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 symptoms 1.
  - **Motor**: resting tremor, rigidity, Bradykinesia, postural instability, hypokinesia, hypophonia, dysphonia, dystonia, hypomimia, gait abnormalities, dysphagia, etc. 2, 3
  - **Non-motor**: sleep disturbances, psychosis, hallucinations, depression, visual alterations, cognitive communication deficits, etc. 4, 5

- These signs and symptoms may result in communication difficulties, difficulty with completion of activities of daily living (ADLs), and dependence on a caregiver 6.
- 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 caregiver 7.
- 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 care 8.
- Higher emotional distress among elderly caregivers has been identified as a significant risk factor for mortality 9.
- 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, PsycINFO, Cochrane Library, Academic OneFile.
- The 11 articles selected for this review were found from the following databases: Medline (10), Academic Search Premier (6), and PsycINFO (5).
- To ensure the comprehensiveness of our literature search, the following search terms were used: "Parkinson's disease", "non-motor", "caregiver", "burden", "disease", "symptoms", "progression", "cognitive changes".
- Additional "hand searches" were conducted for relevant background information regarding PD with the following keywords: "caregiver", "burden", "disease", "parkinson", "symptoms", "strain", "burnout", "spouse", "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**

**General Cognitive Status:**
- Mild cognitive impairment (MCI), PD dementia

**Specific Cognitive Deficits:**
- executive function, attention, language, and memory, and ability to care for one’s self

**Neuropsychiatric Symptoms:**
- sleep disturbances, hallucinations, psychosis, apathy, anxiety, behavioral disturbance, and depression

**Table 1: Trends in the reviewed literature**

<table>
<thead>
<tr>
<th>Peer-reviewed article</th>
<th>Relationship Between General Cognitive Status and Caregiver Burden</th>
<th>Relationship Between Specific Cognitive Deficits and Caregiver Burden</th>
<th>Relationship Between Neuropsychiatric Symptoms and Caregiver Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Carter, Stewart, Lyons, &amp; Archibald (2008)</td>
<td>Caregivers of patients with depression were found to have greater risks of depression and caregiver burden.</td>
<td>Executive dysfunction was found to be the strongest predictor of caregiver burden.</td>
<td>Caregiver strain and depression were found to be significant predictors of caregiver burden.</td>
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<td>2. Grum, Pier, Valikent, &amp; Diederen (2016)</td>
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<td>3. Kuchinka, Child, &amp; Hinkle (2014)</td>
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<td>4. Lawson et al. (2018)</td>
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<td>5. Lommi, Molsom, Panteli, &amp; Hafner (2012)</td>
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<td>6. Martinez-Martin et al. (2013)</td>
<td>The presence of cognitive impairment was a statistically significant predictor of caregiver burden.</td>
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<td>7. Miyake, Moodie, &amp; Osakeya (2017)</td>
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<td>8. Santos-Garcia &amp; Fuente-Fernandez (2013)</td>
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<td>9. Schrag, Hollocks, Merley, Quinn, &amp; Lehtoehanto (2008)</td>
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<td>10. Shin, Lee, Youn, Kim, &amp; Choi (2012)</td>
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<td>11. Zhang, Poppard, VelaKoulis, &amp; Evans (2018)</td>
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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, MCI, Mild Cognitive Impairment as compared with those without cognitive challenges 10, 11, 12.
- 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, 13, 14.
- Neuropsychiatric alterations such as sleep disturbance, hallucinations, and delusions were found to be significant predictors of caregiver burden 5, 13, 14, 15.

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) 16.
- Evaluate level of caregiver burden and make appropriate referrals to specialized health professionals such as psychiatrists and psychologists 17.
- Review how PD can result in speech and language disorders 18.
- Provide pertinent, educational resources with typical communication changes associated with PD and tools for preventing and appropriately managing communication breakdowns 19.

References