own home.

Introduction

Assistive technologies supporting people with dementia in their own homes are becoming increasingly available to occupational therapists. Of these, tagging and tracking technology is arguable the most controversial. As experts in risk assessment, the home environment, and the use of a wide range of adaptive strategies to support participation, occupational therapists are ideally placed to advise on and prescribe tagging and tracking technology. In determining our response to this technology, occupational therapists need to examine the problems that are caused by wandering, understand what technology is available and start to consider the ethical questions this technology raises.

Problems caused by wandering

'Wandering', one behaviour problem associated with dementia, is one issue most frequently identified as problematic by carers (Corcoram and Gitlin 2001). Wandering is a complex behaviour involving walking-type movements that include rummaging, walking around the home, and going out doors (Dewing 2005). People who wander are typically younger, have a greater level of cognitive impairment, are more commonly male, have a higher incidence of sleep problems and had a more active lifestyle prior to the onset of the dementia illness (Lai and Arthur 2003).

The increased risks associated with wandering include increased risk of falls (Katz et al 2004), risk of damage in the home, the risk of becoming lost, and the risk of injury or death (Beattie et al 2005; Shinoda-Tagawa et al 2004). People who wander have a higher level of use of psychotropic medication (Lai and Arthur 2003). For carers and professionals, wandering behaviour increases the need for surveillance and intervention (Ward et al 2003), and increases caregiver burden (Miyamoto et al 2002).

Tracking and Tagging technology available

Occupational therapists play a key role in assessing these risks of wandering in people with dementia and in implementing interventions such as activity programs, behavioural modification and environmental adaptation, none of which has been shown to be more effective (Lai and Arthur 2003). Three areas of telecare technology have emerged that offer increased effectiveness in the assessment and reduction of wandering (British Geriatric Society 2006).

The first, tagging technology, is a wrist or ankle tagging device emitting an alarm when the person with dementia leaves the designated safe area (Welsh et al 2003), thereby limiting the person with dementia to their own home or garden area (BBC 2004). Carers can be alerted by specific pager messages. This technology is significantly reliable and effective (Miskelly 2004). The second, satellite tracking (GPS), includes either a similar fitted ankle or wrist device, or tracking through a mobile telephone (BBC 2004). Information held by a central control centre provides concerned carers with the whereabouts of

the wearer within 5 metres. The third, infra-red technology, emits an alarm if the person with dementia does not move in the house, does not return home within a pre-determined time, or goes out at an unexpected time (e.g. late at night).

At face value, these technologies may be a way of creating a more secure environment (Welsh et al 2003) and offer the potential to increase freedom of movement and independence, reduce drug use and reduce carer stress (Alzheimer's Society 2004). However, it is not these technologies themselves that pose the problem, but failure to question the ethics around their use (Eltis 2005).

Ethical Issues for Occupational Therapists

Tagging and tracking technology raises human rights concerns in the areas of liberty, privacy, potential equality and dignity (Eltis 2005). People with dementia's basic human rights are at risk for three reasons. Firstly, they fall within three of the most commonly marginalised groups in society - they are older, generally female and have mental health concerns. Issues around maintaining their rights and liberties are therefore not a 'hot topic' for political and public debate. Secondly the more concrete and measurable rights to physical health and safety overshadows their rights to dignity and privacy. Finally, often any abuse that does happen is unintentional and unconscious, occurring as a result of the well meaning of family carers and professionals (Eltis 2005).

Debate within the medical profession around the ethics of tagging and tracking has been fierce. On one hand opinions have been expressed that tagging technology may increase the liberty and dignity of people with dementia by leading to a timely debate on the restrictions that locked door facilities place on residents (Hughes and Louw 2002; Bail 2003). On the other hand, others suggest that tagging should be limited to babies in maternity units, convicted criminals and animals (O’Niell 2003); and that while technologies other than tagging clearly have a role to play in dementia care, as tagging removes personhood and infringes human rights, it is unacceptable (Cahill 2003).

The College of Occupational Therapists’ Code of Ethics and Professional Conduct (COT 2005) clearly states that ‘Occupational therapy personnel shall promote the dignity, privacy and safety of all clients with whom they have contact’ (p. 4). If we are to advise on and prescribe tracking and tagging technology for our clients with dementia, we need to do this in a way that preserves their personhood and maintains their functional capacity. As assistive technology should be provided when it offers immediate therapeutic benefits, it may useful to consider its potential within the occupational therapy process.

Using Tagging and Tracking in Practice?

Occupational therapists use home visits to develop collaborative strategies to maximise safety and functional capacity for older people living at home (2002). Occupational therapists often assess the risks at home using clinical expertise and reasoning rather than standardised methods of assessment. Tagging and tracking technology may provide us with an opportunity to accurately determine if and how often a person with dementia is actually wandering, enabling a more accurate assessment of the frequency of risky wandering behaviour. As wandering is one of the key behaviours of people with dementia that leads to admission to specialist nursing care (Aud 2004), accurate assessment of risk may enable people with dementia to remain in their homes for longer. The short-term use of tagging and tracking technology that has a specific purpose and that demonstrates a clear benefit to our clients seems to raise less questions than its long term use. As an accurate assessment tool, tagging and tracking technology may also provide us with an accurate method of evaluating the outcomes of our therapy. This could enable both therapists and researchers accurately determine the effectiveness of other, less restrictive, solutions to wandering such as environmental adaptation and provision of meaningful occupation.

The use of tagging and tracking in the longer term at first appears to make sense given the deteriorating nature of the dementia illness. However, if tagging and tracking technology is used in the longer term, the risk seems greater that rights to personal health and safety will be considered above the rights to privacy and dignity. The fact that monitoring of this technology would need to pass from one agency to another would significantly reduce the

person with dementia's privacy while the wearing of a tagging and tracking device in and of itself can be seen as an infringement of the person's dignity, particularly due to its association with prisoners and monitoring of animals. As a treatment tool, tagging and tracking also open the possibility of less frequent contact with health and social care practitioners and increases the risk of even further reductions in staff in long term care facilities. As a treatment tool, tagging and tracking is not a replacement for staff providing good quality person-centred care.

Responding Proactively to Ethical Issues

Although tagging and tracking technology can be useful, it needs to be approached with caution by occupational therapists. In our efforts to reduce the risk of wandering while also maintaining the personhood of the person with dementia, we need to first fully understand the person's behaviour through careful inquiry, negotiation and clinical judgment (Hughes and Louw 2002). As occupational therapists, we then need to consider the least restrictive method of dealing with the problem. If tagging or tracking technology does then appear to be the best option for the person with dementia, and they agree to its use, we need to give careful consideration to the conflicting moral and ethical questions relating to the individual, and address these through comprehensive care planning, close collaboration with carers and joint risk assessment with others involved either in health or social care (Welsh et al 2003). This can be achieved through the introduction of

clear protocols and guidelines that demonstrate good practice (Welsh et al 2003).

Conclusion

This article does not claim to even begin to address the incredibly complex issue of tagging or tracking people with dementia in order to maintain their safety. It rather aims to alert occupational therapists in all areas of practice to the technology that is available, its possible utility within the occupational therapy process, and the ethical and moral problems that are being debated in the wider health and social care literature. Occupational therapists urgently need to contribute to the multidisciplinary research that is needed in this area, in order to ensure that if this technology is used, it is for the maintenance or improvement in function of the person with dementia.

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