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Ethics of electronic tagging of dementia patients

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Dementia is one of the most common neuropsychiatric disorders seen in old age with accompanying memory loss, aggressive behaviour, sleep problems and wandering behaviour with confusion (1). Many patients with dementia may be all alone at home with a domestic help and no family caregiver for most of the day and may sometimes wander off from their homes. Hence, dementia care programmes insist that an identity card with the patient's key details be worn, in case the patient wanders away and is unable to return home or inform people about the location of their home.

A medical company in India has recently launched an electronic tagging device for cell phones, to help relatives track the whereabouts of dementia patients beyond a certain perimeter of the home address fed into the device.

We raise here some ethical dilemmas involved in the electronic tagging of dementia patients. These are:

- Weighing the safety of the individual against the restrictions on their liberty, we may argue that electronic tagging may keep the person safe from an accident, or from being robbed or attacked. Studies show tagging has helped to find wandering patients faster, besides allowing them greater mobility. It may help reduce the anxieties of caregivers in a home or nursing home setting. Respectfully, electronic tagging is like wearing a waist band and far better than a patient with dementia being restrained in a nursing home to prevent wandering (2).
- Who takes the decision to use electronic tagging and when it is to be installed? Does the first instance of wandering warrant tagging, or is it installed after repeating wanderings? There are no guidelines for this. When patients with dementia lack total capacity, the relatives make this decision but the dilemma arises when patients have partial decision-making capacity and need to be involved in such decisions. Is the decision taken in the patient's interest or that of peace of mind for the caregivers? Tagging may be

the least restrictive remedy for wandering, but would it make the caregiver less vigilant knowing that the alarm would beep in case of their charge wandering away? (3)

- Some studies find that wandering within limits may provide exercise and an enhanced sense of independence to the individual (4). In light of recent positive trends in psychology, based on the concepts of personhood and citizenship, such devices may help in ensuring a better quality of life for people living with dementia (5).

In India, tagging may have specific social and cultural implications. People may feel that it is like tagging of criminals or animals. However, several patients with dementia in India are kept behind locked doors and a wandering episode can precipitate a patient's placement in residential care. Assistive technology, like e- tagging may facilitate the patient's remaining at home. On the other hand, 24-hour call centres will be needed for monitoring these devices and tracking them, using up the country's scarce resources (6).

- Patients with dementia need social interaction for a better quality of life, and dependence on electronic tagging may result in caregivers spending less time with patients. Clinicians and caregivers must note that tracking methods cannot replace quality care and meaningful relationships in patients with dementia (7).
- GPS tracking technology and personal information revealed by the linking of personal and Google accounts may be used by companies to electronically bombard caregivers with information about dementia care products and shelters and raise privacy concerns for patients and caregivers.
- A final issue is that while there are small anecdotal case studies and case series, no trials have been found for the efficacy of this technology. Though no safety issues have been noted so far, efficacy is difficult to establish reliably, unless randomised controlled trials are undertaken. After considering the pros and cons of this technology, it inevitably raises privacy and human rights concerns. However, it must be kept in mind that individuals using smart phones, often use "location services" for tracking their children or friends for safety during late night taxi rides or travelling to relatively unsafe places; or to provide the location of a particular place. Such use does not necessarily make caregivers lax.

This technology needs to be tested. In comparison to locked rooms, physical restraint and sedation, it is the least restrictive method of handling wandering behaviour (8) and further trials can provide information on real-time efficacy in order to understand its applications. We also suggest that changing the terminology to replace the word "tagging" can also help to perceive the device as more acceptable and user-friendly.

Pragya Lodha, (pragya6lodha@gmail.com), Independent Clinical Psychologist, Mumbai, **Avinash De Sousa** (corresponding author - avinashdes888@gmail.com), Research Associate, Department of

Psychiatry, Lokmanya Tilak Municipal Medical College, Mumbai.

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Paradise under siege: Healthcare elusive under Kashmir lockdown

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"I will never allow patriotism to triumph over humanity for as long as I live."

—Rabindranath Tagore, in a letter to AM Bose, 1908

The famous poet, Amir Khusro, said of Kashmir: "If there is heaven on earth, it is here, it is here, it is here"(1). That heaven and crown of India has been under siege now for over four months (2). Due to the war-mongering of our neighbour, and terrorists playing their gory games for several decades, as also as our incumbent "strong" Government of India—with its brute majority—wanting to rapidly control the situation there, is subduing its own citizens for want of a better war-room strategy to selectively target organised terrorists.

These punitive measures by our elected government don't distinguish between trained criminals and their handlers; and an average citizen, eg a woman in labour (3) or a terminal patient of chronic kidney disease-needing regular dialysis just to see another sunrise (4). By deploying the blunt weapon of severance of connectivity, it wants to isolate everybody regardless of their needs and position. One does not need to be an expert to understand the plight of a snake-bite victim, if he does not reach hospital in time and succumbs to an easily preventable death, due the blockade erected to achieve illusory goals.

Patients and their attendants are reportedly forced to go to Delhi as the public hospitals are running out of stocks of essential drugs. A urologist was arrested when he tried to raise concerns about the plight of his patients (5). A senior

cardiologist, a former Professor at AIIMS New Delhi, was summoned by the investigative agencies, merely on the basis of a text message which they misunderstood, from a patient belonging to a banned organisation (6). The investigative agencies withdrew only when the cardiologist explained the correct meaning of the text message and that he was merely doing what he was supposed to do. An average Kashmiri may not be lucky enough to be cleared so quickly, and may face prolonged harassment.

The authors of the *IJME* editorial on the lack of access to healthcare in Kashmir in the current situation (2) point out that a team of doctors which wants to visit the valley is still waiting for the approval of the Union Home Ministry. Hence, we believe that our Government needs to either rapidly grant that approval or explain to its citizens what stops it from allowing the visit by health professionals offering medical care. The Hippocratic Oath obliges us to save lives regardless of the status or other characteristics of a patient. And when scores of our patients are suffering, how can we ignore their collective plight? All of us want enduring peace, harmony, coexistence, inside and even outside our borders, but in the process no innocent should suffer.

This land of Buddha, Ashok and Akbar has been a continuous source for teaching the philosophy of non-violence and unity-in-diversity to the world for centuries. Today, we need to follow the path shown by them to walk through the present mist. For Mahatma Gandhi, the purity of means was as important as the ends sought to be achieved. On the occasion of his 150th birth anniversary, when our popular Prime Minister has written an editorial in his memory in *The New York Times* (7), we need to remember his message and follow his teachings, not only in our intentions but also in our actions.

Sudhir Kumar Verma (sudhirkrgmu@gmail.com), Associate Professor, Department of Internal Medicine, King George's Medical University, Chowk, Lucknow, UP INDIA; **Nitu Nigam**, (nigamnitu@gmail.com), Assistant Professor, Cytogenetics Unit, (CFAR), King George's Medical University, Chowk, Lucknow, UP, INDIA; **Harish Gupta**, (mdkgmc@gmail.com), Associate Professor, Department of Internal Medicine, King George's Medical University, Chowk, Lucknow, UP 226 003 INDIA

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