Chapter 9

The level of acceptance of the disease and the quality of life of patients with Parkinson's disease

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Abstract
Introduction: More and more cases of Parkinson's disease are diagnosed each year. Currently, nearly 6 million people suffer from it. Those affected by the disease are forced to make changes in many areas of their lives.
Aim: The aim of this study is to identify the relationship between the assessment of the level of acceptance of the disease and the quality of life of patients with Parkinson's disease.
Material and methods: The study included 108 people with Parkinson's disease. The research tool was a self-administered survey questionnaire and questionnaires: WHOQOL-BREF and Acceptance of Illness Scale (AIS).
Results: Respondents experienced communication problems, fewer friends and social withdrawal. A large percentage of patients have problems related to sleep

disorders, mood swings and depressive disorders. More than 60% of respondents were dissatisfied with their quality of life and health. The level of acceptance of the disease was low (AIS: 16.81).
Conclusions: Parkinson's disease negatively affects every sphere of life. The level of acceptance of the disease and quality of life were at a low level and independent of the duration of the disease. There is no connection between quality of life and the degree of acceptance of the disease.

Key words: Parkinson's disease, quality of life, acceptance of the disease

Introduction

The progressive aging of the population is causing more and more cases of nervous system diseases and disorders, including Parkinson's disease (PD), to be diagnosed each year [1]. An estimated 6 million of the general population suffers from it, with 10% of cases diagnosed in people over the age of 65. In these people, symptoms usually appear around the age of 60. The annual incidence in Poland ranges from 5 to 25 per 100,000 people, representing 1.5% to 3% of the population [2].

The causes of the disease are not fully understood, but socioeconomic factors (age, sex, place of residence, toxins) and genetic factors are mentioned in its etiology [3]. Researchers also report that the process of nerve cell death can occur through such mechanisms as aging and oxidative stress [4].

PD is a progressive disorder of the central nervous system with a destructive effect on the nerve cells of the black matter. It is characterised by a slow progression of symptoms due to atrophy of the dopaminergic neurons [5]. PD is characterised by specific motor symptoms, such as motor slowing, postural abnormalities, muscle rigidity or resting tremors [6]. In addition, patients have a number of extraocular symptoms, which include speech, sleep, and autonomic (incontinence, constipation) disorders. Cognitive (mental retardation, impaired thinking) and sensory functions are also impaired. It is not uncommon for patients to experience psychiatric disorders, drug states or depression [7]. PD can be treated in several ways. The most important method is pharmacotherapy, which aims to support symptomatic treatment and also provide a better quality of life for patients by reducing bothersome discomforts [8]. An integrated, holistic approach also includes treatment of other symptoms of the disease. Painkillers, therapy for dementia, depression, psychotic disorders, as well as sleep disorders and autonomic symptoms, and psychomotor rehabilitation should be introduced [9].

PD is chronic in nature. With its development and progressive disability, patients are forced to make changes in many areas of their lives and adapt to disadvantageous living situations [10]. Due to specific symptoms, visits to doctors, and multidirectional diagnosis, the process of diagnosing and treating PD significantly affects life comfort. The comfort of further life depends on the acceptance of the disease. For the greater the acceptance of the condition, the better the quality of life in the physical, social, socio-economic and psychological spheres [11]. The aim of this study is to identify the relationship between the assessment of the level of acceptance of the disease and the quality of life of patients with PD.

Material and methods

This study was conducted on a group of 108 people diagnosed with PD and residing at the Helcl Social Welfare Home in Krakow. One of the criteria for inclusion in the study was the informed consent of the patients. Another was their health status, which allowed them to answer the questions in the research tools. This study was approved by the Bioethics Committee of the Andrzej Frycz Modrzewski Krakow University (Resolution 37/2020 dated 06.04.2020 on opinion KBK/8/O/2020) and the Directorate of the Helcl Social Welfare Home in Krakow.

The research tool prepared for the study is two standardised questionnaires and one of the authors' own. The self-administered questionnaire includes questions about the duration of the disease and problems of functioning in the biological, physical, mental and social spheres, among others. The standardised survey tool is an abbreviated version of the WHO-QOL-BREF form for assessing quality of life, as well as the Acceptance of Illness Scale (AIS), which aims to obtain information on the degree of acceptance of an illness. A version of the WHOQOL-BREF questionnaire by WHO combines questions regarding the physical, social, psychological and also socio-economic spheres. In addition, it includes questions relating to a patient's individual and general perception of their quality of life and individual health. When analysing the standardised questionnaire, the total number of points from the four spheres of life mentioned above is taken into account. The higher the number of points means the better the quality of life. The scores for the domains are determined by calculating the arithmetic average of the items included in each domain.

The AIS scale is used to survey people with a variety of medical conditions. It is used to measure the degree of acceptance of the disease. The higher the level of the respondent's acceptance of the disease means the better the adaptation, and the less psychological discomfort in daily life. The AIS scale contains eight statements describing the negative consequences of poor health. The respondent completing the AIS questionnaire selects responses to each of the eight statements relating to the disease, giving them a point value from 1 to 5 ("strongly agree" – 1; "strongly disagree" – 5). The sum of the points is an overall measure of the degree of acceptance of the disease. The higher the number of points means the higher the level of acceptance of the disease [12].

The quantitative variables were analysed by calculating the mean, standard deviation, median, quartiles, minimum and maximum. The qualitative variables were analysed by calculating the number and percentage of occurrences of each value. The quantitative variables in the two groups were compared using the Mann-Whitney test. Comparisons in three or more groups were made using the Kruskal-Wallis test. The correlations between the quantitative variables were analysed using Spearman's correlation coefficient. The analysis assumed a significance level of 0.05. So, all p-values below 0.05 were interpreted as indicating significant correlations. The analysis was performed using the software R, version 3.6.2.

Results

A total of 108 people participated in the survey, of whom 55.56% were men and 44.44% women. The age of the respondents averaged 71.61 years and ranged from 59 to 96 years. The majority of patients participating in the study had a vocational education (34.26%), and the fewest respondents had graduated from university: 18.52%. More than 75% of the respondents had been ill for more than six years. The vast majority of respondents – 92.59% – admitted that daily functioning with the disease in the biological sphere caused difficulties. More than 60% of patients had a problem when performing body toileting and preparing and eating meals, and 50.93% could not cope with getting out of bed on their own. In addition, 42.59% of respondents found it difficult to perform physical activities appropriate to their abilities, 37.96% could not cope with keeping their immediate surroundings tidy, and 32.41% of respondents needed help with dressing. Also, in the mental sphere, most patients (75%) admitted to the presence of problems such as concentration and sleep disorders (50.93%), mood swings (37.96%), anxiety and fear for their life and health (35.19%) and depressive states (32.41%). The vast majority of respondents (78.70%) believed that the disease had a significant impact on the deterioration of life in relation to the social sphere. These include difficulties in communicating with others (58.33%), reluctance to engage in the social life of the institution (48.15%), a reduction in the number of friends (37.96%), lack of visits or lower frequency of meetings with loved ones (32.41%), and less enthusiasm for social roles (27.78%). Deterioration in the socio-economic field was noted by 85.19% of respondents, and included deterioration in living conditions and financial problems – a total of 37.96% of respondents.

The WHOQOL-BREF questionnaire assesses the quality of life in six dimensions. The average rating of the quality of life made by the respondents was 2.36 points, which means that they rated their quality of life between bad and average. It was rated as very bad by 35.19% of respondents, and as bad by 23.15% of respondents. The average assessment of their own health made by the respondents was 2.11 points, which means that patients rate their health as unsatisfactory. Very dissatisfied with their current health situation are 36.11% of the respondents, and dissatisfied, are 31.48% of the respondents. Respondents rated their quality of life best in the environmental domain (10.80), and rated their quality of life slightly worse in the psychological domain (10.78) and social domain (10.12).

Respondents rated their quality of life worst in the physical domain (9.40) (Table 1).

Table 1. Areas of quality of life

WHOQOL-BREF	N	Average	SD	Median	Min	Max	Q1	Q3
Physical field	108	9.40	2.1	9	5	15	8	11
Psychological field	108	10.78	2.3	11	5	17	9	13
Social field	108	10.12	2.9	10	4	17	8	12
Socioeconomic field	108	10.80	2.2	10	5	16	10	12

Source: Own compilation of research.

The patient's degree of acceptance of the disease was examined. The average AIS score was 16.81 points, indicating that the respondents did not accept their illness. The level of acceptance was very low (Table 2).

Table 2. Degree of acceptance of the disease

AIS									
Point range	N	Average	SD	Average per question	Median	Min	Max	Q1	Q3
8–40	108	16.81	3.43	2.1	16	10	26	14.75	19

Source: Own compilation of research.

This analysis shows that the quality of life in the physical ($p = 0.008$) and socio-economic ($p = 0.009$) spheres is significantly higher in women than in men. The correlation is statistically significant. In the other domains – psychological ($p = 0.227$) and social ($p = 0.534$) – there is no correlation. Also, in the case of the evaluation of the perception of quality of life ($p = 0.781$) and perception of one's own health ($p = 0.634$), no correlation was shown ($p < 0.05$). No effect of age on the perception of quality of life ($p = 0.941$) or one's own health ($p = 0.753$) was observed. There are also no such correlations in individual domains relating to quality of life in the physical ($p = 0.49$), mental ($p = 0.85$), social ($p = 0.422$) and socioeconomic ($p = 0.479$) domains. The variable of marital status was also evaluated. The correlations turned out to be statistically insignificant. The correlation coefficient for perception of quality of life was $p = 0.811$, and perception of one's health was $p = 0.64$. There was also no correlation between education and perception of one's own health and sense of quality of life. Therefore, it can be concluded that, apart from the significant relationship occurring between female gender and quality of life in the physical and socio-economic domains, no correlation was found in the other cases studied. Thus, the hypotheses that there is a relationship between the factors gender, age, marital status, education, and perceptions of patients' perceptions of their own quality of life, health, quality of life in the physical, social, socio-economic and psychological spheres were not confirmed.

There was also no correlation between disease duration and quality of life and the level of acceptance of the illness. Nor was there a correlation between disease duration and quality of life and level of acceptance of the condition.

The analyses show that there is no correlation between the duration of the disease and the perception of quality of life and one's own health in the four areas studied. Analysing the relationship between the level of acceptance of the disease and its duration, it turns out that as the years go by, the respondents' tolerance of the condition does not increase (p = 0.903) – no statistical correlation.

After analysing the data, it follows that there are no correlations indicating a correlation occurring between acceptance of the disease and the quality of life of respondents with Parkinson's (all p > 0.05). The acceptability level of the condition does not increase with the quality of life (Table 3).

Table 3. The relationship between disease acceptance and quality of life in patients with Parkinson's disease

WHOQOL-BREF	AIS
	Spearman's correlation coefficient
Perception of quality of life	r = -0.017, p = 0.862
Perception of own health	r = 0.061, p = 0.534
Physical area	r = -0.001, p = 0.994
Psychological area	r = 0.132, p = 0.173
Social area	r = -0.057, p = 0.556
Socio-economic area	r = 0.073, p = 0.452

Source: Own compilation of research.

Discussion

The literature on the subject describes a number of publications in which the authors have undertaken studies on the level of acceptance of illness and assessment of quality of life. The need for these studies is due to the rate of aging of the population, in which the presence of chronic conditions, such as oncological, cardiovascular, respiratory and musculoskeletal diseases, is of significant importance in daily functioning. Pain, numerous limitations and the need for assistance from others cause a lack of acceptance of the disease and a low assessment of the quality of life in each of the spheres, biological, psychological, social and also economic [12].

The results of our own study show that in patients with PD, quality of life is low, as is the level of acceptance of the disease. In addition, no correlation was observed between acceptance of the condition and quality of life in patients with Parkinson's. The duration of the disease also did not affect greater acceptance of the condition. The study found that women rated their quality of life better in the physical and socio-economic spheres. There was no significant correlation between the other socio-demographic factors and quality of life and acceptance of the disease.

Undoubtedly, PD reduces patients' quality of life, as shown by numerous studies. For example, Lorencowicz *et al.* showed in their study that respondents affected by Parkinson's had great difficulty in performing household chores such as laundry, cleaning and meal preparation [13]. In addition, lack of education contributed to a faster decline in functional ability caused by PD. The differences found were close to statistical significance (p = 0.05).

Our study did not show such statistical significance between education and quality of life. The study by Lorencowicz and *et al.* shows that patients who run their households alone are slightly more (no statistical significance p = 0.50) affected by dysfunction resulting from functional decline than those living with family. Also, with regard to the mental sphere, Lorencowicz *et al.* showed that PD has a devastating effect on the patient's mental state. This is reflected in the fact that as many as nearly two-thirds of the respondents (64%) showed greater or lesser severity of depressive symptoms. In their study, they also showed the respondents' problems with memory (93.33%), limitations in life activities and a reduction in their range of interests (90.33%). In addition to the above, in the study by Lorencowicz *et al.* respondents admitted that the disease reduces their motivation to get out of the house and meet with friends (78%), contributes to lower economic status (73.33%) and lower mood (68%). It is noteworthy, however, that in this study the majority of patients affected by PD were satisfied with their life (69.33%) and appreciate its value (68%) [13]. This is in contrast to our own study, where the majority of respondents rated their quality of life as very bad or bad.

There are many theories of quality of life in the literature, which are sometimes difficult to define. Certainly, quality of life is a multidimensional and interdisciplinary concept, combining important areas of life. Studies have confirmed that patients with PD have a reduced quality of life. In the study by Lorencowicz *et al.*, despite the positive assessment of quality of life by those surveyed, it was also demonstrated that PD negatively affected all the components of quality of life studied. In addition, Lorencowicz *et al.* showed a significant positive correlation between the level of functional ability and the following components of the quality of life assessment: mobility ($r = 0.74$), activities of daily living ($r = 0.54$), emotional well-being ($r = 0.36$), and cognitive function ($r = 0.27$) and communication. This analysis also indicates that the higher the level of education, the less devastatingly PD affects patients' quality of life. Lorencowicz *et al.* shows that depressive symptoms are one of the factors that reduce the quality of life of respondents in PD [13]. In our study, 32.41% of respondents indicated that the disease influenced the development of depression. However, the effect of depression on patients' quality of life was not studied.

An assessment of the quality of life of patients with PD was also undertaken by Cholewa *et al.* This study found that those who participated in the process of physical rehabilitation declared a better quality of life in comparison to non-exercisers, which may indicate the important role of rehabilitation activities as a factor in delaying the disease process and thus prolonging the ability to perform professional work.

In addition, it has been shown that appropriate physiotherapeutic management, correlated with the professional work of people with PD, can delay the severity of disease symptoms. In their study Cholewa *et al.* showed that people with PD who work professionally and participate in the process of physical rehabilitation have a better declared level of quality of life compared to both the working non-exercise group and the non-exercise group. Cholewa *et al.* concluded on the basis of their study that working professionally, proper education of the patient, his or her environment, and physiotherapy can significantly reduce fear of the future. Vocational activity and participation in appropriately planned physiotherapy activities reduce the severity of symptoms and improve the quality of life of people with PD. Cholewa *et al.* also showed that the quality of life of people with PD is determined by occupational work and participation in the process of physical rehabilitation [14].

It seems important to cite the results of other authors who have examined the level of quality of life in patients suffering from other chronic conditions.

An example of such a study is presented by Chrobak-Bień *et al.*, who surveyed a group of fifty people with Crohn's disease. The respondents voluntarily completed the WHOQOL-BREF and AIS questionnaire. Analysis of the survey showed that respondents' acceptance of their disease significantly affected the quality of life with this chronic condition. Patients who accept their disease function better in the emotional, physical and professional spheres. Acceptance of the disease has a significant impact on the quality of life of patients with this chronic disease [15]. In comparison, no effect of disease acceptance on improving quality of life was observed in our study.

Another example would be the study by Zielińska-Więczkowska *et al.* on the topic of psoriasis. In 101 respondents, a high level of acceptance of the disease was found, which affected functioning mainly in the psychological and physical spheres, and slightly worse in the social and societal domains. The overall quality of life was rated as good by the respondents, and the average acceptance of the disease was 30.37 points (definitely higher in men than in women, which was significantly influenced by the visual aspect) [16]. Our own research, on the other hand, showed a smaller group of people with a high level of acceptance of the illness. The overall level of acceptance of the disease was very low. In contrast to the study by Zielinska-Więczkowska *et al.* in their own research, it was women who experienced a better quality of life in the environmental and physical domains.

PD is a condition that affects not only the motor zone, but also the mental zone. Coexisting neuropsychiatric conditions have a huge impact on the course of the disease itself, as well as on the quality of life of the patient and his or her loved ones.

Conclusions

The considerations undertaken in this study indicate the negative impact of PD on the quality of life of patients. Among other things, the study found that:

- Patients with PD have a worsening quality of life in each of the domains studied, namely biological, environmental, social and psychological.
- There is a correlation between specific domains of quality of life and gender: women rated their quality of life better in the physical and environmental domains.
- The level of acceptance of PD in nursing home care patients was low and independent of its duration.
- Both the quality of life and the level of acceptance of the disease of nursing home residents with PD were low, but no effect of the level of acceptance of the disease on quality of life was observed.

Bibliography

1. Gaweł M, Potulska-Chromik A. *Choroby neurodegeneracyjne: choroba Alzheimera i Parkinsona*. Postępy Nauk Medycznych. 2015;28(7):468–476.
2. Struensee M, Idzikowski M, Przytalska L, Bułatowicz I, Kaźmierczak U, Srokowski G. *Ocena wpływu kinezyterapii na sprawność motoryczną pacjentów z chorobą Parkinsona*. Nowiny Lekarskie. 2010;79(3):191–198.

3. Głąbiński A. *Podstawy struktury i funkcji układu nerwowego* [in:] Adamkiewicz B, Głąbiński A, Klimek A. *Neurologia dla studentów wydziału pielęgniarstwa*. Wolters Kluwer Polska, Warszawa 2010:11–19.
4. Jopkiewicz S. *Stres oksydacyjny. Część I. Stres oksydacyjny jako czynnik rozwoju chorób cywilizacyjnych*. Medycyna Środowiskowa – Environmental Medicine. 2018;21(2):48–52, https://doi.org/10.19243/2018207.
5. Biercewicz M, Filipska K, Rybka M, Haor B, Głowacka M, Kędziora-Kornatowska K. *Nursing Problems of Patients with Parkinson's Disease – Case Report*. The Journal of Neurological and Neurosurgical Nursing. 2016;5(4):156–161, https://doi.org/10.15225/PNN.2016.5.4.5.
6. Reuter I. *Choroba Parkinsona*. Red. wyd. pol. S Budrewicz, tłum. M Góral, M Nowakowska-Kotas. Edra Urban & Partner, Wrocław 2019.
7. Stępień A. *Leczenie objawów pozaruchowych choroby Parkinsona. Raport Quality Standards Subcommittee American Academy of Neurology*. Medycyna po Dyplomie. 2010;19(9):22–24.
8. Fiszer U. *Aktualne miejsce lewodopy w leczeniu choroby Parkinsona*. Postępy Nauk Medycznych. 2012;25(1):60–64.
9. Szołna A, Harat M, Gryz J. *Leczenie dystonii pierwotnej stereotaktyczną palidotomią i talamotomią*. Neurologia i Neurochirurgia Polska. 2006;40(3):186–193.
10. Kurpas D, Kusz J, Jedynak T, Mroczek B. *Stopień akceptacji choroby przewlekłej wśród pacjentów*. Family Medicine & Primary Care Review. 2012;14(3):396–398.
11. Jankowska-Polańska B, Ilko A, Wleklik M. *Wpływ akceptacji choroby na jakość życia chorych z nadciśnieniem tętniczym*. Nadciśnienie Tętnicze. 2014;18(3):143–150.
12. Kurowska K, Lach B. *Akceptacja choroby i sposoby radzenia sobie ze stresem u chorych na cukrzycę typu 2*. Diabetologia Praktyczna. 2011;12(3):113–119.
13. Lorencowicz R, Jasik J, Podkowiński A, Ruchała M, Przychodzka E, Brzozowska A. *Wybrane uwarunkowania jakości życia w chorobie Parkinsona*. Pielęgniarstwo Neurologiczne i Neurochirurgiczne. 2012;1(2):48–57.
14. Cholewa J, Gorzkowska A, Nawrocka A, Cholewa J. *Jakość życia osób z chorobą Parkinsona w kontekście pracy zawodowej i rehabilitacji ruchowej*. Medycyna Pracy. 2017;68(6):725–734, https://doi.org/10.13075/mp.5893.00590.
15. Chrobak-Bień J, Gawor A, Paplaczyk M, Małecka-Panas E, Gąsiorowska A. *Wpływ akceptacji choroby na jakość życia pacjentów z chorobą Leśniowskiego-Crohna*. Nowa Medycyna. 2017;24(1):5–17.
16. Zielińska-Więczkowska H, Pietrzak N. *Akceptacja choroby i jej związek z jakością życia pacjentów z łuszczycą*. Medycyna Rodzinna. 2018;21(1):3–9.