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Patient education for patients with Parkinson's disease: A randomised controlled trial

M. Chlond[a,1], F. Bergmann[a,1], C. Güthlin[b], H. Schnoor[a], A. Larisch[c], K. Eggert[c,*]

[a] Department of Educational Sciences, Philipps University of Marburg, Wilhelm-Röpke-Straße 6b, 35032 Marburg, Germany
[b] Institute of General Practice, Johann Wolfgang Goethe University of Frankfurt am Main, Theodor-Stern-Kai 7, 60590 Frankfurt, Germany
[c] Department of Neurology, Philipps University of Marburg, Baldingerstraße, 35043 Marburg, Germany

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ABSTRACT

Objective: To evaluate the effectiveness of the Patient Education Programme Parkinson (PEPP) in patients with Parkinson's disease (PD) in a randomized controlled trial and its sustainability after a 3-month follow-up.
Methods: Thirty-nine patients were allocated to the intervention group and participated in the 8-week PEPP. Thirty-four patients were assigned to the control group undergoing routine neurological care. Primary outcome was the Parkinson's disease quality of life questionnaire (PDQ-39) measured at baseline, directly after the programme and at 3-month follow-up. Secondary outcomes assessed coping behavior, psychosocial strain, health-related quality of life (HrQoL), sense of coherence, self-efficacy, anxiety and depression.
Results: A significant effect for the intervention group on the PDQ-39 ($p = .001$) and on the active problem-oriented coping subscale of the Freiburg Coping with disease questionnaire ($p = .027$) was found at 3-month follow-up.
Conclusion: In this study the PEPP improved disease-specific HrQoL and helped patients to cope with the disease.

1. Introduction

Parkinson's disease (PD) is one of the most common neurodegenerative diseases affecting about 1–2% of individuals aged 65 years and older [1]. It is characterised by a variety of physical, cognitive, and psychological symptoms that have considerable impact on patient's health-related quality of life (HrQoL) [2,3]. Disorders affecting patients' self-concept, emotional balance and body image [4,5] often lead to feelings of stigmatisation, depression and anxiety [6–9]. Coping strategies [10,11], a strong and stable sense of coherence [12] and high perceived self-confidence [13] can help counter this disease-related burden. Patient education and multidisciplinary rehabilitation have shown to reduce disease-related stress and thus improve coping styles [14–17]. Therefore, psychosocial issues and their management need to be implemented in routine neurological care. The current german guideline on diagnosis and therapy for PD [18] is focused on the treatment of motor symptoms as well as non-motor symptoms, but recommendations on psychological and social issues are missing. This may be due to insufficiently and contradictorily documented effectiveness of comprehensive psychosocial care in PD.

The Patient Education Programme Parkinson (PEPP) is the first standardised structured psychosocial education programme for PD patients, developed by a European consortium (EduPark) [19]. During formative evaluation in patients and caregivers, its feasibility and positive impact on mood and disease-related psychosocial aspects were shown while effects on HrQoL were missing [20,21]. There is only one randomised controlled trial testing its effectiveness, that found a significant effect for the caregivers on psychosocial problems but only a trend for significance for patients' HrQoL [22]. The same authors assessed the sustainability of the effectiveness of the programme in a non-controlled trial after a 6-month follow-up [23]. This time, patients HrQoL assessed by the Parkinson's Disease Questionnaire (PDQ-39) directly after the programme improved significantly, but the score returned to baseline level at 6-month follow-up. With regard to these contradictory results of short-term efficacy on patients'

* Corresponding author at: Philipps, Universität Marburg, Department of Neurology, Baldingerstraße, D-35043 Marburg, Germany.
Fax: +49 6421 58 65308x8955.
E-mail address: eggert@med.uni-marburg.de (K. Eggert).
[1] Joint first authors.

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Table 1
Topics of the Patient Education Program for Parkinson's disease (PEPP).

Session	Content
1. Information	Basic information about the training programme is provided, along with strategies for finding additional information about the disease.
2. Self-monitoring	Self-monitoring as an instrument to uncover the links between internal and external events and one's mental and physical condition is explained theoretically and practically.
3. Health promotion	The participants' attention is drawn towards well-being and how it can be improved through pleasant activities.
4. Stress management	The participants are enabled to cope with stressful situations.
5. Anxiety and depression management	The participants are informed about causes of depression and anxiety, and the self-management thereof.
6. Social competence	Difficult social situations related to the disease (e.g. talking about the disease, taking certain actions in public) are discussed and possible coping strategies are exercised.
7. Social support	Various strategies for obtaining active social support are described and practised.
8. Evaluation	Different aspects of each session are reviewed and evaluated.

HrQoL and lacking long-term effect we aimed to re-evaluate the effectiveness of the PEPP among German PD patients by assessing HrQoL, psychosocial strain, anxiety, and depression in a randomised controlled trial. The second aim was to assess the sustainability of the effect in order to define the time when a booster session is needed to maintain long-term efficacy.

2. Methods

2.1. Design and recruitment

In this randomised controlled trial patients of the intervention group (IG) attended the 8-week PEPP. Patients assigned to the control group underwent routine neurological care. The assessments were conducted at baseline ($t0$), directly after the programme ($t1$) and at 3-month follow-up ($t2$). All patients' gave their informed consent to participate. The study protocol was approved by the ethics committee of the Philipps University of Marburg in agreement with the ethical principles of the Declaration of Helsinki.

Patients of the outpatient neurological department of the Philipps University of Marburg were informed about the programme by mail. Flyers were distributed to office-based neurologists in Marburg and Giessen, and the study was presented to patient advocacy groups. The patients were all diagnosed with idiopathic PD (UK, PD Society Brain Bank Clinical Criteria) excluding those with a Mini-Mental State Examination (MMSE) [24] score $\leq$24 and clinical relevant psychosis or depression, that interfere with the training programme according to the estimation of the physician.

2.2. Intervention

Patients assigned to the IG participated in the PEPP in addition to routine neurological care. The IG comprised six independent training groups with 4–8 patients each. The programme consisted of eight weekly sessions of ninety minutes. Each session concentrated on the psychosocial burden with a similar didactic design in order to improve understanding, management and coping with the disease. The programme was presented by two certified educationists and is described in Table 1.

2.3. Efficacy measurements

Disease-specific quality of life, measured by the Parkinson's Disease Questionnaire (PDQ-39) [25], was considered the primary endpoint. The PDQ-39 consists of 39 items covering eight subscales (i.e. 'mobility', 'activities of daily living', 'emotional well-being', 'stigma', 'social support', 'cognitions', 'communication', and 'bodily discomfort'). The subscale and total scores were transformed to bring the values within the range of 0–100 (0 = absolutely no limitation–100 = the greatest possible limitation to health).

Secondary outcome measures were: the Euroqol-5D (EQ-5D) [26] to measure the general HrQoL containing 5 items scored from 1 to 3 (no to severe problems) and a VAS scale; the Freiburg Coping with Disease Questionnaire (FKV-LIS-SE) [27] to measure patients' coping behavior on five dimensions (depressive coping, active problem-oriented coping, distraction and self-affirmation, religiosity and search for meaning, and trivialisation and wishful thinking) indicating agreement on a 5-point scale (1 = not at all, 2 = a little, 3 = moderately, 4 = strongly, 5 = very strongly); the psychosocial strain and Parkinson's Disease Questionnaire (BELA-P-k) [28] to assess the psychosocial strain consisting of 19 items in 4 subscales (achievement capability/physical symptoms, fear/emotional symptoms, social functioning and partner-bonding/family) on a 5-point Likert scale (0 = not at all to 4 = a great deal); the Sense of Coherence Scale (SOC-29) [12] to measure the sense of coherence on three scales (comprehensibility, manageability and meaningfulness) with higher total score value indicating a greater sense of coherence; the General Self-Efficacy Scale (GSE) [29] to measure optimistic expectations regarding oneself involving 10 items rated on a 4-point scale: (1 not at all true to 4 exactly true); the German version of the Hospital Anxiety and Depression Scale (HADS-D) [30,31] to measure 14 items of two independent subscales (anxiety and depression) on a 4-point (0–3) response category (score 0–7 normal, score 8–10 suggestive of the presence of mood disorder, score $\geq$11 probable presence of mood disorder).

2.4. Statistical analysis

SPSS 17.0 for Windows was used to analyze the data. Sociodemographic data were examined with a t-test and chi-square test for a uniform distribution, comparing the IG and CG. The metric data of the first measuring point were examined with the Shapiro-Wilk test for a normal distribution, while Levene's test was used to determine variance homogeneity. After these conditions were fulfilled, the data obtained upon each assessment ($t0$, $t1$ and $t2$) were compared using the general linear model (GLM, variance analysis with repeated measures). Given that the t-test is solely applicable to compare two means, the GLM was chosen to compare the changes of the means over time (both groups at $t0$, $t1$ and $t2$) resulting in a single p-value. There were significant differences in the means obtained for two subscales of the FKV-LIS-SE, and the total SOC-29 score and the score on one of its corresponding subscales at $t0$. The four were included as covariates in the variance analysis. Analysis was done by intention-to-treat. The missing data for the PDQ-39 were replaced through the expectation-maximisation algorithm (EMA) [32].