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ORIGINAL ARTICLE

HEALTH RELATED QUALITY OF LIFE IN PARKINSON'S DISEASE PATIENTS IN TIKUR ANBESSA SPECIALIZED HOSPITAL AND ZEWDITU MEMORIAL HOSPITAL, ADDIS ABABA, ETHIOPIA

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ABSTRACT

Background: *Recently, studies have suggested both motor and non-motor symptoms (NMS) have an impact on the health-related quality of life (HrQoL) among patients with Parkinson's Disease (PD). However, little is known about health-related quality of life (HrQoL) among people with PD in Ethiopia.*

Objective: *To determine the health related quality of life in PD patients seen in the outpatient clinics of Tikur Anbessa Specialized Hospital (TASH) and Zewditu Memorial Hospital, (ZMH) Addis Ababa, Ethiopia.*

Methods: *All PD patients attending neurology follow up clinic aged 18 years and above at TASH AND ZMH from October 2014 to January 2015 were included in the study. Health-related quality of life was evaluated using PDQ -39 which is a 39 item questionnaire. Motor symptoms severity was evaluated with UPDRS: part 3, which assesses severity of motor signs using a scale 0 to 4. Hoen and Yahr stage was used to assess severity. Multiple linear regression analysis was used to predict demographic and clinical factors for HrQoL in PD patients.*

Results: *A total of 128 PD patients participated in the study. The mean age of the participants was 59.5 years. Mean duration of illness was 6 years. The mean PDQ 39 Summery Index (SI) was 40.5 (95% CI: 37-44). The PDQ 39 domains with higher scores were Activity of Daily living (ADL), emotional wellbeing, body discomfort and cognition; profiles such as social support, communication, stigma and mobility showed lowest scores (good QoL). The demographic and clinical factors that predicted HrQoL were education, (β =0.053, $p<0.01$), duration of disease (β=0.152, $p<0.001$), UPDRS 3 unified PD rating scale total score (β=0.083, $p< 0.001$), H&Y score (β=0.140, $p< 0.001$), depression (β=0.339, $p< 0.001$ and anxiety (β=0.423, $p< 0.000$).*

Conclusion: *HrQoL worsens with increased depression, anxiety, and disease severity. Therefore it is prudent to recognize and assess depressive symptoms and disease severity so that symptoms may be managed enabling patients to enjoy a better quality of life.*

Key Words: *Parkinson's Disease, PDQ-39, Quality of life in PD*

INTRODUCTION

Parkinson's disease (PD) is a progressive neurodegenerative disorder characterized by cardinal motor symptoms including tremor, rigidity, bradykinesia and postural instability (1,2). New evidences suggest that PD has various non-motor symptoms (NMS) which include neuropsychiatric symptoms, sleep disorders and autonomic and sensory symptoms. The NMS of Parkinson's disease that are seen in the early stages of the disease have been found to be dominant in the late stages and may also precede the motor symptoms by several years although they are not recognized and managed by clinicians. It was found out that both the motor and non-motor symptoms of PD affect the health related quality of life (2). Health-Related Quality of Life (HrQoL) may be defined as the perception and self-evaluation by patients of the disease's impact on their life and its consequences (3).

Age and sex were the demographic factors that were most frequently examined as a predictor of HrQoL. Many other demographic factors were reported to predict HrQoL, these included rural residence, financial problems and the number of household members (4). Conflicting results were reported by previous studies on the effects of age, educational level and gender on the HRQoL (4). Poor HrQoL was also attributed to disease severity and disability in people with PD (5). A very significant determinant of HrQoL in people with PD that is frequently identified is the presence of depressive symptoms. Depression was found to be the main factor associated with

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poor health related quality of life (6). In a review of determinants of QoL among patients with Parkinson's disease, anxiety was found to predict adverse QoL in 83% of cases (4). In the past 20 years, the impact of motor symptoms such as rigidity, bradykinesia, tremor, gait and impaired balance on the decline of HrQoL has been well understood. Recently, the impact of NMS on the HrQoL of PD patients has attracted substantial attention. Many studies from the west have suggested that both the motor and NMS play a more important role in the decline of HrQoL The correlation between motor, NMS and HrQoL in PD may differ among populations of different ethnic, economic, cultural and educational backgrounds.

However little is known about health-related quality of life (HrQoL) among people with Parkinson's Disease (PD) in Ethiopia, and in general in Africa (7, 8). The evaluation of HrQoL is thus important among patients with PD, as the information gained from it can lead to a better understanding of the disease's consequences and suggest optimum treatment. Therefore the study aimed to determine the HrQol among patients with PD in an Ethiopian setting.

PATIENTS AND METHODS

A cross-sectional study was conducted at the Neurology follow up clinics of TASH and ZMH. The source population was all adult PD patients aged 18 years and above in Ethiopia. TASH is the main teaching hospital of the College of Health Sciences, School of Medicine of Addis Ababa University and ZMH is also one of the major teaching hospitals for the School of Medicine. Both hospitals have outpatient specialty and subspecialty clinics in different fields of Medicine. Of these, the general neurology clinic, headache, movement disorder, stroke and seizure adult outpatient neurology clinics convene three times a week, and provide follow up care in the range of 40-130, 10-20, 10-15 and 30-40 patients per clinic session, respectively. The general neurology clinic is conducted by neurology attached internal medicine and neurology residents with one consultant neurologist and the subspecialty clinics are under the direction of a consultant neurologist.

Patients with symptoms that suggested other causes of Parkinsonism such as history of repeated strokes or head injury, oculogyric crisis, neuroleptic treatment at onset of symptoms, supranuclear gaze palsy, cerebellar signs, early severe autonomic involvement, early severe dementia, Babinski sign, presence of cerebral tumor or communicating hydrocephalus on neuroimaging, negative response to large doses of levodopa, were excluded.

Data was collected on variables such as age, sex, marital status, ethnicity, educational level, occupation, religion, duration of illness, UPDRS part 3, and H&Y scoring as factors for PDQ-39 score**.** The PDQ -39 is a widely used, well validated and highly reliable questionnaire employed in different parts of the world. In relation to the specific measures, the PDQ-39 is the most thoroughly tested and used HRQoL questionnaire for PD. It has 39 questions measuring the effects of Parkinson's Disease on QoL It measures the impact of PD on HRQoL of affected patients in the past one month under 8 parameters including mobility (10 questions), activities of daily living (6 questions), emotional wellbeing (6 questions), stigma (4 questions), social support (3 questions), cognitive impairment (4 questions), communication (3 questions) and bodily discomfort (3 questions). There were a number of questions under each item that were coded on a scale of 0-4 (0= never; 1=seldom; 2=sometimes; 3=often; 4=always, or cannot do at all). A sum of all these scores form the basis for the scale score that ranged between zero and hundred (0= no problems; 100=maximum level of problems). The PDQ-39 questionnaire was translated into Amharic and back translated into English to ensure quality of translation.

Protocol approvals were obtained from the ethical review Committee of the Department of Neurology and the Institutional Review Board (IRB) of the College of Health Science of Addis Ababa University. Study subjects provided informed written consent.

Data were entered and analyzed using SPSS for Windows version 20.0. Comparisons of PDQ 39 SI among different demographic and illness variables were made using t-test or F-test, as appropriate. To determine which items contributed most to HrQoL, correlation coefficients with their 95% confidence intervals were calculated between the total PDQ 39 to sub-scores of UPDRS3. Multiple linear regression analysis was done to determine which factors were most predictive of QoL scores.

RESULTS

Socio-demographic characteristics: One hundred and twenty eight patients participated in this study of which 36.7% and 63.3% were females and males respectively. The mean age of participants was 59.5 years with SD of 11.1 years; 91.4% of the partici-

pants were right handed. Seventy-eight (60.9%) participants were living with their partners and 39.1% did not have partners. Twenty five (19.5%) and 103 (80.5%) were employed and unemployed respectively. A higher proportion (41.1 %) of the unemployed were retired. Sixty six (51.6%) of the participants had no formal education and 18.8% of those who had formal education had attended above secondary school level. Ninety eight (76.6%) participants were Orthodox Christians, 20 (15.6%) Muslims and 10 (7.8%) were Protestant Christians. Sixty seven (52.3%) of the participants were from the Amhara ethnic group while 30 (23.4%) were of Oromo ethnicity and 22 (17.2%) were of Gurage ethnicity. The

Table 1. Socio demographic characteristics of PD patients in TASH and ZMH from October 2014- January 2015 (N=128)

Characteristics	Number	Percent
Handedness:		
Right	117	91.4
Left	11	8.6
Age group (years):		
≤60	68	53.1
>60	60	46.9
Mean (SD)	59.5(11.1)	
Gender:		
Female	47	36.7
Male	81	63.3
Educational level:		
Cannot read & write	66	51.6
Literate	62	48.4
Marital status:		
Living with partner	78	60.9
Has no partner	50	39.1
Employment status:		
Employed	25	19.5
Unemployed	103	80.5
Status if unemployed:		
House wife	22	21.4
Retired	43	41.7
Out of job	17	16.5
Other	21	20.4
Religion:		
Orthodox	98	76.6
Muslim	20	15.6
Protestant	10	7.8
Ethnicity:		
Amhara	67	52.3
Oromo	30	23.4
Gurage	22	17.2
Others	9	7.1
Duration of illness:		
≤5 years	75	58.6
>5 years	53	41.4

PDQ 39 dimension score:
As shown on Table 2, the mean PDQ39 SI was 40.5 (95% CI: 37-44).The PDQ 39 domains with higher scores were ADL (mean=53.2, 95% CI:47-57.5), emotional wellbeing (mean=44.1, 95% CI:39-48.6), body discomfort (mean=40.6, 95% CI: 36-45.6) and cognition (mean=40.2, 95% CI:35.7-45.1). Profiles of QoL that showed the lowest scores (good QoL) were social support (mean=35, 95% CI:29.7-41.1), communication (mean=35.6, 95% CI:31.2-40.5), stigma (mean=36.4, 95% CI:30.3-42.3) and mobility (mean=38.9, 95% CI:34.2-43.6).

Concerning clinical features of PD patients, the UPDRS part 3 for the assessment of motor symptoms, the overall mean score was 42.8. Disease severity in terms of H&Y was as follows: H&Y (0-2) which indicated mild disease was 63.3%, H&Y 3 which indicated moderate disease was 20.3% and those in stage 4 which indicated severe disease were 16.4% (Table 2).

Table 2. Mean Scores of PDQ 39 domains and clinical features of PD patients in TASH and ZMH from October 2014 – January 2015 (N=128)

Domain	Clinic Sample Mean	95% CI
Mobility	38.9	34.2 - 43.6
ADL	53.2	47.0 - 57.5
Emotional Wellbeing	44.1	39.0 - 48.6
Stigma	36.4	30.3- 42.3
Social Support	35.0	29.7- 41.1
Cognition	40.2	35.7 - 45.1
Communication	35.6	31.2 - 40.5
Bodily discomfort	40.6	36.0 - 45.6
PDQ39 Summary Index	40.5	37.0 - 44.0
Clinical features		
H & Y Score:		Percent
0-2	81	63.3
3	26	20.3
4	21	16.4

Association between scores on PDQ 39 and socio demographic and clinical characteristics: PDQ 39 SI was significantly associated with employment, education and duration of disease. Concerning education, those who could neither read nor write had a higher PDQ 39 score compared to patients who were literate, with a mean difference of 10.4 (t=2.9, p=0.004). Concerning employment status, the unemployed had a higher PDQ 39 score compared to the employed with a mean difference of 10.6 (t=-2.31, p=0.02). Also duration of illness of more than 5 years had a higher score on PDQ 39 compared to those with less than or equal to 5 years, with a mean difference of 14 (t=-3.731, p<0.001). However no significant difference was observed in the mean scores of PDQ 39 by age, gender, marital status and ethnicity. Mean scores of PDQ 39 was found to be significantly associated with H&Y scale (F=6.347, p<0.001), with stage 4 having a higher mean score of 56.3 and stage 0 having mean score of 32.2 (Table 3).

Table 3. Correlation of demographic and clinical factors with PDQ 39 SI

Characteristics	PDQ 39 SI Mean (SD)	t-test/F-test	p-value
***Gender*:**			
Female	41.3 (22.6	0.31	0.71
Male	40.1 (20.2)		
Age category (years):			
≤60	39.5 (21.40	-0.56	0.57
>60	41.6 (20.7)		
Marital status:			
Living with partner	39.7 (20.7)	-0.53	0.59
Has no partner	41.7 (21.7)		
Duration of illness:			
≤5 years	34.8 (17.8)	-3.73	<0.01
>5 years	48.6 (22.6)		
Employment status:			
Employed	31.9 (18.9)	-2.31	0.02
Unemployed	42.6 (21.0)		
Religion:			
Orthodox	40.1 (21.9)	0.97	0.27
Muslim	38.4 (17.0)		
Protestant	49.4 (18.9)		
Ethnicity:			
Amhara	39.3 (21.1)	1.08	0.19
Oromo	37.5 (19.0)		
Gurage	46.9 (23.4)		
Others	41.5 (15.4)		
***Educational status*:**			
Cannot read and write	45.6 (20.1)	2.9	0.01
Literate	35.1 (20.7)		
H & Y stage:			
0	32.2 (29.1)	6.35	<0.01
1	31.6 (15.9)		
2	40.1 (19.9)		
3	44.9 (20.5)		
4	56.3 (22.2)		

The UPDRS had a significant positive correlation with PDQ-39 score (r=0.47, p<0.001). To determine which items contributed most to HrQoL, the correlation between the total PDQ 39 to sub-scores of UPDRS3 were calculated. Although the magnitudes of the correlation coefficients were low, items with statistical significance were: rising from chair (r=0.461, p<0.001), bradykinesia (r=0.458, p<0.001), freezing of gait (r=0.443, p<0.001), rigidity (r=0.287, p<0.001), finger tapping (r=0.412, p<0.001), toe tapping (r=0.381, p<0.001), postural instability (r=0.346, p<0.001), gait (r=0.34, p<0.001), speech (r= 0.277, p=0.002) and facial expression (r=0.258, p=0.023). Tremor had little impact on HrQol (p=0.229, r=0.107) (Table 4).

To determine which factors contributed most to QoL scores, we performed a linear regression entering all factors that were shown to have an impact on QoL scores. The most important predictive factors were feelings of anxiety, feelings of depression, the Hoehn and Yahr stage, duration of illness, education and employment which together accounted for 65.1% of the variation of QoL scores. None of the other variables added in the model contributed for the variation explained above.

Table 4. Correlation of PDQ 39 SI with UPDRS total and subscores of PD patients in TASH and ZMH from October 2014- January 2015 (N=128)

Variables	Correlation coefficient (r)	P value
UPDRS Total	0.417	<0.001
Rising from chair	0.461	<0.001
Bradykinesia	0.458	<0.001
Freezing of gait	0.443	<0.001
Finger tapping	0.412	<0.001
Toe tapping	0.381	<0.001
Postural stability	0.346	<0.001
Gait	0.340	<0.001
Rigidity	0.287	0.002
Speech	0.277	0.002
Facial expression	0.258	0.023

DISCUSSION

In this study PDQ 39 domains that were found to have higher scores were ADL, emotional wellbeing, body discomfort and cognition. Profiles of QoL that showed lowest scores indicating good QoL were social support, communication, stigma and mobility. The demographic and clinical factors that predicted HrQoL were employment, education, duration of disease, UPDRS 3 total score, H&Y stage, depression and anxiety.

Our patients had worse QoL compared to patients reported in a study carried out on 143 PD patients where the mean PDQSI was 36.5 (26). In a study of 141 Polish PD patients the mean PDQSI was 35.3 (39). Profiles of quality of life that showed the lowest score (<40, to indicate good QoL) were for the magnitude of bodily pain, social support and communication (9). In our study major complaints were body discomfort, cognition and emotion. In contrast to other studies that showed mobility, body discomfort and ADL to be impaired (10), in our study, mobility and ADL were not major problems as H&Y stage 4 was observed in only 16.4% of cases.

Age and sex were not identified as predictors of HrQol in this study. Many studies have also found conflicting results (4). In our study employment was a predictor of HrQol similar to what a study done in Croatia found (11), where unemployment was associated with higher PDQ 39 scores. Educational level was also found to be a predictor of HrQol. Our results concurred with findings from another study which found that a patient's education influences QoL in general (12). Patients with higher educational background may be more aware about their physical and psychological needs resulting in a better search and access to better health care resources.

Duration of illness was found to be a predictor of HrQol (9,12). Mean duration of PD for our patients was 6 years which is shorter than what other studies have reported and which ranged from 6.7-9 years (9, 13, 12,14). In this study longer duration of PD was associated with poorer HrQoL which is similar to atleast one other report (10). In our study duration of disease did not affect the social support dimension of PDQ 39, similar to findings from other studies (9,10).This can be explained by the fact that support received by the patient did not depend on the phase of the disease, but on a patient's family relationships.

In our study we assessed self perceived symptoms of depression in PD patients using item 17 of the PDQ-39, which refers to complaints that could be attributed to depression. Eight nine of 141 patients (69.5%) reported they had experienced such ailments. The presence of symptoms of depression was significantly correlated with PDQ-39 SI (r=0.579 p<0.01) suggestive of poorer QoL in depressive PD patients; this finding was similar to a what was reported from a study in Polish patients(10), in which depression affected 68.1% of the study participants. Our result is lower than the reported prevalence that depression can occur in 80% of PD patients. Depression is often untreated as it is usually mistaken for other symptoms of PD (4).

Self perceived symptoms of anxiety was found in 71.1% of the study participants and had a strong correlation with HrQol (r=0.664, p=0.000). Anxiety often occurs in combination with depression and can manifest as excessive nervousness or worrying, generalized anxiety disorder, panic attacks, or obsessive compulsive disorder. Although limited attention has been paid to PD-related anxiety disorders, they contribute substantially to morbidity and caregiver burden (4).

UPDRS was found to be significantly associated with HrQol. In our study rising from a chair, bradykinesia, freezing of gait, gait, rigidity, finger tapping, toe tapping, postural instability, speech and facial expression were found to be significantly associated with HrQol, similar to what a study from Spain reported (13). Specific motor impairments such as tremors (15) were not consistent predictors of HrQol. Axial symptoms such as postural instability and gait impairments contributed to worsening of QoL of patients; these symptoms are attributable not only to degeneration of the dopaminergic system but aging itself. Quality of life was strongly correlated with disease severity as measured by Hoehn and Yahr scale (9, 11, 16, 17, 18).

The number of patents in our study was small and hence it is difficult to generalize the conclusion to the society at large. Besides, the complexity of the concept of QoL might be another and important limitation of this study, as many variables that potentially contribute to QoL, such as social support and individual coping strategies, were not directly measured.

In conclusion, our study revealed that the HrQoL worsens with increased depression, anxiety and disease severity. Therefore it would be prudent to recognize and assess depressive symptoms and disease severity so that such symptoms could be managed leading to a better quality of life for patients. To minimize the functional consequences of PD, it will be beneficial for clinicians to consider how demographic factors and motor and non-motor symptoms contribute to HRQoL.

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