



## Role of clinical neuropsychology in deep brain stimulation: Review of the literature and considerations for clinicians

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### ABSTRACT

Deep Brain Stimulation (DBS) is an effective surgical therapy for several neurological movement disorders. The clinical neuropsychologist has a well-established role in the neuropsychological evaluation and selection of surgical candidates. In this article, we argue that the clinical neuropsychologist's role is much broader, when considered in relation to applied psychologists' core competencies. We consider the role of the clinical neuropsychologist in DBS in relation to: assessment, formulation, evaluation and research, intervention or implementation, and communication. For each competence the relevant evidence-base was reviewed. Clinical neuropsychology has a vital role in presurgical assessment of cognitive functioning and psychological, and emotional and behavioral difficulties. Formulation is central to the selection of surgical candidates and crucial to intervention planning. Clinical neuropsychology has a well-established role in postsurgical assessment of cognitive functioning and psychological, emotional, and behavioral outcomes, which is fundamental to evaluation on an individual and service level. The unique contribution clinical neuropsychology makes to pre- and postsurgical interventions is also highlighted. Finally, we discuss how clinical neuropsychology can promote clear and effective communication with patients and between professionals.

### KEYWORDS

Clinical neuropsychologist;  
deep brain stimulation;  
neuropsychology; surgery

### Introduction

In this article we will discuss the role of the clinical neuropsychologist in Deep Brain Stimulation (DBS), structured around the five core competencies that the British Psychological Society (BPS, 2008) states underpin applied psychologists' professional practice: assessment, formulation, evaluation and research, intervention, or implementation and communication. Although this article focuses on the core competencies outlined by the BPS (2008), as these are relevant to our practice within the United Kingdom, these competencies are not unique to the United Kingdom and are conceptualized in similar ways internationally.<sup>1</sup> A helpful review of the role of the clinical neuropsychologist has previously been published by Okun et al. (2007). In the current article, we seek to add to this dialogue, by considering recent evidence and mapping the role to core clinical competencies.

### Deep Brain Stimulation (DBS)

DBS is an effective therapy for several neurological movement disorders, such as Parkinson's disease (PD)

(Verhagen Metman, Pal, & Slavin, 2016; Walter & Vitek, 2004), Essential Tremor (ET) (Nazzaro, Lyons, & Pahwa, 2013) and dystonia (Vidailhet, Jutras, Grabli, & Roze, 2013). DBS is internationally recommended for these conditions (Albanese et al., 2011; NICE, 2003a, 2006a; Zesiewicz et al., 2005). In the United States, it is Food and Drug Administration approved as a humanitarian device exemption and in Europe, it is Conformité Européene certified and uniformly reimbursed by health-insurance carriers (Albanese et al., 2011). Novel applications of DBS include refractory epilepsy (Fridley, Thomas, Navarro, & Yoshor, 2012) and chronic pain disorders (Bittar et al., 2005; Boccard, Pereira, Moir, Aziz, & Green, 2012). For example, Gray et al. (2014) found that DBS of the periventricular/periaqueductal gray and/or sensory thalamus for neuropathic pain led to improvements in quality of life and emotional well-being. However, NICE suggest that, whereas there is evidence that the procedure is efficacious for some chronic pain patients (NICE, 2011b), the evidence supporting the use of DBS for those with trigeminal autonomic cephalalgias is limited and inconsistent (NICE, 2011a). Research has also been

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<sup>1</sup>For example, following the Specialties and Proficiencies of Professional Psychology Competencies Conference, in Arizona, Rodolfa et al. (2005) developed a framework in which the "functional" competencies of professional psychologists include: assessment/diagnosis/conceptualization, intervention, consultation, research/evaluation, supervision/teaching, and management/administration.

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conducted into the use of DBS in several mental health conditions, such as Tourette's syndrome, depression, obsessive-compulsive disorder, and anorexia nervosa (Pereira, Green, Nandi, & Aziz, 2007), but further work is required to demonstrate treatment efficacy (American Psychiatric Association, 2013; Kennedy et al., 2009) and DBS for these disorders is not routinely commissioned (NICE, 2016, November 22) or funded by insurers (UnitedHealthcare, 2017a, February 23). For these reasons, this article will focus on the application of DBS to movement disorders such as PD, ET, and dystonia.

DBS involves placing one or more electrodes into subcortical structures, which has the effect of altering the nature and rate of activity in surrounding neurons, although the exact cause of its therapeutic effect remains a point of contention (Verhagen Metman et al., 2016). The neuroanatomical "target" for stimulation depends on the condition being treated and the symptoms that have become most problematic, for example, the globus pallidus internus (GPi) is preferred for primary dystonia (Vidailhet et al., 2013) and the ventral intermediate nucleus of the thalamus is targeted in ET (Nazzaro et al., 2013) and PD tremor (Walter & Vitek, 2004). In PD, the subthalamic nucleus (STN) or GPi are effective at reducing tremor, rigidity, and dyskinesia (Walter & Vitek, 2004); although there is debate over which of the two is superior for PD (Bronstein et al., 2011). It should be noted that thalamic stimulation is often used where the primary complaint is tremor (Cury et al., 2017) and pedunculopontine nucleus stimulation may be more appropriate where postural instability and gait disturbance are the most debilitating symptoms (Mazzone et al., 2005).

The surgical risks of DBS include stroke, hemorrhage, hydrocephalus, seizures, and hypotension (Fenoy & Simpson, 2014). Significant complications occur at experienced centers in <5% of operations (Okun et al., 2007). Beyond the actual operative procedure, additional risks involve lead fractures, infections, and premature battery failure. See Thevathasan and Gregory (2010) for a description of the surgical procedure and Chiken and Nambu (2015) for a review of the underlying mechanisms.

### **Criteria for patient selection**

There is international consensus among experts that patient selection should involve a multidisciplinary team (Abboud et al., 2014; Bronstein et al., 2011; NICE, 2003a, 2006a). In this context, multidisciplinary teams are typically comprised of a neurologist, neurosurgeon, neuropsychologist, specialist nurse, and sometimes a

neuropsychiatrist (Bronstein et al., 2011). Patients are selected based on an evaluation of the likely risks and benefits for them as an individual. Essential criteria are that the patient's condition is refractory to other interventions, it is highly probable that quality of life will improve and the likely benefits outweigh the risks (Glannon, 2010). Although there are currently no standardized criteria for choosing candidates, there are additional factors to consider for different conditions.

For patients with PD, a paper reporting the conclusions of an international consortium of experts stated the best results have been reported in patients who have idiopathic PD (not parkinsonism), are younger than age 69, have no or minimal cognitive and psychiatric difficulties and respond well to dopaminergic medication (but with significant medication-related side effects and/or a reduced therapeutic window) (Bronstein et al., 2011). At present, many organizations do not commission (e.g., NHS England, 2013) or fund (UnitedHealthcare, 2017b, July 03) DBS for patients with dementia.

NHS England (2013) specifies that the Mattis Dementia Rating Scale 2 (Jurica, Leitten, & Mattis, 2004) should be used to screen for cognitive impairment and a patient must achieve an age scaled total score of  $\geq 7$ . Response to medication is measured using the movement scale of the Unified Parkinson Disease Rating Scale (Goetz et al., 2008), on which patients should show at least 40% improvement when tested "on" compared to "off" medication (Okun et al., 2007). Patients with ET are considered eligible if the tremor significantly interferes with quality of life (Zesiewicz et al., 2005). People with dystonia are considered good candidates if they have primary dystonia, as secondary is less responsive to DBS (Martínez et al., 2014). DBS is particularly helpful if undertaken before abnormal joint postures become fixed (Okun et al., 2007). Younger age at surgery (<21 years old) and shorter symptom duration (<15 years) are associated with reduced dystonia severity, whereas age at onset and presurgical dystonia severity are not (Vidailhet et al., 2013). There are no exclusion criteria in regard to cognitive impairment for people with ET or dystonia, but cases are considered on an individual basis and several factors, such as the presence of mental health difficulties, are not absolute exclusion criteria and care is taken not to prevent patients from accessing potentially beneficial treatment. Similarly, Deuschl and Agid (2013) have made the argument for the use of STN DBS earlier in the disease course of PD but suggest that, when DBS is undertaken earlier, strict inclusion criteria should be followed and the benefits of treatment must be weighed against the surgical risks and need for life-long postsurgical care.

## Assessment

*Assessment ... is derived from the theory and practice of both academic and applied psychology ... it includes both assessing change and stability and comparison with others. Assessment procedures include: the development and use of psychometric tests in best-practice ways; the application of systematic observation and measurement of behaviour in a range of contexts and settings; devising structured assessment strategies for individual clients, teams and organizations; and the use of a range of interview processes with clients, carers and other professionals.* (BPS, 2008, p. ii).

In the context of DBS, assessment may involve psychometric testing, systematic observation and measurement of behavior, structured assessment, and clinical interviews (American Academy of Clinical Neuropsychology, 2007; BPS, 2008). Neuropsychological assessment is an essential component of pre- and postoperative assessment (Saint-Cyr & Trépanier, 2000) and is standard practice across DBS services (Okun et al., 2007). Typically, it is recommended that this should be undertaken by psychologists qualified at a doctoral level with specialist neuropsychological knowledge and experience (American Academy of Clinical Neuropsychology, 2007; BPS, 2003). Here, we distinguish between assessment (where the clinical neuropsychologist gathers relevant information from the clinical interview, observation, questionnaires, and neuropsychological assessment) and formulation, where he/she draws on this, and other information relating to relevant psychological, biological, and systemic factors, to provide a framework for holistically describing the development and maintenance of the individual's difficulties. Whereas assessment is an activity that the clinical neuropsychologist undertakes individually, formulation is something that the clinical neuropsychologist can do individually or with the multidisciplinary team.

## Capacity and consent

Consent to the surgical procedure is typically obtained by the surgeon, whereas consent to the neuropsychological assessment is obtained by the psychologist (American Academy of Clinical Neuropsychology, 2007; American Psychological Association, 2002; BPS, 2008; National Academy of Neuropsychology, 2003). In some cases, for example, when the patient has a learning disability, assessing the patient's capacity to consent to surgery may form an important part of the psychologist's assessment. Where the services of a translator are required, it is important that this person is not someone with whom the client has a pre-existing

personal relationship in order to optimize the person's ability to make an independent decision.

The context of DBS raises a number of issues relating to patients' capacity to consent to surgery. As DBS is often used as a last resort procedure, patients may be unduly influenced by desperation or pressure from family members (Bell, Mathieu, & Racine, 2009). Another common issue that arises in the assessment of patients with chronic debilitating illnesses that are refractory to traditional treatments is the patient belief that any treatment is "worth a go," as they falsely believe that nothing could be worse than their current situation. However, perioperative complications and stimulation-related side effects mean that their situation could well deteriorate. In addition, a qualitative study undertaken by Gray (2010) found that patients undergoing STN DBS appeared to show insufficient concern regarding stimulation-related side effects while instead focusing more on perioperative complications, despite the fact that the former were more likely to impact on satisfaction with treatment. Patients were also found to misunderstand the pace of postsurgical change and the medical demands placed upon them (Gray, 2010). In terms of the neuropsychological assessment, the ability to provide valid consent requires that patients are aware of potential outcomes. For example, if the assessment identifies severe cognitive problems it may mean that they cannot go forward for surgery. Importantly, patients must also be aware that a possible outcome of the assessment is that dementia may be diagnosed.

## Presurgical assessment of cognitive abilities

Experts (Bronstein et al., 2011), commissioners (NHS England, 2013), and funding bodies (UnitedHealthcare, 2017b, July 03) argue that patients are ineligible for DBS if there is evidence of dementia (or significant cognitive impairment), as cognitive difficulties may be exacerbated, interfere with device management, or limit the gains in quality of life. There is a minimal amount of consensus among professionals regarding the level of cognitive impairment that would exclude patients from DBS (Bronstein et al., 2011). The lack of clarity regarding the extent of caution applied in mild-moderate cognitive impairment highlights the importance of the recommendation on a person's suitability for surgery to be based on an expert clinical judgement. In our center, mild cognitive impairment is not an exclusion criterion. Patients that are found to have moderate cognitive difficulties are discussed at a clinical team meeting and re-assessed in 6 months to measure whether their cognitive abilities have improved,

remained stable, or have deteriorated. It is also not sufficient to rely solely on absolute test scores, as these alone might either unnecessarily exclude those with lower premorbid intellectual functioning or equally fail to identify those people who have suffered severe cognitive decline in the context of high average/superior range premorbid functioning. For the purposes of neuropsychological assessment, tests of premorbid functioning are available in UK DBS centers. Clinical judgment is crucial, however, when using measures that provide only a single cut-off score, as they may give a false impression of cognitive decline in individuals with lower levels of premorbid functioning.

To undertake their role effectively, neuropsychologists must give consideration to test selection. Although the Mattis Dementia Rating Scale 2 can be used to screen for severe cognitive impairment, this instrument suffers from ceiling effects (Matteau, Dupré, Langlois, Provencher, & Simard, 2012) and lacks normative data for adults younger than 55 (Lucas et al., 1998). Therefore, in addition to screening, more comprehensive assessment is required (Okun et al., 2007). It is important that the test battery is short enough to be tolerated by patients with fatigue. Tests should also be sensitive to cognitive difficulties typically associated with the condition being treated and other neurological or psychiatric conditions. Many authors have provided suggestions for tests that might be appropriate for this task, for example for patients with PD (Defer, Widner, Marié, Rémy, & Conference Participants, 1999) or dystonia (Jahanshahi, Czernecki, & Zurowski, 2011), but there is no “gold-standard” battery. As is standard in clinical practice, test selection will always be driven by several factors including availability, range, and quality of tests, as well as the need to assess all the major cognitive domains (Marras et al., 2014). Given the requirement for a follow-up assessment after surgery, consideration needs to be given to the availability of parallel forms, the sensitivity of the tests to change, and the magnitude of practice effects (Duff, 2012). Test selection may be influenced by whether the data gathered from the tests will also be used at a service level to monitor neuropsychological outcomes from surgery for the whole patient group. When it is necessary to make comparisons across different services, this may be best achieved by implementing a standardized test battery (Saint-Cyr & Trépanier, 2000). Finally, consideration of general testing conditions is important. For example, the interaction between cognitive performance and the timing of medication must be considered (Okun et al., 2007). The typical test battery used in our service is as described in the following sections.

### **Cognitive screening: Mattis Dementia Rating Scale – Version 2**

The DRS-2 (Jurica et al., 2004) is a cognitive screening tool comprised of five subscales (attention, initiation/perseveration, construction, conceptualization, and memory) that yield individual scaled scores and percentiles together with an aggregate for the test. The DRS-2 has “very high” (see Tables 1–4 in Strauss, Sherman, & Spreen, 2006) test–retest reliability ( $r = .97$ ).

### **Premorbid intellectual ability**

The Test of Premorbid Function – UK (TOPF; PsychCorp, 2009) yields a predicted Wechsler Adult Intelligence Scale Version IV (WAIS-IV; Wechsler, 2008) full scale IQ (FSIQ). It was selected over the Wechsler Test of Adult Reading (WTAR; Wechsler, 1997) and the National Adult Reading Test (NART; Nelson, 1982) as it had been cross validated against other tests used within the assessment battery such as the WAIS-IV and the Wechsler Memory Scale Version IV (WMS-IV; Wechsler, 2009). It has “high” to “very high” reliability ( $r = .89-.95$ ).

### **General intellectual ability and reasoning**

The Matrix Reasoning and Similarities subtests were selected from the WAIS-IV as measures of visual and verbal reasoning and to provide an indication for current general intellectual ability. Both subtests are strongly correlated with FSIQ (Matrix Reasoning:  $r = .67$ ; Similarities:  $r = .71$ ) and demonstrate “adequate” to “high” test–retest reliability respectively ( $r = .74$ ;  $r = .87$ ).

### **Memory and learning**

The Logical Memory (LM) subtests from the WMS-IV and the California Verbal Learning Test Version II (CVLT-II; Delis, Kramer, Kaplan, & Ober, 2000) are used as measures of verbal learning ability. Both of these measures have been co-normed with each other and the WAIS-IV. The WMS-IV has adequate test–retest reliability. The CVLT-II demonstrated high reliability ( $r = .81-.88$ ). CVLT-II subtests have modest associations with WAIS-IV FSIQ (Trials 1–5:  $r = .48$ ; Short Delay Free Recall:  $r = .40$ ; Long Delay Free Recall:  $r = .44$ ) as do the WMS-IV Subtests (LM I:  $r = .50$ ; LM II:  $r = .45$ ). Visual memory is assessed using the Doors Recognition task from the Doors and People Test (Baddeley, Emslie & Nimmo-Smith, 1994). No reliability data is available for this scale.

### **Visual-spatial ability**

Incomplete Letters, Dot Counting and Position Discrimination subtests from the Visual Object and

Space Perception Battery (VOSP; Warrington & James, 1991) are used as measures of object perception, perceptual stability, and spatial perception. No reliability data is available for this scale.

### **Attention and executive function**

The Digit Span subtest from the WAIS-IV was selected as a measure of verbal attention and verbal working memory. It has a modest correlation with FSIQ ( $r = .64$ ) and 'marginal' reliability ( $r = .64$ ). Discussion with neuropsychologists working in other DBS centers led to the selection of phonemic fluency, cognitive flexibility, and verbal inhibition as targets for the assessment of executive functioning. The Controlled Oral Word Association Test – Letter Fluency (COWAT; Strauss et al., 2006) was selected as a widely used measure of fluency ( $r = .70$ ), the Brixton Spatial Anticipation Test (Burgess & Shallice, 1997) as a measure of cognitive flexibility ( $r = .71$ ) and Conditions 3 and 4 from the DKEFS Colour-Word Interference test (Delis, Kaplan, & Kramer, 2001;  $r = .75$ ;  $r = .65$ ) as measures of verbal inhibition and attention switching.

### **Psychomotor speed**

The Symbol Digit Modalities Test (SDMT; Smith, 1973) was selected as a measure of thinking speed. The oral subtest allows for the effect of motor slowing (common in PD) to be taken into account when interpreting scores. It has "adequate" reliability ( $r = .76$ ). Oral motor speed is assessed using conditions 1 and 2 from the DKEFS Color-Word Interference test ( $r = .76$ ;  $r = .62$ ).

### **Language**

Semantic fluency is assessed using the category fluency test from the COWAT (Strauss et al., 2006). This task has modest associations with other language based tests such as confrontation naming ( $r = .57$ – $.68$ ; Strauss et al., 2006).

### **Presurgical assessment of psychological, emotional, and behavioral difficulties**

The neuropsychological assessment provides an opportunity to undertake a structured clinical interview and administer standardized screening instruments to evaluate pre- and postsurgical psychological, emotional, and behavioral difficulties. People with severe untreated mental health conditions are generally excluded, although no standardized exclusion criteria exist (Bronstein et al., 2011). This is because severe untreated mental health conditions may interfere with tolerance and compliance (Lang et al., 2006) and increase the

likelihood of adverse events (Hariz et al., 2008), although it should be noted that such events are more common in patients with PD rather than those with other movement disorders (Buhmann et al., 2017) and following STN rather than GPi stimulation (Hariz et al., 2008). For example, Hariz et al. found that patients who experienced postoperative adverse events, such as cognitive, psychiatric, behavioral, speech, gait, and balance difficulties, were more likely to have preoperative psychiatric difficulties. However, it is important to emphasize again that mental health difficulties should not be considered an absolute exclusion factor, as cases are considered on an individual basis. For example, an individual with reactive depression to their motor disability should not be excluded on the basis that they have depression. In practice, the multidisciplinary team considers whether surgery is the most appropriate intervention for the person at that point in time and, if not, how their immediate mental health needs can be met. For example, DBS may not be the right treatment option for someone with severe untreated psychosis at the time of assessment but it may be appropriate once the person's more immediate mental health needs have been addressed. Neuropsychologists' knowledge of biological and psychological functioning means that they are particularly well-placed to consider the overlap of somatic symptoms with the patient's neurological condition and several screening measures have been recommended for particular conditions (e.g., Torbey, Pachana, & Dissanayaka, 2015).

In PD, impulse control disorders are thought to occur in 14–24% of patients (Hassan et al., 2011; Weintraub et al., 2010) and must be assessed (Moum et al., 2012). Impulse control disorder symptoms include hypersexuality, binge eating, gambling, compulsive shopping, and excessive antiparkinsonian medication use. DBS may either directly increase impulse control disorders (through stimulation) or indirectly reduce them (through dopaminergic medication reduction) (Thevathasan & Gregory, 2010). The evidence of the relative risk of impulse control disorders is mixed (Broen, Duits, Visser-Vandewalle, Temel, & Winogrodzka, 2011); therefore, patients' suitability for surgery is decided on the basis of detailed discussions at multidisciplinary team meetings. Although clinical neuropsychology is in a good position to consider the interaction between psychological and neurological difficulties, liaison with psychiatry may be necessary to conceptualize possible interactions with medication (Shotbolt et al., 2012). Finally, information gathered on behavioral symptoms may provide additional evidence of underlying dementia. For example, apathy

is a common clinical feature of PD dementia (Walker, Possin, Boeve, & Aarsland, 2015). The assessment instruments used by our service are detailed in the following sections.

### **Mood**

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) is used as a self-report measure of anxiety and depression. This is probably one of the most widely used scales in neurological populations as it attempts to minimize the confounding effects of somatic symptoms of depression.

### **Neuropsychiatric symptoms**

For patients with PD two additional informant interview scales are used routinely: The Lille Apathy Scale – Carer Version (LARS-C; Sockeel et al., 2006) and the Neuropsychiatric Inventory (NPI; Cummings et al., 1994). These scales include semistructured interviews that attempt to measure the presence and severity of problems such as apathy, hallucinations, and impulse control disorders. The LARS-C yields scores for different aspects of apathy (e.g., novelty seeking, motivation) while the NPI yields scores for each symptom (e.g., agitation, hallucinations) and carer distress.

### **Disability and quality of life**

The Functional Limitations Profile (FLP; Patrick, 2014) and Parkinson's Disease Questionnaire (PDQ-39; Jenkinson, Fitzpatrick, & Peto, 1998) are used to measure PD related disability. The PDQ-39 provides a self-reported measure of the impact that PD has on different aspects of day to day life, with higher scores representing greater impact. The FLP provides self and other rated scores for the physical, psychosocial, and overall disability associated with index diagnosis, with higher scores indicating greater levels of disability.

### **Formulation**

Formulation is:

*the summation and integration of the knowledge that is acquired by this assessment process, which may involve a number of different procedures. This will draw on psychological theory and research to provide a framework for describing a client's problem or needs* (BPS, 2008, p. ii).

In the context of DBS, clinical neuropsychologists use formulation individually to synthesize and make sense of the information gained during their assessment

and when working with the multidisciplinary team. Team formulation involves the integration of information from multidisciplinary team members into a shared understanding, from which hypotheses are generated that can inform intervention planning (Johnstone, 2014). Neuropsychologists can provide information gained from the neuropsychological assessment and may be asked to comment on factors such as patient motivation and engagement, which may be crucial in planning the management of patients pre-, peri-, and postoperatively (Bell et al., 2009). They can also use collaborative formulation explicitly to facilitate team decision making (Christofides, Johnstone, & Musa, 2012).

Training in multiple psychological models allows neuropsychologists to formulate from a systemic perspective (BPS, 2011). This may highlight practical barriers, such as whether the patient's support network is adequate to provide support them through surgery (Okun et al., 2007). However, Bell et al. (2009) point out that this raises ethical issues, as: "to abandon patients without social support or equal access would create additional disparities in the level of care for these patients, further disadvantaging them" (p. 579). It may also raise awareness of other relevant factors, such as whether family or social stressors might be a barrier to participation and whether the system's flexibility/inflexibility might facilitate or limit postsurgical improvements (Saint-Cyr & Trépanier, 2000).

Selecting the nucleus that is to be the target for stimulation is an multidisciplinary team decision and based on a range of factors, including dyskinesia severity, therapeutic goals of DBS (e.g., medication reduction), cognitive and behavioral factors, and the surgeon's expertise (Okun & Foote, 2010; Tan, Zhou, Huang, & Jiang, 2016; Verhagen Metman et al., 2016). In PD, for example, although STN stimulation may enable greater medication reduction (Tan et al., 2016), GPi stimulation may be more appropriate for some individuals, as it is associated with less significant postsurgical cognitive decline, greater increases in quality of life and larger decreases in depressive symptoms (Combs et al., 2015; Tan et al., 2016). Although a minimal amount of well-controlled research exists, the GPi is considered preferable for patients with impulse control disorders and psychiatric difficulties (Okun & Weintraub, 2013). Recent evidence suggests that motor improvements are equivalent between GPi and STN stimulation (Tan et al., 2016). Therefore, whether or not it is made explicit, the team bases target selection on formulation, as information from different sources is synthesized into a shared understanding, upon which intervention is based.

## Evaluation and research

### Evaluation

*Evaluation is ... a critical and integral part of the applied Psychologists' work. This includes assessment of change and whether patients' needs are met. All actions and interventions need to be evaluated both during their implementation and afterwards (BPS, 2008, p. iii).*

In contrast to assessment and formulation, evaluation is performed following surgery and includes a broader range of activities, including service evaluation and research and assessment of changes in the individual patient's functioning. Postoperative neuropsychological assessment provides an opportunity to assess the effects of surgery on cognitive functioning and psychological, emotional, and behavioral difficulties. It is considered good practice to conduct neuropsychological assessment preoperatively and postoperatively, with the patient "on" medication and the stimulator activated. The Core Assessment Program for Surgical Interventional Therapies in Parkinson's disease (Defer et al., 1999) recommends conducting two postoperative cognitive assessments, at 6 and 24 months, although Okun et al. (2007) state that it is typical practice to conduct one follow-up neuropsychological assessment 6–12 months postoperatively.

### Postsurgical assessment of cognitive abilities

There is a growing literature on whether DBS is associated with postsurgical cognitive decline in PD (Combs et al., 2015). Many studies have been underpowered (Woods et al., 2006) or have not included control patients who did not receive DBS (Witt et al., 2008). These limitations are clinically important. For example, research studies may fail to detect postsurgical decline due to limited statistical power, which would impact on individual patients' understanding of the surgery's potential costs and benefits, and, therefore, the validity of their consent (Woods et al., 2006). Several large randomized control trials have found that, 6 months postsurgery, the cognitive performance of participants with PD who underwent DBS was poorer than that of participants who received alternative treatments, particularly on measures of executive functioning and verbal memory (Rothlind et al., 2015; Smeding et al., 2006; Witt et al., 2008). It is possible that some aspects of cognitive decline, particularly in verbal fluency, are related to the surgical intervention of inserting electrodes, rather than the effects of stimulation, and are thus nonreversible (Massano & Garrett, 2012). Combs et al. (2015) conducted a recent meta-analysis of 41 studies of the cognitive effect of DBS for PD

and found that STN stimulation was associated with small declines in psychomotor speed, attention, memory, executive functioning and overall cognition, with moderate declines in semantic and phonemic fluency. In people with ET, studies have found declines following thalamic DBS in general cognitive functioning, attention, executive functioning, visual perception and memory. These appear to be associated with older disease onset (>37 years) and higher DBS pulse-width settings, rather than age, presurgical tremor severity or cognitive difficulties (Holker, Lucas, Uitti, F, & Wharen, 2001; Woods, Fields, Lyons, Pahwa, & Tröster, 2004). Although very little research has been conducted, some evidence suggests that the cognitive effects of STN and GPi DBS for dystonia are much smaller than for PD (Dinkelbach et al., 2015; Hung et al., 2007; Mills et al., 2015).

### Postsurgical assessment of psychological, emotional and behavioural difficulties

Evidence suggests that DBS for PD is associated with increased quality of life and decreased anxiety and depression but findings are mixed (Combs et al., 2015; Smeding et al., 2006; Witt et al., 2008). Although some case reports have suggested that DBS is associated with increased suicidal ideation and behaviors, this has not been found by carefully controlled studies where comprehensive pre- and postsurgical assessments have been undertaken (Weintraub et al., 2013). It is important to note that group-based studies are insensitive to the deterioration in a small subset of patients when the group effect is towards a slight improvement in emotional well-being and further research is needed to investigate individual trajectories, for example, by using reliable change scores. Evidence is mixed about the relationship between DBS and impulse control disorders, as these have been found to improve and worsen following DBS (Nassery et al., 2016; Okun & Weintraub, 2013). Although the literature is smaller than that on PD, DBS for ET has been found to result in reduced anxiety and sustained increases in quality of life (Fields et al., 2003; Hariz, Lindberg, & Bergenheim, 2002; Nazzaro, Pahwa, & Lyons, 2012; Tröster et al., 1999). DBS for dystonia is associated with increased quality of life (Vidailhet et al., 2013) and reduced depression (Jahanshahi et al., 2011). Nevertheless, more research is needed into psychological, emotional and behavioural outcomes following DBS (Combs et al., 2015) and the mixed evidence regarding DBS and adverse outcomes, such as impulse control disorders (Nassery et al., 2016; Okun & Weintraub, 2013), highlight the need to carefully monitor postsurgical outcomes (Defer et al.,

1999; Gilbert 2012; Okun et al., 2007). This is an appropriate role for the clinical neuropsychologist, as they have the opportunity and relevant training (BPS, 2008).

### **Postsurgical assessment of patient goals and satisfaction**

Patient satisfaction should be a key goal of DBS, both in terms of providing person-centred care and for maintaining the engagement required to optimise the effects of treatment. Indeed, Gray (2010) highlights that evidence shows that satisfied patients show greater adherence to medical advice (O'Brien, Petrie, & Raeburn, 1992; Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992) and have better health outcomes (Brody & Miller, 1986). It is crucial to identify patients' unique goals for treatment and ensure that their views are represented throughout the treatment process (Gray, 2010). Practically, psychologists have the opportunity to identify and monitor progress towards these goals during pre- and postoperative clinical interviews and to represent the views of the patient in multidisciplinary team meetings.

### **Service evaluation and research**

*“Clinical audit or service evaluation is a systemic approach to the peer review of clinical care in order to identify opportunities for improvement and to provide a mechanism for bringing them about” (Cooper et al., 2005, p. 15), “In contrast, research is concerned with generating new knowledge that will have general application, as for example in determining whether a new treatment is superior to an existing one or evaluating whether a particular theory provides an adequate explanation for a clinical phenomenon” (Cooper et al., 2005, p. 8).*

In the United Kingdom clinical guidelines state that DBS should be undertaken with ‘normal arrangements’ for routine outcome monitoring, for PD, ET and dystonia (NICE, 2003a, 2006a). Although it does not specify which outcomes should be monitored, the NICE ‘audit tools’ for DBS in refractory epilepsy and trigeminal autonomic cephalalgias state that adverse outcomes such as meningitis, improved disorder specific symptoms and other outcomes, including quality of life, cognitive performance, depression and anxiety should be evaluated (NICE, 2011a, 2011c). As discussed, patient satisfaction is a key goal. This outcome may be evaluated quantitatively through the systematic administration of goal-based outcome measures. Clinical neuropsychologists can meaningfully contribute by maintaining a database of information collected relevant to these outcomes.

Further knowledge is needed about many aspects of DBS, such as cognitive and psychosocial outcomes (Combs et al., 2015). Neuropsychologists contribute to the literature, even when they are not involved in randomised controlled trials. Although these trials are often regarded as the ‘gold-standard’ in medical research, Saint-Cyr and Trépanier (2000) state that much can be learned from data collected routinely, as this allows investigation of individually-tailored treatment and enables comparison between different centres. This consideration influences test selection, as comparison between centres requires standardised neuropsychological assessment batteries to be used with most patients.

### **Intervention and implementation**

Psychological intervention is the application of formulation and psychological models/approaches to facilitate change, solve problems or improve the quality of relationships (BPS, 2008). This may be delivered by one to one therapy, supervision of team members or consultation.

### **Presurgical intervention**

Several authors have proposed that patients with severe mental health conditions should not be excluded from DBS indefinitely. Instead, surgery may be reconsidered after addressing these difficulties (Bronstein et al., 2011; Saint-Cyr & Trépanier, 2000; Walter & Vitek, 2004). However, there has been no research into whether treating mental health conditions before DBS actually reduces the chances of adverse outcomes. Furthermore, several ethical and practical issues require consideration. For example, patients may feel coerced to undergo and benefit from psychiatric or psychological treatment or regard it as simply a “hoop” to jump through and thus not fully engage with the process. Neuropsychologists are trained to draw on formulation to make sense of patients' current difficulties and can discuss appropriate options for intervention, whilst remaining alert to any ethical issues.

Where psychological interventions may be appropriate before surgery, the clinical neuropsychologist can assist with a referral to the most appropriate service, rather than simply tell patients or families where they need to go to access help, when severe mental health conditions might make navigating referral processes challenging. Having trained in physical and mental health settings, the neuropsychologist may be the surgical team member with the broadest overview of mental and physical health services.



### **Interventions for psychosocial difficulties when DBS is not undertaken**

When multidisciplinary teams judge patients to be unsuitable for DBS, patients and families should be given a clear explanation for the decision and they may require support. In addition to having their hopes for physical improvement dashed, further challenges, such as dementia, may be discovered by the assessment process (Saint-Cyr & Trépanier, 2000). Neuropsychologists may have a role in assisting the patient, family, and multidisciplinary team to consider unmet health and social needs and which services are most appropriate to meet these needs.

### **Postsurgical intervention**

Patients can have difficulties in adjusting to life after DBS, despite improvements in motor functioning (Agid et al., 2006; Gisquet, 2008; Schüpbach et al., 2006; Schüpbach & Agid, 2008). For example, Agid et al. found that many patients who experienced postsurgical improvements in motor functioning, mood and quality of life had difficulty adopting a new self-image, loss of direction in life, and altered body-image. Similarly, Schüpbach et al. (2006) observed that patients who received STN DBS for PD had postoperative problems with social adjustment, affecting their perception of themselves and their body, marital situation, and professional life.

Gilbert (2012) suggests that patients may experience the “burden of normality” syndrome. This describes an adjustment process that may occur when patients change rapidly from “chronically ill” to “well” after surgery (Bladin, 1992; Wilson, Bladin, & Saling, 2001). However, the burden of normality is based on the epilepsy literature and may be less common in people with movement disorders, as burden of normality is greater when neurological conditions begin during identify-forming adolescent years (Wilson, Wrench, McIntosh, Bladin, & Berkovic, 2010); whereas, the movement disorders discussed here typically have an adult-onset (Lezak, Howieson, Bigler, & Tranel, 2012).

Psychosocial challenges may emerge for families after DBS, such as the spouse experiencing loss of a caregiver role (Bell, Maxwell, McAndrews, Sadikot, & Racine, 2011). In Agid et al.’s (2006) study, a postsurgical “conjugal crisis” was experienced by 65% of the patients who were married or lived with a partner. Although the literature on psychosocial difficulties following successful DBS is small and there appear to be no published reports directly evaluating interventions for these difficulties, Gilbert (2012) argues that postoperative

assessments should seek to identify and discuss adverse psychosocial outcomes. Within the DBS team, clinical neuropsychologists typically take on this role. Service constraints may dictate whether psychological intervention or cognitive rehabilitation is provided within the same service or elsewhere. In either case the neuropsychologist can ensure that the most appropriate intervention is made available to the patient. Although, at present, there is no published research into the effectiveness of psychological interventions for such difficulties following DBS, this challenge is not unique to DBS and existing interventions for other neurological conditions might be adapted (BPS, 2009).

### **Communication**

*Communication skills include communication with individuals, groups or organisations, all forms of electronic and verbal communication, and the dissemination of research findings (BPS, 2008, p. iii).*

Effective communication is central to the work done by all healthcare professionals, as poor communication is often associated with poor clinical care (Department of Health, 2001; Kapur, 2014). For clinical neuropsychologists working in the context of DBS, communication is particularly central to their interactions with patients and the multidisciplinary team.

#### **Communication with patients**

In DBS, effective communication between clinicians and patients is crucial (Pahwa et al., 2006). Consenting to surgery requires an understanding of a large amount of information. To assist patients, resources have been produced about DBS (NICE, 2003b, 2006b; Okun & Zeilman, 2017, February 23) although Bell et al. (2009) point out that patients may also receive inaccurate information from other sources, such as the media, which presents DBS as a “miracle cure.” Gray (2010) found that many patients who chose to undergo DBS formed their expectations of surgery through hearing stories of other surgical candidates who had experienced very positive outcomes, which he argued were unlikely to be fully representative of all surgical patients. To combat misinformation and to help patients to digest relevant material, all professionals, including clinical neuropsychologists, must have a good understanding of all aspects of DBS, such that this can be discussed during every patient-professional interaction. This can be challenging, as much of this information is based on a technical, incomplete, and emerging evidence-base. Helpfully, research suggests that several communication

strategies can increase patients' understanding of medical evidence, such as providing structured information and making material personally meaningful (Trevena, Davey, Barratt, Butow, & Caldwell, 2006). Recent guidance has been produced to help clinicians to discuss the aims and outcomes of neuropsychological assessment (Postal, 2013). Gray (2010) suggests that clinicians should also ensure that patients understand that very positive outcomes are possible but atypical, by providing them with the opportunity to speak to previous DBS patients judged by staff to have had a more typical outcome.

When communicating with patients about potential postsurgical outcomes, the neuropsychologist may have a role in discussing the likelihood and extent of adverse cognitive and psychosocial outcomes. In this context the clinical neuropsychologist may also be required to break bad news and/or advise colleagues on breaking bad news (Phillips, Kneebone, & Taverner, 2013). For example, when it is necessary to inform the patient that he/she is not an appropriate candidate for surgery.

### Multidisciplinary team working

DBS involves joint decision making, which requires effective communication between professions. However, a number of individual, group, and organizational factors, can affect communication in healthcare (Dayton & Henriksen, 2007). Kapur (2014) has argued that psychologists have the knowledge and tools to tackle many problems facing healthcare, of which ineffective communication is one. For example, communication between professionals can be adversely affected when team members have differing levels of professional stature and seniority, experience or expertise. Such 'authority gradients' may contribute to medical error, for example, if less senior professionals identify issues relating to risk but feel unable to challenge more senior colleagues and are therefore discouraged from communicating important information (Cosby & Croskerry, 2004). Clinical neuropsychologists may identify when authority-gradients influence professionals' abilities to communicate their professional opinions regarding patients' surgical suitability and implement interventions to overcome this. Kapur has suggested that standardized procedures may help to overcome authority gradients. For example, having a set time on the agenda for multidisciplinary team meetings for every professional to voice their opinion on the patient's suitability for surgery may redress power imbalances that could impede more junior colleagues from sharing information effectively.

## Conclusions

The clinical neuropsychologist makes a contribution to the assessment, selection, management, and postoperative care of patients who are being considered for DBS. They have a role in expert assessment and formulation, which makes a contribution to patient selection, especially when there are conflicting cautions and indications or where the evidence-base to guide decision making is limited. Their role involves direct patient care but they may also contribute more broadly to support the clinical governance of the multidisciplinary team through evaluating outcomes. Communications skills are central to the neuropsychologist's role within the team and with the patient and family.

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