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Non-motor Symptoms among Patients with Parkinson's Disease attending Multidisciplinary clinic in a Tertiary care hospital and its Association with Family Caregiver Burden

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Abstract

Background: Several citations were explored to find the association between non-motor symptoms among Parkinson's patients and caregiver burden among their caregivers. Different studies showed various outcomes and relationships between the two variables. This study was conducted to understand the relation between caregiver burden and non-motor symptoms among patients and their caregivers attending a multidisciplinary clinic in a tertiary care hospital. Failure to recognize and manage caregiver burden could potentially lead to burnout and premature institutionalization of the patient.

Methods: Ethical approval was obtained from the Institutional health research ethical committee. The outcome measures used to assess non-motor symptoms and caregiver burden were Non-motor Symptoms Questionnaire (NMSQ) and the Zarit Burden Interview (ZBI) respectively which are standardized tools. Data was collected to assess the same after informed consent from Parkinson's patients and their caregivers attending the multidisciplinary clinic at our hospital. Data analysis and scoring were done using the Spearman’s rank correlation coefficient.

Result: There is a strong positive association between non-motor symptoms and caregiver burden in the urinary and memory domains and a moderate positive association between Gastro and anxiety domains that are statistically significant. A weak positive correlation that was not statistically significant was found in the domains of hallucination, miscellaneous, cardiovascular with caregiver burden. A very weak positive association was observed between sexual drive and sleep domains with caregiver burden, however they were not statistically significant while a negative correlation was seen between pain and caregiver burden.

Conclusion: There is positive association observed from the total score of non-motor symptoms and caregiver burden, that is statistically significant.

Keywords: Parkinson’s Disease, Non-motor Symptoms, Caregiver burden

Introduction

Parkinson’s disease (PD) is a complex, chronic and progressive disease both motor as well as non-motor symptoms manifest. Non-motor symptoms (NMS) include indicators involving other functions of the body such as speech and voice, sleep, bowel motility, cognitive function and mood which in turn affect the quality of life of an individual. Hence, it is important that non-motor symptoms are also identified and addressed.

Early cognitive difficulties associated with PD include working memory problems, slowed information processing speed, difficulty in learning and recall and executive dysfunction. The domains of cognition that PD impacts include: Executive functioning, information processing, speed, attention, memory, language, visuospatial / visuoperceptual functioning and general intellectual functioning.

Sleep disorders have been associated with PD since the condition was first identified. Specific sleep disorders associated with PD include the inability to fall asleep as well as difficulty to stay asleep. Some people have very vivid dreams and may talk or have involuntary movements in their sleep.

Within the main psychiatric diagnostic criteria, there are separate classifications for mood disorders attributable to medical conditions, including PD. Non-pharmacological treatments for mood disorders associated with PD are psychological interventions like Cognitive Behavioral Therapy(CBT). Mood disorders include depression and anxiety.

Non-specific discomfort may be a part of PD. Pain also limits the patient from engaging in activities which further leads to hopelessness, worthlessness and social withdrawal. The patient, quite often, also requires psychological support.

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Pharmacological treatment for some people with PD have side effects that lead to neurobehavioral problems such as hypersexuality, preoccupation with complex motor acts such as disassembling electrical equipment, hypomania and mania, aggression and heightened irritability, an urge to walk considerable distances without purpose, pathological gambling, shopping and food cravings.[i] [ii]

Parkinson's Disease is associated with a significant decline in Health Related Quality of Life (HRQoL) of the patient and the caregivers which in turn creates a real emotional, economic, and social problem. Indeed, caring for a patient with PD can sometimes have negative implications which cause a significant deterioration in the relationship between patient and caregiver and even compromise continuity of the same, due to a change in roles or personality [iii].

According to Hiseman and Facjrell (2017), a caregiver's burden can be defined as the load or strain placed on a person caring for a disabled, chronically ill, or elderly family member. It is a multidimensional response to the physical, emotional, social, psychological and economic stressors associated with the caregiver experience.[iv]

Female gender, poor or minimal education, financial stress, increased demand on caregiving time and efforts, lack of choice, depressive symptoms, as well as the perceived patient distress have been identified among the risk factors that affect the caregiver's burden.[v]

Significantly, increased levels of caregiver burden not only influence the perceived quality of life of caregivers themselves but can also negatively affect the quality of care for individuals with PD that they attend to. Consequently, this creates a detrimental cycle that adversely affects the health outcomes of people with PD.

Furthermore, informal caregivers have a crucial part in preventing or, at the very least, postponing the emergence of complications associated with PD. These complications often lead to the institutionalization of individuals with PD, however, the informed and empathetic involvement of informal caregivers, individuals with PD can extend the duration of their time within the community. This aligns with the fundamental wishes of many persons with PD.[vi]

Hence this study aims to understand the relationship between caregiver burden and non-motor symptoms of Parkinson's disease among Parkinson patients and their caregivers.

Review Of Literature

Parkinson's disease is a common neurodegenerative disorder with motor as well as non-motor symptoms affecting approximately 1% of the population over 60 years, the prevalence of which increases with age.[vii] PD is a disorder of the extrapyramidal system, which includes motor structures of the basal ganglia, and is characterized by the loss of dopaminergic function and consequent diminished motor function, leading to clinical features of the disease. Research in the late 1950s identified striatal dopamine depletion as the major cause of the motor symptoms of PD, although the presence of nonmotor features supports the involvement of other neurotransmitters of the glutamatergic, cholinergic, serotonergic and adrenergic systems, in addition to the neuromodulators adenosine and enkephalins.[viii]

The four hallmark symptoms that are characteristic of Parkinson's which are important for diagnosing the neurodegenerative disorder are: resting tremor, bradykinesia, rigidity and postural instability. People with Parkinson's also likely experience other motor symptoms, such as freezing, impaired coordination, and difficulty speaking. Non-motor symptoms are also associated with the disease.[ix] Persons with PD, in addition to problematic motor symptoms, may develop non-motor symptoms like anxiety, apathy, depression, impulse control disorders, dementia, psychotic symptoms, hearing problems and sleep disorders.[x]

Neuroanatomically, non-motor symptoms may be subdivided into cortical manifestations (cognitive and psychotic impairment), basal ganglia symptoms (apathy, impulse control disorders and restlessness or akathisia), brainstem symptoms (anxiety, depression and sleep disorders) and the peripheral nervous system disturbances (orthostatic hypotension, constipation, pain and sensory disturbances). Recently non-motor symptoms are acknowledged as an integral part of PD symptoms which are a significant cause of disability and poor quality of life for PD patients and receiving medical attention as a focus of care.[xi] While NMS exhibit a strong association with the progression of the disease, they are also likely to manifest before the emergence of motor symptoms by several years.

There is a growing acknowledgment that non-motor symptoms impose a substantial burden on individuals with PD and impact the quality of life (QoL) to a greater degree than motor characteristics. However, NMS often remains undiagnosed and untreated. Although no treatment prevents disease progression, pharmacotherapy is found to control symptoms, maintain patient's independence and delay the progression and improve the quality of life. Over time, medication loses effectiveness, the patient's disability increases and care becomes palliative. Given the progressive nature of the disease, people with PD typically experience a progressive impairment in performing daily activities and a similarly progressive loss of autonomy, gradually, leading to a higher dependency on others in supporting their daily living requirements.[xii] It has direct implications upon the quality of life (QOL) of both the patient and the caregiver, as more time and energy are spent on the caregiving process.[xiii]

Caregiver burden refers to physical, mental, social and financial problems encountered by the caregivers of patients with chronic disease. Factors affecting caregiver burden are related to both caregiver and patient characteristics, including clinical disease manifestations and complications.[xiv]

Evidence from the scientific domain indicates that a secure caregiver can be viewed as having the capability not only to utilize existing social supports but, more importantly, to manage and incorporate the emotions related to the patient. This includes being more emotionally available and reducing the subjective sense of burden associated with the illness.[xv] Conversely, insecure attachment styles in a caregiver may spill over into situations of increased conflict, ambivalent feelings, and difficulty in coping and regulating emotions. In fact, the role of adult attachment styles indicated that the attachment anxiety of caregivers was negatively tied to a greater degree of resolution of PD.[xvi] Greater care for advanced PD patients is enabled by informal caregivers.[xvii] Such caregivers experience a large burden, which can lead to physical and psychological complaints.[xviii] General risk factors for caregiver burden are female gender, cohabitation with the care recipient, the amount of caregiving time and effort and lack of choice.[xix] Women providing care for individuals with PD experience a diminished quality of life (QOL), with compromised mobility, emotional well-being, and the non-motor symptoms of the PD patient serving as predictors of caregiver burden..[xx] The patients' caregivers perform a wide range of tasks and are involved for long hours in caring for and supporting the patient. Caregivers face huge responsibilities as their future becomes uncertain as the disease progresses and prognosis is variable, making the amount of care needed unpredictable. As a consequence, the impact of PD on patients is of great importance, but also the impact on caregivers and caring for the caregiver becomes crucial.[xxi] Challenges for PD caregivers also include financial burden and other long-term complications, such as lack of family support and competing role responsibilities, such as caring for children, elderly parents or spouses with PD.[xxii] Caretakers face an even greater burden from mental stress caused by worrying about a patient's safety than from physical stress.[xxiii] An excessive burden can cause depression and, eventually, lead to burnout of the caregiver, which may result in institutionalization of the PD patient.[xxiv] Therefore, it is pivotal to engage other family members to uncover and reduce caregiver burden and prevent premature institutionalization.[xxv] The progressive and multifocal characteristics of PD compounds the complexity of managing this condition, which is particularly significant given its growing prevalence in the aging population.

Recent progress in understanding PD not only sheds light on the mechanisms of the disorder but also enhances comprehension of patients' requirements and the application of pertinent tools to enhance their quality of life (QoL). Consultants have a significant role to play in both the early and advanced stages of PD, especially when maintaining effective and timely communication with a multidisciplinary team. This communication is valuable for seeking advice, implementing support interventions, or making referrals when necessary.[xxvi]

Methodology

A cross sectional study was done among Parkinson patients and their caregivers. In the current study the sample consisted of 65 patients from all Parkinson patients and their caregivers attending the multidisciplinary clinic in Believers Church Medical College Hospital, Tiruvalla, Kerala. The duration of data collection was 6 months. Convenient sampling technique was used to collect the sample.

The dependent variable in this study was caregiver burden, measured utilizing the Zarit Burden Interview (ZBI). This measure was found to have excellent psychometric properties with a Cronbach's alpha coefficient of 0.91 in a previous study using the same sample as that of the current study. This instrument was translated from English into Malayalam and then retranslated by other translators. The independent variable in this study was non-motor symptoms, measured using the Non-Motor Symptom Questionnaire (NMSQ) with psychometric properties of Cronbach's alpha of 0.77. NMSQ consists of 30 items.This instrument was translated from English into Malayalam and then retranslated by other translators.

Inclusion criteria includes all patients diagnosed with Parkinson's disease and their caregivers and exclusion criteria of patients with brain injury, patients with dementia, patients who did not give informed consent and who are not cooperative for study.

After explaining the purpose and confidentiality of the study, a written informed consent form was obtained from the participants. In this study, a socio-demographic sheet was used to collect information regarding relevant variables such as name, age, gender, education, occupation, marital status, duration of illness, comorbidities and caregiver. After obtaining the approval of the ethics and research committee, the investigator met the participants individually and received consent to participate in the study and collected data from participants through a multidisciplinary clinic. The collected data was scored according to the scoring procedures. Data was analyzed by scoring the response.

Result

Table 1: Showing the association between NMSQ domains and Caregiver burden categories

Correlation category	NMSQ Domains	Pearson r	Spearman	P value
Strong positive correlation	Domain 2	0.2752	0.2911	0.0099**
	Domain 5	0.3268	0.3253	0.0040**
Positive correlation	Domain 7	0.2358	0.2479	0.0244*
	Domain 1	0.2717	0.2453	0.0206*
No correlation	Domain 4	0.1973	0.1807	0.0739
	Domain 6	0.1514	0.1188	0.1642
	Domain 3	-0.1038	-0.1189	0.8312
	Domain 8	0.0103	0.0467	0.3545
	Domain 9	0.1012	0.0221	0.4374
	Domain 10	0.1123	0.1436	0.1241

***(Domain 1- Gastro, Domain 2- urinary, Domain 3- Pain, Domain 4 -Miscellaneous, Domain 5- Memory, Domain 6- Hallucination, Domain 7- Anxiety ,Domain 8- Sexual drive, Domain 9- Sleep, Domain 10- Cardiovascular)**

Table 1 shows the association between NMSQ domains and Caregiver burden categories. Two domains have strong positive associations, which includes NMSQ Domain 2 - Urinary" and "CGB Category" across different levels of burden. The correlation coefficients (Pearson's r: 0.2752, Spearman's rho: 0.2911). The p-value less than 0.01 from the test of concordance indicates a significant agreement between the variables, NMSQ Domain 5 - Memory" and "CGB Category" across different levels of burden. The correlation coefficients (Pearson's r: 0.3267, Spearman's rho: 0.3253).The p-value is less than 0.01 from the test of concordance signifies significant agreement between the variables.

Two domains have positive association. NMSQ Domain 1 - Gastro and CGB Category with various levels of burden. The correlation coefficients (Pearson's r: 0.2717, Spearman's rho: 0.2453). The p-value is less than 0.05 from the test of concordance suggesting significant agreement between the variables, NMSQ Domain 7 - "Anxiety" and "CGB Category" across different levels of burden. The correlation coefficients (Pearson's r: 0.2358, Spearman's rho: 0.2479). The p-value is less than 0.05 from the test of concordance indicates a significant agreement between the variables.

Domain 4, 6, 3, 8, 9, 10 have no correlation between the variables. It includes NMSQ Domain 4 - "Misc" and "CGB Category" across various levels of burden. The correlation coefficients (Pearson's r: 0.1973, Spearman's rho: 0.1807). The p-value is greater than 0.05 from the test of concordance indicates a marginally significant agreement between the variables. Domain 6 - “Hallucination" and "CGB Category" across various levels of burden. The correlation coefficients (Pearson's r: 0.1514,Spearman's rho: 0.1188),The p-value is greater than 0.05 from the test of concordance indicates a marginally significant agreement between the variables. Domain 3, 8 and 9 have weak negative, very weak and weak to negligible association respectively. NMSQ Domain 3 - “Pain" and "CGB Category" across different levels of burden. The correlation coefficients (Pearson's r: -0.1038, Spearman's rho: -0.1189). The p-value is greater than 0.05 from the test of concordance indicates no significant agreement between the variables. NMSQ Domain 8 - “Sex Drive" and "CGB Category" across various levels of burden. The correlation coefficients (Pearson's r: 0.0103, Spearman's rho: 0.0467). The p-value is greater than 0.05 from the test of concordance suggesting no significant agreement between the variables. Domain 9 - ”Sleep" and "CGB Category" across different levels of burden. The correlation coefficients (Pearson's r: 0.1012, Spearman's rho: 0.0221). The p-value is greater than 0.05 from the test of concordance suggests no significant agreement between the variables. Domain 10 - “Cardiovascular” and "CGB Category" across different levels of burden. The correlation coefficients (Pearson's r: 0.1123, Spearman's rho: 0.1436). The p-value is greater than 0.05 from the test of concordance suggests no significant agreement between the variables.

Table 2 shows the association between NMSQ category and Caregiver burden category

	NMSQ category	**Pearson r**	**Spearman**	**P value**
Caregiver burden category		0.2218	0.2236	0.0342*

Table 2 shows the association between NMSQ categories and Caregiver burden categories. The correlation coefficients (Pearson's r: 0.2218, Spearman's rho: 0.2236) suggests a moderate positive association between the ordinal variables. The p-value is less than 0.05 from the test of concordance suggests a significant agreement between the variables.

Discussion

There is limited literature supporting NMSQ and Zarit caregiver burden association available. There is other literature that supports caregiver burden with other outcome measures that exhibits positive correlation between non-motor symptoms and caregiver burden.[xxvii] [xxviii] One study, reporting the sum scores of the Non-motor Symptom Assessment Scale for Parkinson’s disease, which covers nine non-motor domains, found a moderate association with the ZBI sum score.[xxix]

In the present study there was seen a strong positive correlation between caregiver burden in two NMSQ domains namely urinary and memory. A moderate positive correlation was seen in the gastro and anxiety domains while a weak positive correlation was seen in the cardiovascular, hallucination and miscellaneous domains of NMSQ. Very weak positive correlation between caregiver burden and NMSQ was observed in the sleep and sexual drive domains. Negative correlation was observed between caregiver burden and the pain domain of NMSQ.

In the urinary domain, a statistically significant strong positive correlation was observed. The urinary domain comprises nocturia and an increased urge and frequency to urinate. Caregivers reported sleep disturbances, increased dependence of the patient on the caregiver, reduced opportunities for socialisation and the fear of urinary accidents which in turn increased mental stress and responsibility for caregivers.

The domain of Memory in the NMSQ includes reduced attention span, loss of interest and concentration in which a statistically significant strong positive association was found. The intolerance and irritability in the patient as a result of poor memory tended to cause interpersonal conflict between caregiver and the patient.

The moderate positive and statistically significant correlation seen in the gastro domain of NMSQ includes drooling, difficulty in swallowing, vomiting, constipation and bowel incontinence. These may be caused by multiple drug prescriptions that practitioners prescribe when patients raise symptomatic concerns which in turn has side effects as mentioned above. It was observed from caregiver reports that a patient's dietary preferences demanded more effort and time from the caregiver to prepare their nutritional needs. Increased dependency on caregivers was also reported to address their personal toileting needs, requiring a greater demand on their time which affected the caregivers’ quality of life and well being, consequently affecting their mental health.

A moderate positive and statistically significant association was seen in the domain of Anxiety in NMSQ which exhibits in the form of sad or low mood, anxiety or panic attacks. Caregivers observed that a low mood and depression in the patient tended to be a prime reason for emotional outbreaks in the caregiver which consequently led to the need for assistance in emotional management for both the patient as well as the caregiver. Thoughts and worries related to safety also cause more anxiety and panic episodes in patients that in turn leads to increased dependence on caregivers for all Activities of Daily Living (ADLs).

A weak positive association was seen in the cardiovascular domain, that is not statistically significant. This domain includes risk of fall, lightheadedness, dizziness from lying to sitting and sitting to standing. Few patients reported more fear and anxiety which indirectly resulted in increased dependence on caregivers which further demanded more time of the caregiver with the patient. This resulted in greater burnout in the caregiver draining them both emotionally and physically.

The miscellaneous domain in the NMSQ comprises taste, smell, body weight, swelling of legs, excessive sweating and double vision. A weak positive but not statistically significant association was seen which could be put down to environmental factors like climate changes, decreased ambulation, changes in food intake habits and appetite which patients have accepted as a result of which caregivers are less weighed down.

In the domain of hallucination, a weak positive however not statistically significant association was also seen. This may be attributed to the pre-existing knowledge that both patients and their caregivers have about their medical condition and few of the neuropsychiatric symptoms commonly discussed with the family and acceptance of medical conditions by the caregiver and less dependency on caregivers.

The Sexual Drive and sex difficulty domain had a very weak level of association that was not statistically significant. Resulting from decreased interest, other physical disabilities and reduced openness to discuss sexual drive or difficulty, therefore, did not affect caregiver burden very much.

The domain of sleep expands in the form of frightening dreams, acting out, difficulty to maintain sleep and unpleasant sensations in the leg. A very weak or negligible association that was not statistically significant was seen in this domain. The weak positive association due to reduced sample size and within the sample only few experienced sleep disturbances. Sleep disturbances were attributed to incidences of multiple drug use, increased motor symptoms, other non motor symptoms that affected the patient’s sleep, disability and advancing age in patients. Caregivers reported that their own sleep was disturbed which led to increased fatigue.

A weak negative association that is not statistically significant, was observed in the domain of pain which is seen in the form of unexplained pain or known conditions such as arthritis. A poor association may be attributed to the importance given to other domains, giving lesser importance to such complaints by the caregiver especially because of the difficulty in localisation. However, such pain could also be seen as attention seeking which could often be ignored by the caregiver.

Overall, there is a positive association between caregiver burden and non-motor symptoms. The total score of caregiver burden against the NMSQ shows a positive correlation that is statistically significant. This is because caregivers' experiences have indicated that their involvement with the patient has had significant effects on the caregiver's well-being.

Conclusion

The study revealed that non-motor symptoms among Parkinson's patients are a significant contributor to caregiver burden. Results showed a strong positive association between non-motor symptoms and caregiver burden in the urinary and memory domains, a moderate positive association in the Gastro and anxiety domains that were statistically significant. A weak positive correlation was observed in the domains of hallucination, miscellaneous, cardiovascular and caregiver burden that were statistically not significant There was a very weak positive association between sleep and sexual drive domains with caregiver burden and a negative correlation between pain and caregiver burden that were not statistically significant.

Limitation Of The Study

- The population of the sample is limited to patients from Central Travancore, Kerala.
- The sample size obtained for the study is small
- Type of caregivers are not included in demographic data.

Recommendations Of The Study

- A study of this nature would be more effective with a larger sample size and conducted in a wider community that includes people from a variety of cultural contexts.
- Further studies in this area will provide more insight and enable better support for caregiver well being and timely referrals to the multidisciplinary team.
- Areas for further research - find an aspect of NMS to study further and why this aspect may be relevant or focus the study on a specific subset of people - a different age group or gender.

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