

# Survey Findings: Impact of Dementia-Related Hallucinations and Delusions

Find out how your peers responded to questions from a recent survey.

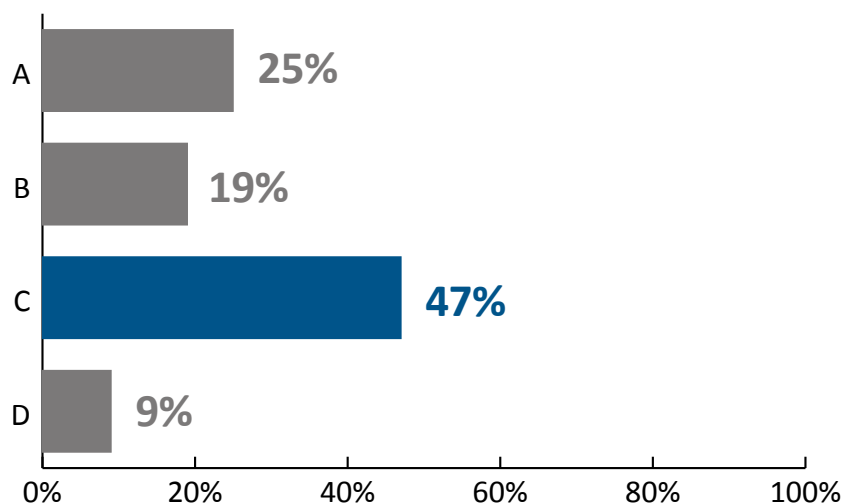
With insights on the findings from Ara S. Khachaturian, PhD, and commentary from Jacobo Mintzer, MD, MBA  
Paid consultants of ACADIA Pharmaceuticals Inc.

The graphs below depict the percentage of respondents who correctly or incorrectly chose each answer. The key at the bottom of each graph contains the answer options for each question, with the correct answer indicated.

## Question 1 of 5: Approximately \_\_\_\_\_ of older adults with dementia receive help from family caregivers, according to a study.

**Finding:** About half of respondents correctly identified that 70% of older adults with dementia receive help from family caregivers, according to a study. Interestingly, one-quarter of respondents believed that only 30% of older adults with dementia receive familial help.

**Faculty commentary:** Although the survey results show that most respondents are aware of the critical role that family caregivers play in dementia care, some healthcare professionals still do not recognize the burden that these caregivers endure. As a result, this highlights the need for additional educational opportunities so that family caregivers receive adequate attention and support.



This information is derived from a knowledge survey of healthcare professionals on MoreThanCognition.com; data collected from November 2019 to April 2020 (N=146).

Key: A. 30%; B. 50%; C. 70%; D. 90%

### Explanation

The 2015 National Health and Aging Trends Study and its companion study, the National Study of Caregiving, included 2204 caregivers of 2417 people with dementia aged  $\geq 65$  years, who lived in community settings and received help with self-care, mobility, or household activities.<sup>1</sup> As context on the prevalence of informal caregiving for older adults with dementia, approximately 70% received care from family caregivers, ie, their spouse or children.<sup>1</sup>

Yet, some common delusions in people with dementia target those closest to them—the caregivers. These delusions include theft, abandonment, Capgras syndrome, and spousal infidelity.<sup>2</sup>

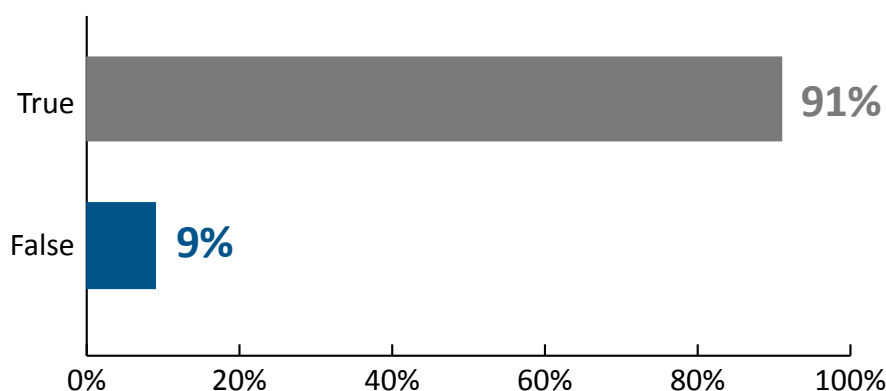
### For additional information, see:

1. Chi W, Graf E, Hughes L, et al. *Community-Dwelling Older Adults With Dementia and Their Caregivers: Key Indicators From the National Health and Aging Trends Study*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation; January 2019.
2. Ballard C, Saad K, Patel A, et al. The prevalence and phenomenology of psychotic symptoms in dementia sufferers. *Int J Geriatr Psychiatry*. 1995;10(6):477-485.

## Question 2 of 5: According to one study of 280 individuals diagnosed with dementia, the total Neuropsychiatric Inventory (NPI) score and subdomains predicted increased informal caregiver expenditure.

**Finding:** The majority of respondents were aware that the total NPI and subdomains were predictive of increased informal caregiver expenditure.

**Faculty commentary:** These results are encouraging since awareness is the first step toward action. The challenge is to convert this awareness into a commitment to address these neuropsychiatric symptoms associated with dementia and to adequately support the caregivers.



This information is derived from a knowledge survey of healthcare professionals on MoreThanCognition.com; data collected from November 2019 to April 2020 (N=146).

**Key:** True/False

### Explanation

According to the Cache County Dementia Progression Study of 280 individuals diagnosed with dementia (72.1% with Alzheimer's disease), the total Neuropsychiatric Inventory (NPI) score and subdomains predicted increased informal caregiving expenditure.

Rattinger and colleagues examined the relationship between informal care cost and NPI total, as well as individual subdomains. Informal costs of care were based on a caregiver activity survey in which the caregiver estimated how much time he or she spent assisting the person with dementia over 24 hours. Assistance was defined as answering questions, leaving reminders, providing transportation, and helping with activities of daily living (eg, dressing, grooming, meals and eating). Total caregiving time was capped at 16 hours, and informal care cost was calculated using the Utah median hourly wage and represented in 2015 dollars.

Informal care costs increased approximately 2% with each point increase in the NPI total, and they increased 7.6%, 6.4%, and 5.6% with each unit increase in the agitation/aggression, affective symptoms, and psychosis subdomains, respectively. However, the interaction with time as a variable was not significant for NPI total, agitation/aggression, affective symptoms, and psychosis.

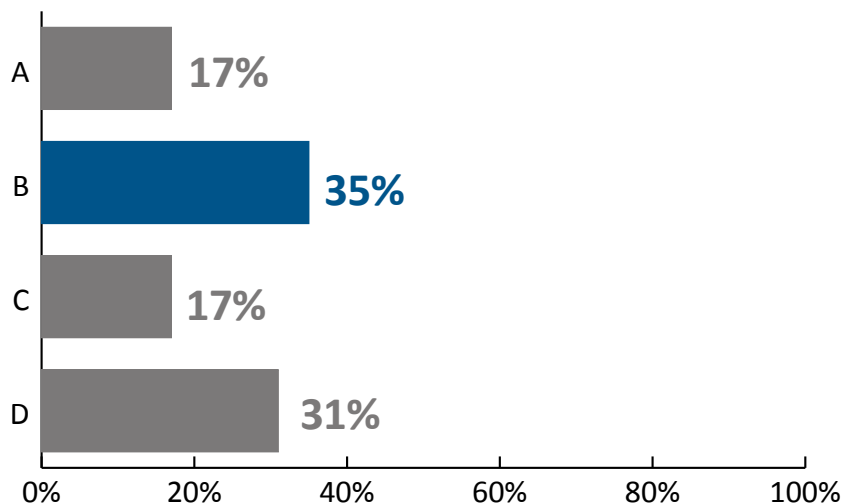
### For additional information, see:

Rattinger GB, Sanders CL, Vernon E, et al. Neuropsychiatric symptoms in patients with dementia and the longitudinal costs of informal care in the Cache County population. *Alzheimers Dement (NY)*. 2019;5:81-88.

## Question 3 of 5: According to one study of older people with Alzheimer’s disease, a 10% increase in total Neuropsychiatric Inventory (NPI) score was associated with:

**Finding:** More than half of respondents correctly identified that an increase in the total Neuropsychiatric Inventory (NPI) score was associated with an increase in the odds of nursing home placement. Approximately one-third of respondents correctly identified the magnitude of the increased odds as 30%.

**Faculty commentary:** This information highlights the need to educate healthcare professionals about the actual risk of nursing home placement among patients with dementia-related neuropsychiatric symptoms. However, it is encouraging to note that the respondents are at least aware of the increased odds of institutionalization associated with these symptoms.



This information is derived from a knowledge survey of healthcare professionals on MoreThanCognition.com; data collected from November 2019 to April 2020 (N=146).

**Key:**

- A. A 20% decrease in the odds of nursing home placement
- B. A 30% increase in the odds of nursing home placement
- C. A 40% decrease in the odds of nursing home placement
- D. A 50% increase in the odds of nursing home placement

### Explanation

Neuropsychiatric symptoms may increase the likelihood of nursing home placement for older people with dementia.

A case-control study that used data from the South Carolina Alzheimer’s Disease Registry compared Neuropsychiatric Inventory (NPI) scores for older people with Alzheimer’s disease who entered nursing homes within 6 months of study initiation (352 cases; mean age, 84 years) versus those who remained in the community (289 controls; mean age, 83 years). A 10% increase in the total NPI score was associated with a 30% increase in the odds of nursing home placement (odds ratio [OR], 1.30; 95% confidence interval [CI], 1.14-1.50).

The NPI total, the NPI-4, and the individual items of the NPI were examined for main effects as models of interest. In addition to main effects of the NPI total and the NPI-4 (OR, 1.21; 95% CI, 1.10-1.34), the following NPI items significantly increased the odds of nursing home placement:

- Agitation/aggression (OR, 1.10; 95% CI, 1.06-1.23)
- Disinhibition (OR, 1.18; 95% CI, 1.07-1.29)
- Irritability (OR, 1.10; 95% CI, 1.03-1.18)
- Delusions (OR, 1.10; 95% CI, 1.03-1.19)
- Sleep (OR, 1.12; 95% CI, 1.05-1.19)
- Appetite (OR, 1.10; 95% CI, 1.02-1.18)

Hallucinations did not significantly increase the odds of nursing home placement (OR, 1.07; 95% CI, 0.99-1.15).

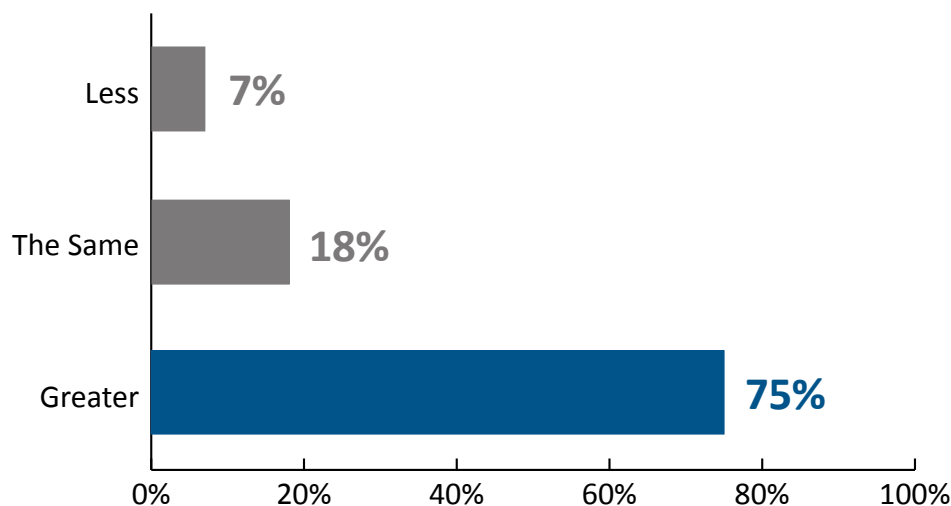
### For additional information, see:

Porter CN, Miller MC, Lane M, Cornman C, Sarsour K, Kahle-Wroblewski K. The influence of caregivers and behavioral and psychological symptoms on nursing home placement of persons with Alzheimer’s disease: a matched case-control study. *SAGE Open Med.* 2016;4:1-9.

## Question 4 of 5: The presence of delusions in older adults with dementia has been shown to be related to \_\_\_\_\_ severity of cognitive and functional impairment than for adults with dementia who do not experience delusions, according to a study.

**Finding:** Three-quarters of respondents correctly associated the presence of dementia-related delusions in older adults with a greater severity of cognitive and functional impairment relative to adults with dementia who do not experience delusions.

**Faculty commentary:** It is clear that the respondents appreciate the negative impact of delusions in patients with dementia. Moreover, they associate the presence of these symptoms with disease progression. This awareness is a positive trend, though it may lead to the perception among healthcare professionals that treatment may be ineffective due to the progression of disease. Therefore, it is important to inform clinicians that patients with dementia should have a documented treatment plan that includes appropriate nonpharmacologic and pharmacologic interventions.



This information is derived from a knowledge survey of healthcare professionals on MoreThanCognition.com; data collected from November 2019 to April 2020 (N=146).

**Key:** Greater; Less; The Same

### Explanation

In a prospective, longitudinal study of 78 people with Alzheimer's disease (mean age, 74 years) who were followed for 2 years, Haupt and colleagues found that, at the final examination, delusions were associated with greater severity of cognitive and functional impairment.

Specific delusions were predictive of specific negative outcomes. At the last evaluation in the 2-year observational period:

- The delusion of theft was related to the degree of cognitive dysfunction, as measured with the Mini-Mental State Examination (MMSE), as well as to functional disabilities, as measured with the Dementia Scale.
- The delusion of abandonment was related to the severity of cognitive impairment, as measured with the Cambridge Cognitive Examination.

Hallucinations were also examined in this study and were not associated with the degree of cognitive and functional impairment.

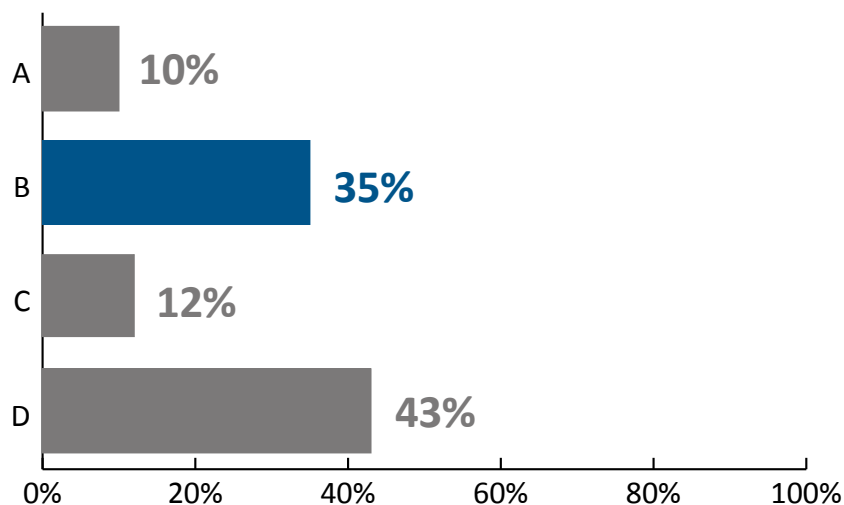
### For additional information, see:

Haupt M, Romero B, Kurz A. Delusions and hallucinations in Alzheimer's disease: results from a two-year longitudinal study. *Int J Geriatr Psychiatry*. 1996;11(11):965-972.

## Question 5 of 5: Which of the following is true related to young-onset dementia caregivers, according to a study?

**Finding:** About one-third of respondents correctly answered that hallucinations and delusions in young-onset dementia patients may contribute to higher caregiver burden. However, 10% of respondents incorrectly believed that caregivers of young-onset dementia patients have significantly lower burden levels than caregivers of late-onset dementia patients.

**Faculty commentary:** This response shows the bias of the respondents with regard to the relationship between older age and burden of dementia care. The fact is that most caregivers will experience more distress in providing care for younger individuals than older ones, and the presence of hallucinations and delusions play a role—an important educational opportunity.



This information is derived from a knowledge survey of healthcare professionals on MoreThanCognition.com; data collected from November 2019 to April 2020 (N=146).

**Key:**

- A. Young-onset dementia caregivers have significantly lower burden levels than late-onset dementia caregivers
- B. Hallucinations and delusions in young-onset dementia patients may contribute to higher caregiver burden
- C. 20% of young-onset dementia caregivers experienced high burden
- D. 60% of caregivers of young-onset dementia patients with hallucinations reported a high burden level

### Explanation

Young-onset dementia caregivers report higher burden than late-onset dementia caregivers, with patient symptoms of hallucinations and delusions as a contributing factor.

In a cross-sectional, prospective study, Lim et al sought to evaluate the caregiver burden levels in young-onset and late-onset dementia and to understand the specific factors that may contribute to caregiver burden in young-onset dementia (symptom onset earlier than age 65 years).

The study included a total of 183 patient-caregiver dyads from a tertiary neurology center who were studied for 1 year. Among them were 57 young-onset dementia dyads and 126 late-onset dementia dyads. Patients had diagnoses of Alzheimer’s disease, vascular dementia, or frontotemporal dementia.

Caregivers of subjects with young-onset dementia reported significantly higher burden levels (mean Zarit Burden Inventory [ZBI] score, 17.36) compared with caregivers of individuals with late-onset dementia (mean ZBI score, 13.94;  $P=0.015$ ). More than half (52.6%) of the young-onset dementia caregivers experienced high burden, categorized as a ZBI score of at least 17, compared with 32.5% of late-onset dementia caregivers. The researchers found that multiple Neuropsychiatric Inventory (NPI) domains contributed to this high caregiver burden, including hallucinations and delusions: 23% of caregivers of young-onset dementia patients with hallucinations and 40% of caregivers of young-onset dementia patients with delusions reported a high burden level.

### For additional information, see:

Lim L, Zhang A, Lim L, et al. High caregiver burden in young onset dementia: what factors need attention? *J Alzheimer’s Dis.* 2018;61(2):537-543.