

Stimulating debate: ethics in a multidisciplinary functional neurosurgery committee

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Multidisciplinary healthcare committees meet regularly to discuss patients' candidacy for emerging functional neurosurgical procedures, such as Deep Brain Stimulation (DBS). Through debate and discussion around the surgical candidacy of particular patients, functional neurosurgery programs begin to mold practice and policy supported both by scientific evidence and clear value choices. These neurosurgical decisions have special considerations not found in non-neurologic committees. The professional time used to resolve these conflicts provides opportunities for the emergence of careful, ethical practices simultaneous with the expansion of therapy applications

these committees provides the opportunity for the emergence of careful practice guidelines informed by both science and values, while therapy applications for functional neurosurgery, such as DBS, expand.

The emergence of multi-disciplinary patient management teams for neurosurgical procedures such as Gamma Knife Surgery, Resective Epilepsy Surgery, and DBS arise from the need for cross-disciplinary expertise to establish good practices and to confer regarding complex cases.^{2–4} Much of the need for these committees arises from the relatively limited understanding of the potential impact of the proposed neurosurgical procedure on the brain, including the neural underpinnings of mood, personality, and cognitive abilities. In addition, functional neurosurgical patients frequently present unique challenges regarding peri-operative and post-operative management. For instance, many functional neurosurgeons prefer to have the patient awake during specific procedures—for example, DBS placement and epilepsy resections near eloquent cortex. The patient's cooperation during surgery allows the surgeon to complete functional mapping studies such that the surgery is individually tailored to provide maximum benefit with minimal side-effects. Awake neurosurgical procedures can present unique challenges to the surgical team as patients with psychiatric disorders, such as anxiety, and/or cognitive deficits might have significant difficulties complying with the demands of surgery and may even revoke consent intra-operatively. Functional neurosurgical patients can also provide unique management challenges following surgery. Unlike resective surgery for intractable epilepsy that is potentially curative, DBS for Parkinson's disease is palliative and aimed at improving the patient's quality of life and reducing motor symptoms. Appropriately titrating stimulation settings and medications in patients with ongoing neurodegenerative disorders with potentially significant neuropsychiatric symptoms can be challenging and require a committed multidisciplinary team. We contend that this commitment to the long-term care of patients must be made explicit prior to offering surgery.

These elements feed into the uncertainties inherent in and reliance on professional judgements, including value judgements, in discerning good courses of therapy. As noted above, the issues confronting functional neurosurgical committees differ from those facing other surgical

Increasingly, multidisciplinary committees review the candidacy of complex patients under evaluation for functional neurosurgical procedures. As with other types of multidisciplinary health care committees, such as transplant selection committees,¹ considerable debate arises concerning the appropriate application of emerging treatment modalities. Through debate and discussion about the surgical candidacy of particular patients, a functional neurosurgery committee begins to mold practice and policy supported both by scientific evidence and value choices. We describe a number of ethical questions faced by functional neurosurgery committees in determining the appropriateness of surgical intervention for specific patient groups. These interactive team meetings often result in guidelines for patient care, while leaving open the possibility of special accommodations for unusual cases. We largely limit our discussion to clinical decision-making regarding candidacy for Deep Brain Stimulation (DBS) for the treatment of Parkinson's disease in order to more fully highlight the specific ethical challenges inherent in this emerging technology and to discuss the values that can be made explicit through dialogue in such committees. Although practices vary between institutions, it is important for similar functional neurosurgery patient management committees to recognise the basic value considerations in these deliberations. Further, these committees have special considerations not found in non-neurologic committees that go beyond inter-disciplinary conflicts. Functional neurosurgery has the potential to alter essential features of a patient's personhood, including mood, personality, and cognitive abilities. The professional time used to resolve conflicts in

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multi-disciplinary team conferences in that they must consider potential cognitive, personality, and psychiatric risks that may not be reversible. Unlike neurology or psychiatry, neurosurgical practice can result in non-reversible destructive brain procedures and/or the implantation of brain devices in which the precise neurophysiological mechanisms are not fully understood.⁵ Further, the history of abuses in the application of neurosurgical procedures, such as frontal lobotomy, and the common fear of mind control provide a backdrop of anxiety.⁶⁻⁸ An additional concern, unique to functional neurosurgery teams, is the reliance on neuroimaging technologies in guiding clinical decision-making. The thorny ethical issues inherent in the interpretation of neuroimaging have been well identified by others and will not be explicitly addressed here.^{2 9 10} As noted above, the range of ethical challenges in functional neurosurgery extend much beyond concerns about imaging.⁵

Although this list of complexities and concerns may appear daunting, there are many patients who undergo surgery with little need for special consideration because they fall well within the accepted practices. The decision to proceed in these cases relies on good patient-doctor communication about risks and benefits and established practices. The neurosurgical multidisciplinary committee serves its most important function when some element of the patient's situation deviates significantly from established guidelines making the patient's candidacy uncertain. When this occurs, all of the before mentioned complexities and considerations are open for discussion and debate from the varieties of professional and personal perspectives serving on the committee.

DBS COMMITTEE AND PATIENT CANDIDACY

Before discussing the ethical challenges further, it is important to understand the context of a functional neurosurgical committee. This necessitates a brief discussion of the therapy, indications, and committee composition. DBS refers to the placement of electrodes in brain structures deep within the brain. Most often the electrodes are placed in specific nuclei of the basal ganglia or thalamus. The electrodes are connected by wires, tunneled beneath the skin, to an electrical generator that is implanted in the chest or abdomen, much like a generator for a heart pacemaker or defibrillator. The known complications related to the implantation of the leads include hemorrhage, stroke, and infection. The rate of significant complications is relatively low, but for those few patients unfortunate enough to have complications, the sequelae can be significant.^{11 12}

DBS has been approved for treatment of idiopathic Parkinsonism and essential tremor. It is also used for dystonia and chronic pain. The technology is being studied, or being considered for study, in a number of non-movement disorder diseases such as depression, obsessive compulsive disorder, Tourette's disorder, epilepsy, minimally conscious states, chemical addiction, and even weight loss. Even among the class of movement disorders for which the therapy has become an accepted intervention, there continues to be uncertainties surrounding the mechanism of action, cognitive risks, neuroprotective properties, and long-term outcomes. Contraindications for surgery vary, but usually include significant dementia or psychiatric illness.

DBS patient management committees uniformly include neurologists, neurosurgeons, and advanced care nurses/physician assistants. Many programs also include a neuropsychologist or psychiatrist in the evaluation process and in committee deliberations. Occasionally, a bioethicist may be consulted or actually be a full member of the committee. In the case of our institution's DBS patient management

committee, a neuropsychologist and bioethicist regularly attend the meetings as committee members.

At our institution, the committee discusses surgical candidacy and concerns regarding postoperative management of patients with movement disorders. The meetings provide opportunities to have focused discussions about which therapies should be offered to particular patients and the boundaries of good practice. Generally, a patient's movement disorder neurologist is the first to present the patient's information. The presenting neurologist raises concerns and gives an opinion about the patient's surgical candidacy. This is followed by the neurosurgeon's comments and further group discussion. Finally, the neuropsychologist presents the patient's results and her opinion regarding the patient's candidacy for surgery. All patients complete a pre-operative neuropsychological assessment that includes evaluation of the patient's current cognitive abilities, psychiatric status, goals for surgery, and level of family support. The other members of the committee comment during these presentations when appropriate. Since the bioethicist on the committee only rarely meets the patients, there is seldom a formal ethics report. The discussion ends with either a final decision regarding surgery or a proposal that further evaluations should be undertaken and/or conditions (see section below, "Healthcare team considerations") be met before a surgical decision can be made. A committee member is designated to contact the patient about the team's decision and recommendations. The team seeks consensus decisions with participation from a variety of viewpoints. Although all committee members have the opportunity to voice concerns, there are various roles and levels of responsibility. Clearly, if the surgeon believes that the surgery should not be done, the committee cannot (and should not) compel her/him to perform the operation. However, the situation becomes more interesting when there is a lack of consensus among the committee and the surgeon believes the surgery is ethically permissible. In these cases, the surgeon and movement disorder neurologists have the strongest voices. However, even in the case of an overwhelming majority decisions, reasonable attempts are made to address the concerns of the minority through additional safeguards. This strong push to find consensus and to alleviate concerns in cases where consensus cannot be reached finds its roots in the physicians' belief in the committee process. They hold themselves accountable to the group as colleagues striving for good patient care decisions. Though the committee does not wield a legally binding power on the procedure, it does have a strong professional force to encourage careful reflection. The final decision regarding whether or not to proceed with surgery must rest with the surgeon, as the surgeon is the team member who is primarily responsible for the patient's care during surgery.

PATIENT AND FAMILY/CAREGIVER CONCERNS

During the committee meeting, considerable discussion occurs regarding the patient and the patient's support structure, both social and caretaker. One of the sticking points about surgery is the potential to fundamentally altering the way in which a patient understands the world. It can be argued that end stage Parkinson's disease patients have already undergone a change in their self-identities due to the significant unpredictability in their motor symptoms that profoundly alters both their ability to interact with the world around them and their reliance on others for basic care. Despite these presumed changes, DBS has the potential to alter the brain itself that results in a more fundamental change in the self and being. These changes may include risks to memory, executive function, language, or personality variables. In difficult cases, in which there are concerns that

patients might be more vulnerable to neurocognitive or neuropsychiatric risks, patients may be asked to weigh the high probability of an improvement in physical movement—for example, increased control over one's body and interaction with the environment—in light of potentially significant risks to cognition. Many patients indicate that they would risk anything in order to improve physical function. The physical symptoms may be so incapacitating and prominent that the patient is unable to fully appreciate the potential cognitive and neuropsychiatric ramifications of the decision. The presence of cognitive deficits, including limited insight, can further complicate this decision-making process further. In such situations, it is essential that patients receive guidance in avoiding unacceptable risks through assistance from the health care team as part of its fiduciary responsibility and from those who are relationally close, such as family members.

It is also important to recognise that families and caregivers have a great deal at stake personally in these types of surgeries. The surgery may not only give the patient greater freedom to act volitionally in her world, but also relieve caregivers from assisting the patient with basic personal care tasks throughout the day. Some family members specifically mention reduced caregiver burden among their goals for the patient's surgery. This goal might skew the caregiver's advice toward influencing the patient to take more risks for the caregiver's benefit.¹³ Conversely, if the surgery holds a risk of exacerbating executive dysfunction or if the family member enjoys the caregiver role, a spouse may have significant interest in dissuading the patient from undergoing the surgery because of the harm it could do to the family and/or the caregiver's identity. These various interests in the patient's life should be carefully considered.

HEALTHCARE TEAM CONSIDERATIONS

The fundamental challenge to team members during the patient management meeting is whether the implantation of the DBS electrode(s) will likely result in greater disability than that evident prior to surgery. This is particularly relevant in the borderline cases in which there are significant concerns regarding pre-operative cognitive function or neuropsychiatric status but the concerns are not sufficiently severe to be absolute contraindications to surgery. Although the committee embraces a model of patient centered care with shared decision making, there are also clear limits regarding the types of risks/harms at which the team is willing to place the patient. Patients cannot demand to receive a therapy from a physician if the physician believes the risks and benefits do not balance. Finding this boundary can be very difficult in patients with late stage disease who have exhausted all other treatment modalities and are desperate for a final therapeutic attempt.

These clinical decisions are very challenging as there are clear data supporting the efficacy of DBS in improving motor disability.¹¹ Unfortunately, there are limited outcome data describing cognitive and neuropsychiatric effects in borderline patients who go on to surgery. Consequently, the literature provides no conclusive data that these patients will inevitably have greater neuropsychiatric difficulties following surgery.

Often in borderline cases, the team stipulates a series of interventions including psychiatric care, further evaluations, and very close monitoring in order to protect the patient and avoid unnecessary future health risks. These requirements raise a number of thorny questions about shifts in relationships and obligations. If the patient and family members comply with the team's request, is the team then obligated to provide surgery? How much can be asked of a patient in participating in this decision-making process in order to allay

the healthcare team's concerns regarding the patient's surgical candidacy? One could compare this to the requirement in Liver Transplantation of enrollment in a drug rehabilitation program prior to being listed.

The implantation of a DBS electrode and stimulator is only a first step in the effective application of DBS. Since the stimulators need to be programmed in order to optimize the settings initially and throughout the patient's life, the surgery commits the team to the patient's long-term care. During stimulation, current may spread to non-motor circuits in the brain and potentially influence cognitive or psychiatric behaviours. This presents challenges since some effects of a particular stimulator setting may be identified as problematic by the neurologist and family, but viewed as a benefit to the patient. For example, some patients may have longstanding problems with impulsivity that predated surgery. The impulsivity might be exacerbated following surgery. Whether this is due to disease progression, surgery, stimulation or medication effects is unknown. DBS surgery may successfully improve the patient's motor status such that the patient is much more mobile, but unfortunately the combination of impulsivity and greater mobility results in increased risk for falls and injuries. This highlights the continued challenges through the course of a patient's life with respect to the stimulator. What is the team's obligation to the patient and family members when the stimulator may be causing social harm? Is it ethical to reduce the motor benefits by reducing the stimulation in order to protect the patient or patient's relatives from future injury? Finally, the device is not self-sustaining and, at the current time, the batteries are not rechargeable. Consequently, future surgeries to replace worn out generators are required. This necessitates guidelines for potentially refusing to replace the generator because of harmful patient behaviour.

As an increasing number of centres begin to offer DBS to patients, other ethical challenges arise. Best practices and expansion of a technology in non-specialised settings and the commitment of centres to patients must be addressed. Given the expertise required to program and manage these patients, it is not appropriate to assume that local community physicians can, or should, manage their care. Furthermore, many local physicians are uneasy assuming care of patients with implantable brain devices and insist that the patients be followed for most of their health care needs by the surgery team. If a patient does not have the means for adequate follow-up, a surgical centre could put the patient at surgical risks for little or no benefit.

Another major ethical challenge for health care workers caring for functional neurosurgery patients is the importance of balancing their roles as health care providers versus researchers. Functional neurosurgery patients offer unique opportunities to better understand the brain. Ethical conflicts can arise between health care providers' desire to further explore the limits of a technology and better understand how the brain functions all the while ensuring patient safety. Innovative patient care and technologies inherently involve risk as outcome data are not always available. The lines between innovative clinical care and research can be easily blurred. For some health care providers it might be difficult to be cognizant of their own intellectual interests and values and how they might influence clinical decision-making. Again the multi-disciplinary committee functions to help the entire team remain focused on patient care and distinguish between research and care issues.

CASE EXAMPLE

In order to bring these elements together, it is useful to give a generic example of the type of patient who might engender considerable discussion at such a committee meeting. The

following case example represents an amalgamation of different patients and is not specific to any one patient. The patient is a 65 year old, man with a 15 year history of Parkinson's disease characterised by bilateral tremor (right sided worse than left), stiffness, gait problems, and medication-induced dyskinesias. His symptoms were well controlled with medication for several years; however, more recently his symptoms have increased and he is experiencing wearing off of medication benefit every two hours. The neuropsychological assessment reveals a poor memory and other cognitive deficits suggestive of mild dementia. In addition, marked impulse control problems are apparent. There is a remote history of depression that remitted following Electro-Convulsive Therapy. More recently, the patient has experienced a recurrence of depression that he attributes to his increased motor disability. His ex-wife accompanies him to his appointments and indicates that he has occasional panic attacks. The patient has adult children, all of who live out of state. His ex-wife is his only support locally, and she lives an hour away from him.

In this case, the committee might be concerned that the patient's quality of life would decrease significantly if his cognition were further harmed. There are also concerns regarding poor impulse control and potentially poor judgment. These cognitive limitations might result in the patient participating in unsafe activities. These concerns are heightened given the limited social support. He does not have family available to help during the post-operative recovery period and to monitor his behaviour to help ensure safety. He may be at risk of falling during months where there is an attempt to optimise stimulator settings. In this case, the question arises as to whether the team should risk what quality of life the patient currently has, for a potential improvement in quality of life he might obtain from the DBS. This more paternal response to protecting the patient from undue risk hinges partially on the fact that the patient has some cognitive dysfunction and may not be in a good position to carefully balance risks and benefits. This process is understood as a collaborative decision making between patient and team, but with significant limits. Given that DBS is an elective surgical procedure and not an emergency or life saving procedure, the team has a responsibility to ensure that the proper social, psychological, psychiatric supports are in place before proceeding. The DBS team's primary value is to avoid undue risk/burden on the patient while allowing patients access to surgery for those patients who might benefit significantly.

CONCLUSION/SUMMARY

The previous discussion has highlighted many of the ethical dilemmas facing DBS multidisciplinary teams on a regular basis. As more patients undergo this procedure and we continue to learn more about the technology and outcome following surgery, patient eligibility criteria, and guidelines regarding clinical decision-making develop. Clinical decision-making is inherently an evolving process as more and more information is available to help guide clinical decision making. The role of health care providers as clinician researchers, whose practice is informed by the current

literature, is well recognised in health care settings. What is less well emphasised is the role that values play in clinical decision making and the importance of multi-disciplinary committees in uncovering these values in particularly complex cases. Explicit recognition that all clinical decisions are made within a value-laden framework improve decision-making guidelines for borderline cases. Over time, the various members of a team can develop a cohesive set of values that help define patient care standards. Inclusion of a bioethicist in these team meetings helps focus the discussion in a bioethical framework and can assist in identifying and prioritising the values that are important to the team. Given the chequered history of psychosurgery and the significant follow-up needed for patients with stimulators, an ongoing multidisciplinary conversation around patient selection and care provides an important avenue for establishing good practice.

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