



12th AMER International Conference on Quality of Life
The Magellan Sutura Resort, Kota Kinabalu, Malaysia, 26-28 Jan 2024

Patients' Awareness of Symptoms, Understanding and Perception of Parkinson's Disease

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Abstract

This study investigates the crucial role of Parkinson's disease (PD) patients' awareness, understanding and perception in achieving positive treatment outcomes. Using the Knowledge and Perception of Parkinson's Disease Questionnaire (KPPDQ), a survey was conducted among 169 PD patients in one of the teaching hospital's Neurology Clinic. Significant correlations were found between age, duration since diagnosis, ethnicity, employment status, information sources, and patients' understanding levels. The study highlights the necessity for targeted interventions and continuous research to enhance patient education, correct misconceptions, and foster a more informed and supportive society for PD patients and their families, contributing to overall well-being.

Keywords: Parkinson's disease, awareness, understanding, perception

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DOI: <https://doi.org/10.21834/e-bpj.v9i27.5656>

1.0 Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disorder that primarily affects movement. A comprehensive understanding of Parkinson's disease (PD) is crucial for achieving optimal treatment outcomes. Patients play a significant role in this process by familiarising themselves with their condition and facilitating easier management by healthcare providers. Unfortunately, studies such as Know PD indicate a substantial lack of knowledge among patients, with 90% reporting insufficient awareness of PD symptoms, medications, deep brain stimulation (DBS), rehabilitation, and other aspects of disease management (Salinas et al., 2020). Survey findings highlight widespread patient unawareness regarding PD, encompassing diagnosis, treatment options, and disease progression. While motor symptoms like tremors and bradykinesia were well understood, confusion around the diagnosis and awareness of non-motor and prodromal symptoms persisted. Patients also harboured misconceptions about therapy choices, with varied beliefs about the benefits of medications, disease progression, DBS, and stem cell therapy (Jitkriksadakul et al., 2017).

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Titova and Chaudhuri (2018) emphasise the significant burden faced by PD patients due to symptoms such as urinary dysfunction, constipation, memory issues, anxiety, depression, exhaustion, and insomnia. Urinary dysfunction emerged as a prevalent and challenging symptom, particularly in advanced stages. Viwattanakulvanid et al. (2020) note that patients with higher education levels exhibit more excellent knowledge about the disease, treatment, and self-care. The burden experienced by PD patients encompasses physical, psychiatric, and socio-economic challenges. Lee et al. (2019) in Korea found that insufficient knowledge and understanding of these elements can overwhelm patients, making it challenging to cope with the stress associated with the disease.

2.0 Literature review

The education was essential for assisting patients in coming to grips with their diagnosis and developing tools to tackle these challenges. Some studies showed that there were misunderstandings about Parkinson's disease therapy and symptomatology among a patient group that self-identifies as being informed about the condition. The high degree of perceived PD expertise was unrelated to demographic factors such as gender, whether treatment was predominantly given by a movement disorder specialist or education level (Salinas et al., 2020). Patients were often exposed to information supplied by a physician or nurse or through a booklet, internet resources, community resources such as support groups, or prescription handouts.

In another study, non-motor symptoms such as urine difficulties, visual hallucinations, and pain were underappreciated. Many (50–80 per cent) respondents mistakenly believed that all Parkinson's disease patients had tremors, that the disease was generally hereditary, and that there was a cure for Parkinson's disease. One-half thought Parkinson's disease was caused by anything the patient had done in the past and that PD medicines were likely to cause internal organ harm. Other than knowledge and understanding of PD in view of motor and non-motor symptoms, genetics in PD is also essential to notify and understand patients. In addition, some studies said that participants were shown to have a somewhat limited understanding of the genetics of Parkinson's disease (Falcone et al., 2011).

Another study by Choo et al. (2020) shows that respondents and their caregivers have better-recognised knowledge regarding motor symptoms. Nevertheless, for the understanding part, the result showed the most common misconceptions among both respondents and caregivers. Insufficiency of knowledge and understanding led to a burden in the management of PD and respondents themselves. Burden-versed broad aspects would simultaneously affect respondents' quality of life. This was often occurring in every respondent with Parkinson's. So, knowledge and understanding have been essential for awareness and recognition since the early stage of Parkinson's.

Lee et al. (2019) found that there are misunderstandings about Parkinson's disease therapy and symptomatology among a patient group that self-identifies as being informed about the condition. A similar study by Viwattanakulvanid et al. (2020) found that the level of knowledge regarding Parkinson's disease was affected by the patient's educational background. Health education is an excellent technique for local physicians and patients to learn about Parkinson's disease, which might enhance early identification and management (Lee et al., 2019). According to a 2018 report by the Department of Statistics Malaysia, it is anticipated that the number of individuals diagnosed with Parkinson's disease in the country will undergo a fivefold increase, rising from the current estimated 20,000 to reach 120,000 by the year 2040.

In Malaysia, there are limited published studies on recognising symptoms, perception, and knowledge of Parkinson's disease among patients. The aim of this study is to identify the awareness of symptom, understanding and perception of Parkinson's disease. Therefore, the outcomes from this study may benefit patients and improve healthcare professional service and management of Parkinson's disease.

3.0 Methodology

3.1 Study design and setting

A cross-sectional study is used to collect data from the respondents in Neurology Clinic in one of Klang Valley teaching hospital. Total population of PD was about 500 patients in this study setting. The selection of this setting was based on its designation as a referral center for patients with Parkinson's disease.

3.2 Sample size and criteria

Purposeful sampling method was used due to selective sample where Idiopathic PD being the only sample for this study. Using Andrew Fisher's formula, with confidence level of 95%, the sample size for this study is 169 respondents with 5% margin of error. The researcher recruits Idiopathic Parkinson's disease patients with follow up at Neurology Clinic. The inclusion criteria participants include above 18, able to speak and understand English and Malay and ability to give informed consent. Meanwhile, PD patient's with multiple system atrophy, progressive supranuclear palsy, Lewy body dementia, significant cognitive impairment that can affect the response and have communication problems were excluded from the study.

3.3 Questionnaire

Instrument for this study was the questionnaire adapted from (Choo, et al., 2020). A backwards-translation approach was used to translate the English and Bahasa Melayu items to ensure linguistic and conceptual equivalence. Overall, the KPPDQ showed good internal consistency with Cronbach's alpha of 0.796 for part 1 and 0.562 for part 2. (Choo, et al., 2020). This questionnaire was divided into two parts: knowledge (part 1) and perceptions (part 2). Recognition of Parkinson's disease symptoms (5 motor and 11 non-motor) was tested using a "Yes/No/Do not know" format (Part 1A), and general Parkinson's disease knowledge was tested with 12 statements

using a "True/False/Do not know" format (Part 1B). Next, for part 2A, for perceptions, a Likert scale ("Strongly agree/Agree/Disagree/Strongly Disagree") was used to assess nine domains with a total of 22 items (covering aspects of: Burden of PD; Access to information and community supports; Misperceptions regarding PD causation and treatment effects; Satisfaction with treatment and care; Complementary and alternative treatments; Stigma of PD; Assistance for disability; Treatments for advancing disease.

3.4 Data collection and procedure

Data collection occurred from January 2023 to March 2023. The ethics application was approved by the UiTM Research Ethics Committee (REC) (FERC/FSK/ MR /2022/0323). The researchers approached participants, which are selected based on the inclusion criteria. The questionnaires were distributed to the participants once they were given informed consent. The explanation were given before the data collection were conducted. The researchers also informed the participants that their data would remain confidential and anonymous. Participants spend their time for 10 to 15 minutes to complete the survey.

3.5 Data analysis

The data on demographics was described and conveyed in frequency, and percentage. The data's normality was ensured before the statistical analysis was conducted. A p-value of 0.05 was established as the threshold for significance. SPSS software, version 26.0, was utilised for these analyses. Descriptive test with results reported in frequencies and percentages for recognition of symptoms, knowledge (understanding) and perception of disease.

4.0 Results

4.1 Data demographic of the participants

A total of 169 participants were recruited and completed the KPPDQ. Demographic characteristics of the participants are shown in Table 1. More than half of the participants are male 107(63.3%) compared to female 62 (36.7%). Ethnicity of the participants consists of Malay 75 (44.4%), Chinese 81 (47.9%), Indian 12 (7.1%) and others one (0.6%). Half of the participants received at least secondary education 85 (50.3%), while the rest received primary education 24 (14.2%) and tertiary education 59 (34.9%). Around three-quarters of the participants were retirees 127 (75.1%), while the rest are still working full time 27 (16.0%), unemployed 2 (1.2%) or were housewives 13 (7.7%). Almost all of the participants did not work in healthcare related field 151 (89.3%) while only a few worked in healthcare related field 18 (10.7%).

Table 1. Demographic Data

Total n = 169	Values	Percentage (%)
Mean age ± SD (range) (years)	66.88 ± 10.63 (30 - 84)	
Gender	n = 169	
Male	107	63.3
Female	62	36.7
Race	n = 169	
Malay	75	44.4
Chinese	81	47.9
Indian	12	7.1
Others	1	0.6
Education level	n = 169	
None	1	0.6
Primary Education	24	14.2
Secondary Education	85	50.3
Tertiary Education	59	34.9
Current Employment Status	n = 169	
Full time work	27	16
Retired	127	75.1
Unemployed	2	1.2
Housewife	13	7.7
Healthcare Related Work	n = 169	
Yes	18	10.7
No	151	89.3

4.2 The awareness of PD symptoms among the participants

Motor symptoms of PD were recognized to a greater extent (93.5-98.8%) compared to non-motor symptoms (24.3-84.6%). Among the motor symptoms, slowness of movement was the well-recognized (98.8%), followed by imbalance (95.9%), tremors (94.1%), walking problems (94.1%), and rigidity (93.5%). In terms of non-motor symptoms, speech difficulty was the most recognized symptom (84.6%),

followed by constipation (83.4%) and acting out dreams (76.9%). Urinary problems were the least recognized symptom (24.3%), followed by insomnia (24.9%) and visual hallucinations (26.6%).

Table 2. Awareness of Symptoms

Recognition of PD Symptoms	No		Yes	
	n	%	n	%
Slowness of movement	2	1.2	167	98.8
Tremors (involuntary shaking movements)	10	5.9	159	94.1
Rigidity (muscle stiffness)	11	6.5	158	93.5
Imbalance / tendency to fall	7	4.1	162	95.9
Walking problems	10	5.9	159	94.1
Memory problems	60	35.5	109	64.5
Low mood / depression	83	49.1	86	50.9
Visual hallucinations (seeing things or people that are not really there)	124	73.4	45	26.6
Reduced sense of smell	67	39.6	102	60.4
Speech difficulty	26	15.4	143	84.6
Swallowing difficulty	43	25.4	126	74.6
Pain	49	29.0	120	71.0
Urinary problems	128	75.7	41	24.3
Constipation	28	16.6	141	83.4
Acting out dreams (e.g. punching, kicking or shouting) during sleep	39	23.1	130	76.9
Difficulty sleeping / insomnia	127	75.1	42	24.9

4.3 The understanding of PD among the participants

The highest number of questions correctly answered by participants was 155 (91.7%). The second highest was statement number 10. The data shows 154 (91.1%) correctly answered questions by participants. Thirdly, the sixth statement represents 149 (88.2%). Overall, the understanding of participants regarding PD was good due to the high percentage of correct answers.

Table 3. Understanding of PD

Understanding of PD	Wrong		Correct	
	n	%	n	%
Parkinson's disease and Alzheimer's disease are different names for the same disease	14	8.3	155	91.7
Parkinson's disease is a degenerative disease of the brain (associated with loss of brain cells)	24	14.2	145	85.8
In Parkinson's disease, the level of a chemical (neurotransmitter) in the brain called dopamine is reduced	22	13.0	147	87.0
All patients with Parkinson's disease experience tremor (involuntary shaking movements)	84	49.7	85	50.3
Parkinson's disease can initially affect one side of the body	31	18.3	138	81.7
Parkinson's disease is more common in older persons	20	11.8	149	88.2
Parkinson's disease can also affect young adults	39	23.1	130	76.9
Parkinson's disease usually affects multiple members of the same family	100	59.2	69	40.8
Parkinson's disease is diagnosed using a brain scan (MRI)	81	47.9	88	52.1
There are treatments that can improve the symptoms of Parkinson's disease	15	8.9	154	91.1
There are new treatments that can cure Parkinson's disease	46	27.2	123	72.8
Patients with Parkinson's disease usually become wheel chair dependent	70	41.4	99	58.6

4.4 The perception of the participants

Table 4 summarizes the findings from the participants' perspectives of Parkinson's disease (PD) and its treatment. The researcher concluded the positive and negative perception by the sum of total agree and strongly agree respond from the participants. The highest percentage for positive perception was 163 (96.4%) that participants agree they received a good care from healthcare provider. The second highest of positive perception was 157 (92.9%) which they feel that medications have helped significantly to control their Parkinson's symptoms. Thirdly, the positive perception was about able to access PD information easily 143 (84.6%).

However, the highest perspectives of negative perception was 127 (75.2%) that participants feeling burden to others because of the PD. Following by the second negative view 121 (71.6%) where the participants feel people are uncomfortable around them because of the disease. Finally, the third lowest of negative perception was 99 (58.6%) which the participant feel ashamed for having Parkinson's disease.

Table 4. Perceptions towards PD

	Strongly disagree	Disagree	Agree	Strongly Agree
	n (%)	n (%)	n (%)	n (%)
I feel that I am receiving good care from my Parkinson's healthcare providers (doctors, therapists, etc.)	0	6 (3.6)	71 (42)	92 (54.4)
I feel that medications have helped significantly to control my Parkinson's symptoms	0	12 (7.1)	107 (63.3)	50 (29.6)
I feel that I can get information about Parkinson's easily.	2 (1.2)	24 (14.2)	131 (77.5)	12 (7.1)
I feel that I am a burden to others because of my Parkinson's	3 (1.8)	39 (23.1)	112 (66.3)	15 (8.9)
I feel that people are uncomfortable around me because of my Parkinson's	7 (4.1)	41 (24.3)	120 (71)	1 (0.6)
I feel ashamed for having Parkinson's	4 (2.4)	66 (39.1)	97 (57.4)	2 (1.2)

5.0 Discussion

Following to the participant's respond, they recognized the motor symptoms better in comparison to the non-motor symptoms. Results show that the motor symptoms that are most well recognized were slowness of movement, followed by imbalance, tremors, walking problems and rigidity. Non-motor symptoms in Parkinson's disease are characterized by various manifestations. Speech difficulty stands out as the most widely acknowledged symptom, reported by majority of the participants, followed closely by constipation and acting out dreams. On the other hand, urinary problems are the least recognized symptom, trailed by insomnia, and visual hallucinations.

Similar findings by Choo et al. (2020) studied amongst a multi-ethnic urban Asian cohort, it showed a related result as well. The patients recognized the motor symptoms better than the non-motor symptoms. Agreeably, since the motor symptoms manifest more obviously and the diagnosis of PD is primarily based on the motor features, these are identified earlier and naturally pointed out by the healthcare professionals to the patient and their family members at the point of diagnosis, or even during follow-up assessments. According to DeMaagd & Philip (2015), bradykinesia and rigidity occurs in 80-90%, and tremor at rest occurs as an initial symptom among 70-90% of PD patients. A few researchers also found that slowness of movement was most well recognized and rigidity was both the least recognized (Choo et al., 2020; DeMaagd & Philip, 2015). These obvious alterations, which is not only limited to their gait but also other voluntary actions for daily functioning, most likely makes recognition of this symptom much easier.

Non-motor symptoms in relation to motor symptoms however, are often disregarded or assumed to be associated with other comorbidities such as prostate enlargement, diabetes mellitus, depression and so on, hence are recognized much less. Most often, the patients also misattribute their non-motor symptoms to the normal ageing process. In fact, according to an international survey, 62% of non-motor symptoms among PD patients were not brought up to the healthcare professionals due to their lack of knowledge or awareness of the connection between these symptoms and PD, and therefore resulting in inadequate treatment of the symptoms. The unidentified non-motor symptoms among PD patients could be detrimental to their quality of life and bring a huge negative impact. A study shows that patients experiencing both motor and non-motor symptoms had worse quality of life compared to those with only motor fluctuations (Rodríguez-Violante, et al., 2018). This suggests that the identification and treatment of non-motor symptoms in PD patients should be an important objective in the management of PD.

When assessing the participants understanding in the present study, the results displayed a relatively higher level of understanding compared to a previous study conducted by Choo et al. (2020). Notably, only one statement from Part 1B of the KPPDQ reflected a misconception held by more than half of the respondents, which was the belief that PD is familial. In contrast, Choo et al. (2020) found that four statements were inaccurately answered by more than half of the PD patient cohort. The percentage of accurate answers provided by the participants in the current study was also higher than Choo et al. (2020). One potential explanation for these differences in knowledge could be attributed to the fact that the participants in this study were recruited from the Neurological Clinic of one of the teaching hospital, where they have access to a wealth of PD-related knowledge through dedicated nurses who provide assistance and education about the disease. The presence of a large number of specialized healthcare professionals in teaching hospital enables them to allocate more time and attention to patients, ensuring they gain a better understanding of their condition.

In the aspect of perception, majority of participants in the current study expressed satisfaction with the care they receive from their healthcare providers. This high level of satisfaction reflects not only the patients' relatively better understanding of the disease but also their perception of the positive effects of treatment and their trust in healthcare professionals when it comes to decision-making. In fact, majority of the participants acknowledged that the medication they received significantly helped in controlling PD symptoms and they can easily get information about PD. Interestingly, more than half of the participants expressed a preference for their healthcare professionals to actively make treatment decisions on their behalf. This findings contrasts with the Dutch research, which found that the vast majority of patients wanted to be included in decision-making (Nijhuis, van den Heuvel, Bloem, Post, & Meinders, 2019).

One plausible explanation for this difference in decision-making preference could be the cognitive impairments that PD patients often experience as the disease progresses. These cognitive impairments can limit their ability to make complex decisions independently. While this possibility may apply to the participants in the present study, it is important to note the lack of information regarding their cognitive status and the relatively smaller knowledge gap within the cohort. Thus, it is more likely that the preference for doctor-led decision-making among these patients is rooted in a foundation of trust rather than cognitive impairment. Given the absence of a reliable test for subjective cognitive impairment in PD and the impracticality of administering objective cognitive tests in a self-reported questionnaire (Aarsland et al., 2017), healthcare professionals should be cautious about imposing an active decision-making role on all patients.

6.0 Conclusion and Recommendation

This study has provided valuable insights into the knowledge gaps, misconceptions, and perspectives surrounding Parkinson's disease (PD). These findings highlight the importance of evaluating and improving the current patient education system. The identified weaknesses and strengths of the system serve as a foundation for enhancing educational efforts in order to bridge the knowledge gap and shape patients' perceptions of PD.

Future studies should aim to expand the scope of the KPPDQ by including a broader range of participants. This could involve sampling the general public in various geographical areas, particularly rural communities where access to information and healthcare resources may be limited. Additionally, involving PD patients from the general community, rather than solely focusing on those attending a University hospital, would provide a more comprehensive understanding of the knowledge gaps and educational needs across different settings. By considering the unique needs and challenges of diverse populations, interventions and educational initiatives can be tailored to effectively address specific knowledge gaps and misconceptions. This will ensure that the educational efforts are inclusive, reaching a wide range of individuals affected by PD and enabling them to make informed decisions about their healthcare. However, this study, conducted in a single center, had limited representation due to the narrow scope of data collection.

In conclusion, this study highlights the importance of continuous efforts to improve patient education and knowledge about PD. By actively addressing knowledge gaps, dispelling misconceptions, and promoting accurate information, healthcare professionals and support organizations can empower individuals with PD to better manage their condition and enhance their overall well-being. Through targeted interventions and ongoing research, we can work towards creating a more informed and supportive society for individuals living with PD and their families.

Acknowledgments

The authors gratefully acknowledge the participants who participated and spent their time in this study.

Paper Contribution to Related Field of Study

The research findings may contribute to promoting a better understanding of PD and guide the design of effective interventions targeting healthcare providers and caregivers. The organization, nurses and health professional may able to enhance the patient care and give holistic management to PD patients.

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