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An empirical study on the application of the burden of normality to patients undergoing deep brain stimulation for Parkinson's disease

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Abstract

Aims: Psychosocial maladjustment frequently occurs following deep brain stimulation (DBS) in patients with Parkinson's disease (PD). This paper aimed at investigating, for the first time with first-hand data, whether the burden of normality model (BoN) could adequately describe the manifestations and underlying dynamics of psychosocial maladjustment after DBS for PD.

Methods: In a mixed experimental design including quantitative and qualitative data, 19 patients treated with DBS for PD were interviewed on their post-DBS lived experience with the Austin CEP Interview, a semi-structured instrument addressing all elements of the BoN. In addition, health-related quality of life was measured before surgery and at the time of interview with the Medical Outcome Study 36-Item Short Form Health Survey ~~(SF-36)~~.

Results: All patients experienced clinical manifestations of psychosocial maladjustment as described in the BoN. Yet, there was a great interindividual heterogeneity in descriptions of the perceived course of the post-DBS life. Experiencing various types of symptoms was nevertheless associated with the perception of a less satisfying life after surgery. In addition, most patients had realistic expectations on the surgical outcome, and those with unrealistic or mixed expectations did not differ from other patients in terms of psychosocial maladjustment.

Conclusions: The BoN accurately conceptualizes psychosocial maladjustment experienced by DBS patients with PD. However, no relationship was established between the nature of pre-operative expectations and BoN symptoms.

Key words: Burden of normality; Deep brain stimulation; Expectations; Parkinson's disease; Rehabilitation; Consultation-liaison psychiatry

Introduction [A]

In chronic diseases, psychosocial adjustment refers to the patients' capability of achieving healthy rebalancing by adopting coping strategies adapted to their altered medical condition (1). Somewhat counterintuitively at first glance, problems of psychosocial adjustment (hereinafter referred as "psychosocial maladjustment") may also occur in response to a *positive* outcome like a new treatment alleviating symptoms. This phenomenon has been well documented in various conditions such as epilepsy surgery (2–5), medication-treated chronic narcolepsy (6), cardiac surgery (7), or Parkinson's disease (PD) treated with deep brain stimulation (DBS) (8–10).

In the case of PD, patients not responding adequately to dopaminergic medication may be proposed to undergo DBS, a stereotactic surgical procedure in which electrodes are implanted into specific brain nuclei to reduce motor symptoms (11). Compared to patients only treated with medication, those undergoing DBS significantly improve motor symptoms, decrease medication intake, and ameliorate mental health (12). However, many patients successfully treated with DBS for PD (PD-DBS) also experience problems related to their identity, emotions, couple and social relationships, or activities of daily living (10,13–16) with suicides documented in worst-case scenarios (17–19). Psychosocial maladjustment has been noticed up to two years after surgery, suggesting that it differs from a mere DBS adaptation issue (8,9).

Despite this growing evidence, no theoretical model has been used yet to account for the dynamics of psychosocial maladjustment in the PD-DBS context. Various authors have nevertheless suggested that the burden of normality model (2,20), initially designed to conceptualize psychosocial maladjustment in patients with epilepsy receiving antero-temporal lobectomy, could be applied to PD-DBS (21–24).

As summarized in Figure 1, the burden of normality model (BoN) is structured around three levels. It defines precursory conditions necessary for potential occurrence of psychosocial maladjustment: the presence of a chronic disease, which is disabling and for which a treatment dramatically alleviating symptoms is available (level 1); It posits that pre-operative expectations regarding life after treatment are pivotal in the psychosocial adaptation process (level 2); It lists a range of possible manifestations of psychosocial maladjustment classified into four categories, specifically psychological, behavioral, affective and sociological (level 3). The BoN has been supported as a relevant reading grid to understand psychosocial maladjustment in patients suffering from a variety of chronic diseases and receiving different kinds of treatment (3–7,25–28).

[Insert Figure 1 about here]

To date, no study has attempted to test empirically the BoN within the context of PD-DBS, making impossible to draw any definitive conclusion on its applicability. The present study ~~was designed~~ aimed to remedy this situation by exploring whether the BoN could adequately predict and describe psychosocial adjustment after PD-DBS. To this end, ~~analyzing~~ data and testimonies from patients regarding their lived experience of post-DBS life were analyzed as follows: ~~The three constitutive levels of the BoN were explored as follows:~~

1. *Life perception after DBS*: Is patients' perception of a life better after DBS than before? More specifically, do patients describe a three-phase post-operative trajectory characterized by an initial period of euphoria occurring immediately after DBS, followed by a period of adjustment to new life demands, and finally a period of acceptance of life with DBS (29) ?
2. *Expectations*: Do patients with pre-operative unrealistic expectations experience more manifestations of psychosocial maladjustment than those with realistic expectations?

3. *BoN syndrome*: Do patients identify manifestations of psychosocial maladjustment that can be classified into psychological, behavioral, affective and sociological categories?

Methods [A]

Participants [B]

The study was proposed to 26 patients diagnosed with PD and treated with DBS at the XXX University Hospitals, XXX, between April 23, 2013 and May 18, 2015. Five patients refused to participate in the study, one living abroad was not able to travel to XXX and one was excluded due to significant impairment of her cognitive abilities. Thus, a total of 19 individuals were incorporated into the study protocol.

As summarized in Table 1, participants were aged 58.8 ± 10.1 years old and had been diagnosed with PD for 11.3 ± 3.5 years. Most of them were men, in a couple relationship, and professionally inactive at study inclusion. In addition, every participant had a score ≥ 130 at the Dementia Rating Scale (DRS) (30) before surgery as requested by the DBS protocol inclusion criteria of the neurology unit.

[Insert Table 1 about here]

Procedure [B]

Participants were initially asked to fill out a quality of life questionnaire, the Medical Outcome Study 36-Item Short Form Health Survey (SF-36), two weeks before undergoing DBS. After surgery, participants were invited retrospectively to answer questions regarding their DBS experience from a semi-structured interview (Austin CEP Interview adapted to PD-DBS) and completed the SF-36 again. These interviews took place 24.5 ± 7.7 months post-operatively so that patients should have had enough time to adjust to life under stimulation, a process that may take 12 months (29). Similarly to previous studies conducted with the BoN

framework (6,27), patients were encouraged to be interviewed along with their partner (i.e., in the same room for a common interview), viewed as capable of testifying of possible changes following surgery in the patient's everyday life. A senior clinical psychologist met participants between January 27 and June 8, 2016 in their own homes or in a quiet room at the XXX University Hospitals. The study was undertaken in accordance with the regulations of the XXX ethics committee on research (registration number: 14-182).

Instruments [B]

The *Austin CEP Interview* (2,4) is a semi-structured instrument based on the BoN investigating psychosocial maladjustment after a medical treatment. This tool, initially developed in the context of antero-temporal surgery for epilepsy, features in its original version questions to be responded before and after treatment. Respondents are asked about their medical and family history, impressions about treatment, pre-operative expectations, family dynamics, and post-treatment adjustment. For the specific needs of the present study, we adapted the instrument so that it corresponds to the PD-DBS situation and its retrospective design. An example of questions that were asked, presence of excessive activity (a behavioral manifestation of psychosocial maladjustment) was assessed with the following inquiry: "Have you been more active after DBS surgery ?"

Next, we created dummy variables for each BoN manifestation (0 = absent, 1 = present) in order to constitute a BoN score similarly to previous work (27), see Table 2. Pre-operative expectations were classified as "realistic" (i.e., centered on symptom and medication improvement), "unrealistic" (i.e., centered on improvement unrelated to treatment, such as psychological mood), and "mixed" (i.e., including concomitant realistic and unrealistic elements). Patients' discourse was analyzed independently by ~~Interrater agreement between~~ a senior clinical psychologist and a senior psychiatrist, each attributing a score when

manifestations/expectations were identified. Interrater agreement was a prerequisite for final coding: in case of disagreement, discussion was pursued until consensus was reached.

[Insert Table 2 about here]

During the administration of the Austin CEP Interview, we presented patients with a scale picturing a timeline from the day of DBS surgery and the day of the interview. We asked them to draw a line that would be representative of the course of their post-DBS experience, and gathered their comments and impressions about it.

By the same token, the general perception of post-DBS life was assessed with five 7-point Likert-type questions (Figure 2). Each could be answered negatively (-3, -2 or -1), neutrally (0), or positively (+1, +2, +3) with extreme ratings corresponding to polarized responses.

[Insert Figure 2 about here]

In addition, physical and mental aspects of quality of life were assessed with the SF-36 (31). This self-administered questionnaire comprises 36 items designed as Likert scales, which are representative of 2 subscales of physical (PCS) and mental (MCS) quality of life. PCS and MCS scores are computed in pondering scores from other subscales (not considered in the present study), with high scores indicating high quality of life.

~~Along with qualitative analysis of the Austin CEP Interview, quantitative analyses were carried out and consisted in *t* tests and linear regression equations. A threshold of .05 was adopted for all statistical analyses, which were carried out with Statistica version 13.0~~

~~(StatsSoft Inc., Tulsa, OK, USA).~~

Statistical analyses [B]

This study was constructed with a mixed experimental design including quantitative and qualitative data. Although mixed methods research is time consuming as two different types of data must be analyzed, it provides advantages over exclusive qualitative or quantitative methodology in increasing validity of findings, enhancing the global comprehension of the investigated topic or fueling the creativity of researchers for future studies (32). Life perception after DBS was explored using descriptive and inferential (multiple linear regressions) analyses; pre-operative expectations were investigated through discourse analysis and *t*-tests. Finally, BoN manifestations were assessed with descriptive statistics and discourse analysis. Preliminary analyses did not reveal violation of normality assumptions in the data set. A threshold of .05 was adopted for all inferential analyses, which were carried out with Statistica version 13.0 (StatsSoft Inc., Tulsa, OK, USA).

Results [A]

Life perception after DBS [B]

All patients reported a positive life perception after DBS, suggesting that surgery has allowed a "dramatic cure" effect similar to that described in the BoN. To the questions "Are you happy with DBS surgery outcome?" (mean: 2.3 ± 0.8, range: 1-3) and "Do you think that DBS surgery was successful?" (mean: 2.5 ± 0.7, range: 1-3), every patient attributed a positive rating suggesting that they unanimously acknowledged the favorable impact of DBS on symptoms and secondary effects of PD. In line with this, most participants would "do surgery again" (mean: 2.4 ± 0.9, range: 0-3) and "recommend surgery to somebody else" (mean: 2.3 ± 1.0, range: 0-3). In other words, no participant felt dissatisfied regarding DBS

surgery, the worst rating corresponding to a "neither positive nor negative" opinion.

Next, we built a multiple linear regression equation with scores at the five questions illustrating life perception after DBS (see Figure 2) as predictors of the BoN score. The question "Are you happy with your post-DBS life?" was the only significantly predictor of the BoN score, b = -1.304, t = -2.604, p = .022, with a model accounting for 21.6% of the variance (adjusted R^2). Interestingly, this question received a scoring worse (mean: 1.8 ± 1.0, range: 0-3) than other questions more directly related to the surgical procedure.

Similarly, we conducted multiple linear regressions with scores at the five questions as predictors of PCS, respectively MCS. The only significant association was Question 3 ("Would you do DBS surgery again?") positively predicting post-DBS physical quality of life, b = 5.641, t = 2.837, p = .020, with a model accounting for 21.2% of the variance (adjusted R^2).

Trajectories. [C] The course of the post-DBS life was perceived with great heterogeneity among patients asked to draw a timeline supposed to be representative of their DBS experience. Four participants (21.1%) reported the three distinct periods of euphoria, adjustment and acceptance observed in previous work (29). However, such a pattern did not clearly emerge in most patients. Six of them (31.6%) pictured a continuous line and three (15.8%) underscored feelings of discontinuity mainly characterized by *"ups and downs"*. In addition, not all individuals described distinct phases.

Although most patients (11/19 or 57.9%) experienced the initial weeks/months following DBS positively, four participants on the contrary reported strong difficulties suggesting that maladjustment can sometimes occur without delay. Difficulties to find adequate stimulation parameters were regularly pointed out as a significant problem of the post-DBS life, and some participants had the impression that PD was eventually taking over

despite those adjustments.

Pre-operative expectations [B]

Most participants (15/19, 78.9%) formulated realistic expectations regarding DBS outcome, characterized by alleviation of motor symptoms, diminution of medication intake, and reduction of medication-related secondary effects. These expectations mainly originated in the *"clear explanation provided by the medical staff"* regarding the benefits and limitations of DBS, as Patient 3 said (46 years old, male).

In contrast, three patients had unrealistic and magical expectations. Patient 7 (60 years old, male) was *"persuaded that he would more or less return to the state before PD"* while Patient 8 (65 years old, male) *"hoped that DBS would totally cure the disease"*. This latter patient admitted that doctors warned him about the absence of curative treatment for PD; yet he *"secretly thought that [he] would heal"*. Similarly, Patient 19 (61 years old, female) had secret hopes that surgery would heal PD, suppress all medication and *"take her back to the life she had before"*. In addition, Patient 2 (51 years old, female) had mixed expectations as, on the one hand, she realistically expected an improvement of disease- or medication-specific symptoms but, on the other hand, she expected *"a better experience of the post-DBS life despite admitting that the information given by doctors was very clear"*.

We separated participants with realistic expectations (n = 15) from those with unrealistic/mixed expectations (n = 4) and conducted descriptive and inferential analyses. As summarized in Table 3, descriptive statistics suggested a global trend with those with unrealistic/mixed expectations having higher quality of life scores than those with realistic expectations before but not after surgery. In line with this, post-surgical life perception and BoN scores were worse for participants with unrealistic/mixed expectations than for other participants. Nevertheless, these descriptive observations did not find inferential support as

the two groups did not significantly differ on any of these variables according to *t*-tests. Similarly, having unrealistic/mixed expectations did not significantly predict either BoN score or quality of life (PCS and MCS).

[Insert Table 3 about here]

BoN syndrome [B]

Psychological manifestations. **[C]** Most patients (11/19, 57.2%) experienced negative psychological manifestations during the course of the post-DBS period. Five of them (26.3%) showed tendencies to prove that they had recovered a kind of "normality", which resulted in ~~unapproved~~ inappropriate behaviors—such as Patient 15 (48 years old, male) who renovated during two weeks his entire house on his own only a few days after hospital discharge—or rejection of the sick status notably illustrated by refusal to take medication.

Four patients (21%) felt nostalgia regarding aspects of the pre-DBS life, regretting a loss in creativity or increased expectations formulated by others. In line with this, three participants (15.8%) expressed bitterness toward PD, which had *"broken down"* Patient 18 (61 years old, male) or *"ruined the retirement plans"* of Patient 16 (69 years old, male). Finally, six patients (31.6%) testified of difficulties to deal with their personal identity after DBS. Four of them were ~~notably~~ uncomfortable regarding the fact of living with the DBS equipment, such as Patient 6 who said that she felt *"like a robot dependent on iron wires to move"*. The other two patients complained of self-image alteration associated with diminished intellectual abilities and weight gain.

Behavioral manifestations. [C] Fifteen patients (78.9%) had experienced problematic behavioral changes since they underwent DBS surgery. ~~Four of them (21.0%) acknowledged excessive behaviors, such as Patient 11 (72 years old, female) who decided to repaint her house and buy new furniture on her own, *"something that [she] would have never done*~~

~~*before".* On the other hand, fifteen patients (78.9%)~~ All reported that they were globally less active than before surgery. Some participants lacked self-confidence in being autonomous for reasons such as the fear to be alone, or impressions of impairing cognitive or motor abilities. Thus, Patient 17 (61 years old, male) did not dare to go hunting anymore *"because [he] feared for the safety of the stimulator"*. In the same vein, others felt that symptoms of PD remained significant enough to prevent them to drive, go back to work, or go out for leisure or physical activities. Some participants felt apathetic with lack of motivation and energy, as illustrated by Patient 1 (61 years old, female) who said that she enjoyed gardening less than before *"because vegetables are cheap in the supermarket anyway"* and reduced her painting activities *"after [she] was turned down to participate to an exhibition"*.

In addition, four of them (21.0%) acknowledged concomitant excessive behaviors, which were either transient—such as Patient 11 (72 years old, female) who decided to repaint her house and buy new furniture on her own, *"something that [she] would have never done before"*—or associated with a return to daily activities experienced as tiring.

Affective manifestations. [C] Almost all patients (18/19, 94.7%) testified of significant affective changes during the post-DBS period. Six participants (31.6%) experienced euphoria in the weeks or months directly following surgery. More than half (10/19, 52.6%) underwent a period of increased depressive mood, which was long-lasting in five cases and transient in five others. Additional affective alterations were identified, for instance increased anxiety (5/19, 26.3%), irritability (6/19, 31.6%), and sensibility/emotiveness (5/19, 26.3%).

Sociological manifestations. [C] Perception of couple relationship throughout the DBS process was generally stable as only two participants (10.5%) reported negative changes. For both, redefinition of roles seemed to have stirred up strains, as illustrated by Patient 1:

"My husband has to take care of me, do household tasks, run errands and prepare meals. He definitely doesn't have the kind of retirement he wanted to and doesn't hesitate to point this out to me." Similarly, five patients (26.3%) observed negative alterations in social and familial relationships, associated with distancing or non-empathetic friends or further deterioration of already complicated relationships. Finally, eight patients (42.1%) endorsed new life projects and activities following DBS, which were all described as positive.

Discussion [A]

This study is the first one, to our knowledge, to test empirically an application of the BoN in PD patients treated with DBS. Our findings suggest that patients acknowledged the beneficial effects of DBS and had a positive experience of post-surgical life; yet, ~~they~~ all of them also reported having experienced ~~various and numerous~~ symptoms of psychosocial maladjustment. This was notably pregnant on the affective (94.7%) and behavioral (78.9%) levels. Confirming the impact of psychosocial manifestations on life perception, the degree of happiness regarding post-DBS life negatively predicted the number of BoN manifestations.

The temporal evolution of life perception after PD-DBS strongly differed between patients, and all did not achieve acceptance of their new life condition. Similarly, manifestations of psychosocial adjustment were not always associated with negative outcomes, as notably illustrated by redefinition of life goals or new vocational projects. In this regard, the use of the Austin CEP Interview was not restricted to symptom identification. Considering these findings, the BoN was useful to identify various kinds of psychosocial adjustment difficulties in PD-DBS patients. This suggests that the model is applicable to PD-DBS even though specific attributes of PD (e.g., no cure available) should be borne in mind when interpreting data, as pointed out elsewhere (24).

As hypothesized in the BoN, our patients reported a range of clinical manifestations

occurring in their post-DBS experience, which raises different considerations. First, despite several testimonies of changes in self-perception notably associated with the implementation of the electric device, no patient felt that his/her identity had been fundamentally altered by DBS as identity-related complaints were either transient or not associated with severe distress. This is an important finding as risks of identity changes after DBS have been pointed out as a potential ethical issue (33,34) despite the lack of empirical evidence (35). Second, many of our patients pointed out a decrease of behavioral activities, which was unsurprising as presence of apathy and reduction of impulsive behaviors up to three years post-operatively have been well identified in the literature (36–39) while a recent meta-analysis confirmed the deterioration of apathetic behaviors following surgery (40). The causes underlying these post-DBS shirking behaviors are yet to be specified and could be multifactorial, such as the drastic medication decrease in DBS candidates accustomed to take high daily dosages of dopaminergic drugs (41), the consequences of redefinition of life priorities (42), or the lack of self-confidence regarding the DBS device and its manipulation (29,42–44). Third, we have observed a high incidence of mood alteration, which somewhat contrasts with the numerous studies underscoring global mood improvement following DBS (24). This suggests that transient depressive or anxiety feelings, possibly triggered by psychosocial adjustment difficulties or an external life event, may co-occur with more general mood improvement. In addition, there may be disagreements between patients and caregivers/health professionals regarding the valence of emotions, notably during the “honeymoon” period often occurring directly after surgery. Euphoric mood has been regularly reported in a positive way by patients (27,29) and was notably illustrated in our study with the testimonies of Patients 11 and 15 mentioned above; yet, this emotional state may also induce fatigue and non-compliance with medication. This shows that BoN symptoms may overlap the discrete categories proposed in the model. Fourth, by rating the question “Are you happy with your

post-DBS life?" less positively than inquiries directly addressing the perception of DBS outcome, participants implied that surgery success is not a necessarily synonymous of life satisfaction. This finding is in line with previous research suggesting that psychosocial maladjustment can occur despite perceived treatment success (4,8,9).

According to the BoN, presence of unrealistic expectations is predictive of post-treatment psychosocial maladjustment. This association has been qualitatively (29) and statistically demonstrated (45,46). Our findings showed that patients with unrealistic expectations experience psychosocial maladjustment, but there was no significant difference in terms of BoN symptoms with patients having endorsed realistic expectations. The rate of patients with such unrealistic or mixed thoughts in our sample was low (21.1% or 4/19), which is a possible explanation for this result. This low rate is probably due to the specific emphasis on expectations routinely set up in our hospital at the pre-DBS psychiatric evaluation.

The testimonies of these patients nonetheless provided information on the nature of unrealistic expectations, suggesting that the latter may be comprised of at least two components: a *cognitive* facet—for example, intellectually acknowledging the science-based medical discourse held by health professionals—, and an *emotional* facet—for example, hopes that treatment will lead to an extraordinarily positive outcome. In our sample, the three individuals with unrealistic expectations were successful in concealing these secret hopes to the medical staff, which is strongly reminiscent of the "hidden agendas" of patients or significant others regarding post-surgery life pointed out in other BoN research (2,3,6). Interestingly, two of these three patients associated well-being improvement, post-operatively, with awareness of the unrealistic feature of their expectations. Patient 8 observed that he started feeling better when he *"became aware that there would be no total cure [for Parkinson's disease]"*. Three years after surgery, he still had *"some hope"* but endorsed a

more realistic stance notably toward medication that he *"would always have to comply with"*. By the same token, Patient 7 described a very difficult post-operative period with emotional lability and oversensitivity, which significantly improved following a clinical visit to the hospital where he was tested under the four combined conditions of on/off DBS and medication—a test scheduled at 12 months post-surgery in the clinical routine. This experience helped him to *"become aware of the surgical benefits"*, facilitating the transition toward a greater acceptance of his post-DBS condition. Thus, the emotional component of expectations might be associated with disappointment regarding post-treatment outcomes, and should constitute a prime target in the pre-treatment clinical work.

In line with this, a potential research axis on expectations could consist in investigating the relationship between presence of unrealistic expectations and preoperative perception of the PD degree of intrusion in patients' daily living, as patients with good acceptation of life with PD experience fewer feelings of self-estrangement after DBS (47). This suggests that formation of unrealistic expectations may be triggered by a strong desire to become free of a non-integrated chronic condition.

This study has a number of limitations that should be underlined. The experimental design was retrospective, which has advantages and disadvantages. The major advantage was that patients were likely to highlight manifestations deemed as representative of their post-operative experience. For example, identifying retrospectively an episode of impairing depressive mood suggests that the latter had an impact strong enough for patients to remember it, while assessing mood prospectively would have induced the risk to overestimate a transient episode—a "snapshot" of the current mood—significant at the time of the interview but not necessarily representative of the post-DBS experience. On the other hand, such a retrospective study lacks specificity as it relies on participants' memories. This aspect was partly accounted for by considering a post-DBS score of ≤ 123 at the DRS as exclusion

criterion as it would have suggested a possible dementia associated with PD (48). Yet, it was difficult to precisely associate a BoN manifestation with a given period of time or the occurrence of a specific adverse life event, limiting the understanding of causal and temporal dynamics of psychosocial adjustment. Prospective research is then warranted to confirm the conclusions of this study and further validate the BoN application in patients treated with DBS.

Next, in comparison to previous data (9), our participants were rather experiencing satisfaction in their couple relationships and only one participant separated from his girlfriend for reasons, according to them, unrelated to DBS. Yet a number of patients known by the medical staff to undergo difficulties in their couple relationship refused to participate to the study. This suggests that problematic couples were underrepresented in our sample. In the same vein, conducting common interviews might have discouraged participants from disclosing sensitive information (e.g., problems in the couple relationship) in the presence of the other member of the dyad. In addition, as we did not formally incorporate significant others in the clinical protocol, some partners did not understand the reason why they were asked to participate to this study, while others regretted that they had been left out from patients' care. On the other hand, all the five partners interviewed found the idea of being associated to such a clinical protocol meaningful, which suggests that including significant others from the very beginning would have been well accepted.

Finally, inferential statistical analyses should be interpreted with caution with regard to the small sample size ~~was small for a quantitative design~~ of this study, which fostered risks of type II errors ~~in statistical analyses~~. Future research making up for some of the methodological flaws of the present study, such as featuring a greater number of participants and a control group, is therefore required to validate the findings of the present work.

Conclusion [A]

~~This study showed that~~ In this study, manifestations of psychosocial maladjustment occurred ~~frequently~~ in every patient after PD-DBS and could be adequality described by the BoN. Nevertheless, DBS was unanimously praised as a valuable and effective treatment, which suggests that psychosocial adjustment can occur despite perceived medical success. The causal role of pre-operative unrealistic expectations in the development of psychosocial maladjustment could ~~nevertheless~~ not be statistically demonstrated. Further research on the BoN model in general and on pre-operative expectations is warranted to provide support to health professionals working on clinical rehabilitation.

Conflict of interest [A]

No conflict of interest has been declared by the authors.

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Table 1

Sociodemographic characteristics of participants (n = 19)

		n	%			*n*	%
Gender	Women	7	36.8	Psychotherapy at surgery	Yes	3	15.8
	Men	12	63.2		No	16	84.2
Marital status at surgery	In a relationship	14	73.7	Psychotherapy after surgery	Yes	7	36.8
	Single	5	26.3		No	12	63.2
Marital status at interview	In a relationship	12	63.2	Physical comorbidities at surgery	Yes	2	10.5
	Single	7	36.8		No	17	89.5
Partner present at interview	Yes	5	26.3	Psychiatric diagnosis at surgery	Yes	5	26.3
	No	7	36.8		No	14	73.7
	N/A	7	36.8				
Professional status at surgery	Active (full time)	3	21.1	History of psychiatric diagnosis	Yes	5	26.3
	Active (part time)	2	10.5		No	14	73.7
	Inactive	1	5.3				
	Retired	8	42.1				
	Disability insurance	5	26.3				

	Mean ± Standard deviation
Age at surgery	58.8 ± 10.1 years
Duration of Parkinson's disease at surgery	11.3 ± 3.5 years
Time between surgery and interview	24.5 ± 7.7 months

Table 2

Investigated features of psychosocial adjustment

Domain	BoN symptoms	Examples	Coding		
Expectations			Realistic	Mixed	Unrealistic
Psychological					
	Proof of normality	• Refusing to take one's medication after symptom decrease • Attempting to ignore symptom-induced limitations in doing activities of the daily living	Absent		Present
	Grief for the disease	• Missing aspects of pre-DBS life related to the ill condition (e.g., exemption from household tasks, greater presence of significant others)	Absent		Present
	Regret for lost times	• Strong resentment regarding the missed opportunities attributed to pre-DBS condition	Absent		Present
	Self-image alteration	• Difficulties to cope with DBS electronic device • Feelings of identity change	Absent		Present
Behavioral					
	Shirking behaviors	• Lack of motivation/desire to do even pleasant things • Apathy	Absent		Present
	Excessive behaviors	• Excessive activity despite warnings from the medical staff and/or significant others	Absent		Present
Affective					
	Anxious mood	• Anxiety significantly stronger than in the pre-DBS period	Absent		Present

	Depressive mood	• Depression significantly stronger than in the pre-DBS period	Absent			Present
	Euphoria	• Euphoria significantly stronger than in the pre-DBS period	Absent			Present
Sociological						
	Alteration in couple relationship	• Changes in the couple relationship dynamics (e.g., separation, divorce, significant improvement/impairment of the relationship)	Absent	Positive change	Negative change	Present
	Alteration in relationships with family or friends	• Changes in relationships with family of friends (e.g., social withdrawal)	Absent	Positive change	Negative change	Present
	New social or vocational horizons	• New career plans, vacation projects, life priorities • Starting new leisure activities	Absent			Present

Note. Coding of each BoN symptom of the psychological, behavioral, affective and sociological domains was transformed into dummy variables (absent = 0, present = 1) to constitute a BoN score. “Present” coding was attributed only if the symptom was negatively experienced (e.g., a new vocation deemed as positive would not be coded “present”). “Alteration in couple relationship” was not considered for computation of BoN score as not every participant was in a couple relationship.

Table 3

Quantitative analyses for participants with realistic vs. unrealistic pre-operative expectations

	Realistic expectations (n = 15)			Unrealistic expectations (n = 4)		
PCS-pre	37.61	±	7.61	39.68	±	6.16
PCS-post	42.65	±	5.49	35.40	±	10.21
MCS-pre	38.96	±	6.31	42.18	±	10.42
MCS-post	40.93	±	8.81	35.15	±	8.53
Life perception	11.40	±	2.92	10.76	±	3.21
BoN	3.87	±	1.81	5.76	±	2.22

Note. No between-group means significant according to *t*-tests.

Figure 1

The burden of normality model (retrieved from Wilson et al., 2001)

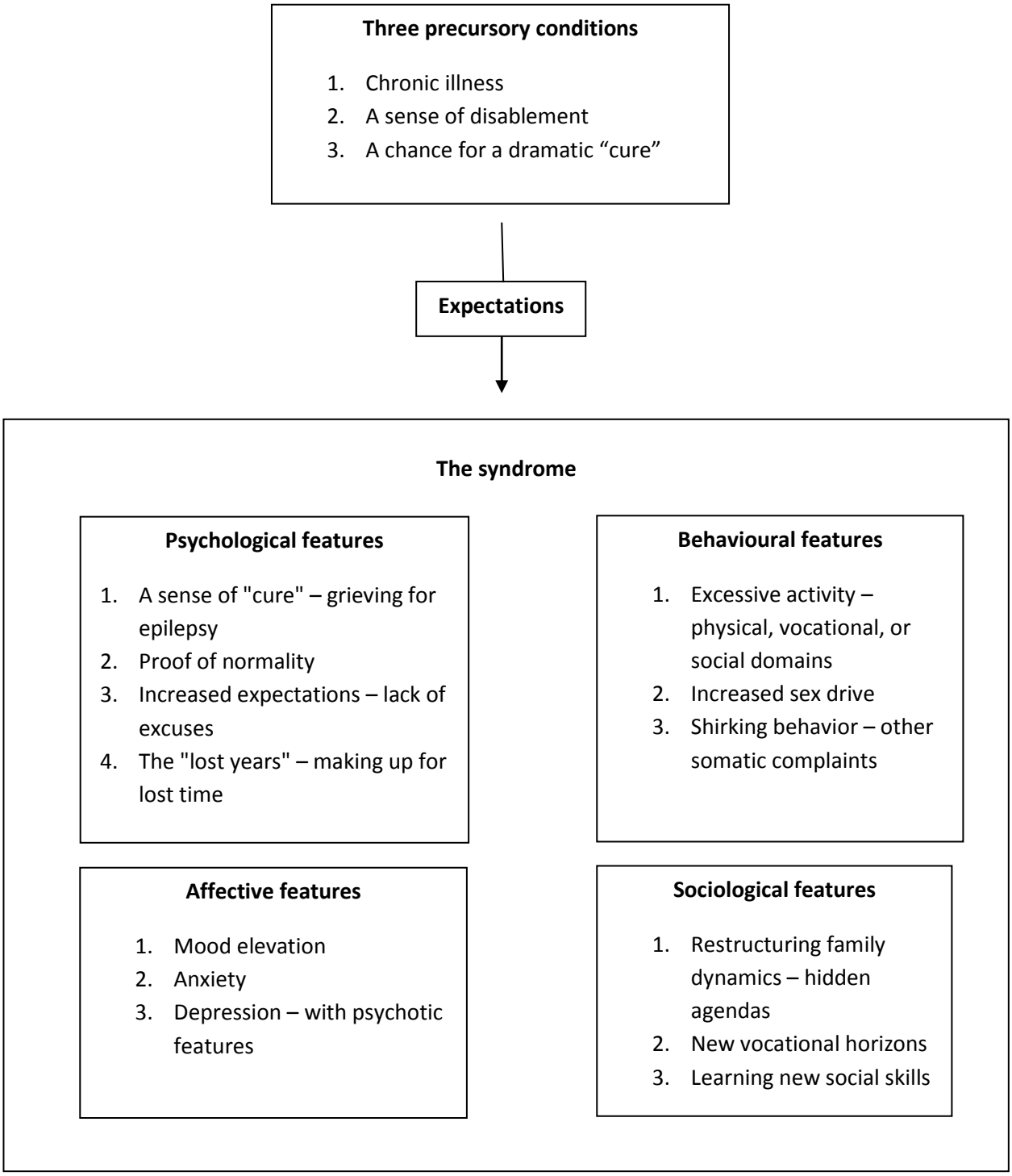

Figure 2

Perception of post-DBS life

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1. Are you happy with DBS surgery outcome?
2. Do you think that DBS surgery was successful?
3. Would you do DBS surgery again?
4. Are you happy with your post-DBS life?
5. Would you recommend DBS surgery to somebody else?