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The burden of normality as a model of psychosocial adjustment after deep brain stimulation for Parkinson's disease: A systematic investigation

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Abstract

Objective: Deep brain stimulation (DBS) has become a well-established treatment that significantly improves the motor symptoms of Parkinson's disease (PD). Patients may nevertheless experience psychosocial maladjustment after surgery, as reported by an increasing body of research. Yet, no comprehensive theoretical approach has been proposed to account for this. Initially conceptualized for postsurgical epilepsy, the burden of normality (BoN) may be viewed as a model that is potentially applicable to psychosocial maladjustment after PD-DBS. ***Method***: We systematically examined the literature to verify this assumption by scrutinizing the three theoretical levels of the BoN, specifically, precursory conditions for the applicability of the model, clinical manifestations of psychosocial maladjustment, and two mediating variables: expectations and discarding the roles associated with the pretreatment condition. ***Results***: The applicability of the BoN to PD-DBS found support for the first two of these three levels in 88 scientific articles included in the review. The number of studies that addressed the mediating variables was nevertheless insufficient to draw any definitive conclusion. The degenerative condition of PD further limits the distinction between symptoms pertaining to psychosocial maladjustment and disease progression. ***Conclusions***: Considering psychosocial maladjustment through the lens of the BoN is complementary to the traditional medical perspective of PD-DBS and illuminates the potential contribution of specialists from multiple disciplines in clinical rehabilitation.

Keywords: deep brain stimulation, Parkinson's disease, burden of normality, psychosocial adjustment, rehabilitation

Public significance statement

Deep brain stimulation efficiently alleviates motor symptoms of Parkinson's disease. Nonetheless, some patients experience intra- and interpersonal difficulties after surgery.

Through a review of the literature, we examine whether the burden of normality, a theoretical model of psychosocial adjustment, could illuminate this issue. We conclude that psychosocial adjustment plays a pivotal role in rehabilitation and advocate the implementation of multidisciplinary programs.

The burden of normality as a model of psychosocial adjustment after deep brain stimulation for Parkinson's disease: A systematic investigation

Deep brain stimulation (DBS) refers to a stereotactic neurosurgical procedure during which electrodes are implanted into strategic deep nuclei of the brain to regulate motor dysfunction in patients with various movement disorders. Delivered by an internal pulse generator, electrical current is applied to specific targets, leading to neuromodulation by mechanisms still incompletely elucidated. Introduced in the late 1980s and early 1990s for tremor, Parkinson's disease (PD), and dystonia, DBS provides many advantages over lesioning approaches, including minimizing irreversible changes to brain structures, carrying a relatively small risk of surgery-related complications, and offering the possibility to continually adjust the parameters of electrical stimulation (Larson, 2014; Miocinovic, Somayajula, Chitnis, & Vitek, 2013). As of today, over 100,000 patients have been treated with DBS worldwide and the future of the procedure looks promising (Lozano & Lipsman, 2013). Indeed, beyond movement disorders, DBS has been applied to a variety of therapy-resistant neuropsychiatric and other clinical conditions, such as Tourette syndrome, depression, or obsessive-compulsive disorder (Miocinovic et al., 2013). It is therefore anticipated that an increasing number of patients with an increasing variety of clinical profiles will be offered the possibility to undergo DBS surgery in the future (Cohen, 2012).

PD has been by far the most studied clinical condition among those considered candidates for DBS (Larson, 2014). A neurodegenerative disease without curative treatment, PD articulates around four cardinal symptoms, specifically bradykinesia, tremor, rigidity, and postural instability. However, other motor and nonmotor symptoms occur throughout the course of the disease, leading to strong differences among clinical profiles (Jankovic, 2008). Development of PD has traditionally been associated with a reduction of dopamine neurons in the substantia nigra and the presence of Lewy bodies, although research has pointed out that

other brain areas, pathways, and neuronal populations are involved as well (Halliday, Lees, & Stern, 2011). The preferential treatment for PD nevertheless remains substitutive dopaminergic therapy with levodopa and dopamine agonists, which allows patients to sustain independent living conditions with significantly improved motor symptoms. Yet, benefits of levodopa progressively decrease, leaving room for disabling side effects, including motor fluctuations and dyskinesia (Obeso, Olanow, & Nutt, 2000). Notably, dyskinesia severity was shown to covary positively with impairment of quality of life and depressive symptoms (Péchevis et al., 2005). A relationship has also been established between the use of dopamine agonists and various appetitive behaviors—also referred to as impulse control behaviors—such as pathological gambling, hypersexuality, binge eating, and compulsive shopping (Voon & Fox, 2007).

Patients with PD are also concerned with nonmotor symptoms, which are, in the long run, experienced as more disabling than motor symptoms (Hely, Morris, Reid, & Trafficante, 2005). The causal chain of nonmotor symptoms remains speculative; they are thought to appear before motor symptoms and may include sleep disturbance, depression, anxiety, apathy, psychosis, cognitive impairment, pain, constipation, and sexual and olfactory dysfunction (Chaudhuri, Healy, & Schapira, 2006; Chaudhuri, Odin, Antonini, & Martinez-Martin, 2011). In addition, patients with PD undergo major psychosocial challenges in terms of self-image, social and couple relationships, and living habits as they struggle with the consequences of the disease's progression (Caap-Ahlgren & Lannerheim, 2002; Haahr, Kirkevold, Hall, & Østergaard, 2011, 2013; Van der Bruggen & Widdershoven, 2004; Wressle, Engstrand, & Granérus, 2007).

DBS as the last option

Thus, at an advanced stage of PD, patients arguably suffer from a significant number of the motor, nonmotor, and psychosocial features as mentioned above. When limits of drug

treatment have been reached, DBS may be viewed by patients as the only remaining hope for symptom improvement (Bell, Maxwell, McAndrews, Sadikot, & Racine, 2010). DBS is usually proposed to patients who have been diagnosed with PD for 11 to 13 years (Deuschl et al., 2006; Follett et al., 2010; Okun et al., 2012; A. Williams et al., 2010), although it has also been successfully applied to patients at an earlier stage of the disease, that is, a duration of 7.5 years on average (Schüpbach et al., 2013). In PD, this surgical procedure aims to replicate the lesioning effects in the basal ganglia associated with motor improvement that have been observed in animal models (Obeso & Olanow, 2001). Patients undergoing DBS of the subthalamic nucleus or the globus pallidus internus showed larger improvement in terms of motor symptoms than did those who were treated with medication only (Cohen's d = 1.35 in the off-medication condition and d = 0.53 in the on-medication condition). Similarly, patients who underwent this procedure could reduce their medication intake as measured with levodopa-equivalent units (d = 1.36). DBS patients also spent more waking time without experiencing dyskinesia (d = 0.71). In addition, DBS had a small impact on other areas, such as mental health (d = .29) and depression (d = .30). Finally, activities of daily living were improved after surgery, with effect sizes being small in the on-medication condition (d = 0.33) but large in the off-medication condition (d = 1.05; Perestelo-Pérez et al., 2014).

In line with this, patients undergoing DBS for PD (PD-DBS) generally have higher scores for health-related quality of life in comparison with the preoperative period and with control patients (Deuschl et al., 2006; Schüpbach et al., 2013; Smeding et al., 2006; Smeding, Speelman, Huizenga, Schuurman, & Schmand, 2011; Weaver et al., 2009; A. Williams et al., 2010; Witt et al., 2008). However, a significant minority of patients, ranging from 21% to 43%, noted no benefit of quality of life during the first postoperative year (Daniels et al., 2011; Smeding et al., 2011). Moreover, physical variables showed more improvement than mental variables did, the latter tending to return to preoperative scores in the long run

(Deuschl et al., 2006; Funkiewiez et al., 2004; Kaiser, Kryspin-Exner, Brücke, Volc, & Alesch, 2008; Volkmann et al., 2009).

Psychosocial adjustment after PD-DBS

The cause of this heterogeneous outcome in mental variables observed after successful DBS is likely to be multifactorial. One possible explanation is methodological, as patients who undergo DBS constitute a specific nonrepresentative subgroup of those at an advanced stage of PD; candidates for DBS should indeed meet a number of conditions to be considered eligible (Rodriguez, Fernandez, Haq, & Okun, 2007). The cause could also be related to the degenerative nature of PD, which in most cases requires patients to continue complying with demanding treatment after surgery because DBS does not prevent symptom progression. This complicated situation may have a potential negative impact on quality of life (Volkmann et al., 2009).

One may also wonder whether DBS *itself* may be responsible for mood alteration. Indeed, case studies have shown affective and behavioral symptoms directly triggered by high-frequency stimulation, such as hypomania (Krack et al., 2001; Kulisevsky et al., 2002; Ulla et al., 2011), pathological gambling (Smeding et al., 2007), and depressive symptoms (Bejjani et al., 1999; Tommasi et al., 2008). However, these disturbances occurred mainly during the initial postoperative phase and were either completely rectified after adjustment of DBS electrical parameters and/or drug treatment (Volkmann, Daniels, & Witt, 2010), or disappeared gradually within a few months (Herzog, Reiff, et al., 2003; Romito et al., 2002). Moreover, DBS is generally followed by positive outcomes (Perestelo-Pérez et al., 2014) regardless of electrode position (Boel et al., 2016; Flores Alves Dos Santos et al., 2017).

In light of this, an increasing number of authors have interpreted post-DBS dissatisfaction from the perspective of psychosocial adjustment. Psychosocial adjustment refers to the

continuous changes that a patient with chronic illness has to make in terms of social environment and psychological state of mind (Larsen, 2015). Studies have underscored the difficulties of PD patients in adapting to post-DBS life regarding their self, the couple relationship, and professional and social circles (Agid et al., 2006; Haahr, Kirkevold, Hall, & Østergaard, 2010; Haahr et al., 2013; Houeto et al., 2002, 2006; Schüpbach et al., 2006). Interestingly, these difficulties seem to predominantly occur later during the first postoperative year (Haahr et al., 2010); mood elevation or excessive behaviors observed in the immediate period following DBS—notably, manifestations that were not reversible by changing parameters (Herzog, Reiff, et al., 2003; Romito et al., 2002)—may at least partly stem from a "honeymoon" effect associated with the spectacular motor improvement.

Psychosocial difficulties have been referred to as a "burden of health" after the suicide rate increased in patients who underwent surgery for a variety of movement disorders, including PD (Burkhard et al., 2004). The consideration of life after DBS through the lens of psychosocial adjustment appears to be a complementary approach to the methodological and medical perspectives applied to an understanding of the complex pre-/postsurgical process. Attributing importance to psychosocial adjustment in PD has not only pivotal, but clinical, implications: It acknowledges the intervention of health professionals from multiple disciplines, such as neuropsychology, clinical psychology, and consultation-liaison psychiatry, and releases neurosurgeons and neurologists from the entire responsibility of the clinical follow-up (Schüpbach et al., 2006).

To our knowledge, no theoretical model addressing the ins and outs of adjustment to life after PD-DBS has been proposed so far. This issue has nevertheless been considered in other medical conditions that share a number of similarities with PD-DBS. Specifically, the psychosocial maladjustment experienced by epilepsy patients after treatment by antero-temporal lobectomy (ATL) has been associated with difficulties in adjusting to daily living

becoming "normal" again (Bladin, 1992; Wilson, Bladin, & Saling, 2001). The term *burden of normality* (BoN) was initially coined by Bladin (1992) to underscore a range of psychosocial difficulties related to family dynamics and individual behavior frequently observed during the rehabilitation period in patients successfully treated with ATL. Later, Wilson, Bladin, and Saling (2001) proposed a theoretical model conceptualizing these psychosocial difficulties as a process of adjustment to a life free from seizures. The BoN model found its rationale in a series of empirical phenomenological studies that gathered data by using a standardized semi-structured instrument (Bladin, Wilson, Saling, McIntosh, & O'Shea, 1999; Wilson, Bladin, Saling, McIntosh, & Lawrence, 2001; Wilson, Kincade, Saling, & Bladin, 1999; Wilson, Saling, Kincade, & Bladin, 1998; Wilson, Saling, Lawrence, & Bladin, 1999). As shown in Figure 1, the BoN articulates around three theoretical levels. First, it supposes precursory conditions necessary for the development of psychosocial maladjustment; specifically, patients with a disabling chronic disease for which they undergo drastic treatment such as ATL with a successful medical outcome—in this case, a significant reduction in seizures—would be at risk of experiencing psychosocial maladjustment, illustrated by a range of clinical manifestations. Second, it describes the latter clinical manifestations in four interrelated psychological, behavioral, affective, and sociological categories. Third, it posits the existence of two mediating variables that play a central role in the occurrence or nonoccurrence of psychosocial maladjustment, namely, treatment expectations for postsurgical outcome and the ability to discard the roles associated with the preoperative condition (Wilson, Bladin, & Saling, 2004).

[INSERT FIGURE 1 ABOUT HERE]

The BoN has been further specified in subsequent studies. For instance, postoperative trajectories of patients in terms of psychosocial adjustment (Wilson, Bladin, Saling, & Pattison, 2005) and predictors of psychosocial outcome (Kemp et al., 2016; Wilson, Wrench,

McIntosh, Bladin, & Berkovic, 2010) were investigated in longitudinal frameworks. The model has also been applied to other chronic conditions (Genardini, Wilson, Lawrence, & Hare, 2008; Wilson, Frazer, Lawrence, & Bladin, 2007; Wrench, Wilson, & Bladin, 2004), and, interestingly, authors have proposed that the BoN would be suitable to account for post-DBS adjustment difficulties in PD patients (Bell, Maxwell, McAndrews, Sadikot, & Racine, 2011; Flores Alves Dos Santos et al., 2017; Gilbert, 2012).

To the best of our knowledge, however, no study has specifically addressed the strengths and limitations of applying the BoN to psychosocial maladjustment after DBS surgery in patients with PD. In the absence of original empirical studies that used the BoN with PD-DBS, the present paper constitutes an essay that aims to examine (a) whether the literature provides evidence of psychosocial consequences after PD-DBS and (b) whether the BoN constitutes a valid theoretical framework to account for the latter consequences.

Method

We followed the PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009) to conduct a systematic review of the PD-DBS literature. We searched the databases PubMed (www.ncbi.nlm.nih.gov/pubmed) and PsycINFO (www.apa.org/pubs/databases/psycinfo/index.aspx) between June 21, 2017, and December 20, 2017, entering terms directly related to each of the three theoretical levels of the BoN (e.g., “psychosocial adjustment,” “depression,” appetitive behaviors,” couple relationship,” “expectations”).

We considered only scientific articles for this review. All selected studies had to be based on original data; thus, theoretical essays, reviews, and meta-analyses were not considered. Other exclusion criteria were studies with nonlongitudinal data, studies focusing on nonpsychosocial variables (e.g., cognitive, experimental, and somatic variables; medication

effects; stimulation parameters), single or multiple case studies, studies with participants undergoing unilateral DBS, and studies drafted in non-English languages.

We considered three types of sources. As it has been suggested that adverse effects following DBS were sometimes identified from nonrigorous methodological settings (Witt et al., 2008), we decided to primarily select longitudinal cohort studies that included a control group (Source Type 1). Because symptoms of the BoN were nonetheless observed more than 1 year postoperatively (Wilson, Bladin, Saling, McIntosh, & Lawrence, 2001), we also considered longitudinal cohort studies without a control group designed with a follow-up of more than 12 months (Source Type 2). However, it quickly became apparent that these two source types would not cover all domains of the BoN. Indeed, no Type 1 source addressed either the psychological and sociological manifestations, or the mediating variables, and only 18.4% provided information on the behavioral category. Similarly, Type 2 studies did not address expectations at all, and only two articles mentioned the sick role issue. Similarly, only 12.8% investigated the psychological domain, 15.4% the sociological domain, and 41.0% the behavioral domain. Thus, we decided to extend the literature review to longitudinal cohort studies with a follow-up of less than 12 months and to longitudinal studies with qualitative data (Source Type 3) specifically for the BoN domains not satisfactorily covered by Source Types 1 and 2, namely, the two mediating variables and the clinical manifestations of the psychological, behavioral, and sociological areas. We held that considering qualitative sources was also theoretically coherent, as most BoN research has collected data through phenomenological studies.

We screened 1,911 research items, of which 1,097 were assessed for eligibility, through PubMed and PsycINFO databases. At the end of the assessment process, 75 were retained to be included in the review. In addition, we selected 13 articles after examining the reference lists of the latter 75 items, leading to a final pool of 88 scientific articles (see Figure 2).

Additional details of the review procedure are available online as supplementary material and under PROSPERO registration number XXX. This study took place in a larger project that investigated the psychological predictors of quality of life in patients treated with DBS, which has been approved by the XXX ethics committee under registration number XXX.

[INSERT FIGURE 2 ABOUT HERE]

Results

Precursory conditions

The BoN is posited to apply to patients who meet three precursory conditions: the presence of a chronic illness, a sense of disablement, and the opportunity to experience a dramatic improvement in symptoms related to the chronic illness (Wilson, Bladin, & Saling, 2001). PD is a chronic illness (Jankovic, 2008) that causes significant disablement to patients in an advanced stage of the disease (Haahr et al., 2011). In this section, we focus on reviewing the third condition in the BoN.

Type 1 studies have shown that DBS provides patients with drastic motor improvement in comparison with control patients, as assessed by the third part of the Unified Parkinson's Disease Rating Scale. This has been attested to at various times during the first postoperative year, when patients were either deprived of anti-parkinsonian drugs (the off-medication condition: Deuschl et al., 2006; Okun et al., 2012; Smeding et al., 2006, 2011; Weaver et al., 2009; A. Williams et al., 2010; Witt et al., 2008) or had taken this medication (the on-medication condition: Chang et al., 2012; Deuschl et al., 2006; Okun et al., 2012; A. Williams et al., 2010; Witt et al., 2008). The motor benefits of DBS patients over their control counterparts were significant 1 week after implantation (Chang et al., 2012), suggesting an immediate surgical effect. These benefits were then sustained in the on-medication condition

(A. E. Williams et al., 2011) and in both conditions (Schüpbach et al., 2013) at the 24-month follow-up assessment.

Type 2 studies have shown that DBS-induced motor improvement is sustained in the long run in the off-medication condition, namely, after 15–24 months (Bickel et al., 2010; Castelli et al., 2006, 2007; Ferrara et al., 2010; Herzog, Volkmann, et al., 2003; Houeto et al., 2006; Lezcano et al., 2004; Nunta-Aree, Sitthinamsuwan, Boonyapisit, & Pisarnpong, 2010; Ortega-Cubero et al., 2013; Ory-Magne et al., 2007; Schüpbach et al., 2006; Sobstyl, Ząbek, Górecki, & Mossakowski, 2014; Vingerhoets et al., 2002; Zibetti et al., 2007), at 3 to 5 years (Amami et al., 2014; Contarino et al., 2007; Fluchere et al., 2014; Gervais-Bernard et al., 2009; Jiang et al., 2015; Krack et al., 2003; Rodriguez-Oroz et al., 2000; Schüpbach et al., 2005; Visser-Vandewalle et al., 2005; Volkmann et al., 2009; Weaver et al., 2012; Zibetti et al., 2009), and after 8 years (Aviles-Olmos et al., 2014; Fasano et al., 2010; Rizzone et al., 2014; Zibetti et al., 2011). Similar improvement was observed under the on-medication condition between 19 and 24 months (Bickel et al., 2010; Herzog, Volkmann, et al., 2003; Houeto et al., 2002; Nunta-Aree et al., 2010; Ory-Magne et al., 2007; Sobstyl et al., 2014; Vesper, Haak, Ostertag, & Nikkhah, 2007), at 36 months (Kaiser et al., 2008; Volkmann et al., 2009), and at 60 months (Schüpbach et al., 2005).

A significant reduction in medication, measured in terms of levodopa equivalent units, has also been observed during the first postoperative year (Deuschl et al., 2006; Okun et al., 2012; Schüpbach et al., 2013; A. Williams et al., 2010; Witt et al., 2008), after 2 years (A. E. Williams et al., 2011), and after a mean of about 6 years of follow-up (Merola et al., 2014) in comparison with control patients who did not undergo DBS. Type 2 studies have shown that this reduction was sustained in the years that followed, namely, after 15–24 months (Bickel et al., 2010; Castelli et al., 2006, 2007; Deli et al., 2015; Herzog, Volkmann, et al., 2003; Houeto et al., 2002, 2006; Lezcano et al., 2004; Ortega-Cubero et al., 2013; Ory-Magne et al., 2007;

Sobstyl et al., 2014; Vesper et al., 2007; Vingerhoets et al., 2002; Zibetti et al., 2007), at 3 to 5 years (Amami et al., 2014; Contarino et al., 2007; Fluchere et al., 2014; Gervais-Bernard et al., 2009; Jiang et al., 2015; Krack et al., 2003; Rodriguez-Oroz et al., 2000, 2005; Schüpbach et al., 2005; Visser-Vandewalle et al., 2005; Weaver et al., 2012; Zibetti et al., 2009), and after 8 years (Fasano et al., 2010; Rizzone et al., 2014; Zibetti et al., 2011).

This suggests that PD-DBS fulfils the prerequisites for the occurrence of BoN symptoms, as described by the model and in conformity with previous observations (Gilbert, 2012). However, in contrast to epilepsy, which can be curative when treated with ATL, PD is neurodegenerative and DBS does not stop its progression. This has been illustrated by the tendency for patients to return to preoperative motor scores in the on-medication condition at the 12-month (Gervais-Bernard et al., 2009), 24-month (Vingerhoets et al., 2002), 36-month (Weaver et al., 2012), 4-year (Visser-Vandewalle et al., 2005), and 5-year (Rizzone et al., 2014) assessments. Motor deterioration was observed after 1–5 years of follow-up and kept worsening after 8 years, mainly because of axial symptoms and bradykinesia (Aviles-Olmos et al., 2014; Janssen et al., 2014; Krack et al., 2003; Merola et al., 2014; Rizzone et al., 2014). This constrains physicians to adapting the stimulation parameters and the medication of patients when symptoms appear. Consequently, symptoms specifically related to disease progression cannot always be controlled or clearly isolated from clinical manifestations of psychosocial adjustment. The neurodegenerative status of PD also implies that psychosocial adjustment for PD-DBS patients is challenged continuously and can never be definitively achieved.

Clinical manifestations

Referred to as a “syndrome,” the clinical manifestations of psychosocial maladjustment are presented in the BoN model as belonging to four distinct, but nonetheless interrelated, psychological, behavioral, affective, and sociological categories (Wilson, Bladin, & Saling,

2001). Psychological manifestations may relate to a sensation of grief for the loss of the disease, regrets for missed opportunities because of the disease, or the desire to prove that "normality" has been recovered after a successful treatment. Behavioral manifestations are characterized by excessive activity or, in contrast, avoidant behaviors. Affective manifestations involve mood alterations such as anxiety, depression, euphoria, or psychosis, and sociological manifestations depict challenges in the dynamics of the couple, family, and social and professional circle, implying a redefinition of roles or a reformulation of life goals. Illustrating the possible interrelation between these symptom categories, Bladin and colleagues (1999) reported cases of patients who triggered seizures by not complying with medication, an excessive behavior "justified" by psychological feelings of normality, as these patients no longer experienced seizures after successful surgery. Research on post-ATL patients has shown that about two thirds experienced clinical manifestations of psychosocial maladjustment during the 2 years following surgery (Wilson, Bladin, Saling, et al., 2001). The consequences of these manifestations may be serious, as a considerable proportion (21%) of patients undergoing ATL required hospital readmission at some point during the postoperative period because of affective (anxiety, depression, psychosis) or sociological (disruption of family dynamics, limited social network) manifestations of the BoN (Wilson, Kincade, et al., 1999). Suicide attempts and suicides were also documented, the latter being referred as the "ultimate paradox of treatment 'cure'" (Bladin, 1992; Wilson et al., 2004, p. 14). In this section, we investigate whether the clinical manifestations of the BoN identified in post-ATL patients correspond to the psychosocial symptoms observed after DBS in PD patients.

Psychological. A range of psychological difficulties has been observed in PD-DBS patients during the 2 years following surgery. A considerable percentage of patients experienced feelings of strangeness (66%) and helplessness regarding the consequences of PD (48%) and had difficulties resuming activities of daily living (28%; Agid et al., 2006;

Schüpbach et al., 2006). Others were reluctant to abandon the advantages provided by their illness status, such as receiving particular attention from their partner (Perozzo et al., 2001). In line with this, some patients had the impression of losing control of their body, which was notably the case within the first 6 months of surgery when physicians endeavored to find an adequate adjustment of the stimulation parameters (Haahr et al., 2010; Perozzo et al., 2001). The patients' dependency on health professionals and, in general, hospital settings made their return home difficult (Hariz & Hamberg, 2014). In this context, patients reported new symptom occurrence and difficulties trusting their post-DBS physical abilities (Haahr et al., 2010). Some had problems accepting a self-image that incorporated an artificial device in their body and reported feelings of dehumanization after 24 months (Agid et al., 2006; Schüpbach et al., 2006) and 36 months (Hariz & Hamberg, 2014). This was nevertheless the case for only a minority, suggesting that patients generally tolerated the device well.

In another vein, changes in personality traits have been identified after PD-DBS. Some patients had lower scores of persistence and self-transcendence at the 3-month evaluation (Pham et al., 2015) and were less obsessive-compulsive and paranoid after 15 months of follow-up (Castelli et al., 2006). In addition, 30–45% of patients showed personality modifications toward more hypomanic traits 12 months after surgery (C. J. Lewis, Maier, Horstkötter, Zywczok, et al., 2015). Other investigators noted that an equivalent number of patients worsened, improved, or stagnated on personality traits 19 months after DBS (Houeto et al., 2002). On the other hand, some studies reported that there were no global changes in terms of personality after 6 months (Perozzo et al., 2001), 12 months (Castelli et al., 2008), and 24 months (Houeto et al., 2006). Similarly, coping strategies were not modified during the 12 months following surgery (Soulas, Sultan, Gurruchaga, Palfi, & Fénelon, 2011).

Behavioral. Appetitive behaviors identified after PD-DBS have been associated with impulse control deficiency and refer to disinhibition, compulsive behaviors (eating,

medication use, shopping), pathological gambling, hypersexuality, or drug dependence. Most of these behaviors were transient and observed in the first postoperative months (Amami et al., 2014; Aviles-Olmos et al., 2014; Bickel et al., 2010; Fasano et al., 2010; Funkiewiez et al., 2004; Houeto et al., 2002; Kim et al., 2013). A decrease in appetitive behaviors was noticed within 3-4 years (Amami et al., 2014; Merola et al., 2017), sometimes as early as the first year (Castrioto et al., 2015; Eusebio et al., 2013; Gee et al., 2015; Lhommée et al., 2012). The proportion of patients experiencing appetitive behaviors was estimated to be between 12.5% and 22.5% (Amami et al., 2014; Fasano et al., 2010; Kim et al., 2013) and reached 35% in a 10-year follow-up (Janssen et al., 2014). All appetitive behavior subtypes do not appear to be uniformly prevalent, as compulsive eating was persistent in the short (Eusebio et al., 2013) and long (Amami et al., 2014) run, but patients did not differ from controls in terms of disinhibition during the first postoperative year (Smeding et al., 2011; Tröster, Jankovic, Tagliati, Peichel, & Okun, 2016). Yet, some authors reported different results, finding, for instance, that disinhibition was significantly impaired after a mean of 40 months after DBS (Denheyer, Kiss, & Haffenden, 2009), or that preoperative dopamine dysregulation syndrome did not improve in 71% of patients within the first postoperative year (Lim et al., 2009). Notably, some patients developed de novo appetitive behaviors after surgery (Kim et al., 2013; Lim et al., 2009; Rizzone et al., 2014). Excessive activity in the initial months following DBS was also attributed to the willingness to take up new opportunities provided by the sudden improvement in motor symptoms (Haahr et al., 2010).

Avoidant behaviors after PD-DBS have generally been associated with apathy, which seems in many cases to appear transiently in the initial months following surgery (Drapier et al., 2006, 2008; Le Jeune et al., 2009; Thobois et al., 2010). The proportion of patients who develop apathy in the first postoperative year was estimated to be between 23.5% and more than 50% (Gesquière-Dando et al., 2015; Martinez-Fernandez et al., 2016; Thobois et al.,

2010). Not all occurrences of apathy appearing in the first months after DBS positively responded to medication adjustment (Krack et al., 2003; Thobois et al., 2010), which, in addition to highlighting interindividual differences, also implies that various types of apathy may coexist.

In line with this, some authors pointed out that apathy scores did not differ from control patients or did not change compared with baseline after 6 months (Chou, Persad, & Patil, 2012; C. J. Lewis et al., 2014; Lozachmeur et al., 2014; Witt et al., 2008), 12 months (Smeding et al., 2011), and 15–17 months (Castelli et al., 2006, 2007). This suggests that postoperative apathy may occur at a later stage, as observed at the 12-month evaluation (C. J. Lewis et al., 2014; Maier et al., 2016) and after 24 months (Schüpbach et al., 2013), 36 months (Funkiewiez et al., 2004), or 40 months (Denheyer et al., 2009) of follow-up, but may also improve at various times during the postoperative period, namely, after 3 months (Tröster et al., 2016), 12 months (Thobois et al., 2010), and 24 months (Bickel et al., 2010). Apathy was positively correlated with age (Ory-Magne et al., 2007) and cognitive decline (Krack et al., 2003), which might partly account for the persistence of apathetic patients observed in the long term (Contarino et al., 2007). Cases of transient and permanent apathy were noted in 4.3% to 16.6% of patients over up to 8 years of follow-up (Fasano et al., 2010; Gervais-Bernard et al., 2009; Zibetti et al., 2007), and no difference was observed between DBS and control patients over such a long period (Lilleeng, Gjerstad, Baardsen, Dalen, & Larsen, 2015). Alternatively, apathetic behaviors might be related to an adaptation phase in which patients test their physical abilities, as suggested by Haahr and colleagues (2010). Hariz and Hamberg (2014) observed that about one third of patients were excessively careful or tended to avoid certain activities because of discomfort or anxiety related to the stimulation device. Thus, excessive and avoidant activities could, to a certain extent, illustrate the degree of comfort and confidence about the stimulated body.

Affective.

Depression. In general, Type 1 studies have pointed out a greater improvement in depression values in PD-DBS patients compared with control patients in the first months following surgery, as observed after 3 months (Okun et al., 2012; Tröster et al., 2016; Wang et al., 2009), 6 months (Wang et al., 2009; Witt et al., 2008; York et al., 2008) and 24 months of follow-up (Schüpbach et al., 2013). This initial improvement was nevertheless followed by stabilization or a return to preoperative values in the long run (Lilleeng et al., 2015; Wang et al., 2009). Others found no between-group differences either in the initial postoperative 3 months (Morrison et al., 2004) or after 6 months (Deuschl et al., 2006; Smeding et al., 2006) and later (Merola et al., 2014). Interestingly, DBS patients had higher levels of depression than did controls after 6 months for cognitive-emotional aspects (i.e., discouragement, failure, guilt, self-disappointment, self-criticalness, and lack of interest) but not for physical aspects (Strutt, Simpson, Jankovic, & York, 2012).

Longer term Type 2 studies also suggest that PD-DBS patients undergo postoperative improvement in depressive symptoms that is sustained for up to 36 months (Agid et al., 2006; Bickel et al., 2010; Castelli et al., 2006, 2007; Deli et al., 2015; Funkiewiez et al., 2004; Houeto et al., 2006; Schüpbach et al., 2006). However, others noted that depressive symptoms improved in the first year after surgery but returned to preoperative values after 36 months (Kaiser et al., 2008). This progressive deterioration, which seems to occur in a second step, might explain why no difference in baseline scores was observed in studies that assessed depression after 2 and 3 years of follow-up (Nunta-Aree et al., 2010; Ory-Magne et al., 2007; Weaver et al., 2012; Zibetti et al., 2007, 2009). In line with this, studies with a longer follow-up also did not find a significant difference in baseline scores after 5 years (Aviles-Olmos et al., 2014; Fluchere et al., 2014; Gervais-Bernard et al., 2009; Jiang et al., 2015; Krack et al.,

2003; Schüpbach et al., 2005) and after more than 8 years (Aviles-Olmos et al., 2014; Fasano et al., 2010; Janssen et al., 2014; Rizzone et al., 2014; Zibetti et al., 2011).

Anxiety. Type 1 studies have shown that PD-DBS patients are less anxious than their control counterparts in the initial months following surgery (Chang et al., 2012; Witt et al., 2008), suggesting a relieving effect of stimulation. However, anxiety in general tends to worsen with time, as both state and trait anxiety were higher in DBS patients than in controls at the 6-month evaluation (Strutt et al., 2012; York et al., 2008) and were higher than the preoperative values after about 1 year (Chang et al., 2012). Nonetheless, one study did not find a difference in state and trait anxiety between patients and controls either at baseline or after a mean of 6 years of follow-up (Merola et al., 2014).

In accordance with this, Type 2 studies suggest that anxiety symptoms initially improve, as measured within the first 2 postoperative years (Agid et al., 2006; Bickel et al., 2010; Houeto et al., 2006; Rizzone et al., 2014; Schüpbach et al., 2006). However, a tendency to return to preoperative values was noticed after 36 months (Kaiser et al., 2008). Similarly, others found that no difference was observable after 15 months (Castelli et al., 2006) or in the longer run, namely, after 3 years (Zibetti et al., 2009), 5 years (Aviles-Olmos et al., 2014; Jiang et al., 2015), 8 years (Aviles-Olmos et al., 2014; Fasano et al., 2010), and 9 years (Zibetti et al., 2011). A study nevertheless noted that longitudinal findings could strongly differ depending on the measurement tools used (Rizzone et al., 2014).

Other. Other affective symptoms have been identified after PD-DBS, notably irritability, emotional lability, psychotic episodes, hallucinations, and manic or hypomanic behaviors. Type 1 studies suggest that psychotic episodes such as hallucinations and paranoia may occur in DBS patients (Smeding et al., 2006; A. Williams et al., 2010; Witt et al., 2008). However, these cases were mostly transient (Lilleeng et al., 2015; Smeding et al., 2006) and less frequent than in control patients (Witt et al., 2008). DBS patients improved in

irritability/lability more than controls did after 6 months (Smeding et al., 2006), whereas mania did not occur or was rare in the first postoperative year (Smeding et al., 2006; Witt et al., 2008). Yet, in an 8-year follow-up, about 50% of patients and controls experienced hallucinations, with no between-group difference (Lilleeng et al., 2015).

Type 2 studies led to mixed results, as some authors found that psychosis globally improved in the first year after surgery (Kaiser et al., 2008), as did irritability and agitation after 24 months (Bickel et al., 2010), but other authors reported that psychosis returned to preoperative values after 36 months (Kaiser et al., 2008) and some noted that hallucinations and delusions worsened during the first 15 months after surgery (Castelli et al., 2006). Still others found that psychosis and irritability remained stable after 24 months (Nunta-Aree et al., 2010; Zibetti et al., 2007) and 36 months (Kaiser et al., 2008), respectively.

In addition, Type 1 and 2 studies have regularly described cases of psychiatric adverse events, which have been related to depression (Castelli et al., 2006; Deuschl et al., 2006; Fasano et al., 2010; Funkiewiez et al., 2004; Gervais-Bernard et al., 2009; Herzog, Volkmann, et al., 2003; Houeto et al., 2002, 2006; Janssen et al., 2014; Krack et al., 2003; Okun et al., 2012; Rodriguez-Oroz et al., 2000, 2005, Schüpbach et al., 2005, 2006, 2013; Weaver et al., 2009; Witt et al., 2008; Zibetti et al., 2007), anxiety (Castelli et al., 2006; Houeto et al., 2002, 2006; Okun et al., 2012; Schüpbach et al., 2006), psychosis (Aviles-Olmos et al., 2014; Castelli et al., 2006; Deuschl et al., 2006; Fasano et al., 2010; Fluchere et al., 2014; Funkiewiez et al., 2004; Gervais-Bernard et al., 2009; Herzog, Volkmann, et al., 2003; Houeto et al., 2002; Jiang et al., 2015; Rodriguez-Oroz et al., 2000; Schüpbach et al., 2005; Vesper et al., 2007; A. Williams et al., 2010; Witt et al., 2008; Zibetti et al., 2007), mania and hypomania (Aviles-Olmos et al., 2014; Contarino et al., 2007; Fasano et al., 2010; Funkiewiez et al., 2004; Gervais-Bernard et al., 2009; Herzog, Volkmann, et al., 2003; Houeto et al., 2002, 2006; Krack et al., 2003; Nunta-Aree et al., 2010; Schüpbach et al., 2005, 2006; Visser-

Vandewalle et al., 2005), and confusion (Aviles-Olmos et al., 2014; Fluchere et al., 2014; Gervais-Bernard et al., 2009; Herzog, Volkmann, et al., 2003; Okun et al., 2012; Rodriguez-Oroz et al., 2000; Schüpbach et al., 2005; Visser-Vandewalle et al., 2005; Weaver et al., 2009). Although most of these adverse events transiently appeared in the first months following DBS, some were also described as being permanent. In general, most psychiatric adverse events that occurred in patients undergoing DBS had also been experienced preoperatively (Houeto et al., 2002, 2006), with the exception of hypomania (Schüpbach et al., 2006).

In the initial 6 months following surgery, DBS patients and controls were no different in terms of suicidal ideation and no suicide behavior was observed (Weintraub et al., 2013). However, although rare, cases of suicidal ideation, suicide attempts, or suicides in PD-DBS patients have been regularly documented, notably during the early period following surgery (Deuschl et al., 2006; Funkiewiez et al., 2004; Gervais-Bernard et al., 2009; Schüpbach et al., 2005, 2013; Strutt et al., 2012; A. Williams et al., 2010; Witt et al., 2008; York et al., 2008), as well as after 1 year (Fluchere et al., 2014; Vesper et al., 2007) and during 24 months of follow-up (Houeto et al., 2002).

Sociological. Despite the motor improvement brought about by DBS, social relationships, leisure, and family life remained stable or deteriorated compared with preoperative values in the two postoperative years (Houeto et al., 2002, 2006). This has been associated with a subjective negative DBS outcome (Maier et al., 2016). After initial improvement, social activities decreased toward preoperative scores at 1 year follow-up (C. J. Lewis et al., 2014), which does not seem to prevent most patients from remaining active in a social organization 3 years after surgery (Boel et al., 2016).

The consequences of DBS surgery also affect patients' caregivers, that is, spouses, partners, and significant others. On the one hand, these consequences can be positive, as

caregivers improved their scores on various dimensions such as quality of life after 12 months (Soulas, Sultan, Gurruchaga, Palfi, & Fénelon, 2012) and 24 months (Lezcano et al., 2004), depression after 12 months (Soulas et al., 2012), and burden after 12 months (Soulas et al., 2012). Other studies nevertheless specified that caregivers' well-being improved in the first months following DBS before returning toward preoperative values at 12 months (C. J. Lewis et al., 2014). This has been associated with the patients' struggle to find adapted parameters after a few months of stimulation, leading caregivers to fear endorsing a role similar to that of the preoperative period after initial relief (Perozzo et al., 2001). Similarly, authors found that the caregiver burden did not improve at the 6-month assessment (Soileau, Persad, Taylor, Patil, & Chou, 2014) and that well-being was negatively evaluated by 50% of caregivers at 12 months (C. J. Lewis, Maier, Horstkötter, Eggers, et al., 2015). Postoperative dissatisfaction was related to various dimensions, such as quality of life, mood, and burden (C. J. Lewis, Maier, Horstkötter, Eggers, et al., 2015; Schüpbach et al., 2006), and was experienced by a significant subgroup of caregivers. Specifically, physical and mental quality of life deteriorated in 35% and 42% of caregivers, respectively, while 19% felt that their burden was heavier than before surgery (Soulas et al., 2012). Interestingly, younger age was significantly related to better outcome (C. J. Lewis, Maier, Horstkötter, Eggers, et al., 2015; Soulas et al., 2012).

DBS can influence the couple relationship as well. The necessity to find the best adjustment of stimulation parameters was perceived as a continuous challenge in the couple (Haahr et al., 2013; Perozzo et al., 2001). Disagreements regarding the patient's capabilities (Haahr et al., 2010), feelings of rejection in both patient and partner (Agid et al., 2006; Schüpbach et al., 2006), and difficulties in endorsing new roles (Perozzo et al., 2001) have been observed. As a consequence, no improvement in the couple relationship was noted after DBS (C. J. Lewis, Maier, Horstkötter, Eggers, et al., 2015; Schüpbach et al., 2006), and

relationship impairment was noticed with partners who experienced disappointment, depression, and deterioration of quality of life (Houeto et al., 2002; Schüpbach et al., 2006; Soulas et al., 2012). On the other hand, some authors found that marital satisfaction was sustained in most couples up to 3 years postoperatively (Boel et al., 2016).

Few studies have specifically addressed post-DBS psychosocial adjustment regarding employment and vocations. PD-DBS has a limited impact on the professional area, as the great majority of patients with PD do not work after 10 years of establishment of their diagnosis (Schrag & Banks, 2006). Undergoing surgery nevertheless fosters individuals who remain active to keep their job (80% after 24 months), but it does not seem to allow those who had interrupted their professional activity to restart a career (5% after 24 months; Deli et al., 2015). Another study found that about half of participants (13 of 29) experienced a worsening of their professional life after DBS and, interestingly, seven of them did not return to work despite excellent motor improvement (Schüpbach et al., 2006). Projects that include going back to work may indeed be impaired by psychosocial maladjustment after PD-DBS. Patients may feel physically and psychologically damaged by years of PD, and DBS, even if successful, does not necessarily fix this negative impression about themselves and the impression that they are no longer capable of being professionally efficient. Another possibility that has been raised in studies is that a number of patients choose to prioritize leisure activities over their career (Agid et al., 2006; Schüpbach et al., 2006).

Mediating variables

The BoN posits that posttreatment psychosocial adjustment mainly depends on two mediating variables: preoperative expectations of posttreatment outcome—hereafter referred to as "expectations"—and patients' capability of forgoing the roles associated with the disabling chronic disease and endorsing new roles adapted to a less symptomatic posttreatment condition (Wilson et al., 2004; Wilson, Bladin, & Saling, 2001).

Expectations. Considered from the BoN perspective of epileptic patients undergoing ATL, expectations exerted a significant effect on perceived treatment success independently from the objective medical outcome, in this case seizure occurrence (Wilson, Saling, et al., 1999). This finding suggests that adjustment begins in the pretreatment phase (Wilson et al., 2004; Wilson, Bladin, & Saling, 2007; Wilson, Saling, et al., 1999). Concretely, patients who formulated expectations of practical improvements (e.g., seizure discontinuation, driving a car, finding a job) perceived surgery to be more successful, experienced fewer postoperative seizures, and had fewer psychosocial difficulties than did patients who emphasized psychosocial expectations such as increasing personal independence or improving family dynamics (Wilson et al., 1998). Having positive and realistic expectations of posttreatment change thus seems to predict less problematic psychosocial adjustment, characterized by fewer BoN manifestations (Wilson et al., 2004; Wilson, Saling, et al., 1999).

Research has shown that pre-DBS expectations of patients with PD cover numerous areas, similar to those of patients about to undergo ATL for epilepsy. Patients expect to improve in all of these areas after surgery (Hasegawa, Samuel, Douiri, & Ashkan, 2014). On the one hand, expectations may be of objective motor- and disease-related improvements, such as increasing mobility and body comfort, reducing or discontinuing medication intake, or ameliorating activities of daily living. On the other hand, expectations can address psychosocial domains, such as improving nonmotor symptoms (e.g., sleep, pain, or

depression), quality of life, emotional well-being, and social relationships (Hasegawa et al., 2014; Maier et al., 2013). Expectations from the latter category have been considered unrealistic because they are not directly linked to the motor and medication-induced symptoms targeted by DBS. Unrealistic expectations have been associated with dissatisfaction in the perception of PD-DBS outcomes (Maier et al., 2013). However, dissatisfaction was also related to unmet expectations of the former category. For example, patients did not always anticipate how demanding it would be after surgery to find adequate stimulation parameters (Hariz & Hamberg, 2014). In general, postoperative improvement measured at the 6-month assessment was significantly inferior to the improvement expected preoperatively in every dimension except social support (Hasegawa et al., 2014).

In a pivotal study on expectations in PD-DBS, Maier and colleagues (2013) showed that patients with a negative perception of their post-DBS outcome endorsed more unrealistic expectations than did participants with a perceived positive outcome. Although all patients had expectations that DBS would improve their motor functions, those with unrealistic expectations experienced a smaller subjective improvement in motor and autonomy areas. A positive correlation between the magnitude of expected changes and the motor changes that did occur after DBS surgery was also reported (Hasegawa et al., 2014), suggesting that positive expectations of motor improvement contribute to perceived positive outcome in PD-DBS.

Discarding the sick role. Issues related to forgoing sick roles might, according to BoN studies, affect up to 31% of patients and 7% of siblings at some point during the years following surgery (Bladin, 1992; Wilson et al., 2005). In successful PD-DBS, difficulties in relinquishing attitudes and habits inherited from the preoperative condition were observed in 28% of patients (Schüpbach et al., 2006). Qualitative data suggest that patients were able to cognitively recognize the incoherence of persisting with a sick attitude despite acknowledged

motor improvement (Agid et al., 2006). Concretely, these sick roles were illustrated by maintained rituals before taking medication, activity avoidance in anticipation of motor problems, or unwillingness to relinquish the dependent attitude of someone with illness status (Agid et al., 2006; Perozzo et al., 2001; Schüpbach et al., 2006).

Discussion

In this literature review, we have highlighted elements in the pre- and post-PD-DBS process that could be interpreted as pertaining to psychosocial maladjustment and, in this regard, fit within the BoN framework. First, DBS provides immediate benefits for PD patients in significantly improving motor symptoms and global functioning and in reducing medication intake. This suggests that the conditions for risk of psychosocial maladjustment after treatment as hypothesized in the BoN are met in the PD-DBS situation. Second, post-DBS symptoms found in the PD literature match categorization into psychological, behavioral, affective, and sociological domains proposed by the BoN as a syndrome of psychosocial maladjustment. Third, literature findings that refer to the mediating variables of preoperative expectations and discarding the sick role support a possible function in the rehabilitation process as hypothesized in the BoN. However, only a few studies have directly addressed these two variables in the DBS rehabilitation process; additional research is required to draw solid conclusions about their validity within the BoN framework.

For these reasons, the applicability of the BoN, as a theoretical model, in the pre- and post-DBS process undergone by PD patients is currently sustained by promising yet mixed evidence. This evidence remains notably limited to fundamental differences in the BoN model and the medical situation from which it stems, namely, ATL for epilepsy. In contrast to some successful cases of ATL with epilepsy, DBS does not cure PD. Consequently, any psychosocial interpretation should simultaneously consider the neurobiological variables inherent to PD. A variety of clinical profiles are characteristic of pre-DBS PD, differing from

one another in terms of age of onset, type of motor and cognitive symptoms, or speed of deterioration (Graham & Sagar, 1999; S. J. G. Lewis et al., 2005). In addition, a line of relative recent research has shown that neuron deterioration progressively extends throughout the brain, at different stages of the disease affecting areas responsible for functions as diverse as motor, sensory, and associative, and giving rise to a variety of motor and nonmotor symptoms (Braak et al., 2003, 2006). In comparison to effects on motor symptoms, DBS has only mild to moderate effects on specific types of non-motor symptoms (Fasano, Daniele, & Albanese, 2012). Because DBS does not seem to influence the degenerative process of PD (Hilker et al., 2005), it is likely that the heterogeneity of clinical profiles after surgery, as shown in the results of this study, is associated with persistence of nonmotor symptoms. Yet, nonmotor symptoms are globally under considered (Chaudhuri et al., 2011); because DBS specifically targets motor symptoms, patients and health professionals might all the more overlook the role of nonmotor symptoms when they formulate and discuss presurgical expectations. Similarly, nonmotor symptoms that occur after DBS as a consequence of natural PD degeneration likely contribute to attenuating the beneficial effects of surgery on motor symptoms in quality-of-life assessment.

Despite these important limitations, other elements suggest that the concept of psychosocial adjustment is relevant for addressing some of the difficulties experienced by patients after PD-DBS. First, psychosocial maladjustment after DBS may arguably be viewed, at least partly, as a consequence of a sudden paradigmatic change in the way PD is experienced by patients. Those with advanced PD undergo major psychological challenges as they face the consequences of the disease's progression, such as dealing with self-image and perceiving stigmatization, in a context in which anticipating the fluctuating periods of active and inactive medication—the so-called on-off phenomenon—becomes increasingly difficult (Caap-Ahlgren & Lannerheim, 2002; Haahr et al., 2011; Van der Bruggen & Widdershoven,

2004). In PD, fluctuation happens with motor and nonmotor symptoms (Thobois et al., 2010). In order to address fluctuation unpredictability, patients may use strategies such as sustaining a positive state of mind despite the increasing burden of the disease, or attempting to control as many aspects of daily living as possible, such as sticking to a routine for general activities and medication intake (Haahr et al., 2011). Thus, the question arises as to the extent to which these strategies can become an integral part of patients' identity. For a considerable number of PD patients, motor complications start to have a significant impact on quality of life within 5 years of starting medication (Welsh, 2008). In other words, the potentially long time that elapses between the appearance of symptoms and DBS surgery—which occurs after an average of 11–13 years of PD—suggests that these strategies might have been, at least in some way, implemented and automated in patients' own self or identity. Therefore, the motor improvement brought by DBS could lead these patients to experiencing all of these well-embedded behaviors and strategies as no longer appropriate. The DBS transition could make these patients undergo a dramatic loss of control as they suddenly have no other choice but to depend on medical support (Gisquet, 2008; Haahr et al., 2010; Perozzo et al., 2001).

Second, despite the occurrence of both excessive and avoidant behaviors after PD-DBS, it has been suggested that, overall, these patients tend to switch from a preoperative appetitive mode to a postoperative apathetic mode (Lhommée et al., 2012). The diminution of appetitive behaviors has been associated with the drastic reduction in dopaminergic medication following motor improvement (Amami et al., 2014; Eusebio et al., 2013; Lhommée et al., 2012). Appetitive behaviors were mostly transient and sensitive to medication readjustment (Amami et al., 2014), but persisted in patients who remained highly medicated (Merola et al., 2017). Yet, one study reported that these postoperative behavioral dysfunctions were not associated with changes in dopaminergic medication (Kim et al., 2013). In addition, apathy did not worsen after 6 months in comparison with baseline scores despite a 50% decrease in

dopaminergic medication (Witt et al., 2008). This suggests that mechanisms other than alteration in dopaminergic activity are involved in post-DBS behavioral manifestations, leaving room for a possible role of psychosocial adjustment.

Third, findings highlighted in numerous studies suggest that affective manifestations such as depression and anxiety tend to improve postoperatively before returning to preoperative values. Interestingly, a similar symptomatic trajectory was observed with postoperative apathy, which is conceptually difficult to isolate from depression, as they are frequently concomitant (Bickel et al., 2010; Gervais-Bernard et al., 2009). Moreover, such a trajectory also occurred in sociological areas, as suggested by caregiver experiences. This implies that the sudden motor benefits induced by DBS provide an initial relieving effect that is subsequently dampened, possibly because of side effects of degenerating PD (e.g., struggling to find adequate stimulation parameters, occurrence of new symptoms related to PD progression). Nevertheless, the persistence or de novo occurrence of psychiatric adverse events in the long run—that is, in a period during rehabilitation when stimulation parameters or medication are not likely to be drastically modified—suggests that clinical manifestations are at least partly related to the necessity for patients to cope with new life demands requiring continuous psychosocial adjustment.

The BoN underscores the pivotal function of expectations and sick roles in the formation of posttreatment psychosocial adjustment symptoms. These two variables stem from the pretreatment phase, which implies that rehabilitation should begin before treatment (Gilbert, 2012; Kaiser et al., 2008; Maier et al., 2013; Wilson et al., 2004) and should also involve significant others whose expectations about treatment outcome may have an impact on the patient's psychosocial adjustment (Agid et al., 2006; Bell et al., 2011; Haahr et al., 2013). Our review identified studies that, although few in number, consistently pointed out the central role of preoperative expectations in the subjective perception of DBS outcome in accordance

with BoN predictions. The risk that unrealistic expectations engender a negative perception of DBS outcome has been well identified by health professionals, who may appear to be disarmed in managing this phenomenon (Bell et al., 2010; Bell & Racine, 2013). Although neurologists have traditionally been in charge of dealing with the unrealistic expectations expressed by PD patients (Pollak, 2013), the psychological dimension of expectations and, more generally, the psychosocial impact of successful DBS, suggest that specialists from other disciplines, such as neuropsychology, clinical psychology, or consultation-liaison psychiatry, could play a role in PD-DBS rehabilitation as well.

Many issues related to expectations could benefit from psychological management. Unrealistic expectations might stem from a state of despair after patients at an advanced stage of PD have realized that DBS constitutes their ultimate possibility to get better (Bell et al., 2010), an impression fostered by an overoptimistic depiction of DBS in the media (Racine & Bell, 2012). Expectations might also be of different kinds, such as those related to the warnings of health professionals and cognitively acknowledged by patients and those related to emotional secret hopes that treatment will result in an outstanding outcome (Bowling et al., 2012). In addition, although expectations have been conceptualized in the BoN from a pre- to a post-DBS perspective, the model also implies that it may be relevant to consider posttreatment *increased expectations*, endorsed by patients or their significant others, as a psychological variable of psychosocial adjustment. Authors have indeed shown that expectations regarding the future are formulated by patients and partners during PD-DBS rehabilitation after the benefits of treatment are concretely experienced (Haahr et al., 2010, 2013; Perozzo et al., 2001). Posttreatment expectations have notably been associated with pressure to be performant and responsible, and, interestingly, to behave accordingly by taking on “cured” roles (Wilson, Bladin, et al., 2007; Wilson et al., 2005).

In order to respond to these issues and others, psychoeducational programs have been proposed to PD-DBS patients in the perioperative period, showing promising results in the long run in terms of psychosocial adjustment (Flores Alves Dos Santos et al., 2017). We recommend the implementation of a screening and counseling protocol at specific times, before and after surgery, involving patients and significant others. Screening should be conducted with a semi-structured interview that addresses the main components of the BoN in order to phenomenologically identify elements at risk of fostering psychosocial maladjustment. Such a semi-structured instrument could notably be inspired by the Austin CEP Interview (Bladin, 1992; Wilson, Saling, et al., 1999), which has been used to investigate psychosocial adjustment in patients undergoing ATL for epilepsy. This would allow a finer psychiatric and psychological assessment than the usual procedure conducted with standardized measurement tools. This might also help clinicians to better identify patients with sub-syndromic profiles who do not stand out with their psychiatric symptoms and it might constitute a gateway for individual, couple, or family counselling or psychotherapy. Psychological support following PD-DBS could favor subsequent successful psychosocial adjustment given that, in epilepsy, post-ATL perception of identity change and successfully treated anxiety were associated with long-term positive psychosocial outcomes (Wilson et al., 2005, 2010). We thus encourage clinicians and researchers to address post-DBS rehabilitation by considering psychosocial variables; yet, we also advocate an integrated, multidisciplinary approach in which elements of psychosocial maladjustment (e.g., decrease in leisure activities) are addressed in light of objective medical data (e.g., dyskinesia improvement induced by DBS) and in close collaboration with health professionals from neurosurgery and neurology units.

As no original, empirical research has yet used the BoN in the context of PD-DBS, this review was exploratory and should be considered an investigation. In light of its conclusions,

the next stage consists of collecting first-hand data from patients undergoing DBS for PD in order to further test the applicability of the BoN model. This includes, as mentioned earlier, developing a semi-structured instrument adapted to the specific context of PD-DBS rehabilitation that ultimately would provide qualitative and quantitative information to allow inferential analyses. This would permit researchers to critically investigate each element of the BoN and to confirm—or invalidate—the clinical relevance of domains that have not been thoroughly addressed in the literature, such as the mediating variable of the sick role or categorization in four symptomatic manifestations that potentially overlap one another (e.g., psychosis and confusion, depression, and apathy). In addition, a semi-structured approach would be useful to reflect on the way that significant others may be included in rehabilitation for the benefit of patients and their entire social environment. Future studies might also target specific elements of psychosocial adjustment as additional measures of the BoN construct validity. For instance, assessing the longitudinal trajectory of couple relationships before and after PD-DBS would provide information about a particular aspect of psychosocial adjustment pertaining to the sociological manifestations of the BoN model. Taken together, these lines of research might eventually lead to modification or adjustment of elements of the BoN so that the model best fits within the PD-DBS context.

Finally, this review highlighted the psychosocial maladjustment that may occur in PD patients undergoing successful DBS surgery. The risk of undertaking this kind of research is that it might mislead readers by implying that DBS has a prevailing negative outcome for patients. This surgical procedure provides moderate to large beneficial effects on motor symptoms, daily functioning, quality of life, and mental health in general (Perestelo-Pérez et al., 2014). However, DBS may also result in negative outcomes as illustrated by the psychiatric adverse events, including isolated cases of depression, anxiety, and suicide, that have been regularly observed in randomized controlled trials (Deuschl et al., 2006; Okun et

al., 2012; Weaver et al., 2009; A. Williams et al., 2010; Witt et al., 2008). Similarly, DBS appears to favor risk of cognitive impairment with small effects found in executive functioning, memory, and verbal learning and moderate effects measured in verbal fluency (Parsons, Rogers, Braaten, Woods, & Tröster, 2006). In light of this, DBS candidates should be carefully selected to reach a favorable risk-benefit ratio (Schermer, 2011). The present study suggests that considering additional elements of psychosocial adjustment by using the BoN framework would improve the selection process and postsurgical rehabilitation.

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Figure 1

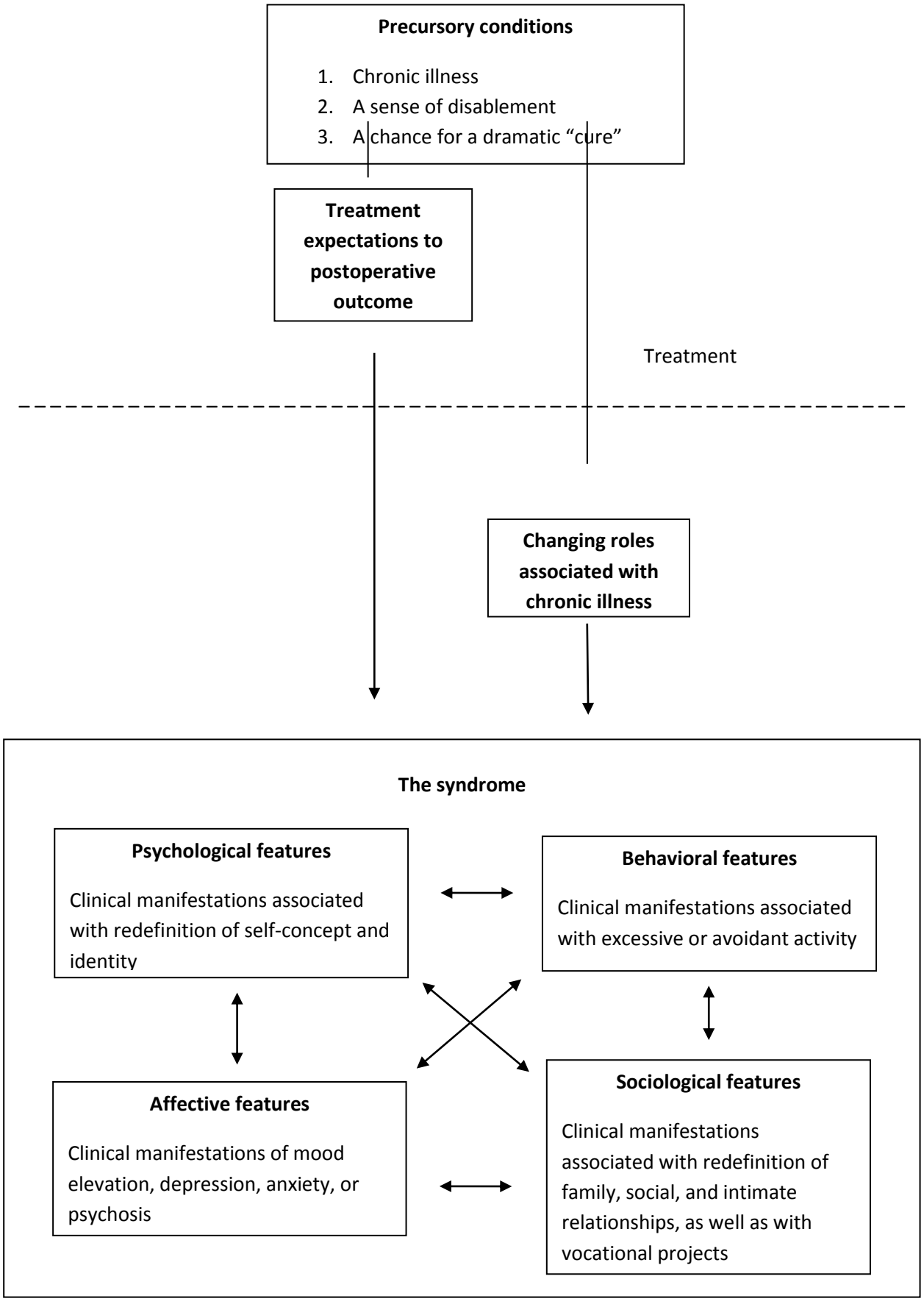

Figure 1. The burden of normality model (adapted from Wilson et al., 2001).

Figure 2

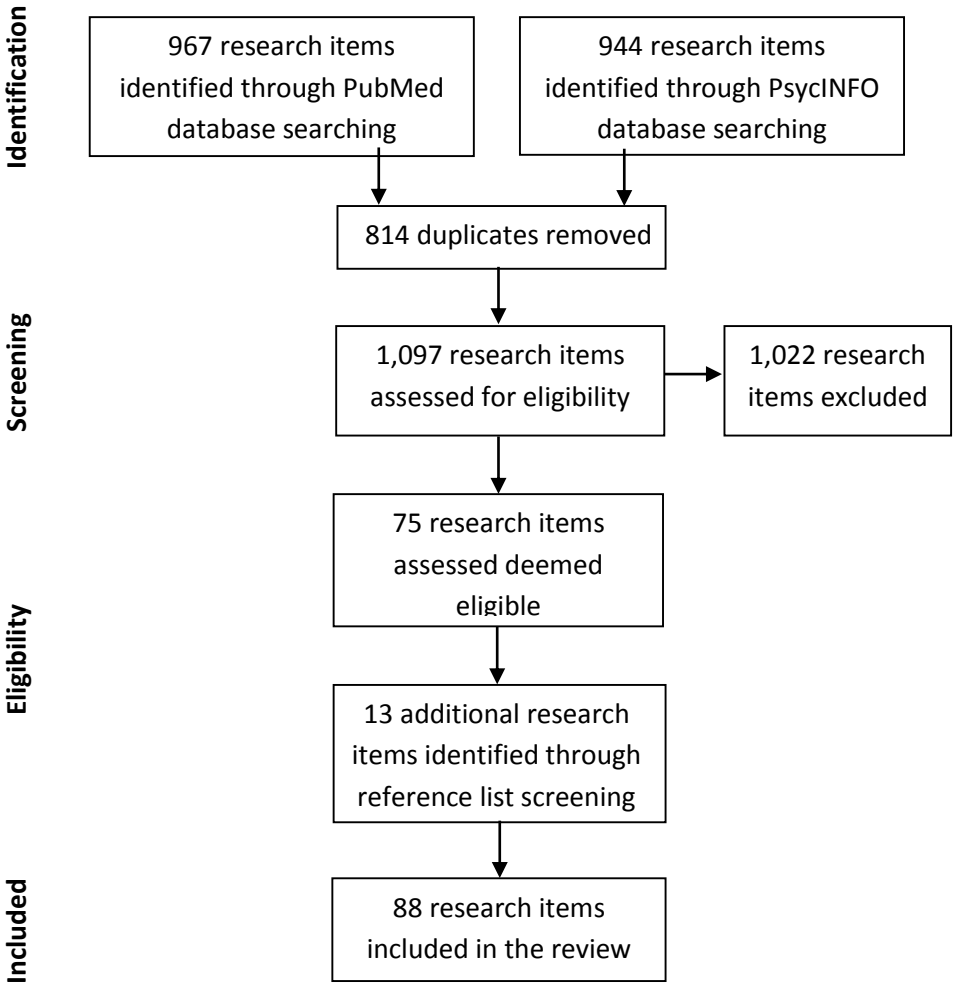

Figure 2. Flow of information through the different phases of the systematic review.