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The Effect of the Burden on the Quality of Life of Caregivers of People with Parkinson's Disease

Wpływ stopnia obciążenia opiekunów osób z chorobą Parkinsona na jakość ich życia

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Abstract

Introduction. Parkinson's disease is one of the most common neurodegenerative diseases. This condition is progressive in nature. In Europe, Parkinson's disease is estimated to affect mainly people over the age of 60. It is assumed that around 80–100,000 people in Poland currently suffer from Parkinson's disease. The disease mainly affects men.
Aim. Assessment of the level of burden on caregivers of people with Parkinson's disease and evaluation of their quality of life.
Material and Methods. The study was conducted in the Koło Przyjaciół Ludzi z Chorobą Parkinsona TWK (Friends of People with Parkinson's Disease TWK Group) in Wrocław and the Leszczyńskie Stowarzyszenie Osób z Chorobami Alzheimera i Parkinsona (Leszno Association of People with Alzheimer's and Parkinson's Diseases) in Leszno on a group of 92 Parkinson's disease patients and their 92 caregivers. The study was conducted using a diagnostic survey method with a self-designed questionnaire and the following standardised instruments for caregivers: the WHOQoL-BREF questionnaire, the CBS caregiver burden scale and the HADS anxiety and depression scale. The present study also used questionnaires addressed to Parkinson's disease patients: a sociodemographic questionnaire, the PDQ-39 quality of life questionnaire, the Hoehn–Yahr disease stage scale and the Beck depression scale BDI.
Results. Analysis of the research material showed that: the quality of life of caregivers in the physical, environmental and psychological domains was significantly better in those providing care for 1–5 years than in those looking after patients for more than 10 years. The author's own research showed that the overall burden among caregivers was significantly higher when the patient had been ill for more than 5 years than when the patient had been ill for 2–5 years, and it was found that the lower the overall level of quality of life and severity of depressive symptoms among PD patients, the lower the quality of life of their caregivers. On the overall burden scale, 47 of the 92 survey participants (51.09%) experienced a medium level of burden and 24 respondents (26.09%) experienced a high level of burden. In addition, the long duration of the disease leads to a higher burden on caregivers.
Conclusions. The difficulties associated with the burden of care for caregivers of people with PD represent a significant clinical, social and also economic problem. Moreover, they significantly reduce the quality of life of caregivers, often taking away the joy of caring for loved ones with Parkinson's disease. **(JNNN 2021;10(4):144–152)**
Key Words: care burden, caregiver, Parkinson's disease, quality of life

Streszczenie

Wstęp. Choroba Parkinsona jest jednym z najczęściej występujących chorób neurodegeneracyjnych. Schorzenie to występuje w charakterze postępującym. Określa się, że na chorobę Parkinsona chorują w Europie głównie osoby powyżej 60 roku życia. Zakłada się, że w Polsce na chorobę Parkinsona obecnie choruje około 80–100 tys. osób. Choroba dotyka głównie mężczyzn.
Cel. Ocena poziomu obciążenia opiekunów w opiece nad osobami z chorobą Parkinsona oraz ocena ich jakości życia.
Materiał i metody. Badania zostały przeprowadzone w Kole Przyjaciół Ludzi z Chorobą Parkinsona TWK we Wrocławiu oraz w Leszczyńskim Stowarzyszeniu Osób z Chorobami Alzheimera i Parkinsona w Lesznie na grupie 92 chorych

na chorobę Parkinsona oraz ich 92 opiekunów. Badanie przeprowadzono za pomocą metody sondażu diagnostycznego z wykorzystaniem kwestionariusza ankiety własnego autorstwa oraz następujących wystandaryzowanych narzędzi dla opiekunów: kwestionariusza WHOQoL-BREF, skali obciążenia opiekunów CBS oraz skali lęku i depresji HADS. W niniejszej pracy wykorzystano również kwestionariusze skierowane do chorych na chorobę Parkinsona: ankietę socjodemograficzną, kwestionariusz jakości życia PDQ-39, skalę określającą stadium zaawansowania choroby według Hoehn–Yahra oraz skalę depresji Becka BDI.

Wyniki. Analiza materiału badawczego wykazała, że: jakość życia opiekunów w dziedzinie fizycznej, środowiskowej i psychologicznej była istotnie lepsza u osób sprawujących tę opiekę od 1–5 lat, niż u opiekunów zajmujących się chorymi ponad 10 lat. Badania własne wykazały, że obciążenie ogólne wśród opiekunów było istotnie większe gdy pacjent chorował ponad 5 lat, niż gdy chorował od 2–5 lat oraz stwierdzono, że im niższy ogólny poziom jakości życia i nasilenie objawów depresji wśród chorych na PD, tym gorsza jakość życia ich opiekunów. Na skali obciążenia ogólnego 47 spośród 92 uczestników ankiety (51,09%) miało średni poziom obciążenia, 24 ankietowanych (26,09%) miało wysoki poziom obciążenia. Ponadto długotrwały czas trwania choroby skutkuje wyższym poziomem obciążenia opiekunów.

Wnioski. Trudności związane z obciążeniem opieką opiekunów osób chorujących na PD stanowią istotny problem kliniczny, społeczny a także ekonomiczny. Co więcej w istotny sposób wpływają na obniżenie jakości życia opiekunów niejednokrotnie odbierając im radość czerpaną z opieki nad najbliższymi chorującymi na chorobę Parkinsona. **(PNN 2021;10(4):144–152)**

Słowa kluczowe: obciążenie opieką, opiekun, choroba Parkinsona, jakość życia

Introduction

According to the World Health Organisation, Parkinson's disease is one of the most common neurodegenerative diseases. It is progressive in nature. In Europe, PD is estimated to affect mainly people over the age of 60. It is assumed that around 80–100,000 people in Poland currently suffer from PD. The disease mainly affects men [1]. The intense progression of Parkinson's disease causes: autonomic, cognitive and emotional disturbances [2]. As the disease progresses and physical function deteriorates significantly, the patient becomes more dependent on the caregiver, who is overburdened with excessive daily responsibilities due to the progression of the disease. They are often accompanied by fatigue and chronic stress, which contributes to reduced daily functioning. The burden of daily responsibilities resulting from caring for a sick person leads to a deterioration in the quality of physical and mental health. Therefore, improving and caring for the physical and mental health of caregivers is essential. Patients require constant care and total commitment from the caregiver [3,4]. The adverse health status of the caregiver affects the quality of life of the patient. The burden on the caregiver is determined through the effects that the disease has on them. People who provide long-term care to patients with PD are limited in bio-psycho-social functioning [2,3].

According to Clarke C.E. et al. [5], caregivers of people with PD experience varying degrees of impairment to their health and quality of life, including increased risk of premature death, high levels of stress and depression as well as reduced family and social lives. Extremely expensive treatment and physiotherapy procedures lead to a worsening of the material situation.

The main aim is to assess the level of burden on caregivers and their quality of life while caring for people with Parkinson's disease.

Material and Methods

The study was conducted among caregivers and patients with Parkinson's disease in the Koło Przyjaciół Ludzi z Chorobą Parkinsona TWK (Friends of People with Parkinson's Disease TWK Group) in Wrocław and the Leszczyńskie Stowarzyszenie Osób z Chorobami Alzheimera i Parkinsona (Leszno Association of People with Alzheimer's and Parkinson's Diseases) in Leszno. Virtual online surveys have also been carried out. The study group consisted of 91 people with PD (39 women and 53 men) and their caregivers (48 women and 44 men). The present study used the following questionnaires directed at caregivers: a sociodemographic questionnaire, the CBS caregiver burden scale, the WHOQoL-Brief scale, the HADS anxiety and depression scale and the following questionnaires directed at the patient: a sociodemographic questionnaire, the PDQ-39 quality of life questionnaire, the Hoehn–Yahr disease stage scale and the Beck depression scale BDI. The results of the study were statistically analysed. MS Excel was used to collect data, while Statistica 12 was used to perform statistical calculations.

Results

Hypothesis 1: It is Assumed that the Higher the Stage of the Disease of the People under Care, the Lower the Level of Quality of Life of the Caregiver

The Hoehn–Yahr scale correlates significantly (p<0.05) and negatively (r<0) with all domains of caregiver quality of life, thus the later the stage of disease among the patients, the worse the quality of life in all domains. The results defining the relationships are presented below in tabular form (Table 1).

Table 1. Correlation between disease stage and WHOQoL-BREF caregiver quality of life

WHOQoL-BREF (caregivers)	Hoehn–Yahr Scale (people under care)
	Spearman's correlation coefficient
Perception of the quality of life	r=–0.277, p=0.008*
Perception of own health	r=–0.283, p=0.007*
Physical domain	r=–0.339, p=0.001*
Psychological domain	r=–0.3, p=0.004*
Social domain	r=–0.29, p=0.005*
Environmental domain	r=–0.276, p=0.008*

*statistically significant relationship (p<0.05)

Hypothesis 2: It is Assumed that there is a Relationship between the Quality of Life of Patients and the Caregiver Burden Level on the CBS

Intellectual functioning correlates significantly (p<0.05) and positively (r>0) with emotional involvement, thus the greater the patient's problems with intellectual functioning the greater the level of burden in this area. The results defining the relationships are presented below in tabular form (Table 2).

Table 2. Correlation between intellectual functioning and caregiver burden on the CBS

CBS (caregivers)	Intellectual functioning PDQ-39 (people under care)
	Spearman's correlation coefficient
General burden	r=0.113, p=0.282
Social isolation	r=0.18, p=0.087
Disappointment	r=0.177, p=0.091
Emotional commitment	r=0.269, p=0.01*
Environment	r=0.133, p=0.208

*statistically significant relationship (p<0.05)

Overall quality of life correlates significantly (p<0.05) and negatively (r<0) with all domains of caregiver quality of life, thus the greater the overall problems of the patient the worse the quality of life in all domains of caregivers' lives. The results defining the relationships are presented below in tabular form (Table 3).

Table 3. Correlation between overall quality of life and WHOQoL-BREF caregivers' quality of life

WHOQoL-BREF (caregivers)	Overall quality of life PDQ-39 (people under care)
	Spearman's correlation coefficient
Perception of the quality of life	r=–0.275, p=0.008*
Perception of own health	r=–0.292, p=0.005*
Physical domain	r=–0.338, p=0.001*
Psychological domain	r=–0.382, p<0.001*
Social domain	r=–0.307, p=0.003*
Environmental domain	r=–0.337, p=0.001*

*statistically significant relationship (p<0.05)

Hypothesis 3: It is Assumed that there is a Relationship between the Duration of the Disease and the Level of Caregiver Burden

The overall burden was significantly higher when the patient had been ill for more than 5 years than when they had been ill for 2–5 years. In contrast, Disappointment was significantly higher when the patient had been ill for up to a year or more than 5 years than when they had been ill for 2–5 years. The results defining the relationships are presented below in tabular form (Table 4).

Hypothesis 4: It is Assumed that there is a Relationship between the Age of the Person under Care and the Level of Caregiver Burden

General burden, social isolation and disappointment were significantly higher when the patient was up to 60 years old. The results defining the relationships are presented below in tabular form (Table 5).

Table 4. Relationship between the duration of the disease and the caregiver burden on the CBS

CBS (caregivers)		Disease duration (people under care)			p-value
		Up to one year — A (N=6)	2–5 years — B (N=42)	Over 5 years — C (N=43)	
General burden	Mean±SD	2.46±0.66	2.25±0.72	2.64±0.69	p=0.049*
	Median	2.31	2.25	2.5	
	Quartiles	1.97–2.94	1.66–2.62	2.19–3.12	C>B
Social isolation	Mean±SD	2.39±1.1	2.25±0.66	2.39±0.66	p=0.648
	Median	2.17	2.33	2.33	
	Quartiles	1.75–3.08	1.67–2.67	2–2.67	
Disappointment	Mean±SD	2.6±0.63	2.25±0.54	2.6±0.51	p=0.014*
	Median	2.5	2.4	2.6	
	Quartiles	2.2–3.1	1.8–2.6	2.3–3	A, C>B
Emotional commitment	Mean±SD	2.33±1.17	1.94±0.76	2.12±0.83	p=0.511
	Median	2	2	2	
	Quartiles	1.33–3.17	1.33–2.33	1.33–2.67	
Environment	Mean±SD	2.11±0.96	2.2±0.62	2.4±0.64	p=0.222
	Median	2	2.33	2.33	
	Quartiles	1.5–2.5	1.67–2.58	2–2.67	

p — Kruskal–Wallis test+post hoc analysis (Dunn's test)
*statistically significant relationship ($p<0.05$)

Table 5. Relationship between patient age and the caregiver burden on the CBS

CBS (caregivers)		Patient's age (people under care)		p-value
		Up to 60 years (N=10)	60 years and more (N=82)	
General burden	Mean±SD	2.86±0.48	2.39±0.72	p=0.03*
	Median	2.88	2.38	
	Quartiles	2.44–3.25	1.91–2.88	
Social isolation	Mean±SD	2.8±0.71	2.26±0.66	p=0.036*
	Median	2.67	2.33	
	Quartiles	2.33–3.25	1.67–2.67	
Disappointment	Mean±SD	2.82±0.38	2.39±0.55	p=0.02*
	Median	2.8	2.4	
	Quartiles	2.6–3.15	2.05–2.8	
Emotional commitment	Mean±SD	2.1±0.99	2.04±0.8	p=1
	Median	2	2	
	Quartiles	1.33–2.67	1.33–2.67	
Environment	Mean±SD	2.47±0.63	2.27±0.66	p=0.337
	Median	2.5	2.33	
	Quartiles	2.08–2.67	2–2.67	

p — Mann–Whitney U test
*statistically significant relationship ($p<0.05$)

Hypothesis 5: It is Assumed that there is a Relationship between the Presence of Anxiety in Caregivers and their Level of Quality of Life

Anxiety correlates significantly ($p<0.05$) and negatively ($r<0$) with the perception of quality of life, thus the stronger the anxiety symptoms the worse the quality of life in this domain. The results defining the relationships are presented below in tabular form (Table 6).

Table 6. Correlation between anxiety and WHOQoL-BREF caregivers' quality of life

WHOQoL-BREF (caregivers)	Anxiety (HADS) (caregivers)
	Spearman's correlation coefficient
Perception of the quality of life	r=–0.626, p=0.029*
Perception of own health	r=0.18, p=0.575
Physical domain	r=–0.196, p=0.542
Psychological domain	r=–0.282, p=0.375
Social domain	r=0.075, p=0.818
Environmental domain	r=–0.26, p=0.415

*statistically significant relationship ($p<0.05$)

Hypothesis 6: There is a Strong Association between the Presence of Depression in People under Care and the Degree of Burden on Caregivers and their Level of Quality of Life

The Beck scale correlates significantly ($p<0.05$) and negatively ($r<0$) with all domains of caregiver quality of life, thus the higher the severity of depression the worse the quality of life in all domains. The results defining the relationships are presented below in tabular form (Table 7).

Table 7. Correlation between presence of depression and WHOQoL-BREF caregivers' quality of life

WHOQoL-BREF (caregivers)	BDI (people under care)
	Spearman's correlation coefficient
Perception of the quality of life	r=–0.274, p=0.008*
Perception of own health	r=–0.208, p=0.047*
Physical domain	r=–0.305, p=0.003*
Psychological domain	r=–0.253, p=0.015*
Social domain	r=–0.272, p=0.009*
Environmental domain	r=–0.293, p=0.005*

*statistically significant relationship ($p<0.05$)

Hypothesis 7: There is a Relationship between the Amount of Time Spent Caring for People with PD and the Level of Burden and Quality of Life of Caregivers

Quality of life in the physical and environmental domains was significantly better in those providing care for 1–5 years than in those providing care for more than 10 years. In contrast, quality of life in the psychological domain was significantly better in those providing care for 1–5 years than in those providing care for up to one year and more than 10 years, and was also significantly better in those providing care for 5–10 years than in those providing care for more than 10 years. The results defining the relationships are presented below in tabular form (Table 8).

Table 8. Relationship between duration of care and WHOQoL-BREF caregiver quality of life

WHOQoL-BREF (caregivers)		Duration of care				p-value
		Up to one year — A (N=9)	1–5 years — B (N=38)	5–10 years — C (N=32)	>10 years — D (N=13)	
1		2	3	4	5	6
Perception of the quality of life	Mean±SD	3.11±1.05	3.26±0.86	2.78±0.87	2.69±0.85	p=0.094
	Median	3	3	3	3	
	Quartiles	2–4	3–4	2.75–3	2–3	
Perception of own health	Mean±SD	2.78±0.83	3.26±0.92	2.75±0.88	2.77±0.73	p=0.072
	Median	3	3	3	3	
	Quartiles	2–3	3–4	2–3	2–3	
Physical domain	Mean±SD	10.33±2.29	11.87±2.27	10.91±2.07	9.77±2.45	p=0.028*
	Median	10	12	11	10	
	Quartiles	9–11	11–13.75	10–12	9–12	B>D

Table 8. Continued

1		2	3	4	5	6
Psychological domain	Mean±SD	10.56±2.3	13.08±2.68	11.91±2.36	10.31±2.63	p=0.003*
	Median	11	13	12	10	
	Quartiles	10–11	11–15	11–13	9–11	B>A,D; C>D
Social domain	Mean±SD	10.89±3.18	13.42±3.85	11.84±2.49	10.46±3.2	p=0.053
	Median	11	13	12	11	
	Quartiles	8–12	11–16	11–13	9–13	
Environmental domain	Mean±SD	10.67±2.18	12.29±2.8	11.44±2.5	9.77±2.55	p=0.032*
	Median	10	12	11.5	10	
	Quartiles	10–11	10–14	10–12.25	8–12	B>D

p — Kruskal–Wallis test+post hoc analysis (Dunn's test)
*statistically significant relationship (p<0.05)

Hypothesis 8: It is Assumed that there is a Strong Association between the Presence of Depression in People under Care and the Degree of Burden on Caregivers and their Level of Quality of Life

No significant relationships (all p>0.05) between Beck Depression scale and degree of care burden of the caregiver. The results defining the relationships are presented below in tabular form (Table 9).

Table 9. Correlation between presence of depression and the caregiver burden on the CBS

CBS (caregivers)	BDI (people under care)
	Spearman's correlation coefficient
General burden	r=0.058, p=0.585
Social isolation	r=0.105, p=0.318
Disappointment	r=0.147, p=0.162
Emotional commitment	r=0.147, p=0.162
Environment	r=0.084, p=0.428

*statistically significant relationship (p<0.05)

Discussion

Caring for a chronically ill person whose disease is progressive and over time increasingly restricts the patient's capacity for self-care can significantly reduce the caregiver's sense of quality of life. The constant care provided to a patient with Parkinson's disease can cause feelings of exhaustion, burnout, lowered mood, physical fatigue and other distressing symptoms [6].

When analysing own research material, it was observed that the majority of caregivers were women (52.17%) while men constituted a smaller group (47.83%). A study by Pooyania S. et al. [7], which is related to the topic of caregiver burden, indicates that men tend to be more involved in patient care. In the self-reported study, the largest age group among caregivers consisted of those aged 40–49 years (23.91%). A much higher proportion of caregivers cared for their parents (36.96%).

One of the factors influencing the burden on caregivers of people with PD is the duration of care. The authors' study showed that the overall burden was significantly higher when the patient had been ill for more than 5 years than when they had been ill for 2–5 years. The disappointment was significantly higher when the patient had been ill for up to a year or more than 5 years than when they had been ill for 2–5 years. Similar results were obtained by Korean researchers [6], who found that duration of disease was an important determinant of caregivers' quality of life; the longer the duration of disease, the poorer the quality of life and caregiving experience scores. A study by Karakiewicz B. et al. [8] addressed the impact of demographic factors on the quality of life of people with multiple sclerosis. The duration of the disease significantly affects the physical functioning of people with multiple sclerosis and their caregivers. The duration of the disease has little impact on quality of life. This means that the longer the disease lasts, the more severe the motor and emotional disturbances become. Self-study together with the results of other authors share common findings. This demonstrates that the duration of the disease affects the quality of life of patients with PD as well as their caregivers. Another aspect of the conducted study was to find out the influence of the patient's intellectual functioning on the burden status and quality of life of caregivers of people with Parkinson's disease. Intellectual functioning was found to correlate significantly and negatively with all domains of the caregiver's quality of life. The greater the problems in this domain, the poorer the quality of life of caregivers [9]. Szluz B. states that entering a new position as a caregiver becomes more and more absorbing for the individual as the patient's health deteriorates. Focusing on the patient's disability results in failure of the caregiver to meet their needs, while problems with cognitive functioning and communication can result in a significant reduction in the caregiver's quality of life [9,10].

The results from the CBS questionnaire showed that on the general burden scale, 47 of the 92 survey participants (51.09%) experienced medium levels of burden, 24 respondents (26.09%) experienced high levels of burden and 21 respondents (22.83%) experienced low levels of burden. On the social isolation scale, 53 of the 92 survey participants (57.61%) experienced medium levels of burden, 24 respondents (26.09%) experienced low levels of burden and 15 respondents (16.30%) experienced high levels of burden. On the disappointment scale, 55 of the 92 survey participants (59.78%) experienced medium levels of burden, 19 respondents (20.65%) experienced low levels of burden and 18 respondents (19.57%) experienced high levels of burden. On the emotional involvement scale, 41 of the 92 survey participants (44.57%) experienced low levels of burden, 31 respondents (33.70%) experienced medium levels of burden, and 20 respondents (21.74%) experienced high levels of burden. On the environmental scale, 54 of the 92 survey participants (58.70%) experienced medium levels of burden, 21 respondents (22.83%) experienced low levels of burden and 17 respondents (18.48%) experienced high levels of burden. A study by Szluz B. [9] states that entering a new position as a caregiver becomes more and more absorbing for the individual as the patient's health deteriorates. Focusing on the patient's disability results in failure of the caregiver to meet their needs, while the problems associated with caring for someone with PD can result in a significant reduction in the caregiver's quality of life [9,10]. A study conducted by Grabowska-Fudala B. et al. [11] shows that high levels of burden occur in a small group of caregivers. The greatest burden among caregivers occurs in the emotional domain. The authors' self-report study did not match the results presented by Grabowska-Fudala B. et al. [11].

A self-report study using the Beck Depression Scale showed that there was a statistically significant correlation with all domains of the caregiver's quality of life. This correlation is negative, meaning that the greater the severity of depression, the worse the quality of life in all domains. The patient survey showed that 51 of the 92 participants in the survey experienced moderate depression, 34 respondents experienced mild depression, 6 respondents experienced no depression, and 1 respondent experienced severe depression. The authors of another study indicated [10] that the psychological state of the caregiver is primarily affected by the overload of responsibilities that results from combining work with care given to a person with Parkinson's disease. It was found that "for most of the respondents, the excessive effort resulting from the need to reconcile various life responsibilities causes stress, feelings of fatigue, depressive states, feelings of depression, loneliness". It seems that providing emotional support to caregivers would be very important here. Nevertheless, the literature reports that in most cases, caregivers are deprived of psychological or therapeutic support, which consequently negatively affects their overall emotional state and may intensify negative feelings [9].

Similar results were found in relation to anxiety experienced by the caregivers. It was found that the more severe the anxiety symptoms, the worse the perception of quality of life. A study by Eloise H et al. [12] confirmed that depression and anxiety were the largest negative predictors of quality of life in caregivers and further highlighted the role of personality factors. Neuroticism was negatively associated with psychological quality of life among caregivers, whereas conscientiousness, openness and extraversion appeared to be positively protective.

According to Perek-Białas J. [10], 40% of respondents involved in the care of a person with Parkinson's disease experience a deterioration in their own health, which increases the risk of premature death and developing depression. This risk is significantly higher for caregivers compared to non-caregiver control subjects.

Analysis of the research material showed that: the quality of life of caregivers in the physical, environmental and psychological domains was significantly better in those providing care for 1–5 years than in those looking after patients for more than 10 years. The patient survey showed that 51 of the 92 participants in the survey experienced moderate depression, 34 respondents experienced mild depression, 6 respondents experienced no depression, and 1 respondent experienced severe depression. The authors' study showed that the overall burden was significantly higher when the patient had been ill for more than 5 years than when they had been ill for 2–5 years. The disappointment was significantly higher when the patient had been ill for up to a year or more than 5 years than when they had been ill for 2–5 years. On the overall burden scale, 47 of the 92 survey participants (51.09%) experienced a medium level of burden and 24 respondents (26.09%) experienced a high level of burden. Regarding the assessment of quality of life using the WHOQoL-BREF questionnaire, the perception of quality of life given by the respondents results in a score of 3 (SD=0.9), which means that caregivers assess their quality of life as average (neither good nor bad). The respondents' perception of their own health amounts to 2.97 points (SD=0.9), which means that they assess their health as average (neither satisfactory nor unsatisfactory). When it comes to quality of life domains, caregivers rated their quality of life best in the social domain, slightly lower in the psychological domain and in the environmental domain, and worst in the physical domain.

Scores from the Hoehn–Yahr scale indicated a negative correlation with all domains of caregiver quality of life, thus the later the stage of the disease the worse the quality of life in all domains. The study by Perek-Białas M. et al. **[10]** reports that the assessment of the impact of the provided care on the caregiver's health depends mostly on the psychophysical condition of the patient. The caregiver is negatively affected by a variety of situations in which the patient requires complex care and situations in which contact with the patient is difficult to establish. The level of severity of the disease affects the mental capacity of the caregiver. Long-term care adversely affects the well-being of the caregiver, which contributes to the increased feelings of loneliness associated with care. Constant care of the sick person can lead to deterioration of mental and general health. The study by Perek-Białas M. et al. **[10]** shows that support from society in the form of family and various institutions plays an extremely important role. Based on studies conducted by Sobstyl M. **[13]** and Martinez-Martin P. **[14]** on the subjective and objective assessment of the quality of life in patients with PD, it was found that the patient's dependence on the caregiver is predominant in the presence of motor symptoms. Patients' mobility is limited and they need support and long-term care provided by other people.

All the predictors of feelings of burden and the negative consequences of care presented in this dissertation add up to the current picture of the problem. Distinguishing the factors is important in order to be able to intervene early enough in the context of preventing excessive feelings of burden in caregivers of people with Parkinson's disease. A reduction in the sense of burden is associated with an increase in the quality of life of both the caregivers themselves as well as their family members.

Conclusions

1. The more advanced the stage of the disease, the higher the care burden on the caregivers.
2. Low quality of life of patients positively correlates with higher levels of caregiver burden and their low quality of life.
3. The long duration of the disease and the advanced age of the person under care result in higher levels of burden among caregivers.
4. There is a strong relationship between the presence of depression in people under care and the degree of burden on caregivers and their level of quality of life.
5. There is a relationship between the presence of anxiety in caregivers and the level of burden of care for people with PD.
6. There is a relationship between the duration of the disease and the level of burden on caregivers.
7. There is a relationship between the amount of time spent caring for people with PD and the level of burden and quality of life of caregivers.

Implications for Nursing Practice

All the predictors of feelings of burden and the negative consequences of care presented in these study results add up to the current picture of the problem. Distinguishing the factors is important in order to be able to intervene early enough in the context of preventing excessive feelings of burden in caregivers of people with Parkinson's disease. A reduction in the sense of burden is associated with an increase in the quality of life of both the caregivers themselves as well as their family members. This means that it is important to implement measures in nursing practice that prevent the effects of the care burden on caregivers and provide ongoing support and assistance in difficult situations.

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