PSYCHIATRIC NEUROSURGERY IN THE MODERN ERA:
PUBLIC, MEDIA AND CLINICAL PERSPECTIVES

by

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Abstract

Neurosurgical interventions are returning to psychiatry with many familiar and challenging ethical, social and legal questions of the past. Narratives about the benefits, risks, and promise of novel medical and surgical innovations are shaped and circulated among the public, media, and medical communities. Through three studies conducted within the scope of this thesis, I focus on a central research question: What are the perspectives of the public, the media, and clinical stakeholders on the re-emergence of neurosurgical interventions for treatment-refractory mental health disorders? I address this research question through the lens of a pragmatic neuroethics framework using both qualitative and quantitative analyses. In the first study, I explore the perspectives of members of the public toward the re-emergence of psychiatric neurosurgery in three countries. I find optimism about innovations in the mental health landscape but concerns about the preservation of an authentic self, the last resort nature of surgical procedures, the capacity of patients with mental health disorders to consent to invasive interventions, and the lingering societal stigma attached to both psychiatric disorders and treatments for them. In the second study, I explore the experiences of mainstream science writers who report on psychiatric neurosurgery and other innovative medical technologies. I find that these journalists value balanced reporting practices and consider the controversial history of psychosurgery as a contributor to both the newsworthiness of contemporary procedures and the importance of cautious communication. In the third study, I survey North American functional neurosurgeons to obtain an updated account of their practices, predictions and perceptions of modern psychiatric neurosurgery. I uncover a sustained role for ablative procedures despite recent evolution in neuromodulatory interventions. I also find greater support for the use of psychiatric neurosurgery in the treatment of obsessive-compulsive disorder (OCD) than for major depressive disorder.
(MDD). Overall, the findings unite the voices of key stakeholders and support a commitment to ethical translation of re-envisioned neurointerventions for psychiatric disorders.
Lay Summary

Psychiatric neurosurgery refers to the surgical treatment of major mental health disorders that are not responsive to drug therapy. Mishaps of the past involving psychosurgery provide a cautionary tale for intervening on the mind and brain, but advances in brain technology and improved ethics oversight today respond to this dark history. In this thesis, I explore the perspectives of members of the public, journalists, and doctors who perform surgery on the brain to characterize social and ethical concerns and hopes for the continued development of these treatments. My findings shed light on understandings, priorities and informational needs of stakeholders, and support the importance of aligning the evolution of novel psychiatric treatments with societal values.
Preface

This thesis is based in part on the work of an international consortium investigating the ethical, legal and social implications (ELSI) of contemporary psychiatric neurosurgery (ERA-NET NEURON European Research Projects on Ethical, Legal, and Social Aspects of Neuroscience, 2016). None of the text of the dissertation is taken directly from previously published articles.

Chapter 3

The study in Chapter 3 was conceptualized Dr. Laura Cabrera and designed jointly with Dr. Judy Illes. Approval for the study was obtained from the Institutional Review Boards (IRBs) of each of the universities of the investigators (University of British Columbia (UBC) [H17-00013], Michigan State University as a subcontracting collaborating site to UBC (IRB# x16-520e), Institut des recherches cliniques de Montréal (IRCM) [ 2018-913], and Charité–Universitätsmedizin Berlin CCM [EA1/123/17]). Data were collected chiefly by Dr. Laura Cabrera (Spain, Vancouver), Mr. Merlin Bittlinger (Germany), and Dr. Eric Racine (Montreal). Ms. Hayami Lou, Dr. Roberto Martinez, and Mr. Merlin Bittlinger oversaw study recruitment in Vancouver, Madrid, and Berlin, respectively. I recruited participants in Montreal, performed qualitative data analysis for the focus groups conducted in Vancouver and Montreal, and performed quantitative analysis of all data presented in Chapter 3. Final presentation of results was a collaborative effort involving me, Dr. Laura. Cabrera, Dr. Judy Illes, Mr. Merlin Bittlinger, and Dr. Sabine Müller.
Chapter 4

The study in Chapter 4 was conceptualized and designed jointly by Dr. Judy Illes and Dr. Laura Cabrera. We acknowledge the contribution of Dr. Jeannie Shoveller to the conceptualization of this study. Approval for the study was obtained from the UBC Behavioural Research Ethics Board (BREB) [H17-00013]. I recruited participants for this study with assistance from Dr. Alexandra Olmos-Perez and conducted interviews jointly with Dr. Judy Illes. I performed qualitative data analysis for this study with assistance from Mr. Jacob McFarlane and directed the final presentation of results.

Chapter 5

The study in Chapter 5 was conceptualized by Dr. Laura Cabrera and was jointly designed by me, Dr. Laura Cabrera, and Dr. Judy Illes. Ethics approval for this study was obtained from the Michigan State University IRB (STUDY00001237). I acknowledge the assistance of Dr. Zelma Kiss in piloting the survey described in this chapter, as well as the support of Ms. Melodie Dian and Dr. Robert Gross from the World Society of Stereotactic and Functional Neurosurgeons (WSSFN) in distributing the survey. I performed the descriptive and inferential statistical analyses and directed the final presentation of results.
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<th>Full Form</th>
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<tr>
<td>ADHD</td>
<td>Attention-deficit hyperactivity disorder</td>
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<tr>
<td>ASSFN</td>
<td>American Society for Stereotactic and Functional Neurosurgery</td>
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<tr>
<td>DBS</td>
<td>Deep brain stimulation</td>
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<tr>
<td>ELSI</td>
<td>Ethical, legal, and social implications</td>
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<td>ECT</td>
<td>Electroconvulsive therapy</td>
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<td>MDD</td>
<td>Major depressive disorder</td>
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<td>MRgFUS</td>
<td>Magnetic-resonance-guided focused ultrasound</td>
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<td>MST</td>
<td>Magnetic seizure therapy</td>
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<td>OCD</td>
<td>Obsessive-compulsive disorder</td>
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<td>PTSD</td>
<td>Post-traumatic stress disorder</td>
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<td>TMS</td>
<td>Transcranial magnetic stimulation</td>
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<td>VNS</td>
<td>Vagal nerve stimulation</td>
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<tr>
<td>WSSFN</td>
<td>World Society for Stereotactic and Functional Neurosurgery</td>
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À Georgette, ma grand-mère,
dont le courage et la curiosité continuent à m’inspirer.
Chapter 1: Introduction

1.1 Overview

In this thesis, I bring together the voices of the public, the media, and clinicians to bring new knowledge to and inform the evolution of modern psychiatric neurosurgery in an ethically- and socially-minded way. My work is anchored by the following, overarching research question:

*What are the perspectives of the public, the media, and clinical stakeholders on the re-emergence of neurosurgical interventions for treatment-refractory mental health disorders?*

I elaborate on this central research question through three sub-questions:

1. What are the perspectives of members of the public from three different countries regarding innovations in psychiatric neurosurgery?
2. How do journalists select, research, and disseminate news about technological and surgical advances in the mental health sphere?
3. What are the attitudes, practices and predictions of functional neurosurgeons during an era of rapid development within the field of psychiatric neurosurgery?

Throughout my thesis work, I apply a pragmatic neuroethics framework (Racine, 2010) to answer these questions.

The thesis is formatted as a collection of independent but related manuscripts about stakeholder perspectives at the interface of neurosurgery and psychiatry. After this first chapter in which I introduce the landscape of psychiatric neurosurgery, I provide an overview of research designs used across the three studies in Chapter 2, as well as a discussion of the qualitative and quantitative methods used throughout this thesis. Additional details about methods are described
within Chapters 3-5, which are stand-alone papers that have been submitted or prepared for publication.

In Chapter 3, I present the results of a collaborative, cross-national study that explores the attitudes and perceptions held by members of the lay public towards psychiatric neurosurgery. This study applies focus group methodology on an international scale and seeks to gauge the knowledge, concerns, and expectations of a diverse subsection of the public in Canada, Germany and Spain. These three Western countries represent partnering nations in an international collaboration investigating the ethical, legal and social implications (ELSI) of contemporary psychiatric neurosurgery procedures.

In Chapter 4, I explore the perspectives of journalists who have written about contemporary psychiatric neurosurgery throughout the last two decades of its renaissance. In this qualitative study, I used semi-structured interview methodology to elicit the values, practices and perceived ethical barriers considered by journalists when reporting on the topic of psychiatric neurosurgery and other innovative medical technologies.

In Chapter 5, I capture the views of North American functional neurosurgeons towards psychiatric neurosurgery through a survey distributed to members of the American Society of Stereotactic and Functional Neurosurgery (ASSFN). This survey offers an updated account of clinical practices, preferences and predictions after nearly a decade of innovation within the psychiatric neurosurgery landscape, building upon prior relevant studies (e.g., Lipsman, Mendelsohn, Taira, & Bernstein, 2011; Mendelsohn, Lipsman, Lozano, Taira, & Bernstein, 2013).
In Chapter 6, I bring together each arm of my thesis research into a set of conclusions and directions for future research.

1.2 Mental Illness and the Brain

Competing theories about the origins of mental illness have fueled both medical and philosophical debates throughout history. In Hellenic times, the medical profession chiefly serviced ailments of the body, while patients with mental disturbances were referred to treatment by philosophers, the self-proclaimed experts of the soul (Ahonen, 2019). The Roman physician-philosopher Galen was a convincing advocate for encephalocentrism, supporting his philosophy that the mind resides in the brain through clinical casework, surgical lesioning studies, and nervous system dissections (Crivellato & Ribatti, 2007). Galen firmly believed in a distinction between mental illness and emotional distress, the former requiring a correction of “physical imbalance,” and the latter resolvable through behaviour modification and other psychological approaches (Ahonen, 2019, p. 12).

The speculation that some physical, neural substrate could contribute to disordered affect and cognition approximating modern psychiatric illness inspired many medical practitioners proceeding Galen in medical history, and perhaps even his Neolithic antecedents who practised trephination (Robison, Taghva, Liu, & Apuzzo, 2013). It was not until the mid-20th century, however, that the formalization of psychosurgery affirmed the understanding of mental illness as an intrinsically neurological phenomenon. While the lobotomy era holds a mark of intense opprobrium in modern society, writings by Valenstein remind us that “these operations were very much a part of the mainstream of medicine of their time, and the factors that fostered their development and made them flourish are still active today” (1987, p. 4). In the wake of a revived
interest within the medical community to explore psychiatric neurosurgery as a treatment for severe mental illness, a consideration of relevant social factors and their ethical consequences are explored throughout this thesis.

Approximately 30% of the global adult population will be affected by a mental health disorder at some point during their lifetimes (Steel et al., 2014). These conditions rank as the leading causes of disability worldwide and have significant health, social, and economic consequences (Walker et al., 2016; Whiteford et al., 2013). Despite investigational efforts aimed at increasing the knowledge of psychopharmacology and biomarkers of psychiatric illnesses, failure to respond to any of a number of medication trials is reported to occur 30% to 55% of the time (Souery et al., 2007; Trivedi et al., 2006; Wiles et al., 2014). In addition to medication non-response, high rates of relapse and side-effects from pharmacotherapy, considerable drop-out rates from psychotherapeutic interventions, repeat hospitalizations, and overall treatment non-compliance all comprise significant hurdles for patients seeking psychiatric care. For treatment refractory patients, the pool of accessible, evidence-based therapies beyond front-line treatments is limited.

With increasing recognition of the burden that psychiatric illness poses to affected patients, their families, and society at large, a renewed interest in the development of safe and effective surgical interventions for a subset of treatment refractory patients has surfaced within the medical community (Cleary et al., 2015). This revival is described by Goodman and Insel (2009) as constituting a third-wave of evolution in the suite of neurosurgical interventions developed and applied to the treatment of psychiatric conditions. The first wave of interventions dates back to 1930s, when psychosurgeries such as the leucotomy and prefrontal lobotomy gained credence
across both public and medical communities struggling to combat the escalating social, medical and political consequences of major mental illness (Valenstein, 1986). These procedures were theoretically founded upon primitive understandings of the neural circuitry of human emotion and involved the surgical disconnection of white matter fibre tracts between the frontal lobes and subcortical brain structures (Goodman & Insel, 2009; Lévêque, 2014). Indeed, one of the most infamous proponents of these procedures, American neurologist Walter Freeman, considered the mere dulling of patient affect to be a successful post-operative outcome. He put into question the scientific validity of these first-wave psychosurgeries alongside a multitude of bioethical concerns surrounding their practice (El-Hai, 2005). The advent of psychopharmacology and mounting public backlash towards psychosurgery quieted this pursuit, however, a second wave of psychiatric neurosurgical development arose from the work of neurosurgical teams at select medical centres that continued to research and refine these procedures.

Bolstering this evolution, technological innovations and neuroscientific discoveries throughout the last half-century in the areas of surgical stereotaxy, neuroimaging, neuroanatomy, and radiosurgery have enabled several ablative neurosurgical procedures to offer relief to specific subsets of psychiatric patients (Dyster, Mikell, & Sheth, 2016; Lozano & Lipsman, 2013; Robison et al., 2013; Goodman & Insel, 2009). Anterior cingulotomy and capsulotomy, for example, are options for patients with severe forms of obsessive-compulsive disorder (OCD) and depression (Lévêque, 2014). More rarely, subcaudate tractotomy and amygdalotomy may be offered to patients with the aforementioned disorders and for pathologically aggressive behaviour, respectively (Bridges et al., 1994; Mpakopoulou, Gatos, Brotis, Paterakis, & Fountas,
2008). These ablative surgical procedures, together with a newer third-wave of neuromodulatory interventions, are collectively brought together under the term psychiatric neurosurgery.

1.3 Contemporary Psychiatric Neurosurgery

Psychiatric neurosurgery as a terminology for the surgical modification of neural circuitry in patients afflicted with psychiatric disease represents a deliberate, rhetorical dissociation from the infamous term psychosurgery. Johnson asserts that this value-laden distinction serves the primary function of differentiating modern procedures from a collectively-remembered predecessor, the frontal lobotomy (2014). Most medical scholars agree that modern psychiatric neurosurgical procedures are vastly improved successors of psychosurgery, offering the safety, precision, and efficacy that procedures like lobotomy and leucotomy failed to achieve (Müller, 2017; Ducharme, Price, & Dougherty, 2016; Lévêque, 2014). What they do share is an epistemology of psychiatric illness as a product of brain dysfunction, whereby modulation or destruction of overactive neural circuitry can lead to symptom improvement. However promising, the field still faces a number of hurdles with respect to therapeutic validity. The design of rigorous clinical trials is hampered by factors such as heterogeneous referral patterns, a lack of consensus on the definition of treatment resistance, and competition for an already small pool of patients across multiple ongoing trials (Lozano et al., 2019). At present, ablative psychiatric neurosurgical procedures are approved although not thoroughly researched (Fins, 2016; Nuttin et al., 2014), and neuromodulatory procedures have failed to prove efficacy in rigorous clinical trials (e.g., Dougherty et al., 2015; Holtzheimer et al., 2017) and therefore remain investigational (Fins et al., 2017).
1.3.1 Contemporary Ablative Procedures

Stereotactic ablation in functional neurosurgery is achieved predominantly through the use of microablative thermocoagulation or radiosurgery. The former is an invasive procedure in which a heated electrode is inserted into the brain and used to destroy a localized region of parenchyma (Lévêque, 2014). The latter directs gamma radiation through the cranium at pre-identified neural targets, producing localized lesions through a gradual process of radioactive decay. As Müller and colleagues suggest, each procedure operates under a distinct featural paradigm: microablation offers a quick-fix incentive while radiosurgery offers minimal invasiveness (2015). A third alternative, magnetic resonance-guided focused ultrasound (MRgFUS), is an emerging neurosurgical technology offering what might appear to be the best of both worlds — rapid onset of effects without breaking skin. Bilateral anterior capsulotomy using MRgFUS has been performed in only a handful of patients with OCD and major depressive disorder (MDD) at a single clinical site in Korea (Kim, Kim, Jung, Kim, & Chang, 2018; Na, Jung, & Chang, 2015). Further investigation is currently underway in at least one surgical centre in Canada (ClinicalTrials.gov no. NCT03421574).

1.3.2 Neuromodulation

Interest in the application of neuromodulatory techniques in the treatment of psychiatric disorders dates back to the lobotomy era (O’Neal, Baker, Glenn, Conner, & Sughrue, 2017), however, their resurgence in modern psychiatric research stems from mounting evidence of efficacy in neurological conditions such as Parkinson’s Disease (PD), essential tremor and dystonia. One such modality is deep brain stimulation (DBS), which involves the implantation of battery-powered electrodes into a targeted brain region and the creation of transient lesions in
surrounding parenchyma via chronic electrical current (Müller, 2017). The exact mechanism by which DBS creates a lesion-like effect is disputed, however, the effects of stimulation can be observed at the ionic, protein, cellular and network levels (Lozano et al., 2019). Deep brain stimulation of cortico-limbic, motor, and reward circuitry is currently under clinical investigation for the treatment of MDD, OCD, Tourette syndrome, chronic pain, addiction, anorexia nervosa, and post-traumatic stress disorder (PTSD). Preclinical studies are also exploring the efficacy of DBS in modifying positive and negative symptoms of schizophrenia (e.g., Corripio et al., 2016).

Two commonly noted advantages of DBS are its adjustability and relative reversibility (Greenberg et al., 2003; Kuehn, 2007; Lipsman, Giacobbe, Bernstein, & Lozano, 2012; Roh, Chang, Chang, & Kim, 2012). Clinicians can make post-implantation adjustments to stimulation parameters via digital interrogation and manipulation of the internal pulse generator. Closed-loop DBS devices are currently in the developmental pipeline which would enable automatic stimulation adjustment through biofeedback-driven systems (Klein et al., 2016). Unlike the permanency of lesions produced through ablation, DBS devices can be explanted if determined to be ineffective or harmful. Nevertheless, some authors claim that DBS-induced neuroplastic alterations to local cellular environments make the claim of reversibility inexact (Hariz, 2002; Synofzik & Schlaepfer, 2011).

There is currently no evidence to suggest that psychiatric DBS is more clinically effective than its ablative contemporaries; however, some researchers propose that its current popularity is influenced largely by patient and clinician preferences (Pepper, Hariz, & Zrinzo, 2015). In 2009, DBS for OCD was granted a Humanitarian Device Exemption from the US Food and Drug
Administration (FDA). This has been disputed on grounds that OCD is neither an orphan disease nor were there clinical trials of adequate size or statistical power performed to assume its efficacy in this population (Fins et al., 2011). The costs, maintenance burden and time to onset of therapeutic effect of DBS all surpass those of ablative interventions. Nevertheless, each modality offers a distinct combination of benefits, accommodations, surgical risks, and potential adverse effects (Müller, 2017).

In addition to DBS, stimulation of the vagus nerve has also been explored as a therapeutic intervention for refractory psychiatric disorders. Vagus nerve stimulation (VNS) adopts a bottom-up approach to modulating neural circuitry, wherein electrodes are surgically implanted into the neck to stimulate afferent fibres of the vagus nerve (O’Reardon, Cristancho, & Peshek, 2006). Although the precise mechanism of action of VNS remains unclear, the prevailing hypothesis is that the electrical impulses generated by a subcutaneous stimulator are transmitted via the vagus nerve to the brainstem, ultimately increasing the availability of neurotransmitters and other metabolites in the cerebrospinal fluid (Jotterand, McClintock, Alexander, & Husain, 2010; O’Reardon et al., 2006). Interest in applying VNS to the treatment of psychiatric disorders grew from anecdotal reports of mood elevation in patients undergoing VNS treatment for intractable epilepsy. VNS was later approved as an adjunctive therapy for MDD by the FDA in 2005 despite failure to demonstrate superiority over sham therapy, and has since been investigated in the treatment of bipolar disorder, schizophrenia, dementia and post-traumatic stress disorder (Cimpianu, Strube, Falkai, Palm, & Hasan, 2017).
1.4 A Call to Neuroethics

The field of neuroethics aims to align neurotechnological innovation with societal values through dedicated attention to their ethical, legal, and social implications (Illes & Racine, 2005). Against a backdrop of historical malpractice, it is unsurprising that the re-emergence of psychiatric neurosurgery has raised prominent ethical, legal and social concerns. Extensive ethical guidance for these procedures has been offered on the matters of conflict of interest, ethical and regulatory oversight, informed consent and patient decision making capacity, subject selection, and responsible experimental and publication practices (e.g., Bell & Racine, 2012; Carter, Bell, Racine, & Hall, 2011; Dunn et al., 2011; Kuhn, Gaebel, Klosterkoetter, & Woopen, 2009; Lipsman, Bernstein, & Lozano, 2010; Mian, Campos, Sheth, & Eskandar, 2010; Nuttin et al., 2002, 2014; Synofzik & Schlaepfer, 2011). Many ethicists have also addressed the normative concepts of personality, authenticity, and identity in psychiatric patients who receive DBS implants, particularly with respect to post-operative experiences of self-estrangement (Gilbert, 2015, 2018), artificiality of emotion (Johansson et al., 2011; Kraemer, 2013b), and lack of autonomy, especially in the wake of closed-loop devices (Goering, 2015; Kraemer, 2013a).

From a legal standpoint, national legislation and international law can both limit the field of psychiatric neurosurgery and shape perception of it by the public. For example, in some jurisdictions, even modern forms of psychiatric neurosurgery are forbidden (Loo, Trollor, Alonzo, Rendina, & Kavess, 2010). By contrast, these procedures have reigned as largely exploitative practices in countries like China without proper government regulation (Wu, Gabriels, & Nuttin, 2012). Legislation is informed and influenced by clinicians and bioethicists who have commented on the development of modern psychiatric neurosurgery from its
inception. Many of these individuals are directly involved in psychiatric neurosurgery research projects and sit on committees that publish guidelines and recommendations. Additionally, the media influences legal theorists and politicians who ultimately decide on the admissibility of these procedures within society (Caulfield, Bubela, & Murdoch, 2007).

Media reports play a crucial role in the social acceptance of psychiatric neurosurgery, as do the values of functional neurosurgeons expanding the scope of their practice into the psychiatric domain. Reporters are undeniably influenced by patient success stories, enthusiasm from researchers and clinicians, publication bias in scientific journals, and by diverging statements from bioethicists (Gilbert & Ovadia, 2011; Racine, Waldman, Palmour, Risse, & Illes, 2007; Schlaepfer & Fins, 2010). In a seminal study tracing the tone of popular press articles in the United States throughout the lobotomy era, Diefenbach et al. (1999) described how sensationalism and uncritical reporting enabled lobotomy to gain significant traction within the public sphere throughout the 1930s and 1940s. A similar trend has been noted in recent years: press reports of modern psychiatric neurosurgery interventions, particularly neuromodulation, are largely optimistic and uncritical of relevant social, political, ethical and philosophical issues (Cabrera, Bittlinger, Lou, Müller, & Illes, 2018b). Further, nearly 90% of functional neurosurgeons feel optimistic about the future of psychiatric neurosurgery, with many anticipating that the practice will only grow in years to come (Lipsman et al., 2011; Mendelsohn et al., 2013).

All told, acknowledgement of the intrinsic interconnectedness of the public, the media, and clinicians in the wake of promising medical advances is crucial, as this relationship can be easily
jeopardized by inattention to ethical concerns (Diefenbach et al., 1999). This interconnectedness, together with hope and promise for some of the most vulnerable people in our modern society, and the imperative to promote and uphold the highest standards of trust among stakeholders, motivated the present research.
Chapter 2: Research Methods

This chapter provides an overview of the qualitative and quantitative methods used in this thesis. I begin by explaining the relationship between qualitative and quantitative research, followed by a statement of personal perspectives that situates my role as a researcher in this body of work. I then describe key ethics considerations in conducting human subjects research and discuss the theoretical and methodological footings of the research presented in this thesis.

2.1 Research Traditions and Epistemologies

Bias is eschewed in the empirical research paradigm that values rigor as measured by internal validity, external validity, reliability and objectivity (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Indeed, empirical or positivist research is defined by Alvesson and Sköldberg (2000) as a process that involves the rendering of “data, facts, the unequivocal imprints of ‘reality’” to inform empirically-grounded conclusions which lend themselves to generalizations and theory building (p. 1). Inductive forms of qualitative research, by contrast, require that researchers construct meaning rather than pursue an objective reality within their data. This view lends itself to the notion that the qualitative researcher is often regarded as the instrument of research (Given, 2008). As such, an implicit interdependency exists between the researcher, selected methods, and the data yielded (Mauthner & Doucet, 2003). Measures of rigor within the qualitative paradigm, as pioneered by Lincoln and Guba (1985), centre not on the generalizability of findings, but rather aim to achieve trustworthiness through the concepts of credibility, transferability, dependability, and confirmability. Overall, qualitative research complements the positivist paradigm by delivering an in-depth and interpretive understanding of the social world of research participants through learning about their perspectives, experiences,
and life histories (Ritchie, Lewis, Nicholls, & Ormston, 2013). In this thesis, I combine both qualitative and quantitative research approaches to answer the following question:

What are the perspectives of the public, the media, and clinical stakeholders on the re-emergence of neurosurgical interventions for treatment-refractory mental health disorders?

While the fusion of research methods from two seemingly distinct paradigms may appear antithetical, Johnson and Onwuegbuzie (2004) assert that mixed methods research, borrowing from both quantitative and qualitative traditions, creates an opportunity to address research questions in coherence with post-positivist epistemological and pragmatic theoretical stances. The epistemological and theoretical considerations that shape the research presented in this thesis are discussed below.

Epistemology is a branch of philosophy that is concerned with the nature of knowledge, justification, and the rationality of belief (Steup, 2005). Further, epistemology guides methodological choices and is axiological (Carter & Little, 2007). My epistemological stance is influenced by my exposure to a range of research traditions and experiences throughout my academic journey. My background in cellular and molecular neuroscience forms the basis of my understanding of empirical research and has also engendered post-positivist values in my current approach to research. The post-positivist epistemology, compared to positivism, recognizes that empirical methods have inherent limitations and therefore can only provide an approximation of reality (Creswell, 2014). While positivists emphasize independence between the researcher and
the researched, post-positivists amend this view, arguing that the theories, background, knowledge and values of the researcher can influence what is observed (Robson, 2002). This philosophical outlook can be applied to both quantitative and qualitative research designs and is thus particularly amenable to the body of research presented throughout this thesis (Johnson & Onwuegbuzie, 2004). I also accommodate elements of social-constructivist inquiry, which aims to explore a subjective truth and, like post-positivism, embraces bias (Creswell, 2014). Social constructivist epistemology is concerned with how knowledge is constructed and understood through human interactions and accepts that multiple objective realities exist (Creswell & Poth, 2018). This stance asserts that each individual reality is subjectively constructed, rather than discovered, and that each individual has developed unique, subjective meanings of their own personal experiences (Crotty, 1998). Further, social constructivist methodology regards the social practices that people engage in as the focus of inquiry, promoting co-construction of reality between the researcher and the researched. This can occur, for example, in the dialogic exchanges that occur between researcher and participant in the interview process (Mayan, 2016).

Researcher identity is intrinsically linked to the personal ethics that a researcher applies to their research, and therefore, is a subject warranting critical conscious reflection when designing and executing research within a post-positivist paradigm (Sethi, 2012). Indeed, over the course of my undergraduate and graduate studies I have hoped for the development, refinement, and increased accessibility of interventions for patients living with psychiatric illness. Whether my hopes have been influenced by my involvement in community supports for individuals affected by mental health disorders, my foundational interests in molecular neuroscience and circuit-level theories of psychopathology, or my continuing educational pursuits within the field of neuropsychology, I
recognize that there is a possibility that my views may have influenced participants during the research process. As such, the strategies that I used to promote rigor and reflexivity within the qualitative segments of this thesis and to mitigate the influence of my perspectives on the results are described in Section 2.4.1.5 (Lincoln & Guba, 1985; Mayan, 2016)

2.2 Ethics Review

This thesis includes human subjects research and complies with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf). The studies presented in Chapter 3 and 4 were reviewed by the University of British Columbia Behavioural Research Ethics Board (BREB) and approved under certificate H17-00013. The Michigan State University Institutional Research Board (IRB) approved the study presented in Chapter 5 (STUDY00001237). Informed consent was obtained from all research participants (Appendix B). They were informed that participation was voluntary, anonymous, and that withdrawal from research was an option at any time. Given the sensitive nature of some of the studies that addressed experiences with mental health disorders, participants were reminded to divulge only as much information as was comfortable for them. To protect the privacy of participants, all transcript data obtained from focus groups and interviews were assigned alphanumeric codes, de-identified, and stored in a secure locked cabinet at Neuroethics Canada. All data will be retained for a minimum of 5 years after the publication of the studies described in this thesis and subsequently destroyed.
2.3 Theoretical Framework

Theoretical frameworks offer a guiding structure from which to develop study procedures, analysis, and representation of results. In this thesis, pragmatic neuroethics is the underlying epistemological framework (Racine, 2010). Neuroethics is a field that aims to align “the exploration and discovery of neurobiological knowledge with human value systems” (Illes, 2007, p. S57). To this end, neuroethics has evolved as an interdisciplinary research area that seeks to navigate ethical tensions within the domain of neuroscience and its contributions to contemporary understandings of the human brain, and is concurrently shaped by emergent social, scientific and technological developments (Emerging Issues Task Force, International Neuroethics Society, 2019). Pragmatic neuroethics descends from an epistemological lineage of anti-naturalist and naturalist debates in bioethics, the former accepting that ethical norms derive from theoretical reasoning and a priori sets of moral principles, the latter instead suggesting that ethical norms represent outgrowths of empirical knowledge and are fundamentally rooted in biology. Racine (2010) asserts that pragmatic neuroethics espouses a pluralistic, moderate pragmatic naturalism epistemological stance, accepting that “ethical predicates are properties that cannot be reduced to natural properties but are best understood within a fact-value continuum” (p. 65). In other words, moderate pragmatic naturalism connects ethics exploration to empirical research but rejects reductionist intents.

Pragmatism is a humanist tradition that endorses an approach to research that is intentionally situated within a continually-evolving landscape of human values (Johnson & Onwuegbuzie, 2004). In rejecting a dogmatic adherence to normative moral principles (Racine, 2010), pragmatism welcomes the application of knowledge from an eclectic set of moral theories
Overall, pragmatic neuroethics emphasizes the importance of pluralistic and inclusive deliberations at the intersection of science and society (Illes et al., 2005; Racine, 2008). This theoretical grounding is therefore congruent with the methodological approach of eliciting the perspectives of diverse stakeholders about the ethical and social issues that accompany the development of novel neurotechnologies, and the further aim of applying this evidence to inform best practices in ethics and patient care (Racine, Bell, Di Pietro, Wade, & Illes, 2011). While the work in this thesis attends to the perspectives of non-patient stakeholders regarding neurosurgical interventions in psychiatry, an overview of literature that explores patient experiences within this domain is presented in Section 3.1.

2.4 Methods

I utilize two approaches to address the primary research questions: (1) qualitative descriptive inquiry (Chapter 3, Chapter 4); and, (2) survey methodology (Chapter 5).

2.4.1 Qualitative Descriptive Inquiry

2.4.1.1 Overview

Interpretive frameworks can prescribe choices of method, resonate with particular academic disciplines, and encourage or discourage the use or development of theory. In Chapter 3 and Chapter 4, I use a method of qualitative description as described by Sandelowski (2000; 2010). Qualitative description is particularly amenable to studies that seek to characterize phenomena of interest through the production of detailed, interpretative accounts of data (Sandelowski, 2010). Rather than produce a theoretical or conceptual outlook as rendered by other qualitative approaches, the goal of qualitative description, as Bradshaw and colleagues suggest (2017), is to
“provide a rich description of [an] experience depicted in easily understood language” so as to be applicable to both research and praxis (p. 4). Qualitative descriptive studies are grounded in the general principles of naturalistic inquiry (Lincoln & Guba, 1985). This form of inquiry encompasses research traditions originally developed in anthropology and sociology and is particularly valuable for exploratory research where little is known about the experiences, perspectives or values of the group to be studied (Armstrong, 2010). Consistent with the naturalist paradigm, qualitative descriptive inquiry does not endorse the pre-selection of study variables, manipulation of variables, or make commitments to a priori theoretical outlooks. Instead, the researcher is expected to commit to observing the phenomenon of interest in its natural state (Bradshaw, 2017; Sandelowski, 2000).

The methods nested within qualitative description methodology are eclectic in that they tend to borrow from a variety of qualitative traditions, such as ethnography, phenomenology and grounded theory (Sandelowski, 2000). Rather than commit to paradigmatic theory, however, qualitative description studies are diverse and are founded in existing knowledge, thoughtful linkages to the work of others in the field of inquiry, and the clinical experience of the research group (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Indeed, while “no description is free of interpretation” (Sandelowski, 2000, p. 335), qualitative description is classified as a low-inference methodology compared to other qualitative approaches. Qualitative description thus aims to stay as close to the data as possible (Neergaard et al., 2009), and also benefits from its ability to yield a high consensus among researchers with regards to the final presentation of study results (Sandelowski, 2000).
2.4.1.2 Sampling and Recruitment

Purposive sampling methods were used in all studies presented in this thesis. A purposive sampling approach is non-randomized and involves the selection of participants based on pre-defined characteristics such as membership within a particular social group (Denscombe, 2014). Eligibility criteria for each individual study are discussed in Sections 3.3, 4.3, and 5.3. Members of the public were recruited for the study in Chapter 3 using print and web advertisements posted in community centres, mental health agencies, and on the Neuroethics Canada website and social media accounts (Appendix A). Journalists were recruited for the study in Chapter 4 through email or LinkedIn In-Mail (Appendix A).

2.4.1.3 Data Collection

Focus groups (Chapter 3) and semi-structured interviews (Chapter 4) were conducted with research participants by myself or other members of the research team. Focus group guides (Appendix C) were developed to expand the findings of Cabrera et al. (2018) on media representations of psychiatric neurosurgery. Focus group methodology is a form of data collection distinct from the one-on-one interview. Indeed, the focus group format encourages participants to exchange ideas, anecdotes, and dialogues with one another, allowing the researcher to gather a rich and diverse body of data that capitalizes on inherent group processes and dynamics (Kitzinger, 1995). Focus group data collection is sensitive to cultural variables such as the operation of humour, consensus, and dissent within the participant group, making this data collection strategy particularly amenable to cross-cultural research designs (Kitzinger, 1995). Focus groups ranged from approximately 1 to 2 hours in length. Group discussions were
held at a central, convenient location within each of the cities included in the study. All focus groups were audio recorded.

For the research described in Chapter 4, semi-structured interview guides were developed to capture both general reporting practices within science and medical journalism (e.g., Leask, Hooker, & King, 2010) and journalist perspectives specific to reporting on psychiatric neurosurgery. Semi-structured interviews are useful for research objectives where some knowledge exists regarding the phenomenon of interest (e.g., Amend & Secko, 2012), but subjective and situationally-relevant knowledge is lacking (McIntosh & Morse, 2015). Indeed, the semi-structured interview allows for data collection to be flexible and participant-driven, but can also accommodate a structure that supports analytic comparison of responses between participants (McIntosh & Morse, 2015). Interviews ranged from approximately 20 minutes to 35 minutes in length. Interviews were conducted by me or J. Illes over the phone or by video conference based on participant preference. All interviews were audio recorded.

2.4.1.4 Data Management

Data management complied with the guidelines of the Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans (http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf). Focus groups and interviews were audio-recorded and professionally transcribed verbatim. To protect the privacy of research participants, transcripts were de-identified, and participants were assigned alphanumeric codes. I used NVivo 12 software (QSR International) to organize and analyze the data. NVivo 12 is a qualitative data
analysis software package that allows the researcher to manage, annotate, code, query and visualize data, as well as document the analytic process (Bazeley & Jackson, 2013).

2.4.1.5 Data Analysis

Directed and conventional content analysis approaches (Hsieh & Shannon, 2005) were applied to the data collected in Chapter 3 and Chapter 4, respectively. Directed content analysis is a valuable analysis method for studies where some existing research or theory already exists (Jiggins Colorafi & Evans, 2016). This existing research can contribute to the development of an initial coding scheme or can be used to delineate relationships between codes (Hsieh & Shannon, 2005). Researchers who use directed content analysis must still make commitments to the naturalistic paradigm, and as such, modify, refine, and iteratively apply codes to the collected data. Indeed, the codebook used in Chapter 3 was initially developed to explore themes uncovered by Cabrera and colleagues (2018b) in their content analysis of psychiatric neurosurgery media coverage. Each participant within a focus group was considered a single source of data, and the interactions between participants were traced and noted in order to capture assenting or dissenting sentiments. Each researcher engaged in an iterative process of coding wherein codes were initially applied to relevant sections of the transcript texts to capture salient, summative, and essence-capturing elements of the focus group narratives (Saldaña, 2015). Researchers also noted phenomena that were not readily captured by the initial coding frame. Subsequent rounds of coding further managed, filtered and focused the salient features of the data to generate themes, sub-themes and categories that emerged from the data. The patterns within and relationships between themes were articulated and detailed (Vaismoradi, Turunen, & Bondas, 2013). The frequencies of theme prevalence are reported in this study to illustrate
similarities and differences among major themes endorsed by participants across the four cities (Vancouver, Montreal, Madrid and Berlin) where data were collected (Hsieh & Shannon, 2005).

In Chapter 4, a similar approach was used, however the nature of this study did not lend itself to *a priori* theoretical assumptions, making conventional content analysis the strategy of choice. Within this approach, I developed a codebook that reflected a hierarchy of data-driven themes and sub-themes in consultation with a second coder (Hsieh and Shannon, 2005). Deliberation about the structure, organization, and definitions of the codebook were iterative until consensus was reached between coders and other members of the research team. Data in the interview transcripts were initially analyzed line by line, noting remarkable phenomena and applying primary codes. Similarities and differences were queried within and between transcripts, and primary codes were then organized into major themes and sub-themes. To ensure dependability of the coding, the second coder coded 15% of the sample. A Cohen’s kappa test performed on this sample yielded a coefficient of 0.91, indicating considerable inter-coder reliability (Neuendorf, 2016).

### 2.4.1.6 Trustworthiness

As discussed in Section 2.1, *trustworthiness* is the defining standard of rigor in the qualitative research paradigm and is governed by the concepts of credibility, confirmability, dependability and transferability (Lincoln & Guba, 1985).

*Credibility* is the qualitative analog of internal validity (Morse et al., 2002), and is asserted as a measure of how accurately and comprehensively the researcher has described the phenomenon of
interest (Lincoln & Guba, 1985). To maintain credibility, I first compared each professionally transcribed interview to original audio recordings to verify accuracy, incorporate details noted in field notes, and ensure software readiness. I used NVivo 12 to create an audit trail of the data analysis process, as well as to promote consistency and transparency in data interpretations (Noble & Smith, 2015). All codebooks used in data analysis were developed cyclically with a research team (Chapter 3) or second coder (Chapter 4) until consensus was reached regarding the final organization of codes, themes, and categories into a relational hierarchy. Finally, I acknowledge the potential impact of sampling bias on the credibility of the qualitative studies presented in this thesis in Sections 3.6 and 4.6.

Confirmability parallels the quantitative concept of objectivity and represents a measure of compatibility between the research findings and the data (Morse et al., 2002; Lincoln & Guba, 1985). To maintain confirmability, I embedded quotes throughout Chapter 3 and Chapter 4 to transparently display my interpretive process to the reader. I used carefully placed ellipses and parentheses to shorten or clarify segments of the original data; however, I ensured that my manipulations did not alter the original meaning of participant narratives. Member checking, a process of returning to participants to ensure that interpretations accurately represent their experiences, is an additional strategy that methodologists encourage to promote credibility and confirmability in qualitative research (Thomas & Magilvy, 2011). While not all scholars subscribe to the philosophy that member checking is methodologically valuable (Morse, 2015; Sandelowski, 1993), I acknowledge that the absence of member checking for the present work may be viewed as a limitation.
Dependability parallels the quantitative concept of reliability (Morse et al., 2002) and represents a measure of how well a study would generate similar findings if it were to be similarly implemented in the future (Shenton, 2004). Unlike reliability, however, dependability does not require replication of study results. Methodologists agree that the observations of the researcher and their interactions with participants are contextually and temporally situated, and as such, can never be fully replicated (Shenton, 2004). Instead, dependability can be promoted by providing a rich description of the study context, the procedures of the research, and by creating an audit trail as mentioned above. To promote dependability, I therefore provided in-depth descriptions of recruitment strategies, research participants’ characteristics, data management methods, and data analysis techniques throughout the qualitative studies presented in this thesis.

Transferability describes the extent to which study results can be applied to populations beyond those included in the study, comparable to the qualitative concept of external validity (Lincoln & Guba, 1985; Polit & Beck, 2010). Polit and colleagues (2010) contend that transferability, like confirmability and dependability, is a largely collaborative enterprise, calling on readers to determine the degree to which findings may apply to new situations. Thick description aided readers in this evaluative process (Finlay, 2006) as did diverse sampling.

2.4.2 Survey Methodology

2.4.2.1 Design

Surveys are a quantitative research strategy that elicit empirical data but, like qualitative approaches, can be used to observe and elicit descriptions of social phenomena (Kelley, Clark, Brown, & Sitzia, 2003). In Chapter 5, an online survey was developed based on previous studies (Lipsman, Mendelsohn, Taira, & Bernstein, 2011; Mendelsohn et al., 2013) of functional
neurosurgeon attitudes and practices regarding psychiatric neurosurgery. A survey was selected as the research tool for this population given the ability to gather large amounts of data about participants in a relatively short amount of time. The total time to complete our survey ranged from approximately 5 minutes to 10 minutes. The survey was comprised of a mixture of close-ended, rank-order, and Likert-type questions. The survey was piloted with members of the study team and with members of the population of interest in order to avoid instances of double-barreled questions, formatting errors, and to ensure overall logical flow.

2.4.2.2 Analysis
Descriptive statistics (e.g., frequencies, contingency tables) were used to characterize categorical data. Non-parametric measures were used to characterize interval data (e.g., range, median, mean). Likert-type data was treated as ordinal, and was subjected to distribution-free analysis methods, including Fisher’s exact probability test (Allen & Seaman, 2007). Likert-type data was collapsed into agreement and non-agreement categories to gain simplicity and interpretability. I note, however, that collapsing Likert-type data can reduce knowledge about the poles of responses. Further limitations of this survey relating to the design, execution, and the response rate obtained are discussed in Section 5.6.
Chapter 3: Looking Back and Looking Forward: Public Perceptions of Psychiatric Neurosurgery in Canada, Germany and Spain

3.1 Synopsis

In a 1919 address to Oxford’s Classical Association, Sir William Osler admonished the divide between the sciences and the humanities, observing that “… the so-called Humanists have not enough Science, and Science sadly lacks the Humanities” (as quoted in Fins, 2008). In the wake of a revived medical interest in investigating neurosurgical techniques for psychiatric disease, a need exists to bridge the perspectives of the scientific and lay communities. Our research team and collaborators, consisting of Dr. Laura Cabrera, Dr. Judy Illes, Mr. Merlin Bittlinger, Dr. Eric Racine, Dr. Sabine Müller and I, sought to harness the voices of a diverse, multi-national public to better understand the expectations, hopes and concerns surrounding a psychiatric neurosurgery renaissance that targets mental illness at the level of neural circuitry. We conducted eight focus groups across four cities — Vancouver, Canada (English), Montreal, Canada (French), Berlin, Germany (German), Madrid, Spain (Spanish) — with 48 members of the general public. Focus group transcripts were analyzed for recurring themes using directed content analysis. We found that the overarching themes of authentic self and last resort were prominent in all groups across all cities. The intersection of choice and consent was a dominant conjoined theme for Vancouver, Montreal, and Berlin groups. Stigma surrounding mental health conditions was a common theme among participants in both Vancouver and Madrid, while lack of knowledge about innovations in psychiatric neurosurgery was the dominant theme for participants in Madrid. The important views we captured serve to inform the future development of a framework that will advance the appropriate use of psychiatric neurosurgery, promote sound
health policy, and foster scientific literacy about these interventions internationally.

3.2 Introduction

Within the field of functional neurosurgery, the race to re-invigorate older surgical interventions as a treatment option to otherwise treatment-refractory conditions, and to develop new ones, has escalated over the past two decades (Barrett, 2017). Methods such as DBS, ablative microsurgery, radiosurgery, and MRgFUS are currently undergoing clinical investigation in human trials for the treatment of psychiatric conditions that fail to respond to front-line therapies. In animal research, studies have also shown the potential of optogenetics to rapidly modify depression- and anxiety-related behaviours (Albert, 2014). Little is known about public perceptions and attitudes towards this trend, yet history has shown that fear and skepticism on the one hand, and overly optimistic views on the other, can stifle scientific progress and safe translation of potentially promising therapeutics equally (Johnson, 2014; Lauber et al., 2005; Valenstein, 1986).

Previous studies have explored patient views toward the use of DBS for MDD and OCD. For example, Leykin and colleagues examined the perceptions of 31 MDD patients in the United States towards DBS research using self-report questionnaires (Leykin et al., 2011). The authors found a reasonable grasp of risks and benefits, and an overall positive attitude toward research. However, while participants understood the experimental stage of DBS for depression, there was still some evidence for therapeutic misconception.
In the Netherlands, de Haan and colleagues conducted in-depth interviews with 18 DBS-implanted OCD patients about their personal, social, relational and existential experiences (de Haan, Rietveld, Stokhof, & Denys, 2015). All participants viewed DBS as their last resort after having tried other treatments unsuccessfully. Participants expressed worries that the device might cease to function properly, but they did not express concerns about having a device physically implanted in their brains. In a secondary analysis of the interview data, the authors reported that while nearly all participants underwent changes in feelings, thoughts, behavior and interpersonal interactions following DBS surgery, these changes may not always constitute clinically- or existentially-relevant forms of personality change. The authors posit that divergent reports of becoming a different person following DBS implantation hinge on definitional interpretations of the self and personhood: nearly all participants experienced changes in behaviours and interactions that were not possible to undertake without DBS, yet their convictions and world views remained largely the same as they were prior to DBS (de Haan, Rietveld, Stokhof, & Denys, 2017).

Klein and colleagues interviewed 15 participants implanted with DBS for MDD or OCD about their perspectives towards closed-loop or next-generation DBS devices (Klein et al., 2016). The authors identified control over device function, authenticity of the self, relationships with others, and meaningful consent as major themes. Participants expressed optimism that closed-loop technology could improve upon certain limitations of open-loop devices, particularly the maintenance burden of traditional open-loop devices. However, divergent views were captured regarding the ability of closed-loop DBS to promote authenticity: some participants endorsed this stance, while at least one participant expressed concern that an autonomously-regulated implant
might undermine their personal autonomy. Finally, many participants recounted significant changes to familial relationships following DBS implantation, a common challenge being the psychological burden placed on patients by their families to always maintain a level of technologically-assisted calm or happiness. In successfully overcoming debilitating aspects of their mental illness with DBS, some patients also discussed experiencing the burden of normality, which has been reported in other narrative inquiries of psychiatric DBS patients (Bosanac, Hamilton, Lucak, & Castle, 2018).

The study team’s own prior work (Cabrera et al., 2018b; Cabrera, Bittlinger, Lou, Müller, & Illes, 2018a) demonstrated that media reporting about psychiatric neurosurgery, a key conduit to how public attitudes are shaped, has increased over time and is generally positive. However, media reporting has largely neglected ethical considerations. Reader comments to media reports reveal skepticism about irreversible, ablative interventions redolent of historical psychosurgeries. Stigma continues to be a key issue for psychiatric treatments and the disorders they aim to treat. Ultimately, much work remains to be done to raise public understanding about the benefit-risk ratio of re-emerging and new psychiatric neurosurgical interventions, and to engage different stakeholders in discussions about ethics oversight if these approaches are to find a safe and receptive place in health care. The present study represents a first attempt at advancing an understanding of public perceptions towards contemporary psychiatric neurosurgery to better inform ethical oversight of these emerging technologies.
3.3 Methods

3.3.1 Recruitment and Enrollment

Focus groups were conducted with members of the general public between October 2017 and June 2018, in four different cities: Vancouver and Montreal (Canada), Berlin (Germany) and Madrid (Spain). These cities are home to the research team collaborating in a multinational consortium exploring the ELSI of psychiatric neurosurgery. The focus groups aimed to: (a) explore awareness of different psychiatric neurosurgery procedures; (b) characterize the understanding of and values related to the different procedures; and, (c) identify key ethical concerns.

Participants were recruited through mental health community organization newsletters, social media and hard copy postings. We used the term community conversation in recruitment media to emphasize the open and interactive nature of the focus groups. Respondents had to be 18 years or older to be eligible to participate, and able to converse in the language in which the focus group was conducted (English, French, German or Spanish). Participants were screened through a telephone interview or online survey and excluded if they self-reported an active, clinically-diagnosed psychiatric disorder or had undergone one of the procedures under study. This exclusion criterion was implemented as a means to recruit non-patient members of the lay public, as well as to mitigate the potential for individuals to participate under the false premise of gaining medical advice. No exclusion criteria prevented participants from attending more than one focus group in a given city. In the case of Madrid, two participants attended both focus groups and were counted as unique participants for analysis.
Eligible participants were scheduled for a focus group held in a convenient location in each city, such as a community centre or in a conference room at a university. The research team aimed to achieve a diversity of gender, age, and ethnicity in each group. Participants were compensated for their time and travel expenses with an equivalent, modest reimbursement after completion of the focus group. Approval for the study was obtained from the Institutional Review Boards of each of the universities of the investigators (University of British Columbia (UBC) [H17-00013], Michigan State University as a subcontracting collaborating site to UBC (IRB# x16-520e), Institut des recherches cliniques de Montréal (IRCM) [2018-913], and Charité–Universitätsmedizin Berlin CCM [EA1/123/17]).

3.3.2 Focus Group Procedures

A facilitator from the research team who was fluent in the local language moderated the sessions in each city (Vancouver: Dr. Laura Cabrera, Montreal: Dr. Eric Racine, Berlin: Mr. Merlin Bittlinger, Madrid: Dr. Laura Cabrera). Each focus group took approximately two hours. In the first hour, moderators reviewed consent materials, introduced four relevant interventions (DBS, ablative microsurgery, radiosurgery, and optogenetics) to prime the discussion (Appendix D), and addressed questions about these interventions and others. Moderated focus group discussions were completed within the second hour. All materials were made available in the local language of the focus group. Sessions were audio recorded. I took field notes to document verbal and nonverbal cues for tone of the conversation and other relevant information in focus groups held in Vancouver and Montreal. A second researcher followed similar procedures in Berlin and Madrid.
The moderator followed a detailed, semi-structured focus group discussion guide (Appendix C) that was informed by the findings from the media and reader comments studies (Cabrera et al., 2018b; 2018a). An English-language version was developed first, and then translated into German, French and Spanish before implementation (Table 3-1).

Table 3-1 Semi-structured focus group discussion guide

<table>
<thead>
<tr>
<th>Question Order</th>
<th>Question Cluster</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Why are you interested in the topic of psychiatric neurosurgery?</td>
</tr>
<tr>
<td>2</td>
<td>Have you heard of all the different procedures before today? If so, which ones? Where?</td>
</tr>
<tr>
<td>3</td>
<td>What are your thoughts regarding psychiatric neurosurgery? Any positive features? Any negative ones? Hopes? Expectations? Perceptions of risk? Benefits? If there is mention of historical issues, ask participants to elaborate. If not, ask about whether they have heard of psychosurgery.</td>
</tr>
<tr>
<td>4</td>
<td>What do you think are the main challenges surrounding the adoption and acceptance of psychiatric neurosurgery (e.g., patient concerns, reimbursement, regulation)?</td>
</tr>
<tr>
<td>5</td>
<td>Is there anything else you would like us to know about you?</td>
</tr>
</tbody>
</table>

3.3.3 Data Analysis

Recordings of the interviews were professionally transcribed and made software-ready in NVivo 12 (QSR International) for analysis, with the exception of the Madrid focus groups that were coded using Microsoft Excel. A member of the research team from each country corrected transcription errors and clarified inaudible speech and misattributed statements. Non-content words and expressions were removed for readability and analysis.

I analyzed the transcript data from Canadian focus groups qualitatively using directed content analysis by coding and organizing the data systematically (Hsieh & Shannon, 2005). Codes were
assigned to segments of the transcript texts. Coded segments of data were then grouped into
categories and themes derived a priori from the media analysis study (Cabrera et al., 2018b). The
categories and the themes within them were refined and revised to incorporate additional insights
that emerged from the data. The patterns within and relationships between themes were
articulated and detailed. These analysis procedures were mirrored by Mr. Merlin Bittlinger for
Berlin data and Dr. Laura Cabrera for Madrid data.

Each category had a number of themes, and most themes had subthemes. For example, the theme
cost could refer to costs related to intervention access, or to costs related to industry funding.
Mentions of specific intervention modalities and mental health disorders by focus group
participants were also coded to gauge participants’ familiarity with established psychiatric
interventions and conditions, as well as to assess depth of discussion about the primed
neurosurgical interventions.

Research team meetings and electronic communication were used to discuss questions about
coding and accuracy of the codes. A major theme was defined by its frequency and presence in
the discussion in both focus groups in a city, as well as its assertion by more than one participant
within that city. Research team discussions were used to select interviewees’ statements that
were regarded as typical or representative of a theme. We repeated these processes until we
reached consensus regarding the final presentation of the results.
3.4 Results

We conducted eight focus groups, each with 3 to 13 participants in 4 different cities (n=48 participants) (Table 3-2).

Table 3-2 Focus group demographics

<table>
<thead>
<tr>
<th>City, Country</th>
<th>Number of Participants</th>
<th>Gender</th>
<th>Age Range (Years)</th>
<th>Ethnicity/Origin (% of Participants)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vancouver, Canada</td>
<td>FG#1: 3</td>
<td>FG#2: 3</td>
<td>2F/1M</td>
<td>2M/1F</td>
</tr>
<tr>
<td>Montreal, Canada</td>
<td>FG#1: 5</td>
<td>FG#2: 3</td>
<td>3F/2M</td>
<td>2F/1M</td>
</tr>
<tr>
<td>Berlin, Germany</td>
<td>FG#1: 9</td>
<td>FG#2: 13</td>
<td>6F/3M</td>
<td>10F/3M</td>
</tr>
<tr>
<td>Madrid, Spain</td>
<td>FG#1: 7</td>
<td>FG#2: 5</td>
<td>4F/3M</td>
<td>5F/2M**</td>
</tr>
</tbody>
</table>

* German privacy laws prohibit collection of data regarding ethnic origin.
** Two attended both Madrid focus groups and were counted as unique participants for analysis.

Overall, we captured and analyzed 750 units of data, defined as unique instances of coded text (Vancouver: 233; Montreal: 136; Berlin: 187; Madrid: 194).

3.4.1 Interventions and Conditions

DBS was the only psychiatric intervention discussed by participants across all focus groups. Psychiatric medication, historical ablative procedures (e.g., lobotomy, trepanation), and psychotherapy were the interventions most frequently mentioned overall (DBS: 11/89 [12%] total intervention mentions; medication: 22/89 [25%]; historical ablative procedures: 17/89 [19%]; psychotherapy: 14/89 [16%]) (Figure 3-1). Depression and obsessive-compulsive disorder were discussed in focus groups across all cities (depression: 20/70 [29%]; OCD: 12/70 [17%]). Parkinson’s Disease was discussed frequently with reference to DBS, while anorexia
nervosa was mentioned exclusively by participants in the Madrid focus groups (Figure 3-2).

**Figure 3-1 Interventions mentioned across cities**

![Interventions mentioned across cities](image)

**Figure 3-2 Psychiatric and neurological conditions mentioned across cities**

![Psychiatric and neurological conditions mentioned across cities](image)
3.4.2 Emergent Themes

Two major themes emerged from the focus group content analysis for all cities, capturing areas where participants had either substantial concurrence of opinion or a marked disagreement:

- **Authentic self:** This refers to the capability of a neurosurgical intervention to interfere with expression of the authentic self, including perceived risks to personality, identity and authenticity of surgery recipients.

- **Last resort:** This refers to the use of psychiatric neurosurgery interventions only after other treatment options have been exhausted.

The intersection of *choice and consent* was also a prominent combined theme, emerging with substantial frequency in all focus groups except Madrid. *Stigma* towards mental health conditions was the most prevalent theme in Vancouver groups, and was also frequently mentioned in Madrid. *Lack of societal and personal knowledge* about psychiatric neurosurgery interventions was the most prevalent theme that emerged in focus group discussions in Madrid. Major themes and supplementary themes are displayed by frequency of occurrence within each city in Figure 3-3.
Figure 3-3 Theme frequency by city: (A) Vancouver; (B) Montreal; (C) Madrid; (D) Berlin
3.4.2.1 Authentic Self

Participants across all focus groups discussed that psychiatric neurosurgery has the potential to alter the personality, identity, or authenticity of a recipient (Vancouver: 15/233, 6% of all coded data; Montreal: 9/136, 7%; Berlin: 14/187, 7%; Madrid: 12/194, 6%). This was raised in two ways. The first was a belief that the invasive nature of psychiatric neurosurgery increases the potential for iatrogenic harm, which in turn could undermine the expression of a recipient’s authentic self after surgery. Respondents expressed worries about the precision of the interventions, as well as the integrity of the motive for surgically interfering with the circuitry of the brain. The latter of these concerns tended to be expressed by participants who viewed mental illness as an intrinsic feature of a person’s identity, and to try to interfere with this would constitute an attack on the authentic self. An alternative perspective of authentic self was also discussed pertaining to the potential misuse of psychiatric neurosurgery in pursuit of an ideal or socially-acceptable personality type.

“I would also be afraid that some of these operative methods might change my personality, which I feel is a risk” (Berlin Focus Group 1, Female 1, translated by MB).

“...you might come out a different person, and that’s something I feel like could be probably one of the main reasons people would be kind of afraid of [psychiatric neurosurgery], or against it” (Vancouver Focus Group 2, Male 2).

“... is this treatment to treat the patient or just to make the patient fit better in society?” (Montreal Focus Group 1, Female 2).

Some participants, on the other hand, expressed that the effects of psychiatric neurosurgery necessarily alter personality, as mental illness itself hinders the ability to experience an authentic self. These participants stressed that psychiatric neurosurgery could bring about desired changes to personality traits, and specifically improve traits that are pathologic or dysfunctional. Some
participants viewed psychiatric neurosurgery in its capacity to alter the authentic self as no
different than modern psychiatric medications. Competing societal views about psychiatric
illness and neurological illness were also highlighted in this context, particularly with regard to
how questions of identity or personality are unlikely to be raised in the context of neurosurgery
to remove a terminal brain tumour.

“… well I think [personality change is] the whole point of [psychiatric neurosurgery],
 isn’t it? We don’t want [patients] to have OCD, we don’t want them to have Parkinson’s,
we don’t want them to have [mental health disorders] – that in itself is personality
change” (Vancouver Focus Group 1, Female 2).

“But don’t drugs also do that? If you take antidepressants for years, it also changes your
personality” (Berlin Focus Group 2, Female 3, translated by MB).

“In the case of a brain tumour people do not think about … touching something that may
alter your personality, or your way of being” (Madrid Focus Group 2, Female 1,
translated by LC).

3.4.2.2 Last Resort

The notion of psychiatric neurosurgery as a last resort treatment for mental health disorders was
a major theme arising in all focus group locations (Vancouver: 11/233, 5%; Montreal: 13/136,
10%; Berlin: 17/187, 9%; Madrid: 18/194, 9%). Most participants mentioned that psychiatric
neurosurgery should be used only after other, less invasive therapeutic options have been
exhausted. A commonly raised concern was the reductionist nature of neurosurgical
interventions. Participants felt that neuromodulatory or ablative procedures alone were unlikely
to have an effect on the broader psychological, sociological or environmental contributors to
mental health disorders. Another concern raised by participants was a lack of formal guidance
about when in the course of a psychiatric disease a patient should be deemed eligible to receive a
neurosurgical intervention. Some participants also considered the potential devastating effects of
neurosurgical treatment failure.

“To me it would be a last resort... [depression is] a very severe disease that we don’t really have any solutions for, so if you suffer a lot and it affects you every day, and there’s no therapy to help cure you, then I would consider surgery, but in general, the way I see the brain, I look at people as a mix of personalities, and it’s not just the brain that makes somebody depressive” (Montreal Focus Group 1, Female 1).

“Well, I think it's a pretty good idea to keep this in the backhand only as a last resort, because it contains an irreversible aspect” (Berlin Focus Group 2, Male 2).

“Is it legitimate to decide to use this because a person is highly suicidal?” (Montreal Focus Group 1, Female 2).

“If it is used as a last resort, going through that whole brain surgery must be really complicated and then [if] you leave, and it doesn’t work, it must really hit you, especially for the person and their family. They have to live with that” (Montreal Focus Group 2, Female 2).

By contrast, some participants questioned the rationale behind reserving psychiatric neurosurgery as a last resort treatment option, particularly considering the speed at which some interventions can bring about symptom relief. Participants expressed empathy for those suffering from mental illness and supported accessibility to psychiatric neurosurgery procedures for those with severe, debilitating conditions. Some participants advocated for more liberal access to procedures like DBS despite their relative infancy in treating psychiatric conditions. Ultimately, most participants agreed that they would prefer to see more research before they could fully support widespread use of psychiatric neurosurgery for the treatment of mental illnesses.

“I think [DBS] should be more accessible, I think it’s a shame that it’s a last resort... if you are going through a period of depression ... you go through individual therapy, medication, and often it doesn’t work, it’s often complicated and it takes a long time to access the services, so I’m very “for” that type of intervention that can be almost instantaneous and help people” (Montreal Focus Group 2, Female 2).
“These are patients that have tried several medications and that they are so extreme that nothing else can help them” (Madrid Focus Group 2, Female 4, translated by LC).

“I have seen patients that were in such desperate OCD ... I was in so much pain seeing them, and I think if I was one of them, I would want [psychiatric neurosurgery]” (Vancouver Focus Group 2, Female 1).

“...when people [have a severe mental health condition] and tell you about their suffering, if this is the solution for them and there’s informed consent and it is proven, then it might be worth going forward” (Montreal Focus Group 1, Female 4).

3.4.2.3 Choice and Consent

The intersection of choice and consent was the most frequent theme arising in focus groups held in Montreal (15/136, 11%) and Berlin (21/187, 11%), and was also discussed frequently among participants in Vancouver (23/233, 10%). This theme encompasses ideas related to patient decision-making, self-advocacy, and capacity to consent to a procedure. Most participants agreed that although the decision to undergo a psychiatric neurosurgical procedure should be made exclusively by the potential recipient, significant barriers exist that may limit the ability of physicians and researchers to obtain unbiased informed consent within this clinical population. Of major concern to most participants was the way in which the manifestations of mental illness can impact an individual’s capacity to adequately weigh the risks and benefits associated with psychiatric neurosurgical interventions. Participants in Canadian focus groups mentioned alternative consent paradigms such as advanced directives and proxy consent. A few participants also raised concerns about the possibility of physician or family coercion in the decision-making process. Ultimately, participants agreed that a transparent consent process that clearly establishes the risks and benefits of any candidate procedure would be the most ideal approach in ensuring respect for patient autonomy.
“... these surgical procedures are obviously invasive... how much we can push someone else to [have] surgery if they’re not mentally in the right place?” (Vancouver Focus Group 2, Male 2).

“... one’s own consent is extremely important, and I just wonder to what extent a young person who is perhaps not medically educated and is in a distressed situation because he or she is really sick and suffering ... can really assess these risks” (Berlin Focus Group 1, Female 3, translated by MB).

“It seems very difficult, when you are depressed, imagining that you could not be depressed anymore, just with surgery... if ever you get treated and become happy, then “yes, thankfully I accepted the surgery,” but you will never know unless you do the surgery... it’s difficult to impose something on someone who doesn’t want it, but at the same time, is it someone who will be able to judge whether they will feel better or not?” (Montreal Focus Group 1, Male 1).

“... the person may be tempted by the surgery because they are desperate. The person is going to consent, but I wouldn’t call it free and informed consent... [Physicians] may sell this solution as being the only solution” (Montreal Focus Group 1, Female 2).

“It’s not the doctor who decides [on the treatment], the doctor needs to give all the information, all the risks ... there may even be a chance that [one’s condition] gets worse, so you really need to give total information and total transparency” (Montreal Focus Group 2, Male 1).

“... it is empowering for the person, to be able to choose [psychiatric neurosurgery] and have it work, I think there needs to be a feeling of finally controlling your life, which must be without equal” (Montreal Focus Group 2, Female 2).

3.4.2.4 Stigma

Stigma was the most prevalent theme arising in the Vancouver focus groups (25/233, 11%) and was also a major topic of discussion among participants in Madrid (22/194, 11%). Participants from these cities highlighted the problematic consequences of societal views that endorse mental illnesses as less deserving of medical attention than clinical conditions with physical origins. Some expressed worry that recipients of psychiatric neurosurgery would incur stigma or
marginalization greater than those treated for mental health disorders via more conventional methods. Participants further considered the role that media plays in shaping public perception, as well as the potential for public resistance to limit research that aims at improving the safety and efficacy of psychiatric neurosurgical interventions.

“...there’s a lot of ignorance about mental health. People don’t see it as an illness, [they just think] ‘snap out of it, smarten up’... unless you have someone very close to you who is going through this extreme pain ... you think they’re just being lazy” (Vancouver Focus Group 2, Female 1).

“People do not see mental health disorders as disorders, but as weaknesses of the will” (Madrid Focus Group 2, Female 4, translated by LC).

“[Modern psychiatry] is just painted in a very bad light, I think there has to be better media, better ways than it’s portrayed” (Vancouver Focus Group 2, Male 1).

“Stigma... [hinders] funding ... [for] research and access” (Vancouver Focus Group 1, Female 1).

### 3.4.2.5 Lack of Knowledge

Lack of knowledge was the most prevalent theme arising in Madrid focus groups (37/194, 19%). This theme pertains to both a perceived lack of knowledge in society about psychiatric neurosurgery, as well as a self-proclaimed lack of knowledge about these interventions among participants themselves. Participants from Madrid emphasized the former of these two interpretations, which included perceived knowledge deficits about both interventions and candidate psychiatric conditions. This often complemented the remarks made by participants about stigma, that is, if the public knew more about these disorders, people would have a different perspective around psychiatric conditions and the interventions used to treat them. Participants also emphasized lack of information as a driver of societal knowledge deficits.
around these interventions.

“… the question should be why there is so much lack of knowledge around psychiatric disorders, instead of around psychiatric neurosurgery” (Madrid Focus Group 1, Female 1, translated by LC).

“… [there is a] lack of knowledge about how bad these disorders themselves can be…if people knew what these patients go through, they will get a different perspective” (Madrid Focus Group 1, Male 3, translated by LC).

“… if there was more information about those disorders, it would help people make a correct idea but there is a lot of ignorance and lack of information” (Madrid Focus Group 2, Female 1, translated by LC).

3.5 Discussion

In this cross-national, multi-site qualitative study we examined opinions, concerns, hopes, expectations and ethical challenges about contemporary psychiatric neurosurgery. The study team explored key topics identified in two previous stages of this large-scale effort to investigate the social implications of contemporary psychiatric neurosurgery as a form of validation and elaboration, and to explore other relevant aspects, such as familiarity with psychiatric neurosurgery procedures. The results support findings from prior work that centre on identity, personality and authenticity (Cabrera et al., 2018b, de Haan et al., 2017). Many participants framed their concerns in terms of the brain as the seat of the self, endorsing that direct modification of the brain can bring unwanted changes to behavior and personality. Others supported the idea that severe mental illness can undermine personal authenticity; as such, neurosurgical modifications may help patients to regain a true sense of self. Research with patients receiving DBS for refractory OCD suggests that while patients do report experiencing post-operative changes in interaction style and self-expression, personal convictions and moral outlooks on life remain relatively stable (de Haan et al., 2017).
The concept of existential risk invoked by DBS implantation for both neurological and psychiatric conditions has fueled discussion among neuroethicists, particularly concerning the potential for patients to post-operatively experience self-estrangement or alienation from their concept of the self (Kraemer, 2013; Gilbert, Cook, O’Brien, & Illes, 2017; Gilbert, 2018). Some scholars, however, warn that neural interventions should not be cursorily understood as threats to authenticity or identity (Specker Sullivan, 2019). Instead, Specker Sullivan (2019) suggests that implanted neural devices be regarded the same as any “causal element [in] a system of relationships” and monitored within multidisciplinary care teams to promote the best interests of patients (p. 493). Clinical trials of implanted devices also raise ethical questions at the intersection of informed consent and the evolving, post-operative values of DBS-implanted patients (Gilbert, 2015; Kubu et al., 2018, Sankary and Ford, 2019). In the present study, members of the public highlighted informed consent largely in the context of vulnerability, desperation and capacity of patients to execute decisions around both invasive and irreversible interventions.

The last resort status of psychiatric neurosurgery procedures, a significant theme in the normative and empirical literature on the topic (Kuhn et al., 2009; Glannon, 2010; Woopen, 2012; Klein et al., 2016), was discussed divergently by study participants. A recent study of public information-seeking behaviours about DBS for movement and psychiatric disorders (Robillard, Cabral, & Feng, 2018) also uncovered mixed opinions about whether DBS should be introduced early in the course of clinical care or reserved until all other options have been exhausted. Procedural features like irreversibility and invasiveness deterred some participants from fully supporting the use of psychiatric neurosurgical procedures, however, continued
innovation within the mental health landscape was unanimously endorsed.

Stigma towards mental health conditions, partly related to lack of knowledge, remains an ongoing concern. Participants commented that there are still many people who see mental health disorders as a weakness of the will, putting into question the etiology of these disorders. Lack of information and understanding about both mental health disorders and viable treatment options only perpetuate distorted perceptions of these conditions and may stifle the progress of emerging invasive therapies.

Beyond the major themes presented, other common concerns arose pertaining to cost, distributive justice, and disparities in access to potentially effective treatments (Figure 3-3). Regulation is essential given the vulnerability of the populations and severity of the disorders in question. In addition, mirroring past work on media reporting and reader responses to news articles (Cabrera et al., 2018b; 2018a), field notes support that the overall tone of focus groups in Canada and Spain was more optimistic than in Germany.

3.6 Limitations

Focus groups are a well-established research method to gather views from participants as they explore phenomena of interest and interact with others about them in a discrete time and context (Kitzinger, 1995). Resulting findings can be used only to generate, but not to test hypotheses. Findings also represent a range of opinions from a small and selected sample of participants, in a limited number of cities and countries. While two participants attended both Madrid focus groups, the ideas they expressed in each were unique.
Participants were recruited using advertisements listed in both regional mental health organizations and general community spaces (i.e., community centres, libraries, coffee shops) which may have resulted in a sample of participants with a necessarily vested interest in the topic, not a naïve or unaffected public. Further, while it was essential to provide participants with a briefing to ensure they had a shared understanding of the topic, we do not know what impact this procedural step may have had on the discourse.

3.7 Conclusion

Research into the knowledge, opinions and values of members of the public about topics in health and medicine gives individuals a voice that can powerfully lead to well informed agendas and policy for the biosciences, the translation of discoveries into care, and trust that is essential in the relationship between science and society. Moreover, the understanding of views as they pertain to historically contentious interventions for mental health disorders that continue to be the subject of misunderstanding and stigma, has the potential to shape strategies that can transform public engagement.

This is the first study of which we are aware that directly examines public perceptions about modern forms of psychiatric neurosurgery. A larger sample would allow for more definitive conclusions about geographical and educational differences that contribute to the most important social and ethical themes from this population. Nevertheless, the primary observations presented here suggest that issues related to the authentic self, the capacity to consent to last resort therapies, stigma, and lack of knowledge about emerging interventions should be considered for their impact on public perceptions of contemporary psychiatric neurosurgery.
The largely investigative status of the neurosurgical interventions at the moment and the fact that there are no meta-analyses comparing different modalities in terms of safety and efficacy, prohibit comment on policies directed to particular interventions. Nonetheless, the participants in the present study were positive about the need for more efficacious and safe therapies to treat mental health disorders, and for the need for further knowledge and discovery within this landscape.
Chapter 4: Journalist Reporting in the Age of Psychiatric Neurosurgery

4.1 Synopsis

In declaring the inescapably rhetorical nature of the scientific genre, Kenneth Burke famously asserted that “[e]ven if any given terminology is a reflection of reality, by its very nature as a terminology it must be a selection of reality; and to this extent it must function also as a deflection of reality” (1989, p. 115). The popular press, in turn, is equally responsible for conveying certain beliefs about the nature of science and technology to the public through the very words, metaphors and headlines that are selectively enlisted in news stories about scientific events (Nelkin, 1995). In this chapter, I report on the perceptions, values, and decisions of journalists who write about contemporary psychiatric neurosurgery. Findings suggest that journalists are committed to practices that promote veracity and independence in their reporting. The controversial history of psychiatric neurosurgery is both a source of news value and of cautious reporting in this arena.

4.2 Introduction

Health and science journalists occupy a unique role at the interface of scientific discovery and public scientific knowledge. This role is often connected to metaphorical imagery of gatekeepers or watchdogs (Borden & Tew, 2007; Rensberger, 2009), both of which assume that journalists will abide by particular moral standards and engage in practices that reflect accuracy, truthfulness, and independence in their reporting (Borden & Tew, 2007; Singer, 2003). Despite these professional ideals, journalists are not immune to cultural, institutional, political or social biases (Nelkin, 1995). These biases, in turn, influence media decisions regarding what content should be reported to the public, and how it should be delivered. Health and science journalists
face a number of professional and institutional barriers that inform such decisions, some of which include meeting deadline pressures, identifying credible sources, managing the repercussions of budget cuts, and responding to the increasing commercialization of mass media (Amend & Secko, 2012). Amid these factors, the dynamic interactions between scientists, reporters, members of the public and media texts engender “in-the-moment frames that shape each actors’ interpretation of scientific research” (Davis & Russ, 2015, p. 221).

Inaccurate, uncritical, and sensationalized reporting of medical research can lead to real health consequences for the public (Schwitzer, 2017; Schwitzer et al., 2005). Many scholars and advocates of science journalism integrity have advised, therefore, that journalists adopt rigorous approaches to investigate and report conflicts of interest, study design limitations, risks and costs associated with new treatments, and potential ethical issues, and solicit a range of expert opinion, when reporting on scientific and medical affairs (e.g., Ashe, 2013; Bubela & Caulfield, 2004; Cassels et al., 2003; Caulfield, Clark, McCormack, Rachul, & Field, 2014; Dentzer, 2009; Holtzman et al., 2005; Racine et al., 2006). Media coverage of historical psychosurgery (Diefenbach, Diefenbach, Baumeister, & West, 1999) and modern psychiatric neurosurgery (Cabrera et al., 2018b; Racine et al., 2007) have both raised similar concerns for public risk-benefit perceptions of these interventions, as well as appraisal of relevant ethical issues.

4.2.1 Psychiatric Neurosurgery in the Popular Press

Valenstein considers unbalanced media coverage of lobotomy during its early inception to be a key conduit towards the widespread adoption of the procedure throughout the 1940s, suggesting that “[it was] generally known that patients were referred to [psychosurgeons] as a result of all
the publicity” (1986, p. 160). An analysis of newspaper articles published about lobotomy during the 1930s and 1940s showed that the tone of media reports was initially positive, but became more critical over time (Diefenbach et al., 1999). In its early years, lobotomy was often glorified in the media as a technically precise procedure and a miraculous cure for otherwise hopeless patients. As opposition to the procedure grew within the medical community throughout the 1950s, journalists began to raise questions about the permissibility of lobotomy in their reporting, noting a need for further scientific evidence, stricter selection criteria, and publication of the concerning side effects of the procedure (Diefenbach et al., 1999). Overall, media-driven enthusiasm for lobotomy may explain in part how upwards of 40,000 Americans underwent this procedure in the nearly two decades that it reigned as a publicly- and medically-accepted psychiatric intervention (El-Hai, 2005; Valenstein, 1986).

In the wake of successful scientific reports of deep brain stimulation (DBS) as a treatment for hyperkinetic and hypokinetic movement disorders, and its experimental application to psychiatric disorders (Miocinovic, Somayajula, Chitnis, & Vitek, 2013), Racine and colleagues (2006) conducted an analysis of print media in the United States and the United Kingdom to investigate trends in coverage of emerging neuromodulatory technologies. In the decade between 1995 and 2004, these authors found that 21% of 235 news stories that met inclusion criteria featured an application of neuromodulation to psychiatric conditions. The remaining stories featured applications to neurological conditions. Most articles conveyed information about neuromodulation optimistically, highlighting opportunities for clinical or non-clinical benefit without discussions of health risks or research limitations (51%); 31% were considered balanced by conveying information about both benefits and potential risks; and, roughly 30% featured a
patient narrative or celebrity account of DBS surgery. Only 14% of all articles considered ethical, legal or social issues in their coverage, a finding over which the authors expressed concern.

Most recently, Cabrera and colleagues (2018b) conducted a media content analysis of 517 articles covering psychiatric neurosurgery within North America, Spain and Germany from 1974 through to 2016. Coverage of psychiatric neurosurgery has surged since 2011 with a focus on neuromodulatory interventions and potential futuristic applications of optogenetics for the treatment of mental health disorders. Like Racine et al. (2006), the authors identified a larger proportion of positive reporting over balanced reporting in all countries, with minimal discussion of social and ethical issues. Of those issues that were discussed, North American media coverage reflected critical interests in regulatory issues and informed consent, while German coverage addressed societal issues about social control and neuro-enhancement.

4.2.2 Study Aims

The press shoulders an important responsibility to accurately communicate advances in brain science to the public, and in doing so, influences social values, perceptions, and views about risk and hope. Responsible science communication relies not only on the actions of journalists, however, but also on the actions of scientists and journal editors. For example, publication bias in the psychiatric DBS literature can encourage optimistic reporting the press, who often interpret peer review as validation of scientific fact (Nature News, 2017). Responding to biases on either end of the science communication process, Schlaepfer and Fins (2011) assert that “while science and a democratic society thrive on the open exchange of ideas and a free press,
those who are privileged to produce, assess, disseminate, and report new knowledge have a responsibility to place scientific work into proper context” (pg. 776).

To this end, this study explores the experiences of individuals who professionally assess, disseminate and report on knowledge about psychiatric neurosurgery for public audiences. I gather the perspectives of generalist and specialist journalists who have reported on psychiatric neurosurgery with the goal of enriching an understanding of the logic behind journalistic judgments in reporting on these and other novel medical interventions. I additionally seek to elucidate factors that drive media coverage of this topic, as well as the perceived responsibilities of journalists in relation to the social and ethical concerns that contour the history of neurosurgical procedures in psychiatry.

4.3 Methods
I used a purposive sampling approach to recruit potential participants based on the eligibility criteria that the individual: (1) identifies occupationally as a journalist (i.e., not a clinician, academic, or a policymaker who only occasionally write pieces for the press); and (2) has reported on at least one psychiatric neurosurgery intervention in a major North American news outlet. To identify eligible participants, I used the Factiva database and websites of English-language newspapers in Canada and the United States with a daily circulation greater than 100,000 to search for articles about psychiatric neurosurgery and to compile a list of eligible journalists. Terms and keywords for the search were consistent with those used by Cabrera et al. (2018) in their analysis of contemporary psychiatric neurosurgery articles. Potential participants were contacted by email or by LinkedIn InMail with an invitation to participate in the study.
(Appendix A). A reminder email was sent after two weeks, after which no further contact was made.

Following approval by the University of British Columbia Research Ethics Board (H17-00013) and standard procedures for acquiring informed written and verbal consent, J. Illes and I conducted semi-structured interviews with participants. The interview guide was informed by previous studies of journalist practices and perceptions when covering emergent public health issues (e.g., Leask, Hooker, & King, 2010). Participants were asked general questions about journalistic practice followed by specific questions about reporting on psychiatric neurosurgery (Appendix E). General questions probed for descriptions of how stories were selected, how the focus or angle was formed, and how journalists perceived ethical, social and other issues in their work. Questions specific to psychiatric neurosurgery probed for the features of these procedures that are important for the story, the role that the history of psychosurgery played in their work, and public feedback, if any, that arose from their reporting.

Dr. Judy Illes and I conducted all interviews over the phone or via video-conference and took detailed field notes. Verbatim transcripts of interviews were verified for accuracy by comparison with original audio recordings, and then managed using NVivo 12 qualitative analysis software (QSR International).

Using qualitative content analysis methods and a deliberative approach (Hsieh & Shannon, 2005; Sandelowski, 2000), I developed a codebook that reflected the emerging phenomena and the hierarchy of themes and sub-themes in the dataset in consultation with a second coder. The
deliberations about the organization of the codebook were iterative until we reached consensus. Data were initially analyzed line by line, noting remarkable phenomena and developing primary codes (Saldaña, 2015). Similarities and differences were queried within and between transcripts, and primary codes were then organized into major themes and sub-themes. To ensure dependability of the coding, the second researcher coded 15% of the sample. A Cohen’s kappa test performed on this sample yielded a coefficient of 0.91, indicating substantial inter-coder agreement (Neuendorf, 2016).

4.4 Results

Seven journalists were interviewed (Table 4.1). While small, this sample size is consistent with several similar studies (e.g., Balasegaram, Balasegaram, Malvy, & Millet, 2008; Chew, Mandelbaum-Schmid, & Gao, 2006; Henderson & Kitzinger, 2007; Hodgetts, Chamberlain, Scammell, Karapu, & Waimarie Nikora, 2008; Reed, 2001; Roy, Faulkner, & Finlay, 2007; Trumbo, Sprecker, Dumlao, Yun, & Duke, 2001; Wilkinson, Allan, Anderson, & Petersen, 2007).
Table 4.1 Participant characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number of Participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2 (29)</td>
</tr>
<tr>
<td>Female</td>
<td>5 (71)</td>
</tr>
<tr>
<td>Professional designation</td>
<td></td>
</tr>
<tr>
<td>Specialist</td>
<td>3 (43)</td>
</tr>
<tr>
<td>Generalist</td>
<td>3 (43)</td>
</tr>
<tr>
<td>Health editor</td>
<td>1 (14)</td>
</tr>
<tr>
<td>Experience level</td>
<td></td>
</tr>
<tr>
<td>9 years or fewer</td>
<td>1 (14)</td>
</tr>
<tr>
<td>10 to 19 years</td>
<td>0 (-)</td>
</tr>
<tr>
<td>20 to 29 years</td>
<td>5 (71)</td>
</tr>
<tr>
<td>30 years or more</td>
<td>1 (14)</td>
</tr>
<tr>
<td>Reported intervention</td>
<td></td>
</tr>
<tr>
<td>DBS</td>
<td>5 (71)</td>
</tr>
<tr>
<td>Ablative surgery</td>
<td>2 (29)</td>
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</table>

The journalist sample reflects a highly experienced population and includes views from both generalist and specialist reporters. Generalist reporters write on a variety of news topics, known to the journalism community as beats, while the specialist reporters in this study write exclusively on topics relevant to science and medicine. One participant identified as a health editor for a media outlet but wrote their article about psychiatric neurosurgery while working as a specialist journalist. Most journalists interviewed had previously written about a psychiatric application of DBS; however, two journalists had previously reported on ablative surgical techniques. The date of publication of journalists’ articles about psychiatric neurosurgery articles ranged from 2005 to 2018. Interviews ranged between 21 minutes and 36 minutes (mean interview duration: 27.5 minutes) for a total of 3.25 hours of audio-recorded data for analysis. The final codebook consisted of 4 major themes — evidence, bioethical and social issues, newsworthiness, and history — and 11 sub-themes that were generated by journalist narratives (Table 4.2). The major themes were defined by their prominence and relevance to the objectives.
of the study. Themes are discussed by prevalence within the data. Sub-themes and quotations are presented in a sequence that best embodies the logic and flow of emerging narratives.

Table 4-2 Major themes and sub-themes

<table>
<thead>
<tr>
<th>Major Themes and Sub-Themes</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence</td>
<td>Practices and values that reflect a pursuit of journalistic truth</td>
</tr>
<tr>
<td>Accuracy</td>
<td>Ethical and social issues relevant to reporting on surgical and technological innovations in psychiatric care</td>
</tr>
<tr>
<td>Source selection</td>
<td></td>
</tr>
<tr>
<td>Bioethical and social issues</td>
<td></td>
</tr>
<tr>
<td>Patient vulnerability</td>
<td></td>
</tr>
<tr>
<td>Last resort</td>
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4.4.1 Evidence

As a major theme, evidence encompassed the practices, judgments, and intentions that governed a journalist’s pursuit of truth. The most prominent sub-themes nested within this theme were accuracy and source selection, which are explored below.

4.4.1.1 Accuracy

All journalists endorsed that reporting accurately, truthfully, and in a way that minimizes risks to the public is a quintessential element of their professional duty. When writing about both
psychiatric neurosurgery and other novel medical technologies, all journalists sought to explicitly highlight potential side effects, risks and uncertainties about treatment efficacy.

“There’s that balance of showing the promise of something, but also there are going to be downsides with any approach. And making it clear [to readers] that there are many unknowns” (Journalist 3, Specialist Reporter).

Some elaborated further on this stance, suggesting that failure to attend to risks, uncertainties and the limitations of medical research could create a sense of false hope for patients.

“... I do think that that has been a trend, and certainly in the time that I’ve been covering science, to really actively... point out when a study is falling short or whether it’s a small population or a very select population, so as not to give false hope” (Journalist 4, Specialist Reporter).

Several journalists expressed concerns about how other members of the media contribute to the creation of hype and sensationalism in their coverage of medical topics by failing to critically engage with available evidence.

“I think science journalism and medical journalism has a lot of responsibility for how many so-so treatments or even harmful treatments are seen by the public as a great thing or something that really works ... the coverage is generally not as skeptical as it should be” (Journalist 5, Generalist Reporter).

One journalist specifically perceived an axiological divide between the reporting styles of specialist and non-specialist journalists. This participant described the latter group as more prone to trends and superficial reporting practices.

“... people who are not beat specialists, you know, they want to just report on the latest trend or robotic surgery or some new technology that sounds really good. They are chomping on these kinds of stories more quickly and not reporting in a very comprehensive way. There’s a deep divide depending on the journalist” (Journalist 2, Specialist Reporter).
Overall, participants cited three strategies that they use to avoid hype in their work: patience, challenging authority figures, and seeking opportunities for development and support. Patience was defined as the act of waiting for evidence to accumulate from multiple scientific studies prior to reporting and was discussed by several journalists as a means to prevent sensationalistic reports from reaching the public.

“I’m just waiting more to see results rather than reporting on pharmacotherapies that are said to be the next best thing but often turn out not to be… [experienced journalists] are not as keen about new things. We really, you know, sort of sit back and wait for evidence to unfold” (Journalist 2, Specialist Reporter).

“I’m often encouraging the editors to move away from jumping on a single study. I’d rather be covering emerging trends and fields where there’s some momentum from replicated research” (Journalist 3, Specialist Reporter).

Most journalists explained that during their reporting process, they asked questions to challenge scientists, physicians and other actors conventionally regarded as authority figures. This technique was operationalized to prevent reporting on biased accounts of the success of new medical technologies, as well as to expose conflicts of interest or hidden funding agendas.

“[I use patient accounts] to talk to the surgeons who are offering [novel] procedures to perhaps challenge them if the [patient] said it was a horrendous procedure or to use any information that they can provide on that to perhaps spur further questions on the topic.” (Journalist 1, Health Editor).

“… even if this approach works it may ultimately fail, which again, is not something I would have learned had I not probed and asked the right questions.” (Journalist 3, Specialist Reporter).
Finally, several journalists mentioned that through accumulated experience, professional development, and access to resources specific to health and science journalism, they had refined their approach to covering novel medical interventions.

“... my approach more recently is probably different than when I first started out as a medical reporter because of all the professional development that I’ve had on medical evidence and analyzing it to determine whether it is a true and safe advance” (Journalist 2, Specialist Reporter).

“...a resource that I do sometimes consult when I’m unsure of how to approach a story [is] called “HealthNewsReviews.org” ...They provide resources for journalists on how to avoid hype and what language to avoid, and things that should be in a story on an important health issue” (Journalist 3, Specialist Reporter).

4.4.1.2 Source Selection

Most journalists indicated that, when covering psychiatric neurosurgery, engaging with multiple sources was an essential journalist ethic that allowed them to verify data and engage in a process of meaningful truth-seeking. This process included interviewing patients who had undergone a psychiatric neurosurgery procedure, their physicians, as well as other health specialists and researchers to obtain a range of opinions. Journalists endorsed this pluralistic approach as a means to reduce the possibility of bias in their selection of sources, as well as to investigate countering or divergent ideologies regarding scientific or medical advances.

“I think you would’ve been much more likely to see, say in the 50s and the 60s and so on, and going back even further for reporters to take at face value what a scientist told them about a particular procedure. Whereas, you know, now you would be remiss as a reporter not to talk to other people to get and to actively seek out countering views” (Journalist 4, Specialist Reporter).

“... you have to go in and ... talk to the doctors, ask for them to explain what exactly they’re doing. Get all sides of the story. I mean, you owe that. You need to talk to the ethicists. You need to talk to, you know, the professors, the people who are the sufferers, the sufferers’
family... it’s a wide circle.... it’s not a two or three interview story ... when you get into a story like this, you owe the general public the full explanation, the hour lecture versus the ten-minute slideshow” (Journalist 6, Generalist Reporter).

Indeed, one participant expressed that capturing more perspectives could have enriched their own coverage of psychiatric neurosurgery.

“I feel, in the future, in reporting on this, I would have gotten a wider variety of people speaking to me in the article, and sort of getting a range of experiences rather than sort of like this one patient experience with their immediate health care team. In that sense, I don’t know if that was the best way to tackle the story” (Journalist 7, Generalist Reporter).

Participant narratives also suggested that journalists value patient perspectives and that patients play a pivotal role in creating a story that is accessible to a public readership. As such, some journalists described the use of patient narratives as an inherent component of the story development process.

 “[When writing, I] look to have a bit of colour to open the piece, with something from somebody who’s undergone this procedure themselves, hopefully so that they give their first-person accounts of what it is like to have this experience, whether it was good or bad” (Journalist 1, Health Editor).

Several reporters, however, noted that overly enthusiastic patient narratives can misrepresent the efficacy of a procedure, particularly in the mental health sphere where remission is rarely a linear process.

“I really try ... to not [rely] too heavily on the strongly emotional impact of a signal patient anecdote, you know, the personal story. We always want to have them in because they make them relatable, but there’s a danger with that. That you give a false impression of the efficacy of an approach...” (Journalist 3, Specialist Reporter).
4.4.2 Bioethical and Social Issues

Journalists were asked to reflect on the features of psychiatric neurosurgery that they deemed important for their coverage of the topic, as well as any ethical issues that they felt necessitated explicit attention in media stories about these interventions. In order of theme prevalence, patient vulnerability, the last resort nature of psychiatric neurosurgery procedures, mental health stigma, and treatment access were major considerations for the journalists in this study.

4.4.2.1 Patient Vulnerability

Several journalists noted that psychiatric patients should be regarded with special sensitivity by the media, particularly with respect to the interview process. The complexities associated with justly portraying individuals suffering from severe mental illness to the public were also raised in a number of participant narratives.

“I probably exercise a little bit more caution, especially when interviewing people who have [psychiatric] illnesses. I think that … you just have to have more sensitivity to them and you certainly don’t want to trigger anything” (Journalist 2, Specialist Reporter).

“[My story] had a woman who couldn’t speak for herself. So, I had to make sure that her guardian knew … exactly what I was saying about her daughter. I had to make sure that her side of the story was fully pulled. I had to make sure, the woman at the end of the story suffered from a severe OCD, that she didn’t… [become] ostracized” (Journalist 6, Generalist Reporter).

Nevertheless, most journalists remained undecided about whether psychiatric patients were in fact more vulnerable than other types of patients or health news consumers. Indeed, several journalists asserted that accuracy, truthfulness and minimization of risks should be upheld in health reporting independent of the intervention described or the patient population affected.
“... I just did a story about a type of transplant that really showed me that ... patients of any sort are very vulnerable because they’re trusting” (Journalist 5, Generalist Reporter).

“I think there’s exceptional responsibilities for all health writers writing about anything to do with health... there’s quite a huge responsibility to report accurately, as accurately and truthfully as is possible given the available evidence” (Journalist 1, Health Editor).

4.4.2.2 Last Resort

Several journalists discussed the last resort nature of psychiatric neurosurgery interventions and highlighted the importance of conveying to readers that patients who elect to undergo these procedures have exhausted other therapeutic alternatives.

“I think you have to be really careful about when you’re writing about these kinds of procedures that you do really emphasize the fact that this is not a first resort for mental illness. Patients who find themselves having surgery for whatever they’re in for have had a long road...they’ve been through a lot before they’ve arrived at this final point or decision” (Journalist 7, Generalist Reporter).

4.4.2.3 Stigma

Many journalists remarked that the societal stigma surrounding mental illness permeated their coverage of psychiatric neurosurgery. On the one hand, this stigma was thought to be intrinsically linked to the controversial history of these procedures.

“...there is, you know, a widespread fear and some pretty negative connotations connected with [psychiatric neurosurgery]” (Journalist 3, Specialist Reporter).

On the other hand, some journalists considered the investigational nature of these procedures, together with limitations in the ability of neuroscience to explain psychiatric conditions, as factors contributing to public stigma.
“...whether it be a drug or surgery, so much [is] unknown, the mechanism or the pathway isn’t as clearly understood when it comes to treating mental health... I think that’s a big part of the resistance around using surgical treatments for psychiatric ailments” (Journalist 4, Specialist Reporter).

4.4.2.4 Access

Finally, several journalists discussed issues of justice and access. Some journalists indicated that their work is a major source of medical information for the public, and that they have sometimes even acted as an intermediary point of contact between patients and physicians when reporting on novel therapeutic technologies. This position raises inevitable ethical concerns, particularly given that journalists are not regularly equipped with the resources needed to address inquiries about novel interventions from eager patients.

“... I'm not a medical professional. That's the weird thing about being a health reporter... I have no business making health recommendations. However, things that I write are widely read often. And people do – it does inform people’s knowledge about various topics” (Journalist 3, Specialist Reporter).

“I hear from people who often hear about [new therapies] and then want access to it” (Journalist 2, Specialist Reporter).

4.4.3 Newsworthiness

Journalists were asked to consider the factors that initially led them to report on contemporary psychiatric neurosurgery and the drivers behind its perceived news value. Indeed, the decision to dedicate news coverage to a topic is inherently value-laden and can be influenced by the experiences and worldviews of a journalist and by their dynamic interactions with other media actors. In order of prevalence, novelty, personal connections, and public relevance emerged as factors that encouraged the journalists in this study to report on psychiatric neurosurgery.
4.4.3.1  Interest or Topic Novelty

All participants in this study expressed that the novelty inherent to psychiatric neurosurgery motivated them to investigate and develop a story, often connecting their interest to issues such as the controversial past of psychosurgery or the subsequent renaissance of invasive psychiatric interventions.

“...I think there was a certain kind of fascination with the ghoulish element of [psychiatric neurosurgery]. I’d read about Walter Freeman and his lobotomobile, and now it seemed to be that there was a new type of psychosurgery in town and I wanted to know how things had moved on from that time, if at all” (Journalist 1, Health Editor).

“...it just sounded fascinating, all of the issues that were raised by this, like what is depression? Do you really want to bring back surgery like this? All kinds of things, finding an effect when you actually didn’t think you’d get one, and then what do you do? And that story is still unspooling [for DBS]” (Journalist 5, Generalist Reporter).

4.4.3.2  Personal Connection

Several journalists also discussed, upon deeper reflection, how their own personal connections to mental or neurological illness provoked an interest in the topic. Indeed, personal experiences were often described as shaping the ways in which journalists chose to develop their story or represent these interventions to the public.

“I had some pretty serious mental health issues in my family and I suffered pretty severe depression myself ... enough to know what it tastes like and how desperate it can be, so I think that adds to my awareness and sensitivity of the vulnerability of the patients” (Journalist 5, Generalist Reporter).

“I know people who have been harmed by some of those things... my father’s brother had epilepsy and he went to Montreal to have the surgery with that really famous guy at the Montreal Neurological Institute. His arm was paralyzed [afterwards] although his seizures stopped... I think when you have a personal experience with this or observe somebody in a personal way, it does tend to leave a bigger impression so that I will always inquire about
the potential side effects of whether it’s deep brain stimulation or [any other intervention]” (Journalist 2, Specialist Reporter).

### 4.4.3.3 Public Relevance

Finally, several journalists considered psychiatric neurosurgery to be a topic of public relevance due to the sweeping prevalence of mental health conditions in society.

“...mental health problems account for a very large portion of illnesses and hospitalizations and there are so many people are troubled by these things” (Journalist 2, Specialist Reporter).

### 4.4.4 Historical Context

Nearly all journalists elected to research the history of psychosurgery and situate their news stories within the context of historical procedures. Many journalists further indicated that gaining an understanding of the history and evolution of these procedures over time was a necessity for both writers and their public audiences.

#### 4.4.4.1 Framing the Story

Most journalists agreed that the history of psychosurgery and other psychiatric treatments contribute to the ways in which they research, develop, and ultimately frame their stories about contemporary procedures.

“I think it’s important to take [the] deeper look that I like to take when I can, because otherwise you’ll make some really stupid mistakes and then write about [Helen] Mayberg’s work or DBS and not be aware of the varied and variegated history of physical interventions in the brain for behavioural or mood issues... you’re playing with fire... [the history] has to be implicit in your understanding ... to know what you’re getting into or even your own proper level of awareness and skepticism” (Journalist 5, Generalist Reporter).
Several furthered this sentiment by describing their approach to writing on this topic as more cautious or circumspect than other medical content in light of past atrocities and wide-reaching public aversion following the lobotomy era.

“I think that because of experiments that have been done, those sort of crude and barbaric experiments of the past, it should make the journalists very careful and circumspect about whatever new things are in the pipeline” (Journalist 2, Specialist Reporter).

“Anything where there’s a ghastly historical precedent, like eugenics or psychosurgery, then I’m immediately aware that I need to tread carefully and make sure I mention the historical context” (Journalist 1, Health Editor).

4.4.4.2 Shift in Perceptions

Some journalists disclosed that their initial views about modern psychiatric neurosurgery are shaped largely by a calamitous historical precedent. The knowledge and perspectives to which journalists are exposed throughout the reporting process, however, contributed to the realization that their initial apprehensions were unsubstantiated.

“When I first [heard of psychiatric neurosurgery’s comeback] I was just, sort of, taken aback by the fact that someone might actually preform the modern-day lobotomy, so to speak. As I got further into my research, I realized that oh, hang on a second, it’s way more nuanced than that, and, as a matter of fact, deep brain stimulation has now been used to treat Parkinson’s disease, I think, to some great effect” (Journalist 6, Generalist Reporter).

4.5 Discussion

This qualitative study of journalist perspectives about reporting on developments in modern psychiatric neurosurgery unveils four salient themes: evidence; bioethical and social issues; newsworthiness; and historical context. Results reveal a perceived commitment to public readership through journalistic practices aimed at curbing sensationalism, as well as a continued
role for the history of psychosurgery in preparing members of the media to report on evolutions in psychiatric neurosurgery. Journalists are largely drawn to report on psychiatric neurosurgery by its controversial history and the ways in which this topic challenges conventional understandings of mental health disorders. Ethical and social issues were discussed by all participants as priorities for the story development process; however, some journalists do not readily perceive these issues to hold particular normative significance.

4.5.1 Perceived Reporting Style

Journalists in this study frequently discussed a commitment to a balanced reporting style. This contrasts the findings of studies analyzing media coverage of neuromodulatory and psychiatric neurosurgery, both of which have suggested that balanced reporting is overshadowed by one-sided reporting of intervention benefits without explanation of potential risks (Cabrera et al., 2018b; Racine et al., 2007). Given the high experience level of reporters in this study, the views captured likely reflect those of a subset that is highly cognizant of the impact that positively-biased reporting can have on public health decision-making.

Balanced reporting alone is insufficient to ensure accuracy, particularly in scientific reporting. For example, Dixon and Clarke (2013) demonstrated that participants who read news articles that balanced the weight of claims for and against links of vaccines to autism were subsequently more likely to reconsider their stance on the issue, often resulting in decreased personal certainty of vaccine safety. Providing an equal platform for countering views on a topic despite the existence of scientific consensus can therefore result in a false balancing effect and can ultimately mislead the public about the validity of scientific and medical claims. To mitigate the
effect of false balancing, the Association of Health Care Journalists (AHCJ) encourages journalists to quantify the magnitude of risks and benefits associated with medical interventions upon which they report (AHCJ, 2019). This includes providing information about absolute risk or benefit, relative risk, and number needed to treat, together with full explanations of these terminologies. The journalists in this study did not discuss psychiatric neurosurgery in the context of risk quantification, however, which may be inherently linked to the proof-of-concept investigational status of these procedures.

4.5.2 Representation of Social and Ethical Issues

While all journalists in this study discussed issues that bear social or ethical significance, not all participants agreed that they actively sought to include a discussion of such issues in their news stories. At least one participant — a health editor — confessed that a discussion of ethical issues was purposefully avoided due to lack of expertise and comfort with neuroethics. Nevertheless, mass media coverage of topics within the fields of genomics (Racine et al., 2006), regenerative medicine (Kamenova & Caulfield, 2015) and neurotechnology (Gilbert & Ovadia, 2011) is often criticized by academics for omissions of ethical discourse. Enhancing direct collaboration between journalists and ethicists is unlikely to prevail as a strategy to combat this perceived void, as such a collaboration would interfere with a journalistic ethic of disinterested reporting (Nelkin, 1995). Instead, one specialist reporter suggested that ethical discourse should occur earlier in the scientific pipeline, encouraging ethicists to collaborate with clinicians and researchers who produce journal articles. Collaborative authorship between scientists and ethicists is indeed encouraged by some professional associations (e.g., International Neuroethics Society, www.neuroethicssociety.org; Canadian Bioethics Society, www.bioethics.ca); however,
it is unknown whether implementations of this directive have impacted the ways in which journalists report on health and science topics. While some participants in this study mentioned accessing scientific journal articles to enhance their understanding of scientific concepts pertinent to their news coverage, none expressed a need to consult or cover relevant perspectives presented in social sciences or humanities literature.

Gilbert and Ovadia (2011) argue that media inattention to ethical issues can turn “ethical neglect into de facto ethical approval” (p. 2); however, Secko and colleagues (2013) contend that a lack of normative discourse alone is insufficient to deem media coverage incomplete or invalid. Instead, these authors offer that the omission of ethical issues may represent an operationalization of a traditional model of science journalism which views science as a fundamentally fixed and certain entity, and is chiefly concerned with information transmission (Secko, Amend, & Friday, 2013). Opposing, non-traditional models of science journalism view science as uncertain and socially bound, and thus place more emphasis on public engagement and relevant societal values. While a story written under either model has the potential to mispresent scientific issues to the public, these axiologically divergent models can both foster a diversity of “good science stories that matter” for an inherently diverse public (Secko, Amend & Friday, 2013, p. 69). In effect, the personal values of journalists and their views towards science as a paradigm can continue to provide greater insight into the rhetorical decisions that contour their coverage of health and science issues. Indeed, these values are sensitive to cultural and institutional practices. For example, many of the journalists interviewed in this study boasted about their efforts to challenge scientists and clinicians on experimental and therapeutic claims. By contrast, other researchers have reported that Brazilian journalists covering science news
endorse a view of scientists as authoritative advocates of the natural world, seldom taking action to expose biases in this population (Liskauskas, Ribeiro, & Vasconcelos, 2019).

4.5.3 Historical Significance

While the last frontal lobotomy was performed over half a century ago, it is undeniable that this procedure is preserved in the collective memory of the nations where it thrived (Johnson, 2014). Journalists in this study endorsed that the history of psychiatric neurosurgery drove not only the news value of their stories, but also a comparative instinct to distinguish modern procedures from their historical predecessors. Analysis of reader comments to news coverage of contemporary psychiatric neurosurgery suggests that negative evaluations of historical psychosurgery fuel public skepticism about modern ablative procedures (Cabrera et al., 2018a). Several journalists in the present study discussed their initial skepticism of modern psychiatric neurosurgery based on the demise of psychosurgery, but they also illuminated the need to fairly portray patients who elect to undergo these procedures to the public. Continued media coverage of modern psychiatric neurosurgery that accurately depicts risks, benefits, and the complexities and intricacies of patient selection may indeed bring about a greater understanding of and less aversion towards emerging ablative surgical techniques like focused ultrasound (Mahdavi et al., 2019).

4.6 Limitations

This study has a small sample size and only included journalists who have covered psychiatric neurosurgery for North American audiences. As standard in qualitative inquiry, this study can only represent a snapshot of the current views of participants. Furthermore, this study does not
aim to be generalizable. Given the limited role for theory development within this qualitative
descriptive study, the concept of theoretical saturation is not emphasized within the present
inquiry (van Rijnsoever, 2017; Saunders et al., 2018). Nevertheless, the small sample size and
the unexpected occurrence of sub-populations within this data set may have limited the depth or
scope of themes uncovered. Recruitment strategies produced a study sample that may be
impacted by self-selection bias, as well as the inherent biases of the research team. Indeed, most
participants had 20 years or more experience in the journalism profession, and some expressed
familiarity with the work of our research unit. For example, the finding that balanced reporting is
important to journalists who write about psychiatric neurosurgery may be confounded by a self-
selection bias of those who perceive their work to be unequivocally balanced. An adjunct
analysis of the articles written by those who participated is beyond the scope of this study and
could indeed compromise participant confidentiality. The views of less experienced journalists
are undoubtedly important to seek in future studies; however, members of this population may be
less accessible than journalists with more seniority, or, could feel less inclined to participate in
research aimed at learning about a profession in which they have had limited experience.

4.7 Conclusion

Public perceptions of science and medicine are tacitly shaped by the events portrayed to them by
the popular press. In the wake of a revived medical interest in pursuing psychiatric neurosurgery
procedures for refractory mental health conditions and a corresponding surge in its media
coverage, the experiences of journalists offer a window into the professional priorities, personal
biases, and decisions that contour the reporting of this medical advance. Reporting accuracy is a
foremost priority, while the history of these interventions provides an opportunity to explore the
ways in which the field of psychiatry and contemporary understandings of mental illness have evolved over time. Normative discourse should not be the responsibility of journalists alone and should be encouraged through collaborative partnerships among their sources.
Chapter 5: Practice, Perceptions and Predictions: Clinical Opinions about Psychiatric Neurosurgery

5.1 Synopsis

Several surgical interventions are under investigation to remediate psychiatric conditions resistant to conventional therapies. Given the complicated history of psychosurgery and its recent renaissance, we sought to gauge current attitudes held by functional neurosurgeons towards contemporary psychiatric neurosurgery procedures. We designed a 51-question online survey comprising Likert-type, multiple-choice, and rank-order questions and distributed it to members of the American Society for Stereotactic and Functional Neurosurgery (ASSFN). Descriptive and inferential statistical analyses were performed on the data obtained. We received 38 completed surveys. Half (n = 19) of 38 respondents reported devoting at least a portion of their clinical practice to the treatment of psychiatric conditions. Among those who perform psychiatric neurosurgery, DBS was the most frequently utilized intervention, and OCD was the most frequently treated condition. Seventy-one percent of all respondents (n = 27) supported the clinical utility of ablative surgery in modern neuropsychiatric practice. Eighty-seven percent (n = 33) agreed that ablative procedures constitute a valid treatment alternative to DBS for some patients, and 61% (n = 23) agreed that ablative surgery may be an acceptable treatment option for patients who are unlikely to comply with postoperative care. Respondents were more likely to agree that psychiatric neurosurgery is more medically effective (odds ratio 0, p = 0.03242, two-sided Fisher’s exact test) and has clearer clinical indications for the treatment of OCD than for the treatment of depression (odds ratio 0.09775, p = 0.005137, two-sided Fisher’s exact test). This up-to-date account of functional neurosurgeon practices, perceptions and predictions helps
to trace the evolution of clinician attitudes captured in surveys distributed nearly one decade ago and can also help to inform priorities for public education and further ethical innovation in the psychiatric neurosurgery landscape.

5.2 Introduction

While far safer than their psychosurgery predecessors of the mid-20th century, current psychiatric neurosurgical procedures continue to pose significant ethical challenges, particularly with regard to informed consent, delineating acceptable uses from misuses (e.g., cognitive enhancement, criminality), potential harm to patients caused by overly reductionistic explanations of mental illness, and stigma stemming from the dark history of psychosurgery (Kvaale, Haslam, & Gottdiener, 2013; Lipsman et al., 2010; Müller, 2017; Nuttin et al., 2014). Functional neurosurgeons practising in this area share an integral part of the care of psychiatric patients and therefore a responsibility for the scientific integrity of these procedures. Despite this, little is known about current practices and attitudes towards psychiatric neurosurgery among these clinicians. As this discipline continues to expand and evolve rapidly, an up-to-date exploration of functional neurosurgeon preferences, beliefs, and predictions is required.

Previous studies have employed semi-structured interview and survey methodologies to assess opinions held by the neurosurgical community on the topic of psychiatric neurosurgery (Lipsman et al., 2011a; Mendelsohn, Lipsman, & Bernstein, 2010; Mendelsohn et al., 2013). In a qualitative study of 47 neurosurgical staff and trainees, Mendelsohn and colleagues (2010) found that all participants endorsed psychiatric neurosurgery for refractory conditions as an ethical pursuit, stressing the importance of safety, efficacy, patient consent and the severity of the illness
as important decision-making criteria. By contrast, most participants opposed the application of neurosurgery to enhance non-pathological traits, such as cognition, memory or personality. Participants also supported the notion that societal attitudes will dictate the permissibility of surgical innovation in psychiatry, many rejecting the readiness of psychiatric neurosurgery interventions for widespread public acceptance.

Online surveys distributed to North American and international members of the World Society for Stereotactic and Functional Neurosurgery (WSSFN) have expanded on these findings (Lipsman et al., 2011; Mendelsohn et al., 2013). Both surveys sought to characterize extant psychiatric neurosurgery practice, beliefs and predictions among functional neurosurgeons within these societies. Lipsman et al. (2011) surveyed 84 North American members of the WSSFN, 49% of whom indicated that psychiatric neurosurgery was a component of their functional neurosurgery practice. All psychiatric neurosurgeons reported that psychiatric conditions contributed to a small proportion (< 25%) of their total clinical practice. Interventions employed by psychiatric neurosurgeons predominantly involved stimulation, with 50% reporting the use of stimulation exclusively, and another 31% reporting a combination of stimulation and lesioning procedures with a focus on stimulation. Only 14% of psychiatric neurosurgeons indicated that lesioning procedures were used exclusively in their psychiatric neurosurgery practice. OCD and depression were the top two most frequently reported indications for psychiatric neurosurgery.

When asked about the future of these procedures, more surgeons who practiced psychiatric neurosurgery predicted that these interventions would become more widespread within their own
(78%) and global functional neurosurgery practices (86%) than those without psychiatric neurosurgery as a component of their practice. Both groups ranked the reluctance of psychiatrists to refer patients, stigma surrounding psychiatric disease, and the historic misuse of neuromodulation as the three most significant obstacles preventing widespread use of functional neurosurgery to treat psychiatric illness.

In 2012, Mendelsohn et al. distributed this survey on an international scale. Researchers obtained 106 responses from members of the WSSFN outside of North America, with respondents from Europe (43%) and Asia (39%) comprising the majority of their sample. Similar to results from their North American survey, approximately half of respondents indicated the use of psychiatric neurosurgery within their clinical practice. The proportion of practice devoted to psychiatric neurosurgery remained small among this sample; however, proportions of psychiatric neurosurgeons reporting the use of lesioning exclusively (16%) and lesioning in combination with stimulation (26%) in their practice were higher than those reported by North American psychiatric neurosurgeons (14%; 6%). While the authors did not address this finding, regional variations in the permissibility, cost-efficiency, and incentivization of ablative surgical procedures may have contributed to this discrepancy (Wu et al., 2012). OCD was the most frequently treated condition within this sample; however, some psychiatric neurosurgeons reported aggression (8%), schizophrenia (8%), and addiction (2%) as the most commonly-referred psychiatric conditions in their practice, despite limited and conflicting evidence for their use (Schwabe & Krauss, 2018).
Similar to the findings of Lipsman et al. (2011), more clinicians who practiced psychiatric neurosurgery predicted a greater role for these procedures within their own clinical practice in the future than those who did not practice psychiatric neurosurgery. However, both psychiatric neurosurgeons and non-psychiatric neurosurgeons in this cohort believed that global trends for psychiatric neurosurgery would increase substantially in the years to come. Reluctance of psychiatrists to refer patients, stigma surrounding psychiatric disease, and a lack of convincing evidence for psychiatric neurosurgery ranked as the top three impediments to greater acceptance of these procedures.

In the time since publication of these landmark surveys, much has evolved within the psychiatric neurosurgery landscape. Clinical guidelines governing the investigational and therapeutic applications of psychiatric neurosurgery were published in 2014, inviting functional neurosurgeons, psychiatrists, neurologists, neuropsychologists and neuroethicists to formally engage in the advancement of these procedures (Nuttin et al., 2014). Clinical trials for DBS alone now span numerous psychiatric indications — from depression to schizophrenia to addiction — across 14 countries (Cabrera et al., 2018b; Lozano et al., 2019). Most recently, magnetic-resonance guided focused ultrasound (MRgFUS), a minimally-invasive, fast-acting lesioning technique that targets brain tissue using ultrasonic radiation, has entered Phase I clinical trials for patients with treatment-resistant depression, OCD, and Alzheimer’s disease (Meng et al., 2017).

Despite the pioneering technological advances that continue to shape this field, the North American public remains skeptical of ablative psychiatric procedures (Cabrera et al., 2018a). In this study, we sought to build upon the work of Lipsman et al. and update a current
understanding of functional neurosurgeon practices, views and predictions about psychiatric neurosurgery. We additionally probed functional neurosurgeons’ views of contemporary ablative and neuromodulatory interventions with respect to clinical applicability, evidence quality, and future directions. Ultimately, this survey extends the goal of engaging a diverse set of stakeholders in evolving care options for patients with refractory mental illness.

5.3 Methods

5.3.1 Survey Development

A 51-question, computerized, Internet-based survey was developed based on the previous work of Lipsman et al. (2011) and Mendelsohn et al. (2013) (Appendix F). Questions were divided into three main categories: basic demographics, clinical practice, and attitudes towards psychiatric neurosurgery. Unlike surveys developed by Lipsman et al. (2011) and Mendelsohn et al. (2013), our survey included an adaptive element. Respondents who indicated that psychiatric neurosurgery was a component of their clinical practice received questions belonging to a fourth category that explored the frequency of techniques utilized and conditions treated. Questions posed later in the survey about perceptions towards psychiatric neurosurgical procedures and conditions were correspondingly adapted based on responses received from functional neurosurgeons within this fourth category. For example, if a functional neurosurgeon indicated that psychiatric neurosurgery was a component of their clinical practice and that DBS was their most-frequently used intervention, subsequent questions about psychiatric neurosurgery attitudes and perceptions were tailored to the most frequently utilized intervention specifically. Functional neurosurgeons reporting no current use of psychiatric neurosurgery in their clinical practice received default questions that assessed perceptions towards ablative surgery as an intervention.
and depression as a condition. The survey was piloted among members of the study team. Institutional Research Board approval was obtained from Michigan State University (STUDY00001237).

5.3.2 Survey Distribution

The survey was distributed by e-mail to members of the American Society of Stereotactic and Functional Neurosurgery (ASSFN) by an administrator of the WSSFN. A reminder e-mail was sent two weeks after the initial distribution. Responses to the survey were voluntary and anonymous.

5.3.3 Data Preparation

Fifty-four survey responses were obtained, 16 of which were incomplete. Incomplete responses were excluded from analysis. Three null-responses among the remaining 38 responses were tagged and excluded from relevant sub-analyses.

5.3.4 Data Analysis

Descriptive statistics are reported as frequencies and rounded percentages. Response comparisons between the following groups were assessed post-hoc for group differences using two-sided Fisher’s exact tests: (1) functional neurosurgeons who treat psychiatric conditions and those who do not; (2) functional neurosurgeons with 15 years or more experience and those with 14 years or less; (3) attitudes regarding neuromodulatory interventions and attitudes regarding ablative interventions; and (4) attitudes regarding psychiatric neurosurgery for the treatment of OCD and attitudes regarding psychiatric neurosurgery for the treatment of depression. Group
differences were probed in Group (1) based on previous surveys distributed within this population (Lipsman et al., 2011; Mendelsohn et al., 2013). The responses of physicians who indicated the use of psychiatric neurosurgery in their own clinical practice delineated comparison Groups (3) and (4) based on responses representing surgeons’ most frequently utilized interventions and most frequently treated disorders, respectively. We additionally hypothesized that group differences may occur at the level of clinical experience, which prompted the statistical comparisons for Group (2). Data were analyzed using R v3.5.2 (R Core Team, 2018).

5.4 Results

5.4.1 Demographics and General Practice

Thirty-eight survey responses were obtained. Respondents in our sample were predominantly male (n = 34, 89%), and two-thirds were between the ages of 33 and 54 (Table 1). The majority of respondents reported practising in the United States (n = 32, 84%), the remainder practiced in Canada (n = 6, 16%). Fifty-five percent (n = 21) of respondents had at least 10 years of experience in the field, and twenty-six percent (n = 10) indicated 20 years or more. Two-thirds of respondents obtained formal fellowship training in stereotactic and functional neurosurgery. Most attended medical school within the United States (n = 27, 71%); the remainder attended medical school in Canada (n = 9, 24%) or internationally (n = 2, 5%).
Table 5-1 Demographic data

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total (n=38)</th>
<th>Years in practice (cont.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>34 (89%)</td>
<td>10-14</td>
</tr>
<tr>
<td>Female</td>
<td>3 (8%)</td>
<td>15-19</td>
</tr>
<tr>
<td>Prefer not to respond</td>
<td>1 (3%)</td>
<td>20 or more</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-34</td>
<td>1 (3%)</td>
<td>Yes</td>
</tr>
<tr>
<td>35-44</td>
<td>13 (34%)</td>
<td>No</td>
</tr>
<tr>
<td>45-54</td>
<td>12 (32%)</td>
<td></td>
</tr>
<tr>
<td><strong>Fellowship training in functional neurosurgery</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>9 (24%)</td>
<td>Academic</td>
</tr>
<tr>
<td>65 and older</td>
<td>3 (8%)</td>
<td>Community</td>
</tr>
<tr>
<td><strong>Country of practice</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>6 (16%)</td>
<td>Other</td>
</tr>
<tr>
<td>USA</td>
<td>32 (84%)</td>
<td>Medical school</td>
</tr>
<tr>
<td><strong>Years in practice</strong></td>
<td></td>
<td>Canada</td>
</tr>
<tr>
<td>Less than 5</td>
<td>6 (16%)</td>
<td>USA</td>
</tr>
<tr>
<td>5-9</td>
<td>11 (29%)</td>
<td>Abroad</td>
</tr>
</tbody>
</table>

Most clinicians practised in academic, university-affiliated hospitals (n = 33, 81%), with a minority practising exclusively or concurrently in private or community settings. Movement disorders accounted for an average of 46% of all functional neurosurgery referrals within the study sample (SD = 34%) (Figure 1). Psychiatric conditions excluding chronic pain accounted for an average of just 7% of all respondents’ clinical practices (SD = 20%); however, two functional neurosurgeons reported that psychiatric referrals comprise 80% and 100% of their individual practices, respectively.
5.4.2 Psychiatric Neurosurgery Practice

Half of 38 respondents (n = 19) reported that psychiatric referrals accounted for a component of their functional neurosurgery practice. DBS was ranked as the most frequently performed procedure for psychiatric referrals by 47% (n = 8) of functional neurosurgeons who answered questions about their psychiatric neurosurgery practice, while OCD was ranked as the most frequently treated condition (n = 13, 72%) (Table 2). Most neurosurgeons reported using a combination of neuromodulatory and ablative interventions when treating psychiatric conditions (n = 12, 71%); however, 35% indicated that while they utilize both methods, neuromodulation was more frequently used than ablation (n = 6). Thirty-five percent reported using neuromodulatory methods exclusively (n = 6), and 12% reported using only ablative methods.
(n = 2). Nearly two-thirds of neurosurgeons performing psychiatric procedures reported having less than 15 years of experience in the field of functional neurosurgery (n = 14).

Table 5-2 Practice information of neurosurgeons performing psychiatric procedures

<table>
<thead>
<tr>
<th>Use of ablation and neuromodulation (n = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ablation exclusively</td>
</tr>
<tr>
<td>Combination of both but mostly ablation</td>
</tr>
<tr>
<td>Combination of both but mostly neuromodulation</td>
</tr>
<tr>
<td>Neuromodulation exclusively</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Most common psychiatric disease referred (n = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>OCD</td>
</tr>
<tr>
<td>Depression</td>
</tr>
</tbody>
</table>

1 17/19 respondents who devote a portion of their practice to psychiatric conditions answered these questions.

2 One surgeon indicated that they treat both OCD and depression equally; both responses were included.

5.4.3 Ablative Procedures

No statistical differences were observed between respondents who treated both psychiatric and neurological conditions and those who treated only neurological conditions, nor surgeons with 15 years or more years of experience in the field and those with fewer than 15 years of experience when asked about attitudes towards ablative forms of psychiatric neurosurgery. Most respondents supported an ongoing role for ablative surgery for psychiatric conditions; only 16% (n = 6) preferred that ablative surgery not be performed in a psychiatric context (Table 3). However, many respondents endorsed that the utility of ablative methods may be short-lived, with 66% of respondents indicating that there would soon no longer be physicians who are experts in ablative psychiatric procedures (n = 25). Nonetheless, 87% of respondents agreed that ablative surgical procedures represent a valid alternative to DBS for some psychiatric patients.
(n = 33). Sixty-one percent of respondents supported the indication of ablative neurosurgery for the treatment of patients who would be least likely to comply with post-operative care (n = 23).

<table>
<thead>
<tr>
<th>Attitudes</th>
<th>Psychiatric Practitioners (n = 19)</th>
<th>Non-Psychiatric Practitioners (n = 19)</th>
<th>≥ 15 Years of Experience (n = 16)</th>
<th>&lt;15 Years of Experience (n = 22)</th>
<th>Total (n = 38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ablative surgery is obsolete; it should not be performed anymore</td>
<td>3 (16%)</td>
<td>3 (16%)</td>
<td>2 (13%)</td>
<td>4 (18%)</td>
<td>6 (16%)</td>
</tr>
<tr>
<td>Ablative surgery may be acceptable in some circumstances if non-invasive methods (e.g. radiosurgery) are used</td>
<td>14 (74%)</td>
<td>9 (47%)</td>
<td>8 (50%)</td>
<td>15 (68%)</td>
<td>23 (61%)</td>
</tr>
<tr>
<td>It is acceptable to offer ablative surgery to patients who will likely not comply with postoperative care</td>
<td>13 (68%)</td>
<td>10 (53%)</td>
<td>8 (50%)</td>
<td>15 (68%)</td>
<td>23 (61%)</td>
</tr>
<tr>
<td>I expect that soon there will no longer be physicians who are experts in ablative surgical procedures</td>
<td>11 (58%)</td>
<td>14 (74%)</td>
<td>13 (81%)</td>
<td>12 (55%)</td>
<td>25 (66%)</td>
</tr>
<tr>
<td>For some psychiatric patients, ablative surgery may be a valid alternative to DBS</td>
<td>18 (95%)</td>
<td>15 (79%)</td>
<td>12 (75%)</td>
<td>21 (95%)</td>
<td>33 (87%)</td>
</tr>
<tr>
<td>Ablative surgery is more cost-effective than DBS</td>
<td>16 (84%)</td>
<td>14 (74%)</td>
<td>13 (81%)</td>
<td>17 (77%)</td>
<td>30 (79%)</td>
</tr>
</tbody>
</table>

### 5.4.4 Ablative vs. Neuromodulatory Interventions

Respondents were asked about the clinical applicability of either ablative (n = 22) or neuromodulatory (n = 14) interventions for neuropsychiatric indications (Table 4). No group differences were found to be statistically significant. Nearly all functional neurosurgeons agreed
that ablative and neuromodulatory interventions have the potential to improve the quality of life for properly selected patients (ablation, 92%; neuromodulation, 93%). Most respondents indicated that they remained optimistic that ablative and neuromodulatory procedures would be accessible to patients in need (ablation, 71%; neuromodulation, 79%) and that, as these treatments evolve, experience in the field would help physicians and researchers to better understand the neurological basis of psychiatric diseases (ablation, 67%; neuromodulation, 71%). Forty-two percent of surgeons asked about ablation (n = 10) and 36% of those asked about neuromodulation (n = 5) agreed that these treatments remained only as last-resort interventions for psychiatric conditions. Very few respondents indicated that ablative (13%, n = 3) or neuromodulatory (7%, n = 1) interventions presented relatively high risks of surgical complications. Finally, although opinions were evenly split as to whether some applications of ablation were unethical, only 29% of respondents agreed that some applications of neuromodulation could be ethically contentious (n = 4).
Table 5-4 Perceived clinical applicability of ablative and neuromodulatory interventions

<table>
<thead>
<tr>
<th></th>
<th>Ablation (n = 24)</th>
<th>Neuromodulation (n = 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ablation/Neuromodulation will help physicians and researchers to understand the neurological basis of psychiatric diseases</td>
<td>16 (67%)</td>
<td>10 (71%)</td>
</tr>
<tr>
<td>Ablation/Neuromodulation will be an option for the treatment of severe, otherwise untreatable psychiatric diseases</td>
<td>17 (71%)</td>
<td>11 (79%)</td>
</tr>
<tr>
<td>Ablation/Neuromodulation has the potential to substantially improve the quality of life for carefully selected patients</td>
<td>22 (92%)</td>
<td>13 (93%)</td>
</tr>
<tr>
<td>Some applications of ablation/neuromodulation are unethical</td>
<td>12 (50%)</td>
<td>4 (29%)</td>
</tr>
<tr>
<td>Ablation/neuromodulation has a high risk of complications</td>
<td>3 (13%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Ablation/Neuromodulation is still a last-resort treatment in psychiatry</td>
<td>10 (42%)</td>
<td>5 (36%)</td>
</tr>
</tbody>
</table>

5.4.5 Psychiatric Conditions

Respondents were asked to consider the clinical applicability of psychiatric neurosurgery for the treatment of either depression (n = 24) or OCD (n = 13) (Table 5). Functional neurosurgeons overwhelmingly agreed that for either psychiatric condition, neurosurgical interventions are safe. However, opinions significantly diverged when respondents considered medical efficacy and the strength of clinical indications warranting the use of psychiatric neurosurgery for these conditions. All respondents agreed that psychiatric neurosurgery was a medically effective treatment for OCD; however, only two-thirds (67%) agreed that psychiatric neurosurgery for depression was medically effective (odds ratio 0, p = 0.03242, two-sided Fisher’s exact test). In addition, surgeons much more readily supported the clinical justification for using psychiatric neurosurgery as a treatment for OCD (85%) than for depression (33%, odds ratio 0.09775,
p = 0.005137, two-sided Fisher’s exact test). More surgeons considered psychiatric neurosurgery to be a cost-effective treatment for OCD (92%) than for depression (58%), however, this difference was not statistically significant (odds ratio 0.1226, p = 0.05735, two-sided Fisher’s exact test).

Table 5-5 Attitudes towards the use of psychiatric neurosurgery for OCD and depression

<table>
<thead>
<tr>
<th></th>
<th>Depression (n = 24)</th>
<th>OCD (n = 13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supporters (% Agreement)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>For the treatment of depression/OCD, psychiatric neurosurgery is safe</td>
<td>22 (92%)</td>
<td>12 (92%)</td>
</tr>
<tr>
<td>For the treatment of depression/OCD, psychiatric neurosurgery is medically effective</td>
<td>16 (67%)</td>
<td>13 (100%) *</td>
</tr>
<tr>
<td>For the treatment of depression/OCD, psychiatric neurosurgery is cost effective</td>
<td>14 (58%)</td>
<td>12 (92%)</td>
</tr>
<tr>
<td>For the treatment of depression/OCD, psychiatric neurosurgery has clear clinical indications</td>
<td>8 (33%)</td>
<td>11 (85%) *</td>
</tr>
</tbody>
</table>

* p < 0.05

5.4.6 Barriers and Future Predictions

Functional neurosurgeons unanimously agreed that barriers exist for both patients and clinicians when considering the use of psychiatric neurosurgery (Table 6). The potential for adverse effects was endorsed as the most ubiquitous hurdle surrounding psychiatric neurosurgery procedures (97%), followed by similarly strong endorsements of uncertainty about when to resort to surgical methods in neuropsychiatry and the historic misuse of psychosurgery (92%; 92%). Eighty-two percent of all respondents agreed that stigma towards psychiatric disease presented a barrier towards the adoption of these interventions; however, functional neurosurgeons with less experience in the field were more likely than those with more experience to consider stigma to be
an important hurdle (<15 years of experience, 95%; ≥ 15 years of experience, 63%, odds ratio 0.08503, p = 0.02838, two-sided Fisher’s exact test). Future predictions regarding the use of psychiatric neurosurgery were not significantly different among surgeons on the basis of psychiatric neurosurgery practice or experience level within the field (Table 7). Half of all respondents indicated that psychiatric neurosurgery will contribute to a larger component of their own clinical practice in the future, with a non-significant but proportionally larger contribution to this prediction derived from both clinicians who treat psychiatric conditions and less experienced surgeons ([psychiatric practitioners, 63%; non-psychiatric practitioners, 37%], [(<15 years of experience, 64%; ≥ 15 years of experience, 31%]). On a global scale, two-thirds of respondents (n = 25) believed that psychiatric neurosurgery will become more common over time.

Table 5-6 Perceived barriers for patients and clinicians when considering psychiatric neurosurgery

<table>
<thead>
<tr>
<th></th>
<th>Psychiatric Practitioners (n = 19)</th>
<th>Non-Psychiatric Practitioners (n = 19)</th>
<th>≥ 15 Years of Experience (n = 16)</th>
<th>&lt;15 Years of Experience (n = 22)</th>
<th>Total (n = 38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concerns about adverse effects</td>
<td>19 (100%)</td>
<td>18 (95%)</td>
<td>16 (100%)</td>
<td>21 (95%)</td>
<td>37 (97%)</td>
</tr>
<tr>
<td>The historic misuse of psychosurgery</td>
<td>18 (95%)</td>
<td>17 (89%)</td>
<td>15 (94%)</td>
<td>20 (91%)</td>
<td>35 (92%)</td>
</tr>
<tr>
<td>Uncertainty about when psychiatric neurosurgery should be utilized</td>
<td>18 (95%)</td>
<td>17 (89%)</td>
<td>16 (100%)</td>
<td>19 (86%)</td>
<td>35 (92%)</td>
</tr>
<tr>
<td>Reluctance of psychiatrists to refer</td>
<td>18 (95%)</td>
<td>16 (84%)</td>
<td>14 (88%)</td>
<td>20 (91%)</td>
<td>34 (89%)</td>
</tr>
<tr>
<td>Stigma surrounding psychiatric disease</td>
<td>18 (95%)</td>
<td>13 (68%)</td>
<td>10 (63%)</td>
<td>21 (95%)*</td>
<td>31 (82%)</td>
</tr>
<tr>
<td>No barriers exist</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

* p < 0.05
Table 5-7 Future predictions about the prevalence of psychiatric neurosurgery

<table>
<thead>
<tr>
<th></th>
<th>Psychiatric Practitioners (n = 19)</th>
<th>Non-Psychiatric Practitioners (n = 19)</th>
<th>≥ 15 Years of Experience (n = 16)</th>
<th>&lt;15 Years of Experience (n = 22)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatric neurosurgery will be a larger component of my practice in the future</td>
<td>12 (63%)</td>
<td>7 (37%)</td>
<td>5 (31%)</td>
<td>14 (64%)</td>
<td>19 (50%)</td>
</tr>
<tr>
<td>Psychiatric neurosurgery will significantly increase globally in the future</td>
<td>14 (74%)</td>
<td>11 (58%)</td>
<td>9 (56%)</td>
<td>16 (73%)</td>
<td>25 (66%)</td>
</tr>
</tbody>
</table>

5.5 Discussion

The present study provides an up-to-date examination of attitudes, applications and predictions of the use of psychiatric neurosurgery among North American functional neurosurgeons following nearly a decade of continued innovation in the field. Similar to benchmark surveys on this topic, we found that half of respondents engage in some form of psychiatric neurosurgery, predominantly DBS, with an emphasis on the treatment of OCD (Lipsman et al., 2011; Mendelsohn et al., 2013). Recent reports of public aversion towards irreversible, ablative procedures prompted us to inquire about the permissibility and clinical utility of lesioning procedures in modern psychiatric neurosurgery (Cabrera et al., 2018a).

Despite early excitement afforded to DBS as an adjustable, reversible alternative to the more permanent effects of surgical ablation, we found that most respondents reported using at least ablative procedures to varying degrees when treating psychiatric disorders. This proportion is slightly larger than results reported by Lipsman et al. in 2011, and may be attributed to a number of factors alone or in combination: the affordability of lesion therapies over DBS, particularly in the United States, evolutions in Gamma Knife radiosurgery protocols for OCD that have
curtailed instances of adverse events, and by new research interests in MRgFUS as a fast-acting and minimally invasive alternative to other ablative procedures (Hooper et al., 2008; Miguel et al., 2019; Na et al., 2015; Kim et al., 2018).

Functional neurosurgeons in this cohort more readily endorsed psychiatric neurosurgery as a medically effective and clinically indicated treatment for OCD than for depression. This finding may be an artifact of the HDE granted by the FDA in 2009 for the use of DBS in treatment-resistant OCD. Alternatively, it could reflect the scarcity of available non-invasive interventions for refractory OCD. For example, electroconvulsive therapy (ECT), magnetic seizure therapy (MST), and repetitive transcranial magnetic stimulation (rTMS) all represent treatment options for patients with medication-refractory depression, and are often trialed prior to a surgical referral, yet none of these interventions are currently supported as effective treatments for OCD (Lévêque, 2014). Nevertheless, recent results from a clinical trial of deep TMS for refractory OCD, and subsequent FDA approval of this technology, may inspire an expansion of non-invasive neuromodulatory treatment options for this population (Carmi et al., 2018).

Through further questions about psychiatric neurosurgery, we found that functional neurosurgeons consider both ablative and neuromodulatory interventions to have minimal risks and few complications. Nearly all respondents indicated that psychiatric neurosurgery is safe for the treatment of both OCD and depression. Nevertheless, they also signaled that concerns about adverse effects is the most substantial hurdle faced by patients and clinicians when considering psychiatric neurosurgery for medically-refractory patients. This could be interpreted in one of two ways. First, functional neurosurgeons may conceptualize complications as pertaining
exclusively to the act of performing surgery. Given that psychiatric neurosurgery procedures vary from non-psychiatric neurosurgical procedures solely on the basis of target selection and not by underlying techniques, functional neurosurgeons may simply not acknowledge complications from such procedures as being any more prominent than those that accompany all other neurosurgeries. Concerns about adverse effects may then pertain exclusively to a worsening of psychiatric symptoms, as opposed to post-surgical complications such as edema, hemorrhage, or infection. A second interpretation is that surgeons believe that patients are wary of adverse effects when considering psychiatric neurosurgery due to the invasive nature of these procedures in comparison to non-invasive, front-line psychiatric treatments like pharmacology and psychotherapy. While adverse events in neurosurgery are not invariably rare, those that are classified as unpredictable or due to medical errors are exceedingly uncommon, despite what patients and individuals in the community believe (Houkin et al., 2009).

We found that perceptions of stigma as an impediment to electing psychiatric neurosurgery for a treatment-refractory patient varied with respect to neurosurgeon experience level, and by proxy, neurosurgeon age. Stigma ranked among the top three concerns reported by North American- and internationally-based functional neurosurgeons in previous surveys of attitudes towards psychiatric neurosurgery (Lipsman et al., 2011; Mendelsohn et al., 2013.) This finding may lend itself to future research, as little work has been done to examine whether factors like age or professional medical experience alter perceptions of stigma faced by those with mental illness. It is possible that older clinicians may view the stigma surrounding psychiatric illness as less severe now than in earlier time points in their careers. In acknowledging a contemporary change in public attitudes towards mental illness, these physicians may be less likely to endorse stigma
as a prominent hurdle for the modern psychiatric patient. Nevertheless, this hypothesis warrants future research.

Most functional neurosurgeons surveyed do not view psychiatric neurosurgery procedures as last-resort options for mentally-ill patients. In Chapter 3, we reported that members of the public voice mixed opinions about a last-resort designation for psychiatric neurosurgery. On one hand, the public fears a widespread, uncritical adoption of neurosurgery for the treatment of mental illness. On the other, they feel that some front-line treatments in psychiatry, such as medication, can often fail to alleviate a patient’s symptoms in a timely manner. Disease burden is a significant feature of psychiatric illness, and the results of both this survey and those of the public may suggest that timelier interventions are a priority for the humane treatment of the mentally ill.

Half of respondents in this study indicated that some applications of ablative surgery for psychiatric conditions could be unethical, while less than a third maintained this opinion when considering neuromodulatory procedures. While this modality-based difference was not statistically significant, a milder appreciation of the ethical complexity of neuromodulation may be due, in part, to value-laden device features like reversibility and adjustability (Muller, Riedmuller, & Van Oosterhout, 2015). Synofzik and Schlaepfer argue, however, that even though active neuromodulatory interventions like DBS can be easily discontinued, a patients’ psychologic states might not simply fully reverse to a pre-DBS baseline condition after longer periods of treatment (2011). They assert that given the myriad of social, ecological and biological changes that can be induced following DBS implantation, “the assumption that DBS
effects are fully reversible, which is commonly taken as one of the strongest ethical arguments in support of psychiatric DBS, might be both inaccurate and even potentially dangerous” (Synofzik & Schlaepfer, 2011, p. 10). These considerations should not be taken lightly, and future work should address whether the neuroethical implications of DBS are interpreted differently than those of ablative interventions by functional neurosurgeons who administer these procedures.

Finally, predictions regarding the future use of psychiatric neurosurgery in this survey were not as zealous as those captured by Lipsman and colleagues in 2011. It remains a possibility that in the time that has elapsed since the seminal survey by Lipsman and colleagues (2011), functional neurosurgeons in North America have realized other limitations of these procedures. As mentioned above, non-invasive treatments for refractory psychiatric conditions, such as TMS and MST, have also made advances in the past decade, and may present a more favorable option to patients and their treating psychiatrists than neurosurgery. The treatment preferences of psychiatric patients have been extensively explored with respect to psychological and pharmacological monotherapies (McHugh, Whitton, Peckham, Welge, & Otto, 2013); however, in the wake of emerging stimulation-based therapies, an understanding of treatment-refractory patient preferences is lacking. Further research is needed to assess the clinical decision-making preferences of psychiatric patients resistant to front-line therapies as well as the preferences of their treating psychiatrists.

5.6 Limitations

This study has several important limitations. The first stems from the relatively low number of responses. While an exact number of surgeons belonging to the ASSFN at the time of survey
distribution was not available, an estimate of approximately 300 would indicate a response rate of just over 12%. We made several efforts to try to mitigate low response rates, including timing survey distribution to coincide with the ASSFN’s bi-annual conference, issuing an electronic reminder, and designing the survey to be web-compatible with both computer and smartphone interfaces. Nevertheless, and while this number is small, it is consistent with other studies involving physicians (e.g., Cunningham et al., 2015). The possibility also exists that this survey appealed more to functional neurosurgeons who have some experience in performing psychiatric neurosurgery or who hold vested interests in these procedures, leading to an over-representation of such views. However, given that half of the respondents dedicated some portion of their clinical practice to psychiatric conditions and half did not, the opinions of both groups were represented in our results and tended to be quite similar between groups.

Another limitation is the lack of representation of North American countries beyond Canada and the United States, particularly given that functional neurosurgery practice in Mexico has expanded to include interventions for neuropsychiatric conditions over the past few decades (Beltrán & Carrillo-Ruiz, 2019). Future surveys should be aimed at capturing views from a more geographically and culturally diverse population. Finally, while members of the ASSFN are predominantly stereotactic and functional neurosurgeons, other members include but are not limited to psychiatrists, neurologists, and neuropsychologists. This survey was targeted towards clinicians who are trained in and practice as functional neurosurgeons, however; it is possible that non-functional neurosurgeon members of the ASSFN completed this survey. For this reason, we did not include responses from partially-completed surveys in the analysis presented.
5.7 Conclusion

In this study, we surveyed functional neurosurgeons in North America to assess current views towards the role of neurosurgery in the treatment of psychiatric conditions, given the rapid changes in this field over the last several years. Ablative surgery continues to play an important role in the renaissance of psychiatric neurosurgery from the perspective of neurosurgeons, despite reported aversion to it by the public. Medical and social barriers have persisted throughout the last decade that may continue to limit the accessibility of these procedures to those in need. Given the potential benefits of these interventions for patients with treatment-refractory conditions, increased public education efforts and continued innovation in the field of psychiatric neurosurgery, with proper ethical oversight, is an imperative.
Chapter 6: Conclusion

6.1 Synopsis

Following the introduction of lobotomy to the United States in the mid-1930s, Portuguese neurologist and lobotomy creator Egas Moniz warned an opportunistic Walter Freeman that “the psychiatric doctors professing the classic and psychological school that divorced the mind from the brain … will have a certain resistance to [your] organic orientation, for a long time” (Moniz, 1936, as quoted in El-Hai, 2005). Indeed, this tension between biological and psychological conceptualizations of mental illness persists today. The last half century has borne transformational advances in the neurosciences, neuroimaging, and surgical technologies, which have aided in this dissociation, setting the stage for a resurgence of medical interest in surgical techniques for the treatment of severe psychiatric conditions. History has shown, however, that fear and skepticism on the one hand, and overly optimistic views on the other, can stifle both scientific progress and safe translation of potentially promising therapeutics (Lauber et al., 2005; Valenstein, 1986). In this thesis, I explored the present-day attitudes of members of the public, the media, and the medical community regarding the renaissance of psychiatric neurosurgery and the social and ethical implications inherent in its practice.

The social relevance of contemporary psychiatric neurosurgical techniques is reflected in the increased circulation of mass media reports about these interventions, as well as through online public discourse prompted by media exposure (Cabrera et al., 2018b, 2018a; Cabrera, Brandt, McKenzie, & Bluhm, 2019). In addition, functional neurosurgeons have expressed hope for
continued innovation on this front, predicting that the practice of psychiatric neurosurgery will only expand over time (Lipsman et al., 2011; Mendelsohn et al., 2013).

### 6.2 Integrating Perspectives

These studies revealed that members of the public in Canada, Germany and Spain were attuned to the preservation of autonomy and authenticity in patients who are candidates for psychiatric neurosurgery. In contrast, divided opinions surfaced regarding the last resort designation of these procedures among members of the public and functional neurosurgeons, who furthermore proposed that ablative surgical techniques should continue to play an important role in both investigational and therapeutic applications of psychiatric neurosurgery. Journalists maintained that media coverage of psychiatric neurosurgery should seek to highlight both the benefits and potential risks of these interventions and acknowledged the complexities of writing for and about vulnerable patient populations. Overall, mental health stigma and a cautionary carry-over from the history of psychosurgery were salient concerns of all stakeholder groups and support the continuation of public and interdisciplinary engagement efforts to define and develop ethically responsible and socially acceptable innovations in the field of psychiatry.

### 6.3 Future Directions

The exploratory nature of the studies presented in this thesis encourages future refinements and expansions of research aims. To accommodate a wider range of cross-cultural views, future work within these stakeholder groups should seek to move beyond a Western-centric model of inquiry. Indeed, Specker Sullivan (2019) argues that, axiologically, the preservation of an authentic self is incompatible with Buddhist philosophies that reject the existence of a permanent or engrained
self. It can thus be speculated that Eastern cultural values may provide very different perceptions of psychiatric neurosurgery than those that I have presented in Chapter 3.

The work presented in Chapter 4 may inspire future inquiry into the experiences of journalists who elect to include or exclude normative content in their press coverage of scientific and medical innovations. Results could eventually help align the interests of ethicists, scientists and journalists who all engage in distinct information synthesis processes for public audiences (O’Connor, Rees, & Joffe, 2012). In addition, critical clinical perspectives relevant to the re-emergence of psychiatric neurosurgery should not be limited to those of functional neurosurgeons alone (Nuttin et al., 2014). Future studies should investigate the values and interdisciplinary dynamics of all clinical neuroscientists, including, but not limited to, psychiatrists, neurologists, and neuropsychologists, who all uniquely contribute to advancing psychiatric patient care at the mind-brain interface. Finally, the continued inclusion of patient populations in the refinement and development of novel interventions in psychiatry is essential to support advanced and truly ethical innovation along this frontier.
Bibliography


Illes, J. (2007). Empirical neuroethics: Can brain imaging visualize human thought? Why is neuroethics interested in such a possibility? *EMBO Reports, 8*(1S), S57–S60. https://doi.org/10.1038/sj.embor.7401007


https://doi.org/10.1080/2326263X.2016.1207497


Appendices

Appendix A  Recruitment Materials

A.1  Vancouver Focus Groups Print Advertisement

NEW WAYS TO TREAT MENTAL HEALTH DISORDERS

ARE YOU 18 YEARS OR OLDER AND INTERESTED IN TREATMENTS FOR MENTAL HEALTH CONDITIONS?

WE WOULD LIKE TO FIND OUT WHAT YOU THINK ABOUT THE USE OF NEUROSURGERY TO TREAT MENTAL HEALTH DISORDERS.

PARTICIPATION WILL INVOLVE ABOUT TWO HOURS OF YOUR TIME IN A COMMUNITY CONVERSATION AS A PART OF A RESEARCH STUDY.

REFRESHMENTS WILL BE PROVIDED AND YOU WILL RECEIVE A $25 GIFT CARD FOR PARTICIPATING.

NOV 20-21

1 ATHLETES WAY, VANCOUVER, BC V5Y 0B1

FOR MORE INFORMATION ABOUT THE STUDY AND TO SEE IF YOU ARE ELIGIBLE TO PARTICIPATE, PLEASE CONTACT:

HAYAMI LOU, RESEARCH ASSISTANT
PHONE: 
EMAIL: 

AND/OR VISIT:
HTTP://NEUROETHICSCANADA.CA/OPPORTUNITIES/ERANETCOMMS/

PRINCIPAL INVESTIGATOR: DR. JUDY ILLES
PROFESSOR, DEPARTMENT OF NEUROLOGY
UNIVERSITY OF BRITISH COLUMBIA
DE NOUVELLES FAÇONS DE TRAITER LES TROUBLES DE SANTÉ MENTALE

Vous avez plus de 18 ans, vous êtes francophone et vous êtes intéressés par les traitements pour les troubles de santé mentale?

Nous aimerions savoir votre point de vue sur l'utilisation de la neurochirurgie pour traiter les troubles mentaux.

La participation dure environ 2 heures et se compose d'un groupe de discussion dans le cadre d'une étude de recherche. Les séances auront lieu au centre-ville de Montréal.

Nous vous fournirons des rafraîchissements et vous recevrez une compensation pour votre participation.

28 JUIN, 2018 · 17H30-19H00
29 JUIN, 2018 · 12H00-13H30

Pour plus d'infos sur l'étude et pour voir si vous êtes admissible à participer, SVP contactez Caitlin Courchesne, étudiante en doctorat:

T: [phone number] · C: [phone number]
http://neuroethicscanada.ca/opportunities

Vérifiez votre admissibilité: scannez ce code QR
Probanden gesucht für Studie zur öffentlichen Wahrnehmung der psychiatrischen Neurochirurgie

Interessieren Sie sich für die Forschung zu psychiatrischen Behandlungsmöglichkeiten?


Die Sitzungen finden an der Charité - Universitätsklinik Berlin in Berlin Mitte statt. Erfrischungsgetränke werden bereitgestellt und Sie erhalten eine Aufwandsentschädigung in Höhe von 20 Euro.

Termine
Gruppendiskussion 1: Datum, Uhrzeit, Ort
Gruppendiskussion 2: Datum, Uhrzeit, Ort
Gruppendiskussion 3: Datum, Uhrzeit, Ort

Teilnahmevereuroaussetzungen: mindestens 18 Jahre alt und Deutschkenntnisse auf muttersprachlichem Niveau. Für weitere Informationen über diese Studie kontaktieren Sie bitte:

Merlin Bittlinger, M.A., Wissenschaftlicher Mitarbeiter
E-Mail: PNS@charite.de
(Please hinterlassen Sie uns bei Interesse Ihre Telefonnummer und einen Terminvorschlag für unseren Rückruf.)

Diese Studie wurde von der Ethikkommission der Charité begutachtet und genehmigt.

Version 1: June 15, 2017
A.4 Madrid Focus Groups Print Advertisement

SE BUSCAN PARTICIPANTES PARA PROYECTO DE INVESTIGACIÓN SOBRE COMO SE PERCIBE SOCIALMENTE LA NEUROCIRUGÍA PSQUIÁTRICA

¿Eres mayor de 18 años de edad y estás interesado en los tratamientos para las condiciones de salud mental?

Nos gustaría saber que piensas acerca del uso de la neurocirugía para tratar trastornos de salud mental. La participación implicará dos horas de tu tiempo en una conversación comunitaria.

Las sesiones tendrán lugar en [Madrid].
Se ofrecerá un refrigerio y recibirás una tarjeta de regalo con un valor de $[25CAN] por participar.

Conversación Comunitaria 1: Fecha Hora Lugar
Conversación Comunitaria 2: Fecha Hora Lugar
Conversación Comunitaria 3: Fecha Hora Lugar

Para más información sobre el estudio y para ver si eres candidato/ta para participar, por favor contactar:

Laura Cabrera, Project Leader
Phone: XXX XXX XXX
Email: [redacted]

Este estudio ha sido revisado y aprobado por el Comité de Ética universidad Estatal de Michigan.
Psychiatric Neurosurgery – Ethical, Legal, and Societal Issues

VIA EMAIL

Dear [Journalist],

We are contacting you about a study we are conducting on media coverage of psychiatric neurosurgery. The study aims to uncover themes about how reporting about re-emergent and new procedures informs both the public and affected individuals with mental health conditions, the perceptions they hold, and decisions they make.

We are contacting you because you are a journalist who has published on psychiatric neurosurgery interventions or related topics. Your participation will involve a short (about 30 min) audio-recorded interview conducted in person or by telephone or Skype.

If you are interested in participating, please reply to this email or contact the Research Assistant, Caitlin Courchesne at caitlin.courchesne@ubc.ca so we can send you the consent form and arrange a time for your interview. The Principal Investigator, Dr. Judy Illes, Professor of Neurology and Canada Research Chair in Neuroethics at UBC, will conduct the interview.

By not replying to this email or contacting the Research Assistant you are opting out of further contact. We will not contact you again.

We know you are busy but hope you will be able to take a few minutes of your time to answer our questions. Thank you in advance for your generosity toward the success of this project.

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For questions or additional information, please contact the Research Assistant, Caitlin Courchesne by e-mail at caitlin.courchesne@ubc.ca or by phone at [number]
Appendix B  Consent Forms

B.1  Vancouver Focus Groups Consent Form

Psychiatric Neurosurgery – Ethical, Legal, and Societal Issues

Consent Form

Principal Investigator:  Judy Illes, PhD, FRSC, FCAHS
Canada Research Chair in Neuroethics
Professor of Neurology
University of British Columbia
Phone: [redacted]

Faculty:  Laura Cabrera, MA, PhD
Faculty Affiliate, National Core for Neuroethics

Sponsor:  CIHR

Contact Person:  Hayami Lou
Research Assistant
Phone: [redacted]
Email: [redacted]

PURPOSE
You are being asked to participate in a study that is designed to explore perceptions and attitudes about psychiatric neurosurgery across three different countries. The results of this research will bring awareness about the hopes, concerns and expectations around these interventions towards better care of patients with mental health disorders.

PSYCHIATRIC NEUROSURGERY
Psychiatric neurosurgery uses a surgical approach to try to treat mental health disorders in people who have not benefitted from other treatments such as behavioral or drug therapy. Some methods use electrical signals to stimulate the brain; others use procedures to remove small amounts of brain tissue. In the 1970s, the use of psychiatric neurosurgery was nearly stopped completely because of complications and public concerns about abuses. Today, thanks to advances in medicine, the procedures are much safer and more precise than before.
WHO IS CONDUCTING THE STUDY?
The study is being conducted by researchers at the National Core for Neuroethics at the University of British Columbia (UBC).

WHO CAN PARTICIPATE IN THIS STUDY?
You can participate in this study if you are:
18 years of age or older and interested in psychiatric neurosurgery
able to converse in English

WHAT DOES THE STUDY INVOLVE?
If you consent to participate and return this signed consent form, the Research Assistant will contact you to schedule your participation in a community conversation about:
Your knowledge about psychiatric neurosurgery
Your attitudes and perceptions about psychiatric neurosurgery
Your concerns about psychiatric neurosurgery

The community conversation will be audio recorded. Confidentiality of this community conversation will be protected to every extent possible, as described below. The total time for participation will be about 2 hours. During the first part of the community conversation the research team will present an overview on the topic at hand and answer any questions that might remain in the group. After that, the research team will present some initial questions to start the conversation. The sessions will take place in Vancouver.

Taking part in this study is entirely your choice. You have the right to refuse to participate in this study. If you decide to take part, you may choose to withdraw at any time without giving a reason.

STUDY RESULTS
After the study is finished, the results will be accessible on the National Core for Neuroethics website, http://neuroethicscanada.ca. Results will also be shared through publications in peer-reviewed academic journals and presentations at conferences and scholarly meetings. If you wish to receive a summary of the results after it is completed, please initial here ____________.

POSSIBLE HARMS AND BENEFITS OF PARTICIPATING
There are no known risks to participating. You may decline to answer any questions you do not wish to answer during the community conversation. While participation in this study does not have any direct benefits, indirect benefits may include gaining a clearer understanding of psychiatric neurosurgery interventions and of the ethical issues surrounding them.

PAYMENT FOR TAKING PART IN THIS RESEARCH STUDY
You will be paid $25 CAD in a gift certificate after completing the community conversation. Refreshments will be provided. If you leave early, you will be compensated for the amount of time you participated.
CONFIDENTIALITY OF PARTICIPATION IN THIS STUDY
Your confidentiality will be respected. A number will be used to identify study participants. The audio recordings will be transcribed into written form for analysis. No names will appear on the recordings or typed transcripts. Both the recordings and the transcripts will be kept on an encrypted and password-protected computer file or in locked filing cabinets in secured offices at the National Core for Neuroethics at UBC. The recordings and transcriptions will be kept at UBC for at least 5 years from the time of publication of the results of the study. After this period, the paper forms will be shredded and any electronic records with raw data destroyed. No names will be used in any published and written findings resulting from the study. We encourage all participants to refrain from disclosing the contents of the discussion outside of the community conversation, but we cannot control what other participants do with the information discussed.

CONTACT FOR QUESTIONS ABOUT THE STUDY
If you have any concerns or questions about this study, you may contact the principal investigator, Dr. Judy Illes at ____________

If you have any concerns or complaints about your rights as a research participant and/or your experience while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 604-822-8598, by email at RSIL@ors.ubc.ca, or call toll-free to 1-877-822-8598.

SUBJECT CONSENT TO PARTICIPATE
By signing this form, you acknowledge that you have been fully informed about the procedures to be followed and have been given a description of the risks, and benefits to be expected. By signing this consent form, you agree to having the community conversation digitally recorded and understand that you are free to withdraw from the study at any time, without giving a reason.

Your signature indicates that you have read and understood the above information, received a copy of this consent form for your own records, and that you have decided to participate based on the information provided.

Participant’s Signature ______________________ Date ____________

Printed Name of the Participant ______________________
Signing Above ______________________
B.2 Montreal Focus Groups Consent Form

FORMULAIRE D’INFORMATION ET DE CONSENTEMENT

Titre du projet de recherche : Neurochirurgie Psychiatrique – Questions d’ordre éthique, juridique et sociétale

Chercheur responsable du projet de recherche :
Eric Racine, Ph.D.
Directeur, unité de recherche en neuroéthique
Professeur titulaire de recherche IRCM
Professeur chercheur agrégé, Département de médecine (accréditation en médecine sociale et préventive / bioéthique), Université de Montréal
Professeur associé, Département de médecine (Division de médecine expérimentale) et Département de neurologie et de neurochirurgie, Université McGill
Téléphone :

Co-chercheur(s) :
Judy Illes, Ph. D., FRSC, FCAHS
Chaire de recherche du Canada en neuroéthique
Professeure de neurologie
Université de Colombie-Britannique
Directrice, la Neuroéthique
Téléphone :

Laura Cabrera, MA, Ph. D.
Affiliation de la faculté, la Neuroéthique

Caitlin Courchesne, B.Sc.
Étudiante au doctorat
Faculté de médecine
Université de Colombie-Britannique

Personne à contacter :
Caitlin Courchesne
Téléphone :
Courriel :

Organisme subventionnaire : IRSC
PRÉAMBULE

Nous vous invitons à participer à une étude conçue pour explorer les perceptions et les attitudes à l'égard de la neurochirurgie psychiatrique dans trois pays différents. Les résultats de cette recherche permettront de mieux connaître les espoirs, les préoccupations et les attentes concernant ces interventions en vue d'améliorer les soins aux patients atteints de troubles mentaux.

NATURE ET OBJECTIFS DU PROJET DE RECHERCHE

La neurochirurgie psychiatrique utilise une approche chirurgicale pour tenter de traiter les troubles de la santé mentale chez les personnes qui n'ont pas bénéficié de d'autres traitements tels que la thérapie comportementale ou la pharmacothérapie. Certaines méthodes utilisent des signaux électriques pour stimuler le cerveau; d'autres utilisent des procédures pour éliminer de petites quantités de tissu cérébral. Dans les années 1970, l'utilisation de la neurochirurgie psychiatrique a été presque complètement arrêtée en raison des complications et des préoccupations du public concernant les abus. Aujourd'hui, grâce aux progrès de la médecine, les procédures sont beaucoup plus sûres et plus précises qu'autrefois.

Notre objectif primordial est de découvrir des thèmes, des tendances et des valeurs transnationales autour de l'utilisation de différentes procédures de neurochirurgie psychiatrique.

Pour la réalisation de ce projet de recherche transnationale, nous comptons recruter entre 64 et 96 participants, hommes et femmes, âgés 18 ans ou plus, dont 16 à 24 à l’IRCM.

DÉROULEMENT DU PROJET DE RECHERCHE

Ce projet de recherche se déroulera à l’IRCM (Montréal), l'Université de la Colombie-Britannique (Vancouver), Charité Universitätsmedizin (Berlin), et Hospital Ruber Internacional (Madrid).

NATURE DE LA PARTICIPATION DEMANDÉE

Si vous consentez à participer et renvoyez ce formulaire de consentement signé, l'assistant de recherche vous contactera pour planifier votre participation à une conversation communautaire sur :

• Vos connaissances sur la neurochirurgie psychiatrique
• Vos attitudes et vos perceptions sur la neurochirurgie psychiatrique
• Vos préoccupations concernant la neurochirurgie psychiatrique

La conversation communautaire sera enregistrée sous forme audio. La confidentialité de cette conversation communautaire sera protégée par tous les moyens possibles, comme décrit ci-dessous. Le temps total de la participation sera d'environ 2 heures. Au cours de la première partie de la conversation communautaire, l'équipe de recherche présentera un aperçu du sujet en question et répondra aux questions qui pourraient subsister dans le groupe. Après cela, l'équipe de recherche présentera quelques questions initiales pour commencer la conversation. Les séances auront lieu à Montréal.
RISQUES ET INCONVÉNIENTS
Participer à cette étude est entièrement votre choix. Vous avez le droit de refuser de participer à cette étude. Si vous décidez de participer, vous pouvez choisir de vous retirer à tout moment sans donner de justifications. Il n'y a aucun risque connu de participer. Vous pouvez refuser de répondre à toutes les questions que vous ne souhaitez pas répondre lors de la conversation communautaire.

AVANTAGES
Vous ne retirerez aucun bénéfice personnel de votre participation à ce projet de recherche. Par ailleurs, les résultats obtenus contribueront à l’avancement des connaissances scientifiques dans ce domaine de recherche.

CONFIDENTIALITÉ
Durant votre participation à ce projet de recherche, le chercheur responsable de ce projet ainsi que les membres de son personnel de recherche recueilleront, dans les enregistrements audio, les renseignements vous concernant et nécessaires pour répondre aux objectifs scientifiques de ce projet de recherche.


Les enregistrements et les transcriptions seront conservés à l'Université de la Colombie-Britannique pendant au moins 5 ans à partir du moment de la publication des résultats de l'étude. Après cette période, les formulaires en papier seront déchiquetés et les enregistrements électroniques contenant des données brutes seront détruits. Si vous choisissez de vous retirer de l'étude lors de la conversation communautaire, vos données seront détruites après la transcription, avec seulement le sens général de vos interactions avec d'autres personnes dans le groupe maintenu pour la cohérence. Si les données ont déjà été analysées, elles ne peuvent être retirées car elles seront anonymes et nous ne pourrons vous connecter à vos contributions de groupe.

Aucun nom ne sera utilisé dans les résultats publiés et écris de l'étude. Nous encourageons tous les participants à s'abstenir de divulguer le contenu de la discussion à l’extérieur de la conversation communautaire, mais nous ne pouvons pas contrôler ce que les autres participants font avec les informations discutées.

Les données de recherche pourront être publiées ou faire l’objet de discussions scientifiques, mais il ne sera pas possible de vous identifier.

COMMUNICATION DES RÉSULTATS GÉNÉRAUX
Une fois l'étude terminée, les résultats seront accessibles sur le site web de Neuroéthique, http://neuroethicscanada.ca. Les résultats seront partagés par le biais de publications dans des revues académiques, des présentations à des conférences et réunions académiques.
FINANCEMENT DU PROJET DE RECHERCHE
Le chercheur responsable de ce projet de recherche et l’établissement ont reçu un financement de l’organisme subventionnaire (IRSC) pour mener à bien ce projet de recherche.

COMPENSATION
Vous recevrez un certificat-cadeau de 25 $ CAD après avoir terminé la conversation communautaire. Des collations et boissons seront servies. Si vous partez tôt, la compensation sera proportionnelle à la durée de votre participation.

EN CAS DE PRÉJUDICE
Si vous deviez subir quelque préjudice que ce soit dû à votre participation au projet de recherche, vous recevrez tous les soins et services requis par votre état de santé.

En acceptant de participer à ce projet de recherche, vous ne renoncez à aucun de vos droits et vous ne libérez pas le chercheur responsable de ce projet de recherche, IRSC et l’établissement de leurs responsabilités civile et professionnelle.

PARTICIPATION VOLONTAIRE ET DROIT DE RETRAIT
Votre participation à ce projet de recherche est volontaire. Vous êtes donc libre de refuser d’y participer. Vous pouvez également vous retirer de ce projet à n’importe quel moment, sans avoir à donner de raison, en informant l’équipe de recherche.

Si vous vous retirez du projet ou êtes retiré du projet, l’information et le matériel déjà recueillis dans le cadre de ce projet seront néanmoins conservés, analysés ou utilisés pour assurer l’intégrité du projet.

Toute nouvelle connaissance acquise durant le déroulement du projet qui pourrait avoir un impact sur votre décision de participer à ce projet vous sera communiquée rapidement.

IDENTIFICATION DES PERSONNES-RESSOURCES
Si vous avez des questions ou éprouvez des problèmes en lien avec le projet de recherche, ou si vous souhaitez vous en retirer, vous pouvez communiquer avec le chercheur principal local, Dr Eric Racine, au [numéro de téléphone].

Pour toute question concernant vos droits en tant que participant à ce projet de recherche ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec le Commissaire local aux plaintes et à la qualité des services du CHUM au numéro 514-890-8484.

SURVEILLANCE DES ASPECTS ÉTHIQUES DU PROJET DE RECHERCHE
Le Comité d’éthique de la recherche de l’IRCM a approuvé le projet et en assura le suivi.
SIGNATURE

Titre du projet de recherche : Neurochirurgie Psychiatrique – Questions d’ordre éthique, juridique et sociétale

Signature du participant

J’ai pris connaissance du formulaire d’information et de consentement. On m’a expliqué le projet de recherche et le présent formulaire d’information et de consentement. On a répondu à mes questions et on m’a laissé le temps voulu pour prendre une décision. Après réflexion, je consens à participer à ce projet de recherche aux conditions qui y sont énoncées.

Nom du participant 

Date 

Signature

Signature de la personne qui obtient le consentement

J’ai expliqué au participant le projet de recherche et le présent formulaire d’information et de consentement et j’ai répondu aux questions qu’il m’a posées.

Nom de la personne qui obtient le consentement 

Date 

Signature

Engagement du chercheur responsable

Je certifie qu’on a expliqué au participant le présent formulaire d’information et de consentement, que l’on a répondu aux questions qu’il avait.

Je m’engage, avec l’équipe de recherche, à respecter ce qui a été convenu au formulaire d’information et de consentement et à en remettre une copie signée et datée au participant.

Éric Racine 

Nom du chercheur responsable 

Date 

Signature
B.3 Berlin Focus Groups Consent Form

CharitéCentrum für Neurologie, Neurochirurgie und Psychiatrie
Charité | Campus Charité-Mitte | Charitéplatz 1, 10117 Berlin
PD Dr. phil. Dipl.-Phys. Sabine Müller
Charité – Universitätsmedizin Berlin
Klinik für Psychiatrie und Psychotherapie CCM
Charitéplatz 1
10117 Berlin
Tel: 1234567
Fax: 12345678
Email: PNS@charite.de

Psychiatrische Neurochirurgie – ethische, rechtliche und soziale Aspekte

Projektleitung: PD Dr. phil. Dipl.-Phys. Sabine Müller
Charité – Universitätsmedizin Berlin
Klinik für Psychiatrie und Psychotherapie CCM
E-Mail: munz@

Mitarbeiter: Merlin Bittlinger
Wissenschaftlicher Mitarbeiter
Charité – Universitätsmedizin Berlin
Klinik für Psychiatrie und Psychotherapie CCM
E-Mail: munz@

Sponsor: Bundesministerium für Bildung und Forschung

Kontakt: Merlin Bittlinger
E-Mail: pns@charite.de

Einwilligungserklärung

Ziel der Studie

Wer führt die Studie durch?
Die Studie wird von Wissenschaftlern der Charité – Universitätsmedizin Berlin durchgeführt. Entsprechende Gruppendifskussionen in Kanada und Spanien werden durch Wissenschaftler der
University of British Columbia (Vancouver und Montreal) und des Hospital Ruber Internacional (Madrid) durchgeführt.

**Wer kann an der Studie teilnehmen?**
Sie können an der Studie teilnehmen, wenn Sie:
- mindestens 18 Jahre alt sind
- sich in deutscher Sprache unterhalten können (muttersprachliches Niveau)

**Was beinhaltet die Studienteilnahme?**
Wenn Sie einwilligen an der Studie teilzunehmen, laden wir Sie zu einer Gruppendiskussion ein, für die wir Sie bitten:
- Ihr Wissen, Ihre Wahrnehmung und Einstellung zu der psychiatrischen Neurochirurgie mitzuteilen
- Ihre Erwartungen zum möglichen Nutzen sowie Ihre Bedenken zu dieser Forschung zu äußern.

Die Gruppendiskussion wird zur wissenschaftlichen Auswertung auf Tonband aufgezeichnet. Die Gesamtdauer der Studienteilnahme beträgt ca. 80 Minuten.

Wenn Sie sich entscheiden an dieser Studie teilzunehmen, können Sie Ihre Teilnahme jederzeit ohne Nennung von Gründen formlos wiederrufen.

**Was passiert mit den Studienergebnissen und Ihren Daten?**
Nach Beendigung der Studie werden die Ergebnisse in einer wissenschaftlich begutachteten Fachzeitschrift (Peer Review) veröffentlicht sowie auf wissenschaftlichen Konferenzen und Projekt treffen präsentiert.
Sie können gerne eine Zusammenfassung der Ergebnisse per E-Mail erhalten. Kreuzen Sie bitte das Zutreffende an:

☐ Ja, ich möchte eine Zusammenfassung der Studienergebnisse an meine E-Mail-Adresse erhalten.
☐ Nein, ich verzichte auf den Erhalt der Studienergebnisse als E-Mail.

Um Ihre Diskretion zu wahren, werden Ihre Daten streng vertraulich behandelt und pseudonymisiert ausgewertet. Die Tonaufnahme wird in Schriftform transkribiert ohne die Verwendung Ihres Namens, Anschrift oder Kontaktdaten. Die Tonaufnahme wird nach der Transkription gelöscht. Die Abschrift wird auf einem verschlüsselten und passwortgeschützten PC oder einer verschlüsselten und passwortgeschützten externen Festplatte der Charité für maximal 10 Jahre gespeichert und danach vernichtet. Zur Publikation der Ergebnisse werden keine Daten verwendet, die Rückschlüsse auf die Identität Ihrer Person erlauben würden (Name, Anschrift, E-Mail, Telefonnummer, etc.).

**Möglicher Schaden und Nutzen durch eine Studienteilnahme**
Es sind keine durch die Teilnahme entstehenden Risiken bekannt. Sie können jederzeit ablehnen, eine bestimmte oder mehrere Fragen zu beantworten.
Aufwandsentschädigung
Wenn Sie die volle Zeit an der Studie teilnehmen, erhalten Sie eine Aufwandsentschädigung in Höhe von 20 Euro für die investierte Zeit.

Kontakt für Rückfragen zu der Studie
Sollten Sie irgendwelche Rückfragen zu der Studie haben, kontaktieren Sie uns gern (pns@charite.de).

Schriftliche Einwilligung

Hiermit erkläre ich,
Name: 
Vorname: 
Anschrift: 
Geburtsdatum: 
dass ich durch Herrn/Frau
Ich bin bereit, an der wissenschaftlichen Untersuchung im Rahmen der o.g. Studie teilzunehmen.

2. Einwilligungserklärung zur Datenerhebung- und Datenverarbeitung

Ich erkläre mich damit einverstanden, dass im Rahmen dieser Studie mich betreffende personenbezogene Daten/Angaben erhoben und pseudonymisiert auf elektronischen Datenträgern aufgezeichnet und verarbeitet werden dürfen. Ich bin auch damit einverstanden, dass die Studienergebnisse in anonymer Form, die keinen Rückschluss auf meine Person zulassen, veröffentlicht werden.

Berlin, den 

(Unterschrift des/der Versuchsteilnehmer/in)

Hiermit erkläre ich, den/die o.g. Teilnehmer/in am _________ über Wesen, Bedeutung, Tragweite und Risiken der o.g. Studie mündlich und schriftlich aufgeklärt und ihm/ihr eine Ausfertigung der Information sowie dieser Einwilligungserklärung übergeben zu haben.

Berlin, den 

(Unterschrift des/der aufklärenden Wissenschaftlers/in)
Neurocirugía Psiquiátrica - Asuntos Éticos, Jurídicos y Sociales

Formulario de consentimiento

Investigator Principal: Judy Illes, PhD, FRSC, FCAHS
Cátedra de Investigación de Neuroética de Canadá
Profesor de Neurología
Universidad de Columbia Británica
Teléfono: 

Co-investigador: Laura Cabrera, MA, PhD
Afiliado de la facultad, National Core for Neuroethics

Sponsor: CIHR

Persona de contacto: Laura Cabrera, MA, PhD
Afiliado de la facultad, National Core for Neuroethics
Correo electrónico: 

PROPÓSITO
Se le pide participar en un estudio que está diseñado para explorar las percepciones y actitudes acerca de la neurocirugía psiquiátrica en tres países diferentes. Los resultados de esta investigación darán a conocer las preocupaciones, esperanzas y expectativas en torno a estas intervenciones con el fin de mejorar la atención de los pacientes con trastornos de salud mental.

NEUROCIRUGÍA PSIQUIÁTRICA
La neurocirugía psiquiátrica utiliza un enfoque quirúrgico para intentar tratar los trastornos de salud mental en personas que no se han beneficiado de otros tratamientos como la psicoterapia o la terapia con fármacos. Algunos métodos utilizan señales eléctricas para estimular el cerebro; otros usan procedimientos para remover o destruir pequeñas cantidades de tejido cerebral. En la década de 1970, el uso de la neurocirugía psiquiátrica fue casi detenido completamente debido a las complicaciones y las preocupaciones del público sobre sus abusos. Hoy en día, gracias a los avances en medicina, los procedimientos son mucho más seguros y precisos que antes.

¿QUIÉN ESTÁ REALIZANDO EL ESTUDIO?
El estudio está siendo realizado por investigadores del National Core for Neuroethics de la Universidad de Columbia Británica (UBC) y de la Universidad Estatal de Michigan (MSU).
¿QUIÉN PUEDE PARTICIPAR EN ESTE ESTUDIO?
Puede participar en este estudio si usted:
• es mayor de 18 años de edad y está interesado en el tema de neurocirugía psiquiátrica
• es capaz de conversar en español

¿QUÉ INVOLUCRARÁ EL ESTUDIO?
Si usted acepta participar y devuelve este formulario de consentimiento firmado, el Asistente de Investigación se comunicará con usted para programar su participación en una conversación comunitaria sobre:
• Sus conocimientos sobre neurocirugía psiquiátrica
• Sus actitudes y percepciones sobre la neurocirugía psiquiátrica
• Sus preocupaciones acerca de la neurocirugía psiquiátrica
La conversación comunitaria será grabada en audio. La confidencialidad de esta conversación comunitaria estará protegida en la medida de lo posible, como se describe a continuación. El tiempo total de participación será de aproximadamente 2 horas. Durante la primera parte de la conversación comunitaria, el equipo de investigación presentará una visión general sobre el tema en cuestión y responderá cualquier pregunta que pudiera permanecer en el grupo. Después de eso, el equipo de investigación presentará algunas preguntas iniciales para iniciar la conversación. Las sesiones tendrán lugar en Madrid.

Participar en este estudio es enteramente su elección. Usted tiene el derecho de negarse a participar en este estudio. Si usted decide tomar parte, puede optar por retirarse en cualquier momento sin dar razón alguna.

RESULTADOS DEL ESTUDIO
Una vez finalizado el estudio, los resultados estarán disponibles en el sitio web del Nacional Core for Neuroethics (Nucleeo Nacional para la Neuroética), http://neuroethicscanada.ca. Los resultados también serán compartidos a través de publicaciones en revistas académicas revisadas por pares y presentaciones en conferencias y reuniones académicas. Si desea recibir un resumen de los resultados cuando el estudio sea completarlo, escriba aquí sus iniciales ____________.

POSIBLES DAÑOS Y BENEFICIOS DE PARTICIPAR
Su participación no conlleva a ningún riesgo conocido. Puede negarse a contestar cualquier pregunta que no quiera responder durante la conversación comunitaria. Aunque la participación en este estudio no tiene ningún beneficio directo, los beneficios indirectos pueden incluir una comprensión más clara de las intervenciones de neurocirugía psiquiátrica y de las cuestiones éticas que las rodean.

PAGO PARA PARTICIPAR EN ESTE ESTUDIO DE INVESTIGACIÓN
Se le pagará el equivalente de $ 25 CAD en un certificado de regalo después de completar la conversación comunitaria. Se ofrecerá un refrigerio. Si usted se retira antes de que el estudio sea completado, será compensado por la cantidad de tiempo en la que participo.

CONFIDENCIALIDAD DE LA PARTICIPACIÓN EN ESTE ESTUDIO
Su confidencialidad será respetada. Se utilizará un número para identificar a los participantes del estudio. Las grabaciones de audio serán transcritas en forma escrita para su análisis. No
aparecerán nombres en las grabaciones o transcripciones mecanografiadas. Tanto las grabaciones como las transcripciones se mantendrán en un archivo de computadora encriptado y protegido con contraseña o en archivadores cerrados en oficinas aseguradas en la Universidad Estatal de Michigan (MSU). Las grabaciones y transcripciones se mantendrán en MSU durante al menos 5 años a partir de la publicación de los resultados del estudio. Después de este período, los formularios de papel se triturarán y se destruirán todos los registros electrónicos con datos. No se utilizarán nombres en ningún resultado publicado como parte de este estudio. Animamos a todos los participantes a que se abstengan de revelar el contenido de la discusión fuera de la conversación comunitaria, sin embargo no podemos controlar lo que otros participantes hagan con la información discutida.

CONTACTO PARA PREGUNTAS SOBRE EL ESTUDIO
Si tiene preguntas, inquietudes o quejas sobre esta encuesta, comuníquese con la Dra. Laura Cabrera a través del siguiente correo electrónico: laura.cabrera@hc.msu.edu. Si tiene preguntas o inquietudes sobre su papel y sus derechos como participante en la investigación, desea obtener información o sugerencias o desea registrar una queja sobre este estudio, puede ponerse en contacto de forma anónima si lo desea con el Programa de Protección de la Investigación de la Universidad Estatal de Michigan al 517-355-2180, Fax 517-432-4503, o correo electrónico irb@msu.edu o correo regular en 4000 Collins Rd, Suite 136, Lansing, MI 48910.

CONSENTIMIENTO PARA PARTICIPAR
Al firmar este formulario, usted reconoce que ha sido completamente informado sobre los procedimientos a seguir y que se le ha proporcionado una descripción de los riesgos y los beneficios que se esperan. Al firmar este formulario de consentimiento, usted acepta que la conversación comunitaria en la que usted participará sea grabada digitalmente y entiende que usted es libre de retirarse del estudio en cualquier momento, sin dar razón alguna.

Su firma indica que ha leído y entendido la información anterior, que ha recibido una copia de este formulario de consentimiento para sus propios registros y que ha decidido participar basándose en la información proporcionada.

Firma del participante

Fecha

Nombre impreso del participante que firma arriba
B.5 Journalist Consent Form

Psychiatric Neurosurgery – Ethical, Legal, and Societal Issues

Consent Form

Principal Investigator: Judy Illes, PhD, FRSC, FCAHS
Canada Research Chair in Neuroethics
Professor of Neurology
University of British Columbia
Phone: [redacted]

Faculty: Laura Cabrera, MA, PhD
Faculty Affiliate, National Core for Neuroethics

Sponsor: CIHR

Contact Person: Caitlin Courchesne
Graduate Research Associate
Phone: [redacted]
Email: [redacted]

PURPOSE
You are being asked to participate in a study about media coverage and publication patterns of psychiatric neurosurgery. Psychiatric neurosurgery uses a surgical approach to try to treat mental health disorders in people who have not benefitted from other treatments such as behavior or drug therapy. Some methods use electrical signals to stimulate the brain; others use procedures to remove small amounts of brain tissue.

WHO IS CONDUCTING THE STUDY?
The study is being conducted by researchers at the National Core for Neuroethics at the University of British Columbia (UBC).

WHO CAN PARTICIPATE IN THIS STUDY?
You can participate in this study if you are:
- a journalist who has published on psychiatric neurosurgery or related topics,
- able to converse in English.

WHAT DOES THE STUDY INVOLVE?
If you consent to participate and return the signed consent form, the Research Assistant will contact you to schedule a 30 to 60 minute interview about:
- Your knowledge about psychiatric neurosurgery
- Your motivations for writing about psychiatric neurosurgery
• Your choices about topics you raise when covering psychiatric neurosurgery and related advances in interventions for mental health disorders.

The interview may be conducted in person, over the phone, or by Skype to accommodate your preference. All interviews will be conducted in a location that ensures your confidentiality. The interview will be audio recorded. Confidentiality will be protected to every extent possible, as set out below.

Taking part in this study is entirely voluntary. You have the right to refuse to participate in this study. If you decide to take part, you may choose to withdraw at any time without giving a reason and without any negative impact on your employment or other services.

STUDY RESULTS
After the study is finished, the results will be accessible on the National Core for Neuroethics website, http://neuroethicscanada.ca. Results will also be shared through publications in peer-reviewed academic journals and presentations at conferences and scholarly meetings. If you wish to receive a summary of the results after it is completed, please initial here ____________.

POSSIBLE HARMS AND BENEFITS OF PARTICIPATING
There are no known risks to participating. You may decline to answer any questions you do not wish to answer during the interview. While participation in this study does not have any direct benefits, indirect benefits may include societal benefits from knowledge gained about media coverage and publication patterns of psychiatric neurosurgery.

PAYMENT FOR TAKING PART IN THIS RESEARCH STUDY
You will not be paid for the time you take to be in this study.

CONFIDENTIALITY OF PARTICIPATION
Your confidentiality will be respected. A number will be used to identify study participants. The audio recordings will be converted into written form for analysis. No names will appear on the recordings or typed transcripts. Both the recordings and the transcripts will be kept on computer files that are encrypted and password-protected or in locked filing cabinets in secured offices at the National Core for Neuroethics at UBC. The recordings and transcriptions will be kept at UBC for at least 5 years from the time of publication of the results of the study. After this period, the paper forms will be shredded and any electronic records with raw data destroyed. No names will be used in any published and written findings resulting from the study.

CONTACT FOR QUESTIONS ABOUT THE STUDY DURING OR AFTER PARTICIPATION
If you have any concerns or questions about this study, you may contact the Principal Investigator, Dr. Judy Illes at [__].

If you have any concerns or complaints about your rights as a research participant and/or your experience while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 604-822-8598, by email RSIL@ors.ubc.ca, or call toll free to 1-877-822-8598.

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SUBJECT CONSENT TO PARTICIPATE
By signing this form, you acknowledge that you have been fully informed about the procedures to be followed and have been given a description of the risks, and benefits to be expected. In signing this consent form, you agree to have the interview digitally recorded and understand that you are free to withdraw from the study at any time without giving a reason.

Your signature indicates that you have read and understood the above information, received a copy of this consent form for your own records, and that you have decided to participate, based on the information provided. Please return this signed form by e-mail to

[Email Address]

Participant’s Signature   Date

Printed Name of the Participant
Signing Above
Introduction:

1. Welcome
   Introduce yourself and the note-taker.

Review the following:
- Who we are and what we are trying to do
- What will be done with the information collected
- Why we think their participation is important

2. Explanation of the process
   Explain that community conversations are being used more and more often to involve community members to engage in active discussion about topics of shared interest.

About community conversations:
- We want to learn about their position and reasons behind (positive and negative)
- Not trying to achieve consensus
- In this project, we are doing community conversations. The reason for using this tool is that we can engage interest members of the public and get a more in-depth perspective.

Logistics:
- Presentation will last about 10 to 15 minutes
- Discussion will last about 1 hour
- Feel free to move around
- Where is the bathroom? Exit?

Ask if anyone has any questions.

3. Ground rules
   - Everyone is expected to participate
   Information provided in the community conversation must be kept confidential. Say: “Please respect everyone here and do not share information from this conversation with others. However, you should be aware that we cannot guarantee that what you say will not be disclosed outside the group.”
   - No side conversations
   - Turn off cell phones
   - Remind participants that they do not need to answer all questions and can stop their participation at any time.
Ask if anyone has any questions.

4. Presentation of media results.
Ask if anyone has any questions.

5. **Turn on tape recorder**

**Questions:**

1. Why are you interested in the topic of psychiatric neurosurgery?

2. Have you heard of all the different procedures before today? If so, which ones? Where?


4. If there is mention of historical issues, ask participants to elaborate. If not, ask about whether they have heard of psychosurgery.

5. What do you think are the main challenges surrounding the adoption and acceptance of psychiatric neurosurgery? (E.g. Patient concerns, reimbursement and regulation)

6. Is there anything else you would like us to know about you?

That concludes our community conversation. Thank you so much for coming and sharing your thoughts and opinions with us.

**Probes for Discussion:**

- Technology
- Disorders
- Benefits
  - Localization
  - Reversibility
  - Adjustability
  - Not-invasive
- Safety
  - Risks of brain surgery
  - Invasiveness
  - Direct modification of the brain
- State of Technology/intervention
  - New technology
  - Adopting technology
  - Only animal research
  - Still experimental
- Social Issues
- Cost
- Stigma
- Industry/medical professional issues

- Regulation
- Patient outcomes
  - Hope of cure, normal life
- Therapeutic need
  - Last resort
  - Desperation
- Ethical/philosophical issues
  - Autonomy
  - Informed consent
  - Justice (access)
  - Dignity/integrity
  - Identity/authenticity
  - Control
  - Privacy
  - Human enhancement

Materials and supplies for community conversations

- Sign-in sheet
- Consent forms (one copy for participants, one copy for the team)
- Community conversation guide for the facilitator
- 1 recording device; 1 spare
- Batteries for recording device
- Nametags
- Extra tapes for recording device
- Notebook for note-taking and pens
- Refreshments
C.2 Montreal

Guide de Conversation Communautaire

Introduction :
1. Accueil
Présentez-vous et présentez le preneur de notes.

Rédigez ce qui suit :
• Qui sommes-nous et ce que nous essayons de faire
  • Nous sommes une équipe de chercheurs de l'IRCM et de l'Université de la Colombie-Britannique. Nous souhaitons en savoir plus sur les attitudes et les perceptions du public au sujet de l'utilisation de la neurochirurgie psychiatrique pour traiter les troubles de santé mentale.
  • Nous avons organisé des groupes de discussion/conversations communautaires en Allemagne, en Allemagne et dans l’ouest du Canada (Vancouver) et nous souhaitons maintenant connaître les perceptions des personnes qui vivent au Québec.
• Que se passera-t-il avec les informations recueillies
  • Cette conversation sera enregistrée en audio comme expliqué dans le formulaire de consentement.
  • Nous voulons analyser la discussion pour mieux comprendre les idées principales qui seront discutées aujourd'hui.

• Pourquoi nous croyons que leur participation est importante
  • Les idées et les attitudes que vous partagez aujourd'hui peuvent aider les médecins et les chercheurs à mieux comprendre ce que le public ressent face à l'utilisation d'interventions chirurgicales pour traiter les troubles de santé mentale.

2. Explication du processus
Expliquez que les conversations communautaires sont de plus en plus utilisées pour impliquer les membres de la communauté afin de discuter activement des sujets d'intérêt général.

À propos des conversations communautaires :
• Nous voulons connaître leurs positions et raisonnements (positifs et négatifs)
• Ne pas essayer de parvenir à un consensus
• Dans ce projet, nous réalisons des conversations communautaires. Nous utilisons cet outil parce qu’il nous permet d’impliquer des membres intéressés du public et apporte une perspective plus approfondie.
Logistique:
- La présentation dure environ de 10 à 15 minutes
- La discussion durera environ 1 heure
- N'hésitez pas à vous déplacer
- Où se trouvent les toilettes? Sortie?

Demandez si quelqu’un a des questions.

3. Règles de base
- Tout le monde devrait participer

Les informations fournies dans la conversation communautaire doivent être confidentielles. Dites: « Veuillez respecter tous les membres ici et ne pas partager des informations issues de cette conversation avec d'autres personnes. Cependant, vous devez savoir que nous ne pouvons pas garantir que ce que vous dites ne sera pas divulgué en dehors du groupe. N’oubliez pas d’utiliser votre nom de famille dans le groupe pour protéger votre vie privée. »
- Pas de conversations en parallèle
- Éteindre les téléphones cellulaires
- Rappelez aux participants qu’ils n’ont pas besoin de répondre à toutes les questions et peuvent arrêter leur participation à tout moment.

Demandez si quelqu’un a des questions.

4. Présentation des résultats dans les médias/infos sur la neurochirurgie psychiatrique

Demandez si quelqu’un a des questions.

5. Activez l’enregistreuse

Des Questions :
1. Pourquoi êtes-vous intéressé par le sujet de la neurochirurgie psychiatrique?
2. Avez-vous entendu parler de toutes les différentes procédures avant aujourd'hui? Si oui, lesquelles? Où?
4. Si l'on mentionne des problèmes historiques, demandez aux participants d'élaborer. Sinon, demandez s'ils ont entendu parler de la psychochirurgie.
5. Selon vous, quels sont les principaux défis liés à l'adoption et à l'acceptation de la neurochirurgie psychiatrique? (Par exemple, préoccupations concernant les patients, remboursement et règlement)
6. Y a-t-il autre chose que vous aimeriez que l'on sache à votre sujet?

Cela conclut notre conversation communautaire. Merci beaucoup d'être venu et d’avoir partagé vos opinions avec nous.

Points de Discussion :
- Technologie
- Troubles de santé mentale
• Avantages
  o Localisation
  o Réversibilité
  o Ajustable
  o Non invasif
• Sécurité
  o Risques de la chirurgie du cerveau
  o Nature invasive
  o Modification directe du cerveau
• État de la technologie/intervention
  o Nouvelle technologie
  o Adoption de la technologie
  o Seulement la recherche sur les animaux
  o Toujours expérimentale
• Questions sociétales
  o Coût
  o Stigmatisation
  o Problèmes liés à l’industrie et aux professionnels médicaux
• Règlement
• Résultats du patient
  o Espérance de guérison, vie normale
• Besoin thérapeutique
  o Dernier recours
  o Désespoir
• Questions éthiques/philosophiques
  o Autonomie
  o Consentement éclairé
  o Justice (accès)
  o Dignité/intégrité
  o Identité/authenticité
  o Contrôle
  o Confidentialité
  o Amélioration humaine

Matériaux et fournitures pour les conversations communautaires
• Feuille de présence
• Formulaires de consentement (une copie pour les participants, une copie pour l’équipe)
• Guide de conversation communautaire pour l’animateur/l’animatrice
• 1 enregistreur; 1 pièce de rechange
• Batteries pour enregistreur
• Étiquettes de nom
• Bandes supplémentaires pour enregistreur
• Cahier pour la prise de notes et les stylos
• Collations et breuvages
Leitfaden zur Moderation der Gruppendiskussion
Einführung:

1. Begrüßung

Vorstellung:
- Wer sind wir und worum geht es in dem Projekt?
- Was passiert mit den gesammelten Daten?
- Weshalb ist die aktive Teilnahme an einem lebhaften Diskurs wichtig?

2. Darstellung des Ablaufs
Erläuterung weshalb Gruppendiskussionen als Forschungsmethode für einen Dialog mit der Öffentlichkeit zunehmend an Bedeutung gewinnen. Nachfrage, ob bereits jemand schon einmal an einem öffentlichen Dialog als Forschungsmethode teilgenommen hat.

Ziele:
- Wir möchten das Spektrum der Einstellungen, Werthaltungen und Ansichten kennenlernen, was sowohl positive und bejahende als auch ablehnende oder negative Meinung einschließt. Zudem ist es uns wichtig, die Gründe für diese Einstellungen in Erfahrung zu bringen.
- Das Ziel ist es ausdrücklich nicht, einen Konsens zu erzielen oder zu einer bestimmten Überzeugung zu gelangen.
- In vorangegangenen Studie haben wir die Medienberichterstattung untersucht. In dieser Studie geht es nun darum, das Meinungsspektrum in der Allgemeinbevölkerung zu untersuchen und besser zu verstehen, was an dem Thema interessierte Vertreter der Öffentlichkeit über psychiatrische Neurochirurgie denken.

Ablauf:
- Präsentation der gegenwärtigen neurochirurgischen Behandlungsmöglichkeiten für psychiatrische Indikationen (10 bis 15 min)
- 60 Minuten Diskussion
- Zögern Sie nicht, sich frei zu bewegen und den Raum zu verlassen
- Hinweis auf Toiletten und Ausgänge

3. Diskursregeln
- „Ihre Meinung ist uns sehr wichtig“. Aktive Teilnahme wird erbeten.
- „Äußerungen, Beiträge und Inhalte der Gruppendiskussion müssen vertraulich behandelt werden.
- „Vermeiden Sie alle Nebengespräche“. Wenn mehr als eine Person gleichzeitig spricht, erschwert das die Transkription und wissenschaftliche Auswertung des Diskurses.
- „Bitte schalten Sie Ihr Mobiltelefon aus.“
• Erneute Aufklärung der Teilnehmer über die Offenheit des Diskurses, dass sie auf keine der Fragen antworten müssen, wenn sie dies nicht wünschen und dass das Ziel nicht die Herstellung von Einigkeit oder eines Konsens ist.

4. Präsentation der länder-spezifischen Ergebnisse unserer vorangegangenen Medienanalyse als Hintergrundinformation.

5. Einschalten der Tonaufnahme


Fragen:

1. Wieso interessieren Sie sich für das Thema psychiatrische Neurochirurgie?

2. Haben Sie bereits zuvor schon einmal von den verschiedenen neurochirurgischen Verfahren in der Psychiatrie gehört? Wenn ja, von welchen und in welchem Kontext?


4. Falls historische Bezüge zur Psychochirurgie (Leukotomie, Lobotomie, Hypothalamotomie etc.) genannt werden, wird um weitere Ausführung gebeten. Falls nicht, wird nachgefragt, ob die Teilnehmer mit historischen Vorläufern der psychiatrischen Neurochirurgie vertraut sind.

5. Was sind Ihrer Meinung nach die größten Herausforderungen für die psychiatrische Neurochirurgie? Welche Faktoren fördern oder behindern Ihrer Meinung nach die Akzeptanz der psychiatrischen Neurochirurgie?

6. Gibt es noch weitere relevante Themen, über die Sie sprechen müssten? Möchten Sie uns noch etwas über sich selbst wissen lassen? Haben Sie noch weitere Fragen oder Bemerkungen?


Stichworte zur Moderation der Diskussion:
• Beschreibung der verschiedenen Verfahren, z.B. Tiefe Hirnstimulation, Radiochirurgie, Gamma-Knife, etc.
• Nennung der zugelassenen Indikation (schwere therapierefraktäre Zwangsstörung) sowie Indikationen im experimentellen Stadium (Depression, Anorexia nervosa, Alkoholsucht, Schizophrenie, Posttraumatische Belastungsstörung)
• Vor- und Nachteile verschiedener Verfahren
  o Präzision des Eingriffs und fokale Wirkweise
Reversibilität des Eingriffs
Modifizierbarkeit der Stimulationsparameter
Invasivität des Eingriffs

Patientensicherheit
Risiken des neurochirurgischen Eingriffs
Nebenwirkungen auf das subjektive Erleben oder die Persönlichkeit
Direkte Manipulation von Gehirnprozessen

Stadium der experimentellen Forschung
Erstmalige Anwendung neuartiger Verfahren
Ausweitung vorhandener Verfahren auf neue Indikationen
Erstmalige Anwendung auf ausschließlicher Grundlage von Tierstudien

Soziale Aspekte
Verbundene Kosten
Stigma
Mögliche Interessenskonflikte, wirtschaftliche Interessen der Hersteller von neurochirurgischen Geräten

Zulassung
Patientenperspektive und Erfahrungen
Hoffnung auf Heilung, Rückkehr ins “normale” Leben
Realistische Erwartungen im Forschungskontext experimenteller Verfahren

Therapeutischer Nutzen
Letzter Ausweg
Verzweiflung
Evidenzbasierte Beurteilung benötigt mehr, bessere und umfassendere Daten

Ethische und philosophische Aspekte
Wird die Autonomiefähigkeit durch psychiatrische Neurochirurgie beeinflusst (beeinträchtigt oder wiederhergestellt)?
Ist die informierte Einwilligung ein Thema (Verzweiflung, letzter Ausweg, experimentelle Verfahren, wenig evidenzbasierte Information)?
Gerechtigkeit: Sollte der Zugang zu psychiatrischer Neurochirurgie allen offen stehen?
Menschenwürde
Persönlichkeitsveränderungen (Identität und Authentizität der Person)
Kontrolle von außen (Tiefe Hirnstimulation)
Schutz der Privatsphäre
Enhancement

Liste der verwendeten Materialien
- Einwilligungserklärung (ein Exemplar je Teilnehmer und je ein Exemplar zu Dokumentation für die Studie)
- Leitfaden für den Moderator der Gruppendiskussion
- 1 Aufnahmegerät für die Tonaufnahme; 1 Ersatzgerät
- Namenschilder zum Selbstbeschriften mit selbstgewählten Namen zur Anrede
- Notebook/Laptop sowie Stift und Papier zum Protokollieren der Diskussion
- Erfrischungsgetränke
Guía de conversaciones comunitarias

Introducción:

1. Bienvenida
Preséntese usted mismo y al tomador de notas.

Revise lo siguiente:
• ¿Quiénes somos y qué estamos tratando de hacer?
• ¿Qué se hará con la información recopilada?
• ¿Por qué creemos que su participación es importante?

2. Explicación del proceso
Explique que las conversaciones comunitarias se están utilizando cada vez con más frecuencia con objeto de involucrar a los miembros de la comunidad para participar en una discusión activa sobre temas de interés compartido.

Acerca de las conversaciones comunitarias:
• Queremos aprender sobre su posición respecto a la neurocirugía psiquiátrica y las razones que la sustentan (positivas y negativas)
• No intentamos alcanzar un consenso
• En este proyecto, estamos haciendo conversaciones comunitarias. La razón para usar esta herramienta es que podemos involucrar a los miembros del público interesados en el tema obteniendo una perspectiva más profunda.

Logística:
• La presentación durará de 10 a 15 minutos
• La discusión durará aproximadamente 1 hora
• Siéntase libre de moverse
• ¿Dónde está el baño? ¿Dónde está la salida?

Pregunte si alguien tiene alguna pregunta.

3. Reglas básicas
• Se espera que todos participen
La información proporcionada en la conversación comunitaria debe mantenerse confidencial.
Diga: "Por favor, respete a todos aquí y no comparta información de esta conversación con otros. Sin embargo, usted debe ser consciente de que no podemos garantizar que lo que usted diga aquí no será revelado fuera del grupo."
• No hay conversaciones paralelas
• Apague los teléfonos celulares
• Recuerde a los participantes que no necesitan contestar todas las preguntas y que pueden detener su participación en cualquier momento.

Pregunte si alguien tiene alguna pregunta.

4. Presentación de los resultados de los medios.

Pregunte si alguien tiene alguna pregunta.

5. Encienda la grabadora

Preguntas:
1. ¿Por qué le interesa el tema de la neurocirugía psiquiátrica?
2. ¿Ha oído hablar de todos los diferentes procedimientos antes de hoy? ¿De ser así, cuáles? ¿Dónde?
4. Si se mencionan cuestiones históricas, pida a los participantes que expongan su información. Si no, pregunte si han oído hablar de la psicocirugía.
5. ¿Cuáles cree que son los principales desafíos que rodean la adopción y la aceptación de la neurocirugía psiquiátrica? (Por ejemplo, preocupaciones de los pacientes, reembolso y regulación)
6. ¿Hay algo más que le gustaría que supiéramos sobre usted?

Eso concluye nuestra conversación comunitaria. Muchas gracias por venir y compartir sus pensamientos y opiniones con nosotros.

Temas para la discusión:
• Tecnología
• Trastornos
• Beneficios
  o Localización
  o Reversibilidad
  o Exactitud
  o No invasivo
• La seguridad
  o Riesgos de la cirugía cerebral
  o Invasivo
  o Modificación directa del cerebro
• Estado de la Tecnología / intervención
  o Nueva tecnología
  o Adopción de tecnología
  o Sólo investigación en animales
  o Todavía experimental
• Asuntos Sociales
  o Costo
  o Estigma
  o Industria / problemas profesionales médicos
• Regulación
• Resultados de los pacientes
  o Esperanza de cura, vida normal
• Necesidad terapéutica
  o Último recurso
  o Desesperación
• Aspectos éticos / filosóficos
  o Autonomía
  o Consentimiento informado
  o Justicia (acceso)
  o Dignidad / integridad
  o Identidad / autenticidad
  o Control
  o Privacidad
  o Mejora humana

**Materiales y suministros para conversaciones comunitarias**
• Hoja de registro
• Formularios de consentimiento (una copia para los participantes, una copia para el equipo)
• Guía de conversación comunitaria para el facilitador
• 1 dispositivo de grabación; 1 repuesto
• Baterías para el dispositivo de grabación
• Etiquetas de nombres
• Cintas adicionales para el dispositivo de grabación
• Cuaderno de notas y bolígrafos
• Refrigerio
Appendix D  Focus Group Introduction Presentations

D.1  Vancouver

Community Conversations: Neurosurgery for Psychiatric Disorders

What procedures exist?

What is the current state of research?

What does the media report?

Disclaimer

- This presentation is designed for educational purposes only. If you have any concerns or questions about your health, please consult with a physician or other health care professional.
- Quotes depicted reflect individual opinions and should be questioned at all times.

Deep Brain Stimulation

Procedure: Electrical impulses sent to localized area in brain

Established as therapy: Parkinson’s Disease

In psychiatry: For research purposes; in practice as last resort for Obsessive-Compulsive Disorder

Disadvantages: Surgical risks, infection

Long term risk: battery depletion, infection of implanted medical device

Advantages: Can be turned off, adjustable, spatially precise

Ablative Microsurgery

Procedure: Destruction of brain tissue

Established as therapy: Epilepsy, Parkinson’s Disease

In psychiatry: For research purposes; in practice as last resort for Obsessive-Compulsive Disorder

Disadvantages: Surgical risks, not adjustable

Advantages: Spatially precise, immediate effects

Ablative Microsurgery

Procedure: Radioactive radiation is locally focused to modify or destroy brain tissue

Established as therapy: Brain tumors, Epilepsy

In psychiatry: For research purposes; in practice as last resort for Obsessive-Compulsive Disorder

Disadvantages: Not adjustable, delayed onset of effects (6-12 months)

Advantages: No surgical incision in the skull, spatially precise, ambulant setting, relatively inexpensive
Optogenetics

**Procedure:** Neurons are made light-sensitive by way of genetic modification; neurons can then be selectively be “switched on” or “off”.

**Established as therapy:** No (only basic science)

**In psychiatry:** Not established (currently only performed in animal research)

**Disadvantages:** Surgical risks, infections and risk from foreign genetic material

**Advantages:** Selective effects on nerve cells

---

What does the media report?

---

Main Themes

**Last Resort and Desperation**

*“For that reason, only severely ill patients are operated on, for whom no other treatment can provide relief and for whom there are prospects of benefit.”*

*“[This] is a new option for patients who are otherwise considered treatment-resistant.”*

**Costs**

*“[No] one sees this becoming the new Prozac. The procedure costs too much.”*

*“In the long run, we can save substantial amounts of money for nursing care and medication.”*

---

Main Themes

**Expected Outcomes**

*“A new therapy [that may] promise hope.”*

*“According to a new study, [this] can relieve depression.”*

*“[This] only transforms severely ill patients into ordinarily ill patients.”*

**Risks**

*“A deviation of 0.2 millimeters could result in severe harms and adverse personality changes.”*

*“An intervention of the brain has never been without risks.”*

---

Main Themes

**Other Relevant Themes**

*“Why only heal a sick brain? Why not improve healthy ones?”*

*“Is [this] really the right means for curing psychiatric disorders?”*

*“Currently, there are major debates on control or manipulation of human behavior via electric stimulation of the brain.”*

*“We need more independent and sound studies.”*

*“So far, it is unclear which brain areas are the ideal targets for psychiatric disorders.”*
Discussion

Your opinion is important!

What are your thoughts?
D.2 Montreal

Conversations communautaires: La neurochirurgie pour les troubles psychiatriques

Quelles procédures existent?
Quel est l’état actuel de la recherche?
Qu'est-ce que les médias ont rapporté?

Juin 2018
Montréal, QC

Avertissement

- Cette présentation est conçue uniquement à des fins éducatives.
- Si vous avez des préoccupations ou des questions concernant votre santé, veuillez consulter un médecin ou un autre professionnel de la santé.
- Les citations reflètent des opinions individuelles et doivent être remises en question en tout temps.

Stimulation Cérébrale Profonde (SCP)

**Procédure:** Impulsions électriques envoyées à la région localisée dans le cerveau
**Établie comme thérapie:** Maladie de Parkinson
**Dans la psychiatrie:** À des fins de recherche, en pratique en dernier recours pour le trouble obsessionnel-compulsif

**Inconvénients:** Risques chirurgicaux, infection
*Risque à long terme:* épuisement de la pile, infection du dispositif médical implanté
**Avantages:** Peut être éteint, réglable, spatialement précis

Microchirurgie Ablative

**Procédure:** Destruction de tissu cérébral
**Établie comme thérapie:** Épilepsie, maladie de Parkinson
**Dans la psychiatrie:** À des fins de recherche, en pratique en dernier recours pour le trouble obsessionnel-compulsif

**Inconvénients:** Risques chirurgicaux, pas réglable
**Avantages:** Spatialement précis, effets immédiats

Radio-chirurgie

**Procédure:** le rayonnement radioactif est focalisé localement pour modifier ou détruire le tissu cérébral
**Établie comme thérapie:** Tumeurs cérébrales, épilepsie
**Dans la psychiatrie:** À des fins de recherche, en pratique en dernier recours pour le trouble obsessionnel-compulsif

**Inconvénients:** Non ajustable, retard d'apparition des effets (6-12 mois)
**Avantages:** Pas d'incision chirurgicale dans le crâne, spatialement précis, réglage ambulant, relativement peu coûteux
L'optogénétique

**Procédure:** Les neurones sont rendus sensibles à la lumière au moyen de modifications génétiques; les neurones peuvent ensuite être sélectivement activés ou désactivés.

**Établie comme thérapie:** Non (seulement dans la science fondamentale)

**Dans la psychiatrie:** Non établie (en ce moment, effectué seulement dans la recherche animale)

**Inconvénients:** Risques chirurgicaux, infection, et risque de matériel génétique étranger

**Avantages:** Effets sélectifs sur les neurones

---

**Qu'est-ce que les médias ont rapporté?**

---

**Les thèmes principaux**

_Dernier recours et désespoir_
- « Pour cette raison, seuls sont opérés les patients gravement malades, pour lesquels aucun autre traitement ne peut fournir de secours et pour lesquels il existe des perspectives de bénéfice. »
- « [Ceci] est une nouvelle option pour les patients qui sont autrement considérés comme résistants au traitement. »

**Coûts**
- « [Personne ne] voit cela devenir le nouveau Prozac. La procédure coûte trop cher. »
- « À long terme, nous pouvons économiser des sommes substantielles pour les soins infirmiers et les médicaments. »

---

**Les thèmes principaux**

_Résultats attendus_
- « Une nouvelle thérapie [qui peut] promettre l'espoir. »
- « Selon une nouvelle étude, [cela] peut soulager la dépression. »
- « [Cela] transforme seulement les patients gravement malades en patients normalement malades. »

**Risques**
- « Une déviation de 0,2 millimètres pourrait entraîner des dommages sévères et des changements de personnalité défavorables. »
- « Une intervention du cerveau n'a jamais été sans risques. »

---

**Les thèmes principaux**

_Autres thèmes pertinents_
- « Pourquoi seulement guérir un cerveau malade? Pourquoi ne pas améliorer ceux qui sont sains? »
- « Est-ce que [cela] est vraiment le bon moyen pour guérir les troubles psychiatriques? »
- « Actuellement, il y a des débats majeurs sur le contrôle ou la manipulation du comportement humain via la stimulation électrique du cerveau. »
- « Nous avons besoin d'études plus indépendantes et plus solides. »
- « Jusqu'à présent, on ne sait pas quelles zones du cerveau sont les cibles idéales pour les troubles psychiatriques. »

---

**Couverture médiatique au fil du temps**

<table>
<thead>
<tr>
<th>1960</th>
<th>2000</th>
<th>2017</th>
</tr>
</thead>
</table>

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154
Votre opinion est importante!
Dites-nous ce que vous en pensez.
D.3 Berlin

Warnhinweis

- Die präsentierten Informationen sind nicht als ärztliche Beratung gedacht. Wenden Sie sich hierfür immer zunächst an Ihren Hausarzt.
- Zitate spiegeln die Meinung einzelner wider und sollten stets hinterfragt werden.

Tiefe Hirnstimulation

**Wirkmechanismus:** elektrischer Impuls; biologische Details noch nicht völlig bekannt

**Etablierte Therapie:** Morbus Parkinson

**Psychiatrie:** nicht etabliert, bei Zwangsstörung als letztes Mittel; sonst nur zu Forschungszwecken

**Nachteile:** Operationsrisiken (Selten: Infektionen oder Hirnblutung)

**Vorteile:** abschaltbar, veränderbar, räumlich präzise

Ablative Mikrochirurgie

**Wirkmechanismus:** Entfernung von Hirngewebe

**Etablierte Therapie:** Hirntumor

**Psychiatrie:** nicht etabliert, nur als letztes Mittel oder zu Forschungszwecken

**Nachteile:** unveränderlich, Operationsrisiken (Selten: Infektionen oder Hirnblutung)

**Vorteile:** räumlich präzise, sofortige Wirkung

Gamma-Strahlentherapie

**Wirkmechanismus:** fluoraktive Strahlung wird örtlich gebündelt; biologische Details noch nicht völlig bekannt

**Etablierte Therapie:** Hirntumor

**Psychiatrie:** nicht etabliert, nur zu Forschungszwecken

**Nachteile:** unveränderlich, verzögerte Wirkung erst nach 6-12 Monaten

**Vorteile:** kein Öffnung des Schädels, räumlich präzise
Optogenetik


Etablierte Therapie: keine, nur Grundlagenforschung

Psychiatrie: nicht etabliert, nur für Forschung mit Tieren

Nachteile: unausgereift, Operationsrisiken (Infektionen oder Hirnblutungen), genetischer Eingriff

Vorteile: selektive Wirkung auf Nervenzellen

Was ist der Stand der Forschung?

Zunahme der Forschung weltweit

Zunahme der Medienberichte

Hoffnung und Verzweiflung

- „Operiert werden deswegen nur Schwerkranke, denen keine andere Therapie hilft - und bei denen Aussicht auf Erfolg besteht.“
- „Die Tiefe Hirnstimulation ist eine neue Option für zwangserkrankte Patienten, die als 'austherapiert' gelten.“
- „Er verspricht sich jetzt alles von dem Eingriff, zu dem ihm auch seine Eltern Mut gemacht haben.”

Was berichtet die Presse zu dem Thema?
Kosten

- „Ein Schrittmacher und seine Elektroden dagegen kosten einmalig 17 000 Euro, die gesamte Operation mit Material etwa 30 000 Euro.“
- „Auf längere Sicht könne bei Pflegekosten und Medikamenten kräftig gespart werden, jüngere Patienten können sogar wieder arbeiten.“

Chancen

- „Hilfe verspricht eine neue Therapie mit Hirnschrittmachern.“
- „Stromstoße, die direkt ins Gehirn geschickt werden, können die Depression einer neuen Studie zufolge lindern.“
- „Wunder sollte man sich also nicht erhoffen: ‘Die Tiefenhirnstimulation macht aus schwerstkranken Patienten lediglich durchschnittliche Patienten’“

Risiken

- „Eine Abweichung um 0,2 Millimeter hätte schon schwere Schäden und unbeabsichtigte Persönlichkeitsveränderungen bewirken können.“
- „Frei von Risiko war der Griff ins Hirn nie“
- „Ich darf keine Blutgefäße verletzen – jede Abweichung, ein kleiner Rutscher können schwerste Schäden hervorrufen, eine Hirnblutung könnte tödlich sein.“

Kontroversen

- "Warum sollte man nur ein kran kes Hirn heilen? Warum nicht auch ein gesundes verbessern?"
- "Ist Hirnchirurgie tatsächlich das richtige Mittel zur Therapie psychischer Störungen?"
- "Eine Art Wettrüsten der Gehirne steht an."

Stand der Forschung

- "Es ist offenbar möglich, eine Depression im Gehirn gezielt an- oder abzuschalten."
- „Wir brauchten mehr unabhängige, seriöse Studien“
- „Bisher ist offenbar nicht geklärt, welche Gebiete des Gehirns bei psychiatrischen Erkrankungen die idealen Zielorte der tiefen Hirnstimulation sind."

Diskutieren Sie mit

Ihre Meinung ist uns wichtig!
Was denken Sie über das Thema?
Conversación Comunitaria: Neurocirugía para trastornos de salud mental

¿Cuáles son los procedimientos?
¿Cuál es el estado actual de la investigación?
¿Qué informan los medios de comunicación?

¿Qué piensas?

UBC | NEUROETHICS
NEUROETHICS CANADA
BRING HEALTH HUMAN VALUES

A Abril 2018
[Location]

La información presentada no pretende ser un consejo médico

Consulte a su médico si necesita consejo médico.

Estimulación Cerebral Profunda

Cómo funciona: Los impulsos eléctricos se envían a un área específica del cerebro.
Terapia hoy: Enfermedad de Parkinson
Investigación hoy: En psiquiatría, puede ser un último recurso para el trastorno obsesivo compulsivo.

Ventajas: Puede encenderse y apagarse; colocado con precisión.
Desventajas: Riesgos quirúrgicos como infección; agotamiento de la bacteria.

Procedimientos

Cirugía Estereotaxica Ablativa

Cómo funciona: Tejido cerebral es alterado.
Terapia hoy: Epilepsia, enfermedad de Parkinson.
Investigación hoy: En psiquiatría, puede ser un último recurso para el trastorno obsesivo compulsivo.

Ventajas: Se puede enfocar con precisión; efectos inmediatos.
Desventajas: No es reversible; riesgos quirúrgicos como infección.

Radiocirugía

Cómo funciona: La radiación se aplica con gran precisión para alterar el tejido cerebral.
Terapia hoy: Tumores cerebrales, epilepsia.
Investigación hoy: En psiquiatría, puede ser un último recurso para el trastorno obsesivo compulsivo.

Ventajas: No requiere incisión quirúrgica; se puede enfocar con precisión; relativamente barato.
Desventajas: No reversible; retraso en la manifestación de efectos (6-12 meses).
Optogenética

Cómo funciona: Las células cerebrales llamadas neuronas se vuelven sensibles a la luz mediante modificación genética y luego pueden “activarse y desactivarse”.

Terapia hoy: No está en uso para la terapia.

Investigación hoy: Esta siendo probado en animales.

Ventajas: Efectos en células nerviosas específicas.

Desventajas: Riesgos quirúrgicos como infección; riesgo de material genético extraño.

Informes de medios de comunicación

Temas Principales

Último recurso y desesperación

“Por esa razón, solo se opera a pacientes gravemente enfermos, para quienes ningún otro tratamiento puede proporcionar alivio y para los que hay perspectivas de beneficio.”

“Se trata de una nueva opción para los pacientes que de otra manera se consideran resistentes al tratamiento.”

Costos

“Nadie ve que esto se está convirtiendo en el nuevo Prozac. El procedimiento cuesta demasiado.”

“A lo largo, podemos ahorrar cantidades sustanciales de dinero en relación con la atención de enfermería y la medicación.”

Aumento en la Cobertura de los Medios

Cobertura de los medios

1960 2000 2017

Temas Principales

Resultados Esperados

“Una nueva terapia que crea expectativas en pacientes con serios problemas.”

“Según un estudio reciente, este procedimiento puede aliviar la depresión.”

“Esta intervención disminuyen la severidad de los síntomas pero no cura a los pacientes.”

Riesgos

“Una desviación de 0.2 milímetros podría provocar daños severos y cambios adversos en la personalidad.”

“Una intervención del cerebro nunca ha estado exenta de riesgos.”

Otros Cuestionamientos e Ideas

“¿Por qué solo sanar un cerebro enfermo? ¿Por qué no mejorar los sanos?”

“¿Esta intervención es realmente el medio correcto para curar los trastornos psiquiátricos?”

“Actualmente, hay debates importantes sobre el control o la manipulación del comportamiento humano a través de la estimulación eléctrica del cerebro.”

“Necesitamos mas estudios independientes y sólidos.”

“Hasta ahora, no está claro que áreas del cerebro son los objetivos ideales para los trastornos psiquiátricos.”
Discusión

Tu opinión es importante!

Comparte lo que piensas
Appendix E  Semi-Structured Interview Guide

Questions for Journalists

Introduction:
1. Welcome
2. Say: <Name OF PERSON>. Thank you very much for taking the time to talk with me.

As you know, I am the Director of Neuroethics Canada at UBC in Vancouver, Canada. This centre is dedicated to ethical, legal and social issues in neurosciences, and here specifically, to the re-emergence and emergence of surgical techniques for psychiatric illness.

We have read your article(s) on XX in <YY> with great interest. Drawing on this, I would like to talk to you the reporting you have done on psychiatric neurosurgery. This interview should take about 30 minutes.

I will be taping the session because I don’t want to miss any of your comments. Is that ok?

3. Do you have any questions before we get started with the interview?

4. Turn on tape recorder.

Questions:
1. For how many years have you been working as writer or journalist?
2. What motivated you to write about psychiatric neurosurgery?
3. Do you generally write on current trends or seek unique or novel topics?
4. How do you feel about reporting about these technologies?
5. Is this area of focus any different from other on which you have written?
6. Have the historically significant events of the past had an impact on your approach?
7. How do you think your work impacts public opinion/public policy/legislation on these procedures?
8. Do you think that responsibilities for reporting on these issues is different from other types of content?
9. What changes have you seen in the reporting of these issues over time?
10. What are the particular features of psychiatric neurosurgery that you consider for your coverage when you are writing your story?
11. What ethical issues (if any) are you most concerned about when writing about these procedures?

12. Have you received any reader feedback about these stories and topics? If so, are they positive (give examples) or negative (give examples)?

**Closing key components:**

Is there anything more you would like to add?

Thank you for your time.
Appendix F  Functional Neurosurgeon Survey

Attitudes and perceptions towards psychiatric neurosurgery interventions

Start of Block: Introduction

Psychiatric Neurosurgery – Ethical, Legal, and Societal Issues Attitudes and Perceptions Towards Psychiatric Neurosurgery Interventions
You are being asked to participate in a research study of attitudes and perceptions towards psychiatric neurosurgery.

Interest in neurosurgery for psychiatric diseases has grown in past years. As a result, the treatment of psychiatric conditions by neurosurgeons is becoming more widespread and a larger part of a functional neurosurgeon's practice. Given the history of psychiatric neurosurgery and its current renaissance, it is important to evaluate the attitudes and perceptions of physicians surrounding different psychiatric neurosurgical interventions (e.g., deep brain stimulation, ablative procedures, radiosurgery, closed-loop implantable devices, and focused ultrasound).

This survey is divided into two sections and should take approximately 10 minutes to complete. The first section constitutes questions about you and the setting in which you practice. The second section constitutes questions about your practice as a functional neurosurgeon and your attitudes and perceptions towards psychiatric neurosurgery.

Participation in this research project is completely voluntary. You have the right to say no. You may change your mind at any time and withdraw. You may stop participating at any time. Your responses are completely anonymous.

There are no direct benefits to you in taking part in this survey. However, information from the study will help researchers to learn more about the practice of psychiatric neurosurgery and may benefit others in the future.

If you have any questions, concerns, or complaints about this survey, you may contact the Principal Investigator, Dr. Laura Y. Cabrera at [redacted] or at [redacted]. If you have any concerns or complaints about your rights as a research participant and/or your experience while participating in this study, contact the Michigan State University’s Human Research Protection Program at 517 355 2180, Fax 517 432 4503, or e-mail irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI 48910.

End of Block: Introduction

Start of Block: Demographics & Functional Neurosurgery Practice
Q1 Where do you practice?
  - United States (1)
  - Canada (2)

Q2 How many years have you practiced in a field involving psychiatric neurosurgery?
  - Fewer than 5 (1)
  - 5 - 9 (2)
  - 10 - 14 (3)
  - 15 - 19 (4)
  - 20 or more (5)

Q3 Where did you attend medical school?
  - United States (1)
  - Canada (2)
  - Abroad (3)

Q4 Have you completed a formal fellowship in stereotactic and functional neurosurgery?
  - Yes (1)
  - No (2)
Q5 In which of the following medical settings do you practice? Select all that apply.

- [ ] Academic or university-affiliated hospital (1)
- [ ] Private practice (3)
- [ ] General or community hospital (4)
- [ ] Other (5)

Q6 As a percentage of total functional neurosurgery referrals, how frequently do you treat the following conditions? Total must equal 100%.

Movement disorders: _______ (1)
Epilepsy: _______ (2)
Chronic pain: _______ (3)
Depression: _______ (4)
OCD: _______ (5)
Other: _______ (6)
Total: _______

Q7 Approximately how many surgeries do you perform per year for psychiatric disorders?

More than 12

<table>
<thead>
<tr>
<th>0</th>
<th>2</th>
<th>4</th>
<th>6</th>
<th>8</th>
<th>10</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of psychiatric neurosurgeries per year. ()</td>
<td>[ ]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Display This Question:

If Approximately how many surgeries do you perform per year for psychiatric disorders? [ Number of psychiatric neurosurgeries per year. ] Is Empty

Q7.1 If more than 12, please provide an estimate

__________________________________________________________________________
Q8 What is your age?

- 25-34 (1)
- 35-44 (2)
- 45-54 (3)
- 55-64 (4)
- 65 or older (5)

Q9 What is your gender?

- Male (1)
- Female (2)
- Other (4)
- Prefer not to respond (5)

End of Block: Demographics & Functional Neurosurgery Practice

Start of Block: Psychiatric Neurosurgery Practice

Display This Question:

If Approximately how many surgeries do you perform per year for psychiatric disorders? [Number of psychiatric neurosurgeries per year.] > 0

Or If more than 12, please provide an estimate. Text Response Is Displayed

Q10 Rank the following psychiatric neurosurgery interventions from 1 to 5 according to the frequency with which you use them in your practice (1: most frequent, 5: least frequent). If you have never used one of the options below, please leave its box blank.

- DBS (1)
- VNS (2)
- Ablation (e.g., MR-guided focused ultrasound, chemical ablation, electrocoagulation) (5)
- Stereotactic Radiosurgery (6)
- Other (8)
Q10.1 If other, please specify

________________________________________________________________

Q11 Rank the following psychiatric conditions from 1 to 7 according to the frequency with which you have used a psychiatric neurosurgery intervention as treatment (1: most frequent; 7: least frequent). If you have never treated one of the conditions below with a form of psychiatric neurosurgery, please leave its box blank.

- OCD (1)
- Depression (2)
- Schizophrenia (3)
- Eating Disorders (5)
- Aggression (7)
- Autism Spectrum Disorder (8)
- Other (9)

Q11.1 Other, please specify

________________________________________________________________

Q12 To what extent do you agree with the following statements about ablative surgeries for psychiatric disorders?
<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree (1)</th>
<th>Agree (2)</th>
<th>Somewhat agree (3)</th>
<th>Neither agree nor disagree (4)</th>
<th>Somewhat disagree (5)</th>
<th>Disagree (6)</th>
<th>Strongly disagree (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ablative surgery is obsolete; it should not be performed anymore (1)</td>
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<tr>
<td>Ablative surgery may be acceptable in some circumstances if non-invasive methods (e.g. radiosurgery) are used (3)</td>
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<tr>
<td>It is acceptable to offer ablative surgery to patients who will likely not comply with postoperative care (4)</td>
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<tr>
<td>I expect that soon there will no longer be physicians who are experts in ablative surgical procedures (5)</td>
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<tr>
<td>Strongly agree (1)</td>
<td>Agree (2)</td>
<td>Somewhat agree (3)</td>
<td>Neither agree nor disagree (4)</td>
<td>Somewhat disagree (5)</td>
<td>Disagree (6)</td>
<td>Strongly disagree (7)</td>
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<tr>
<td>For some psychiatric patients, ablative surgery may be a valid alternative to DBS (7)</td>
<td>☐</td>
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<tr>
<td>Ablative surgery is more cost-effective than DBS (9)</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
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</tbody>
</table>
Display This Question:

If Approximately how many surgeries do you perform per year for psychiatric disorders? [Number of psychiatric neurosurgeries per year.] > 0

Or If more than 12, please provide an estimate. Text Response Is Displayed

Q13 To what extent do you agree with the following statements?
<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Strongly agree (1)</th>
<th>Agree (2)</th>
<th>Somewhat agree (3)</th>
<th>Neither agree nor disagree (4)</th>
<th>Somewhat disagree (5)</th>
<th>Disagree (6)</th>
<th>Strongly disagree (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will help physicians and researchers to understand the neurological basis of psychiatric diseases</td>
<td></td>
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<tr>
<td>Will be an option for the treatment of severe, otherwise untreatable psychiatric diseases</td>
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<tr>
<td>Has the potential to substantially improve the quality of life for carefully selected patients</td>
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<tr>
<td>Some applications of are unethical</td>
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<tr>
<td>Has a high risk of complications</td>
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<tr>
<td>in psychiatry is still a treatment of last resort</td>
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<tr>
<td>Has sufficient evidence to support its use</td>
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<tr>
<td>Psychiatric neurosurgery will become a larger component of my practice in the future</td>
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<tr>
<td></td>
<td>Strongly agree (1)</td>
<td>Agree (2)</td>
<td>Somewhat agree (3)</td>
<td>Neither agree nor disagree (4)</td>
<td>Somewhat disagree (5)</td>
<td>Disagree (6)</td>
<td>Strongly disagree (7)</td>
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<tr>
<td><strong>The use of psychiatric neurosurgery will significantly increase globally in the future (9)</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Q14 To what extent do you agree with the following statements?
<table>
<thead>
<tr>
<th>Strongly agree (1)</th>
<th>Agree (2)</th>
<th>Somewhat agree (3)</th>
<th>Neither agree nor disagree (4)</th>
<th>Somewhat disagree (5)</th>
<th>Disagree (6)</th>
<th>Strongly disagree (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ablative surgery will help physicians and researchers to understand the neurological basis of psychiatric diseases (1)</td>
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<tr>
<td>Ablative surgery will be an option for the treatment of severe, otherwise untreatable psychiatric diseases (2)</td>
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<tr>
<td>Ablative surgery has the potential to substantially improve the quality of life for carefully selected patients (3)</td>
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<tr>
<td>Some applications of ablative surgery are unethical (4)</td>
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<tr>
<td>Ablative surgery has a high risk of complications (6)</td>
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</tr>
<tr>
<td>Ablative surgery in psychiatry is still a treatment of last resort (7)</td>
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<tr>
<td>Ablative surgery has sufficient evidence to support its use (10)</td>
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<tr>
<td>Psychiatric neurosurgery will become a larger component of my practice in the future (8)</td>
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<tr>
<td>The use of psychiatric neurosurgery will significantly increase globally in the future (9)</td>
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</tbody>
</table>

**Display This Question:**

If Approximately how many surgeries do you perform per year for psychiatric disorders? [Number of psychiatric neurosurgeries per year] > 0

Or If more than 12, please provide an estimate Text Response Is Displayed
Q15 For the treatment of $Q11/ChoiceGroup/ChoiceWithLowestValue$, to what extent do you agree with the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree (1)</th>
<th>Agree (2)</th>
<th>Somewhat agree (3)</th>
<th>Neither agree nor disagree (4)</th>
<th>Somewhat disagree (5)</th>
<th>Disagree (6)</th>
<th>Strongly disagree (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatric neurosurgery is safe (1)</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
</tr>
<tr>
<td>Psychiatric neurosurgery is medically effective (2)</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
</tr>
<tr>
<td>Psychiatric neurosurgery is cost effective (3)</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
</tr>
<tr>
<td>Psychiatric neurosurgery has clear clinical indications (4)</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
<td>⬜</td>
</tr>
</tbody>
</table>

Display This Question:

If Approximately how many surgeries do you perform per year for psychiatric disorders? [ Number of psychiatric neurosurgeries per year. ] = 0
Q16 For the treatment of **depression**, to what extent do you agree with the following statements?

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree (1)</th>
<th>Agree (2)</th>
<th>Somewhat agree (3)</th>
<th>Neither agree nor disagree (4)</th>
<th>Somewhat disagree (5)</th>
<th>Disagree (6)</th>
<th>Strongly disagree (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatric neurosurgery is safe (1)</td>
<td>○  ○  ○  ○  ○</td>
<td>○</td>
<td></td>
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<td>○</td>
</tr>
<tr>
<td>Psychiatric neurosurgery is medically effective (2)</td>
<td>○  ○  ○  ○  ○</td>
<td>○</td>
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<td></td>
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<td>○</td>
</tr>
<tr>
<td>Psychiatric neurosurgery is cost effective (3)</td>
<td>○  ○  ○  ○  ○</td>
<td>○</td>
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<tr>
<td>Psychiatric neurosurgery has clear clinical indications (4)</td>
<td>○  ○  ○  ○  ○</td>
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</tbody>
</table>
Q17 Which of the following do you think are significant barriers for patients and clinicians when considering psychiatric neurosurgery?

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Strongly agree (1)</th>
<th>Agree (2)</th>
<th>Somewhat agree (3)</th>
<th>Neither agree nor disagree (4)</th>
<th>Somewhat disagree (5)</th>
<th>Disagree (6)</th>
<th>Strongly disagree (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reluctance of psychiatrists to refer patients (1)</td>
<td></td>
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<td>Stigma surrounding psychiatric disease (2)</td>
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<tr>
<td>The historic misuse of psychiatric neurosurgery (3)</td>
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<tr>
<td>Concern about adverse effects (6)</td>
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<tr>
<td>Uncertainty about when psychiatric neurosurgery should be utilized (7)</td>
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<tr>
<td>No barriers exist (8)</td>
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</table>

End of Block: Psychiatric Neurosurgery Practice