OXFORD UNIVERSITY PRESS Archives of CLINICAL NEUROPSYCHOLOGY

Archives of Clinical Neuropsychology 33 (2018) 365-374

The Role of a Neuropsychologist on a Movement Disorders Deep Brain Stimulation Team

Cynthia S. Kubu^{1,2,3,*}

¹Center for Neurological Restoration, Cleveland Clinic, Cleveland, OH, USA ²Department of Bioethics, Cleveland Clinic ³Department of Psychiatry and Psychology, Cleveland Clinic

*Corresponding author at: Center for Neurological Restoration, Cleveland Clinic, P57, 9500 Euclid Ave, Cleveland, OH 44195, USA. Tel.: +216-445-6848; fax: +216-444-4525.

E-mail address: kubuc@ccf.org (C.S. Kubu).

Editorial Decision 1 November 2017; Accepted 6 December 2017

Abstract

The term movement disorders is misleading in the implication that the symptoms are limited to motor problems. Most movement disorders include a variety of neurobehavioral and neurocognitive symptoms that require neuropsychological expertise. The goal of this paper is to provide a rationale and practical roadmap for neuropsychologists' involvement in a Movement Disorders team with a specific focus on pre-operative deep brain stimulation (DBS) evaluations. Pragmatic recommendations regarding requisite skills, clinical practice, recommendations, communication, and benefits are outlined.

Keywords: Movement disorders; Parkinson's disease; Professional issues

Introduction

There is a long history in functional neurosurgery, such as epilepsy surgery and more recently deep brain stimulation (DBS), to include neuropsychologists on the clinical team. This history is reflected in many of the published guidelines for DBS teams which specifically argue for the inclusion of neuropsychologists on the treatment team (Bronstein et al., 2011; Lang et al., 2006; Rezai et al., 2008). The goal of this paper is to provide pragmatic information in support of neuropsychologists' involvement in functional neurosurgery movement disorder teams. It is beyond the scope of this paper to address all movement disorders; consequently, this paper will focus on Parkinson's disease (PD) which is the second most common neurodegenerative disorder and affects 1% of the population worldwide (Tanner & Goldman, 1996)

Rationale

The term movement disorders is misleading as the symptoms these patients experience are not limited to motor symptoms. Patients with movement disorders may present with very complicated neuropsychiatric and neurocognitive symptoms which may be more distressing to the patients and family members than the motor symptoms (Pandya, Kubu, & Giroux, 2008). As is the case with many patients neuropsychologists assess, the underlying functional neuropathology and neuroanatomy are essential to understanding the potential clinical presentations in patients with PD.

Braak and colleagues (2006) relied on α -synuclein immunoreactivity staining to identify six neuropathological stages in PD. Stage 1 is defined by pathological changes in the dorsal motor nucleus of the vagus nerve and anterior olfactory structures. This is followed by Stage 2 in which the lesions in the dorsal motor nucleus are more severe with additional involvement of inclusion bodies in the raphe nuclei, magnocellular portions of the reticular activating formation, and the locus coeruleus. In Stage 3, the pathology is present in the basal portions of the midbrain and forebrain, including the central

© The Author(s) 2018. Published by Oxford University Press. All rights reserved. For permissions, please e-mail: journals.permissions@oup.com. doi:10.1093/arclin/acx130

subnucleus of the amygdala and regions of the basal forebrain such as the nucleus basalis of Meynert. It is during Stage 3 that changes begin to be apparent in the pars compacta of the substantia nigra and initial motor symptoms may first be present. Stage 4 is characterized by transition of neuropathological changes to the temporal mesocortex with significant involvement of the amygdala and initial cortical involvement of the anteromedial temporal mesocortical regions. Stage 5 is characterized by even greater temporal mesocortical involvement as well as pathological changes in related insular and anterior cingulate cortical regions. Stage 6 represents the most severe of the stages with even greater cortical involvement. Braak, Rub, and Tredici (2006) have demonstrated that severity of cognitive impairment assessed via the MMSE corresponds to these six stages. The neuropathological changes outlined above provide ample evidence that PD is not simply a disorder associated with dopamine loss in the pars compacta of the substantia nigra; multiple neurotransmitter systems, subcortical and cortical regions are impacted by this disease.

Functional neuroanatomical models can also provide a helpful framework from which to better understand the neurocognitive and neurobehavioral symptoms in PD. Many movement disorders arise from disruption to critical cortico-striato-thalamocortical (CSTC) networks involving the frontal cortex and basal ganglia. In their seminal paper, Alexander, DeLong, and Strick (1986) articulated the presence of five segregated, parallel circuits that originate in different regions of the frontal lobe and traverse to specific regions within the striatum. The networks then travel to regions within the thalamus and ultimately return to the cortical region of origin. In their initial conceptualization, Alexander, DeLong and Strick argued that these five CSTC networks included: (a) a motor network whose origin was the supplementary motor area; (b) an eye movement network originating in the frontal eye fields; (c) a cognitive network originating in the dorsolateral prefrontal cortex (DLPFC); (d) a limbic network arising from the anterior cingulate cortex (ACC); and (e) another limbic network arising from the orbitofrontal cortex (OFC). Over time, it has been well established that many classic movement disorders (e.g., PD, Huntington's disease) entail neuropathological changes that extend beyond the motor circuit and may directly involve the neurocognitive and neurobehavioral circuits as well (Lichter & Cummings, 2001). Cummings (1993) elaborated on these networks and, with respect to the neurobehavioral networks, illustrated the importance of the DLPFC network to executive cognitive function, the ACC network with respect to motivation, and the OFC network with respect to inhibition. The influential CSTC model has subsequently been revised (Middleton & Strick, 2001). Nonetheless, the initial hypothesis put forward by Alexander, DeLong, and Strick continues to be very powerful and provides a scaffold from which to better understand the neurobehavioral and neurocognitive symptoms that can arise in the context of movement disorders.

Not surprisingly, the cognitive symptoms that can be evident in movement disorders often resemble what can be observed in patients with DLPFC dysfunction, including problems with complex attention (i.e., maintenance of attention, mental flexibility), impairments on problem solving tests, perseveration, difficulties with response inhibition, and reduced scores on tests of word fluency. Slowed processing speed is also common, particularly in patients with Parkinson's disease (PD). Qualitative features can include difficulties maintaining train of thought, concrete thinking, poor planning/organization on tasks, perseveration, and bradyphrenia. Generally speaking, cognitive symptoms may not be detectable early in the course of idiopathic PD. As the disease progresses, mild difficulties may become apparent on isolated tests assessing processing speed, planning, mental flexibility, response inhibition, and word fluency with inefficiencies on memory testing characterized by an organizationally based memory impairment (i.e., less efficient word list learning relative to memory for more structured information such as short stories). A bit later in the course of cognitive changes, patients may exhibit impairments on measures assessing visuospatial skills with more widespread impairments in the domains listed above. As the cognitive symptoms progress, a frank dementia may emerge. Similarly neuropsychiatric symptoms are very common in PD such as depression, anxiety, apathy, poor mood regulation, and in some cases, disinhibition reflecting disruption to limbic circuits. The neurocognitive and neurobehavioral changes appear to reflect the underlying functional neuroanatomy and progression of neuropathological changes.

In addition to the underlying functional neuroanatomy of PD, many of the medications used to address motor symptoms associated with movement disorders may result in neurobehavioral or neurocognitive symptoms that can best be discerned in the context of a careful neuropsychological assessment including a detailed interview. For example, there is a clear association between dopamine agonists for the treatment of PD and impulse control disorder symptoms (Weintraub et al., 2010). Similarly, memory impairments characteristic of medial temporal memory dysfunction and word finding difficulties may occur in the context of anticholinergic medications for the treatment of tremor symptoms. In addition, neurosurgical treatments (e.g., deep brain stimulation, DBS) designed to address motor symptoms in patients with PD may also theoretically result in neurocognitive and neurobehavioral changes due to stimulation spread to adjacent non-motor CSTC networks and/or microlesion effects associated with placement of the lead.

In summary, the underlying neuropathological and neuroanatomical basis of PD as well as the potential neurocognitive and neurobehavioral side-effects that may be associated with either pharmacological or neurosurgical treatments provide two very strong arguments for including neuropsychologists in a movement disorder integrated care team. The remainder of this paper will focus more specifically on the role of a neuropsychologist on a DBS Movement Disorder team using PD as a prototypical example. However, similar principles and recommendations apply to other movement disorders as well (Box 1).

Essential Skills and Specific Competencies

Clinical neuropsychology's sweet spot is the intersection between functional neuroanatomy, assessment, and behavior. This is particularly true for neuropsychologists embedded in integrated care movement disorder teams.

Functional neuroanatomy provides the scaffold from which to make predictions regarding potential neurocognitive and neurobehavioral symptoms that might arise in the context of specific movement disorders. Functional neuroanatomy also includes basic knowledge of the impact of disruption in specific neurotransmitter systems on neurocognitive and neurobehavioral variables. A common neuroanatomical vocabulary facilitates communication with the neurologists and neurosurgeons on an integrated care movement disorders team and helps establish mutual respect for individual areas of expertise within the neurosciences.

Expertise in assessment and psychometrics are highly valued and essential skill sets. These skills represent the neuropsychologist's bread and butter. Neuropsychologists' expertise in measurement and ability to reliably and validly characterize patients on a number of neurobehavioral variables, examine changes over time in a rigorous manner, determine the neuropsychological safety of specific treatments, and identify patients at potential risk for proposed treatments are essential on a movement disorders DBS team. It is appropriate to include knowledge of appropriate research design and statistics within the domain of assessment and psychometrics. These skills, that are covered in all training programs that follow the Houston guidelines, are highly valuable especially given the increasing emphasis on outcome assessments in medicine.

Finally, neuropsychologists' expertise in behavioral observation and communication skills are essential in the identification of qualitative features that can be critically important for case conceptualization, eliciting sensitive information from the patient and family, and communicating in an effective manner to both patients, families, and colleagues.

In addition to these broad domains, neuropsychologists working on movement disorder teams benefit from specialized knowledge regarding the presentation and course of the most common movement disorders. It is helpful to understand the core features that distinguish PD from other parkinsonian disorders (e.g., multisystem atrophy, progressive supranuclear palsy, normal pressure hydrocephalus, vascular parkinsonism, Lewy Body Disease; see Benecke, 2002). Clear understanding of the

Box 1. What is DBS?

Deep brain stimulation for the treatment of PD is a well-established treatment for motor symptoms of PD (Benabid, Chabardes, Mitrofanis, & Pollak, 2009; Deuschl, Schade-Brittinger, et al., 2006; Weaver et al., 2009). Deep brain stimulation involves the placement of a stimulating electrode(s) in deep brain structures. The DBS electrode is connected to an internal pulse generator (IPG), similar to a cardiac pacemaker, that can be programmed along specific stimulation parameters. Deep brain stimulation is theoretical reversible and allows for titration of stimulation parameters to maximize benefit and minimize side-effects. Its safety is well established. The most common target is the subthalamic nucleus (STN) followed by the globus pallidus pars interna or ventral intermediate nucleus of the thalamus. Some motor symptoms are better treated with DBS than others and some targets are preferred over others depending on the primary symptoms, goals, and potential risks. On the morning of surgery, patients are off their medications which is most often a very uncomfortable state characterized by marked tremor and rigidity. Typically at our site, patients are sedated early in the morning while a stereotactic frame is attached to their skull. (Although, not all patients will have DBS surgery with a stereotactic frame). Once the target has been identified with three-dimensional coordinates, a burr hole is placed and an electrode is inserted. Preferably, patients will be awoken at this time. During this stage, intra-operative mapping occurs in which the patient will participate in various tasks to help identify the best target location based on response to stimulation. Once that target is identified, the patient is sedated, the stimulating electrode is withdrawn, and the surgery continues with placement of the DBS electrode. At our center, the patient most often returns for a second surgery to place the IPG (typically in the chest) and connecting cable. The patient typically returns a few weeks following placement of the IPG for their initial programming session. It may take several visits to identify the optimal stimulation parameters.

expected cognitive changes associated with PD and the typical course of cognitive changes in idiopathic PD is also critically important. Finally, additional knowledge of the disease specific measures most commonly reported in the outcome literature for PD is also helpful (e.g., Unified Parkinson's Disease Rating Scale, Fahn, Elton, & UPDRS Development Committee, 1987; Parkinson's Disease Questionnaire-39, Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997). The NINDS Common Data Elements site is particularly helpful (https://www.commondataelements.ninds.nih.gov/PD.aspx#tab=Data_Standards) as is the International Parkinson and Movement Disorder Society website (http://www.movementdisorders.org/MDS.htm) for identifying commonly used outcome measures in the assessment and treatment of patients with a number of movement disorders. For those neuropsychologists working on DBS or other neuromodulation teams, it is important to know the relevant published guidelines (Bronstein et al., 2011; Deuschl, Herzog, et al., 2006; Dubois et al., 2007; Lang et al., 2006; Litvan et al., 2011; Voon, Kubu, Krack, Houeto, & Troster, 2006) and outcome studies (Elgebaly, Elfil, Attia, Magdy, & Negida, 2017; Smeding et al., 2006; Voon et al., 2006; Woods, Fields, & Troster, 2002).

Roadmap to Integration

My involvement with the DBS team at the Cleveland Clinic predated the guidelines cited above. Briefly, I had worked previously at another academic medical center on an established epilepsy surgery team. I intentionally expanded my role to include evaluations of patients who were candidates for pallidotomy, thalamotomy, and DBS to increase the breadth of my clinical expertise. When I arrived at the Cleveland Clinic, I scheduled a meeting with the neurosurgeon who was leading the DBS group. He had to leave shortly after our meeting started for a surgery and left me with two other members of the team. I indicated my interest in working with functional neurosurgery teams, shared my prior experiences, and advocated for what I could bring to the team: solid clinical knowledge; years of experience with working on functional neurosurgery teams with a clear understanding of the need to identify patients at potential neuropsychological risk following an elective neurosurgical procedure; and experience conducting and publishing outcome studies. I exchanged emails with the surgeon in which he expressed continued interest in having me see the patients but I was not included in the team meetings. A few months after our initial meeting, I ran into the surgeon at a seminar on DBS and epilepsy. He invited me to a meeting with the DBS surgeons and movement disorder neurologists. I advocated for having a neuropsychologist embedded in the team. One of the neurologist did not see the value but the surgeon did and argued strongly in support of me. Within a month, I was a full member of the DBS team and subsequently helped shape our team. Briefly, the lessons from my experience are: (i) use historical precedents; (ii) advocate your case; (iii) be gently persistent; (iv) secure the support of the leader of the team; and (v) do not hide in your office-showing up counts.

Reimbursement

There is a large infrastructure at the Cleveland Clinic that supports billing and staff do not have to assume those responsibilities. Medicare covers the costs of DBS and the necessary related evaluations. We have been advised that Medicare will not cover the costs of two neuropsychological evaluations within 1 year; consequently, we ensure that our post-operative DBS evaluations occur outside of that window. The neuropsychology section employs a technician model; thus, billing includes the relevant number of hours for both 96118 (\sim 3 h) and 96119 (\sim 3 h) CPT codes. The most commonly used diagnoses in our pre-operative DBS evaluations are: PD, Frontal lobe and executive cognitive impairment, MCI, and Situational anxiety and depression.

Setting

The Cleveland Clinic is a large academic medical center with over 48,000 employees and over 3,000 staff. The Movement Disorders team includes 10 neurologists, 3 neurosurgeons, 2 neuropsychologists, a health psychologist, a bioethicist, and several advanced practice nurses. The Movement Disorders group at Main Campus saw over 1,700 patients with PD in 2016 and there were over 6,000 patients with PD seen throughout the Cleveland Clinic enterprise (including family health centers in the Cleveland region, other associated hospitals, and sites in Florida, Las Vegas, Toronto, and Abu Dhabi).

Cases Per Week

The DBS/Movement Disorder caseload represents approximately half of a full time neuropsychologists' clinical load. Our model is based on approximately 10–12 total patients scheduled per week factoring in a 15% no show rate. The 10–12

patients scheduled reflect a typical adult half day battery; those volumes may be adjusted if the referral questions differ (e.g., a brain tumor protocol is typically a briefer screening battery with more patients scheduled throughout the day). Consequently, approximately five to six movement disorder or DBS evaluations are conducted weekly.

Focus of the Evaluation

The pre-operative neuropsychological DBS assessment should address four primary goals: (i) identify the relevant neurocognitive factors, including potential risk factors; (ii) identify relevant neurobehavioral factors; (iii) assess level of family support; and (iv) elicit the patient's and family's goals for DBS (Ford & Kubu, 2006; Rezai et al., 2008).

It is important to characterize the patient's neurocognitive status for a variety of reasons. Perhaps the most salient reason is to determine if the patient meets diagnostic criteria for dementia. The general consensus in the literature (Bronstein et al., 2011; Lang et al., 2006; Voon et al., 2006) is that patients who meet criteria for dementia should not be approved for DBS. However, there are no randomized controlled trials that unequivocally demonstrate that patients with dementia are at increased risk of cognitive decline following DBS. There are data, however, that indicate that pre-operative cognitive status is associated with post-operative complications such as confusion or longer hospital stays (Mikos et al., 2010; Pilitsis et al., 2005). Yaguez and colleagues (2014) demonstrated that general intellectual function and word list learning were the best predictors of verbal memory decline following DBS in a sample of 30 patients with PD. A more detailed study examined the impact of mild cognitive impairment (MCI) on immediate post-operative outcome (e.g., length of post-operative hospitalization, post-operative confusion), intermediate (i.e., 6-month post-operative) and longterm (1 year post-operative) motor and quality of life outcomes (Abboud et al., 2015). Patients with PD were classified into three groups prior to DBS: (i) patients with multidomain MCI; (ii) patients with single domain MCI; and (iii) normal cognition. Pre-operative confusion. Evidence of visuospatial impairments prior to surgery showed a trend toward occurrence of post-operative confusion. Evidence of visuospatial impairments prior to surgery showed a trend towards less improvement in 6 months PD functional score (p = 0.065) and 1 year quality of life score (p = 0.051).

As noted above, neurobehavioral symptoms associated with PD or the medications used to treat PD may present more challenges to the patient and family than the actual motor symptoms. Depression, anxiety, and apathy are very common in PD and may reflect the underlying neuropathological changes associated with the disease, psychosocial factors, or other aspects of the treatment (Pandya et al. 2008). There is some debate regarding increased risk of suicide following DBS (Voon et al., 2008; Weintraub et al., 2013) and suicidality should be assessed directly. Impulse control disorder symptoms (i.e., hypersexuality, increased gorging, gambling, impulsive spending, substance abuse) may also be present and/or exacerbated due to use of dopaminergic medications (Weintraub et al., 2010). Parkinson's disease can be associated with hallucinations or delusions due to neuropathological changes associated with the disorder and/or medication side-effects (Fenelon, Mahieux, Huon, & Ziegler, 2000). The role of personality disorders in selecting candidates for DBS has not been well studied, but is also an important consideration. A diagnosis of a personality disorder may not preclude surgical candidacy, but team members, particularly those who will be spending significant time programming the device, will benefit from a better understanding of relevant personality characteristics and assistance in setting appropriate boundaries. The patient's ability to comply with treatment demands and programming requirements is an important consideration in our team. Evidence of a history of poor compliance might tip the decision toward not offering surgery in a questionable case.

As noted above, DBS is a treatment that requires a commitment to continued follow-up for programming appointments as well as replacement of internal pulse generators for many patients. It is important that the patient have a good support network to help provide care immediately following surgery and over the course of the disease. This is not necessarily limited to family members, it can include friends, professional care providers, and/or temporary residence in an assisted living facility immediately after surgery. The psychosocial support is just as important as the instrumental support. It is important to ascertain if the family is supportive of the patient's decision to seek out surgery. Rarely, our team has encountered situations in which the patient did not want surgery and the family was pushing for it or, conversely, the patient was keen yet the family had significant reservations. Specifically inquiring about the level of support and interest in exploring DBS provides important information that helps improve communication, identify interpersonal dynamics that may impact treatment care, and ensure that the patient has the necessary support in place after surgery.

Finally, it is important to identify the patient's and family member's goals for DBS. Deep brain stimulation is an elective neurosurgical procedure designed to improve quality of life. If the patient's goals cannot be addressed with DBS, he or she may be dis-satisfied with the surgical results despite significant improvements on standard motor scales. Systematic assessment of patient's goals opens up an opportunity to clarify expectations and leads to better informed consent and, potentially, improved patient's satisfaction with surgery (Kubu & Ford, 2012; Kubu et al., 2017).

370

Table 1. Cleveland Clinic PD DBS Neuropsychology Protocol

Dementia Rating Scale-II WASI Wechsler Memory Scale-III: LM, LNS, Digit Span Oral Symbol Digit Modality Test Wisconsin Card Sorting Test D-KEFS Stroop Test Wide Range Achievement Test—Single word reading Boston Naming Test Controlled Oral Word Association Test Semantic Fluency Test Judgment of Line Orientation Test Rey Auditory Verbal Learning Test Beck Depression Inventory Beck Anxiety Inventory Parkinson's Disease Questionnaire-39

In order to address these four essential goals, we have tailored a DBS PD protocol (see Table 1) that is particularly sensitive to impairments we would expect to see in PD, minimizes motor demands, and is relatively brief (i.e., most patients complete testing in approximately 2–3 h) in order to obtain the most reliable and valid data. Some measures were included as they are commonly administered in other DBS centers thereby providing an opportunity to share results and experiences across different sites. Other measures are included (e.g., Boston Naming Test) to help rule out potential co-morbid disorders. The formal cognitive tests are accompanied by a semi-structured interview that specifically includes assessment of neurobehavioral concerns, family support, and goals/expectations regarding DBS. We do our best to ensure that the patient is tested in the on state. Our protocol is similar to what others have recommended in the literature (Marras, Troster, Kulisevsky, & Stebbins, 2014; Okun et al., 2007).

Recommendations

Neurocognitive Factors

It is rare that patients with frank dementia are referred for an interdisciplinary DBS assessment at our center. Most of the pre-operative DBS patients will demonstrate only isolated cognitive impairments on measures sensitive to processing speed and/or executive cognitive dysfunction. Those cases are typically not at great risk for cognitive changes following DBS per clinical experience. Slightly more concerning are those patients who have developed visuospatial impairments based on the assumption that greater progression of cognitive impairments associated with PD may reflect a more vulnerable brain. Our group is more concerned about patients who present with a pattern of cognitive impairments that is not typical of idiopathic PD (e.g., anomia, medial temporal memory impairments) or frank dementia. In those cases, careful consideration of any potential situational factors that might have resulted in the poor scores (e.g., patients tested in the "off" medication state, potential medication side-effects, marked fatigue, pain) is required. In these cases, we consult with our neurology colleagues regarding the potential role of medication side-effects negatively impacting cognitive performance (e.g., anticholinergics). If all other members of the team believe that the patient is a good candidate, we will often complete a reassessment in a few months following changes in medications, if necessary, in order to obtain the most valid assessment of cognitive function. If deficits continue to be present, the patient may be denied surgery.

Neurobehavioral Factors

Patients with active severe psychiatric disease (e.g., severe depression, mania) or frank psychotic symptoms are not approved for DBS surgery at our center until their symptoms are under control. Anxiety is common in PD. In order to help address patient's anxiety during an awake surgery, we have included psychologists in the OR to help reduce patient's anxiety and thereby improve the intra-operative mapping process (Broer, Chapin, & Kubu, 2008). This practice was driven by a case in which a patient became so anxious during the surgery that he revoked consent in the midst of surgery (Ford, Boulis, Montgomery, & Rezai, 2007). The surgery was eventually aborted after an urgent consult with the bioethicist and discussion

with the family. Pre-operative identification of patients with significant anxiety helps the surgical team prepare by having extra support in the OR and/or using other neurosurgical options that do not require patient participation during the surgery.

Patients with impulse control symptoms generate considerable discussion in our center. If the symptoms appear to solely reflect dopaminergic medication side-effects, a strong argument in favor of moving ahead with surgery can be made since DBS results in a reduction in medication burden, thereby reducing these side-effects. In order to assess if the impulse control symptoms are clearly linked to medication use, our team may request that patients reduce their dopaminergic burden (most often dopamine agonists) in order to fully evaluate this relationship. A clear cessation of the symptoms following medication reduction provides a stronger rationale for moving forward with surgery. However, if inappropriate symptoms persist or are severe we have been less favorable with moving forward with surgery. These cases are relatively rare, but still occur.

Finally, neuropsychological assessment may identify patients with less severe neurobehavioral symptoms who will benefit from behavioral and/or pharmacological intervention in order to improve their quality of life. We are fortunate to have dedicated mental health experts on our team who can address these concerns.

Support

As touched on briefly above, one of the goals of neuropsychological assessment is to ascertain the level of family support for the patient's decision to consider DBS. If there is limited instrumental support, our team may work with the patient to arrange for in-home care or brief admission to a nursing facility during the immediate post-operative period. Additionally, if discrepancies are evident during the neuropsychological interview between the family's and patient's interest in pursuing DBS that information can highlight the need for more education and/or trigger a bioethics consult.

Goals

Patients and clinicians may have very different goals for DBS. If unrealistic goals are identified during the neuropsychological assessment, those are shared with the other team members. This information provides an opportunity to improve communication and the informed consent process (Kubu & Ford, 2012; Kubu et al., 2017).

Communication

The neuropsychology results are communicated in at least two ways. First, a brief report is written that is posted in the EMR so that all members of the team can access it (see Box 2 for a typical case report). The goal of the report is to communicate the most essential information in as concise and cogent a manner as possible. Consequently, raw test data are not included since those data are meaningless to most members of the team and inclusion of test scores might distract from the most clinically important aspects of the assessment. Topic sentences are used to help draw the referring physicians' attention to the most relevant aspects of the assessment. The recommendations included in our reports are shared directly with the entire treatment team. Every patient who is a candidate for DBS is reviewed in an interdisciplinary team meeting that includes nursing staff, neuropsychologists, a health psychologist, psychiatrist, neurologists, neurosurgeons, a bioethicist, and trainees. It is essential that the neuropsychologist convey the most important information relevant to the individual case in a concise, non-technical manner. On our team, we typically say very little if the patient looks like a good candidate per our four goals. If there are concerns, we highlight them, solicit others' perspectives, and may make specific recommendations per above. Occasionally, patients and families may request feedback from our evaluations, in such cases we may forward them a copy of the report or conduct a feedback session in person or via the telephone.

In summary, the neuropsychology results are communicated via written and verbal form to the referring physicians and entire DBS team. In many cases, feedback is provided to the patient by the treating neurologist or we may provide direct feedback either by forwarding a copy of the report to the patient/family or discussing the findings in a phone call or clinic visit.

Impact

The results of the neuropsychological assessment directly impact clinical team decision making. Cognitive contraindications (32.7%) and neurobehavioral/psychiatric concerns (21.3%) are two of the top three reasons patients with PD are not approved for DBS at our center (Abboud et al., 2015). Unrealistic or unfeasible patient goals account for 9.8% of those cases not approved whereas lack of family support was much rarer (1.6%). There are no good data illustrating the true return on investment of neuropsychological evaluation prior to DBS since no team has gone on to offer DBS surgery to patients with

Box 2. Illustrative report

RELEVANT BACKGROUND: Ms. Patient is a 62-year-old, right-handed, married woman who completed 12 years of formal education. She worked throughout her entire career for company as an assembler or press operator until she had to stop working in 2000 due to back disease. Ms. Patient was referred for neuropsychological assessment as part of her interdisciplinary investigations to determine her candidacy for placement of deep brain stimulating electrodes for the treatment of motor symptoms of PD. The results of this evaluation will be communicated with the referral source via the shared electronic medical chart.

Ms. Patient was interviewed with her husband. She was initially diagnosed with PD in Year following gait difficulties; in retrospect, Ms. Patient suspects that she had some symptoms of PD in the 1990s. Her symptoms have progressed over time and Ms. Patient is currently considering neurosurgery. Her goals with DBS are to return to her former activities and be able to complete valued activities more quickly. Specifically, Ms. Patient is eager to see improvements in her walking, ability to ride a bicycle, drive, crochet, bake, and care for her elderly mother. Her husband is very supportive of Ms. Patient's decision to seek out surgery and hopeful that DBS will result in a reduction in her medication burden.

Ms. Patient's medical history is otherwise remarkable for Ms. Patient was treated for a brief period with Paxil around the time of her retirement to address situational anxiety and depression. There is no other reported history of mental health difficulties or treatment. There is no family history of significant psychiatric difficulties, tremor, PD, or stroke but Ms. Patient's family history is remarkable for... She reported no alcohol use at the present time and denied tobacco and illicit drug use. Her medications are listed elsewhere in her medical chart note. Ms. Patient attributed dyskinesias, nausea, stomach upset, and weight loss to her current regimen. Presently, Ms. Patient lives with her husband of 30 years. She described their relationship very positively and noted close relationships with her mother, step-daughter, and some friends.

INTERVIEW AND BEHAVIORAL OBSERVATIONS: [omitted]

SUMMARY AND IMPRESSIONS: Ms. Patient is a 62-year-old, right-handed woman whose neuropsychological assessment was notable for indications of mild to moderate psychological distress characterized by symptoms of anxiety and more marked depression, per her responses to self-report measures. In contrast, the formal cognitive data were unremarkable. Ms. Patient is a woman of average range intellectual abilities. She achieved low average to average scores on tests assessing basic attention, working memory, processing speed, response inhibition, problem solving, abstract verbal reasoning, vocabulary, single word reading, confrontation naming, and word fluency. Similar range scores were evident on measures assessing block construction, visuospatial conceptual reasoning, and visuospatial matching. Her recall of short stories was high average to average and Ms. Patient achieved average to very superior scores on a word list learning test.

In summary, the current data were most remarkable for the mood and anxiety findings coupled with reports of RBD symptoms and a history of impulsive spending presumably associated with previous dopamine agonist use. Ms. Patient performed very well on all of the cognitive measures. It is apparent that her husband is very supportive of her decision to consider DBS. Ms. Patient may benefit from further discussion regarding her goals for DBS, specifically her desire to ride a bicycle. Referral to Dr. Psychiatrist for treatment of her mood symptoms is recommended. The current findings will serve as a baseline from which to evaluate any changes over time in Ms. Patient's neuropsychological function. Thank you for the opportunity to meet with this interesting woman and her husband. Please feel free to contact me if you have any questions regarding my report or recommendations.

Note: This patient was approved for DBS and is awaiting surgery.

PD regardless of the pre-operative neuropsychological data. Consequently, the data in support of neuropsychological assessment are indirect and limited by a truncated range (i.e., patients with significant impairments do not proceed to surgery). Despite this limitation, cognitive status prior to DBS may help identify patients at risk for complications in the immediate post-operative period (Mikos, et al., 2010; Pilitsis et al., 2005), specific cognitive profiles may help identify patients at risk for post-operative cognitive decline (Yaguez et al., 2014) or reduced PD functional outcome and quality of life (Abboud et al., 2014). In addition, several neuropsychological outcome studies have demonstrated that DBS results in relatively mild cognitive decline of questionable clinical significance. The most common cognitive changes evident following DBS are mild declines on measures of word fluency and, to a lesser extent, memory tests (Elgebaly et al., 2017; Smeding et al., 2006; Voon et al., 2006; Woods et al. 2002). These observations suggest that the existing guidelines are beneficial in minimizing cognitive risk. We have also argued that systematic assessment of patient's goals and family support help improve the informed consent

373

process and better mirror the goals of patient-centered care (Kubu & Ford, 2012; Kubu et al. 2017). Finally, neuropsychologists can be involved in mentoring other medical specialists such as neurosurgeons and neurologists (Abboud et al., 2014, 2015; Azmi et al., 2008a, 2008b; Pilitsis, et al., 2005) as well as authoring publications that highlight the importance of neuropsychologists as key members of DBS teams (Deuschl, Herzog, et al., 2006; Lang et al., 2006; Rezai et al., 2008; Voon et al., 2006). These educational and leadership roles help shape the field.

Role Satisfaction

I often tell the medical students that I have the best job in the world. I have the opportunity to study patients prior to and following a controlled neurosurgical procedure. Those data provide a rare opportunity to study brain-behavior relationships. However, beyond the research opportunities, I have the privilege of working with complex patients with significant disability whose lives improve as a result of our work. That is extremely satisfying and relatively rare in the context of neurodegenerative disorders. My colleagues on the Movement Disorder team are extremely bright, dedicated scientists and clinicians. I have learned a tremendous amount from them about neurology, neurosurgery, neuroanatomy, neuropsychiatry, neuroscience, bioethics, communication, and effective teams. The neuropsychologists' contributions are valued and we have had the opportunity to help shape the field both directly through participation in developing guidelines for DBS and publishing as well as indirectly by training and supervising a variety of students, residents, and fellows.

Advice

Neuropsychology's sweet spot lies at the intersection of functional neuroanatomy, assessment, and behavior. No other specialty has that unique expertise. Do not forget the psychology part of neuropsychology. Those clinical skills are very important in working with patients, families, and other providers and are also critical in addressing the four goals of a pre-operative DBS neuropsychological assessment. Communicate concisely in non-technical terms. Be open to learning from all other team members. Advocate for your role, be gently persistent, garner support, and show up.

Conflict of Interest

None declared.

References

- Abboud, H., Floden, D., Thompson, N. R., Genc, G., Oravivattanakul, S., Alsallom, F., et al. (2015). Impact of mild cognitive impairment on outcome following deep brain stimulation surgery for Parkinson's disease. *Parkinsonism and Related Disorders*, 21, 249–253.
- Abboud, H., Mehanna, R., Machado, A., Ahmed, A., Gostkowski, M., Cooper, S., et al. (2014). Comprehensive, multi-disciplinary DBS screening for Parkinson patients: No room for "Short Cuts". *Movement Disorders Clinical Practice*, 1, 336–341. doi:10.1002/mdc3.12090/full.
- Alexander, G. E., De Long, M. R., & Strick, P. L. (1986). Parallel organization of functionally segregated circuits linking basal ganglia and cortex. Annual Review of Neuroscience, 9, 357–381.
- Azmi, H., Kubu, C., Machado, A., Deogaonkar, M., Frazier, T., & Rezai, A. (2008a, June). Neuroimaging variables predict post-operative neuropsychological performance in patients with Parkinson disease (PD) following placement of bilateral deep brain stimulating (DBS) electrodes in the subthalamic nucleus (STN). Paper presented at the American Association for Stereotactic and Functional Neurosurgery, Vancouver, Canada.
- Azmi, H., Kubu, C., Machado, A., Deogaonkar, M., Frazier, T., & Rezai, A. (2008b, June). Degree of cortical atrophy affects neuropsychological outcome following bilateral subthalamic (STN) deep brain stimulation (DBS) in patients with Parkinson disease (PD). Paper presented at the American Association for Stereotactic and Functional Neurosurgery, Vancouver, Canada.
- Benabid, A. L., Chabardes, S., Mitrofanis, J., & Pollak, P. (2009). Deep brain stimulation of the subthalamic nucleus for the treatment of Parkinson's disease. *Lancet neurology*, 8, 67–81.
- Benecke, R. (2002). Clinical features and laboratory findings for differentiating parkinsonian syndromes. Journal of Neurology, 239, 6-14.
- Braak, H., Bohl, J. R., Muller, C. M., Rub, U., de Vos, R. A. I., & Del Tredici, K. (2006). Stanley Fahn lecture 2005: The staging procedure for the inclusion body pathology associated with sporadic Parkinson's disease reconsidered. *Movement Disorders*, 21, 2042–2050.
- Braak, H., Rub, U., & Tredici, K. D. (2006). Cognitive decline correlates with neuropathological stage in Parkinson's disease. Journal of the Neurological Sciences, 248, 255–258.
- Broer, K., Chapin, J. S., & Kubu, C. S. (2008). Counselor trainees in the operating room. Counseling Today, September 2008, 44-47.
- Bronstein, J. M., Tagliati, M., Alterman, R. L., Lozano, A. M., Volkmann, J., Stefani, A., et al. (2011). Deep brain stimulation for Parkinson disease. An expert consensus and review of key issues. *Archives of Neurology*, *68*, 165–171.
- Cummings, J. L. (1993). Frontal-subcortical circuits and human behavior. Archives of Neurology, 50, 873-880.
- Deuschl, G., Herzog, J., Kleiner-Fisman, G., Kubu, C., Lozano, A., Lyons, K. E., et al. (2006). Deep brain stimulation: Postoperative issues. *Movement Disorders*, 21, S219–S237.

- Deuschl, G., Schade-Brittinger, C., Krack, P., Volkmann, J., Schäfer, H., Bötzel, K., et al. (2006). A randomized trial of deep-brain stimulation for Parkinson's disease. *New England Journal of Medicine*, 355, 896–908.
- Dubois, B., Burn, D., Goetz, C., Aarsland, D., Brown, R. G., Broe, G. A., et al. (2007). Diagnostic procedure for Parkinson's disease dementia: Recommendations from the Movement Disorder Society Task Force. *Movement Disorders*, 22, 2314–2324.
- Elgebaly, A., Elfil, M., Attia, A., Magdy, M., & Negida, A. (2017). Neuropsychological performance changes following subthalamic versus pallidal deep brain stimulation in Parkinson's disease: A systematic review and metaanalysis. CNS spectrums, 2017 Feb 27, 1–14. doi:10.1017/S1092852917000062.
- Fahn, S., & Elton, R. L., UPDRS Development Committee. (1987). Unified Parkinson's disease rating scale. In Fahn S., Marsden C. D., Calne D. B., & Goldstein M. (Eds.), *Recent developments in Parkinson's disease* (pp. 153–163). Florham Park, NJ: Macmillan.
- Fenelon, G., Mahieux, F., Huon, R., & Ziegler, M. (2000). Hallucinations in Parkinson's disease. Prevalence, phenomenology and risk factors. *Brain*, 123, 733–745.
- Ford, P. J., Boulis, N. M., Montgomery, E. B., & Rezai, A. R. (2007). A patient revoking consent during awake craniotomy: An ethical challenge. *Neuromodulation: Technology at the Neural Interface*, 10, 329–332.
- Ford, P. J., & Kubu, C. S. (2006). Stimulating debate: Ethics in a multidisciplinary functional neurosurgery committee. *Journal of Medical Ethics*, 32, 106–109.
- Jenkinson, C., Fitzpatrick, R., Peto, V., Greenhall, R., & Hyman, N. (1997). The Parkinson's disease questionnaire (PDQ-39): Development and validation of a Parkinson's disease summary index score. Age and Ageing, 26, 353–357.
- Kubu, C. S., Cooper, S. E., Machado, A., Frazier, T., Vitek, J., & Ford, P. J. (2017). Insights gleaned by measuring patients' stated goals for deep brain stimulation: More than tremor. *Neurology*, 88, 124–130.
- Kubu, C. S., & Ford, P. J. (2012). Beyond mere symptom relief in deep brain stimulation: An ethical obligation for multi-faceted assessment of outcome. American Journal of Bioethics, Neuroscience, 3, 44–49.
- Lang, A. E., Houeto, J.-L., Krack, P., Kubu, C. S., Lyons, K., Moro, E., et al. (2006). Deep brain stimulation: Preoperative issues. *Movement Disorders*, 21, S171–S196.
- Lichter, D. C., & Cummings, J. L. (2001). Frontal-subcortical circuits in psychiatric and neurological disorders. New York: Guilford Press.
- Litvan, I., Aarsland, D., Adler, C. H., Goldman, J. G., Kulisevsky, J., Mollenhaur, B., et al. (2011). MDS Task Force on mild cognitive impairments in Parkinson's disease: Critical review of PD-MCI. *Movement Disorders*, 26, 1814–1824.
- Marras, C., Troster, A. I., Kulisevsky, J., & Stebbins, G. T. (2014). The tools of the trade: A state of the art "How to assess cognition" in the patient with Parkinson's disease. *Movement Disorders*, 29, 584–596.
- Middleton, F. A., & Strick, P. L. (2001). A revised neuroanatomy of frontal-subcortical circuits. In Lichter D. C., & Cumming J. L. (Eds.), Frontal-Subcortical circuits in psychiatric and neurological disorders (pp. 44–58). New York: Guilford Press.
- Mikos, A., Pavon, J., Bowers, D., Foote, K. D., Resnick, A. S., Fernandez, H. H., et al. (2010). Factors related to extended hospital stays following deep brain stimulation for Parkinson's disease. *Parkinsonism and Related Disorders*, *16*, 3240328.
- Okun, M. S., Rodriquez, R. L., Mikos, A., Miller, K., Kellison, I., Kirsch-Darrow, L., et al. (2007). Deep brain stimulation and the role of the neuropsychologist. *The Clinical Neuropsychologist*, 21, 162–189.
- Pandya, M., Kubu, C., & Giroux, M. (2008). The many faces of Parkinson's disease: Not just a movement disorder. *Cleveland Clinic Journal of Medicine*, 75, 856–864.
- Pilitsis, J. G., Rezai, A. R., Boulis, N. M., Henderson, J. M., Busch, R. M., & Kubu, C. S. (2005). A preliminary study of transient confusional states following bilateral subthalamic stimulation for Parkinson's disease. *Journal of Stereotactic and Functional Neurosurgery*, 83, 67–70.
- Rezai, A. R., Machado, A., Deogaonkar, M., Azmi, H., Kubu, C. S., & Boulis, N. (2008). Surgery for movement disorders. Neurosurgery, 62, 809-838.
- Smeding, H. M. M., Speelman, J. D., Koning-Haanstra, M., Shcuurman, P. R., Nijssen, P., van Lear, T., et al. (2006). Neuropsychological effects of bilateral STN sitmulation in Parkinson disease. A controlled study. *Neurology*, 66, 1830–1836.
- Tanner, C. M., & Goldman, S. M. (1996). Epidemiology of Parkinson's disease. Neurologic clinics, 14, 317-335.
- Voon, V., Krack, P., Lang, A. E., Lozano, A. M., Dujardin, K., Schupbach, M., et al. (2008). A multicenter study on suicide outcomes following subthalamic stimulation for Parkinson disease. *Brain*, 131, 2720–2728.
- Voon, V., Kubu, C. S., Krack, P., Houeto, J.-L., & Troster, A. I. (2006). Neuropsychiatric and cognitive issues in the evaluation of Parkinson's disease. *Movement Disorders*, 21, S305–S327.
- Weaver, F. M., Follett, I., Stern, M., Hur, K., Harris, C., Marks, W. J., Jr, et al. (2009). Bilateral deep brain stimulation vs best medical therapy for patients with advanced Parkinson disease: A randomized controlled trial. *JAMA* : the Journal of the American Medical Association, 301, 63–73.
- Weintraub, D., Duda, J. E., Carlson, K., Luo, P., Sagher, O., Stern, M., et al. (2013). Suicide ideation and behaviours after STN and GPi DBS surgery for Parkinson's disease: Results from a randomized, controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry*, 84, 1113–1118.
- Weintraub, D., Koester, J., Potenza, M. N., Siderowf, A. D., Stacy, M., Voon, V., et al. (2010). Impulse control disorder in Parkinson disease. A crosssectional study of 3090 patients. Archives of Neurology, 67, 589–595.
- Woods, S. P., Fields, J. A., & Troster, A. I. (2002). Neuropsychological sequelae of subthalamic nucleus deep brain stimulation in Parkinson's disease: A critical review. *Neuropsychology review*, 12, 111–126.
- Yaguez, L., Costello, A., Moriarty, J., Hulse, N., Selway, R., Clough, C., et al. (2014). Cognitive predictors of cognitive change following bilateral subthalamic nucleus deep brain stimulation in Parkinson's disease. *Journal of Clinical Neuroscience*, 21, 445–450.