



Do not forget about caregivers in autonomic medicine!

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Cardiovascular autonomic dysfunction is a common feature of neurodegenerative disorders associated with autonomic failure such as multiple system atrophy, Parkinson's disease, pure autonomic failure, and dementia with Lewy bodies [1]. Orthostatic hypotension in Parkinson's disease carries a worse prognosis with shorter survival, increased risk of falls, and a higher rate of institutionalization and dementia [2, 3]. For the patients, orthostatic hypotension is associated with greater levels of functional impairment [4]. Taking care of a patient with a chronic disease may result in a mixture of fulfillment and challenges, but the progressive nature of the disease often negatively impacts caregivers' physical and mental health [5]. Risk factors for caregiver burden include female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver [6]. In Parkinson's disease, caregiver burden is associated with the severity of the disease and the physical and mental health of both the patients and the caregivers [7]. However, little is known about the relationship between autonomic dysfunction in Parkinson's disease and caregiver burden.

In this issue of *Clinical Autonomic Research*, Ledda and colleagues prospectively enrolled 36 patients with Parkinson's disease (24 males and 12 females) and their informal caregivers (14 males and 22 females) to investigate the relationship between caregiver burden, patients' health-related quality of life (HRQoL), and the severity of cardiovascular autonomic dysfunction [10]. Patients underwent a comprehensive clinical assessment of motor and non-motor features

of the disease with the MDS Unified Parkinson's Disease Rating Scale, Montreal Cognitive Assessment, 39-Item Parkinson's Disease Questionnaire (PDQ-39), and the Scales for Outcomes in Parkinson's Disease-Autonomic questionnaire (SCOPA-AUT). Caregiver burden was assessed with the Zarit Burden Interview (ZBI), a validated and reliable scale for caregivers in Parkinson's disease. Patients underwent cardiovascular autonomic testing with analysis of heart rate variability and beat-to-beat blood pressure measurements during deep breathing, Valsalva maneuver, and active standing. Moderate-to-severe caregiver burden ($ZBI \geq 41$) was more frequent in caregivers of patients with cardiovascular autonomic failure ($N = 12$, Composite Autonomic System Score (CASS) ≥ 4) compared to caregivers of patients without cardiovascular autonomic failure ($N = 23$) with a prevalence of 41.7 vs. 8.7%, respectively. The difference remained significant after correcting for patients' age, disease duration, level of cognition, motor disability, and caregivers' age. Cardiovascular autonomic failure was independently associated with tenfold higher odds of producing a moderate-to-severe caregiver burden. Finally, caregiver burden correlated with the CASS, SCOPA-AUT, and PDQ-39. We invite readers to read the full article for more details.

This study highlights the independent role of cardiovascular autonomic dysfunction in Parkinson's disease in increasing caregiver distress. The comprehensive clinical assessment and standardized autonomic testing are strengths of this study. Limitations include the single center design, small sample size, and the lack of caregiver psychological and cognitive evaluations. Future prospective studies with larger sample sizes and multimodal assessments of both patients and caregivers should investigate the impact of autonomic dysfunction on caregiver burden.

There are several reasons why specialists in autonomic medicine should pay close attention to caregivers. First, informal caregivers play a vital role in supporting individuals with autonomic failure, often helping with medications

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and nonpharmacological measures to treat various autonomic manifestations such as orthostatic intolerance, constipation, or urogenital dysfunction among others. Thus, caregivers and clinicians are allies, and we should regularly assess caregivers' "well-being" to provide optimal care to our patients with chronic autonomic diseases. Second, caregiver burden can result in burnout, acute and chronic physical disorders, depression, social isolation, and financial concern [8]. If we are not vigilant, soon enough the caregiver becomes the patient. Third, research on other chronic conditions such as dementia suggests that poor caregiver mental health is associated with worse patient outcomes with higher rates of emergency visits [9], and increased mortality possibly due to lower quality of care, damaged interpersonal relationships and social bonds, or higher patient stress related to caregiver burden or to the patient's perception of being a burden to the caregiver [11]. Finally, targeted intervention to limit caregiver burden will likely result in healthcare cost savings, as Parkinson's caregivers exhibit high direct and indirect costs and greater income loss [12]. Future research should also investigate the potential benefits of dyadic interventions. For example, studies investigating rehabilitation strategies with exercise could benefit both the patients and caregivers.

As clinicians, it is our responsibility to support and guide caregivers. We hope that the study by Ledda and colleagues and this accompanying editorial will foster collaborative projects to investigate caregiver burden in various autonomic disorders. A better understanding of what drives caregiver burden in autonomic disorders would guide the design of effective interventions to reduce it, which may result in better health and lower costs for patients and caregivers alike. Let us not forget one of the greatest human qualities we all share: the simple act of caring.

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Declarations

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