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## RESEARCH ARTICLE

# Subjective Self-Rated Speech Intelligibility and Quality of Life in Patients with Parkinson's Disease in a Malaysian Sample

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### Abstract:

#### Objectives:

This study compared the Quality of Life (QOL) of individuals with Parkinson's disease (PD) with a healthy control from a sample in Malaysia. The relationship between the QOL, age, gender, duration of disease, self-rated speech scale, and life satisfaction level was examined.

#### Methods:

Fifty-four individuals with PD and 55 non-PD control adults completed the Parkinson's Disease Questionnaire-39 (PDQ-39) and rated their speech intelligibility [Self-Rated Speech Scale (SRSS)] and life satisfaction level [Life Satisfaction Scale (LSS)] on a 10-point scale.

#### Results:

PD participants reported significantly lower QOL scores than the control group (Mann-Whitney U). Although there was no significant relationship between the QOL, age, gender, and duration of disease for PD participants, moderately significant correlations were observed between QOL, LSS and SRSS ratings (Spearman correlation). Individuals with PD showed lower QOL and higher concern in their communication than the control group.

#### Conclusion:

Identifying patients' perception of their speech performance could help clinicians to better understand patients' needs when delivering speech therapy services.

**Keywords:** Parkinson's disease, Quality of life, Communication, Social support, Questionnaire, Self-Rated Speech Scale, Life Satisfaction Scale.

## 1. INTRODUCTION

Parkinson's Disease (PD) is the world's second most common neurodegenerative disease, and affects over 10 million people worldwide [1, 2]. Apart from resting tremor, slowness of movement, stiffness in muscle tone, and imbalance of body posture, PD is frequently accompanied by depression, dementia, swallowing difficulty, and speech and voice disorders [3 - 5]. Hypokinetic dysarthria, a speech disorder that commonly presents in patients with PD, often results in limitation in their social interactions [6, 7]. PD affects many aspects of patients' lives and since this disease is

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progressive, it is important to maintain functional abilities related to independent living when providing rehabilitation services [8 - 10] in order to maintain their quality of life [11, 12] and reduce the burden on caregivers [13].

Quality of life is defined as an individual's perception of their experiences in life [14]. It also reflects the degree of challenges that one faces in life [15], including social functions, emotional, physical, and mental conditions. Quality of life has been used as a clinical outcome measure for service delivery in different disorders, including PD [5, 16]. Some of the commonly used tools that quantify quality of life in PD are the Parkinson's Disease Questionnaire (PDQ-39), Parkinson's Disease Questionnaire Short Form (PDQ-8), Parkinson's Impact Scale (PIMS), Parkinson's Disease Quality of Life Questionnaire (PDQL), and Scales for Outcomes in Parkinson's Disease–Psychosocial (SCOPAPS) [17]. Among these, the PDQ-39 is commonly used to measure one's experiences of the impact of PD on life. It is widely used in determining treatment outcomes and when reviewing the overall impact of PD [18]. It consists of 39 items and measures eight dimensions of quality of life relating to PD (*i.e.*, mobility, activities of daily living, emotional, stigma, social support, cognitions, communication, and bodily discomfort).

Using the PDQ-39, PD patients reported higher scores (indicates poorer experience) in the mobility dimension. This indicates that PD is severely affecting the patients' mobility, and the rank is followed by activities of daily living dimension or bodily discomfort [7, 19, 20]. When comparing quality of life between people with PD and the general population, Schrag and colleagues (2000) found that individuals with PD showed greatest impairment in the areas related to physical and social functioning. For instance, the core features of PD such as slowness of movement and muscle stiffness could have limited their daily physical function in feeding themselves, doing household chores, *etc.* and thus, further affected their social interactions with others when physical movement including speech are greatly impaired [21]. However, both those with PD and the general population showed similar scores in emotional adjustment, indicating that PD interferes with various aspects of quality of life, particularly those related to physical and social functioning. By understanding an individual's quality of life, clinicians could determine the difficulties experienced by individuals. Therefore, the PDQ-39 could be used to better understand the person's perspective of goals and disability when planning a treatment protocol that promotes the social, emotional, and physical well-being of individuals with PD [22]. While quality of life helps evaluate an individual's life experiences, the individual's satisfaction about life may be measured by the life satisfaction scale, a subjective measure that focuses on one's perspectives on life as a whole [23]. A psychological study on the elderly showed that better life satisfaction could reduce the risk of mortality by 18% [24]. To date, there is no research which examines the life satisfaction levels of people with PD; their satisfaction towards life with PD is yet to be defined. It is difficult to improve life's satisfaction when the relationship between life's satisfaction and quality of life is not explained.

Apart from quality of life and life satisfaction level, communication is another important aspect of life. Communication is essential for social interaction and is strongly associated with the quality of life [25]. It is crucial to understand the communicative difficulties experienced by individuals, and to develop effective interventions to achieve the rehabilitative goals of improving the quality of life [11, 22]. When treating patients with a progressive disorder such as PD, dealing solely with physical function is insufficient. Clinicians should take into account various life domains, including social interaction and communication factors when working with PD patients. According to the American Speech-Language-Hearing Association (2016), speech-language pathologists should address patients' communication skills in order to increase their quality of life. However, quality of life is often overlooked by speech-language pathologists due to the absence of a conceptual relationship between communication and quality of life [25]. In fact, speech and language changes in PD have negative impacts upon individuals and their family lives before the frank impairments of intelligibility are apparent [26]. One common way to assess patients' speech intelligibility is by using a self-rating scale. Self-rating of speech performance was designed to measure an individual's perception of his or her speech performance to measure the outcomes of speech treatment such as stuttering and motor speech disorders [27 - 29].

Although speech-language pathologists have been practicing in Malaysia for over 20 years, no research has been conducted to determine the quality of life and communication component of individuals with PD [30]. Hence, this research had three goals. First, to compare the quality of life of individuals with PD with healthy controls. Second, to determine if the communication component of the Parkinson's Disease Questionnaire (PDQ-39) differed between these two groups. Third, to evaluate the relationship between QOL, age, gender, duration of disease, Self-Rated Speech Scale (SRSS), and Life Satisfaction Scale (LSS) for the PD group.

## 2. METHODS

### 2.1. Participants

A total of 55 individuals with PD and 55 non-PD healthy control adults participated in this study. One of the PD participants was excluded because subject did not complete all questions in the survey package. Hence, data from 54 individuals with PD and 55 controls were compared. Of PD participants, 94% were active members of the Malaysia Parkinson's Disease Association (MPDA). All PD patients were diagnosed by neurologists. The remaining 6% of PD participants and all of the control participants were recruited through word of mouth and advertisement at the University's Audiology and Speech Sciences Clinic. Ethics approval for this study was obtained from the National Universiti Kebangsaan Malaysia Board of Ethics. All participants provided informed consent before participating in the study.

### 2.2. Measures

#### 2.2.1. Parkinson's Disease Questionnaire (PDQ-39)

The Parkinson's Disease Questionnaire (PDQ-39) (Isis Innovation Limited 1998) was used to compare the quality of life of individuals with PD and controls across eight dimensions: mobility (10 items), activities of daily living (6 items), emotional well-being (6 items), stigma (4 items), social support (3 items), cognitions (4 items), communication (3 items), and bodily discomfort (3 items). The PDQ-39 consists of 39 items, presented with a 5-point ordinal Likert scale (0 = never, 1 = occasionally, 2 = sometimes, 3 = often, 4 = always). Each dimension score was calculated, and the total score was computed into the PD Summary Index score (PDSI). A lower PDSI score indicates a better quality of life and vice versa. The PDQ-39 has been tested for validity and reliability [17], with a satisfactory level of internal consistency, content and convergent validity, and stability [19, 31].

### 2.3. Procedure

A survey package with an information sheet, consent form, demographic sheet, and PDQ-39 was distributed by hand to each participant. Additionally, the participants were requested to rate their perceptions of their speech intelligibility [Self-Rated Speech Scale (SRSS)] and their life satisfaction level [Life Satisfaction Scale (LSS)]. The SRSS consists of an ordinal 10-point scale (1 = excellent, 10 = worst) to "Grade your speech after having Parkinson's disease." Similarly, the LSS stated, "Grade your life satisfaction after you have Parkinson's disease" on a scale with "1" indicating 'excellent', and "10" indicating 'worst'. The PD participants were asked to complete the survey based on their latest one-month experience of PD, whereas the control group was requested to complete the questionnaire by reflecting on their daily experiences. To examine the reliability of the PDQ-39, twelve participants were asked to refill the PDQ-39 form across a period of 2.5 weeks. Spearman's correlation was selected to examine reliability, and the result showed that the PDQ-39 is moderately reliable ( $r = 0.60, p = 0.041$ ) [32].

### 2.4. Data Analysis

The descriptive statistic for the demographic information was calculated for both groups. Mann-Whitney U tests were used because data were non-normally distributed for both PD [*Kolmogorov-Smirnov D* (54) = 0.147,  $p = 0.004$ ] and control groups [*Kolmogorov-Smirnov D* (54) = 0.140,  $p = 0.009$ ]. The similar test (Mann-Whitney U tests) was used to examine the difference of the item's score for the Communication Dimension. The three items ("Had difficulty with your speech?", "Felt unable to communicate with people properly?", "Felt ignored by people?") that examined the Communication dimension in the PDQ-39 form were compared between groups. Additionally, Spearman correlation was conducted between the PDSI score and the age, gender, SRSS, and the LSS, for PD group.

## 3. RESULTS

### 3.1. Demographic Data

PD participants were aged between 45 and 86 years (Mean = 66.75, SD = 7.35). Among them, 25 (45%) were males, and 30 were females (55%). The non-PD control group were aged between 53 and 85 years (Mean = 65.25, SD = 7.50), and included 28 males (51%) and 27 females (49%). An independent samples *t*-test showed a non-significant difference in age between the PD and control groups,  $t(110) = 1.05, p = 0.30$ . Additionally, a non-significant difference in gender was found between groups,  $t(110) = 0.33, p = 0.70$ . Only ethnic Chinese (PD group = 85%) and Indians were recruited

into this current study as Malays are not active members of the MPDA. Employment status differed significantly, with a notably higher number of participants unemployed in both groups (PD= 84% unemployed, control= 56% unemployed),  $X^2(1) = 11.28, p < .001$ .

### 3.2. PDQ-39

The Parkinson’s disease questionnaire summary index (PDSI) mean score for the PD group (Mean= 31.38; SE= 2.34) was higher than the control group (Mean= 11.75; SE= 1.46), suggesting that the PD group had a poorer quality of life. Additionally, all of these dimensions were significantly different between groups, except for the social support dimension ( $U = 1199.00, p = 0.05$ , (Table 1). Specifically, the PD and control groups had an average score of 19.24 (SE= 2.66) and 11.97 (SE= 2.05) respectively. Additionally, the three items (“Had difficulty with your speech?”, “Felt unable to communicate with people properly?”, “Felt ignored by people?”) that examined the Communication Dimension in the PDQ-39 form were compared between groups (Table 2). All three items showed significant differences between the PD and control groups ( $p < 0.001$ ). More specifically, the PD group reported a higher mean score (Mean= 1.47, SE= 0.16) on the item 34 “Had difficulty with your speech?” than those in the control (Mean= 0.27, SE= 0.09) group.

Table 1. Mann-Whitney values across the PDQ-39 for the PD group.

	Mann Whitney U	p-value	Z score	Medial IQR	Effect Size	Mean Rank PD	Mean Rank Controls
Mobility	507.00	0.001	6.033	26.63 43.13	0.575	73.78	37.22
Activities of daily living	333.50	0.001	7.328	8.33 30.21	0.699	76.94	34.06
Emotional	731.00	0.001	4.700	20.83 29.17	0.448	69.71	41.29
Stigma	747.50	0.001	5.173	0.00 12.50	0.493	69.41	41.59
Social support	1199.00	0.05	1.959	8.33 25.00	0.187	61.20	49.80
Cognition	779.50	0.001	4.411	25.00 26.56	0.421	68.83	42.17
Communication	705.00	0.001	5.056	8.33 33.33	0.482	70.18	40.82
Bodily Discomfort	900.50	0.001	3.688	25.00 41.67	0.352	66.63	44.37
PD Summary Index	474.50	0.001	6.206	18.51 22.67	0.592	74.37	36.63

Table 2. Mann Whitney values on Communication Dimension.

Item	Mann Whitney U	p-value	Z score	Medial IQR	Effect Size	Mean Rank PD	Mean Rank Controls
Item 34: Had difficulty with your speech?	661.00	0.001*	-5.695	0.002	0.543	70.98	40.02
Item 35: Felt unable to communicate with people properly?	846.50	0.001*	-4.625	0.002	0.441	67.61	43.39
Item 36: Felt ignored by people?	1009.5	0.01*	-3.381	0.001	0.322	64.65	46.35

### 3.3. Correlations Between PDQ-39, Age, Gender, Duration of PD, SRSS, and LSS

The Spearman correlation coefficient of the relationship between PDQ-39, age, gender, duration of PD, SRSS, and LSS is tabulated in Table 3. Overall, age, gender, and duration of disease show no significant correlation with PDQSI score. However, the SRSS ( $\rho = 0.329, p < 0.05$ , mean=5.41, SD=2.14) and the LSS ( $\rho = 0.464, p < 0.001$ , mean=4.95, SD=2.16) were moderately positively correlated to the PDQSI score. A strong correlation was considered to be over 0.60, a moderate correlation between 0.30 and 0.60, and a low correlation is below 0.30 [33].

Table 3. Correlation of PDSI score with age, gender, duration of PD, SRSS, and LSS.

	Spearman's rho	p value
Age	0.002	0.986
Gender	0.197	0.150
Duration of PD	0.131	0.341
Self-rated Speech Scale (SRSS)	0.315	< 0.05
Life Satisfaction Scale (LSS)	-0.448	< 0.001

#### 4. DISCUSSION

To our knowledge, this is the first study evaluating QOL and subjective self-rated speech intelligibility in patients with PD in comparison with a control group in Malaysia. Consistent with the previous research, our findings showed that the PD group scored higher in PDSI scores than the control group [21, 34]. Individuals with PD had worse QOL scores in all dimensions than the control population, indicating that individuals with PD tend to have a lower quality of life than controls. Although PD and control groups had significant differences in mobility, activities of daily living, emotional, stigma, cognition, communication, and bodily discomfort scores as reported in the PDQ-39, such group differences were not observed in the social support dimension. This result might be due to the sample recruitment location, given that 96% of the participants were recruited from a support group. The present data indicate that participation in a support group provides benefits in improving their social support. Indeed, previous studies have shown that members of a PD support group would have greater acceptance of the disease and cope better with difficulties in life than non-members [35 - 37]. Further research is warranted to determine whether social support is more positive for those who participated in the self-help group than those who do not.

In PD, speech impairment often leads to communication difficulties and affect participation in life, and quality of life [7]. This was supported by our finding that individuals with PD struggle with more communication issues than the control group. Additionally, PD participants who have a better perception of their speech intelligibility (*i.e.*, lower scores on the SRSS) tend to have a better quality of life and vice versa. This suggests that the feeling of being “able to communicate” is important in maintaining social relationships with one’s family and relatives, and “feeling accepted by others” is important because it provides patients with feelings of acceptance and assurance. Again, communication deficits appear to be a significant concern in individuals with PD because they might limit their social relationships [20, 38]. As such, poor speech intelligibility in individuals with PD could lead to social exclusion, which can negatively affect their health and well-being due to increasing allostatic load [39]. The allostatic load theory aims to explain the physiological mechanisms that lead from various stressors experienced over the lifespan [40]. However, some participants also reported that communication does not affect their overall quality of life. One possibility is that this claim might result from lack of clarity in the SRSS scale. More specifically, some participants reported that they were unsure how to answer this question. The research team is aware that PD patients are seldom asked to judge their speech in clinical settings. For all of our participants, this appears to be the first time they had been asked to judge their speech using the SRSS scale. Given that communication difficulties affect quality of life, clinicians should take into account the need to educate patients to rate their speech, particularly when considering their speech intelligibility expectations. Future studies in this population should include both subjective and objective speech measurements that provide more clinical data assessing the relationship between speech intelligibility and quality of life. This could guide clinicians to better understand their clients’ needs when providing speech treatment to increase their quality of life and enhance good practice standards, as required by the Speech Therapist’s professional’s guidelines [41].

In general, age and gender showed no significant correlation with the PDSI score, indicating that the PDQ-39 is an age- and gender-free survey. In addition, the non-significant correlation between the duration of disease and the PDSI score implies that the PDQ-39 is a quality of life measurement for PD patients regardless of the duration of the patient having the disease. However, this was not the case for life satisfaction levels. Respondents from this study reported a moderate correlation between the LSS and PDSI scores, indicating that life satisfaction could affect their quality of life. Additionally, when asked to fill in the life-satisfaction scale, approximately 80% of the participants commented that their life-satisfaction level is greatly affected by their medication. For instance, patients with inconsistent medication effects would report lower life-satisfaction scales than those who are more consistently responsive to drugs. It seems that medication effects significantly affect these patients’ levels of quality of life [42].

## 5. LIMITATIONS

Two limitations are relevant to the present study. First, PD participants were instructed to fill in this survey based on their impression of the ‘medication ON’ stage. Results reported in this current study do not reflect their quality of life levels at the ‘medication OFF’ stage. Most of the participants commented that they have different performances depending on whether medication is ON or OFF state. Future studies should compare the QOL of PD participants during both medications ON and OFF states to determine whether medication stage affects an individual’s overall quality of life. Further analysis, such as the Bayes methods, could be conducted to expand the scope of our research question to better understand the factors that could affect quality of life levels at medication ON vs OFF stages in these patients [43, 44].

Second, some participants commented that two items from the PDQ-39 (item 2- “Had difficulty looking after your home, e.g. DIY (Do-It-Yourself), housework, cooking?”) and (item 15- “Had difficulty cutting up your food?”) might not be culturally appropriate. In Malaysian culture, the term “DIY” is not in common daily usage, particularly by the elderly. Additionally, the term “look after” does not typically include cooking or housework; it means to keep an eye on the home from robbery or fire by most of the participants. For item 15, “cutting up food” using fork and knife is not part of Malaysian culture. Malays and Indians use their right hands without utensils during meals, while the Chinese use chopsticks or spoons and forks. Most of the participants commented that they do not need to cut their food with a knife while eating. A slight modification of these two items to become more culturally appropriate would also increase clarity in future studies.

## CONCLUSION

The present study shows that PD patients have a lower quality of life than the general public, and demonstrated that PD support groups could help to improve social support. This study also indicates that the PDQ-39 is an age- and gender-free survey. In addition, the duration of having PD does not affect quality of life as measured by the PDQ-39 in the current sample. It was also found that medication responsiveness may be one factor that influences life satisfaction and quality of life. Given that SRSS and quality of life scores are moderately correlated, identifying patients’ perceptions of their speech intelligibility could help clinicians to better understand patients’ needs during speech therapy. Future studies should examine the effects of medication, SRSS, and LSS on the quality of life of PD patients to provide a high quality of service delivery.

## ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was approved by the Research Ethics Committees, Universiti Kebangsaan Malaysia.

## HUMAN AND ANIMAL RIGHTS

No animals/humans were used for studies that are the basis of this research.

## CONSENT FOR PUBLICATION

For the consent, one-page subject information sheet and informed consent letter were attached to each questionnaire and it explained that participation was voluntary, confidential, and no risk or harm, and any demanding privacy were respected.

## CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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