



The benefits of a standardized patient education program for patients with Parkinson's disease and their caregivers

L.E.I. A'Campo^{a,*}, E.M. Wekking^b, N.G.A. Spliethoff-Kamminga^a, S. Le Cessie^c, R.A.C. Roos^a

^a Department of Neurology, Leiden University Medical Centre, The Netherlands

^b Department of Clinical, Health and Neuropsychology, University of Leiden, Leiden, The Netherlands

^c Department of Medical Statistics, Leiden University Medical Centre, The Netherlands

ARTICLE INFO

Article history:

Received 21 November 2008

Received in revised form

1 July 2009

Accepted 20 July 2009

Keywords:

Education program

Parkinson's disease

Caregivers

Psychosocial

Quality of life

ABSTRACT

The Patient Education Program Parkinson (PEPP) is a standardized psychosocial intervention aiming at improving the health-related quality of life (Hr-QoL) of patients with Parkinson's disease (PD) and caregivers. A randomized controlled trial was performed to assess its effectiveness. Sixty-four PD patients and 46 caregivers were allocated to either the intervention group (PEPP) or the control group (usual care). The intervention consisted of eight weekly sessions of 90-minute duration. Assessments were performed on psychosocial problems (BELA-P/A-k), Hr-QoL (PDQ-39/EQ-5D) and depression (SDS) at baseline and one week after the end of the PEPP. Participants rated their mood on a visual analogue scale before and after each session. A significant effect for the caregivers on psychosocial problems and need for help was found and a trend for significance for patients' quality of life. Patients' and caregivers' mood improved significantly after each session. This study provides indications that PD patients and caregivers benefit from the PEPP.

© 2009 Elsevier Ltd. All rights reserved.

1. Introduction

Parkinson's disease (PD) is one of the most common neurodegenerative diseases. All symptoms have considerable impact on daily life activities [1]. Most care for PD patients is provided by informal caregivers, mainly partners. Caregivers often experience long term strain across all stages of the patient's disease [2]. Psychosocial problems such as communication problems, feelings of stigmatization, sexual problems, loss of control, depression and anxiety make coping with PD difficult for the patient as well as for the caregiver [3,4].

Because of the severe negative impact on the quality of life, psychosocial issues need attention in the treatment of PD [4]. Therefore, a European consortium (EduPark) [5] developed the Patient Education Program Parkinson (PEPP), which addresses these psychosocial issues. The PEPP can be defined as: a systematic and professional approach to support patients and caregivers by teaching them knowledge and skills in order to improve their quality of life, complementing the medical treatment [5]. The goal is to improve the coping skills of patients and caregivers [5]. The consortium adopted the bio-psychosocial model from the

International Classification of Functioning, Disabilities and Health (ICF) [6]. The program was evaluated on its feasibility [5], but not on its effectiveness. Therefore, the aim of this study is to evaluate the effectiveness of the PEPP.

2. Methods

2.1. Participants

Sixty-five PD patients and 47 caregivers applied for participation (Fig. 1). The recruitment went via the outpatient neurological department of the Leiden University Medical Centre (LUMC), by means of an advertisement and during several meetings of the patient lay organisation. All patients had to fulfill the following criteria: 1) idiopathic PD; 2) no severe psychiatric problems (psychotic symptoms or personality disorders). Eligible caregivers were partners or close relatives, although partners were the primary target group. Patients were requested not to change their medication during the study. One patient and one caregiver were excluded because of severe psychiatric problems. Eventually, 64 patients and 46 caregivers participated and were randomized to either an intervention (PEPP) or to a control group (usual care). Both members of a couple were placed in the same group. The control group received no intervention, however, it was offered after the end of the study. Three patients and two caregivers dropped out during the study because of medical problems or other personal circumstances (Fig. 1). The study was approved by the medical ethical committee of the LUMC.

2.2. Intervention

Participants randomized to the intervention group participated in the standardized Patient Education Program Parkinson (PEPP) in addition to the usual neurological care. The PEPP addresses psychosocial issues (Fig. 2) due to PD and uses

* Corresponding author. Tel.: +0031 71 5262125; fax: +0031 71 5248205.

E-mail address: l.e.i.a_campo@lumc.nl (L.E.I. A'Campo).

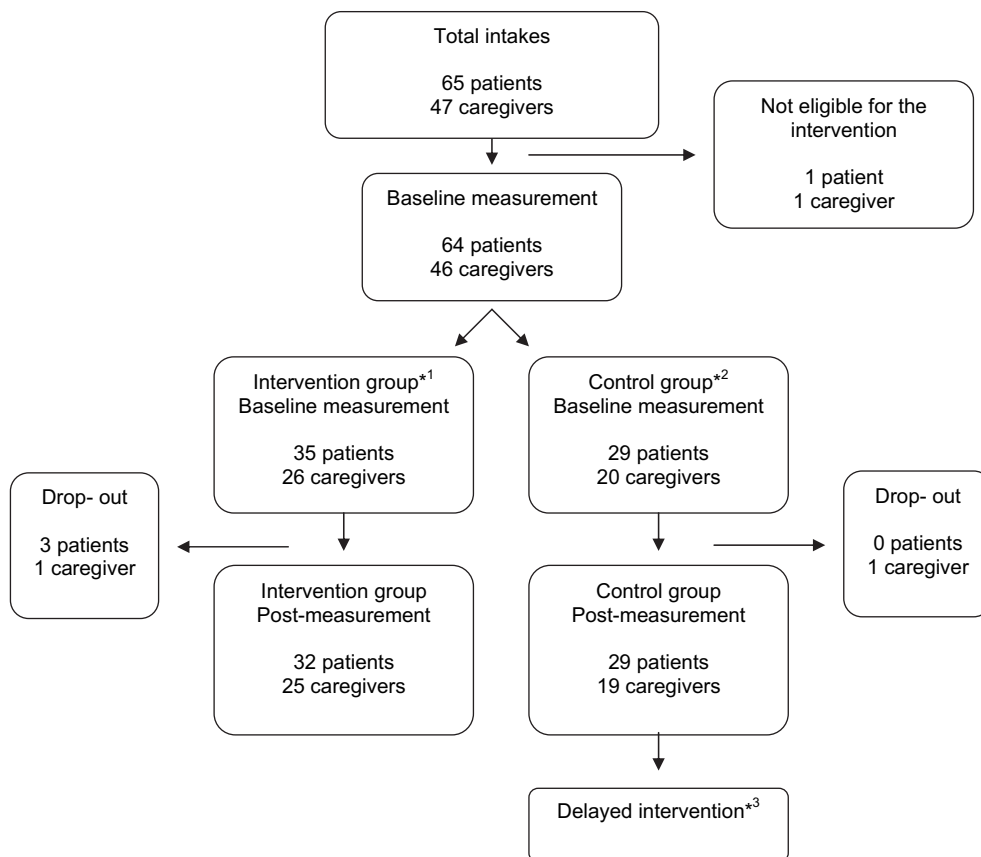


Fig. 1. Flow diagram of the sample. Randomization was performed after the baseline assessment to blind investigators and participants during this assessment. *1 The intervention group participated in the Patient Education Program Parkinson (PEPP) in addition to the regular neurological care. *2 The control group received no PEPP during the study, just the usual neurological care. After the last assessment they were offered the PEPP conclusively (delayed intervention *3). Evaluations and mood ratings of these delayed intervention group were included in the analyses.

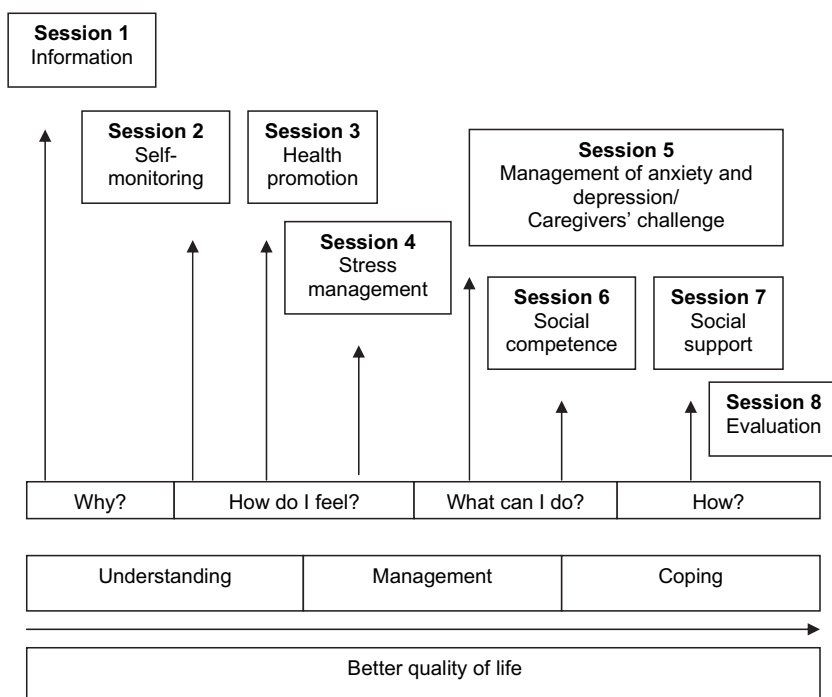


Fig. 2. The topics of and aims of the eight sessions of the PEPP.

techniques from the cognitive behavioral therapy. The manual was strictly followed; the content was standardized across groups and because the detailed manual is available in six languages, including Dutch and English [7,8], the intervention can be easily replicated. The program consisted of eight weekly sessions of 90 min duration. A description of the content of each session can be found in Table 1. Patients and caregivers participated separately but simultaneously in groups of 5–7 members at the LUMC. The relatively small group size is necessary to give all the participants the opportunity to participate actively. Trainers followed a two-day training for this PEPP intervention.

2.3. Assessment

At baseline, all patients were measured with the Hoehn & Yahr scale [9], the Activities of Daily Living scale [10], and the Mini Mental State Examination (MMSE) (caregivers also) [11].

The impact of psychosocial problems and need for help due to Parkinson's disease were assessed by the Dutch version of the 'Belastungsfragebogen Parkinson kurzversion (BELA-P-k)' [12]. For the caregivers, the caregiver version was used: the 'Belastungsfragebogen Parkinson Angehörigen kurzversion (BELA-A-k)' [13]. Both scales contain a 'bothered by' and a 'need for help scale' consisting of four domains (achievement capability, emotional functioning, social functioning, partner/family).

Scores of the subscales and total scores for the 'bothered by' and 'need for help' scale are derived by summing up the individual items. Both versions of the questionnaire have a good internal consistency and construct validity [12,13].

The health-related quality of life (Hr-QoL) of the patients was assessed by the Dutch version of the Parkinson's Disease Questionnaire (PDQ-39) [14,15]. The PDQ-39 contains 39 items that cover 8 dimensions (mobility, activities in daily life, emotional wellbeing, stigma, social support, cognitions, communication, and physical complaints). The Summary Index (SI) is calculated by dividing the sum of all dimensions by the number of dimensions. The PDQ-39 has been validated in terms of internal consistency and test-retest reliability [14,15].

In the caregivers, Hr-QoL was assessed by the Dutch version of the EuroQoL-5D (EQ-5D) [16,17], consisting of 5 items scored from 1 to 3 (no to extreme problems). Each score profile then is transformed into a utility value (EQ-Tariff), ranging from 0 to 1 (worst to perfect health state). The EQ-5D also consists of a VAS scale to assess current health state (from 0 to 100 = worse to best imaginable health state). The EQ-5D has been validated for Parkinson's disease (not caregivers) in terms of internal consistency and construct validity [16,17].

The Self-rating Depression Scale (SDS) [18,19] was used to measure depression. The 20 items are scored on a 4-point Likert-scale, and a total score is derived by summing up the individual item scores and then divided by 0.8 (range: 25–100 points). A score between 50 and 59 indicates a mild depression, between 60 and 69

Table 1

Thematic structure of the education program.

The PEPP sessions	Structure	Main focus
1 Information	Introduction Active information Exercise Homework Appetizer	The acquaintance and an overview of the program The importance of taking an active and central role in the health care system. How to ask questions to health care professionals To draft questions for a visit to professionals Past experiences with keeping a diary/journal
2 Self-monitoring	Homework discussion Active information Exercise Homework Appetizer	Homework discussion of session 1 To learn about self-monitoring techniques, like a diary. An exercise 'body awareness' focused on breathing and muscular tensions Option 1: Using a diary to record i.e. fluctuations in mood or PD symptoms Option 2: Performing the exercise 'body awareness'. Bringing something pleasant to the next session (i.e. an object or experience)
3 Health Promotion	Homework discussion Active information Exercise Homework Appetizer	Homework discussion of session 2 To improve wellbeing through pleasant activities Exploring pleasant activities Performing a new pleasant activity every day Observing your own behavior in a stressful situation
4 Stress Management	Homework discussion Active information Exercise Homework Appetizer	Homework discussion of session 3 The role of unrealistic and unhelpful thoughts in stressful situations Option 1: Learning to use alternative ways of thinking Option 2: Performing relaxation exercises to deal with stress Option 1: Trying out alternative ways of thinking Option 2: Relaxation training Observing changes of mood and causes of worry
5 Management of anxiety and depression (patients)/Caregiver's challenge	Homework discussion Active information Exercise Homework Appetizer	Homework discussion of session 4 To teach about the difference between normal feelings of anxiety and sadness and when they turn into anxiety disorders or depression/caregiver overload. Second, learning about the role of unrealistic, unhelpful cognitions Option 1: Positive thoughts Option 2: Maintaining healthy activities Option 1: Thinking of a positive event Option 2: Maintaining healthy activities Noticing situations in which you want to express your thoughts and feelings but not have the confidence to do so
6 Social Competence	Homework discussion Active information Exercise Homework Appetizer	Homework discussion of session 5 Social skills like communication are discussed. Option 1: Unhelpful and helpful thoughts in communication Option 2: Ways of communication Discussion of a video clip addressing communication problems Option 1: Noting situations in which unhelpful thoughts contributed to a lack of socially competent behavior Option 2: Telling someone that you have PD To focus on the informal or formal support they would like to receive
7 Social Support	Homework discussion Active information Exercise Homework Appetizer	Homework discussion of session 6 To discuss the importance of and how to obtain social support Role play/discussion Finding sources of support and asking for support Reflecting about the entire program
8 Evaluation	Homework discussion Active information Exercise	Homework discussion of session 7 The group goes through the previous sessions and the program is evaluated. Expectations and achievements are compared Writing a postcard for each other and filling in an evaluation questionnaire

The topics are the same for patients and caregivers, who participate in separate but parallel groups. Only session five has a different topic for patients (Management of anxiety and depression) and caregivers (Caregivers' challenge). A detailed description of the intervention can be found in the manual, which is available in six languages, including Dutch and English.

moderate depression, and a score of 70 and above indicates severe depression. The SDS had been validated in terms of internal consistency and construct validity [19].

Participants in the intervention as well as in the control group (delayed intervention) were asked to rate their present mood before and after each session on the Mood scale, a 100-point visual analogue scale (0 = extremely bad mood, 100 = extremely good mood). This instrument was validated in terms of construct validity and test-retest reliability [20].

Participants in the intervention as well as in the control group (delayed intervention) were asked to fill in an evaluation questionnaire with a three-point scale (agree/agree somewhat/disagree) to learn if their understanding of PD had improved and their expectations were fulfilled.

3. Statistical analysis

Analyses were performed with SPSS (14.0). Missing values were replaced by the person-mean on that particular subscale, when at least 75% of the items of the (sub) scale was available for a participant. The significance level used for all analyses was $p < 0.05$.

First, *t*-tests and Chi-square tests were performed to compare the demographic characteristics and the baseline scores of the intervention and the control group.

The effects of the program were measured by comparing the change scores (pre- minus post-intervention scores) of the

outcome measures between the groups, for patients and caregivers separately. The multiple endpoints due to the many subscales of the questionnaires are summarized into four total scores [21] for the patients (BELA-P-k bothered by total and need for help total, PDQ-SI and the SDS total score) and five for the caregivers ('BELA-A-k bothered by total', 'BELA-A-k need for help total', EQ-5D utility, EQ-5D VAS and the SDS total score). These total scores are the primary outcomes.

Univariate tests (*t*-tests) were performed to compare the change scores between the intervention and control group for the primary outcome measures separately. The tests on the subscales of the BELA-P/A-k and PDQ-39 (the EQ-5D and SDS do not include subscores) are secondary outcomes and are only reported for explorative purposes if the result of the total score is significant. A Bonferroni adjustment for multiple comparisons was used.

To compare pre/post -session mood ratings, a linear mixed model with random participant effect, fixed time and a fixed before-after session effect was performed. Univariate analyses (*t*-tests) were considered if the multivariate tests were significant. A *p*-value with Bonferroni adjustment for multiple comparisons was used for the univariate tests.

Table 2
Sample characteristics of the intervention and control group.

	Patients			Caregivers		
	Intervention group (<i>n</i> = 35)	Control group (<i>n</i> = 29)	<i>p</i> -value	Intervention group (<i>n</i> = 26)	Control group (<i>n</i> = 20)	<i>p</i> -value
Men/women, <i>n</i>	20/15	15/14	0.665 ^a	9/17	8/12	0.708 ^a
Age (Years)						
mean (SD)	65.54 (8.94)	64.24 (9.13)	0.568 ^b	63.39 (8.83)	61.50 (11.26)	0.528 ^b
range	48–83	45–80		43–81	39–76	
Partner/no partner, <i>n</i>	30/5	24/5	0.746 ^a	26/0	20/0	
Education level, <i>n</i> (%)						
Education till 18 yr	18 (51)	13 (45)	0.599 ^a	14 (54)	12 (60)	0.676 ^a
Higher education	17 (49)	16 (55)		12 (46)	8 (40)	
Employment, <i>n</i> (%)						
Working	8 (23)	8 (28)	0.664 ^a	8 (31)	6 (30)	0.955 ^a
Not working	27 (77)	21 (72)		18 (69)	14 (70)	
Duration illness (Years) mean (SD)	5.95 (5.33)	5.46 (4.45)	0.697 ^b	–	–	–
range	0.2–20	0.2–14				
MMSE mean (SD)	27.41 (3.37)	28.78 (1.07)	0.041 ^b	28.85 (1.12)	28.78 (1.71)	0.819 ^b
range	17–30	27–30		26–30	24–30	
H&Y stage						
mean (SD)	2.41 (1.01)	2.31 (0.72)	0.686 ^b	–	–	–
Stage 1, <i>n</i>	11	7				
Stage 2 & 3, <i>n</i>	18	20				
Stage 4 & 5, <i>n</i>	4	0				
ADL mean (SD)	76.00 (18.82)	78.85 (15.05)	0.528 ^b	–	–	–
range	30–100	30–100				
SDS, mean (SD)	54.41 (9.37)	51.63 (8.70)	0.229 ^b	43.34 (10.68)	45.01 (8.11)	0.565 ^b
No depression, <i>n</i>	9	13		18	17	
Minimal depr., <i>n</i>	16	13		6	1	
Moderate depr., <i>n</i>	7	0		1	2	
Severe depr., <i>n</i>	2	2		0	0	
PDQ-39 SI, mean (SD)	33.04 (13.49)	26.58 (12.09)	0.053 ^b	–	–	–
EQ-5D, mean (SD)						
Utility	–	–	–	0.84 (0.21)	0.91 (0.15)	0.189 ^b
VAS	–	–		73.73 (14.99)	76.95 (10.64)	0.429 ^b
BELA-P/A-k, mean (SD)						
Bothered by total	30.34 (10.87)	26.81 (8.06)	0.153 ^b	12.65 (9.11)	9.89 (8.15)	0.308 ^b
Need for help total	36.48 (12.61)	33.19 (9.54)	0.252 ^b	18.92 (11.59)	15.50 (11.53)	0.344 ^b

^a Chi-square test.

^b Independent *t*-test. Abbreviations: SD, standard deviation; MMSE, Mini Mental State Examination; H&Y, Hoehn & Yahr; ADL, Activities of daily living; SDS, Self-rating Depression Scale; depr., depression; PDQ-39 SI, Parkinson's Disease Questionnaire Summary Index; EQ-5D, EuroQol-5D; VAS, visual analogue scale; BELA-P/A-k, Belastungsfragebogen Parkinson (Angehörigen) kurzversion.

The data from the evaluation questionnaire were analyzed descriptively, i.e. the percentages of patients who fully agreed with the statements in the questionnaire.

The sample size was based on feasibility.

4. Results

There were no baseline differences on characteristics or outcome measures between the intervention and control group, except for significantly lower scores on the MMSE of the patients in the intervention group (Table 2).

4.1. Changes in patients' scores

The results of the primary outcome measures of the patients (Table 3) showed that, with a Bonferoni adjusted significance level, none of the effects were significant. There was a trend towards significance for the PDQ-SI: the intervention group improved and the control group worsened ($p = 0.015$).

4.2. Changes in caregivers' scores

The results of the primary outcome measures of the caregivers (Table 4) showed that, with a Bonferoni adjusted significance level, there was a significant effect for the BELA-A-k total scores of the 'bothered by' ($p = 0.001$) and 'need for help' scale ($p = 0.001$). The scores of the intervention group improved after participation in the PEPP, while scores of the control group worsened.

The results from of the subscales of the BELA-A-k as secondary outcome measures are presented in Table 5. With a Bonferoni adjusted significance level, the sub scores of 'bothered by achievement capability' ($p = 0.001$) and 'need for help' regarding 'achievement capability' ($p = 0.001$), 'emotional functioning' ($p = 0.006$) and 'social functioning' ($p = 0.002$) showed significantly improved scores for the intervention group, and worsened scores for the control group.

4.3. Mood changes

Patients' mood significantly improved from pre- to post-sessions on the 100-point VAS with a mean difference of 5.72 (CI: -7.01 to -4.37 , $p = 0.000$). Caregivers' mood improved as well, with a mean difference of 6.21 (CI: -7.53 to -4.90 , $p = 0.01$). Mood also improved from session 1 to 8 in the patients group with a mean difference of 5.04 (CI: 2.74 – 7.28 , $p = 0.000$) as well as in the caregivers group with a mean difference of 3.81 (CI: 1.52 – 6.09 , $p = 0.001$). Univariate tests (Table 6) show that, with a Bonferoni

Table 3
Patients' changes on the primary outcome measures.

Summary scores	Intervention group ($n = 29$)	Control group ($n = 28$)	Difference between groups	p -value
	Mean change (SD)	Mean change (SD)	Mean difference (95% CI)	
BELA-P-k				
Bothered by total	2.32 (5.27)	0.59 (6.05)	1.74 (-1.27 – 4.74)	0.252
Need for help total	1.68 (7.56)	-0.36 (7.61)	2.04 (-2.0 – 6.06)	0.316
PDQ-39-SI	3.07 (7.81)	-1.79 (6.73)	4.86 (0.98–8.73)	0.015
SDS	1.96 (6.51)	-1.55 (6.73)	3.51 (-0.00 – 7.02)	0.050

Positive change scores indicate improvement; negative change scores indicate worsening on the outcome measure. Abbreviations: CI, confidence interval; BELA-P-k, Belastungsfragebogen Parkinson kurzversion; PDQ-39 SI, Parkinson's Disease Questionnaire Summary Index; SDS, Self-rating Depression Scale. 3 patients of the intervention group and 1 from the control group were excluded from the analyses because of missing values on a subscale.

Table 4
Caregivers' changes on the primary outcome measures.

Summary scores	Intervention group ($n = 21$)	Control group ($n = 15$)	Difference between groups	p -value
	Mean change (SD)	Mean change (SD)	Mean difference (95% CI)	
BELA-A-k				
Bothered by total	2.25 (5.41)	-4.80 (6.66)	7.05 (2.96–11.14)	0.001*
Need for help total	5.05 (9.03)	-6.33 (8.37)	11.38 (5.36–17.40)	0.001*
EQ-5D				
Utilities	-0.07 (0.23)	0.03 (0.15)	-0.10 (-0.24 – 0.04)	0.159
VAS	0.67 (14.91)	2.00 (14.01)	-1.33 (-11.33 – 8.66)	0.788
SDS	1.39 (8.22)	-1.23 (10.46)	2.62 (-3.71 – 8.94)	0.407

Positive change scores on the BELA-A-k and SDS indicate improvement; negative change indicates worsening on the outcome measure. Positive change scores on the EQ-5D utilities and VAS indicate worsening, negative change indicates improvement. Abbreviations: CI, confidence interval; BELA-A-k, Belastungsfragebogen Parkinson Angehörigen kurzversion; EQ-5D, EuroQol-5D; VAS, visual analogue scale; SDS, Self-rating Depression Scale. * $p < 0.01$ (Bonferoni adjustment for multiple comparisons). 4 caregivers of the intervention group and 4 from the control group were excluded from the analyses because of missing values on a subscale.

adjusted p value of 0.006 for multiple comparisons, patients and caregivers' mood improved significantly after each session, except for session 1 and 2 in the patients group.

4.4. Evaluation

Of the 58 patients and 39 caregivers who evaluated the program, about 90% agreed that the exchange of experiences within the group was helpful; more than half of them reported an improvement of understanding of PD; more than 50% said they could deal better with the problems due to the disease now; in more than 75%, expectations were fulfilled. In the patients as well as in the caregivers, 50% of the patients and caregivers rated session 4, 'stress management' as the most valued session.

5. Discussion

The Patient Education Program Parkinson is the first completely standardized international psychosocial intervention designed for PD patients and their primary caregivers. With this randomized controlled trial, we found an effect of the PEPP in the caregivers group; the intervention group experienced less psychosocial problems and less need for help after participation in the PEPP compared to the control group, which experienced more psychosocial problems and need for help. In the patients group, a trend towards significance was found for quality of life, yielding better results for the intervention group after the PEPP.

The clinical relevance of the found improvements is supported by the positive evaluations of the participants, i.e. the self-reported improved ability to deal with PD in more than 50% of the participants.

The improvements on mood measured with the VAS indicate that the participants felt better post-session; however we have to be cautious with the interpretation of a visual analogue scale, because it is a simplified measure of mood [20]. There was no significant reduction in depressive symptomatology, but considering our sample characteristics, most of the participants had no or minimal depressive complaints, so further reduction of depressive symptomatology may therefore not have been likely (floor-effect). The lack of change also may have been due to the choice of the instrument (SDS). Since cognitive behavioral therapy has already been proved to reduce depressive symptoms in PD patients and caregivers [22–24] and these techniques are applied in the protocol

Table 5

Changes on caregivers' secondary outcome measures: BELA-A-k sub scores.

BELA-A-k		Intervention group (n = 21)	Control group (n = 15)	Difference between groups	p-value
		Mean change (SD)	Mean change (SD)	Mean difference (95% CI)	
Bothered by subscales	Achievement capability	1.11 (2.06)	−1.47 (1.88)	2.58 (1.21–3.95)	0.001*
	Emotional functioning	0.95 (2.62)	−1.40 (2.90)	2.35 (0.47–4.23)	0.016
	Social functioning	0.10 (1.89)	−1.00 (2.07)	1.10 (−0.25–2.44)	0.107
	Partner/family	0.10 (2.07)	−0.93 (2.25)	1.03 (−0.45–2.50)	0.166
Need for help subscales	Achievement capability	2.62 (3.80)	−1.33 (2.50)	3.95 (1.67–6.24)	0.001*
	Emotional functioning	1.24 (3.87)	−2.47 (3.61)	3.71 (1.16–6.25)	0.006*
	Social functioning	1.05 (2.46)	−1.73 (2.55)	2.78 (1.07–4.50)	0.002*
	Partner/family	0.14 (3.07)	−0.80 (2.81)	0.94 (−1.09–2.98)	0.354

Positive change scores on the BELA-A-k subscales indicate improvement; negative change indicates worsening. Abbreviations: BELA-A-k, Belastungsfragebogen Parkinson Angehörigen kurzversion; CI, confidence interval. * $p < 0.00625$ (Bonferroni adjustment for multiple comparisons). 4 caregivers of the intervention group and 4 from the control group were excluded from the analyses because of missing values on a subscale.

of the PEPP, the PEPP has the potential to reduce depressive symptoms. Therefore future research should evaluate the possible effectiveness of the PEPP, additional to medical treatment, in treating PD patients with moderate to severe depression.

Although we found improvements on psychosocial functioning of the caregivers, no change in their Hr-QoL was found. A possible explanation could be the choice of our evaluation instrument, the EuroQoL-5D. The five dimensions (self-care, usual activities, pain/discomfort and anxiety/depression) covered by the EQ-5D are probably too limited and too general. Therefore, this instrument is probably not sensitive enough to take into account the specific issues in PD caregivers, which are addressed in the PEPP. In the patients, a contrary result was found: Hr-QoL improved (although not significantly), but not the psychosocial problems measured with the BELA-P-k. In the study of Macht et al. patients' psychosocial problems did diminish after the PEPP [5].

During the development stage, Simons et al. [25] evaluated the data from the English patients and caregivers in the sample of Macht et al. [5] as part of the same uncontrolled study. They did not find any improvements on Hr-QoL, psychosocial problems and depression. Only improvements in mood were found. This lack of significant results seems to be the result of their small sample size (22 patients, 14 caregivers), because Macht et al. did find psychosocial improvements in the complete sample (151 patients).

Two other PD patient education programs have been described in the literature. Sunvisson et al. evaluated a six-week patient education program with weekly two-hour sessions [26]. They also found significant improvements on psychosocial functioning and Hr-QoL, measured with the Short Form Health Survey 36-item (SF-36), in a non-controlled study with 43 patients. However, these results could not be replicated (with the SF-12) in a subsequent controlled, but non-randomized study of Lindskov [27] with 96 patients. Lindskov et al. related the lack of results among others to

a suboptimal match between the intervention effects and the outcome measure used. The SF-12 is a general quality of life measurement and the short version of the SF-36 and may not be sensitive enough to detect the effects of the intervention. Also some differences in the content of the intervention are important. 1) The PEPP is more standardized and has been assessed on its feasibility in a pilot study (151 patients, 137 caregivers) and was then described in a manual. 2) In the PEPP, one trainer is present during the whole program, because it is important that participants feel confident with the trainer, in view of the intimate discussions in the group. During the different sessions of Lindskov et al. different professionals were involved. 3) In the PEPP, patients as well as caregivers learned management strategies, while in the study of Lindskov et al. caregivers only received peer-support. We do not know if these differences are responsible for the differences in results, but they are important considerations for future research.

6. Limitations and recommendations for future research

Because many of the scales showed relatively large confidence intervals for the differences between the groups, a larger sample size, which increases the power, would have been better, however this was not feasible.

Despite the randomization, the groups differed in MMSE scores at baseline, which could have introduced a bias in the study. Also, the participants applied for participation in the study, which has implications for the generalizability.

An additional value of the PEPP, besides the provision of knowledge and skills, is that participants experience attention from the trainers and interactions with the fellow-sufferers. Most participants experienced the exchange within the group as very helpful. A meta-analysis on behavioral therapy indicated that the specific therapy effects are larger than those achieved by placebo control

Table 6

Univariate tests for changes in scores on the 100-point mood VAS pre- versus post-session.

Session number	Patients (n = 47–56)			Caregivers (n = 34–40)		
	Before session	After session	p-value	Before session	After session	p-value
	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
1	68.87 (12.23)	71.93 (14.38)	0.041	69.21 (17.65)	74.92 (12.36)	0.002*
2	67.48 (15.13)	71.16 (13.63)	0.025	70.38 (16.78)	76.30 (12.00)	0.003*
3	67.10 (14.45)	74.53 (10.20)	0.000*	72.86 (16.33)	79.44 (9.78)	0.002*
4	67.39 (15.62)	74.33 (10.59)	0.000*	71.97 (16.38)	78.08 (10.50)	0.002*
5	63.43 (19.59)	73.90 (14.54)	0.000*	69.32 (19.40)	75.76 (13.19)	0.001*
6	69.94 (14.73)	74.15 (12.09)	0.002*	71.26 (17.33)	77.38 (10.65)	0.001*
7	69.88 (11.79)	74.88 (11.19)	0.001*	73.90 (10.91)	78.84 (10.12)	0.000*
8	71.94 (13.28)	77.70 (11.95)	0.000*	75.41 (12.88)	81.78 (9.89)	0.000*

* $p < 0.006$ (Bonferroni adjustment for multiple comparisons). Higher scores on the 100-point mood VAS indicate a better mood.

conditions [28]. However, this has not yet been studied with regard to this particular education program and we recommend this for future research. Social desirability, i.e. pleasing the trainers with improvements on the mood scale, may have introduced a bias in the results. Furthermore, we recommend measuring the effectiveness of the PEPP after a follow-up period, for example after 6 months. Also important for future research are cost-analyses on the PEPP. Preliminary results in the study on self-management programs in other diseases show that self-management interventions are able to reduce health care costs [29,30]. A consideration for future studies is the application of the PEPP to other chronic diseases.

In conclusion, the present study provides indications that patients and caregivers benefit from participation in the PEPP. The program appears to be a valuable addition to the treatment of patients with PD and caregivers.

Conflict of interest

None declared.

Acknowledgement

We would like to thank: All the patients and caregivers who participated; The trainers: J. Voorham, M. Scholte, L. Esmeyer, M. v/d Plas & S. Muntz; The research associates: A. Hooghiemstra, I. ter Doest, R. Ruigrok and S. de Kreek.

References

- [1] Jankovic J. Parkinson's disease: clinical features and diagnosis. *J Neurol Neurosurg Psychiatry* 2008;79:368–76.
- [2] Carter JH, Stewart BJ, Archbold PG, Inoue I, Jaglin J, Lannon M, et al. Living with a person who has Parkinson's disease: the spouse's perspective by stage of disease. *Parkinson's study group. Mov Disord* 1998;13:20–8.
- [3] Macht M, Schwarz R, Ellgring H. Patterns of psychological problems in Parkinson's disease. *Acta Neurol Scand* 2005;111:95–101.
- [4] Ellgring H, Seiler S, Perleth B, Frings W, Gasser T, Oertel W. Psychosocial aspects of Parkinson's disease. *Neurology* 1993;43:SS441–4.
- [5] Macht M, Gerlich C, Ellgring H, Schrader M, Rusinol AB, Crespo M, et al. Patient education in Parkinson's disease: formative evaluation of a standardized program in seven European countries. *Patient Educ Couns* 2007;65:245–52.
- [6] WHO. International Classification of functioning, Disability and health, <http://www3.who.int/icf/icftemplate.cfm>; 2000.
- [7] Spliethoff-Kamminga NGA, Vreugd J. Patiënt educatie programma Parkinson. Amsterdam: Harcourt Publishers; 2006.
- [8] Smith Pasqualini MC, Simons G. Patient education for people with Parkinson's disease and their carers: a manual. Chichester: John Wiley & Sons; 2006.
- [9] Hoehn MM, Yahr MD. Parkinsonism: onset, progression, and mortality. *1967. Neurology* 2001;57:S11–26.
- [10] Schwab RS, England AC. Projection technique for evaluating surgery in Parkinson's disease. In: Gillingham FJ, Donaldson IMI, editors. Third symposium on surgery in Parkinson's disease. Edinburgh: Livingstone; 1969.
- [11] Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189–98.
- [12] Spliethoff-Kamminga NGA, Zwiderman AH, Springer MP, Roos RAC. Psychosocial problems in Parkinson's disease: evaluation of a disease-specific questionnaire. *Mov Disord* 2003;18:503–9.
- [13] Spliethoff-Kamminga NGA, Zwiderman AH, Springer MP, Roos RAC. A disease-specific psychosocial questionnaire for Parkinson's disease caregivers. *J Neurol* 2003;250:1162–8.
- [14] Peto V, Jenkinson C, Fitzpatrick R, Greenhall R. The development and validation of a short measure of functioning and well being for individuals with Parkinson's disease. *Qual Life Res* 1995;4:241–8.
- [15] Marinus J, Visser M, Jenkinson C, Stiggelbout AM. Evaluation of the Dutch version of the Parkinson's disease questionnaire 39. *Parkinsonism Relat Disord* 2008;14:24–7.
- [16] Schrag A, Selai C, Jahanshahi M, Quinn NP. The EQ-5D—a generic quality of life measure—is a useful instrument to measure quality of life in patients with Parkinson's disease. *J Neurol Neurosurg Psychiatry* 2000;69:67–73.
- [17] EuroQol—a new facility for the measurement of health-related quality of life. The EuroQol Group. *Health Policy* 1990;16:199–208.
- [18] Zung WW. A self-rating depression scale. *Arch Gen Psychiatry* 1965;12:63–70.
- [19] Biggs JT, Wylie LT, Ziegler VE. Validity of the Zung self-rating depression scale. *Br J Psychiatry* 1978;132:381–5.
- [20] Luria RE. The validity and reliability of the visual analogue mood scale. *J Psychiatr Res* 1975;12:51–7.
- [21] Neuhauser M. How to deal with multiple endpoints in clinical trials. *Fundam Clin Pharmacol* 2006;20:515–23.
- [22] Dobkin RD, Allen LA, Menza M. Cognitive-behavioral therapy for depression in Parkinson's disease: a pilot study. *Mov Disord* 2007;22:946–52.
- [23] Cole K, Vaughan FL. The feasibility of using cognitive behaviour therapy for depression associated with Parkinson's disease: a literature review. *Parkinsonism Relat Disord* 2005;11:269–76.
- [24] Secker DL, Brown RG. Cognitive behavioural therapy (CBT) for carers of patients with Parkinson's disease: a preliminary randomised controlled trial. *J Neurol Neurosurg Psychiatry* 2005;76:491–7.
- [25] Simons G, Thompson SB, Smith Pasqualini MC, Members of the EduPark consortium. An innovative education program for people with Parkinson's disease and their carers. *Parkinsonism Relat Disord* 2006;12:478–85.
- [26] Sunvisson H, Ekman SL, Hagberg H, Løkk J. An education program for individuals with Parkinson's disease. *Scand J Caring Sci* 2001;15:311–7.
- [27] Lindskov S, Westergren A, Hagell P. A controlled trial of an educational program for people with Parkinson's disease. *J Clin Nurs* 2007;16:368–76.
- [28] Bowers TG, Clum GA. Relative contribution of specific and nonspecific treatment effects: meta-analysis of placebo-controlled behavior therapy research. *Psychol Bull* 1988;103:315–23.
- [29] Groessl EJ, Cronan TA. A cost analysis of self-management programs for people with chronic illness. *Am J Community Psychol* 2000;28:455–80.
- [30] Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis Rheum* 1993;36:439–46.