Factors that predict a change in quality of life among Parkinson's disease patients participating in a patient education program

C. Derollez, N. Carriere, Maéva Kyheng, Kathy Dujardin, A. Faillon, D. Haidon, S. Peres, Luc Defebvre

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Authors: Celine Derollez (a), Nicolas Carriere (a,b), Maeva Kyheng (c), Kathy Dujardin (a,b), Amandine Faillon (a), Dominique Haidon (a), Sophie Peres (d), Luc Defebvre (a,b)

Affiliations :

(a) Neurology and Movement Disorders Department, Hopital Roger Salengro, 1 Avenue du Professeur Emile Laine, F-59037 Lille, France

(b) INSERM UMR 1171, University of Lille, 1 Place de Verdun, F-59045 Lille Cedex, France.

(c) Univ. Lille, CHU Lille, EA 2694 - Santé publique: épidémiologie et qualité des soins, F-59000 Lille, France

(d) Santelys, 351 rue Ambroise Paré, F-59120 Loos, France

Corresponding author: Dr Nicolas Carrière

Address: Neurology and Movement Disorders Department,

Hopital Roger Salengro

1 avenue du Professeur Emile Laine

F-59037 Lille

France

E-mail: nicolas.carriere@chru-lille.fr

Abstract :

BACKGROUND**:** Patient education is essential in Parkinson's disease (PD). However, it is not known which aspects of patient education are associated with an improvement in quality of life (QoL). OBJECTIVE: To identify factors that predicted an improvement in QoL in PD patients that participate in an education program. METHODS: EduPark is a community-hospital patient education program. PD Patients that had participated in the program between September 2013 and March 2017 were retrospectively included. QoL was prospectively evaluated (using the PDQ-8 questionnaire) before and after the patient's participation. We used mixed linear models (adjusted for the initial value of the PDQ-8) to determine socio-demographic and clinical variables that predicted the change in the PDQ-8 score. RESULTS: A total of 181 patients were included (mean ± standard deviation age: 62.9 ± 8.2 years; disease duration: 9.1 ± 5.3 years). 76.7% of the 103 patients having undergone a cognitive evaluation did not display cognitive impairment. We did not identify any factors that predicted the program's impact on the patient's QoL. Participation in the program was associated with a significant decrease (improvement) in the PDQ-8 score (39.4 ± 17.81 before and 35.6 ± 15.9 afterwards, $p<0.001$). CONCLUSION: We did not identify any factors that were predictive of the patient education program's impact on QoL in patients with PD. Participation in the program was associated with a significant improvement in QoL. Our results suggest that Patient Education Programs should be more widely prescribed and developed in the management of PD.

Keywords: Patient Education, Parkinson Disease, Quality of Life, cohort studies

Abbreviations: PD: Parkinson's disease; QoL: Quality of life ; PEP: Patient education program; PDQ-8: short-form (8-item) Parkinson's Disease Questionnaire; SCOPA-PS: psychosocial section of the Scales for Outcomes in Parkinson's disease;

MDS-UPDRS: Movement Disorders Society-Unified Parkinson's Disease Rating Scale; MDRS: Mattis Dementia Ratting Scale; MOCA: Montreal Cognitive Assessment; MMSE: Mini-mental test evaluation

Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disease characterized by motor and non-motor symptoms that degrade the patient's quality of life (QoL) [1]. For obvious ethical reasons and with a view to improving treatment compliance and effectiveness, it is essential for patients with PD to get involved in the management of their disease [2]. As a result, the patients' knowledge and understanding of their disease increase [3]. As in other chronic diseases, patient education programs (PEPs) have been developed for patients with PD in the United States [4; 5] and in Europe [6; 7; 8; 9; 10; 11; 12]). In France, the first PEPs were developed at the turn of the century [13]. The EduPark PEP for patients with PD has been running in northern France since 2013. The impact of a PEP on the patients' QoL has been evaluated in several studies, although the results diverge: some studies failed to detect an impact [8; 9], whereas others reported a non-significant improvement [4; 5; 10; 11; 12; 13] or a significant improvement [5; 6; 14]. However, there are few literature data on which elements of a PEP are predictive of a change in QoL. The identification of predictive factors might help to improve a PEP's content and refine the selection criteria for participation in a PEP. The primary objective of the present study was to identify factors that were predictive of a change in QoL among patients with PD having participated in the EduPark PEP. The secondary objective was to study the EduPark PEP's impact on the patients' QoL.

1. Materials and Methods

2.1 Population

We included patients with a neurologist-confirmed diagnosis of PD and who had participated in the EduPark PEP between July 2013 and March 2017. We studied two groups: a group of patients having participated in PEP sessions in a specialist PD tertiary care center (the “hospital group”), and a group of patients having participated in PEP sessions at home via a homecare association (the “home group”).

2.2Evaluation

Each patient prospectively filled out the various questionnaires before and after participating in the PEP, in order to evaluate the disease’s impact on their QoL and activities of daily living.

The main criterion for evaluation was the change over time in the short-form (8-item) Parkinson's Disease Questionnaire (PDQ-8) score. The PDQ-8 is a widely used, validated means of evaluating the impact of PD on a patient's QoL [15]. The initial score ranges from 0 to 32 before being normalized on a 0-to-100 scale; the higher the score, the greater the negative impact of PD on the patient’s QoL. The psychosocial section of the Scales for Outcomes in Parkinson's disease (SCOPA-PS) was also administered. The SCOPA-PS score ranges from 0 to 33, a higher score corresponding to a greater impact [16].

Others data were extracted retrospectively from the patients’ electronic and paper-based medical records, as follows:

- Sociodemographic information (gender, age, marital status, presence of a caregiver, and the distance between the home and the place where the EduPark PEP was delivered).
- Clinical data (any history of depression and/or anxiety, cognitive status, years since PD diagnosis, disease severity the “on-drug” and “off-drug” states according to the Movement Disorders Society-Unified Parkinson's Disease

Rating Scale (MDS-UPDRS) part III score [17] and the Hoehn and Yahr scale score [18], and the levodopa equivalent dose).

- Information related to the PEP (the duration of participation).

Clinical data on disease severity or cognition were only recorded if these aspects had been evaluated in the 18 months preceding inclusion in the EduPark PEP. Cognitive functions were assessed on several scales: the Mini Mental State Examination (MMSE) [19], the Montreal Cognitive Assessment (MoCA) [20] and the Mattis Dementia Ratting Scale (MDRS) [21]. When results on several different scales for a given patient, we chose the most recent and/or the most accurate in PD (the MDRS or the MoCA, followed by the MMSE). Depending on the score on the selected scale, the patients were classified in one of three categories: no cognitive impairment (MDRS score > 134 or MOCA > 24 or MMSE >26), mild cognitive impairment (MDRS ≤134 and ≥130 or MOCA ≤24 and ≥22 or MMSE ≤26 and ≥24) or moderate-to-severe cognitive impairment (MDRS <130 or MOCA <22 or <24). The levodopa equivalent dose was calculated according to standard methods [22].

2.3 Organization of the EduPark PEP

The EduPark PEP has been implemented since 2013 in the Neurology and Movement Disorders Department at Lille University Medical Center (Lille, France), in association with at homecare provider (Santelys, Loos, France). The PEP's structure is summarized in Figure 1. Patients (and, if needed, their caregiver) are referred by their neurologist or general practitioner. All the participants first had a preparatory individual interview with a trained nurse or neurologist, during which their specific needs and expectations are determined. Depending on these needs, attendance at different educational workshops is suggested. These workshop sessions can either take place on a group basis (four to six patients) at hospital or on an individual basis at home. The

choice of individual vs. group workshops depends on each patient's wishes and logistic/practical parameters. Some patients attended both individual and group workshops. The workshops are supervised by different healthcare professionals with expertise in PD management and PEP delivery (i.e. neurologists, physiotherapists, nurses, speech therapists, psychologists, nutritionists). The duration and the number of sessions depended on the topic. A total of 10 workshops were organized (Table 1).

After having participated in the program, each patient was evaluated during an individual interview with a trained nurse; for practical reasons, this interview took place three months after the last session for the hospital PEP, and at the end of the last session for the home PEP. The objective was to evaluate (i) the level of knowledge acquired during sessions, (ii) patient satisfaction with the workshops and the EduPark PEP, and (iii) the need for further participation in the program. The exclusion criterion for inclusion in the study was the lack of both pre- and post-PEP scores for the PDQ-8.

During the preparatory interview, all the patients gave their written informed consent to participation after having been fully and clearly informed about the PEP and the study. The data collection process was registered with the French National Data Protection Commission (*Commission Nationale Informatique et Liberté*; reference: DEC20130814-1031).

2.4 Statistical analysis

Categorical variables were expressed as the frequency (percentage). Quantitative variables were expressed as the mean ± standard deviation (SD) or, for non-normally distributed variables, the median [interquartile range (IQR)]. The normality of distribution was assessed graphically (using histograms) and by applying the Shapiro-Wilk test. Differences between pre- and post-PEP scores were analyzed using a paired

Student's T test (for normally distributed variables) or the Wilcoxon signed-rank test (for other variables).

Associations between patient characteristics and a change in the PDQ8 score were analyzed using linear regression models adjusted for the pre-PEP PDQ8 score. The normality of the models' residuals was checked and confirmed in all cases. The threshold for statistical significance was set to $p<0.05$. All tests were two-tailed. Statistical analyses were performed with SAS software (version 9.3, SAS Institute Inc., Cary, NC).

3 Results

3.1 Characteristics of the study population

From July 2013 to March 2017, 268 patients participated in the EduPark PEP; 181 of these had completed the PDQ-8 before and after the PEP and were included in the present study. 120 patients attended in-hospital sessions, 85 had home sessions, and 23 had both types of session. The patients' characteristics are summarized in Table 2. Cognitive test were available for 103 patients, 61 were classified according to their MDRS score, 37 according to their MoCa score and 5 according to their MMSE score. Workshops on oral medications, appropriate physical activities and motor fluctuations were most frequently delivered to the patients (to respectively 65.2%, 59.7% and 56.4% of the total study population).

3.2 Predictive factors

None of the variables was significantly associated with a change in the PDQ-8 score after having participated in PEP (Table 3). In particular, we failed to see any impact of the patient's cognitive status.

3.3 Changes in clinical scores

In the study population as a whole, the mean ± SD PDQ-8 score decreased

significantly from 39.4 ± 17.81 before the EduPark PEP to 35.6 ± 15.9 afterwards (corresponding to a mean change of -3.8 ± 13.1; p<0.0001). We also observed a significant decrease in the PDQ-8 score in the home group (42.8 ± 18.1 to 37.5 ± 16.9; p<0.001), whereas the decrease in the hospital group showed a nonsignificant trend (from 36.9 ± 16.9 to 34.7 ± 19.1; p=0.0565*).* There was a significant reduction in the disease's psychosocial impact following participation in the EduPark PEP, as evidenced by a decrease in the SCOPA-PS score from 12.3 ± 6.5 before the PEP to 11.5 ± 5.8 afterwards (p<0.001*)* in the study population as a whole; from 11.9 ± 6.1 to 10.6 ± 5.7 (p=0.005) in the hospital group, and from 12.7 ± 6.5 to 11.5 ± 5.8 (p=0.016) in the home group).

4 Discussion

The present study failed to highlight any predictive factors for a benefit of the EduPark PEP with regard to QoL in patients with PD. However, our results evidenced a significant improvement in QoL after participation in the PEP.

Although we did not find any predictive factors, their existence cannot be ruled out. We selected and studied the variables that we expected to be the most accurate for patients with PD. However, factors on which we did not collect data (such as apathy, anxiety, depression, and level of motivation) might have been of importance. Two studies have evaluated other PEPs offered to consecutive patients (i.e. regardless of their level of interest) and then to motivated patients only; the PEP's impact on QoL was found to be greater among patients who were more motivated at baseline [10; 14]. In the present study, we did not specifically assess the patients' level of motivation before the PEP but this might be a key issue; apathy is a common symptom of PD.

Among the potential predictive factors, we were particularly keen to look at the impact of cognitive impairment. However, we did not find any correlation between the degree

of cognitive impairment and the change in QoL. This finding has been reported by other researchers [23] but should be considered with a degree of caution. In order to ensure that the patients' cognitive data were still valid, we decided to exclude patients whose neuropsychological status had been assessed more than 18 months before inclusion in the PEP. Given that cognitive impairment can be evaluate with several tools, we chose to categorize the patients into three severity classes; this might, however, have reduced the sensitivity and thus our ability to detect subtle cognitive impairments. The EduPark PEP's primary goal is to deliver educational messages - implying that patients must have the cognitive ability to understand, practice and apply these message in their daily life. Hence, patients with little cognitive impairment are primarily invited to participate in a PEP. Most of the patients in our study population did not present cognitive impairment or presented with only mild cognitive impairment. Few of our patients had moderate cognitive impairment (15.5%), and fewer still had severe cognitive impairment (7.8%). The cognitive impaired patients participated only in workshops requiring fewer cognitive skills (appropriate physical activity, for example) or participated with the assistance of a caregiver. Our findings indicate that cognitive functions should still be evaluated and taken into account before a PEP, in order to offer workshops that are suited to a patient's cognitive abilities. The evaluation could be based on MoCa [20], a simple a relatively quick test that seems appropriate and recommended in such a screening setting [24].

We observed a significant improvement in the patients' QoL following their participation in the EduPark PEP. This type of program has been applied to PD for several years now, and a number of studies have evaluated the impact of PEPs on QoL. The main characteristics of these studies (notably the study populations, methods and results)

are summarized in Table 4. With the exception of two studies that failed to observe an impact on QoL (because of a potentially inappropriate outcome measure in one study [8] and a lack of power due to a high number of withdrawals in another [9]), all found a significant improvement [5; 6; 14], or a non-significant trend towards an improvement [4; 7; 10; 11; 12; 13 ; 25] in QoL - corroborating our findings.

The discrepancies in the literature might be due to methodological differences. Although our study did not feature a control group and was mainly based on the retrospective collection of data (which necessarily resulted in a proportion of missing data), we used a robust, validated tool (the PDQ-8 [15]) as the main criterion for QoL evaluation. The scores obtained before and after participation in the EduPark PEP were collected prospectively during the program itself. Moreover, the availability of pre- and post- PDQ-8 scores was a study inclusion criterion, and helped to avoid attrition bias. However, with a view to confirming our present results, it would be valuable to perform a controlled study of the EduPark PEP's impact. In our study, PD diagnosis relied on neurologist diagnosis without strictly requiring to meet standardized diagnosis criteria. This could induce some heterogeneity in the patients included in the study, and participate to the discrepancies with previous between studies. Meanwhile, it increase the representativeness of the study as patients included strictly reflect patients to which the PEP is proposed.

The disparities in the literature data might also be related to the various PEPs' structures and delivery modes. Indeed, PEPs have been regularly modified since their introduction, and several educational methods have been used (Table 4). As in other centers [13], each patient was offered a personalized program that focused on his/her specific needs. A total of ten workshops were run, in order to cover the broad range of symptoms (both motor and non-motor) and difficulties encountered by patients with

PD. The benefit of targeting patients' needs and expectations has already been demonstrated [26]; this approach may avoid information overload and might thus promote the greater uptake and retention of a program's educational messages. The EduPark PEP was specifically adapted to the context of PD, since a patient's attentional level may fluctuate. Accordingly, each session should be tailored with regard to its duration, content, and number of participants (four to six). One of the strengths of the EduPark program is its ability to offer group sessions in hospital and individual sessions at home. In fact, we had identified several factors that limit participation in hospital: poor mobility, logistic difficulties, work-related constraints, and refusal by the patient. This prompted the idea of individual at-home sessions or a mixture of in-hospital and at-home sessions – a configuration that might facilitate patient participation. In fact, patients attending at-home sessions appeared to have slightly more severe disease than those attending in-hospital sessions. Another limitation related to the emergence of logistic issues and or inability to perform the final interview at home 3 months after the end of the PEP (as performed for hospital-only programs). The difference in the QoL results between the hospital and home groups raises questions about the long-term effect of a PEP on QoL. The need for educational follow-up after the PEP has finished has already been suggested [14]. In the EduPark PEP, patients can attend further sessions at any time if relevant. At the time of our study, few patients had attended the program more than once; this prevented us from performing a sufficiently powered statistical analysis of their specific characteristics. Further studies that specifically explore these patients and thus the PEP's long-term impact in PD would be needed. Nevertheless, our patients appeared to benefit significantly from a personalized, focused PEP. We recommend the continued development and application of PEPs in the field of PD.

Our present data did not highlight factors that were predictive of the EduPark PEP's impact on QoL in patients with PD. However, we found that the EduPark PEP had a significant, positive impact on the patients' QoL. These findings suggests that PEPs should be offered to a greater proportion of patients with PD - especially if the program can be delivered either in hospital and/or at home. In view of the covid-19 pandemic, the opportunity to offer individualized at-home sessions allow to maintain patient education program, without exposing the participants to an increased contamination risk. As group sessions have specific interests (increase motivation, experience sharing with peer…) and may be preferred by some patients, remote group sessions using webconference are another possibility to overcome the barrier related with the pandemic but remains to be tested.

Further work will be needed to confirm our present results. A number of important aspects of PEPs in PD were not studied in our trial but warrant examination in the future; these include a PEP's potential socio-economic impact and the role of specific workshops (e.g. third-line therapies, the effect of early PEPs on patients newly diagnosed with PD, the effect of appropriate physical activities, etc.).

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Table 1: Workshops in the EduPark PEP.

I have just been diagnosed with a Parkinson's disease: *de novo* PD" (diagnosis in the last 3 years)
How to identify my motor fluctuations
Non-motor symptoms: how to identify my non-motor fluctuations
My antiparkinson medications: improving my knowledge and management of my oral antiparkinson medications
I can improve my daily life with appropriate physical activity: tips and tricks
I have just had deep brain stimulation electrodes implated for Parkinson's disease
How to subcutaneously administer apomorphine injections / I have just been prescribed an apomorphine pump
I have just been prescribed a Duodopa pump
Nutrition and deglutition
Caregiver and patient relation: managing improvement of negative effects of the disease

Table 2: Demographic and clinical characteristics of the study population.

	Overall population *(n=181)*	**Hospital group *(n=120)***	**Home group *(n=85)***
Male, n (%)	103/181 (56.9)	75 /120 (62.5)	43/85 (50.6)
Age (years)	62.9 ± 8.2	62.7 ± 7.5	64.1 ± 9
Educational level (years) [1], median [IQR]	11 (9 to 13)	12 (10 to 14)	10 (9 to 12)
Marital status, n (%):			
- married	137/181 (75.7)	93/120 (77.5)	64/85 (75.3)
- unmarried	30/181 (16.6)	20/120 (16.7)	12/85 (14.1)
- widower	14/181 (7.7)	7/120 (5.8)	9/85 (10.6)
Presence of a caregiver, n (%)	155/180 (86.1)	104/120 (86.7)	74/84 (88.1)
History of depression, n (%)	65/178 (36.5)	39/118 (33.1)	35/84 (41.7)
History of anxiety, n (%)	94/178 (52.8)	62/119 (52.1)	45/83 (54.2)
Cognitive decline, n (%)			
- No cognitive impairment	79/103 (76.7)	63/77 (81.8)	27/43 (62.8)
- Mild cognitive impairment	16/103 (15.5)	8/77 (10.4)	12/43 (27.9)
- Moderate or severe cognitive, impairment	8/103 (7.8)	6/77 (7.8)	4/43 (9.3)
PD duration (years)	9.1 ± 5.3	8.8 ± 5.0	9.8 ± 5.7
Hoehn & Yahr stage, “on-drug”, n (%)			
- Stage 1	62/179 (34.6)	42/119 (35.3)	26/84 (31.0)
- Stage 2	86/179 (48.0)	63/119 (52.9)	38/84 (45.2)
- Stage 3	25/179 (14.0)	12/119 (10.1)	15/84 (17.9)
- Stage 4	5/179 (2.8)	1/119 (0.8)	4/84 (4.8)
- Stage 5	1/179 (0.6)	1/119 (0.8)	1/84 (1.2)
Hoehn & Yahr stage, “off-drug”, n (%)			
- Stage 1	47/180 (26.1)	31/120 (25.8)	21/84 (25.0)
- Stage 2	84/180 (46.7)	61/120 (50.8)	35/84 (41.7)
- Stage 3	39/180 (21.7)	22/120 (18.3)	23/84 (27.4)
- Stage 4	9/180 (5.0)	5/120 (4.2)	4/84 (4.8)
- Stage 5	1/180 (0.6)	1/120 (0.8)	1/84 (1.2)
MDS-UPDRS III “on-drug” score[2] median [IQR]	16 (10 to 23)	14 (9 to 21)	18 (13 to 25)
MDS-UPDRS III “off-drug” score[3] median [IQR]	39.2 ± 16.6	37.7 ± 16.9	44.3 ± 14.4
Levodopa equivalent daily dose (mg) median [IQR]	826 (500 to 1200)	835 (410 to 1210)	826 (510 to 1191)
Deep brain stimulation, n (%)	19/181 (10.5)	12/120 (10)	8/85 (9.4)
Duration of the PEP (days), median [IQR]	111 (62 to 191)	158 (100 to 208)	77 (54 to 159)
Distance between home and hospital (km), median [IQR]	14.9 (0 to 43.1)	31.3 (15.4 to 54.7)	0 (0 to 3.7)
Overall satisfaction with the EduPark PEP (score out of 10)[6]: median [IQR]	8 (8 to 9)	8 (8 to 9)	9 (8 to 10)

Data are presented as the mean ± SD, unless otherwise indicated

[1] 3 missing data (2 in the hospital Group); [2] 86 missing data (49 the hospital group); [3] 132 missing data (82 the hospital Group); [4] 137 missing data (76 the hospital group); [5] 33 missing data (32 the hospital group); [6] 15 missing data (3 the hospital group)

Table 3: Association between patient characteristics and the change in the PDQ8 score after the PEP

	Estimate (β)	Standard deviation	p-value
Age[1]	-0.27	0.34	0.43
Men	0.13	0.57	0.82
History of depression	0.61	0.59	0.30
History of anxiety	0.40	0.58	0.49
Time of inclusion in TEP[2]	-0.03	0.10	0.78
Education level	0.15	0.10	0.16
Marital status:			
married	0.12	1.04	0.40
not married	1.11	1.20	
Presence of a caregivers	- 0.89	0.80	0.27
Distance between home and CHU[3]	0.28	0.88	0.75
PD duration	0.03	0.05	0.61
MDS- UPDRSS « ON » score	-0.27	0.36	0.45
Hoehn & Yahr stage "OFF »:			
Stage 1	- 0.17	3.77	0.82
Stage 2	0.39	3.75	
Stage 3	0.22	3.79	
Stage 4	1.39	3.93	
Cognitive impairment:			
Mild cognitive impairment	- 2.11	1.01	0.11
Moderate or severe cognitive impairment	- 0.10	1.38	
Levodopa equivalent daily dose [4]	-0.25	0.38	0.52

[1] Per 10-year increment [2] Per 1-month increment [3] Per 100 km increment [4] Per 1000-dose-unit increment

Table 4: Published studies of PEP in Parkinson's disease.

Study	Study characteristics	Publication date	Country	PEP modalities	n	Target population	Duration of inclusion in PEP	Evaluation scale(s) used	Results
RANDOMIZED CONTROLED TRIALS									
Dos Santos and al [11]	Single-blind, randomized, controlled trial	2017	France	6 group sessions and 1 individual session at the hospital	19	*Age* 60 (52-65) years *M/F sex:* 8/1 *UPDRS III-ON:* 3 (2-15)	2.5 years	SAS PDQ-39	Trend towards a decrease in psychosocial maladjustment (3 [2;3] vs. -1 [-1;0] Trend toward an improvement in QoL (35 [31;53] MCAI -11.7 [-14;-10])
Montgomery and al [4]	Randomized controlled trial	1994	United-states	Educational pamphlets and individualized letters mailed to patients	290	*Age:* 68.1 ± 0.9 years *UPDRS III-ON*: 21.7 ± 1.3	6 months	Visual analogue scale (0 to 100)	Trend towards an improvement in QoL (41.0 ± 1.8 vs. 43.5 ± 2.0)
Mercer and al [5]	Randomized controlled trial	1996	United-States	Educational pamphlets and individualized letters mailed to patients	46	*Age:* 66.7 years *M/F sex:* 18/7 *Hoehn and Yahr scale:* stages from 1 to 4	12 months	Visual analogue scale (0 to 100)	Significant improvement in QoL (59.5 vs. 60.6)
Grosset and al [9]	Randomized, controlled trial	2007	UK	Individual verbal and written information at the hospital	69	*Age:* 61 ± 10 years *M/F sex:* 21/12 *Hoehn and Yahr scale:* 2.4 ± 0.7 *UPDRS III-ON:* 30 ± 12 *MMSE:* 28 ± 2 28	Unknown	PDQ-39	No change in QoL (30 ±15 vs. 36 ± 15)

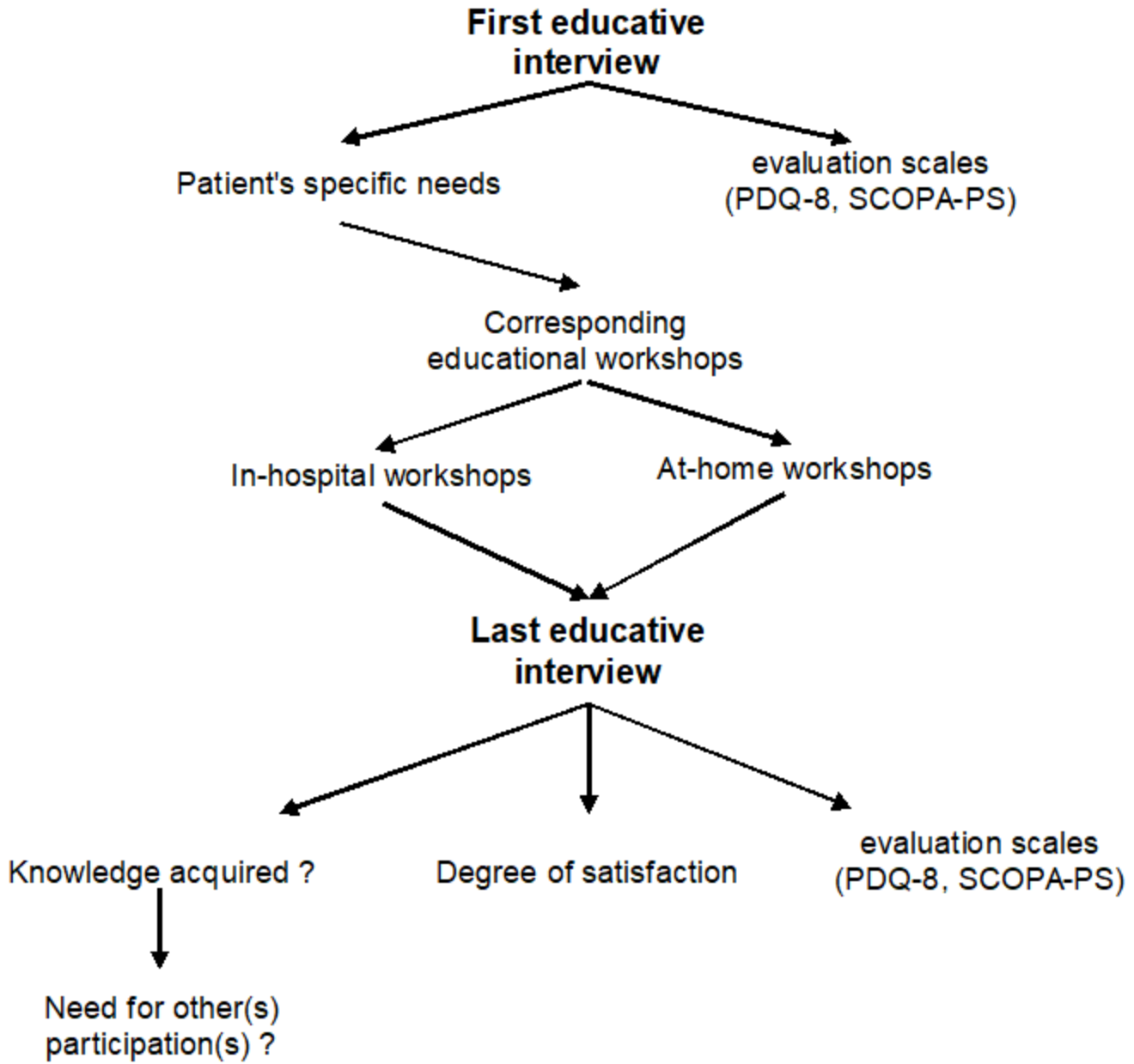
A'Campo and al [10]	Randomized, controlled trial	2009	The Netherlands	8 weekly group sessions at the hospital	64	*Age:* 65.54 ± 8.94 years *M/F sex:* 20/15 *Hoehn and Yahr scale:* 2.41 ± 1.01 *MMSE:* 27.41 ± 3.37	8 weeks	PDQ-39 BELA-P-k	Trend towards an improvement in QoL (33.04 ± 13.49 MCAI 3.07 ±7.81) No significant reduction in psychosocial problems (30.34 ± 10.87 MCAI 2.25 ± 5.41)
A'Campo and al [14]	Randomized, controlled trial	2011	The Netherlands	8 weekly group sessions at the hospital	55	*Age:* 68.0 ± 11.1 years *M/F sex:* 37/18 *Hoehn and Yahr scale:* 2.1 ± 1.1 *MMSE:* 27.9 ± 1.8	8 weeks	PDQ-39	Significant improvement in QoL at the end of the PEP (37.9 ± 13.4 vs. 34.2 ± 13.1) No change in QoL at the 6-month follow-up (37.9 ± 13.4 vs. 36.8 ± 13.0)
Canivet and al [25]	Single-center prospective, randomized, controlled trial	2016	France	Individual and group sessions at the hospital	120	*Age:* 62.1 ± 7.1 years *M/F sex:* 40/20 *Hoehn and Yahr scale*: 20% at stage 1, 60% at stage 2, 21.6% at stage 3.*UPDRS III-ON:* 12.2±7.2	12 months	PDQ-39	Trend towards an improvement in QoL (31.8 ± 21.1 MCAI -4.37 ± 16.52)
NON-RANDOMIZED CONTROLLED TRIALS									
Lindskov and a [8]	Non-randomized, controlled trial	2007	Sweden	Weekly group sessions at the hospital	96	*Age:* 69.3 ± 8.4 years *M/F sex:* 28/20	6 weeks	SF-12	No change in QoL (47.5 ± 10.9 vs. 47.3 ± 11.6)

						Hoehn and Yahr scale (median [IQR]): 1 (1-2; 1-3)			
NON-CONTROLLED PROSPECTIVE TRIALS									
Sunvisson and al [6]	Non-controlled prospective trial	2001	Sweden	2 weekly sessions at the hospital (theory and practice)	43	*Age:* 75 (53-85) years *M/F sex*: 27/16 *Hoehn and Yahr scale:* 1.84 ± 0.679	5 weeks	SIP	Significant reduction in psychosocial dysfunction (11.99 ± 1.23 vs. 1.41 ± 9.52)
Macht and al [12]	Non controlled prospective trial	2006	Estonia Finland Germany Italy The Netherlands Spain UK	8 structured weekly 90-minute group sessions at the hospital	151	*Age*: 64.4 ± 9.2 years *M/F sex*: 90/61 *Hoehn and Yahr scale:* 2.0 ± 0.8 *MMSE:* 28.0 ± 2.1	8 weeks	PDQ-39 BELA-P-k	Trend towards an improvement in QoL (30.8 ± 16.2 vs. 30.7 ± 7.7) Significant reduction in psychosocial problems (26.7 ± 15.6 vs. 21.0 ± 14.7)
Simons and al [7]	Non-controlled prospective trial	2006	UK	8 structured weekly 90-minute group sessions at the hospital	31	*Age:* 65 ± 7.3 years *M/F sex*: 9/13 *UPDRS III-ON:* 9.81 ± 4.58	8 weeks	PDQ-39 BELA-P-k	Trend towards an improvement in QoL and a reduction in psychosocial problems (data not available)
RETROSPECTIVE TRIALS									
Ory Magne and al [13]	Non-controlled retrospective trial	2013	France	Individual and group workshops on specific themes at the hospital	231	*Age:* 64.05 ± 10.5 years *UPDRS III-ON*: 12 ± 7.9	Mean number of	Visual analogue scales	Trend towards an increase in QoL (7 ± 0.8 vs. 7.8 ± 0.9) and self-esteem (6.2 ± 1.4 vs. 7.3 ± 1.1) at

		sessions by patient: 6.	the end of the PEP and at 12 months.

BELA-P-k: The psychosocial problems in Parkinson's disease questionnaire (*Belastungsfrageboden Parkinson kurzversion*); F: female; IQR: interquartile range; M: male; MCAI: mean change after intervention; MMSE: Mini Mental State Examination; PD: Parkinson's disease, PDQ-39: the 39-item Parkinson's disease questionnaire; QoL: quality of life; SAS: Social Adjustment Scale; SF-12: short version of the SF-36 (see next abbreviation); SF-36: The Medical Outcomes Study 36-Item Short Form; SIP: Sickness Impact Profile; PEP: patient education program; WHOQOL 26: the World Health Organization quality of life survey

Figure 1: Organization of the Edupark Patient Education Program. PDQ-8: short-form (8-item) Parkinson's Disease Questionnaire; SCOPA-PS: psychosocial section of the Scales for Outcomes in Parkinson's disease -


First educative interview
Patient's specific needs
evaluation scales (PDQ-8, SCOPA-PS)
Corresponding educational workshops
In-hospital workshops
At-home workshops
Last educative interview
Knowledge acquired ?
Degree of satisfaction
evaluation scales (PDQ-8, SCOPA-PS)
Need for other(s) participation(s) ?