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**A patient and caregiver education program : in Parkinson's disease,  
Huntington's disease, and other chronic diseases**

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# **Caregiver education in Parkinson's disease: Formative evaluation of a standardized program in seven European countries**

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**Abstract**

*Purpose:* The formative evaluation of a standardized psychosocial education program for patients with Parkinson's disease (PD) and their caregivers. The results of the participation of the caregivers are presented next to the data of the patients.

*Methods:* Caregivers (n=137) and PD patients (n=151) participated in the eight-week program in separate groups. Measurements were performed on psychosocial problems (BELA-P/A-k), health state (EQ-5D VAS), quality of life (PDQ-39) and depression (SDS) one week before and one week after the program. Participants rated their mood on a visual analogue scale before and after each session and they filled in an evaluation questionnaire after the last session.

*Results:* Scores on the BELA-P/A-k improved significantly on the Bothered by as well as the Need for help scale. No improvements were found on EQ-5D VAS, PDQ-39 and SDS. Mood ratings improved significantly after each session. Most participants evaluated the program as positive. Feedback led to improvements in the program, which are incorporated in a final manual.

*Conclusions:* The program was feasible to run in the different countries. This exploratory study led to improvements in the program and recommendations for further research. A study on the effectiveness of the program is the next step.

## Introduction

Parkinson's disease (PD) is one of the most common neurodegenerative diseases and affects about 160 per 100,000 people (age-adjusted prevalence rate).<sup>1</sup>

The emotional and practical care to most PD patients is provided by informal caregivers, such as partners.<sup>2-4</sup> Caregivers often experience long term strain across all stages of the patient's disease.<sup>5</sup> As a consequence, they are at risk of social isolation, losing their job, emotional burden, and a reduction in quality of life.<sup>3,4,6-10</sup> Caregivers have significantly

higher rates of affective (6.3 % vs. 4.2%) and anxiety (17.5% vs. 10.9%) disorders than non-caregivers and use health services for mental health problems at nearly twice a rate.<sup>11</sup>

The caregivers' wellbeing deserves attention for several reasons. Firstly, there is a shift taking place from institutional to community care.<sup>3,12,13</sup> Moreover, caregiver burden may

reduce the quality of care given to the patient and, consequently, may affect the patient's health. The caregivers' capacity to provide care determines institutional placement. Most

patients prefer to live at home as long as possible<sup>14</sup> and for the health care budget,

institutionalization is more expensive than community care.<sup>4,9,14</sup> Although treating

caregivers is recommended as an important component of a comprehensive treatment for chronic diseases<sup>8,12,14-17</sup> only few intervention studies of PD caregivers have been

reported.<sup>6,12</sup> The present study evaluates the Patient Education Program Parkinson (PEPP),

a structured psychosocial education program for patients suffering from PD as well as their caregivers. The PEPP is developed by a consortium of experts with different disciplines

(including neurologists and psychologists) from seven European countries (Estonia,

Finland, Germany, Italy, The Netherlands, Spain and The United Kingdom).<sup>18-23</sup> Also, PD

patients, caregivers and lay organizations contributed to the development. Patients and

caregivers participated in a steering committee and gave their advice regarding the

development of the program. The program is set up to be a systematic and professional

way to support patients and their caregivers (in separate groups) by means of educating

them and teaching them skills, in addition to their medical treatment, aiming to improve

their quality of life. The aim was to help patients and caregivers to adapt their cognitions

and behavior to the changes in their life caused by Parkinson's disease. A critical aspect of

the PEPP is its person-centered approach. Patients and caregivers are viewed as experts of

the disease. Participants learn that through cognitive behavioral techniques they can

improve their own carrying capacity and interactions with the medical or social systems in

which they participate. This aspect is particularly important with a chronic progressive

disease such as PD, as a loss of control over their own life is what people with PD and their caregivers fear most. The participation of the patients in the PEPP has been evaluated in the study of Macht et al.<sup>24</sup> Simons et al. evaluated the English part of the data (22 patients, 14 caregivers).<sup>25</sup> The aim of the present study is to present the evaluation of the participation of the caregivers from the whole sample of the seven European countries next to the results of the patients derived from the study of Macht et al.<sup>24</sup>

## **Methods**

### *Design and procedure*

All patients and caregivers attended the same treatment condition, i.e. the education program PEPP. Standardized self-report questionnaire measures were obtained one week before and one week after the program (single group pre-test-post-test design). All questionnaires were filled out by the participants at the research location, in the presence of a researcher. Additionally, mood ratings were obtained before and after group sessions, and an evaluation questionnaire was given after participation. We will present the new data of the caregivers together with the key data of the patients derived from the study of Macht et al.<sup>24</sup>

### *Participants*

PD patients and caregivers were recruited from local self-help groups and outpatient clinics in the seven participating European countries: Estonia (n = 18), Finland (n = 23), Germany (n = 11), Italy (n = 17), The Netherlands (n = 16), Spain (n = 38) and The United Kingdom (n = 14). The patients were all diagnosed with idiopathic PD. Eligible caregivers were partners, close relatives, close friends or professional caregivers, although partners were the primary target group. The characteristics of the patients and caregivers are presented in Table 1.

During the first assessment, patients were assigned to Hoehn & Yahr<sup>26</sup> stage 1 or 2, stage 3, and stage 4 or 5, to indicate the relative disability level (stage 5 is the most disabled level). The Mini Mental State Examination (MMSE)<sup>27</sup> was used to indicate that none of the patients had marked cognitive impairments. Patient and caregiver characteristics were homogenous across countries. All participants gave their informed consent to participate.

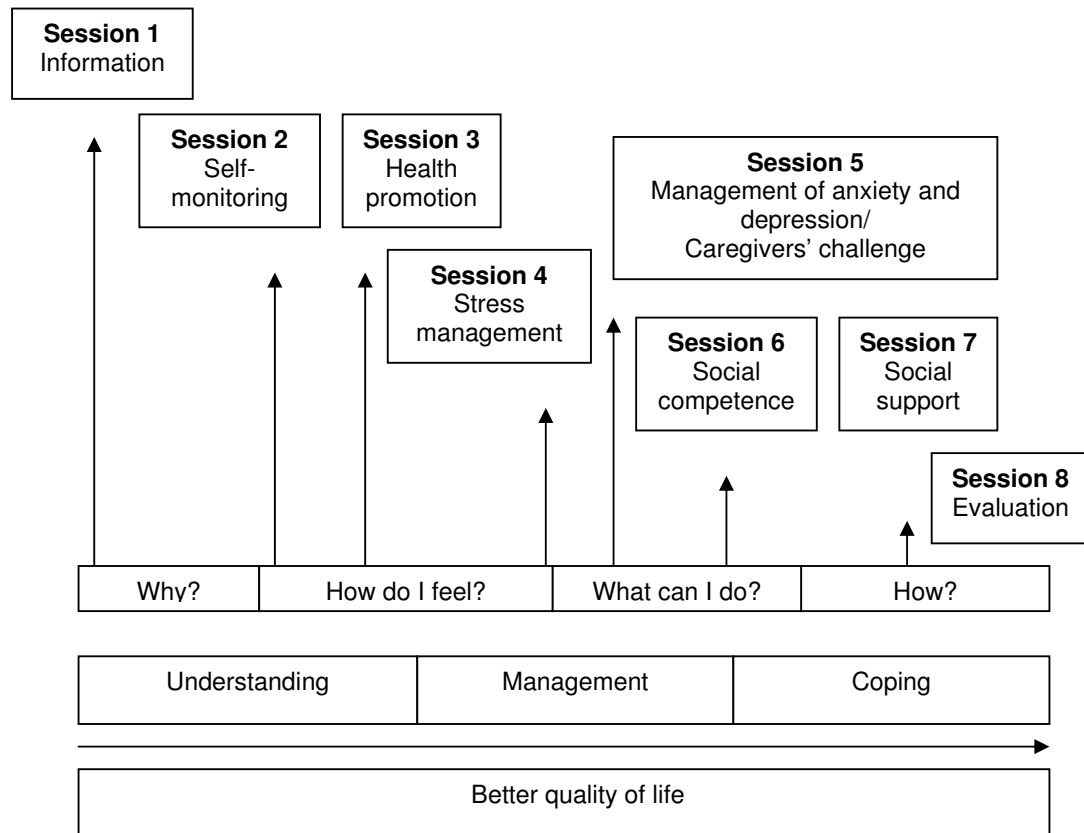
**Table 1** Sample characteristics of the patients and the caregivers

	Patients	<i>n</i>	Caregivers	<i>n</i>
Men/women	90/ 61	151	27/ 110	137
Age (Years) mean (SD)	64.4 (9.2)	149	62.2 (11.3)	136
Relation to patient:				
Partner/ Child/ Friend/ Sibling/ Professional	-	-	119/ 9/ 4/ 2/ 2	136
Marital status:				
Single/ Married/ Widowed / Divorced	13/ 109/ 15/ 12	149	5/ 127/ 2/ 2	136
Education till age of 18/ Higher education	97/ 51	148	88/ 43	131
Years since diagnosis: mean (SD)	6.5 (4.3)	149	-	
MMSE: mean (SD)	28.0 (2.1)	147	-	
H & Y stage: mean (SD)	2.0 (0.8)		-	
Stage 1 & 2/ Stage 3/ Stage 4 & 5	107/ 29/ 5	141		

Abbreviations: MMSE, Mini Mental State Examination; H&Y, Hoehn & Yahr.

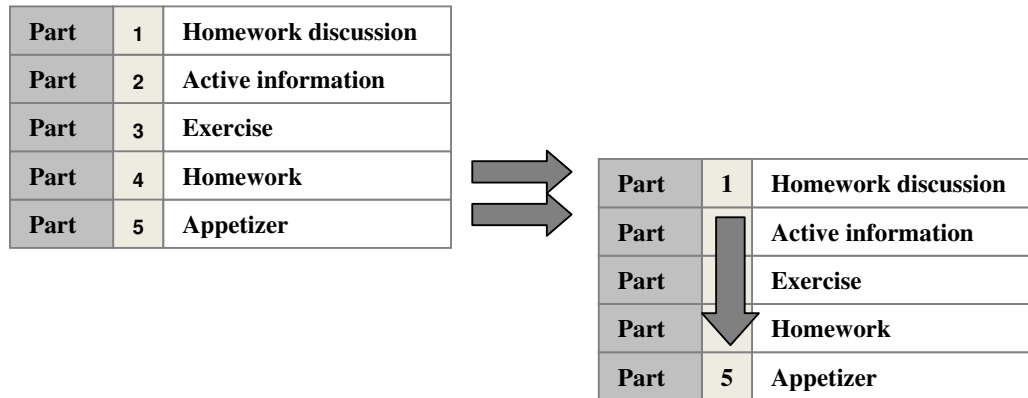
### *Intervention*

The education program had a separate but parallel program for patients and caregivers. The program consisted of eight weekly sessions of ninety minutes. Groups consisted of 4-7 participants. This relatively small group size was chosen to give all the participants the opportunity to participate actively. Trainers were professional group leaders, mostly psychologists, who were knowledgeable about patient education and the psychosocial problems of PD caregivers. Each session had its own topic (Figure 1). The topics were mostly the same for patients and caregivers (except for session 5), but from a different perspective. During each session, the same structure was followed (Figure 2): 1) homework discussion, 2) active information (The trainer provided information on the topic of the particular session and self-management strategies and asked about the experiences of the participants with the particular subject. The patients and caregivers were motivated to participate actively), 3) exercise (practical task during the session), 4) homework for the next session, and 5) appetizer (preview of the topic of the next session to enable participants to prepare themselves). The themes of the sessions overlapped: the homework assignment regarding the topic of the particular session was discussed at the beginning of the next session. Also, the appetizer returned in the active information part of the next session. Printed materials were handed out to the participants. The method used in the PEPP is based on principles of the cognitive-behavioral therapy. Interventions like systematic relaxation training, cognitive restructuring, situational behavioral analysis, and training in social skills were included. The aim was to help caregivers to adapt their cognitions and behavior to the changes in their life caused by the illness of their partner.

**Figure 1** The topics and aims of the seven sessions of the PEPP

During the program, the following questions are addressed: “Why is the particular topic important?”, “How does the participant feel about the topic?”, “What can the participant do?” and “How can he/she do it?”. The aim of the program is to improve understanding, management and coping, with the ultimate goal to improve the quality of life of PD patients and caregivers.



**Figure 2** Structure of the sessions

The arrows indicate the continuation of the themes in follow up sessions. The homework of the previous session is always discussed first in the next session and the appetizer returns in the active information part of the next session.

### *Assessment*

The impact of psychosocial problems and need for help of the patients were assessed by the Dutch version of the 19-item Belastungsfragebogen Parkinson kurzversion (BELA-P-k).<sup>28</sup> The Belastungsfragebogen Parkinson Angehörigen kurzversion (BELA-A-k)<sup>10</sup> is the caregiver version and contains 15 items. The questionnaire comprises four psychosocial domains (achievement capability, emotional functioning, social functioning, partner/family). Each item contains a ‘bothered by’ question with a Likert scale from 0 to 4 (0 = not at all, 1 = somewhat, 2 = moderately, 3 = considerably, 4 = a great deal) and a ‘need for help’ question also on a Likert scale from 0 to 4 scale (0 = not important, 1 = hardly important, 2 = slightly important, 3 = rather important, 4 = very important). Total scores for the ‘bothered by’ and ‘need for help’ scale are derived by summing up the individual items of the subscales ranging from 0 to 74 in the patients and 0 to 60 in the caregivers. The higher the scores on the ‘bothered by’ or ‘need for help’ scales, the more a person is bothered by psychosocial problems or the more a person indicates that psychosocial support is important. The BELA-P/A-k has a validated version in Dutch.<sup>10,28</sup> The other countries used a forward-backward translated version in their own language. The validated visual analogue scale of the EuroQol five-dimension questionnaire (EQ-5D VAS)<sup>29</sup> was used to assess caregivers’ present health state (from 0 = worse imaginable health state to 100 = best imaginable health state). The quality of life (QoL) of the patients was assessed by the Dutch version of the Parkinson’s Disease Questionnaire (PDQ-39).<sup>30</sup> The PDQ-39 contains 39 items that cover 8 dimensions (mobility, activities in daily life,

emotional wellbeing, stigma, social support, cognitions, communication, physical complaints). Each item can be answered on a five-point Likert scale (from 0 = never to 4 = always). The Summary Index (SI) is calculated by dividing the sum of all dimensions by the number of dimensions (ranging from 0 = best QoI to 100 = worst QoI). The validated Self-rating Depression Scale (SDS)<sup>31,32</sup> was used to measure depression in both the patients and caregivers and consists of 10 psychological and 10 somatic symptoms. Each item is scored on a Likert scale from 1 to 4, and a total score is derived by summing up the individual item scores (20-80 points). A score between 40 and 49 indicates a mild depression, while a score above 50 indicates a moderate to severe depression. Patients and caregivers were asked to rate their present mood before and after each session on a visual analogue scale (mood VAS),<sup>33</sup> from an extremely bad (0) to an extremely good (100) mood. Participants were asked to evaluate the program after participation by means of an evaluation questionnaire. They could answer on a three-point scale (agree/agree somewhat/disagree). The questionnaire was adapted from a previously used evaluation tool.<sup>34</sup>

#### *Statistical analysis*

The data were analyzed with the Statistical Package for the Social Sciences (SPSS) version 14.0. For pre/post-session mood ratings and change in depression, psychosocial problems, health state and quality of life paired-samples t-tests were used. The data from the evaluation questionnaire were analyzed descriptively, i.e. the percentages of participants who agreed with the statements in the questionnaire. The significance level used for all analyses was  $p < 0.05$ . No adjustments were made for multiple testing, because of the exploratory approach and the correlation between the outcome measures, making a Bonferroni adjustment too conservative.<sup>35</sup>

## Results

The program was successfully applied in different settings and different cultural contexts. The caregiver burden and need for help (BELA-A-k) diminished significantly, except for the sub score ‘partner/family bothered by’ (Table 2). Health state, measured with the EQ-5D VAS, and depression, measured with the SDS, showed no significant improvement after finishing the program. As described in Macht et al.,<sup>24</sup> patients’ psychosocial burden and need for help (BELA-P-k) diminished significantly (Table 2). Quality of life measured with the PDQ-39 and depression measured with the SDS, showed no significant improvement after participation in the PEPP. The mood ratings on the VAS of the caregivers consistently improved after each session of the PEPP (Table 3). Patients’ mood ratings also improved significantly ( $p < 0.001$ ) after each session.<sup>24</sup> Caregivers’ data from the evaluation questionnaire are presented in figure 3: 80% of the caregivers fully agreed that the PEPP was appropriate to them and 86% would recommend the PEPP to other people. A high percentage (90%) evaluated the exchange of experiences and ideas within the group as helpful. The PEPP improved understanding of PD in most of the caregivers (65%). In 20% of the caregivers the exercises were considered too difficult; 60% found the group leader too directive; and less than 10% experienced no active involvement. The patients’ evaluation<sup>24</sup> showed that 70% fully agreed that the intervention was appropriate to them and that the PEPP fulfilled their expectations. Many patients (80%) reported having received helpful information in the PEPP and in 53% understanding of PD had improved. More than half (55%) of the patients said there was too little practice. About 75% would participate in a similar program. Most valued sessions by the caregivers ( $n = 73$ ) were session 4 ‘Stress management’ and 5 ‘Caregivers’ challenge’. The patients ( $n = 110$ ) valued session 4 ‘Stress management’ and 2 ‘Self-evaluation’ as most important. Both the patients ( $n = 110$ ) and the caregivers ( $n = 62$ ) evaluated session 7 ‘Social support’ as least helpful. The formative evaluation conclusively resulted in some adaptations to the program. The most important adaptation is that it now offers both a basic and an advanced option for exercises and homework to allow group leaders to more easily adapt to the educational and cognitive level of the group. The adaptations made because of this formative evaluation are incorporated in the final manual of the PEPP in six languages.<sup>18-23</sup> A description of the final content of each session can be found in Table 4.

**Table 2** Pre- and post-intervention scores of the patients and the caregivers

Scale	Patients * <sup>1</sup>					Caregivers				
	<i>n</i>	Before	After	<i>T</i>	<i>p</i>	<i>n</i>	Before	After	<i>T</i>	<i>p</i>
BELA-P/A-k										
Total Bb	103	26.7 (15.6)	21.0 (14.7)	4.8	< 0.001	77	17.7 (11.1)	13.4 (11.5)	2.8	0.006
Total Nfh	102	34.9 (17.2)	27.5 (16.6)	5.5	< 0.001	74	22.7 (13.2)	1.1 (0.9)	14.6	< 0.001
Achievement capability										
- Bb	108	8.3 (4.5)	6.7 (4.7)	4.2	< 0.001	88	5.1 (3.3)	4.0 (3.4)	2.7	0.008
- Nfh	108	10.7 (4.7)	8.4 (5.0)	5.5	< 0.001	86	6.5 (4.2)	4.8 (3.8)	3.0	0.004
Emotional functioning										
- Bb	110	6.7 (3.9)	5.0 (3.5)	5.3	< 0.001	94	6.1 (3.7)	4.3 (3.4)	3.7	<0.001
- Nfh	110	8.5 (4.4)	6.4 (3.9)	5.2	< 0.001	91	7.6 (4.0)	5.2 (3.8)	4.1	<0.001
Social functioning										
- Bb	104	6.1 (4.7)	4.7 (4.3)	3.6	0.001	80	4.3 (3.5)	2.8 (2.8)	3.4	0.001
- Nfh	104	7.9 (5.2)	6.2 (5.0)	4.2	< 0.001	78	5.0 (3.9)	3.7 (3.3)	2.3	0.027
Partner/family										
- Bb	90	5.7 (5.2)	4.6 (4.0)	2.8	0.006	67	3.2 (2.7)	2.4 (2.6)	1.3	ns
- Nfh	91	7.6 (5.7)	6.1 (4.7)	3.2	0.002	65	4.3 (3.3)	3.0 (3.1)	2.2	0.033
EQ-5D VAS* <sup>2</sup>	-	-	-	-	-	42	69.1 (19.2)	75.6 (20.5)	-1.6	ns
PDQ-39 SI	133	30.8 (16.2)	30.7 (7.7)	-0.3	ns	-	-	-	-	-
SDS	122	42.4 (8.6)	42.7 (10.6)	-0.4	ns	11 8	39.2 (9.4)	38.3 (8.7)	0.6	ns

Values are mean (standard deviation), unless otherwise indicated. In the BELA-P/A-k, lower scores reflect less psychosocial problems or need for help. Lower scores on the EQ-5D VAS reflect worse health state. Higher scores on the PDQ-39 reflect worse quality of life. In the SDS, lower scores reflect less depressive complaints.

Abbreviations: BELA-P(A)-k, Belastungsfragebogen Parkinson (Angehörigen) kurzversion; Bb, Bother by scale; Nfh, Need for help scale; PDQ-39 SI, Parkinson's Disease Questionnaire-39 items Summary Index; EQ-5D, EuroQol-5D VAS, visual analogue scale; SDS, Self-rating Depression Scale.

\*1 Patients' data are derived from the study of Macht et al. [24], except for the 'Need for help scale' data.

\*2 The EQ-5D VAS (n= 42) was not assessed in Spain (n = 38), Italy (n = 17), the Netherlands (n = 16) and Estonia (n = 18).

**Table 3** Pre- and post-session mood-VAS ratings of the caregivers

Session:	<i>n</i>	Before session	After session	<i>T</i>	<i>P</i>
1	81	66.4 (18.4)	75.0 (16.1)	-5.2	<0.001
2	118	67.3 (20.4)	73.6 (20.1)	-5.5	<0.001
3	101	69.9 (16.8)	77.8 (15.2)	-5.5	<0.001
4	97	64.3 (21.8)	71.4 (20.6)	-5.6	<0.001
5	106	63.9 (21.0)	73.0 (20.1)	-7.1	<0.001
6	107	68.9 (15.7)	76.3 (14.4)	-6.2	<0.001
7	106	71.5 (15.2)	77.2 (13.7)	-4.6	<0.001
8	66	73.1 (15.0)	82.9 (13.5)	-7.1	<0.001

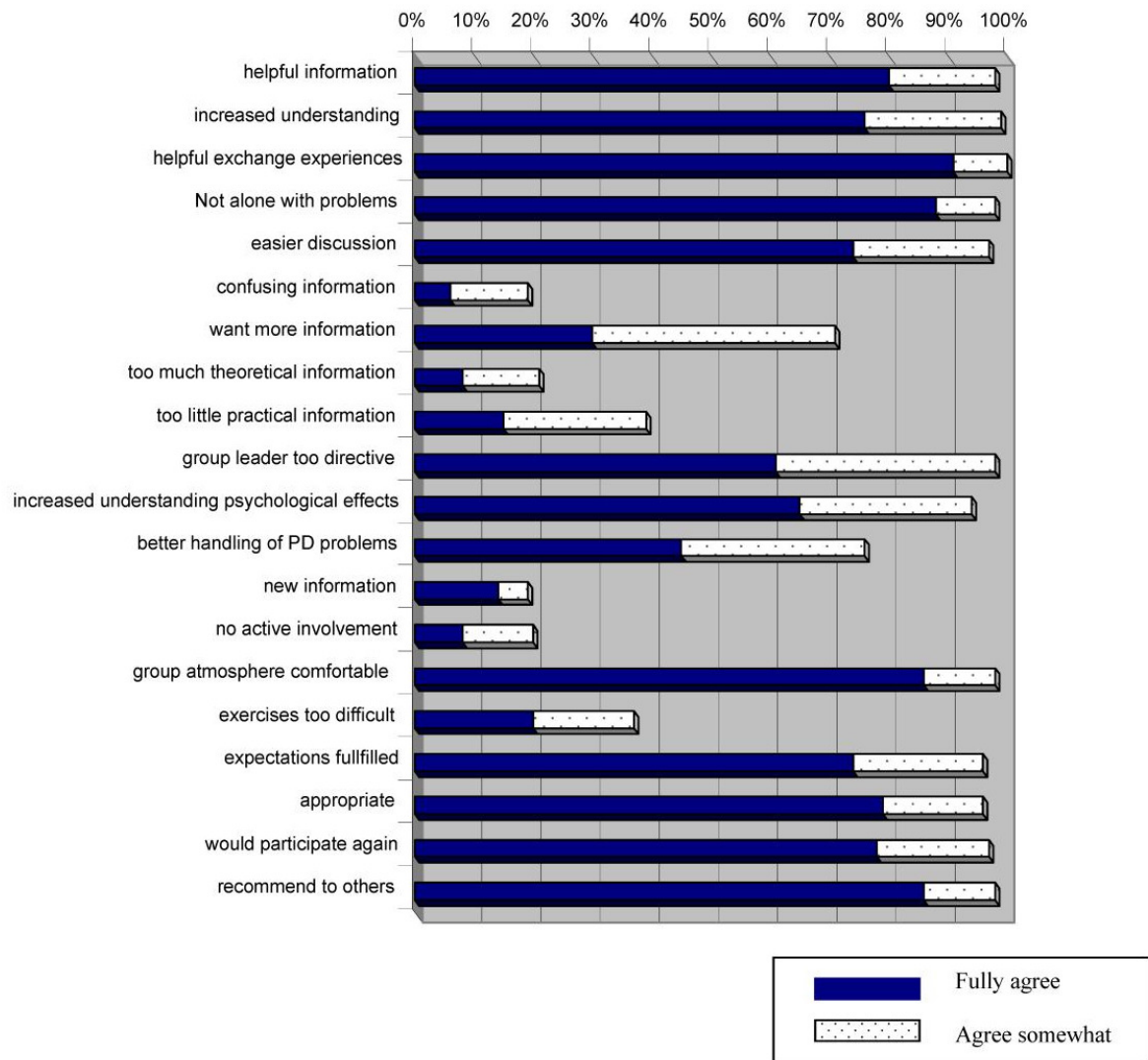
Values are mean (standard deviation), unless otherwise indicated.

**Table 4** The final thematic structure of the education program

The PEPP sessions	Structure	Main focus
1 Information	Introduction	The acquaintance and an overview of the program
	Active information	The importance of taking an active and central role in the health care system.
	Exercise	How to ask questions to health care professionals
	Homework	To draft questions for a visit to professionals
2 Self-monitoring	Appetizer	Past experiences with keeping a diary/journal
	Homework discussion	Homework discussion of session 1
	Active information	To learn about self-monitoring techniques, like a diary.
	Exercise	An exercise 'body awareness' focused on breathing and muscular tensions
	Homework	Option 1: Use a diary to record (e.g. fluctuations in mood or PD symptoms) Option 2: Perform the exercise 'body awareness'.
3 Health Promotion	Appetizer	Bring something pleasant to the next session (e.g. an object or experience)
	Homework discussion	Homework discussion of session 2
	Active information	To improve wellbeing through pleasant activities
	Exercise	To explore pleasant activities
	Homework	Perform a pleasant activity every day
4 Stress Management	Appetizer	Observe your own behavior in a stressful situation
	Homework discussion	Homework discussion of session 3
	Active information	The role of unrealistic and unhelpful thoughts in stressful situations (ABC scheme)
	Exercise	Option 1: Learn to replace unrealistic and unhelpful thoughts through realistic helpful thoughts Option 2: Perform relaxation exercises to deal with stress
	Homework	Option 1: Try alternative ways of thinking Option 2: Relaxation training
5 Management of anxiety and depression (patients)/ Caregiver's challenge	Appetizer	Observe changes of mood and causes of worry
	Homework discussion	Homework discussion of session 4
	Active information	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 thoughts (ABC-scheme)
	Exercise	Option 1: usage of positive thoughts (illustrative video clip) Option 2: Maintaining healthy activities
	Homework	Option 1: Think of a positive event Option 2: Maintain healthy activities
6 Social Competence	Appetizer	Notice situations in which you want to express your thoughts and feelings but not having the confidence to do so
	Homework discussion	Homework discussion of session 5
	Active information	Social skills like communication are discussed. Option 1: Unhelpful and helpful thoughts in communication Option 2: Ways of communication
	Exercise	Discussion of a video clip addressing communication problems
	Homework	Option 1: Note situations in which unhelpful thoughts contributed to a lack of socially competent behavior Option 2: Tell someone that you have PD
7 Social Support	Appetizer	To focus on the informal or formal support you would like to receive
	Homework discussion	Homework discussion of session 6
	Active information	To discuss the importance of, and how to obtain social support
	Exercise	Role play/discussion
8 Evaluation	Homework	Finding sources of support and asking for support
	Appetizer	Reflecting about the entire program
	Homework discussion	Homework discussion of session 7
	Active information	The group goes through the previous sessions and the program is evaluated. Expectations and achievements are compared
	Exercise	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). Sessions have a standardized sequence: skills learned in previous sessions return in and are necessary for next sessions. The detailed description of the intervention has been written down in a manual, which is available in several languages in bookshops. Future studies are therefore able to replicate this intervention in several countries.

**Figure 3** Caregivers' evaluation of the program (n = 112-128)



Abbreviations: PD, Parkinson's disease.

## Discussion

The Patient Education Program Parkinson (PEPP) has been developed by a European consortium in order to improve the quality of life of PD patients and caregivers. This formative evaluation has been done to evaluate the feasibility of the program and, if necessary, to make adaptations in the program, resulting in a manual in the seven participating countries (Estonia, Finland, Germany, Italy, The Netherlands, Spain and The United Kingdom). This article presents the data gathered from the caregivers in regard to their overall evaluation and the short-term benefits on psychosocial problems, depression, mood and health state received from participating in the program. We also restated the key data of the PD patients from the article of Macht et al.<sup>24</sup> to compare the results of the patients with the results of their caregivers. The majority of the patients and caregivers evaluated the program as positive. The PEPP appears to provide knowledge and skills essential for the self-management of PD. Especially the exchange of information between the participants was rated to be helpful. This underlines the added value of a group format. Other advantages have been reported, such as reducing isolation and modelling one another.<sup>36</sup> One fifth of the patients and caregivers evaluated the exercises, which were introduced to help them learn and develop new skills and integrate them into their daily life, as too difficult. These results correspond with the informal feedback we received from group leaders who often noted that it would have been useful to have the option of offering more basic exercises to target behavioral change as a substitute for the more cognitively demanding exercises. In response to the feedback, an adaptation in the final program, regarding both a basic and an advanced option for exercises and homework was made. This adaptation allows group leaders to adapt the program more easily to the educational and cognitive level of the group. The final manual,<sup>18-23</sup> with these improvements incorporated, enables professionals from different countries to replicate the intervention of this study and researchers to further investigate this particular intervention on its effectiveness. Another result from the evaluation questionnaire was that about 35% of the participants found the group leader being too directive. This may be due to the training style of the trainers or it may be that participants expected more a form of self-help support group in advance instead of a structured training. For professionals, it is therefore important to explain the directive style of the program at the intake meeting; being directive is sometimes necessary to provide the participants with knowledge and skills to provide more than only contact between fellow-sufferers.

After each individual session, patients and caregivers consistently reported an elevated mood as compared to their mood before the session. These mood elevations suggest a positive influence of the interventions on the participants and may be due to the specific interventions and/or to non-specific influences such as interactions between the participants.

Caregivers are less bothered by psychosocial problems due to the disease of the patient and they have less need for help after finishing the program. The same result was found in the patients' group.<sup>24</sup> The program addresses psychosocial issues, like the prevention of and dealing with symptoms of depression and anxiety or caregiver burden/overload, social competence including communication problems and addressing the importance of social support. This finding suggests that the program may be effective in teaching the patients as well as the caregivers skills and in educating them about coping with the disease and the psychosocial issues. Reductions of psychosocial problems after interventions for other chronic diseases have been reported in other studies.<sup>17</sup>

The caregivers (and also the patients) showed no improvement in health state/quality of life and depressive symptoms after finishing the program. Quality of life was expected to improve because psychosocial functioning is a component of quality of life. In other studies regarding caregivers of different chronic diseases, improvement of health related quality of life after participating in patient education programs has been observed.<sup>16,17</sup> It may be that our instrument (EQ-5D VAS) is not sensitive enough to detect improvements after participation in the PEPP. Or maybe the improvement of psychosocial problems was not large enough to improve the quality of life also. Because quality of life in PD decreases over time, because of the neurodegenerative character of PD,<sup>37</sup> in future research, the effects on Qol should be further assessed by means of a control group. Maybe the control group would worsen in Qol, while the PEPP group would remain stable, so indicating a benefit in Qol for the patients and caregivers participating in the PEPP after all.

An absence of change in depressive symptoms seems to be due to the minimal amount of depressive complaints at baseline in most of the patients and caregivers (floor effect). Future research should evaluate the possible effectiveness of the PEPP in treating PD patients and caregivers with moderate to severe depression. Despite the fact that these



persons may be hard to recruit because of their depressive symptoms (e.g. reduced interest in activities, feelings of hopelessness), they may be the persons who benefit most.

Simons et al. evaluated the data from the English patients and caregivers.<sup>25</sup> They did not find any improvements on QoL, psychosocial problems and depression. Only improvements on mood were found. This lack of significant results seems to be the result of their small sample size (22 patients, 14 caregivers), because this study and the study of Macht et al.<sup>24</sup> did find psychosocial improvements in the complete sample (151 patients, 137 caregivers).

The present study has some methodological limitations that need to be addressed. First, no control group was included, because it was a formative first evaluation of the program. A randomized controlled trial is needed to draw further conclusions on the effectiveness of the program. Another limitation of the present study is the amount of missing values, resulting in the variety of number of cases in the data. This was mostly due to the fact that not all of the research centers assessed all of the questionnaires. Besides that, there were missing values due to participants who did not fully fill in the self-report questionnaires at pre- or post-measurements. It may be that they found the questions difficult to answer or they omitted some questions by accident. Extra checkups by the researchers directly after filling out the questionnaires by the participants are important in future research to limit the amount of missing values. The BELA-P/A-k questionnaire was translated into the languages of the participating countries by means of a careful forward-backward method. The scale was feasible to use in the different countries. However the scale was only validated in the Dutch language. As a consequence, the results should be interpreted with caution. In future research, the BELA-P/A-k translations should be assessed on their validity, before assessing the program on its effectiveness. Two more recommendations for future research are 1) follow-up measurements, for example after six months after participation in the PEPP, in order to examine if the benefits resulting from the program continue in the near future. 2) The value of an education program like the PEPP may not be restricted to PD, but may be adapted to other neurological disorders or to chronic diseases in general. With the worldwide increase in chronically ill patients and, with that, an increase in caregivers, interventions to improve quality of life of these people will become even more important.

In conclusion, the results of this exploratory formative evaluation indicate that the PEPP was feasible to run in different settings and different cultural contexts. Because of the limitations of this study consistent with its explorative characterization, no definite conclusions can be drawn on the program's effectiveness yet. This study led to improvements of the program incorporated in a manual and to important recommendations for future research. A study to evaluate the PEPP on its effectiveness is the next step.

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## References

1. De Rijk MC, Tzourio C, Breteler MM et al. Prevalence of parkinsonism and Parkinson's disease in Europe: the Europarkinson collaborative study. *Journal of Neurology, Neurosurgery and Psychiatry*. 1997; 62:10-15
2. Aarsland D, Larsen JP, Karlsen K et al. Mental symptoms in Parkinson's disease are important contributors to caregiver distress. *International Journal of Geriatrics and Psychiatry*. 1999; 14:866-874
3. Thommessen B, Aarsland D, Braekhus et al. The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *International Journal of Geriatric Psychiatry*. 2002;17:78-84
4. Martinez-Martin P, Benito-Leon J, Alonso F et al. Quality of life of caregivers in Parkinson's disease. *Quality of Life Research*. 2005; 14:463-472
5. Carter JH, Stewart BJ, Archbold PG et al. Living with a person who has Parkinson's disease: the spouse's perspective by stage of disease. *Parkinson's Study Group. Movement Disorders*. 1998; 13:20-28
6. Secker DL, Brown RG. Cognitive behavioural therapy (CBT) for carers of patients with Parkinson's disease: a preliminary randomised controlled trial. *Journal of Neurology, Neurosurgery and Psychiatry*. 2005; 76:491-497
7. Bhatia S, Gupta A. Impairments in activities of daily living in Parkinson's disease: implications for management. *NeuroRehabilitation*. 2003; 18:209-214
8. Oertel WH, Ellgring H. Parkinson's disease: medical education and psychosocial aspects. *Patient Education and Counseling*. 1995; 26:71-79
9. Spector J, Tampi R. Caregiver depression. *Annals of Long-Term Care*. 2005; 13:34-39
10. Spliethoff-Kamminga NG, Zwinderman AH, Springer MP et al. A disease-specific psychosocial questionnaire for Parkinson's disease caregivers. *Journal of Neurology*. 2003; 250:1162-1168
11. Cochrane JJ, Goering PN, Rogers JM. The mental health of informal caregivers in Ontario: an epidemiological survey. *American Journal of public health*. 2002; 87:2002-2007
12. Habermann B, Davis, LL. Lessons learned from a Parkinson's disease caregiver intervention pilot study. *Applied Nursing Research*. 2006; 19:212-215
13. Han B, Haley WE. Family caregiving for patients with stroke. Review and analysis.

- Stroke. 1999; 30:1478-1485
14. Mittelman, M. Taking care of the caregivers. *Current Opinion in Psychiatry*. 2005; 18:633-639
  15. Acton GJ, Kang J. Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis. *Research in nursing & health*. 2001; 24:349-360
  16. Pinquart M, Sorensen S. Helping caregivers of persons of dementia: which interventions work and how large are their effects? *International Psychogeriatrics*. 2006; 11:1-19
  17. Sorensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? an updated meta-analysis. *Gerontologist*. 2002; 42:356-372
  18. Ellgring H, Gerlich C, Macht M et al. *Psychosoziales Training bei neurologischen Erkrankungen-Schwerpunkt Parkinson*, W. Kohlhammer, Stuttgart, 2006
  19. Smith Pasqualini MC, Simons G. *Patient education for people with Parkinson's disease and their carers: a manual*. John Wiley & Sons, Chichester, 2006
  20. Spliethoff-Kamminga NGA. *Patiënt Educatie Programma Parkinson*. Harcourt Publishers, Amsterdam, 2006
  21. Lankinen A, Viemero V, Lehtonen A et al. *Psykososiaalinen valmennusohjelma Parkinsonin tautia sairastaville ja heidän läheisilleen*, Suomen Parkinson-liitto ry, Turku, 2005
  22. Ricci Bitti PE, Candini L, Carlini M et al. *Intervento psicoeducativo nella malattia di Parkinson*. Erickson, Gardolo, 2006
  23. Taba P, Krikmann U, Kanarik E et al. *Koolitusprogramm Parkinsoni tovega inimestele ja nende tugiisikutele*. Tartu Parkinsoni Haiguse Selts, Tartu, 2005
  24. Macht M, Gerlich C, Ellgring H et al. Patient education in Parkinson's disease: Formative evaluation of a standardized programme in seven European countries. *Patient Education and Counseling*. 2007; 65:245-252
  25. Simons G, Thompson SB, Smith Pasqualini MC. An innovative education programme for people with Parkinson's disease and their carers. *Parkinsonism and Related Disorders*. 2006; 12:478-485
  26. Hoehn MM, Yahr M.D. Parkinsonism: onset, progression, and mortality. 1967. *Neurology*. 2001; 57:S11-S26
  27. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975; 12:189-198

28. Spliethoff-Kamminga NG, Zwinderman AH, Springer MP, Roos RA. Psychosocial problems in Parkinson's disease: evaluation of a disease-specific questionnaire. *Movement Disorders*. 2003; 18:503-509
29. The EuroQol Group. EuroQol: a new facility for the measurement of health-related quality of life. *Health Policy*.1990; 16:199-208
30. Peto V, Jenkinson C, Fitzpatrick R, Greenhall R. The development and validation of a short measure of functioning and wellbeing for individuals with Parkinson's disease. *Quality of Life Research*. 1995; 4:241-248
31. Zung WW. A Self-rating Depression Scale. *Archives of General Psychiatry*. 1965; 12:63-70
32. Biggs JT, Wylie LT, Ziegler VE. Validity of the Zung Self-rating Depression Scale. *British Journal of Psychiatry*. 1978; 132:381-385
33. Luria RE. The validity and reliability of the visual analogue mood scale. *Journal of Psychiatric Research*. 1975;12:51-57
34. Macht M, Ellgring H. *Psychologische Interventionen bei der Parkinson-Erkrankung: Ein Behandlungsmanual*. W. Kohlhammer GmbH, Stuttgart, 2003
35. Neuhauser M. How to deal with multiple endpoints in clinical trials. *Fundamental and clinical Pharmacology*. 2006; 20:515-523
36. Yalom I. *Theory and practice of group Psychotherapy*. Basic Books, New York, 1975
37. Visser M, Verbaan D, Van Rooden et al. A Longitudinal Evaluation of Health-Related Quality of Life of Patients with Parkinson's Disease. *Value in Health*. 2009; 12:392-296

