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To cite this article: S. Welsh , A. Hassiotis , G. O'mahoney & M. Deahl (2003) Big brother is watching you--the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties, *Aging & Mental Health*, 7:5, 372-375, DOI: [10.1080/1360786031000150658](https://doi.org/10.1080/1360786031000150658)

To link to this article: <https://doi.org/10.1080/1360786031000150658>



Published online: 09 Jun 2010.



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ORIGINAL ARTICLE

Big brother is watching you—the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties

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Abstract

Electronic surveillance has insidiously seeped into the fabric of society with little public debate about its moral implications. Perceived by some as a sinister Orwellian tool of repression and social control, the new technologies offer comfort and security to others; a benevolent parental watchful eye. Nervousness at being watched has been replaced increasingly by nervousness if we're not. These technologies are now becoming widely available to health care professionals who have had little opportunity to consider their ethical and moral ramifications. Electronic tagging and tracking devices may be seen as a way of creating a more secure environment for vulnerable individuals such as the elderly with dementia or people with learning disabilities. However, the proponents of surveillance devices have met with considerable resistance and opposition, from those who perceive it as contrary to human dignity and freedom, with its connotations of criminal surveillance. In addition, they cite increased opportunity for abuse through, for example, the withdrawal of staff and financial resources from the care of people with complex needs. Implementing these technologies, therefore, has ethical implications for human rights and civil liberties. Optional alternatives to long-term and/or restrictive care, in the context of the practical difficulties involved in caring for those who represent a risk to themselves from wandering, demands rigorous exploration of pragmatic questions of morality, with reference to risk versus benefit strategies. Like reproductive cloning techniques, the mere existence of surveillance technologies is morally neutral. Rather it is the use (in this instance that of health and social care settings) to which it is put which has the potential for good or bad.

Introduction

In the clinical practice (SW), I met an elderly woman who cared for her cognitively-impaired husband alone at home, a formidable 24 hour occupation. She devised a failsafe method of ensuring his safety by meticulously embroidering his name and address on all his shirts and jumpers, as he was known to wander. By doing so, she reasoned, he could be brought back by strangers or police, if he lost his way. She could, of course have locked the door, on the rare occasions when she had to leave him, but she recognized his vulnerability if a fire should start and he would be unable to escape. Tagging is not new therefore, only more sophisticated.

A range of systems already exists, which are designed to compensate for disability and promote independent living (Marshall, 1997). These include

the more common gas alarms (to alert when cookers are unlit), thermostats and smoke alarms, to the more sophisticated timer-set magnets on front doors which alert distant carers to night-time wandering behaviour, and reminder systems which prompt people to perform essential safety tasks in the home. In addition, telephone dialling pads with familiar faces rather than numbers demonstrate the vast range and increasing potential for the maintenance at home and normalisation of those who might otherwise be destined for institutional care environments. The Astrid Project (2001), which aims to respond to the needs of individuals with dementia, is one of a number of initiatives with UK and European Union-wide research bases, and includes a demonstration house in Northampton, equipped with the latest gadgetry. The HUSAT team in Loughborough is likewise committed to improving the safety of

vulnerable adults through application of technology (Nicolle & Richardson, 1996). They all deserve praise, and developments could potentially be extended to include people with a severe learning disabilities.

Into this arena, the promotion of surveillance measures in the form of bracelet sensors to alert care staff when a resident tries to leave (tagging), to the more complex (tracking) systems that indicate a wandering person's geographical location might nevertheless appear to some as a step too far on a historical continuum of dehumanising affronts to personal autonomy and concepts of liberty committed against those who have not always been able to speak for themselves (Counsel and Care, 2001; 2002).

Controlling the behavioural consequences of dementia (and learning disabilities) such as agitation and wandering poses serious practical problems (Hughes & Louw, 2002). As inappropriate neuroleptic prescribing in residential and nursing care homes is increasingly recognized (McGrath & Jackson, 1996; Ray, Thapa & Gideon, 2000), could technological measures mitigate against incidences of what might be deemed 'cabin fever', through a greater perceived sense of freedom? Mandatory confinement indoors has been shown to correlate with an increased incidence of physical and verbal aggression and subsequent prescription of neuroleptic medication (McMinn & Hinton, 2000). Medication side effects are common, including hastening cognitive decline, confusion, and increased risk of falls, yet practical alternatives that minimize agitation are often hard to find. The tenet that people should have the freedom to go outdoors or have access to space if they wish, should be written into the care philosophy of every social and nursing home environment, but achieving this worthy aim requires imaginative solutions.

Rights and obligations

As the social climate moves however, towards ever increasing liberal individualism, the probity and accountability of practices within health and social care services are being subjected to unprecedented scrutiny. Against this background of change, we must continually demonstrate a commitment to the highest standards of medical ethics. These attitudes are clearly evident in the National Service Framework for Older People (NSF) (Department of Health, 2001), which presents us with an opportunity to re-examine the procedures and processes by which decisions are made on behalf of all vulnerable members of society. Implicit in the NSF remit is a commitment to tailor services and resources to individual social and health care needs. Reflecting sound moral argument in its intentions, the NSF commits health and social care profes-

sionals to mirror such sentiments and examine everyday practices in order to promote services that maximise independence and good health. 'Specialised services for key conditions' and 'respect, dignity and fairness' for older people and their carers are worthy principles to be maintained, promoted and developed. Could tracking and tagging devices be candidates for consideration in this debate, and what is the legal position?

This changing social climate that puts individuals' needs at the forefront of care planning might favour such solutions. The Human Rights Act (1998) explicitly recognizes individuals' rights to freedom from state interference in pursuit of their personal goals. Public authorities, including Social Services and the NHS, now have an undeniable obligation to identify and provide services that reflect individual needs and which are least restrictive of a person's liberty. Relevant Articles from the Act include Three, Five and Eight. Concepts of inhumane and degrading conditions from Article Three will be open to interpretation, as will the ethos of Article Five, with the Right to Liberty and Security of the Person contradictory in some respects. In some circumstances, a choice between the relative merits of liberty or security, rather than both, with tagging and confinement offering differing forms of liberty and security presenting their own dilemmas. Article Eight (the Right to Respect for Private and Family Life) is equally open to interpretation in certain instances. Privacy is clearly breached in any surveillance process, but if applied with the intention of maintaining a person at home, or free from a locked door in residential settings, where is the greater breach of rights? The principles of the Human Rights Act have been further reinforced by more specific legislation such as the Adults with Incapacity (Scotland) Act (2000) (due to go before Westminster Parliament when parliamentary time allows). These legislative commitments may herald a long-awaited era of increasing attention being paid towards the rights and needs of many, to make a range of decisions for themselves, with the voice of healthcare proxies and of advance directives increasingly dictating the direction and form of care for all those who lack capacity.

Unfortunately, the principles enshrined in existing legislation, though laudable, offer little practical guidance to the clinician faced with a wandering patient and who is considering the use of tagging technology. For mental health professionals, the question arises of whether the application of technological tracking measures constitute a 'treatment' for mental disorder in those who lack capacity, designed to alleviate symptoms and consequences of the disorder and/or ancillary to core treatments. Furthermore, as the law currently stands, it must be shown to be necessary in the 'best interests' of the person concerned, that is, necessary to save life or ensure improvement or prevent deterioration in physical or

mental health (Department of Health and Welsh Office, 1999).

With wandering a passport into residential care for patients with dementia, could some form of warning system delay the trauma of being forced to leave their own home? The changing locus of care from institution to community, with its emphasis on multidisciplinary working and a consumer-led interest in care options has all too often bypassed the dementia sufferer. Many former psychiatric institutions have been reborn in the guise of sprawling highly populated care homes, in some instances run by poorly trained, underpaid and de-motivated staff accorded minimal public sympathy or respect. The 'best interests' of the individual is of paramount importance rather than that of the latter institutions with their paternalistic interpretations of safety and human dignity. Condemning vast numbers of older people to being locked in residential care environments, or at home, with limited prospect of seeing the outside world because of safety fears, might sit easy with our consciences, but that does not make it right, or morally justifiable, if there is the possibility of a less restrictive alternative. Exaggerated (or in some cases realistic) perceptions of risk of harm with subsequent fear of litigation might deter wholesale acceptance of alternative forms of 'security', but if so, then this must be clearly stated, not couched in (immoral) ethical defences. A society free from risk may be seductive, but in reality it is unattainable and would impose unacceptable restrictions on freedom.

Preliminary research

The ethical debate and practical application of surveillance technology has already begun in the area of electronic tagging in its many forms for people with learning disabilities and for those dementia sufferers, with a number of articles and discussion papers, which include the views of carers (e.g., Male & El Komy, 1991; McShane *et al.*, 1994; 1998). These have shown that the latter welcome the possibilities offered by the new technologies. A recent consultation paper commissioned by Age Concern, Mind, Alzheimer's Society, and others, in highlighting a number of ethical difficulties, also recognized the beneficent potential (Charlesworth, 1993). They reasoned that the use of technology could deprive some people of necessary resources rather than enhance their freedom. If staff in care homes can relax their observations and be lulled into a false sense of security by the attachment of bracelets to residents which set off an alarm when they leave, or, worse still, if already low staffing levels are cut further, then electronic tagging might lead to increasingly little need for human contact, and resources. Bentham's Panopticon—the quintessen-

tially efficient prison system that allows total surveillance of prisoners without a thought for them as human beings—must never be permitted to approach reality in caring for those with complex mental health needs.

Conclusion

While the use of technology is clearly still an unknown quantity, and preliminary studies have recognised its limited potential in terms of beneficent outcome and practical application (Male & El Komy, 1991; McShane *et al.*, 1998), we nevertheless find ourselves at a crossroads. On the one hand we have the option of exploring a range of mechanisms for managing challenging dilemmas and creating specialized services for key conditions, or we can become complacent and maintain the status quo. Our current systems of promoting safety and security of vulnerable individuals are not ideal and nor for that matter are the new technologies. We are often given the choice between two or more imperfect systems of care, and it is imperative that we carefully study each for optimal human dignity and freedom, whatever that may be for each individual person. Avoiding Dowie's quoplegic myopia (Dowie, 1994) (the syndrome of seeing weaknesses and deficiencies in current systems, yet becoming blind to them as soon as an alternative is proposed) represents a formidable challenge unless the will exists to embrace change.

The use of tagging technologies requires careful attention to conflicting moral considerations and comprehensive care planning. The use of such technology also demands the introduction of clear protocols and guidelines representing 'good practice'.

As mechanisms evolve for discussion between social and healthcare professional teams, joint mandatory risk assessments take place and full communication and cooperation with carers becomes a prerequisite, an explicit process can be created which identifies those actions producing the greatest balance of benefit over harm for the individual.

Tagging and tracking technologies could, in the right circumstances, offer an increased range of options in maintaining the safety and welfare of vulnerable individuals, whether suffering from dementia or a learning disability. Before their widespread introduction, further detailed evaluation is essential to ensure that the principle of non-exploitation is rigidly adhered to. What is heralded as an opportunity for increased liberty must not degenerate into the denial of basic human rights and dignity.

Electronic surveillance and 'tagging' in particular is most frequently associated in the media with the criminal justice system as an alternative to imprisonment (Bewley, 1998). Regardless of any ethical con-

siderations or clinical merit the use of these measures will inevitably be seen against this background and will almost certainly unwittingly increase stigma and the negative image of psychiatry in the eyes of the public.

Have we been offered the prospect of a better NHS for those most in need, with tagging and tracking technologies? Clearly there is a need for a wider debate about the rights and dignities of a vulnerable population. If we don't accept these challenges now, we will deny our patients the chance of a better existence and fail in our own professional ethical and moral duty.

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