

Effect of Instructional Guidelines on Caregivers' Burden of Care and Quality of Life in Parkinson's Patients

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Abstract

Background: Parkinson's is a progressive disease so patients require more and more assistance in everyday life which increase caregivers' burden. Aim of the study was to evaluate effect of instructional guidelines on caregivers' burden of care and quality of life in Parkinson's patients. Design: A quasi-experimental design was used. Setting: The current study was conducted at the neurological outpatient clinics of Benha Teaching Hospital and Benha University Hospital. Subjects: Purposive sample was used in this study. 30% of patients with Parkinson's and their caregivers were chosen randomly from the mentioned setting, the total number 60 patients with Parkinson's and 60 caregivers. Tools of data collection: Three tools were used. I- A structured interviewing questionnaire: consisted of 3 parts to assess: 1) demographic characteristics of Parkinson's patients and their caregivers. 2) The caregiver's knowledge about Parkinson's disease and caregiver's needs and problems. 3) Caregivers' reported practices regarding assistance in daily living activities of Parkinson's patients. II- Zarit Burden Interview (ZBI) to assess caregivers' burden of care. III-PDQ-39 Questionnaire to assess quality of life for Parkinson's patients. Results: of this study showed; 51.7% of Parkinson's patients aged from 61 to 70 years old, 46.7% of caregivers aged from 46 to 55 years old, 73.7% of them were female. 43.3% were caring for their husbands, 70% provided care for ≥ 4 hours/day. Regarding caregivers knowledge; pre-instructional guidelines, 0%, 13.3% of caregivers had good and average total knowledge scores regarding Parkinson's disease and caregiver's needs and problems which increased to 48.3%, 26.7% post- instructional guidelines respectively. The total scores of caregivers' practices were satisfactory for 16.7 % of them before the instructional guidelines and increased to 81.7 % after the instructional guidelines. 81.7% of caregivers had high burden pre- instructional guidelines which decreased to 10% post- instructional guidelines. 26.7% of Parkinson's patients had moderate total quality of life pre-instructional guidelines which increased to 60 % post-instructional guidelines. Conclusion: This study concluded that: the instructional guidelines had a significant effect on the improvement of the caregivers' knowledge, practices and quality of life in Parkinson's patients. There was a significant decrease in caregivers' burden of care. Recommendations: Further studies should be provided to assess factors that increase caregivers' burden of care and affect their quality of life. Community support should be provided to Parkinson's caregivers.

Key words: Instructional guidelines, Caregivers, Burden of Care, Quality of Life and Parkinson's Patients

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I. Introduction

Parkinson's disease (PD) is a neurological disorder in which a gradual loss of brain cells that make and store a neurotransmitter dopamine, which sends messages that control movement. PD is one of the long-term conditions that largely affect the older population over 50 years old (Schrage et al., 2014). One million patients in the United States, and four to six million patients worldwide, are living with Parkinson's (Michael J. Fox Foundation for Parkinson's Research, 2015).

The prevalence of PD in Africa is 160 per 100,000 people and expected to increase by 200% in 2025 if the population structure follows the current predictions. The Egyptian population is characterized by large family units and high rates of birth and consanguinity marriage. Former studies on Arab and North African populations showed that such demographic structure can increase the risk of familial PD. Therefore, the burden of PD will increase (Egyptian Parkinson's Disease Study Group, 2017).

Parkinson's disease is a progressive condition characterized by motor symptoms such as tremors, rigidity, impaired balance and coordination, and non motor symptoms as tiredness, pain, memory problems, sweating, excessive saliva production, sleep problems, dizziness and constipation that can have a profound impact not only on the patients but also on family members who often adopt the role of a caregiver (Clark et al., 2017).

The exact cause of Parkinson's disease is still unknown, while research points to a combination of genetic and environmental factors. Some cases may be caused by genetic factors and others due to environment. Some factors are associated with either greater or lesser risk of Parkinson's disease. These risk factors include; advancing age, family history, male, head injuries and exposure to toxins as pesticides (**American Parkinson Disease Association, 2016**).

Daily living activities with PD is usually a challenge, as postural instability, movement difficulties, and other signs and symptoms can compromise the functional capacity, independence and autonomy of sufferers, necessitating assistance in performing daily activities, such as dressing and feeding oneself, as well as in the instrumental activities of daily living. The need arises for a caregiver to assist in the carrying out of such activities, to preserve bio psychosocial well-being and consequently quality of life (**Ferreira et al., 2017**).

Caregiver burden (CB) refers to the stress and impact of looking after a relative which accompanied by physical, mental, and socioeconomic problems that caregivers may encounter. PD can place significant burden on the caregiver, as they take on more daily tasks and provide physical, emotional, and economic support to patient according to disease progression (**Tew et al., 2013**).

Significance of the study:

Parkinson's patients experience changes that affect them in every aspect of life. Debilitation of PD patients is imminent and they will eventually need help with almost daily activities. As the condition progresses, patients rely more on other people to take care of them. Although there has been a great deal of research conducted on how this disease affects PD patients, there is little knowledge on how their caregivers are affected (**Petracci, 2017**).

Although the seriousness of PD and its direct impact on caregivers, there is little research exposed to the experience of the caregivers with Parkinson's disease. Caregivers face many pressures as, decreased social status, role reversal, loss or decrease of peer and sexual partnership, marital partner's conflict and economic limitations. Little information is available regarding the needs of caregivers. So the need for further research to determine the needs of the caregivers of patient with Parkinson's disease emerged for alleviating burden of care and improving patient's quality of life (**Villiers et al., 2008**).

Aim of the study:

The study aimed to evaluate the effect of instructional guidelines on caregivers' burden of care and quality of life in Parkinson's patients.

Hypothesis:

To fulfill the aim of this study the following research hypotheses formulated:

- 1-The instructional guidelines will improve caregivers' knowledge regarding Parkinson's disease and caregivers' needs and problems. Also caregivers' practices will be improved.
- 2- The instructional guidelines will improve quality of life in Parkinson's patients.
- 3- The instructional guidelines will decrease caregivers' burden of care.

II. Subjects and Methods

Research Design:

A quasi experimental research design was utilized.

Setting:

The current study was conducted at the neurological outpatient clinics at Benha Teaching Hospital and Benha University Hospital.

Subjects:

Purposive sample was used in this study. The total number of Parkinson's patients attending the neurological outpatient clinics in the last six months of (2016) was about 200, 30% of Parkinson's patients and their caregivers were chosen randomly. The total number 60 Parkinson's patients and 60 caregivers, according to the following criteria for the Parkinson's patients:

Inclusion criteria

- Aged from 50-80 years
- Both sexes
- No other medical problems

Data Collection Tools:

Three tools were used by researchers to collect data:

Tool I- A structured interviewing questionnaire, developed by the researchers based on literature review. And written in simple clear Arabic language consisted of **three parts as the following:**

Part one: It was designed to collect data about the demographic characteristics of Parkinson's patients (age, sex, marital status, occupation, educational level and residence) and their caregivers' demographic characteristics. It included questions about age, sex, marital status, occupation, educational level, residence, degree of relationship, living with patient, duration of care, daily time of care and support person.

Part two: It was devoted to assess the caregiver's knowledge about Parkinson's disease, caregiver's needs and problems. It included close-ended questions. The questions covered areas such as, (meaning, causes, stages, signs and symptoms, effect of treatment, most susceptible age group, high risk gender, types of caregiver's problems, types of caregivers problems with patient daily living activities, financial needs, need for knowledge about disease, social needs, emotional needs, need for others support, physical needs and personal needs to provide proper care. These areas included 70 items.

Scoring system: All knowledge variables were scored according to the items included in each question. A question which implies a 4 items answer would have a score of 4 and another that implies 5 items answer would have a score of 5 and so on and each item has answer with " unknown" that implies 0. The score of the items was summed – up and the total divided by the number of the items, giving a mean score for the part and means and standard deviations were computed. Total knowledge score presented in three categories as, Good >75%, average 50 – 75%, and poor <50%.

Part three: Focused on caregivers' reported practices regarding assistance in daily living activities of patient with Parkinson's. These practices covered 7 areas (nutrition, hygiene, treatment and follow up, sleeping, physical activities, transportation and marketing and home duties), which included 33 items.

Scoring system: Practices scoring were calculated as, 2 score for always, 1 score for sometimes and 0 score for never. Practices was calculated and summarized by means and standard deviations in the results. Total practices were considered satisfactory if the score > or equals 60% and considered unsatisfactory if the score < 60%.

Tool II- Zarit Burden Interview (ZBI): It was adopted from (**Grün, et al., 2016**), translated by the researchers to assess caregiver's burden. The ZBI is a questionnaire composed of 22 items. The caregiver indicates the frequency of various social, economic, and health aspects in relation with the caregiving experience on a 5-point Likert scale from 0 (never) to 4 (nearly always).

Scoring system: A total score is calculated by summing the score of items, which ranged from 0 – 88 and presented as; no burden 0-20, moderate burden 21-60, and high burden 61-88.

Tool III- PDQ-39 QUESTIONNAIRE (Cholewa et al., 2014): The Parkinson's disease Questionnaire (PDQ-39) was used to assess quality of life in Parkinson's patients. It is composed of 39 self-report items over 8 dimensions (Mobility 10 items, Activity of daily living 6 items, Emotional wellbeing 6 items, Stigma 4 items, Social support 3 items, Cognitive impairments 4 items, Communication 3 items and Bodily impairment 3 items). Answers of patients with Parkinson's disease was indicated using a 5-point Likert scale from 0 (never) to 4 (always). Questionnaire total score equals 156 points.

Scoring system: Each item scored on likert scale and each dimension score was calculated by summing its items. A total score is calculated by summing the score of the 8 dimensions. Total quality of life score presented in three categories as, low quality >75% (>117 point), moderate quality 50 – 75% (78- 117), and high quality <50% (<78). a higher score representing a lower quality of life.

Validity and reliability of tools:

Validity was checked before the pilot study and the actual data collection, through distribution of tool to five experts in the field of the study, with a covering letter and explanation sheet that explains study, purpose and other related information to ensure appropriateness, relevancy, clarity and completeness of tools. Modifications and changes were done as required. Reliability was measured by using cronbach, alpha test (.882).

Pilot Study:

A pilot study was carried out on 10% of the total study sample to evaluate the clarity and practicability of the tools and estimate time required to fill the questionnaires. There were no unclear questions, or statements. Pilot subjects were later included in the study as no further modifications were required at this stage of tools development.

Ethical Considerations:

The purpose of the study was explained to Parkinson's patients and their caregiver's informed consent was obtained from them to participate in the study. They were given an opportunity to withdraw from the study, they were assured that anonymity and confidentiality of information was protected. Ethics, values, culture, and beliefs were respected.

Field work:

- Official permissions were obtained from the administrative director of Benha University Hospital and Benha Teaching Hospital.
- Each caregiver and patient with Parkinson's was interviewed after illustrating the aim of the study to obtain his / her informed consent to participate in the study.
- Instructional guidelines were constructed by the researchers after reviewing of related literature, then revised and modified according to the expertise comments, it was written in clear, Arabic language
- A pilot study was carried out to test clarity and simplicity of questions.
- Data collection was carried out in the period from beginning February to the end of June 2017, three days weekly for three hours/daily

Guidelines construction:

The current study was carried out on four phases, assessment phase, development phase, implementation phase and evaluation phase:

- 1. Guidelines assessment phase:** A pre assessment was done, using the previous interviewing questionnaires. This phase aimed at collecting data from caregivers and Parkinson's patient and identifying needs of caregivers.
- 2. Guidelines development phase:**
 - The instructional guidelines were developed based on the actual results that were obtained from pre-guidelines assessment, literature review, researchers experience and opinions of nursing and medical expertise's.
 - General objective of the instructional guidelines** was to improve knowledge and reported practices of caregivers.
 - Guidelines contents:** The content of the guidelines was designed to meet caregiver's needs and to fit into their interest and level of understanding. These contents were:
 - **Knowledge about Parkinson's disease**
 - Meaning.
 - Symptoms.
 - Causes.
 - Stages.
 - Treatments.
 - The impact of Parkinson's on everyday life.
 - Access resources.
 - Role in caregiving.
 - **Knowledge about Caregivers' needs and problems**
 - Types of caregivers' problems when assisting Parkinson's patient in daily living activities.
 - Financial needs.
 - Need for information.
 - Social needs.
 - Emotional needs.
 - Need for support.
 - Physical needs.
 - **Practices regarding caregivers' self-care and health**
 - Balanced diet.
 - Practice of hobbies and regular activities.
 - Rest and relaxation techniques.
 - Build in special own time
 - Regular check-ups.
 - **How to organize caregiving time to decrease burden of care.**
 - **How to share care with supported persons.**
 - **How to connect community resources that provide support (medical, financial, social....etc).**

III. Guideline implementation phase:

- The instructional guidelines were discussed with caregivers through 5 sessions, the duration of each session were 30 minutes. The researchers meet each caregiver individually.
- The first session included an orientation about the guidelines and its purpose, also the study tools were filled by caregivers. Parkinson's patients were interviewed in the first session to obtain demographic data and assess their quality of life.
- The instructional guidelines were presented to caregivers in the form of handouts and printed material. It included diagrams, pictures with colors for attracting and guiding caregivers.
- Each session started by a summary about what has been discussed in the previous session

IV. Guidelines evaluation phase

Immediate posttest was done after guidelines implementation using the same data collection tools to evaluate the effectiveness of the instructional guidelines.

Administrative and ethical considerations:

An official permission was obtained using proper channels of communication. Prior to pilot study, an informed consent was obtained from the vice dean for be affairs at which the study was conducted. The investigator took an oral consent from patient, caregivers to participate in the study. The participant has the right to withdraw at any time. Explanation of the procedure and assurance of confidentiality were done.

Statistical analysis

The collected data were verified prior to computerized entry; statistical analysis was done by using the Statistical Package for Social Science (SPSS) version 20. Data were presented in tables by using mean, standard deviation, number, percentage distribution, and Chi- Square. Statistical significance was considered at: P- Value > 0.05 insignificant- Value < 0.05 significant, P- Value < 0.001 highly significant.

V. Results

Table (1) shows that; 51.7% of Parkinson's patients aged from 61 to 70 years old with mean age 58.49 ± 9.53 , 60% of them were male. 65% had secondary education, and 90% of them weren't working. Also, 51.7% of Parkinson's patients were residing in urban.

Table (2) shows that; 46.7% of caregivers aged from 46 to 55 years old with mean age 37.23 ± 9.78 , 73.7% of them were female, 58.3% were married. 51.7% of caregivers had secondary education, and 61.7% of them were working.

Table (3) illustrates that; 43.3% of caregivers were caring for their husbands, 68.3% of them were living with Parkinson's patients. As regards duration of care, 65% of caregivers provided care for < 5 years, 70% of them provided care for ≥ 4 hours/day, and 68.3% of them didn't receive any help.

Table (4) explains that; the caregivers' total mean knowledge score about Parkinson's disease and caregiver's needs and problems was improved significantly post guidelines implementation ($P < 0.001$).

Figure (1) illustrates that, pre-Instructional guidelines; 0%, 13.3% of caregivers had good and average total knowledge scores regarding Parkinson's disease, caregivers' needs and problems which increased to 48.3%, 26.7% post-Instructional guidelines respectively.

Table (5) shows that; the caregivers' total mean practices score about assistance in daily living activities of Parkinson's patients was improved significantly post guidelines implementation ($P < 0.001$).

Figure (2) displays that; the total scores of caregivers' practices were satisfactory for 16.7 % of them before instructional guidelines implementation and increased to 81.7 % post instructional guidelines.

Table (6) shows that; there was improvement in quality of life for Parkinson's patients post guidelines with highly statistical significance in all quality of life related items ($P < 0.001$).

Figure (3) displays that; the total quality of life score for Parkinson's patients was high for 0 % of them pre-instructional guidelines and increased to 40 % post-instructional guidelines. 26.7% of Parkinson's patients had moderate total quality of life pre-instructional guidelines which increased to 60 % post-instructional guidelines.

Table (7) indicates that; there was no significant difference ($P > 0.05$) between total quality of life in Parkinson's patients and caregivers' total knowledge and practices pre-guidelines implementation.

Table (8) indicates that; highly statistical significant difference ($P < 0.001$) between total quality of life in Parkinson's patients and caregivers' total knowledge and practices post-guidelines implementation, this means that when caregivers' knowledge and practices increased, the quality of life in Parkinson's patients increased.

Figure (4) explains that; there was a significant decrease in caregivers' total burden of care, as 81.7% of them had high burden pre-guidelines which decreased to 10% post-guidelines.

Table (9) illustrates that; there was highly negative association between Parkinson's caregivers' total burden of care and their total knowledge and practices pre/post-instructional guidelines; this means that when caregivers' knowledge and practices increased their burden of care decreased.

Table (1) Distribution of Parkinson's patients regarding their demographic characteristics (n=60).

Demographic characteristics	No.	%
Age in years		
51-60	11	18.3
61-70	31	51.7
71- 80	18	30.0
Mean ±SD	58.49±9.53	
Educational qualification		
Basic education	8	13.3
Secondary education	39	65.0
Universal education	13	21.7
Gender		
Male	36	60.0
Female	24	40.0
Marital status		
Married	43	71.7
Not married	17	28.3
Residence		
Urban	31	51.7
Rural	29	48.3
Occupation		
Working	6	10.0
Not working	54	90.0

Table (2) Distribution of Parkinson's caregivers regarding their demographic characteristics (n=60).

Demographic characteristics	No.	%
Age in years		
25-35	10	16.7
36-45	22	36.7
46-55	28	46.7
Mean ±SD	37.23±9.78	
Educational qualification		
Basic education	8	13.3
Secondary education	31	51.7
Universal education	21	35.0
Gender		
Male	16	26.7
Female	44	73.3
Marital status		
Married	35	58.3
/Not married	25	41.7
Residence		
Urban	31	51.7
Rural	29	48.3
Occupation		
working	37	61.7
Not working	23	38.3

Table (3) Distribution of caregivers regarding their caregiving experience (n=60).

Caregiving experience	No.	%
Degree of relation with client		
Son	7	11.7
Husband	8	13.3
Daughter	11	18.3
Wife	26	43.3
Father/mother	8	13.3
Living with person with Parkinson's		
Yes	41	68.3
No	19	31.7
Duration of care		
Less than 5 years	39	65.0
More than 5 years	21	35.0
Daily time of care		
Less than 4 hours	18	30.0
≥ 4 hours	42	70.0
Other persons help you		
No	41	68.3
Yes	19	31.7

Table (4): Mean knowledge score of caregivers regarding Parkinson's disease, caregiver's needs and problems pre and post instructional guidelines. (n=60)

Knowledge	No of items	Pre-instructional guidelines.	Post-instructional guidelines.	Paired t test	P value
		Mean ±SD	Mean ±SD		
Parkinson's disease:					
Meaning	2	.6833±.65073	1.4000±.82749	-5.019	<0.001
Causes	3	.8667±.87269	2.0333±1.11942	-6.732	<0.001
Stages	2	.5500±.59447	1.3833±.73857	-7.132	<0.001
Signs and symptoms	16	4.6167±2.08377	11.3167±4.02741	-12.809	<0.001
Effect of treatment	2	.4333±.64746	1.3333±.81650	-6.621	<0.001
Most susceptible age group	3	.4667±.62346	2.0833±1.02992	-11.824	<0.001
High risk gender	3	.7333±.75614	2.2167±.97584	-8.871	<0.001
Parkinson's caregivers' needs and problems					
Types of caregivers problems	4	.7667±.78905	2.7167±1.41531	-9.384	<0.001
Types of caregivers problems with patient daily living activities	4	1.2167±.80447	2.5667±1.59837	-5.895	<0.001
Financial needs	5	1.8333±1.06033	3.4667±1.76084	-6.005	<0.001
Need for knowledge about disease	5	1.6667±1.00282	3.4333±1.68107	-7.571	<0.001
Social needs	5	1.2667±1.05552	3.3167±1.78023	-8.360	<0.001
Emotional needs	4	1.1667±.92364	2.4333±1.40660	-5.621	<0.001
Need for others support	4	.9833±.79173	2.4000±1.39247	-6.610	<0.001
Physical needs	3	.7500±.70410	1.7667±1.16977	-5.641	<0.001
Personal needs to provide proper care	5	.8500±1.17639	3.2333±1.43050	-9.600	<0.001
Total knowledge	70	18.8500±6.527	47.100±16.09	24.007	<0.001

Figure (1): Distribution of caregivers' total knowledge regarding Parkinson's disease and caregiver's needs and problems pre and post instructional guidelines. (n=60)

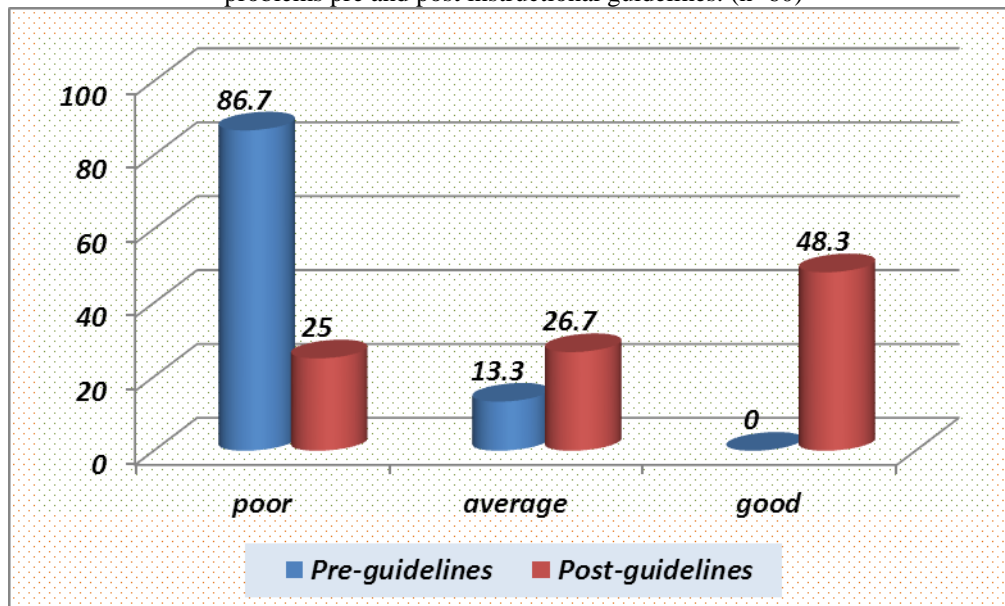


Table (5): Mean practices score of caregivers regarding assistance in daily living activities of Parkinson's patient pre and post instructional guidelines. (n=60)

Practices	No of items	Pre- instructional guidelines	Post- instructional guidelines	Paired t test	P value
		Mean ±SD	Mean ±SD		
Nutrition	6	1.7500±1.14426	4.3333±1.29754	-10.592	<0.001
Hygiene	6	1.6500±1.19071	4.3833±1.76685	-8.721	<0.001
Home duties	5	1.3167±.99986	3.3833±1.68836	-8.258	<0.001
Sleeping	4	.9000±1.06882	2.9500±1.19922	-9.931	<0.001
Physical activity	5	1.2500±.93201	3.7000±1.51042	-11.639	<0.001
Treatment and follow up	4	1.1167±.76117	2.6333±1.10418	-8.490	<0.001
Transportation and marketing	3	.9000±.81719	2.1167±1.04300	-7.092	<0.001
Total	33	8.8833±3.44984	23.5000±6.08276	-14.633	<0.001

** Highly statistically significant difference (P < 0.001).

Figure (2): Distribution of caregivers' total practices regarding assistance in daily living activities of Parkinson's patient pre and post instructional guidelines. (n=60)

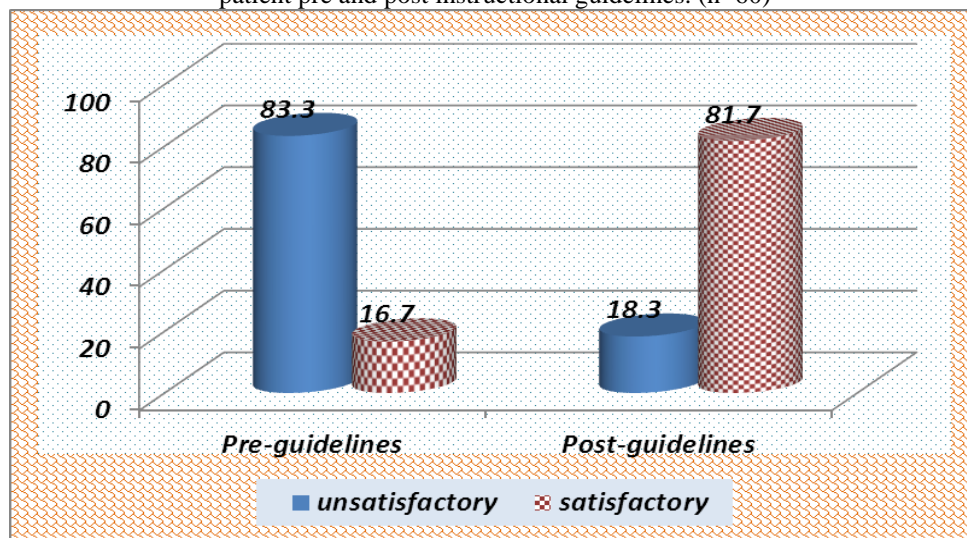


Table (6): Mean and standard deviation of Parkinson's patients regarding their quality of life pre and post instructional guidelines. (n=60)

Practice	No of items	Pre- instructional guidelines	Post- instructional guidelines	Paired t test	P value
		Mean ±SD	Mean ±SD		
Mobility	40	14.3667±3.67754	28.1667±4.25925	-21.021	<0.001
Activity of daily living	24	10.7500±2.36231	18.6667±1.52567	-27.078	<0.001
Emotional wellbeing	24	10.1833±2.22841	19.0333±2.30671	-26.813	<0.001
Stigma	16	6.9000±1.72420	10.6500±1.47090	-12.410	<0.001
Social support	12	4.8333±.97714	9.1500±1.23268	-23.350	<0.001
Cognitive impairments	16	7.1500±1.66545	9.7667±2.93065	-6.068	<0.001
Communication	12	5.4000±1.68945	9.0833±.96184	-14.546	<0.001
Bodily discomfort	12	4.3000±2.01099	8.9500±1.01556	-15.523	<0.001
Total quality	156	64.5554±6.95641	114.2712±4.78442	-42.505	<0.001

** Highly statistically significant difference (P < 0.001).

Figure (3): Distribution of Parkinson's patients regarding their total quality of life pre and post instructional guidelines. (n=60)

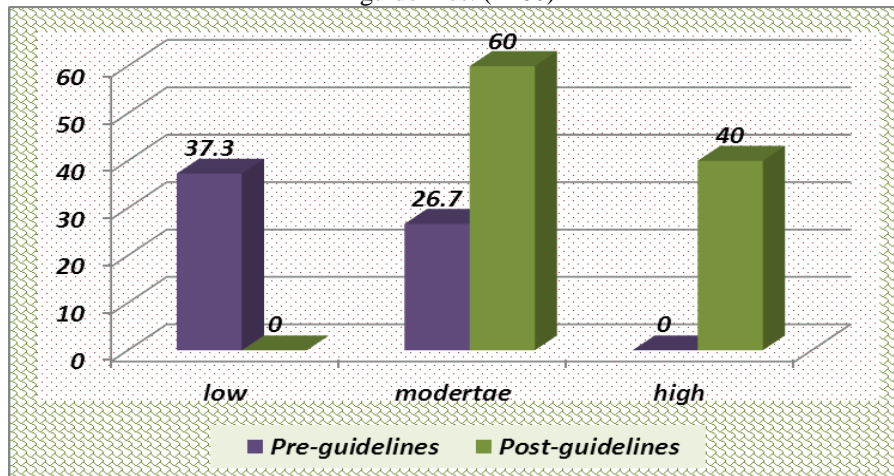


Table (7): Relationship between total quality of life in Parkinson's patients and caregivers' total knowledge and practices pre-instructional guidelines.

Variables	Score	Total quality of life pre-instructional guidelines	Independent t test	P value
		Mean ±SD		
Total practice pre- instructional guidelines	Unsatisfactory	64.6400±7.29204	0.297	>0.05
	Satisfactory	64.1000±4.72464		
Total knowledge pre- instructional guidelines	Poor	64.4808±7.18520	0.256	>0.05
	Average	65.0000±4.98569		
	Good	68.6964±9.89780		

Table (8): Relationship between total quality of life in Parkinson's patients and caregivers' total knowledge and practices post- instructional guidelines.

Variables	Score	Total quality of life post-instructional guidelines	Independent t test / F test	P value
		Mean ±SD		
Total practice post- instructional guidelines	Unsatisfactory	108.7273±5.27429	4.04	<0.001**
	Satisfactory	115.4898±3.65218		
Total knowledge post- instructional guidelines	Poor	109.8000±3.44757	40.18	<0.001**
	Average	111.8125±3.48748		
	Good	117.8966±2.69052		

Figure (4): Distribution of caregivers regarding total burden of care pre and post instructional guidelines. (n=60)

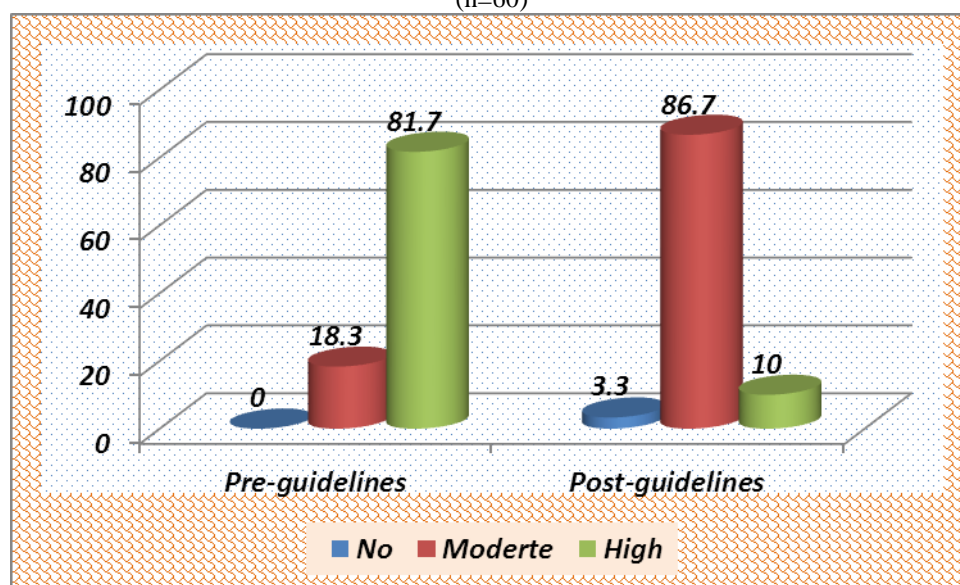


Table (9): Correlation between caregivers' total burden of care and their total knowledge and practices pre/post- instructional guidelines.

Variables	Total burden of care pre-instructional guidelines		Total burden of care post-instructional guidelines	
	R	P value	R	P value
Total knowledge pre- instructional guidelines	-0.072	0.584	-	-
Total practices pre- instructional guidelines	-0.369**	0.004	-	-
Total knowledge post- instructional guidelines	-	-	-0.322*	0.012
Total practice post- instructional guidelines	-	-	0.838	<0.3001**

VI. Discussion

Concerning demographic characteristics of Parkinson's patients table 1. The finding of the present study showed that, more than half of patients aged from 61 to 70 years old with mean age 58.49 ± 9.53 years, three-fifth of them were male. Also, more than half of patients were residing in urban. This finding in the same line with (Soleimani et al, 2016) who found that, around three-fifth of the respondents was males. While incongruent with (Corallo et al., 2017), who reported that, Parkinson's patients had an average age of 73.5 ± 8.3 years. Also (Horsfall et al., 2013) agreed that the urban population had higher incidence rate of Parkinson's than rural population.

With regard to demographic characteristics of caregivers table 2: about half of caregivers aged from 46 to 55 years old. Nearly three-quarters of them were female. This supported by (Tan et al., 2010) reported that the majority of caregivers were 51 to > 61 years of age and 78.7% of caregivers were female.

More than half of caregivers were secondary educated and three-fifths were working. In contrast with (Tew, 2013) who clarified that over half of caregivers were retired and 29.6% continued their education at University.

Regarding caregivers experience table 3: Two-fifths of caregivers were caring for their husbands and around three-quarters of them living with the patients. This result was in agreement with (Tan et al., 2010) who found that most of the caregivers were the spouses and lived with the care recipients.

As regards duration of care, more than three-fifths of caregivers provided care for < 5 years, around three-quarters of them provided care for ≥ 4 hours, and didn't receive any help. This disagreed with (Villiers, 2008) who found that the median time period which caregivers had cared for the Parkinson's patient was 7 years and 61% of them received adequate support. While in the same line with (Tew, 2013) who reported, caregivers had been caring for the patient for around four years.

Respecting caregivers' knowledge regarding Parkinson's disease, caregiver's needs and problems table 4 & figure 1, none of caregivers had good total knowledge score pre- instructional guidelines which increased to

around half of them had good total knowledge score post-instructional guidelines with significant improvement. Similarly with (Corallo, 2017) who stated that caregivers do not have sufficient information about Parkinson's disease and its impacts on patients and caregivers. Special education programs would increase the awareness and knowledge about Parkinson's disease among caregivers. Also, agreed with (Gultekin et al., 2017) who reported that education programs may have a positive effect on imparting knowledge of the caregivers of Parkinson's patients.

Considering caregivers' practices regarding assistance in daily living activities of Parkinson's patients table 5 & figure 2, total practices scores was improved significantly post guidelines implementation. This reflected the importance of caring for caregivers and improving their functioning through educational interventions. In the same line with (Ferreira et al., 2017) who reported how important to improve the support provided to the caregiver, either through the availability of knowledge and the management practices of the disease or accessibility to quality content, this will enable the caregiver to understand and deal with Parkinson's patients. Also similar to (Tew et al., 2013) told supported knowledge and practices for caregivers can significantly improve daily living activities.

There was highly statistical significant improvement in Parkinson's patients' quality of life post instructional guidelines as, two-fifth of them had high quality of life, and three fifth had moderate quality of life table 6 & figure 3. This result agreed with (Clark et al., 2017) who found that Parkinson's disease participants reported a significant improvement in quality of life scores and 55% of them had increased quality five points and over post program. This may be related to the impact of Parkinson's disease progression and gradual loss of motor and non-motor functions which mainly affect quality of life.

In the present study, there was no significant relation ($P>0.05$) between Parkinson's patients total quality of life and caregivers' total knowledge and practices pre-instructional guidelines, while post instructional guidelines highly statistical significant relation ($P<0.001$) was found between Parkinson's patients' total quality of life and caregivers' total knowledge and practices. This reflected that the Parkinson's patients quality of life mainly affected by caregivers knowledge and practices level. This result supported by (Gultekin et al., 2017) they founded that the Parkinson's patient treatment and well-being may be negatively affected by decreased level of caregivers knowledge, perception and training. Also agreed with (Duncan & Rositano, 2011) they reported that many of Parkinson's patients' problems might be overcome and quality of life could be improved by increased caregiver's knowledge and awareness.

The current study showed a significant decrease in caregivers' total burden of care, as four-fifth of them had high burden pre-instructional guidelines decreased to one-ten post instructional guidelines. This might be related to that, instructional guidelines concerned with solving problems facing caregivers and fulfill their needs. Similar to (Baik et al., 2017) they reported that perceiving the difficulties and needs of caregivers early can help to prevent and decrease the burden of Parkinson's disease. Also (Corallo et al., 2017) emphasized the importance of implementing early instructional guidelines to prevent and ameliorate caregiver's burnout.

In the current study, there was highly negative association between caregivers' total burden of care and their total knowledge and practices pre/post-instructional guidelines; this means that when caregivers' knowledge and practices increased their burden of care decreased. Similar to (Ferreira et al., 2017) they found that caregivers facing a challenge of inadequate knowledge and practices about Parkinson's disease which hinder understanding of the health-disease process and contribute to physical and emotional exhaustion. So, providing suitable knowledge and practices help to minimize caregivers' burden of care.

VII. Conclusion

According to results this study concluded that: the instruction guideline had a significant effect on the improvement of the caregivers' knowledge and practices and quality of life in Parkinson's patients. There was a significant decrease in caregivers' burden of care. There was highly statistical significant difference ($P<0.001$) between total quality of life in Parkinson's patients and caregivers' total knowledge and practices post-guidelines implementation There was highly negative association between caregivers' total burden of care and their total knowledge and practices pre/post- instructional guidelines

VIII. Recommendations

- 1- Further studies should be provided to assess factors that increase caregivers' burden and affect their quality of life.
- 2- This instructional guidelines should be applied on a wide range.
- 3- Community support governmental or non- governmental should be provided to Parkinson's caregivers.

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