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Results of a Survey of Care Partners of People Living with Alzheimer's Disease Agitation

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Key Objective

To characterize the lived experience of caregivers of people with agitation associated with dementia due to Alzheimer's disease (AAD) in the United States (US)

Introduction

- Agitation is a highly prevalent and debilitating neuropsychiatric symptom of Alzheimer disease (AD) that affects ~70% of patients over the course of the disease[1]
- Agitation associated with dementia due to Alzheimer's disease (AAD) is characterized by a range of symptoms, including aggressive verbal and physical behaviors, emotional distress, disruptive irritability, and disinhibition, markedly worsening burden for patients and caregivers[1-4]
- While non-pharmacological interventions are recommended as first line treatment for neuropsychiatric symptoms like agitation,[5] behavioral interventions are often difficult to implement and maintain[6]
- Antipsychotics have historically been used off-label for AAD, and brexpiprazole, an atypical antipsychotic, was recently approved for this indication[7]
  - Safety concerns related to increased risk for death and cerebrovascular adverse reactions (e.g., stroke, transient ischemic attack) are associated with the use of antipsychotics in elderly patients with dementia, which led the United States Food and Drug Administration to issue a Boxed Warning for all antipsychotics in this population[8]
- This large, quantitative survey of caregivers of individuals with AAD in the US was conducted to better understand the impact of AAD on quality of life, goal setting, and factors influencing treatment and care decisions

Methods

Study design and Population

- A cross-sectional, online survey was conducted in the US between October 7 and October 28, 2025
- Participants were adults (≥18 years) providing informal, unpaid care for individuals with AD in their own or the care recipient's home; care recipient (person with AAD polled as "loved one") must be experiencing ≥2 agitation symptoms (verbal aggression, physical aggression, physical restlessness, and/or non-aggressive verbal behaviors)

Sampling and Data Collection

- The Harris Poll facilitated participant recruitment and survey administration; the survey (~15 minutes) was completed entirely online
- The sample reflected diverse caregiver relationships, demographics, and geographic regions; weighting was applied, as needed, to align with population distributions

Ethics

- Study procedures were reviewed and approved by an independent Institutional Review Board

Analysis

- Descriptive analyses were conducted
- Continuous variables were summarized using mean and standard deviation, and categorical variables as frequencies and percentages

AAD, agitation associated with dementia due to Alzheimer's disease; AD, Alzheimer's disease

Results

Caregiver and Person With AAD Characteristics

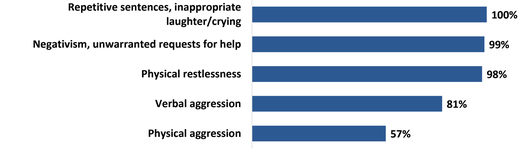
N=751	Person with AAD
Mean Age, years (SD)	71.1 (7.92)
Female, n (%)	400 (53)
AD Stage, n (%)	
Early Stage/Mild Cognitive Impairment (MCI)	159 (21)
Mild	244 (33)
Moderate	255 (34)
Severe	92 (12)
Length of Time Living with AD, n (%)	
Less than 1 year	43 (6)
1–2 years	375 (50)
3–4 years	239 (32)
5+ years	93 (12)

N=751	Caregiver
Mean Age, years (SD)	54.5 (13.2)
Female, n (%)	452 (60)
Married, n (%)	537 (72)
Employed, n (%)	414 (55)
Relationship to Loved One with AAD, n (%)	
Spouse/partner	354 (47)
Child	308 (41)
Mean Length of Time Providing Care, months (SD)	28.4 (18.0)
Location Where Care is Provided, n (%)	
Caregiver's own home	537 (71)
Person With AAD's home	214 (29)
Mean number of Hours Providing Care Per Week (SD)	33.3 (10.5)

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Frequency of Agitation Symptoms

Figure 1. Proportion of Caregivers Reporting Agitation Symptoms ≥1–2×/Week in Person with AAD



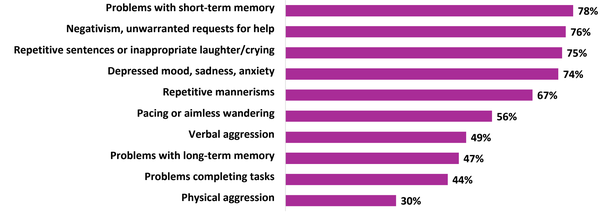
AAD, agitation associated with dementia due to Alzheimer's disease.

Quality of Life

Quality of Life for Person With AAD

- Nearly all caregivers (97%) reported agitation negatively impacting the quality of life of the person with AAD

Figure 2. Top 10 Symptoms of AD Most Negatively Affecting Quality of Life in Person with AAD

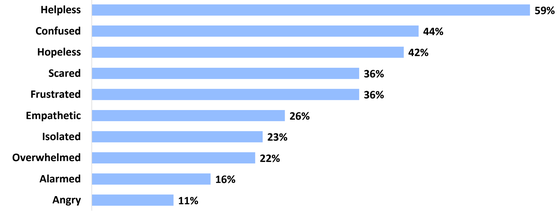


- Adult children are more likely than spouses to report agitation having a great deal of negative impact on person with AAD's life (40% vs. 25%)
- Adult children are more likely than spouses to report physical/verbal aggression (55% vs. 40%) among the symptoms most negatively affecting the overall quality of life for the person with AAD

Quality of Life for Caregiver

- Most (89%) caregivers indicated an adverse effect on their own quality of life

Figure 3. Top 10 Words/Phrases Caregivers Feel When Person with AAD Exhibits Agitation Symptoms

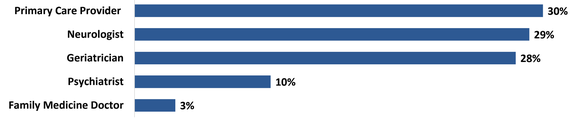


- Spouses are more likely than adult children to report feeling hopeless (48% vs. 37%) and isolated (31% vs. 14%)

AAD, agitation associated with dementia due to Alzheimer's disease; AD, Alzheimer's disease; QoL, quality of life.

HCP Management, Goal Setting, and Non-Drug Strategies

Figure 4. HCP Primarily Responsible for Managing AAD



AAD, agitation associated with dementia due to Alzheimer's disease.

- Those with AAD who have ever displayed physical aggression are more often managed by a neurologist (39% vs 15%) or psychiatrist (15% vs 2%) vs those without

Goal Setting

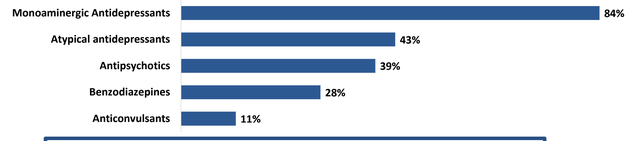
- Setting everyday goals (e.g., getting dressed, going on a walk, sharing a meal) was considered absolutely essential / very important by 87% of all caregivers and 95% of those caring for individuals with a history of physical aggression (vs 78% for those without)

Non-Drug Strategies to Manage AAD

- Non-drug strategies to manage AAD were widely used, including calming activities (85%), music therapy (70%), and physical activity (69%)

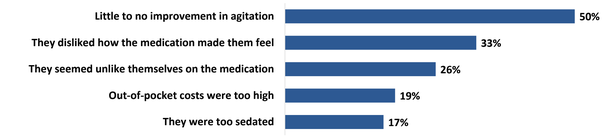
Medication Usage and Discontinuation

Figure 5. Medications to Treat AAD (% Ever Used)



- Adult children are more likely than spouses to report the person with AAD has ever used antipsychotics (43% vs. 31%) or benzodiazepines (31% vs. 20%)
- Adult children are more likely than spouses to report the person with AAD is currently using antipsychotics (37% vs. 23%) or anticonvulsants (6% vs. 1%)

Figure 6. Top 5 Reasons for Discontinuation of AAD Medication(s) (Among Prior Users)



- Adult children are more likely than spouses to report they made the decision to stop treatment because they felt guilty about how it changed the person with AAD (12% vs. 3%)

AAD, agitation associated with dementia due to Alzheimer's disease.

Conclusions

- This represents one of the largest and most recent surveys to date of caregivers for individuals with agitation associated with dementia due to Alzheimer's disease
- Findings underscore the profound impact of agitation and Alzheimer's disease on both patient and caregiver quality of life
- Most caregivers view setting everyday goals as highly important, with even greater importance among those caring for individuals with a history of physical aggression compared to those without
- Monoaminergic antidepressants were the most frequently used treatment
- Lack of efficacy was the primary reason for medication discontinuation, highlighting the need for more effective management strategies

References
1. 2025 Alzheimer's Disease Facts and Figures. www.alz.org/alzheimers-dementia/facts-figures. Accessed December 1, 2025. **2.** Tractenberg et al. / *Neuropsychiatry Clin Neurosci.* 2002;14:11-18. **3.** Porsteinsson and Antonsdottir. *Expert Opin Pharmacother.* 2017;18:611-620. **4.** Rabins et al. *Alzheimers Dement.* 2013;9:204-207. **5.** Lee. Expert Opin Pharmacother. 2023;24(6):691-703. **6.** Wong. BMC Geriatr. 2024;24(1):330. **7.** REXULTI [prescribing information]. Rockville, MD: Otsuka America Pharmaceutical, Inc. **8.** Koenig AM, et al. *Curr Psychiatry Rep.* 2016;18:3.

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Disclosures
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