



Approach to Management of Wandering in Dementia: Ethical and Legal Issue

Adesh Kumar Agrawal¹ , Mahesh Gowda², Umesh Achary¹, Guru S. Gowda¹  and Vijaykumar Harbishettar³

ABSTRACT

Wandering behavior is one of the most important and challenging management aspects in persons with dementia. Wandering behavior in people with dementia (PWD) is associated with an increased risk of falls, injuries, and fractures, as well as going missing or being lost from a facility. This causes increased distress in caregivers at home and in healthcare facilities. The approach to the comprehensive evaluation of the risk assessment, prevention, and treatment needs more strengthening and effective measures as the prevalence of wandering remains high in the community. Both the caregiver and clinicians need a clear understanding and responsibility of ethical and legal issues while managing and restraining the PwD. Ethical and legal issues especially in the light of the new Indian Mental Healthcare Act of 2017, related to confinement by family members in their homes by family caregivers, seclusion, physical or chemical restraints, other pharmacological and behavioral treatment, highlighting their effectiveness as well as adverse consequences are

discussed. This article attempts to address an approach in managing wandering behavior in PwD in light of MHCA, 2017

Keywords: Wandering, dementia, risk-factors, management, ethical issue

Dementia is a progressive neurodegenerative disorder which affects one or more cognitive domain (concentration, memory, learning and memory, language, executive function, and social cognition) with significant impairment in activities of daily living of a person.¹ With the exponential surge in the elderly population due to decreased mortality rate and high life expectancy rate, there is an increase in the prevalence of dementia that is getting attention worldwide.² As per the World Health Organization 2019 report, each year, 10 million new cases of dementia occur throughout the world, and thus one new case every 3.2 seconds.³ It is estimated that 5.3 million people above the age of 60 have dementia in India in 2020.³ Person with dementia also suffers

with behavioral and psychological symptoms (BPSD). Although it is difficult to estimate the exact prevalence of BPSD, almost all persons with dementia develop at least one BPSD symptom in the course of dementia.⁴

Wandering is considered to be related to aimless locomotion behavior. In 2007, a team of researchers proposed the following operational definition of wandering: “a syndrome of dementia-related locomotion behavior having a frequent, repetitive, temporally-disordered, and/or spatially-disordered nature that is manifested in lapping, random, and/or pacing patterns some of which are associated with eloping, eloping attempts, or getting lost unless accompanied.”⁵ In this manuscript, the authors conducted a narrative review on the prevalence, risk factors, causes, and outcomes of wandering in dementia. Furthermore, the article also discuss the medicolegal and ethical issues surrounding the assessment, comprehensive approaches, and management of wandering in a person with dementia.

¹National Institute of Mental Health and Neurosciences, Bengaluru, Karnataka, India. ²Spandana Nursing Home (Postgraduate Institute, DNB Psychiatry), Bengaluru, Karnataka, India. ³Health Heal Home Healthcare Services, Bengaluru, Karnataka, India.

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Address for correspondence: Guru S. Gowda, National Institute of Mental Health and Neurosciences, Hosur Road, Bengaluru, Karnataka 560029, India. E-mail: drgsgowda@gmail.com

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Prevalence of Wandering in Dementia

The exact prevalence of wandering in dementia varies from study to study due to poor definition of wandering in dementia, complexities in assessments, ethical concerns, and heterogeneous sampling. The Alzheimer's Association estimated that up to 60% of people with dementia would "wander" into the community at some stage during their illness.⁶ The estimates of the incidence of wandering differ, with rates as high as 50% in patients with severe dementia and 63% in people who live in community-based care homes.^{7,8}

Risk Factors and Causes of Wandering in Dementia

Even though wandering is a common clinically recognized behavior, the exact risk factor and cause for wandering in dementia are unknown. Although wanderers do not differ from non-wanderers in dementia by gender, age, and ethnicity, some studies reported it is more prevalent in men younger than other elderly and people of African descent.^{7,8,9} Furthermore, people with Alzheimer's disease and dementia with Lewy bodies (DLB) are more likely than those with vascular dementia (VaD) to wander.¹⁰ Wandering is linked to the severity of cognitive impairment (Mini-Mental State Examination score of 13 or less), including issues with recent and remote memory, time and place orientation, and the ability to react appropriately to a given conversation subject.^{11,12} Persons with Dementia (PwD) on antipsychotic treatment or who had comorbid depression, psychosis, or externalizing behaviors like arguing and threatening were more likely to wander.¹³⁻¹⁵

The causes of wandering are elusive, though hypotheses have been proposed ranging from biomedical to biopsychosocial to person-environment interactions.¹⁴ This includes the following:

1. A neuropsychological or biomedical explanation that relates wandering behavior to visuospatial dysfunction, visuo-constructional disability, or poor topographical memory. This theory is supported by imaging studies that report hypoperfusion in the

TABLE 1.

Risk Factors for Wandering in Person with Dementia

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| 1. Male gender |
| 2. Younger age |
| 3. MMSE<13 with preserved locomotor activity |
| 4. Alzheimer's disease, Lewy body dementia |
| 5. Dementia with significant visuospatial disorientation |
| 6. Agitation |
| 7. Psychotic symptoms |
| 8. Substance use and externalizing traits |

left temporoparietal brain region and reduced glucose utilization in fronto-temporal regions.¹⁴⁻¹⁷

2. A psychosocial explanation that relates wandering to the day-to-day challenges that PwD face to fulfill their physiological or psychological needs. It can be a part of coping with trauma and stress or a means for relieving loneliness and separation.^{14,18}
3. Wandering can be a result of person-environment interaction.^{14,18,19} Other reasons can be the unfamiliar environment to the patient, recent medication changes, the severity of cognitive decline, changes in schedule, and loss while searching for things in need.¹⁹ These are all the most important aspects of wandering as finding. It helps us to relate to and clearly understand how a patient with cognitive deficits communicates with their environment to chalk appropriate solutions.

Outcome of Wandering in Dementia

The consequences of the wandering can vary from minor injury on the body to severe injury and death.^{20,21} The persistent wandering behavior and weak gait and balance have been shown to increase the risk of falls, fractures, and accidents in PwD.^{22,23} It was also found that patients who wander often and are unable to sit down for meals can suffer from malnutrition, weight loss, and fatigue as a result of their high caloric needs.²² In addition, swelling and abrasions, soft tissue injuries, and abnormal body temperature (hypothermia or

hyperthermia) was also observed among eloped dementia patients.²³

Another negative aspect of wandering in dementia is the "elopement." It is described as "leaving one's dwelling unescorted." Elopement occurs not only among patients of long-term care facilities but also among community-dwelling people with dementia.²⁴ The study by Ali demonstrated that eloping behaviors are common even in mild dementia and account for 43.7%.²⁵ The persistent wandering and elopement are linked to the high morbidity and mortality rates among PwD.²⁶ The common cause of death in PwD who wander or elope from the facility is fatal accidental hypothermia, orthopedic injuries, soft tissue injuries, malnutrition, weight loss, and accidents.²⁶ The wandering and elopement associated with possible life-threatening morbidity and mortality are preventable, so comprehensive approaches that include assessing wandering risk are sturdily encouraged by the studies.^{27,28} The other common consequences of wandering are increased caregiver burden, increased cost of care, and increased negative emotions. It also raises the chance of institutionalized care for PwD. The wandering can put a caregiver or a carer's home into potential civil tort claims and regulatory penalties.^{29,30}

Management of Wandering in Dementia

It is a challenge to cope with troubling behaviors of the PwD and hence make the caregiving more difficult. Caregivers must understand that the PwD are not deliberately doing these. Many families insist on using sedation, confinement, and restraints to limit wandering and address the safety concern related to wandering PwD.³⁰ Based on the severity of dementia, the attitude of caregivers, the nature of wandering, and its consequences, management of wandering can be individualized. The mainstay of management remains psychoeducation of caregiver and behavioral management after detailed antecedent-behavior-consequences (ABC) analysis. The management should focus on identifying high-risk patterns, preventing measures to reduce the risk of wandering, and approaches once a PwD has been wandered/eloped.

Risk Assessment

Considering the severe consequences of wandering in dementia, there is a compelling need to assess the probability of wandering in clinical practice. Many studies looked into the different kinds of variables and tools to measure and predict the risk of elopement and wandering. The Algate wandering scale has been developed for the same and comprises 28 questions measuring five-dimensional factors, including persistent walking, spatial disorientation, eloping behavior, routinized walking, shadowing with moderate reliability, and validity suiting at long-term care centers.³¹ However, this needs more refinement and additional clinical and cognitive factors to apply to heterogeneous populations of dementia with wandering behavior. Risk of Wandering (RoW) scale which assess the caregiver report in a retrospective manner, has been constructed and includes nine screening items focusing on cognitive and problem behaviors.³² It showed comparable prediction with other scales but had limitations in the form of higher chance of recall bias from the caregiver and limited evidence among caucasian populations. Jorm et al., 1989, developed the Informant Questionnaire's Performance on Cognitive Decline in the Elderly (IQCODE).³³ This includes a 26-items informant questionnaire evaluating various aspects of memory and intelligence with statistically significant reliability and validity compared to Mini Mental State Examination and is helpful for informants with less or no educational background. Teri et al., have developed a psychometric tool, the Revised Memory and Behavioural Problems Checklist (RMBPC), a caregiver report containing 24 items of questions broadly on three main factors of illness, that is, depression, disruption, and memory-related problems. This scale may predict wandering tendency indirectly as these factors are presumed to be the probable contributing symptoms of wandering behavior.³⁴ Most tools have acceptable reliability and validity; however, the differences in sociocultural and educational background, race, and ethnicity need to be considered. Nonetheless, the clinician's role plays a vital role in judging the wandering behavior

that might not be accessible objectively most of the time in practice.

Psychoeducation

Psychoeducation is the prominent step of management, and it has to be done for both patients and caregivers. Many PwD might have insight into their problems, and hence the patient and caregiver should know about the diagnosis and the extent of the problem. Of the studies, 86% have shown the benefit of psychoeducational interventions. These interventions include multicomponent interventions and have an optimistic impact on caregivers, including benefits in caregiver self-confidence in caregiving and caregiver burnout, although these have less effect on patient outcomes, including the reduction of BPSD.³⁵

Behavioral Interventions

Most of the studies suggest that non-pharmacological strategies have better effectiveness in treating BPSD symptoms than pharmacological measures. Pharmacotherapy produces more side effects; therefore, non-pharmacological therapies are considered the first choice.³⁶ These non-pharmacological strategies should be continued even when there is a need for pharmacotherapy. Various algorithms have been validated to assess and guide for management of BPSD. BPSD-DATE algorithm (Figure 1 shows a modified DATE algorithm for management of wandering behavior in dementia) has been considered an easy algorithm can be used in wandering behavior in dementia. We modified the BPSD-DATE algorithm for approach and management

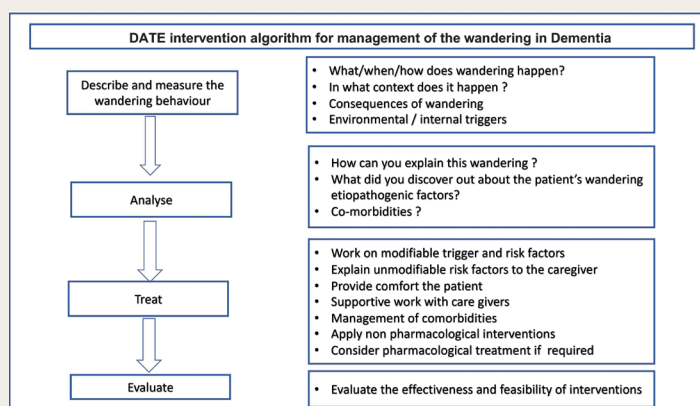
of wandering behavior in dementia.³⁶ Similarly Innovative dementia-oriented Assessment system—version 3 is a comprehensive assessment tool to analyze the challenging behavior. It has seven different domains with 89 items. However, this tool is time-consuming and has been validated only for nursing care home.³⁷ Other modalities of behavioral intervention are distraction therapies (music, walking/exercise), sensory therapies (massage, aromatherapy, multi-sensory environments), physical activity, reality orientation and cognitive stimulation therapy, validation therapy, reminiscence therapy, carer interventions, and environmental modifications.^{38,39}

Physical Barriers/Restraints

Wandering behavior in dementia will increase the chances of both chemical and physical restraints. The identified risk factors, in general, are older age, comorbidities such as cerebrovascular accident, cancer, and depression, impairment in cognition and sensory modality, incontinence, problematic behavior (disruptive, wandering, confusion), medication (antipsychotics, benzodiazepines, opiates, polypharmacy), history of falls, increasing physical dependency, institutional culture, and poor staffing.⁴⁰ The use of restraints to limit PwD wandering has been considered a traditional method, especially in nursing homes and daycare centers. However, recent research advances caution while using restraints.⁴¹ The use of physical restraint can have various consequences from mild peripheral injury of muscle, decreased blood circulation over the site of restraint,

FIGURE 1.

DATE Interventional Algorithm for management of the wandering in Dementia



weakness, joint contractures, constipation and impaction, incontinence, decubitus ulcers, cardio-pulmonary deconditioning, increased agitation and confusion, social isolation, and a loss of autonomy and dignity.⁴¹ Appropriate education of caregivers at home and residential facilities can reduce significant possibilities of using physical restraints. Studies have shown that removing restraints resulted in no major adverse consequences for PwD. It did not increase use of psychotropics or staff deployment or incidents like serious falls or fractures.⁴²⁻⁴⁶ Hence, the focus should be on restraint reduction strategies like individualized management plans and guided caregiver and staff training.⁴⁷

Well-developed Standard Operating Procedures (SOP) and care guidelines coupled with training and support of healthcare workers and family members will help create and maintain a restraint-free environment.⁴⁷ Given the downside of loss of patient autonomy and dignity when using restraints, its use may be contemplated only as a last resort. In India, The Mental Healthcare Act (MHCA) of 2017, advocates limiting the use of “physical restraint” in patient care. It mandates a qualified psychiatrist to order it based on patient’s assessment. If a healthcare professional wishes to administer physical restraint following a psychiatrist’s order, he or she should be trained in administering the restraint and regularly monitor for complications. Even if a healthcare professional wishes to use physical restraint, he or she must follow the SOP or protocols. Physical restraining orders must be communicated to family members and caregivers within 24 hours and communicated with the mental health review board.⁴⁸

Confinement

Confinement is defined as restraining or isolating a person. It can happen at home or in long-term institutional care settings. Confinement of a person with dementia is associated with severity of dementia, neuropsychiatric symptoms like aggression and wandering behavior, degree of locomotion difficulty, awareness about nature of the problem by the caregivers, existing infrastructure, support system, and caregiver burnout. Confinement and restriction of movement in institutional care are determined not only by the form

or severity of dementia but also by the organization’s policy and SOP, and the availability of resources and infrastructure. This method could amount to the deprivation of liberty of the PwD. People with dementia in institutional care expressed dissatisfaction with segregation and locked rooms on online focus group interviews and discussions. Confining patients for prolonged periods to prevent wandering will be counterproductive as confinement is associated with increased agitation, aggression, and nurse-initiated medication use.⁴⁹ Patients desire freedom of movement, exercise facilities, and recreational outdoor and community participation activities.⁵⁰ Unreasonable confinement is considered abuse and neglect. Individuals with dementia have the right to live just like everyone else and have autonomy in their daily lives, so confinement in the institutional care or home cannot be a solution for wandering in dementia. The MHCA of 2017 advocates that confinement can only be used as a last resort when there is an immediate risk to an individual with mental illness. A qualified psychiatrist should only prescribe it. Furthermore, justification for usage, length, and regular monitoring is required for the mental health review board. Physical restraining orders must be communicated to family members and caregivers within 24 hours and communicated with the mental health review board.⁴⁸

Sedation and Other Pharmacological Interventions

Recently, many research studies have looked at non-pharmacological management methods for wandering behavior. Additionally, PwD are particularly vulnerable to adverse effects of drugs and multiple medication groups for other medical conditions, so psychotropics should be used very cautiously.³⁶ Psychotropics are indicated for wandering-related neuropsychiatric symptoms that are not amenable to nonpharmacological methods. Anti-dementia drugs such as donepezil and memantine that reduce BPSD may also reduce the risk of wandering.³⁶ The use of SSRI for depression, anxiety, and atypical antipsychotics

for agitation and psychosis can reduce the severity of problem behaviors and hence the risk of wandering.^{51,52} The frequent and long-term antipsychotic use are associated with movement disorders, diabetes, a higher risk of stroke and mortality, and impaired cognition.⁵³ Regardless of the indication, the fundamental concepts of pharmacotherapy in elderly dementia populations include start low and go slow, monitoring for excessive sedation, and respiratory depression; administering minimum effective dose for a short period; and to be cautious about pharmacodynamics and pharmacokinetic interactions with other drugs, while prescribing any medication.^{53,54}

Electronic Devices (Tagging and Tracking)

Wandering can be encouraged if it is not leading to any risks to a certain extent. The architecture of the long-term care homes specific for PwD must be made suitable for such behaviors, that is, less slippery, lack of obstructions, etc. Those residing in their own homes are at risk of getting lost. Such incidents are gradually increasing. Recent advancements in healthcare technology have resulted in devices that can assist in locating wanderers, detecting wandering behavior, alarming wandering, and assisting in wayfinding. These can aid wandering in people with a cognitive disability, but they have not yet been clinically confirmed. These technologies include using phone applications, piezoelectric pressure mats, Global Positioning System (GPS) watches and wristbands, personal GPS locators, and GPS smart soles.^{55, 56} A review showed that wearable devices, child-safety devices, and ambient noninvasive sensors are the most commonly used devices. And the main reasons for using these devices are for activity detection and monitoring. Using these digital devices can improve dementia care. The cost of the device varies from its type, features, and manufacturer. The use of these devices should be individualized and should be based on need. However, there is a need for systematic research in this particular area on the efficacy of these devices. It allows some freedom to move safely with restrictions and

reduces the need for chemical and physical restraints. When used correctly, it also reduces the risk of elopement and the burden on caregivers. So, it has to be understood that these devices should not become the alternative to behavioral management. It can sometimes give a false sense of security to the security personnel in a residential care home.

Electronic gadgets are associated with a violation of the right of privacy and liberty of the person.⁵⁷ So, clinicians and caregivers should be aware of the right violations associated with the use of electronic devices and evaluating the decision-making of an individual with dementia. If the person with dementia can decide to use gadgets, then their autonomy should be respected.⁵⁸ If a person does not have the capacity, the decision should be for the person's best interests, not just for the sake of person's best medical interests. In general, it is advisable to make this decision in the presence of the person with dementia, caregiver, and a health professional after complete assessments on the need for electronic gadgets with a tracking system in a person with dementia. Additionally, electronic gadgets with tracking systems violate the fundamental rights of individuals, so there is a need for clear guidelines to ascertain good practice based on the law of the land.^{58,59}

Indian Scenario on Wandering/Elopement in Dementia

India is the second most populous country in the world with many cultural diversities. Hence, it is difficult and challenging to trace and find a person with dementia who wanders. At present, we don't have any clear data on the prevalence of dementia in the wandering population from India, either in the community or in government or nongovernment-run institutions. According to National Crime Records Bureau (NCRB) data of 2019, a total of 13,721 elderly people went missing in 2019, with 41.1% of them being traced back via existing legal systems.⁶⁰ In addition to the existing system, NGOs such as the "Missing Senior Citizen Alert Blog" established the Silver Inning Foundation, which works in the search

for missing senior citizens. According to them, 80% of missing elderly people have already been diagnosed with dementia.⁶¹ There is a legal provision under the Indian law to file missing First Information Report complaints under the Indian Penal Code. Section 100 of the Mental Health Care Act of 2017 also has legal provisions for finding a wandering individual, providing protection, and taking them to the nearest health facility to determine their physical and mental health, trace their families, and reintegrate them into society.⁴⁸

In western settings, a police personnel is involved in the search strategy of missing PwD by using high technology such as radio signals to locate the person, uncrewed aerial vehicles such as drones, and the evaluation of a geographically aware information support system to provide a live display of search team positions. Other strategies like educating the public and family members, tactical rules, active identification, and community engagement are adapted. Community-based strategies, such as Silver Alert and the Medic Alert and Safe Return programs, reported successful outcomes in facilitating the return of missing PwD. Silver Alert is a public alert system in the USA for missing PwD. In contrast, Medic Alert and Safe Return serve as identification strategies for those lost and found by someone in the community.⁶²

Way to trace the wandered dementia person in India involves collaborative, an intersectoral approach; it includes lodging complaint in the police station and publishing in media/newspaper by their family. Non-governmental Organizations (NGOs) or police or hospital authority that come across wandering dementia patients try to identify the individual's details by looking at the person's wallet, handbag, packet items, tattoo mark, wrist band, ID card, and so on. When such attempts fail, there is an attempt to trace the person using the thumbprint record of AADHAAR in liaison with the appropriate authority as a goodwill gesture.⁶³ Once contact is established with a family, reaching out to them becomes easy through a home visit or sending a postal letter. Sometimes, using the community resources and technology which can help in finding a wandered person like (a) liaison with Dis-

trict Mental Health Programme (DMHP) multidisciplinary team, (b) local non-governmental organizations (NGOs), (c) children's/women's/elder's helpline number, (d) contacting local temple, mosque, church, (e) using modern technologies such as Google Map, Google database, electronic record, fax, and social media like WhatsApp messenger and others.^{63, 64} The existing Elder Helpline in Bangalore regularly receives missing person complaints and assists in finding the missing persons. There is a pressing need to educate the general public and youth and make the community dementia friendly, and thus someone could spot and assist the wandering person's home.⁶⁴

When finding family members is difficult, finding a community-based rehabilitation center is challenging due to a lack of government-run elderly care facilities for the wandering community in India. Currently, elderly care facilities for the wandering are treated in the same way as other wandering groups. 'Swadhar Greh' (its literal sense is "self-sufficient home") is one of the few Government of India initiatives. This center is situated in each district's headquarters. The Swadhar Greh provides shelter, food, clothing, medical treatment, care, and rehabilitation for women. Through the Nirashrithara Parihara Kendra (Centre for Homeless Person), the Social Welfare and Labour Department of Karnataka provides food, shelter, medical treatment, and rehabilitation to homeless people and beggars, regardless of mental illness status. Furthermore, several NGOs in India are important collaborators in treating homeless people across the country. The Social Welfare and Labour Department of Karnataka provides food, shelter, medical care, and rehabilitation to homeless people and beggars, irrespective of mental illness status, through the Nirashrithara Parihara Kendra (Centre for Homeless Person). In addition, many NGOs in India are key partners through the length and breadth of India in the care of the homeless person in India. These include Aashray Adhikar Abhiyan; Apnagar; Ashadeep, Guwahati; Banyan, Chennai; Chittadhama, Karnataka; Humana, Delhi; Hans Foundation, Delhi; Karuna Trust, Mysore; Parivartan Trust; Shantivanam, Trichy;

Shraddha Rehabilitation Foundation, Mumbai; and Uday foundation, Delhi. Locally, these centers recognize HMI and provide basic housing, treatment, and assistance. With the idea of community-based inclusive living for HMI make concerted efforts to rehabilitate and reintegrate them into communities and families using available local services.⁶⁵

Conclusion

Wandering and elopement are common neuropsychiatric concerns in PwD. Due to the heterogeneity of definitions and the study population, it is difficult to estimate the precise prevalence of wandering and elopement. The consequences of wandering and elopement can range from minor injuries and starvation to accidents, polytrauma, and death. The risk of wandering can directly relate to the severity of dementia, mobility, caregiver burnout, and associated agitation and psychotic symptoms. So, a proper risk assessment should be done on all patients with dementia who have cognitive deficits and depend on their daily living activities. Nonpharmacological interventions are the mainstay of wandering prevention management. The first stage in management should be the psychoeducation of the patient, caregiver, and staff at nursing homes and daycare centers. The DATE algorithm makes it simple to understand problematic behavior, reflects it to PwDs and carers, and assists professionals in developing strategies to limit or prevent wandering. Pharmacological modalities should be cautiously used when nonpharmacological modalities have failed. There is no strong evidence to suggest that using electronic devices can help reduce wandering episodes and prevent elopement. In addition, before using these devices, consider their decision-making capacity and potential for violation of privacy. Physical restraints and confinement have been used judiciously and should only be used to measure last resort if all other options have failed. In India, a strong collaborative (governmental organizations and NGOs) system should be in place to identify the wanderer and reintegrate the person with dementia back into the society.

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ORCID iDs

Aadesh Kumar Agrawal  <https://orcid.org/0000-0003-4296-2542>
Guru S. Gowda  <https://orcid.org/0000-0003-4600-0551>

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