

Getting to Know Your Patient with Neuropsychiatric Symptoms of Alzheimer's Disease

Overview

- Clinicians who have familiarity with their patients with Alzheimer's disease (AD) and with the patient's history may be able to more readily identify NPS.
- Clinicians often find it helpful to gather additional information from the patient's care partners* and support systems to provide context to the situation.
- It is important that clinicians gather information about the patient's family dynamics, current living arrangements, and support systems, and identify their patient's "decision makers" in order to optimize diagnosis and management of NPS.

NPS of AD: ~98% patients with AD will have \geq 1 NPS during course of their disease

- Apathy, agitation/aggression, anxiety, and depression
- Sleep disorders, motor/gait disturbances (pacing, wandering)
- Psychotic symptoms (delusions and hallucinations)
- Eating problems, disinhibition

NPS may precede cognitive/memory impairments and be the first AD symptoms

- NPS may be the first AD symptoms to be identified by patients or care partners.
- Identification of NPS in the elderly should prompt a more thorough AD evaluation.

Current criterion for diagnosing NPS in patients with AD:

- Established by the International Society to Advance Alzheimer's Research and Treatment (ISTAART)
- Requires that the symptoms represent a "clear change from the individual's typical behavior/personality that persists for at least 6 months."¹
 - \circ $\,$ This information is often provided by the care partner.
 - Clinicians may initiate treatment even if the symptoms have not been apparent for <6 months, but have been consistent for at least a few weeks in the absence of other factors that could explain the change.
 - However, clinicians should immediately evaluate any acute changes that could be indicative of a potential medical issue (delirium, infection, stroke).

The presence of NPS:

- Increases caregiver burden;
- Increases morbidity, mortality, and hastens need for long-term care placements;
- And increases the cost of AD care by an estimated \$85,000/patient/year.²

Clinical Challenges in Recognizing NPS:

- Not knowing the patient well enough to determine a "clear change from typical behavior"
- Patients may be on their "best behavior" and hide aspects of their disease in front of their clinician.
 - Clinicians only see the patient for a brief period of time compared to care partners, who may live with them and are more aware of any concerning behavioral changes.
 - This highlights the importance of collaborating with care partners whenever possible.
- Patient lacks awareness of the symptom(s)
- Lack of a consistent care partner who might recognize the changes
- Care partner may not realize the new symptom is associated with AD
- Care partner may be embarrassed by the new symptom

Information that is <u>Useful</u> for Clinician to Have About AD Patients:

- Family dynamics
 - Who does the patient currently live with?
 - Who cares for the patient if the patient lives alone?
 - Who is the patient's contact person (if not care partner)?
- Current living situation
 - Who can assess the home environment for safety considerations?
 - Does the home have stairs, and can the patient climb the stairs without assistance?
 - o Are there external stairs that the patient must climb to enter/exit the home?
 - o Is the patient able to easily access medical care (office visits, pharmacy, etc.)?
 - o Does the patient still work? Drive? Volunteer? Participate in social activities?
- Financial considerations to discuss with patient and patient's contact person
 - What kind of insurance does the patient have, and what services are covered?
 - Does the patient have any long-term care insurance? And if so, what is covered?
 - What types of expenses might the patient be facing?
 - Full-time in-home skilled caregivers (Note: family members may not be able to address all of the patient's needs as the disease progresses)
 - "Unskilled" caregivers: persons to help with household chores that the patient can no longer manage (lawncare, house cleaning, driving, pet care)
 - Nurses, physical or occupational therapists

- Medication costs and costs for imaging and other diagnostics (especially with the newer therapies such as lecanemab [Leqembi] and donanemab [Kisunla]
- ED visits and hospitalizations
- Potential Need for Alternative Future Living Situations/ long-term or memory care facilities
 - Discuss <u>early</u> in the disease process that living alone or in the current situation may eventually become unfeasible, while the patient can provide input into options for future living arrangements.
 - Recognize that <u>any</u> life changes are always difficult for patients with AD.
 - Suggest that one way to ease the transition to an alternative living situation is to bring items to the new facility that are familiar to the patient—e.g. blanket, table, lamp, photos, pillows.
 - o Identify inevitable changes that will make staying at home challenging:
 - Inability to perform activities of daily living (ADL)
 - Inability to toilet oneself
 - Inability to cook/feed oneself
 - Inability to manage personal finances
 - Appearance of aggressive outbursts
 - Motor inabilities and need for assistance in walking
 - Inability to drive oneself
 - Other safety concerns—e.g., falls, illnesses
- Resources:
 - The Alzheimer's Association (<u>www.alz.org</u>)
 - Case workers (through Medicare, local Social Services)

*care partner: We have chosen to use the term "care partner" because it implies a more collaborative and intimate relationship between the patient receiving the care and the person(s) providing the care. It refers to the person who either lives with the patient or sees them \geq 1-2X/week and is a "softer" term than "caregiver."

References

¹Ismail Z, Agüera-Ortiz L, Brodaty H, et al. The mild behavioral impairment checklist (MBI-C): a rating scale for neuropsychiatric symptoms in pre-dementia populations. *J. Alzheimers Dis.* 2017;56:929–938.

²Cloutier M, Gauthier-Loiselle M, Gagnon-Sanschagrin P, et al. Institutionalization risk and costs associated with agitation in Alzheimer's disease. *Alzheimers Dement (NY)*.2019;5:851–861.