

Impact of Motor and Non-Motor Symptoms on Quality of Life in Parkinson's Disease - A Questionnaire Based Observational Study from Karad, India

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ABSTRACT

BACKGROUND

Parkinson's disease is a chronic neurodegenerative disorder with a prevalence rate of 108 - 257 per 100,000 people, occurring in later half of life and affecting both genders equally. The progressive nature of the disease is associated with growing disability and has a considerable impact on quality of life. Quality of life (QOL) is an important goal in every rehabilitation process and its impact on disease process, stage and prognosis is closely associated, which often gets neglected. Thus, it was necessary to conduct this study to establish actual impact of Parkinson's disease on quality of life, emphasizing on disease duration.

METHODS

A questionnaire based observational study was carried out among patients with Parkinson's disease in Maharashtra. The survey was conducted in Parkinson's Association Group by handing over the hard copies of questionnaires to 120 patients and their respective care takers. Questionnaire used was 'The Parkinson's Disease Questionnaire (PDQ39)'. It had 39 items grouped into 8 domains. Statistical analysis of the collected data was carried out using InStat software and Microsoft excel.

RESULTS

In motor symptom-based questions, the impact on quality of life was more significant i.e., 54 % (P < 0.0001) compared to non-motor symptoms which was 46 % (P < 0.0001). Maximum number of subjects were from age group 71 to 80 while minimum number of subjects were from 91 to 100 yrs.

CONCLUSIONS

There was significant impact of motor as well as non-motor symptoms on patient's quality of life; but motor symptoms like tremors and slowness of movement had greater impact compared to non-motor symptoms which included speech difficulty and social stigma. There was no co-relation between specific age group and incidence of disease.

KEY WORDS

Parkinson's Disease, PDQ - 39 Questionnaire, Quality of Life (QOL), Motor and Non-Motor Symptoms, Activities of Daily Living

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BACKGROUND

Parkinson's disease is a chronic neurodegenerative disorder occurring in older age groups. James Parkinson was first to coin the term Parkinson's disease, in 1817. Nowadays, since new biopsychosocial models of medicine are adopted, quality of life in patients with Parkinson's disease is very important. Quality of life (QOL) is a perception by patients themselves of the impact caused on their life by the disease and its consequences.¹ Quality of life is a structured idea containing three aspects which covers the individual as a whole that are social aspect, physical aspect, and mental wellbeing. These three factors have equal importance in everyone's life. Alteration of even a single aspect affects the person greatly. In this disorder, the main aim of therapy should be to improve patient's quality of life as it is a predominant predictor of the person's well-being. Varied representation of this condition through motor and non-motor symptoms in overall population makes it a very complex condition to cope up with.

The Parkinson's Disease Questionnaire (PDQ - 39) is useful and effective in quantifying the quality of life specifically in patients with Parkinson's disease. This questionnaire contains eight various domains with questions related to motor as well as non-motor aspect of person's life. With a promising application in clinical trials, quality of life assessment in Parkinson's disease is necessary. Thus, to identify the factors that are most disabling to patient is very important in Parkinson's disease.² The slow progression of the disease with prominent tremors in some body parts or slowness of movement were described initially. The findings also included sleep disturbance, constipation, dysphagia, salivation problem and delirium.³

Usually treatment of Parkinson's disease mainly focuses on improving motor functions. The disease in its advanced stage is usually complicated by other problems like falls, depression and dementia which has a great impact on quality of life in Parkinson's patients. In such patients PDQ - 39 has been shown to have great validity, responsiveness, and reliability for disease specific quality of life. Parkinson's Disease Questionnaire - 39 is a great tool to assess the overall impact of illness through disease specific questions and the single summary index and is easy to interpret with adequate score reliability.⁴ There is significant impact of Parkinson's disease on health-related quality of life.⁵ Other symptoms which affect the QOL immensely in Parkinson's Disease are depression, sleep disorders, urinary incontinence, night-time restlessness, and fatigue. To improve the quality of life of patients, depression and anxiety associated with Parkinson's disease must be assessed and managed.⁶

Age of a person is a major contributing factor in declining quality of life, as it is a contributing factor in increasing the risk of health-related conditions like stroke and hypertension. Risk of Parkinson's disease also increases with growing age and its severity increases with presence of comorbidities.⁷ In addition to characteristic symptoms, the major predictors of QOL are difficulty while walking and turning around, increased risk of falls, difficulty in day-to-day activities like dressing and undressing, unpredictable fasciculation and sensory symptoms such as pain in addition to sleep related problems,

depression, anxiety and social difficulties like stigma and problems while communicating with others. Therefore, we used this questionnaire as a tool to have equal focus on impact of motor as well as non-motor symptoms on patient's quality of life.

In this study we have assessed as well as compared the impact of motor and non-motor symptoms on quality of life. Both the motor and non-motor features are seen which have lot of diversity in terms of age which in turn affects the performance in daily activities and quality of life. The association of these symptoms on quality of performance is neglected often while planning their treatment program as the it is mainly restricted to pharmacological management. Therefore, role of all these symptoms on functional performance and quality needs to be analysed. Affection of quality of life due to motor symptoms is derived through domains like mobility, activities of daily living and bodily discomfort while that due to non-motor symptoms is derived through emotional well-being, stigma, social support, cognition and communication. Based on these domains we observed the different levels of impact of motor and non-motor symptoms.

Objectives

- To screen whether the patients with Parkinson's disease are predominantly motor or non-motor symptomatic.
- To compare the effect of motor symptoms and non-motor symptoms on the quality of life in patients with Parkinson's disease
- To find co-relation between age of the patient and the disease

METHODS

This is a cross sectional observational study and ethical approval was obtained from the ethical committee of Krishna institute of medical sciences (deemed to be university) Karad. A survey study was carried out in Parkinson's Mitra Mandal, Pune. All the subjects (when subjects were unable to respond properly, their care givers) were provided with printed consent forms in Marathi and English languages and copies of the questionnaire. Study duration was for 6 months from 18 November 2020 to 18 May 2021. The calculated sample size was 120 (1). The selection of participants was done using purposive sampling method considering the inclusion and exclusion criteria. Participants included in the study were registered members of Parkinson's Mitra Mandal, Pune.

Inclusion Criteria

Individuals diagnosed with Parkinson's disease

1. From all age groups
2. Males and females both were included.

Exclusion Criteria

1. Individuals recently diagnosed with Parkinson's disease (for less than 1 year)

- 2. Individuals with other neurological disorders along with Parkinson’s disease.

Sample Size

Formula (1) used for calculating the sample size is

$$N = 2 \times \frac{4SD^2}{M \times \epsilon^2}$$

$$M \times \epsilon)^2$$

Where, $\epsilon = 0.2$

SD = 43.99

M = 57.08

n = sample size

Purposive sampling technique was used for sample selection. Data collection was done using a structured questionnaire called Parkinson’s Disease Questionnaire–39⁸ with good test - retest as well as internal reliability and good validity.⁹ This questionnaire contained 39 questions under 8 different domains related to both motor and non-motor symptoms. Each question carried five possible responses graded as,

- 0 - never
- 1 - occasionally
- 2 - sometimes
- 3 - often
- 4 - always

Materials used for data collection were consent form, hard copy of PDQ - 39 Questionnaire and writing materials.

Statistical Analysis

InStat software was used to analyse collected data. Results are shown through mean and percentage forms using graphical method.

RESULTS

Based on data collected and analysed mainly two factors have impact on quality of life in Parkinson’s Disease, that is motor and non-motor symptoms and age does not show any significant correlation with the incidence of disease.

Age Distribution

A total of 120 subjects were taken for the study. Out of 120 subjects, 18 were in the age group 51 - 60 years (15 %), 34 between 61 and 70 years (28 %), 39 between 71 and 80 years (33 %), 22 between 81 and 90 years (18 %), and 7 in the age group of 91 - 100 years (6 %). Maximum participants were from age group of 71 – 80 yrs., but it does not have significant correlation with their quality of life.

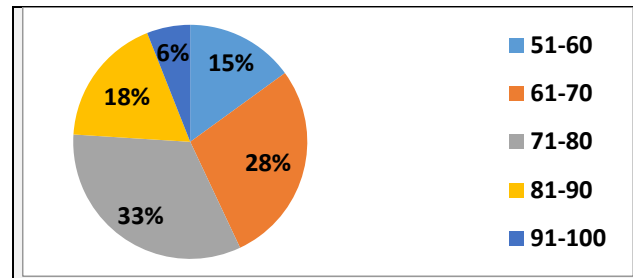


Figure1 Percentage Wise Representation of Different Age Groups (yrs.) Included in the Study

Comparison of Overall Impact of Motor and Non-Motor Symptoms on Quality of Life

Both motor and non-motor symptoms affect quality of life, but comparatively motor symptoms affect more that is 54 % than non-motor that is 46 %.

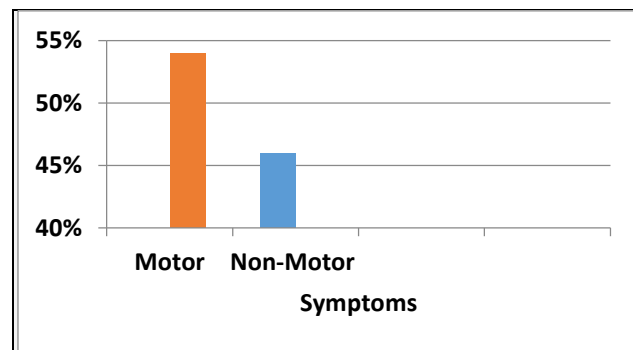


Figure 2. Graphical Representation of Comparison between Motor and Non-motor Symptoms Affecting Quality of Life

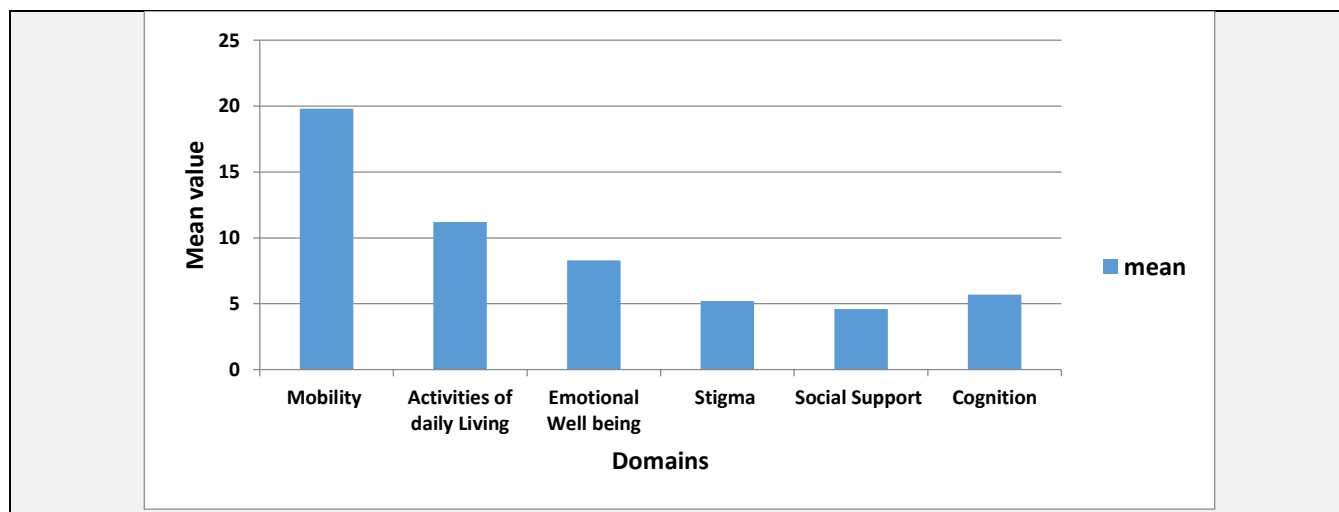


Figure 3. Mean Values of Different Domains of PDQ - 39 Questionnaire

Domain Wise Mean and Standard Deviation

The study shows us that motor and non-motor symptoms have effect on quality of life in respective subjects with Parkinson's Disease.

Domain	Mean	Standard Deviation
Mobility	19.3166	11.95579
Activities of daily living	11.1749	6.87687
Emotional well being	8.0858	6.55649
Stigma	5.6417	4.39626
Social support	3.1834	3.75438
Cognition	6.5833	4.67504
Communication	6.675	3.59919
Body discomfort	6.7333	3.32273

Table 1. Tabular Representation of Domain Wise Mean and Standard Deviation Values

This study provides us detailed data about symptoms and their effect on quality of life. Among 120 participants it was seen that motor symptoms affect the quality of life more than non-motor symptoms. chi square test application to each question in PDQ - 39 questionnaire shows significance with P value (< 0.05).

DISCUSSION

Parkinson's disease is one of the most disabling neurodegenerative disorders in elderly population and is an emerging condition nowadays. It not only affects the person physically but also mentally. The characteristics of the Parkinson's disease are slow movements, tremors, postural abnormalities, and rigidity all over the body. Altered gait, speech slurring and expressionless face hinders them from participating in different social aspects, these further leads to social stigma and results in their withdrawal from social life and this condition also affects activities of daily living greatly.

Activities of daily living are the usual tasks a person performs every day on his own and any alteration in one's normal condition or presence of any disease / disorder affects activities of daily living primarily. We used questionnaire to see the patient's perception of his own condition. This gives us idea about the severity of the person's condition and its effect on his life through his or her own perception. Support from family also plays a very important role in these people's lives, absence of family support and their loved ones may result in mental stress and anxious behaviour. Motor and non-motor symptoms are important aspects in Parkinson's disease so both should be equally focused on while assessing and treating patients. This study helps to bring light on the fact that unidirectional approach cannot help patient heal completely and effectively and a group of various professionals should work together to make the patient's condition better.

This Parkinson's disease-based study analyses the relation between symptoms (motor and non-motor) and its impact on patient's quality of life. Even though the risk of Parkinson's disease increases with growing age, there is no significant co-relation between the age of the patient and the affection of the quality of life. The severity of symptoms varies according to presentation of the symptoms and patient's ability to cope with it. The observation clearly shows tremendous impact of motor and non-motor symptoms on QOL. Our study shows that since motor and non-motor symptoms collectively affect patient's QOL, special attention needs to be given to motor

symptoms, mainly physical disability and gait impairment because most of them showed less non motor problems because of social acceptance and family support. However, some studies have shown that though disorders and altered gait have the greatest impact on QOL, sleep disorders also influence patient's QOL.² Anxiety is prevalent in Parkinson's disease (PD) and symptoms of anxiety affect health related QOL more than depression.¹⁰

Other impairments like cognitive, depression, dementia, disturbed olfactory sense and altered sleep are also experienced in Parkinson's disease.¹¹ Other than these symptoms, factors like number of family members, their support and patient's own education level play an important role in their independent daily lives.¹² In some neurological conditions, overall quality of life is hampered and various health care professionals have important role in their rehabilitation.¹³ Non-motor symptoms like nocturia, fatigue, dribbling of saliva were present in almost all patients but, overall impact of non-motor symptoms was less significant.

Patients do not only have symptoms because of the disease but also show some adverse effects of the medication they are taking. In our study we found that, the impact of motor symptoms was more (54 %) compared to that of non-motor symptoms (46 %), but non-motor should not be ignored because even though they are less perceived by patient they also significantly affect the QOL.

The non-motor aspect in PDQ - 39 included items like social support, emotional wellbeing, stigma, cognition and communication. In some studies, they have found that patients had the most problems with social function followed by mobility control and psychological autonomy and communication¹⁴ while in some studies, it was indicated that symptoms like bradykinesia, postural alterations and abnormalities in gait pattern strongly affected the scores of PDQ - 39 Questionnaire.¹⁵ Affection of quality of life depends upon presenting symptoms, their severity, rehabilitation therapy received by patient, any other comorbidities present and patient's coping strategies.¹⁶ Thus, in the present study we have tried to quantify the individual effect of various motor and non-motor symptoms. This study provides evidence for importance of assessing motor and non-motor symptoms while evaluating patients with Parkinson's disease. There are various scales to either measure demographic and psycho - social factors or motor symptoms so we used PDQ - 39 Questionnaire as it involves all three factors and makes the comparison better. PDQ - 39 questionnaire helps to quantify overall condition and wellbeing of a person through above mentioned eight domains.

This questionnaire is ideal for the study as it is specific to Parkinson's disease. So, it solely focuses on the alteration of quality of life in Parkinson's Disease.¹⁷ Some generic health status measures like SF - 36 can be used, but in Parkinson's disease, some areas are affected which are not included in these measures¹⁸ like sleep problems, fatigue, nocturia etc.¹⁹ Results of this study showed that motor symptoms affect the QOL more compared to non-motor symptoms, but both the aspects need to be considered while planning treatment program as non-motor symptoms, though less visible, also greatly affect the patient's quality of life. A multidisciplinary approach needs to be considered while treating patients with Parkinson's Disease. A good team of physician, physical

therapist, psychiatrist, speech therapist and counsellors would improve the overall condition of a patient.

CONCLUSIONS

There is a significant impact of motor as well as non-motor symptoms on patient's quality of life; but motor symptoms have greater impact compared to non-motor symptoms. Commenting on age, there is no co relation between specific age group and incidence of disease. Age group of 71 – 80 yrs. showed maximum number of subjects in this study.

Data sharing statement provided by the authors is available with the full text of this article at jemds.com.

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