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**RESEARCH PAPER** 

# The role of social support in anxiety and depression among Parkinson's disease patients

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# Abstract

Purpose: To explore how social support is associated with anxiety and depression in Parkinson's disease (PD) patients controlling for gender, disease duration and disease severity. Methods: The sample consisted of 124 patients (52.4% male; mean age 68.1±8.4 years; mean disease duration  $6.3 \pm 5.5$  years). Anxiety and depression were measured with the Hospital Anxiety and Depression Scale, social support with the Multidimensional Scale of Perceived Social Support and disease severity with the Unified Parkinson Disease Rating Scale. Data were analyzed using linear regression. Results: Gender, disease duration, disease severity and social support explained 31% of the total variance in anxiety in younger PD patients but did not significantly contribute to the explanation of depression. In the older group, this model explained 41% of the variance in depression but did not significantly contribute to the explanation of anxiety. Conclusion: PD patients experience the positive influence of social support differently according to age. In the younger group, disease duration plays the primary role regarding anxiety. In the older group, poor social support especially from friends is associated with more depression after controlling for the relevant variables.

# Implications of Rehabilitation

- PD is a disease of older age with a neurodegenerative character and treatment should focus on increasing quality of life.
- · Anxiety and depression are common co-morbidities in PD patients.
- The support network should also be screened regularly and involved in enhancing the quality of life.

# Introduction

Depression in Parkinson's disease (PD) is a common and underrecognized non-motor symptom that affects up to 45% of PD patients and has a major impact on a patient's quality of life [1–9]. Most patients with depression also meet the criteria for an anxiety disorder [4,6]. Brown et al. [10] identified that depression may manifest in different clinical phenotypes, one of which is "anxious-depressed" and the other is "depressed". Furthermore, isolated anxiety may occur in a large proportion of patients. The etiology of these comorbidities remains unknown. There is no consistent conclusion among related clinical studies; therefore, it is currently unclear why some people with PD experience mood distress and others do not [5,7]. In general, it probably results from a complex interaction of psychological and neurobiological factors; in addition, there is an acknowledged overlap between PD

and depression [1,9]. Some depressive symptoms can also be understood as symptoms of Parkinsonism. "Overlap" symptoms between Parkinsonism and depression, were represented by motivation and concentration problems, appetite problems and especially the symptom of fatigue (energy loss) [10]. Furthermore, depressive symptoms may often arise for the first time in later life because of how the multiple biologic processes are selectively affected, or "pushed" in a disease direction, by the complex phenomenon of aging [11].

For effective management of this psychological distress, it is important to monitor the relevant signs, such as worries about being a burden, social withdrawal and a reluctance to be with friends, engage in activities or leave home [8]. The increasing dependence on help from others, which is considered to be the most stressful symptom among disease-related stressors, and a sense of isolation, may cause a feeling of alienation [12]. Patients sometimes withdraw, "locked inside their homes as well as themselves", which is associated with a paradoxical expectation. On one hand, as Van Der Bruggen and Widdershoven [13] put it; it means "don't touch me; leave me alone" and on the other "involve me in everything; don't lose sight of me". RIGHTSLINK()

# **Keywords**

Anxiety, depression, Parkinson's disease, social support

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# History

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It provokes both wanting contact and distance at the same time, resulting in a feeling of loneliness. Coping with how to live with PD can involve support from family or friends [12].

Social support may be regarded as a resource provided by others, as coping assistance or as an exchange of resources [14–16]. Support usually, although not always, comes from family and from partners; therefore, it can be argued that good relationships between people with PD and their partners would be important for the reduction of symptoms of anxiety and depression [7,17,18]. However, family members - partners in particular - are often those who take on the role of informal caregiver. The burden of caring for a person with a chronic disease is associated with persistent stress and impaired psychosocial functioning of the caregiver and eventually might cause mood distress in the patient as well [19-22]. This brings up the question of whether the family as a social resource actually reduces a patient's distress or might presumably worsen it. In general, family support is commonly the studied topic, but there is also a great deal of evidence regarding how the support concept per se can be overestimated and that there is a potential derogative effect of over-involvement in close relationships [21]. Surprisingly, only one study by Cheng [3] has investigated this relation in PD patients. They found that, worse functional status and low social support were in the depressed group compared to the non-depressed group of PD patients.

Other social resources may play a role: for example, perceived availability and help from friends or other significant people in a patient's life who are not in such intense every day relationship with the PD patient. Well-being does not necessarily depend on the provision of support but is connected with participation in a meaningful social context, and this might mean the likelihood of being with friends, engaging in activities with different people and profiting from these resources psychologically [23]. There is evidence that the need for these resources differs over time and increases according to age [24]; therefore, we aimed to investigate these associations in two different age groups – younger and older PD patients.

The associations between social support and anxiety and depression have not yet been studied in PD. In neurology, however, attention has already been paid to investigating this as a health-enhancing factor but this attention has focused mainly on the structure of social support (emotional, instrumental) [25] and not on the resources of social support provision. Thus, the aim of this study was to evaluate how social support from family, friends and significant others is associated with anxiety and depression in two different age groups of PD patients, independently from gender, disease duration and disease severity. We expected to find more social support to be associated with less anxiety and with less depression in PD patients.

# Methods

# Sample and procedure

The sample consisted of 124 PD patients recruited from hospitals and neurology outpatient clinics in the Eastern Slovakia region. Neurologists from 4 hospitals and 17 outpatient clinics gave us access to their databases of patients with Parkinson's disease.

An invitation letter, questionnaires and written informed consent were sent to patients diagnosed with PD by postal mail 3 weeks before the interview with the researchers. After we received the filled-in questionnaires and signed informed consent from patients, a phone call was made to invite them for an interview. All patients were interviewed by a trained interviewer on the medical history, sociodemographic information and a scan for missing values. After this structured interview with a psychologist, a neurologist specialized in Movement Disorders assessed each patient's disease severity using the Unified Parkinson's Disease Rating Scale [26] to confirm the initial diagnosis of PD. Furthermore, this was done because patients were enrolled from primary care neurologists. To decrease the chance of the misdiagnosis of PD as assessed by a primary care neurologist ( $\sim$ 30–40% versus 10% misdiagnosis by an expert), patients were examined also by a movement disorder specialist in order to confirm the diagnosis of PD made by the primary care neurologist.

Each patient's cognitive status was assessed using the Mini-Mental State Examination [27]. All patients were diagnosed according to the United Kingdom Parkinson's Disease Society Brain Bank Clinical Criteria [28]. The exclusion criterion was an MMSE score <24. Sociodemographic data were derived from medical records and from questionnaires filled in by the patients themselves. Those unable to fill in the questionnaires by themselves because of motor impairment answered the questions during the interview.

Participation in the research was voluntary. The study was conducted only after informed consent was obtained from each patient prior to the interview. The study was approved by the Ethics Committee of the School of Medicine at Safarik University in Kosice.

#### Measures

#### Demographic data and disease duration

Demographic data (age, gender) were obtained from medical records and during the structured interview. The age cut-off at 69 years was based on a median split, which gave us equal sample sizes of younger and older participants. Disease duration was obtained from medical records.

# **Disease severity**

The Unified Parkinson's Disease Rating Scale (UPDRS) is a foursubscale combined scale (mental state, activities of daily living, motor examination and complications). Two further instruments were attached to the UPDRS, namely: a modified Hoehn & Yahr staging, which is an ordinal scale that is applied to gauge the course of the disease over time; and the Schwab & England Scale, a measure of functional independence providing scores that, though expressed as percentages, form an ordinal scale. The UPDRS is currently used as a standard reference scale in clinical practice and research [26].

# Social support

The Multidimensional Scale of Perceived Social Support (MSPSSS) measures the perceived adequacy of support [29]. The scale yields three subscale scores: for family, friends and significant others, and a total score. The group "significant others" includes persons who are relevant for the patients, in this case health care professionals or other PD patients [18,19]; that is, relevant persons excluding "family (including partner)" and "friends". Apart from these, peer groups or psychotherapeutic groups led by experts could be important sources of informational support. Subjects who participate in a work team or activity group can feel positive relationships with significant others such as fellow participants, teachers or co-workers who can provide them social support. Significant others may also be individuals with the same chronic disease. Using a 7-point Likert scale, the items were scored from 1 (very strongly disagree) to 7 (very strongly agree). The values of the items were then added together for each of the three dimensions. A higher score means a higher level of social support [29]. In the present study, Cronbach's alpha for the total MSPSSS score was 0.94; for social RIGHTSLINK() support provided by family members 0.95; by friends 0.90 and by significant others 0.89.

#### Anxiety and depression

Anxiety and Depression were measured using the Hospital Anxiety and Depression Scale (HADS). This self-administered scale simultaneously evaluates anxiety (HADS-A) and depression (HADS-D) in non-psychiatric outpatient attendees. The scale consists of 14 items, 7 of which are related to anxiety and 7 to depression. Patients respond on a 4-point scale from 0 (no problem) to 3 (extreme problem). The cut-off values as proposed by the HADS authors [30] were applied in order to determine the proportion of patients considered as unimpaired (scoring  $\leq 8$  on each subscale), possibly impaired (8-10 on each subscale) or probably impaired ( $\geq 11$  on each subscale). There is no consensus about optimal cut-off scores for PD patients [8]; we used a cut-off point of 8 for categorization as suffering from "anxiety" or "depression". In the present study, Cronbach's alpha was 0.77 for the scale as a whole. Cronbach's alphas for the partial domains were 0.69 for the anxiety subscale and 0.73 for the depression subscale.

# Statistical methods

Mean scores and standard deviations were calculated for all variables. All data were inspected for normality. Except age, the variables had a normal distribution (data not shown).

Next, after having performed a median split of the sample, associations between the variables were tested by means of Pearson correlations in the groups of younger (<69) and older ( $\geq69$ ) PD patients. Furthermore, we compared anxious and depressed cases with those with low scores in HADS. Finally, hierarchical linear regression (enter method) analysis was conducted in order to identify how much of the variance of the dependent variables (HADS-A, HADS-D) may be explained by a model consisting of gender, disease duration, disease severity (UPDRS) and the different domains of social support

(MSPSSS-family, MSPSSS-friends, MSPSSS-significant others). Data were analyzed using the IBM SPSS Statistics version 20, 2011.

# Results

About 512 PD patients were invited to participate in our study. A total of 230 responded (45.1%) but 87 of them did not meet the inclusion criteria (17.4%) and 19 were excluded because of missing data (3.7%). Non-respondents did not differ significantly from the analyzed group regarding gender [mean difference = 0.00860; SE = 0.048; CI 95% (-0.08, 0.10)] and age [respondents mean  $\pm$  SD=70.08  $\pm$  8.62 (CI 95% = 68.5,71.5); non-respondents mean  $\pm$  SD=71.77  $\pm$  8.11 (CI 95% =70.9,72.5)]. Finally, 124 PD patients remained for analysis (24.2%).

The socio-demographic and clinical characteristics of the participants are presented in Table 1. The mean age was  $68.1 \pm 8.4$  years, and the sample consisted of 52.4% males. We distinguished two age subgroups: a group of younger PD patients (<69 years old; mean age  $60.8 \pm 6.3$ ; 42.1% male) and a subgroup of older PD patients ( $\geq 69$  years old; mean age  $74.4 \pm 3.6$ ; 61.2% male). Of the younger subgroup, 28% was anxious and 7% was depressed; 20% of the older subgroup was anxious and 12% suffered from depression.

Significant differences were found between the anxious and non-anxious group regarding social support from family (p < 0.05). Also, we found significant differences between the depressed and non-depressed group regarding social support from friends (p < 0.01) (Table 2).

The relationships between the study variables were calculated with Pearson correlations (Table 3). In the subgroup of younger PD patients, longer disease duration and worse disease severity were significantly correlated with more anxiety (r=0.37, p<0.01; r=0.31, p<0.01, respectively) and less social support from family and from friends were significantly correlated with

Table 1. Description of the demographic, clinical and psychosocial variables of the sample.

Variable	Total sample ( $n = 124$ ) $n(\%)$ or mean $\pm$ SD	Age group <69 $(n = 57)$ $n(\%)$ or mean $\pm$ SD	Age group $\geq 69 (n = 67)$ $n(\%)$ or mean $\pm$ SD	Range	p Value
Gender (male)	65 (52.4)	24 (42.1)	41 (61.2)		0.034* <sup>b</sup>
Age	68.1 + 8.4	60.8 + 6.3	74.4 + 3.6		
Disease duration <sup>a</sup>	$6.3 \pm 5.5$	$5.6 \pm 4.8$	$6.8 \pm 6.0$	0-33	$0.339^{\circ}$
UPDRS	$33.2 \pm 19.1$	$30.4 \pm 20.0$	$35.7 \pm 18.2$	8-91	$0.050^{\circ}$
H&Y	2.0 + 1.1	$1.8 \pm 1.1$	2.1 + 1.0	0-5	$0.087^{c}$
<2.0	86 (69.4)	42 (76.4)	43 (64.2)		0.145 <sup>b</sup>
>2.0	38 (30.6)	13 (23.6)	24 (35.8)		
S&E	$73.0 \pm 19.7$	$77.0 \pm 21.0$	$71.1 \pm 18.2$	20-100	0.006* <sup>c</sup>
<70%	47 (37.9)	15 (27.3)	31 (46.3)		0.031* <sup>b</sup>
	77 (62.1)	40 (72.7)	36 (53.7)		
Anxiety				0-19	
<8	62 (50)	25 (43.9)	37 (55.2)		$0.480^{b}$
8-10	32 (25.8)	16 (28.1)	16 (23.9)		
>11	30 (24.2)	16 (28.1)	14 (20.9)		
Depression				0-16	
<8	82 (66.1)	40 (70.2)	42 (62.7)		$0.541^{b}$
8-10	30 (24.2)	13 (22.8)	17 (25.3)		
>11	12 (9.7)	4 (7.0)	8 (12.0)		
MSPSSS family	$23.1 \pm 6.0$	$22.6 \pm 6.2$	$23.5 \pm 5.8$	4-28	$0.507^{\circ}$
MSPSSS friends	$19.2 \pm 5.8$	$19.5 \pm 5.5$	$18.9 \pm 6.1$	4-28	$0.647^{c}$
MSPSSS signif. others	$22.8 \pm 5.8$	$22.7 \pm 6.0$	$23.0 \pm 5.7$	4-28	0.771 <sup>c</sup>
MSPSSS total	$64.9 \pm 15.8$	$64.8 \pm 16.4$	$65.1 \pm 15.4$	4–28	0.998 <sup>c</sup>

UPDRS, Unified Parkinson's Disease Rating Scale; H&Y, Hoehn and Yahr Staging Scale; S&E, Schwab and England Scale; MSPSSS, The Multidimensional Scale of Perceived Social Support. <sup>a</sup>Disease duration is in years. Differences across age-groups tests: <sup>b</sup>Chi-squared, <sup>c</sup>Mann–Whitney.

\*p < 0.05.

Table 2. Differences in social support between anxious/non-anxious and depresses/non-depressed PD patients (N = 124).

Variables	Mean $\pm$ SD	p Value
Social support family		
Anxious	$22.2 \pm 5.6^{*}$	
Non-anxious	$24.1 \pm 6.3^{*}$	0.05
Social support friends	—	
Anxious	$18.4 \pm 5.5$	
Non-anxious	$19.9 \pm 6.1$	Ns
Social support Sig. others		
Anxious	$22.2 \pm 5.9$	
Non-anxious	$23.6 \pm 5.6$	Ns
Social support family		
Depressed	$22.8 \pm 5.2$	
Non-depressed	$23.3 \pm 6.4$	Ns
Social support friends		
Depressed	$17.4 \pm 5.3^{**}$	
Non-depressed	$20.1 \pm 5.9^{**}$	0.01
Social support Sig. others		
Depressed	$22.1 \pm 5.5$	
Non-depressed	$23.3 \pm 6.0$	Ns

Significant values are in bold.

SS, social support; anxious – HADS  $\geq 8$ ; depressed – HADS  $\geq 8$ . p < 0.05; \*\*p < 0.01.

Table 3. Correlations between disease duration, disease severity, different domains of social support and anxiety and depression (Pearson's p).

	PD gro	up <69	PD gro	up ≥69
	HADS-A	HADS-D	HADS-A	HADS-D
Disease duration	0.37**	ns	ns	ns
UPDRS	0.31**	0.32*	ns	ns
MSPSS family	-0.32*	ns	ns	ns
MSPSS friends	-0.33*	ns	ns	$-0.49^{**}$
MSPSS signif. Others	Ns	ns	ns	$-0.32^{**}$

UPDRS, Unified Parkinson's Disease Rating Scale; MSPSS, The Multidimensional Scale of Perceived Social Support; HADS -- A. Hospital Anxiety and Depression Scale - subscale Anxiety; HADS - D, Hospital Anxiety and Depression Scale - subscale Depression. p < 0.05; \*\*p < 0.01.

more anxiety (r = -0.32, p < 0.05; r = -0.33, p < 0.05, respectively). Regarding depression in the younger PD patients, worse disease severity was significantly correlated with more depression (r=0.32, p<0.05). In the older group, less social support from friends and from significant others was significantly correlated with more depression (r = -0.49, p < 0.01; r = -0.32, p < 0.01, respectively).

In the younger group of PD patients, 31% of the variance in anxiety was explained by a model consisting of gender, disease duration, disease severity and social support (p < 0.05) (Table 4). Disease duration was the variable significantly associated with anxiety in the younger subgroup ( $\beta = 0.23$ ;  $\Delta R^2 = 0.13$ , p < 0.05). Social support failed to explain any variance in anxiety in this group of PD patients; however more social support from significant others appeared to be associated with more depression in younger PD patients ( $\beta = 0.85$ , p < 0.05).

In the older subgroup of PD patients, the regression model failed to explain any variance in anxiety; however worse disease severity appeared to be associated with more anxiety  $(\beta = 0.30; \Delta R^2 = 0.07, p < 0.05)$ . The same model explained 41% (p < 0.001) the total variance in depression. More social support from family appeared to be associated with more \* 1 ø

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			PD gro	dı <69					PD grc	up ≥69		
	Ή	ADS-A		Ή	ADS-D		H/H	ADS-A		Η	DS-D	
	Standardized <sup>β</sup>	$R^2/\Delta R^2$	smc	Standardized $\beta$	$R^2/\Delta R^2$	smc	Standardized β	$R_2/\Delta R_2$	smc	Standardized β	$R^2/\Delta R^2$	smc
Step 1												
Gender (male) Sten 2	-0.04	0.00/0.00	ns	0.00	0.00/0.00	su	0.18	0.05/0.05	ns	0.15	0.07/0.07	ns
Disease duration (in years)	0.23	0.14/ <b>0.13</b>	*	0.12	0.05/0.04	su	-0.24	0.05/0.00	ns	0.11	0.12/0.05	us
UPDRS	0.23	0.17/0.03	ns	0.18	0.09/0.04	su	0.30*	0.12/0.07	*	0.11	0.14/0.02	su
MSPSS family MSPSS friends	-0.52			-0.79			0.12			0.49* 0.42**		
MSPSS signif. others	0.34	0.31/0.14	*	0.85*	0.18/0.09	su	-0.22	0.17/0.05	ns	-0.51*	0.41/0.27	* * *
Significant values are in bold. Smc, significance of model chi	nge for the added var	riable(s); impro	vement of	f the model due to the	he addition of th	he variab	le concerned the F c	hange test.				

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Multidimensional Scale of Perceived Social Support.

p < 0.05, \*\*p < 0.01, \*\*\*p < 0.00

depression in the group of elderly PD patients ( $\beta = 0.50, p < 0.05$ ). Less social support from friends and from significant others appeared to be associated with more depression in elderly PD patients ( $\beta = -0.42, p < 0.001; \beta = -0.51, p < 0.05$ , respectively) (Table 4).

# Discussion

The aim of this study was to explore how different types of social support are associated with anxiety and depression in PD patients stratified by age after controlling for gender, disease duration and disease severity. In our study, the association of social support with anxiety and depression differs between younger and older PD patients. Younger patients do not seem to profit from social resources as much as elderly patients do.

For the younger subgroup, disease duration is the variable most strongly related to anxiety. There are several explanations for this. Illness and its duration are likely to be more disruptive for younger people who have family and financial commitments. If something is experienced as predictable, it produces a lower level of stress than when completely unanticipated [24,31]. Thus, for older people who are used to existing chronic conditions, disease duration and disease severity does not seem to be as threatening as it is for younger patients.

Furthermore, we found that what is important for older PD patients is social support from friends and that this is associated with depression. PD focus groups have revealed that social relationships are eminently important factors for quality of life; PD participants especially emphasized the importance of support from friends [32]. Social support also meant belonging to groups or clubs that allow patients to share the same conditions and overcome depression [32].

According to previous research, support from family may have a mediating effect on the association between stress related to chronic disease and depression [19,22,33-35]. These findings may help explain our observations. Family members are usually caregivers and experience distress from caring for a PD relative themselves [36-38]. Thus, in some cases, social support from family might not be as beneficial as social support from a wider social environment. Social support from friends and significant others could be a considerable health-improving factor for older PD patients, and our findings strongly support this view. However, it could also be true that the more symptoms of depression patients have, the more negatively they rate their family in response to their disability [39]. Also, we have to consider the possibility and the presence of widowhood in this age group, which is also in line with our findings. A widowed PD patient may find meeting friends to be extremely supportive. Very recently, Benka et al. [25], in their 4-year prospective study on social support and psychological distress in rheumatoid arthritis, found that it is emotional support from the social environment that acts as a protection against psychological distress. Instrumental support was not found to be associated with psychological distress. The explanation for this may be that patients adapt better to their chronic condition over the years, and it is rather psychological vulnerability that is more closely related to their social environment [40].

In China, Cheng et al. [8] found social support to have a moderating effect on depression in a sample of 121 PD patients. The possibility that the importance of different social resources might vary within the eastern and western cultural context should also be taken into consideration. For example, a study on family care-providers of Alzheimer's disease patients in USA reported more anxiety and depression compared to care-providers of Alzheimer's disease patients in China, although coping styles and behaviors were similar between the two groups [41]. The reasons for these differences are unclear, and they remain open to further study.

What is also important to keep in mind is that The Multidimensional Scale of Perceived Social Support measures the perceived adequacy of support and so we may expect a discrepancy between need and availability in relation to mood.

Our study explored a rarely investigated topic in Parkinson's disease – social support. Furthermore, we explored the association between social resources and anxiety and depression according to two age groups. Some limitations, however, should be noted regarding the generalization of our results. The prevalence of clinically relevant depression vary according to used self-report questionnaires – with the HADS the prevalence tend to be smaller) [42] whereas with other scales such as the GDS15 or the BDI they tend to be higher [43,44] and that this could be one of the limitations of such studies, our study included. A full psychiatric examination would have been more appropriate which was however not as we did not have a psychiatrist in the examination team. However, the HADS scale was recently used to screen for anxious, depressed and anxious-depressed mood class in PD [42].

Next limitation to note is that we did not include coping style and personality as important variables in relation to social support and mood. The explained variance might increase when including these variables.

With its cross-sectional design, it is not possible to distinguish the erosion of social support; that is, whether distress from PD reduces support. The issues of causality cannot be adequately addressed from this study. The main limitation of our study is the low response rate and the composition of our sample – our sample consisted only of patients who were able to come for a neurological examination and participate in an interview; therefore, we assume that non-respondents were patients with worse disease severity and that outcomes from the total group of PD patients compared with our sample are probably worse.

Social support from friends and significant others is inversely associated with depression in the older group of PD patients, and disease duration is associated with anxiety in the younger group. A follow-up study is needed not only to support our findings, but also to unravel the causal pathways existing between social support from several resources, anxiety, depression and the role played by age. Different studies might explore the relationship between the quality of social resources, the provision of social support and their associations with anxiety and depression.

Organized social support through community clubs of PD patients might be appropriate for expressing and sharing problems and experiences of elderly PD patients with unsatisfactory social resources. For younger PD patients, the focus should be on the medical treatment of the disease itself and of anxiety and depression.

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#### **Declaration of interest**

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