Burden of Care among Caregivers of Aging Patient with Parkinson's Disease

Esraa Said Sayed Ahmed[1] , Ebtisam Mohamed Abd-ElAall[2] and Wafaa Atta Mohamed[3]

(1) Nursing Specialist at Neurosurgery Hospital, in Shbein-Elkom, Egypt,(2) Professor of Community Health Nursing, Faculty of Nursing, Benha University, and (3) Lecturer of Community Health Nursing, Faculty of Nursing, Benha University.

Abstract

Background: Parkinson's Disease is a progressive disease so patients require more assistance in everyday life which increase caregivers' burden. **Aim**: This study aimed to assess burden of care among caregivers of aging patient with Parkinson's disease. **Research design:** A descriptive research design was utilized in this study. **Setting:** This study was conducted at the Neurological outpatient clinic of Benha University Hospital and Benha Teaching Hospital. **Sample:** Simple random sample which included 218 aging patient with Parkinson's disease and their caregivers. **Tools:** Two tools were used in this study: **Tool 1:** Structured interviewing questionnaire to assess socio-demographic characteristics of the studied aging patient with Parkinson's disease and socio-demographic characteristics of caregivers, also their knowledge and their reported practice for the aging patient with Parkinson's disease. **Tool 2:** Burden level of caregivers regarding care of aging patient with Parkinson's disease. **Results:** 58.7% of studied aging patients were male and 43.1% of them aged from 60 to less than 70 years old, while; 61.9% of studied caregivers were female and age 42.7% of then aged from 40 to less than 50 years old. In addition, 63.8% of studied caregivers had poor total knowledge level, while had regular total reported practices regarding care of aging patient with PD. Moreover; 61.9% of them had high total burden level. **Conclusion:** There were highly statistically significant relation between total burden level and total practices among studied caregivers (P<0.001). **Recommendations:** Health educational program should be developed and implemented for patients with Parkinson disease and their caregivers to improve, updated knowledge and practices and reduce burden level.

Key words: Aging patient, Burden of care, Caregivers, Parkinson's Disease

Introduction

Aging is a natural phenomenon accompanied by a progressive loss of functional capacity, physiological integrity, and morphological features of the organism. Aging can be classified as biological, psychological, social, chronological and functional aging. Biological aging refers to physical aging that involve the loss of cells over time as the body ability to repair itself slow down and the immune functions decline making the body more prone to infection. Psychological aging involves changes in intelligence, personality and coping. Social aging involves changes in responsibilities and relationships and functional aging related to how people compare psychologically to other in similar age (**Mohamed et al., 2023**).

Parkinson's Disease (PD) is the second most important age-related neurodegenerative disorder after Alzheimer disease. It is a complex disorder, described by the loss of dopamine producing neurons in Substantia Nigra Pars Compacta (SNPC) as well as the presence of Lewy bodies in the SNPC and locus coeruleus leading to poor motor control. Parkinson disease typically develops between the ages of 55 and 65 years and occurs in 2% of people over the age of 60 years, rising to 3.5% at age 85–89 years (**Tan et al., 2019**).

Burden of Care among Caregivers of Aging Patient with Parkinson's Disease

Parkinson's disease has both motor and non-motor dysfunctions. Symptoms typically occur gradually over several years, making diagnosis challenging. PD is traditionally characterized as a motor system disorder with four cardinal symptoms; bradykinesia (slowness of movement), rigidity (stiffness of the limbs and trunk); postural instability (impaired balance and coordination), and tremor (trembling in hands, arms, legs, and face). The most common non-motor symptoms of PD include constipation, urinary dysfunction, depression, psychosis, apathy, and sleep disorders **(Church, 2021)**.

Parkinson's disease is a prime example of a disease that confronts affected persons with high and evolving challenges in taking up decade-long task. Experience an increasingly complex disease burden with an array of motor and non-motor symptoms, require a multidimensional pharmaceutical and non-pharmaceutical treatment regimen and experience a varying therapeutic effectiveness along the disease course from caregiver. Caregivers are known as the person most closely involved in caring and assisting the patient to accommodate and maintain patient health from chronic illness during treatment. Also, caregivers are people who meet the majority of the patient's physical, psychological, emotional, social and financial needs. Caregivers are usually a close relative, parent, or spouse. **(Tennigkeit et al., 2020; Ahmed et al., 2021)**.

The burden of caregivers is defined as objective and subjective negative consequences, such as psychological stress, physical health problems, social and financial problems, family relationships breakdown**.** The accumulation of activities generate stress and affect many aspects of a person's life, putting the quality of life of the caregiver at risk. **(Ahmed et al., 2021).**

Community Health Nurse (CHN) has a great role in helping patients with PD to attain better quality of life, the caring aspect of nursing is not only concerned about the patients with PD but also their families. Nurses help families to manage side effects of treatment to be adjusted psychologically and physically to the stressors, deal with ill relatives and detect abnormal behavior. So quality of life of both the patients with PD, and their families may be affected by the ability of nurses to help with the required support, information and adjustment **(Karlstedt et al., 2020).**

Significance of the study

Parkinson's Disease is expected to affect about ten million patients by the year 2030. In a previous Egyptian study, the crude incidence of PD was 84 per 100,000 person/year. The rise in Parkinson's Disease prevalence estimates calls attention to the increasing individual and societal burden and the pressing need for measures to address and impact this challenging. 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. The incidence and prevalence of PD increase with age and most people diagnosed with Parkinson's are in their sixties. PD affects more than one million individuals in the USA **(Khalil et al., 2020; Maserejian et al., 2020; Bloem et al., 2021).**

Aim of the study:

This study aimed to assess burden of care among caregivers of aging patient with Parkinson's disease.

Research Questions:

1. What is the knowledge of caregivers regarding Parkinson's disease?

2.   What are the reported practices of the caregiver's regarding care of aging patient with Parkinson's disease?

3.   What is the burden of caregivers regarding care of aging patient with Parkinson's disease?

4.   Is there a relation between practices of caregivers and their burden regarding care of aging patient with Parkinson's disease?

Subject and Methods

Research design:

A descriptive research design was used for this study.

Setting:-

This study was conducted at the Neurological Outpatient Clinics of Benha University Hospital and Benha Teaching Hospital.

Sampling type:

Simple random sample of aging patients with Parkinson's disease and their caregivers.

Sample size:

Sample size was calculated using the following formula.

$$n = \frac{N}{1+N(e)2}$$

Where 'n' is sample size

'N' is total number of Parkinson's patients attending the previous mention setting in 2021 which was about 483 .

Sample size = 218

Tools of data collection: Two tools were used in this study:

Tools (1): A structured Interviewing Questionnaire: It was developed by researchers in an Arabic language after reviewing the related literatures and under supervision of supervisors, it was divided into three parts.

First Part was concerned with: Socio-demographic characteristics of the aging patient involved in the study. It included 7 questions about age, gender, material status,

educational level, occupation, place of residence and monthly income.

Second part was concerned with: Socio-demographic characteristics of studied caregivers involved in the study. It included 11 questions about age, gender, material status, occupation, educational level, monthly income, place of residence, living with the aging patient, relation with the patient, other helps in care, onset and caregiving hours.

Third part: Was concerned with knowledge of studied caregivers regarding Parkinson's Disease. It included 9 questions about meaning, causes, sign, symptoms, high risk groups, complications, disease stages, medication and prevention method.

Scoring system:

The scoring system for studied caregivers' knowledge was calculated as follows (2) score for correct and complete answer, and (1) score for correct and incomplete answer while (0) for don't know. For each area of knowledge, the score of items was summed-up and the total divided by the number of items, giving a mean score for the part. These scores were converted into a percent score. The total knowledge score =18 points which considered good if the score of the total knowledge ≥75 % (≥13point), and considered average if it equals 50<75% (9<13 point), while considered poor if it is < 50% (<9points).

Fourth Part: Was concerned with caregiver reported practices regarding care of the aging patient with PD which included 8 items:

 (1) Nutrition of aging patient: which included 4 questions (buy cooking supplies for the aging patient, prepare and cook food for the aging patient, help the aging patient in eating food and feed the aging patient completely.).

(2) Personal hygiene of aging patient: which included 3 questions (wash the face and teeth

for the aging patient daily upon waking up, wash the mouth and hands for the aging patient before and after eating and shave the excess hair for the aging patient.).

(3) Bathing of aging patient: which included 3 questions (prepare the bathroom for the aging patient, such as choosing the water temperature, preparing bathing tools such as shampoo and soap, preparing towels and clothes, Assist the aging patient in bathing, and Make a complete bath for the elderly, including undressing and dressing, washing and drying his entire body).

(4) Mobility of aging patient: which included 4 questions (help the aging patient to fall asleep and get out of bed, massage and exercise as a physical therapy for the aging patient, help the aging patient to get up and sit down and assist the aging patient in using means of movement such as crutches, walker or wheelchair).

(5) Toileting of aging patient: which included 3 questions (help the aging patient during toileting, help the aging patient rinse and arrange clothes after elimination and change diapers when get dirty in the case the aging patient use diapers).

(6) Wearing clothes for aging patient: which included 3 questions (offer a little help to the aging patient as wear shoes, help the aging patient to arrange clothes completely and assist the aging patient in put on and take off clothes completely).

(7) House cleanliness for aging patient which included 3questions (wash the dirty clothes, wash the dishes and utensils and cleans upholstery, furniture, and floors for the aging patient).

(8) Medical care for aging patient which included 3 questions (take the aging patient to the doctor/ care centers, give medication to the aging patient and do exercises/ physiotherapy to the aging patient).

Scoring system:

The scoring system for caregivers' reported practices was calculated as follows (2) score for always, while (1) score for sometimes and (0) for never. For each step of reported practice, the score of items was summed- up and the total divided by the number of items, giving a mean score for the part. These scores were converted into a percent score. The total practice score 52 points, which considered regular if the score of the total practices ≥60% (≥31 points), while considered irregular if it is < 60% (< 31 points).

Tools (2): Burden level of caregivers regarding care of aging patient with Parkinson's disease, adopted from **Zarit Burden Interview (ZBI,1980)** which was modified by the researchers to assess caregivers burden level regarding care of aging patient with Parkinson's disease. It was translated into Arabic by the researchers, and it included 3 items as following:

(1) Physical burden: which included 6 questions (feel that the aging patient ask for help more than needs, feel pressured between caring for the aging patient and trying to meet other responsibilities, feel that health has been affected by the care of the aging patient, feel that the aging patient depends for everything, feel tired from caring for the aging patient and feel tired from caring for the aging patient).

(2) Social burden: which included 7 questions (feel care for the aging patient affect family and social relationships, feel don't have the privacy need in life because of caring for the aging patient, feel lose of control of life because of caring for the aging patient, feel don't have enough time because of caring for the aging patient, feel caring for the aging patient effect on social life, feel don't have enough friends because of caring for the aging patient and feel that caring for the aging patient affects financial level).

(3) Psychological burden: which included 9 questions (feel embarrass over the aging patient behavior, feel angry over the aging patient behavior, feel afraid of what the future holds for the aging patient, feel nervous about being with the aging patient, feel that the aging patient wait for care from only caregiver, feel can't provide care for the aging patient for a longer period, wish to leave the care of the aging patient to someone else, feel hesitant about what want to do for the aging patient and feel bear the burden of caring for the aging patient)

Scoring system:

The scoring system for burden level of studied caregivers regarding care of aging patients with Parkinson disease, was calculated as follows: (2) score for always, and (1) score for sometimes while (0) score for never. The total burden level score = 44 points. The total burden score considered high total burden level ≥75 % (≥33point), and considered moderate total burden level 50>70% (22<33point), while considered low when total burden level < 50% (<22 points).

Content validity of the tools:

Content validity of the tools was done by three of Faculty's Staff Nursing experts from the Community Health Nursing Specialties who reviewed the tools for clarity, relevance, comprehensiveness, applicability and give their opinions.

Reliability of the tool:

The reliability was done by Cronbach's Alpha coefficient test which revealed that the two tools consisted of relatively homogenous items as indicated by the moderate to high reliability of each tool. The internal consistency of the knowledge was 0.732, and practice was 0.843, while burden was 0.801.

Ethical considerations:

All ethical issues were assured, oral consent has been obtained from each aging patient with Parkinson's disease and his/him caregiver before conducting the interview and given brief orientation to the purpose of the study. They were also reassured that all information gathered would be treated confidentiality and used only for the purpose of the study and each patient and his/her caregiver had right to withdraw from the study at any time without giving any reasons.

Pilot study:

The pilot study was carried out on 22 patients and 22 caregivers who represented 10% of the sample size. The pilot study was aimed to assess the tool clarity, applicability and time needed to fill each sheet, completing the sheet consumed about 30-45 minutes. No modification was done, so the pilot study sample was included to the total sample.

Fieldwork:

The actual field work was carried out over about 6 months from the beginning of May 2022 to the end of October 2022. The researchers visited the Out-Patient Clinic at Benha University Hospital from 9 am to 12 pm, one day per week (Mondays) while visited the Out-Patient Clinic at Benha Teaching Hospital from 9 am to 12 pm, two days per week (Sunday and Wednesday) to collect data from the aging patients and their caregiver. The average time needed for the sheet was around 30-45 minutes, the average number interviewed at the Out-Patient Clinics were 2-3 patients and their caregiver /day depending on their responses of the interviewers. At the first, the interview was conducted with both patient and caregiver together to assess their socio-demographic characteristics and their medical history. Then, conduct the interview with patient's caregiver alone to assess his/her knowledge, practices and the burden of care.

Burden of Care among Caregivers of Aging Patient with Parkinson's Disease

Statistical analysis:

All data collected were organized, tabulated and analyzed using appropriate statistical test. The data were analyzed by using the Statistical Package for Social Science (SPSS) version 21, which was applied to calculate frequencies and percentages, mean and standard deviation as well as test statistical significance and associations by using Chi-square test (x2) and linear correlation coefficient (r), and matrix correlation to detect the relation between the variables (P value).

Significance levels were considered as follows:

Highly significant (HS) P ≤ 0.001**
Statistically Significant (S) P ≤ 0.05*
Not significant (NS)   P > 0.05

Results:

Table (1): Shows that; 43,1% of studied aging patients aged from 60 years to less than 70 years with mean ±SD 68.51±9.47 years, 58.7% of them were male and 47.7% of studied aging patients were married. Regarding educational level, 36.7% of studied aging patients couldn't read or write and 46.3% of them didn't work. In addition, 53.7% were living in the rural area and 41.7% had not enough monthly income.

Table (2): Shows that; 42.7 % of studied caregivers aged from 40 years to less than 50 years with mean ±SD 46.47±5.42 years, 61.9 % of them were females and 38.1 % of studied caregivers were married. Concerning occupation, 63.3% of studied caregivers were working, 26.6% of them couldn't read or write and 42.7% of studied caregivers didn't have enough monthly income. Regarding residence, 56 % of studied caregivers were living in the rural area, 56.9% of them were living with the aging patient, and 77.1% had another help in caregiving. According to relativeness, 47.2% of studied caregivers were

spouse of the aging patient and 70.3% of them spend more than 12 hours in caregiving.

Figure (1): Illustrates that; 63.8 % of studied caregivers had poor total knowledge level about Parkinson's disease and 23.4% of them had average total knowledge level, while only 12.8% of them had good total knowledge level about Parkinson's disease.

Figure (2): Illustrates that; 63.8% of studied caregivers had regular total reported practices level regarding care of aging patients with Parkinson's disease. While, 36.2% of them had irregular total reported practices level regarding care of aging patients with Parkinson's disease.

Figure (3): Reveals that 61.9% of studied caregivers had high total burden level regarding care for the aging patient with Parkinson's disease, while 27.5% of them had moderate total burden level and 10.6% of studied caregivers had low total burden level regarding care for the aging patient with Parkinson's disease.

Table (3): Demonstrates that; there were highly statistically significant relation between total burden level and total practices among studied caregivers (P<0.001).

Table (4): Indicates that, there were significant positive correlation between total knowledge, total practices, and total burden level among studied caregivers.

Table (1): Frequency distribution of studied aging patients regarding their socio-demographic characteristics, (n=218).

Socio demographic characteristics	No	%
Age		
60<70 years	**94**	**43.1**
70<80 years	82	37.6
80<90 years	29	13.3
≥90 years	13	6.0
Mean ±SD	**68.51±9.47**	
Gender		
Male	**128**	**58.7**
Female	90	41.3
Marital status		
Single	35	16.1
Married	**104**	**47.7**
Divorced	31	14.2
Widow	48	22.0
Educational level		
Can't read or write	**80**	**36.7**
Basic education	75	34.4
Secondary education	59	27.1
University or more education	4	1.8
Occupation		
Retired	87	39.9
Free business	30	13.8
Not work/ Housewife	**101**	**46.3**
Residence		
Rural	**117**	**53.7**
Urban	101	46.3
Monthly income		
Enough and save	40	18.3
Enough	85	39.0
Not Enough	**91**	**41.7**

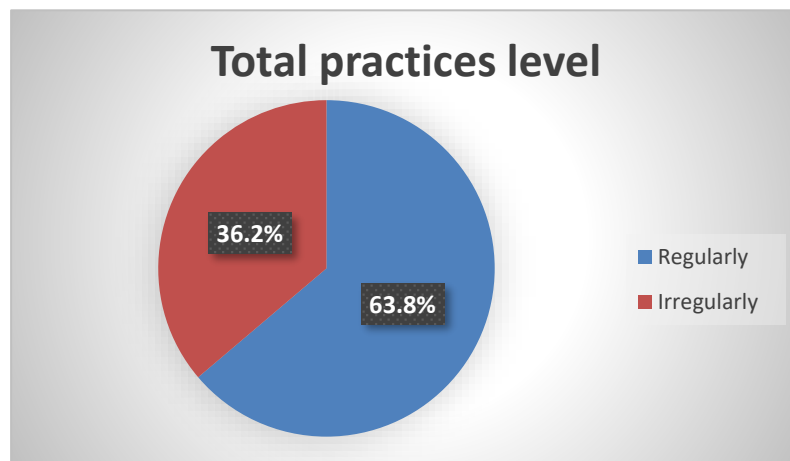# Burden of Care among Caregivers of Aging Patient with Parkinson's Disease

Table (2): Frequency distribution of studied caregivers regarding their socio demographic characteristics, (n=218).

Socio demographic characteristics	No	%
Age		
20<30 years	28	12.8
30<40 years	57	26.1
40<50 years	**93**	**42.7**
≥50 years	40	18.3
Mean ±SD	**46.47±5.42**	
Gender		
Male	83	38.1
Female	**135**	**61.9**
Marital status		
Single	43	19.7
Married	**83**	**38.1**
Divorced	59	27.1
Widow	33	15.1
Occupation		
Worked	**138**	**63.3**
Not worked	79	36.2
Educational level		
Can't read or write	**78**	**35.8**
Basic education	42	19.3
Intermediate education	51	23.4
University education	47	21.6
Monthly income		
Enough and save	41	18.8
Enough	84	38.5
Not enough	**93**	**42.7**
Residence		
Rural	**122**	**56.0**
Urban	96	44.0
Living with the patient		
No	94	43.1
Yes	**124**	**56.9**
Relation with the patient		
Son/daughter	66	30.3
Spouse	**103**	**47.2**
Son's wife	49	22.5
Other help in care		
No	50	22.9
Yes	**168**	**77.1**
Caregiving hours		
<6 hour	25	11.5
6<12 hours	40	18.3
≥12 hours	**153**	**70.2**

Esraa said Sayed Ahmed , Ebtisam Mohamed Abd-ElAall, Wafaa Atta Mohamed
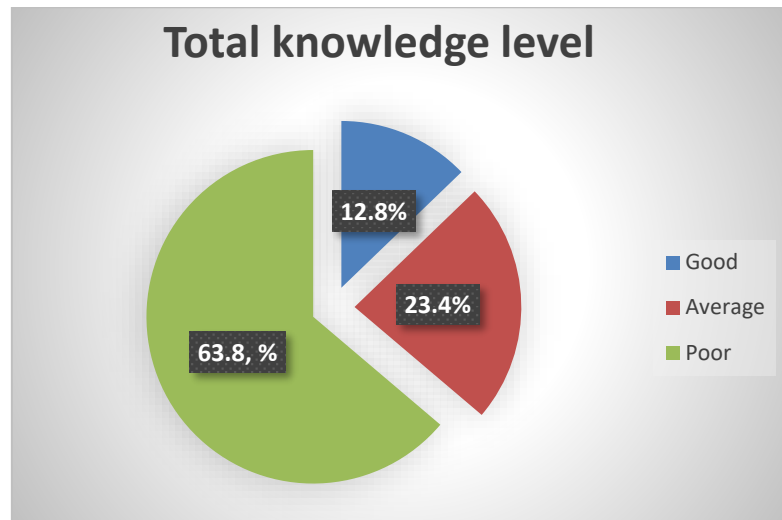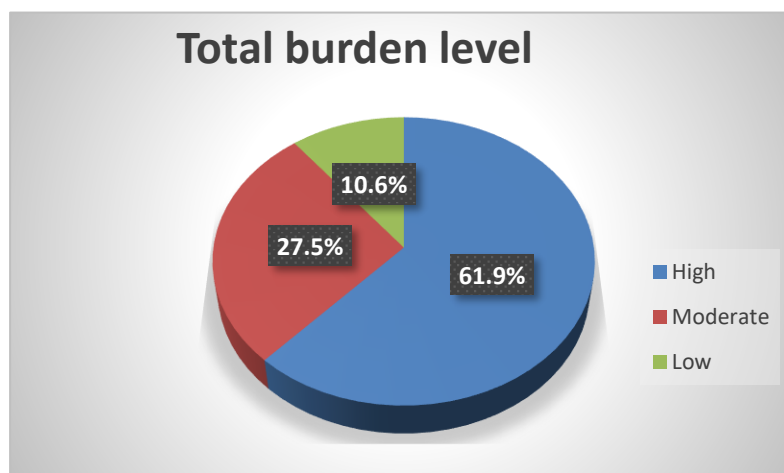

Figure (1): Percentage distribution of studied caregivers regarding their total knowledge level about Parkinson's disease, (n=218).

Figure (2): Percentage distribution of studied caregivers regarding their total reported practices regarding care of aging patients with Parkinson's disease, (n=218)

Figure (3): Percentage distribution of studied caregivers regarding their total burden level (n=218)

Table (3): Statistically relation between total practices and total burden level among studied caregivers, (n=218).

Total burden level	Total reported practices				X²	p-value
	Irregular (n=79)		Regular (n=139)			
Low (n=23)	13	16.5	10	7.2	14.36	.001**
Moderate (n=60)	30	38.0	30	21.6		
High (n=135)	36	45.6	99	71.2		

Table (4): Correlation matrix between total knowledge, total practices, and total burden level among studied caregivers, **(n=218).**

Items		Total knowledge	Total practices	Total level of burden
Total knowledge	r	1	.574	.124
	p-value		.038*	.067
	n	218	218	218
Total practices	r	.574	1	.465
	p-value	.038*		.014*
	n	218	218	218
Total level of burden	r	.124	.465	1
	p-value	.067	.014*	
	n	218	218	218

Discussion

Aging is a natural, long and psycho-physiologically process that involves irreversible biological, psychological and social changes. In this process the body and organ systems begin to slow and become unbalanced and these changes affect the functioning of all body systems. Aging is the most powerful risk factor for developing Parkinson's disease. PD is a progressive disorder that affects the nervous system and the parts of the body controlled by the nerves. PD prevalence is increasing with the age, its effects 1% of the population above 60 years (**Jasiński, 2017; Socha et al., 2019).**

Aging patient with PD needs help with many aspect of life including personal hygiene, mobility, medication compliance, daily activities and social involvement. It creates a great burden on the caregivers. Caregivers help to complete scales of functional ability, dependence, neuropsychiatric symptoms, quality of life and mood, and their impressions are used in conjunction with a clinician's ratings (**Ptacek, 2019; Chen et al., 2021).**

Regarding the studied aging patients' socio-demographic characteristics, the present study showed that more than two fifth of studied aging patients aged from 60 to less than 70 years with mean age 68.51±9.47 years and more than half of studied aging patients were males. These findings were supported by a study done by **Hoseinipalangi et al. (2023),** who studied " Quality of life of patients with Parkinson disease: a global systematic review and meta-analysis, in Iran." (n=4060), and revealed that the overall mean age of studied patient was 64.5±9.2 years and more than half of them were males. Also, these results were

in the same line with **Oftedal et al. (2023),** who studied " Association of CSF glucocerebrosidase activity with the risk of incident dementia in patients with Parkinson disease, in Southwestern Norway." (n=117), and reported that mean age of studied patients was 67.2±9.53 years and more than half of them were males. This might be due to aging is a most common risk factor for developing Parkinson's disease, also, this result might be justified as the increase incidence in men might be due to men more likely to exposed to environmental and occupational hazards of neurotoxic agents than women, and decrease incidence in women might be attributed partially to neuroprotective effect of estrogen.

Also, the present study revealed that approximately less than half of studied patients weren't working, two third of them didn't have enough monthly income, more than half of them were living in rural area and less than half of them were married. These finding were consistent with **Mohammed et al. (2020),** who studied "Relationship between caregiving burden and health status of elderly patients with Parkinson's Disease, in Egypt.", (n=75), and found that majority of studied patient weren't working, didn't have enough income, most of them were living in the rural area and were married. This result might be due retirement age and high cost of medications.

Regarding the educational level of the studied aging patients, the present study revealed that more than one third of the studied aging patients couldn't read or write. This result was disagreed with a study done by **Islam et al. (2019),** who studied "Socio-demographic characteristics of Parkinson's Disease patients Dhaka city, Bangladesh" (n=40), and reported that one third of studied patients had primary level of education, this finding might be due to most of them were from rural area and in the past there was no education in the rural areas.

Regarding the studied caregivers' age, the present study revealed that more than one third of the studied caregivers aged from 40 to less than 50 years with mean ±SD 46.74±5.42 (table 2). This finding differed with **Navarta et al. (2023),** who studied " Perspectives of people with Parkinson's disease and family carers about disease management in community settings. A cross-country qualitative study, in Spain." (n=39), and found that the mean age of studied caregivers was 64.2 years.

The current study revealed that more than three fifth of studied caregivers were females. This finding agreed with **lee et al. (2022),** who studied "Prevalence and risk factors of depression between patients with Parkinson's Disease and their caregivers. A one-year prospective study, in Taiwan." (n=101), who reported that more than half of studied caregivers were females. Also, this finding was consistent with **Martinez et al. (2023),** who studied "Impact of advanced Parkinson's disease on caregivers: an international real-world study, in Spain." (n=721), and reported that more than two thirds of studied caregivers were females. This result acceptable as, natural of Egyptian community, the females are the heads of their house and have the most of responsibility of taking care for other family members and their health condition.

Also, the present study revealed that slightly more than three fifths of the studied caregiver were working, and slightly more than two fifth of them didn't have enough monthly income. This result supported by **Sarhan & Elsayed (2018),** who studied "Effect of instructional guidelines on caregivers' burden of care and quality of life in Parkinson's Patients, Egypt."(n=75), and reported that

more than half of studied caregivers were working. This finding might be due to majority of studied patients weren't work so the caregivers had to work.

Concerning the studied caregivers' educational level, the present study revealed that slightly more than one third of studied caregivers couldn't read or write. This finding was incongruent with **Yue et al. (2022),** who studied" Caregiving stress among family caregivers of older adults living with disabilities in China."(n=220), and reported that slightly more than half of studied caregivers had elementary or lower education. This finding might be due to the majority of studied caregivers were females who were living in rural area and in rural area didn't interest about females' education.

According to residence of studied caregivers, the present study showed that more than half of studied caregivers were living in rural area and were living with their aging patients. Also, slightly more than three quarters of studied caregivers had other help in care for aging patients. These findings were consistent with **Mohammed et al. (2020),** who reported that more than two third of studied caregivers were living with the patient and more than half of them had secondary caregivers. However, these findings disagreed with **Baik et al. (2017),** who studied "Patients and their caregivers' burdens for Parkinson's disease in Korea."(n=853), and reported that more than half of caregivers weren't living with the patient. This might be due to the tradition of Egyptians rural families and strong family relationship.

According to this study less than half of studied caregivers were spouses. This finding was in accordance with **chen et al. (2022),** who studied "Living with Parkinson's disease: disease and medication experiences of patients and caregivers, in Taiwan."(n=32),

and reported that more than two thirds of studied caregivers were Spouses.

Also, the present study showed that two third of studied caregivers were providing care for the aging patient more than twelve hours per day. This finding was inconsistent with **Heine et al. (2021),** who studied " Relationship satisfaction in people with Parkinson's disease and their caregivers: a cross-sectional observational study, in Germany."(n=79), and reported that caregivers spending an average of five to eight hours per day in patient care. This result might be due to most of the studied sample were from rural and according to tradition in rural usually spouses in position of responsibility.

Also, the present study revealed that slightly more than two thirds of studied caregivers had poor total knowledge level regarding Parkinson's Disease. This finding agreed with **Corallo et al. (2017),** who studied "Observational study of quality of life of Parkinson's patients and their caregivers, in Italy."(n=60), and stated that caregivers do not have sufficient information about Parkinson's disease and its impacts on patients and caregiver. This result might be due to low caregivers' level of education.

The current study showed that, more than three fifth of studied caregivers acquired their knowledge from health team (figure2). This result disagreed with **Choo et al. (2020),** who studied "Understanding patients' and caregivers' perspectives and educational needs in Parkinson's disease. A multi-ethnic, Asian study." (n=273), and reported that slightly less than three fifth of studied caregivers had their knowledge from internet. This might be due to low studied caregivers' educational level and they couldn't use the internet.

The present study showed that three fifth of studied caregivers had regular total reported

practices regarding care of aging patients with Parkinson's disease. While, slightly two thirds of them had irregular total reported practices regarding care of aging patients with Parkinson's disease. This result was in congruent with **Sarhan & Elsayed, (2018),** who reported that four fifth of studied caregivers had satisfactory daily practices for their aging patient with Parkinson's disease while less than one fifth of studied caregivers had unsatisfactory daily practices for their aging patient with Parkinson's disease. This finding might be due to more than half of studied caregivers were lived with the aging patients.

The present study illustrated that more than three fifth of studied caregivers had high total burden level regarding care for the aging patient with Parkinson's disease, while slightly more than quarter of them had moderate total burden level and one tenth of studied caregivers had low total burden level. This finding was in the same line with **Khalil et al. (2020),** who "Studied effectiveness of in-person tele-support management on perceived burden, health-promoting practices, and sense of coherence among caregivers of Older Adults with Parkinson's Disease, in Egypt." (n=39), and reported that more than three quarters of studied caregivers had moderate to high burden.

The present study, demonstrated that, there were highly statistically significant relation between total burden level and total practices level among studied caregivers (P<0.001). This finding agreed with **Mohammed et al. 2020,** who revealed statistically significant relation between total burden level and practices. This might be due to as Parkinson's disease progress, patient health status decrease and that make the patient more dependent on caregivers which require more practices and that increase burden level.

Concerning correlation matrix between total knowledge level, total practices level, and total burden level among studied caregivers, the present study, showed that there were significant positive correlation between total knowledge level, total practices level, and total burden level among studied caregivers(table4). This finding might be due to by the time practices became routine don't needs information to do.

Conclusion:

More than three fifth of studied caregivers had poor total knowledge level about Parkinson's disease, while had regular total reported practices level regarding care of aging patients with Parkinson's disease. In addition, more than three fifth of them had high total burden level regarding care of aging patients with Parkinson's disease. There were highly statistically significant relation between total burden level and total practices among studied caregivers (P<0.001). Also, there were significant positive correlation between total knowledge, total practices, and total burden level among studied caregivers.

Recommendations:

1- Health educational program should be developed and implemented for patients with Parkinson disease and their caregivers to improve, and updated knowledge and practices

2- Disseminate booklet with illustrated pictures included all information and lifestyle measures towards Parkinson's disease at Outpatient Clinic to be available for patients and their caregivers to enhance knowledge and practice, and to decrease burden level.

3-Regular follow up for Parkinson's disease patients and their caregivers to ensure effectiveness of medication and avoiding complications.

4- Further studies needed to be applied the same study in large sample size in different setting in Egypt.

References:

Ahmed, S., Saif, S., & Hamedy, S. (2021). Burden and Coping Mechanisms among Caregiver for Old Adult with advanced illness. Niles journal for Geriatric and Gerontology; 4(2): 318-345.

Baik, S., Kim, S., Koh, B., Cho, W., Lee, H., Ma, I., & Kim, T. (2017). Patients and their caregivers' burdens for Parkinson's disease in Korea. Journal of movement disorders; 10(3): 109-115.

Bloem, R., Okun, S., & Klein, C. (2021). Parkinson's disease. The Lancet; 397(10291), **2284**-2303.

Chen, C., Chen, S., Weng, H., Huang, Z., Chen, C., Hung, J., & Lin, Y. (2021). The severity progression of non-motor symptoms in Parkinson's disease. A 6-year longitudinal study in Taiwanese patients. Scientific reports, 11(1), 14781.

Chen, W., Huang, Y., Chen, H., Hsiao, L., Hong, T., Wu, Y., & Chang, H. (2022). Living with Parkinson's disease: disease and medication experiences of patients and caregivers. International Journal of Qualitative Studies on Health and Well-being, 17(1), 2018769.

Choo, Y., Lim, Y., Chinna, K., Tan, J., Yong, W., Lim, L., & Tan, H. (2020). Understanding patients' and caregivers' perspectives and educational needs in Parkinson's disease: A multi-ethnic Asian study. Neurological Sciences, 41, 2831-2842.

Church, C. (2021). Treatment options for motor and non-motor symptoms of Parkinson's disease. Biomolecules, 11(4), 612.

Corallo, F., Cola, M., Buono, V., Lorenzo, G., Bramanti, P., and Marino, S. (2017). Observational study of quality of life of Parkinson's patientsand their caregivers, Psychogeriatrics journal; 17: pp. 97–102.

Heine, J., von Eichel, H., Staege, S., Höglinger, U., Wegner, F., & Klietz, M. (2021). Relationship satisfaction in people with Parkinson's disease and their caregivers: a cross-sectional observational study. Brain Sciences; 11(6), 822.

Hoseinipalangi, Z., Pashazadeh Kan, F., Hosseinifard, H., Doustmehraban, M., Masoumi, M., & Rafiei, S. (2023). Quality of life of patients with Parkinson disease: a global systematic review and meta-analysis. East Mediterr Health J, 29(1).

Islam, U., Momin, A., Sharmin, F., Sarkar, K., & Hoque, A. (2019). Socio-demographic Characteristics of Parkinson's Disease Patients attended at a Tertiary Care Hospital in Dhaka City. Journal of Current and Advance Medical Research; 6(2): 106-110

Jasiński, M. (2017). The Psychological difficulties of adapting to the aging process. ocznik teologii Katolickiej; 16(2), 111-123.

Karlstedt, M., Fereshtehnejad, M., Aarsland, D., & Lökk, J. (2020). Mediating effect of mutuality on caregiver burden in Parkinson's disease partners. Aging & mental health; 24(9): 1421-1428.

Khalil, M., Sorour, M., Shaala, S., & Mousa, S. (2020). Effectiveness of in-person tele-support management on perceived burden, health-promoting practices, and sense of coherence among caregivers of older adults with Parkinson's Disease. Niles journal for Geriatric and Gerontology; 3: 65-93.

lee, Y., Chang, Y., Chen, F., Lin, K., Hung, F., Chiou, J., & Wang, J. (2022). Prevalence and risk factors of depression between patients with Parkinson's Disease and their Caregivers: A One-Year prospective study. In Healthcare; 10(7): 1305).

Martinez, P., Skorvanek, M., Henriksen, T., Lindvall, S., Domingos, J., Alobaidi, A., & Antonini, A. (2023). Impact of advanced Parkinson's disease on caregivers: an international real-world study. Journal of Neurology, 1-12.

Maserejian, N., Vinikoor-Imler, L., & Dilley, A. (2020). Estimation of the 2020 global population of Parkinson's disease (PD). In Movement Disorders ; 35: 79-80).

Mohamed, M., Sabry, S., & Ibrahim, S. (2023). Burden of care among caregivers for elderly cancer patients. Journal of Nursing Science Benha University ; 4(1):457-473

Mohammed, A., Elmawla, D., Hassan, S., & Elhameed, A. (2020). Relationship between caregiving burden and health status of elderly patients with Parkinson's Disease. IOSR Journal of Nursing and Health Science (IOSRJNHS), 9(1)

Navarta, V., Santos, A., Pedraz-Marcos, A., Reidy, C., Soilemezi, D., Haahr, A., & Portillo, C. (2023). Perspectives of people with Parkinson's disease and family carers about disease management in community settings. A cross-country qualitative study. Journal of Clinical Nursing.; 10(111):16636

Oftedal, L., Maple-Grødem, J., Dalen, I., Tysnes, B., Pedersen, F., Alves, G., & Lange, J. (2023). Association of CSF glucocerebrosidase activity with the risk of incident dementia in patients with Parkinson disease. Neurology; 100(4): e388-e395.

Ptacek, S., Dahlrup, B., Edlund, K., Wijk, H., & Eriksdotter, M. (2019). The caregiving phenomenon and caregiver participation in dementia. Scandinavian journal of caring sciences; 33(2): 255-265.

Sarhan, M., & Elsayed, S. (2018). Effect of instructional guidelines on caregivers' burden of care and quality of life in Parkinson's Patients. IOSR Journal of Nursing and Health Science;7(1):15-26.

Socha, E., Koba, M., & Kośliński, P. (2019). Amino acid profiling as a method of discovering biomarkers for diagnosis of neurodegenerative diseases. Amino Acids; 51: 367-371.

Tan, H., Karri, V., Tay, R., Chang, H., Ah, Y., Ng, Q., & Candasamy, M. (2019). Emerging pathways to neurodegeneration: Dissecting the critical molecular mechanisms in Alzheimer's disease, Parkinson's disease. Biomedicine & Pharmacotherapy; 111: 765-777.

Tennigkeit, J., Feige, T., Haak, M., Hellqvist, C., Seven, S., Kalbe, E., & Loewenbrück, F. (2020). Structured care and self-management education for persons with parkinson's disease: why the first does not go without the second—systematic review, experiences and implementation concepts from Sweden and Germany. Journal of Clinical Medicine; 9(9): 2787.

Yue, L., Jia, C., Hu, B., Zhang, Z., Bai, M., Wang, S., & Yao, N. (2022). Caregiving stress among family caregivers of older adults living with disabilities in China. Geriatric Nursing; 47: 226-231.

Zarit, H., Reever, E., and Bach, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 20, 649–655.