

Knowledge of the general public about Parkinson's disease

Wiedza społeczna na temat choroby Parkinsona

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Abstract

Introduction. Parkinson's disease (PD) is a neurodegenerative disorder, affecting mainly elderly people. In the face of the increase in this population, a higher number of people have been suffering from PD. Misconceptions about PD may delay diagnosis, encourage unrealistic expectations from health-care services or lead to the social isolation exclusion of the patients. **Aim.** The aim of this study was to evaluate social knowledge about PD, its occurrence, symptoms, and problems of those affected. **Material and methods.** The study involved 268 respondents, such as medical staff and students as well as those not connected to health-care services. A self-designed questionnaire has been used, which included 35 questions, mainly closed-ended. **Results.** Most of the respondents associated PD with an age-related, progressive, incurable disease, which significantly affects the quality of life (QoL). In our study, respondents most often reported tremor as symptoms of PD, much less often indicating other typical symptoms, such as bradykinesia or increased muscle tone, and quite often some other symptoms not related to the disease (e.g. paresis). The respondents rarely referred to the non-motor manifestation of the disease, and they had insufficient knowledge about diagnosis and possible therapeutic options in PD. Most respondents indicated the Internet as their source of PD knowledge. **Conclusion.** Knowledge about PD in society still requires dissemination, as it is still insufficient. (*Gerontol Pol* 2019; 27; 265-271)

Key words: Parkinson's Disease (PD), Social Adjustment, Surveys and Questionnaires

Streszczenie

Wprowadzenie. Choroba Parkinsona (chP) jest chorobą neurodegeneracyjną, która dotyczy przede wszystkim osób w wieku starszym. Wraz ze zwiększaniem się tej populacji liczba chorych rośnie. Błędne przekonania dotyczące chP. mogą opóźniać rozpoznanie, sprzyjać nierealnym oczekiwaniom pacjentów wobec służby zdrowia czy prowadzić do społecznego wykluczenia chorych. **Cel.** Celem niniejszej pracy było badanie wiedzy społecznej na temat choroby Parkinsona - jej występowania, objawów i problemów osób nią dotkniętych. **Materiał i metody.** W badaniu wzięło udział 268 osób, zarówno niezwiązanych zawodowo z ochroną zdrowia, jak też personel medyczny i studenci Uniwersytetów Medycznych. Wykorzystano autorską ankietę dotyczącą szeroko pojętej wiedzy o chP, która zawierała 35 pytań, większość o charakterze zamkniętym. **Wyniki.** Większość badanych kojarzyła chP ze schorzeniem związanym z późnym wiekiem, postępującym, nieuleczalnym i znacznie wpływającym na jakość życia. W naszym badaniu respondenci najczęściej jako objawy chP podawali drżenie, znacznie rzadziej wskazując na inne typowe objawy jak bradykinezę czy wzmożone napięcie mięśniowe, dość często podawano objawy niezwiązane z chorobą (np. niedowład). Respondenci rzadko odnosili się do pozaruchowej manifestacji choroby, mieli także niewielką wiedzę na temat diagnostyki i możliwych opcji terapeutycznych w chP. Najwięcej badanych wiedzę na temat chP czerpało z Internetu. **Wnioski.** Wiedza o chP w społeczeństwie wymaga ciągle upowszechniania, gdyż jest nadal niewystarczająca. (*Gerontol Pol* 2019; 27; 265-271)

Słowa kluczowe: choroba Parkinsona (chP), nastawienie społeczne, ankiety i kwestionariusze

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Introduction

Over 200 years ago, in 1817, James Parkinson – an English doctor, geologist, paleontologist, and social activist – described a characteristic set of symptoms, at that time named ‘shaking palsy’, for the first time in his “An Essay on the Shaking Palsy” [1]. Nowadays Parkinson’s disease (PD) is second to Alzheimer’s disease most frequent neurodegenerative disease and affects about 1% of patients after 60 years of age [2,3]. PD is characterized by progressing motor dysfunctions most important of which are slowness of motion (bradykinesia), tremor, stiffness of muscle and postural instability. Moreover, many non-motor symptoms occur in the course of PD – cognitive, behavioral or autonomous. Patient’s condition deteriorates gradually over many years. The advancement of medical science enabled us to understand the pathogenesis of PD and also develop diagnostic criteria and many effective symptomatic treatments [3,4].

It is interesting to notice how well social knowledge corresponds with clinical knowledge about PD. For instance, the last examination checking the knowledge about the PD of Poles was conducted in 2013, and determined that it was insufficient. The majority of respondents associated PD only with limbs tremor and a person of late pope John Paul II [5]. Only 15% of respondents were aware that PD is incurable and progressive. Over half of them did not know how numerous the population of patients suffering from PD was and selected the answer “fewer than 10 thousand”. At the same time, every 5-th respondent indicated that they had PDs among their relatives (family / friends). It appears that higher knowledge of PD can result in an earlier diagnosis or can positively affect the attitude towards patients, who often feel isolated from social life [5].

Material and method

The study involved 268 respondents [189 females (70.5%) and 79 males (29.5%)], including 122 medical staff members and medical students (45.5%). Demographic data concerning the respondents were gathered in table I.

A self-designed questionnaire was used, which included 35 questions, mainly closed-ended. Questionnaires were gathered both online and directly from the respondents. The first part of the survey included questions about the basic demographic data of the respondents. Further questions were focused on the most important aspects of PD: clinical symptoms, their association with gender, age, co-morbidities, rate of development, quality of life (QoL) and life expectancy of the affected per-

Table I. Characterisation of respondents

Age	
18-25	166 (61.9%)
26-35	38 (14.2%)
36-45	18 (10.4%)
46-55	27 (10.1%)
>55	9 (3.4%)
Educational stage	
Primary education	1 (0.4%)
Lower secondary	4 (1.5%)
Vocational	8 (3.0%)
Secondary	176 (65.7%)
Higher	72 (26.9%)
Zamieszkanie	
Rural area	83 (31.0%)
Small town up to 25 000 inhabitants	51 (19.4%)
Medium-size town up to 100 000 inhabitants	33 (12.3%)
City over 100 000 inhabitants	99 (37.0%)

son, heredity, diagnosis, therapy, risk factors, number of people affected by PD and their potential stigmatization in society. The last questions concerned the patients’ perception of social activities and sources from which healthy people are getting information about the disease.

It should be noted that some of the questions were multiple choice – this is why percentages do not always add exactly to 100%. Additionally, some of the respondents did not answer all of the questions.

Descriptive statistics were performed. Statistical analysis was performed in the STATISTICA program. Student t-test and Pearson’s Chi-squared test were applied, and $p < 0.05$ was assumed as statistically significant.

Results

As the general symptoms of PD, the respondents most often indicated tremor, slowness of movement, speech slowness, and postural instability (in addition, up to approximately 40% of the respondents incorrectly indicated paresis as a PD symptom).

As the specific symptoms of the PD, the respondents were more likely to report tremor, to be usually related to the early PD stage, while postural instability, slowness of speech, muscle pain and paresis, to be more often associated with the advanced PD stage (Table II). The respondents more often associated the PD with the male gender. The majority of them also indicated the occurrence of depression and dementia in the course of PD. The vast majority of respondents associated PD with slow progress, a significant impact on QoL and incurability. According to the respondents, the most severe aspects of PD

were: physical disability and dependence on others, and relatively rarely indicated dementia or social exclusion in this context. The vast majority of respondents associated the PD with advanced age. Among the modifiable PD risk factors, the most frequently indicated were: drug use, excessive alcohol consumption, and lack of physical activity. However, none of these factors was indicated more often than 40%. Moreover, a significant proportion of the respondents saw the possible genetic basis of the disease.

With regard to the PD diagnosis, the respondents saw the greatest role of imaging and clinical tests. As the therapeutic options for patients, the vast majority of respondents indicated pharmacological treatment and physical rehabilitation. In terms of estimating the costs of treatment and the size of the patient population in Poland, the most

diversified answers were received. The majority of respondents believed that patients with PD were not stigmatized in society. Also, the respondents reported that they would support the professional activity of those patients. However, the majority of respondents would postulate that the patients with PD should give up their driving licenses.

Most of the respondents declared their willingness to care for relatives with PD, but a large part would expect some support from public services and about 7.5% would decide to transfer a family member with PD to a specialist medical center. However, the majority of respondents declared that there are no people burdened with PD in their environment (87.3%). The Internet was most often indicated as the source of knowledge about the PD (Table III).

Table II. Symptoms of PD and characteristic symptoms for early and advanced PD according to the respondents, divided into those who are related and unrelated to the health service (p - Pearson's Chi-squared test)

Symptoms characteristic of PD				
	Σ	People related to health care	People unrelated to health care	p (significant when < 0.05)
	n (%)	n (%)	n (%)	
Tremor	259 (96.6%)	140 (95.89%)	119 (97.5%)	0.891
Movement acceleration	17 (6.3%)	9 (6.2%)	8 (6.6%)	0.899
Slowness of movement	179 (66.8%)	80 (54.8%)	99 (81.2%)	<0.01
Muscle stiffness	141 (52.61%)	68 (46.6%)	73 (59.8%)	0.136
Mental disorders	70 (26.1%)	33 (22.6%)	37 (30.3%)	0.218
Slow speech	188 (70.2%)	90 (61.6%)	98 (80.3%)	0.069
Muscular pains	60 (22.4%)	33 (22.6%)	27 (22.1%)	0.935
Paresis	107 (39.9%)	62 (42.5%)	45 (36.9%)	0.472
Postural instability	171 (63.8%)	91 (62.3%)	80 (65.6%)	0.741
Symptoms characteristic of the early stage of PD				
Tremor	181 (67.5%)	91 (62.3%)	90 (73.8%)	0.256
Movement acceleration	8 (3.0%)	5 (3.42%)	3 (2.5%)	0.649
Slowness of movement	117 (43.7%)	58 (39.7%)	59 (48.4%)	0.287
Muscle stiffness	81 (30.2%)	38 (26.0%)	43 (35.3%)	0.172
Mental disorders	17 (6.34%)	7 (4.79%)	10 (8.2%)	0.271
Slow speech	80 (29.9%)	34 (23.29%)	46 (37.7%)	0.031
Muscular pains	62 (23.1%)	37 (25.3%)	25 (20.5%)	0.411
Paresis	32 (11.9%)	24 (16.4%)	8 (6.6%)	0.020
Postural instability	91 (34.0%)	49 (33.6%)	42 (34.4%)	0.904
Symptoms characteristic of advanced PD				
Tremor	112 (41.8%)	66 (45.2%)	46 (37.7%)	0.344
Movement acceleration	4 (1.5%)	2 (1.37%)	2 (1.6%)	0.857
Slowness of movement	102 (38.1%)	52 (35.6%)	50 (41.0%)	0.478
Muscle stiffness	103 (38.4%)	57 (39.0%)	46 (37.7%)	0.861
Mental disorders	87 (32.5%)	47 (32.2%)	40 (32.8%)	0.932
Slow speech	129 (48.1%)	70 (48.0%)	59 (48.4%)	0.961
Muscular pains	51 (19.0%)	32 (21.9%)	19 (15.6%)	0.236
Paresis	126 (47.0%)	65 (44.5%)	61 (50.0%)	0.515
Postural instability	113 (42.2%)	62 (42.5%)	51 (41.8%)	0.934

PD – Parkinson's disease

Table III. Results of the PD knowledge survey with regard to people related and unrelated to the health service (p - Pearson's Chi-squared test)

	Σ	People related to health care	People unrelated to health care	p (significant when <0.05)
	n (%)	n (%)	n (%)	
What is the relationship between PD se and gender?				
Men suffer more often	136 (50.8%)	68 (46.6%)	68 (55.7%)	0.294
Women suffer more often	28 (10.5%)	18 (12.3%)	10 (8.2%)	0.297
Gender is not related	101 (37.7%)	58 (39.7%)	43 (35.3%)	0.552
What is the relationship between depression and PD?				
It is a permanent element of PD	19 (7.1%)	4 (2.7%)	15 (12.3%)	<0.01
It affects the majority of patients	119 (44.4%)	63 (43.2%)	56 (45.9%)	0.736
If affects the minority of patients	50 (18.7%)	30 (20.6%)	20 (16.4%)	0.433
There is no such a relationship	78 (29.1%)	49 (33.6%)	29 (23.8%)	0.139
What is the relationship between dementia and PD?				
It is a permanent element of PD	46 (17.2%)	21 (14.4%)	25 (20.5%)	0.229
It affects the majority of patients	99 (36.9%)	62 (42.5%)	37 (30.3%)	0.104
If affects the minority of patients	59 (22.0%)	25 (17.1%)	34 (27.9%)	0.062
There is no such a relationship	60 (22.4%)	37 (25.3%)	23 (18.9%)	0.263
Does PD affect people under 30?				
Yes	148 (55.2%)	74 (50.7%)	74 (60.7%)	0.274
No	119 (44.4%)	71 (48.6%)	48 (39.3%)	0.256
How fast does PD develop??				
Slow (years)	232 (86.6%)	118 (80.8%)	114 (93.4%)	0.269
Fast (several months)	34 (12.7%)	27 (18.5%)	7 (5.7%)	<0.01
How PD affects the quality of life?				
To a small extent	6 (2.2%)	5 (3.4%)	1 (0.8%)	0.156
Mediocrely	28 (10.5%)	19 (13.0%)	9 (7.4%)	0.155
Significantly	231 (86.2%)	121 (82.9%)	110 (90.2%)	0.522
Does PD shorten the predictable life time?				
Yes	210 (78.4%)	115 (78.8%)	95 (77.9%)	0.934
No	56 (20.9%)	29 (19.9%)	27 (22.1%)	0.686
Is PD curable?				
Yes	25 (9.3%)	20 (13.7%)	5 (4.1%)	0.010
No	241 (89.9%)	125 (85.6%)	116 (95.1%)	0.416
Is PD related to age?				
Yes	253 (94.4%)	138 (94.5%)	115 (94.3%)	0.983
No	14 (5.2%)	8 (5.5%)	6 (4.9%)	0.841
Is PD hereditary?				
Yes	62 (23.1%)	35 (24.0%)	27 (22.1%)	0.755
No	84 (31.3%)	41 (28.1%)	43 (35.3%)	0.297
Tak. w niektórych przypadkach	121 (45.2%)	69 (47.3%)	52 (42.6%)	0.574
Is PD an infectious disease??				
Yes	0 (0%)	0 (0%)	0 (0%)	
No	266 (99.3%)	146 (100%)	120 (98.7%)	0.893
What do you consider a risk factor for PD? (you can select several answers):				
Diet	59 (22.0%)	31 (21.2%)	28 (23.0%)	0.765
Smoking	72 (26.9%)	40 (27.4%)	32 (26.2%)	0.854
Alcohol consumption	95 (35.5%)	50 (34.3%)	45 (36.9%)	0.718
Drugs	86 (32.1%)	46 (31.5%)	40 (32.8%)	0.854
Low physical activity	86 (32.1%)	53 (36.3%)	33 (27.1%)	0.183
None of the above	123 (45.9%)	68 (46.6%)	55 (45.1%)	0.857

What do you consider the most severe aspect of PD? (you can select several answers)				
Pains	65 (24.3%)	35 (24.0%)	30 (24.6%)	0.919
Physical disability	227 (84.7%)	124 (84.9%)	103 (84.4%)	0.964
Dementia	96 (35.8%)	42 (28.8%)	54 (44.3%)	0.035
Social exclusion	97 (36.2%)	48 (32.9%)	49 (40.2%)	0.323
Dependence on others	200 (74.6%)	103 (70.55%)	97 (79.5%)	0.398
Being a "burden" for the family	152 (56.73%)	75 (51.4%)	77 (63.1%)	0.204
Costs of treatment	78 (29.1%)	39 (26.7%)	39 (32.0%)	0.427
What are the approximate monthly costs of treatment for people with PD?				
< 100 PLN	6 (2.2%)	1 (0.7%)	5 (4.1%)	0.063
100-300 PLN	65 (24.3%)	31 (21.2%)	34 (27.9%)	0.272
300-500 PLN	106 (39.6%)	65 (44.5%)	41 (33.6%)	0.157
> 500 PLN	89 (33.2%)	48 (32.9%)	41 (33.6%)	0.918
What types of therapies are used in PD? (you can select several answers)				
Pharmacotherapy	256 (95.5%)	136 (93.2%)	120 (98.4%)	0.664
Rehabilitation	248 (92.5%)	131 (89.7%)	117 (95.9%)	0.601
Surgery	55 (20.5%)	25 (17.1%)	30 (24.6%)	0.179
Chemotherapy	3 (1.1%)	2 (1.4%)	1 (0.8%)	0.672
How is the diagnosis of PD carried out? (you can select several answers)				
Medical imaging	191 (71.3%)	99 (67.8%)	92 (75.4%)	0.463
Investigation of serum markers	53 (19.8%)	23 (15.8%)	30 (24.6%)	0.105
Clinical tests	158 (59.0%)	84 (57.5%)	74 (60.7%)	0.740
Biopsy	25 (9.3%)	19 (13.0%)	6 (4.9%)	0.031
What part of the population of people aged 40-60 suffers from PD?				
0.1%	32 (11.9%)	14 (9.6%)	18 (14.8%)	0.223
1%	109 (40.7%)	51 (34.9%)	58 (47.5%)	0.107
5%	107 (39.9%)	68 (46.6%)	39 (32.0%)	0.059
10%	19 (7.1%)	12 (8.2%)	7 (5.74%)	0.447
How many Poles suffer from PD?				
Over 100 thousand	56 (20.9%)	25 (17.1%)	31 (25.4%)	0.139
Approx. 80 thousand	65 (24.3%)	34 (23.3%)	31 (25.4%)	0.725
Approx. 40 thousand	85 (31.7%)	50 (34.3%)	35 (28.7%)	0.421
Approx. 20 thousand	37 (13.8%)	24 (16.4%)	13 (10.7%)	0.205
Under 10 thousand	21 (7.8%)	11 (7.5%)	10 (8.2%)	0.847
Do you think people with PD are being stigmatized by society?				
Yes	87 (32.5%)	45 (30.8%)	42 (34.4%)	0.606
No	177 (66.0%)	99 (67.8%)	78 (63.9%)	0.698
Do you think. that people with PD should be professionally active?				
Alone/with the help of the family	158 (59.0%)	84 (57.5%)	74 (60.7%)	0.740
I would require help of the public service	86 (32.1%)	45 (30.8%)	41 (33.6%)	0.689
I would put a sick person in a specialist center	20 (7.5%)	14 (9.6%)	6 (4.9%)	0.163
Do you think. that people with PD should be professionally active?				
Yes	176 (65.7%)	98 (67.1%)	78 (63.9%)	0.748
No	90 (33.6%)	46 (31.5%)	44 (36.1%)	0.521
Do you think people with PD should give up their driving licenses?				
Yes	211 (78.7%)	116 (79.5%)	95 (77.9%)	0.884
No	54 (20.2%)	27 (18.5%)	27 (22.1%)	0.509
Do you think people with PD should give up their driving licenses?				
Television	102 (38.1%)	65 (44.5%)	37 (30.3%)	0.061
Internet	165 (61.6%)	86 (58.9%)	79 (64.8%)	0.543
Books	103 (38.4%)	36 (24.7%)	67 (54.9%)	<0.01
Friends/family	97 (36.2%)	46 (31.5%)	51 (41.8%)	0.163
Journals	66 (24.6%)	32 (21.9%)	34 (27.9%)	0.328
School/university	104 (38.8%)	45 (30.8%)	59 (48.4%)	0.022
Doctor	7 (2.6%)	3 (2.1%)	4 (3.3%)	0.537

Answers to the above questions were analyzed in two subgroups of participants: 1). persons professionally associated with healthcare services or studying medical disciplines, and 2). people not associated with the healthcare sector. In these two subgroups, significant differences between answers concerned the early and late-stage PD symptoms were noted. In the first subgroup (associated with the healthcare sector), slowness of movement, and slowness of speech (as more frequent symptoms of the early PD stage) and paresis (as less frequent PD symptoms) were more often reported. Also, the participants from the first subgroup more often pointed to depression (as a permanent element of PD) and dementia (as a very severe symptom of the disease). In the second subgroup (not associated with the healthcare sector), the possibility of curing the PD, and rapid disease course (e.g. within months) were significantly more often indicated. Significant differences in answers provided by the first subgroup of responders could be related to various sources of knowledge about the PD (e.g. books and research data from educational institutions, which were more often selected than the data from the Internet) (Tables II and III).

Discussion

Our study results indicate that the level of social knowledge about PD in Poland is insufficient and there are still many misconceptions about the patients suffering from PD.

In general, the respondents, similarly to other studies in this area, associated PD with some disease-related factors, including advanced age, progressive course, incurable status, and significant deterioration of the QoL [7-9]. In the present study, respondents most often associated tremors with PD symptoms, but it is worth remembering that this symptom is not necessary to make a PD diagnosis [6]. Other common symptoms, such as bradykinesia or increased muscle tone were much less frequently indicated. Moreover, some symptoms unrelated to the PD were reported quite often (e.g. paresis). The respondents rarely mentioned non-motor symptoms of the disease, which also have a significant impact on the QoL of the patients [7,8]. This is convergent with the research of other authors, showing the lack of common knowledge about non-motor manifestations of the disease [8,10]. A similar lack of knowledge in this area has been demonstrated in a study conducted in China, among neurologists [10]. Although some of the respondents pointed depression and dementia as elements of PD, they did so only in questions, where they were asked for it in a direct way (rarely choosing these

options in the multiple-choice questions). It should be highlighted that depression represents another important factor affecting the patient's QoL [11].

As diagnostic tools in diagnosing PD, our respondents indicated mainly imaging and clinical tests. In particular, quite a large group of our respondents saw the role of blood serum tests, while in the study of other authors, such a group was much larger [7,9]. As therapeutic options for patients with PD, respondents correctly indicated pharmacotherapy and physical rehabilitation, and every fifth person knew about the possibility of surgical intervention. Although the possibilities of speech therapy and neuropsychological therapy were omitted, the role of diet was noticed [12]. The latter might have been the result of intensive dissemination of knowledge about the importance of proper diet for human health, in recent years.

In accordance with other studies, our respondents were convinced that PD had a significant impact on the patient's life expectancy [7,9]. The relevant studies also pointed out to physical disability, as the most acute aspect of the disease (that agrees with the patients' own perception of PD) [13].

Most of our respondents disagreed with the thesis that patients with PD were socially stigmatized, although a study conducted among patients showed that as many as 41% felt discriminated due to their condition [14]. A reflection of this problem was presented in the study Banks et al., in which only 35% of patients with PD reported to their employer that they were diagnosed with this disease [15].

Despite the belief that patients with PD are not stigmatized, up to one-third of our respondents did not support their professional activity. This is a relatively large percentage, even in comparison to the population participating in a similar study in Australia (in which, every fifth person expressed a similar opinion) [7]. However, in another study, the patients themselves admitted that after developing the disease, their professional work turned out to be more difficult for them than before [15]. For instance, in our study, as many as 82% of patients with PD reported difficulties in daily activities, which were mainly related to fatigue and slowness of movement [15].

Relatively small differences in responses between the two groups of participants (related versus unrelated to the healthcare sector) appear quite surprising. Our results revealed that knowledge in the first group of respondents needs improvement.

This observation was confirmed by the research of other authors [10, 16]. In the presented work, such findings may be partly due to the heterogeneity of the par-

ticipants associated with the healthcare services (e.g. medical students of different years - both before and after the course of neurology). The results of this study indicate the continuous need for education of the whole society in the field of PD, representing a serious neurodegenerative disease.

Conclusions

Undertaking the subject of social knowledge of PD is important because of its relatively frequent occurrence and the possible lack of understanding of its essence by healthy people. The study indicates that there is still a need for professional education in this area.

Conflict of interest

None

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