“Going Under the Gamma Knife”: A Phenomenological Analysis of the Modern Practice of Psychiatric Neurosurgery for Obsessive Compulsive Disorder

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Introduction

In this thesis, I aim to critically examine the modern practice of psychiatric neurosurgery for the treatment of intractable Obsessive-Compulsive Disorder (OCD). In an effort to contextualize the procedures I begin with a brief discussion of the history of psychosurgery in Chapter 1 beginning with the first “psychosurgeries,” highlighting key individuals who advanced the science, and ending with the fall of psychosurgical practice in the United States. In Chapter 2, I discuss modern psychiatric neurosurgery by first beginning with a discussion of the shifts that psychosurgery set into motion in the fields of philosophy of mind and clinical neuroscience. Later in Chapter 2, I provide an in-depth review of the modern practice of neurosurgery by examining the surgical procedures in use today.

In Chapter 3 my goal is to provide a working definition of OCD by examining OCD through three epistemological lenses, as it exists most predominantly today: As a clinical category, as a neurobiological phenomenon, and as a lived experience. I argue that all three views of OCD critically inform the understanding and treatment of OCD.

Chapters 4 and 5 are where I present my findings from over a year of qualitative research examining the practice of modern psychiatric neurosurgery at Butler Hospital and Massachusetts General Hospital, two of the few institutions in the United States that practice psychiatric neurosurgery. In Chapter 4, I attend specifically to the clinicians involved in conducting psychiatric neurosurgical procedures, beginning with the processes they use for decision-making and ending with a discussion informed by unstructured ethnographic interviews of clinicians to determine how they conceptualize the treatment of individuals with severe OCD with surgery. In chapter 5, I attend more specifically to the primary focus of my project, the “lived experiences” of psychiatric neurosurgery for OCD among patients.
I conclude this thesis with a discussion of what phenomenological analysis of psychiatric neurosurgery for the treatment of OCD reveals when considering both the clinician and the patient perspectives.
Chapter 1: From Psychosurgery to Psychiatric Neurosurgery - A Brief History

Psychosurgery, or more broadly the act of attempting to treat maladies of the mind through the use of surgical procedures, can trace roots back to 5100 BCE (Diering and Bell 1991). Archeological evidence of skulls with burr holes dating back to antiquity reveal evidence that trephination, a surgical practice of drilling holes into the skull with the potential aim of relieving “unexplained and unbearable pain…melancholia” or “releas[ing] demons” in the mind (Diering and Bell 1991; Silverman 2001). While many historians speculate that trephination in ancient history represents the earliest evidence of brain surgery, the term “psychosurgery” was not coined by Egas Moniz until the late 1930’s when he developed a signature neurosurgical procedure intended to treat patients with psychiatric illness (Diering and Bell 1991; El-Hai 2005). From then onwards, the practice of psychosurgery would forever change the fields of psychiatry and neurosurgery, affect the lives of thousands of individuals, and change western thought about the mind, definitively situating it and its maladies in the tangible biology of the brain.

In this chapter, I will highlight some of the key moments in the history of psychosurgery starting with the first surgeries conducted in the late 19th century and continuing with the rise in popularity of psychosurgery during 20th century followed by its quick decline in the wake of psychopharmacology. The history of psychosurgery is well studied and often focusses on the contributions of a few men in the field, which I will do here. I do not attempt to provide a full history of psychosurgery, as many have already done, but rather highlight notable people and their ideas that contributed to the theory and practice of psychosurgery. After this more detailed history, I will zoom out and examine the practice of psychosurgery and how it came to be accepted, as well as how it fit into debates about what direction the fields of psychiatry and
neuroscience were heading. This chapter will hopefully provide a context with which to critically examine the practice of modern psychiatric neurosurgery.

*The First Psychosurgeon*

Our discussion of the origins of surgery to treat mental illness necessarily begins in the last decade of the 19th century, with Dr. Gottlieb Burckhardt, a Swedish neuropsychiatrist with no surgical training who was the first to attempt to treat purely psychiatric patients by surgical excision of significant chunks of cortical brain tissue (Stone 2001; Cosgrove and Rauch 2005; Diering and Bell 1991; Anderson and Arciniegas 2004). In 1888 Dr. Burckhardt, the director of a small mental hospital in Neuchâtel, Switzerland performed the first surgical procedure on a patient in an attempt to treat her primary symptom: “aggression” (Joanette et al. 1993; Manjila et al. 2008; Stone 2001).

The woman Burckhardt operated on first was 51 years old, and had been at the hospital for 15 years for “manic agitation,” or as Burckhardt put it “irritability and changes in her mood” (Manjila et al. 2008). In an attempt to treat this patient’s illness and loosely based on established localization of the language areas of the brain, on December 29, 1888 Burckhardt “removed 5 g of cortex from 2 cm of the lateral part of the superior parietal lobe and the medial part of the left supramarginal gyrus in a 4-hour procedure” (Manjila et al. 2008). Burckhardt went on to perform three additional surgeries on this same patient, resecting different areas of cortical tissue each time. The patient saw little improvement of her primary symptom according to Burckhardt, though notably after the last surgery she was in a state of “quiet dementia,” no longer speaking continuously or exhibiting aggression towards the hospital staff (Manjila et al. 2008; Joanette et
Burckhardt described the patient as having improved to some degree with the only metric of this success being a quieter patient:

Mrs. B changed from a dangerous and excited demented person to a quiet demented one. She has not regained her intelligence but she has definitely not lost anything that she had before; the continuous flow of her speech has been disrupted and she has become quiet. (Joanette et al. 1993)

Quite disturbingly the record seems to indicate that after the third surgery the patient began to exhibit new positive symptoms that were likely iatrogenic including logorrhea, a symptom marked by continuous nonsensical speech. (Joanette et al. 1993)

Burckhardt went on to operate on five more patients, removing portions of cortical tissue from different regions of the frontal lobe, procedures that have come to be known as topectomies. The patients that Burckhardt operated on had diagnoses including “primary dementia” and “original paranoia” with a very broad range of primary symptoms including “excitement,” “violence,” and “delusions.” In every case, Burckhardt sought to treat these primary symptoms by removing regions of the frontal, frontotemporal, and temporoparietal brain areas. Burckhardt reported that one patient died five days after their surgery, two showed no change in their primary symptoms, two were said to have become “quieter” as a result of the surgery, and one was said to have improved.

Burckhardt shared the results of his surgical procedures at the Berlin Medical Congress soon after his last operation and his results evidently “caused a chill in the room” (Joanette et al. 1993). Not only did physicians at the time feel “ill-at-ease when he presented,” but many expressed outright opposition to his topectomies for psychiatric indications (Joanette et al. 1993; Kotowicz 2005). Wanting to “bury the idea of psychosurgery straightaway,” many clinicians at
the time were firmly opposed to Burckhardt’s work (Kotowicz 2005). Historians and physicians
Manjila et al. cite Giuseppe Seppilli, a neuropsychiatrist as one example of critical opposition to
psychosurgery at the time:

Burckhardt’s modular view did not “fit in well with the view held by most
[experts] that the psychoses reflect a diffuse pathology of the cerebral cortex and
[ran counter to] the conception of the psyche as a unitary entity.” Due to his
theoretical weakness, Seppilli concluded, it would be most unlikely that anyone
would follow Burckhardt’s ideas and procedures and concluded that “an absence
of treatment was better than a bad treatment. (Manjila et al. 2008).

Despite opposition from colleagues such as Sellippi and others concerning theoretical differences
linking the “psyche” and “psychoses” to the structures of the brain, Dr. Burckhardt published the
results of his findings, and even acknowledged that there may be criticism of what he viewed as
pioneering medical work in the following comment near the end of his paper: “Doctors are
different by nature. One kind adheres to the old principle: first, do no harm: the other one says: it
is better to do something than nothing. I certainly belong to the second category (translation by
authors)”(Joanette et al. 1993). Burckhardt, however, did not continue psychosurgical work for
the rest of his life and retired soon after the publication of his report (Stone 2001; Kotowicz

While much of the medical community at the time rejected Burckhardt’s work as
“immoral” and unsupported by the science of the time, Burckhardt’s efforts to treat severe
mental illness by destroying or removing brain tissue was only the beginning for psychosurgical
practice (Stone 2001). Burckhardt may have retreated from psychosurgical research in response
to his colleagues, but four decades later, a few physicians, determined to belong to that “second
category” of doctor that Burekhartd describes, would take up the torch of psychosurgery and forever change the field of psychiatric medicine.

*The man who invented the leucotomy*

In 1935, at the 2nd International Conference of Neurology in London, researchers Fulton and Jacobson presented research that would reignite the practice of surgical ablation, the selective destruction of brain tissue in humans as a potential treatment for mental illness, so much so that the fundamental principle persists in medical practice today. Fulton and Jacobson performed surgical ablation of both frontal lobes in non-human primates and noted that after the surgery the chimpanzees showed less “neurosis” and improved “cooperative[ity]” in completing certain behavioral tasks (Diering and Bell 1991; Cosgrove and Rauch 2005). While this result was accompanied with evidence that the chimpanzees exhibited deficits in their ability to complete the behavioral tasks many took Jacobson and Fulton’s results as evidence that ablating frontal cortical tissue may prove therapeutic in resolving neuroses in human patients (Diering and Bell 1991). None seemed more excited by these results than Egas Moniz, who became convinced that “certain obsessive and melancholic persons could be helped if their frontal lobes were excised,” and who later that year would go on to perform and develop the leucotomy, a frontal lobe procedure for those with mental illness for which he would later win the Nobel Prize (Tan and Yip 2014).

Egas Moniz, a physician and political figure from Portugal, born António Caetano de Abreu Freire in 1874 to an aristocratic family helped transform the science of functional neurosurgery as well as the perception of the scientific community at the time (El-Hai 2005). Dr. Moniz, a previously elected member of “the national parliament of Portugal, minister to Spain,
minister of foreign affairs, and his nation’s signatory of the Treaty of Versailles” was no stranger to the notion of public perception, but in the scientific community, scientific authority is not necessarily accompanied by fame (El-Hai 2005; Tan and Yip 2014). In Dr. Moniz’s case, however, he found himself pushed out of politics in the 1920’s and devoted his time to medical research that ultimately led to his invention of cerebral angiography, a method for visualizing the cerebral blood vessels that is still in use today (El-Hai 2005; Tan and Yip 2014). Prominent clinicians at the time including Dr. Walter Freeman praised the invention: “Here was a new method for exploration of the brain without opening the skull...[observing] not only the normal pattern of arteries and veins, but also their abnormalities in cases of tumors, cysts, abscesses, thrombosis and aneurysms” (El-Hai 2005). Dr. Moniz’s invention of cerebral angiography would garner him a nomination for the Nobel Prize in medicine a year after its invention in 1927, but he would fall short of winning the grand prize that year (El-Hai 2005; Tan and Yip 2014).

Moniz, a neurologist by training soon became very interested in psychiatric illnesses, believing like many at the time that “biologically-based, somatic treatments, not behaviorally based therapies, offered the best hope for these patients” (El-Hai 2005). It was not until after returning from the International Conference of Neurology in London that Moniz began to consider the hypothesis that specific circuits in the brain’s of mentally ill patients could be fixed surgically. Later that year, Moniz and his partner Almeida Lima, a neurosurgeon, with whom he devised a surgery that preserved the brains gray matter and sought instead to sever white matter connections in the frontal lobes as a treatment for severe mental illness (El-Hai 2005). November of 1935, Moniz and Lima operated on their first patient, a 65-year-old woman diagnosed with “depression, anxiety, paranoia, hallucinations and insomnia” (Tan and Yip 2014). For this first procedure Moniz and Lima injected alcohol directly into the brain tissue as a method of
destroying brain cells, and psychiatrist Barahona Fernandes who evaluated the patient after surgery stated that “the patient’s anxiety and restlessness had declined rapidly with a concomitant marked attenuation of paranoid features” (Tan and Yip 2014; Valenstein 1974). Moniz declared this patient cured, and while the patient is said to have reported some relief, she never left the hospital (El-Hai 2005).

Moniz and Lima went on to modify their procedure eventually replacing alcohol injection, used in six patients, with the leukotome, a surgical instrument that consisted of “a wire snare that passed into the posterior aspect of each frontal lobe and rotated in order to cut the white matter” (Haas 2003; Diering and Bell 1991). Moniz and Lima reported on 20 patients, arguing that 14 of these cases were successes based upon subjective evaluation of the patients after surgery (Diering and Bell 1991; Cosgrove and Rauch 2005). Moniz and Lima’s work is highly criticized by medical historians and physicians for its lack of objective measures but also for the poor scientific basis for the procedure:

Moniz’s own theoretical justification for the procedure was weak. Following a strictly biological approach to psychiatric problems, he believed in the presence of pathological circuits in the brain that became fixed and perseverant as a result of abnormal conditioning. These circuits were hypothesized to be associated with specific ideas that reverberated in the brain, creating common symptoms of mental illness such as delusions, obsessions, and anxiety. Moniz further conjectured that the relevant circuits were located in the frontal lobes and in the connections between these lobes. (Tierney 2000)

While there was some criticism from the medical community at the time, Moniz and Lima’s work received general praise from the broader scientific community (Cosgrove and Rauch 2005).
Perhaps, in part the enthusiasm surrounding Moniz and Lima’s procedure, despite its “weak” scientific justification and highly subjective results, resulted from the dire conditions that characterized mental asylums at the time, where there were few available treatments for individuals with chronic, severe mental illness (Cosgrove and Rauch 2005; Tierney 2000; El-Hai 2005).

Moniz would eventually garner the Nobel Prize in Medicine for his work with Lima on the prefrontal leucotomy, the first official “psychosurgery,” a term coined by Moniz himself (El-Hai 2005). The Nobel committee in 1949 that awarded Moniz with their highest honor described his work as “one of the most important discoveries ever made in psychiatric medicine” (Haas 2003). Many experts in the field did not support Moniz’s work, because they felt the surgery was based on loose hypotheses and the results were not convincing. Dr. José de Matos Sobral Cid, a prominent Portuguese psychiatrist, and director of the hospital where Moniz worked went as far as to call the supposed link between psychiatric behavior and pathology neural circuitry “pure cerebral mythology” (El-Hai 2005; Lieberman and Ogas 2015). Regardless of controversy, many in the field did support Moniz’s works, and few did so as adamantly as Dr. Walter Freeman, who would take Moniz’s procedure and run with it making psychosurgery a mainstay of psychiatric practice in the United States for decades (El-Hai 2005; Valenstein 1974).

**Bringing Psychosurgery to the US**

Walter Jackson Freeman was born in 1895 to Corinne Keen Freeman, the daughter of William Williams Keen a prominent surgeon who was among the first physicians to successfully remove a brain tumor (The Editors of Encyclopædia Britannica 2009; El-Hai 2005). After attending Yale as an undergraduate, and later medical school at the University of Pennsylvania,
Freeman earned his medical degree and specialized in neurology, interested primarily in pathology (El-Hai 2005; Rogers 2015). Thanks to connections in the medical community through his grandfather, Dr. Keen, Freeman was able to assume a position in 1924 as “director of laboratories at Saint Elizabeth’s Hospital, then a leading psychiatric institution in Washington, D.C.” (Rogers 2015; El-Hai 2005). Freeman would soon take up a position as professor at the George Washington School of Medicine and gain some acclaim as a neuropathologist, all the while treating patients at Saint Elizabeth’s and growing more interested in the treatment of individuals with psychiatric illnesses (El-Hai 2005).

In 1935, Freeman attended an annual medical conference in London that would change the course of his career forever. Freeman presented some research at the conference, but the issue most hotly debated that year were the findings by Dr. Moniz who had first revealed the findings of his initial leucotomies (El-Hai 2005). Fascinated by the new work being presented, and seeing an opportunity, Freeman “initiated a correspondence with Moniz” a year after the conference, praising his research and setting into motion the beginning of psychosurgery in the United States (El-Hai 2005). “‘I enjoyed particularly your research on the reduction of psychotic symptoms following operation on the frontal lobe,’ Freeman wrote, and ‘I am going to recommend a trial of this procedure in certain cases that come under my care’” (El-Hai 2005). Moniz responded to Freeman enthusiastically, encouraging him to carry out his procedure and report back his results (El-Hai 2005).

Later in 1936, Freeman, like Moniz before him, partnered with a neurosurgeon to carry out procedures on certain psychiatric patients (Rogers 2015). James W. Watts was a neurosurgeon trained by Harvey Cushing who is regarded by many as the father of modern neurosurgery (Rogers 2015). Watts, after being persuaded by Freeman, took up a position at the
George Washington University medical school where Freeman worked (El-Hai 2005). Almost immediately, Freeman and Watts set out actualize their plans of carrying out psychosurgical procedures, inspired by Moniz’s results as well as those of Fulton and Jacobson, whom Watts knew professionally (El-Hai 2005).

In September of 1936, Freeman and Watts completed their first psychosurgery with Moniz's method on a 63-year-old woman named Alice Hammatt who came to Freeman seeking help for her symptoms of "insomnia, anxiety, and debilitating depression" (El-Hai 2005; Rogers 2015). Soon after Alice was checked into the George Washington University Hospital by Freeman, her symptoms deteriorated and Freeman noted that she “showed uncontrollable apprehension, was unable to sleep, laughed and wept hysterically” (El-Hai 2005). Soon after the surgery, which resulted in no unplanned hemorrhage or other complications, Ms. Hammat was followed-up closely by Freeman who reported that she was much improved:

A month after operation, the patient asserted that she was no longer inclined to worry, that she could follow out a trend of thought without distraction, that she could enjoy the company of a very energetic friend whose company formerly she could scarcely endure without exhaustion, and that she was content to grow old gracefully. She was well dressed, talked in a low natural tone, volunteered relatively little, but upon questioning showed excellent appreciation of her changed condition. Her husband asserts that she is more normal than she has ever been. (Pressman 2002)

While the theoretical basis for Moniz’s procedure had been criticized, with Freeman himself even admitting in a review of Moniz’s operations that his theory was “naïve,” Freeman and
Watts were very encouraged by the response of this first patient to the surgery and proceeded full speed ahead (Pressman 2002; El-Hai 2005).

Freeman and Watts were determined to complete psychosurgical procedures so much so that within two months of their first procedure they had completed surgeries on their first six patients for a variety of indications including obsessive-compulsive disorder, suicidality, and schizophrenia (El-Hai 2005; Pressman 2002). The patient treated for obsessive-compulsive disorder had struggled with contamination obsessions for 30 years that forced her to wash her hands for hours and clean excessively (El-Hai 2005). The leucotomy according to Freeman resulted in a short-lived improvement where she shared that she “realized [her] fears were foolish” and was able to have an “anxiety-free life” until her symptoms of obsessions and compulsions returned in full force six weeks after discharge (El-Hai 2005). Another patient suffering from severe depression and brain damage showed no improvement after the leucotomy: “Freeman found that she ‘[was] still quite confused, inattentive, and forgets easily’” (El-Hai 2005). In addition, this surgery came with complications since Freeman and Watts damaged several blood vessels in the brain during the operation, which led the patient to suffer incontinence and seizures (El-Hai 2005). Freeman and Watts would go on to report the results of their first six patients in late November of 1936 convinced that the operations overall had been a success: “These symptoms have become more placid, more content, and more easily cared for by their relatives. The symptomatic relief has been almost immediate, and has persisted to the present time” (Pressman 2002).

Watts and Freeman modified Moniz’s surgery after performing the leucotomy on about 20 patients by accessing the brain through two burr holes on the side of the skull (Valenstein 1974; El-Hai 2005). The American physicians called their modified technique the “precision
method,” because they hypothesized that the anatomical landmarks were more consistent from patient to patient, and they would use “X-Ray view of the lateral ventricles to guide the knife severing the fiber connections of the frontal lobes” (Valenstein 1974). The method Freeman and Watts used to access the white matter tissue is illustrated in Figure 1. Watts and Freeman called their modified procedure the “lobotomy,” a procedure whose impact would leave an indelible mark on American neurosurgery, psychiatry, and medicine as a whole.

Figure 1. This diagram illustrating Freeman and Watts’ modified lobotomy was taken from W. Freeman and JW Watts, Psychosurgery in the treatment of Mental disorders and Intractable Pain, 2nd edition (Valenstein 1974).

After widely perceived success lobotomies became a go-to clinical practice for individuals with “untreatable” mental illnesses with Freeman and Watts alone having operated on 1000 patients by 1950 (Valenstein 1974). Freeman would again modify the procedure in 1946, this time unbeknownst to his partner, in an attempt to make the procedure an outpatient one. Through careful review of the literature, Freeman came across an operation described by Italian physician Fiamberti who destroyed prefrontal white matter by chemical ablation after inserting a type of cannula or large needle through the anterior eye socket (El-Hai 2005; Valenstein 1974; Pressman 2002; Rogers 2015). Freeman would modify this approach and instead opt to mechanistically sever prefrontal white matter fibers by inserting an “ice-pick,” which was later replaced with “a specially forged instrument – a stronger, blunter, and calibrated
version which [Freeman] termed a ‘transorbital leucotome’” (Pressman 2002). The transorbital
leucotome would be “inserted through the orbital roof into the brain and the handle… swung
medially and laterally to sever fibers at the base of the frontal lobes” (Valenstein 1974). See
Figure 2.

Figure 2. This drawing illustrates the point of access and essential steps in the transorbital
leucotomy that Freeman developed. Since the operation was a closed procedure that did not involve opening the skull from above in an
operating room as was the case with the lobotomies, Freeman thought the transorbital surgery would be less
expensive and could be completed as an outpatient procedure. The figure is taken from W. Freeman, "Transorbital

Freeman developed the transorbital leucotomy without informing Watts, and even began
performing the operation himself on a few patients in 1946 (El-Hai 2005; Valenstein 1974;
Pressman 2002; Rogers 2015). Watts soon learned of the procedure after Freeman shared the
results of a subset of patients he had operated on, and Watts was reportedly furious and
threatened to dissolve their partnership (Rogers 2015; Pressman 2002). Freeman believed the
transorbital leucotomy to be a minor procedure, but Watts adamantly disagreed:

> It is Walter Freeman’s opinion that transorbital lobotomy is a minor operation.

This is clearly indicated by the fact that of the first ten cases he reported, four
were not disabled and six had been disabled less than six months…. It is my
opinion that any procedure involving cutting of brain tissue is a major surgical
operation, no matter how quickly or atraumatically one enters the intracranial cavity. (Valenstein 1974)

Watts concerns were also expressed by others in the surgical field who felt that the potential risks of hemorrhage or injury to unintended brain regions in a closed procedure completed in an outpatient setting were quite high (Valenstein 1974; Rogers 2015; Pressman 2002). Freeman and Watts eventually did end their partnership, as Freeman “performed the procedure elsewhere and for a period of time toured the country, operating on patients in hospitals and sometimes in other settings, such as hotel rooms” (Rogers 2015).

Freeman continued to operate through the 1950s and even 60s after many had left psychosurgery behind, in favor of psycho-pharmaceuticals that had become “increasingly sophisticated” (El-Hai 2005). In February of 1967, Freeman’s career as a psychosurgeon ended with his last transorbital lobotomy patient passing away, due to complications in the procedure: “This time, to my dismay, she had a hemorrhage and died in three days…. This was the last day I operated” (El-Hai 2005). Freeman enjoyed a dazzling career in which he introduced the lobotomy to psychiatry resulting in an estimated 40,000 procedures performed in the United States alone, countless published articles, and even an individual tally of nearly 3500 patients whom he operated on himself (Valenstein 1974; Rogers 2015).

**Psychosurgery in context**

Psychosurgery as it was practiced in the late 19th and early to mid-20th centuries was highly contentious and fraught with fundamental problems. Even very early on, after Burckhardt’s initial experimental procedures, psychosurgery faced a great deal of criticism. Many of the problems in psychosurgery arose from either a poorly understand foundation of
basic science about how the brain functions or from questionable clinical research practices and findings.

When considering the state of neuroscience at the inception of psychosurgery it is critical to keep in mind when the first surgeries were done. At the time of Burckhardt’s experiments very little was understood about how the brain functioned relative to what we now know. For instance, it was only about a decade before Burckhardt's first surgeries in 1873 that scientist Camillo Golgi first discovered how to visualize neurons under the microscope, and it was not until 1887, a year before Burckhardt began his surgeries that Santiago Ramón y Cajal was able to define and characterize the cellular structure of these key functional units of the nervous system (Schoonover 2010). The existence of neurotransmitters, the primary mechanism by which brain cells communicate with one another and the basis of modern psycho-pharmacotherapy, had not even been discovered by Otto Loewi (McCoy and Tan 2014).

Perhaps the point is more effectively made if we consider what was not known even when Moniz and Lima performed their first leucotomies. Little to nothing was known about neurotransmitters, and virtually nothing was known about how neurons communicate with one another via synaptic transmission. The research that uncovered and began to describe these phenomena was not done until the 1950s by Fatt and Katz (Purves et al. 2001). Watson and Crick had not and would not for another twenty years have isolated and discovered the structure of DNA (Beckett 2004). And these are just a few salient examples. Our understanding of biological science and especially neuroscience was very poor when psychosurgeries were first being performed, and while it is easy to look back on the state of science and marvel at what was not known, it is clear from critics at the time, that scientists were aware to some degree that the
science of the brain was not advanced enough to be able to justify much of the theoretical basis for ablative procedures (Valenstein 1974; Joanette et al. 1993).

Given how little was known it is remarkable that researchers like Moniz and Freeman were able to carry out clinical investigations to the degree that they did and report successes, but the reliability of this clinical work is questionable. Valenstein argues that a problem facing psychosurgical investigation was the lack of objectivity in analysis:

One recurrent difficulty in evaluating all psychosurgical procedures is that it is usually not possible to make an independent judgment about the results. Clinical records generally are written in a very subjective style, leaning heavily on impressions of the ward staff. It is rare indeed that any data obtained from objective tests are included in the reports. (Valenstein 1974)

The “subjective style” that Valenstein discusses includes the ways in which physicians report how a patient responded to surgery. This is especially challenging in psychiatry because at the time, as well as today, much of the diagnostic process relies upon subjective analysis and description of symptoms. The lack of a consistent metric to determine whether the psychosurgeries were successful made the resulting analyses difficult and their findings ungeneralizable. For instance, one well-known retrospective review of over 10,000 psychosurgical cases between 1943 and 1954 conducted by Tooth and Newton found that 70% of patients were said to have “improved” (Cosgrove and Rauch 2005). But the definition of “improvement” was unclear and likely variable from case to case and physician to physician:

Although the large-scale evaluations of prefrontal lobotomy appear to present favorable statistics, considerable skepticism towards these figures has to be maintained. In judging improvement, most of the studies gave exaggerated
weighting to the elimination of behavior that was most troublesome to the hospital staff and society in general and attached considerably less importance to the qualitative aspects of the adjustment level. (Valenstein 1974).

Here Valenstein points out the need for being critical of the results of psychosurgical reports, one because the subjective nature of the analyses can become dangerous when “exaggerated weighting” obscures the degree to which a patient is affected by a surgical procedure. In addition, Valenstein also makes the critical point that “improvement” was often determined by whether or not a “troublesome” behavior that placed a burden on hospital staff or society at large was eliminated or reduced by the surgery, and it should be noted that this may or may not be related to the most problematic symptom of a patient’s pathology.

Psychosurgeries were carried out more and more frequently in hospitals throughout the United States in the 1940s and 50s. Many of these cases were likely poor indications for surgery and ablation in some cases may have done more harm than good. Take for instance the case of a 6-year-old girl that Freeman and Watts operated on for her “pattern of destructive behavior,” which included “using toys as weapons and tearing her clothes” (Valenstein 1974). This patient ended up having two surgeries and after the second operation, she was described as "quite withdrawn, but less troublesome” (Valenstein 1974). Where we draw the line between pathological and healthy or normal behavior is not always clear. Unfortunately, there did, however, seem to be cases such as that of this little girl where the definition of "pathology" appeared to be set not by the well-being of the child but by how “troublesome” she was for her caretakers to deal with. Undoubtedly too many procedures were done in hindsight, and many of them were likely done for the wrong reasons.
Many medical ethicists, historians, and clinicians today, look at the unregulated and often poorly justified psychosurgery of the 20th century as a set of “barbaric” methods that only rarely succeeded in achieving the goal of treating those with mental illness. Given the numerous problems that were underlying the science and medical practice of psychosurgery, it is difficult in retrospect to understand how the practice became so widespread in American psychiatry. However, it is critical to keep in mind the poor state of psychiatric medicine and the limited understanding of neuroscience at the time.

In the 1920s, American psychiatric hospitals were often overcrowded and many of the institutions “lacked treatments that healed, or even helped, many patients” (El-Hai 2005; Cosgrove and Rauch 2005). Psychiatric historian Edward Shorter described mental hospitals at the time as a type of “sterile incarceration” where “there was little scientific understanding of mental illness” and “one could cure nothing” (El-Hai 2005). The poor living conditions that marked psychiatric institutions such as the one in which Dr. Freeman found himself at St. Elizabeth’s Hospital were often dehumanizing:

Freeman initially regarded most of the forty-three hundred patients at St. Elizabeth’s as pitiful and disgusting. They made him experience “a weird mixture of fear, disgust, and shame,” he wrote. “The slouching figures, the vacant stare or averted eyes, the shabby clothing and footwear, the general untidiness—all aroused rejection rather than sympathy or interest.” (El-Hai 2005)

This passage provides some insight about the state of psychiatric institutions at the time, and many of the feelings Freeman expresses were not uncommon among “younger, often idealistic psychiatrists,” who Shorter discussed often “sought alternatives” to working at these hospitals.
(El-Hai 2005). One can begin to imagine the desperation of clinicians and the broader public for treatments that at least seemed to offer some relief for patients.

During the advent of psychosurgical procedures, the available treatments for patients were highly ineffective. Freudian psychoanalysis was in its prime amongst American psychiatrists at the time, but therapeutic techniques that were offered were very often ineffective for a large and growing proportion of the mentally ill population. Dr. Benjamin D. Greenberg MD, Ph.D., clinical neuropsychiatrist and prominent researcher in the field of psychiatric neurosurgery at Butler Hospital described the growing sentiment towards psychoanalysis at the time in saying that “psychoanalysis overpromised and under delivered” (Dr. Greenberg Interview). This notion about psychoanalysis was beginning to be uncovered at the time of psychosurgery as well. For instance in 1948 researchers found it difficult to assess “the medical effectiveness” of psychoanalysis because of inconsistency and lack of cooperation in the discipline (El-Hai 2005). In 1962, a study on schizophrenic patients showed that patients receiving psychotherapy actually did worse than those treated with medication and those who received no treatment at all, proving what many clinicians already believed based on their hospital experiences (El-Hai 2005).

Psychosurgery was able to enter as a therapeutic option and perhaps gained popularity because it offered a way to treat at some level a whole array of patients. While it is often discussed that the patients treated with psychosurgery at the time were the most severe patients, the notion of severity is a sliding scale. If patients had limited options and the therapies available were poor, then it is likely that the population of very severe mentally ill patients was different from what it is now, simply because improved treatment has redefined what it means to be a severe patient. This notion explains both the rise and fall in popularity of psychosurgery. The rise
in popularity of psychosurgery makes sense given the limited availability of treatments. Even though surgery was considered a radical option for only the most extreme cases, it was one of the few that actually appeared to benefit patients. And it was not until 1954 and the introduction of chlorpromazine, a “tranquilizing medication” that came to be known as the first antipsychotic drug, that a seemingly less risky and similarly efficacious therapeutic option was able to outcompete prefrontal lobotomies, bringing us out of the era of psychosurgery and into that of psycho-pharmaceuticals.

*What Psychosurgery left behind*

While psychosurgery had many problems, including as we have discussed a weak underlying theoretical and scientific basis, highly subjective clinical research practices, and harmful overuse in American psychiatric practice, it is not without its merits. Indeed, while there was a poor scientific understanding of the brain at the time when these procedures were first being conducted, it is remarkable how to some degree clinicians were able to identify that selectively damaging brain regions such as prefrontal cortical white matter support, at least some, individuals. While the degree to which patients improved is questionable, without a doubt there were numerous cases of patients that themselves reported getting better as a result of their surgeries. From our vantage point today, we may easily forget these successes just as Freeman and colleagues may have been tempted to exclusively highlight them, but I caution characterizing the complex and nuanced history of psychosurgery in broad sweeps. Dr. Elliot Valenstein offers the following more useful view near the end of his book *Brain Control:*

> In general, there seems to be strong suggestive evidence (if not absolutely convincing) that some patients may have been significantly helped by
psychosurgery. There is certainly no grounds for either the position that all psychosurgery necessarily reduces people to a “vegetable status” or that it has a high probability of producing miraculous cures. The truth, even if somewhat wishy-washy, lies in between these extreme positions. (Valenstein 1974)

Going forward in this thesis I aim to elucidate and critically examine psychiatric neurosurgery as it continues to be practiced today, focusing on the modern scientific underpinnings of the practice, the perspectives of clinicians who take part in psychiatric neurosurgery today, and the lived experiences of patients who undergo psychiatric neurosurgical procedures.
Chapter 2: State of Psychiatric Neurosurgery Today

Despite the somewhat immediate shift from psychosurgery to psychopharmacotherapy in the 1950’s, psychosurgery left an undeniable mark on the history of psychiatric practice. Here I argue that psychosurgery brought about two interconnected paradigm shifts in the way we conceptualize the brain and the mind that paved the way for modern psychiatric neurosurgery. The first shift, most notable in the field of psychiatry, involved changing the way mental illness was viewed: as problems with a biological basis rather than solely subjective experience with patients who have not adjusted well from trauma or other life events (Samuel H Barondes 1990). The second shift I will discuss encompasses the older and broader argument of whether the mind or soul is situated in the organ of the brain.

Biological Psychiatry

The shift from the psychoanalytic, Freudian view of mental illness to a more biological view of the mind had been developing with the growth of neuroscience, but I would argue that very few scientific pursuits solidified the connection between the mind and the anatomy of the brain as much as psychosurgery. By showing, case by case, that altering or destroying tissue in the brain led to marked changes in personality, mental state, and in some cases mental illness psychosurgeons paved a path for a new “biological psychiatry.” This ideological shift in conceptualizing mental illness as a question of neural circuitry also supported the subsequent rise in psychopharmaceuticals because they too could address the biological “origin” of mental illnesses but seemed to do so with less risk.
In the heyday of psychosurgery as was discussed in the last chapter better therapies for mental illness were desperately sought. With this new search came a progressive ideological shift towards conceptualizing mental illness as a disease that was fundamentally tied to the brain.

Over the course of the 20th century, many “biologically oriented psychiatrists” presented a compelling argument in favor of situating diseases of the mind in the brain. These self-titled organicists were “those who believed that psychiatric illnesses resulted from biological disorders of the brain.” (El-Hai 2005). Their argument stood in contrast to those of many other psychiatrists and psychoanalysts who believed that “mental disease originates… in an individual’s imperfect adjustment to life events and traumas” (El-Hai 2005). Here we see that the “organicists” viewed psychiatric illnesses in a manner distinct from many psychologists in the early 20th century.

One might imagine, correctly, that Dr. Walter Freeman, the most infamous psychosurgeon of the 1900s, was a believer of the “organicist” model to understanding mental illness. As a neuropathologist, Freeman often viewed psychiatric patients under the lens of biological psychiatry or organicism, a prevailing view of psychiatric illness that was strictly opposed to Freudian psychoanalysis arguing that treatments for psychiatric illnesses needed to address the biological roots of disease:

[Freeman] called the neural network of the brain “the matrix of the mind” and asserted that “interrupting the vicious circles which form the basis of abnormal states” could successfully treat psychiatric disorders. (El-Hai 2005)

Freeman went on to assert that “Mental disease in fact can be looked upon as little more than [the brain’s] faulty interpretation of sensory data… and if it is possible to help the mentally ill to interpret their sensations more correctly, it is clearly our duty as physicians to do so, whatever
may be the means employed to achieve this end” (El-Hai 2005). In the above passages, we see the perspective held by Walter Freeman of mental illness as a disease of the nervous system, and this is a good representation of the view held by professionals who supported psychosurgery at the time.

Many psychiatrists were attracted to the approach of biological psychiatry, in part because it fit well with established models of treatment in other medical disciplines, which already used surgical and pharmaceutical techniques with a high degree of efficacy. The push for biological psychiatry was so strong that modern psychiatric practice aligns almost entirely with a biological view of mental illness. Dr. Samuel Barrondes, a psychiatrist at the University of California San Francisco argued in the early 1990’s in favor of a continued development of biological models of psychiatric illness claiming that “psychiatry [had] been dominated, for many years, by subjective approaches to mental illness that are as far as one can get from quantitative science” (S H Barondes 1990). This criticism of psychiatry, marks an important point in history when the field of neuroscience began to bloom in the United States, the field of psychiatry began moving towards what they considered a more robust biological approach that Barrondes believes “psychiatry already accommodates” (S H Barondes 1990).

The shift towards biological psychiatry, while supported by psychosurgery and blossoming psychopharmaceutical treatment of mental illnesses was also supported by evolving medicine that was able to cure or eradicate previously untreatable psychiatric illnesses. Barondes cites psychiatric disorders for which “overt brain pathology” has been discovered including “dementia paralytica” and “phenylketonuria,” that have been dramatically improved in clinical treatment through a biological approach. Biological psychiatry one might say holds the position that psychiatric illnesses are fundamentally neurological illnesses, or illnesses of the brain, for
which the biological mechanism of action is not fully understood and for which brain functions or malfunctions rather than structure alone are responsible. Through biological science, physicians are equipped with tools and modes of analysis that are promising for many psychiatrists, in so far as it offers the kind of “quantitative data” that Barondes discussed as a missing component of psychiatric practice in the past. In that regard, researchers have sought to uncover the genetic and molecular basis for different mental illnesses in the hopes of advancing psychiatric treatment:

…contemporary social and behavioral sciences appear to be as limited in addressing psychotherapy and psycho-prophylaxis as the biology of Freud’s time was in approaching the molecular genetics of mental illness. So the next revolution in psychiatry must await new ways of approaching behavior. Meanwhile, the psychiatrists and biologists who are committed to a molecular approach to mental illness can confidently look forward to some very productive years. (S H Barondes 1990)

Here Barondes, points to an important lack in the ability to analyze behavior well, acknowledging, as do many practitioners today, that better methods are needed to study the social and behavioral facets of mental illness. Only after making this point does he uphold biological psychiatry as a critical approach for advancing our knowledge of mental illness.

As with many positions in ideology, an extreme view in favor of biological psychiatry can be dangerous. In particular, biological psychiatry can render subjective experience and the role trauma can play in disease inconsequential. This fault is best elucidated by the extreme position held by Walter Freeman who believed “Patients with mental disease are often poorly equipped to discuss their symptoms” so much so that he “used to remind the students” at
Georgetown medical school “to rely on objective or laboratory findings rather than upon the [patient’s social and medical] history” because treating individuals with mental illness was for him “like veterinary medicine” (El-Hai 2005). This shocking and inhumane perspective elucidates how biological psychiatry that ignores patient experience can become harmful, and can even lead to the radical experimentation with psychosurgery that later marked Freeman’s career.

*From Dualism to Embodiment*

The second ideological shift I will discuss was philosophical and inherently linked to the shift towards a more biological psychiatry. This philosophical shift spurred by psychosurgery and neuroscience more generally, attempted to answer an even broader question about human experience: whether the mind and the brain were one and the same. In the 17th century, philosopher René Descartes distinguished between the mind and the body arguing that “the existence of two classes of substance that together constituted the human organism: palpable body and intangible mind” were inherently separate (Schepers-Hughes and Lock 1987). Descartes posited that the mind or spirit is a metaphysical entity that is separate from the physical body and only communicates its desires to the body through the brain’s pineal gland, which he believed to be the “seat of the soul” (Bear, Connors, and Paradiso 2007; Yalowitz 2012). More specifically, Cartesian Dualism as it is known opted for a model of conceiving of the mind or mental phenomenon as necessarily distinct from the body and its organs:

According to Descartes, mind and body are distinct substances in part because they do not share essential properties in common. In particular, minds do not occupy a spatial location, while bodies necessarily do. Since mental events
thus constitute changes occurring in a nonspatially-located entity, they also do not occupy a spatial region. Bodily events, on the other hand, do occupy spatial locations by virtue of being changes in material substances, which themselves are spatially located. (Yalowitz 2012)

As we can see Descartes’ view is in stark opposition to the fundamental notions of the organicists or biological psychiatrists who aimed to treat diseases of the “mind” by primarily altering the structure of the tangible “body,” specifically the brain (Yalowitz 2012; Smart 2007).

The position in the field of neuroscience today directly opposes this Cartesian Dualism arguing instead for a model that situates, or at the very least correlates the conscious phenomena of the mind to the biochemical and molecular processes of the brain. Nobel laureate and neuropsychologist Roger Wolcott Sperry was among the first neuroscientists to explicitly oppose mind-brain dualism:

Conscious phenomena as emergent functional properties of brain processing exert an active control role as causal determinants in shaping the flow patterns of cerebral excitation. Once generated from neural events, the higher order mental patterns and programs have their own subjective qualities and progress, operate and interact by their own causal laws and principles, which are different from and cannot be reduced to those of neurophysiology. (Sperry 1981)

What Sperry discusses here is a model for understanding how mental or, “conscious phenomena” both emerge from brain processes and drive or control neural activity. Interestingly, this notion aligns well with a model of “embodiment” taken from modern feminist and anthropological theory that, unlike Cartesian dualism, argues in favor of a unified view of the brain and mind
(Scheper-Hughes and Lock 1987; Haraway 1988; Keller and Scharff-goldhaber 1987). Now recent feminist philosophical theory of embodiment, approached from the perspective of addressing social phenomena that give rise to gendered experience, situates not only the mind and conscious phenomena in the biology of the body, but also “has extended beyond a simple reductionist picture of the relation between mind and brain, to consider an embodied self, embedded within an environment” (Lennon 2014). It is within this later anthropological and feminist theoretical framework that I base my methodological framework for phenomenological analysis in subsequent chapters of this thesis.

While psychosurgeons did not necessarily go as far as to support a social embodiment, they did support embedding the mind within the brain. In fact, psychosurgery as a field depends upon a collective rejection of mind-body dualism, in favor of an embodied mind that for better or worse situates maladies of consciousness, mental illnesses, in the neural circuitry of the brain. Psychosurgery pushed against a dualistic model of the mind and brain, which persisted into modern psychiatry even as the field evolved.

Modern Psychiatric Neurosurgery

While psychosurgery has fallen out of favor in the public eye of modern western medicine, surgical treatment aimed at treating certain mental illnesses never truly ended. Today, very few procedures are conducted around the world to treat individuals with mental illness that is not amenable to conventional pharmaceutical and behavioral therapies (McLaughlin; Bourne et al; Anderson et al; Doshi et al). Clinicians involved in conducting these procedures differentiate the modern neurosurgical interventions for mental illness, termed “psychiatric neurosurgery”, from the ethically contentious psychosurgery of the past by emphasizing that the
current clinical practice today is highly specific, more ethically-conscientious, and guided by much-improved scientific knowledge about the biological bases of certain mental illnesses (Greenberg).

Modern psychiatric neurosurgery is predominantly aimed at treating severe depression and Obsessive-Compulsive Disorder (OCD). It is on the latter that I will focus the rest of my analysis in this thesis. Specifically, I will first discuss the scientific rationale and theory behind psychiatric neurosurgery for OCD and then address clinical studies of psychiatric neurosurgery, attending specifically to the methods of surgery, analysis, and the efficacy of treatment options.

*Modern Psychiatric Neurosurgical Practice*

Despite significant advances in clinical pharmacotherapy for mental illnesses there remains a significant number of patients within many psychiatric illness categories that are considered to have “medically refractory” or “intractable” illness (Greenberg et al. 2003a). Medically refractory or intractable mental illness is defined as illness that for one reason or another is not amenable to conventional pharmacological and cognitive-behavioral therapy (Rasmussen et al. 2000; Greenberg et al. 2003a; Cosgrove and Rauch 2005). In OCD, it is believed that anywhere from 10 to 20% of the population is medically refractory or does not respond to traditional pharmaceutical and cognitive behavioral therapy (McLaughlin; Greenberg et al. 2003). This represents a significant number of individuals OCD that do not achieve sustainable improvement in their obsessions or compulsive behaviors, and who often are “extremely ill and essentially nonfunctional” (Jenike et al. 1998). Researchers and clinicians who conduct neurosurgical procedures today for OCD patients often cite the severity and intractability of patient illness saying that “clinicians are obligated to consider any treatments,
even neurosurgical options, that could possibly provide some relief” for “such treatment-refractory and severely ill OCD patients” (Jenike et al. 1998).

While the days of conducting thousands of psychosurgeries a year for various clinical indications is over, “the use of surgery to treat tough psychiatric problems never truly vanished” (El-Hai 2005). Physicians in the 1980s and 90s instead turned to surgical techniques that aimed to be less invasive and enabled “great[er] precision” (Jenike et al. 1998). Today, “a few centers in the world” conduct surgical procedures as a “therapeutic option for intractable illness” and the number of surgeries performed annually in the United States is said to be around 250, a marked decrease from the estimated average of 3000 procedures a year from 1936 to 1956 (Jenike et al. 1998; Anderson and Arciniegas 2004; Feldman, Alterman, and Goodrich 2001). Of those 250 estimated psychiatric surgical operations only a handful of them are for OCD, and a number of distinct surgical procedures are conducted to treat the same illness at different medical centers: “Each center tends to favor one particular type of operation, often determined by local tradition rather than by comparison of the relative merits of different methods” (Jenike et al. 1998).

The procedures I will discuss first are known as ablative procedures, and like the early work of psychosurgeons operate under the theory that certain psychiatric pathologies could be treated by the removal or destruction of specific brain tissue (Jenike et al. 1998; Valenstein 1974; El-Hai 2005). Unlike the lobotomies performed by Freeman these procedures continue into the modern day because they have shown significant safety, in part due to smaller, more precise lesion placement, and exhibit some notable efficacy in terms of providing some relief to patients (Jenike et al. 1998; McLaughlin, Stewart, and Greenberg 2016). It should also be noted that some of the precision in these procedures derives not only from the technical capacity of surgeons and technology, but also enhanced specificity when it comes to the diagnoses for which
surgery is being considered. As I mentioned earlier, rather than being employed for a wide variety of clinical presentations, psychiatric neurosurgery is almost exclusively used to treat two specific diseases: depression and OCD. I will focus on those procedures that have been aimed at specifically treating OCD and have shown some efficacy in relieving OCD symptoms in patients.

There are four ablative procedures, surgeries that remove or destroy tissue, in use today to treat OCD, and they include subcaudate tractotomy, cingulotomy, limbic leucotomy, and capsulotomy. Each surgery is named for the brain region or neural fibers in which the lesion is made, and a variety of techniques have been used to create those lesions as we will discuss in more detail. In addition to the ablative procedures, which bear resemblance to older psychosurgical work, more recent work in the past decade has made use of Deep Brain Stimulation (DBS), a technology that has revolutionized movement disorders and is now in use as a way of disrupting, through electric stimulation, neural activity in specific brain regions to treat OCD symptoms (Kopell, Greenberg, and Rezai 2004; Abelson et al. 2005). In an effort to provide a comprehensive review of the procedures in use to treat OCD, I will describe each ablative procedure in detail and only briefly mention the relatively new use of DBS going forward. For the ablative procedures, I will describe the intended target(s) or region(s) in the brain, the methods of ablation used and how they work, and the clinical efficacy of each procedure in terms of treating intractable OCD.

Subcaudate Tractotomy

In 1964 Knight and colleagues in London, developed the subcaudate tractotomy, a procedure intended to create a bilateral lesion in the gray and white matter fibers ventral and anterior to the head of the caudate nucleus (See Figure 3) (Cosgrove and Rauch 2005; Jenike et
al. 1998; Rasmussen et al. 2000). This procedure was first successfully achieved by using “beta radioactive 90-Yttrium rods” that were inserted into the desired brain region in rows, but this method has since been replaced with a thermocoagulation method by which a probe is inserted into burr holes in the skull and heat is used to destroy tissue in the specific area described above (Jenike et al. 1998; Rasmussen et al. 2000). Researchers at the time used X-ray ventriculogram imaging to view the anatomical target after surgery, and relied upon skull sutures and other anatomic landmarks to place the lesion during the operation (Jenike et al. 1998; Rasmussen et al. 2000; Newcombe n.d.; Knight 1972). This lesion location is intended to interrupt “the relay between the cortex and thalamus via the striatum,” which is hypothesized to be beneficial in reducing OCD symptoms (Rasmussen et al. 2000).

Two major retrospective studies examining the efficacy of subcaudate tractotomy in treating OCD were published in the early 1970s by Strom-Olsen and Carlisle as well as by Göktepe et al (Jenike et al. 1998; Cosgrove and Rauch 2005). In both studies approximately 50% of 20 or so patients included in the studies were said to have “either completely recovered” or showed “clinical improvement” in their OCD symptoms after a minimum of 1-year follow-up. More recent review of 1,300 patients who underwent psychiatric neurosurgical procedures, revealed that 40-60% of patients showed some improved outcome after subcaudate tractotomy (Shah et al. 2008; Greenberg et al. 2003).
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Figure 3. This figure illustrates the anatomical locations for lesions in the subcaudate tractotomy (3) and the cingulotomy (2). This figure is taken from Greenberg, Benjamin D, Scott L Rauch, and Suzanne N Haber 2010 Invasive Circuitry-Based Neurotherapeutics: Stereotactic Ablation and Deep Brain Stimulation for OCD. Neuropsychopharmacology 35(1). Nature Publishing Group: 317–336.

Cingulotomy

First proposed by Fulton, removal or destruction of the anterior portion of the cingulate gyrus is a procedure that has remained and shown considerable benefit in treating patients with both OCD and depression (Cosgrove and Rauch 2005). The cingulotomy involves a lesion in the target region shown in Figure 3(2) and “interrupts afferent and efferent connections between the anterior cingulum, the ventral striatum, the anterior dorsomedial, and other midline nuclei of the thalamus,” is one of the most widely used surgical procedures to treat OCD (Rasmussen et al. 2000; Cosgrove and Rauch 2005). Whittey and colleagues were the first group to show considerable benefit in treating patients with OCD using the cingulotomy: “Four out of five patients in their initial sample showed significant improvement in symptoms and function” (Rasmussen et al. 2000). Much of the work involving the placement of lesions in the anterior cingulate gyrus was conducted at Massachusetts General Hospital (MGH) and here is how that psychiatric neurosurgical team describes the method of conducting the cingulotomy:
Initially these procedures were carried out with ventriculography but over the past several years this has been replaced by MRI (Magnetic Resonance Image) guided stereotactic techniques. Target coordinates are calculated for a point in the cingulum 7 mm from the midline and 20 - 25 mm posterior to the tip of the frontal horns. Lesions are created by thermocoagulation, the technical details of which have been well described previously. Intraoperative stimulation is not performed routinely but neurological testing is carried out during lesioning to insure that no impairment of motor or sensory function especially in the lower extremities is incurred. On the day after surgery, a post-operative MRI scan is obtained to document the placement and extent of the lesions. (Cosgrove and Rauch 2005)

In the above description of the surgical procedure we see that relatively small lesions are made in the anterior cingulate using the thermoablative method used for the subcaudate tractotomy.

Clinical research studies have shown that the cingulotomy can lead to both slight and substantial improvement in OCD symptoms (Rasmussen et al. 2000). Cingulotomies conducted at MGH are considered to be a very safe procedure: “Cosgrove, et al., recently reported on the safety of over 800 cingulotomies performed over a 40-year period at Massachusetts General Hospital, with no deaths and only two infections being reported” (Shah et al. 2008; Cosgrove and Rauch 2005). It is important to note that the 800 cingulotomies performed were not only for OCD, but also included major depressive disorder, other anxiety disorders, and intractable pain (Shah et al. 2008; Cosgrove and Rauch 2005). Nevertheless, the surgical procedure is identical and has proven safe in human patients. As far as the benefit of cingulotomy older studies showed response rates, or rates of improvement in OCD symptoms after surgery, from 25-28% (Rasmussen et al. 2000; Cosgrove and Rauch 2005), however more recent retrospective studies
of larger patient cohorts have shown that some improvement in symptoms occurs in 60% of surgical cases (Shah et al. 2008; Greenberg et al. 2003a).

**Limbic Leucotomy**

The limbic leucotomy, as the name describes is somewhat vague in that it only hints at the ablation of white matter tracts in the limbic system. The limbic leucotomy however is essentially a procedure that combines both the subcaudate tractotomy and the cingulotomy in one procedure (Greenberg et al. 2003b; Jenike et al. 1998; Rasmussen et al. 2000). In the 1970s, Richardson and Kelly developed this procedure with multiple targets including the dorsal cingulate gyrus and the white fiber tracts anterior to the caudate nucleus in the hopes of further improving outcomes of surgery for OCD: “proponents of this operation feel that lesions in both sites produce better results in OCD than lesions in either area alone” (Jenike et al. 1998).

This procedure, like the cingulotomy involved the use of the ventriculogram and now makes use of intraoperative MRI to visualize the anatomical locations where the lesions will be placed. Historically, this lesion is made by using thermocoagulation, a cryoprobe, or radiofrequency-heated electrodes to ablate the tissue through bilateral burr holes near the dorsal midline of the skull (Cosgrove and Rauch 2005; Jenike et al. 1998).

The limbic leucotomy was found by Mitchell-Heggs et al to reduce OCD symptoms in 89% of patients in a 27-person prospective study, though this figure has since been disputed (Rasmussen et al. 2000). Kelly et al, however, found that in a group of 49 patients 84% showed some improvement, approximately 20 months after surgery on average (Rasmussen et al. 2000).
**Capsulotomy**

The capsulotomy was a procedure first performed by Tailarach and colleagues in France and later developed and popularized by Lars Leksell in Sweden as a means of treating OCD (Greenberg, Rauch, and Haber 2010; Cosgrove and Rauch 2005). The procedure involved placing a lesion in the “anterior limb of the internal capsule” in an effort to “interrupt fibers of passage between prefrontal cortex and subcortical nuclei including the dorsomedial thalamus” (See figure 4) (Greenberg, Rauch, and Haber 2010).

![Anterior limb of internal capsule](image)

**Figure 4. Transverse section showing the location or region in the brain representing the intended target for ablation in a capsulotomy. This image is taken and adapted from Christmas, David, Colin Morrison, Muftah S. Eljamel, and Keith Matthews 2004 Neurosurgery for Mental Disorder. Advances in Psychiatric Treatment 10(3).**

The capsulotomy was first performed by placing burr holes in the skull and using thermocoagulation to make the lesion in the anterior internal capsule (Greenberg, Rauch, and Haber 2010). Early reports of this method suggested that the anterior capsulotomy may prove beneficial in OCD patients with one report finding “either ‘good’ or ‘fair’ outcomes in 78% of 18 patients” and another showing that 71% of patients 35-months after the procedure “were either ‘free of symptoms’ or ‘much improved’” (Jenike et al. 1998). Leksell himself, conducted the
capsulotomy on 116 patients for several indications including OCD, depression, and schizophrenia, and found that “50% of patients with obsessional neurosis” showed improvement after the capsulotomy (Cosgrove and Rauch 2005).

Leskell and his colleagues also developed a novel method for placing the lesion in the internal capsule that has come to be known as the “gamma knife” method:

In… gamma capsulotomy… lesions are produced by [the] cross-firing of approximately 200 narrow beams of 60-Cobalt gamma irradiation from a stereotactic gamma unit. Craniotomy and shaving are unnecessary. Although the biologic effect of any individual gamma beam is negligible, at the point of focus, the effects are combined to produce a radiosurgical lesion. (Jenike et al. 1998)

The use of the gamma knife method allows for the destruction or ablation of tissue inside the brain without the placement of burr holes, as described above. Patients are essentially placed in what seems like an MRI-machine and after a frame is surgically attached to their head, beams are localized, and they lie down for a few hours until the radiation has been given in ample dosage (Ethnographic Field interview notes). Greenberg and colleagues at Butler Hospital who specialize in Gamma knife procedures assert that the gamma knife technique is easier and less invasive to the point that it “may be performed as an outpatient procedure” (Greenberg, Rauch, and Haber 2010). Most notably, gamma knife capsulotomy treatment appears to result in satisfactory improvement in OCD symptom severity for 64-70% of patients depending on the study (Greenberg, Rauch, and Haber 2010; Jenike et al. 1998; Shah et al. 2008; Cosgrove and Rauch 2005).
Deep Brain Stimulation

More recently DBS has been employed as a novel method for creating functional lesions by stimulation in order to treat OCD (Kopell, Greenberg, and Rezai n.d.; Sachdev and Chen 2009; Kohl et al. 2014; Abelson et al. 2005). Instead of functioning by severing fibers small electrodes are placed in specific regions of the brain and these electrodes send out antidromic and orthodromic electric pulses along the neural fibers where they are placed leading to a disruption in the signal that would normally travel along those fibers (Kopell, Greenberg, and Rezai n.d.; Greenberg et al. 2003a; Fornaro et al. 2009).

Researchers have attempted to place electrodes in the same locations as those used in the ablative procedures with relative success:

Recent trials of deep brain stimulation in OCD at several targets have indicated distinct benefit. One target is the anterior limb of the internal capsule, the site used in capsulotomy. Targeting of the anterior capsule is believed to disrupt activity in the loop fibers that connect the cortex with the thalamus, thus, in theory, disrupting that pathological circuit. (Shah et al. 2008)

While the exact mechanisms of action in DBS are not entirely known, it is believed that the signals sent by the electrodes disrupt the pathway in much the same way as placing a lesion. For this reason, Greenberg at Brown University along with colleagues at several centers around the US and in Europe conducted a DBS trial where electrodes were placed in the anterior internal capsule: “a lead design was selected that allowed stimulation along the dorsal–ventral extent of the capsule, extending into ventral striatum… [and the] lead implantation site became systematically more posterior during these studies, based on the clinical results observed, other empirical results and theoretical considerations” (Greenberg et al. 2010). This trial conducted
over 8 years and enrolling 26 patients found that OCD severity was markedly decreased by about a year after implantation as measured by significantly decreased Yale-Brown Obsessive-Compulsive Scores, a measure of OCD symptom severity (Greenberg et al. 2010). The DBS treatment also demonstrated a comparable rate of efficacy to the ablative procedures: “Overall, a total of 73 percent of patients had at least a 25-percent YOBCS improvement at last follow-up” (Shah et al. 2008; Greenberg et al. 2010).

Navigating which Surgical procedure to choose

Given the variety of surgical approaches available that are all intended to treat intractable OCD, patients are often faced with the challenging decision of which surgery to undergo. This decision is made especially challenging by the fact that none of the described approaches is considered more efficacious than another, in part, because cross-study comparisons are difficult to conduct retrospectively:

Unfortunately, there have been few comparison studies of these operations. In addition, diagnostic criteria for OCD were not consistent across studies, outcome standards varied among research groups, and complications were not always reported… [in fact] there are essentially no negative reports of neurosurgical procedures in the medical literature suggesting that only favorable or partly positive results have been published. (Jenike et al. 1998)

What Jenike is describing above is a significant challenge that has faced psychiatric neurosurgery going back to the 1970s that has limited our understanding of the relative therapeutic efficacy of these treatments and supported the preservation of “varied” surgical approaches in different institutions resulting from historical practice. In other words, the
cingulotomy, the standard psychiatric neurosurgical procedure at MGH and the gamma knife capsulotomy, the primary psychiatric neurosurgical procedure performed at Butler Hospital have been consistently maintained at these institutions in part because these institutions founded or were among the first sites to conduct these surgical approaches (Jenike et al. 1998). Institutions have been forced to maintain their distinct procedures in part because comparing results, particularly those in the late 20th century, when many of these studies began, can be challenging when the diagnostic categories for the disease were different. For instance, Lars Leksell originally used the capsulotomy in Sweden to treat individuals with “obsessional neuroses,” a less robust criteria than the current criteria for OCD that could have included other illness categories (Cosgrove and Rauch 2005). Further, it is difficult to assess what is considered a favorable outcome given inherent biases in different studies and most notably the different methods of categorizing treatment response (Jenike et al. 1998; Valenstein 1974; Greenberg et al. 2003a; Rasmussen et al. 2000). For example, some studies report only those patients with “satisfactory” response, but have questionable or limited criteria for what that category means while others use psychological exam metrics that provide a detailed perspective on individual patient illness, and it can be difficult if not impossible to compare the relative efficacy of two studies when tools for measuring efficacy are virtually incomparable (Jenike et al. 1998; Cosgrove and Rauch 2005; Greenberg et al. 2003a).

More recently, researchers have made efforts to conduct comparison studies of the relative efficacy of certain procedures that for the past decade or two have used much more uniform metrics. This is in part due to better communication and more comprehensive study designs have been established between peer institutions conducting psychiatric neurosurgical procedures for OCD. One study by Brown et al. sought to compare the “objective clinical
measures before and after cingulotomy or capsulotomy (surgical and radiosurgical) in patients with OCD” (Brown et al. 2016). The study found that the relative efficacy and safety of both procedures were very similar, with capsulotomy resulting in a 54% full response rate winning out over a 41% response rate in cingulotomy patients but also a higher rate of serious adverse events compared to cingulotomy (Brown et al. 2016). Despite these differences, the statistical significance is not present to say with any predictive certainty that one procedure is more likely to improve outcome, thus only “observational” data was reported limiting the degree to which researchers could “directly compare these procedures” (Brown et al. 2016). The authors conceded that “Controlled or head-to-head studies are necessary to identify differences in efficacy or AEs and may lead to the individualization of treatment recommendations” (Brown et al. 2016).

It is generally agreed upon in the field that the current procedures including DBS exhibit similar rates of efficacy in treating OCD. But how does making lesions or stimulating in distinct brain regions result in similar reductions in symptom severity? The current perspective is that the different “neurosurgical procedures… might have overlapping effects on… [neural] circuits” involved in OCD and “although different surgical interventions have different stereotactic targets, they might directly or indirectly affect the same brain system(s)” (Greenberg 2002; Jenike et al. 1998).

While the procedures discussed show some efficacy in relieving serious OCD symptoms, clinically, we have not yet discussed how these surgeries are thought to work. Before addressing the evidence that supports current hypotheses for the neurobiological basis for OCD it should be noted that there is considerable uncertainty in the field about exactly how the neurocircuitry functions and gives rise to the complex symptomology of OCD or how the surgeries themselves
function to correct or adjust these circuits (Jenike et al. 1998; Kopell, Greenberg, and Rezai 2004; Wichmann and DeLong 2006). Jenike et al clearly discuss the uncertainty in the field about how these circuits function:

“Despite many hypotheses, it remains unknown why these operations might improve symptoms in some patients and not others… It appears that different surgical approaches all have the common objective of severing interconnections between the orbitomedial areas of the frontal lobes and limbic or thalamic structures. (Jenike et al. 1998)

Despite some uncertainty, there appears to be a growing rationale for targeting the specific brain areas and “interconnections” that Jenike et al mentions. In some ways the clinical practice is ahead of the neurobiological understanding of function, in that the surgical procedures conducted appear to provide benefit to patients with intractable OCD with some efficacy but the precise mechanism by which the procedures succeed in doing so is not entirely well understood.

Examination of the modern practice of psychiatric neurosurgery reveals that while the surgical practice today is more targeted, precise, and efficacious than the psychosurgeries of the past there remains a great deal of ambiguity in the clinical science and practice. It is unclear exactly what each surgery is doing on a molecular level to alleviate OCD symptoms, however the scientific rationale and basis for OCD rests on a much more established understanding of neural circuitry that will be discussed in detail in Chapter 3 and that was completely absent in the early days of psychosurgery. Clearly the surgeries have advanced and the safety of these procedures has dramatically increased in the past decades since the last psychosurgeries. However, modern psychiatric neurosurgery like psychosurgery still remains at the center of dialogues in psychiatry supporting ideological views such as a firm rejection of mind-body
dualism in favor of a more integrated model, while pushing for a more biologically-oriented psychiatry.
Chapter 3: Obsessive Compulsive Disorder: Neurobiology and Phenomenology

While we have discussed the surgical options for OCD it is critical to have a working understanding of the illness itself. OCD is a complex and uniquely human illness for which there is still a very limited understanding. As a psychiatric illness, OCD represents an active negotiation between three different but not disparate epistemological paradigms that I would like to highlight. The first paradigm is the clinical definition of OCD, which arises from literature and the community of psychiatrists and psychologists who have developed and agreed upon a working definition and criteria for the diagnostic category of OCD used in healthcare. The second epistemological paradigm is that of biomedical research, which bares resemblance to the clinical definition but shifts focus depending upon the experimental method and theory, such that OCD embodies and indexes isolated behaviors, complex neurobiological mechanisms, and specific neural circuitry allowing for a good fit with established methods of experimentation that adhere to the scientific method. Lastly, OCD exists as a lived experience that comes to be defined differently by individuals with OCD and those that interact with them. In this way, OCD exists as a phenomenological category as well, that situates itself in people’s lives and is redefined, not in clinical terms alone, but also through language that denotes the experience of OCD.

In this chapter I will begin by providing the standard definitions of OCD taken from the medical diagnostic literature and from clinical tests that are used by psychiatrists to diagnose OCD. I will then discuss the neurobiological basis and current understanding of OCD pathophysiology drawing from the scientific literature. This is partly to provide a more detailed explanation of the science underlying the neurosurgical procedures outlined in the previous
chapter. My primary aim, however is to illustrate the experimental approaches used to understand OCD as a biological phenomenon defined not just by clinical symptoms but grounded in neural processes. Later, I will begin a discussion of the phenomenology of OCD, drawing from literature on the lived experience of OCD which includes literature in psychology and anthropology as well as from first-hand, autobiographical accounts of what it is like to have OCD.

_Obsessive Compulsive Disorder: A clinical category_

As one of the most common psychiatric illnesses, OCD is thought to affect approximately 2.3% of the United States population (Ruscio et al. 2010). OCD is classified as an anxiety disorder defined by anxiety-inducing “intrusive thoughts or images (obsessions)” accompanied by recurrent compulsive behaviors that are often “ritualistic” and represent an attempt to reduce the obsession-induced anxiety (Stein 2002).

Obsessions are defined in the _Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition_ (DSM V) as “Recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress” (American Psychiatric Association 2013; Stein 2002; First 2016). While the definition may at first seem quite broad, it is critical to understand that clinicians are attempting to include an expansive list of obsessions, some of the most common including: obsessions about contamination or infection, harming oneself or others, religious beliefs, sexual concerns, and symmetry or precision (Stein 2002). The list of obsessions here, or in literature, is by no means exhaustive because almost any idea an individual has, could theoretically become an obsession. Despite this, many individuals present with similar types of
obsessions. Pathological scrupulosity for instance, a symptom in OCD “primarily characterized by pathological guilt or obsession associated with moral or religious issues,” is a common obsessive thought in OCD across many cultures around the world though the specific religious or moral obsessions may differ (Miller and Hedges 2008; Stein 2002).

In the DSM V obsessions are in-part defined by whether or not they spur compulsions, because in order for an obsession to qualify as an OCD obsession individuals must “attempt to ignore or suppress such thoughts, urges, or images, or to neutralize them with some other thought or action (i.e., by performing a compulsion)” (First 2016). In other words, obsessions in OCD are defined by the content of the obsessions, how the individual responds to that content, and by extension how the clinician interprets the nature of a patient’s response to their obsessions. Often, time-consuming, compulsive behaviors are the most obvious outward clinical sign of the disease, and they can manifest as a host of distinct behaviors (Doshi 2009; Stein 2002). The DSM V outlines clear criteria for compulsions based upon clinical presentations of OCD:

Compulsions are defined by the following two criteria: 1. repetitive behaviors (e.g. hand washing, ordering, checking) or mental acts (e.g. praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession, or according to rules that must be applied rigidly. 2. The behaviors or mental acts are aimed at preventing some dreaded event or situation; however these behaviors or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive”(First 2016).
These criteria represent the standards used in clinical settings to diagnose an individual with OCD. Psychiatrists draw upon their clinical knowledge and experience to determine whether a patient’s symptoms adhere to these criteria well enough to make a diagnosis of OCD.

OCD symptoms include a wide, if not potentially limitless, variety of specific obsessions and compulsions that clinicians believe show up in clinical settings consistently enough to represent a single pathology. In this way, OCD has come to represent many obsessions from scrupulosity to cleanliness and their associated compulsions, because clinicians hold that the nature of the illness is the same regardless of the specific manifestations of an individual’s thoughts or repetitive behaviors (Stein 2002).

The DSM V is not the only diagnostic tool used in OCD by clinicians. Because while the presence or absence of OCD is an important clinical distinction, most are also interested in the degree of symptom severity. Clinicians believe OCD exists not as a binary, but rather as a graded phenomenon, such that some individuals have OCD symptoms that are more severe than others. This notion led to the development of the now widely used Yale-Brown Obsessive Compulsive Scale (Y-BOCS), so named after the institutions that developed the clinical measure (Goodman et al. 1989). The Y-BOCS is a measure of symptom severity and was “designed to … [provide] a specific measure of the severity of symptoms of obsessive-compulsive disorder that is not influenced by the type of obsessions or compulsions present”(Goodman et al. 1989). The Y-BOCS is a questionnaire that consists of a series of questions such as “how much of your time is occupied by obsessive thoughts?” and “how strong is your drive to perform the compulsive behavior?” (Yale-Brown Obsessive-Compulsive Score Screening Tool n.d.). The researchers that developed the Y-BOCS describe in detail how the clinical measure is meant to be used:
The Y-BOCS is a 10-item clinician-rated scale, each item rated from 0 (no symptoms) to 4 (extreme symptoms). The Y-BOCS was designed as an observer-rated instrument because of evidence from assessment of other disorders that ratings based on self-report alone, particularly during acute stages of illness, correlate poorly with more objective evaluations. For all items, a higher numerical score corresponds to greater illness severity. The total Y-BOCS score is the sum of items 1 to 10 (range, 0 to 40). (Goodman et al. 1989)

A Y-BOCS score from 0-7 is said to be “subclinical,” from 8-15 is considered “mild,” 16-23 moderate, 24-31 severe, and 32-40 is considered extreme OCD symptom severity (Stanford University School of Medicine 2017) Amongst clinicians the Y-BOCS has become the “gold standard” measure for OCD severity, with many physician using the scale in practice and with widespread use in clinical trials and studies of OCD (Stein 2002). The Y-BOCS has withstood the test of time because it does not vary much between skilled administrators of the questionnaire and shows low rater bias (Goodman et al. 1989; López-Pina et al. 2015; Stein 2002).

The Y-BOCS and DSM V both certainly represent broad collective efforts and agreed upon standards in the medical community regarding the diagnosis and symptom severity of OCD. OCD has come to be defined in clinical practice as the combination of obsessive and compulsive behaviors described in the DSM V, as well as a psychiatric illness for which clinicians can determine symptom severity. This definition of OCD forms the foundation for how OCD is discussed in clinical settings as well as research settings. In biomedical research contexts, however the definition of OCD becomes more complex and begins to take on additional components that ultimately guide treatment measures.
The Neurobiological Basis of Obsessive Compulsive Disorder

OCD like many psychiatric illnesses has come under the purview of a biological psychiatry model, based upon ideological shifts in the field of psychiatry discussed in the last chapter. With this underlying notion that OCD is fundamentally a biological phenomenon, researchers apply methods such as the use of animal models of disease and functional neuroimaging to uncover the mechanism and biological basis of OCD. The use of the scientific method and modern experimental techniques serves to redefine and reshape the understanding of OCD beyond its simple status as a clinical phenomenon.

In order to better understand how neurobiological research has and continues to reshape OCD, we must examine the current scientific understanding of OCD pathophysiology. In an effort to highlight the neurobiological language used to redefine OCD in research contexts and to elucidate the scientific rationale for the surgical procedures described in the last chapter, I will provide a brief literature review underscoring the basic science of OCD and the proposed neurobiological basis of OCD. I begin this discussion with what has been ascertained from animal studies, then address clinical research findings that implicate specific brain regions in order to provide a foundation for a subsequent discussion of the current functional neurocircuitry model for OCD.

Most biomedical science in the current era of “evidence-based medicine” involves an established continuum or ordered process that goes from basic science or bench research to clinical or “bedside” research (Drolet and Lorenzi 2011). This often entails the use of animal model organisms for various diseases, because animal studies can enable scientists to learn much more about the function and action of biological mechanisms through more invasive experimental approaches that cannot be done in human subjects. There is some inherent
difficulty, however, in finding and using animal models for many psychiatric diseases including OCD. Because OCD is a complex, “heterogeneous” illness with numerous presentations, potential symptoms, and features of higher order processing and cognition that may only possible in humans, OCD is a difficult illness to replicate in animals (Ahmari and Dougherty 2015).

Due to this complexity, “it is generally accepted that no one animal model will be able to recreate all aspects of any complex neuropsychiatric disorder, including OCD” however animal researchers have still made significant efforts to identify and develop animal models for specific features or symptoms that can be found in animal models, in the hopes of identifying specific circuits (Ahmari and Dougherty 2015). In rodent models for instance, researchers have employed two approaches: “symptom modeling,” and “genetic modeling,” (Ahmari and Dougherty 2015).

Symptom modeling involves identifying specific behaviors that appear to be similar to those found in OCD patients, and this approach has led to the development of models that focus on “the presence of stereotyped and compulsive behaviors” (Ahmari and Dougherty 2015). In rats for instance behaviors such as excessive cleaning, licking, or learned behaviors such as lever pressing have been studied either by attempting to induce the behavior through pharmacological means or observing the naturally occurring behavior and studying neural substrates (Drolet and Lorenzi 2011; Malkki et al. 2011). Some of the involvement and mechanisms of action of certain brain regions found in humans have been uncovered through symptom modeling. For instance, researchers working with rats have uncovered the potential involvement of dopamine neurotransmission in compulsive behaviors (Szechtman, Sulis, and Eilam 1998). Szechtman, Sulis, and Eilam found that by treating rats with quinpirole, a dopamine blocker, they were able to induce a robust and abnormal checking behavior that is analogous to the common OCD compulsive symptom of checking (Szechtman, Sulis, and Eilam 1998). Work on symptom
modeling is able to correlate specific stereotyped behaviors with neurochemical changes in specific brain regions of interest. For instance, another research team uncovered that “in wild-type rats … striatal NMDA-antagonist injections led to increased perseveration on a T-maze delayed alternation task,” which is to say that a behavior that appears excessive and may be analogous to the excessive compulsions found in OCD was associated with NMDA receptor activity in the striatum. Humans have this brain region in common with rats and it is thought to be critically involved in OCD pathophysiology (Ahmari and Dougherty 2015; Hauber and Schmidt 1989).

Genetic modeling in theory involves reverse genetics or taking identified genetic markers associated with OCD pathology in humans and creating model organisms such as mice in which the same genes are removed or upregulated and then the animals are observed for behavioral or physiological abnormalities (Ahmari and Dougherty 2015). Unfortunately, few well-established “candidate genes” have been found in OCD, so genetic modeling of the disease has primarily consisted of somewhat serendipitous findings in which certain mutations were completed based upon an understanding of the neurobiological basis of disease in humans and resulted in phenotypes that appeared similar to certain facets of OCD symptomology. For instance, one group found that “knockout of the developmentally-expressed Hoxb8lox gene leads to perseverative grooming” in mice, a behavior analogous to excessive washing a common symptom in OCD (Chen et al. 2010). A similar phenomenon was observed by a different group who removed the gene encoding for “SAPAP3, a corticostriatal postsynaptic density protein” and noted that the mice that were manipulated groomed themselves so extensively that they developed “face lesions,” which reminded researchers of the common clinical finding of OCD patients that have developed sore skin or cuts from excessive hand-washing (Wan et al. 2014;
Welch et al. 2007). Results from some researchers using genetic modeling has also uncovered the involvement of brain regions thought to be involved in OCD such as the orbitofrontal cortex (OFC):

In a more recent study, Shmelkov et al. inactivated Slitrk5, a member of a gene family implicated in obsessive–compulsive spectrum disorders and Tourette's syndrome that encodes a postsynaptic density transmembrane protein. Slitrk5 KOs demonstrate increased anxiety and perseverative grooming that are reversed by chronic treatment with fluoxetine, demonstrating relevance to human OCD. Interestingly, Slitrk5 KOs also have OFC overactivation as measured with baseline c-fos staining, paralleling findings from human neuroimaging studies. (Ahmari and Dougherty 2015; Shmelkov et al. 2010)

These genetic studies have supported our understanding of the involvement of specific genes and proteins in the development of stereotyped behavior and neural activation in specific brain regions of the animals studied. There is always an inherent difficulty in making the claim that the animal models are models of OCD, particularly because grooming and cleaning appear analogous to, but may not be entirely the same for rodents and humans. Excessive cleaning is only one possible symptom in OCD and it is unclear whether obsessions are driving the stereotyped behavior as is known to be the case in humans.

While behavioral and genetic animal studies represent one approach to experimentation for studying OCD, the most influential work has come from using functional imaging techniques that have helped researchers identify specific brain regions that appear to be involved in OCD pathophysiology. Studies that have been most instrumental in identifying regions and circuits in the brain involved in OCD come from functional neuroimaging experiments, some of which has
been done in non-human primates, but most of which comes from the clinical research literature on humans.

In order to understand the neural circuitry researchers have had to use non-human primates, whose cerebral anatomy is most similar to humans, to tease apart nerve fiber pathways and connections that exist in the brain (Greenberg, Rauch, and Haber 2010). Through “conventional tract tracing methods and 3-D modeling in nonhuman primates” combined with work in humans implicating specific brain regions involved in OCD, researchers have been able to narrow down and identify specific brain circuits that may underlie OCD (Parent and Hazrati 1995; Haber et al. 2006). Many researchers point to the presence of OCD-like symptoms in conjunction with specific structural brain differences, as initial evidence that began to identify relevant brain regions of interest and strengthen the hypothesis that OCD symptoms emerged from a malfunctioning brain system:

Although exact findings have varied across studies, structural abnormalities in CSTC circuits involving OFC, ACC, and striatum have been repeatedly demonstrated in OCD. The largest structural MRI [Magnetic Resonance Imaging] study to date reported reduced OFC gray matter…, increased gray matter in the highly connected ventral striatum (VS)… [and] changes in ACC [Anterior Cingulate Cortex], OFC [orbitofrontal cortex], and striatal volume despite some inconsistencies across studies. (Ahmari and Dougherty 2015)

Here we see researchers have identified key regions from structural imaging alone that seem to be associated with OCD. By conducting MRI studies on individuals with OCD and comparing the brain structure of these individuals to those without OCD, researchers have uncovered anatomical changes in the striatum, Anterior Cingulate Cortex (ACC), and orbitofrontal cortex
(OFC). It is important to note at this time that the brain regions highlighted (the OFC, ACC, and striatum) are highly interconnected regions that are thought to operate within the same functional circuits in the brain. As I present more evidence discussing these brain regions, I will highlight studies showing their involvement in OCD and ultimately their coordinated interactions hypothesized to underlie the neurobiological mechanism(s) of OCD (Kopell and Rezai 2000; Kopell, Greenberg, and Rezai 2004).

The brain regions identified through structural imaging of abnormalities in OCD patients, have also been implicated in OCD through functional neuroimaging studies in humans which by in large has provided the most experimental evidence in favor of a neuro-circuit model for OCD:

“The investigational use of functional neuroimaging has revolutionized understanding of the functional neuroanatomy of psychiatric disorders, giving rise to complex neurocircuitry-based models that provide a foundation for the development of neurosurgical and other targeted biologic treatments for psychiatric disorders. (Vago et al. 2011)

Methods of “functional neuroimaging” that have been most predominantly used to “revolutionize” the understanding of OCD circuitry include two methods of indirectly measuring brain activity while individuals are conscious and capable of completing tasks: the use of functional MRI (fMRI) to measure blood flow in the brain and Positron Emission Tomography (PET) to measure glucose-levels in the brain (Greenberg, Rauch, and Haber 2010; Ahmari and Dougherty 2015).

Numerous studies have found that those regions with structural changes in OCD patients have also been associated with functional imaging changes. In one study using PET, researchers looked at OCD patients at rest and also in a “provoked condition” where a provocative stimuli
such as “a ‘contaminated’ object” was used for “patients with contamination obsessions (Rauch et al. 1997). In this study, researchers found that the OFC exhibited increased activation in the OCD group at rest and when provoked (Rauch et al. 1997; Ahmari and Dougherty 2015).

Through many similar types of studies the “OFC, ACC, and caudate (specifically the head) have … been implicated in OCD using positron emission tomography (PET) and functional magnetic resonance imaging (fMRI)” (Ahmari and Dougherty 2015).

The hypothesis that activity in the OFC, ACC, and caudate nucleus is involved in, or maybe even responsible for OCD has been more recently supported by findings indicating that clinical therapies used for OCD may directly affect these circuits. For instance, two recent studies examining the effect of fluvoxamine and cognitive behavioral therapy on brain activity in OCD patients revealed in both PET and fMRI that changes in frontal lobe activity, specifically decreased activity in the OFC and increased activity in the posterior cingulate cortex (PCC) were correlated with better treatment response (Ahmari and Dougherty 2015; Nakao et al. 2005; Rauch et al. 2002).

Some of the most definitive evidence supporting the specific brain regions comes from evidence from psychiatric neurosurgical procedures, which target brain region or their connections that are consistent with those regions identified in functional and structural imaging such as the ACC, which is directly ablated in the cingulotomy procedure. One study that combined the use of functional imaging with psychiatric neurosurgery demonstrated that the procedure led to functional changes in the “OFC, ACC, putamen, globus pallidus during acute stimulation” (Rauch et al. 2006; Greenberg et al. 2003a; Ahmari and Dougherty 2015). For this experiment patients at Rhode Island Hospital or Cleveland Clinic Foundation Hospital had electrodes implanted in the “anterior limb of the internal capsule,” the same region targeted in
ablative capsulotomy (Rauch et al. 2006). To summarize, this study demonstrated that stimulating fibers in the internal capsule a region where fibers pass between the thalamus and OFC appeared to reduce activity in the OFC and this was most notable because all “six participants showed a decrease in the severity of their OCD symptoms” as measured by Y-BOCS scores after 3 months of “chronic stimulation” (Rauch et al. 2006). More recent studies examining the effects of surgical procedures including DBS and anterior cingulotomy have shown that both procedures modulate activity in the OFC and ACC, and that those individuals who respond best to treatment show significant changes in the neuroanatomy and neural fiber tracts as measured by MRI and Diffuse Tensor Imaging (DTI), a method for visualizing the connections and fibers in the brain (McGovern and Sheth 2017; Szeszko et al. 2005; Hartmann et al. 2016; Sheth, Ogas, and Eskandar 2016; Wichmann and DeLong 2006; McLaughlin, Stewart, and Greenberg 2016).

Taken together these findings all appear to consistently affirm the presence of significant biological mechanism(s) involving the specific brain regions identified through multiple experimental methods and paradigms. These findings have led to a predominant working hypothesis for the functional changes in neural circuitry thought to underlie OCD pathophysiology. Next, I would like to briefly outline the proposed neurocircuitry of OCD in order to elucidate how biomedical research has expanded the definition of OCD as a clinical phenomenon, and situated the category of symptoms in the anatomy and physiology of the brain.
Neurocircuitry of OCD

In the following review, Dr. McGovern and Dr. Sheth introduce the basic circuitry of OCD:

The prevailing theory regarding the neurobiology of OCD consists of the cortico-striato-thalamo-cortical (CSTC) loop model. In this model, regions of cortex, basal ganglia, and thalamus that subserve related functions are anatomically and functionally interconnected. (McGovern and Sheth 2017)

The “cortico-striato-thalamo-cortical (CSTC)” model represents a hypothesized set of loops of neural connections that have been discussed extensively as the basis for OCD (McGovern and Sheth 2017; Kopell, Greenberg, and Rezai 2004; Kopell and Rezai 2000; Wichmann and DeLong 2006). Specifically two loops are thought to be involved in OCD due in large part to the functional and structural imaging findings discussed earlier: the lateral orbitofrontal loop and the anterior cingulate loop (Kopell, Greenberg, and Rezai 2004). The two loops that have been associated with OCD pathophysiology depicted in Figure 5, are suspected primarily because the regions highlighted in the name of both loops, the OFC and ACC, have been repeatedly implicated in OCD pathology. The ACC in particular, is even a site of ablation in the cingulotomy and limbic leucotomy procedures for treating OCD.

In addition to the CSTC loops, researchers also suspect a neural circuit known as the Papez circuit may be involved in the pathology of OCD. The circuit of Papez has direct connections from the OFC and widespread connections to the ACC in the brain’s wiring, and the Papez circuit, which involves the brain’s limbic system is thought to be essential for “subjective emotional experience,” which researchers suspect “could subserve the anxiety/emotional component of OCD” (Kopell, Greenberg, and Rezai 2004).
Researchers characterize these circuits and loops as either “excitatory” or “inhibitory” based upon the types of neurotransmitters released between neurons in those circuits. This is important to note, because pervading neuroscientific theory of cortical function implies that a balance between cortical excitation and inhibition is what regulates brain activity and promotes optimal functioning. Researchers have observed elevated activity in the OFC and ACC in OCD patients and have developed a hypothesis for how the circuits may work together in OCD to produce the characteristic hyperactivity or overexcitation in these regions (Kopell, Greenberg, and Rezai 2004; Kopell and Rezai 2000; Ahmari and Dougherty 2015). Here researchers Kopell, Greenberg, and Rezai discuss the pervading theory for how the three loops may work together giving rise to OCD symptoms:

By synthesizing these three components, OCD symptoms could occur when an aberrant positive feedback loop develops in the reciprocally excitatory frontothalamic neuronal pathway [the relay between OFC and thalamus,] that is inadequately inhibited/modulated … Obsessive-compulsive symptoms would thus
be expected to appear when...[there is] an imbalance between the direct and indirect pathways or when orbitofrontalthalamic activity is abnormally increased...Additionally modulation of the Papez circuit would in turn remove some of the disturbing effect the obsessions or compulsions have on a patient’s emotional state. (Kopell, Greenberg, and Rezai 2004)

Researchers describe their detailed reasoning for how the neuronal circuits including the OFC, thalamus, and Papez circuits may interact with one another through complex patterns of excitation and inhibition to produce an “imbalance” which can result in OCD symptoms and associated anxiety.

The neurocircuitry model described is only a hypothesis that researchers are still working to verify and uncover. Biomedical researchers in the field hold that “it is unlikely that a single ‘center’ or anatomic/physiologic defect is responsible for the pathogenesis of psychiatric symptoms” but rather “dysregulation between several neural circuits” (Kopell, Greenberg, and Rezai 2004). While researchers believe they have identified some of the circuitry involved, the precise neurobiological mechanisms in OCD remain unclear. Psychiatric neurosurgical work has helped to support the development of the neurocircuitry model, in part due to the relatively equal response rates of patients with OCD to ablation and stimulation in distinct brain regions. In other words, the cingulotomy, capsulotomy, and subcaudate tractotomy may all have similar efficacy in treating OCD symptoms because while they target different regions of the brain, each target is thought to play a role in the circuitry that becomes “imbalanced” in OCD, and by removing specific regions of the circuit the hyperactivity that is thought to underlie OCD may be attenuated.
Clearly the involvement of biomedical research approaches for OCD have significantly altered the language used to discuss the illness. From animal studies, we see that OCD is translated from a complex human disorder with obsessions and compulsions to isolated behaviors that may or may not represent the illness, but are nevertheless used in an attempt to apply animal models to a psychiatric disease. Through functional and structural neuroimaging, a metaphor of “circuitry” emerges grounded in neuroscientific language of “excitation” and “inhibition” which eventually redefine and add nuance to the concept of OCD. OCD remains a nosological category, but the biomedical research perspective transforms it. This is particularly significant, and I highlight it, because the last section of this chapter introduces the notion of OCD as a phenomenological concept. Meaning that OCD is not just the clinical category or maladaptive circuitry in the brain but also a lived experience and social phenomenon that is influenced by the clinical and biomedical narratives that we have discussed. In later chapters through ethnographic fieldwork with clinicians and semi-structured interviews with OCD patients.

The Phenomenology of OCD

In addition to and encompassing of the working definitions of OCD developed as a clinical diagnostic category and subject of biomedical research, OCD exists as a phenomenological concept. In this section I will first define phenomenology and provide a brief discussion of its philosophical underpinnings, then I will transition to discuss the importance of a phenomenology of OCD and literature that has laid the groundwork for a phenomenology of OCD, and finally a discussion of the existing literature in the phenomenology of psychiatric neurosurgery for OCD.
Phenomenology

Phenomenology concerns examining the perspectives of individuals in their own terms and is a mechanism aimed at studying the “set of invariant properties lying underneath the subjective perception of individual manifestations of” any given phenomenon from “first-order personal experience” (Smith, Flowers, and Larkin n.d.). In other words, phenomenology is a study concerned with our conscious experience of phenomena (i.e. objects, life events), and phenomenology attempts to explore this from the first-person perspective or through the eyes of the individual experiencing said phenomena (Smith, Flowers, and Larkin n.d.; Smith 2013).

One of the earliest proponents of phenomenology was Edmund Husserl who developed and supported phenomenology as a valid theoretical approach to studying phenomena especially conscious phenomena. Husserl asserted in his 1970 publication on the philosophy of phenomenology that he believed phenomenology was the only mechanism to get at first-hand experience and was critical given that science could only provide “second-hand” knowledge:

From objective self-evidence (mathematical ‘insight,’ natural-scientific, positive-scientific ‘insight, as it is being accomplished by the inquiring and grounding mathematicians, etc.) the path leads back, here, to the primal self-evidence in which the life-world is ever pre-given. (as cited in Smith, Flowers, and Larkin n.d.)

Here Hursell clearly delineates what he believe was the critical importance of phenomenology: a mechanism of studying the way we consciously experience phenomena, especially since scientific methods of study, a “second-order knowledge system,” can only at its best capture information through a person’s (the scientist’s) observations (Smith, Flowers, and Larkin n.d.;
Smith 2013). Husserl’s philosophy of phenomenology aligns well with the notion of an embodied scientific approach set forth by feminist philosopher Donna Haraway, who argued against the notion of objective science that stemmed from the “splitting of subject and object,” advocating for a more integrated approach:

Situated knowledges require that the object of knowledge be pictured as an actor and agent, not as a screen or a ground or a resource, never finally as slave to the master that closes off the dialectic in his unique agency and his authorship of “objective” knowledge. The point is paradigmatically clear in critical approaches to the social and human sciences, where the agency of people studied itself transforms the entire project of producing social theory. (Haraway 1988)

In the above passage, while Haraway is not opting specifically for a phenomenological approach, her critique of science is that an attempt at purely “objective” knowledge ignores “the agency of people studied” and by extension the people who are studying a phenomenon. Another feminist philosopher and proponent of embodiment Evelyn Fox Keller further explicates Haraway’s idea making the argument that all “we know about nature we know only through our interactions with, or rather, our embeddedness in it” (Keller and Scharff-go\l{}dhaber 1987). The feminist concept of embodiment I think best captures the underlying motivation behind a phenomenological approach, because as Husserl mentions, a scientific approach is only a second-hand account of phenomena but necessarily depends upon the first-order personal experience or what Harraway and Keller would call the “situated” or “embedded” perspective.

Phenomenology operates under the assumption that perspectives are always first-hand, even the researcher when attending to the experience of another can only interpret that shared experience through their own lens and thus biases (Smith, Flowers, and Larkin n.d.). Heidegger,
another early proponent of phenomenology, articulated this view by arguing that an individual is always a “person-in-context” (Smith, Flowers, and Larkin n.d.). Phenomenology attempts to privilege the perspectival, focusing on the “perception, imagination, thought, emotion, desire, volition, and action” of an individual embedded within a specific context (Smith 2013). This approach has been particularly useful when studying medicine and illness because it supports a narrative approach, which allows for discussion of how individuals conceptualize their illness which can provide insight for how to provide and improve healthcare:

The lived body … [is an] important aspect of our being-in-the-world which is most often significantly involved in illness. In illness the body is experienced as alien, as a “broken tool”, which gives rise to helplessness, resistance and lack of control. Yet the body is not just any tool of the world, but belongs to the projective power of the self and is consequently tied to the most intimate and irreplaceable parts of the being-in-the-world of the person. (Svenaeus 2001)

By using a phenomenological approach to study illness and ascertain how individual narratives come to define and shape the lived experience of illness, we can better address illness and truly understand what it means as a social phenomenon.

**OCD**

Given that phenomenological study can provide us with the perspective of the lived experience of an illness and help researchers understand the conscious experience of disease, it seems that there is no more area of illness where this is most critical than in psychiatric illness. In psychiatric illness, the symptoms and signs of disease are far less tangible, the biological mechanisms of illness less well-understood, and most fundamentally the object of study in
phenomenology, conscious experience, is often the very manifestation of pathology, so to speak. In other words, psychiatric illnesses are characterized by how they alter conscious experience and therefore the lived experience of an individual, which is what phenomenological study aims to understand. Psychiatrists and psychologists are intimately aware of the importance of lived experience when it comes to mental illness because their practice consists primarily of story-telling:

…when faced with patients who are grief stricken, demoralized, angry, and so forth, psychiatrists, usually without reflecting on the process, use a method of explanation quite distinct from that of science. They fall back on the most natural method of reasoning humans have: they explain the problem with a story.

(McHugh and Slavney 1998)

The pervasive use of narrative in psychiatry and medicine, reveals how fundamentally social the phenomenon of illness is. In the case of psychiatric illness, clinicians find time and time again that the disease comes to manifest itself very differently for each person based on their individual life experiences, thoughts, and disposition (McHugh and Slavney 1998).

It follows, that a phenomenological approach to studying OCD would further enhance our understanding of the clinical category. After all, it is only through a phenomenological and narrative method of study that we have any concept of what the underlying anxiety caused by obsessions may be like (Shavitt et al. 2014). However, as I review the existing literature on the phenomenology of OCD I want to take a step further arguing that phenomenology does not just afford an enhanced understanding of OCD as a disease category but also can potentially influence how the illness is treated:
The life-story perspective provides both an understanding of psychological distress and an ingredient for psychotherapy…The life-story perspective presumes that much distress stems from events. The support of such a premise is plain.

Grief surely comes from loss, home-sickness from displacement, and discouragement from failure. At the same time, psychotherapists assume that patients benefit from those interpretations of their mental woes that help them understand and surmount them. (McHugh and Slavney 1998)

Phenomenological study of OCD is thus critical for advancing knowledge of the disease process and providing insight for clinical intervention.

The phenomenological study of OCD has come about through the combined efforts of social scientist, clinicians, and even individuals with OCD interested in enhancing and communicating narratives of the lived experience of OCD. Phenomenological study of OCD has helped communicate the obsession and compulsions of OCD as experiences that are not alien to healthy experience but rather deeply close to us, allowing us to conceive and perhaps even better empathize with individuals with OCD. De Haan and colleagues describe the nature of obsessions and compulsions based on patient narratives in the following way that denotes the pathology without alienating the experience of it:

Obsessions and compulsions are easily comprehensible and utterly elusive. They are comprehensible because we are all familiar with their mild variants. When we go on vacation we double check whether we locked the door – just to be sure. Of course we know it is nonsense, but still, we knock on wood when we talk about our hopes… we can understand the urge to do something that we recognize as not
being entirely reasonable. Likewise, we may also be familiar with annoying thoughts or images that keep on popping up. (de Haan et al. 2015)

Here the authors are able to explain the nature of obsessive and compulsive behaviors in terms that transcend the clinical descriptions of the phenomena and can only be ascertained from a first-person account of the experience of OCD. Segrott and Doel argue that often OCD is described as “abnormal, irrational and seemingly excessive,” but phenomenological analysis of the behaviors “point to the fact that the obsessions and compulsions present in OCD are ‘normal’ in that they are experienced to a lesser degree by most, if not all of us” (Segrott and Doel 2004).

Murphy and Pererra Delacourt argue that in some ways a purely clinical or biological definition of OCD that is often used in the treatment of OCD can serve to alienate OCD:

Psychological processes are conceptualized as mechanistic in nature and [therapy] offers a solution to “errant” thoughts and behaviors in the individual. This reinforces our perceptions that mental ill health is located at the level of the individual and should be dealt with at the level of the individual. Dependency on such mechanistic understandings of the psyche can lead us to over rely on dualist and reductionist accounts of human behavior and distances OCD from “normal” states of being. (Murphy and Perera-Delcourt 2014)

This notion that clinical and less formal social narratives often serve to alienate and reify a narrative of ab-“normality” when referring to individuals with mental illness, broadly, and especially OCD, as we will see later.

Further work by Segrott and Doel has aimed to shift this narrative of OCD as a psychiatric illness and “critique the depiction of OCD as irrational and excessive” (Segrott and Doel 2004). Through phenomenological analysis Segrott and Doel argue that obsessions
surrounding contamination and resulting compulsions to wash and clean can and ought to be described in the following way: “Obsessions can transform ‘harmless’ artifacts into sources of deadly contamination (telephones, toothbrushes, mail, dust motes, etc.), compulsions can find creative uses for materials such as parcel tape and kitchen roll to restore order and bring about relief” (Segrott and Doel 2004). In other words, Segrott and Doel are arguing in favor of viewing the compulsive behaviors patients have not as the primary illness but rather a “creative” response and ritualistic practice aimed at creating relief. While the compulsions may sometimes logically follow the obsession, they just as often do not, and only be studying the lived experience of OCD might an outside observer become attuned to this subtle shift in conceptualizing the disease, because from an external viewpoint the compulsions are the most visible and apparently challenging symptom of OCD.

It becomes clear then if we carefully consider the nature of obsessions and compulsions in OCD, we see that OCD is as much a social phenomenon as it is a biological one. Obsessions often reflect the socio-cultural context of an individual such as their upbringing. Take for instance the relatively frequent obsession of scrupulosity in OCD. You may recall as discussed earlier, scrupulosity relates to obsessions concerning religious and moral beliefs, and these dictate the obsessions that accompany OCD. Cobb showed that amongst members of the Catholic faith there is particular concern in OCD patients with scrupulosity about topics such as “mortal sin,” or “going to hell” (Cobb 2014). Cobb goes on to state that scrupulosity manifests in this population as individuals that “perceive themselves almost always to be in a state of mortal sin” for which they must seek atonement, often through compulsive practices dictated by the religion such as praying to God for forgiveness (Cobb 2014).

In *Purity and Danger* Douglas argues that our notions of taboo and even contamination
are dictated by our cultural contexts and narratives pervasive in our societies:

We moderns operate in many different fields of symbolic action. For the
Bushman, Dinka and many primitive cultures the field of symbolic action is
one… Both we and the Bushmen justify our pollution avoidances by fear of
danger. They believe that if a man sits on the female side his male virility will be
weakened. We fear pathogenicity transmitted through microorganisms. Often our
justification of our own avoidances though hygiene is sheer fantasy. The
difference between us is not that our behavior is grounded on sciences and theirs
on symbolism. The real difference is that we do not bring forward from one
context to the next the same set of ever more powerful symbols: sub-worlds,
unrelated. Their rituals create one single, symbolically consistent universe.
(Douglas 2003)

What Douglas is arguing here is that cross-cultural examples of beliefs take on different foci and
symbolic language but maintain similar qualities. The different beliefs in what could be
considered “contamination” in both cultural contexts lead to very different ritualistic behaviors
but both are grounded in similar abstract concepts. The nature of obsession in OCD can be
dictated by similar concepts and individuals in each culture take on the distinct narratives of
contamination.

While it may seem obvious to deem an OCD patient’s scrupulosity or notions of
contamination as ‘irrational,’ it is important to recognize that many of the social categories of
taboo, purity, dirt, and order are equally prone to contradiction when scrutinized. The building
blocks were already misshapen so to speak, the pathology may just exaggerate these
contradictions to us and those with stricter adherence to the rules come to be deemed
pathological, because while many may navigate the contradictions with ease, those with OCD may find it more difficult to do so. This of course provides a different phenomenological explanation of OCD pathology as an inability or diminished capacity to make exceptions or handle contradictions for notions or ideas that we have selected to adhere to. For instance, if we accept the narrative that the world is full of microbes and we are constantly at risk of exposure to then washing one’s hands constantly or refusing to contact surfaces without cleaning them is a compulsion consistent with this idea. Not to do so, would be to invite the constant invasion of microbes.

Compulsions also offer an opportunity for phenomenological analysis to reveal the social nature of OCD. Many have drawn parallels between ritualistic behaviors in religious practices around the world, including Freud who argued that “obsessional neuroses resemble religious rituals” (Dulaney and Fiske 1994). Dulaney and Fiske arguably contributed the most significant work linking OCD rituals to cultural rituals when they uncovered through qualitative and quantitative analysis that cultural “rituals contain more OCD-like features than comparable episodes of work” after analyzing the features of nearly 20 different ritual practices around the world (Dulaney and Fiske 1994). The authors note that OCD contains features similar to those of many religious rituals. For instance, both cultural and OCD rituals are often motivated by similar fears: such as the “fear that something terrible will happen,” and the “fear that they themselves might cause harm to themselves or to others” (Dulaney and Fiske 1994). OCD rituals also often contain similar components to cultural rituals such as the symbols or components of a ritual: “concern or disgust with bodily wastes or secretions,” attention “to thresholds or entrances,” and “repetitive actions” (Dulaney and Fiske 1994). All of these behavioral features were statistically shown to coincide in both OCD and cultural rituals to a greater degree than OCD behaviors.
corresponded with behaviors done in a workplace environment (Dulaney and Fiske 1994).

In addition, a few autobiographical accounts have been written by individuals with OCD that have sought to describe the phenomenological experience of OCD in the most theoretically appropriate way: through first-hand lived experience. An “autoethnography” written by Ragan Fox describes OCD through the use of narrative and metaphor, which the author argues is critical to understand their illness:

> Like many people writing about mental illness, I utilize metaphors to understand OCD. Illness metaphors structure our perceptions of the conditions we aim to describe. Comparisons also lay the foundation for how clinicians treat abnormal anxiety. Numerous metaphors have been used to explicate OCD. Most of these associations obfuscate OCD insofar as [these metaphors] depict the ailment as a force outside a patient’s mind and body. (Fox 2014)

Fox argues that while metaphors are useful they can inaccurately depict phenomena such as OCD, which he argues is not a “force outside a patient’s mind and body,” but rather “flawed intrapersonal communication, or unproductive chatter that occurs inside a person’s mind” (Fox 2014). In his narrative about his illness he describes two facets of his brain a “logical” component and an “emotional” component that includes his anxiety due to obsessions (Fox 2014). He describes the experience of checking a door to make sure it is locked several times by explaining that while his logical inner dialogue knows that he “already locked it” his emotional inner dialogue fills him with distrust and consists of extreme, anxiety inducing thoughts (i.e. “What if tonight’s the night a serial killer enters your apartment through an unlocked front door?”) that force Ragan to get out of bed and check his lock “five times”(Fox 2014).

This perspective of OCD is critical, because it provides a notion of the inner dialogue
involved in OCD that could not be ascertained except through phenomenological analysis. Fox argues that this perspective can enhance the treatment and discussions between clinicians and OCD patients. The importance of attending carefully to the metaphors used to describe OCD seems self-evident since metaphor, as linguistic anthropologists Lakoff and Johnson point out, is an unavoidable aspect of communication (Lakoff and Johnson 1980). Communication is a critical component of the psychiatric treatment of OCD, so the metaphors that will inevitably be used should be as effective and intentional as possible, and the perspectives best equipped to develop these metaphors are those of individuals with lived experience of OCD.

It becomes clear from our discussion that OCD is a social phenomenon in addition to being a biological one, and as a result, phenomenological study is critical and affords a valuable perspective of OCD. Attending specifically to the phenomenology of OCD uncovers the underlying metaphors, narratives, and socio-cultural underpinnings of the disease experience. Like the biomedical and clinical perspectives, the phenomenological one reshapes and defines OCD along new, dependent but not necessarily visible paradigms. Specifically, we see that through a phenomenological approach the obsessions and compulsions that mark OCD pathology are not just clinical criteria, or faulty neuro-circuitry, but also becomes a perspectival lived experience explained through metaphor and symbolic language that can make it easier to conceive of OCD as an illness that is relatable, and human, rather than alien or abnormal. It also becomes clear that a phenomenological approach could equip clinicians and society at large with better language to discuss mental illness that comes from the experience of those with the mental illness, which can only serve to enhance clinical practice and understanding.
The three epistemological approaches when considered together provide a more encompassing view of OCD as it is conceived today. This perspective is however limited and what becomes evident when considering both the biological and phenomenological perspectives is that a great deal of further investigation is critical. I would argue that the phenomenological perspective gets the least attention and support at the moment even though biomedical researchers and clinicians look to the phenomenological for insights and qualitative research methods are often an important mechanism for hypothesis-generation. In these last two chapters I present the results of my own phenomenological analysis of the psychiatric neurosurgical treatment of OCD to further our understanding of OCD, severe and intractable OCD, and the lived experience of psychiatric neurosurgery today.
A Phenomenology of Psychiatric Neurosurgery for OCD

In the next and last two chapters of this thesis I am to provide a phenomenological analysis of the practice of psychiatric neurosurgery for OCD. Psychiatric neurosurgery developed out of a highly contentious and complex history of psychosurgery that has left a permanent, notably unflattering stain on the collective memory of psychiatric treatment. As discussed, psychiatric neurosurgery operates and represents a firm stance within a highly complex ideological framework that rejects mind-body dualism and upholds biological psychiatry. Further I aim to study the practice of psychiatric neurosurgery to treat the complex psychiatric illness of OCD, a clinical, biomedical, and social phenomenon. It became clear early on that a phenomenology of psychiatric neurosurgery for OCD would necessitate phenomenological and qualitative study of both clinicians and patients involved in the practice of psychiatric neurosurgery. After all, it is both clinicians and patients who by a social contract and many written contracts agree to participate and together delineate the shared practice of surgery for the psychiatric treatment of OCD. In other words, psychiatric neurosurgery for OCD is a social agreement like many medical interventions such as surgery that is made manifest by both the clinicians involved in the diagnosis and performance of the surgeries, and the patients who undergo them. Phenomenological literature of illness rarely discusses the clinician’s perspective(s), but I think clinicians hold critical narratives that impact the phenomenology of treatment and argue that this is especially important to consider when conducting research aimed at understanding not just the disease but primarily the procedure or medical treatment.

To this end, I have employed qualitative methods including ethnographic field observations, ethnographic interviews, and semi-structured interviews with patients and clinicians, as well as analyzed video data and live interactions between clinicians and patients.
Through the presentation of my “results” in the next two chapters I aim to focus on the phenomenology of surgical treatment for OCD through the sample surgical procedure of Gamma Knife Capsulotomy (GKC), the main procedure conducted at Butler Hospital to treat OCD, my main research study site. To analyze the clinical perspective of treating OCD, I conducted ethnographic field observations in clinical team committee meetings and in the operating room during Gamma Knife Capsulotomy procedures, as well as conducted individual interviews with different members of the psychiatric neurosurgical team including, psychiatrists, neurosurgeons, ethicists, nurses, research coordinators and a reverend (Chapter 4). To assess patients, I conducted retrospective medical chart review analysis on patients who had undergone GKC for OCD at Butler to assess the social and medical features of patients that were considered “intractable” and qualified for surgery (Chapter 5). My primary aim was to also gain an understanding of the lived experience of these OCD patients by conducting semi-structured interviews and employing interpretive phenomenological analysis (Chapter 5).
Chapter 4: A Phenomenological Analysis of the Clinical Practice of Modern Psychiatric Neurosurgery for OCD

“Who knows? In 20 or 30 years, folks may look back at what we are doing now and be shocked by how little we know. They might look at our surgeries the same way we look at the frontal lobotomies done 50 years ago. I hope not. We just have to be as careful as possible to do our best supporting the people suffering from OCD today with the best tools we have.”

– Dr. Nicole McLaughlin, PhD Neuropsychologist and Director of Psychiatric Neurosurgery at Butler Hospital

In this chapter, I will describe modern psychiatric neurosurgery as it is practiced today, basing my discussion on ethnographic field work and interviews with various members of the clinical team conducted at two prominent teaching hospitals in New England with the oldest and most established psychiatric neurosurgical programs in the United States: Butler Hospital and Massachusetts General Hospital. Analysis of the phenomenology of the clinical practice of psychiatric neurosurgery, which included re-reading interview transcripts and ethnographic field notes revealed four central ideas which I will discuss here in more detail. The first idea addresses my initial question after learning about modern psychiatric neurosurgery for OCD: How is the clinical decision to perform surgery made? The second idea concerns the phenomenology of the surgical operation itself, specifically gamma knife capsulotomy. The third concerns the “checks and balances” in place to ensure best ethical practice and safeguard patients. The fourth is an insight about how clinicians conceive of their work doing psychiatric neurosurgery for patients. How is the clinical decision to perform surgery made?

At the center of the room was an enormous oval table that spanned nearly the entire length of the room and had 8 to 12 chairs around its periphery. The official meeting had not yet begun, and several clinicians seated around the table were speaking casually. Later, a few more
clinicians entered the room and took their seats. “Before we begin, we must first approve the minutes,” announced Dr. McLaughlin, the director of psychiatric neurosurgery, from the head of the table. Each clinician had a document in front of them that was handed out and contained the plan for the meeting. Afterwards Dr. McLaughlin announced that there was “one case to review today.” The clinicians all bowed their head towards the document handed to them which contained a clinical summary of the case Dr. McLaughlin was referring to.

“We have a young female patient with high functioning OCD. With a Y-BOCS of 28, no 29. She is just below the cutoff,” Dr. McLaughlin reviewed.

“What procedure would this be for?” asked another clinician at the table.

“The procedure is the single ventral shot,” responded Dr. McLaughlin. “Are there any concerns for the low Y-BOCS score?” Dr. McLaughlin asked. The room fell silent as all the clinicians were reading the history of the patient carefully.

At Butler hospital, one of my earliest experiences with clinicians was the scene described above. What was taking place is called a Psychiatric Neurosurgery Committee (PNC) meeting. Originally conducted at Massachusetts General Hospital (MGH), the PNC meeting is a discussion amongst numerous members of the clinical and research team in which decisions are made concerning patient eligibility for and response to psychiatric neurosurgery. Over the course of a year, I attended several PNC meetings at Butler Hospital and MGH with the aim of understanding how clinical decisions concerning conducting psychiatric neurosurgical procedures were made.

While the first moments of the initial meeting at Butler Hospital were a bit disorienting it became clearer as the meeting went on that physicians were discussing which patients were eligible for surgery. The pattern of discussion became pretty apparent after a few patients were
discussed. First the patient’s history would be presented by one of the clinicians at the table, usually Dr. McLaughlin, and the clinicians would read along as the clinician speaking briefly summarized the components of the written history contained in the copy of the meeting document and then discussed the chief complaints or primary symptoms of the patient. “This patient is an adult male who has had OCD for some time, and whose chief complaints include compulsions related to severe contamination concerns and a fear of ‘going to Hell.’ The patient avoids swallowing foods which brings up a concern about whether he can take medications,” explained Dr. McLaughlin.

A psychiatrist at the table immediately asked “Has he been on any medication?”, to which another clinician at the table Dr. Rasmussen responded “Yes. Three months of oral Paxil and Zanax. Meds are a condition of approval for surgery.” Dr. Rasmussen the lead psychiatrist for the gamma knife surgery study for the treatment of OCD explained to this same psychiatrist, “I know you are not as familiar with the study, but they do need prior medication trials to be considered for surgery.” I learned later that this psychiatrist was a part of the PNC meeting in the capacity of an “objective” medical practitioner who had no vested interest in the study but could speak to the medical rationale for conducting surgery.

Regarding the same male patient as above the clinicians spent another 15 minutes discussing the history of medications and treatment this patient had undergone. “Has this patient been compliant with taking the medication trials we have suggested since he first came to us?” asked Dr. Rasmussen. In response, Dr. McLaughlin states that “He has. But once he gets the surgery I don’t know. He is compliant because he knows he needs to be for surgery” (emphasis added). “Perhaps we should push the dose, and keep the patient at a higher rate of pharmaceutical treatment and perhaps try an augmentation trial” suggests Dr. Greenberg a
psychiatrist and lead member of the OCD research team. “I agree I would like to see him on meds a little longer,” stated Dr. Rasmussen. After some silence and general gestures of agreement and nods from the members of the table Dr. McLaughlin asked whether the committee agrees to “do another trial” of medications by asking for “all those in favor of the proposed plan.” All members of the committee then responded in the affirmative one by one.

The above partial account of the proceedings of one PNC meeting provides a great deal of insight about how clinicians that perform psychiatric neurosurgical procedures decide whether or not to include patients in studies for surgical ablation. I want to highlight three specific components of the ethnographic account of this PNC meeting that are particularly insightful: the presentation of the patient history and chief complaint, the specific notion concerning the patient’s motivations concerning medications and the surgery, and the mechanism by which the committee comes to a group decision about a patient.

I noted that once the PNC meeting begins and the clinicians begin to discuss patients, their discussion of new patients follows the same specific pattern discussed above whereby first the patient history is presented, followed by the patient’s chief complaint and diagnosis, only after which the committee begins to deliberate in a free form manner on the patient’s illness and whether they should move forward towards surgery. This system was consistent for all the meetings I observed at both Butler Hospital and MGH for new patients being considered for surgery. One individual, typically the study coordinator or director would present the history of each patient focusing specifically on the age and sex of the patient, followed by a brief discussion of when they first started having symptoms. I note this phenomenon as significant simply because it is remarkably consistent between institutions and between patient discussions.
The content and order of how patient history and symptoms is discussed may provide the PNC team with an organization that if nothing else serves to standardize patients such that the process of consideration does not change with changing patient histories and chief complaints.

When Dr. McLaughlin mentions that the patient “is compliant because he knows he needs to be for surgery” in the discussion of whether the patient will be able to take medications given that he does not like to swallow food, she provides some insight about the phenomenology of how clinicians perceive and anticipate patient behavior. The notion expressed by Dr. McLaughlin comes from an understanding that the patient population desperately wants these surgeries, so much so, McLaughlin claims in this instance that they may be willing to complete an action that is likely anxiety-inducing. This suggests that the prospect of surgery itself may be a strong motivator for patients, or are at least thought to be so by clinicians in some cases. We will explore the notion of the motivation and drive to have psychiatric neurosurgery in more depth in our discussion of patient lived experience of disease.

According to Dr. McHugh and Dr. Slavney, one critical component to psychiatric practice is “anticipating” the motives and behaviors of patients (McHugh and Slavney 1998). The clinicians uncovered from the patient’s history that he avoids swallowing foods out of a concern for contamination, and likely from clinical experience with similar symptoms, anticipate that swallowing medications may be difficult for this patient as well. This is significant because one of the main criteria by which a patient becomes eligible for surgery is sufficient evidence that “standard treatments” have not resulted in long-lasting benefit (McLaughlin, Stewart, and Greenberg 2016). The psychiatrists begin to question this patient’s history of pharmaceutical treatment, since psychopharmaceuticals may not have proven effective only because this patient’s fear of contamination interferes with his ability to consistently take the medications
prescribed. This discussion, and resulting decision to have this particular patient adhere to medications for longer, to ascertain whether standard “pharmaceutical” treatment will work, speaks to the underlying intentions of the clinicians: “We want to make sure we have exhausted all other possible treatment options before we consider surgery” explained Dr. McLaughlin to me after the meeting.

The specific process by which the committee operated to make the decisions is also especially important because this system at least at Butler and MGH appears to deliberately embed one specific notion in the practice that speaks to the intention of the PNC meeting: that every committee member’s input is equally valid. At both Butler and MGH each member of the committee was expected to contribute to the decisions regarding the next steps for patients. At Butler hospital it was explicitly stated that for the PNC meetings a quorum, or number of committee members that need to be present and vote in favor of a course of action did not apply:

We’ve never had a number for quorum for the committee. Historically we have always sought unanimity, I suppose. We wouldn’t have moved forward if any committee member disagrees. – Dr. Rasmussen, PNC meeting field notes

Here Dr. Rasmussen discusses how a unanimous vote amongst the committee members is the essential requirement for making decisions about what the next steps are for patients being considered for psychiatric neurosurgery. While this was not explicitly stated during my visits to MGH meetings, it was clear that everyone’s input was necessary before moving on to a new patient in every case. This practice speaks to the intention of the meeting which is to take the decision-making power out of the hands of one individual. Further, the committee composition at both Butler, as mentioned above, and at MGH represented an attempt to assuage any potential researcher bias or motivation by including one or two clinicians in the meetings that were not
involved in the psychiatric neurosurgery research directly. By having committee members that had no motivation to want to recruit or increase the number of psychiatric neurosurgery cases and setting up a practice of equal voting power, the PNC displayed clear attempts to regulate its own potential biases and shift the decision-making process away from a single individual. Dr. Wael Asaad, the primary neurosurgeon involved in the psychiatric neurosurgery procedures for OCD at Brown University, expressed the motivation behind the PNC meetings and in so doing explained the intention behind multiple clinicians and making attempts to counteract the motivator of research:

I think you need to have a real sort of organized committee of people to evaluate these cases, because otherwise we risk sort of going back to the era when it was overdone. Walter Freeman took it upon himself, well he was a neurologist, but he took it upon himself to do these procedures and you know really gave

neurosurgical treatments of psychiatric disorders a bad name.

Here Dr. Asaad describes historically motivated reasoning that was consistently expressed by numerous clinicians I interacted with when they explained the purpose of the PNC meetings. It becomes clear that PNC meetings serve as a “final step” for vetting candidates for the neurosurgical procedure, and clinicians feel compelled to develop a structured process that combats any potential motivations to enroll individuals in these surgical trials. To that end, they distribute the power of decision-making and make attempts to approach each case in a

standardized way in an effort to protect patients and hold one another accountable to values such as ensuring that patients “have exhausted all other possible treatment options” before surgery is considered.
So what decisions are typically made at PNC meetings regarding new patients? While PNC meetings represent the “final step,” it does not appear that clinicians necessarily view the first time a patient is considered at a meeting as the last time a patient is considered. One difference in the apparent PNC practices between Butler Hospital and MGH had to do with precisely when patients were brought up in the committee meetings. At MGH for instance, Ms. Valerie Giorgione, the research coordinator for the psychiatric neurosurgery program explained to me that “We screen patients at these meetings” (Interview with Ms. Valerie Giorgione 2016). And this was evident in numerous examples of patients brought up during the MGH PNC proceedings. The committee’s most common decision about new patients was that “more records” needed to be obtained because of a “limited” a record of patient’s medication or treatment history to come to a decision about surgery.

At Butler PNC meetings, the patients are usually “reviewed and vetted” with greater detail prior to PNC meetings. This appears to be a function of the frequency of PNC meetings. At MGH the meetings are monthly, whereas at Butler they occur about every two-months, so both groups may prepare patient records at different rates to make their meetings as productive as possible. Nevertheless, sitting in on PNC meeting proceedings revealed to me that the researchers did not appear eager to perform surgeries in the patient population, but rather expressed a great deal of hesitance and caution. The motivations for this caution, I think stem back to a desire to best support patients that clinicians and researchers perceive to represent a “vulnerable” population and to also avoid one mistake of past psychosurgical practice: “overdoing” surgeries of this kind.
**Surgical procedures**

In a sterile and rather cold room underneath Rhode Island Hospital, I watched from about a meter away as Dr. Asaad screwed the stereotactic frame depicted in Fig. 6 to the skull of a patient as they sat upright in the bed. “Ouch!” the patient exclaims as the surgeon is screwing one of the last bolts into the patient’s skull, “That stings!” The team quickly increases the local anesthetic in this region, and Dr. McLaughlin reassures the patient saying “that’s the worst part” immediately after the frame has been placed. The patient relaxes soon after the placement of the stereotactic frame. The surgeon and the entire team of psychiatrists, a radiologist, and neuropsychologist are crowded around one computer while the patient sits in the room where the frame was placed with two nurses.

![Figure 6. Image of the Stereotactic Frame used at Rhode Island Hospital by Brown University and Butler research team for GKC procedure.](image)

The MRI “viewing party,” as I have come to call it, consisted of the entire psychiatric neurosurgery team examining the brain image of the patient in the next room and making measurements and discussing where to place the lesions precisely. “We want the lesions as
ventral as possible, since we think those are the fibers that travel to the brain region we think is responsible for the OCD symptoms” Dr. McLaughlin says to the group as the gamma knife programmer is clicking on the image of the brain in the anterior internal capsule where the ablation will take place. The neurosurgeon clicks on a more ventral portion of the internal capsule and this results in a ring of circles overlaid on the brain image that one researcher says “represents the isodose area that will receive focal radiation.” Dr. Asaad says that he does not want to hit a specific region that is nearby but not involved in the process with even “minimal radiation, because that area is important for vision,” and another neurosurgeon Dr. George Noren agrees. The researchers continue to go back and forth discussing the precise location of where the lesion will be placed within the ventral internal capsule. It should be noted that the anatomic region targeted by this procedure is very small so the negotiations that took over an hour between all the members of the clinical team, as they peered at the computer images, were discussions that resulted in millimeter sized changes in the location of the targeted regions.

“Does everyone agree on this region?” Dr. Greenberg asks the team. After the team affirms, then Dr. Asaad tells the gamma knife technician to “use these coordinates.” The technician announces to the team that the coordinates have been “locked in.” The clinicians sign a waiver and the patient is moved to the gamma knife bed which looks like an MRI machine where they were told they would lie for a couple hours while the radiation was delivered. The surgeon leaves the room as do other members of the clinical team, because while the surgical procedure is actually just beginning, the work of the clinicians is over, and now the gamma knife machine will place the lesion in the precise location of the patient’s brain that the clinicians decided upon moments ago.
The GKC is considered to be a relatively “low risk” procedure in which no open brain surgery is necessary and patients do not have to be placed under general anesthesia. The process described above, illustrates what I observed from a shadowing experience observing the GKC. The most salient aspect of the surgical procedure is the process of focused discussion and negotiation of the precise part of the anatomical region of interest to target. Given the biomedical discussion of the neural circuitry underlying OCD, the nature of this discussion was of particular interest because the nature of the clinical discussion to decide upon where to place the lesion reached a level of precision that was at least an order of magnitude greater than that understood from reading the literature alone. In order to better understand the negotiation and reason behind the phenomenon of coming to a collective decision on the coordinates for the lesion, I conducted semi-structured interviews with the surgeons specifically, as well as Dr. McLaughlin the research team director and neuropsychologist with expertise in the neural circuitry of OCD.

Dr. George Noren a retired neurosurgeon and the former director of the Rhode Island Hospital Gamma Knife center describes that while the radiation is aimed at targeting specific fibers thought to underlie OCD the precise location of the diseased fibers cannot be visualized:

Targets for functional procedures are defined as “invisible targets.” You need to use specific anatomical atlases to find the target. Gamma knife is more often used for tumors than psychiatric cases, and tumors can be visualized with MRI, but the diseased and healthy tissue in psychiatric cases is not so easily visualized. For this reason, a neurosurgeon is needed to plan the target, because knowledge of the detailed anatomy of structures in the brain is essential. (Interview with Dr. George Noren 2016)
Here, Dr. Noren defines the key reason behind the uncertainty and negotiation that takes place when deciding upon a precise location to place lesions for each patient. In psychiatric cases such as that with OCD, the primary challenge in uncovering a definitive biomarker for the illness lies in the fact that our tools for visualizing the brain are not able to identify the difference between healthy and pathogenic fibers when it comes to OCD. This is hypothesized to be due to the fact that researchers “don’t think anything is wrong with the structure of the fibers causing OCD but rather that they are just sending signals or firing in an aberrant way” explained Dr. McLaughlin. In other words, researchers are making lesions in the the anterior internal capsule, but because it is not yet possible to visualize which fibers in the relay between the thalamus and orbitofrontal cortex are the ones causing illness in a given patient there is uncertainty about whether the clinicians are “hitting the right fibers” McLaughlin explains.

Dr. Asaad corroborated Dr. McLaughlin’s explanation of uncertainty and also expressed that there is uncertainty or ambiguity in the biomedical science explaining how the current neurocircuitry models are linked to the precise symptoms and behaviors observed in OCD:

Is there one consistent biological substrate or is it a set of different biological mechanisms that give rise to these different manifestations? Suppose somebody has a certain set of strong obsessions and you know, lacks certain compulsions, and another person is the other way around. So you know they have complimentary symptoms but they are both diagnosed with OCD. Is the difference between them, because you have fairly similar prefrontal cortex architectures that in one case a certain set of pathways or a certain region is affected and in the other case a different set of cortical areas and connections are affected, or is it that you have different underlying organizations of the prefrontal
cortex and the same biological mechanism affecting what looks like the same pathway? Maybe the same part of the brain or something is really dealing with two functionally different circuits just because of the way each person developed and the way the brain gives rise to their behavior. You get different functions that are in slightly different places or are organized in a different way. And I don’t think that we have any good evidence that the truth is one or the other. And I think that makes it doubly difficult because you don’t know whether you are dealing with sort of baseline anatomical or circuit level variability. (Interview with Dr. Wael Asaad 2016)

Dr. Asaad further elucidates the current challenge of performing surgical changes to neural circuitry without a complete understanding of how the implicated circuits give rise to disease in different individuals. Dr. Asaad uses a hypothetical scenario to illustrate that researchers are not yet entirely sure whether the different symptoms or degrees of symptom expression between individuals are primarily due to structural differences in the circuits of individuals with OCD or functional differences in what the circuitry of a particular set of fibers becomes responsible for through an individual’s lifetime and specific disease.

Dr. Asaad also explained that “there is some variability” in each individual person’s brain structure, which provides additional rationale for negotiating the position of a target from one region to another. During one procedure, Dr. Rasmussen mentioned to Dr. Greenberg how wide one patient’s internal capsule was compared to another previous patient, illustrating the very kind of variability that necessitates that clinicians optimize the precise location if only by millimeters for each surgical procedure. Despite the theoretical uncertainty and likely variation in pathogenic neural circuitry the primary deciding factor guiding where clinicians set the coordinates for a
lesion in any given patient is identifying a location and position of injury that reduces the amount of radiation affecting nearby brain regions that are not the target of ablation. The radiation oncologist, present for the optimization of location, will frequently contribute to the discussion, not by suggesting a location for getting the right neural circuits, but rather by arguing to reduce the amount of radiation received by nearby brain structures: “The current protocol calls for 150 gray [Joules/kg] in the focal region” explained Dr. McLaughlin to the radiation oncologist who responded with “Ok. But the dose of radiation is too high” in the tissue immediately surrounding the region of interest.

It becomes evident that the negotiation of where to place lesions in the brain during the surgical procedure is a phenomenon motivated by the desire of the clinical research team members to balance targeting the areas they believe based upon a biomedical research framework to be most likely to result in OCD symptom relief and the more immediately critical requirement of safety. In this negotiation alone the clinical team is forced to navigate two distinct interests: to provide relief of OCD symptoms to a desperate patient population and to ensure that they uphold their Hippocratic oath and “abstain from doing harm.”

Checks and Balances

As discussed earlier, clinicians in the field of psychiatric neurosurgery are often frustrated by the contentious and problematic history of psychosurgery that they believe was problematic primarily because of “its rather indiscriminate application and the high incidence of side effects seen with the early procedures” (Cosgrove and Rauch 2005). As a result, clinicians have and continue to make efforts to distinguish and distance the modern practice of psychiatric
neurosurgery from its ethically contentious roots. This is evident in the language used, the formation of multi-disciplinary teams, and deliberate efforts to inform patients who undergo PN.

Upon first meeting Dr. Greenberg, I asked him to discuss the practice of “psychosurgery” at Butler hospital and was immediately corrected by him: “The term ‘psychosurgery’ is outdated the term psychiatric neurosurgery is what we use now.” The distinction is critical because for many clinicians who practice psychiatric neurosurgery, psychosurgery functions as an indexical term that points to the ethically contentious surgeries performed by Freeman and his colleagues that are believed now to have been in many cases harmful and problematic procedures. Psychiatric neurosurgery on the other hand, represents language that modern clinicians use to make the sharp distinction between the procedures of the past and the modern operations, which are framed with language emphasizing the enhanced “precision” and “accuracy” of procedures used today to treat psychiatric illness. The use of specific language not only indicates shifts in the improved technological capacity, but also indexes the intentional checks and balances that researchers and clinicians in the US have made a point to include in their practice to protect patients in ways that were not present when Freeman and Watts were first conducting frontal lobotomies.

We have discussed in some detail that the decision-making process includes many team members. Researchers and clinicians have made a point to create multi-disciplinary teams that include surgeons, neurologists, psychiatrists, psychologists, and in a number of cases bio-ethicists or medical ethicists. The multi-disciplinary team takes advantage of the specific skills and training of different medical specialties. For example, the neurosurgeons role is often “to evaluate the surgical risks and … talk about different surgical options” as Dr. Asaad mentions, whereas psychiatrists “have the training to say ok this is an extreme case for OCD” and
determine if a person with mental illness has “tried all [the standard] medications… and treatments” (Interview with Dr. Wael Asaad 2016).

Importantly ethicists are included in the multi-disciplinary teams, and at Butler Hospital this role was filled by a reverend who specialized in medical ethics. Rev. David Shire at Butler hospital described his role as a check of sorts for the PNC, by offering a perspective that differs from the clinical or research background of the other members of the team: “They need civilians who are not researchers to be part of the process. To really, keep ‘em honest” (Interview with Rev. David Shire 2016). Dr. Paul J. Ford, a neuroethicist at Cleveland Clinic, explained that there are certain ethical concerns that are important to keep in mind and safeguard against when doing psychiatric neurosurgery and surgical procedures in general:

The broad stroke view is people entering research that believe the research is intended to benefit them, so the most classic example of bad therapeutic misconception is somebody in a classic phase 1 oncology trial that is only testing toxicity. So if those folks come in thinking that they’re getting a treatment then they fall into therapeutic misconception. They are not informed; you are preying upon the vulnerability of having no other option left here. (Interview with Dr. Paul Ford 2016)

The concept of therapeutic misconception as Dr. Ford discusses is a concern of researchers in the field of PN, because they do not want to give the impression that the surgical procedures will definitely cure an individuals OCD, because as we have discussed there is uncertainty in the underlying science and the response rates of modern psychiatric neurosurgery procedures for OCD lies between 40-60%, meaning a significant portion of the population will not get better. It appears critical, in the minds of clinicians involved in psychiatric neurosurgery, to properly
inform patients in order to avoid therapeutic misconception, and build multi-disciplinary teams
to safeguard patients and ensure that the modern clinical practice of psychiatric neurosurgery
remains markedly distinct from the practice of psychosurgery.

Clinicians as caring individuals navigating uncertainty

Careful, phenomenological study of the perspectives of clinicians who work in the field
of psychiatric neurosurgery to treat OCD reveals a group of individuals that appear to deeply
care about supporting the health of patients suffering from OCD. The OCD research teams at
Butler hospital and MGH seem interested in addressing both the biomedical and personal aspects
of individuals with severe OCD. A superordinate theme that seems ever-present amongst
members of the clinical teams was a narrative of “hope,” or notion that the surgical option
represents the “last hope” for patients with severe OCD. One way this becomes apparent in
clinical practice is through repeated examples of overt celebration of narratives of patient
recovery and good outcome, and the unique practices by which clinicians exert self-protective
mechanisms to conceptualize and face poor patient outcomes.

In particular, it became apparent during the PNC meetings at MGH that the clinicians
tended to pay special attention and spend more time discussing those patients that had
particularly positive outcomes after surgery. In one instance, a patient who responded positively
to the surgery expressed that they were “feeling better now than in 30 years” and the entire room
of clinicians let out a collective expressions of satisfaction: “Wow!” “That’s great news.”
Another instance where a patient was described as “doing really well” since the surgery and “has
a boyfriend now and she goes out” resulted in similar positive responses amongst the PNC
members and collective lingering on the discussion of that patient. In other words, the pace of the
meetings seemed to slow down when particularly positive patient outcomes were shared. Clinicians appeared to relish in the successes of patients who do much better. For instance, Mr. Richard Marsland, a nurse at Butler Hospital, keeps a poster sized photo of one of the past psychiatric neurosurgery patients that had the surgery and then went on to graduate medical school. Mr. Marsland shared the story of this patient who clinicians at the time did not think could be helped:

He had very bad obsessions and was very debilitated. But after we did the gamma knife procedure he started to get a lot better. And you know he was able to go on and finish college and then even graduated from medical school and he is a doctor now! Isn’t that something?

During the telling of this story there was a clear shift in affect and tone that indicated a great deal of excitement and satisfaction came from reflecting upon the successful recovery of this patient.

The responses to poor outcome were markedly different. In the PNC meetings at MGH, it became apparent that as a collective, if the patient had a poor outcome the discussion of that patient was rather quick, often with only one person commenting. The comments for poor outcomes in the majority of instances were non-specific and short: “[This patient] is not so great.” In some cases, when a patient’s outcome appeared to not exhibit post-surgical improvement, clinicians would often use descriptors that suggested the patient might still improve, quickly responding in some cases where patient’s express no improvement after surgery by stating that “It’s still early…and they could still see a response in a while.” This was evident in the clinicians at Butler as well. In one instance, Dr. McLaughlin was speaking with a patient who had not experienced any improvement after nearly a year of surgery and was adamant to point out that “there are patients that take more than 9 months to get better.”
McLaughlin then expressed to the patient that “we are still optimistic,” that the procedure may work. There is uncertainty about how long it takes to see improvement in patients after surgery and in some cases, clinicians are able to leverage that uncertainty to support patients in their recovery, but I also think this practice can serve to allow clinicians to remain optimistic and even hopeful themselves.

I believe clinicians deeply care for patients and are in a position, given the ambiguity in the science and how much is still unknown about how these surgeries work, that makes it difficult to predict who will get better and who will not. This leads to language that differs in type from the clinical and biomedical vernacular that characterizes most of the language used by clinicians. Dr. Dougherty at MGH expressed such language in frustration after a brief discussion of a patient that was doing worse post-surgically: “I know this is a downward spiral after she was doing better. And I know this is the pattern, but I had hope.” This type of emotional admission is very rarely expressed by clinicians outright, but on occasion during interactions with other clinicians it becomes clear that like their patients they are hopeful for positive outcomes and troubled by negative ones.

To clinicians, as is the case with most phenomenological work when presented to the individual whose lived experience is being discussed, the notion I discuss here will seem obvious. Nevertheless, I include this argument because one functional role of phenomenology is to provide the opportunity to discard simplistic narratives in favor of more nuanced and complex ones, in an effort to make lived experiences relatable and improve our capacity for empathy. I hope to dispel the narrative that clinicians in the field of psychiatric neurosurgery are intent on taking advantage of patients or are exploitative in any manner. I argue in favor of a perspective of clinicians that shifts the discussion of ambiguity in the clinical science of psychiatric
neurosurgery for OCD from being a source of criticism of clinicians, to instead suggest that the ambiguity is something clinicians are deeply aware of, and as a result, share in the complex emotional and behavioral responses to the disease and treatment of mentally ill patients. Here, I aim to offer a narrative of clinicians as conscientious and caring individuals, who like their patients, are navigating an uncertain science in an attempt to provide support and some relief for those that come to them, suffering from OCD.
Chapter 5: “Like losing a ‘nasty’ old friend”: A Retrospective and Phenomenological Analysis of the Patient Experience of Modern Psychiatric Neurosurgery for OCD

Aim and Methods of Analysis

In this last chapter, I attend now to the most important perspective, that of patients who undergo psychiatric neurosurgical procedures to treat their medically refractory OCD. In order to better understand these patients, I first attend critically to the notion of “intractability.” I then focus more directly on the patients’ lived experiences of psychiatric neurosurgery for OCD using Interpretive Phenomenological Analysis (IPA) to identify specific themes and narratives in patient perspectives of undergoing psychiatric neurosurgery for OCD.

What makes a patient’s illness intractable, how is this communicated, and are there clinical features that can be gleaned from the medical record of patients with intractable illness that distinguish them from the larger OCD population? In order to assess the first two questions, I address the clinical definition of “intractability” and draw from ethnographic fieldwork and interviews as well as recent literature in the field of psychiatric neurosurgery for OCD. To address the latter question, I conducted a retrospective medical chart review on past OCD patients (n=38) at Butler Hospital treated with Gamma Knife radiosurgery. Looking specifically for features in the clinical and social history I use descriptive statistics to provide information about the patients in order to assess clinical features of intractability.

In order to assess the lived experience of individuals who undergo psychiatric neurosurgery for OCD, I conduct IPA to uncover superordinate and subordinate themes by conducting forty minute to hour long semi-structured interviews over the phone and in-person with patients treated at Butler Hospital with Gamma Knife Radiosurgery for their OCD. IPA is a
method synthesized and developed by clinician Jonathan Smith and others who called “for a method in psychology that was able to capture experientable [, a term coined to mean that which can be experienced,] … dialogue” (Smith 1996; Smith, Flowers, and Larkin n.d.). IPA traditionally consists of semi-structured interviews in which the interview process is guided by the subject and the experiences they wish to highlight are what is discussed. IPA is based on a combination of phenomenological, hermeneutic, and idiographic theory that aims to capture a patient or subject's experiences in their own terms (Murphy and Perera-Delcourt 2014). Researchers argue that “successful interpretative phenomenological analyses move beyond empathic accounts and question, analyze, illuminate and make sense of people’s lived experiences” (Murphy and Perera-Delcourt 2014).

I attempt to replicate IPA by interviewing patients using a patient interview outline, but having the subject guide the interview and take it in any direction they feel is appropriate (See Appendix B). I recorded audio of each patient interview, transcribed, and later examined each interviews audio and transcript several times. After analyzing each patient interview for ideas and themes that struck me as salient at the time, I examined the ideas presented by each patient in their own terms without drawing on other patient perspectives. After completing the above analysis on each subject, capturing their experience or set of experiences in their own terms, and as is consistent with other methods of verification in IPA, I make comparisons between the analyses of the patient experiences from the different interviews, recognizing that no patients are identical, but searching for similar themes or ideas that may be described by different patients in the study group (Smith, Flowers, and Larkin n.d.; Smith 1999; Smith 1996; Murphy and Perera-Delcourt 2014).
Examining “Intractability”

You may recall, that the primary rationale for performing psychiatric neurosurgery on patients with OCD is the clinical feature of “intractability.” A patient’s OCD is said to be intractable or medically-refractory when standard medical treatment including conventional pharmacotherapy and cognitive-behavioral therapy fails to sustainably improve OCD symptoms (Lopes et al. 2014; Garnaat et al. 2015; Rasmussen et al. 2000; Greenberg et al. 2003a). In principle the notion of intractability seems clear, but in clinical practice it can be difficult to precisely characterize a patient’s illness as intractable.

Intractability may be a challenging clinical feature to characterize, because in some ways it is a diagnosis of exclusion, in that a patient can only be deemed intractable if they have received all of the standard treatment measures for a significant amount of time and shown little to no improvement. The problem of defining intractability becomes even more difficult when one considers the use of somewhat ambiguous terminology such as “unsatisfactory results” or “moderate patient response” to describe the level of improvement or worsening after treatment, since the definition of a “satisfactory” result or “moderate” response is somewhat non-specific (Ferrão et al. 2006; Albert et al. 2002; Jenike and Rauch 1994; Rasmussen and Eisen 1997). As a result, researchers and clinicians define specific clinical criteria for intractability somewhat differently, with different OCD research teams establishing criteria that are more or less robust than others.

One research group in Brazil conducted a study that attempted to determine differences in clinical characteristics between OCD patients that respond to treatment and those that are “medically refractory” (Ferrão et al. 2006). In this study, Ferrão et al define refractory OCD with a set of criteria: “(1) a decrease of less than 25% in the initial Yale-Brown Obsessive
Compulsive Scale (Y-BOCS) score or a less than minimal improvement on the Clinical Global Impressions (CGI) scale after treatment with first-line drugs for at least 16 weeks each” (Ferrão et al. 2006). Two other research teams in Israel and Italy set forth the following, slightly different criteria for determining “refractory” OCD:

As a general rule, response could be classified as a rating of much or very much improved on the Clinical Global Impressions (CGI) scale and a >35% reduction in the Y-BOCS score from baseline. Partial response could be classified as a reduction of between 20% and 35% in the Y-BOCS score. Treatment resistance could be defined as having not responded to one adequate trial of an [Selective Serotonin Reuptake Inhibitor] (SSRI), and treatment refractory as having not responded to at least two adequate SSRI trials with minimal or no response to treatment. (Abudy, Juven-Wetzler, and Zohar 2011; Pallanti, Hollander, and Goodman 2004)

Here it is clear that criteria for determining OCD intractability often uses similar metrics such as Y-BOCS and evidence of attempted treatment drug treatment between the Brazilian research group and the criteria used by the Italian and Israeli group shown above. Specific differences are clear, however, between the two criteria. A single failed medication trial of at least 16 weeks is what the Brazilian team uses to define refractory which is distinct from the requirement of “at least two adequate SSRI trials” in the other teams. I use these two examples to illustrate that intractability is defined differently by different research teams in different areas and often differ in details such as the required number of medication trials, the percentage of Y-BOCS score reduction, as well as other criteria.
While intractability is the main rationale for psychiatric neurosurgery procedures for OCD, it should be noted that researchers think the number of patients that would be eligible for surgery is markedly smaller than even the population thought to have intractable illness. In a study by the Brown OCD Research team, even more strict requirements were used by the team to determine if a person meets the criteria for surgery and by extension “intractability” (Garnaat et al. 2014). This study does not explicitly set forth criteria for “intractability,” but instead applies inclusion criteria for the surgical treatment of OCD on a longitudinal cohort of patients with OCD to identify which patients in the general population might meet surgical criteria (Garnaat et al. 2014). The research team at Butler used the following criteria shown in to determine intractability in the general OCD patient population:

1. Primary diagnosis of OCD as diagnosed by the SCID-IV
2. OCD symptoms judged to be of disabling severity, as indicated by a Y-BOCS score $\geq 28$
3. Significantly impaired functioning, as indicated by a GAF score of $\leq 45$
4. Previously stated severity and impairment criteria must be met in spite of at least three trials of different SRIs (fluoxetine, sertraline, fluvoxamine, paroxetine, citalopram, escitalopram, or clomipramine). Use of fluoxetine, sertraline, fluvoxamine, paroxetine, or clomipramine for at least a month or any reported use of citalopram or escitalopram for OCD is counted as a trial. These trials may include any of the agents above, but must include an adequate course of clomipramine.
5. Use of a neuroleptic and a benzodiazepine for OCD for a least 1 month.
6. Adequate behavior therapy, defined as $\geq 20$ sessions of ERP. (Garnaat et al. 2014)

Here we see that the criteria for inclusion in surgery at Butler Hospital is a bit more robust than the criteria for intractability from previous teams. Part of this increase in criteria is likely due to additional criteria aimed at getting at the “severity” of illness including the minimum Y-BOCS score of 28 and high Global Assessment of Function cutoff.\(^1\) The criteria 4, 5, and 6 in the Garnaat et al study, do however appear only to be criteria for definitively determining that patients are intractable as exhibited by continued exhibition of severe OCD symptoms after attempts at nearly every available standard therapy. These measures of intractability also differ significantly from the previous two sets of criteria from other research teams, most notably in their inclusion of a failed behavior therapy trial and treatment with a neuroleptic. In the study by Garnaat et al, researchers uncovered that approximately “0.6% of treatment seeking patients” would be eligible for surgery, which illustrates that the population that receives surgery is a very small subset of the OCD population that presents with both intractable and severe illness (Garnaat et al. 2014).

Given the discrepancies in criteria for determining intractability, it seems critical to further standardize the field of psychiatric neurosurgery to increase consistency when examining intractable patients. One step that could improve our understanding of intractable patients in the meantime would be examining the facets of the social and medical history of patients with intractable OCD to learn more about the population and potentially glean information about what distinguishes them from the larger OCD population.

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\(^1\) It should be noted that although high “severity” is not analogous to intractability many researchers have included severity as a feature of intractable or medically-refractory illness, noting that patients with intractable illness suffer from “severe, debilitating illness” (Greenberg et al. 2003a; Cosgrove and Rauch 2005; Jenike et al. 1998)
In order to identify specific features of the intractable OCD patient, I retrospectively reviewed patients who received Gamma Knife Radiosurgery at Butler and thus were selected based on surgical inclusion criteria essentially identical to that described by Garnaat and colleagues.

Results of Retrospective Chart Review of patients with “Intractable” OCD

Table 1 summarizes the demographic features of 38 randomly selected patients treated at Butler Hospital for intractable OCD with Gamma Knife Radiosurgery from 1993 to 2016. The study population’s age at the time of their surgical intervention varied with the eldest and youngest patients being 66 and 18 years old, respectively. The mean age of the population at the time of their surgery was 34 years. The patient population contained slightly more male subjects (n=21) than female subjects (n=17) from the analyzed group. All patients but one self-reported “White” as their Race/ethnicity, with the exception being a single patient who indicated they were Asian.

Table 1. Demographics of patients treated with Gamma Knife Radiosurgery

<table>
<thead>
<tr>
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<th>n (%)</th>
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<tbody>
<tr>
<td>Total population studied</td>
<td>38</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>21 (55.3)</td>
</tr>
<tr>
<td>Female</td>
<td>17 (44.7)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>37 (97.4)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (2.6)</td>
</tr>
</tbody>
</table>
The most striking feature of the data in Table 1 is the marked homogeneity in the surgical population in terms of “Race/Ethnicity.” This is notable given that numerous epidemiologic studies indicate that Black/African-American and Asian populations are at an increased risk of contracting OCD (Nota et al. 2014; Ruscio et al. 2010). Despite this, there is little to no representation of these ethnic groups in the study sample (Chow, Jaffee, and Snowden 2003; Littlewood and Cross 1980; Gary 2005). A number of factors may contribute to this phenomenon including the regional diversity in Rhode Island coupled with the documented decreased use of psychiatric care by minority populations due to complex social factors and structural barriers. In addition, a long-term OCD population study conducted at Butler Hospital showed that 96% of the OCD population treated at Butler are white, so it makes sense that this number would be reflected in the severe, intractable OCD patients treated at Butler Hospital as well (Pinto et al. 2006). While it makes sense that racial and ethnic minority groups would have less access to these procedures due to the simple fact that to qualify for surgery, years of psychiatric care are critical, so if there is diminished use of psychiatric care by minority populations then we would expect these requirements would only serve to exaggerate that disparity. That being said, this issue is certainly far more complex than I have discussed here, and merits further study into the sociology of access as well as the phenomenology of how patients find their way to PN.

In order to begin to look at some of the clinical features in patient’s history that may accompany a diagnosis of intractability, I started by looking at the time course of an individual's OCD starting with the age of symptom onset and then also analyzing other related data such as the length of treatment history prior to surgery, the time between
symptom onset and treatment, and the percentage of life years spent with OCD. The results of this descriptive statistic analysis are summarized in Table 2.

Examination of Table 2, reveals some aspects of severe, intractable illness that are consistent with previous reports such as a very low average onset of symptoms, where some patients reported OCD symptoms starting as low as age 2, and many years of OCD with a mean of 22 in this sample population (Ferrão et al. 2006). In order to better assess the degree and impact of disease, I calculated the percentage of life years spent with OCD symptoms and the percentage of life years spent receiving treatment for OCD by dividing the years of OCD symptoms or years since treatment onset by each subject’s age. This analysis revealed that, on average, patients in the study group spent more than half, nearly 60% of their lives with OCD symptoms, and nearly a third of their lives receiving treatment for their OCD. It was also observed that subjects experience approximately a decade of OCD symptoms prior to receiving treatment. It is unclear whether this is because prior to initial treatment patient OC symptoms are subclinical and not consistent/severe enough to require treatment or if patients are suffering in silence for years prior to treatment.

Table 2. OCD and OCD Treatment History

<table>
<thead>
<tr>
<th></th>
<th>Mean ± SEM</th>
</tr>
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<tbody>
<tr>
<td>Age</td>
<td>34.6 ± 1.63</td>
</tr>
<tr>
<td>Age of OCD symptom onset (self-report)</td>
<td>10.9 ± 1.10</td>
</tr>
<tr>
<td>Years of OCD symptoms</td>
<td>22.9 ± 1.87</td>
</tr>
<tr>
<td>Percent of life years spent with OCD</td>
<td>59.5 ± 4.36%</td>
</tr>
<tr>
<td>Age at OCD Diagnosis and initial treatment</td>
<td>20.8 ± 1.25</td>
</tr>
</tbody>
</table>
I later examined the study population’s medical history, paying attention to comorbidities or additional psychiatric diagnoses and found that almost all patients had at least one co-occurring psychiatric diagnosis. The most common were MDD and Generalized Anxiety disorder. We also further examined the social history of patients looking for risk factors including a history of mental illness in the family and history of trauma or suicidality noted by patient self-reports.

Table 3. Co-Occurring Diagnoses, Social History

<table>
<thead>
<tr>
<th>Co-Occurring Diagnosis</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Depressive Disorder (MDD)</td>
<td>32 (84.2)</td>
</tr>
<tr>
<td>Generalized Anxiety</td>
<td>12 (31.6)</td>
</tr>
<tr>
<td>Anorexia Nervosa/Bulimia/Body Dysmorphic disorder</td>
<td>4 (10.5)</td>
</tr>
<tr>
<td>Obsessive Compulsive Personality Disorder</td>
<td>2 (5.3)</td>
</tr>
<tr>
<td>Bipolar Disorder White</td>
<td>2 (5.3)</td>
</tr>
<tr>
<td>PTSD</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (23.7)</td>
</tr>
<tr>
<td>Family History of Mental Illness</td>
<td>25 (65.8)</td>
</tr>
<tr>
<td>Family History of OCD</td>
<td>15 (40.5)</td>
</tr>
<tr>
<td>History of Abuse or Trauma</td>
<td>6 (15.8)</td>
</tr>
<tr>
<td>History of Suicidality or Suicidal Ideation</td>
<td>20 (52.6)</td>
</tr>
</tbody>
</table>

*SEM: Standard Error of the Mean; If not otherwise specified as a percentage or score then the units are years.
I found that most of our study population had a family history of mental illness of some kind, and 60% of those patients had a family history positive for OCD in particular. Further analysis revealed that a history of trauma which included physical and sexual abuse for some patients was present in the medical history of about 15.8% subjects in our study population. Lastly, we see that over half of the patients who received Gamma Knife Radiosurgery for OCD at Butler hospital had a history of either attempted suicide or suicidal ideation. All patients with a history of suicidality or suicidal ideation also had a diagnosis of MDD, and we noted that 62.5% of the MDD population in our study were positive for suicidality or ideation, which speaks to the severity of the co-occurring diagnosis of MDD in the intractable OCD population.

Overall our results suggest that the patient population that receives surgeries and is thus deemed intractable, may have specific clinical and life courses that distinguish them from the larger OCD patient population. These patients certainly experience OC symptoms earlier than is reported for the general OCD population (Ruscio et al. 2010; Stanford University School of Medicine 2017). Our findings suggest that perhaps these patients also go for a significant portion of time with untreated OC symptoms, and may receive treatment for OC symptoms for a significant portion of their lives. The social history of patients reveals how vulnerable the severe, intractable OCD patient population that receives surgeries is, given the high co-incidence of other mental illnesses, the history of abuse, and history of suicidality or suicidal ideation. The descriptive statistics also revealed a high rate of OCD in the family history of patients which may implicate psychosocial and biological mechanisms in illness etiology.

The analyses above are only preliminary and need to be applied to a larger population of patients, tested against other patients with OCD that is not considered refractory, and may also
be important factors to test against the rate and degree of recovery after surgery to determine if any of these factors increased or decreased an individual’s chance of responding positively to psychiatric neurosurgery. Nevertheless, it is clear that the characterization of “intractability” is a challenging clinical determination that requires further research and may benefit from a less ambiguity.

Understanding the lived experience of Post-surgical Gamma Knife Radiosurgery Patients before, during and after surgery

Institutional Review Board Approval and Patient Consenting

All the data presented below are from semi-structured interviews conducted either over-the-phone or in-person with past Gamma Knife Radiosurgery patients at Butler Hospital. This study was approved as a sub-study protocol and amendment to the existing Gamma Knife Surgery protocol by the Butler Hospital Institutional Review Board (See Appendix A). In accordance with Butler Hospital policy, verbal and/or written consent was obtained for each participant prior to participation in the study (See consent forms in Appendix B). Subjects are de-identified in this study to protect their privacy.

Superordinate Themes

Analysis from n=5 patient interviews are included in this analysis. All participants in this study were male, which is a notable limitation in the study since about 50% of the population that undergoes psychiatric neurosurgery for OCD is female, and the lived experiences may differ. To address this limitation, I will also draw from narrative examples taken from pre-surgical videos (n=4) from OCD capsulotomy archival data of
patients who underwent psychiatric neurosurgery at Butler as well as from the autobiographical account, *Contaminated: My Journey Out of Obsessive Compulsive Disorder* by Gerry Radano, a patient who underwent surgery at Butler Hospital for OCD.

The semi-structured interviews of all patients included perspectives that fell into one of three superordinate themes or categories of perspective: “Before the surgery,” “The surgery,” and “after the surgery.” In other words, each subject shared perspectives of their lived experience of psychiatric neurosurgery for OCD and oriented their discussion in a chronology of their experience of OCD before the surgery, their experience of the surgery and days leading up to it, and their experience after their surgery. Each of these superordinate themes contained notions, ideas, and themes that were salient to me as the primary analyst often because they were commonly expressed and in some cases because of their unique and impactful content.

“Before the surgery”

All participants in the study reflected on their experience of OCD prior to the surgical procedure. Common themes emerged as patients described their illness as ab-“normal,” conceptualized the surgery as their “last hope,” experienced profound “desperation” for relief, and aimed to qualify to receive the surgery by presenting themselves as “viable candidates.” I will introduce and critique each of the the following subordinate themes that played a role in the patient’s lived experience “before the surgery.”
Achieving “normal”

The notion that “being normal” was deeply disrupted by OCD in the lives of the patients became clear throughout each interview, with patients expressing the notion that OCD has made it difficult for them to live “normal” lives. In fact, the word “normal” or a description of their illness in terms of a typical or regular life to describe what patients felt unable to achieve as a direct result of their OCD symptoms, was present in nearly all patient interviews and in the pre-surgical patient videos. One young, female patient from the video recorded cohort described this notion of being able to live a normal life:

I know it won’t go away entirely, but I just want to just like, sort of do everyday necessary activities. I want to be able to finish school and get a job, and maybe go to grad school … be more normal. (Patient Pre-Surgical Videos from Butler Hospital OCD Research Team Server n.d.)

In this quote we begin to see what it means to be normal in the list of achievements or goals that the patient expresses, namely finishing her studies at the university and going on to get a job or pursue further education afterward.

The notion that “being normal” was deeply disrupted by OCD in the lives of the patients became very clear over the interviews as well. Subject 1702, a middle-aged male patient hoped that the surgery would “cure” his disease so that he could lead a more “normal” life. He felt that his OCD was a barrier to him living a normal life, and hoped before the surgery that surgical treatment would help him overcome this barrier. In effect, this notion contextualizes subject 1702’s neurosurgical procedure such that it is not so much a tool to eliminate brain tissue and fix neural circuitry, but rather a tool by which he might achieve a more normal life. A life which he
defined as one where he can “spend time” with his family and “spend more time with [his] daughter” without being plagued by “constant obsessions” (Patient Interview 1702 2017).

In all cases, patients seemed to use the notion of “normality” to index a healthier state in which they could achieve their goals. Their criteria for normal, while varying depending on their individual ages and circumstances were consistent in that the language concerned certain life cycle achievements and goals. It became clearer that “normal” represented a personalized metric that patients developed in order to characterize the impact of their OCD and define Gamma Knife Radiosurgery as a tool that if successful would provide relief by helping patients achieve normal. Subject 1701, a middle-aged male discussed described during his interview how he defined “normal” and the role that determination had in how he framed what he thought the surgery would do:

*Interviewer:* When you were getting ready to have the surgery and you imagined it having an effect on your OCD symptoms what did you imagine it affecting? What did you think it would help you the most with?

*1701:* I don’t know living a little bit better some kind of. I just a little bit more normal I guess. Make me a little bit more free. More free you know? Give me a little bit more freedom it’s like it’s hard to explain, it’s like I’m a prisoner in my mind. (Patient Interview 1701 2017)

It becomes clear from this portion of the interview that the patient conceptualized normal as being “more free” from OCD symptoms. The subject uses the metaphor of a “prison” to describe his mind, a pervasive metaphor used for mental illness. He hopes that the surgery will make him more “normal,” as he imagines that “normal” is a sense of freedom rather than imprisonment.
Early on in his interview patient 1701 discussed his early experiences with OCD at the age of 10 and provides further insight about how he conceptualized “normality”:

Boy I think I had it all my life I just didn’t know it. I remember when I was 10 years old, like the light switch I would click it on and off repeatedly I didn’t know why. But I used to do it. I didn’t know why. I was 10 years old. And it just went on you know, throughout high school and stuff. And then, I’ve always had depression like a big hole inside me throughout high school and all that. But I didn’t know it I just figured that’s how it is. That’s just life. That’s just normal I didn’t know. (Patient Interview 1701 2017)

Contextualizing the concept of “normal” in this patients lived experience is critical to understanding the basis of his metric for improvement after surgery. Patient 1701’s metric of “normality” appears more abstract than that of the other patients described earlier and perhaps makes use of non-specific, metaphorical language in-part because as he says he thinks he has had OCD “all his life” such that he even perceived his lived experience as “normal.” Dr. Greenberg, a psychiatrist and leading authority on psychiatric neurosurgery says “[Surgery] only enables somebody who has the capacity to heal to heal themselves. That’s all it does. It doesn’t fix them. And if they don’t have the capacity to have ever experienced a reasonable functional state… they may not” reach a reasonable functional state after surgery (Interview with Dr. Benjamin Greenberg 2017).

While normal may not be the best metric of success or health in patients, the way that each individual conceptualizes normal appeared to play a large role in how they viewed their OCD prior to surgery and delineated what they hoped to get out of their surgery.

*Surgery as the “last hope”*
Across the patient interviews and video data, it became clear that before getting the surgery patient’s viewed psychiatric neurosurgery as the very last available treatment option and thus their “last hope” for treating their OCD symptoms. In a video account one subject describes his upcoming gamma knife capsulotomy and expresses the notion that may underlie patients’ sentiment when they characterize their surgery as the “last” hope or option available:

What I hope what the gamma knife does, well I hopefully it’ll cure it. I don’t, I mean I don’t put all my faith in that, but hopefully it’ll be able to make me stay faithfully taking the drugs. There aren’t that many options left at this point.

[patient laughs]. (Patient Pre-Surgical Videos from Butler Hospital OCD Research Team Server n.d.)

Here this subject describes the notion of his “last” option being the surgery, and while he expresses knowledge that the procedure may not work, his optimism remains. The language this patient uses here is especially interesting because it points to his unique positionality as a patient with intractable OCD and identifies the real risk of the procedure not working. His unique positioning within the biomedical framework as a patient with intractable OCD is unique because he is part of a very small subset of patients who do not respond to conventional medical treatments for OCD. Further, because his illness is not fully understood and the procedure he will take part in is experimental, there is a very real possibility that the intervention will not alleviate his symptoms. This uncomfortable reality is difficult to face especially because of the idea that he clearly expresses: There are few “options left.” This balance between optimism and recognition that the surgery may be the last novel treatment option that patients have not yet tried provides some insight about what may be contained in the common phrases “last hope,” “last
step,” or as Gerry Radano expresses in her autobiography “the last brick road” (Patient Pre-Surgical Videos from Butler Hospital OCD Research Team Server n.d.; Radano 2007).

This patient and indeed all patients with intractable OCD at this point do not have another biomedical treatment option available to them, as we have discussed. Especially given that they have exhausted all possible pharmacological and behavioral therapy options in order to even be considered for surgery (Garnaat et al. 2014). Patients are in the vulnerable position of depending upon something that is uncertain. This uncertainty is something nearly every patient interviewed described, yet the prevailing theme regarding the pre-surgical perspective was one that highlighted and uplifted notions of “hope” and “faith” in their narratives. This was true of patients that benefitted considerably from the surgery who collectively expressed that they had a great deal of hope going into the surgery:

“Yeah I was very hopeful anyway that this would make a difference… I think I was very hopeful that it would work or at least provide a significant benefit” –Patient 1705 (Patient Interview 1705 2017).

“I was, I was hopeful that this could be a, not like a, maybe a small [help]” –Patient 1703 (Patient Interview 1703 2017).

“I don’t regret the surgery. I just want you to know that. I don’t regret it at all, because like I said I felt hopeless. I felt hopeless you know. And the surgery was my hope to get better” –Patient 1702 (Patient Interview 1702 2017).

The above patients have all shown significant improvement in their OCD symptoms since their surgeries. Patients 1705 and 1703 in particular have had many years since their surgery and
describe themselves as nearly “symptom free.” Patient 1704 was a more recent surgical patient who has experienced “ups and downs,” but has gradually improved and has experienced “moments of peace” that he feels justify the surgery. I point out these patient outcomes because while this superordinate theme concerns what the patients thought “before their surgery,” all the data being retrieved from interviews is retrospective in that patients are being asked to reflect on their experiences in the past. It would make sense that their current outcome, if good, may lead them to have more positive views of their pre-surgical thoughts of the surgery. Insight from Patient 1701’s interview transcript, who has yet to improve by clinical measures or in his own perception since the surgery, however still illustrate a pre-surgical perspective that uplifts the narrative of hope he had prior to surgery, though with a marked shift in tone from the previous cases:

*Interviewer:* Do you remember what you thought of the first time when you read about the surgery?

1701: Yeah I was happy. I wanted to do it. I couldn’t wait to do it. But I haven’t lost hope. I haven’t lost hope… I was happy I wanted you know to be cured…. I felt, like from God, that this is the right thing to do now, to get the surgery. That’s what I believed that’s how I believe. The feelings that are good ones I get from God…. the feeling I got I believe was from Jesus from Mary to do the surgery and I did.

*Interviewer:* And the feeling you got was it that if you got the surgery you would feel better?

1701: Yeah, it was so that I would feel better. (Patient Interview 1701 2017)
In this interview, we see that Patient 1701 certainly had a great deal of hope for the surgery early on, however in his description of his pre-surgical perspective there is a sudden shift to the present, where he says “I haven’t lost hope.” This shift in tense was accompanied by a poignant shift to a more somber tone. This shift indicated that the patient perhaps felt differently about his pre-surgical perspective given that he does not feel he has improved since the procedure he had 9 months ago, yet, “hope,” was still a central part of his narrative about how he conceptualized the surgery before having it. This patient’s unique source of support and hope before the surgery came from God, Jesus, and Mary which are actors in his faith system, and perhaps appear to represent a narrative of religiosity as a mans of dealing with the uncertainty surrounding the procedure.

The involvement of magical, metaphysical, and/or religious thought amongst patients is not an uncommon feature. Indeed, other interviewed patients discussed, though less directly, that they “prayed to God” that the surgery would cure them (Patient Interview 1702 2017). Radano states that she believed prior to her surgery that “God had brought [her] to … the bottom of the mountain. And if He brought [her] this far, He would indeed get [her] to the top” (Radano 2007). While some of the magical thinking like that described, which often invokes religious faith, were expressed with a level of certainty and conviction, individuals often recognized some of their other thoughts about the surgery as “magical” hopes:

Shouldn’t there be some kind of magical transformation? In my hopeful fantasy, I felt that the gamma rays would act like Tinkerbelle’s fairy dust and instead of being able to fly or turned into a princess, in the case of OCD, I would be totally free of obsessions and compulsions. (Radano 2007)
The mixture of the uncertainty of the procedure and the worry and desperation surrounding how patient’s viewed their illness is likely responsible, at least in part, for the involvement of religious beliefs and magical thinking in patient narratives. The involvement of religious narrative in medicine is a well-known phenomenon among clinicians in virtually every field of medicine.

Interestingly, the involvement of the metaphysical and religious is often tied directly with hope about the surgical procedures in this study population. During a PNC meeting at MGH a letter from a depressed OCD patient who had not improved from surgery was shared that stated that they “had hoped this would be the magical surgery that cured them.” Here this patient expresses some of the potential harm in the narrative of psychiatric neurosurgery as the “last hope,” that can lead to deleterious outcome, and may even limit a patient’s capacity to recover and function. Take for instance the notion expressed by Patient 1701, that God had told him the surgery would make him feel better. If this patient does not improve after surgery, not only is he faced with the natural disappointment of another failed intervention, he is also potentially forced into a complex crisis by which he must address the magical thinking that was a source of hope. In so doing, this metaphysical source of hope may turn into a source of dread linked to the surgery, as it may have been for the patient who wrote the letter that essentially renounced their earlier thinking of the surgery as “magical.” This disillusionment is an important perspective to consider and be aware of, particularly as it may be an essential component to address in cognitive-behavioral therapy and psychoanalysis for patients after they undergo PN.

Dr. Nicole McLaughlin, the coordinator of the OCD research team at Butler hospital shared that “many patients feel as though the surgery is their last hope or last option, and that can be particularly devastating for those that don’t do well after the surgery and they may get worse
as a result.” Patient 1704, clearly expressed this very notion when he described what made him nervous about the surgery: “I guess that’s probably what I felt the most nervous about. Because if it didn’t work, then what? (Patient 1704 2017). The development of the narrative of surgery as a “last hope” is not only devised and used as a descriptor by patients but may be a constructed narrative upheld by clinicians as well. Reviewing grant proposals and research papers on psychiatric neurosurgical procedures for OCD reveals the consistent use of language that describes the surgery as the “last hope” for desperate or otherwise incurable patients (Jenike et al. 1998). While it is unclear whether the narrative originated from patients or clinicians (it was likely both), what becomes obvious is that characterizing the surgery as the “last hope” only works for those patients who markedly benefit from surgery. The learned and shared narrative amongst clinicians and patients of surgery as the “last hope” may be harmful and may inhibit the recovery of or as Dr. McLaughlin says even “worsen” the symptoms of a patient who does not immediately respond to surgery. This may be an important narrative for clinicians and patients to reshape and address because for 40-50% of the population that undergoes surgery the outcome will not be markedly positive.

While I do not claim to know what narrative could replace the “last hope” theme it seems important to maintain the possibility of pre-surgical optimism and “hopefulness,” because it may be supportive for patients, many of whom describe “less anxiety” and “happiness,” the days leading up to the surgery. And in an OCD patient population with such a high co-incidence of depression, moments of happiness can be important for many. Patient 1702 pointed to the potential positive effects on his emotional state of his hopeful narrative the days leading up to the surgery:
I was excited. You wouldn’t think someone would be excited about having a brain surgery, but I was ecstatic that I was going to have it. I wasn’t scared at all. Like I said I have a lot of faith in God and like I said I had a lot of prayers for me before the surgery and while the surgery was going on, I really had no fears about it. I felt great about it. (Patient Interview 1702 2017)

Desperation and Hopelessness

“I think somebody, my wife was asking there you know if your husband’s worried about the brain surgery and she was like no, he’d let me do it. I’d let her do it! I said I didn’t, if I didn’t wake up id be fine with it too. I would’ve preferred that to just years of OCD.” – Patient 1704

Throughout the interviews the most frequently expressed sentiment was one that for patients was critical to express because it justified their experience of psychiatric neurosurgery for OCD. Patients characterized their stories and experience of psychiatric neurosurgery as one of desperation. Patients described themselves as “bed-bound,” “stuck at home,” or “unable to spend time with [friends and family]” as a direct result of their symptoms. Patients characterized their OCD as severely “debilitating” or even “life-threatening,” marked by constant obsessions that included “violent images and intrusive thoughts,” obsessions surrounding “God, Jesus, and the Virgin Mary,” and fears of contamination or harming others, and severe compulsions such as “praying,” “counting,” and taking “three-hour showers.” Patients cited their OCD symptoms and severity to illustrate the reason they were “desperate” and “willing to try anything” that may help.
Patients expressed that they were desperate for relief from their OCD symptoms and they discuss their decision to undergo surgery based upon that lived experience of severe illness. One clear pre-surgical view across all patients was the desperation they felt to experience relief, no matter the means. One patient described how the severity and constancy of his obsessive thoughts were such that he would have done anything to eliminate them:

A story came up about a 19 year-old I think it was several years ago that had OCD and I think shot himself in the head. And I guess he shot himself pretty precisely and he didn’t have OCD anymore. And I, literally I thought about doing that. I asked, I asked my wife, if I do it in a hospital parking lot, and you know… if I died would that still be suicide [laughs]. No I literally considered suicide. You know this, you’re not talking to a mediocre case of OCD. I had, I would’ve traded for any other disease in the world. (Patient Interview 1704 2017)

Patient 1704 described a desperation to the point of suicidal ideation that was not uncommon amongst many patients interviewed. Another patient described throughout their interview that they felt as though the surgery would be justified if it provided a small amount of relief:

If it means moments of peace in your brain you’d be willing to have that. And that’s why I felt great about it, because I knew if there was a chance I could get 1% better then its worth. Because my obsessions before the surgery were just constant they were constant…like I said I felt hopeless. I felt hopeless you know. And the surgery was my hope to get better. And the peace I’ve had, you know, the peaceful moments I’ll never take those for granted for the rest of my life if I continue to get them and you know if it gets better. (Patient Interview 1702 2017)
The sense of hopelessness and desperation patients felt as a result of their OCD symptoms was constantly cited by patients as a type of justification behind their decision to undergo surgery. It may be difficult to conceive of wanting “brain surgery”, one patient said, but when one considers the sense of desperation to the point of self-harm that many of these patients feel, it becomes clear how the prospect of destroying some of their brain tissue did not deter these patients. In reality, not only were these patients not deterred, they were profoundly motivated to do all they could to ensure they received surgical treatment.

**Becoming a “viable candidate” for surgery**

“I wasn’t worried at all about meeting the medication and behavioral treatment requirements because I was sure I had been through all of them,” explains Radano as she reflects in her autobiography about her experience prior to gaining approval to participate in a Gamma Knife for OCD at Butler Hospital:

I had taken every OCD medication known to humankind, including herbal supplements. I had been to a myriad of OCD specialists, not to mention hypnotists. I had even traveled to Florida to meet with a therapist I had seen on TV. I spent over 20 weeks in three different psych hospitals all of which could be documented. With these credentials, I felt pretty confident that I had more than met all the protocols necessary for being a viable candidate for the operation.

(Radano 2007)

Here we see how Radano describes having the necessary “credentials” to qualify for the surgery using language similar to that used in job applications. This is notable as it may describe an “application” process in psychiatric neurosurgical treatment. In this application process, OCD
sufferers are placed in the unique social position of wielding the severity of their OCD symptoms and history of unsuccessful treatments and using them as a means to convince clinicians whose “vote” and “approval” impacted their lives.

This sentiment expressed by Gerry Radano was also reflected in patient interviews, where patients expressed concern about garnering approval for the Gamma Knife Radiosurgery procedure. Patient 1704, for instance, shared that throughout the process of determining whether he qualified for surgery he was “nervous,” because he “was stressed that [he] wouldn’t get approved” (Patient Interview 1704 2017). Patient 1704 expressed significant determination to get the procedure and to a degree seemed to conceptualize himself as having some agency in that decision: “My goal was to get approved for the surgery.” As with job or other applications the individual disposition of applicants can vary between expressing confidence to concern. Other patients expressed a similar concern about whether they would qualify for surgery and went further to describe how this positionality and desire for surgery affected their behavior:

I was nervous. Because I wanted so bad to have the surgery because I knew the relief that [a previous patient] had gotten… I was a bit nervous. Yeah I was trying to make sure I said the right things. You know I would stay honest about everything. But I was nervous. (Patient Interview 1702 2017)

This patient describes the sense of nervousness he felt about qualifying the surgery to the point that he “was trying to make sure” to say the “right things.” This is a significant perspective because it indicates that patients see the surgery as such a source of “hope” that they were alter the behavior and even performance to prove their “viability” for surgery.

The metaphor of “applying” to be a viable candidate for surgery describes a phenomenon and positionality that has been discussed in addiction treatment centers and may explain the
homogeneity in narratives and language used to describe pre-surgical experience amongst OCD patients. Sociocultural and linguistic anthropologist, Summerson Carr, has shown that in clinical addiction treatment centers clinicians and patients will often use the same language and metaphors to describe and conceptualize an illness as well as treatment in her book Scripting Addiction. Specifically, she argues that patients through trial and error go through the process of learning the best language to use in a clinical setting in order to gain access to certain treatment and benefit from positive therapeutic interactions (Summerson Carr 2011). It is possible that a similar phenomenon is occurring in the field of psychiatry with regard to describing OCD and OCD symptoms.

The premier clinical measurement tool involved in OCD treatment and diagnosis, the Y-BOCS, may support a clinical environment with specific linguistic requirements that may explain how some themes expressed by patients become so consistent and are explained with identical language. The Y-BOCS is assessed by “incorporate[ing] patient report, others’ accounts, and the clinician’s observations and judgment” (Storch et al. 2010). The Y-BOCS assessment is largely based on the specific descriptions patients provide concerning their symptoms, and for this reason I argue that patients with intractable OCD, who undergo years of clinical treatment, learn to characterize their disease with specific language in order to achieve the status of an OCD diagnosis with a specific level of severity that is appropriate for a specific level of treatment. When patient 1702 suggested that he wanted to say “the right things,” I believe he may have been discussing not what he was saying, but how he would say it in order to improve his chances of receiving the surgery. Dr. McLaughlin pointed out that the OCD patients that undergo surgery have had so much treatment for their OCD that they know the metric “very
The self-presentation as a viable candidate for surgery was not only tied in the Y-BOCS as we have discussed. It was imperative that patients provide evidence that their illness was intractable. Patients prepared often over the course of a year with the Butler Research team to coordinate the transfer of medical records and even undergo specific medication or behavioral therapy trials they may have been missing in their medical history. For many of these patients they did not view these steps as potential treatments that might work, but rather as a “waiting period” in which they had to delay receiving the only thing that patient’s believed might work: the surgery (Patient Interview 1704 2017). Patient 1704 described how his surgery as delayed by what he describes as “useless” other treatments:

…there was a lot of the prerequisites and that complicated matters. That was a lot of the waiting I guess. But like I had to take certain drugs for a while and the CBT, or EBT, or CBT whatever it was, but I had a certain amount of time with that. So that took time too. So I guess if I had done it earlier before I’d found the surgery then maybe I wouldn’t have to wait so long…. But therapy, what’s the type of therapy that’s more specific for it’s starts with an E? ERP! That stuff, which I think could have been more successful if I’d done it at the beginning [of my OCD symptoms] fifteen years ago I guess. But at the stage I was at, it was kind of useless. (Patient Interview 1704 2017)

Here the patient describes some of the process of qualifying for surgery as hurdles to get over to achieve surgery rather than, as clinicians may see it, as treatment options that have not been exhausted and could potentially benefit the patients so that they do not need to undergo surgery.
Patients however more frequently characterized the process of qualifying for surgery in a way that was consistent with the metaphor I use of an application whereby even the treatments being offered were boxes to check off the application list to becoming a “viable candidate.” Patients seemed convinced that surgery was their “last hope” even when there were treatments they had not tried yet perhaps because cognitive behavior therapy and medication trials seemed to be of the same kind of ineffective treatment they had experienced in the past, whereas surgery was markedly distinct and more “serious” (Patient Interview 1703 2017).

“The surgery”

When asked about the experience of the day of the surgery, subjects often described the experience in step-by-step descriptions that were remarkably detailed. Patient 1705 very clearly illustrated his memory of a surgical procedure that was conducted nearly 20 years ago at the time of the interview:

Yeah I was very hopeful anyway that this would make a difference, I guess. I didn’t really know what to expect, but you know all the nurses and physicians at the Rhode Island gamma knife center I think took very good care of me. You know the process of getting ready for the surgery involved going to the gamma knife center and having the frame attached to the head. And then undergoing an MRI and subsequently. I think I went back to the hospital room I think for a while to wait for I guess the group of neurosurgeons to look at the MRI and determine the best spot to focus the treatment on. Once that was the case they brought me down to the gamma knife center and I was placed in the gamma knife machine.
And I believe I was there for about 70 minutes for treatment of each side of the brain. (Patient Interview 1705 2017)

Patient 1705’s account of the experience was remarkably detailed and consistent with my ethnographic fieldwork accounts of observing surgeries conducted in the past two years. This was notable because it suggests that from the patient perspective much of the Gamma Knife Radiosurgery process has been consistent. The degree of detail that Patient 1705 and some other patients interviewed remembered the day of their surgery spoke to how salient the experience was for them. One patient even recalled the exact time of the early morning they remember waking up to go to the hospital for surgery.

Despite the detail with which patients interviewed could directly recall their experience of the day they underwent surgery, most offered very little about how they felt during the experience. Given that patients were never placed under general anesthesia many were conscious yet when prompted to discuss how they felt during the surgery or asked to characterize the experience many offered short and non-specific responses:

“Oh I slept through most of it. They gave me I think a sedative or something. Or something to relax the nerves or something. I woke up probably like in the middle of it, but went back to sleep or something. Literally yeah so I slept through most of it” (Patient Interview 1704 2017).

“I was nervous, but I wasn’t really too nervous the procedure was rather long cuz I would go into a machine after they put the helmet on I would go in for a little while it was almost like an MRI machine…I really wasn’t, I wasn’t nervous, and um, I don’t know.” (Patient Interview 1703 2017)
“Interviewer: what did you think of the surgery when it was going on? What was running through your head? 1701: Oh when I was doing it in there? Uh nothing, I was ok. I was just. I was happy I wanted you know to be cured.” (Patient Interview 1701 2017)

These are only a few examples that indicate that while the experience was salient for patients they did not necessarily think much about their feelings during the surgery. Despite not being put under general anesthesia patients either fell asleep or observed their surroundings in a detached way such that they were aware of what was taking place but not necessarily engaging with it too much. The experience was described by Patient 1705 as “pleasant,” which like the other accounts indicates that patients were comfortable.

Overall patients did not offer much more about their internal dialogue or emotional state during the surgery, perhaps because for them the surgery was so much more than the act of sitting in the gamma knife suite and receiving the one-time dose of radiation. For patients, as we have discussed, their lived experience prior to the surgery transformed the surgery into a symbol of “hope” for them to achieve “normalcy.”

“After the Surgery”

Patients usually described their response to the surgical operation as an experience of “waiting.” And those patients that did experience some relief or improvement after OCD described their improvement as a welcomed “loss” of a disease that for many had come to represent a personified aspect of their psyche.

Clinicians expect that Gamma Knife Radiosurgery results in a lesion over the course of months after the surgery, and as a result have come to observe significant improvement in OCD symptoms 6 months to a year after the surgery for most patients that respond positively to
surgery. This often leaves patients in a type of limbo after the surgery, where they are waiting to see if indeed their OCD symptoms do improve. Many patients described their recovery after surgery as “not instantaneous,” citing different intervals of time until they first noticed improvement in their symptoms ranging from “several months” to “about a year” after the surgery. One patient described his post-surgical experience of OCD as a slow improvement in symptoms that he noticed as his ability to respond to more standard treatments:

> After each of the procedures I guess I didn’t notice a significant difference right away. But I think about a year later I got to a point where I felt like I was much more ready to start doing regular behavioral therapy and participate in the therapy more fully. It seemed like the symptoms were getting to a point where they were more controllable at that point. At least at the point where I started doing behavioral therapy it seemed more effective than it had been before. (Patient Interview 1705 2017).

Many of the patients that recovered described their time course in this way. One patient interviewed that had not yet seen improvement in his OCD symptoms also used the notion of a timeline to describe his lack of improvement: “I know. I keep praying and hoping that the surgery will do something. It may, now I still have time I think. It’s been, it’ll be a year pretty soon but … I kinda count the days [laughs briefly]” (Patient Interview 1701 2017). The experience that recovery after surgery is not instantaneous was consistent across all patients, and represented a significant alignment between what clinicians believed to be true and what patients expected and experienced after surgery. In those patients that had not yet shown recovery at the time of the interview used the timeline of a year to determine whether they would maintain “hope” for improvement.
It became clear that while patients remained optimistic during the year after recovery their “hopefulness” became more difficult to maintain as they approached the one-year mark and this was a source of concern for them, perhaps that their “last option” would not work for them:

Well I just think that I’m coming up on a year…But you know I expected to be better than what I am, to be honest with you. At this point, almost a year. And I know Dr. McLaughlin says there’s ups and downs and it takes two-years, you know I don’t know. I mean the lesions have already formed, they formed at like three months, you know. I don’t understand that really…I just don’t think I just don’t see see how I’m gonna get better if they’ve already formed. I don’t understand that. You know what I mean I’m not a doctor. I don’t understand how a year from now I’m gonna be better than I am now. (Patient Interview 1702 2017)

The uncertainty about recovery post-surgery was immense and perhaps best reflects how the ambiguity and uncertainty in the biomedical science and clinical practice of psychiatric neurosurgery for OCD manifests itself for patients. As discussed in the previous chapter, clinicians too are uncertain about exactly how long it will take for an individual to recover or whether they will recover at all. This uncertainty in the eyes of clinicians and patients is what is most difficult for patients to navigate, and influenced the experience of patients a year to two years after surgery.

After a year of waiting, most of the patients I was able to interview described experiencing marked improvement after their surgery that they often uncovered as a result of either an increased ability to respond to conventional treatments or a reduction in the amount of time spent on obsessive thoughts. The way one patient described his recovery was interesting
because it elucidated how he conceptualized his illness, and I would argue explains how the lived experience of OCD might align with neurosurgical intervention from a phenomenological and linguistic perspective. This patient whose illness had been marked by constant obsessions and intrusive thoughts of violent and sexual imagery described his recovery as a “loss”:

…things got a little bit easier, but all I’ve known is to obsess over the last eight years, so it actually came as like I. It’s like losing an old friend. It’s like you have this nasty friend OCD, which you have no choice but to accept that you have it and live your life with it. And during those times … now when I notice I’m not obsessing, then I all of a sudden start obsessing. Because I start thinking that, well I should be thinking about slitting people throats [or other violent acts] … it just it comes at you like that, and it’s still taking time, and I think it’s gonna take more time to just accept those times when I have some clarity and some piece you know for 10 minutes, 30 minutes, an hour. (Patient Interview 1702 2017)

For this patient the characterization of his post-surgical recovery as a loss of a “nasty friend” was particularly striking and salient to me for two reasons: characterizing psychiatric neurosurgery recovery as a loss and characterizing OCD as a “nasty friend.”

Patient 1702’s characterization of his recovery as a “loss” was interesting because it aligned both metaphorically and literally with what the gamma knife procedure entailed. The surgery both removed his symptoms as well as a portion of his anterior internal capsule in the brain. The alignment of these two symbolic losses is interesting when considering that this patient had to make the same ideological link between his brain tissue and OCD symptoms that clinicians have used to argue against mind/body dualism. This patient was one of the few to frequently point to neurobiology, supporting this ideological link and explaining how he may
come to view brain surgery as a reasonable if not more appropriate option for treating his psychiatric illness: “I thought all the thoughts were my fault, even though they are intrusive and it’s caused by you know the glitch in the brain” (Patient Interview 1702 2017).

This same patient’s specific metaphor for his OCD as a “nasty friend” was unique amongst patients in the population but spoke to a more common facet of the illness expressed in some ways by all patients: egodystonicity. OCD has long been characterized as an “egodystonic” illness (Denys 2011; Kuczynski 2016; Rasmussen et al. 2000; Pierre 1903). Phenomenologist Denys offers the following definition for egodystonia: “Egodystonia means that a behavior, a desire, a dream, an impulse or a thought, is not recognized as your own or is in conflict with your self-image, in contrast to egosyntonia which expresses the harmony between an experience and our self-image (Denys 2011). In other words, a mental illness is said to be egodystonic if patients characterize the illness as separate from their true feelings or desires. And this is often communicated as either an expression of obsessive thoughts that don’t reflect the patients true feelings or as a personified aspect of the individual’s psyche that they view as an “other,” that while a part of them is distinct from how they view their “true” self (Denys 2011).

In her autobiography, Radano described the separateness she felt from the illness as so dramatic that she did not even know “what it was called” until viewing a television program. This sense of psychological disconnect from her illness is frequently described by psychiatrists as the egodystonic characteristic of OCD, which manifests itself as individuals with OCD describing their illness as “separate from them,” and Radano goes on to characterize her OCD as an “enemy” or “invisible opponent” for the rest of her book. Indeed, the patients interviewed all characterized their OCD in a somewhat similar way some using personification while others a more abstract separation:
“You know I can open the door and go, but it’s got a grip on me, it like controls me” (Patient Interview 1701 2017).

“I didn’t feel like I had my OCD under enough control so maybe this could be sort of another, another piece that could bring it under better control” (Patient Interview 1703 2017).

“But it’s like you have two brain’s you’ve got your OCD brain and your regular brain and you can’t shut the OCD brain off” (Patient Interview 1702 2017).

The egodystonic nature of OCD is evident and has been well-characterized, to the point that for a proper diagnosis of OCD the psychiatrist must determine that the symptoms are egodystonic in nature otherwise the illness is likely a personality disorder, distinct from OCD (Denys 2011; Interview with Dr. Benjamin Greenberg 2017; Cobb 2014).

The surgical treatment OCD aligns well with an egodystonic view of disease because in some ways the act, both literal and symbolic, of destroying the part of the brain responsible for OCD only works if there is a belief amongst clinicians and patients that the neuromodulation being done is not changing the nature of the person being treated. Dr. Ford a neuroethicist discussed the bioethical concern of neurosurgery may lie in the possibility that you are changing something about the “essential nature” or “true self” of an individual (Interview with Dr. Paul Ford 2016). OCD however often manifests as an illness that patients view as separate from themselves, which is an important distinction in psychiatric illnesses. Unlike in physiologic illness where a symbolic separation between a person’s illness and who they are is assumed, psychiatric illnesses are often more directly tied to a person’s psyche. This is not the case with physiological illness in the western biomedical framework where it would be absurd to link a
person’s bacterial or viral infection to their essential nature and concept of the self (Martin 1994; Scheper-Hughes and Lock 1987).

The view that one is losing “an old nasty friend” when exhibiting a positive clinical response to gamma knife surgery to treat OCD, is a use of metaphor that engulfs much of the ideological and epistemological debate surrounding psychiatric neurosurgical procedures. By viewing the gamma knife surgery as a tool for removing or taking away a person’s symbolically separate torturer, OCD, Patient 1702 articulated a fundamental alignment with the ideological shift from mind/body dualism to biological psychiatry and a conceptual shift that separates a person’s mental illness from their own mind the way infections or tumors are thought to be separate from the organs they invade. In so doing, we see that the patients who underwent psychiatric neurosurgery to varying degrees accepted and reified the notion that their mental illness is one that can be addressed by surgical techniques.

From the various perspectives in time that patients provided before, during, and after their surgeries, we see that the lived experiences of undergoing Gamma Knife Radiosurgery for OCD are remarkably complex, filled with symbolic language and narratives. The lived experience of patients who undergo Gamma Knife Capsulotomy for their intractable OCD remains to be fully understood. Evidence from this IPA suggests that patients characterize their lived experience of psychiatric neurosurgery before surgery as filled with desperation and hopelessness as they try to achieve normalcy. Patients seem to view surgery as a last hope and as a result are willing to put effort into communicating that they are viable candidates for surgery. The experience of the gamma knife surgery itself did not appear to be the primary focus for patients. Instead, patients saw Gamma Knife Radiosurgery as a means to an end. They describe their post-surgical
experience as typically gradual and slow as well as sometimes as a loss of an illness they view as separate from them. Patients view their illness not just through the biological or clinical lens but also phenomenologically, as a part of their psyche, separate from them, and as a result psychiatric neurosurgery also becomes a social phenomenon through which patients hope to achieve normalcy and relief. Further phenomenological analysis of this kind is critical to continue to uncover the perspectives and lived experiences of this unique patient population. There is academic and therapeutic value to listening to patient perspectives in their own terms.
Conclusion

Through a critical view of the history of psychosurgery it becomes evident that many clinicians had good intentions and sought to bridge gaps between mental illness and the brain. While the history of psychosurgery was fraught with clinical tragedy, it was also marked by individual successes that spurred the science forward. The modern practice of psychiatric neurosurgery, made distinct from psychosurgery of the past, is marked by more precise targets in the brain and scientific rationale. Psychiatric neurosurgery today, however, shares with its predecessor a push towards a more biologically-supported psychiatry and by extension attempts to embed psychiatric illness, such as OCD, in the neural circuitry of the brain. In so doing, mental illness can become a tangible phenomenon on which scientist and clinicians can perform surgery.

Psychiatric neurosurgery today is practiced by clinicians of various specialties who aim to support patients with severe psychiatric conditions as best they can. Operating on patients and constantly making efforts to distinguish the current practice from an ethically contentious past, select specialized teams across the nation form decision-making committee’s and involve ethicists to protect patients and indeed medical science from the lack of regulation and broad overuse of surgical techniques for mental illness that stained the history of psychiatry in the US. Despite the advanced scientific understanding of the biological basis of disease surgeon, psychiatrists, psychologists, and other clinicians involved operate within a framework of tremendous uncertainty. While benefit is seen for some, there is uncertainty about who will benefit from surgery as well as what precisely the surgeries do biologically that offers relief. In this way the clinicians, moving boldly forward while unaware of how history will view their efforts, like their patients are forced to rely on “hope” in conjunction with careful medical
practice to try and treat a vulnerable and desperate patient population. Patients who undergo surgery like clinicians, navigate uncertainty, but unlike clinicians are forced to do so while suffering from a mental illness that plagues them with anxiety and severe obsessions that often beget compulsive behaviors. Patients, driven by a desperate desire to live a more “normal” life, take steps to receive surgical intervention with the “hope” that the “invisible opponent,” OCD will be vanquished. In order to do this patients and clinicians develop a shared language and indeed social experience marked by a consistent attempt to navigate uncertainty through hope, faith, and science.

By situating the mind in the brain, and more broadly in the social world, we see that psychiatric neurosurgery is as much a social operation as it is a surgical one. Operating on the back of a historically stigmatized view of psychosurgery, the modern practice has had to remain small and take special care to justify itself. Patients and clinicians see the benefits of surgery, yet the science is not perfect. While it is easy to characterize these surgeries as dangerous we must question what facets of psychiatric neurosurgery give us pause. And we should apply that line of questioning to all areas of medical science, because I would argue that no branch of medical care, by virtue of operating at the crossroads of science and society, is truly devoid of uncertainty and ambiguity. It seems what is most important is remaining reflexive about how surgical practice especially on the brain and mind must be cautious while operating in neuroscience, a field of great uncertainty, for which there is still much to discover. It is critical therefore that in our social efforts to advance psychiatric neurosurgery, and neuroscience more broadly, we employ all epistemological methods of study, especially phenomenological ones, to better situate our minds in our bodies and our bodies within our broader social world. OCD a psychiatric illness is not an isolated event, but rather, as Scheper-Hughes and Lock argue of all illness, is “a
form of communication-- the language of the organs-- through which nature, society, and culture speak simultaneously."
Bibliography


Drolet, Brian C., and Nancy M. Lorenzi 2011 Translational Research: Understanding the


Interview with Dr. Benjamin Greenberg 2017

Interview with Dr. George Noren 2016

Interview with Dr. Paul Ford 2016

Interview with Dr. Wael Asaad 2016. Providence, RI.

Interview with Ms. Valerie Giorgione 2016. Boston.

Interview with Rev. David Shire 2016


First. Little, Brown and Company. 

http://onlinelibrary.wiley.com/store/10.1111/1467-9566.ep10487792/asset/1467-9566.ep10487792.pdf?v=1&t=j1fvhlyk&s=93bacf80b81e1ae3133ee892ac80e4f3e5636c67&systemMessage=Pay+Per+View+on+Wiley+Online+Library+will+be+unavailable+on+Saturday+15th+April+from+1, accessed April 12, 2017.


Martin, Emily. 1994 Flexible Bodies: Tracking Immunity in American Culture from the Days of Polio to the Age of AIDS. Beacon Press. 
https://books.google.com/books/about/Flexible_Bodies.html?id=c-C3m6dgTs4C, accessed April 14, 2017.


127.

Patient Interview 1701 2017

Patient Interview 1702 2017

Patient Interview 1703 2017

Patient Interview 1704 2017

Patient Interview 1705 2017

Patient Pre-Surgical Videos from Butler Hospital OCD Research Team Server N.d.


Shavitt, Roseli G., Maria Alice de Mathis, Fábio Oki, et al. 2014 Phenomenology of


Valenstein, Elliot S. 1974 Brain Control; a Critical Examination of Brain Stimulation and Psychosurgery. Wiley.


Appendix A: Butler Hospital Institutional Review Board Documents:
IRB Approval Letter, Sub-study proposal, Amendment/Modification Request Form

DATE: March 1, 2017
TO: Steven Rasmussen, MD
FROM: Care New England - Butler Hospital Institutional Review Board
PROJECT TITLE: [793406-8] Cognition and Magnetic Resonance Imaging after Psychiatric Neurosurgery for Intractable Obsessive-Compulsive
REFERENCE #: 2010-001
SUBMISSION TYPE: Other
ACTION: APPROVED
APPROVAL DATE: March 1, 2017
EXPIRATION DATE: September 30, 2017
REVIEW TYPE: Expedited Review
REVIEW CATEGORY: Expedited review category # 45 CFR 46.110

Thank you for your submission of Other materials for this project. The Care New England - Butler Hospital Institutional Review Board has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of September 30, 2017.
Amendment/Modification Request Form

Use this form when submitting a request for changes to IRB approved research. Changes in approved research cannot be initiated without IRB review and approval unless necessary to eliminate apparent immediate hazards to the subject(s) [45 CFR 46.103(h)(4) and 21 CFR 56.108(a)(3)(4)]. To permit an accurate and streamlined review of your proposed amendment or revision, please provide the following information:

**DOES THIS RESEARCH PROJECT MEET FEDERAL REGULATIONS FOR “MINIMAL RISK”?**

- Yes □ No □ Unknown

45 CFR 46.102(i) and 21 CFR 56.102(i) define "minimal risk" as “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.” The minimal risk determination is indexed to experiences ordinarily encountered in the daily life of the average healthy person (age adjusted to proposed subjects’ age) rather than to the population involved in the research. For additional guidance, see: http://www.hhs.gov/ohrp/sachrp/sachrppminrisk20080131.htm

Attach supporting documents: If the proposed change(s) require revisions to existing documents, submit tracked changes version of each affected document.

Principal Investigator: Steven A. Rasmussen, MD, Nicole C. McLaughlin, PhD

IRBNet#: 793406-4 Local Board Reference #: 2010-001

Title: Cognition and Magnetic Resonance Imaging after Psychiatric Neurosurgery for Intractable Obsessive-Compulsive Disorder

Date: 2/1/17

Proposed modification involves a change in: (select all that apply)

- Revision to currently approved protocol
- Submission of new study document(s)
- Revision to currently approved consent form(s)
- Revision to key study personnel
- Revision to sponsor/funding source
- Other (recruitment materials, investigator brochure, letters, etc)

I. Effects of Modification:

1) Will this revision increase risks to participants enrolled in the study? □ Yes ☒ No
   If yes, describe how risk has increased and what has been done to minimize risk.

2) Will this revision affect benefits to subjects or others? ☒ Yes □ No If yes, explain.
   Patients will receive additional follow-up that captures their personal narrative.
3) Will the modification(s) require a revised data safety monitoring plan? □ Yes ☒ No  If yes, explain.

4) Will the modification(s) affect the privacy or confidentiality of subjects? □ Yes ☒ No  If yes, explain.

5) Does this study include prisoners, minors, pregnant women or fetuses? □ Yes ☒ No  Will the modification(s) affect the protection of vulnerable subjects? □ Yes ☒ No □ N/A  If yes explain

II. Description of Changes:

1) Provide a brief description of the requested modification(s) and clearly reference materials to be amended. Include an itemized list of changes and location of the change(s) within the document, if applicable.
   1) A sub-study protocol was added to original protocol to include over-the-phone follow-up semi-structured interviews and YBOCS.
   2) Verbal informed consent for the phone interview substudy, for those participants who have already signed a PHI waiver within the original study consent.
   3) Full informed consent form for the phone interview substudy, for those participants who were enrolled prior to the addition of the PHI waiver to the original study consent.
   4) Information about risks of audiotaping, as well as data storage and destruction was added to each of these consent forms.
   5) Patient interview outline.

2) Provide brief justification for the proposed modification(s) and indicate whether the change alters the overall study goals.
   This study will allow for improved understanding of patient perspective and narrative concerning OCD and psychiatric neurosurgery. The change does not alter the study goals, and adds a dimension to ascertain how patients are responding to treatment.

3) Will any aspects of this research increase risk to participants? □ Yes ☒ No □ N/A  If yes, explain.

III. Studies with Human Subject Participants:

1) At the time of this submission, have any subjects been enrolled, or completed the screening process and signed a consent form, for this study? ☒ Yes □ No □ N/A

2) Does this change/addition require notification of currently enrolled subjects? □ Yes ☒ No  If yes, describe how subjects will be notified (letter, phone call, in-person visit, etc. Attach any correspondence to be used)

3) Is there any new information that may affect a participant’s willingness to continue to take part in this study? □ Yes ☒ No  If yes, describe:

IV. Attachments: (check all being attached in this package)

☒ ICF(s) (tracked)  ☒ Protocol (tracked)  ☐ Sponsor Correspondence
☐ Investigator’s Brochure  ☐ FCOI  ☐ DSMB Minutes

CNE IRBs Amendment/ Modification Form
Revised: 03/10/2016  Page 2 of 3
☐ Advertisement(s)  ☑ CNE Research Application (revised)
☐ Other: __ patient interview outline
Appendix B: Research Sub-Study Proposal, Patient Interview Outline, Verbal and Written Consent Forms

BUTLER HOSPITAL
INSTITUTIONAL REVIEW BOARD
PROTOCOL FOR RESEARCH INVOLVING HUMAN SUBJECTS

I. TITLE OF PROJECT:
Cognition and Magnetic Resonance Imaging after Psychiatric Neurosurgery for Intractable Obsessive-Compulsive Disorder

Principal Investigator (P.I.)s: Steven A. Rasmussen, MD, Nicole C. McLaughlin, PhD

Signature(s) of the P.I.:

Other Investigator(s): Benjamin D. Greenberg, MD, PhD., Paul F Malloy, PhD

Corresponding Investigator: Nicole C. McLaughlin, PhD
Mailing Address: 345 Blackstone Blvd. Providence, RI 02906
Telephone/FAX/E-mail: 455-6608/455-6617/Nicole_mclaughlin@brown.edu

Protocol Status: New _ Renewal _

Funding (Source, P.I.): Internal

Duration of Project: ___ years
Duration for Individual Subjects: up to ___ years
Specific Location(s) of Project: Butler Hospital, Brown University

Research Subjects (check if applicable):

Have all investigators completed research ethics training?
YES ☒ NO

Have all investigators completed FCOI training in the past 4 years?
YES ☒ NO

Have all investigators completed FCOI Disclosure forms?
YES ☒ NO

ATTENTION:
Before completing this protocol, go to the Butler IRB Forms website:
http://www.butler.org/irb/forms.cfm
Sub-Study: Understanding the patient experience after Psychiatric Neurosurgery for Intractable Obsessive-Compulsive Disorder

A. Specific Aims

1) To conduct semi-structured interviews with individuals who have undergone psychiatric neurosurgical procedures to treat medically-refractory obsessive compulsive disorder (OCD). The interviews are aimed at understanding how each patient conceptualizes his or her disease, treatment, and life experience since their surgical procedure. Patients who have undergone gamma knife radiosurgery (GKRS) for the treatment of intractable OCD will be given an opportunity to share their experience of the treatment process and the impact it has had in their lives.

2) To uncover common themes and ideas expressed by post-surgical OCD patients to gain a comprehensive understanding of how patients view their treatment. Such themes and ideas may yield insights that can be used to improve clinician-patient communication, ethical practices, and the clinical understanding of psychosocial factors that affect this patient population and that objective clinical measures may not capture.

B. Experimental Method

Semi-structured interviews will be conducted over the phone with patients. Patients contact information will be accessed in order to reach out to Gamma Knife Radiosurgery patients who have been treated at Butler Hospital for OCD. Patient interviews will be tailored to each patient based upon examination of their individual medical history and course. The interviews will consist of a series of yes/no questions as a survey in order to acquire baseline data and the rest of the interview will be guided by the patients and what they choose to share or discuss. Patient interviews are meant to gather phenomenological data and such will be guided primarily by the information and experiences shared by the study population. Phone interviews will be recorded for analysis.

Interpretive phenomenological analysis (IPA) will be used to assess the responses of subjects after numerous interviews have taken place. IPA is a qualitative research method that Smith, Flowers, and Larkin describe as “committed to the examination of how people make sense of their major life experiences. IPA is phenomenological in that it is concerned with exploring experience in its own terms” (1). IPA is a method of research which in this research study will consist in examining themes presented by the subjects concerning their experience with OCD and surgical treatment for OCD. Themes will be ascribed to each individual patient interview and after all interview analyses are complete overarching or common themes among many patients will be developed, quantified, and examined.

Yale-Brown Obsessive Compulsive Severity Scale (YBOCS; Goodman et al 1009)

The YBOCS will be completed over the phone to ascertain current levels of OCD severity.

C1. Brief Description of Subjects

Adults with OCD of disabling severity, refractory to prolonged treatment attempts with conventional medication and behavioral therapies, who have undergone ventral capsulotomy (either gamma knife or thermocapsulotomy) as a clinical treatment at Rhode Island Hospital.

D. Material Inducements

There are no material inducements in this substudy.

E. Potential Benefits
The semi-structured interviews present no direct benefit to patients beyond providing an opportunity for patients to share their personal story with OCD and surgical treatment. The study has the potential to provide valuable insight into the personal lived experience of patients with intractable OCD who have undergone surgical treatment. The perspective gained from the study can advance anthropological and psychological understanding of OCD and how modern psychiatric neurosurgery is perceived by patients. In psychiatric neurosurgery, a field of study where the perspective of patients on their treatment and disease have been historically underreported, this study could support best ethical practices and guide post-surgical treatment in this population.

F. Risk-Benefit Ratio
Risks for participation in this study are very low. The primary risk is due to audiotaping of the interviews. To manage this risk, interviews will be stored on our password-protected server, and will be only be accessible by our study team. Interviews will be destroyed at the end of the study. On the other hand, the potential benefits and insight into the lived experience and psychology of patients who have undergone psychiatric neurosurgical procedures for OCD include broadening the scientific understanding of the disease, the clinical management of OCD, and social awareness of the modern psychiatric neurosurgical patient.
Patient interview outline
Appendix A: Patients Interview Outline and Script

Interviewer: Hello, thank you for agreeing to speak with me today. Before we begin I would like to ask a few yes or no questions:

1) Are you in a comfortable and private place to take part in an interview concerning your personal experience with OCD and OCD treatment? In case of emergency we would like to be able to notify the appropriate entities of your whereabouts could you provide me with an address for your current location?

   Yes _____ No _
   Address: ________________________________

2) Are you aware that participating in this interview is not mandatory and that you may ask to stop or pause the interview at any time for any reason?

   Yes _____ No _

Thank you. Now we can begin.

[The following main topics (I, II, III) will be addressed in the interview. They may not all be discussed in the order presented here. The interview will follow the lead of the patient with the following questions only representing potential example questions or prompts (a, b, c...) that participants may be asked.]

I. OCD experience
   a. Tell me about your experience with obsessive compulsive disorder
   b. When did you first notice symptoms and what were they?

II. Surgical Procedure
   a. How did you come to decide on having surgery to treat your OCD?
   b. What did you think of the surgery?
   c. What was the process of becoming part of the study like?
   d. What type of procedure did you have completed? How did you decide?
   e. What was your feeling towards having an electrode placed in your brain? What was your feeling toward a lesion being made in your brain?
   f. What were the biggest deciding factors when having surgery?
   g. Did any concerns come up? If so, how were they addressed

III. Post-Surgical experience
   a. Describe your journey after the surgery
   b. Did you see, feel, think differently after the operation?
   c. How did the surgery affect your symptoms?
   d. How did the surgery affect your daily life, family, friends?
   e. In hindsight, would you have the surgical procedure completed again?
   f. What was most important for you after the surgery?
   g. Do you think about the surgery regularly now?
BUTLER HOSPITAL CONSENT FOR PARTICIPATION IN A RESEARCH PROJECT AND AUTHORIZATION FOR USE/DISCLOSURE OF HEALTH INFORMATION THAT IDENTIFIES YOU FOR A RESEARCH STUDY

Cognition and Magnetic Resonance Imaging after Psychiatric Neurosurgery for Intractable Obsessive-Compulsive Disorder

Patient Interview Substudy

**Invitation to Participate and Description of Project**
Hello, may I speak with [xx]? Do you have a few minutes to talk? I am calling from the OCD clinic at Butler Hospital to ask if you would participate in a research study over the phone. In this study we are aiming to understand the perspectives in participants own words about the experience of psychiatric neurosurgery. Are you willing to hear more information before making a final decision about participation? If yes, I will read the consent form to you now.

You are invited as a participant in our ongoing study on gamma-knife capsulotomy for obsessive compulsive disorder. This phase of the project is intended to follow-up with patients who have had surgery and is aimed at understanding your experiences of having the surgery. Your participation in the study will consist of a phone call interview that can be as long or short as you would like. We anticipate that a full interview will take about 1-2 hours in length. In order to decide whether or not you wish to be a part of this phase of the research study, you should know enough about its risks and benefits to make an informed judgment.

**Description of Procedures**
If you decide to participate, you will be asked to speak over the phone about your experience with OCD and having surgery for OCD, as well as complete a rating scale about your current OCD symptoms. We would ask you to share as much as you would like about your experience having the surgery and how the surgery has affected your life. The interview will be guided by you, so you will only have to share what you feel comfortable sharing. The phone interview can be completed over several phone calls for your convenience. You may decide whether or not to answer any question posed throughout the interview. We will audiotape your responses to these questions in order to ensure that we do not miss important information.

**Risks and Inconveniences**
One inconvenience in this study is that you may be asked questions that are uncomfortable and personal, please know that you may choose to decline to answer any question, pause the process, or stop the interview at any time. Your voice will be recorded during the interview. The main risk in this study is the risk of loss of privacy or confidentiality given voice recording during the interview, as well as storage of your information on our computers. However, we will take careful steps to store your data on our secure, password-
protected server, and there will be limited access to the data, as it will only be accessible by researchers working on this study. Data will be destroyed at the end of the study. Nothing you share will be entered or stored in a Butler Hospital medical record. There are no interventions or drugs involved in this study and there is minimal risk.

**Confidentiality and Protection of Your Health Information**
You will not be personally identified in any reports or publications that may result from this study. The confidentiality of the information you provide to us will be maintained in accordance with state and federal laws. If you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies. The health information that we may use or share with others for research purposes includes information collected as part of the interview, and information you have already given during your participation in research visits. Butler Hospital is required by law to protect your health information.

**Benefits**
We hope that in a small way the study may provide you the opportunity to share your personal story with OCD and surgical treatment for that OCD on your own terms. Your participation in the study has the potential to provide valuable insight about what it is like to have severe OCD and how the experience of surgical treatment for OCD has impacted your life. The perspective you provide can help improve our understanding of OCD, modern psychiatric neurosurgery, and how clinicians and researchers can better serve patients with severe OCD going forward.

**Alternative Treatments/Alternative to Participation**
No treatments are being offered in this study. You can choose not to participate in this interview and continue to be part of our other capsulotomy research protocol.

**Financial Disclosure**
This protocol is not supported by grant or research support and no researchers have significant financial disclosures relevant to this study.

**Voluntary Participation**
You are free to decide whether or not to participate in this study, and you are free to withdraw from the study at any time by informing the researchers verbally or in writing. If you decide you do not wish to provide additional protected health information to the researchers, you may withdraw from the study. Research information collected up to the time that you decide to withdraw will remain as part of the study data. A decision not to participate or to withdraw from the study will not adversely affect future interactions with Butler Hospital or Brown University. Your participation in the study may be terminated by the researchers without regard to your consent; in that case, you are entitled to an explanation of the circumstances leading to that decision.

**Questions**
Please ask for an explanation of anything I said that was unclear or that you did not understand.
**Authorization:** I have been read this form and have decided that I, ____________________________,
(name of subject)
will participate in the project described above. Its general purposes, the nature of my
involvement, and possible hazards and inconveniences have been explained to my
satisfaction.

Do you agree to participate in the study: ☐Yes ☐No

---

**Signature of Person Obtaining Consent**

Date

If you have further questions about this project or about research-related injuries, please
contact Dr. Nicole McLaughlin at 455-6608 or Nicole_mclaughlin@brown.edu. If you have
questions about your rights as a research subject, please contact Linda L. Carpenter, M.D.,
Chair, Butler Hospital Institutional Review Board, at 401-455-6349.

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**THIS FORM IS NOT VALID UNLESS THE FOLLOWING BOX HAS BEEN COMPLETED BY THE IRB OFFICE**

<table>
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<th>DATE: September 30, 2017</th>
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<td>IRBNET ID# 793406</td>
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<td>BUTLER IRB REFERENCE# 2010-001</td>
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Revised: 2/28/17
Substudy ICF Verbal
BUTLER HOSPITAL CONSENT FOR PARTICIPATION IN A RESEARCH PROJECT AND AUTHORIZATION FOR USE/DISCLOSURE OF HEALTH INFORMATION THAT IDENTIFIES YOU FOR A RESEARCH STUDY

Cognition and Magnetic Resonance Imaging after Psychiatric Neurosurgery for Intractable Obsessive-Compulsive Disorder
Patient Interview Substudy

Sponsorship
This study is being paid for by a grant from the National Institute of Mental Health.

Invitation to Participate and Description of Project
You are invited to participate in a sub-study within our ongoing gamma knife capsulotomy study that aims to understand the perspectives in participants’ own words about the experience of psychiatric neurosurgery. You are being asked to participate in this study because you are a participant in our primary study examining gamma knife capsulotomy in severe obsessive-compulsive disorder (OCD). This phase of the project is intended to follow-up with patients who have had surgery and is aimed at understanding your experiences of having the surgery.

In order to decide whether or not you wish to be a part of this research study, you should know enough about its risks and benefits to make an informed judgment. This consent form gives you detailed information about the research study, which a member of the research team will discuss with you. This discussion should go over all aspects of this research: its purpose, the procedures that will be performed, any risks of the procedures, possible benefits, and possible alternative treatments. Once you understand the study, you will be asked if you wish to participate; if so, you will be asked to sign this form. You will be given a copy of this form to keep.

Your participation in the study will consist of a phone call interview that can be as long or short as you would like. We anticipate that a full interview will take about 1-2 hours in length. In order to decide whether or not you wish to be a part of this phase of the research study, you should know enough about its risks and benefits to make an informed judgment.

Description of Procedures
If you decide to participate, you will be asked to speak over the phone about your experience with OCD and having surgery for OCD, as well as complete a rating scale about your current OCD symptoms. We would ask you to share as much as you would like about your experience having the surgery and how the surgery has affected your life. The interview will be guided by you, so you will only have to share what you feel comfortable sharing. The phone interview can be completed over several phone calls for your convenience. You may decide whether or not to answer any question posed throughout the interview. We will audiotape your responses to these questions in order to ensure that we do not miss important information.

Revised: 2/28/17
Substudy ICF
Risks and Inconveniences
One inconvenience in this study is that you may be asked questions that are uncomfortable and personal, please know that you may choose to decline to answer any question, pause the process, or stop the interview at any time. Your voice will be recorded during the interview. The main risk in this study is the risk of loss of privacy or confidentiality given voice recording during the interview, as well as storage of your information on our computers. However, we will take careful steps to store your data on our secure, password-protected server, and there will be limited access to the data, as it will only be accessible by researchers working on this study. Data will be destroyed at the end of the study. Nothing you share will be entered or stored in a Butler Hospital medical record. There are no interventions or drugs involved in this study and there is minimal risk.

Confidentiality and Protection of Your Health Information
You will not be personally identified in any reports or publications that may result from this study. The confidentiality of the information you provide to us will be maintained in accordance with state and federal laws. If you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies. The health information that we may use or share with others for research purposes includes information collected as part of the interview, and information you have already given during your participation in research visits. Butler Hospital is required by law to protect your health information.

Benefits
We hope that in a small way the study may provide you the opportunity to share your personal story with OCD and surgical treatment for that OCD on your own terms. Your participation in the study has the potential to provide valuable insight about what it is like to have severe OCD and how the experience of surgical treatment for OCD has impacted your life. The perspective you provide can help improve our understanding of OCD, modern psychiatric neurosurgery, and how clinicians and researchers can better serve patients with severe OCD going forward.

Economic Considerations
There are no financial incentives for participating in this study.

Alternative Treatments/Alternative to Participation:
No treatments are being offered in this study. You can choose not to participate in this interview and continue to be part of our other capsulotomy research protocol.

In Case of Injury
Injuries sometimes happen in research even when no one is at fault. There are no plans to pay you or give you other compensation for any injury, should one occur. However, you are not giving up any of your legal rights by signing this form. If you think you have been injured or have experienced a medical problem as a result of taking part in this research study, tell the person in charge of this study as soon as possible. The researcher’s name and phone number are listed on the last page of this consent form.
Financial Disclosure
This protocol is not supported by grant or research support and no researchers have significant financial disclosures relevant to this study.

Voluntary Participation
You are free to decide whether or not to participate in this study, and you are free to withdraw from the study at any time by informing the researchers verbally or in writing. If you decide you do not wish to provide additional protected health information to the researchers, you may withdraw from the study. Research information collected up to the time that you decide to withdraw will remain as part of the study data. A decision not to participate or to withdraw from the study will not adversely affect future interactions with Butler Hospital or Brown University. Your participation in the study may be terminated by the researchers without regard to your consent; in that case, you are entitled to an explanation of the circumstances leading to that decision.

Confidentiality
You will not be personally identified in any reports or publications that may result from this study. The confidentiality of the information you provide to us will be maintained in accordance with state and federal laws. If you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies.

To keep your information safe, your answers to the questionnaires, your performance on the experimental tests, and your MRI scan results that are collected as part of this study are all confidential. They will remain in secure paper or computer files to which only the research team has access. In the event that any reports or publications result from this study, your name will not be used, and careful consideration will be taken to avoid including any other information that will permit readers to identify you. You will not be personally identified in any reports or publications that may result from this study.

If you sign this document, you give permission to all OCD departments at Butler Hospital to use and share your health information that identifies you, for the purpose of conducting the research study described above.

Your health information may also be shared with a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, and conducting public health surveillance, investigations, or interventions.

Butler Hospital is required by law to protect your health information. Individuals outside of Butler that receive your health information may not be required by Federal privacy laws (such as the HIPAA Privacy Rule) to protect it, so we cannot guarantee that they will not share it without your permission.
Please note that:

- You do not have to sign this consent form, but if you do not, you may not participate in or receive research-related treatment in this study.
- Butler Hospital may not withhold treatment or refuse to treat you, based on whether you sign this consent form.
- You may change your mind and revoke (take back) this consent and authorization at any time. If you no longer want to give us permission to use your health information for this research study, you must contact the Principal Investigator, Nicole C. McLaughlin, PhD, and you will be instructed to provide a written statement.
- Even if you revoke (take back) this consent and authorization, Butler researchers may still use or share health information about you that they already have obtained, when doing so is necessary to maintain the integrity or reliability of the current research.
- You generally will not have access to your personal health information related to this research until the study is completed. At the conclusion of the research and at your request, you will have access to your health information that Butler Hospital maintains in a designated record set, according to the Notice of Privacy Practices provided to you by Butler Hospital. The designated record set includes medical information or billing records used by doctors or other health care providers at Butler Hospital to make decisions about individuals.
- Your health information will be provided to you or to your physician if it is necessary for your care.

This Authorization does not have an expiration date.

Questions
In preparation of this consent form it was necessary to use several technical words. Please ask for an explanation of any that you do not understand.
Authorization: I have read this form and decided that ____________________________
(name of subject)
will participate in the project described above. Its general purposes, the nature of my
involvement, and possible hazards and inconveniences have been explained to my
satisfaction. My signature also indicates that I have received a copy of this consent form.

________________________________________
Signature

________________________________________
Relationship (self, parent, guardian)

________________________________________
Date

________________________________________
Signature of Principal Investigator

________________________________________
TelephoneNumber

or

________________________________________
Signature of Person Obtaining Consent

________________________________________
TelephoneNumber

If you have further questions about this project or about research-related injuries, please
contact the Principal Investigator, Steven A. Rasmussen, M.D., who can be reached at 401-
455-6209 from 8 am to 5 pm weekdays, or the Co-Principal Investigator, Nicole C.
McLaughlin, Ph.D., who can be reached at 401-455-6608 from 8 am to 5 pm weekdays. If
you have questions about your rights as a research subject, please contact Linda L.
Carpenter, M.D., Chair, Butler Hospital Institutional Review Board, at 455-6349.

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BOX HAS BEEN COMPLETED IN THE IRB OFFICE

THIS FORM IS VALID UNTIL
DATE: September 30, 2017
IRBNET ID# 793406
BUTLER IRB REFERENCE# 2010-001
BY (ADMINISTRATOR): Corduro

Revised: 2/28/17
Substudy ICF
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