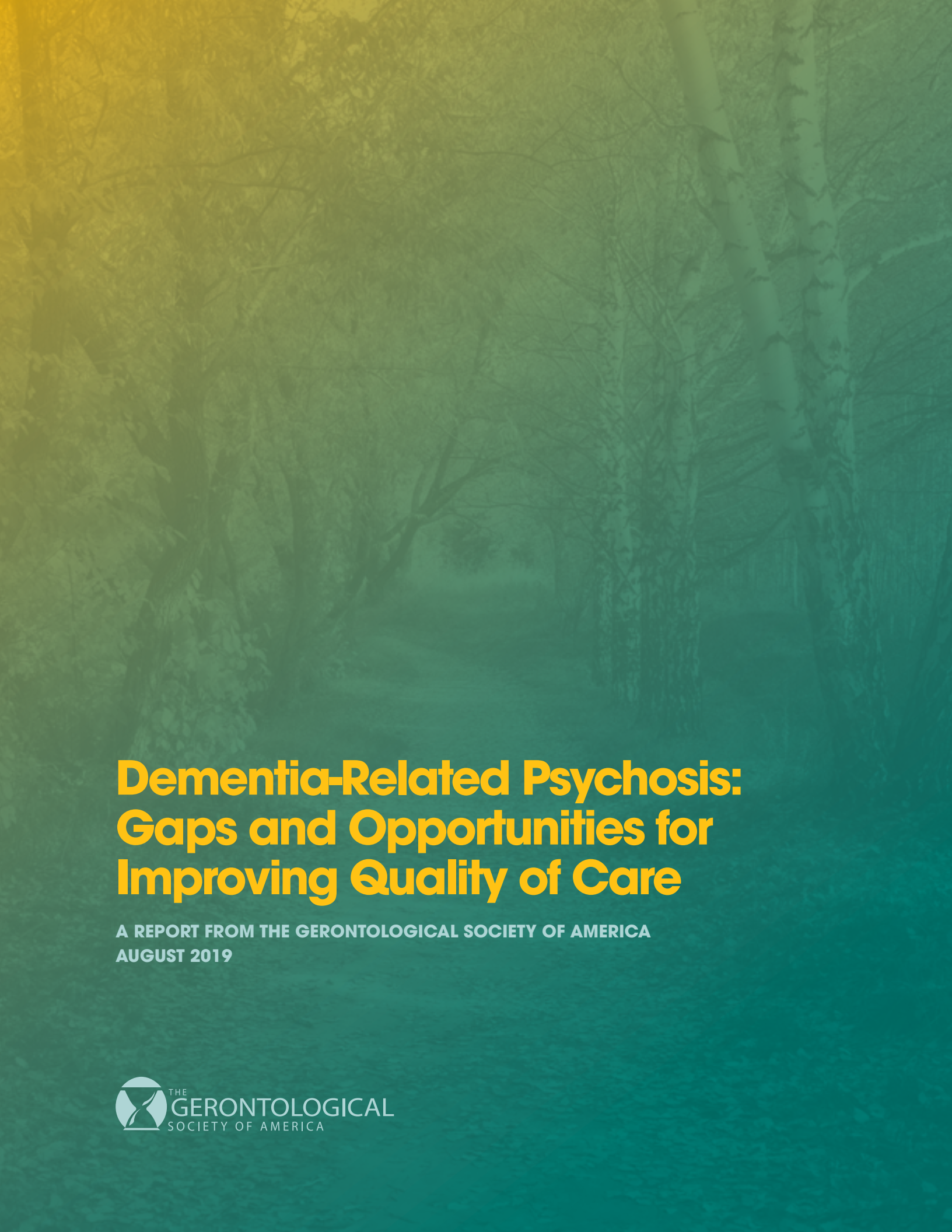

Dementia-Related Psychosis: Gaps and Opportunities for Improving Quality of Care

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Introduction

Dementia-related psychosis, characterized by the presence of delusions and hallucinations, is common in patients with dementia and affects patients with all forms of dementia. Patients with dementia-related psychosis have more severe neurodegenerative changes and worse outcomes compared with patients who have dementia without psychosis.[1] Although dementia-related psychosis is common in patients with dementia, it may not be recognized or formally diagnosed as such and, when diagnosed, dementia-related psychosis is less likely to be documented using a diagnostic code.[2,3] Gaps in diagnosis and documentation are partially due to a lack of widely accepted diagnostic criteria, insufficient assessment and treatment strategies, as well as an absence of diagnostic codes that are specific to dementia-related psychosis.

The lack of consistent diagnosis and documentation creates a barrier to the delivery of appropriate care for best addressing patient needs. In response to this issue, this report: (1) describes current gaps in assessment and diagnosis of dementia-related psychosis; (2) summarizes best practices for treating the condition; and (3) identifies opportunities to advance quality of care for individuals with dementia-related psychosis, primarily through recommended improvements to patient identification, documentation, and care planning.

Dementia

Dementia is a neurodegenerative condition that results in a progressive decline in multiple cognitive domains that affect a person's behavior and functional abilities. Dementia is not considered a specific disease but rather a constellation of signs and symptoms. Although Alzheimer's disease is the most common form of dementia, there are several types, including vascular dementias (e.g., multi-infarct dementia, Binswanger's disease), dementia with Lewy bodies, Parkinson's disease, frontotemporal dementia, and others.[4] In 2019, more than 5.8 million people in the United States were living with dementia.[5]

Approximately one in three older adults has some type of dementia at the time of death.[5] Patients with dementia generally live for 4 to 8 years after diagnosis; however, the length of time varies significantly depending on the duration of symptoms before diagnosis, the patient's age, and the presence of other health conditions. Patients may live with dementia for as long as 20 years.[4]

Dementia places intense demands on family caregivers. According to estimates, more than 18.5 billion hours of unpaid caregiving assistance, valued at nearly $234 billion, were provided to patients with dementia in 2018.[5] Caregivers often experience substantial emotional, financial, and physical difficulties when caring for those with dementia.

The neuropsychiatric symptoms of the condition contribute to the challenges of delivering appropriate and person-centered care. Evidence suggests that patients with neuropsychiatric symptoms of dementia experience worse outcomes than those without neuropsychiatric symptoms, including the following:

- Greater impairment in activities of daily living[6]
- Worse quality of life[6,7]
- Earlier institutionalization[6,8,9]
- Increased family caregiver burden[10]
- More than $10,000 per year of additional total direct care costs per patient[11]
- Shorter time to severe dementia[12]
- Accelerated mortality[9,12]

In many cases, patients with dementia ultimately require care 24 hours a day, with the caregiving burden exceeding the capacity of family and loved ones. Patients often transition to long-term care facilities. As a result, dementia is one of the costliest health conditions in the United States. In addition to long-term care costs, health care costs in general are higher for patients with dementia, compared with older adults without dementia, because these patients are twice as likely to be hospitalized, are at increased risk for other chronic conditions, and are more likely to receive adult day services and home care visits.[5]

For 2019, total health care costs and long-term care payments for patients with dementia will amount to an estimated $290 billion, with Medicare and Medicaid covering approximately two thirds of these costs.[5]

Diagnosis of Dementia

The fifth edition of the American Psychiatric Association (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) uses the term *neurocognitive disorder* in an effort to minimize some of the stigma associated with the term *dementia*—while recognizing that the term *dementia* will still be widely used.[13] According to the DSM-5, the diagnostic criteria for a major neurocognitive disorder involve one or more acquired significant impairments (independence lost) in cognitive domains such as the following:[13]

- Memory (amnesia)
- Language (aphasia)
- Execution of purposeful movement (apraxia)
- Recognition and familiarity (agnosia)
- Visuospatial function (topographical disorientation)
- Self-control and management (executive functions impairment)

Other impairments may include the following cognitive domains:

- Calculation (dyscalculia)
- Emotional expression and comprehension (dysprosody)
- Writing (agraphia)

WORDS MATTER: STIGMA AS AN IMPEDIMENT TO CARE

Both patients with dementia and their caregivers may experience stigma. Stigma is defined as a discrediting characteristic within a social interaction that may lead to labeling, stereotyping, loss of status, and discrimination.[14] Stigma associated with dementia may lead to low self-esteem, isolation, poor mental health, and decreased quality of life.[15] It may lead others to patronize, stereotype, isolate, or discriminate against those with this condition.[16] Stigma associated with dementia can also impede patient willingness to seek diagnosis and treatment, resulting in delayed access to care and impaired quality of life.[16]

A recent survey of adults in the United States reported that older adults believe patients with a dementia diagnosis would have less support, have social interactions limited by others, and face institutional discrimination. In another survey, respondents reported that they expected an individual with mild dementia would be discriminated against by employers and be excluded from medical decision-making.[16,17]

The term *psychosis* is also associated with stigma for patients. Incorporating discussions of psychosis as a potential future symptom of dementia early in the patient journey may help to decrease stigma. During conversations with patients and caregivers, framing psychosis as a manifestation of a brain disease rather than as a symptom of purportedly "being crazy" is an important skill for clinicians. The goal is to help patients understand that delusions and hallucinations are a manifestation of dementia rather than an indicator of another psychiatric syndrome.

Signs and symptoms of dementia are distinct from normal age-related changes. According to recommendations from the National Institute on Aging and the Alzheimer's Association, dementia is diagnosed when cognitive or behavioral symptoms are present that interfere with the ability to function at work or at usual activities, represent a decline from previous levels of functioning and performing, and are not explained by delirium or a major psychiatric disorder.[18] Cognitive impairment is detected and diagnosed through a combination of (1) history-taking from the patient and from a knowledgeable informant and (2) an objective cognitive assessment, either a bedside mental status examination or neuropsychological testing. Neuropsychological testing should be performed when the routine history and bedside mental status examination cannot provide a confident diagnosis.

"Behavioral and psychological symptoms of dementia are recognized as a common manifestation of dementia and may include agitation, aggression, and psychosis. Although these symptoms can occur in tandem with each other, each symptom can occur individually and warrants specific interventions."



In a diagnosis of dementia, the cognitive or behavioral impairment involves a minimum of two of the following domains:[18]

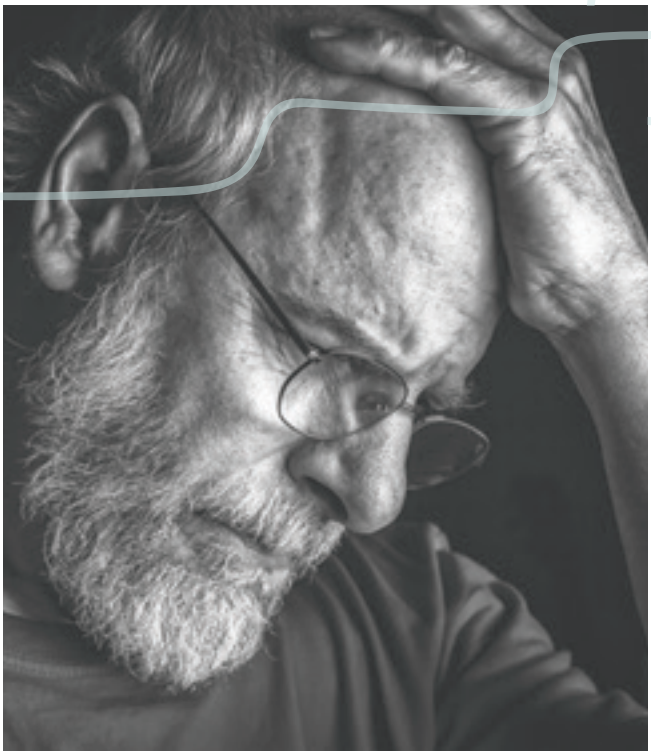
- Impaired ability to acquire and remember new information—symptoms include repetitive questions or conversations, misplacing personal belongings, forgetting events or appointments, getting lost on a familiar route.
- Impaired reasoning and handling of complex tasks, poor judgment—symptoms include poor understanding of safety risks, inability to manage finances, poor decision-making ability, inability to plan complex or sequential activities.
- Impaired visuospatial abilities—symptoms include inability to recognize faces or common objects or inability to find objects in direct view despite good acuity, inability to operate simple implements, inability to orient clothing to the body.
- Impaired language functions (speaking, reading, writing)—symptoms include difficulty thinking of common words while speaking, hesitations; speech, spelling, and writing errors.
- Changes in personality, behavior, or comportment—symptoms include uncharacteristic mood fluctuations such as agitation, impaired motivation, initiative, apathy, loss of drive, social withdrawal, decreased interest in previous activities, loss of empathy, compulsive or obsessive behaviors, socially unacceptable behaviors.

Behavioral and psychological symptoms of dementia (BPSD) are recognized as a common manifestation of dementia and may include agitation, aggression, and psychosis.[19] Although these symptoms can occur in tandem with each other, each symptom can occur individually and warrants specific interventions.[20]

Dementia-Related Psychosis

Symptoms of dementia-related psychosis include delusions (false beliefs) and hallucinations (seeing or hearing things that others do not see or hear). Other symptoms include incoherent or nonsense speech and behavior that is inappropriate for the situation. These behaviors often arise when a person with dementia-related psychosis loses insight and begins to interact with a hallucination. Delusions and hallucinations can be frequent, severe, and persistent, and they may cause distress not only for the person with dementia but also for family caregivers.[18] Ongoing monitoring by health care providers or family caregivers is important because symptoms can worsen over time.[21]





Delusions and hallucinations are often persistent and occur with increasing frequency as dementia progresses.[22] One study found a 1-year psychosis incidence of 10%, which was related to cognitive status.[21] However, the incidence rate reached a plateau during the course of the disease. Cumulative psychosis incidence at 5 years was 61% in individuals with moderate to severe Alzheimer's disease.[21] The prevalence of delusions has been estimated at 18% (range, 4%–41%) for hallucinations and 36% (range, 9.3%–63%) for delusions.[22] Overall, approximately 2.34 million people in the United States have dementia-related psychosis.[23-28]

Psychosis (including delusions and hallucinations) often manifests differently in dementia than it does in patients with psychosis due to other etiologies.[20,29] According to the DSM-5, psychotic symptoms occur in a variety of psychotic and neurodegenerative disorders, ranging from schizoid disorder to schizophrenia. Hallucinations and delusions are components of the neuropsychiatric disturbances seen in these disorders, with other symptoms including abnormal psychomotor behaviors, negative symptoms, cognitive impairments, and emotional disturbances.[3]

Hallucinations are defined as "a sensory perception in the absence of a corresponding external or somatic stimulus and described according to the sensory domain in which it occurs."[30] Delusions are defined as "fixed false beliefs; they are based on incorrect (false) inferences about reality external to, or about, oneself and maintained firmly (fixed) despite the presentation of evidence that obviously and incontrovertibly contradicts the belief."[30] There are two types of delusions: (1) ordinary or simple delusions, which are based on plausible events (e.g., the patient believes someone is stealing from her or him despite evidence to the contrary) and (2) bizarre delusions, which are based on beliefs about physically implausible or impossible occurrences.[30]

Dementia-related psychosis is considered to be a distinct clinical entity with features and manifestations that differ from those seen in patients with other conditions associated with psychosis, such as schizophrenia (Table 1).[20] Whereas patients with schizophrenia often have delusions that are complex or bizarre, patients with dementia usually have delusions that are relatively discrete or simple.[20] Additionally, although patients with schizophrenia often experience hallucinations involving voices, those with dementia experience hallucinations involving a variety of senses (i.e., auditory, visual, olfactory, and tactile).

TABLE 1. FEATURES OF PSYCHOSIS IN ALZHEIMER'S DISEASE COMPARED WITH SCHIZOPHRENIA IN OLDER ADULTS

	PSYCHOSIS IN ALZHEIMER'S DISEASE	SCHIZOPHRENIA
1. Incidence	30% to 50%	Less than 1%
2. Bizarre or complex delusions	Rare	Frequent
3. Misidentification of caregivers	Frequent	Rare
4. Common forms of hallucinations	Visual	Auditory
5. Schneiderian first-rank symptoms	Rare	Frequent
6. Active suicidal ideation	Rare	Frequent
7. Past history of psychosis	Rare	Very common
8. Eventual remission of psychosis	Frequent	Uncommon
9. Need for many years of maintenance on antipsychotics	Uncommon	Very common
10. Average optimal daily dose of an antipsychotic	15% to 25% of dose for a young adult with schizophrenia	40% to 60% of dose for a young adult with schizophrenia

Source: Adapted from Reference 20. Used with permission of American Journal of Geriatric Psychiatry, from Jeste DV, Finkel SI. Psychosis of Alzheimer's disease and related dementias. Diagnostic criteria for a distinct syndrome. 2000;8(1):29–34. Permission conveyed through Copyright Clearance Center Inc.

It is noteworthy that dementia-related psychosis, similar to other BPSDs, presents particular challenges to the quality of care that individuals with dementia receive. Studies have documented that individuals with dementia who present with psychosis symptoms have worse outcomes than those who do not experience symptoms of psychosis. In particular, dementia-related psychosis has been associated with higher mortality and is predictive of progression to nursing home care.[1,31]

Diagnosis, Assessment, and Documentation of Dementia-Related Psychosis: Current Practices and Gaps

Although dementia-related psychosis is common, lack of consensus regarding how to define this condition makes diagnosis a challenge. In 2000, Jeste and Finkel proposed diagnostic criteria for a distinct syndrome (Table 2).[20]

TABLE 2. DIAGNOSTIC CRITERIA FOR PSYCHOSIS OF ALZHEIMER'S DISEASE

A. Characteristic Symptoms

Presence of one or more of the following symptoms:

1. Visual or auditory hallucinations
2. Delusions

B. Primary Diagnosis

All the criteria for dementia of the Alzheimer type are met.

C. Chronology of the Onset of Symptoms of Psychosis vs. Onset of Symptoms of Dementia

There is evidence from the history that the symptoms in Criterion A have not been present continuously since prior to the onset of the symptoms of dementia.

D. Duration and Severity

The symptoms in Criterion A have been present, at least intermittently, for 1 month or longer. Symptoms are severe enough to cause disruption in patient's and/or others' functioning.

E. Exclusion of Schizophrenia and Related Psychotic Disorders

Criteria for schizophrenia, schizoaffective disorder, delusional disorder, or mood disorder with psychotic features have never been met.

F. Relationship to Delirium

The disturbance does not occur exclusively during the course of a delirium.

G. Exclusion of Other Causes of Psychotic Symptoms

The disturbance is not better accounted for by another general medical condition or direct physiological effects of a substance (e.g., a drug of abuse, a medication).

Associated Features: (specify if associated)

With Agitation: when there is evidence, from history or examination, of prominent agitation with or without physical or verbal aggression.

With Negative Symptoms: when prominent negative symptoms, such as apathy, affective flattening, avolition, or motor retardation, are present.

With Depression: when prominent depressive symptoms, such as depressed mood, insomnia, or hypersomnia, feelings of worthlessness or excessive or inappropriate guilt, or recurrent thoughts of death, are present.

Note: Criterion B applies only to Alzheimer's disease and will need to be modified for related dementias, such as vascular dementia.
Source: Reference 20. Used with permission. Used with permission of American Journal of Geriatric Psychiatry, from Jeste DV, Finkel SI. Psychosis of Alzheimer's disease and related dementias. Diagnostic criteria for a distinct syndrome. 2000;8(1):29–34. Permission conveyed through Copyright Clearance Center Inc.

However, these diagnostic criteria have not been widely adopted, and no specific diagnostic codes have been developed for dementia-related psychosis. Thus, formal diagnostic criteria for dementia-related psychosis as a distinct diagnosis are needed to support assessments of epidemiology, clinical impacts, and treatment outcomes.[20]

Furthermore, no specific scales have been developed to assess for dementia-related psychosis, partially because of the lack of a precise definition that clinicians can operationalize.[32] Dementia-related psychosis is frequently characterized as being synonymous with agitation, lability, and irritability. Although these symptoms fall under the same umbrella of BPSD, they do not necessarily stem from hallucinations or delusions; most scales currently used in clinical practice do not account for differences in etiology. Existing assessment tools include the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD), the Neuropsychiatric Inventory–Nursing Home version (NPI-NH), the Consortium to Establish a Registry for Alzheimer's Disease–Behavior Rating Scale for Dementia (CERAD-BRSD), and the Columbia University Scale for Psychopathology in Alzheimer's Disease (CUSPAD). The development of more sensitive and specific indicators for clinicians' inquiry when evaluating patients presenting with dementia-related psychosis symptoms could allow for more accurate patient assessment and lead to more effective treatment protocols.

"The development of more sensitive and specific indicators for clinicians' inquiry when evaluating patients presenting with dementia-related psychosis symptoms could allow for more accurate patient assessment and lead to more effective treatment protocols."

Moreover, no diagnostic codes in the *International Statistical Classification of Diseases–Tenth Revision* (ICD-10) are specifically intended for dementia-related psychosis. As a result, documentation and coding of dementia-related psychosis is not only challenging but also confusing.[2] This situation can result in unintended consequences that negatively affect patient outcomes.[1,31,33,34] Results from a recent study conducted by The Moran Company examined coding for dementia-related conditions in 2016–2017 Medicare claims data. The study assessed the proportion of beneficiaries who initially received a dementia diagnosis and later also received a diagnosis of either psychosis or behavioral disturbance, or both. This study found that most beneficiaries with dementia received a code only for a dementia diagnosis with no additional diagnosis for psychosis. This finding was consistent for all dementia subtypes. Among patients who received an additional diagnosis code, most were coded as having a behavioral disturbance rather than psychosis.[3]

Clinicians, allied health professionals, and patient advocates are concerned about whether the behavioral disturbance code is appropriate for dementia-related psychosis. Behavioral disturbance is defined as violent, aggressive, or combative behavior—which is not reflective of psychosis. This code does not encourage providers to implement interventions that are appropriate for managing delusions and hallucinations or other clinical needs.[2] Moreover, some long-term care facilities may refuse to admit patients who have this code in their files.[2]

Recommended Approaches to Treatment of Dementia-Related Psychosis: Current Practices and Gaps

In individuals who present with symptoms of psychosis, an initial assessment of the type, frequency, severity, pattern, and timing of symptoms can help in treatment planning.[22]

Behavioral interventions are preferred, when possible, to address many behavioral symptoms of dementia. In addition to distinguishing between symptoms of confusion and psychosis, basic principles of care include the following:[35]

- Consider and address sensory impairments (vision, hearing).
- Support patient autonomy and adjust expectations over time.
- Avoid confrontation; if the patient becomes upset, remain calm, firm, and supportive.
- Maintain a consistent, structured environment with an appropriate stimulation level.
- Provide frequent reminders, explanations, and orientation cues.
- Employ guiding, demonstration, and reinforcement.
- Reduce choices, simplify requests, and avoid tasks that cause frustration.
- Consult a health care professional to address sudden declines in function or emergence of new symptoms.

Although a growing body of research is addressing how to implement these principles and other best practices for dementia care in evidence-based programs,[36,37] more research is needed to assess how to implement best-care strategies for BPSD that are most effective for managing dementia-related psychosis.

In addition, training for care team members on how to educate and support family caregivers is crucial. As persons with dementia experience loss of function, they and their family members typically have difficulty adapting to their evolving roles and should be informed about what to expect. Rationalization of symptoms and denial are common. Starting conversations about plans for the patient's care, financial affairs, and legal matters over time can be uncomfortable. Care teams should regularly monitor the patient's health and cognition and offer education and support.

Pharmacological Treatments for Patients With Dementia-Related Psychosis

Although no medications are approved for the treatment of dementia-related psychosis, antipsychotics are commonly used off-label in patients with dementia presenting with neuropsychiatric features.[38,39] Other medications that are sometimes considered include antidepressants (e.g., citalopram, sertraline, trazodone), the anticonvulsant divalproex, or cholinesterase inhibitors—although evidence for the effectiveness of these agents for treating dementia-related psychosis is lacking.[40] These medications tend be used off-label more often for nonspecific agitation.[38]

The use of antipsychotic medication for dementia-related psychosis has been reported historically to have limited efficacy and has been associated with increased short-term mortality.[33] Owing to this associated risk of mortality, the U.S. Food and Drug Administration (FDA) has issued a boxed warning for all atypical antipsychotics.[41] Other common side effects of these medications include sedation, dizziness, postural hypotension, and confusion—and their use may increase the risk of falls. Extrapyramidal symptoms, such as tardive dyskinesia and Parkinsonism, are common in patients with dementia. Antipsychotics may also reduce the seizure threshold.[42]

In 2014, an expert workgroup convened by the APA to review the evidence on available symptomatic treatments for dementia concluded that although newer trials and studies on antipsychotic drugs have better defined adverse effects, they have demonstrated minimal or no efficacy for treating psychosis.[43] For example, in the long-term, randomized, placebocontrolled discontinuation trial, Dementia Antipsychotic Withdrawal Trial–Alzheimer's Disease (DART-AD), 165 patients were randomly assigned to continue or discontinue their antipsychotic medications (specifically, risperidone and haloperidol). DART-AD showed a continuing increase in the risk for death among patients who continued to take anti-psychotics compared with patients for whom antipsychotics were tapered and changed to placebo.[44] Thus, available evidence lends support for attempting nonpharmacological interventions and environmental measures prior to initiating pharmacotherapy to reduce psychosis.[43]

Pimavanserin is a new therapy in this complex treatment landscape. The FDA approved pimavanserin in 2016 as the first treatment for hallucinations and delusions associated with psychosis experienced by patients with Parkinson's disease.[45] Phase 3 clinical studies are underway to assess its safety and efficacy for treating hallucinations and delusions associated with dementia-related psychosis. The FDA has designated the agent as a breakthrough therapy, a designation intended to expedite the review of pimavanserin as a medication that has shown substantial improvement over existing treatments in early clinical data.

ANTIPSYCHOTICS AND LONG-TERM CARE FACILITIES

Under the Centers for Medicare & Medicaid Services' Five-Star Quality Rating System, the use of antipsychotic medications in patients who reside in long-term care facilities is penalized unless patients have schizophrenia, Tourette's syndrome, or Huntington's disease.

Therefore, patients in long-term care facilities who have dementia-related psychosis or other conditions that could benefit from antipsychotic medication (e.g., bipolar depression) may face barriers to accessing appropriate pharmacotherapy. Discontinuing antipsychotic medication upon admission to a long-term care facility can precipitate a further decline in function and behavior and set the patient on a trajectory of decline.[2]

Guideline Recommendations

Based on the mixed body of evidence and no therapies approved for dementia-related psychosis, recent clinical practice guidelines and other guidance documents by professional societies and government agencies recommend caution in prescribing antipsychotics for nonemergency purposes.

The APA's 2016 practice guideline recommends that when treating individuals with dementia for psychosis with antipsychotic medications, "potential for harms must be balanced against their modest evidence of benefit."[22]

Moreover, for the treatment of psychosis, the APA recommends the following:[22]

- As a first-line approach, the use of nonpharmacological interventions prior to nonemergency use of an antipschotic medication.
- The use of nonemergency antipsychotic medication only when "symptoms are severe, are dangerous, and/or cause significant distress to the patient."
- Prior to initiating treatment with an antipsychotic, "the potential risks and benefits from antipsychotic medication be assessed by the clinician and discussed with the patient (if clinically feasible) as well as with the patient's surrogate decision maker (if relevant) with input from family or others involved with the patient."

The APA also notes that although no studies have been conducted to assess the harms of withholding antipsychotic medication from patients with psychosis, "clinical observations suggest that such delays could lead to poorer outcomes for some individuals, such as physical injury to themselves or others, disruptions of relationships with family or other caregivers, or loss of housing due to unmanageable behavioral and psychological symptoms."[22]

The Substance Abuse and Mental Health Services Administration (SAMHSA) recently released its *Guidance on Inappropriate Use of Antipsychotics: Older Adults and People With Intellectual and Developmental Disabilities in Community Settings.* This document affirms that treatment of patients with a history of primary psychotic disorders should be different from treatment of patients who manifest new-onset psychosis due to dementia.[42] Consistent with the APA's recommendation, SAMHSA indicates that although nonpharmacologic treatments are the preferred approach, medications may be indicated if psychotic symptoms cause severe distress or an immediate risk of harm to the individual or others.[42]

SAMHSA offers several principles for prescribing antipsychotics for people with dementia and behavioral disturbances (defined to include psychosis in the guidance document):[42]

- Antipsychotic medications should be avoided when possible.
- If indicated, dosage should be started as low as possible with modest increases only when necessary.
- Second-generation antipsychotics are preferable over first-generation antipsychotics due to more favorable side effect profiles.
- Medications should be discontinued if no clinical benefit is observed.
- Discontinuation may need to be considered for those who experience side effects even if there is improvement in behavioral symptoms.
- Taper should be attempted for all patients within 4 months of treatment with close monitoring.

The guidance document also notes that, as a general principle, the side effect profile of an antipsychotic should be considered in relation to each patient's individual needs and preferences. For example, second-generation antipsychotics are associated with weight gain and therefore should be used with greater caution in patients who are overweight or obese. The type of dementia, if known, may also influence treatment selection. For example, patients with Lewy body dementia or Parkinson's disease are at increased risk for side effects associated with antipsychotics and should avoid use of these medications whenever possible.[42]

Opportunities to Improve Care for Patients With Dementia-Related Psychosis

Ongoing work to refine diagnostic criteria for dementia-related psychosis will allow for greater awareness of the specific features of this condition and establish a foundation for meeting patient needs. The creation of a consensus-based approach to the diagnosis of dementia-related psychosis will allow for wider agreement on the use of assessment tools as well as more uniformity regarding research into various aspects of the condition—including prevalence, disease progression, effectiveness of treatment interventions, real-world effectiveness research, and assessments of outcomes.

Creation of generally agreed-upon assessment tools will also support improved patient identification, which can lead to the development of interventions that are most appropriate for individual patient needs. Some tools already exist to support care management approaches that are individualized to the needs of patients with dementia. For example, The DICE Approach (Describe, Investigate, Create, Evaluate) is designed to help support the care of patients with BPSD using evidence-based strategies to customize interventions.[46] Its aim is to help caregivers better manage BPSD and reduce medication use.

Beyond helping to target specific interventions, dementia-related psychosis assessment and diagnosis are foundational to the creation of care pathways. Potential models include the U.K. National Institute for Health and Care Excellence (NICE) care pathway for dementia and a 2016 report from RTI International that identifies 14 key components or processes of comprehensive dementia care based on a review of clinical guidance.[47,48]

Creation of new ICD-10 codes that are specific to dementia-related psychosis could also help improve the care journey for patients with this condition. Such codes could indicate when patients with various types of dementia experience delusions or hallucinations. The dementia-related psychosis codes would be distinct from other ICD-10 codes for psychosis—which are used to address a wide range of psychosis manifestations—and thus serve as a cohesive addition to existing codes, rather than being a disjointed extension. Creating dementia-related psychosis–specific codes will help all professionals involved in the care of persons with dementia to better recognize and manage the condition and associated symptoms. New codes would support an increased focus on person-centered care, including guideline-recommended nonpharmacologic treatment approaches. These approaches would be included as part of the proper management of the condition, across all care settings, particularly as patients undergo transitions of care. As new therapies receive approval and become available, the existence of dementia-related psychosis codes will facilitate appropriate access for patients who could clinically benefit.

Appropriate documentation of dementia-related psychosis can facilitate better care planning and improved care coordination. Development of effective care plans can support patients and family caregivers in a variety of settings. In the community setting, more effective care plans that address the needs of patients with dementia-related psychosis may be associated with delayed institutionalization, because psychosis can be one of multiple factors (e.g., combative behaviors, challenges with daily living) that may lead families and care providers to transfer loved ones with dementia to a long-term care setting.

“Creation of new ICD-10 codes that are specific to dementia-related psychosis could also help improve the care journey for patients with this condition.”

A noteworthy example of a program focused on supporting caregivers and improving disease management for dementia in general is the Alzheimer's and Dementia Care program at the University of California, Los Angeles. The program has been successful in managing and reducing a variety of patient symptoms (dementia-related psychosis was not explicitly addressed), keeping people in their homes longer and improving the experience of family caregivers. Participants with dementia were 40% less likely to be admitted to a long-term care facility than similar patients with dementia who did not participate in this program.[49]

In addition, comprehensive care planning may enable improvements in management of dementia-related psychosis that can be effective in addressing the adverse health events that frequently lead to hospitalization. Although more clinical studies are needed in this area,[50] patients with comprehensive care plans are less likely to escalate to behaviors that require emergency department visits and hospitalizations, and they are more likely to avoid the downward trajectory in patient function and outcomes.[2]

Finally, diagnostic codes that are specific to dementia-related psychosis, along with appropriate coding practices, would allow researchers and investigators to analyze claims data that more accurately reflect clinical practice. Thus, the creation of proper codes for dementia-related psychosis, and their implementation in clinical practice, will facilitate better tracking of the value of a wide range of interventions for the condition.

Conclusion

Dementia-related psychosis is a highly prevalent condition that often manifests in patients with dementia but is underdiagnosed. Psychotic symptoms in patients with dementia are typically limited to delusions and hallucinations and can be differentiated from the manifestations of psychosis in other conditions, such as schizophrenia. Although diagnostic criteria for dementia-related psychosis were proposed in 2000, these criteria pertained only to Alzheimer's-type dementia. As such, much work is needed to formalize and expand these criteria to include other dementias and to develop sensitive and specific scales for assessment.

Better diagnostic clarity will drive more careful attention to dementia-related psychosis. It follows that the development of ICD-10 codes specific to dementia-related psychosis could improve documentation of the condition and subsequent care planning activities. The field could benefit from further research on evidence-based strategies for treating dementia-related psychosis.

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