

BURDEN OF CARE IN DEMENTIA: THE IMPACT OF NEUROPSYCHIATRIC SYMPTOMS IN A LOW-INCOME BRAZILIAN SETTING

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Women represent the vast majority of caregivers, usually daughters or wives of people living with dementia. Caregiver burden scores were not significantly influenced by demographic characteristic, except for female gender. Symptoms addressed by the BEHAVE-AD and the RMBPC scales differed, but disruptive behaviors – as psychosis or sleep-wake disturbances - appeared as the most burdensome in both scales. The overall impact of BPSD in total ZBI scores was small, indicating that other variables like relationship burden, isolation, lack of support or finances are stronger determinants of caregiver burden in this setting.

INTRODUCTION

Behavioral and psychiatric symptoms (BPSD) in people living with dementia significantly increase caregiver responsibilities, leading to emotional, physical, and psychological burden. Despite their impact, these symptoms are frequently under investigated in routine care, resulting in overuse of medications and inadequate support for caregivers. This study aims to explore the most common BPSD reported by caregivers in a low-income setting at a university hospital in Brazil and to assess their impact on caregiver burden.

METHODS

Caregivers with regular contact with patients living with dementia (any type) were recruited from the Neurology outpatient clinic at a university's hospital in Brazil. Behavioral symptoms were assessed using the Behavioral Pathology in Alzheimer's Disease

(BEHAVE-AD) and the Revised Memory and Behavior Problems Checklist (RMBPC). Caregiver burden was measured using the Zarit Burden Interview (ZBI). Information about caregiver's gender, age, education level, and relationship to the patient was registered. Caregivers of patients with significant visual, auditory, or motor limitations were excluded to avoid confounders.

RESULTS

Fifty caregivers were interviewed, aged 30-80 years (M=61±12.4), predominantly women (86%). Most were sons or daughters (54%), and had completed high school (44,9%), but almost one third (28,6%) had less than 8 years of education. All participants were open to sharing their experiences. ZBI's scores ranged from 1 to 71 (M=33,7±17.1), being slightly higher among spouses. Only female gender was predictive of ZBI variance, but women were the majority in this sample.

The most severe neuropsychiatric symptoms reported on the BEHAVE-AD scale were visual (16%) and auditory hallucinations (14%), and sleep-wake cycle disturbances (14%) (Fig 1).

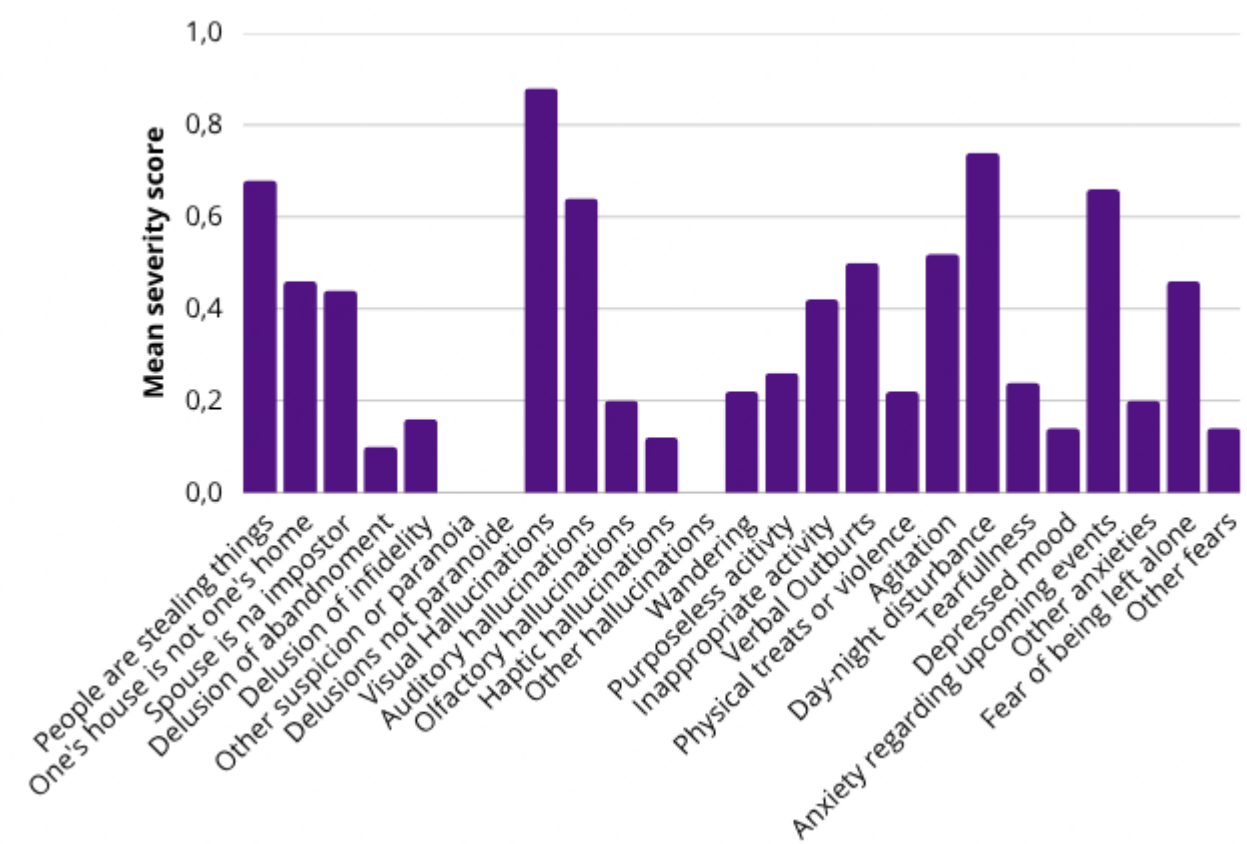


Fig 1: Mean scores from each symptom in BEHAVE-AD

On the RMBPC scale, the symptoms reported as most frequent (daily) were forgetting what day it is (68%), and repetitive questioning (62%). Repetitive questioning was also the most burdensome for caregivers, followed by waking careviger up and engaging behavior dangerous to self or others. The impact of symptoms from the domain of disruptive behavior from the

RMBPC was the only independently associated with ZBI total score, but the overall effect of the impact from RMBPC symptoms was small (R² = 0,098). Frequency of symptoms did not significantly associate with ZBI total scores. In fact, the most frequently reported items in the ZBI were not directly related to BPSD (Fig 2)



Fig 2: Most frequently reported items in ZBI (0=Never to 4=Almost always)

CONCLUSIONS

Women from the family represent the majority of caregivers in this sample. Disruptive behavior were the most burdensome symptoms reported by them, as well as some memory symptoms like repetitive questioning.

However, these symptoms only explained a small part of the total caregiver burden assessed by the ZBI, and other factors such as lack of support and isolation, seem to play an important role in this context.

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