

# THE ROLE OF THE CLINICAL PSYCHOLOGIST IN DEEP BRAIN STIMULATION SURGERY FOR PARKINSON'S DISEASE

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Deep brain stimulation therapy is an effective surgical treatment for people with advanced Parkinson's disease. The clinical psychologist as a core member of the multidisciplinary team plays a multitude of roles to inform medical decisions, improve clinical outcome and patients' quality of life.

## **Deep Brain Stimulation**

Deep Brain Stimulation (DBS) is a surgical treatment which involves the implantation of electrodes into the target area in the brain, usually bilaterally. The implanted electrodes are connected via leads passed behind the ear to a battery-operated pulse generator the size of a stopwatch which is located in the chest cavity. The electrodes deliver high frequency electrical stimulation to the targeted areas of the brain. The mechanisms of action of DBS are not known, although because of the similarity of the therapeutic effects to those produced by surgical lesioning, it is often assumed that DBS also inhibits the target area.

DBS has emerged as an effective treatment for a number of neurological and psychiatric disorders such as Parkinson's disease (PD), Essential Tremor and Dystonia (Limousin et al, 1998; Koller et al, 2001; Deuschl et al, 2006; Vidailhet et al 2005), Tourette's syndrome, Obsessive-Compulsive disorder (Greenberg & Reza, 2003; Nuttin et al 2003; Temel & Visser-Vandewalle, 2004; Welter et al, 2008) intractable Major Depressive disorder (Mayberg et al 2005; Lozano et al, 2008; Giacobbe & Kennedy, 2006; George et al, 2007; Larson, 2008). More recently, DBS has also been applied and found beneficial as a treatment for refractory obesity (for review see Halpern et al, 2008), epilepsy (Hodaie et al, 2002) and cluster headache (Sillay et al, 2009; Grover et al, 2009). To date, DBS for PD has the largest body of evidence supporting its efficacy for improving the motor symptoms and the quality of life of patients and we will therefore focus on the role of the clinical psychologist in DBS surgery for this disorder.

### **Parkinson's disease and DBS surgery**

PD is a progressive neurological disorder. It is mainly characterized by motor symptoms such as tremor of a limb, especially when the body is at rest, bradykinesia (slowness of movement), akinesia (poverty of spontaneous movements e.g. reduced blinking, facial expressions or gestures during speech), rigidity, a shuffling gait and stooped posture. Cognitive deficits, particularly in executive function are also features of PD in the majority of cases from the early stages and dementia can develop in the later stages of the illness in a proportion of the patients. In addition, PD patients also commonly report sleep disturbance, fatigue and depression. These symptoms are due to a degeneration of dopamine producing cells in a part of the basal ganglia called the substantia nigra compacta which creates a reduction of dopamine in the basal ganglia, subcortical brain areas involved in the control of movement. The standard medical treatment for PD is dopamine replacement therapy with levodopa or dopamine agonists. After five or six years of treatment with dopaminergic medication, PD patients can develop dyskinesias (involuntary movements) and on-off fluctuations (periods when medication is or is not working optimally). These side-effects of medication can be disabling. When levodopa medication fails to adequately control the motor symptoms or gives rise to disabling side-effects, PD patients are considered candidates for surgery. In PD, the areas of the brain that DBS targets include the subthalamic nucleus (STN), the internal segment of the globus pallidus (GPi) or the thalamus. The choice of surgical target depends on the specific nature of the patients' symptoms. DBS surgery for PD can produce impressive effects and improve the patients motor symptoms considerably and enable them to resume their daily activities and improve their quality of life. We have illustrated the effects of PD and its treatment with DBS surgery with a case report (see text box).

Mr P was married and had two young children. He worked as an elementary school teacher. He enjoyed travelling with his family and loved sports such as skiing and rafting with his friends. At the age of 47, he developed a slight tremor of the little finger of his left hand which then gradually over a period of couple of years became shaking of the whole hand. He went to see his GP who referred him to a neurologist who diagnosed young-onset PD. He had to come to terms with having an old people's disease at such a young age. For the first five or six years, the levodopa medication was effective in

controlling his motor symptoms. Then he developed on-off fluctuations and dyskinesias and the period during the day when he was 'on' and free of troubling dyskinesias became shorter and shorter. He reached a stage where he had to stop working as he was experiencing difficulties with his concentration and attention while his motor difficulties rendered him incapable even to drink a glass of water without spilling some of the contents. Mr P silently 'mourned' his inability to engage in his favourite sports, his lost aspirations and future plans. The deterioration of Mr P's motor symptoms affected the whole family - their everyday routines and roles in the family changed significantly. Mr P's wife started work to support the family. The children had to make greater contributions to household duties and to the care of their father. During his yearly consultation, his neurologist suggested that Mr P may benefit from a DBS surgery. After discussing it with the family, Mr P decided to have the surgery. Following a series of detailed pre-operative assessments, the day of surgery arrived. The whole procedure did not last more than six hours and took place under local anaesthetic. Mr P was awake and conscious during the operation and at points chatted to the doctors who tested changes in his motor symptoms as the electrodes were inserted into the target areas of his brain. Then under general anaesthetic, the pulse generator unit was positioned in his chest cavity and attached to the electrodes. After a two week stay in hospital, at the end of which the stimulation parameters for optimal control of his motor symptoms were set by the neurologist, Mr P was back home. Within the next few months, his motor symptoms had improved to the extent that his medication was gradually reduced. These changes had a positive impact on Mr P's life, who resumed his role in the family, began socialising again and returned part-time to the teaching profession.

The effectiveness of DBS depends on careful patient selection, surgical planning and targeting, specialist setting of optimal stimulation parameters and continued post-operative care. For this reason, many centres have adopted the multidisciplinary team model, with involvement of a neurosurgeon, neurologist, clinical psychologist, psychiatrist and nurse specialist. Centres with greater resources involve other health care professionals, such as psychiatrists, speech and language therapists, occupational therapists and physiotherapists in the evaluation and post-operative management of patients. As a result complications are reduced and the maximum clinical benefits are obtained. The important primary outcome measure of DBS is its impact on the patient's everyday activities and consequently on their quality of life.

### **The Role of the Clinical Psychologist in DBS Therapy**

The clinical psychologist plays a number of different roles within the multidisciplinary team who care for people with PD. Below, we will discuss of each of these roles.

#### **1. Patient selection: Pre-operative screening and cognitive assessment**

The initial pre-operative screening and cognitive assessment provides information that will assist the neurologist and the rest of the team evaluate the effect of PD on cognitive function, mood and behavior and psychosocial adjustment. This in turn will allow decisions about whether the patient satisfies the selection criteria for DBS therapy and if this is the right treatment for this patient. For example, at most centres, the requirement that PD patients are not demented and do not have a major psychiatric illness are among the selection criteria for DBS surgery. To ensure that PD patients who are candidates for DBS surgery meet these selection criteria, the clinical psychologist obtains relevant information about any past cognitive assessments or previous history of major psychiatric illness or medication related impulse control disorders (e.g. compulsive gambling, shopping, eating, punding, hypersexuality) from the patient's hospital notes, interviews the patient and the caregivers, observes the patient's behaviour and undertakes a cognitive assessment. The assessment prior to surgery may involve two stages. First, a screening stage to rule out dementia and major psychiatric problems. In the course of such a screening assessment, tools such as the P Dementia Rating Scale (Mattis, 1976) and the Neuropsychiatric Inventory (Cummings et al, 1994) or the MINI (Sheehan, 1998) may be administered. Second, once the patient has been identified as a suitable candidate for DBS surgery, a more detailed assessment of different domains of cognitive function (IQ, memory, attention, visuo-spatial function, language, executive function) mood (depression, anxiety, apathy), behavior and quality of life will be scheduled within a month or so prior to surgery. This assessment would use standardized measures of cognition used in routine neuropsychology practice, and standardized self-report measures of mood. The PDQ39 (Peto, 1995) is a disease-specific measure of quality of life for PD which would be completed by all patients prior to DBS surgery, as it is often the primary measure of the outcome of

surgery. The pre-operative assessment provides an initial or baseline measurement against which any future changes in a patient's cognitive status, mood or behaviour can be compared.

## **2. Education and preparation of patients and families for surgery**

DBS surgery is a life-altering treatment for PD. In a short period of time, DBS surgery can improve the motor symptoms and mobility of PD patients so that they are less dependent on others for their self-care and daily activities. The patient may be able to resume some of their previously abandoned roles such as working, care of children or household duties. All these changes would entail role modifications for other members of the family. The clinical psychologist can highlight and discuss these issues with the PD patient and their family to prepare them for the necessary role adjustments to avoid or minimize post-operative frustration or conflict. As part of preparing the patients and their families for the surgery, the clinical psychologist can also emphasize the need to recruit adequate social support, both practical and emotional, for the whole family during the peri-operative period as this is likely to be a period of rapid change and hence stressful.

## **3. Assessment of expectations of surgery and being alert to suicide risk**

Similar to life-altering forms of surgery for other disorders such as epilepsy, an increased rate of suicide following DBS surgery has been documented for PD (Voon et al, 2008). This multi-centre study also considered some of the multitude of biological, medication-related, stimulation-related, psychological and social factors that may contribute to suicide following DBS surgery for PD. Patients attitudes and expectations are relevant to this. DBS surgery is often perceived as a last resort by patients. In this respect, it is important that patients and their families have realistic expectations of what surgery can do for their PD and what aspects of their motor symptoms are most likely to improve with surgery. Ensuring that patients have realistic expectations will prevent post-operative disappointment. The clinical psychologist can help the neurologist and the neurosurgeon in promoting and installing realistic expectations in the patients and their families. Monitoring mood and psychological and social adjustment of patients at regular intervals particularly in the first year after surgery, and ensuring that patients have adequate social support and are not socially isolated, being alert to other factors that are associated with post-DBS suicide such (pre-operative compulsive medication use or impulse control disorders, previous suicide attempt, being single, younger age and age of onset of PD), and directly asking about suicidal ideation during post-operative assessments are other ways in which the clinical psychologist in conjunction with other members of the DBS team can reduce the risk of suicide associated with DBS surgery for PD. Post-operative depression and suicidal ideation should result in psychiatric referral and treatment.

## **4. Monitoring the impact of surgery**

In conjunction, the pre and post assessments can provide reliable and quantitative measures of any improvement or deterioration of cognition, mood and behavior following surgery which will be valuable primary or secondary outcome measures and also inform the neurologist that adjustment of medication or stimulation parameters are required. Reduced disability and improved quality of life are often observed after DBS surgery for PD. Associated with this, may be improvement of depression and anxiety. However, other aspects of mood and behavior may become worse following surgery, requiring adjustment of medication (e.g. apathy) or stimulation parameters (e.g. hypomania) by the neurologist. The pre and post-operative assessments by the psychologist will be useful. In this respect, repeating post-operative assessments of cognition, mood, behaviour and quality of life at yearly intervals after surgery can be of value in evaluating the long-term effects of DBS surgery.

## **5. Counselling for improved post-surgical psychosocial adjustment**

Following DBS therapy, dramatic improvements of symptoms can occur in a short span of couple of weeks. This can bring about rapid change in roles within the family. This in turn can at times give rise to tension, as family members might find it difficult to accept and adjust to the new situation. Therefore, the improved motor status of the PD patient may necessitate major social and role adjustment within the family. For example, the spouse or partner may no longer feel that the patient is entitled to be exempt from household duties or care of the children. The 'carers' may feel that their caring role is no longer appropriate, which would require a shift in the dependence-caring relationship

that they had with the PD patient. The much improved motor status of the patient may be perceived by them as a 'new lease of life' and encourage them to use their time in pleasurable pursuits such as travelling or socializing rather than resuming employment or other responsibilities. All these changes require adjustment. The psychologist can use evidence based therapeutic techniques such as cognitive behaviour therapy to assist the patients and their families to appreciate, accept and adjust to the altered roles after DBS surgery.

## **6. Research**

DBS provides a unique opportunity to the clinical psychologist to carry out research projects on a variety of topics. For example many studies have investigated the effect of DBS surgery on cognition in PD (Ardouin et al, 1999; Smeding et al, 2006), mood and behaviour (Funkiewiez et al, 2004) by comparing pre and post-operative measures. Other studies have examined the acute effects of DBS on specific aspects of cognitive, motor, or emotional functioning or behaviour by comparing performance with the stimulators on and off (Jahanshahi et al, 2000; Pillon et al, 2000; Brown et al, 1998; Funkiewiez et al, 2003; Okun et al, 2009). There is a growing literature on the impact of DBS surgery on psychosocial functioning (eg Schüpbach et al, 2006) and quality of life of the patients (Diamond & Jankovic, 2005). As DBS surgery results in chronic implantation of electrodes in the STN or GPi, it provides a unique opportunity to investigate the contribution of the basal ganglia and striatal-frontal connections to various aspects of motor control (Limouisn et al, 1998), cognition (Schroeder et al, 2002,2003; Thobois et al, 2007) or emotional processing (Geday et al, 2006) using imaging techniques. All these are potential areas of research open to the clinical psychologist.

## **Conclusions**

The above delineate the multitude of different roles that a clinical psychologist can play within the DBS team. We have highlighted how the clinical psychologist can assist the multidisciplinary team to identify those patients who can benefit from DBS surgery, monitor the patient's course following surgery and help improve the patients' and their families' adjustment after DBS surgery. Research by the clinical psychologist into the effects of DBS surgery on cognition, mood, daily activities, psychosocial adjustment and quality of life can provide important information for future applications. The ultimate goal of DBS surgery is to improve function, daily activities and the quality of life of patients. It is clear that the contribution of a clinical psychologist is necessary for DBS surgery to meet these goals.

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