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Quality of life of patients with Parkinson's disease and their families

Jakość życia chorych na chorobę Parkinsona i członków ich rodzin

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STRESZCZENIE

JAKOŚĆ ŻYCIA CHORYCH NA CHOROBĘ PARKINSONA I CZŁONKÓW ICH RODZIN

Cel pracy. Celem było określenie jakości życia pacjentów z chorobą Parkinsona i członków ich rodzin oraz zidentyfikowanie czynników, które na nią wpływają.

Materiał i metody. Próba badawcza obejmowała 183 pacjentów z chorobą Parkinsona oraz 78 członków ich rodzin. Jakość życia oceniano za pomocą Czeskiego Kwestionariusza Jakości Życia Pacjentów z Postępującą Chorobą Neurologiczną.

Wyniki. Pacjenci z dłuższym czasem trwania choroby charakteryzowali się niższą ogólną jakością życia. Związek między większą zależnością pacjentów od codziennych czynności a wyższym stopniem niepełnosprawności ruchowej wiązał się z gorszą jakością życia pacjentów. U członków rodzin wykazano związek pomiędzy starszym wiekiem a niższą jakością życia w zakresie normalnej codziennej aktywności, sfery społecznej i duchowej. Wraz ze starszym wiekiem zwiększało się także nasilenie objawów i pogarszała się ogólna jakość życia. Potwierdzono związek między większą zależnością pacjentów od codziennych czynności a gorszą jakością życia opiekunów w trzech domenach.

Wnioski. Regularna ocena wpływu choroby Parkinsona na jakość życia pacjentów i ich rodzin oraz identyfikacja czynników, które na nią wpływają, może pomóc w ustaleniu priorytetów planowania leczenia.

Słowa kluczowe: **jakość życia, pacjent, członek rodziny, choroba Parkinsona**

ABSTRACT

QUALITY OF LIFE OF PATIENTS WITH PARKINSON'S DISEASE AND THEIR FAMILIES

Aim. The purpose was to determine the quality of life of Parkinson's disease patients and their family members and to identify the factors that affect it.

Material and methods. The research sample included 183 patients with Parkinson's disease and 78 family members. Quality of life was assessed using the Czech Quality of Life Questionnaire of Patients with Progressive Neurological Disease.

Results. Patients with a longer duration of the disease had a lower overall quality of life. The connection between higher dependence of patients on daily activities, and higher degree of motor disability was associated with a poorer quality of life in patients. In family members, an association was demonstrated between older age and a lower quality of life in the domain of normal daily activity, social and spiritual area. With older age, the higher burden of symptoms also increased and deteriorated overall quality of life. The connection between higher dependence of patients on daily activities and a worse quality of life of caregivers in the three domain was confirmed.

Conclusions. Regular assessment of the impact of Parkinson's disease on the quality of life of patients and their family and the identification of factors that affect it can help prioritize the treatment planning phase.

Key words: **quality of life, patient, family member, Parkinson 's disease**

INTRODUCTION

An important priority of the care provided is the emphasis on the quality of life of the patient. Parkinson's disease (PD) is a chronic progressive disease that has a severe impact on the quality of life of patients and caregivers, as it often leads to an irreversible decline in physical, social, and intellectual functions [1,2]. People with Parkinson's disease gradually lose their independence and require increased levels of care and support. At the beginning of the disease, the most significant disability is physical function, but as it progresses, the nonmotor symptoms worsen. Patients must cope with limitations in performing activities of daily life, and the combination of cognitive impairment with movement disorders leads to a gradual dependence of the patient on the care of the other person, increasing the need for care and consequently reducing the quality of life of people with PD and their caregivers [3].

Current medicine cannot cure Parkinson's disease. It only has the ability to alleviate symptoms that are specific to each patient, as well as the course of the disease. The goal of care is to maintain functional abilities for as long as possible, through complex multidisciplinary care and to achieve an optimal quality of life for the patient and his family. Patients with Parkinson's disease are a particularly vulnerable group who may experience impairment in health-related quality of life (due to significant motor impairment and burden of non-motor symptoms).

In patients with PD, monitoring the subjective perception of the impact of the disease and treatment on the patient's daily activities, his ability to self-care, experience emotions, social relationships or the level of anxiety, tension and depression is very important for evaluating the quality of care provided. In recent years, considerable attention has been paid in foreign literature to the determination of factors influencing the quality of life in patients with PD. Martinez-Martin [4] divides these factors into general determining factors and specific factors. The general determining factors influencing quality of life not only in patients with PD, but also in other diseases, include, among others, depression, disability and pain [5]. The main determinants of quality of life in PN patients are not only motor symptoms, but especially non-motor symptoms and other aspects of the disease (e.g. the ability to engage in activities of daily life). Difficulties associated with PD also affect the quality of life of partners and other family members [6].

The quality of life of caregivers is reflected in the quality of life of patients. The assessment of the quality of life of caregivers should be focused both on determining their personal well-being and on determining the ability to perform adequate patient care. PD gradually leads to full dependence of the patient on the care of another person, which is most often a family member [7]. This disease has a profound impact not only on the quality of life of the sick, but also of the caregivers, as it often leads to an irreversible decline in intellectual, social and physical functions. The role of caregiver is often undemanding in the early stages of the disease. The burden usually increases as the disease progresses, with patients becoming increasingly reliant on caregivers and support in daily activities [6]. Carers provide a wide range of practical and emotional support, social care and assistance in everyday life. Caregivers also reduce the risk of institutionalization and reduce the economic burden on society [8].

AIM

The aim of our research was to determine the quality of life of Parkinson's disease patients and their family members and to determine the factors that influence it.

MATERIALS AND METHODS

The research group consisted of 183 patients with PN who were in the care of four neurological outpatient clinics in the Moravian-Silesian Region. The criteria for inclusion of patients in the research group were consent to participate in the research, fulfilment of the ICD-10 criteria for Parkinson's disease, duration of the disease at least one year, MMSE >24 points.

Patients fulfilling the criteria for inclusion in the research group were approached for cooperation when visiting a neurological outpatient clinic during office hours.

The questionnaire set for PD patients included the following areas of assessment:

- degree of motor impairment as measured by the Hoehn Yahr scale (H-Y),
- ability to perform daily life activities as measured by Bartel index (BI) and Schwab English scale (SCH-E) and
- quality of life for PD patients as measured by PNDQoL_P (Quality of life for patients with progressive neurological disease).

Family members

The research group consisted of 78 family members of patients with PN who were in the care of four neurological outpatient clinics in the Moravian-Silesian Region.

Criteria for inclusion in the research group: caring family member providing support to the patient included in the study, age >18 years; consent to cooperation. Of the total number of 183, 78 were family members of patients who were included in the above-mentioned research group. In 105 patients, family members did not agree to be included in the study.

Quality of life of family members (carers) was evaluated by PNDQoL_F (Quality of life of carers of patients with progressive neurological disease) [9].

After training of healthcare professionals, all patients fulfilling the criteria for selection in the research sample were contacted for co-operation between May 2019 and December 2019. The treating physician evaluated functional scales: Hoehn-Yahr scale [10], Schwab and English scale [11], and Activity Daily Living [12] and patients and family members were asked to complete a quality of life questionnaire [9] (PNDQoL_P, PNDQoL_F).

Ethical Aspects

The study respects Helsinki declaration from 1975 (and its 2004 and 2008 revisions). It was approved and the

approval of the ethics committee of the University Hospital Ostrava was granted (10 June 2016, No. 486/2016). All patients and family members were informed of the study details and provided informed consent prior to enrolment in the study.

Data collection

The severity of functional impairment was assessed with the **Hoehn and Yahr** (H-Y) **Scale** [10]. The tool, including seven stages of involvement, looks at two basic aspects. The first is whether the impairment is unilateral or bilateral; the other is concerned with impaired balance and walk. The stages are classified based on disease progression, from unilateral involvement (stage 1), to bilateral motor involvement without impairment of balance (stage 2). Stage 3 is characterized by postural instability but the patient is still physically independent. In stage 4, balance is impaired and physical independence is lost but the patient is still able to walk or stand unassisted. In stage 5, the patient is unable to walk and stand and is confined to wheelchair or bed.

The ability to perform activities of daily living (ADLs) was evaluated using two tools, the Barthel Index and the Schwab and England Scale.

The **Barthel Index** (BI), or Barthel Scale [12], is a tool used worldwide for measuring performance in basic ADLs. The following 10 variables are assessed on a three--point ordinal scale: feeding, dressing, walking, climbing stairs, chair to bed transfer, grooming, bathing, toilet use, urinary and fecal incontinence. The total score (0-100) provides information about the patient's functional independence (totally dependent, severely dependent, moderately dependent, slightly dependent, independent).

The other specific tool measuring ADLs in PD patients was the **Schwab and England** (SCH-E) **Scale** [11]. The scale is used to evaluate difficulties PD patients have with performing everyday activities. It uses percentages to represent how much effort and dependence they need to complete daily chores. A person reaching 100% is completely independent and able to do all chores without difficulty; 90% mean that they are able to do all chores, but with some degree of slowness, difficulty or impairment, and that they might take two times longer than normal to complete chores. Patients with 80% independence take twice longer than normal to complete chores. Those with 70% independence have more difficulties with some chores, might take three to four times longer than normal to complete them and spend a large part of the day performing them. Patients reaching 60% can do most chores, but exceedingly slowly and with much effort; errors are possible when completing them. Fifty percent mean the patient needs help with half of every chore and everything is difficult to them. Patients with 40% independence can assist with chores and can complete some alone. Those reaching 30% can complete few chores with effort and help. Very dependent patients (20%) cannot complete any chores alone. Ten percent represent full dependence and helplessness. Fully dependent patients (0%) are bedridden and almost completely comatose.

To assess the patients' quality of life, we used the Czech questionnaire **PNDQoL_P (Quality of life of patients with progressive neurological disease)** [9], which includes a symptomatic (11 items) and a functional scale (32 items; 4 domains), an assessment of general health (1 item) and overall quality of life (1 item).

The patient version symptom scale includes a rating of 11 symptoms (pain, fatigue, sleepiness, shortness of breath, tremors, stiffness, spasms, swallowing, salivation, voiding, urination) ranging from 0 (none) to 10 (worst). The total score of the symptomatic scale ranges from 0 to 110 points. A higher number means a higher symptom burden.

The symptomatic scale of the family version includes 10 physical problems (pain, fatigue, sleep disturbances, palpitations, shortness of breath, difficulty eating, nausea, skin problems, sexual difficulties, difficulty emptying) ranging from 0 (none) to 10 (very). The overall score on the symptomatic scale ranges from 0 to 100 points. A higher number means a higher burden of symptoms.

The functional quality of life scale includes four domains (daily activities, psychological status, social functioning, spiritual domain), with each domain including eight items. Individual items range from 0 (none) on the Likert scale to very often (4). The domain score ranges from 0 to 100. A higher score indicates a higher burden, i.e. poorer quality. An item on a 10-point scale ranging from 1 (very bad) to 10 (excellent) assesses overall health and overall quality of life.

The assessment of overall health and overall quality of life is evaluated using an item on a 10-point scale ranging from 1 (very bad) to 10 (excellent).

The quality of life of family members (caregivers) was assessed by the **PNDQoL_F questionnaire (Quality of life of caregivers of patients with progressive neurological disease)** [9], which includes a symptomatic (10 items) and functional scale (32 items), assessment of general health (1 item) and overall quality of life (1 item).

The symptomatic scale for family members contains 10 physical problems (pain, fatigue, sleep disturbances, palpitations, shortness of breath, difficulty eating, nausea, skin problems, sexual problems, bowel problems) ranging from 0 (not at all) to 10 (very). The total score of the symptomatic scale ranges from 0 to 100 points. A higher number means a higher symptom burden.

The functional quality of life scale is divided into 4 domains (ordinary daily activities, mental state, social functioning, spiritual domain), each domain contains 8 items. The scale of individual items ranges from 0 (not at all) to very often (4) on a 5-point Likert scale. Domain scores range from 0 to 100. A higher number means a greater burden, i.e. a worse quality of life in the given area.

Evaluation of overall health and overall quality of life is assessed with one item on a 10-point scale ranging from 1 (very poor) to 10 (excellent).

The development questionnaire PNDQoL was tested: convergent validity (confirmatory factor analysis), reliability (Cronbach alpha), test-retest reliability, correlation analysis, construct validity (Spearman coefficient). Acceptable reliability was found in all domains of the PNDQoL

questionnaire (α = 0.727-0.834), test-retest reliability (r = 0.721-0.980; p < 0.001). The PNDQoL questionnaire is valid and is suitable for patients in advanced stages of the disease. It may be used to analyze the impact of the disease and its treatment on patients' life [9].

Data Analysis

The normality of the data distribution was tested by the Shapiro-Wilk test. Nonparametric tests were used due to abnormal data distribution. The data are described using descriptive statistics, arithmetic mean, standard deviation, relative, and absolute frequency. The Kruskal-Wallis test was used to evaluate the differences between the groups. The association between quality of life and the selected factors was determined by the Spearman correlation coefficient. Statistical significance was tested at the significance level p < 0.05. The data was analyzed using SPSS v software SPSS v. 24.0 (IBM, Armonk, NY, USA).

RESULTS

Sociodemographic characteristics of the population

The patients' mean age was 70.1 years (SD = 9.1) and mean disease duration was 10.3 years (SD = 5.6). The most frequent marital status was married (60.7%), followed by widow/widower (23.5%), divorced (13.1%) and single (2.7%). The mean Barthel Index (BI) score was 58.1 (SD = 21.0; range, 0-80); the mean Schwab and England Scale (SCH-E) score was 63.6 (SD = 18.2; range, 0-90) and the mean Hoehn and Yahr Scale score was 2.8 (SD = 1.13; range, 1-5). The sociodemographic characteristics of the sample are shown in Table 1.

The population of family members consisted of 78 family members, 53 females, and 25 males. The mean age of family members was 55.7 years (SD = 14.7), age range 26-85 years. The sociodemographic characteristics of the population are shown in Table 1.

Assessment of quality of life assessment of patients

The overall average quality of life was found to be 44.8 (scale 0-100). We evaluated the average overall quality of life score in each domain. The patients rated the worst quality of life in the spiritual domain ($\bar{x}$ = 47.5; SD = 18.4) (fear of the future, hopelessness, meaning of life, achievement of a life goal, beauty of surroundings and peace and serenity), in everyday activities ($\bar{x}$ = 46.7; SD = 21.9) (restriction of movement, ability to communicate, restriction in favourite activities, impaired ability to concentrate, memory and decision-making) and in the domain of social functioning ($\bar{x}$ = 44.9; SD = 17.0) (restriction in the area of family and social life). On the contrary, they rated best their psychological state ($\bar{x}$ = 41.7; SD = 18.6) (Tab. 2).

In addition, we investigated the association between individual domains of quality of life and selected factors (age, degree of motor disability, length of disease and ability to perform daily activities).

Using the Spearman correlation coefficient, a correlation between higher age and higher symptom burden (r = 0.269) and lower overall quality of life (r = -0.301) was demonstrated.

A correlation in the domain of overall quality of life was also found for disease duration. Patients with longer disease duration had lower overall quality of life (r = -0.266).

At the same time, a correlation was confirmed between higher dependence of patients in activities of daily life as measured by the Schwab English scale and Bartel index and their lower quality of life in all monitored domains. Similarly, higher degree of motor disability was associated with poorer quality of life of patients (Tab. 3).

Assessment of quality of life of family members

In the individual domains, family members rated the worst quality of life in the domain of social functioning ($\bar{x}$ = 44.3; SD = 19.9) (restrictions on family and social life) and in the domain of psychological state ($\bar{x}$ = 36.1; SD = 24.1). Conversely, they rated best in the domain of normal daily activity ($\bar{x}$ = 32.9; SD = 27.7) (Tab. 4).

Tab. 1. Sociodemographic and health characteristics of the population

	PATIENTS	FAMILY		PATIENTS	FAMILY
Number N (%)	N=183	N=78	**Average**	70.1	55.7
Gender N (%)			**Employment status N (%)**		
Men	100 (55)	25 (32)	Employee	43 (23.6)	43 (55.1)
Women	83 (45)	53 (68)	Invalid. Pens.	30 (16.4)	26 (33.3)
Education N (%)			Old-age pens.	108 (59)	2 (2.6)
Basic	27 (14.8)	11 (14.1)	Unemployed	1 (0.5)	6 (7.7)
Apprenticed	55 (30.1)	11 (14.1)	Domestic	1 (0.5)	1 (1.3)
High school	70 (38.2)	33 (42.3)	**Length of disease N (%)**	10,3 years	
University	31 (16.9)	23 (29.5)	Up to 5 years	60 (32.7)	---
Marital status N (%)			5-10 years	65 (35.5)	---
Single	5 (2.7)	10 (12.9)	More than 10 years	58 (31.8)	---
Married	111 (60.7)	57 (73)	**H-Y scale**	13 (19)	---
Divorced	24 (13.1)	11 (14.1)	1 stage	24 (13.1)	---
Widowed	43 (23.5)	0 (0)	2 stage	48 (26.2)	---
Relationship N (%)			3 stage	62 (33.9)	---
Husband/wife	---	45 (58)	4 stage	34 (18.6)	---
Son/daughter		20 (25.5)	5 stage	15 (8.2)	---
Partner	---	4 (5.1)	**SCH-E scale**	13 (19)	---
Other	---	9 (11.4)	<70	83 (45.4)	---
			≥70	100 (54.6)	---

H-Y – Hoehn Yahr scale, SCH-E – Schwab England scale

Tab. 2. Quality of life of patients in domains PNDQoL_P

Domains	$\bar{x}$	SD	Median	Min	Max
Functional scale					
Activity daily living	46.7	21.9	46.8	0.0	100
Emotional functioning	41.7	18.6	43.7	3.1	96.8
Social functioning	44.9	17.0	43.7	3.1	87.5
Spiritual area	47.5	18.4	46.8	0.0	100
Symptomatic scale	43.6	17.8	43.5	5.0	105
Overall quality of life	5.0	1.7	5.0	1.0	9.0
Overall health	4.8	1.6	5.0	1.0	9.0

$\bar{x}$ - mean, SD – standard deviation

Tab. 3. Relationship between PNDQoL_P patient quality of life domains and selected factors

Domains	Age	H-Y	Duration of illness	BI	SCH-E
Functional scale					
Activity daily living	0.158	0.487*	-0.004	-0.514*	-0.406*
Emotional functioning	-0.139	0.366*	0.003	-0.307*	-0.273*
Social functioning	-0.022	0.306*	0.056	-0.273*	-0.298*
Spiritual area	-0.076	0.396*	0.020	-0.414*	-0.334*
Symptomatic scale	0.269*	0.545*	0.155	-0.430*	-0.315*
Overall quality of life	-0.301*	-0.410*	-0.266*	0.522*	0.377*

H-Y – Hoehn Yahr scale, BI – Barthel index, SCH-E – Schwab England scale,
Spearman correlation coefficient * p<0.05

Tab. 4. Quality of life of patients in domains PNDQoL_F

Domains	$\bar{x}$	SD	Median	Min	Max
Functional scale	32.9	27.7	25	0.0	100
Activity daily living	36.1	24.1	34.3	0.0	97
Emotional functioning	44.3	19.9	43.7	6.2	93.7
Social functioning	35.4	18.7	31.2	0.0	78.1
Spiritual area	10.1	8.2	8.5	0.0	4.0
Symptomatic scale	6.2	2.3	7.0	1.0	10
Overall quality of life	6.1	2.3	7.0	1.0	10

$\bar{x}$ - mean, SD – standard deviation

Tab. 5. Relationship between quality of life domains of family members and selected factors

Domains	Age	H-Y	Length of care	SCH-E
Functional scale				
Activity daily living	0.315*	0.487*	0.198	-0.350*
Emotional functioning	0.174	0.366*	0.277*	-0.454*
Social functioning	0.393*	0.306*	0.266*	-0.231*
Spiritual area	0.277*	0.396*	0.122	-0.253*
Symptomatic scale	0.414*	0.152	-0.096	-0.289*
Overall quality of life	-0.495*	-0.382*	-0.117	0.131

H-Y – Hoehn Yahr scale, BI – Barthel index, SCH-E – Schwab England scale,
Spearman correlation coefficient * p<0.05

A correlation was found between the quality of life of family members and patients in 78 family members in which both the family and the patient completed the questionnaire. Using the Spearman correlation coefficient, a correlation between older age and lower quality of life of family members was shown in the domain of daily activities (r = 0.315), social functioning (r = 0.393) and spiritual area (r = 0.277). Higher age also increased the burden of symptoms (r = 0.414) and worsened overall quality of life (r = -0.495).

Family caregivers who cared for the patient for longer periods reported a higher pressure in the field of social functioning (r = 0.266).

At the same time, the association between the higher dependence of patients on activities of daily life measured by SCH-E and the poorer quality of life of caregivers in the domain of daily activity (r = -0.350), mental state (r = -0.454), social functioning (r = -0.231), spiritual area (r = -0.253) and in the symptomatic scale (r = -0.289) was confirmed (Tab. 5).

DISCUSSION

As part of our research, we investigated the quality of life of PD sufferers and their family members and the factors influencing it. The main determinants of quality of life in PN patients are not only motor symptoms, but also nonmotor symptoms and other aspects of the disease (e.g. the ability to participate in activities of daily life) [4,13]. The difficulties associated with PD also affect the quality of life of partners and other family members [6]. Due to the important role of caregivers in the family, it is essential for both the person with this disease and the caregivers that the caregivers maintain a good quality of life.

In our research, patients reported the biggest problem in the domain of spiritual area (fear of the future and hopelessness), in everyday activities (restriction of movement and restrictions in favourite activities), in the domain of social functioning (restrictions in the area of family and social life) and in the domain of psychological state (helplessness and sadness). Ozdilek and Gultekin [14] revealed that hopelessness and helplessness are more common in patients who have been diagnosed with PD at a younger age, in whom the disease lasts for a longer time and depression is present. In the area of social functioning, our patients felt limitations in the area of family and social life. Takahashi et al. [15] revealed in their research as the most important domain of social relations, when limitations in social activities led to a reduction in the quality of life of PD patients. According to Škorvánka et al. [16], significant deterioration in quality of life occurred depending on the duration of the disease, when the overall quality of life was significantly influenced by the patient's subjective perception of the disease. In the domain of mental state, patients most often experienced feelings of helplessness and sadness. PN is an incurable, progressive and disabling disease and as such causes stress and burden to the patient and causes a number of emotions, such as sadness.

We also found that, lower overall quality of life was associated with older age and longer duration of the disease. Similarly, several investigations have shown that quality of life is significantly reduced with longer duration of the disease [17,18]. Dependence in activities of daily life was a significant factor influencing quality of life, e.g., in studies by Carod-Artal et al. [8]; Terriff et al. [19]. In our study, correlation was also found between quality of life domains and functional scales (BI, SCH-E, H-Y). The lower functional status of the patients was associated with a lower quality of life in all domains. These results are consistent with other available studies, e.g., Moreira et al. [18]; Rodriguez-Violante et al. [5].

In PD, in particular, caregivers face a long phase of progressive disability of patients with a decline in motor and cognitive abilities, and thus caregivers are at risk of burnout. Given the important role caregivers play in the family, it is essential for people with the disease and caregivers to maintain a good quality of life. Factors on both the caregiver's side contribute to the caregiver's burden [20]. Studies have shown several characteristics of PN patients that contribute to a higher burden on caregivers. The most significant are the severity of the disease and the presence of non-motor symptoms, especially neuropsychiatric disorders [17]. Other studies suggest that the burden on caregivers is also related to the duration of care [21]. Morley et al. [22] report other characteristics that have a significant impact on the quality of life of caregivers, such as the age of caregivers, sex, the health status of both the caregiver and the patient with PN, the duration of care and mobility. Reduced ability to perform activities of daily life of the patient (impaired physical function) has been shown to be a major factor in increasing the burden of care in the Zhonga et al. study [23]. In our study, a link between older age and symptomatic burden and poorer quality of life was also shown.

In our research study, family members mentioned the most problematic area of quality of life in the domain of social functioning and in the domain of mental state. Research indicates that the mental health of caregivers of patients with PN is lower than that of the general population [24]. Caregivers are approximately 20% more likely to experience mental health problems than non-caregivers [25]. Especially with PN, caregivers face a long phase of progressive disability of patients with a decline in motor and cognitive abilities, and caregivers are thus at risk of burnout. The caregiver thus becomes what has been described as the "invisible patient", which can lead to a reduction in the overall quality of care provided [26]. As a result of the long-term burden, the caregiver may become ill themselves, or may not be able to continue providing care. In some cases, long-term mental and physical stress can even lead to the collapse of the caregiver and the need for hospitalization [27].

The duration of the disease and the associated duration of care had a negative impact on social functioning and general health of caregivers. These results are consistent with previous studies that found that the longer the duration of PD, the lower the quality of life of caregivers [22]. The relationship between the burden of care and the degree of motor impairment (as measured by the H-Y scale) was investigated in the following studies [8]. The caregiver burden was identified at all stages of PD and increased with increasing degree of motor impairment. Furthermore, our findings confirmed that family members of patients with a higher degree of motor impairment reported a poorer quality of life.

The methodological limitation of the research was mainly the size of the research set and their deliberate selection, based on the availability and willingness of patients and family members to participate in the research. This fundamentally limits the possible generalization of the results to the entire population of patients with PD

CONCLUSIONS

The care of PD patients should be comprehensive and holistic from the beginning of the disease, with an emphasis on the quality of life of the patient and his family. For PD patients, quality of life assessment plays an important role as the disease affects all aspects of an individual's life, where a wide range of factors may combine to influence basic areas of well-being and life satisfaction. For PD patients, monitoring the subjective perception of the impact of the disease and treatment on the patient's daily activities, self-care, emotional, social relationships, or anxiety and depression is very important for assessing the quality of medical and nursing care provided. Regular assessment of their condition in the context of a comprehensive assessment of each patient should be a standard part of the care provided. Quality of life monitoring becomes critical for understanding the disease process and seeking strategies for support and planning nursing interventions and the provision of individualised patient-focused care.

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