HOSTED BY

Contents lists available at ScienceDirect

# Saudi Pharmaceutical Journal

journal homepage: www.sciencedirect.com



# Original article

# Level of knowledge and quality of life among Saudi caregivers of Parkinson's disease patients: A study from a tertiary hospital in Riyadh, Saudi Arabia



Abdulhadi A. Al Ofair <sup>a</sup>, Muhanned Alamri <sup>b</sup>, Sultan H. Alshehri <sup>a</sup>, Ziyad A. Alzahrani <sup>a</sup>, Alwaleed K. Alrumaih <sup>a</sup>, Wajid Syed <sup>c</sup>, Mohamed N. Al-Arifi <sup>c</sup>, Moahmmed A. Assiri <sup>d</sup>, Taim A. Muayqil <sup>e</sup>, Abdulrahman Alwhaibi <sup>c,\*</sup>

- <sup>a</sup> College of Pharmacy, King Saud University, Riyadh 11451, Saudi Arabia
- <sup>b</sup> College of Medicine, King Saud University, Riyadh, Saudi Arabia
- <sup>c</sup> Department of Clinical Pharmacy, College of Pharmacy, King Saud University, Riyadh 11451, Saudi Arabia
- <sup>d</sup> Department of Pharmacology & Toxicology, College of Pharmacy, King Saud University, Riyadh 11451, Saudi Arabia
- <sup>e</sup> Neurology Unit, Department of Medicine, College of Medicine, King Saud University, Riyadh, Saudi Arabia

#### ARTICLE INFO

#### Article history: Received 10 May 2023 Accepted 27 August 2023 Available online 9 September 2023

Keywords:
Parkinson's disease
Caregivers
Knowledge
Attitude
Quality of life

#### ABSTRACT

*Purpose*: We aimed to assess the family caregivers' level of knowledge and attitudes about Parkison's disease (PD), identify factors affecting their knowledge, evaluate their quality of life (QoL) and factors influencing it and to define the effect of PD on activities of daily living (ADLs) of PD patients.

Method: We developed and validated a questionnaire to assess the level of knowledge and attitudes of family caregivers toward PD, effects of PD on caregivers' QoL as well as its effects on activities of daily living (ADLs) of patients from the caregivers' perspective. A scoring system was utilized and SPSS was used to evaluate the differences in responses between the groups; p < 0.05 indicated statistical significance

Results: 69 caregivers and their corresponding patients were included in the study. Family caregivers had a low level of knowledge, as reflected by a mean score of 3.45 out of 8. However, 62.3% were aware of all medications used by their patients. Additionally, the level of knowledge was associated with caregivers' gender as 57.1% of the female caregivers had medium PD knowledge scores while 58.5% of the male had low scores (p = 0.038). The level of knowledge was also associated with daily caregiving hours as only 44.5% of caregivers whom spending 0–5 h/day had medium and high knowledge scores while greater proportions with same scoring levels were found among those providing care > 5 h/day (75.0% in > 5–10 hrs; 52.4% in > 10–24 hrs; p = 0.024). Most caregivers confirmed their QoL had declined, yet the male caregivers had better QoL than females (p = 0.026). Longer caregiving time was associated with decline (p = 0.016) and severe effect on QoL of caregivers (p = 0.04).

Conclusion: Caregivers of PD patients had a low level of knowledge. Female caregivers had significantly higher level of PD knowledge than their male counterparts. Low level of PD knowledge was significantly associated with shorter caregiving time per day. Longer caregiving time was significantly associated with a decline in caregivers' QoL. Increasing awareness and knowledge among caregivers is necessary to ensure better treatment outcomes and improve the QoL of both caregivers and patients.

© 2023 The Author(s). Published by Elsevier B.V. on behalf of King Saud University. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

E-mail addresses: wali@KSU.EDU.SA (W. Syed), malarifi@KSU.EDU.SA (M.N. Al-Arifi), moassiri@KSU.EDU.SA (M.A. Assiri), tmuayqil@KSU.EDU.SA (T.A. Muayqil), aalwhaibi@KSU.EDU.SA (A. Alwhaibi).

Peer review under responsibility of King Saud University.



Production and hosting by Elsevier

# 1. Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disease characterized by muscle stiffness, slow movement, tremors, and postural instability (Radhakrishnan and Goyal, 2018; Armstrong and Okun, 2020). As the disease progresses, motor symptoms worsen, and patients develop non-motor and neuropsychiatric deficits.

<sup>\*</sup> Corresponding author.

Overall, patients with PD experience a continuous decline in both their physical and cognitive abilities (Pan et al., 2014).

Epidemiological studies have shown that the prevalence of PD ranges from 41 per 100,000 people in the fourth decade of life to>1,900 per 100,000 people aged  $\geq$  80 years (Pringsheim et al., 2014), making it the second most common neurodegenerative disorder after Alzheimer's disease (AD). In the Saudi population, the estimated prevalence of PD is 27 per 100,000 (Al Rajeh et al., 1993).

According to a prospective observational study conducted in several centers, delayed treatment of PD may lead to worse patient outcomes, possibly due to the onset of functional decline that is difficult to reverse (Grosset et al., 2007). Additionally, as the disease progresses, activities of daily living (ADLs) become difficult for patients to perform; therefore, they gradually require assistance in all aspects of life and eventually become completely dependent on caregivers (White and Palmieri, 2022). Consequently, due to their role, these caregivers bear physical and psychosocial stresses and strains. Therefore, to optimize assistance for patients with PD and improve their lives, knowledge regarding treatment options, insights into patients' and family caregivers' ultimate treatment goals, and clarification of the disease's impacts on both sides are crucial.

Several studies have assessed caregivers' knowledge regarding various diseases, such as epilepsy (Saengsuwan et al., 2013) and AD (Park et al., 2015), and the related burdens for caregivers. Regarding research on caregivers of patients with PD, one study was conducted on 80 caregivers in Turkey but did not examine the impacts on the caregivers' quality of life (QoL) (Gultekin et al., 2017). Meanwhile, Martínez-Martín et al. reported a significant association between disease severity, caregivers' gender, and caregivers' QoL, while no impact of their age and education levels on QoL (Martínez-Martín et al., 2005). Similarly, studies in the UK have shown an association between caregivers' QoL and gender and long duration conditions (Morley et al., 2012). In South Korea, gender of caregivers has been shown to have no impact on their QoL, while the QoL among those who were older and employed was better (Lee et al., 2019). On the other side, the patient's gender (female), duration of illness, patients' comorbidities, and worsened ADLs were significantly linked to lower QoL of caregivers. Despite these studies, none has examined caregivers' knowledge or attitudes about the disease.

In Saudi Arabia, although one study assessed public knowledge and awareness of PD (Alyamani et al., 2018), none has been conducted to assess caregivers' knowledge and attitudes toward PD or the disease's impact on their QoL. Overall, the lack of such studies represents a roadblock to communication between caregivers and healthcare providers and perpetuates the low care quality and QoL for PD patients. Therefore, the overall goal of this study was to investigate caregivers' knowledge and attitudes toward PD and how it affects their QoL as part of a holistic approach to understanding and improving the care quality and QoL of patients with PD.

## 2. Materials and methods

## 2.1. Participants

The study was conducted on caregivers of patients with PD admitted to the Movement Disease Clinic and Neurology Department at King Saud University Medical City between April 2015 and February 2022 after receiving IRB approval (E-22–6630). All patients admitted to the neurology clinic were reviewed for eligibility. Patient data, including diagnoses, contact numbers, medications, and the contact numbers of the family caregivers was extracted. Caregiver were called and verified and the study pur-

pose was explained to them. Caregiver were also asked about their willingness to participate in the study and informed consent was obtained prior to completing the questionnaire.

#### 2.2. Measurements

A questionnaire, which was developed based on relevant studies (Yadav et al., 2012; Gultekin et al., 2017; Jitkritsadakul et al., 2017; Cole et al., 2014) to fulfill the aim of the study, comprised five sections: patients' characteristics, caregivers' characteristics, the level of knowledge and attitude of caregivers towards PD, the effect of PD on caregivers' lives, and the effect of PD on the ADLs of patients from caregivers' perspectives. Eight questions, which were adopted from other studies (Yadav et al., 2012; Gultekin et al., 2017; Jitkritsadakul et al., 2017; Cole et al., 2014) and modified for use in this study, were used to assess the knowledge levels of the caregivers; one point was awarded for each question answered correctly; zero was given to question answered incorrectly [Range of score: 0 (minimum) to 8 (maximum)]. To assess the effect of PD and the extent to which it impacts caregivers' QoL, we adopted a Likert-scale assessment tool comprising 12 variables based on a study evaluating the QoL of caregivers of Alzheimer's disease (AD) patients (Cole et al., 2014). For each variable, one point was awarded for each statement if participants confirmed the existence of that variable in their lives; zero was awarded if they declined their existence (min. = 0, max. = 12), and the sum of the points was calculated for comparison. To evaluate the extent to which each variable influenced caregivers' quality of life, we asked each caregiver to select one of five answers from not at all (score of 0) to extremely (score of 4); the sum of answers was also calculated for comparison. To evaluate the severity of the disease in patients and its impact on their QoL from caregivers' perspective, we employed the Parkinson's Disease Activities of Daily Living Scale adopted from a previously published study (Hobson et al., 2001).

The questionnaire reliability test revealed an acceptable level of internal consistency. The Cronbach's alpha coefficient was calculated using responses from 10 randomly selected family caregivers to 20 questions assessing their knowledge of PD and its impact on their quality of life (Cronbach's alpha = 0.849).

# 2.3. Data analysis

Data analysis was performed using SPSS statistical software package version 28 (SPSS Inc. Armonk, New York, United States). Descriptive analysis was used to estimate frequencies and chisquare test was used to assess group differences. Additionally, an independent t-test was used to assess the significance of the mean difference between the groups when required. Statistical significance was set at p < 0.05.

## 3. Results

Between April 2015 and February 2022, 269 patients diagnosed with PD were identified, of which 39 died, 24 had no family caregivers, 21 had incorrect contact numbers, 72 did not respond, 38 declined to participate in the study, and 6 were later identified as having Parkinsonism. Hence, 69 patients and their corresponding caregivers were included for participation in this study.

More than half of the patients and their family caregivers were male and patients were significantly older than caregivers (53.6%; 73.9 years vs. 59.4%, 43.2 years, respectively). In addition, most of the family caregivers identified themselves as sons/daughters (94.2%), whereas 5.8% were spouses. The mean duration of the disease was approximately 10 years. Of the caregivers, 72.5% were

university graduates, and 62.4% were currently employed. Additionally, 52.2% provided caregiving for  $\leq$ 5 h/day; 52.5% had missed  $\leq$ 5 days in the past 6 months prior conducting this study due to caregiving duties. Further details regarding the caregivers' characteristics are provided in Table 1.

Family caregivers had a low level of knowledge, as reflected by a mean score of 3.45 out of 8, as shown in Table 2. Only one-third (33.3%) of caregivers were aware of the decline in the efficacy of medications over time as the disease progressed. Of those caregivers who heard about surgery as a treatment for PD (n = 31), a few (19.4%) knew that surgery was not more effective than oral treatment. Further information on the proportion of caregivers answering knowledge-related questions is provided in Table 2.

Regarding caregivers' attitudes, 50.7% believed that the number of medications used to treat their patients would not increase over time, whereas 62.3% were aware of all prescription medications and how they were used by their patients (data available upon request).

Regarding the influence of caregiving on QoL, approximately 94% of the caregivers reported the existence of  $\geq 1$  factor; however, the majority (78.2%) also confirmed experiencing  $\geq 5$  factors that negatively impact their QoL, including frustration, sadness, loneliness, worry, and stress, impact on their physical health, sleep, time,

 Table 1

 Demographic data of Parkinson's disease patients and caregivers.

Characteristic	Patients (n = 69)	Caregivers (n = 69)
Male gender [n (%)]	37 (53.6)	41 (59.4)
Relationship with the patient [n (%)]		
Son/daughter	NA	65 (94.2%)
Spouse	NA	4 (5.8%)
Duration of illness [Years, Mean ± SD]	$9.9 \pm 6.6$	NA
Age [Years, Mean ± SD]*	73.9 ± 8.98	43.2 ± 11.3
The age group of patients [n (%)]		
52 to 75 years	36 (52.2)	NA
> 75 to 91 years	33 (47.8)	NA
The age group of caregivers [n (%)]		
22 to 35 years	NA	23 (33.3)
> 35 to 50 years	NA	27 (39.1)
> 50 to 73 years	NA	19 (27.5)
Education level of caregivers [n (%)]		` ,
Elementary	NA	16 (23.2)
Secondary	NA	3 (4.3)
University	NA	50 (72.5)
Diploma	NA	5 (10)
Bachelor	NA	36 (72)
Master	NA	4(8)
PhD	NA	5 (10)
Occupation of caregivers [n (%)]		- ()
Working	NA	43 (62.4)
Retired	NA	7 (10.1)
Not working	NA	19 (27.5)
Occupation status of caregivers [n (%)]		10 (27.0)
Full time	NA	40 (58.0)
Part-time	NA	3 (4.3)
NA	NA	26 (37.7)
Hours of caregiving/day [Mean ± SD]	NA	9.1 ± 9.0
Hours of caregiving/day [n (%)]	1471	5.1 2 5.0
0 to 5	NA	36 (52.2)
> 5 to 10	NA NA	12 (17.4)
> 10 to 24	NA	21 (30.4)
Missing days from work due to caregivi		
[n (%)]	ing duties over the	pust o month.
0–5	NA	36 (52.5)
6–10	NA NA	3 (4.3)
0–10 11–15	NA NA	1 (1.4)
11–13 16–20	NA NA	1 (1.4)
10–20 21–24	NA NA	2 (2.9)
∠1= <del>∠-1</del>	INA	Z (Z.J)

NA: Not applicable.

**Table 2**Proportion of caregivers answering knowledge-related questions and an overall score of knowledge according to their response (n = 69).

Item	Correct answer [n (%)]	Wrong answer [n (%)]	I don't know [n (%)]
Describe Parkinson's Disease	36 (52.2)	31	2 (2.9)
		(44.9)	
Does the disease cause any symptoms	36 (52.2)	24	9 (13.0)
other than movement symptoms?		(34.8)	
What do you understand about the actual	41 (59.4)	26	2 (2.9)
goals?		(37.7)	
Effect of exercise on Parkinson's disease	33 (47.8)	18	18
		(26.1)	(26.1)
Knowing treatments other than oral	32 (46.4)	25	12
treatments		(36.2)	(17.4)
Have you heard of surgery being used for	31 (44.9)	38	
Parkinson's disease?		(55.1)	
Is surgery more effective than oral	6 (19.4)	10	15
medication?		(32.2)	(48.4)
Describe the benefit of the medication	23 (33.3)	41	5 (7.2)
over time.		(59.4)	
Mean score of knowledge [0 – 8, Mean ± SD]	3	3.45 ± 1.75	

Note: All participants answering "I don't know" were considered wrong when calculating the total score of knowledge.

social activities, relationship with PD patients, relationship with friends and family, and personal finance, as shown in Table 3. When the experience of each factor was counted for each caregiver, the overall mean score was 7.3 out of 12. Further information on the proportion of caregivers who experienced each factor is presented in Table 3.

We evaluated the magnitude to which each factor affected the QoL of the caregivers. Considering 0 (*not at all*) and 4 (*extreme impact on life*), a mean score of 20.54 out of 48 was estimated for all caregivers. Further details are presented in Table 4.

**Table 3**Caregivers agreement on factors resulted from or impacting their QoL and the overall score according to their response (n = 69).

Variable	Yes [n (%)]	No [n (%)]
Frustration	41	28
	(59.4)	(40.6)
Sadness	50	19
	(72.5)	(27.5)
Loneliness	32	37
	(46.4)	(53.6)
Worrisome	50	19
	(72.5)	(27.5)
Stress	49	20 (29)
	(71.0)	
Impact on physical health	38	31
	(55.1)	(44.9)
Impact on sleep	48	21
	(69.6)	(30.4)
Impact on time	42	27
	(60.9)	(39.1)
Impact on social activities	39	30
	(56.5)	(43.5)
Impact on relationship with PD patients	44	25
	(63.8)	(36.2)
Impact on relationships with friends and family	43	26
	(62.3)	(37.7)
Impact on personal finance	28	41
	(40.6)	(59.4)
Mean score for the impact on quality of life [0-12, Mean ± SD]	7.3 ±	3.59

Significant difference between patients and caregivers' groups (p < 0.0001).

Answers from 31 caregivers only who have heard of surgery used for PD.

**Table 4**The magnitude of the impact of each variable on the quality of life of caregivers [0 not at all - 4 extremely] and the overall score of severity according to their response (n = 69).

Item	0 [n]	1 [n]	2 [n]	3 [n]	4 [n]
Frustration	28	7	14	9	11
Sadness	19	6	15	14	15
Loneliness	37	5	12	6	9
Worrisome	19	9	9	17	15
Stress	20	9	10	19	11
Impact on physical health	31	5	16	4	13
Impact on sleep	21	5	15	14	14
Impact on time	27	6	13	9	14
Impact on social activities	30	4	12	12	11
Impact on relationship with PD patients	25	2	3	3	36
Impact on relationships with friends and family	26	7	7	8	21
Impact on personal finance	41	4	11	3	10
Total score for the severity of the impact of all variables on the quality of life of the caregiver (no effect = 0, very much = 4; 48 is the worst) [Mean ± SD]			20.54 ± 11.72		

To investigate any associations between caregivers' knowledge and their baseline characteristics, the total knowledge scores were divided into three levels: low (0-3), medium (>3-5), and high (>5-8). No significant association was found between caregivers' level of knowledge and their age (p=0.190), education level (p=0.828), occupation (p=0.640), occupation status (p=0.879), age group of patients (p=0.278), or gender of patients (p=0.761), as shown in Table 5a. Nor was any association observed with assessed severity of patients' disease (p=0.790). It is worth mentioning that of PD patients who extremely affected by the disease (23 (33.3%)), three had their caregivers categorized under the high-knowledge level group, while 10 were in the moderate and 10 in the low-knowledge level group.

Days missed from work by the caregivers due to caregiving duties and during the past 6 months before conducting the study was also assessed for any association with their level of knowledge; however, no significant association was noted (p = 0.458). Despite the caregivers' level of knowledge, the majority (82.4% – 85%; mean 83.6%) had missed only 0–5 days. Intriguingly, none of the high-

knowledge level caregivers had missed > 10 days, while it occurred for one and three caregivers with medium and low knowledge level, respectively. Further details are provided in Table 5a.

Interestingly, a significant association was observed between caregivers' level of knowledge and their gender as well as the hours of caregiving (p = 0.038 and p = 0.024, respectively), shown in Table 5a. In other words, 58.5% of all male caregivers were categorized into the low knowledge level group, whereas 57.1% of all female caregivers were categorized into the medium knowledge level group, as shown in Table 5b.

Regarding the association between hours of caregiving and caregivers' level of knowledge, 44.5% of caregivers providing the least daily caregiving time (0–5 h) were categorized in the medium–high knowledge levels; while 75.0% of those providing > 5 to 10 h and 52.4% of those providing > 10 to 24 h of caregiving were categorized in the aforementioned level (See Table 5c).

The impact of caregivers' level of education and gender on their QoL was also evaluated. Although the association was not significant, higher education was associated with an increase in QoL (av-

**Table 5a**Association between demographic data and level of knowledge of caregivers.

Level of knowledge	Low (0 to 3) [n (%)]	Medium (>3 to 5) [n (%)]	High (>5 to 8) [n (%)]	P-value
Age group of caregivers	33 (47.8)	27 (39.1)	9 (13.1)	0.190
Gender of caregivers				0.038
Education level of caregivers				0.828
Occupation of caregivers				0.640
Occupation status of caregivers				0.879
Hours of caregiving				0.024
Age group of patients				0.278
Gender of the patients				0.761
Severity of the disease of the patients				0.790
Missing days from work over the past 6 months due to caregiving duties	20 (64.5)	17 (39.5)	6 (14.0)	0.458

<sup>¶</sup> Missing answers from 15 caregivers.

**Table 5b** Association between gender of caregivers and level of knowledge.

Level of education		Low	Medium	High
Gender of caregiver	Male [n (%)]	24 (58.5)	11 (26.8)	6 (14.6)
	Female [n (%)]	9 (32.1)	16 (57.1)	3 (10.7)

**Table 5c**Association between daily hours of caregiving and level of knowledge of caregivers.

Level of education		Low	Medium	High
Hours of caregiving	0 to 5 [n (%)]	20 (55.5)	14 (38.9)	2 (5.6)
	>5 to 10 [n (%)]	3 (25)	4 (33.3)	5 (41.7)
	>10 to 24 [n (%)]	10 (47.6)	9 (42.9)	2 (9.5)

erage score of quality of life was 8.4 vs. 7.7 vs. 6.9 in elementary vs. secondary vs. university graduates, respectively). Regarding gender, a higher proportion of those with good QoL and significantly better average QoL scores were observed in males compared to females (29.3% with score of 6.5 vs. 10.7% with score of 8.5, respectively) (data available upon request).

A significant association was revealed when we evaluated the impact of caregiving hours per day on the caregivers' QoL (categorized total QoL score of caregivers (0-4 vs. > 4-8 vs. > 8-12)). We found that longer caregiving time was significantly associated with the highest proportion of those with very declined QoL (p = 0.016); 71.4% of those who provided caregiving of > 10 hr/day (n = 15 of 21) had a significant decline in their QoL and scored > 8-12 vs. 50.0% (n = 6 of 12) among those who provided caregiving of > 5-10 hrs/day, and 25.0% (n = 9 of 36) among those with 0-5 hr/day. At the same time, 9.5% of those who provided caregiving for > 10 hr/dav (n = 2 of 21) scored 0-4 compared to those who provided caregiving for > 5-10 hr/day (25.0% (n = 3 of 12)) and those with 0-5 hr/day (27.8% (n = 10 of 36)). Moreover, when hours of caregiving per day were investigated against the severity of the impact on the QoL of caregivers, longer caregiving time was significantly associated with worse QoL (p = 0.04). In other words, among those who provided caregiving > 10 hr/day, 61.9% had scores > 24, and 38.1% had scores < 24. Meanwhile, 27.8% of those who provided caregiving 0–5 hr had scores > 24, while 72.2% had scores  $\leq$  24. Overall, this indicates that a longer time spent on caregiving exposes caregivers to a decline or worsening of their QoL (data available upon request).

Worsening QoL attributed to longer daily caregiving hours tended to predispose caregivers to miss more work days, as indicated by participants reporting longer caregiving hours (p = 0.057). Those who missed 21–24 days in the past 6 months just before conducting this study were found to spend 10–24 hr caregiving per day, while none of those who provided caregiving 0–5 hr or 5–10 hr per day missed such high number of days (data available upon request).

Finally, with respect to the effect of PD on the ADLs of patients, approximately 9% of the caregivers reported no impact, while 48% reported a high to severe impact of the disease on their patients' ADLs (data available upon request).

## 4. Discussion

Our study revealed a low level of knowledge among caregivers of patients with PD, as reflected by a mean score of 3.45 out of 8. No association was found between caregivers' knowledge levels and patients' baseline characteristics, except for gender and time spent on caregiving. More than half of the male caregivers had low knowledge scores, while the same proportion of female caregivers had medium knowledge scores (p = 0.038). In fact, among all caregivers with low scores, the proportion of female caregivers was lower than that of male caregivers (27.7% vs. 72.7%). With respect to time spent on caregiving, a significantly higher proportion of respondents who provided caregiving for 0-5 hr had a lower level of knowledge than those who provided caregiving for > 5-10 and > 10-24 h (55.5% vs. 25.0% vs. 47.6%, p = 0.024). Finally, approximately 94% of the caregivers confirmed experiencing a decline and negative impact on their lives associated with caring for PD patients, which was reflected by an average score of 7.3 12.

Taking care of patients with chronic diseases influences QoL. However, several caregiver-related factors could influence that as well. A study focusing on caregivers of patients with schizophrenia revealed a decline in their QoL, particularly in social and psychological aspects, compared to normal individuals (Ribé et al.,

2018). Upon further analysis, age was found to significantly influence that as younger caregivers showed better QoL compared to older caregivers. In the same study, education level was also found to affect QoL, as those who completed secondary school or higher demonstrated improved QoL by examining both the social and environmental aspects of their lives. Further studies on patients with mental illnesses have confirmed this positive association between caregivers' level of education and QoL (Wong et al., 2012; ZamZam et al., 2011). The impact of age, education, and gender of caregivers was also reported in a study conducted on family caregivers of community-living Sudanese psychiatric patients, where young, more educated, and male caregivers had significantly higher QoL than older, less educated, and female caregivers (Awadalla et al., 2005). Interestingly, a study conducted on PD caregivers confirmed this association, yet on the opposite side, where caregivers younger than 60 years had lower OoL compared to those older than 60 years (Lee et al., 2019). In contrast to the aforementioned studies, it was reported no association between the age, education level of caregivers of PD patients and their QoL, however this was significantly established with their gender as females had lower QoL compared to the male caregivers (Martínez-Martín et al., 2005). Another study investigating the impact of the patient's degree of kinship on the QoL of caregivers of patients with schizophrenia revealed poorer QoL if they were parents compared to other family members, and mothers had the lowest QoL within this category (Boyer et al., 2012). The same study also showed that better economic opportunities aid in ensuring better patient treatment, resulting in better QoL for caregivers. With respect to PD, one study highlighted the impact of the kinship of patients with PD on the QoL of their caregivers, where spouses had a significantly lower QoL than those with different relationships with the patients (Lee et al., 2019). Another study evaluating the QoL of caregivers of dementia patients showed a decline in QoL secondary to an increase in caregiving burden levels if they were female, older, caring for a spouse, had a lower monthly income, lower education level, and a sense of lower economic position (Kim et al., 2009). Considering the evidence provided in the previous literature, we investigated this in the current study. Our results are consistent with the association between caregiver gender and QoL. In other words, males showed significantly better QoL scores and had higher proportion with good QoL than females (6.5 vs. 8.5 and 29.3% vs. 10.7%, respectively). With respect to the association between education level and QoL, higher-educated caregivers tended to have better QoL, as 72.4% of the caregivers were university graduates and scored 6.94, whereas caregivers who were elementary and secondary school graduates scored 8.3. Additionally, the magnitude of the decline in the latter was greater than that in the former (23.4 vs. 19.4). However, the differences were not statistically significant.

Overall, despite the low level of knowledge among caregivers in this study, it is worth highlighting that more than half of the caregivers (62.3%) had good attitude as they knew all information about the medications prescribed to their patients. This is in line with a previous study published by Yadav et al. among Indian patients and caregivers in which > 90% of the caregivers obtained higher scores on questions related to the pharmacological treatment of PD and the effect of exercise, in addition to other questions related to the body parts affected by the disease and its pathology and epidemiology (Yadav et al., 2012). Finally, the negative effect of caregiving of PD patients on the QoL of family caregivers was observed, as 94.0% reported one existing  $\geq 1$  factor, while the majority (78.2%) reported five factors that negatively impact their QOL.

Our study had some limitations. First, the sample size was small; however, all measures and efforts were implemented to include every patient who visited the neurology clinic at King Saud University Medical City. Second, the study was conducted at a single teach-

ing hospital, which limits the generalizability of the results. Despite these limitations, our study is the first of its kind in Saudi Arabia, as the majority of previous studies focused on the patients themselves without taking into consideration the crucial role played by caregivers. Second, it investigated both the level of knowledge of caregivers and the impact of caregiving on their QoL, while the majority of studies were restricted to the assessment of the caregiving burden on the QoL of caregivers. Finally, our study highlights the importance of caregivers' knowledge, as it could contribute to providing a better quality of care and QoL for patients.

#### 5. Conclusion

A low level of knowledge was found among the caregivers of patients with PD. Despite the patient and caregiver characteristics, male gender and short caregiving hours per day were correlated with a low level of knowledge. Longer caregiving time and lower education levels were associated with a decline in caregivers' QOL. Increasing awareness and knowledge among caregivers of patients with PD is essential to warrant better treatment outcomes, improve the quality of care for patients, and improve the quality of life for both patients and their caregivers.

## **Ethics statement**

This study was reviewed and approved by the Institutional Review Board of King Khalid University Hospital (Research Project No. E-22–6630). All the patients provided written informed consent to participate in the study.

## **Author contributions**

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis, and interpretation, or in all these areas; took part in drafting, revising, or critically reviewing the article; gave final approval of the version to be published; agreed on the journal to which the article has been submitted; and agreed to be accountable for all aspects of the work.

# **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

# Acknowledgment

The authors extend their appreciation to the Deputyship for Research & Innovation, "Ministry of Education" in Saudi Arabia for funding this research (IFKSUOR3–440-1).

## References

Al Rajeh, S., Bademosi, O., Ismail, H., Awada, A., Dawodu, A., Al-Freihi, H., Assuhaimi, S., Borollosi, M., Al-Shammasi, S., 1993. A community survey of neurological disorders in Saudi Arabia: the Thugbah study. Neuroepidemiology 12 (3), 164–178.

- Alyamani, A.M., Alarifi, J., Alfadhel, A., Alfarawi, F., Alshamardl, K., Alassaf, F., Alyamani, M., Alshahrani, F., 2018. Public knowledge and awareness about Parkinson's disease in Saudi Arabia. J. Family Med. Prim Care. 7 (6), 1216–1221.
- Armstrong, M.J., Okun, M.S., 2020. Diagnosis and treatment of Parkinson disease: a review. J. Am. Med. Assoc. 323 (6), 548–560. https://doi.org/10.1001/jama.2019.22360 (PMID: 32044947).
- Awadalla, A.W., Ohaeri, J.U., Salih, A.A., Tawfiq, A.M., 2005. Subjective quality of life of family caregivers of community living Sudanese psychiatric patients. Soc. Psychiatry Psychiatr. Epidemiol. 40 (9), 755–763.
- Boyer, L., Caqueo-Urízar, A., Richieri, R., Lancon, C., Gutiérrez-Maldonado, J., Auquier, P., 2012. Quality of life among caregivers of patients with schizophrenia: a cross-cultural comparison of Chilean and French families. BMC Fam. Pract. 6 (13), 42.
- Cole, J.C., Ito, D., Chen, Y.J., Cheng, R., Bolognese, J., Li-McLeod, J., 2014. Impact of Alzheimer's Disease on Caregiver Questionnaire: internal consistency, convergent validity, and test-retest reliability of a new measure for assessing caregiver burden. Health Qual. Life Outcomes 4 (12), 114.
- Grosset, D., Taurah, L., Burn, D.J., MacMahon, D., Forbes, A., Turner, K., Bowron, A., Walker, R., Findley, L., Foster, O., Patel, K., Clough, C., Castleton, B., Smith, S., Carey, G., Murphy, T., Hill, J., Brechany, U., McGee, P., Reading, S., Brand, G., Kelly, L., Breen, K., Ford, S., Baker, M., Williams, A., Hearne, J., Qizilbash, N., Chaudhuri, K.R., 2007. A multicentre longitudinal observational study of changes in self reported health status in people with Parkinson's disease left untreated at diagnosis. J. Neurol. Neurosurg. Psychiatry 78 (5), 465–469.
- Gultekin, M., Sarılar, A.C., Ekinci, A., Erturk, G., Mirza, M., 2017. The level of knowledge of Parkinson's disease among nonprofessional caregivers in a movement disorders center in Turkey. Parkinsons Dis. 2017, 2652361.
- Hobson, J.P., Edwards, N.I., Meara, R.J., 2001. The Parkinson's Disease activities of daily living scale: a new simple and brief subjective measure of disability in Parkinson's disease. Clin. Rehabil. 15 (3), 241–246.
- Jitkritsadakul, O., Boonrod, N., Bhidayasiri, R., 2017. Knowledge, attitudes and perceptions of Parkinson's disease: a cross-sectional survey of Asian patients. J. Neurol. Sci. 15 (374), 69–74.
- Kim, M.D., Hong, S.C., Lee, C.I., Kim, S.Y., Kang, I.O., Lee, S.Y., 2009. Caregiver burden among caregivers of Koreans with dementia. Gerontology 55 (1), 106–113.
- Lee, J., Kim, S.H., Kim, Y., Kim, Y.L., Sohn, Y., 2019. Quality of life of caregivers of individuals with Parkinson's disease. Rehabil. Nurs. 446, 338–348.
- Martínez-Martín, P., Benito-León, J., Alonso, F., Catalán, M.J., Pondal, M., Zamarbide, I., Tobías, A., de Pedro, J., 2005. Quality of life of caregivers in Parkinson's disease. Qual. Life Res. 14 (2), 463–472.
- Morley, D., Dummett, S., Peters, M., Kelly, L., Hewitson, P., Dawson, J., Fitzpatrick, R., Jenkinson, C., 2012. Factors influencing quality of life in caregivers of people with Parkinson's disease and implications for clinical guidelines. Parkinsons Dis. 2012, 190901.
- Pan, S., Stutzbach, J., Reichwein, S., Lee, B.K., Dahodwala, N., 2014. Knowledge and attitudes about Parkinson's disease among a diverse group of older adults. J. Cross Cult. Gerontol. 29 (3), 339–352.
- Park, M., Sung, M., Kim, S.K., Kim, S., Lee, D.Y., 2015. Multidimensional determinants of family caregiver burden in Alzheimer's disease. Int. Psychogeriatr. 27 (8), 1355–1364.
- Pringsheim, T., Jette, N., Frolkis, A., Steeves, T.D., 2014. The prevalence of Parkinson's disease: a systematic review and meta-analysis. Mov. Disord. 29 (13), 1583–1590. https://doi.org/10.1002/mds.25945 (Epub 2014 Jun 28 PMID: 24976103).
- Radhakrishnan, D.M., Goyal, V., 2018. Parkinson's disease: a review. Neurol. India 66 (Supplement), S26–S35.
- Ribé, J.M., Salamero, M., Pérez-Testor, C., Mercadal, J., Aguilera, C., Cleris, M., 2018. Quality of life in family caregivers of schizophrenia patients in Spain: caregiver characteristics, caregiving burden, family functioning, and social and professional support. Int. J. Psychiatry Clin. Pract. 22 (1), 25–33.
- Saengsuwan, J., Laohasiriwong, W., Boonyaleepan, S., Sawanyawisuth, K., Tiamkao, S., 2013. Integrated Epilepsy Research Group. Knowledge, attitudes, and care techniques of caregivers of PWE in northeastern Thailand. Epilepsy Behav. 27 (1), 257–263.
- White, D.R., Palmieri, P.A., 2022. Women caring for husbands living with Parkinson's Disease: a phenomenological study protocol. J Pers Med. 12 (5), 659.
- Wong, D.F.K., Lam, A.U.K., Chan, S.K., Chan, S.F., 2012. Quality of life of caregivers with relatives suffering from mental illness in Hong Kong: roles of caregiver characteristics, caregiving burdens, and satisfaction with psychiatric services. Health Qual. Life Outcomes 31 (10) 15
- Yadav, R., Shukla, G., Goyal, V., Singh, S., Behari, M., 2012. Knowledge of Parkinson's disease among patients and caregivers attending movement disorder clinic at a tertiary care centre in north India. Ann. Indian Acad. Neurol. 15 (4), 294–296. https://doi.org/10.4103/0972-2327.104339. PMID: 23349596; PMCID: PMC3548369.
- ZamZam, R., Midin, M., Hooi, L.S., Yi, E., Ahmad, S.N., Azman, S.F., Borhanudin, M.S., Radzi, R.S., 2011. Schizophrenia in Malaysian families: a study on factors associated with quality of life of primary family caregivers. Int J Ment Health Syst. 5 (1), 16.