ABSTRACT

Importance: Most people with dementia will experience neuropsychiatric symptoms, including psychosis characterized by hallucinations and delusions. Across dementia subtypes, hallucinations and delusions are common, though their prevalence and presentation may vary. These symptoms have been associated with worse outcomes compared with dementia alone, including accelerated functional decline and mortality. Many people with dementia reside in long-term care facilities, and identification and management of hallucinations and delusions in this setting are critical.

Observations: For residents in long-term care facilities, the following factors can hinder management of hallucinations and delusions related to dementia: (1) delayed recognition of symptoms; (2) reluctance of staff and family members to acknowledge psychiatric issues; (3) lack of approved pharmacotherapies to treat hallucinations and delusions associated with dementia-related psychosis; and (4) regulatory and institutional guidelines, including the long-term care regulatory guidelines established by the Centers for Medicare and Medicaid Services and the 5-star rating system.

Conclusions and Relevance: Barriers to the treatment of hallucinations and delusions in patients with dementia in the long-term care setting are myriad and complex. Early diagnosis of dementia-related psychosis and new treatment options for managing hallucinations and delusions are needed to improve care of this patient population.

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Alzheimer’s Disease

Alzheimer’s disease (AD) is the most common form of dementia and develops with accumulation of neuronal amyloid plaques and neurofibrillary tangles primarily in the hippocampus. As
Barriers to the treatment of hallucinations and delusions in patients with dementia in the long-term care setting are myriad and complex.

Appropriately identifying hallucinations and delusions is difficult, but with or without symptom diagnosis, treatment may be impeded by psychosocial stigma, compliance with complex regulatory requirements around certain medications, and the increased difficulties manifested during acute and post-acute care of patients with psychosis.

Early diagnosis of dementia-related psychosis and new treatment options for managing hallucinations and delusions are needed to improve care of this patient population.

such, patients with AD suffer from progressive deterioration in memory alongside changes in behavior and cognitive abilities. The prevalence rates of delusions in individuals with AD have been reported to range from 16% to 70% (median = 36.5%; Table 1).19 Paranoid delusions are most common (noted in 14.5%–46% of patients), followed by persecutory delusions (7%–40%), delusions of infidelity or jealousy (1.1%–26%), delusions of reference (2%–18.7%), and somatic delusions (1.1%–3.3%).19 Reported prevalence rates of hallucinations range from 4% to 76% (median = 23%), with visual hallucinations most common (median = 19% [range, 4%–59%]) followed by auditory hallucinations (12% [1%–29%]).19 Hallucinations have been reported to manifest early in illness and are more commonly observed in individuals with a severe disease presentation.19 Delusions in patients with AD are commonly observed during the moderate stage of disease, yet the prevalence of both delusions and hallucinations in AD increases slowly with disease progression.19 One study36 found that delusions appeared at a mean (SD) of 2.23 (1.94) years after AD diagnosis, whereas hallucinations appeared at a mean of 2.50 (1.96) years after diagnosis. The preponderance of evidence therefore indicates that delusions occur more frequently than hallucinations in patients with AD, with paranoid delusions and visual hallucinations being the most common.25

Dementia With Lewy Bodies

Dementia with Lewy bodies (DLB) is classified among α-synucleinopathies as a type of dementia that shares symptoms with both AD and Parkinson’s disease (PD).38 Studies suggest that visual hallucinations are more prevalent (estimated pooled prevalence = 61.8%; 95% CI, 49.1%–73.0%) than auditory hallucinations (30.8%; 23.4%–39.3%) in patients with DLB,23 with hallucinations occurring more often than delusions (57.1% and 42.9%, respectively; Table 1).20 Common delusions observed in patients with DLB include misidentification delusions (52.4%), delusions of others stealing (35.3%), delusions of danger to self (21.3%), and delusions of spousal infidelity (7.2%).21,22 Of the misidentification delusion subtype, the most common delusions are house misidentification, Capgras delusions (belief that someone familiar has been replaced by an imposter), and reduplicative amnesia (belief that a place has been duplicated and is present in 2 locations simultaneously). Delusions and greater cognitive decline have been associated in DLB.21,27

Parkinson’s Disease

Parkinson’s disease dementia (PDD) is a complication of the disease marked by deficits in recognition memory, attention processes, and visual perceptions.39 Both neuropathological and genetic factors contribute to disease pathology, with Lewy bodies, neurofibrillary tangles, senile plaques, and microvascular disease all contributing factors.39 Visual hallucinations are more prevalent (28% [95% CI, 19.1%–39.5%]) than auditory hallucinations (8.9% [5.3%–14.5%]) in PDD,23 with some reports suggesting prevalence rates of visual hallucinations as high as 75%.25 Passage hallucinations (sightings of animals or objects passing in the peripheral visual field) are commonly observed in patients with PDD, along with extracampine hallucinations such as presence hallucinations (the sense of someone’s presence).27,40 After visual hallucinations, passage hallucinations are most common, followed by presence hallucinations, olfactory hallucinations (pungent odors such as garbage/rotten food, burning/gas), tactile hallucinations (insects biting or crawling on the skin), and auditory hallucinations (including incomprehensible voices, sound of steps, or music).25 Of note, extracampine hallucinations are often associated with visual hallucination onset, with both commonly presenting at the same time.40 Delusions, although less common, affect 5%–16% of patients with PDD; the most common subtypes are persecutory delusions, delusions of reference (interpreting an innocuous stimulus in the milieu as being specifically directed to them), and misidentification delusions.25–27 The prevalence of psychotic symptoms in PDD is time dependent and increases with duration of PDD.27

Frontotemporal Dementia

Frontotemporal dementia (FTD), a common cause of young-onset dementia, is characterized by intraneuronal tau protein deposition and atrophy of the frontal and anterior temporal lobes.41 As a progressive syndrome, FTD manifests as changes in personality and behavior with decline in language skills.41 Patients with FTD are less likely to present with delusions or hallucinations than are patients with other forms of dementia.37 The reported prevalence rates of delusions in FTD patients range from 2.3% to 28.6%, with prevalence rates of hallucinations ranging from 4.8% to 17.5%.20,28,29 Delusions are most commonly of the persecutory, paranoid, and somatic subtypes.28,29 Visual hallucinations are more commonly observed (14.4%) in FTD patients, with fewer reports of auditory, tactile, and olfactory hallucinations.28

Vascular Dementia

Vascular dementia (VaD) is a heterogeneous syndrome with a variety of pathological subtypes, including dementia
associated with hemorrhagic strokes, cerebral hypoxic-ischemic events, and senile leukencephalopathic lesions. Although cognitive changes in VaD are much more variable, predominant deficits in attention, executive function, and information processing are common. When compared with patients with other forms of dementia such as AD, patients with VaD are more likely to present with psychotic symptoms such as delusions. The prevalence rates for delusions and hallucinations in VaD range from 9.4% to 58.3% and from 4.5% to 66.7%, respectively. Historically, an association between severity of dementia and psychotic symptoms has not been reported; however, recent reports suggest an association between increased frequency of delusions in patients with VaD and more severe disease.

### Traumatic Brain Injury

Traumatic brain injury (TBI)–associated dementia has been attributed to both genetic risk factors and white matter tract and neural network disruptions. Patient history of neurologic and neurodevelopmental conditions is often considered when assessing patient risk of dementia and psychotic disorder due to TBI (PDTBI). Patients with PDTBI are more likely to present with delusions (78.3%) than hallucinations (46.7%), with mean latency between injury and symptom onset ranging from 3 to 5 years. Auditory hallucinations (43.4%) are more common than visual hallucinations (15%) in patients with PDTBI, although visual hallucinations occur more often in patients with later-onset TBI. PDTBI can be categorized into 2 subtypes: delusional disorder (DD) and schizophrenia-like psychosis (SLP). DD involves the occurrence of delusions alone, most commonly Capgras syndrome (32%) and reduplicative paramnesia (32%), followed by delusions of jealousy (16%), Cotard syndrome (16%), Somatic delusions (11%), Delusions of self-harm (16%), and Grandiose delusions (16%). Negative symptoms of psychosis are relatively uncommon, occurring in only 25% of cases. SLP involves the occurrence of both hallucinations and delusions.

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Prevalence of Hallucinations</th>
<th>Most Common Types of Hallucinations</th>
<th>Prevalence of Delusions</th>
<th>Most Common Types of Delusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's disease</td>
<td>23% (4%–76%)</td>
<td>Visual, (19% (4%–59%); Auditory, 12% (1%–29%)</td>
<td>36.5% (16%–70%)</td>
<td>Paranoid delusions (14.5%–46%); Persecutory delusions (7%–40%); Delusions of infidelity or jealousy (1.1%–26%); Delusions of reference (2%–18.7%); Somatic delusions (1.1%–3.3%)</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>57.1%</td>
<td>Visual: estimated pooled prevalence = 61.8%; 95% CI, 49.1%–73.0%; Auditory: estimated pooled prevalence = 30.8%; 95% CI, 23.4%–39.3%</td>
<td>42.9%</td>
<td>Misidentification delusions, 52.4%; House misidentification delusions, 47.6%; Capgras delusions, 33.3%; Reduplicative amnesia, 23.8%; Delusions of others stealing, 35.3%; Delusions of danger to self, 21.3%; Delusions of spousal infidelity, 7.2%</td>
</tr>
<tr>
<td>Parkinson's disease dementia</td>
<td>28%</td>
<td>Visual (28%–75%); Passage, 17.5%; Presence, 6%; Olfactory, 6%; Tactile, 4%; Auditory (2%–14.5%)</td>
<td>5%–16%</td>
<td>Persecutory delusions, 66%; Delusions of reference, 17%; Misidentification delusions, 16.7%</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>4.8%–17.5%</td>
<td>Visual, 14.4%; Auditory Tactile Olfactory</td>
<td>2.3%–28.6%</td>
<td>Persecutory delusions, Paradox delusions, Somatic delusions</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>4.5%–66.7%</td>
<td>...</td>
<td>9.4%–58.3%</td>
<td>...</td>
</tr>
<tr>
<td>Traumatic brain injury–associated dementia</td>
<td>46.7%</td>
<td>Auditory, 43.4%; Visual, 15%</td>
<td>78.3%</td>
<td>Delusional disorder: Capgras syndrome, 32%; Reduplicative paramnesia, 32%; Delusions of jealousy, 16%; Cotard syndrome, 16%; Somatic delusions, 11%; Schizophrenia-like psychosis: Persecutory delusions, 65%; Bizarre delusions, 20%; Ideas of reference, 18%; Grandiose delusions, 16%</td>
</tr>
</tbody>
</table>

Table 1. Prevalence Rates of Hallucinations and Delusions in Dementia

Values are shown as median (range) unless otherwise noted; in some instances, only the median or the range is reported, and no values are available for some variables.
DIAGNOSIS OF DEMENTIA-RELATED PSYCHOSIS

Although understanding the potential for psychosis in patients with dementia may help with recognition of the condition, further challenges may hinder diagnosis and treatment. First, patients may lack insight into their condition, and those who are aware of symptoms may be hesitant to report them. Nonverbal or verbally challenged patients by definition cannot provide the necessary detail to define this issue. Family members may assume that some hallucinations or delusions are a normal process of aging and therefore not inquire about treatment options from health care providers. They may also resist reporting because they cannot imagine these sorts of symptoms or they want to avoid the social stigma of a “psychotic” diagnosis.

For patients in LTC facilities, the treating physician often relies on staff to report symptoms such as hallucinations and delusions. When these symptoms become the resident’s normal behavior pattern, staff members can overlook the frequency and severity of the hallucinations and delusions. The variability of symptom presentation in people with dementia-related psychosis can complicate reporting and diagnosis. Whereas some experience persistent symptoms, others may experience frequent, recurring symptoms.45 If symptoms are not troubling for the patient, they may not even recognize the actual frequency of symptom manifestation.

Additionally, caregivers providing frequent patient care within the LTC setting (eg, nursing staff, certified nursing assistants, restorative nurse assistants, dietary staff) may be concerned that reporting such symptoms will merely complicate care (ie, with additional documentation) and, in many cases, will not lead to any change in the care plan.

Over the past few years, with the focus on reducing unnecessary psychoactive medications across the country, fear around the use of psychoactive medications has also risen among LTC staff members. We must remember that the Centers for Medicare and Medicaid Services (CMS) regulations and guidance are to protect a resident from being prescribed unnecessary medications and to ensure that the lowest effective dose is used. Residents who experience hallucinations and delusions along with dementia or Parkinson’s disease often still need appropriate treatment. Working with an interdisciplinary team can help to ensure that all documentation is complete and includes evidence of the necessity and benefits and risks of any treatment considered.

CURRENT LANDSCAPE

Use of off-label antipsychotics in the elderly has been associated with an increased risk of mortality.46 In 2005, the US Food and Drug Administration (FDA) released a boxed warning of this risk associated with the use of atypical antipsychotics to treat dementia-related psychosis.47 Formal guidelines and recommendations for best practices have incorporated this warning into their recommendations, including those of the American Psychiatric Association (APA), the American Geriatrics Society (AGS), and the CMS.15,16 The degree of efficacy of available off-label antipsychotics has been reported elsewhere48 and is beyond the scope of the current review. However, hallucinations and delusions often warrant pharmacologic treatment to maintain safety of both the individual patient and the milieu as a whole, and there is sufficient efficacy to be considered in the risk-benefit analysis of each patient case. The AGS recommends that typical and atypical antipsychotics be avoided except when treating schizophrenia or bipolar disorder or for short-term management of chemotherapy-induced emesis.16 The APA cautions against the use of antipsychotics except when nonpharmacologic treatment approaches are ineffective and persisting symptoms are severe or dangerous or cause significant distress to the patient. The guidelines clarify that these recommendations apply to hallucinations and delusions caused by psychosis or agitation, rather than delirium, and that when used, antipsychotics should be tapered and withdrawn after 4 weeks if there is no response to the treatment or within 4 months if there is an adequate response to treatment. CMS guidelines, which set the regulatory standard of care for those living in nursing homes, also reflect the FDA boxed warning regarding the use of antipsychotics. Importantly, hallucinations and delusions can be dangerous and distressing to patients and caregivers, and while risk-benefit analyses of treatment options are critical, the use of antipsychotics remains the standard of care.

Several regulatory and organizational barriers impede the pharmacologic treatment of behavioral symptoms, including psychosis, in the LTC setting. The primary regulatory guidelines in the United States are the long-term care regulatory guidelines established by the CMS and the 5-star rating system.17,49 Both were amended in 2012 to specifically address the use of antipsychotics,50,51 and facilities are expected to adhere to both despite their differing requirements. Antipsychotic use has declined following these changes, demonstrating the power of these guidelines in shaping prescribing behavior.51–54

Care provided to residents living in nursing homes is governed by CMS rules and regulations as outlined in Appendix PP of the State Operations Manual (SOM).17 Each nursing home undergoes an annual survey during which it is evaluated for all aspects of care, including the general...
Hallucinations and Delusions With Dementia in LTC

The 5-star rating system was created by CMS to “help consumers, their families, and caregivers compare nursing homes more easily.”49 In theory, this system provides an objective way to evaluate and compare various nursing facilities by using a specific set of criteria associated with better patient outcomes. Families generally prefer to have their loved ones cared for at a highly rated facility, and because acute care settings are also incentivized to minimize rehospitalization, they are more inclined to discharge patients to highly rated facilities. Therefore, LTC facilities are motivated to earn the highest rating possible because it positively impacts their occupancy and finances.

The 5-star rating is divided into 3 areas: health inspection, staffing, and quality measures. Although health inspection and staffing are straightforward, the quality measure is divided into 15 different clinical measurements that are used to determine an overall score. One clinical measurement is the total number of residents within a nursing home who are receiving an antipsychotic for a diagnosis other than schizophrenia, Huntington’s disease, or Tourette’s syndrome, even if the use of the antipsychotic is in accordance with FDA-approved guidelines, is being used on-label, and is consistent with the patient’s overall clinical picture. The following hypothetical case can illustrate the potential problem with this guidance: A 66-year-old woman with longstanding bipolar disorder suffers a fall with resulting hip fracture. After surgical repair at her local hospital, she is admitted to a long-term care facility for rehabilitation. She has been psychiatrically stable on quetiapine 300 mg administered orally twice a day for 5 years. Even though she has had psychiatric stability and favorable treatment outcomes, the facility will now face a drop in their quality measures if they continue to treat this resident with her prior medications.

Although both are created by and enforced through CMS, the SOM and the 5-star rating system are incongruent. These complicated regulatory requirements also create a confusing and frustrating clinical landscape for LTC behavioral health clinicians, who are already few in number.

The decision to prescribe an antipsychotic for patients in LTC requires consideration of the associated risks and benefits specific to each case. Regulatory pressures imposed by the CMS and other guidelines have added additional variables to this equation. While the use of antipsychotics in these patients may have dropped substantially due to guidelines cautioning against their use and incentives for facilities to limit their use,51–54 this drop in use has not necessarily resulted in improved care for all patients. The 5-star rating has made it substantially more difficult for providers to treat patients with psychosis in accordance with guidelines, which do allow for the use of antipsychotics and acknowledge their value in terms of potential benefits in certain circumstances, though the amount of work required to meet the regulatory criteria for documentation (including initial justification for use and subsequent required dose reductions) adds additional stress to a system that is largely underserved. Untreated hallucinations and delusions in patients in LTC could also create risks for staff and impose additional burdens on the health care system, particularly related to costs of hospitalizations prompted by barriers to effective treatment in the LTC setting itself.

CONSEQUENCES OF ANTIPSYCHOTIC MEDICATION REDUCTIONS

Antipsychotic use in the LTC environment has decreased in recent years, partly because of the encouragement from regulators and greater understanding of the risks associated with current antipsychotics, particularly in patients with dementia.54 However, alternative treatment options for LTC residents with psychosis remain limited. Often, LTC facilities attempt nonpharmacologic approaches for the management of behaviors secondary to symptomatology, but if these methods are not effective, little can be done to help patients, especially in cases of dementia-related psychosis. Also, because of the decrease in LTC staffing, facilities do not have the necessary time or expertise to appropriately carry out these nonpharmacologic approaches, leading to suboptimal outcomes and the need for renewed or alternative medication management or adjustments.55 When
an antipsychotic as prescribed and is effective at reducing a patient’s symptoms, tapering and withdrawing a medication can destabilize patients and cause symptoms to recur.\textsuperscript{56,57} In such cases, it is often more difficult to restabilize the patient even if the same medication is reintroduced. Another consequence of the shift away from antipsychotic use is that prescribers may substitute other medications that do not have proven effectiveness, including mood stabilizers (such as antiepileptic drugs) and sedatives.\textsuperscript{54,58} Substituting medications may result in new problems, because doing so can further destabilize the patient while not addressing their underlying psychiatric issue, or introduce new safety and tolerability issues. All of these in turn can lead to increased avoidable hospitalizations or movement from one LTC environment to another.\textsuperscript{59} Many gradual dose reductions and discontinuations within the LTC environment are being completed by nonpsychiatric providers who are not specialists in psychiatric medication management, further destabilizing patients’ psychiatric disorders.\textsuperscript{50}

Encouragement (from a regulatory standpoint) to reduce antipsychotic use in LTC may be directly related to the increase in hospitalizations of patients suffering from mental illness.\textsuperscript{59} Some newly admitted LTC patients have suffered from mental illness before admission, but their antipsychotic medications are reduced or changed in accordance with the guidelines.\textsuperscript{60} Placement into LTC facilities also becomes difficult, with many elderly patients with psychosis "stuck in limbo" in the emergency department/hospital as LTC facilities reject them in favor of other referrals (since accepting patients that need antipsychotic treatment would lower their 5-star rating). Most LTC facilities strive to meet the guideline standards, often at the risk of destabilizing patients or increasing the potential for rehospitalization or movement to another facility, or both.\textsuperscript{59} Within the 5-star system that regulates LTC facilities, antipsychotic use was deemed appropriate for only 3 diagnoses, which do not include all psychiatric diagnoses having FDA approval for the use of antipsychotic medications.\textsuperscript{55} As previously noted, patients with bipolar disorder or treatment-resistant depression require long-term medication regimens to stabilize their disease and maintain optimal mental health, outcomes that are often difficult to achieve when medications are being regularly altered because of regulations. In addition, no antipsychotics are currently approved for treatment of psychosis related to dementia, severely limiting the treatment options for this large population of patients in LTC facilities.

**CONCLUSIONS**

Barriers to treatment of hallucinations and delusions in patients with dementia are myriad and complex, especially within the LTC setting. The statistics around prevalence of this symptomatology are alarming, but the challenges to effectively treating this vulnerable patient population are also daunting. Appropriately identifying these symptoms is difficult, but with or without symptom diagnosis, treatment may be impeded by psychosocial stigma, compliance with complex regulatory requirements around certain medications, and the increased difficulties manifested during acute and post-acute care of patients with psychosis. While this review reflects our opinion and our interpretation and recommendations may not be applicable to settings outside of LTC, a shift in the treatment paradigm for these troubling symptoms that addresses the aforementioned issues is worthy of further discussion.