

Wandering in Dementia

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Wandering is acknowledged as one of the most complex, challenging, and potentially dangerous dementia-related behaviors, and can result in elopement, injury, and even death. For the healthy people, walking is a common and a pleasurable leisure activity. However, wandering in dementia may be an exhausting behavior for caregivers and raise safety concerns. The term 'wandering' covers different types of behavior, including aimless movement without a discernible purpose. Although with respect to the etiology of wandering, biological, psychosocial and person-environment interaction has been suggested, the etiology of wandering is poorly understood. Although it is possible that management of coexistent psychopathology would help to ameliorate this problematic behavior, evidence on the effectiveness of pharmacological and non-pharmacological interventions is limited.

Key Words wandering, dementia, behavior.

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INTRODUCTION

Behavioral and psychological symptoms of dementia (BPSD) have been increasingly recognized as a significant facet of dementia, including Alzheimer's disease (AD). Among them, "wandering" is a particularly exhausting behavior for caregivers of patients with dementia or other cognitive impairments.¹ Although wandering is frequently encountered in patients with dementia, lack of a standard definition has been an ongoing problem. The term 'wandering' is basically defined as seemingly aimless or disoriented ambulating behavior of demented persons with dimensions of pattern (lapping, random, or pacing),²⁻⁵ frequency,^{2,6,7} boundary transgressions,^{8,9} and deficits in wayfinding.^{7,10,11} In addition, the term 'wandering' is frequently used as a broad term encompassing a diverse set of behaviors and is often considered as a kind of agitated behavior.³ Among the various definitions of wandering,

the following two aspects are cardinal: those of an individual moving through space and of being cognitively impaired.¹² In 2007, operational definition of wandering was suggested as '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'.¹³ Regardless of the suggested definition, this behavior has a profound effect on the caregiver and the patient himself/herself; however, little is known about the nature of wandering patients and the independent impact of wandering on the natural history of patients with dementia.

This article presents the epidemiology, phenomenology, and possible pathophysiology of wandering, and the interventional strategy. Then, we eventually tried to show the clinical need for appropriate future research on this devastating behavior.

EPIDEMIOLOGY

A recent study reported that 18.7% of patients with drug-

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naïve AD are wanderers,¹⁴ but estimates of the prevalence of wandering differ across studies, with rates being reported to range from 17.4% to 63%.^{15,16} These variations are partly due to the variety of definitions used, the characteristics of community setting, and the different time periods covered. Another study assessed the prevalence of dementia-related behaviors in a large, multiethnic sample of community-dwelling patients with moderate to severe dementia, and the authors reported that wandering was the most prevalent dementia-related behavior regardless of ethnicity.¹⁷ In a research performed in a long-term care facility, wandering was the second most frequently reported behavioral problem.¹⁸ Some studies reported that pacing was more prevalent in men.^{15,19} Colombo showed that wanderers (51% of the sample) were somewhat younger (76.4 years old vs. 80.5 years old) than nonwanderers among patients in the inpatient special care dementia unit.²⁰ Wanderers and non-wanderers do not differ by gender.²¹ Use of antipsychotic medication was associated with a greater chance of being classified as a wanderer.^{19,22} Furthermore, 70% of the caretakers see wandering as a risk for the care of the patients.²³

ETIOLOGY

In dementia, the etiology of wandering is poorly understood and may remain so for some time until there are more studies assessing the anatomic substrate specific to wandering. In the absence of clearly known etiology, it has been studied in three fields: biological, psychosocial, and person-environment interaction.

A biological hypothesis emphasizes the impairment of certain brain functions, especially in spatial memory, visuospatial processes or executive functions.²⁴⁻²⁶ Tetewsky and Duffy²⁴ suggested that wandering is related to visuospatial problems, while McShane et al.²⁵ showed that spatial memory problems account for wandering in dementia. Another research was performed to focus on impairments in optic flow perception and interpretation lead to spatial navigation failure as the basis for wandering in some AD patients.^{24,27} Benton²⁸ pointed out that execution problem from thoughts to actions, involving decision-making, planning and monitoring lead to wandering. Like other complex repetitive behaviors, wandering may also result from or be facilitated by aberrant distracted attention and executive functions resulting in disinhibited motor programs.²⁹ However, other researchers argued that spatial representation deficits or spatial memory problems in AD are not sufficiently explainable in wandering because these patients can reach a destination without having the complete knowledge about it.³⁰ They suggested that wayfinding diffi-

culties may result from their poorly structured overall decision plans rather than spatial memory problems.

In a single photon emission computed tomography study, wanderers, compared to non-wanderers, had a more severely reduced regional cerebral blood flow in the left temporoparietal region among patients with AD.³¹ Based on positron emission tomography, wandering patients with AD showed frontotemporal glucose utilization and decreased dopamine metabolism in the striatum.³² Circadian rhythm disturbances, particularly sleep disturbances, have also been investigated as a basis for wandering.²⁴ In the lifestyle study, a higher motor reaction to stress and a more motor behavioral style earlier in life was found to be related with wandering.⁷ These studies strongly suggested that the pathophysiological mechanism of wandering involves parietal and frontal dysfunction (and possibly temporal), suggesting that a functionally impaired spatial and executive neural circuit leads to wandering.^{14,33}

Based on a psychosocial approach, environmental, and need-driven factors can also contribute to wandering risk: wandering can occur when internal discomfort, especially when coupled with external demands (e.g., a noisy environment), exceeds the individual's threshold.³⁴ Dementia patients with frustrating physical or psychosocial needs, such as the need for toileting assistance or the need to find a familiar safe place, may be more prone to wandering. Personality and prior behavior patterns of coping with stress, previous work roles, and a need to search for secure people or places are also associated with wandering.² Observable emotional expression can be related with wandering.³⁵ Positive emotional expression was positively related to wandering rates, whereas negative emotional expression and higher cognitive status were negatively related to wandering rates.³⁵ These results suggest that persons with dementia who are prone to express negative feelings such as sad or angry feelings may sit alone or stay in their rooms for longer periods, rather than walk around. In contrast, demented patients who are prone to express pleasant emotions may engage in physical activity such as walking around.

GEOGRAPHICAL PHENOMENOLOGY

The geographic patterns of wandering can be divided into four travel patterns using videotape methods.⁶ Travel patterns include 1) lapping; repetitive locomotion following a circuitous path (closed loop) and the wanderer returns to his or her point of origin, and may include brief (several seconds) stops or hesitations as the wanderer changes directional heading along the path, 2) pacing; repetitive back and forth locomotion between two end points, at which directional heading is

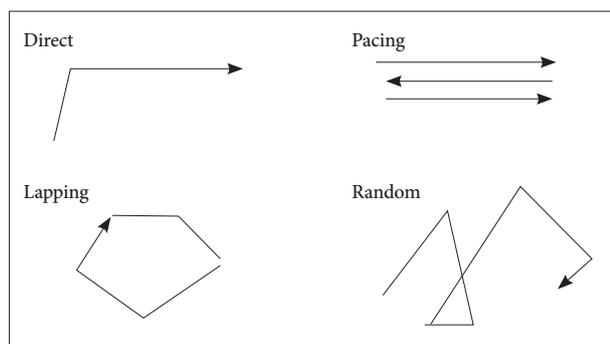


Fig. 1. Schematic travel pattern of wandering.

reversed, 3) random; locomotion along a haphazard path with multiple legs and directional changes and hesitations of up to 30 seconds at any point along the path, and 4) direct; locomotion from a point to a destination along a straightforward or uncomplicated path and without significant hesitation (Fig. 1).

Among these travel patterns, lapping was the most common inefficient travel pattern observed in patients exhibiting low travel efficiency and was closely correlated with dementia severity.⁶ However, until now, the exact anatomic substrate corresponding to these travel patterns remains uncertain.

WANDERING AND DEMENTIA CHARACTERISTICS

The frequency of wandering varies according to the severity of dementia in patients with AD, vascular dementia (VaD), and other types of dementia. Wandering is correlated with the severity of global cognitive impairment,³⁶ problems in recent and remote memory, orientation to time and place, and the ability to respond appropriately to a given conversation topic.³⁷ According to the data from 343 drug-naïve patients with AD, wandering occurs in patients who have more cognitive impairment (on the Mini-Mental State Examination and Clinical Dementia Rating).¹⁴ Cooper collected data of 502 patients with VaD and 810 patients with AD, and showed that wanderers constituted 26% of AD patients and 18% of VaD patients.³⁸ For both diagnoses, wandering rates were low (12% and 9%) in the early stages and higher (37% and 28%) as each disease progressed to the later stages. Klein et al.¹⁵ replicated this trend in the moderate and severe range of dementia: of the 638 community-residing dementia patients examined, 111 patients (17.4%) exhibited wandering behavior. Patients diagnosed with AD were overall significantly more likely to wander than those with VaD or other types of dementia, although this difference did not achieve statistical significance within individual severity ranges. The frequency of VaD did

not significantly differ between wanderers and nonwanderers.

A wide range of behavioral abnormalities have been reported in frontotemporal dementia, including repetitive behaviors.³⁹ In the motor domain, they occur as wandering and pacing.^{40,41} Patients with dementia with Lewy bodies (DLB) share many clinical signs and symptoms with patients diagnosed with AD. Chiu et al.⁴¹ reported that AD and DLB patients have a similar proportion of activity disturbances (i.e., purposeless activity, wandering and inappropriate activities) when considered altogether. However, according to Knuffman et al.,⁴² patients with DLB have a higher incidence of wandering. Despite this, to the best of our knowledge, there have been no systematic studies about wandering in frontotemporal dementia and in DLB.

PSYCHOPATHOLOGY AND WANDERING

Yang et al.¹⁴ reported that wandering is significantly correlated with aggression, disinhibition, depression, and delusions. Lachs et al.⁴³ suggested that wandering is more common in delusional than in non-delusional patients. According to Hope et al.,⁴⁴ there is a correlation between persecutory ideas and increased walking, a correlation between persecutory ideas and attempts to leave home, a correlation between persecutory ideas and aimless walking, and a weaker relationship between hallucinations and increased walking.

Anxious patients may move about in an effort to relieve anxiety, discomfort, or unsettled state, but due to cognitive impairment such motivation may be unknown to observers, so the movement may be perceived as aimless.¹⁹ Moderate to severe depression was found more frequently in demented wanderers.¹⁵ An association between major depression and wandering in Alzheimer's dementia outpatients was also reported.⁴⁵ Consistent with the findings of a previous study,⁴⁶ a wanderer was found to be associated with other disruptive activities such as socially inappropriate behavior and resisting care.²² Wandering is also related to negative behavior such as non-aggressive agitation, screaming and calling out, physical aggression, and disturbed nighttime sleep.^{3,20}

ASSESSMENT

Clinical assessment is important for characterizing, quantitating, and differentiating wandering from similar behavioral problems.²² A valid and reliable assessment provides accurate data to guide reliable care of an individual who wanders. The first step in systematic investigation of wandering is measurement of the phenomenon. A wandering scale that is ad-

ministered to the caregivers, the Algae Wandering Scale, has been developed to characterize a given patient with wandering.⁴⁷ It is a 28-item questionnaire that examines the pattern and rhythm of wandering. Also, revised versions, the Revised Algae Wandering Scale-Nursing Home was developed to provide a more precise standardization of the concept of wandering behavior.²⁶

DISEASE OUTCOME

Wandering behavior seems innocent enough, but it is exhausting for the family and clinicians as well as for health-care policy makers, because accidents, getting lost,⁶ malnutrition,¹ weight loss,⁴⁸ fatigue, sleep disturbance,⁴⁹ social isolation,⁵⁰ earlier institutionalization,³⁴ and increased cost³⁷ are associated with wandering.⁵¹ The risk of fall is 3 times higher in wanderers compared to non-wanderers.²⁰ Wick reported that nursing home residents who wander have double the risk of fracture compared with residents who do not wander.⁵² In a facility, patients with wandering may exhibit undesirable behaviors (e.g., entrance into another patients' room) that result in patient-to-patient violent incidents or may prevent desirable caregiving activity (e.g., eating and toileting).^{53,54} Physical or chemical restraints may be inappropriately used due to wandering.⁵⁵ Wandering can lead to an increase in caregiver stress and safety concerns that present a challenge to care providers responsible for managing behavioral problems.²⁰ Furthermore, it causes problems in the hospital environment.⁵⁶ Finally, wandering behavior has been shown to be a key determinant of patient's death.⁵⁶

PHARMACOLOGICAL MANAGEMENT

There is very little data to support strong recommendations for pharmacological management in patients with wandering and it is challenging due to limited evidence of efficacy (no randomized controlled study), high risk for aggravation, or increasing harm and mortality from commonly used medications.

Several medications are used in patients with undesirable wandering, but strong evidence for their effectiveness is lacking and they can produce adverse effects.⁵⁷ Risperidone, which is an antagonist of serotonin and dopamine receptors, was reported to have some benefit over placebo in reducing wandering, but it increases fall risk.⁵⁷ Moreover, increased mortality and morbidity associated with use of both atypical and conventional antipsychotics has been reported for behavioral management of demented patients. In another study, the researchers reported that cholinesterase inhibitors led to a sta-

tistically significant reduction in wandering when using the same dosage as administered for improving cognitive impairment. But due to lack of randomized controlled clinical trials, further studies are required. A more careful study of anxiolytic agents such as buspirone, antidepressants/mood stabilizers, sleeping pills, and finally beta blockers or antiandrogen/pro-estrogen hormonal treatment is required.

The other approach is that available therapies for other BPSD occurring simultaneously with wandering may indirectly help in decreasing wandering. For example, a previous cluster analysis study in drug-naïve patients with AD showed that each domain of BPSD may not be an independent entity, but may be related to each other in some ways.⁵⁸ And this study showed that aberrant motor (including wandering) symptoms and aggression, delusion, hallucination, disinhibition were clustered as the same group. The reason why these behavioral symptoms co-occur remains uncertain; however, if wandering is secondary to these symptoms, it may be helpful to manage the associated symptoms such as delusion.

NON-PHARMACOLOGICAL MANAGEMENT

Due to lack of clearly known etiology of wandering, researchers and clinicians have been hindered in what to target in interventions. No priority/suggested/additional non-pharmacological management exists for patients with wandering, but these management options may work for some individuals. Traditional management of wandering comprises physical barriers and restraints, but a recent management policy has evolved and it encourages walking in a safe place rather than preventing wandering; balancing between the need for autonomy and the need for minimizing risk is the main aim in a person with dementia.⁵⁹

In this updated evidence-based guideline, non-pharmacological management options for wandering can be grouped into four categories: 1) environmental, 2) technology, 3) physical and psychosocial, and 4) caregiver support and education.⁶⁰

Environmental modification

Environmental modifications to prevent dangerous wandering, the potential for accidents, and increasing caregiver competence are the essential components. Most importantly, providing a secure place for patients to wander, such as a lounge or a garden, and enhancing the environment by increasing visual appeal, such as tactile boards or three-dimensional wall art, are helpful.⁶¹ Finally, a combined approach to environmental modifications is more effective than singular modifications.^{59,62}

Technology

Several technological systems, including verbal alarm system, mobile locator and wearable technology, can provide both autonomy and safety for patients with wandering. For example, electronic tagging with a bracelet was tested in patients with dementia and wandering and it demonstrated good performance and showed none of the adverse effects reported in earlier studies.^{63,64} However, even when technology is applied successfully, there is considerable debate on ethical issues.⁶⁵

Physical and psychosocial

First of all, it is essential to assess the associated psychiatric and functional physical status in patients with wandering. If associated psychiatric symptoms (e.g., depression, anxiety, delusion) are identified, then appropriate intervention is needed. According to Schonfeld et al.,²² the use of interventions such as environmental alterations and social therapeutic activities may help to create a safe and pleasant environment for staff and residents while delivering meaningful programming to people with dementia who wander. A walking program for physically active persons with severe dementia reduced interpersonal tension on the dementia unit of a nursing home.⁶⁶

Caregiver support and education

It may be helpful to educate the caregivers to care for patients with wandering. In a facility, management of wandering should include 1) identification of the wanderer, 2) a wandering prevention program, 3) an alert program when patients are missing, and 4) a staff mobilization program for addressing the problem.⁶⁷ In a community setting, it may be helpful to provide dementia care training to residential care staff using social and professional teams to deal with wandering.

So far, there is currently no adequate, robust evidence from controlled trials to recommend the use of any non-pharmacological intervention to reduce wandering in dementia. However, from both practical and moral perspectives, walking/exercise and music therapy may be acceptable interventions.⁵⁸

CONCLUSION

For the healthy people, walking is a common and a pleasurable leisure activity. Walking has both physical and social purposes and may have a relaxing effect on both healthy people and patients with dementia. Walking may be beneficial for cardiopulmonary function, osteoporosis, muscle fitness, constipation and more. Walking may also be helpful for improving “brain fitness” as it activates brain areas responsible for

gait. However, wandering in dementia raises safety concerns.

Wandering should not be simply considered as a uni-dimensional concept resulting in a simple categorization of wanderers or non-wanderers, but wandering is a complex, multifaceted behavior with variations in its expression often with observable patterns such as lapping, pacing, or random ambulation. It is also one of the most frequently encountered dementia-related behavioral disturbances and has been a major challenge for caregivers. Moreover, it is associated with negative consequences such as higher morbidity and mortality. Although the number of studies related to wandering has increased in recent years, many gaps between “real world” and science remain, limiting the empirical evidence on which to base important clinical decisions. These discrepancies contribute to significant variation in practice associated with assessment practices for wandering as well as interventions used to manage wandering.

Until now, due to lack of randomized controlled trials for wandering, evidence on the effectiveness of pharmacological interventions is limited. Although non-pharmacological interventions are preferred due to limited evidence of pharmacological treatment, there are controversies regarding the clinical and cost-effectiveness of non-pharmacological interventions that allow safe wandering and that are considered practically and ethically acceptable by carers and people with dementia. To overcome these problems, a further well-designed research on wandering is required.

Conflicts of Interest

The authors have no financial conflicts of interest.

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