

# Dementia-Related Psychosis Symptoms and Impact from the Patient and Care Partner (Caregiver) Perspective: An Observational, Prospective Study to Describe the Patient Experience

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## INTRODUCTION

- Dementia-related psychosis is a highly symptomatic condition characterized by hallucinations and delusions that are due to dementia and not to an unrelated cause.<sup>1,2</sup>
- The prevalence of hallucinations and delusions in dementia is often progressive and can double over the course of the disease.<sup>3</sup>
- Dementia-related psychosis increases the burdens placed on individuals already suffering from debilitating diseases such as Parkinson's disease (PD), Alzheimer's disease (AD), and dementia with Lewy bodies (DLB).<sup>4</sup>
- Much of the responsibility for caring for individuals with dementia falls on family members.<sup>5</sup>
- The patient and family experience of dementia-related psychosis can provide valuable information about the impact of psychosis symptoms on patients with dementia. However, there are no studies that describe dementia-related psychosis from a patient and care partner perspective.

## OBJECTIVE

- To collect data on the patient experience of symptoms and impact of dementia-related psychosis from the patient and care partner (caregiver) perspective.

## METHODS

### Qualitative Interviews

- The qualitative component consisted of a prospective, observational, noninterventive, single-visit study involving qualitative interviews approximately 60 minutes in length with eligible English-speaking participants in the United States.
- In-depth interviews were conducted with patients or care partners of patients who have a clinical diagnosis of all-cause dementia with psychotic symptoms (for at least 2 months), recruited through physician referrals.

- Care partners participating in the qualitative interviews included individuals who provided at least 20 hours per week of direct, in-person care for an individual with dementia-related psychosis.

- The semistructured interview was conducted via telephone and 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 Surveys

- The quantitative online survey was completed by patients with dementia-related psychosis (patient reported) or by care partners of patients with dementia-related psychosis (care partner reported) recruited through direct outreach by the advocacy groups UsAgainstAlzheimer's and the Lewy Body Dementia Association.

- The online questionnaire included 35 close-ended items designed to gather patient and care partner feedback on medical history, occurrence, severity, frequency and impact of symptoms, treatments taken, and demographic information.

- Participants reported the severity of symptoms with a visual analog scale of 1 (very mild) to 5 (very severe).

- Care partner burden was beyond the scope of this study.

- Participants in the interview portion of the study were not invited to participate in the survey portion. Pairs of patients and care partners completing the survey were not recruited; however, care partners of patients completing the survey were not explicitly excluded from participating.

## RESULTS

### Qualitative Results

- Sixteen individuals (1 patient, 15 care partners) participated in the qualitative interview (Table 1).

## RESULTS (CONT)

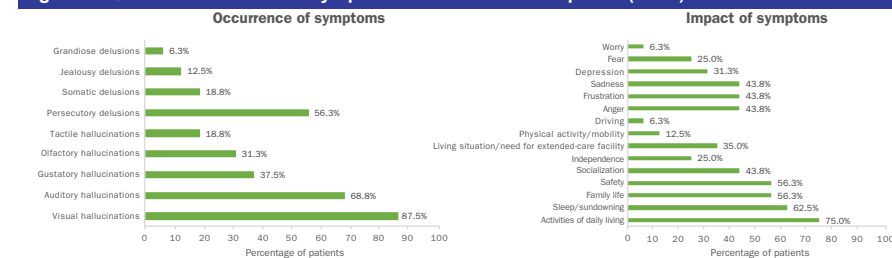
Table 1. Qualitative Interviews: Patient Characteristics

Characteristic	Patient Reports (N=1)	Care Partner Reports (N=15)
Male, n (%) <sup>a</sup>	1	10 (66.7)
Age, mean (range), years	81	85.5 (60–89)
Dementia diagnosis (>1 to ≤5 years), n (%)	<1 y	11 (74)
Dementia diagnosis, n (%)		
PD	1	3 (20.0)
AD	—	9 (60.0)
VaD	—	3 (20.0)
Relationship to person with dementia, n (%)		
Friend	—	5 (33.3)
Spouse (wife)	—	4 (26.7)
Daughter	—	3 (20.0)
Niece, daughter-in-law, or son-in-law	—	3 (20.0)

<sup>a</sup>Sex of person with dementia. AD, Alzheimer's disease; PD, Parkinson's disease; VaD, vascular dementia.

- The most commonly reported symptoms of dementia-related psychosis were visual hallucinations (87.5%), auditory hallucinations (68.8%), and persecutory delusions (56.3%) (Figure 1).
- 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%) (Figure 1).

Figure 1. Qualitative Interviews: Symptom Occurrence and Impacts<sup>a</sup> (N=16)



<sup>a</sup>Patient-reported and care partner-reported data are combined.

### Quantitative Results

- In total, 26 patients and 186 care partners participated in the quantitative online survey.
- Care partner reports reflect individuals who were older (mean age 78.1 years) and more reported patients having AD, PD, and vascular dementia (VaD) relative to patient reports (Table 2).
- Patient reports reflect individuals who were younger (mean age 64.6 years) and more reported having DLB and mild cognitive impairment (MCI) relative to care partner reports (Table 2).
- Care partner reports had a longer span of time since dementia diagnosis in the population (24 years) relative to that of patient reports (10 years).

Table 2. Quantitative Survey: Patient Characteristics

Characteristic	Patient Reports (N=26)	Care Partner Reports (N=186)
Male, n (%) <sup>a</sup>	15 (57.7)	91 (48.9)
Age, mean (range), years	64.6 (49–84)	78.1 (55–97)
Race, white, n (%)	21 (80.8)	167 (89.8)
Dementia diagnosis, date range	2010–2019	1996–2019
Dementia type, n (%) <sup>b</sup>		
AD	6 (23.1)	91 (48.9)
PD	1 (3.8)	32 (17.2)
DLB	13 (50.0)	71 (38.2)
FTD	2 (7.7)	7 (3.8)
VaD	1 (3.8)	18 (9.7)
MCI or mild dementia	11 (42.3)	27 (14.5)
Other (brain trauma, other, aging)	7 (26.9)	53 (28.5)
Living situation of person with dementia, n (%)		
With spouse/partner	17 (65.4)	101 (54.3)
With children	5 (19.2)	29 (15.6)
Alone	6 (23.1)	19 (10.2)
In facility or other	1 (3.8)	65 (34.9)

<sup>a</sup>Sex of person with dementia. <sup>b</sup>Reported by participant; ≥1 subtype could be selected. AD, Alzheimer's disease; DLB, dementia with Lewy bodies; FTD, frontotemporal dementia-spectrum disorder; MCI, mild cognitive impairment; PD, Parkinson's disease; VaD, vascular dementia.

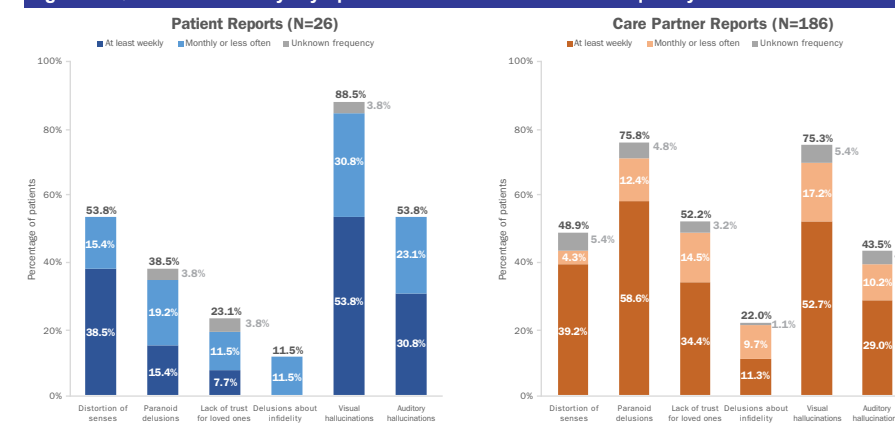
## RESULTS (CONT)

- Many patients (42.3% according to patients; 41.9% according to care partners) were not receiving medications for dementia-related psychosis. For additional details on treatment, see poster 47165 (Brandt T, et al. AAIC 2020).

- The dementia-related psychosis symptoms most frequently reported by patients 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%) (Figure 2).

- Visual hallucinations were reported as occurring weekly by 52.8% of patients and 52.7% of care partners (Figure 2).

Figure 2. Quantitative Survey: Symptom Occurrence and Recent Frequency



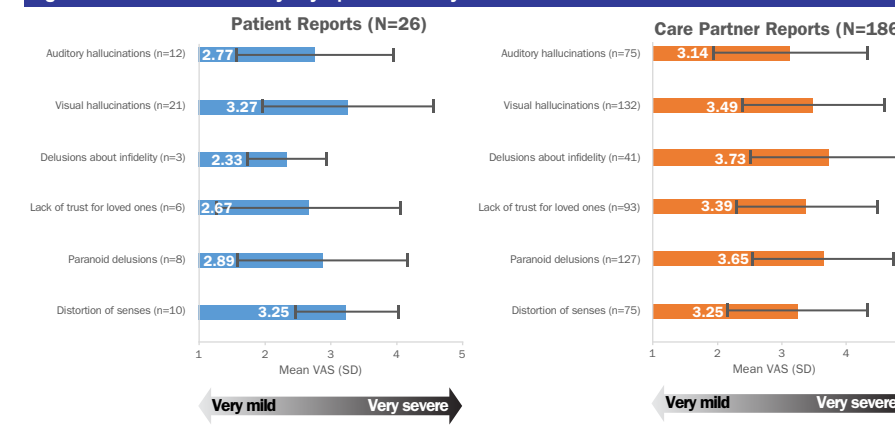
Percentages may not sum to the total percentage for each symptom due to rounding.

- Most (100/186; 53.8%) care partners reported that patients were not at all comfortable or were only a little comfortable discussing the symptoms of dementia-related psychosis with those closest to them.

- 5/26 (19.2%) of patients reported that they were not at all comfortable or only a little comfortable; however, this may be a reflection of the less severe disease progression observed in patient reports.

- On a visual analog scale for symptom severity of 1 (very mild) to 5 (very severe), visual hallucinations were rated a mean 3.27 by patients and a mean 3.49 by care partners (Figure 3).

Figure 3. Quantitative Survey: Symptom Severity<sup>a</sup>

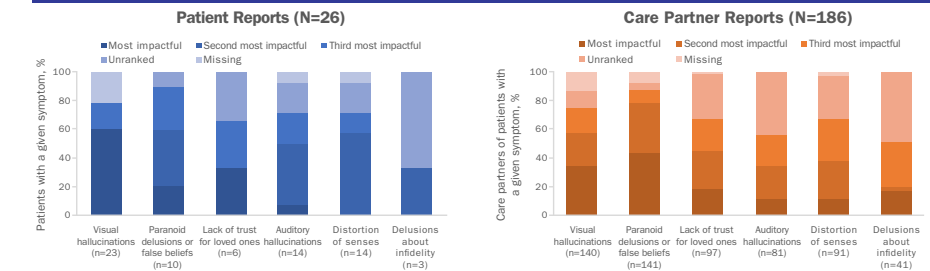


<sup>a</sup>According to the VAS, 1 is defined as very mild and 5 as very severe. SD, standard deviation; VAS, visual analog scale.

- Visual hallucinations were most impactful in the patient self-report group, and paranoid delusions were most impactful in the care partner report group, followed by visual hallucinations (Figure 4).

## RESULTS (CONT)

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.

## CONCLUSIONS

- Persons with dementia-related psychosis experience hallucinations and delusions that have a substantial impact on their lives.
- These episodes of dementia-related hallucinations and delusions greatly impact patients' overall health and quality of life. Interviewed participants described impacts on sleep, family and social life, emotional state, independence, and safety. These impacts substantiated a need for 24-hour care partner support of the patient, with consideration and concerns for future further-altered living situations or the need for placement in an extended-care facility.
- Symptoms of dementia-related psychosis caused patients to question their understanding of reality and decreased their confidence in engaging fully with daily life.
- Differences observed between symptoms and impacts reported by patients versus those reported by care partners are likely related to differences in dementia severity and need for care partner assistance as reflected by mean age, dementia subtype, and time since dementia diagnosis.
- Most care partners reported that patients were not comfortable discussing symptoms of dementia-related psychosis with those closest to them, suggesting a need for greater education on dementia-related psychosis and efforts to reduce stigma associated with the condition.
- This study is limited in that most patients had AD or DLB and data may not reflect all subtypes of dementia. In addition, results of survey data are subject to recall bias.
  - However, the consistency of results from the qualitative interviews and the larger quantitative survey supports the reliability of the findings.
- Patient experience data demonstrate that there is a need for treatments to reduce the symptoms and impacts of dementia-related psychosis. For additional details on treatment, see poster 47165 (Brandt T, et al. AAIC 2020).

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## DISCLOSURES

TF is a consultant with Frangiosa & Associates, LLC. VB and AT have no relevant financial relationships to disclose. TB, BK, and VA are employees of and may hold stock and/or stock options with ACADIA Pharmaceuticals Inc.

