

## Review Article

# A Review of Social and Relational Aspects of Deep Brain Stimulation in Parkinson's Disease Informed by Healthcare Provider Experiences

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*Background.* Although the clinical effectiveness of deep brain stimulation (DBS) in Parkinson's disease is established, there has been less examination of its social aspects. *Methods and Results.* Building on qualitative comments provided by healthcare providers, we present four different social and relational issues (need for social support, changes in relationships (with self and partner) and challenges with regards to occupation and the social system). We review the literature from multiple disciplines on each issue. We comment on their ethical implications and conclude by establishing the future prospects for research with the possible expansion of DBS for psychiatric indications. *Conclusions.* Our review demonstrates that there are varied social issues involved in DBS. These issues may have significant impacts on the perceived outcome of DBS by patients. Moreover, the fact that the social impact of DBS is still not well understood in emerging psychiatric indications presents an important area for future examination.

## 1. Introduction

There is evidence that deep brain stimulation (DBS) can improve both motor function and quality of life in patients suffering from inadequately controlled symptoms of Parkinson's disease (PD), when compared to patients on best medical therapy alone [1, 2]. In addition, DBS is a neurosurgical intervention utilized for the treatment of patients with essential tremor and dystonia [3]. However, aside from the apparent efficacy of DBS, there are also data suggesting psychosocial adjustment difficulties in some patients with DBS which paint a more complex picture of patient outcomes. Powerful questions about whether "the doctor is happy, the patient less so?" [4] and whether there might be a "distressed mind in a repaired body?" [5] suggest

that psychosocial factors after DBS may have a large impact on patients.

The psychosocial challenges that may present after DBS have been explored by Agid and colleagues [4–6]. In their qualitative interview study of PD DBS patients, the authors observed that some patients faced a range of psychosocial challenges including what they interpret to be repercussions and difficulties for the "self" (the patient), with "the other" (the spouse) and with "others" [4]. Additionally, a qualitative interview study of patients and healthcare providers performed by Gisquet demonstrated that some patients who have undergone DBS communicate "a loss of control over managing their illness and over their life," characterized by the fact that patients report being tied to the medical team

to manage their stimulator and their treatment in a way that they were not before [7].

Although, at the core, evaluating the clinical efficacy of an intervention such as DBS relies on measurements of motor improvement, the evaluation of psychosocial factors and challenges is important because these factors will impact overall quality of life, may be integral to the success of the intervention, as well as may impact how successful the intervention is perceived to be by patients and families. These challenges also draw our attention to areas where providers can target psychosocial assistance for patients after DBS (i.e., in their home life and work life). The analysis of the psychosocial aspects of DBS reflects an understanding of the impact of interventions and clinical effectiveness beyond the limits of generic health-related quality of life (HRQoL) measures [8] and motor scales.

In this paper, we discuss and review social and relational aspects of DBS, focusing on issues brought to light in a qualitative interview study examining healthcare provider perspectives on ethical and social issues in DBS (methods published in detail elsewhere, Bell et al., submitted). From these interviews, we have pulled examples provided by healthcare providers describing social contexts and psychosocial challenges for DBS patients. Six examples, provided by healthcare providers in the field, serve as a catalyst for our discussion and allow us to discuss the literature from different disciplines (e.g., neurosurgery, sociology, ethics) to explore social and relational issues of DBS. The examples illustrate the challenges of: (1) social support for patients undergoing the surgical procedure, (2) changes in “self” experienced by patients and families, (3) changes in the relationship with the spouse experienced by patients and spouses, and (4) occupational and social system obstacles for patients. After each case is presented, we explain the challenge communicated by providers in the example, provide any additional qualitative material from the interviews to illustrate this challenge, explore the published literature across disciplines on the topic and conclude by providing considerations of how this challenge may translate for future emerging applications of DBS in psychiatric disorders such as refractory depression [9–11]. Additional qualitative material from the interviews illustrating the challenges is presented as available online supplemental material at doi: 10.4061/2011/871874. Ethics approval and consent were obtained for the qualitative study from which we draw examples.

### 1.1. Social Support for Patients Undergoing the Procedure

*Example 1.* “[...] I can think of an example where we had somebody who has very low level of education, basically doesn't probably read very [...] not illiterate but very low level and lives on his own and um travelling to and from appointments it's a financial strain because he's not working. We did surgery because there were no other medical options but it makes the management very difficult. [...] because he lives a distance away, it's a lot more work for us to coordinate and to set up things to make sure that he knows

his appointments and where he's going and how to get to and from. We do it, but it's not ideal, and we, I actually, I guess we set the expectation that there needs to be somebody that I can teach along with that person uh who will be close to them to know how to use the device for turning the stimulator on and off. I don't, we won't do it without somebody who can come with him to learn that sort of thing” (D6).

This example highlights the importance of social support for patients undergoing DBS, and also demonstrates the weight that considerations of social support carry for healthcare providers in selecting patients for DBS and in assuring adequate patient management over the long term. Here, delicate considerations of a patient's social situation, including their level of education, access to a social support system, and access to nearby care impact the patient's suitability for the procedure because in the long run these factors may influence success or failure of the intervention. As the provider in this example strongly states, “we won't do it without somebody who can come with him to learn” (D6). Evidenced in the example, patients who present with one or more obstacles in social function are not ideal candidates for DBS, and providers may struggle with ways to sufficiently accommodate the patient and remain confident of overall outcome. Although, as this example also demonstrates, providers strive to find solutions with which all parties are comfortable, ensuring as much as possible that a patient will not be turned down for DBS based on a lack of social support, or social means to manage the process or device. The critical nature of assuring caregiver support for patients was also alluded to by other healthcare providers (see online Supplemental Material, Table 1).

A second reason why healthcare providers in our study suggested that a patient's social support network is important was because family members can provide useful collateral information about the patient, their symptoms, and their illness (see online Supplemental Material, Table 1). In some cases, this sort of information might contribute to the patient selection process, helping to better identify symptoms that are present, symptoms which may or may not respond to DBS. In other cases, after DBS has been performed this sort of collateral information is important because family members may be in a unique position to identify unwanted side-effects of stimulation such as cognitive deficits or behavioral or psychiatric problems than either the patient or healthcare team.

*1.1.1. Implications.* The importance of caregiver support, the role they play in assisting patients in receiving care, and the interplay of social support and potential barriers to care such as the physical distance between patient and team have been emphasized in many different contexts related to DBS and PD. In a previous review of ethical and social issues in DBS, Bell and colleagues suggested that considerations of caregiver support factor into patient selection decisions, since physicians have a duty to select the best candidates for DBS. Maximizing the best outcomes involves an estimation of whether the patient has sufficient support to attain

appropriate levels of care and management of the device after the procedure [12]. This may be particularly important as self-programmable devices and rechargeable batteries are introduced for patients with movement disorders. Because of differences in the amount of medication management required after DBS [13], there may also be subtle differences in the need for support by patients and caregivers depending on the site of stimulation. Bell et al. have suggested that lack of adequate support should not necessarily prohibit patients from accessing DBS, but rather highlight where provisions should be put in place to manage special circumstances [12]. Perozzo et al. have discussed the importance of evaluating the family's capability to offer moral and physical support post-operatively [14]. Accordingly, Okun et al. have stressed the importance of assessing family support, while additionally emphasizing that teams assess the patient's ease of access (including distance) to specialized care and for follow-up care before providing DBS [15]. The authors even relate such strong meaning to this point that they suggest patients who live in "remote areas or without access to care may want to consider other alternatives to device-based therapy (e.g., ablative therapy)" [15].

In another context (examining a potential fast-track inpatient procedure for device programming), Cohen and colleagues also comment on the issue of distance between patients and their care centre. In fact, decreasing the difficulties associated with large amounts of travel to and from specialized centers for patients who do not live close to the programming team is one of the reasons why they suggest an inpatient stay for programming might be beneficial and improve outcomes and speed of programming [16].

Collectively, these studies support the view that family support and social means to access the care team are influential in the potential successes or failures of DBS. However, Lang and colleagues assert that there are no empirical data examining the impact of social support or burdens of travel on clinical success or outcomes in DBS although they also claim that "if the patient does not have transportation available to travel to a center for surgery or programming, they may have to be excluded" [17]. It is evident that patients with poor social networks or social means may become disadvantaged in accessing such specialized care as DBS, or may be susceptible to poorer outcomes or failures if these issues are not identified and managed sufficiently. Therefore, the issue of social support is tightly tied to proper identification of needs for social support and issues of fair access (justice). We therefore would benefit from a better understanding of the impact of social factors in influencing success or failure of DBS, as well as more clarity regarding whether social disadvantages prevent patients from currently accessing DBS, or receiving adequate follow-up care for their stimulators.

*1.1.2. Future Challenges.* Emerging applications of DBS for psychiatric conditions such as major depression may require new considerations about what are sufficient or acceptable social supports and means. Many severely ill psychiatric

patients may have limited social supports. This may compromise their ability to access potentially innovative care, which if successful may even contribute to a re-establishment of social relationships lost due to chronic mental illness. Although a patient's ability to access specialized centers has been proposed as an important selection factor in clinical trials in DBS and psychiatry [18], the issue of social support in these patients has not, to our knowledge, been discussed extensively to date.

### *1.2. Changes in Personality and Changes to the "Self"*

*Example 2.* "So for example one man who had ... bilateral subthalamic stimulation, his wife described him after the surgery basically as being like a spontaneous, impetuous, difficult, teenager. They would be out driving ... they lived near to a boarder ... with the United States and he would say: Hey let's go see if we can get across the boarder without our passports. You know this a man in his sixties. He would come home with an all-terrain vehicle. You know this is a man who previously hiked and enjoyed sort of peaceful serenity in the outdoors and now wanted to drive an all-terrain vehicle through the woods" (D3).

Describing a patient having undergone DBS who is by his family's account a significantly *changed* person, this provider's example highlights a number of important issues. It provokes reflection about the causes of the observed alterations in behavior and makes us wonder if the behaviors observed are brought on directly by the stimulation (represent an induced change in the patient's personality)? Or does the behavior relate to the fact that the patient once hindered by chronic illness may be adapting to a new role and a new health status, as well as a new device implanted in their body? Other providers in our study emphasized that patients may face adaptation challenges after DBS, coming to terms with a new identity which includes foregoing the obligations and behaviors associated with being sick (foregoing the *sick role*, see online Supplemental Material, Table 2). They often likened these challenges to well-documented consequences reported in some epileptic patients having undergone neurosurgery. Ultimately, this example also raises questions about the expected role of the healthcare team with regards to potential changes in behavior, personality, and adaptation following DBS.

*1.2.1. Implications.* There are essentially two different aspects to be discussed regarding the role of DBS towards changes in the "self." The first issue revolves around what amount of influence stimulation itself has as a cause or contributing factor to behavior changes or personality changes in DBS patients. The second issue, brought up by several healthcare providers in the study, is what, if any, personal adaptation challenges are faced by PD patients after DBS.

*The Influence of DBS on Behavior and Personality.* The influence of DBS on behavior and personality has not clearly been delineated, and there is conflicting evidence

that changes in mood and anxiety occur after DBS [12]. There are data which demonstrate increased impulsivity in some PD patients after DBS. Although, it is accepted that impulse control disorders can present in PD patients treated with dopamine agonists, several researchers have also demonstrated increased impulsivity in PD patients treated with DBS regardless of the influence of dopamine agonists [19–21]. In fact, after having observed that 3 out of 19 DBS patients studied had impulse control disorders (i.e., compulsive shopping, pathologic gambling), compared to 3 out of 37 patients treated with best medical therapy, Halbig and colleagues reported this observation as an “unexpectedly high frequency of impulse control disorders in PD patients with STN DBS” [21]. Moreover, Gisquet has suggested that the experience of mood or behavior changes after DBS may be so far reaching for patients such that they “have the feeling that their identity has been affected” [7].

The larger question remains whether these types of changes, or others observed after DBS, are substantial alterations in the personality of the patient, especially when we consider that there are many possible conceptions of the terms personality and self? According to Synofik and Schlaepfer's assertions about personality and DBS, it is likely that on some level personality is affected by DBS; although the authors propose it is more important whether the patient's personality is altered in a way that is evaluated to be good or bad by them and their family [22].

Importantly, changes in mood or behavior observed after DBS are not related to the procedure specifically but rather to the stimulation and target of stimulation and there is still active discussion regarding the site of choice for stimulation in advanced PD patients and the side-effects or advantages of these targets. It has been suggested that stimulation of the subthalamic nucleus (STN) results in more mood related adverse events, than stimulation of the pallidal target (reviewed in [23]) and recent data suggests that adverse events to mood (depression/anxiety) may be higher over the long term in patients who undergo STN stimulation than globus pallidus interna (GPi) stimulation [24]. On the other hand, Okun and colleagues (2009) have observed that stimulating the ventral contacts of both STN and GPi can produce negative mood effects, which they suggest likely owes to the ventral spread of activity to nonmotor and limbic circuits [25].

#### *Personal Adaptation Challenges Faced by Patients after DBS.*

A landmark qualitative interview study of PD patients after DBS, conducted by Agid and colleagues, has revealed some of the important social adaptation challenges faced by patients, despite improvements that they experience in their motor symptoms. The authors describe that some patients reported a difficulty adapting to a new concept of themselves and the improvement of their illness [4], or felt strangely about their after-DBS self [5]. At the same time, they present evidence that for some patients there may be a sudden loss of goal or direction for life once the disease symptoms, a previously large focus of daily life, are improved [4]. Other authors have proposed that DBS may

create adaptation challenges for patients because of a discord created between the patients narrative identity before and after DBS [26], or because of an abrupt alteration created in the patients' experience of chronic illness [7]. As Seaburn and Erba comment, “a discontinuous change in the patient's condition (sudden health) because of a surgical or medical intervention, may eliminate the patient's disease and the disease label from the patient's identity” [27]. Healthcare providers have commented that patient outcomes with DBS may be more modest, and mixed, and have suggested that they dedicate substantial time to dispelling the notion among patients that it is a “miracle cure” [28].

However, a common parallel regarding adaptation issues for the *self* was drawn by healthcare providers in our study between PD DBS patients and patients having undergone epilepsy surgery. There is an extensive literature on the social function of refractory epileptics after surgery, which emphasize the difficulties associated with rejecting behaviors associated with illness (discarding the *sick role*) [29]. The process by which patients undergo a “forced normalization” (a term used by healthcare provider B2, see Online Supplemental Material, Table 2) requires them to incorporate a change in self-image which is concurrent to the improvement seen in their illness [29]. The features of this “burden of normality,” the authors suggest, are comparable across “life-changing” medical interventions, and may present wide-ranging challenges for patients, including in psychological, behavioral, affective and sociological function [30]. Although it should also be noted, and we discuss this further in the future challenges section, that significant difference exist between these two patient populations (PD and epilepsy) in terms of onset of the illness, chronicity and may exist with regards to the relative success and goals of neurosurgical therapy.

*1.2.2. Future Challenges.* There is a small but concise literature demonstrating adaptation challenges for PD patients after DBS [4–6]. Whether or not these challenges, or concurrent changes in personality or behavior, are related or caused by stimulation, we should remain cognizant that these challenges may highly impact patient quality of life and social function after the intervention. In addition, healthcare providers may benefit from engaging patients, and their families, in a discussion about psychosocial challenges thereby increasing the early detection of difficulties and facilitating psychosocial interventions. Cohen and colleagues have highlighted the importance of psychological adjustments to DBS by integrating psychological care and psychosocial education in their inpatient fast track procedure for programming [16]. It remains important to further evaluate and delineate the impacts of DBS on behavior and mood. In particular, we are lacking a good understanding of the effects of DBS on these in the context of real life consequences for patients and families. For instance, although some studies have shown that PD DBS patients display impulse control difficulties in cognitive testing, the observations of actual impulse control disorders in PD DBS patients [21] (as well as a



consideration of what the impacts of excessive gambling and shopping might mean) emphasizes the potential importance of establishing if these are in fact *de novo* problems brought on in the DBS patient. Besides numerous pharmacological and disease related factors, the impact of placement of DBS leads in more lateral sensorimotor or medial associative limbic sectors of the subthalamic nucleus may also play a role in emergence of potential mood disorders. Finally, a better understanding of challenges related to self-identify, and personality may be especially important in the face of emerging applications for DBS in psychiatry. We lack evidence on what the impacts of DBS might be for these patients in the context of social function, how they might adjust to DBS, or to improvements in their chronic illness and disability. The fact that patients will likely have suffered chronic illness for long periods of time might be more antagonistic to the process of restructuring identity after DBS, than in PD, where the duration of illness may have been shorter and the onset later in life. In this regard, we could hypothesize that the course of the burden of normality may end up being more like that experienced in epileptic patients where the onset of disease is earlier and where younger patients may have faced lost early opportunities for personal exploration and growth. In addition, neuropsychiatric conditions are tightly linked to the concept of self; DBS for psychiatric disorders has the *goal* of altering personality [22].

### 1.3. Relationship with the Other

*Example 3.* “A wife who has had a husband who has really been I would have thought a great care to her in terms of his Parkinsonian needs and she fulfilled that role, it was doing something for her. Um, is it pathological what it was doing to her? I don't know. At any rate, she got satisfaction on the fact that he was dependent. Where he had previously been the dominant party in the pair, he was now dependent. I don't think that there was abuse in the story, in the particular case, I don't think there was abuse involved but she got satisfaction on the fact that he was now dependent and in need of her. That was satisfying a need with her. [ . . . ] There began to be conflict situations between husband and wife because now he was much more independent. He was driving again, so he said look, I am going to go down and see some of my friends. So I must say that I am not sure that if in the past he had gone down with some of his buddies and spent a lot of time away from home etc. etc. that I am not sure about. Anyway, it was a bad situation. So the two of them had a great deal of conflict and we had to deal with that and get some counseling for the two of them because of these new exchanged roles.” (C2).

*Example 4.* “[ . . . ] we had one fellow for example. His wife was, they were really having marital problems—quite frankly she just didn't want to care about him anymore. She was really tired and feeling really burnt out and hoped that the surgery would make him more independent so she wouldn't have to. He was really a lot better but not quite as well as she hoped, right. So you just see how expectations affected all around.” (C4).

These two examples, described by healthcare providers in our study, depict very different problems that emerged for two couples (the patient and their spouse caregiver) after DBS, resulting in marital discord, and difficulties within their relationship. The first example describes a couple where the patient regained enough independence after surgery such that the caregiver/spouse no longer felt needed in the same way as before. While it may seem contradictory to think that a patient regaining independence (one of the goals of the therapy) can raise any sort of a problem, we clearly see in this example that the issues brought on in the relationship were severe enough that the couple was referred for counseling. In the second example, a very different dynamic is described; here, it would seem that the spouse actually desired more independence of the patient than was achieved and that this failure to attain some relief in the role of caretaker also created a struggle in the couple's relationship. References to the former (patient-caregiver conflict based on regained independence of the patient) were quite common in our data (see online Supplemental Material, Table 3).

*1.3.1. Implications.* The data that we have collected demonstrates the existence of psychosocial challenges between the patient and the spouse after DBS. These correlate with issues that have been previously detailed by Schupbach et al. and Agid et al. in their qualitative interview study of PD DBS patients [4, 5]. Patients communicated being faced with two of the same types of problems after DBS with regards to the relationship with their spouse. On one hand, some patients (in their study 6 out of 24 patients) sought to reclaim the independence they previously lost and “rejected their spouse,” advertently or inadvertently causing the spouse give up the caregiver role they were playing over the length of the illness. On the other hand, other patients (in their study 11 out of 24 patients) may be “rejected by (their) spouse”. In this scenario, the authors claim, marital problems arise because the spouse's expectations of outcome are not met by the patient's actual real-life abilities, ultimately reflected in the fact that life does not return to the way it was before surgery [4, 5]. It would seem that the failure of DBS to meet caregiver expectations, not unlike what has been previously observed with failure to meet patient expectations, risks creating disappointment, and conflict [28]. In the epilepsy literature, Bladin has described a similar phenomenon [31]. When assessing cases where a couple had divorced following epilepsy surgery, he describes finding a “hidden agenda” in some of the partners, where one of the expectations for seeking surgery was “if once I can be set free. . .” [31]. The marital conflicts that may be exacerbated by DBS are not insignificant. Although Agid and colleagues reported that most patients who suffered from marital problems after the intervention had also suffered from problems beforehand, patients reported that the problems had worsened after DBS [4]. Agid et al. specify that 65% of patients they interviewed who were married experienced a “conjugal crisis” following DBS [4]. It's interesting to note that while Schupbach et al.

report that a greater percentage of patients in their study were “rejected by their spouse,” these cases were mentioned in the minority by healthcare providers in our study. Perozzo et al. have also described conflicts between spouses that emerged after DBS surgery in a sample of 15 PD patients. The authors reported that caregivers were reluctant to maintain the role of caregiver after surgery, while patients were reluctant to give up the attention and special treatments that they received from others prior to DBS. They also suggested that the conflict between the spouses could even be marked by hostility [14].

*1.3.2. Future Challenges.* Based on our cases and others, it is clear that the reasons for marital conflict following DBS and possible ways to manage or alleviate patient and caregiver distress warrant more investigation. Specifically, a better understanding of how spousal and patient expectations of outcome may influence the marital relationship after DBS may constitute a key area where DBS healthcare teams could intervene to prevent future problems. In emerging indications, researchers need to consider early on the important role of expectation in influencing psychosocial outcome and the changing dynamics of caregiver-patient relationships after DBS. Research outcomes into emerging indications such as treatment refractory depression may not yet be extensive enough to guide patients or their families with regards to realistic expectations, and this may influence psychosocial adaptations for these patients. In addition, unique issues with regards to family dynamics may exist in psychiatric patient groups, which may need to be considered in evaluating the potential impacts of DBS on the family and spouse of psychiatric candidates.

#### *1.4. Employment, Vocational Opportunities and Disability*

*Example 5.* “Most of the time, by the time they are in this state most of them have been off of work for a long time and there is no practical employment. Having said that, we have done some younger patients who are having difficulty with their employment. There is a guy [· · ·] but this fellow was a journalist. His problem, with his Parkinson's disease wasn't all that bad but it was right-sided. He did a lot of writing and keyboarding. That is what he was doing for a living. He was having difficulty using his hand on the keyboard and so he was very slow in producing written material. He wanted something done about his tremors and stiffness and slowness. We thought he was relatively well optimized in terms of medication and he had had some side-effects when they tried to push his drugs higher than that—mental changes and some hallucinatory material. So we felt that normally we wouldn't have done a guy like this surgically but we did him because he had a specific problem and we felt that this was a reasonable approach—he was a young man. He did very well. His tremors disappeared and his bradykinesia became less. He was able to address the keyboard better and write better and he is a happy camper. He hadn't stopped work in that sense, but he had slowed down his work and he was able to do less.” (C2).

*Example 6.* “[· · ·] a very striking example of a young woman who developed a pretty bad movement disorder specifically a generalized dystonia at a young age and as a result was disabled enough that she couldn't really work and uh and at age forty, having failed medical treatment over the years and the surgery comes along and now is the treatment option, we treated her and it cured her, and so now all of a sudden you've got a forty year old who's for the first time in her life normal, and uh that was a major problem. You wouldn't think fixing a disorder would be an issue uh in that manner but all of a sudden this person's normal, the social services people are saying: well look, you're now well you should go get a job. She had not had any employment experience at all in her life, her peer group who were other people that were living in at kind of that level of society, all of a sudden says: ‘well you kind of don't belong with our group anymore there's nothing wrong for you,’ and so there is an issue of when it works really well people not really being prepared for not being disabled anymore, which often is what we talk about.” (E2).

In the first example, the provider describes the unique case of a young, and still actively employed, PD patient given DBS. For this patient, DBS is an intervention that not only improved the motor symptoms of PD, but also restored the motor skills necessary for his career. Ultimately, in this case, DBS allowed the patient to remain gainfully employed. His situation was clearly facilitated by the healthcare provider who considered the possible positive impacts of DBS for his job. This example was unique because in our discussions with providers we largely gathered that most patients referred for DBS are no longer working (had already retired or stopped working because of their disorder). This example highlights how DBS applied in specific cases to good candidates at a younger age might maximize work opportunities, and to some extent reduce the burden of disability.

In the second, and the very different example, the provider described a patient with early life onset of dystonia. The patient had been unable to work during the time when she was disabled by the disorder. Once DBS was applied later in life, this patient was at a severe disadvantage because she suffered from a lack of necessary skills to access employment opportunities. Even worse, the provider described that once the patient's symptoms improved there was an expectation of employment and an expectation that the patient would not need the same social provisions for her disability. Providing the best therapy for this patient created new social and employment challenges.

*1.4.1. Implications.* The topics of employment and occupational disability, while not well discussed in the context of DBS specifically, have been examined in PD patients more generally. In one UK study, Schrag and Banks found that 52% of patients with PD retire early and that the mean time to loss of employment for patients was only 4.9 years from diagnosis [32]. Moreover, 10 years after the onset of the illness, 82% of PD patients are no longer working [33]. This study highlights the importance of, first, having PD

patients plan for the future early on in their disease and second, of providing accommodations to try to keep patients in the workforce later into the course of their disease [33]. The implication for DBS practitioners and patients who may be good candidates is that it may be important to consider acting sooner than later to prevent loss of employment and the accompanying financial burdens. Alternatively, there may also be a role for providers to assist patients and employers in finding appropriate new roles in the workplace for patients with DBS. In fact, this was something that a provider in our study stated having done in the past. In an earlier study Schrag and colleagues described the impact that a loss of employment might mean for young (onset before age 50) PD patients. These patients may suffer substantial economic consequences as a result of occupational losses, and they have been found to perceive that their disease has a greater impact, when compared to their older counterparts with similar disease duration [32]. Moreover, the authors observed that in their sample, younger PD patients were considered unemployed or had retired early, compared to older PD patients who had either already retired (before their illness onset) or were close to retirement age [32]. The financial burden created by this situation, may also play a role in creating marital conflicts for these patients [32].

On the other hand, for some movement disorder patients it may be the loss of opportunities to gain the skills necessary to be employable that poses the specific problem, rather than the loss of current employment (i.e., the second-case example). This challenge may be revealed after a patient's symptoms improve with DBS. The same sort of problem has been alluded to in the context of epilepsy, where patients who undergo epilepsy surgery may have experienced an early age of onset, creating disadvantages to gain life skills and occupational or educational opportunities. Bladin et al. report that 12% of the epileptic patients they studied after surgery recounted grief or bitterness about the fact that the surgery had not been attempted earlier in their life [31]. We can imagine that a portion of this regret was due to losses in achieving what they considered to be their full potential. For some DBS PD patients, Agid et al. have described that feelings of a "retrospective disaster" can be experienced. Although their motor symptoms have improved, patients have suffered irreparable consequences of the disorder (i.e., loss of friends, loss of employment) [4]. Unfortunately, there is no data, to our knowledge, which captures the challenges directly related to social assistance programs and the abilities of patients to access these services after an intervention such as DBS.

*1.4.2. Future Challenges.* The last comments do not imply that younger patients are all good candidates for DBS or that DBS will have an impact on employment or occupational opportunities for every patient. As our cases suggested, many patients undergoing DBS, particularly for PD, have already left their jobs, but providers may want to discuss with patients and their families what goals they may have with respect to occupation. There are some patients who may make an active choice to not go back to work after

DBS. Agid and colleagues have shown that a number of patients actually decide that work carries less importance after DBS than it did before [4]. It is likely that more occupational challenges will be revealed in emerging uses for DBS, such as refractory depression. As a consequence of a long, severely limiting illness such as refractory depression, we can foresee challenges much like those related in the second example. Patients who have been severely limited in seeking out educational or occupational opportunities may perceive that they have truly "lost" time. Severely impacting patients' abilities to access resources and secure employment opportunities, this also has the potential to influence how patients perceive their long term outcome. Providers may be able to help prepare patients to look ahead and plan for future success.

## 2. Conclusion

Patients undergoing DBS may face a range of psychosocial challenges after the intervention, at home and at work, and psychosocial factors may also impact patients' ability to access and continue successful therapy. A richer understanding of the challenges that patients face is achieved through analyzing cases where patients, and healthcare teams, have been confronted with and/or managed psychosocial challenges. With an increased emphasis being placed on the development and contribution of patient reported outcome measures (PROMs) in neurological trials [34], the perspective of patients on aspects of HRQoL including social functioning and relationships with others is important to capture the actual issues faced by patients [35]. Ideally, these perspectives would be incorporated into PROMs and considered in the demonstration of clinical efficacy of interventions such as DBS. The psychosocial success or failure of DBS may become even more important in emerging psychiatric indications of DBS, and, early on, these factors should be explored systematically among these patients and their families.

## Conflict of Interests

The authors have no conflict of interests to report related to the research in this paper.

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