

Caregiver Stress and Non-Motor Symptoms of Parkinson's Disease: Recommendations for Speech-Language Pathologists



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Introduction

- Parkinson's Disease (PD) is a progressive, neurological disorder characterized by a variable range of motor and non-motor symptoms¹:
 - Motor:** resting tremor, rigidity, bradykinesia, postural instability, hypokinesia, hypophonia, dysphonia, dysarthria, hypomimia, gait abnormalities, dysphagia, etc.^{3, 10}
 - Non-motor:** sleep disturbances, psychosis, hallucinations, depression, visual alterations, cognitive-communication deficits, etc.^{3, 6}
- These signs and symptoms may result in communication difficulties, difficulty with completion of activities of daily living (ADLs), and dependence on a caregiver¹⁴
- Although motor symptoms are often the first to be recognized, it is often the non-motor symptoms that cause the most strain on a patient's relationships with his or her caregiver⁶
- While addressing and remediating the needs of the patient should always be prioritized, it is also crucial to acknowledge and support the needs of the caregiver
 - A greater level of caregiver burden has been found to be detrimental to patient care¹⁵
 - Higher emotional distress among elderly caregivers has been identified as a significant risk factor for mortality¹⁷
- The ultimate aim of this literature review is to educate practicing speech-language pathologists (SLPs) about the effects of non-motor symptoms of PD on caregiver burden and how to appropriately intervene to optimize patient care.

Methods

- The following electronic databases were searched for peer-reviewed articles pertaining to non-motor symptoms of PD and their impact on caregivers: *PubMed, PsychINFO, Cochrane Library, Academic OnFile.*
- The 11 articles selected for this review were found from the following keywords: 'parkinson's disease', 'non-motor', 'caregiver', 'burden', 'disease', 'parkinson's', 'symptoms', 'progression', 'cognitive changes'
- Additional "hand searches" were conducted for relevant background information regarding PD with the following keywords: 'caregiver', 'burden', 'distress', 'parkinson's', 'disease', 'strain', 'burnout', 'spousal', 'familial', 'child'.
- Articles including the effects of non-familial caregivers of patients with PD were not included.

Limitations

- Of the studies examined in this literature review, 10 out of the 11 were classified as cross-sectional designs and 1 as a systematic review.
- Researchers utilized numerous measures to assess motor and non-motor symptoms of PD and their impact on caregivers. This makes it difficult to directly compare results across studies.
- The majority of studies neglected to specify if the caregivers included were spousal or offspring caregivers.
- Several studies reported only surveying caregivers who attended regular follow-up visits. Researchers acknowledged the possibility that more severe cases may have been excluded due to patient restrictions such as immobility.

Results

Predictors of Caregiver Burden

Figure 1. A review of the literature revealed several categories of health issues that were associated caregiver stress 1) General Cognitive Status, 2) Specific Cognitive Deficits, and 3) Neuropsychiatric Symptoms.



General Cognitive Status:
i.e., mild cognitive impairment (MCI), PD-dementia



Specific Cognitive Deficits:
e.g., executive function, attention, language, and memory, and ability to care for one's self



Neuropsychiatric Symptoms:
e.g., sleep disturbances, hallucinations, psychosis, apathy, anxiety, behavioral disinhibition, and depression

Table 1 Trends in the reviewed literature

Peer-reviewed article	Relationship Between General Cognitive Status and Caregiver Burden	Relationship Between Specific Cognitive Deficits and Caregiver Burden	Relationship Between Neuropsychiatric Symptoms and Caregiver Burden
1. Carter, Stewart, Lyons, & Archbold (2008)			Caregivers of patients with depression were found to have greater rates of depression and caregiver burden.
2. Grun, Pieri, Vaillant, & Diederich (2016)			A strong correlation was found between patient sleep disturbances and depression and caregiver burden.
3. Kudlicka, Clare, & Hindle (2014)		Executive dysfunction was found to be the strongest and most statistically significant predictor of caregiver burden.	
4. Lawson et al. (2016)		Cognitive deficits pertaining to attention, memory, and executive functioning were closely aligned with caregiver burden.	
5. Leroi, McDonald, Pantula, & Harbisetar (2012)	Caregiver burden was found to be higher among caregivers of people with MCI than those without cognitive challenges, and highest among caregivers of people with dementia.		
6. Martinez-Martin et al. (2015)	The presence of non-motor symptoms (i.e. cognitive impairment) was a statistically significant predictor of caregiver burden.		
7. Mosley, Moodie, & Dissanyaka (2017)	The presence of cognitive impairment was found to be a consistent predictor of caregiver burden.	Deficits related to language, memory, executive functioning, and attention, were highly associated with caregiver burden.	Depression, anxiety, psychosis, behavioral disinhibition, and apathy were all found to be predictors of caregiver burden.
8. Santos-Garcia & Fuente-Fernandez (2015)		The gradual loss of patient autonomy, or the ability to care for oneself, was found to be the greatest predictor of caregiver burden.	Results indicated that depressive symptoms were significant predictors of caregiver burden.
9. Schrag, Hovris, Morley, Quinn, & Jahanshahi (2006)			There was a significant relationship found between depression scores of the patients and the level of depression reported by the caregivers.
10. Shin, Lee, Youn, Kim, & Cho (2012)			Neuropsychiatric symptoms, such as hallucinations and depression, were more highly associated with caregiver burden among the spousal caregivers.
11. Zhong, Peppard, Velakoulis, & Evans (2015)	There was a significant correlation between severity of cognitive impairment and level of caregiver burden.		

Discussion

- Alterations in general cognitive status were found to be significant predictors of caregiver burden. Caregiver burden tends to increase among caregivers of patients with PD-Mild Cognitive Impairment as compared with those without cognitive challenges^{9, 11, 12, 18}
- Specific cognitive challenges such as executive function, attention, language, memory, and self-care ability were found to be significant predictors of caregiver burden, although results varied regarding which cognitive skills were most predictive of caregiver burden^{7, 8, 12, 15}
- Neuropsychiatric alterations such as sleep disturbances, and hallucinations were found to be significant predictors of caregiver burden^{2, 5, 12, 15, 16, 17}

Recommendations for SLPs

- Assess the extent of a caregiver's knowledge as it pertains to their loved one's disease through the use of open-ended questions and screening tools such as the Zarit Burden Interview (ZBI)¹³
- Evaluate level of caregiver burden and make appropriate referrals to specialized health professionals such as psychiatrists and psychologists¹³
- Review how PD can result in speech and language disorders¹³
- Provide pertinent, educational resources with typical communication changes associated with PD and tools for preventing and appropriately managing communication breakdowns¹³



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