

Relationship between Caregiving Burden and Health Status of Elderly Patients with Parkinson's Disease

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Abstract:

Background: Parkinson's disease is a neurodegenerative disorder that increases with age. It imposes an important burden upon the patient's caregiver as a result of deterioration in health status of elderly patients. **Aim:** Determine the relationship between caregiving burden and health status of elderly patients with Parkinson's disease. **Method:** Descriptive correlational research design was used in this study. This study was conducted in the neurological outpatient clinic at Mansoura University Hospital. A purposive sample of 75 elderly patients with Parkinson's disease and their family caregivers were enrolled in the study. Data was collected using; demographic and clinical data structured interview sheet, Parkinson's disease Questionnaire, and zarit burden interview. **Results:** The mean score of patients' health status was 44.34 ± 13.14 , mobility had the highest mean score (67.33 ± 23.08) indicating a high level of problem. Sixty percent and 28% of the studied caregivers had mild and moderate level of burden respectively. In addition, a strong positive correlation was found between elderly health status and their caregivers' burden. **Conclusion:** This study reflects that; caregivers' burden was common among the informal caregivers who care for elderly patients with Parkinson disease. Also, caregiving burden was strongly associated with patients' health status. **Recommendation:** Develop a guideline to help family caregivers of patients with Parkinson's diseases to care for their patients at home. This will help them to cope with the burden of caring and manage stress associated with it.

Keywords: Caregiving burden, Health status, Elderly patients, Parkinson's disease.

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I. Introduction

Parkinson's disease (PD) is the second most important age-related neurodegenerative disorder after Alzheimer disease¹. PD was originally described by James Parkinson's in 1817 as "An Essay on the shaking palsy"². Moreover, aging is characterized by progressive decline of many physiological functions that increased susceptibility to certain disease³. In Parkinson's disease age-related genetic changes in the substantia nigra due to an accumulation of deletions of mitochondrial DNA in ageing with functional impairment of neurons, these deletions are also prevalent in PD and affect the functioning of neurons⁴. This is resulting in diminished dopamine production and leads to motor disturbance which is characterized by tremors, rigidity, bradykinesia, and postural instability^{5,6}. Also, neurological damage can contribute to a variety of non-motor symptoms as autonomic dysfunction, sensory symptoms, neuropsychiatric disturbances, sleep problems, fatigue, and gastrointestinal disorders⁷.

Worldwide, incidence estimates of Parkinson disease range from 5 to > 35 new cases per 100,000 individuals every year. PD is estimated to increase by more than 50% by 2030^{8,9}. The incidence and prevalence of PD increase with age and most people diagnosed with Parkinson's are in their sixties. PD affects approximately 7-10 million people around the globe and more than 1 million individuals in the USA^{10,11}. In a previous Egyptian study, the crude incidence of PD was 84 per 100,000 person/year. Men are 1.5 times more prone to PD than women^{12,13}.

Elderly patients with Parkinson's disease are particularly vulnerable to deterioration of health status resulting from significant motor disability and the burden of non-motor symptoms¹⁴. These symptoms intensify as the disease progresses and can significantly limit the patient's ability to take part in activities of daily living and participate in social and recreational interests thereby adversely affecting health status¹⁰. Elderly with long-term progressive neurological disorders such as Parkinson's disease may be in great need of assistance¹⁵. As

they often require caregiver assistance for daily activities, personal safety, medication compliance, and social involvement, with a consequent impact on caregiver burden¹⁶.

Most Parkinson disease elderly patients are cared for in their own home and spouses are the main informal caregivers¹⁶. The role of the main caregiver, usually a family member, becomes progressively more important with the disease progression. Therefore, family members take upon themselves the considerable responsibilities, stress associated with providing adequate care and supervision for their older relatives¹⁷. Informal caregivers of individuals with Parkinson's disease face notable challenges that tend to accumulate with disease progression. As well, caregivers commonly experience financial and emotional burden, competing responsibilities, role overload, stress, constraints to their own self-care, perceived lack of appreciation and support, and physical strain. As a result of these stressors, caregivers are vulnerable to decreased health-related quality of life¹⁸.

Caregivers have to deal with stress and coping personally along with older adult patients. Nurses and other health care professional need to encourage caregivers to adopt a healthy lifestyle to maintain their own physical and psychological wellbeing¹⁷. To support caregivers in this role, it is necessary to understand the fact of caregiver burden and factors associated with increased burden and distress among caregivers. Hence, the relation between caregiving burden and health status of elderly patients with Parkinson's diseases should be investigated.

Aim of the study:

Determine the relationship between caregiving burden and health status of elderly patients with Parkinson's disease.

This aim was achieved through the following steps:

1. Assess the health status of elderly patients with Parkinson disease.
2. Assess caregiving burden of the family caregivers caring for elderly patients with Parkinson disease.
3. Investigate the type of relation between caregiving burden and health status of elderly patients with Parkinson disease.

Research question:

What is the type of relationship between caregiving burden and health status of elderly patients with Parkinson's disease?

II. Subjects and Method

Design: The study followed a descriptive correlational research design.

Setting: The study was conducted in the neurological outpatient clinic at Mansoura University Hospital. This outpatient clinic worked every Wednesday and was called movement disorders outpatient clinic. The clinic received approximately 8 patients every day, providing medical checkup and health teaching to elderly patients.

Subjects: The study included 75 elderly patients diagnosed with Parkinson's disease and their family caregivers attending the study setting within a period of six months. Elderly patients were selected according to certain characteristics; aged 60 year and more, able to communicate, accept to participate in the study, and available at the selected setting during the period of data collection. The elderly caregivers aged 18 year and more, responsible for providing direct care for the elderly patients, able to communicate, and accept to participate in the study were included in the study. The sample size was estimated through DSS research.com, sample size calculator software, at 5% α error and 20% β error (80% power of the study), assuming percentage of suffered health among caregivers is (40.0%)¹⁹. It is expected to increase in our community from 10.0 to 15.0%. The calculated sample size is 67 and we can add 10.0% for better quality of collected data, so the field sample was 75.

Tools: Three tools were used in the study to collect the necessary data.

Tool I: Demographic and clinical data structured interview sheet

This tool was developed by the researchers after review of the relevant literature and included 2 parts:

Part I: Elderly patient's demographic and clinical data as follow:

- a) Demographic characteristics of elderly patients such as age, sex, social status, level of education, residence, living condition, and income.
- b) Clinical data such as duration, stages, symptoms of the disease, and family history. The stages of the disease were categorized according **Hoehn and Yahr scale** (1967)²⁰. It is a widely used clinical rating scale which defines broad categories of motor function in PD in form of 5 points of increasing progression (1: Only unilateral involvement, usually with minimal or no functional disability, 2: Bilateral or midline involvement without impairment of balance, 3: Bilateral disease means mild to moderate disability with

impaired postural reflexes; physically independent, 4: Severely disabling disease; still able to walk or stand unassisted, and finally 5: Confinement to bed or wheelchair unless aided. Presence of other chronic diseases was also assessed.

Part II: Caregivers' demographic and clinical data such as age, sex, social status, level of education, work, presence of chronic diseases, and other caregiving properties.

Tool II: Parkinson's Disease Questionnaire (PDQ-39)

This tool was developed by **Jenkinson et al., (1997)**²¹. It is a disease specific measure of health status that measuring the impact of PD on health status by 39 items (ranged from 0=never to 4=always) in eight important areas of health status including; mobility, activities of daily living, emotional well-being, stigma, social support, cognitions, communication, and bodily discomfort. Following patients' response, a summary index for each dimension was calculated by dividing the sum of patient's responses of the included items by the maximum possible score then multiplying by 100. So, each dimension score ranging between 0 (no problems) to 100 (more health problems). The total score was calculated by summation of the eight dimensions' scores divided by 8.

Tool III: Zarit Burden Interview (ZBI)

This tool was developed by **Zarit, et al (1980)**²². It was used to assess the caregiving burden experienced by the family caregivers of elderly patients through 22 items that measuring the impact of the patient's disabilities on caregiver's physical and emotional health, as well as its repercussions on social and financial aspects. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). This tool was translated into Arabic language by **Ali, (2015)**²³, and reliability was assured by Spearman's correlation coefficient ($r=0.85$). This interview is scored by summing the responses of the individual items (range: 0–88). A higher score indicates greater caregiver burden. The total scoring key as follow; 0 to 20 = little or no burden, 21 to 40 = mild to moderate burden, 41 to 60 = moderate to severe burden, 61 to 88 = severe burden.

Method

1. Official permission was issued from the responsible authorities of Faculty of Nursing, Mansoura University.
2. Permission to conduct the study was obtained from the director of the hospital after being informed about the purpose of the study and the time of data collection.
3. The study tool I (Demographic and clinical data structured interview sheet) was developed by the researchers after reviewing the relevant literatures.
4. Tool II (Parkinson's Disease Questionnaire PDQ-39) was translated into Arabic by the researchers. Back translation was used by an expert in English language from Faculty of Education, English Department, Mansoura University to ensure the validity of tool translation.
5. The study tools were tested for content validity by five experts in the related fields of the study and the required modifications were done accordingly.
6. Reliability of tool II was tested by determining the extent to which PDQ-39 scores were stable over repeated uses. It was assured by means of r coefficient ($r=0.87$).
7. The Arabic version of tool III was used in data collection.
8. A pilot study was conducted on 10% of elderly patients and their family caregivers at the neurological outpatient clinic at Mansoura University Hospital before starting the data collection to ascertain the clarity and applicability of the study tools and the necessary modifications were done. These patients and caregivers were not included in the study sample.
9. Based on the schedule of the neurological outpatient clinic at Mansoura University Hospital, the researchers visited the clinic one day/week (every Wednesday) from 9 am to 12 pm and managed to interview 3-5 elderly patients with their caregivers daily. The time taken to fill the study tools ranged from 30 to 40 minutes.
10. Each study subject was interviewed individually by the researcher to collect the necessary data using all study tools in the waiting room in neurological outpatient clinic.
11. The researchers started the interview by introducing themselves to the elderly patient and family caregiver, giving them a brief idea about the aim of the study.
12. Assessment of each elderly patient was done using tool I (part I) and tool II and assessment of each family caregiver was done using tool I (part II) and tool III.
13. A face to face interview was used with each elderly patient and his/her family caregiver who fulfilled the study criteria.
14. Data collection covered a period of six months from the first of October 2018 till the end of March 2019.

Ethical considerations:

Ethical approval was obtained from Mansoura University, Faculty of Nursing Ethic Committee. Verbal consent was obtained from elderly patients and their caregivers after explanation of the nature of the study. The participants were informed that their participation is voluntary and they can withdraw from the study at any time. Confidentiality and anonymity of the collected data were assured.

Statistical analysis:

Data was analyzed using SPSS (Statistical Package for Social Sciences) version 22. Quantitative variables were presented as number and percent. A descriptive analysis was done in the form of frequencies, mean, and standard deviation. While analytical statistics was done using Independent t –test to compare two groups, and one-way ANOVA test for more than two groups' comparison. Pearson's correlation coefficient was used to quantify association between different variables. $P \leq 0.05$ was considered statistically significant. Graphs were done for data visualization using Microsoft Excel.

III. Results

Table 1 shows that, the age of the studied patients ranged from 60 to 93 years, with a mean age of 68.25 ± 8.47 years. Males constituted 61.3% of the studied patients and 61.3% were married. Illiteracy was prevailing among 70.7% and only 6.6% had a secondary education. Eighty percent of elders were residing in rural areas and 82.7% reported that their income was not enough.

For caregivers, their age ranged from 25 to 66 years with a mean age of 42.81 ± 12.89 years. Females constituted 96.0% and 84.0% were married. Illiteracy was prevailing among 45.3% of them, only 4.0% had university degree, 88.0% were not working, and 72.0% of them didn't suffer from any chronic diseases.

Table 2 demonstrates the distribution of elderly patients with Parkinson's disease according to their medical history. About 42.7% of the studied elderly have Parkinson's disease for less than five years and only 6.7% for more than 20 years. As regard to the stage of the disease, 40.0% of the studied elders were in stage 1 (only unilateral involvement), 22.7% in stage 2 (bilateral or midline involvement), and 20.0% in stage 4 (sever disability). Only 6.7% had a positive family history of Parkinson's disease. Moreover, 54.7% of the studied elderly suffer from other chronic disease.

Table 3 shows the distribution of the studied elderly with Parkinson's disease according to the symptoms of the disease. The majority (92.0%) of the elders suffered from tremors followed by bradykinesia, muscle rigidity and postural instability (81.3%, 52.0% and 24.0% respectively). While, non-motor symptoms presented commonly in the feature of constipation, orthostatic hypotension and dysphagia. Moreover, 96.0% of the studied elders reported that motor symptoms have a greater effect than non-motor symptoms.

Table 4 illustrates the health status of the studied elderly with Parkinson's disease using Parkinson's disease questionnaire. Mobility had the highest mean score (67.33 ± 23.08) indicating a high level of problem, followed by activity of daily living (65.89 ± 18.45), cognition (52.42 ± 15.81), stigma (45.25 ± 23.83). While, social support obtains the lowest mean score (11.44 ± 19.02) with a low level of problem.

Table 5 shows that, 44.0% of studied caregivers were spouse and 26.6% were sons or daughters. 77.3% were living with older adults in the same home and 68.0% of them reported presence of secondary caregiver. For period of caregiving, 42.7% were providing care since 1 to less than 5 years and 26.7% for 10 years or more. More than half of the studied caregivers spend 9 hours or more daily in providing care for elderly patients.

Figure 1 presented the level of caregiving burden among the studied caregivers. Sixty percent had mild to moderate burden and only 1.3% had severe burden. The total mean score of burden was 35.71 ± 10.7 .

Table 6 show that, age of the studied elders affects significantly on total mean score of health status in which the mean health status score increases with age indicating the higher level of problem ($P \leq 0.05$). Female had greater problem than male ($P \leq 0.05$). Also, the health status of the studied elders significantly associates with social status, residence, income and living condition ($P \leq 0.05$). The table reveals that, duration of the disease affects significantly on patients' health status as patients who had the disease for a long period had higher mean score of health status that indicate more problems ($P \leq 0.05$).

Table 7 shows that, the mean burden score was higher among caregivers who aged 50 years or more, female caregivers who are married, illiterate caregivers and who not working and the differences aren't statistically significant ($P > 0.05$). The level of burden was lower among caregivers who had secondary caregiver with a statistically significant difference ($p = 0.047$). Number of daily caregiving hours significantly affects the level of caregivers' burden ($P \leq 0.05$). The level of burden increases with the extended period of caregiving, and among caregivers who didn't live with older adults, but there is no statistically significant relation ($P > 0.05$).

Figure 2 represents the correlation between elderly health status and caregivers' burden. A statistically positive significant correlation was found between elders' health status and caregivers' burden ($p=0.000$). As, level of burden was higher among caregivers who are caring for patients with poor health status.

Table 1: Characteristics of the studied patients with Parkinson's disease and their caregivers (n= 75)

Elderly patients	N(%)	Family caregivers	N (%)
Age (years):		Age (years):	
60-	30(40.0)	< 30	16(21.3)
65-	16(21.3)	30-	17(22.7)
70-	13(17.4)	40-	10(13.3)
75+	16(21.3)	50+	32 (42.7)
Mean ± SD (68.25±8.47)		Mean ± SD(42.81 ±12.89)	
Sex:		Sex:	
Males	46(61.3)	Females	72 (96.0)
Females	29 (38.7)	Males	3 (4.0)
Social status:		Social status:	
Married	46 (61.3)	Married	63(84.0)
Widow	26 (34.7)	Widow	5(6.7)
Divorced	2 (2.7)	Single	5(6.7)
Single	1 (1.3)	Divorced	2 (2.6)
Education:		Education:	
Illiterate	53(70.7)	Illiterate	34(45.3)
Read and write	17(22.7)	Secondary	28 (37.4)
Secondary	5 (6.6)	University	7 (9.3)
		Read and write	6 (8.0)
Work pre-retirement:		Work:	
Working	44 (58.7)	Not working	66 (88.0)
Not working	31 (41.3)	Working	9(12.0)
Residence:		Chronic diseases:	
Rural	60 (80.0)	No	54 (72.0)
Urban	15 (20.0)	Yes	21 (28.0)
Income:			
Not Enough	62 (82.7)		
Enough	13 (17.3)		

Table 2: Medical history of the elderly patients with Parkinson's disease (n= 75)

Items	N(%)
Duration of the disease:	
<5 years	32(42.7)
5-	17(22.7)
10-	13(17.3)
15+	13(17.3)
Stages of the disease:	
Unilateral	30(40.0)
Bilateral	17(22.7)
Mild to moderate disability	6(8.0)
Sever disability	15(20.0)
Confined to bed	7(9.3)
Family history of Parkinson:	
Negative	70 (93.3)
Positive	5(6.7)
Suffering from other diseases:	
Yes	41 (54.7)
No	34 (45.3)

Table 3: Symptoms of Parkinson's disease among the studied elderly patients (n= 75)

Symptoms of Parkinson disease #	N(%)
Motor symptoms:	
Tremors	69 (92.0)
Bradykinesia	61 (81.3)
Rigidity	39 (52.0)

Postural instability	18 (24.0)
Non motor symptoms:	
Constipation	47 (62.7)
Orthostatic hypotension	27 (36.0)
Dysphagia	24 (32.0)
Drooling of saliva	12 (16.0)
Depression	10 (13.3)
Sweating abnormalities	9 (12.0)
Mostly affected symptoms:	
Motor	72 (96.0)
Non motor	3 (4.0)
Number of symptoms:	
Two symptoms	5 (6.7)
Three symptoms	26 (34.6)
More than three symptoms	44 (58.7)

#Not mutually exclusive

Table (4): Health status of the studied elderly with Parkinson's disease (n= 75)

Elderly health status	Mean ± SD	Min-Max
Mobility*	67.33±23.08	7.5-100
Activity of daily living*	65.89±18.45	20.83-100
Emotional wellbeing	38.94±23.10	0-83.33
Stigma*	45.25±23.83	0-93.75
Social support	11.44±19.02	0-91.67
Cognition*	52.42±15.81	18.75 -100
Communication	36.56±21.57	0 -100
Bodily discomfort	36.89±21.45	0-100
Total mean score	44.34±13.14	20.57-77.66

* The mostly affected domains of the health status

Table (5): Caregiving properties of the studied caregivers(n= 75)

Items	N (%)
Relation with the elderly:	
Husband/Wife	33(44.0)
Son/Daughter	20 (26.6)
Son's wife	20(26.6)
Others	2(2.8)
Living with the elderly:	
Yes	58 (77.3)
No	17 (22.7)
Availability of secondary caregiver:	
Yes	51(68.0)
No	24 (32.0)
Period of caregiving (years):	
1-	32(42.7)
5-	23(30.6)
10 +	20 (26.7)
Caregiving hours:	
3-6	17(22.7)
6-9	16(21.3)
9+	42 (56.0)

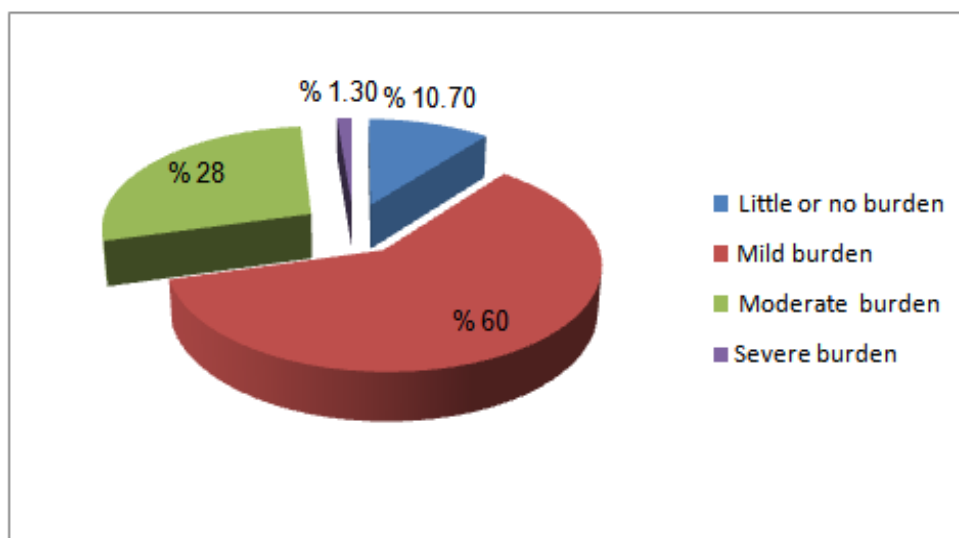


Figure (1): Level of caregiving burden among the studied caregivers(n= 75)

Table (6): Relationship between the studied patients' characteristics and their health status(n= 75)

Patients' characteristics	Health Status	Test of significance
	Mean ± SD	
Age (years):		
60-	40.75 ± 12.85	F = 4.688 (0.005)*
65-	41.21 ± 12.36	
70-	44.28 ± 14.43	
75+	54.24 ± 8.50	
Sex:		
Males	40.99 ± 12.26	T = 2.92 (0.005)*
Females	49.65 ± 12.93	
Social status:		
Married	39.96 ± 11.63	F = 10.96 (0.000)*
Widow	49.96 ± 10.30	
Divorced	77.66 ± 0.00	
Single	33.33 ± 0.00	
Education:		
Illiterate	44.64 ± 13.32	F = 2.152 (0.120)
Read and write	40.63 ± 11.65	
Secondary	53.83 ± 13.09	
Residence:		
Rural	45.89 ± 13.98	T = 2.08 (0.041)*
Urban	38.15 ± 6.16	
Income:		
Not Enough	47.19 ± 12.31	T = 4.634 (0.000)*
Enough	30.75 ± 7.21	
Duration of disease (years):		
< 5 years	38.92 ± 10.81	F = 4.922 (0.001)*
5-	43.09 ± 15.54	
10-	48.21 ± 10.51	
15-	56.82 ± 11.66	
20+	53.25 ± 7.178	

* Significant at $p \leq 0.05$

Table (7): Relationship between the caregivers' characteristics and caregiving burden(n= 75)

Caregivers' characteristics	Caregiver Burden	Test of significance
	Mean ± SD	
Age (years):		
< 30	36.44 ± 6.80	F = 0.516 (0.672)
30-	34.94 ± 11.81	
40-	32.20 ± 15.80	
50+	36.84 ± 10.17	
Sex:		
Females	36.03 ± 10.64	T = 1.272 (0.207)
Males	28.00 ± 13.11	

Education:		
Illiterate	37.15 ± 11.29	F =1.899 (0.120)
Secondary	36.57 ± 9.16	
University	30.42 ± 10.97	
Read and write	30.83 ± 9.37	
Work:		
Not working	36.00 ± 10.11	T =0.637 (0.526)
Working	33.56 ± 15.28	
Relation with elders:		
Sons	41.00 ± .00	F =1.092 (0.367)
Daughters	39.33 ± 6.60	
Husbands / wife	35.42 ± 10.73	
Son wife	32.85 ± 13.83	
Others	31.00 ± 1.41	
Living with elders:		
Yes	35.57 ± 10.86	T=0.203 (0.839)
No	36.18 ± 10.71	
Availability of secondary caregiver:		
Yes	34.02 ± 10.40	T =2.021 (0.047)*
No	39.29 ±10.82	
Period of caregiving (years):		
1-	33.94 ± 9.74	F =0.941 (0.395)
5-	36.09 ± 9.81	
10 +	38.10 ± 13.15	
Caregiving hours:		
3-6	30.13 ± 14.69	F =3.169 (0.048)*
6-9	35.65 ± 6.00	
9 +	37.86 ± 9.95	

* Significant at $p \leq 0.05$

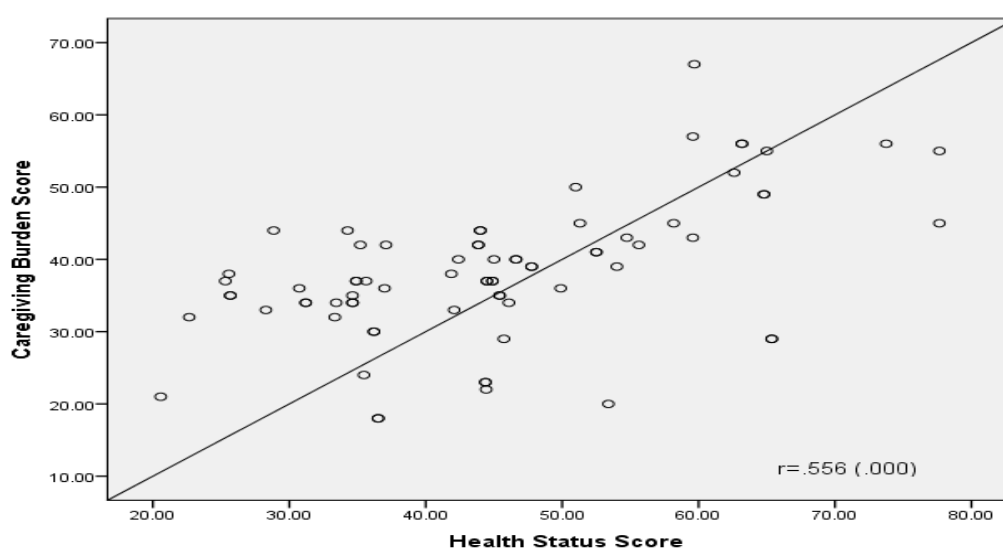


Figure (2): Correlation between elderly patients' health status and their caregivers' burden

IV. Discussion

Parkinson's disease is a common disorder that leads to sever disability despite pharmacological intervention. As the disease progresses, elderly patients experience deterioration in their health and require care from relatives²⁴. The majority of care for patients with PD is provided by family caregivers, who provide physical, emotional support for patients, which impose burden upon the patients' caregivers^{25,26}. So, this study aims to determine the relationship between the caregiving burden and health status of elderly patients with Parkinson's disease.

The present study revealed that, age is the most powerful risk factor for developing PD and encountered more among elderly men than women. This result may be attributed to neuro-protective effect of estrogen and higher incidence in men may be due to that they are more likely to be exposed to environmental and occupational hazards of neurotoxic agents than women or due to social and cultural contexts which prevent

women from seeking health services. This result agrees with studies done in Egypt by Khedr et al., (2015)²⁷, Sarhan and El Sayed (2018)²⁸ and in France by Moisan et al., (2016)²⁹. Also, a study done in Singapore by Abbas et al., (2018)³⁰ found that Parkinson's disease is more common with increasing age and 1.5–2 times more common in males than females. In contrast, a study done in Portugal by Jesus-Ribeiro et al., (2017)³¹, reported that females constituted more than half of the studied subjects.

Elderly patients with Parkinson disease suffer from various motor and non-motor symptoms (Klietz et al., 2018)³². In the present study the majority of the studied patients reported that motor symptoms have greater affection on their health than non-motor symptoms. This may be justified as; motor symptoms affect mainly on muscle, control and balance which interfere independent life of elderly patients. This result is in line with a study done in Iran by Salari et al., (2017)³³. The present study also revealed that, majority of the studied patients was suffering from tremors followed by bradykinesia and muscle rigidity as motor symptoms. While, the most common non-motor symptoms were constipation, orthostatic hypotension and dysphagia. This finding is in agreement with a study done in Turkey by Gokcal et al., (2017)²⁴. Another study done in Egypt by Ragab et al., (2019)³⁴ reported that, gastrointestinal symptoms especially constipation were the most frequent non-motor symptoms followed by sexual dysfunction, depression, and sleep disturbance.

Elderly patients with Parkinson disease are particularly vulnerable to deterioration of their health status resulting from significant motor disability and the burden of non-motor symptoms¹⁴. These symptoms can significantly limit the patient's ability to take part in activities of daily living and participate in social and recreational interests thereby adversely affecting health status¹⁰. In the present study health status was measured by the Parkinson's disease questioner 39 which revealed that, the mobility had the higher mean score which mean the higher level of problem, followed by activity of daily living, cognition, stigma, emotional wellbeing, bodily discomfort, and communication. While, social support obtains the lower mean score, which mean the lower level of the problem. This result is in accordance with other studies in Estonia by Kadastik-Eerme et al., (2015)¹⁴ and in Morocco by Tibar et al., (2018)³⁵ which revealed that; mobility was the most negative health status domain and social support the least negative domain. In contrast, a study done in Egypt by Shalash et al., (2018)⁷ reported that, stigma had the higher mean score followed by mobility, emotional wellbeing, activity of daily livings, bodily discomfort, cognition, communication and finally social support. This difference may be related to community's culture and attitude towards the disease.

Health status of elderly patients with PD may depend on several factors in term of demographic characteristics¹⁴. The present study pointed that; total mean score of health status among the studied elders was increased by age with a statistically significant difference. This result may be due to the effect of the aging process on the health status in addition to the disease progress. On the other hand, other studies done in Croatia by Tomicet et al., (2017)³⁶ and in Philippine by Suratos et al., (2018)³⁷ revealed no relations between subjects' age and their health status. Moreover, the study result revealed that females had greater problem than males, this may be due to nature of females is weaker than males and may have a greater impact on their lives due to the physical difficulties as impaired mobility which caused by PD. This is in line with Kadastik-Eerme et al., (2015)¹⁴ in Estonia. Also, patients who are divorced, living alone and in rural area had greater problem than other. These findings support those of Kadastik-Eerme et al., (2015)¹⁴.

According to Megari (2013)³⁸, the longer the disease's duration the more evident of patients poor health status. In the present study, elderly patients who had the disease for a long duration had poor health status. One possible explanation for this finding is that increasing duration of the disease may be accompanied by bad prognosis in the health condition such as motor complications which affect the patients' ability to carry out the activity of daily living which leads to deterioration of the health status. In contrast, studies done in Croatia by Tomic et al., (2017)³⁶ and in Philippine by Suratos et al., (2018)³⁷ revealed no relation between the disease's duration and health status.

Parkinson's disease has major consequences for society, owing to the resources needed to take suitable care of such patients. The role of the main caregiver, usually a family member, is important in these circumstances. This role becomes progressively more crucial with the disease progression, until caring for the patient becomes the caregiver's main activity. Taking care of a patient is an extremely demanding task, resulting in caregiver burden³⁹. The present study revealed that, most of the studied caregivers had mild level of burden. This result may be justified by despite of caregiving being a satisfying experience some times in our culture, it is still emotionally draining, physically demanding and distracting the caregiver from taking care of self. Also, in Egypt there are limited social services and respite centers. This result is in agreement with a study done in Brazil by Carrilho et al., (2018)²⁵ and in UK by Vatter et al., (2018)⁴⁰. While, a study done in Malaysia by Rajiah et al., (2017)⁴¹ found that, nearly half of the studied caregivers had moderate level of burden. These differences can partly be explained by sampling variations regarding the stage of illness, the lack of availability of support care services and social networks or cultural differences which may aggravate such differences.

The present study revealed that, there was an increase in caregivers' level of burden with increasing age, but without statistically significant difference. This result may be justified by the fact that increasing age was associated with increased responsibilities and risk for comorbid diseases that interfere take care of another person. This result is in agreement with another study done in California by Torres (2018)⁴², and disagree with other studies done in India by Agrawaletal., (2012)⁴³ and in Italy by Tessitore et al., (2018)¹⁶. Also, females had higher level of burden than males, but without significant difference between them. This result may be justified as female caregivers may experience caregiver burden as a result of added responsibility in caring for elderly patients and attempting to maintain the demands of homemaking and child rearing. This result is in agreement with a study done in Egypt by Elkafrawy et al., (2019)⁴⁴, who found that caregiving burden was more in female than male. Also, Tessitore (2018)¹⁶ in Italy revealed no relation between level of burden and caregivers' gender.

In the present study, although illiterate and highly educated caregivers had the highest level of burden, there is no association between caregivers' education and their level of burden. This result may be due to illiterate caregivers may not have knowledge about the disease and unable to understand caregiver's responsibilities and roles. But highly educated caregivers may be engaged in employment that had more demanding, resulting in a higher level of stress in combination with caregiving responsibilities. This result is the same of a study done by Sherif et al., (2014)⁴⁵ who showed no relation between educational level of caregivers and mean score of burden. While, a study done in Iran by Shamsaei et al., (2015)⁴⁶ and in China by Hu et al., (2016)⁴⁷ revealed a significant relation between caregivers' educational level and caregiving burden as caregivers who had secondary education had the highest burden.

The present study showed no relation between caregivers living with elderly patients or not and the level of burden. But caregivers who weren't live with care receiver had higher burden than others. This result may be due to the conflict in organizing activities and time to care for their families and the patients and worrying about health of elderly patients in the time they are away from them. The same findings were reported by other studies done in Egypt by Sherif et al., (2014)⁴⁵ and in Turkey by Yurtsever et al., (2013)⁴⁸.

The current study revealed that sons/daughters and wives had the higher level of burden. This result may be justified as son/daughter and wives were the main responsible for providing care to older adults but there is no significant relation between mean burden score and relation of the caregivers to the elderly. This result is in accordance with a study done in Egypt by Elkafrawy et al., (2019)⁴⁴. In contrary, other studies done in Brazil by Loureiro et al., (2013)²⁶ and in Iran by Shamsaei et al., (2015)⁴⁶ reported a significant relation between caregiver burden and caregivers' relation to the elderly. These differences may be according to the culture of the communities. Moreover, the level of burden was lower among caregivers who had secondary caregiver than who hadn't with a statistically significant relation. This is may be due to the fact that being the main caregiver means taking the main responsibility for caregiving, which is a very distressful job. This result is extended to Alshehri et al., (2016)⁴⁹ in USA who reported that, lack of secondary caregiver was positively associated with caregiving burden. While, this finding contradicts those of Elkafrawy et al., (2019)⁴⁴ in Egypt.

The level of burden increases with increasing the period of caregiving⁴⁸. In this study, caregivers who spent 10 years and more in caregiving had the highest level of burden with no statistically significant relation. This result may be justified by the fact that spending more time means spending more physical and psychological effort and the caregivers would not have more time for them. The same finding was reported by Elkafrawy et al., (2019)⁴⁴. While, Shamsaei et al., (2015)⁴⁶ in Iran and Hu et al., (2016)⁴⁷ in USA revealed a significant relation between caregiving duration and caregiver burden. Moreover, the level of burden increases with increasing caregiving hours with a statistically significant relation. This result may be justified by the fact that spending more hours per day with the elderly means more load in assisting the elderly in all activity of daily livings. On the same line a study done in Egypt by Mohammed and Ghaith (2018)⁵⁰ reported that spending twelve hour and more per day had the highest burden and there is a significant relation between caregiver burden and caregiving hours.

As Parkinson's disease progresses, health status decreases among PD patients. As well, the increased disability and symptoms in advanced stages of the disease the increased level of caregivers' burden (Violante et al., 2015)⁵¹. This is in accordance with the results of the present study as revealed strong positive correlation between elderly health status and their caregivers' burden indicating that caregivers of Parkinson's disease patients with bad health status had higher level of burden. This result may be attributed to deterioration of the patients' health status makes them more dependent on their caregivers in carrying out all activity of daily living which will be more physically and psychologically demanding on the caregivers and leads to higher level of burden. The same result was reported in a study done in Malays by Rajiah et al., (2017)⁴¹, who reported a significant positive correlation between the elders' health status and their caregivers' burden, and revealed that, when the health status of respondents gets worse the caregivers' burden also worsen. Also, a study done in Mexico by Rodríguez-Violante et al., (2015)⁵² identified a moderate correlation between the health status of PD

patients and caregiver burden (poorer health status is linked to higher burden for the caregiver. Finally, this study showed that elderly patients' health status is a strong predictor of caregivers' burden. These findings emphasize the important of designing and implementing early interventions aimed to preventing or lessen caregivers' burden.

V. Conclusion

Based on the results of the present study, it can be concluded that, caregivers' burden is common among the informal caregivers who care for elderly patients with Parkinson's diseases. This burden increases by increasing dependency of the older adult patients. Health status of elderly patients may depend on several factors including age, sex, social status, residence, income and duration of the disease. In addition, a strong positive correlation was found between elderly health status and their caregivers' burden indicating that caregivers of Parkinson's disease patients with bad health status had a higher level of burden.

VI. Recommendations

In the light of the findings, the following recommendations are suggested:

1. Develop a guideline to help family caregivers of patients with Parkinson's diseases to care for their patients at home. This will help them to cope with the burden of caring and manage stress associated with it.
2. Counseling caregivers about problems faced in caring for their patients as well as provide them with adequate knowledge and skills to help them to cope with the present condition. As well as, it is important to assess periodically the caregiver burden in order to institute appropriate intervention to help them to overcome the burden whether physical or psychological, which may have an impact on their efficient functioning.
3. Designing educational program for the Parkinson's disease elderly patients and their family caregivers about the process and management of the disease to help patients in maintaining a good health status and decrease the caregivers' burden through providing them with clear educational materials about the Parkinson's disease.

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