

Caregiver perspectives on the burden and impact of agitation in caring for loved ones with dementia/Alzheimer's disease: A collaboration with UsAgainstAlzheimer's A-LIST®

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Introduction

- Agitation in Alzheimer's disease (AD)/dementia is associated with rapid decline in cognitive functioning, higher healthcare resource use, and increased likelihood of placement in a long-term care facility¹
- Behavioral and neuropsychiatric symptoms including agitation are a common and potentially severe problem complicating dementia²
- While family caregivers are typically the primary caretakers of individuals with dementia, little data is published on the impact of agitation symptoms on caregiver quality of life and burden
- This study assessed the impact of agitation on caregiver outcomes, including treatment satisfaction, burden, and work productivity impairment in the United States

Methods and Study Design

- A cross-sectional online survey of current and former caregivers of patients with AD/dementia was conducted to collect de-identified, individual-level data from caregiver respondents living in the United States (US) caring or having cared for a patient with or without agitation symptoms
- Phase 1 (qualitative): An initial group of 4 caregivers completed semi-structured interviews via telephone to review the survey content, ensure comprehension, and refine questions as needed
- Phase 2 (quantitative): Following Phase 1, the final survey was administered to caregiver members of the A-LIST between April 2 and April 27, 2020
- Caregivers were included if they were aged 18 years or older, provided care to an adult diagnosed with mild cognitive impairment or dementia (care recipient) for ≥1 month, and were able to indicate whether or not the care recipient had experienced symptoms of agitation and could provide information on those symptoms, and, if the care recipient had experienced symptoms of agitation, that symptoms lasted for ≥1 month

Results

- Of the 395 eligible caregivers (Figure 1) who completed the survey, 297 (75.2%) indicated caring for a patient with at least one agitation symptom (Figure 1); resisting care was the most frequently reported symptom (69.4%) followed by pacing, rocking or restlessness (54.9%) and cursing or shouting (45.8%)

Figure 1: Caregiver Recruitment and Cohorts

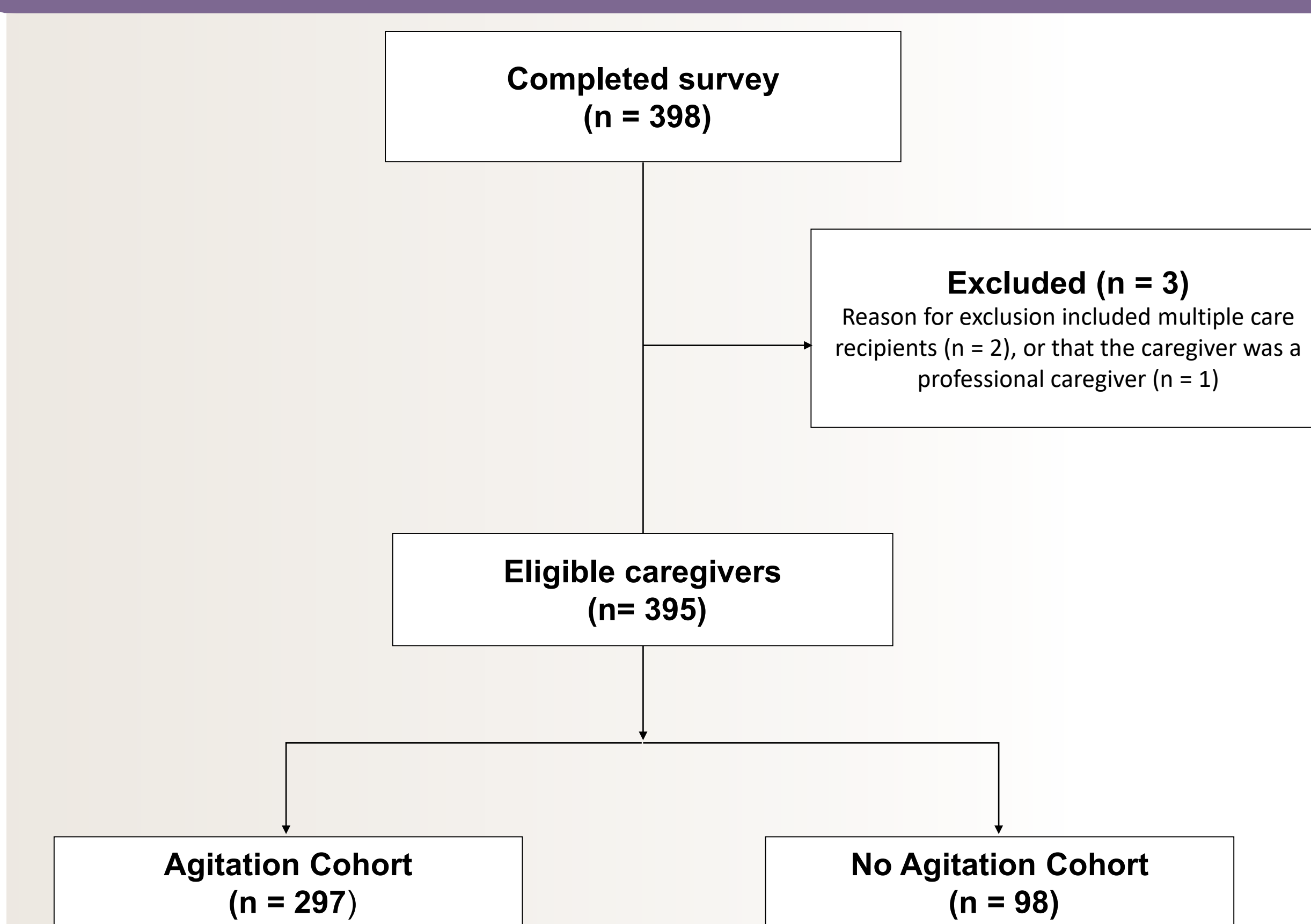
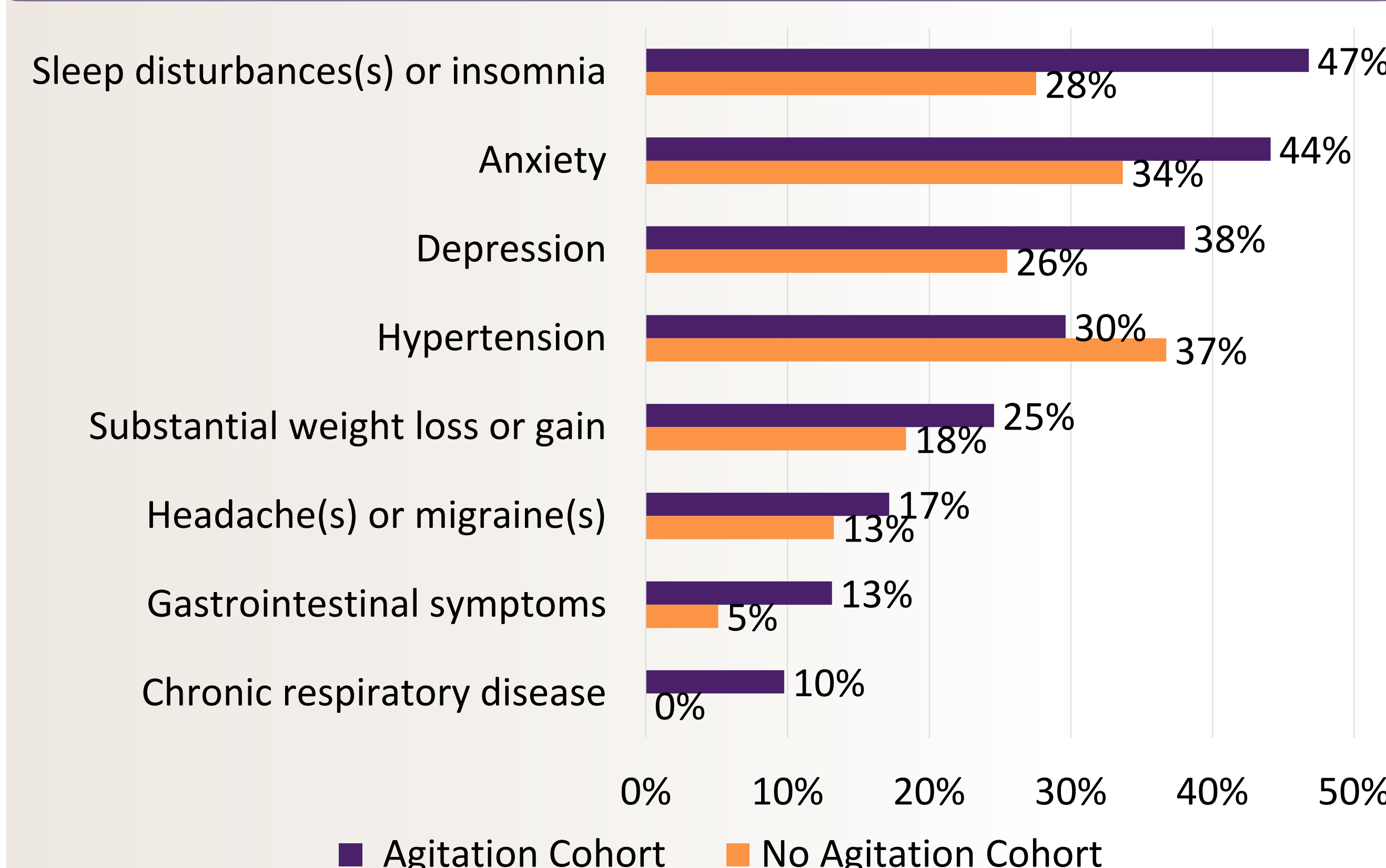
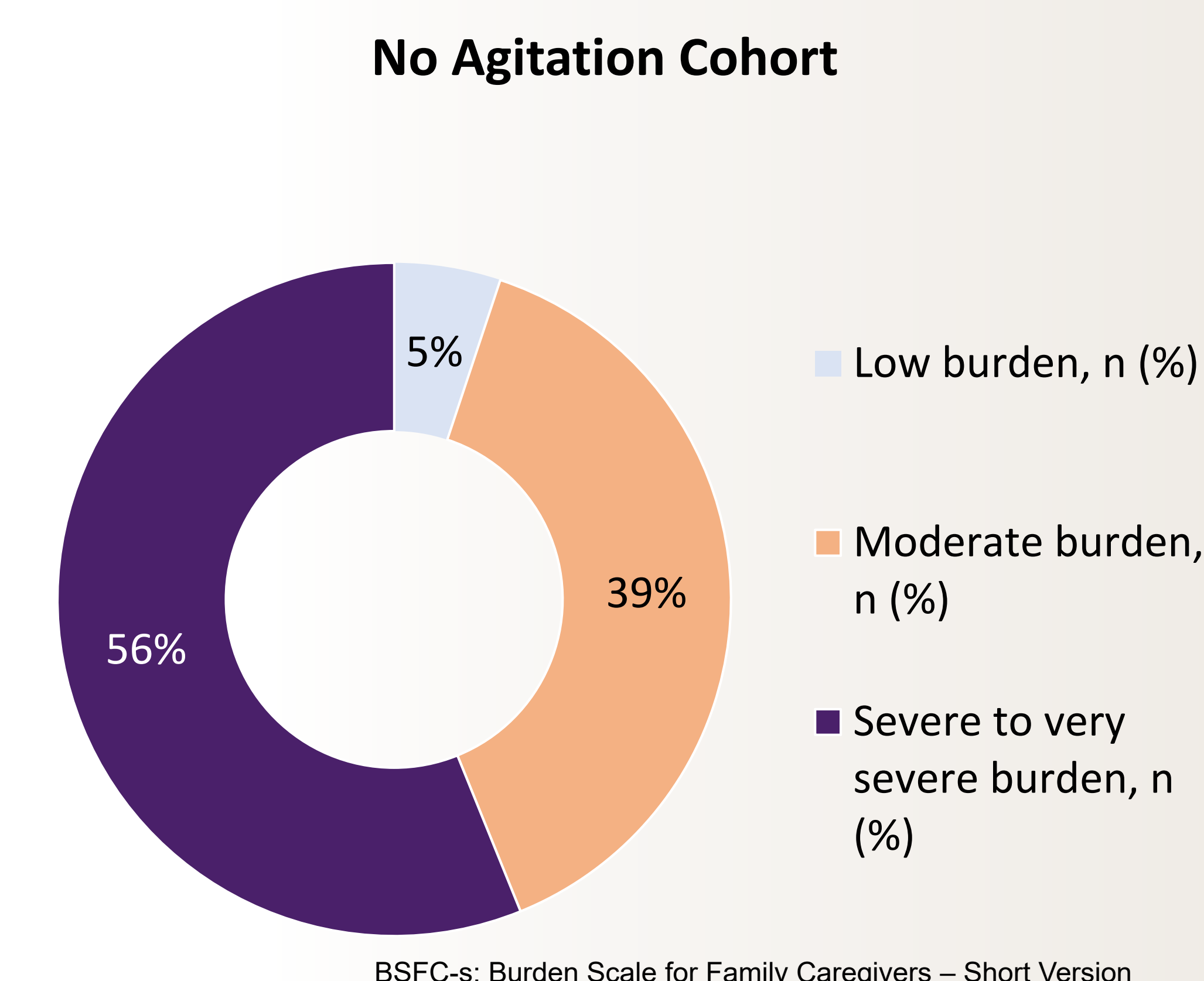
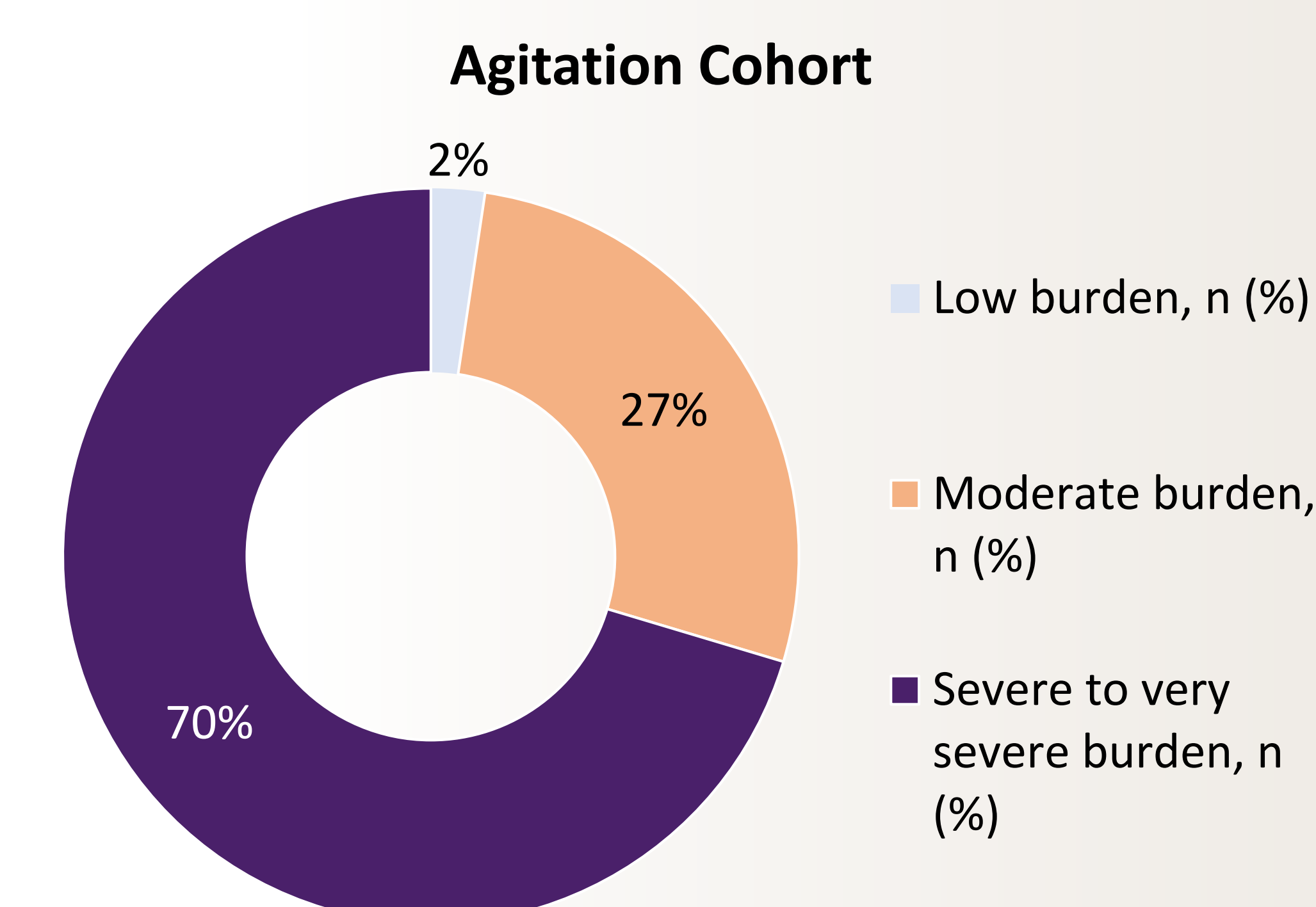


Figure 2: Caregiver Comorbidities



- The majority of caregivers were 55 years or older (90.1%) and female (73.9%); the majority of care recipients were 70 years or older (85.3%), female (62.8%) and white (93.9%)
- The most commonly reported comorbidities (Figure 2) among caregivers included sleep disturbances or insomnia (Agitation Cohort 46.8%; No Agitation Cohort: 27.6%), anxiety (Agitation Cohort 44.1%; No Agitation Cohort: 33.7%), and depression (Agitation Cohort 38.0%; No Agitation Cohort: 25.5%)
- On average, caregivers in the Agitation Cohort reported a numerically greater burden due to caregiving than those in the No Agitation Cohort based on the average BSFC-s score (Agitation Cohort: 18.5; No Agitation Cohort: 14.6). Specifically, 70.4% of caregivers in the Agitation Cohort reported having a severe to very severe burden (BSFC-s ≥ 15) compared to 56.1% in the No Agitation Cohort (Figure 3)
- Caregivers in the Agitation Cohort were more likely to report lacking resources to adequately provide care to the care recipients; the most frequently reported resources that were lacking included the availability of others to provide back-up care (Agitation Cohort: 55.6%; No Agitation Cohort: 43.9%), emotional support from close relatives (Agitation Cohort: 44.1%; No Agitation Cohort: 26.5%), adequate management of care recipient's behavioral symptoms (Agitation Cohort: 35.7%; No Agitation Cohort 13.3%), and information on the availability of non-drug therapies/activities outside of home (Agitation Cohort: 35.7%; No Agitation Cohort: 14.3%)

Figure 3: BSFC-S Caregiver Burden Scale



Discussion/Conclusions

- This study is subject to several limitations including selection bias and recall bias
- However, the results of this study indicate that there is a substantial burden experienced by caregivers, including lack of adequate treatment, when symptoms of agitation are present
- Better management of agitation symptoms has the potential to alleviate the burden associated with agitation in dementia/Alzheimer's disease in caregivers and patients alike
- Additional studies are warranted to better understand the extent of the burden of agitation symptoms in dementia/Alzheimer's disease and develop enhanced support strategies for caregivers and patients

References

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Conflicts of Interest

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