HCP EDUCATION

Caregivers as Catalysts for Earlier Identification of Agitation in Alzheimer's Disease-related Dementia

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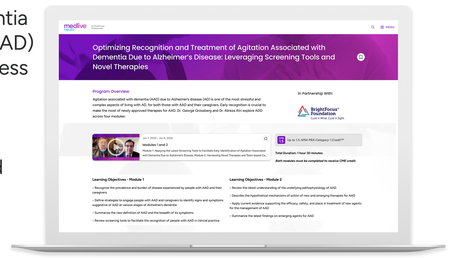
INTRODUCTION

Agitation associated with dementia due to Alzheimer's disease (AADAD) drives substantial caregiver distress and health care utilization. Caregivers are often the earliest observers of agitation, yet their input is inconsistently integrated into clinical assessment and treatment, potentially delaying recognition and effective management.



In collaboration with the BrightFocus Foundation, a caregiver-centered educational initiative was designed to evaluate gaps in clinician preparedness to engage caregivers in the identification and management of AADAD. A national survey of neurologists and psychiatrists assessed clinician confidence in recognizing agitation, using validated assessment tools, and implementing approaches to caregiver communication. Findings informed a multidisciplinary roundtable of family caregivers and clinicians from neurology, psychiatry, nursing, social work, and rehabilitation disciplines. Caregiver narratives were used to identify barriers to reporting symptoms, navigating terminology, and participating in shared decision-making. These insights informed a four-module continuing medical education (CME) program focused on caregiver-inclusive assessment strategies, structured communication, and collaborative care planning.

METHODOLOGY

Educational Program and Evaluation Details

Interventions

An online, video-based, enduring, multi-component CME initiative for healthcare providers (HCPs) featured two multidisciplinary activities, one activity for psychiatrists, and another for neurologists. All four activities launched on January 7, 2025. To extend reach, micro-learning videos were targeted to NPI-verified neurologists and psychiatrists via IQVIA/LinkedIn.

Data Collected

A survey-based approach measured the impact of the CME as aligned with stated learning objectives via pre- and post-activity knowledge/competence questions developed in accordance with National Board of Medical Examiner guidelines,[1] as well as a post-activity evaluation (inclusive of intended practice changes: open-ended). Statistical tests of significance were applied to comparisons of individual questions (pre- vs post-activity).

Reference:
1. NBME Item-Writing Guide. Constructing written test questions for the health sciences. Nov 2020. www.nbme.org/item-writing-guide.

CONCLUSION

Caregivers represent a critical yet underutilized resource in the recognition and management of AADAD. Educational interventions that explicitly center caregiver perspectives and communication strategies can improve clinician readiness to partner with caregivers, potentially enabling earlier identification of agitation and more effective, person-centered care for individuals living with Alzheimer's disease.

RESULTS

National Survey

Survey respondents (n=120) reported low confidence in systematically incorporating caregiver input into AADAD assessments, with inconsistent use of caregiver-informed screening tools.

of survey respondents reported that they were "familiar" or "very familiar" with screening tools for AAD*

*Rating of 4 or 5 on 5-point scale

However, when asked which screening tools were used in clinical practice:

43% stated that they did not use screening tools to identify patients with AAD

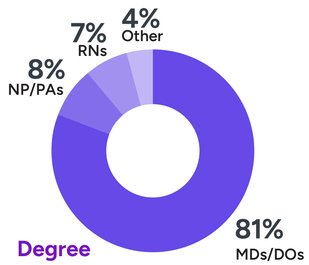
57% indicated that they wanted more education on utilizing novel screening tools for AAD for clinicians and caregivers

42% wanted education on diagnosing patients with AAD

Modular Education

7,939 Total Engagements
2,977 CME activity participations + 4,962 micro-learning completions

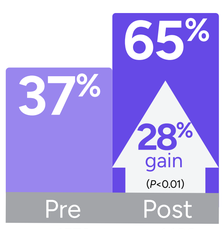
of CME learners completed their activity



Learning Gains

Differentiate agitation from other neuropsychiatric symptoms

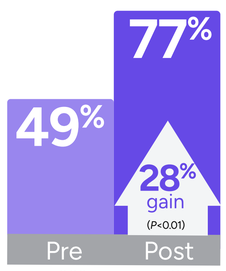
According to the International Psychogeriatric Association (IPA) definition, agitation behaviors in cognitive disorders must meet which of the following criteria?



% correct
Must produce disability beyond that due to cognitive impairment

Ability to recognize caregiver-reported agitation

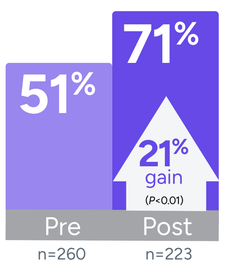
A caregiver of a 76-year-old man with moderate Alzheimer's dementia reports increasing episodes of agitation, including yelling and pacing. Which tool would be most appropriate for screening the patient for AADAD?



% correct
Neuropsychiatric Inventory (NPI)

Engage caregivers in treatment discussions

A 72-year-old woman with Alzheimer's disease and severe agitation is prescribed brexpiprazole. Which safety consideration should be discussed with her caregiver before starting treatment?



% correct
Elderly patients with agitation and dementia-related psychosis are at an increased risk of death when treated with brexpiprazole

Multidisciplinary Roundtable

Caregivers participating in the roundtable described uncertainty about how to label agitation symptoms and expressed reluctance to raise concerns due to fear of stigma or treatment escalation:

> **Holly Strelzik (caregiver):** "It's hard because it just reminds me that he's not who he was. I no longer feel like his wife – I just feel like his caregiver."

> **Holly Strelzik (caregiver):** "I don't want to drug him. I don't want to numb him out."

> **Rick Henkin (caregiver):** "[There's a] general depression that she's just disappearing. She, you know, it sounds like a morbid thought, but sometimes I feel like I'm holding a terrible secret that I can't tell her because I know what the end game is, and she doesn't. It makes me feel really bad."

Roundtable faculty also highlighted concerns about the lack of engagement of caregivers in the diagnostic process and differences in terminology between clinicians and caregivers when describing agitation symptoms and their severity:

> **Dr. Grossberg (psychiatrist):** "Another barrier is often using the wrong terminology, because often, 'agitation' is not something that's meaningful to families. They may describe other things, like their loved one being short-tempered, having less patience, or being more irritable. And all of that takes time…time is something that the HCPs don't have much of."

> **Carolyn Clevenger (NP):** "I think one of the biggest challenges, in terms of recognizing AADAD is that the source of information about that symptom is often somebody other than the patient. In my practice, many times that is a family caregiver…so, if practices don't engage them regularly as part of the visit, then you sort of miss that entire perspective.

> **Carolyn Clevenger (NP):** It also means you have to intentionally be asking about it and seeking information, because what we all understand is AADAD may not look that way to a caregiver, maybe it just looks like a behavior. They may not realize that behavior is part of someone's dementia syndrome or part of their Alzheimer's disease. And so, they're like, we don't use the language that we use as clinicians. So, if we don't ask really specific questions, that's challenging."

Roundtable participants emphasized the need to find therapeutic approaches personalized to each patient and their families, underscoring the need to engage care partners in management discussions:

> **Christine Wilkinson (recreational therapist):** "[To] find the interventions that bring meaning and purpose and joy that are connected to that person…[we should ask] who is that person, past and present, and really tap into that person's needs, their interests, their strengths, their abilities, and provide interventions that connect to all of that."

> **Stacy Smallfield (occupational therapist):** "I would say start small. Don't try and change everything all at once. Choose one thing that's really meaningful and find a way to get it into the routine… It happens daily, whether that's walking or whether that's massage or reminiscence or those kinds of things… And if that's successful, then build on that and add on something from there."

> **Carolyn Clevenger (NP):** "Just think about us as prescribers. The decision to choose any treatment has some standard workflow to it, right? So, the first question is, 'Do I think this is helpful or efficacious for this person?' Or, if I don't know yet, what's the likelihood that this patient will benefit from a particular treatment? You're balancing that with concerns about adverse effects or side-effect profiles that you get from many other medications. And then that third piece for me is what is the patients' and family's priority? What matters most to them at this moment? And that often drives a lot of their risk tolerance and risk."