

## Partners' view after subthalamic deep brain stimulation: Better relationships despite patients being less active



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### ABSTRACT

**Introduction:** After deep brain stimulation (DBS) of the subthalamic nucleus (STN), Parkinson patients report difficulties in the relationship with their partners. The partners' experience after DBS appears to be variable and complex. Purpose of this pilot study was to investigate the partners' perspective on the relationship following STN-DBS.

**Subjects and methods:** We conducted a postoperative questionnaire assessment in 56 partners of Parkinson patients with STN-DBS, using questionnaires addressing partnership satisfaction, dyadic coping, and role allocation in duties and activities of daily living.

**Results:** Regarding overall relationship satisfaction after surgery, 40% of partners were happier with their relationship than before DBS, and 14% were less satisfied. Partners reported that patients involved themselves distinctly less in duties and activities of daily living, leaving partners to take over. A need for more professional support for the relationship following surgery was noted by 27% of the partners.

**Conclusion:** Although quality of relationship and dyadic coping improved or remained unchanged according to the majority of partners, patients became less prone to take over common duties and activities despite being in a better and more stable motor state. Potential conflicts and problems in role allocation in relationships following DBS need to be addressed in patients care.

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## 1. Introduction

Only few treatment options in neurology have a similar marked and often prompt impact on disease and related quality of life like deep brain stimulation in the subthalamic nucleus (STN-DBS) of patients with Parkinson's disease (PD). Notably, the therapeutic effect is usually multidimensional, with positive effects upon tremor, akinesia, motor fluctuations, reduced medication intake and consecutively independency and quality of life, yet with more mixed effects upon a variety of other functions such as gait, speech, cognition, motivation, or impulse control [1].

Still, a cesura like subthalamic DBS does not only affect the patients themselves, but also their caregivers, and particularly their partners [2]. Caregiver strain is experienced across all stages of PD and accumulates significantly as the disease progresses [3]. Soulas and colleagues found that the partners' experience of DBS outcomes is variable and complex, and

that changes in psychological status and quality of life of partners did not correlate with changes in the patients' motor status or quality of life [4]. After 18–24 months on STN-DBS, Schüpbach and colleagues found that activities of daily living and quality of life are still positively rated by patients, whereas social adjustment did not improve, with marital conflicts in 17 of 24 examined couples [5]. Others explored quality of life in partners one year after STN-DBS and found that over 50% of 25 partners rated their subjective well-being as negative [6], amongst other reasons because of more conflicts in their relationship with patients.

Although few studies focused on the partners' perspective, to our knowledge no study has examined partnership satisfaction and dyadic coping after STN-DBS, as stress and coping in couples are increasingly recognized as dyadic phenomena [7]. Dyadic coping is a systemic conceptualization of the processes partners use to cope with stressors, such as stress communication, individual strategies to assist the other partner in coping with stress, and partners' strategies to cope together. It aims to maintain or restore individual and dyadic homeostasis, both partners' well-being, and the couple's functioning [8]. Dyadic coping strongly predicts relationship satisfaction regardless of gender, age, relationship length, education level, and nationality [9]. Because the

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impact of DBS on a partner cannot be fully understood independent of a given relationship, we therefore aim at emphasizing caregivers' coping with the changes after DBS, by shifting from the individual to the dyadic level. As such, mutual coping processes in couples with external stressors such as the diagnosis of a malignant disease or the significant and multidimensional impact of treatments such as DBS are covered by the concept of dyadic coping.

## 2. Subjects and methods

We collected data from partners (if present) of all consecutive PD patients who have been treated with STN-DBS in the Movement Disorders Unit of the Department of Neurology in the University Hospital Zurich between 2014 and 2016, 9–27 months after operation. Ethics approval was obtained from the Committee of the Kantonale Ethikkommission Zürich and complies with the Helsinki Declaration of 1975, as revised in 2000. In a clinical setting, as for this study, we assess motor outcomes during OFF and best medical ON condition before DBS, and during medication and stimulation ON condition after DBS, as we aim to reduce burden to patients and therefore do not regularly perform medication washout after DBS. We sent fully anonymous questionnaires by letter post to the partners of 70 patients. In order to reduce the social desirability bias and given the relatively small sample included in this study, we collected no further data of the patients and their partners except for duration of the partnership and gender. Fifty-six of 70 partners participated in the study and sent fully completed questionnaires back. We did not hear back from 9 partners, and 5 questionnaires were insufficiently completed.

The questionnaires assessed relationship satisfaction, dyadic coping, and changes in specific daily living activities and relationship-associated duties after STN-DBS. We applied a modified short version of the standardized Partnerschaftsfragebogen (PFB-K; Partnership Questionnaire, in German) to measure relationship satisfaction [10]. It consists of three subscales (conflict behavior, tenderness and togetherness/communication), each containing three items with an adapted Likert scale comparing current to pre-DBS state (−2: much less pronounced, −1: less pronounced, 0: unchanged, +1: more pronounced, +2: much more pronounced). In addition, we assessed the change in overall relationship satisfaction after DBS with a similar 5-point Likert scale. To assess dyadic coping, we applied a modified short version of the validated Dyadic Coping Inventory [11]. This inventory assesses four dimensions: (a) communication of stress within the relationship, (b) supportive dyadic coping (understanding and being interested in the stress of the partner), (c) delegated dyadic coping (actively helping and supporting the partner to reduce stress burden), and (d) shared dyadic coping (a shared approach to solve the problem and finding solutions) [11]. Changes after DBS were rated with an adapted 5-point-Likert Scale (ranging from −2 to 2, as introduced above). The two questionnaires have been introduced and validated in German language in healthy subjects, but have so far neither been used nor validated in Parkinson patients [10,11].

Additional questions assessed the frequency of activities performed by both the partner and the patient, from the partners' perspective, including dealing with financial affairs, shopping, performing hobbies, meeting friends, care for the partner, and arranging common activities. Rating was performed with a 5-point-Likert Scale (compared to before DBS: −2: much less often, −1: less often, 0: unchanged, +1: more often, +2: much more often). We assessed satisfaction with role allocation within the relationship after surgery using a 5-point-Likert-Scale (0 = very happy up to 4 = very unhappy), and finally asked whether the partners felt that there was a need for more professional support for the partnership after surgery, using a dichotomous question (yes/no).

## 3. Results

Of the 56 responding partners, 57% were female. Mean duration of relationship was 42 years (range 7–64 years). The majority of patients (61%) suffered from a non-tremor-dominant PD, with a mean improvement on the MDS-UPDRS III in best medication ON condition of 26% (range 12–75) and a reduction in levodopa equivalent dose of 64% (range 18–100). The mean

interval of the assessment to surgery was 17 months (range 9–29). The length of this interval was not associated with any of the relationship satisfaction or dyadic coping outcomes.

Regarding overall relationship satisfaction after surgery, 40% of partners reported to be happier with their relationship, 14% were less happy, and 46% judged partnership as unchanged (Fig. 1). Proneness to conflict behavior was increased in 39% and reduced in 15%, yet tenderness was more experienced in 36% and less in 26%, and communication behavior was improved in 43%, and worsened in 26%. In respect to dyadic coping and from the partners' perspective, communication of stress was improved in 50% of relationship (worsened in 17%), supportive dyadic coping in 43% (worsened in 25%), delegated dyadic coping in 53% (worsened in 29%), and shared dyadic coping in 46% (worsened in 20%) (Fig. 1).

The partners indicated that DBS patients were performing less activities and socialize less than before surgery, whereas partners take over more of the duties in the household (Fig. 2). This is the case for all examined dimensions, i.e. general household activities, performing hobbies and meeting friends, arranging common activities within the partnership, take over responsibilities in budgeting and finances, and shopping. Lastly, 27% of the partners expressed the need for professional support for the partnership following DBS.

## 4. Discussion

The goal of this pilot study was to specifically investigate the partners' perspective on possible changes in partnership following STN-DBS in Parkinson patients, to (1) increase the awareness of treating DBS specialists, and to (2) stimulate further studies offering deeper insights into this complex effect of DBS. A majority of partners reported improved dyadic coping and overall quality of relationship after DBS, yet proneness to conflicts was enhanced and treated patients engaged less in relationship duties and activities of daily living.

Apparently, quality of life ratings significantly differ between patients and their partners. Others have shown that partners rated quality of life worse than patients [6]. In the only study on the relationship between partners and DBS, a shift from a uniting expressed main theme 'living in partnership' prior to surgery to a postoperative 'sense of freedom embracing life' and a 'challenge of changes and constraint' was found [2].

Beyond the individual coping of patients and partners, couples cope with the disease and the therapeutic cesura by DBS in a dyadic way. Hence, it is crucial to also focus on the dyadic level, which has not been done in DBS-patients so far. Bodenmann defined 'dyadic stress' implying that a stressful event or encounter always concerns both partners either directly, if both partners are confronted by the same stressor or when the stress originates inside the relationship, or indirectly when the stress of one partner spills over to the relationship and affects both partners [8].

Here we found that positive dyadic coping efforts improved in about 50% of DBS partners and worsened in a minority, including understanding and being interested in the stress of the partner, actively helping and supporting the partner to reduce stress burden, and trying to find a shared approach to solve the problem and finding solutions (referred to supportive, delegated and shared dyadic coping). Thus, dysfunctional dyadic coping - at least from the partners' perspective - does not appear to be the leading cause for possible partners' dissatisfaction following DBS.

On the other hand, the partners reported that their level of activity in common duties (e.g. financial affairs, housekeeping, shopping, mutual activities, transportation) increased after DBS and patients became rather less active. This distinct outcome (Fig. 2) seems paradoxical, but could potentially be explained by an increased level of apathy in a significant portion of DBS patients, which itself is occasionally seen after reduction of dopaminergic treatment following STN-DBS. This changed allocation of roles might cause conflicts in a relationship, but partners indicated that stress definition and stress communication as well as partnership satisfaction improved. The reason for this somewhat surprising result remains elusive. Stress is a risk factor for couples as it predicts poor relationship functioning and divorce [9]. It is conceivable that a decreased overall stress level due to the improvement of motor functioning and higher stability of

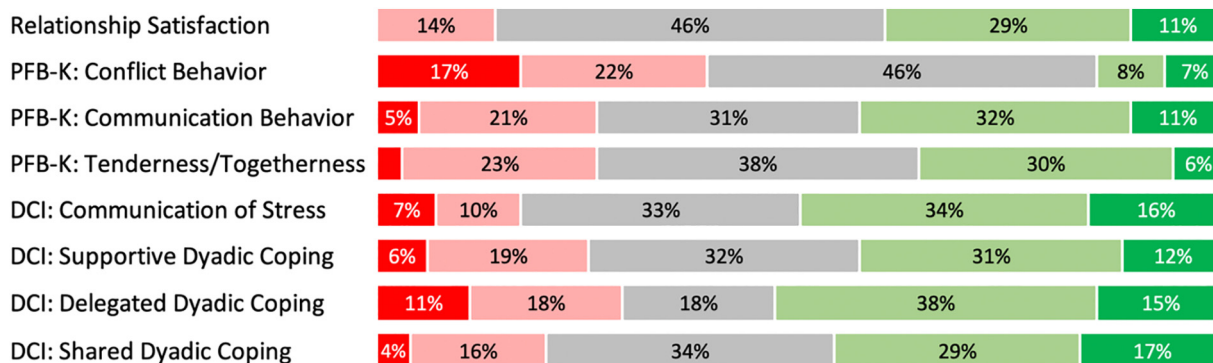


Fig. 1. Overall satisfaction with the relationship; specific relationship-associated topics, assessed with PFB-K, the Partnerschaftsfragebogen-Kurzfassung (short version of the German Partnership Questionnaire), and dyadic coping, assessed with an adapted Dyadic Coping Inventory. All values solely from partners' perspectives. In light red mild deterioration, in dark red severe deterioration; in gray unchanged values, in light green mild improvement, in dark green strong improvement.

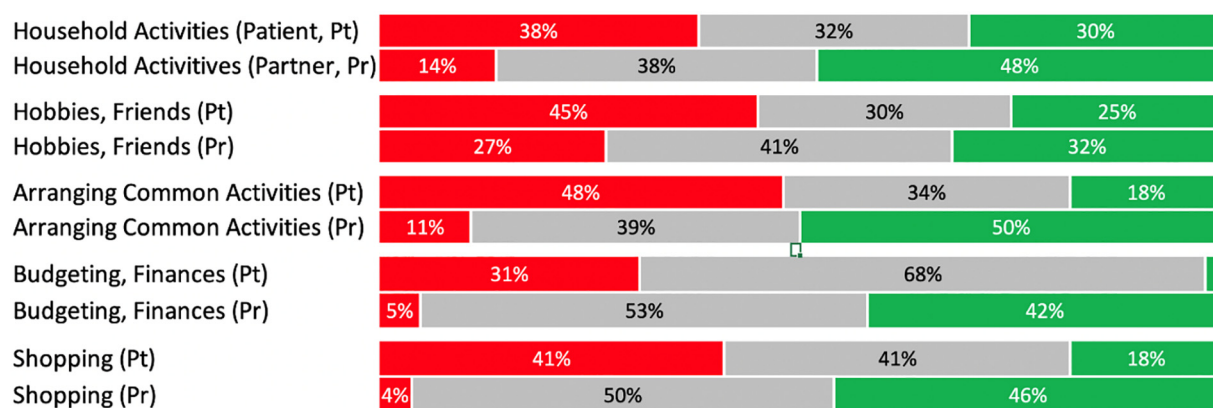


Fig. 2. Taking over of partnership-related duties and activities by either the patient (Pt) or the partner (Pr). All values solely from partners' perspectives. Red bars indicate less activities than before DBS, gray bars indicate no changes in taking over of duties and activities, and green bars indicate that Pt or Pr became more engaged in the respective fields after DBS.

motor states which allows for better planning of common activities explains the reported improvement of the partnership in general, outshining changes in relationship roles.

### 5. Limitations

This study, designed as a purely qualitative and anonymous pilot study, has several limitations. First of all, due to small sample size, we abstained from performing inferential statistical approaches. Second, we focused on partners' views and assessed outcomes only postoperatively and with different inter-individual intervals to surgery. Third, due to the anonymous questionnaire strategy to reduce the social desirability bias, we did not address possible independent variables such as depression, apathy, procedure-related stress, or quality of life in this explorative study. Such parameters, however, are potentially important co-variables, as severity of non-motor signs, particularly patients' and caregivers' mood, and motor disease severity are critical determinants of patient and caregiver burden [12]. For instance, it is conceivable that apathy, a frequent outcome after DBS with consecutive reduction of dopaminergic medication, might at least in part explain the low drive of patients to engage in common activities [13]. Fourth, a certain selection bias cannot be excluded owing to the fact that 20% of the contacted partners did not respond to the invitation to participate. Finally, we are aware that the best motor outcome parameter after DBS would include a full UPDRS III in medication OFF condition and an objective daily assessment of OFF, ON and dyskinesia times. However, the

first assessment is often a burden for patients, and for the second assessment, there is no sufficient method (such as validated wearables) available.

### 6. Conclusion

We documented an overall improvement or at least not change of relationships after STN-DBS from the perspective of the patients' partners, yet patients seem to be less involved in relationship activities and duties following surgery. A considerable fraction of partners expressed the wish for more contextual relationship support after DBS surgery.

### Contributions

- (1. Research project: (A) Conception; (B) Organization; (C) Execution.
- 2. Manuscript Preparation: (A) Writing of the first draft; (B) Review and Critique).
- H.B.V.: 1 A, B, C – 2 A.
- G.B.: 1 A – 2 B.
- J.S.: 1 B, C – 2 B.
- D.W.: 1 A – 2 B.
- C.I.: 1 C – 2 B.
- C.R.B.: 1 A, B – 2 B.

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## Declaration of competing interest

Dr. Baumann-Vogel reports no disclosures.

Dr. Bodenmann reports no disclosures.

Mr. Schmid reports no disclosures.

Dr. Waldvogel reports no disclosures.

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