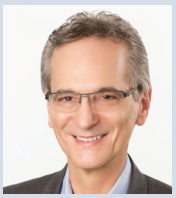
FACULTY

Stephen A. Brunton, MD
Adjunct Associate Clinical Professor
Department of Family Medicine
Touro University
Vallejo, CA
Executive Vice President
Primary Care Education Consortium
Charlotte, NC

Daniel J. Cannone, DO, CMD
Clinical Professor of Geriatric Medicine
Ohio University Heritage College of Osteopathic Medicine
Athens, OH
Consultant Staff Physician
Geriatric Medicine
Western Reserve Hospital
Cuyahoga Falls, OH
President
Consortium Concepts, LLC
Copley, OH



Gary W. Small, MD
Professor of Psychiatry and Parlow-Solomon Professor on Aging
Division of Geriatric Psychiatry
Department of Psychiatry and Biobehavioral Sciences
University of California, Los Angeles
Los Angeles, CA

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This disease-awareness, non-CME newsletter is intended only for healthcare professionals involved in the treatment of people with dementia-related psychosis. This newsletter is not meant to address specific treatment options for dementia-related psychosis.

MORE THAN COGNITION

The Impact and Consequences of Dementia-Related Psychosis on Patients, Caregivers, and Society

A SUPPLEMENT TO NEUROLOGY REVIEWS

A Member of the MDedge Network

Introduction

Dementia is common in older adults in the United States (US); approximately 7.9 million people are living with dementia, of whom 3.95 million carry a diagnosis of at least one dementia type.[1-3] However, data from 2 large databases indicate that more than half of individuals with dementia had mixed neuropathologies.[4] According to the 2015 National Health and Aging Trends Study (NHATS), the prevalence of dementia increases with age, although some individuals experience symptom onset at a younger age.[5] Moreover, as the US population ages, the number of people with dementia is expected to grow.[5]

Dementia involves more than cognition

Neuropsychiatric symptoms are common among people with dementia, and their onset can occur at various times in the course of the illness.[6-8]

> ***Neuropsychiatric symptoms** are a common feature across the dementias and include delusions, hallucinations, agitation/aggression, depression, apathy, elation, anxiety, disinhibition, irritability, and aberrant motor behavior.[6]*

Delusions and hallucinations are prevalent across the dementias

Although the rates of delusions and hallucinations vary based on the dementia type, approximately 2.4 million people in the US have dementia-related psychosis, ie, experience delusions and hallucinations **(Table 1)**.[9-23]

Table 1. Delusions and hallucinations are prevalent across the dementias.

	No. of People in US With Dementia	Overall Psychosis Prevalence	Delusions Prevalence	Hallucinations Prevalence
Alzheimer's Disease Dementia[10-17]	~5.5 million	30%	10%-39%	11%-17%
Vascular Dementia[10,13,15,17]	~1.6 million	15%	14%-27%	5%-14%
Dementia With Lewy Bodies[9,13,18-20]	~430,000	75%	40%-57%	55%-78%
Parkinson's Disease Dementia[13,16,19,21]	~320,000	50%	28%-50%	32%-63%
Frontotemporal Dementia[22,23]	~80,000	10%	2.3%-6%	1.2%-13%
		~2.4 million people in the US have dementia-related psychosis		

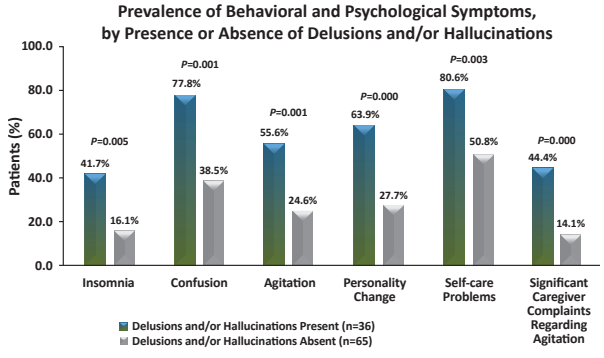
Impact of Delusions and Hallucinations

Neuropsychiatric symptoms—specifically, delusions and hallucinations—are a potentially burdensome healthcare challenge for patients, caregivers, and society and can have considerable consequences.

Patient Burden

In a retrospective study of 101 people diagnosed with Parkinson's disease dementia, individuals with delusions and/or hallucinations were significantly more likely to have insomnia, confusion, agitation (as assessed by the clinical team), personality change, self-care problems, and complaints by caregivers regarding agitation than people without dementia-related psychosis **(Figure 1)**.[24] Further, subjects with symptoms of psychosis had more impairment on several cognitive/functional measures, including the Mini-Mental State Examination (MMSE), Blessed Information-Memory-Concentration Test (BIMCS), and Blessed-Roth Dementia Rating Scale (BRDRS).[24]

Figure 1. Adults with Parkinson's disease dementia-related delusions and/or hallucinations experienced significantly higher rates of behavioral and psychological problems.



Thirty-six (35.6%) of the 101 individuals in a retrospective review from the State of California Department of Public Health Alzheimer's Disease Diagnostic and Treatment Centers database had delusions and/or hallucinations. The study found statistically significantly greater rates of behavioral and psychological symptoms among the subjects with delusions and/or hallucinations compared to those without delusions and/or hallucinations.[24]

Dementia-related psychosis may be associated with worse patient outcomes

The presence of delusions in older adults with dementia has been shown to be related to a severe disease course. A prospective, longitudinal study of 78 people with Alzheimer's disease (mean age, 74 years) who were followed for 2 years found that, at the final examination, delusions were associated with greater severity of cognitive and functional impairment.[25] Moreover, specific delusions were predictive of specific negative outcomes. At the last evaluation in the 2-year observational period, the delusion of theft was related to the degree of cognitive dysfunction (as measured with the MMSE) and to functional disabilities (as measured with the Dementia Scale), and the delusion of abandonment was related to the severity of cognitive impairment (as measured with the Cambridge Cognitive Examination).[25]

In older people with dementia, neuropsychiatric symptoms may increase the likelihood of nursing home placement. A case-control study using data from the South Carolina Alzheimer's Disease Registry compared Neuropsychiatric Inventory (NPI) scores for older people with Alzheimer's disease who entered nursing homes within 6 months of the study initiation (352 cases; mean age, 84 years) versus those who remained in the community (289 controls; mean age, 83 years).[26] A 10% increase in the total NPI score was associated with a 30% increase in the odds of nursing home placement (odds ratio, 1.30; 95% CI, 1.14-1.50).[26] Delusions, in addition to some other NPI items except hallucinations, were significantly associated with increased odds of nursing home placement.[26]

Dementia-related psychosis may also increase the risk for serious patient outcomes. A population-based study of 335 individuals aged ≥65 years with possible or probable Alzheimer's disease dementia who were followed for 3 years to 5 years found that symptoms of psychosis were present in 18% of the population.[27] Individuals with dementia-related psychosis were 2 times more likely to progress to severe dementia (hazard ratio [HR], 2.0; P=0.03) and 1.5 times more likely to progress to death (HR, 1.5; P=0.01).[27]

Caregiver Burden

The burden of dementia typically falls on informal caregivers. In a 2015 population-based analysis, approximately 70% of older adults with dementia receive help from family caregivers (eg, their spouse or adult children).[5]

Common delusions in dementia **target the caregiver**[9]

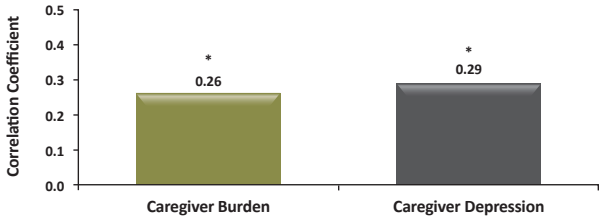
- **Theft:** *"You're stealing my things!"*
- **Abandonment:** *"You're going to abandon me!"*
- **Capgras syndrome:** *"You're not my spouse. You're an imposter!"*
- **Spousal infidelity:** *"You're having an affair!"*

The stress of caring for people with dementia may have physiological consequences and poor outcomes for caregivers. A study that examined 33 family caregivers of individuals with Alzheimer's disease found that caregivers performed significantly worse on memory tests compared with 34 noncaregiver controls (P<0.05), and that nighttime cortisol levels showed a significant negative correlation with contextual memory performance (P<0.001), which may be reversible.[28]

Psychiatric and behavioral symptoms in people with dementia may correlate with caregiver burden, depression, and distress

A meta-analysis that surveyed 228 studies of family caregivers (eg, spouses and adult children) to older adults found statistically significant correlations (P<0.001) between the presence of behavioral symptoms and caregiver burden and depression **(Figure 2)**.[29]

Figure 2. Caregiver outcomes are more strongly associated with older care recipients' behavioral problems in the presence of dementia than with other stressors.



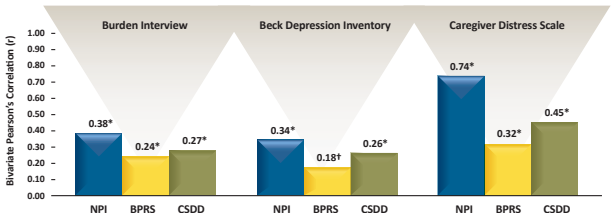
A meta-analysis that surveyed 228 studies of family caregivers (43% focused exclusively on caregivers of people with dementia; mean age of care recipients, 75.7 years) found multivariate associations between behavioral symptoms in older people with dementia and family caregiver burden and depression (*P<0.001).[29]

A study of 421 patients with Alzheimer's disease found that neuropsychiatric and mood symptoms were significantly correlated with burden, depression, and distress in their caregivers (**Figure 3**).[30]

Behavioral problems in older adults factor into caregiver burden and patient's risk of institutionalization

Caregiver burden is important not only because of the suffering it can involve, but because its severity is associated with the institutionalization of the individual with dementia. In the Canadian Study of Health and Aging of 9008 community-dwelling older adults with dementia, 326 were identified as receiving care from an informal caregiver.[31] These subjects were followed for 5 years, during which 166 (50.9%) were institutionalized. In a multivariate analysis, the only factors associated with caregiver burden were patient's behavioral disturbances (assessed via the Dementia Behavior Disturbance scale) and caregiver's depressive mood (r=0.55).[31] The severity of caregiver burden was associated with a higher adjusted odds of institutionalization, with patients whose caregivers reported moderate burden about 1.5 times more likely (95% CI, 0.69-3.99) to be institutionalized, those who reported severe burden about 3 times more likely (95% CI, 1.34-7.59) to be institutionalized, and those who reported extreme burden about 8 times more likely (95% CI, 3.44-22.04) to be institutionalized.[31]

Figure 3. Multiple measures of psychiatric and behavioral symptoms in people with dementia correlated significantly with caregiver burden, depression, and distress.



The Clinical Antipsychotic Trials of Intervention Effectiveness in Alzheimer's Disease, or CATIE-AD, study examined the relationship between neuropsychiatric symptoms in 421 ambulatory patients with Alzheimer's disease and burden, depression, and distress in their caregivers. To assess neuropsychiatric symptoms, the investigators used the Brief Psychiatric Rating Scale (BPRS) and the NPI. Mood symptoms in patients with dementia were assessed with the Cornell Scale for Depression in Dementia (CSDD). Both neuropsychiatric symptoms and mood symptoms were significantly correlated with Burden Interview, Beck Depression Inventory, and the Caregiver Distress Scale (*P<0.0001, †P<0.001).[30]

Even after institutionalization, behavioral disturbances can also take a toll on professional caregivers in long-term care settings and contribute to their burnout. Findings from 3 studies in a non-US meta-analysis noted that 22.1% to 68.6% of staff caring for patients with dementia in a long-term care setting reported high levels of emotional exhaustion.[32] Another 3 studies found a significant association between residents' agitated behavior and care staff burnout and stress, and in one study, caregivers described 75% of residents' challenging behavior as having emotional difficulties.[32,33]

Societal Burden

Neuropsychiatric symptoms contribute to societal burden by increasing the cost of care in people with dementia. A study of 280 individuals diagnosed with dementia (72.1% with Alzheimer's disease) examined the relationship between costs of informal caregiving and neuropsychiatric symptoms for people with dementia in the Cache County population.[34] The study assessed neuropsychiatric symptoms using the NPI—a scale that measures the frequency and severity of 12 neuropsychiatric disturbances, including delusions and hallucinations, with a maximum total score of 144—and modeled the relationship of the NPI total (and individual subdomains) with informal care costs.[34] Informal costs of care were based on a caregiver activity survey in which the caregiver estimated how much time he or she spent assisting the person with dementia over 24 hours. Assistance was defined as answering questions, leaving reminders, providing transportation, and helping with activities of daily living

(eg, dressing, grooming, meals and eating). Total caregiving time was capped at 16 hours, and informal cost was calculated using the Utah median hourly wage and represented in 2015 dollars.[34] Informal costs increased approximately 2% with each point increase in the NPI total score and 7.6%, 6.4%, and 5.6% with each unit increase in the agitation/aggression, affective symptoms, and psychosis subdomains, respectively.[34] However, the interaction with time as a variable was not significant for NPI total, agitation/aggression, affective symptoms, and psychosis.[34]

Conclusions

Delusions and hallucinations are prevalent across the dementias. Adults with dementia-related psychosis may experience higher rates of behavioral and psychological problems, a severe disease course, and an increased likelihood of nursing home placement. Psychiatric and behavioral symptoms also have an impact on caregivers' burden, depression, and distress, which factors in to an increased risk for patient institutionalization and increased costs of care. The aging US population and the prevalence of dementia-related psychosis represent a significant healthcare challenge for patients, caregivers, and society.

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