

# Psychosis Is a Prevalent Feature of Dementias

Dementia Subtype	Overall Prevalence of Psychosis, %	Prevalence of Hallucinations, %	Prevalence of Delusions, %
Alzheimer disease dementia	30	11-17	10-39
Vascular dementia	15	5-14	14-27
Dementia with Lewy bodies	75	55-78	40-57
Parkinson disease dementia	50	32-63	28-50
Frontotemporal dementia	10	1.2-13	2.3-6

# The Experience of Hallucinations and Delusions Associated with Dementia: Data from the AAIC Virtual Congress 2020

Understanding the patient experience of dementia-related psychosis from a diagnosed individual and care partner perspective can help characterize treatment needs, clinically important outcomes, and preferences for benefits and risks of treatment

## Qualitative Interviews: n=16 (1 diagnosed individual, 15 care partners)

- Single-visit, 60-minute interviews with those with a clinical diagnosis of all-cause dementia with psychotic symptoms (for at least 2 months) or their care partners, recruited through physician referrals.
- During phone interviews, participants were asked to describe any current treatments being taken for hallucinations or delusions and their perspective related to expectations for potential new treatments.
- The semistructured interview was based on concepts included within the Scale for the Assessment of Positive Symptoms – Hallucinations+Delusions domains and on data from previously conducted surveys

## Quantitative Survey: n=212 (26 diagnosed individuals, 186 care partners)

- The online, 35-item questionnaire was completed by persons with self-reported dementia-related psychosis or their care partners; recruited through direct outreach by UsAgainstAlzheimer's and the Lewy Body Dementia Association.\*
- Participants reported the effectiveness of current treatments with a visual analog scale (VAS) of 0 ("not at all well") to 5 ("extremely well") and ranked benefits of an ideal treatment
- Participants in the qualitative portion were not participants in the survey. Notably, care partners of patients completing the survey were not explicitly excluded from participating, as well.

\*Care partner burden was beyond the scope of this study

# Qualitative Results: Persons with dementia-related psychosis experience hallucinations and delusions that have a substantial impact on their lives

*When he's having these delusions, there are days when he's really sad [...] I know that this is a disease, and it's a sickness, and it's not his fault. But I would love to see him come back as himself. And even if it's not 100%, but be my husband again."*

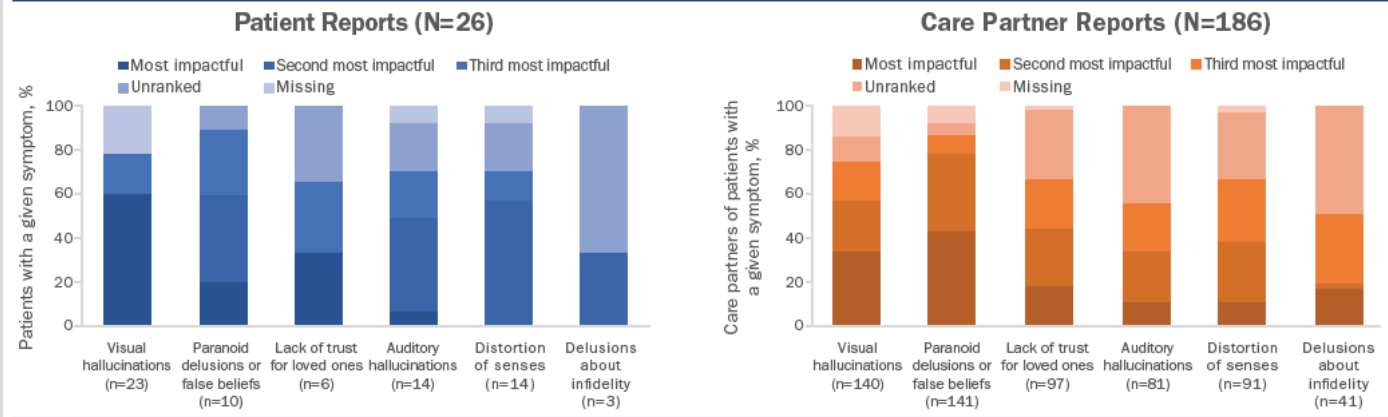
*"...If he could realize it's himself in the mirror and if he could rest at night [...] that's when he can get aggressive because that's when he feels like he needs to do something, go get gas, go to work, go help somebody, and he gets frustrated when he can't get out of the house. And then he's mad at me...I'm the one that's doing all of this and so that's when it gets ugly."*

- The most commonly reported symptoms of dementia-related psychosis were visual hallucinations (87.5%), auditory hallucinations (68.8%), and persecutory delusions (56.3%)
- Participants commonly described dementia-related psychosis as impacting activities of daily living (75.0%), sleep (62.5%), family life (56.3%), and safety (56.3%)
- Regarding treatment, an ideal therapy would have the primary benefits of improving symptoms of dementia-related psychosis and allowing patients with dementia to better distinguish reality from psychotic experiences
  - Care partners expressed concerns about side effects associated with antipsychotics

# Quantitative Results: Data Suggest a Need to Improve Patients' Symptoms and Ability to Know What is Real Versus What is Not Real

- The dementia-related psychosis symptoms most frequently reported by individuals with a diagnosis were visual hallucinations (88.5%), auditory hallucinations (53.8%), and distortion of senses (53.8%); those reported by care partners were paranoid delusions (75.8%), visual hallucinations (75.3%), and lack of trust for loved ones (52.2%).
- Visual hallucinations were reported as occurring weekly by 52.8% of patients and 52.7% of care partners
- Many patients (42.3% according to patients; 41.9% according to care partners) were not receiving medications for dementia-related psychosis.
- Among those who reported discontinuation of treatment, common reasons given were side effects, doctor's recommendation, or lack of symptom improvement

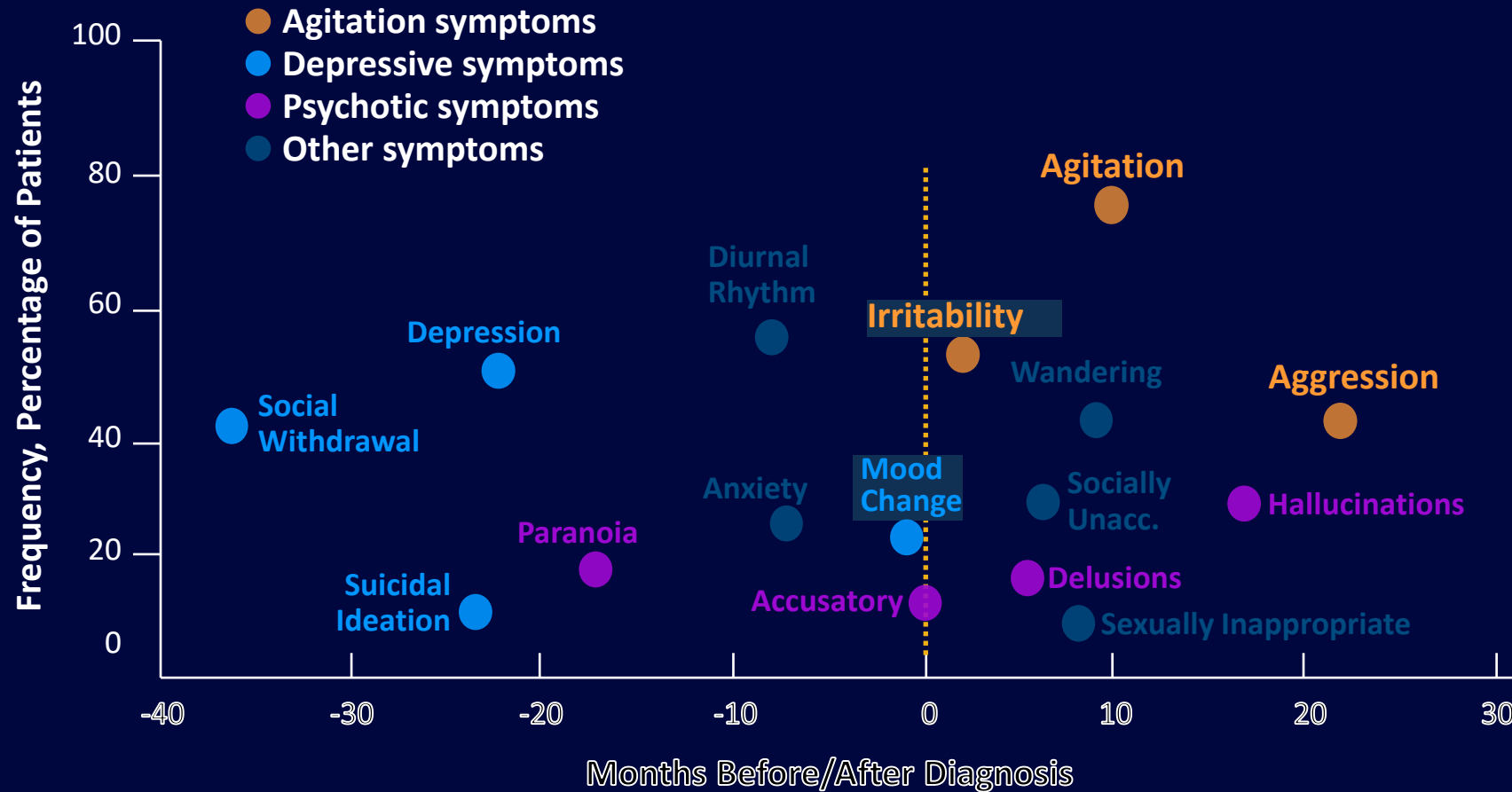
Figure 4. Rankings of the Impact of Symptoms



- For care partners who reported that the patient's paranoid delusions/false beliefs (n=61) or visual hallucinations (n=48) were most impactful, difficulty knowing what is real and what is not (85.2% and 85.4%, respectively), anxiety (85.2% and 72.9%, respectively), and effects on relationships (67.2% and 41.7%, respectively) were common types of impacts reported.

**Symptoms of dementia-related psychosis caused patients to question their understanding of reality and decreased their confidence in engaging fully with daily life.**

# Timeline and Epidemiology of Psychiatric Symptoms in AD



Adapted from Jost BC, Grossberg GT. *J Am Geriatr Soc.* 1996;44:1078-1081; with permission.