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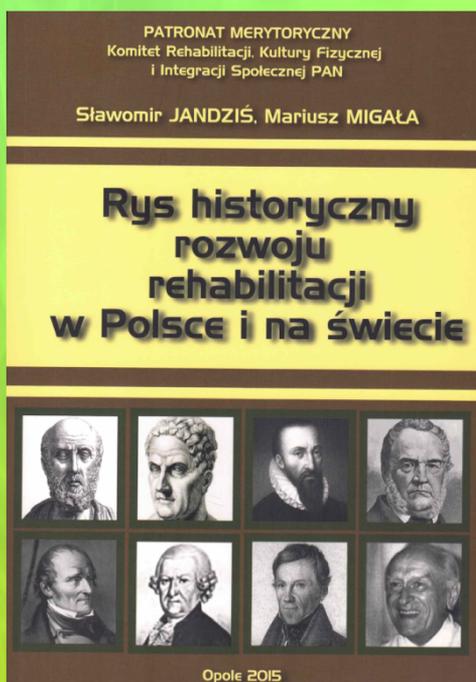
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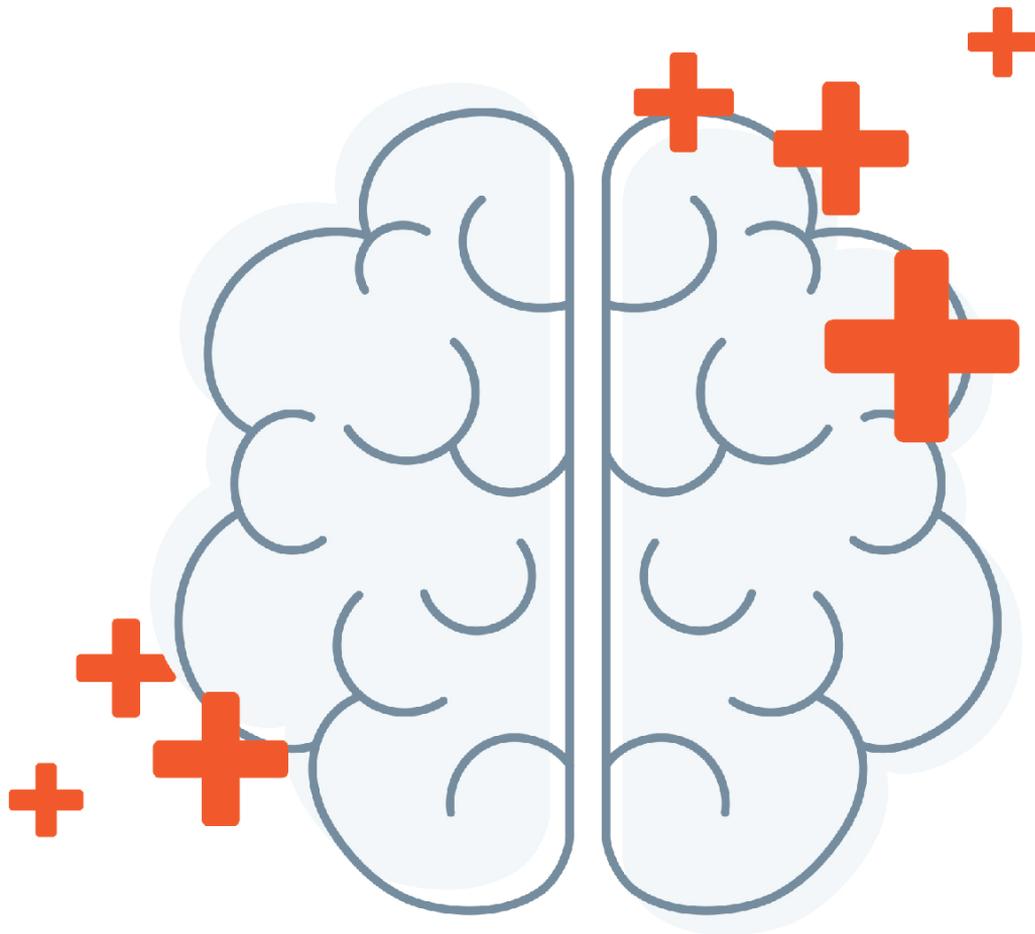
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Impairment of functional ability in patients with Parkinson's disease, a qualitative study

Upośledzenie zdolności funkcjonalnej u pacjentów z chorobą Parkinsona, badanie jakościowe

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Abstract

Background. Population studies on the incidence of Parkinson's are important to scientists' understanding of the history of the disease, its progression, and the risk factors associated with it. Information about the incidence in different age groups and genders can help healthcare experts design strategies to meet patients' needs. **Objective.** To understand the subjective functional Impairment in patients with Parkinson's disease. **Methodology.** It is a qualitative study with a sample size of 10, including Parkinson's disease patients between the age group of 40 to 70 years. The interviews of the patients were conducted either through phone calls or zoom calls depending on their convenience. **Results.** The most mentioned complaints by the patients included in the study are, tremor, masked face, a fixed expression, difficulty in talking, slowness of movement, unsteadiness while walking, fear of fall, short-stepped gait, forward bent or stooped posture, and freezing episodes. Patients require only minimal assistance from caregivers or family members to do their daily activities (n = 4) and are majorly dependent on others for their day-to-day requirements (n = 3), completely dependent, and bedridden (n = 1). **Conclusion:** According to the data collected from the patients, it can be concluded that patients with Parkinson's disease develop difficulties in their functional activities and end up with activity limitations as the disease progresses and the symptoms worsen.

Keywords

Parkinson's disease, quality of life, motor symptoms, activity limitations, functional ability

Streszczenie

Wprowadzenie. Badania populacyjne prowadzone nad częstością występowania choroby Parkinsona są ważne dla zrozumienia przez naukowców historii choroby, jej przebiegu i związanych z nią czynników ryzyka. Informacje o częstości występowania w różnych grupach wiekowych i płciach mogą pomóc ekspertom opieki zdrowotnej w opracowaniu strategii spełniających potrzeby pacjentów. **Cel.** Zrozumienie subiektywnego upośledzenia czynnościowego u pacjentów z chorobą Parkinsona. **Metodologia.** Jest to badanie jakościowe z udziałem 10 osób, w tym pacjentów z chorobą Parkinsona w wieku od 40 do 70 lat. Wywiady z pacjentami przeprowadzono za pomocą rozmów telefonicznych lub rozmów na platformie zoom w zależności od ich preferencji. **Wyniki.** Najczęściej wymienianymi dolegliwościami zgłaszanymi przez pacjentów objętych badaniem są: drżenie, maskowatość twarzy, nieruchomy wyraz twarzy, trudności w mówieniu, powolność ruchów, niestabilność podczas chodzenia, lęk przed upadkiem, krótkie kroki podczas chodzenia, pochylona do przodu lub przygarbiona postura oraz niemożliwość wykonania ruchu. Pacjenci wymagają jedynie minimalnej pomocy ze strony opiekunów lub członków rodziny w wykonywaniu codziennych czynności (n = 4) i są w dużym stopniu zależni od innych w codziennych potrzebach (n = 3), całkowicie niesamodzielni i przykuci do łóżka (n = 1). **Wniosek.** Na podstawie danych zebranych od pacjentów można stwierdzić, że u pacjentów z chorobą Parkinsona pojawiają się trudności w czynnościach funkcjonalnych, a w miarę postępu choroby i nasilenia objawów dochodzi do ograniczenia aktywności.

Słowa kluczowe

Choroba Parkinsona, jakość życia, objawy ruchowe, ograniczenia ruchowe, sprawność funkcjonalna

Introduction

Dr. James Parkinson was the first to diagnose Parkinson's disease as a "shaking palsy" in 1817. It's a chronic, progressive neurodegenerative disease that manifests in both motor and non-motor symptoms. The disease's progressive degenerative effects on mobility and muscular control have a severe clinical impact on patients, their families, and caretakers [1, 2].

The loss of striatal dopaminergic neurons causes motor symptoms, while the neuronal loss in the nondopaminergic region causes nonmotor symptoms. Parkinsonism is the term used to characterize the movement symptoms of Parkinson's disease. Resting tremors, bradykinesia, and muscle rigidity are some of the symptoms. Although Parkinson's disease is the most common cause of parkinsonism, other conditions that mimic Parkinson's disease and drug-induced causes can also cause these symptoms [3, 4].

Parkinson's disease is an extrapyramidal system condition that affects motor components in the basal ganglia [5, 6, 7]. It's defined by a drop-in dopaminergic activity, which leads to reduced motor performance and clinical symptoms [8, 9]. Even though the presence of nonmotor symptoms suggests that other neurotransmitters, as well as the neuro-modulators adenosine and enkephalins, are involved, research in the late 1950s identified striatal depletion of dopamine as the primary cause of motor symptoms in Parkinson's disease [10, 11].

More evidence reveals that PD starts in the vagal and glossopharyngeal neurons, anterior olfactory nucleus, and dorsal motor nucleus, implying a pattern that starts in the brain stem and progresses to higher cortical levels [12, 13].

Parkinson's disease is characterized by the production of Lewy bodies and the loss of pigmented dopaminergic neurons (LBs) [14, 15]. As dopaminergic neurons in the substantia nigra pars compacta that project to the striatum degenerate over time, people with Parkinson's disease lose dopaminergic function (the nigrostriatal pathway) [16].

Motor symptoms are common in Parkinson's disease patients because 50 to 80 percent of their dopaminergic neurons have died, indicating the presence of a compensatory mechanism in the early stages of the disease [17, 18].

A thorough history and physical examination should be included in the differential diagnosis of Parkinson's disease. A movement disorder specialist should be consulted in complex or confusing cases [19, 20]. As there are no conclusive tests available, a clinician must confirm the diagnosis by examining the patient's medical history, assessing symptoms, and ruling out other conditions such as multiple system atrophy, DLB disease, and essential tremor before reaching a clinical diagnosis [21, 22].

Resting tremor, "cogwheel" rigidity, and bradykinesia are the "classical trinity" of motor features in Parkinson's disease [23, 24]. The disease's first clinical signs are usually said to have these important characteristics [25, 26]. Within five years of being diagnosed with Parkinson's disease, roughly half of all patients experience postural instability [27].

Even though PD is regarded as a condition of elderly persons, younger individuals have been identified to have many genetic variants. Younger patients (under 60 years old) may have

less stiffness and bradykinesia in clinical terms, which could result in a missed or delayed diagnosis [28, 29].

Drug-induced parkinsonism (DIP) must be included in the differential diagnosis as it is one of the few causes of Parkinson's disease which can be reversed. To avoid treating patients incorrectly, it is vital to recognize DIP, which requires a complete pharmacological review of patients suspected of having Parkinson's disease [30, 31].

DIP is a condition that affects older women, people with a lot of comorbidities, and people who take a lot of drugs at high doses for a long time [32, 33]. The symptoms of DIP are usually resolved by identifying and eliminating the offending medication(s), but they can continue for months or even a year in some situations [33, 34].

Tremor, stiffness, and bradykinesia are the three clinical motor features recognized in Parkinson's disease patients. Tremor is the easiest of these three basic symptoms for patients and caregivers to notice, especially in individuals with Parkinson's disease subtypes that are characterized by the tremor [25, 31]. The motor symptoms of Parkinson's disease may be linked to the patient's age at onset; for example, tremor is twice as likely in people over 64 years compared to people below this age group [45].

Furthermore, problems related to treatment duration, such as the link between dystonia and dyskinesias and the duration of levodopa medication, are common amongst individuals who are diagnosed at an earlier age (below 55 years of age) [35, 36].

Parkinson's disease tremor is most usually thought of as a hand tremor (pill-rolling tremor), although it can also affect the lower limbs, toes, and jaws [37]. A Parkinson's disease tremor can be exacerbated and worsened by stressful events or requiring the patient to execute a mental task, however on the contrary mobility and sleep can help alleviate the symptoms [38]. Patients belonging to younger age groups may exhibit erratic conduct or tremor that occurs only when they are tired [35, 37].

Bradykinesia is a clinical motor symptom of Parkinson's disease which causes a reduction in the speed of gait, and amplitude of repetitive voluntary movement activity [36, 38]. It is the most prevalent symptom of Parkinson's disease and a crucial criterion for diagnosis [39].

Two common clinical manifestations associated with this trait are a sluggish, shuffling stride and difficulty in getting started or initiating motions. Hastening of gait is a condition in which patients with bradykinesia take tiny, quick steps to "catch up" with their altered Center of Gravity.

Patients may also experience bradykinesia linked with immobility when forced to turn or enter through a narrow door. In the later stages of Parkinson's disease, "freezing" episode is a severe symptom [40].

Rigidity, which manifests as increased muscular tone or resistance to passive range of motion, is the third essential hallmark of Parkinson's disease. This symptom is usually referred to as "cogwheel rigidity" among Parkinson's disease patients [26, 27].

While performing passive movements, cogwheel rigidity is best described as muscle tension that produces little jerks or a ratchet-like sensation. Cogwheel stiffness demands a thorough diagnosis because benign essential tremors can also appear with a cogwheeling disorder [28, 36]. Other body parts, such

as the face, may also be affected by Parkinson's disease stiffness in addition to the limbs, which results to a "masked" look (hypomimia) [38].

Postural instability is a fourth clinical characteristic that usually appears in the later stages of Parkinson's disease.⁴¹ This symptom has a complicated genesis and is linked to further motor complaints such as stiffness and neuronal degeneration in the hypothalamus, brainstem, and peripheral nervous system. Since its linked to loss of balance and the risk of falling, postural instability can be extremely disabling [42, 43].

Other distinctive symptoms of Parkinson's disease include handwriting difficulties (micrographia) and quiet speech (hypophonia) [44].

The Unified Parkinson's Disease Rating Scale is a tool having four parts that evaluate motor features, psychological characteristics, everyday activities, and therapy-related issues [45].

The Hoehn and Yahr staging scale, which has been around since the 1960s, is another instrument that is often utilized in clinical practice. From minimal symptoms to bedbound conditions, this scale divides the degree of disability into five ca-

tegories [46]. Due to deficits in daily activities, the patient's ability to be self-sufficient reduces as Parkinson's disease progresses, necessitating more caregiver assistance [47].

Patients who report tremors as their major symptom may experience a delayed course of illness and a longer response to medicines. Patients with Parkinson's disease in their late 50s or elder, or persons having early-stage motor and gait deficits, as well as instability in maintaining posture, may have a faster disease progression.

Procedure

Initially, the topic was presented to the Institutional Ethics Committee and was approved on 05.04.2021 and the Ethics Clearance number is 2875/IEC/2021.

The study design is a Non-Experimental study, and the type is, Qualitative study, with a sample size of 10, collected through convenient sampling from SRM Medical College Hospital and Research Center.

The participants included in this study are Patients diagnosed with Parkinson's disease, aged between 40-70 years of both genders and patients willing to participate in the interview. The participants excluded were patients with epilepsy, progressive supranuclear palsy, patients with other conditions that can affect their functional ability and persons with any kind of disability such as amputation of a limb.

After receiving the approval, informed consent was obtained from the patients after explaining the study protocol clearly.

After the consent was given by the subjects willing to participate in the study, an interview was conducted based on their comfort and convenience either through direct phone call or through a Zoom meeting.

After a brief self-introduction, the patients were questioned as mentioned below and the reply was noted. The call was recorded for the patients who gave their consent for recording the call, for other patients, their answers to each question were recorded in the case report forms.

Interview schedule

- The interview was conducted on a one-on-one basis through a telephone conversation or zoom call.
- The interview was expected to finish within 1-2 hours, but in case the patient was unable to cooperate for the entire duration, another session was planned.
- The questions asked will cover all information regarding the medical data, activity limitation, and participation of the patient.
- All the information given by the individual patients was taken down in the same words used by them to avoid any lack of explanation of the intensity of the problems faced by the patients.



Figure 1. Interview through WhatsApp call

Table 1. Data analysis

Age / Gender	Medical data	Medication	Occupation	Activity limitation	Social participation
70 years/ Male	Slowness in movement, increased tremor, fixed facial expression, difficulty in talking, monotonous voice, unsteadiness, smaller steps, fear of falling, bent forward.	Tab Triphen Tab levodopa Tab Sinemet	Retired school teacher	Takes longer to complete tasks compared to before, difficulty in writing, and difficulty in walking.	Early retirement from work, depends on a caretaker to have food and doesn't go out for a walk as he used to before the onset of the disease.
68 years/ Male	Mask-like face, complaints of loss of appetite, monotonous speech, tremors present more while attempting to do a task than while at rest, cogwheel rigidity in the left upper limb, short, stepped gait with reduced associated movements.	Tab Texy Tab Seligiline Tab rytary	Retired from Bhartiya telephonic, Nagpur	Others take time to understand what he is trying to say, have difficulty in doing small works in the garden, are unstable while walking, use a cane for support, unable to climb stairs.	His main hobby was looking after the garden, now he has kept gardeners to do the work, he is unable to look after the plants on the terrace as he cannot climb stairs, he feels people cannot understand him and try to avoid him, he has anger issues.
60 years/ Male	Mask like face with reduced blink rate, monotonous speech, tremors present more at rest and distally, cogwheel rigidity present in all limbs but prominent in right, Short stepped gait.	Tab Pacitane, Tab Sinemet, Tab Seligiline	Retired Physices Lecturer	Gradually he was unable to hold the chalk properly, his hands would start trembling, at times students found it difficult to understand his teaching, his writing started worsening, and he had a mask-like face, so it was difficult for others to understand his emotion or mood.	Currently, he is bedridden and is dependent on the caretaker for all his daily requirements, his speech is majorly affected, and is unable to express himself, he has a loss of appetite which is deteriorating his health further.
66 years/ Female	Mask-like face, monotonous speech, tremors were present at rest, cogwheel rigidity present, and short-stepped gait.	Tab Levodopa, Zandupanch ayurvedic medicines	Housewife	She finds it difficult to make chapatis, to hold a glass or vessel but manages to do somehow but slowly, she finds it difficult to undo the knot of her dress.	She feels weakness in her whole body but manages to do her day-to-day work slowly but finds it difficult to undo the knot of her dress, she can manage to do all her activities with minimal assistance. She is comfortable going out and meeting people but finds it difficult to walk for long.
65 years/ Male	Resting tremors accompany the sluggishness of the right upper limb. The left upper and lower limbs are then followed by the right upper and lower limbs. He has started to have a fixed facial expression and finds it difficult to talk, he talks slowly with a monotonous voice. He has unsteadiness while walking and he bends slightly forward and takes smaller steps, and he is afraid of falling.	Tab Triphen Tab Eldepryl Tab Sinemet	Owns a grocery shop	Takes time to do the activities he used to do earlier, has difficulty maintaining the register in the shop as he finds it difficult to write, has difficulty in walking, and uses a cane for support due to fear of falls.	He goes to the shop every day and looks after the shop but is unable to maintain the register or carry anything heavy, when he is in a hurry to go to work, sometimes he just freezes for a few seconds and he feels unable to take a step ahead, this happens occasionally when he is trying to rush with something or is stressed or extremely angry about something.
68 years/Male	A tremor in his right hand while doing his office-related work, slowness in movement, even while walking or trying to do any work. As the years passed, he started getting a mask-like face with a fixed expression and started having difficulty talking.	Tab Triphen, Tab Levodopa, Tab Seligiline	Retired Government worker	Started with a tremor in his right hand while doing his office-related work, slowness of movement, he has a mask-like face with a fixed expression and started having difficulty talking. Unsteadiness while walking and he bends forward and takes smaller steps, and he is afraid of falling.	He was unable to write or put his signature closing to his retirement, he started feeling difficult to talk and he would talk very slowly, later on, he started finding it difficult to button his shirt, recently he experienced a few episodes of freezing and noted that it happened when he was in a hurry and also when he suddenly got tensed to enter a shop.
70 years /Male	Weakness and tremor on the right side of his body and slowness of routine activities. He had intermittent feelings of double vision and feels like his eyes would close suddenly.	Tab Syndopa, Tab Syndopa CR, Tab Prantrol, Tab Coveryl Plus, Tab Ciplar	Retired from a private firm	He started experiencing slowness in his routine activities, he complains of double vision, and he has a feeling that he may close suddenly without his control, he has weakness and tremors on his right side at rest.	He continues to do his routine activities with little assistance from his wife, he faces little difficulty in walking, and he feels his talking speed has reduced but he continues to socialize with friends and family once a while travels with his wife to his daughter's place and can manage his essential activities without much difficulty.

Questionnaire

1. Medical information:

- medical history and present complaints,
- the course of the disease,
- the cause of the ailment (the treating physician's diagnosis),
- the treatment (medicine, in the view of the treating physician).

2. Activity constraints

- types of activity limitations encountered,
- seriousness, examples that are specific and detailed.

3. social participation

- what activities did you do before, and what are the ones you no longer can do?
- what is your description of your functional capability?
- what is your opinion about the doctor's recommendations and medication?

Results

As mentioned in the table above, it has been observed in this study that out of the Seven patients most of them had the same symptoms, namely tremor, masked face, a fixed expression, difficulty in talking, slowness of movement, unsteadiness while walking, fear of fall, short-stepped gait, forward bent or stooped posture and freezing episodes.

Out of the seven patients, prominent cogwheel rigidity (n = 4), and loss of appetite (n = 2).

Most of them had a gradual increase in symptoms and they had a progressive increase in difficulty in doing the tasks they could once do without any difficulty. Patients require only minimal assistance from caregivers or family members to do their daily activities (n = 4) and are majorly dependent on others for their day-to-day requirements (n = 3), completely dependent, and bedridden (n = 1).

Anger management issues and sudden outbursts and pick fights frequently with family members and caregivers (n = 3).

Discussion

For this study, 10 patients were approached and had provided their medical reports but due to covid restrictions I wasn't able to include all of them in the study and three of them dropped out of the study. According to the data collected from the patients through interviews, all of them have some level of activity limitations and few of them are completely dependent on their family members or caregivers for their daily requirements.

As the disease progresses the severity of the activity limitation increases making them more dependent on others for their daily activities. With the progression of their symptoms and the severity, most of them slowly start feeling ignored or left out as they cannot interact socially as they could before. Out of the patients interviewed only three of them still go out to social gatherings and interact with friends and family even though they face few difficulties.

Those who had difficulty in talking felt that others find it difficult to understand what they are trying to say and hence avoid talking or interacting with others and eventually stop going out

because of the physical difficulty due to the disease as well as the insecure feeling of how others perceive them.

Few of them had to stop doing the activities they were doing before, like taking early retirement, stopping gardening activities, stop going out for a walk, etc. Many of them undergo freezing of gait when they are walking and if suddenly someone shouts at them, and they get tensed or when they try to hurry or when they are tensed about something and they feel like they are stuck in that position and are unable to even take a step ahead.

The severity and progression of the disease differed from person to person, but one point which was mentioned by all patients was that there was a reduction in symptoms after taking the medication but as time passes the effect reduces and tremors start again.

Using the medication for a long duration, most of them felt that the medications are no longer effective in reducing the symptoms.

Freezing of Gait severity, frequency, and the severity of start and turn hesitation were all linked to higher levels of activity limitation, this was supported by Nilsson and Hagell et al. and Giladi N et al [49, 50, 51].

Freezing of Gait severity was similarly linked to a slower walking pace. These findings were backed up by prior research that found gait-related issues to be major contributors to illness progression and quality of life [52, 53].

The most common complaint, according to Slawek J et al, is difficulties in walking, followed by problems with a variety of gait-dependent everyday activities like housework, dressing, and transferring in and out of bed [54]. As the independence of these patients is compromised, axial symptoms such as postural instability contribute to the worsening of their quality of life [56, 57].

These symptoms are not just due to dopaminergic system degeneration, but also due to age [58] and the vascular disease that comes with it. Sleep disturbances have also proved to have a significant impact on the quality of life of Parkinson's disease patients [59, 60]. The most prevalent features are sleep disruption, nycturia, and nocturnal motor symptoms [61].

According to Fox S.H., Lang, et al., Peak-dose Dyskinesias, the most common type of dyskinesia, occurs at the end of the dosing cycle when drug-derived dopamine levels are at their highest [62]. Biphase dyskinesias can occur at any time during the drug response cycle, with the latter being more common and severe [63, 64].

A study conducted by Gunzler SA et al. stated that the unpredictable occurrence of off-times (Off-dystonias are dyskinesias that show during off periods) and the abruptness of the transitions between on- and off-times explain a negative effect of on-off fluctuations. Patients may be forced to give up previously enjoyed activities due to the disruptive nature of on-off swings.

This demonstrates a detrimental impact on the ADL and mobility parameters. Furthermore, non-motor changes in mood, sensory, and autonomic symptoms are frequently coupled with motor fluctuations, which may compromise QoL [65, 66].

This study found that the gradual increase in symptoms eventually causes limitations in activities, but the intensity varies from patient to patient. Many of them end up modifying or giving up the activities they once enjoyed or were used to doing.

Most of them feel that the benefit of the medicine lasts only for a few hours and they feel a reduction in the tremor as long as the effect of the medicine lasts, after that the symptoms return to the original intensity. They also said that after some duration of the medication, there was no effect at all and even stopping the medication and continuing after a break of some months gave no benefit and they believe that the medications do not help them anymore.

They might have to give up on any sport that they played, leisure activities like going to the park for a walk or gardening, and a few even had to take early retirement. The symptoms start impeding their daily activities, due to tremors and instability while walking and they experience a constant fear of falls.

It was also seen that patients who had other medical conditions like diabetes, hypertension, thyroid problems, etc. experienced additional problems associated with those diseases which added to their difficulty due to Parkinson's disease.

A few of them also mentioned systemic problems such as loss of appetite, indigestion issues, constipation, sexual problems, fatigue, visual disturbance, tingling sensations, diffused pain, etc. Vinayak Majhi et al. stated that one patient need not exhibit all motor and non-motor symptoms at the same time.

However, depending on the stage of Parkinson's disease, it may manifest itself in a patient in a major or minor way. Given that neurodegenerative diseases such as Parkinson's disease cannot be cured, accurate early detection may aid in preventing the spread of this disease.

It was noticed that out of the seven patients included in this study, all of them were only advised to take medications and come for review after 5-6 months, but none of them were referred to a physiotherapist. Further studies can be conducted to evaluate the efficacy of physiotherapy along with the medications in managing and improving the motor symptoms and eventually improving life satisfaction in Parkinson's disease patients.

Conclusion

According to the data collected from the patients, it can be concluded that Parkinson's disease patients develop difficulties

in their functional activities as the disease progresses and the symptoms worsen. Out of the seven patients, three of them are majorly dependent on their family and caregivers for their activities of daily living. The other four patients can carry out their daily activities with minimal assistance, but they had to either modify or avoid the leisure activities they once could do effectively and enjoyed doing it. It was also observed that as their speech gets affected, others find it difficult to understand, which discourages the patient, and they get irritated by others' responses and avoid talking and interacting with others and slowly withdraw themselves from going to public gatherings and get-togethers and hence their participation becomes limited.

Limitations and recommendations

Limitations

- The sample size was small for the result to be generalized.
- Improper distribution of gender.
- The lack of awareness and acceptance to participate in the study.
- Since it was a telephonic interview and had only one session, there would have been a lack of comfort, due to which some problems might have been hidden by the patients.

Recommendations

The long-term effects can be analyzed.

A similar study could be conducted with a greater number of willing participants.

In future studies, exercise regimens can be included.

Stages of Parkinson's can be assessed, and participants can be selected accordingly.

Functional difficulties and their management specific to the stages of the disease can be done.

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