



Short communication

Changes in quality of life, burden and mood among spouses of Parkinson's disease patients receiving neurostimulation

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ABSTRACT

Background: Deep brain stimulation improves motor function and quality of life in patients with Parkinson's disease. The impact of these changes on patients' spouses is largely unknown.

Methods: Twenty-six spouses of patients undergoing surgery were evaluated before and 12 months after surgery, using the 36-Item Short Form Health Survey for quality of life, the Beck Depression Inventory, and the Zarit Burden Inventory.

Results: The spouses' mean mood and quality of life scores changed little, while burden improved in younger spouses. There was no significant change in the spouses' overall status. However, at the individual level the effect of surgery was more frequently negative than positive. Changes in psychological status and quality of life in the spouses did not correlate with changes in the patients' motor status or quality of life.

Conclusions: Spouses' experience of neurostimulation for Parkinson's disease is variable and complex. The improvement in burden experienced by younger spouses may reflect a greater capacity to cope with new situations.

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1. Introduction

Progression of Parkinson's disease (PD) is associated with higher strain, poorer quality of life (QoL), and increased emotional distress in patients' caregivers [1], about one in five of whom require treatment for mood disorders [1]. PD patients' disability, symptoms and psychological distress (mostly depression, hallucinations and confusion) are associated with a higher burden and poorer quality of life in their spouses [2]. Subthalamic nucleus deep brain stimulation (STN-DBS) improves motor function and QoL in PD patients [3], but the impact of these changes on patients' spouses has rarely been examined. A study of 14 patients and their spouses concluded that STN-DBS improved the caregivers' QoL [4]. The aim of the present study was to assess the impact of STN-DBS on QoL, mood and burden among spouses of patients with PD. Intra-individual changes in QoL were identified using the Reliable Change Index (RCI) [5].

2. Subjects & methods

2.1. Subjects and procedures

The data reported here are from a follow-up study of 41 consecutive patients who underwent STN-DBS [6], 32 of whom were living with a spouse. Six spouses were excluded from this analysis because of events related to the patients (suicide, and infection leading to removal of the stimulation hardware), to the spouses (one declined further participation, one developed cancer, and one died), or to both (divorce). The analysis therefore focused on 26 spouses (19 women, 7 men; age at baseline: 62.7 years \pm 8.8, range 37–77). The patients' characteristics are shown in Table 1.

Evaluations were performed four to two weeks before surgery (M0), and again one year after surgery (M12). The spouses were evaluated with the SF-36 questionnaire for QoL, the Zarit Burden Inventory (ZBI), and the Beck Depression Inventory (BDI-II). The patients' motor status was evaluated with Sections 3 and 4 of the Unified Parkinson's Disease Rating Scale (UPDRS), and their QoL was assessed with the Parkinson's Disease Questionnaire PDQ-39. All participants provided informed consent for participation, and the study protocol received University Review Board approval.

2.2. Statistical analysis

At the group level, changes following treatment and correlations between the spouses' and patients' characteristics were studied with non-parametric tests. Intra-individual changes in QoL, mood and burden were calculated. RCIs were calculated

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Table 1
Patients' characteristics at baseline and one year after surgery ($n = 26$).

	Baseline mean (SD, range)	One year mean (SD, range)	Z based on positive ranks	<i>d</i>
Sex (men/women)	19/7			
Age (y)	63.8 (6.7, 40–75)			
PD duration (y)	16.0 (6.1, 8–40)			
UPDRS III off medication (max = 108)	52.3 (17.4, 13–81)	22.4 (11.2, 5–44)	–4.41**	2.08
UPDRS IV (max = 23)	9.5 (3.1, 4–17)	3.0 (2.5, 0–8)	–4.39**	2.35
Daily levodopa equivalent dose (mg)	1438 (584, 300–3700)	528 (276.0, 120–1160)	–4.38**	2.03
PDQ-39 Summary Index (max = 100) ^a	48.2 (9.5, 32–72)	41.6 (15.2, 13–78)	–2.24*	0.53

* $p < 0.05$; ** $p < 0.001$. According to Cohen (1988), a *d* effect size of 0.2–0.5 might be considered as a small effect, over 0.5–0.8 as a medium effect and over 0.8 as a large effect.

^a A decrease in the PDQ-39 Summary Index indicates an improvement in quality of life.

for the eight SF-36 subscales, referring back to the French norms for this scale. We used the definitive RCI formula developed by Jacobson and Truax [5]:

$$RCI = \frac{\text{Mean } M0 - \text{Mean } M12}{S_{\text{diff}}}$$

where $S_{\text{diff}} = \sqrt{2(SE)^2}$, $SE = S_1 \sqrt{1 - r_{xx}}$. S_1 specifies the standard deviation from the sample at baseline, and r_{xx} is the reliability coefficient. The RCI is the range within which an individual score is likely to fluctuate because of population variance (S_1), test reliability (r_{xx}), and surgery. If the RCI is larger than the z-score desired level of significance (in this study, 1.96; $p < 0.05$), the change is not due to measurement error alone, but is considered as a real change due to surgery. Usually, a cutoff between the normative and clinical groups is calculated. However, calculation of the RCI and of this cutoff depends on the normality of the measurements. As the scores for the eight subscales of the SF-36 had a non-normal distribution, we used an alternative method proposed by Ferguson *et al.* to determine RCI, expressed as a number of scale points by using normative data and reliability coefficients of the French validation of the SF-36, rather than the distribution of our sample at baseline [7].

In order to explore changes in burden and depression, we used cut-points and individual effect sizes, calculated as follows: (mean score at baseline - mean score at M12)/standard deviation at baseline. BDI-II scores were analyzed as both continuous and dichotomous variables, using a cut-point of 18 to define clinical depression.

Associations between the spouses' presurgical characteristics and their individual post-surgical changes were examined by using hierarchical regression analyses predicting QoL, depression and burden scores as dependent variables, and personal and psychological variables as predictors. In the regression model, we also introduced the patients' personal and clinical variables as predictors.

All tests were two-tailed, and significance was assumed at $P < 0.05$. The SPSS 18.0 program and MacRCI freeware for Windows were used for statistical analyses.

3. Results

The patients' motor status and QoL improved one year after surgery (Table 1). The spouses' mean scores for QoL, depression and burden did not change (Table 2). The SF-36 scores (PCS and MCS) were in line with French standards, while the mean BDI-II scores were low (<12), and the ZBI scores were moderately elevated. There was no gender differences in the spouses' mean QoL, depression or burden scores (Mann–Whitney tests NS). The changes in the spouses QoL, burden and depression scores did not correlate with the changes in the patients' motor status (UPDRS III & IV) or QoL (PDQ-39 Summary Index).

Analysis of the RCIs and size effects showed intra-individual variability in the change in QoL. Surgery had a more frequently negative than positive impact on the spouses (Physical QoL: 15% improved vs 35% deteriorated; Mental QoL: 23% improved vs 42% deteriorated; see Table 2). The spouses' physical and social functioning was preserved both at baseline and one year after surgery, but their vitality was undermined by caregiving.

Similar contrasting results were observed for depression and burden (Table 2, lower part). The number of depressed spouses declined between baseline and M12. Using the effects size and

a score cutoff of 18, the four women who had the highest depression scores at baseline recovered, but another woman became depressed (baseline-M12 scores for these 5 women: 22–13, 21–15, 24–16, 28–17 and 10–20).

Based on the cutoff scores proposed by Zarit, burden decreased: at baseline and one year after surgery, burden was 'absent to mild' (0–20) in respectively 8 and 10 spouses (31% vs 39%), 'mild to moderate' (21–40) in 11 and 13 spouses (42% vs 50%), and 'moderate to severe' (41–60) in 7 and 3 spouses (27% vs 12%). However, these positive changes were associated with large or moderate individual effect sizes in only five spouses, whereas burden worsened in three other spouses.

We then looked for associations between the spouses' presurgical characteristics and subsequent changes in their QoL, depression and burden scores. First, we used correlations to examine relationships between personal (age, gender) and psychological variables at baseline (QoL, burden, depression), and changes in these three variables in the spouses from M0 to M12, and in the patients' personal (age at surgery, and age at PD onset) and clinical variables (PD duration, dopatherapy, and UPDRS III & IV). In the spouses, changes in mental QoL were associated with the MCS at baseline ($r = 0.61$, $p = 0.001$) and with the duration of PD ($r = 0.46$, $p = 0.019$). Changes in depression were linked to depression at baseline ($r = 0.61$, $p = 0.001$), whereas changes in burden were associated with the spouse's age ($r = -0.41$, $p = 0.037$) and burden at baseline ($r = 0.42$, $p = 0.034$). No other correlations were found.

We also used hierarchical regression analysis to identify predictors of spouses' psychological status one year after surgery (QoL, depression and burden). As in the bivariate analyses, we introduced the same personal and psychological characteristics of the spouses at baseline and the patients' personal and clinical variables as predictive factors. For all outcomes, the baseline scores were the strongest predictors of the M12 scores (PCS: 26% of the variance, $\beta = 0.51$, $p = 0.007$; MCS: 23% of the variance, $\beta = 0.47$, $p = 0.014$; BDI: 47% of the variance; $\beta = 0.69$, $p < 0.001$; ZBI: 26% of the variance; $\beta = 0.51$, $p = 0.008$). Changes in mental QoL (MCS) were associated with the PD duration (21% of the variance; $\beta = 0.46$, $p = 0.007$). Finally, changes in burden were associated with the spouse's age (18% of the variance; $\beta = 0.43$, $p = 0.011$), the patient's age (12% of the variance; $\beta = 0.35$, $p = 0.045$), and the patient's age at PD onset (16% of the variance; $\beta = 0.42$, $p = 0.021$): the younger the patient at PD onset, the larger the post-surgical improvement in burden. Given this influence of age, we subdivided the spouses into two age groups, using the median (63.5 y) as cutoff. The mean ZBI score (but not the BDI-II or SF-36 scores) improved significantly at M12 in the younger group and worsened in the older group (ZBI change: -8.92 ± 15.39 vs $+5.00 \pm 10.29$; $U = 34.50$, $p = 0.010$).

Table 2
Quality of life, depression and burden in spouses at baseline and one year after surgery: mean scores and individual significant changes, as indicated by RCIs and effect sizes.

	Statistically significant differences				Intra-individual changes: reliable change indices		
	M0 mean (SD) (n = 26)	M12 mean (SD) (n = 26)	Z based on positive ranks	d	Improved n (%)	No change n (%)	Declined n (%)
SF-36 scale (max = 100)							
Physical functioning	86.5 (16.2)	82.7 (17.8)	-1.42	0.32	2 (8%)	20 (77%)	4 (15%)
Role-physical	66.3 (39.3)	60.6 (39.5)	-0.78	0.19	3 (12%)	19 (73%)	4 (15%)
Bodily pain	68.4 (23.3)	62.4 (26.4)	-1.61	0.36	2 (8%)	20 (77%)	4 (15%)
General health	66.3 (15.1)	61.2 (19.8)	-1.52	0.42	1 (4%)	21 (81%)	4 (15%)
Vitality	54.0 (18.0)	50.8 (17.1)	-1.27	0.29	3 (12%)	19 (73%)	4 (15%)
Social functioning	77.9 (22.4)	76.4 (17.4)	-0.39	0.11	3 (12%)	20 (77%)	3 (12%)
Role-emotional	69.2 (38.8)	60.3 (41.1)	-0.84	0.24	2 (8%)	20 (77%)	4 (15%)
Mental health	59.8 (17.4)	54.9 (16.8)	-1.53	0.40	1 (4%)	20 (77%)	5 (19%)
SF-36 summary scores (T notes)	—	—	—	—	Intra-individual effect sizes ^a		
PCS ^b	49.1 (8.4)	49.2 (8.3)	-1.56	0.10	4 (15%)	13 (50%)	9 (35%)
MCS ^b	44.2 (9.0)	41.4 (7.7)	-1.46	0.40	6 (23%)	9 (35%)	11 (42%)
BDI-II ^b (max = 63)	10.9 (7.6)	10.5 (6.0)	-0.44	0.11	6 (23%)	16 (62%)	4 (15%)
ZBI ^b (max = 88)	28.2 (14.3)	26.2 (15.3)	-0.43	0.08	6 (23%)	13 (50%)	7 (27%)

PCS = Physical component score; MCS = Mental component score. NA = Not applicable. A decrease in PCS and MCS indicates a deterioration of the physical or mental components of quality of life.

^a For clinically meaningful changes, 'improved' or 'declined' status is reflected by an effect size ≥ 0.5 .

^b In the absence of available reference data, effect sizes were calculated and considered instead of RCIs on summary component scores (SF-36), depression (BDI-II) and burden (ZBI).

4. Discussion

This study is the first to examine the impact of DBS for PD on spouses' depression, burden and quality of life scores, based on both inter-individual statistics and intra-individual changes identified with the Reliable Change Index (RCI).

The RCI proposed by Jacobson and Truax (1991) was chosen among available indices of clinically meaningful change because it is well suited to psychological measurements of attitude, psychopathological disorders and QoL, it is commonly used, and easy to compute. The RCI method has been used in previous studies of PD, especially for cognitive functions.

In line with previous studies [3], our PD patients' motor status and QoL improved one year after surgery. Although surgery had no positive impact on the spouses' mean QoL, depression or burden scores, different results were obtained when levels of change were analyzed in terms of RCIs and effect sizes. Surgery did not improve the mean scores for the spouses' quality of life, a finding that contrasts with the results of a previous study based on a non-validated QoL scale [4]. Also contrasting with studies of non-surgical patients [2,8], we found no relation between the caregivers' burden and the patients' disability. Although burden scores at baseline were similar to those found in another study of PD patients' caregivers [8], the spouses' QoL was reasonably preserved. Five of the eight SF-36 subscores have ceiling effects (scores of 100), and this could lead to an underestimation of the impact of surgery, as 24–54% of the spouses had the maximal scores for the following QoL subtests at baseline: Physical functioning, Role-physical, Bodily pain, Social functioning, and Role-emotional.

Individual changes in the spouses' depression scores were not predicted by any of the patients' or spouses' baseline characteristics, suggesting that these changes were driven by subtle psychodynamic mechanisms that were not addressed here.

Four major factors might explain the lack of overall improvement in the spouses' burden, as well as the improvement observed in the youngest spouses. Firstly, the patients' emotional distress, and particularly depression, increased following surgery, and this may have increased the spouses' burden [9]. Secondly, caregiver burden is linked to a gradual decline in social activity throughout the course of PD [10]. The spouses whose burden improved most at one year were the youngest, and those whose wife or husband had the shortest PD duration, suggesting that their social network was

more likely to be intact, notably because they were still actively employed, or young retirees. DBS is unlikely to improve mutual support, as suggested by the frequency of marital conflicts following the procedure [11]. However, the larger QoL improvement observed among the patients with the youngest spouses (PDQ-39 improvement: 12.43 vs 0.74; $U = 41.5$, $p = 0.026$) might be associated with the possibility to regain a more satisfying social life. Thirdly, most spouses are reported to have difficulties coping with the new, post-operative situation [11]. Elderly people are reluctant to anticipate future crises. Younger people may employ more active interpersonal problem-solving forms of coping, which could be more adaptive. Moreover, the youngest patients showed the largest improvement in QoL after DBS. Their spouses may therefore find it easier to cope with post-operative changes. Finally, some spouses may find that caring for a partner with PD is not just a burden but also a meaningful and sometimes positive experience. Spouses of PD patients who maintain the best relationships with their partners and who consider caregiving as a meaningful experience express less strain and better QoL [12]. These aspects of the caregiving burden are not taken into account by the ZBI scale, and an instrument such as the Caregiver Reaction Assessment (Given, 1992), designed to assess both negative and positive reactions to caregiving among spouses of chronically ill patients, might be more suitable for future studies.

The main limitations of this study are the small sample size, and the absence of a control group, as is the case of most single-center series of subjects undergoing functional neurosurgery. In addition, more thorough assessment of the patients' and spouses' subjective satisfaction, independently from the objective outcomes of DBS, might add useful data to this type of study.

In conclusion, we found that DBS for PD lightened the burden of younger spouses. However, when individual changes were evaluated with the RCI and intra-individual methods, neurosurgery tended to have a negative impact on some domains of the spouses' QoL.

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M. Soulas has received speaker honoraria from Novartis SA. Dr Fénelon served on a scientific board for Boehringer Ingelheim and for Novartis SA, and has received speaker honoraria and travel funding from Boehringer Ingelheim, Novartis, Teva and Lundbeck. Professor Palfi has received speaker honoraria and travel funding

from Medtronic, Inc. Professor Sultan served on a scientific board for Ipsen and Sanofi-Aventis.

Conflict of interest

None.

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