Short communication

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

T. Soulas a,c,* , S. Sultan c, J-M. Gurruchaga a , S. Palfi a , G. Fénelon b,d,e

*AP-HP, GH Henri Mondor, Department of Functional Neurosurgery, Créteil, France
AP-HP, GH Henri Mondor, Department of Neurology, Créteil, France
University Paris Descartes Laboratory of Psychopathology and Health, Boulogne-Billancourt, France
INSERM U955, Team 1, Créteil, France
Ecole Normale Supérieure, Département d’études cognitives, Paris, France

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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 ± 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...
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]:

\[
\text{RCI} = \frac{S_{\text{diff}}}{2 \times SE_{\text{diff}}} = \frac{S_{\text{diff}}}{2 \times S_{\text{test}}^{1/2}}
\]

where \(S_{\text{diff}}\) is the standard deviation from the sample at baseline, and \(S_{\text{test}}\) is the reliability coefficient. The RCI is the range within which an individual score is likely to fluctuate because of population variance (\(S_{\text{diff}}\)), test reliability (\(S_{\text{test}}\)), and surgery. If the RCI is larger than the \(z\)-score desired level at baseline and one year after surgery, burden was decreased: (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 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, dopapyra, 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 ± 10.29; U = 34.50, p = 0.010).
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 depression, burden and quality of life scores, based on statistically significant differences, as indicated by RCIs and effect sizes.

<table>
<thead>
<tr>
<th>Statistically significant differences</th>
<th>M0 mean (SD)</th>
<th>M12 mean (SD)</th>
<th>Z based on positive ranks</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36 scale (max = 100)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>86.5 (16.2)</td>
<td>82.7 (17.8)</td>
<td>−1.42</td>
<td>0.32</td>
</tr>
<tr>
<td>Role-physical</td>
<td>66.3 (39.3)</td>
<td>60.6 (39.5)</td>
<td>−0.78</td>
<td>0.19</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>68.4 (23.3)</td>
<td>62.4 (26.4)</td>
<td>−1.61</td>
<td>0.36</td>
</tr>
<tr>
<td>General health</td>
<td>66.3 (15.1)</td>
<td>61.2 (19.8)</td>
<td>−1.52</td>
<td>0.42</td>
</tr>
<tr>
<td>Vitality</td>
<td>54.0 (18.0)</td>
<td>50.8 (17.1)</td>
<td>−1.27</td>
<td>0.29</td>
</tr>
<tr>
<td>Social functioning</td>
<td>77.9 (22.4)</td>
<td>76.4 (17.4)</td>
<td>−0.39</td>
<td>0.11</td>
</tr>
<tr>
<td>Role-emotional</td>
<td>69.2 (38.8)</td>
<td>60.3 (41.1)</td>
<td>−0.84</td>
<td>0.24</td>
</tr>
<tr>
<td>Mental health</td>
<td>59.8 (17.4)</td>
<td>54.9 (16.8)</td>
<td>−1.53</td>
<td>0.40</td>
</tr>
<tr>
<td>SF-36 summary scores (T notes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCSª</td>
<td>49.1 (8.4)</td>
<td>49.2 (8.3)</td>
<td>−1.56</td>
<td>0.10</td>
</tr>
<tr>
<td>MCSª</td>
<td>44.2 (9.0)</td>
<td>41.4 (7.7)</td>
<td>−1.46</td>
<td>0.40</td>
</tr>
<tr>
<td>BDI-II (max = 63)</td>
<td>10.9 (7.6)</td>
<td>10.5 (6.0)</td>
<td>−0.44</td>
<td>0.11</td>
</tr>
<tr>
<td>ZBIª (max = 88)</td>
<td>28.2 (14.3)</td>
<td>26.2 (15.3)</td>
<td>−0.43</td>
<td>0.08</td>
</tr>
</tbody>
</table>

<p>| Intra-individual changes: reliable change indices | | |</p>
<table>
<thead>
<tr>
<th>Improved n (%)</th>
<th>No change n (%)</th>
<th>Declined n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 (8%)</td>
<td>20 (77%)</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>3 (12%)</td>
<td>19 (73%)</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>2 (8%)</td>
<td>20 (77%)</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>1 (4%)</td>
<td>21 (81%)</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>3 (12%)</td>
<td>19 (73%)</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>3 (12%)</td>
<td>20 (77%)</td>
<td>3 (12%)</td>
</tr>
<tr>
<td>2 (8%)</td>
<td>20 (77%)</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>1 (4%)</td>
<td>20 (77%)</td>
<td>5 (19%)</td>
</tr>
</tbody>
</table>

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).

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 = 415, 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.

Financial disclosure

M. Soulas has received speaker honoraria from Novartis SA. Dr Fénelon served on a scientific board for Boeheringer Ingelheim and for Novartis SA, and has received speaker honoraria and travel funding from Boeheringer 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.

References


