**Ethical Aspects of Electronic Tagging of Dementia Patients**

Pragya Lodha1

Avinash De Sousa2

1Clinical Psychologist, Private Practice Mumbai.

2Research Associate, Department of Psychiatry, Lokmanya Tilak Municipal Medical College, Mumbai.

**Address for correspondence –**

Dr. Avinash De Sousa, Carmel, 18, St. Francis Road, Off SV Road, Santacruz West, Mumbai 400054. Tel - +91-9820696828. E-mail – avinashdes888@gmail.com

Sir / Madam,

Dementia is one of the commonest neuropsychiatric disorders seen in old age with behavioral and psychological symptoms being seen in many patients which may include memory loss, aggressive behavior, sleep problems and wandering away behavior with confusion (1). Many patients with dementia may be all alone at home with a domestic help and no caregiver for most of the day and may sometimes wander off from their house without the knowledge of caregivers and in the presence of caregivers. Hence, dementia care programs insist that an identity card with the patient’s name, address and phone numbers of immediate relatives always be put in with person in the advent that he / she wanders away and is unable to relocate their way back home or answer people about his / her details when needed to help them get back home (2). A medical company in India recently launched an electronic tagging device which could help relatives track the whereabouts of dementia patients on their mobile phones and whereby relatives would get an intimation about the person leaving beyond a certain perimeter of the home address, which would have been fed into the device. This would help locate the patient in case of any wandering away behavior.

The following letter wishes to put before the journal some of the ethical dilemmas involved in the electronic tagging of dementia patients. Some of the ethical issues arising are as follows –

The first ethical dilemma is, one being drawn between the complexity of safety of the dementia and the civil liberty restriction aspect of human rights by tagging. We may argue that electronic tagging is far better than the rights of dementia patient as tagging would provide for an excellent source to track if there would be any violation of the person (with dementia) who may get robbed or attacked, or were found alone or on a lonely road along with the chances of an accident occurring. It has been documented in studies that patients with wandering behavior that have been tagged have been found faster than those whose whereabouts were unknown. In fact, tagging may also allow greater mobility of freedom while some privacy of the patient may be curtailed. Tagging may help reduce the anxieties of the caregivers and relatives, both in a home-based and nursing home setting, also allowing mobility and freedom to the patient. Respectfully, electronic tagging is like wearing a waist band and is far better than a patient with dementia being restrained in a nursing home due to wandering away behavior (3).

Who takes the decision for electronic tagging and when does it be installed? Does the first instance of wandering warrant tagging or is it installed after repeating wanderings? There are no guidelines for the same. When patients with dementia lack total capacity, the relatives make this decision but the dilemma arises when we have patients with dementia with partial decision-making capacity and whether they be involved in such decisions. Does the decision entail more of the patient’s interests or rather more peace of mind for the relatives and caregiver? Tagging may be the least restrictive method of preventing wandering away but would it also make the caregiver less alert and vigilant considering that the alarm would beep in case of wandering away (4).

It has also been insisted by some authorities that wandering, where the person does not get lost, may yield benefit to people with dementia by providing a form of exercise and an enhanced subjective sense of independence (5). The recent positive psychology approaches to dementia have imbibed the concept of personhood and more recently, citizenship. The aim is towards a positive, holistic and active construction for people living with dementia. The tagging intervention is thus on one hand positive as it takes into account these developments and preserve independences with the positive aspects of wandering (6).

The electronic tagging system in India may have social and cultural implications. Many people may feel that the idea of tagging patients with dementia is like tagging of criminals or animals. Many patients with dementia in India are kept in locked doors and a wandering episode can often precipitate a patient’s placement into residential care or dementia homes. Assistive technology, like electronic tagging may increase the chances that the patient is kept and managed at home. Greater freedom of movement and independence while providing psychological relief for relatives and caregivers. There will be a need for a 24-hours call centers for monitoring these devices and tracking them and resources for the same are scarce in our country (7).

There is also a thought that tracking systems may cause caregivers to pay less attention to dementia patients as they now have the ease of tracking and they may spend less time interacting with patients. Patients with dementia need social interaction to have a better quality of life and dependence on electronic tagging may be a tad detrimental to the patient’s quality of life. Clinicians and caregivers must note that tracking methods should never be a substitute for quality care and the fostering of meaningful relationships in patients with dementia (8).

Another worry that ensues is the use of GPS tracking technology and the personal information by linking personal and google accounts to the same. This information may be used by companies electronically to constantly bombard caregivers with dementia information such as dementia care products and dementia care homes as happens via Google account-linking and Facebook account-linking. By use of such devices our information may be strewed over databases that may worry us with emails and various offers on various products and similar messages may be received on our phones, which raise questions on the privacy concerns for caregivers (8).

The last aspect of electronic tagging that remains is testing it in randomized controlled trial. There are small anecdotal case studies and case series but no trials of its efficacy. Though there are no safety issues noted so far, the efficacy is difficult to be reliably established unless such trials are undertaken. Nursing homes and old age homes where multiple wandering incidents may happen in a day is the best place to try such devices. Having weighed out the pros and cons of the device, it is rather inevitable to consider that the term ‘electronic tagging’ does raise privacy and human rights concerns, however, it must be kept in mind that individuals using smart phones, more than often use ‘location services’ for safety purposes (for example- parents keep a location track of their children; friends and colleagues share their location while in late night taxi rides or travelling to novel places or places marked as relatively unsafe; live location is also shared these days to keep a track of estimated time of arrival (ETA) for friends and colleagues; sometimes even for helping people with the location to a particular place). These location services are used for safety purposes. The chances of missing someone’s location does not necessarily make the caregivers lax because these chances are and can be reduced by switching on alerts that are provided by the applications either in terms of notifications or messages.

This is a technology that needs to be tested as in comparison to locked rooms, physical restraint and sedation, it is the least restrictive method of handling wandering behavior (9) and RCTs can provide with real-time efficacy in order to understand its application for the masses. Ambitiously, we also suggest that changing the terminology to replace the word of ‘tagging’ can also help perceive the device more acceptable and user-friendly.

**REFERENCES**

1. Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. The global prevalence of dementia: a systematic review and meta-analysis. *Alzheim Dement.* 2013 Jan 1;9(1):63-75.
2. Dias A, Dewey ME, D'Souza J, Dhume R, Motghare DD, Shaji KS, Menon R, Prince M, Patel V. The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. *PloS One.* 2008 Jun 4;3(6):e2333.
3. Miskelly F. A novel system of electronic tagging in patients with dementia and wandering. *Age Ageing.* 2004 May 1;33(3):304-6.
4. Bail KD. Electronic tagging of people with dementia: devices may be preferable to locked doors. *BMJ*. 2003 Feb 1;326(7383):281.
5. Robinson L, Hutchings D, Corner L, Finch T, Hughes J, Brittain K, Bond J. Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health Risk Soc.* 2007 Dec 1;9(4):389-406.
6. Baldwin C, Donnelly S, Downs M, Hulko W, Keady J, Manthorpe J, Harrigan M, Hall M, Gillett G, Williams S, Tilse C. *Decision-making, personhood and dementia: Exploring the interface.* Jessica Kingsley Publishers: UK; 2009.
7. White EB, Montgomery P, McShane R. Electronic tracking for people with dementia who get lost outside the home: a study of the experience of familial carers. *Br J Occup Ther.* 2010 Apr;73(4):152-9.
8. Welsh S, Hassiotis A, O'mahoney G, Deahl M. Big brother is watching you--the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties. *Aging Ment Health.* 2003 Sep 1;7(5):372-5.
9. Niemeijer AR, Frederiks BJ, Riphagen II, Legemaate J, Eefsting JA, Hertogh CM. Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature. *Int Psychogeriatr.* 2010 Nov;22(7):1129-42.

Acknowledgements – Nil

Conflict of Interest – Nil

Funding – Nil