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An unmet need for psychosocial treatment in patients with Parkinson's disease

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Abstract

Background: Psychosocial treatment is often recommended to be part of treatment in Parkinson's disease (PD), since increased psychosocial problems are associated with more decline of quality of life (Qol) over time. However, it is not known if this need for psychosocial treatment is sufficiently met. Therefore, the aim of this study is to explore the psychosocial burden and need for help of patients with Parkinson's disease (PD) relative to their current use of psychosocial treatment and their actual request for help.

Methods: A cross-sectional study was performed with data from medical records of PD patients who were attending an outpatient multidisciplinary assessment center. In advance, patients completed a set of questionnaires, including questions on: demographics, current treatment and requested attention for different areas of PD treatment, and standardized self-report questionnaires: psychosocial problems and need for help (BELA-P-k); depression and anxiety (HADS); Qol (PDQL) and self-reported memory functioning (MAC-S).

Results: Eventually, 217 PD patients were included. Ninety-seven percent of the patients reported psychosocial burden and need for help on the BELA-P-k. A higher score on the BELA-P-k Bothered By subscale, indicating more psychosocial burden, correlated with female gender, younger age, lower education, higher depression and anxiety scores and a worse Qol score. Forty-three percent of the patients had scores indicative for a depression or anxiety disorder, or both. Of the patients, 70% reported an actual request for attention for their mood and 50% for social contacts. Eighteen percent of the patients did receive some form of current psychosocial or psychiatric treatment.

Conclusion: The results show an unmet need for psychosocial treatment in patients with PD. Education on psychosocial aspects by means of education of patients and health care professionals can help patients improve their quality of life.

Introduction

Parkinson's disease (PD) is a neurodegenerative disorder with significant impact on patients' quality of life (Qol).[1] It comprises a wide range of motor as well as non-motor symptoms.[2] The cardinal motor features are tremor, rigidity, and bradykinesia. The non-motor symptoms include symptoms such as cognitive impairment, autonomic dysfunction and psychiatric symptoms.[3] During the disease course, patients are faced with multiple psychosocial challenges.[4] Psychosocial refers to the psychological experience of living with PD and the impact of the disease on social functioning. Examples of these psychosocial problems are: difficulty with accepting diagnosis, feelings of shame about visible symptoms, and anxiety for the future and dependency. Social functioning becomes hampered by inabilities to participate in work and activities, reduced emotional expression, speech problems, social anxiety and social isolation. Psychosocial stress, in turn, exacerbates symptoms, such as an increasing tremor and rigidity.[5] Also, it might affect treatment, since affective disorders are a risk factor for non-compliance in medical treatment.[6] Furthermore, increased psychosocial problems and depressive symptoms are associated with more decline of Qol over time and therefore, psychosocial treatment is recommended to be part of PD treatment.[4-6] However, main focus in literature seems to be on medical treatment. A recent study with Dutch focus groups revealed that PD patients desired additional support to cope better with their disease and attention for 'the person behind the disease'.[7] These results underline that patients' needs regarding psychosocial treatment maybe are not sufficiently addressed and met within PD treatment. It is important to gain more insight in patients' needs. Therefore, the aim of the present study is to explore the psychosocial burden and need for help in a Dutch outpatient sample of PD patients relative to their current use of psychosocial treatment and their actual request for help.

Methods

Participants and procedure

A cross-sectional study was performed with data from medical records of 315 patients who were attending the outpatient 'ParC' Multidisciplinary Assessment Center in Nijmegen, the Netherlands, between 2007 and 2009. These patients were referred for multidisciplinary assessment by their general practitioner or medical specialist from different hospitals across the country. They were diagnosed with (probable) idiopathic PD or atypical parkinsonism. Only patients who were diagnosed with idiopathic PD by the Movement Disorders Specialist from 'ParC' were included in the study.

Assessment

Before attending the assessment center, patients received a set of questionnaires by mail in advance. Patients were asked to complete this set of questionnaires themselves, or in case of problems with help from their caregiver. The set comprised questions about demographics, co-morbidities and current forms of treatment. Patient reported co-morbidities were coded with the Cumulative Illness Rating Scale (CIRS)[8] by the researcher. Patients were asked to answer per different area of PD treatment if they wanted attention for it (yes/with doubt/no). The following standardized validated questionnaires were included. To assess psychosocial burden and need for help in PD, the 'Belastungsfragebogen Parkinson-kurzversion (BELA-P-k)'[9] was used. The questionnaire provides two subscales: the Bothered By subscale and Need For Help subscale. These two each are divided into four subscales: 1) Achievement capability/physical symptoms; 2) Fear/emotional functioning; 3) Social functioning; 4) Partner bonding/family. A higher score indicates more psychosocial burden or need for help. The Hospital Anxiety and Depression Scale (HADS)[10,11] provided a depression and anxiety score, with a higher score indicating more depression or anxiety and a score above 8 indicating a depression or anxiety disorder, respectively.[11] Quality of life was measured with the Parkinson's disease Quality of Life Questionnaire (PDQL).[12] A lower score represents poorer quality of life.[13] Self-reported memory functioning was assessed with the Memory Assessment Clinics Self-Rating Scale (MAC-S). In this study the subscale Ability was used with higher scores indicating better cognitive abilities.[14,15] It was asked if patients received help with filling out the questionnaires, and if they found them difficult to complete. The following clinical data as obtained by the neurologist were derived from the medical records: medication use, years since diagnosis, predominant PD symptom, Hoehn and Yahr stage (H&Y),[16] and the final diagnosis after the assessments.

Analysis

The data were analyzed with the Statistical Package for the Social Sciences (SPSS version 16.0). When calculating BELA-P-k scores, missing values were replaced by the person-mean on the particular subscale, when at least *75%* of the items of the sub-scale were available. Patients with too many missing values to calculate a Bothered By total score were excluded. Differences regarding demographics, clinical data or scores on questionnaires between patients with and without a missing total score were examined by means of Pearson Chi-square or independent t-tests when appropriate. Also, patients filling out the questionnaires by themselves versus patients receiving help were compared. Mean BELA-P-k scores were calculated per subscale and per total scores. Since the Bothered By and Need for Help scales of the BELA-P-k were too strongly correlated ($r > 0.9$), indicating multicollinearity, the Bothered By scale was used in further analyses only. Correlations between BELA-P-k Bothered By scores and other variables were calculated. Independent t-tests were performed to assess differences in BELA-P-k scores for dichotomous variables. The significance level used for all analyses was $p < 0.05$. Frequencies of current care and actual requested care were analyzed descriptively. Frequencies of patients reporting an actual request for help per PD treatment area were reported, including those with doubt.

Results

Participants

Data were obtained from 315 patients. Of them, 64 were excluded because no idiopathic PD was diagnosed by the Movement Disorders Specialist after the screening. Furthermore, 34 patients were excluded because of a missing BELA-P-k Bothered By total score. Patients with a missing value on the BELA-P-k Bothered By scale significantly more often reported not wanting attention for their mood and significantly had more often completed the self-report questionnaires without help. No difference was found in finding it difficult to complete the questionnaires when compared to completers. Eventually, 217 PD patients were included (Table 1). More men than women participated in the study. Mean age was 64.7 years (SD = 9.6) and mean disease duration (years since diagnosis) was 9.3 (SD = 6.5). All H&Y stages were represented, but most patients were in the H&Y stage II, indicating bilateral symptoms, no impairment of balance, and physical independence. Tremor was the most predominant PD symptom. About 90% of the patients used PD medication and less than 10% used psychotropic medication. Forty-three percent of the patients had scores on the HADS indicative for a depression or anxiety disorder, or both. Of the participants, 66% reported having completed the questionnaires with help, mostly the spouse. The patients receiving help were significantly younger and lower educated as compared to patients who completed the questionnaires alone. They also reported higher scores on the BELA-P-k Bothered By, indicating more psychosocial burden, and lower PDQL scores, indicating a worse Qol. Receiving help was not dependent on having a partner. Of the patients, 91% found the questionnaires feasible to complete.

Table 1 Patient characteristics (n = 217)

Men	138(64%)
Age (years)	64.7(9.6)
Married/relationship	182(84%)
Higher education [†, Δ]	82(38%)
Working [†]	42(19%)
Years since diagnosis	9.3(6.5)
Hoehn & Yahr stage [†]	2.3(0.7)
Stage 1	25(12%)
2	132(61%)
3	40(18%)
4	11(5%)
5	1(1%)
Predominant PD symptom ‡	
Tremor	65(30%)
Rigidity	28(13%)
Bradykinesia	44(20%)
PIGD	20(9%)
Number of co-morbidities[†]	
1	41(19%)
2	52(24%)
3	57(26%)
>3	49(23%)
CIRS	2.9(2.0)
PD Medication	
Levodopa	146(67%)
Dopamine agonists	82(38%)
COMT inhibitors	16(7%)
Other PD medication	71(33%)
No PD medication	24(11%)
Psychotropic medication	
Antipsychotics[†]	15(7%)
Antidepressants	20(9%)
HADS	
Depression (score >8)	22(10%)
Anxiety (score >8)	30(14%)
Depression and Anxiety (both scores >8)	42(19%)

Data are represented as mean (SD) or number (%). Abbreviations: PD, Parkinson's disease; PIGD, postural instability and gait difficulty; CIRS, Cumulative Illness Rating Scale; COMT, Catechol-O-methyl transferase; HADS, Hospital Anxiety and Depression Scale.

† Missing data (<10%). ‡ No clear predominant PD symptom in 28% of the patients. Δ Higher education was defined as higher vocational education or university.

Table 2 Psychosocial burden and need for help of the patients (n = 217): BELA-P-k scores per subscale

		Bothered By categories:	Not at all	Somewhat	Moderately	Considerably	A great deal
	Mean(SD) min-max	Need for Help categories:	Not important n(%)	Hardly important n(%)	Slightly important n(%)	Rather Important n(%)	Very important n(%)
Achievement capability/ Physical symptoms							
-Bothered By	7.8(5.1) 0-20.0		16(7)	66(30)	72(33)	45(21)	18(8)
-Need for Help	9.5(5.8) 0-20.0		16(7)	41(19)	64(30)	63(29)	33(15)
Fear/emotional functioning							
-Bothered By	5.4(4.3) 0-16.0		23(11)	83(38)	64(30)	31(14)	16(7)
-Need for Help	6.6(4.6) 0-16.0		26(12)	51(24)	66(30)	47(22)	27(12)
Social functioning							
-Bothered By	4.8(4.5) 0-20.0		43(20)	93(43)	52(24)	24(11)	5(2)
-Need for Help	5.9(5.2) 0-20.0		43(20)	78(36)	48(22)	39(18)	9(4)
Partner-bonding/family							
-Bothered By	4.1(3.6) 0-20.0		25(12)	129(59)	52(24)	7(3)	4(2)
-Need for Help	5.0(4.1) 0-20.0		31(14)	102(47)	58(27)	20(9)	5(2)
Total score							
-Bothered By	22.1(15.0) 0-69.3		6(3)	103(48)	76(35)	26(12)	6(3)
-Need for Help	27.2(16.8) 0-76.0		6(3)	70(32)	82(38)	43(20)	12(6)

Abbreviations: BELA-P-k, Belastungsfragebogen Parkinson-kurzversion.

BELA-P-k scores

In table 2, the scores on the BELA-P-k are presented, indicating the psychosocial burden and need for help. Ninety-seven percent of the patients did report psychosocial burden and need for help. More than half of the patients experienced a moderate to great psychosocial burden on the Bothered By scale. About 64% of the patients had a Need for Help score between slightly important and very important. At subscale level, most burden was found in reduced achievement capability and physical symptoms. Fear and emotional functioning was a second highest burden. Least burden was found in social functioning and partner bonding/family. A significant higher BELA-P-k score was found for female gender (mean difference = 5.8, $p = 0.006$) and for a lower education level (mean difference = 5.1, $p = 0.014$). No significant difference was found for marital status, working status, and type of predominant PD symptom. No significant correlation was found for years since diagnosis, H&Y and MAC ability. A higher score on the BELA-P-k correlated significantly with a younger age ($r = -0.156$, $p = 0.022$). The HADS-Anxiety ($r = 0.592$, $p = < 0.001$), HADS-Depression ($r = 0.553$, $p < 0.001$) and PDQL ($r = -0.714$, $p < 0.001$) significantly correlated with the BELA-P-k: more anxiety, depression and a worse Qol correlated with more psychosocial burden.

Patients' current and actual requested help

Patients' current and requested attention for PD symptoms are reported in Table 3. Current care from the neurologist (97%) and general practitioner (92%) was most common. Health care professionals involved in psychosocial care were involved in less than twenty percent of the patients: psychologist (8%), psychiatrist (7%), social worker (6%), or a combination of them (<1%). Patients requested attention for medication (87%), autonomic dysfunction (80%) and their physical condition (82%). Attention for mood was requested in 72% of the patients and 50% of the patients requested attention for social contacts. Patients who requested attention for their mood and social contacts did significantly ($p < 0.01$) had higher scores on the BELA-P-k Bothered By and Need for Help scales. Patients reported doubt in wanting attention most often for mood (48%), memory (40%) and social contacts (30%).

Table 3 Patients' current care and actual requested attention for different treatment areas (n = 217)

Current care	% of the patients	**Requested attention for treatment areas**	% of the patients (including % with doubt[†])
Neurologist	97%	Medication	87% (20%)
General practitioner	92%	Autonomic dysfunction	80% (17%)
Physiotherapist	71%	Physical condition	82% (26%)
Practical support	44%	Walking	74% (24%)
PD nurse	36%	Mood	72% (48%)
Speech therapist	24%	Memory	72% (40%)
Occupational therapist	18%	Posture/balance	68% (26%)
Alternative medicine	11%	Sleep	58% (26%)
Psychologist[‡]	8%	Social contacts	50% (30%)
Psychiatrist	7%	Leisure activities	47% (24%)
Social worker	6%	Dietary advice	40% (21%)
Geriatrician	4%	Brain surgery	38%(24%)
		Intimacy/sexuality	32% (14%)
		Work	21% (7%)

Abbreviations: PD, Parkinson's disease.

[†] Patients answered that they wanted attention 'maybe'.

[‡] 18% of the patients received treatment from a psychologist/psychiatrist/social worker or a combination of them.

Discussion

This study revealed that most patients (97%) experienced psychosocial problems and need for help as was found with a standardized PD-specific questionnaire [9]. Attention for mood and social contacts were actually requested in respectively 72% and 50% of the patients. These results are in contrast with their current care: less than twenty percent of the patients did receive psychosocial support from a psychiatrist, psychologist or social worker. Furthermore, about forty percent of the patients had a probable depression or anxiety disorder, or both, while 7% was treated by a psychiatrist and 9% used antidepressants. Taking into account these results, we found a discrepancy between patients' needs and current care. This is evidently indicating an unmet psychosocial need for help for many PD patients.

As PD is a chronic progressive disorder with currently no cure available, focus in treatment should be at maximizing quality of life. Traditionally, treatment consists mainly of medication. However, as psychosocial problems due to PD have an important influence on quality of life, it is a missed opportunity not to take advantage of the possibilities of psychosocial treatment complementing medical treatment. A psychologist can play an important role within the multidisciplinary team because of their unique expertise to train patients psychological techniques like social-skills training and stress-management by cognitive-restructuring for example.[17] Cognitive restructuring is an important technique from the cognitive behavioral therapy (CBT),[18] which can help break vicious circles of psychosocial stress that negatively influence Qol.[19] Its core assumption is that a situation per se does not cause stress, but the way a person thinks about the situation does.[20] For example, patients may feel ashamed because of the tremor in public situations. The person may have negative thoughts like “everybody looks at me and laughs about me’. Bodily tensions will increase because of this stress-increasing thoughts and tremor will increase. This will lead to even more stress avoidance of public situations and eventually social isolation, which is harmful for emotional wellbeing.[21] Patients can learn to reduce stress by replacing stress-increasing thoughts by alternative stress-reducing thoughts, like: ‘Let them look! It is important for me to be here and I don’t let them spoil my day’.

Psychological techniques have been combined into structured, easy accessible and psychosocial interventions of relatively short duration. An example of such an intervention specifically directed at PD is the Patient Education Program for Parkinson’s disease (PEPP), which has a standardized manual in several languages, including Dutch[22] and English.[20] It consists of eight sessions of ninety minutes in which patients participate in groups of 5-7 members. They learn self-management techniques to deal with psychosocial stressors in order to improve their Qol. This program was found to be effective; Qol of PD patients improved after participation.[23] The program was also found to be suitable for the majority of the patients, which is important since our results suggest that a majority of the patients experienced psychosocial burden.[24] However, a subgroup of patients may need additional treatment because of more severe psychiatric problems. In our sample, a subgroup of about forty percent of the patients had scores indicative for a depression or anxiety disorder (HADS scores >8).[11] These prevalences are in line with prevalences in other studies, although large variation across studies exists.[25] An example of more intensive psychological/psychiatric treatment is individual cognitive-behavioral therapy or psychotropic medication, which have both been proven to be effective in treatment of depression in Parkinson’s disease.[26,27]

It is also important to involve the caregivers in psychosocial treatment as they provide most care at home and the disease had profound negative influences on caregivers’ wellbeing.[28] The PEPP, which was described earlier as an example of a PD psychosocial intervention, has a parallel education and training program for the caregivers (mainly the spouse). A reduction of psychosocial burden and need for help was found for the caregivers after participation in this program.[29,30] CBT also seems beneficial for PD caregivers.[31]

Regarding the request for attention for areas of PD treatment, we found that patients felt most often insecure about their request regarding attention for mood and social contacts as compared to areas of PD treatment like work, autonomic dysfunction or medication. This may be explained by several reasons. First, psychological problems may be considered being of secondary importance in respect to the physical problems and regarded as a logical consequence of the disease. This is not surprisingly since in PD treatment main focus is on motor symptoms and treatment by the neurologist. Secondly, patients may find it shameful to acknowledge psychological problems since these still may be considered as a taboo, especially in elderly. Another aspect may be the lack of knowledge in patients as well as many health care professionals about the role of psychosocial stress and possibilities for education and treatment.

Our results are in line with a study of Macht et al. in which psychological patterns in PD were explored by means of cluster analysis.[17] In that study it was also found that psychosocial problems are frequently present. An early version of the BELA-P-k was used with less items and less response possibilities. Eight-four percent of the patients experienced significant burden on at least one psychosocial problem and two-thirds of the patients were clustered as having significant psychosocial stress. Our finding that attention for mood and social contacts was requested in 50-72% is comparable to 67% of the patients in the sample of Macht who reported that psychosocial help would be beneficial for them. Results from our sample attending an outpatient clinic are thus comparable to results from a sample Macht et al. consisting of patients of a self-help organization who applied for participation in the study.

We did not replicate their findings that patients with more psychosocial stress were characterized by longer disease duration, more co-morbidities, and rigidity as main symptom.[17] In our study, more psychosocial burden was related to a younger age. Years since diagnosis was not related indicating that younger onset might be related to more psychosocial burden. Young onset may be related to additional psychosocial problems for example with work and raising children as opposed to older retired patients with grown-up children. We also found than women experienced more psychosocial burden than men, which is in line with other PD research.[30] Finally, we found a relation between more psychosocial problems and lower education.

We did not find a relation with subjective cognitive functioning (MAC-S) or H&Y stage. Another study using the BELA-P-k also did not find the relation with H&Y and it was suggested that psychosocial aspects are more dependent on coping style instead of severity of symptoms.[9] Active coping has been found to be predictive for better psychological functioning in PD one year later (with no intervention in between),[21] and therefore, active coping may be an important focus in psychosocial interventions.

Study limitations and recommendations for future research

Some limitations should be noted. First of all, many missing values were found in the BELA-A-k resulting in exclusion of 14% of the patients. These patients more often reported no request for psychosocial help and more often completed the questionnaires without help. It may be that they experienced too many difficulties with filling out the questionnaires by themselves. Another explanation might be that they have been unwilling to complete the questionnaire because of lack of need for psychosocial help or resistance to such questions. A last factor to be considered is the possibility of cognitive problems in those patients. Unfortunately, we did not have neuropsychological test scores available to test this hypothesis. Patients included in this study were referred for a multidisciplinary assessment, which may imply that they had relatively more complex symptoms or medication side-effects. These problems may be accompanied by more psychiatric problems and more psychosocial burden. Patients having less complex symptoms and better adaptation or, on the other hand, patients too physically or cognitively impaired, were probably not included. Therefore, caution should be taken when interpreting the results for the general PD population. On the other hand, an advantage of the present study is that patients' data were collected during clinical assessments and patients' inclusion was thus not dependent on their willingness to participate in the study.

It is important to assess longitudinal data in future research to search for predictors of patients who are at risk to develop psychosocial problems and psychopathology. It is likely that patients with particular personality styles and coping strategies are more vulnerable.

Also, more research is needed to determine who will benefit most for each sort of psychosocial intervention, to assess active elements of interventions and to examine at what stage of the disease psychosocial treatment is most valuable.

In conclusion, the results show an unmet need for psychosocial treatment in patients with Parkinson’s disease. More attention for psychosocial aspects by means of education of patients and health care professionals can help patients to improve their quality of life.

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