

**Critical Review:**  
**For individuals diagnosed with Parkinson’s Disease, what are the key characteristics that contribute to increased levels of caregiver burden?**

Tea Vinčić

M.Cl.Sc (SLP) Candidate

University of Western Ontario: School of Communication Sciences and Disorders

The impact of Parkinson’s Disease (PD) ranges much further beyond that of the patient. Previous research has demonstrated various factors that may contribute to increased levels of caregiver burden (CB). Early identification of these variables may be critical to reducing and mitigating the effects of CB with respect to patients of PD. This review focuses on five studies that each focus on specific characteristics of the patient and/or caregiver, and how these may contribute to increased levels of CB. Overall, the studies demonstrate mixed results regarding which characteristics are likely associated with increased levels of CB. However, these data may help to inform clinical practices and interventions by ensuring that care and resources are provided to caregivers of patients of PD as early as possible in the hopes to mitigate their effects.

***Introduction***

A diagnosis of Parkinson’s Disease (PD) may bring with it, in addition to a barrage of symptoms that most often present themselves uniquely to each individual patient, an overwhelming shift in caregiving roles for the primary caregiver of the patient. PD is a neurodegenerative disease caused by the death of dopaminergic neurons in the region of the brain known as the substantia nigra (Parkinson’s Foundation, n.d.). The loss or death of these neurons leads to the manifestation of both motor and non-motor symptoms including, but not limited to tremors, gait imbalance, changes in posture, swallowing difficulties, speech difficulties, slow movement, rigid muscles and changes in writing (Mayo Clinic Staff, n.d.; NIH National Institute of Aging, 2017). As a progressive neurodegenerative disease, PD symptoms evolve and intensify over time, which, in turn, requires the role of the primary caregiver to change and evolve over time as well. According to UCB Canada, PD affects 1 in 500 people across Canada and approximately 4 million people across the globe (n.d.). While a risk factor for PD is age (with the majority of individuals diagnosed at roughly 60 years of age), approximately 5 to 10 percent of individuals may receive a diagnosis of early-

onset PD at younger than 50 years of age (NIH National Institute of Aging, 2017).

Previous literature consistently highlights the relationship between the level of depression of the patient and their decreased perception on quality of life (QoL) (Schrag et al., 2000; Schrag et al., 2006; Santos-García & Fuente-Fernández, 2015). As patients begin to lose the ability to care for themselves in their daily routines, a caregiver becomes essential for the management of day-to-day life at home; in this way, this new caregiving role is most often introduced to a significant other, spouse or older child (Santos-García & Fuente-Fernández, 2015; Genç et al., 2019). Taking on this new role often requires intensive changes to daily routines and may encompass a large portion of each day to ensure that the patient is well cared for.

Given this sudden change, more recent research has begun to shine a light on how caregivers respond to this pressure. Though one may feel a sense of duty in caring for their loved one, this more intensive level of care may introduce its own feeling of “caregiver burden” (CB). CB is characterized by anxiety, depression, psychological stress, isolation, financial stress and impulse control, in addition to overall exhaustion in the spheres of physical, emotional

and mental well-being (Bhimani, 2014; Cleveland Clinic, 2019). For most individuals diagnosed with PD, medical interventions are typically only effective for roughly 10 years; after that, the symptoms will continue to progress for the rest of that person's life (Goldsworthy & Knowles, 2008). As the disease becomes more advanced, patients may find themselves unable to move or feed on their own. Combined with the decreased clarity of speech due to reduced prosody, increased rate, decreased volume and potential dysarthria (Tjaden, 2008), caring for someone with advanced Parkinson's Disease requires a high level of attention and care on behalf of the primary caregiver.

With the potential for caregiver burnout, care should be taken to mitigate the effects of CB however possible. Increasing support will translate to increased quality of life for the patient. Ensuring that caregivers are able to manage their own day-to-day functions before caring for their loved ones is crucial to providing the best care possible. Thus, the purpose of this review is to identify key characteristics that contribute to increased levels of CB in the hopes of more accurately addressing these characteristics and understanding how to mitigate them for the well-being of the caregivers and, in turn, the patients themselves.

### *Objectives*

This critical review aims to describe the key characteristics that contribute to increased levels of caregiver burden for those caring for individuals with Parkinson's Disease. In so doing, the hope is to identify how to address those characteristics in a clinical setting to ensure that patients receive the best care possible both in medical and clinical settings, as well as at home with primary caregivers.

### *Methods*

#### Search Strategy

Articles that were included in the scope of interest were located using online databases including PubMed and Google Scholar. Searches consisted of the following keywords:

(Parkinson's Disease) AND (Caregiver Burden) AND (Quality of Life). The search was limited to articles written in English and published after 2015.

#### Selection Criteria

Studies selected for this paper were required to include descriptions of personal characteristics of caregivers or patients with regard to how they contribute to increased levels of CB. Following these criteria, five papers were chosen for review.

#### Data Collection

Three studies utilized cross-sectional analyses (Tan et al., 2019; Macchi et al., 2020; Santos-García & Fuente-Fernández, 2015), one study utilized a between-group comparison (Genç et al., 2019) and one study utilized a correlational analysis (Lee et al., 2019). Level of suggestion of each article was determined according to three levels: compelling, suggestive and equivocal, following the Critical Appraisal of Systematic Review or Meta-Analysis (CASM) framework by Dollaghan (2007).

### *Results*

#### Cross-Sectional Studies

**Tan et al. (2019)** investigated specific characteristics of patients with PD and how they contribute to levels of CB using a cross-sectional, observational study conducted in Singapore. The study involved 104 patients who were diagnosed with idiopathic Parkinson's Disease (IPD) (excluding those with PD diagnosed as secondary to other causes, or alongside other severe conditions) and their caregivers. Patient characteristics relevant to this study included motor and non-motor symptoms, and perceived QoL. All assessments were collected in-person during specialist visits to the clinic using standardized scales and patient questionnaires. Patient-caregiver pairs were separated into 3 subgroups: no/little burden ( $n=47$ ), mild-moderate burden ( $n=41$ ) and high level of burden ( $n=16$ ), based on measured results from a standardized, 5-point questionnaire of perceived CB. Statistical analyses to control for differences in categorical data between the subgroups were completed.

Researchers used ANOVA testing to make comparisons of characteristics of patient characteristics between these 3 subgroups. Overall, this study found that longer duration of disease, higher daily dosages of levodopa medication and increased complications as a result of the levodopa medication were more likely to result in increased levels of CB. With regard to patient QoL, they found that decreased levels among activities of daily living (ADL), stigma of PD, and decreased cognition were likely to result in increased levels of CB. However, this study excluded all patients whose cognitive abilities were not sufficient enough to provide consent; in this way, a population who requires a much higher level of care and may, perhaps, result in the highest levels of CB were not investigated. Based on the various statistical analyses and use of standardized testing and questionnaires, the data from this study was found to be highly suggestive.

**Macchi et al. (2020)** investigated 175 patients of PD and their caregivers, with regard to specific characteristics and how they relate to increased levels of CB across three medical centers in the US. Data was collected electronically and involved the use of various standardized tests and questionnaires that focused on patient characteristics including motor symptoms, cognition, mood disturbances, functional impairments, QoL, patient grief, CB and palliative performance. Caregiver data was also collected and focused on various characteristics of daily life, in addition to length of caregiving, mood, and use of services related to hospitalizations or other counseling. Researchers of this study used a multivariate linear regression model to identify associations between patient and caregiver characteristics and level of CB; ANOVA models were used to compare categorical data with that of the level of CB. Overall, researchers found that, for patients of moderate to high palliative care needs, the strongest associations between increased level of CB and specific characteristics of patients and caregivers involved patient spiritual well-being and health related QoL, and caregiver anxiety, depression and perception of patient QoL. The results of this study are deemed to be suggestive, given the statistical analyses put forth and the

large, though fairly unified, population sample. A number of univariate analyses were also found to be significant, but when analyzed in the scope of the multivariate data were deemed insignificant; thus, perhaps this is an area of further research to be done with regard to these individual characteristics. As well, the limited diversity of the population investigated may highlight characteristics that are common among predominantly white, educated people, thus excluding other possibilities for associations with increased CB.

**Santos-García & Fuente-Fernandez (2015)** investigated 120 patients and their caregivers in a cross-sectional evaluation study conducted in Spain. As in the previous study, patients with low cognitive functioning who were unable to understand questionnaires were excluded from this study, as well as those who presented with comorbidities or other disorders. Standardized tests and questionnaires were used to collect all data, including level of CB and other factors related to QoL, presence of motor and non-motor symptoms and aspects of daily life. Based on the results, participants were separated into 4 subgroups: little/no burden, mild to moderate burden, moderate to severe burden and severe burden. Multiple linear regression models were conducted to determine associations between various characteristics and the level of CB. Overall, the researchers concluded that the most prominent characteristic associated with higher levels of CB included loss of independence for ADLs. Other factors that increased levels of burden included longer duration of disease (which was not found to be significant in multivariate analyses), impaired mood, decreased QoL, and increased motor and non-motor symptoms (most consistently, general disability and depression). This study focused on patients from Spain, who had sufficient cognitive ability to engage in self-questionnaires. Data was also collected only in the morning, after patients had taken their medications; therefore, by only focusing on the “best” time of day when caregiving needs may be slightly reduced, this does not fully reflect the full range of the caregiving duties. Overall, based on the methods of data collection, inclusion criteria of the sample and the analysis

techniques used, these findings were deemed to be suggestive.

#### Between-Group Studies

**Genç et al. (2019)** investigated 74, randomly selected patients in Turkey with idiopathic Parkinson's Disease (IPD) and their caregivers. The main focus of the study was to determine whether any relationship existed between QoL and CB among patients of early and late stages of IPD. Based on results from standardized assessments, the participants were separated into two groups; Group 1 was identified as patients in Stage I-II ( $n=40$ ) and Group 2 was identified as patients in Stage III-VI ( $n=34$ ). Participants who presented with systemic disease, stroke, dementia, epilepsy or other comorbidities were excluded from the study. Data was collected using various standardized questionnaires and assessments. Researchers used t-test analyses and Chi-square tests to compare the proportion of differences between groups on sex and health status. Overall, this study found that higher levels of patient depression in later stages of IPD contributed to increased levels of CB. As well, it was found that participants in later stages of IPD demonstrated decreased QoL, specifically on general health, pain, emotional role, mental health and social function. Though this study found no significant relationship between duration of disease and level of CB, the authors contribute this to the possibility that tradition in Turkey is for female members of family to care for others and thus, may be treating this caregiving role as an obligation rather than a burden. Overall, this study demonstrates an opportunity for longitudinal studies to be completed in order to demonstrate concrete differences in level of CB with regard to PD progression. Based on the methods of data collection and overall characteristics of the sample population, the findings of this study were found to be suggestive.

#### Correlational Analysis Studies

**Lee et al. (2019)** looked at 142 patients and their caregivers with regard to how the understanding of PD contributed to the overall level of CB. Data was collected based on a newly developed questionnaire consisting of 20 questions that focused on patient and caregiver understanding

of PD. CB was quantified using a standardized questionnaire. Researchers used t-test analyses to compare categorical variables between groups and a multivariate linear regression to determine effects of independent variables on responses to the questionnaires. Overall, this study found that the greatest effect of increased level of CB was the result of increased daily care time; through multivariate analyses, the second strongest effect on CB was having a female patient. With regard to the main focus of the study, researchers found that the level of understanding of PD was significantly correlated with CB, with increased understanding associated with decreased levels of burden. The findings of this study are unique and provide an important foundation for the education of patients and caregivers to mitigate the effects of CB. Overall, based on the use of non-standardized assessments and questionnaires and overall characteristics of the sample, the findings of this study were found to be suggestive.

### *Discussion*

Across all studies, there are mixed results as to which specific characteristics may be the largest contributors to the level of CB for those caring for individuals with PD. Overall, the evidence seems to be highly suggestive that associations between characteristics of patient and caregivers and level of burden do exist. More specifically, across these five studies, it was found that patient characteristics that contributed to increased level of CB included increased patient level of depressive symptoms, decreased QoL and health related QoL, loss of independence for ADLs, increased stigma, decreased cognition, impaired mood, increased motor and non-motor symptoms, duration of disease, spiritual well-being, higher daily dosages of levodopa medication, and increased complications as a result of levodopa. With regard to caregiver characteristics, the factors that were found in these studies to contribute to increased level of CB included level of anxiety, depression, perception of patient QoL, and daily care time.

However, what was not achieved with these studies was a longitudinal view on what changes occur over time as the disease progresses.

Theoretically, as the disease evolves, symptoms would increase, and cognition would decrease; all of these changes would likely impact the level of caregiving to a great degree. Further research should be completed to look at these effects and how the patient and caregiver characteristics may contribute over time. As well, for the majority of the studies, the patients whose level of cognition was deemed as being not sufficient enough to complete questionnaires or give consent were excluded from participating. Thus, the data may not represent the full picture on what caregiving burden looks like with reduced patient cognition. Those who are caring for patients in late stages of the disease are most likely the ones who are most in need of additional support.

Furthermore, none of these studies investigated the impact of potential caregiver burnout. As caregiving needs increase, the physical, financial and mental exhaustion that comes along with caregiver burden may manifest itself into complete burnout. In such cases, burnout may manifest itself into negative impacts on the life and health of the caregiver with regard to diet, stress, depression, weight loss, or insomnia (Katsuya et al., 2000). What is left to identify is how much caregiver burden is too much? When is it necessary to provide additional help in the home/medical institution? And how do we prevent caregivers from reaching that point at all by providing support, counselling and resources?

### ***Clinical Implications***

With such a large range of symptoms, PD may present itself differently to each individual. Thus, the tasks for caregiving may look different for each pair and may evolve over time. As presented by Lee et al. (2019), the importance of understanding what PD is and how it affects the patient may be a large contributor to increased levels of CB. Furthermore, Genç et al. (2019) demonstrated how patient QoL may diminish as symptoms of depression increase in later stages of the disease, both contributing to increased level of CB. What these two studies demonstrate is the importance of providing patients and caregivers with the necessary resources to better

understand PD and its effects on the patients' lives; as such, a mutual connection may be forged and may, in turn, assist in mitigating the effects of CB.

In clinical practice, care should be taken to address these concerns and guide patients and their caregivers through an educational process to learn how their specific and individualized needs can and should be addressed. As well, as the disease progresses and the effects of depression, reduced cognition and increased dependence on the caregiver emerge, additional supports should be introduced to mitigate the effects of that additional burden on the caregiver. Regular check-ins and questionnaires should be provided to the caregiver in order to address these issues and prevent the potential of caregiver burnout.

### ***References***

- Bhimani, R. (2014). Understanding the burden on caregivers of people with parkinson's: a scoping review of the literature. *Rehabilitation Research and Practice*. 1-8. <http://dx.doi.org/10.1155/2014/718527>
- Cleveland Clinic. (2019). Caregiver burnout. *Cleveland Clinic*. <https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout#:~:text=is%20caregiver%20burnout%3F-,Caregiver%20burnout%20is%20a%20state%20of%20physical%2C%20emotional%20and%20mental,are%20able%2C%20physically%20or%20financially.>
- Genç, F., Yuksel, B., & Tokuc, F. E. U. (2019). Caregiver burden and quality of life in early and late stages of idiopathic parkinson's disease. *Korean Neuropsychiatric Association*. 16(4), 285-291. <https://doi.org/10.30773/pi.2019.02.20>
- Goldsworthy, B., & Knowles, S. (2008). Caregiving for parkinson's disease patients: an exploration of a stress-appraisal model for quality of life and burden. *Journal of Gerontology*. 63(6), 372-376.

- Kasuya, R. T., Polgar-Bailey, P., & Takeuchi, R. (2000). Caregiver burden and burnout: a guide for primary care physicians. *Postgraduate Medicine*. 108(7), 119. Retrieved from: <https://www.lib.uwo.ca/cgi-bin/ezipauthn.cgi?url=http://search.proquest.com/scholarly-journals/caregiver-burden-burnout-guide-primary-care/docview/203963826/se-2?accountid=15115>
- Lee, G-B., Woo, H., Lee, S-Y., Cheon, S-M., & Kim, J. W. (2019). The burden of care and the understanding of disease in parkinson's disease. *PLoS ONE*. 14(5), 1-9. <https://doi.org/10.1371/journal.pone.0217581>
- Macchi, Z. A., Koljack, C. E., Miyasaki, J. M., Katz, M., Galifianakis, N., Prizer, L. P., Sillau, S. H., & Kluger, B. M. (2020). Patient and caregiver characteristics associated with caregiver burden in parkinson's disease: a palliative care approach. *Annals of Palliative Medicine*. 9(1), 24-33. <http://dx.doi.org/10.21037/apm.2019.10.01>
- Mayo Clinic Staff. (n.d.) *Parkinson's Disease: Symptoms and Causes*. Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/symptoms-causes/syc-20376055>
- NIH National Institute on Aging. (May 2017). *Health Information: Parkinson's Disease*. NIH National Institute on Aging. <https://www.nia.nih.gov/health/parkinsons-disease>
- Parkinson's Foundation. (n.d.) *Understanding Parkinson's: Causes*. Parkinson's Foundation. <https://www.parkinson.org/Understanding-Parkinsons/Causes>
- Santos-García D., & Fuente-Fernández, R. (2015). Factors contributing to caregivers' stress and burden in parkinson's disease. *Acta Neurologica Scandinavica*. 131, 203-210. doi: 10.1111/ane.12305
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshabib, M. (2006). Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism and Related Disorders*. 12(1), 35-41. <https://doi.org/10.1016/j.parkreldis.2005.06.011>
- Schrag, A., Jahanshahi, M., & Quinn, N. (2000). What contributes to quality of life in patients with Parkinson's Disease? *Journal of Neurology, Neurosurgery and Psychiatry*. 69(3), 308-312. <https://dx.doi.org/10.1136/jnnp.69.3.308>
- Statistics Canada. (2020). Caregivers in Canada. *Statistics Canada*. <https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm>
- Tan, M. M. J., Lim, E. C., Nadkarni, N. V., Lye, W. K., Tan, E. K., & Prakash, K. M. (2019). The characteristics of patients associated with high caregiver burden in parkinson's disease in Singapore. *Frontiers in Neurology*. 10(561), 1-7. doi: 10.3389/fneur.2019.00561
- Tjaden, K. (2008). Speech and swallowing in parkinson's disease. *Topics in Geriatric Rehabilitation*. 24(2), 115-126. doi:10.1097/01.TGR.0000318899.87690.44.
- UCB Canada Inc. (n.d.). Parkinson's disease. *UCB Canada*. <https://www.ucb-canada.ca/en/Patients/Conditions/Parkinson-s-Disease#:~:text=Over%20100%2C000%20Canadians%20are%20living,new%20cases%20per%20100%2C000%20people>