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## Research Article

# The Health-related Quality of Life of Sudanese Patients with Idiopathic Parkinson's Disease -

**Meysoon Adil Abdelrahman Elagib<sup>1\*</sup> and Omer Eladil Abdalla Hamid<sup>2</sup>**

<sup>1</sup>Senior Resident of Internal Medicine, Khartoum, Sudan

<sup>2</sup>Omer Eladil Abdalla Hamid, Department of Neurology, Bashayir University Hospital, Khartoum, Sudan

\***Address for Correspondence:** Meysoon Adil Abdelrahman Elagib, Khartoum, Sudan,  
E-mail: meysoonelagib@gmail.com

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## ABSTRACT

**Background:** Health-related Quality of Life (HrQoL) refers to the health dimension of quality of life and is the dimension that is of most interest to clinicians because it provides an insight into how individuals perceive a disease, such as Idiopathic Parkinson's disease, to impact on their lives, it is considered an important outcome measure in studies involving patients with chronic diseases. The aim of this study was to evaluate the HrQoL of Sudanese patients with Parkinson's disease with a view to identify its different determinants.

**Methods:** In this study, a total of 34 subjects with Idiopathic Parkinson's disease were recruited, the study was conducted in neurology outpatient clinics of three allocated neuroscience centers in Khartoum during a period from January 2018-August 2018, a quantitative cross-sectional study design was used to investigate the HrQoL using a patient assessment form that defines the socio-demographic data of each participant in addition to a generic quality of life questionnaire (SF-36) as a data collecting instruments.

**Results:** According to our model, the participants showed a total SF-36 score representing reasonable HrQoL ( $53.1 \pm 17.7$ ). Among the SF-36 eight domains subscores, role limitation due to physical problems was the predominantly affected domain ( $25 \pm 35.3$ ) compared to higher score in the mental health component ( $72 \pm 14$ ). Female gender showed significant impact on quality of life ( $p = 0.02$ ). Other factors showed an indirect correlation through effect on specific domains; namely, the level of education on mental health component ( $p = 0.04$ ), the occupational status on the physical functioning domain ( $p = 0.007$ ), and the duration of the disease on the general health perception ( $p = 0.006$ ). The study negated the effect of age on HrQoL ( $p = 0.41$ ).

**Conclusion:** Early recognition of the extent to which socio-demographic factors influence quality of life may help to minimize the burden of the disease and improve the treatment strategy.

**Keywords:** Idiopathic Parkinson's disease; Parkinson's disease; Health-related quality of life; Sudanese patients

## ABBREVIATIONS

IPD: Idiopathic Parkinson's Disease; PD: Parkinson's Disease; HrQoL: Health-related Quality of Life; HTN: Hypertension; DM: Diabetes Mellitus; RF: Renal Failure; SF-36: Short Form Health Survey-6 items; ADL: Activity of Daily Living; PDQ-39: Parkinson's Disease Questionnaire-39 items

## INTRODUCTION

Idiopathic Parkinson's Disease (IPD) is a chronic and progressive neurodegenerative condition with no known cure. It affects approximately 1-2 % of people over the age of 60 years and about 3-5 % of those 80 years and older [1]. IPD where manifested by motor and non-motor features is the result of the loss of dopamine-producing brain cells [2].

The complex of motor and non-motor symptoms in addition to individual living factors eg., rural vs. metropolitan has a significant impact not only on patients but also on their spouses and partners. As the disease progresses, both the individuals with PD and their spouses/partners often undergo the difficult challenge of adapting to the disruptions in family roles, loss of employment, stigmatization, coping with increasing physical and sometimes mental disability, and economic consequences, all of which affect satisfaction with life of both groups [3,4].

This wide spectrum of influences has brought growing attention to focus on these aspects of living and not merely to the physical well-being of the patients.

To date, there have been several studies that have separately evaluated the various influences of the disease's motor and non-motor symptoms on the patients' HrQoL. However, few of them have assessed the contribution of other overlooked factors such as social support, self-esteem, optimism, spirituality, and the economic burden of the disease [5,6]. Furthermore, there is scarcity of studies that evaluate the changes in HrQoL domains with time during further follow-up assessments.

Therefore, Health-related Quality of Life (HrQoL) has been considered as an important outcome indicator for management, care, and progression of IPD [7]. Moreover, increased life expectancy owing to the emergence of new treatment options in IPD addresses

the importance of HrQoL in the follow-up of IPD patients [8]. In Sudan, there's little known about the prevalence of IPD. However, it is predicted to be increasing. There's no published data despite the paramount importance of evaluating HrQoL among adult Sudanese patients. This study may add to the knowledge of movement disorders in Sudan by addressing the issue of IPD through the exploration of HrQoL profile among adult Sudanese patients.

## MATERIALS AND METHODS

### Study design

A descriptive, cross-sectional, clinic-based multicenter research study. The study was conducted in three neuroscience centers in Khartoum city, namely, Ibrahim Malik neuroscience center, Bashayir University Hospital and Soba University Hospital. The study covered a period of eight months from January 2018-August 2018. A total of 34 patients were recruited for the study comprising all patients with Idiopathic Parkinson's disease attending the neurology outpatient clinics during the study period.

### Inclusion criteria

- A diagnosis of IPD that was made by a neurologist.
- Age > 18 yrs.
- Duration of the disease > 1 yr.

### Exclusion criteria

- Vascular Parkinson or Parkinson's plus syndrome.
- Other uncontrolled co-morbidities e.g. HTN, DM, RF, hepatic failure, etc.
- Patients diagnosed with psychiatric illness prior to IPD diagnosis.
- Patients who refuse to participate in the study.

### Description of the data collection tools

The study used two types of assessment forms both are in Arabic language. The data collectors were acquainted to the terminologies of each form.

A patient assessment form was completed for each participant. The form includes non-modifiable variables such as the age, gender,



and the level of education. In addition to the occupational status, disease duration and list of the drugs prescribed for the disease.

A health-related quality of life questionnaire was completed for each participant; the instrument used is the Medical outcome study 36-items Short Form health survey (SF-36). The Arabic version was used in this study.

The participants were interviewed in the outpatient clinics upon their attendance for follow up, other participants were interviewed later through the phone.

**Data analysis**

The collected data was analyzed using Statistical Package for the Social Sciences Software (SPSS) version 21. ANOVA test was used to assess the correlation between the HrQoL and the independent variables. Significance was set at  $p < 0.05$ . The results are represented in form of tables and figures.

**RESULTS**

The sample consisted of 34 patients who fulfilled the inclusion criteria for the study. The age ranges from a minimum of 31 to more than 60 years, 58.8% of the participants were of more than 60 years of age (Table 1).

The studied group showed a predominance of male gender (24 patients, 70.6%) and 10 females (29.4%). The age difference between the genders as follows: seven of the females (70%) were in the age range of 31-60 years compared to 7 males (29.2%). While 70.8% of the males (17 patients) were of more than 60 years of age compared to only three females (30%) (Figure 1).

As with regards to the educational level of the subjects, 11 patients (32.4%) had formal education at schools, 10 patients (29.4%) had non-formal education at Khalowa, 7 patients (20.6%) were illiterate, and only six patients out of 34 (17.6%) were university graduates. The variation in the educational level across genders is explained (Figure 2).

Of the 34 patients studied, only seven patients (20.6%) were still working and able to carry on their regular occupations. While in a predominance of 11 patients (32.4%) they had to stop working or changed their occupation because of the disease (Table 2).

Regarding the duration of the disease, it was two to four years in 17 patients (50%), five to ten years in nine patients (26.5%), while in eight patients (23.5%) the duration of the disease was more than 10 years. Figure 3 shows the distribution of disease durations among the genders.

Only five patients (14.7%) were on monotherapy with Levodopa, the rest of the 29 patients (85.3%) were receiving both Levodopa and antimuscarinic treatment for the disease.

Concerning the summary score of the health-related quality of life questionnaire (SF-36), the total SF-36 scores of the study group ranged from 12.9 to 87.5 with a mean value of  $(53.1 \pm 17.7)$ . The summary scores for each eight domains of the SF-36 were calculated as well for each participant. The mean summary scores of the eight SF-36 domains are tabulated (Table 3). Lowest mean value (worse outcome) was in the domain of role limitation due to physical health problems  $(25 \pm 35.3)$ , while it was highest at the domain of mental health  $(72 \pm 14)$  indicating better outcome. It is worth mentioning that the SF-36 scale provides a score range from 0-100 with high scores

**Table 1:** Age distribution of sample.

Age group	Frequency	Percent
31 up to 40	1	2.9
41 up to 50	5	14.7
51 up to 60	8	23.5
More than 60 years	20	58.8
Total	34	100

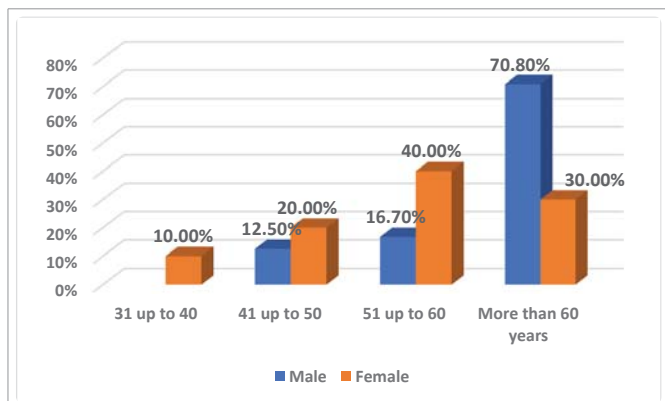


Figure 1: Age distribution among the genders.

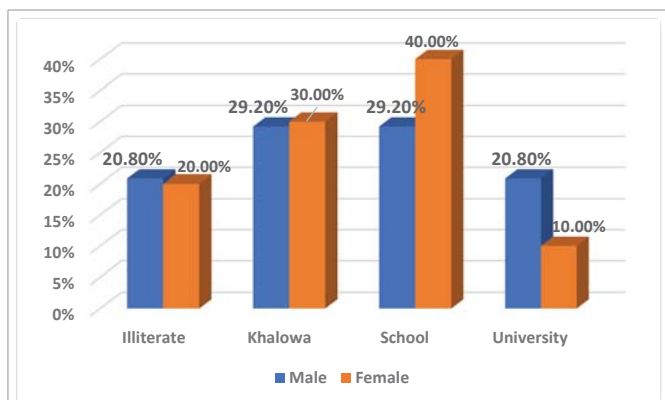


Figure 2: The variation in the educational level across the genders.

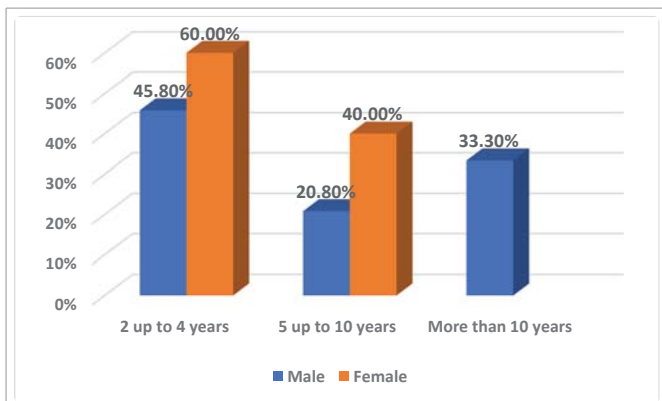
indicating better outcome and vice versa; but it does not provide any cut off values to stratify the score into categorized good or poor outcomes, nevertheless, in the reviewed literature of this study; the summary index score of either the disease specific measures or the generic SF-36 was tested in an univariate or multivariate regression analysis, in addition to prediction tests. However, in our study and because of the small sample size these statistical tests are inapplicable. Instead, to describe the HrQoL status of our study sample we thought to improvise a construct of stratification method to categorize the studied patients into four groups based on their total SF-36 summary scores: very poor, poor, reasonable, and good. Table 4 summarizes the arbitrary of the quality of life status based on the total SF-36 score. According to this construct, the mean value of the total SF-36 score  $(53.1 \pm 17.7)$  categorizes our study group as having (Reasonable) health-related quality of life status.

Among the participants, the physical functioning domain subscores were ranging from 0-90, three patients (8.8%) scored zero,



**Table 2:** The occupational status among the studied patients.

Occupation	Frequency	Percent
Working	7	20.6
Changed or Stop working due to health situation	11	32.4
Retired	6	17.6
Not working	3	8.8
House wife	7	20.6
Total	34	100



**Figure 3:** Distribution of disease durations among the genders.

five patients (14.7%) scored 55, four patients (11.8%) scored 60, and two patients (5.9%) are those who scored 90 in this domain subscale.

In the domain of role limitation due to physical health problems, 19 patients of the 34 patients studied (55.9%) scored zero out of 100 in this domain, followed by six patients (17.6%) scoring 25, four patients (11.8%) scored 100, three patients (8.8%) scored 50, and only two patients (5.9%) had a score of 75.

Whereas in the domain of role limitation due to emotional

problem, 41% of the patients studied had a score of 100, while (38.2%) of patients scored 0, (11.8%) scored 67, and (8.8%) had a score of 33.

Regarding the domain of vitality, the scores ranged from 15-90. Of the 34 subjects, only one patient (2.9%) did score 15, six patients (17.6%) had a score of 45, (14.7%) of the patients scored 30, another (14.7%) of patients had a score of 55, four patients (11.8%) scored 35, (8.8%) of the patients scored 50, while another (8.8%) of patients scored 80, (5.9%) of the participants scored 40, and the highest score 90 was achieved by another (5.9%) of the study subjects.

In the mental health domain, the subscores ranged 44 -92, one patient scored 44, and four patients (11.8%) scored 92, the majority of (23.5%) of the patients studied had a score of 76 in this particular domain.

As for the social functioning domain, the subscores ranged from 0-100, four patients (11.7%) scored less than 20, two patients (5.9%) scored 38, eight patients (23.5%) scored 50, six patients (17.6%) scored 63, five patients (14.7%) scored 75, four patients (11.8%) scored 88, and three patients (8.8%) scored 100.

Regarding the domain of the bodily pain, the total subscores ranged from 0-100. Eight patients (23.5%) had a subscore of less than 40, nine patients (26.4%) had subscores range 41-60, nine patients (26.4%) had a score range of 63-90, while eight patients (23.5%) had a subscore of 100.

Concerning the subscores of the general health perception domain, the range found was 5-100, two patients (5.8%) had a score less than 30, 16 patients (47.2%) scores ranged from 31-60, seven patients (20.6%) scored 65, four patients (11.8%) scored 70, and five patients (14.6%) their scores ranged from 75-100.

In order to identify the determinants of HrQoL, the correlation is tested between the independent variables and the mean value of total SF-36 score. However, the test also detected statistically significant correlations when using the mean scores of each eight domains of the SF-36.

**Table 3:** The mean summary scores of the total SF-36 score and the eight domains subscores.

		Physical functioning	Role limitation due to physical health problems	Role limitation due to emotional problems	Vitality	Mental health	Social functioning	Bodily pain	General health perception	Total SF - 36 score
N	Valid	34	34	34	34	34	34	34	34	34
	Missing	0	0	0	0	0	0	0	0	0
Mean		46.912	25.000	51.971	50.147	72.000	57.941	64.588	56.765	53.129
Std. Deviation		23.8052	35.3553	45.8558	18.6874	14.0992	26.6378	29.4866	17.7475	17.7581
Minimum		.0	.0	.0	15.0	44.0	.0	.0	5.0	12.9
Maximum		90.0	100.0	100.0	90.0	92.0	100.0	100.0	100.0	87.5

(SF-36: Short form health survey-s36 items, Std.Deviation: Standard Deviation)

**Table 4:** Distribution of HrQoL status among study sample.

HrQoL status /total SF-36 score	Frequency	Percent
Very poor ( Less than 25)	1	2.9%
Poor (25 up to 49)	14	41.2%
Reasonable (50 up to 74)	15	44.1%
Good ( more than 75)	4	11.8%

(HrQoL: Health-related Quality of Life, SF-36: Short Form health survey-36 items)



In this study, age was not found to be of statistical significance in correlation with the mean of total SF-36 score ( $p = 0.41$ ), or with the calculated mean of any of the eight domains (Table 5).

On the other hand, gender showed a significant correlation with the total SF-36 score ( $p = 0.02$ ), high mean value found in male gender  $57.5 \pm 16.6$  versus  $42.6 \pm 16.4$  in females. Across the eight domains, the

gender was found to be of significant association with the mean scores in both of the physical functioning ( $p = 0.001$ ) and social functioning ( $p = 0.04$ ) domains (Table 6). As for the physical functioning, the total mean of  $46.9 \pm 23.8$  was found, with  $55.2 \pm 20.4$  for males versus  $27 \pm 19.6$  for females. While regarding the social functioning, the total mean was  $57.9 \pm 26.6$  with lower value representing the females  $42.8 \pm 28.3$  compared to  $64.2 \pm 23.7$  for males.

**Table 5:** Differences in Health-related Quality Of Life (HrQoL) among age groups.

Age group		Physical functioning	Role limitation due to physical health problems	Role limitation due to emotional problems	Vitality	Mental health	Social functioning	Bodily pain	General health perception	Total SF - 36 score
31 up to 40	N	1	1	1	1	1	1	1	1	1
	Mean	10.000	.000	.000	40.000	76.000	13.000	10.000	55.000	25.500
	Std. Deviation	.	.	.	.	.	.	.	.	.
41 up to 50	N	5	5	5	5	5	5	5	5	5
	Mean	52.000	35.000	73.400	42.000	71.200	65.200	76.200	57.000	58.960
	Std. Deviation	20.1866	28.5044	43.4488	7.5829	4.3818	16.4530	18.4445	12.5499	9.2746
51 up to 60	N	8	8	8	8	8	8	8	8	8
	Mean	53.750	37.500	50.000	57.500	65.000	47.125	60.125	58.125	53.600
	Std. Deviation	21.8354	44.3203	47.1744	20.5287	19.5667	31.1331	30.8982	15.7973	22.7075
More than 60 years	N	20	20	20	20	20	20	20	20	20
	Mean	44.750	18.750	50.000	49.750	74.800	62.700	66.200	56.250	52.865
	Std. Deviation	24.8932	33.3196	46.5414	19.8332	13.0489	25.0013	29.7208	20.5116	17.0396
Total	N	34	34	34	34	34	34	34	34	34
	Mean	46.912	25.000	51.971	50.147	72.000	57.941	64.588	56.765	53.129
	Std. Deviation	23.8052	35.3553	45.8558	18.6874	14.0992	26.6378	29.4866	17.7475	17.7581
<i>p</i> value		0.337 Not sig	0.489 Not sig	0.507 Not sig	0.49 Not sig	0.43 Not sig	0.158 Not sig	0.22 Not sig	0.9 Not sig	0.41 Not sig

(HrQoL: Health-related Quality of Life, SF-36: Short Form health survey-36 items, Std. Deviation: Standard Deviation, Sig: Significant)

**Table 6:** Differences in Health-related quality of life (HrQoL) among gender.

Gender		Physical functioning	Role limitation due to physical health problems	Role limitation due to emotional problems	Vitality	Mental health	Social functioning	Bodily pain	General health perception	Total SF - 36 score
Male	N	24	24	24	24	24	24	24	24	24
	Mean	55.208	27.083	58.333	52.500	73.833	64.250	69.958	59.167	57.508
	Std. Deviation	20.4556	38.2474	44.2657	19.7264	14.1042	23.7033	27.1605	15.5806	16.6798
Female	N	10	10	10	10	10	10	10	10	10
	Mean	27.000	20.000	36.700	44.500	67.600	42.800	51.700	51.000	42.620
	Std. Deviation	19.6073	28.3823	48.3277	15.3569	13.7857	28.3737	32.2699	21.9596	16.4754
Total	N	34	34	34	34	34	34	34	34	34
	Mean	46.912	25.000	51.971	50.147	72.000	57.941	64.588	56.765	53.129
	Std. Deviation	23.8052	35.3553	45.8558	18.6874	14.0992	26.6378	29.4866	17.7475	17.7581
<i>p</i> value		0.001 significant	0.60 Not significant	0.215 Not significant	0.26 Not significant	0.24 Not significant	0.03 significant	0.10 Not significant	0.22 Not significant	0.02 significant

(HrQoL: Health-related Quality of Life, Std. Deviation: Standard Deviation, SF-36: Short Form health survey-36 items)

The level of education has also shown a significant correlation with the mental health domain of the SF-36 ( $p = 0.04$ , Mean =  $72 \pm 14$ ), the highest mean was found in those who were non-formally educated at Khalowa  $81.2 \pm 10.1$ , and the lowest was in the category of school education  $64 \pm 15.4$ . Though the educational levels were not shown to be contributory when correlation was tested to the total SF-36 score ( $p = 0.82$ ) (Table 7).

As for the occupational status, this was found to be only contributing to the physical functioning domain of the SF-36 scale ( $46.9 \pm 23.8$ ,  $p = 0.007$ ) compared to the total SF-36 score ( $53.1 \pm 17.7$ ,  $p = 0.54$ ). In this category, the range of the mean was highest for patients who are still working ( $65.7 \pm 16.1$ ) and lowest for the housewife category ( $25.7 \pm 16.4$ ) (Table 8).

The duration of the disease was also correlated with changes in the domain of general health perception ( $56.7 \pm 17.7$ ,  $p = 0.006$ ) compared to the total SF-36 score ( $p = 0.36$ ), the range of the mean was  $45 \pm 17.5-71.2 \pm 14$  being the highest at patients who suffer for more than 10 years, and lowest at those whom durations ranged at 5-10 years (Table 9).

## DISCUSSION

This study is the first study in our country that evaluates Health-related Quality of Life (HrQoL) as an outcome in patients with chronic illness, specifically those with neurodegenerative disorders. Our primary objective was to evaluate the HrQoL profile of the studied patients, and the secondary objectives were to identify the different determinants and assessment of the burden of each. In this study, we thought to evaluate the HrQoL by using the generic SF-36 scale as it

is more relevant to the activities of day-to-day life; moreover it can also provide results comparable to HrQoL of the general population or other patients with different chronic illnesses.

From the socio-demographic characteristics of the studied patients, the majority of patients were of more than 60 years of age and the duration of the disease since diagnosis is 2-4 years 58.8% and 50% respectively. In this study, age did not contribute to any significant changes in HrQoL which is in keeping with the findings of some previous studies [9-12] even though these studies used different HrQoL measures. The smaller sample size and the predominance of older age groups in this study may have limited the chances to detect significant changes between different age groups. On the other hand, the disproportion between the advancing age and the duration of disease may highlight a possibility of delayed diagnosis for reasons that include limited access to health services or due to previous misdiagnosis.

Our study showed that the disease duration did not contribute directly to HrQoL, but rather indirectly through the domain of general health perception which was surprisingly worse in patients with duration of 5-10 years and better in those who suffer for more than 10 years; this is probably because patients of more prolonged disease duration may have developed better coping strategies and thence a reasonably better general health perception. Previously published evidence shows conflicting results on this issue [12,13] where the summary indices of the used HrQoL scales were in direct association with disease duration.

In concordance with other researches [7,14], our data revealed that gender affirms a significant correlation with poor HrQoL total

**Table 7:** Differences in Health-related quality of life (HrQoL) with the level of education.

Educational level		Physical functioning	Role limitation due to physical health problems	Role limitation due to emotional problems	Vitality	Mental health	Social functioning	Bodily pain	General health perception	Total SF - 36 score
Illiterate	N	7	7	7	7	7	7	7	7	7
	Mean	42.143	14.286	61.857	50.000	72.571	50.143	72.000	63.571	53.271
	Std. Deviation	21.1851	19.6699	48.8277	12.2474	10.4380	26.0220	24.0624	8.5217	14.2593
Khalowa	N	10	10	10	10	10	10	10	10	10
	Mean	42.500	17.500	40.000	55.000	81.200	59.000	63.300	51.000	51.160
	Std. Deviation	26.6927	31.2916	46.6405	20.6828	10.1631	20.4396	29.7398	19.9722	16.2303
School	N	11	11	11	11	11	11	11	11	11
	Mean	44.091	34.091	45.455	46.364	64.000	58.182	60.091	59.091	51.391
	Std. Deviation	25.2802	45.1009	47.8024	20.2597	15.4919	36.3093	37.2866	19.9773	22.3307
University	N	6	6	6	6	6	6	6	6	6
	Mean	65.000	33.333	72.333	49.167	70.667	64.833	66.333	54.167	59.433
	Std. Deviation	12.6491	37.6386	38.9495	21.3112	14.2361	18.3675	23.2952	18.0046	17.4275
Total	N	34	34	34	34	34	34	34	34	34
	Mean	46.912	25.000	51.971	50.147	72.000	57.941	64.588	56.765	53.129
	Std. Deviation	23.8052	35.3553	45.8558	18.6874	14.0992	26.6378	29.4866	17.7475	17.7581
<i>p</i> value		0.24 Not significant	0.56 Not significant	0.51 Not significant	0.78 Not significant	0.04 significant	0.812 Not significant	0.87 Not significant	0.51 Not significant	0.82 Not significant

(HrQoL: Health-related Quality of Life, SF-36: Short Form health survey-36 items, Std. Deviation: Standard Deviation)



**Table 8:** Differences in Health-related quality of life (HrQoL) with the occupational status.

Occupation		Physical functioning	Role limitation due to physical health problems	Role limitation due to emotional problems	Vitality	Mental health	Social functioning	Bodily pain	General health perception	Total SF - 36 score
Working	N	7	7	7	7	7	7	7	7	7
	Mean	65.714	35.714	57.143	50.714	69.143	66.143	70.143	55.714	58.771
	Std. Deviation	16.1835	40.4587	46.0450	24.3975	12.7988	21.1930	25.7645	22.4404	15.2620
Changed or Stop working due to health situation	N	11	11	11	11	11	11	11	11	11
	Mean	50.000	13.636	54.545	53.182	72.364	61.545	72.000	57.273	54.273
	Std. Deviation	15.6525	30.3390	47.8024	15.2106	12.5799	26.9902	29.6682	13.1079	14.0534
Retired	N	6	6	6	6	6	6	6	6	6
	Mean	53.333	37.500	44.500	64.167	81.333	60.833	66.000	53.333	57.583
	Std. Deviation	30.1109	49.3710	50.2145	17.7247	18.1842	16.6783	23.9666	27.1416	21.5155
Not working	N	3	3	3	3	3	3	3	3	3
	Mean	28.333	8.333	44.333	35.000	70.667	46.000	52.667	55.000	42.533
	Std. Deviation	27.5379	14.4338	50.9542	20.0000	20.5264	44.1362	50.2129	15.0000	29.1147
House wife	N	7	7	7	7	7	7	7	7	7
	Mean	25.714	28.571	52.429	39.286	66.857	46.714	51.286	60.714	46.414
	Std. Deviation	16.4389	30.3746	50.4112	8.8641	11.0065	32.0817	30.2639	14.8404	18.3276
Total	N	34	34	34	34	34	34	34	34	34
	Mean	46.912	25.000	51.971	50.147	72.000	57.941	64.588	56.765	53.129
	Std. Deviation	23.8052	35.3553	45.8558	18.6874	14.0992	26.6378	29.4866	17.7475	17.7581
P value		0.007 significant	0.53 Not sig	0.98 Not sig	0.08 Not sig	0.44 Not sig	0.622 Not sig	0.60 Not sig	0.96 Not sig	0.54 Not sig

(HrQoL: Health-related Quality of Life, SF-36: Short Form health survey-36 items, Std. Deviation: Standard Deviation, Sig: Significant)

**Table 9:** Differences in Health-related quality of life (HrQoL) with the disease duration.

Duration of disease		Physical functioning	Role limitation due to physical health problems	Role limitation due to emotional problems	Vitality	Mental health	Social functioning	Bodily pain	General health perception	Total SF - 36 score
2 up to 4 years	N	17	17	17	17	17	17	17	17	17
	Mean	44.118	26.471	60.824	44.412	67.765	53.118	66.294	56.176	52.365
	Std. Deviation	22.5856	35.8715	44.4863	17.3099	14.4548	30.7447	34.6298	15.0550	19.3300
5 up to 10 years	N	9	9	9	9	9	9	9	9	9
	Mean	45.000	16.667	33.333	58.889	71.556	55.778	59.111	45.000	48.122
	Std. Deviation	27.9508	27.9508	50.0000	18.6711	14.7573	22.5709	26.1699	17.5000	16.4253
More than 10 years	N	8	8	8	8	8	8	8	8	8
	Mean	55.000	31.250	54.125	52.500	81.500	70.625	67.125	71.250	60.388
	Std. Deviation	22.6779	43.8137	43.4756	19.4569	7.9821	18.8675	22.8501	14.0789	15.1792
Total	N	34	34	34	34	34	34	34	34	34
	Mean	46.912	25.000	51.971	50.147	72.000	57.941	64.588	56.765	53.129
	Std. Deviation	23.8052	35.3553	45.8558	18.6874	14.0992	26.6378	29.4866	17.7475	17.7581
p value		0.55 Not significant	0.69 Not significant	0.35 Not significant	0.16 Not significant	0.07 Not significant	0.30 Not significant	0.81 Not significant	0.006 Significant	0.36 Not significant

(HrQoL: Health-related Quality of Life, SF-36: Short Form health survey-36 items, Std. Deviation: Standard Deviation)



score especially being worse in females. Although it is believed that the worse quality of life in women with a chronic disease is generally resulted from the higher burden of depression and anxiety [7]. However, not all the eight domains of SF-36 were similarly affected; our report shows that female gender has significant effect on both physical functioning and social functioning domains summary scores. This selective impact on specific quality of life areas raises concerns on whether female patients are more prone to lack of social support and social isolation compared to male patients, or whether this is due to more interpersonal factors such as low self-esteem or stigma. In contrast to the reported finding in previous studies [15,16] pain was not significantly prevalent in women nor did it show any direct effect on HrQoL, whereas this result was in line with other researches [17,18] where a history of pain did not condition a significant differences in quality of life scores.

From the reviewed literature for this study, several studies had identified the level of education as one of the personal factors to have an impact on quality of life; poor outcomes were correlated with lower levels of education. However, our findings failed to point out this direct relationship; rather it showed only an indirect effect on HrQoL through the mental health domain ( $p = 0.04$ ). Interestingly, our results have shown higher mean scores in patients with lower level of education which represent better mental health (Khalowa  $81.2 \pm 10.1$ , and illiterates  $72.5 \pm 10.4$ ), it is thought this could be in fact a reflection of their limited expectations of life where their needs are not very high.

As the disease advances, one of the difficult challenges that IPD patients suffer is to maintain their usual lifestyles, independence, and the support system they provide their families with. The occupational status has been one of these challenging sides. Our study has successfully addressed this aspect by identifying a significant correlation with the physical functioning domain of the SF-36 ( $p = 0.007$ ), also the results showed a predominant frequency of patients who changed or quit their occupations due to the disease (32.4% of the participants) which is in agreement with the evidence published by Winter Y, et al. [13] in a cross-sectional study evaluating HrQoL of 100 IPD patients matched with 100 controls, the study revealed that among 19 prematurely retired patients, 10 (52.6%) were prematurely retired due to PD. These findings emphasize the role of occupational therapy in the multidisciplinary treatment strategy for IPD patients.

In our study role limitation due to physical health problems was the dominantly affected area of HrQoL with worst subscore, and consequently identified as an independent determinant. This evidence reflects the daily challenges the patients face especially in those who suffer from increasing physical disabilities, also it supports the reported correlation between the physical component of the generic SF-36 and the domain of mobility and Activity of Daily Living (ADL) in the disease-specific PDQ-39 scale as concluded by Xiao-Jing and colleagues [9]. Moreover, our result represents accordance with the findings from several literatures in this study [11,12,18,19] where the ADL profile was one of the factors predicted poor quality of life in the studied groups.

Although we adopted a quantitative construct for this study, during the interviews the participants had discussed wide ranges of difficulties and daily challenges they suffer because of the disease. This should raise interest in using combined methods of qualitative and quantitative constructs when addressing HrQoL in further studies.

## LIMITATIONS

The authors acknowledge the limitations and drawbacks of this study which are summarized in the following points:

- The study did not take into consideration the medications side effects and their possible impact on HrQoL.
- In the majority of cases, the questionnaire was difficult to be filled by the patients themselves due to either interfering disabilities, or the low level of education that necessitates assistance for clarification; this might have influenced the answers for some study subjects.
- The allocated centers of the study had no disease registry system for IPD; also, most of the patients are usually given appointments for follow-up in long time intervals up to three months; this resulted in the scarcity of study participants.
- Because of the concurrent economic crisis and severe shortage of medication supplies in the country market; most of the participants either were off their anti-parkinsonian treatments or had interrupted their regular dosage for at least a month. This was somewhat confounding, as it had resulted in worsening symptoms and ultimately deterioration in quality of life.
- Finally, the cross-sectional design of our study does not provide any information on changes in HrQoL with disease progression.

## CONCLUSION

The study concluded that Sudanese patients with idiopathic Parkinson's disease have relatively reasonable health-related quality of life. However, according to our model the difference is very little in the percentage of subjects between the two groups of reasonable and the poor (44.1% and 41.2%) respectively, this can be considered alarming; and in terms of practice it predicts an inevitable deterioration in HrQoL if no proper interventions are taken in the treatment strategy. Although it was also highlighted that some areas of the quality of life were more affected which is comparable to the findings from previous studies. The socio-demographic factors did have major contribution to the changes in HrQoL either directly or indirectly through an impact on specific quality of life domains; the complexity of this contribution provides an interesting area for further specified researches. Early recognition of the extent to which socio-demographic factors influence quality of life may help to minimize the burden of the disease and improve the treatment strategy.

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