BODY, SELF, DEVICE: NONHUMAN OBJECTS AND HUMAN IDENTITY

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To my best friend and life partner, Jan.

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This is the space where new scholars praise the people and communities that contributed to their work. I follow that tradition here. The dissertation below is the result of hundreds of conversations and contributions throughout the past several years. I benefited greatly from these conversations and unfailing support, the faults herein are my responsibility alone. The list of supporters is long.

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I have saved the highest praise for last. In 2006, Jan and I left Columbia, Missouri for Charlottesville, Virginia so that I could enter graduate school in a second field. She placed her faith and hope in us as we struggled to build a life together under difficult conditions. Throughout these many years, Jan has weathered the ups and downs of my graduate school career with patience and grace. Although the graduate school process has tested our resolve

more than once, Jan has endured. Her strength sustains me. That is why I am so proud to

dedicate this dissertation to her.

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INTRODUCTION

Prediction is a notoriously difficult and uncertain practice. Social scientists will not be

surprised to hear a joke about how they use statistics to "predict" what has already happened.

Among social scientists, demographers may be most accurate in their predictions. For

example, a rapid growth in family size may portend success for a nation's economy as

population increases and more goods and services are required. When it comes to predictions

concerning the future of technology, a few inventors, authors, and futurists peddle their

insights on the lecture circuit, at the South by Southwest conference, and at institutions like

Singularity University. The singularity is "a future period during which the pace of

technological change will be so rapid, its impact so deep, that human life will be irreversibly

transformed" (Kurzweil 2005:7). The singularity is the era in which technology enhances our

intelligence, making it "trillions of times more powerful than it is today" (singularity.com).

Kurzweil's website for his book *The Singularity is Near* suggests that the singularity amounts

to , "the dawning of a new civilization that will enable us to transcend our biological

limitations and amplify our creativity" (singularity.com).

In fact, the futurist who has done all these things is Ray Kurzweil. Kurzweil, the

inventor, entrepreneur, and author is not afraid to make predictions. His most famous

prediction is that by 2045, computers will have become so fast that they will be capable of

something similar to human intelligence (Grossman 2011). These computers, with their

immense parallel processing capabilities, will develop a kind of artificial intellect that would

pass any version of the Turing test[1]. Once this tipping point is reached, Kurzweil and others

1 More information on the Turing test of human-like machine intelligence is available at the Stanford

believe, computers could direct their own development, and most certainly would. Along the way (Kurzweil says sometime in the 2020s), scientists will successfully re-engineer the human brain. With this information, and with the benefits of other exponentially developing technologies, we will be able to take control of our mental and physiological capacities to an extent previously unimaginable.

While it is not yet 2045, and scientists have yet to re-engineer the brain, some technologies are available that bring to mind the possibilities raised by Kurzweil and others. As an empirical social scientist, I can only study the past and the present, never the future. Although the future will no doubt look quite different from today, my research suggests that predictions of nearly limitless self-invention, and dramatic revisions to human identity that are supposed to follow from these re-framings of human capacities, are often over-exaggerated.

Medical technology is one area where such predictions should be investigated to determine what changes, and what stays the same, when new treatments are developed. What if, instead of enhancing the abilities of human bodies and minds, new medical technologies had more modest aims and resulted in dramatic improvement in disease symptoms without the drama of identity change? Contrary to the nearly breathless predictions of futurists like Kurzweil and scientists like Kevin Warwick about the revolutionary capacities of human-device cyborgs to fundamentally alter the experience of being human by supercharging our capacities for sight, hearing, and even the extension of life, I find that people with cyborg

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Encyclopedia of Philosophy: http://plato.stanford.edu/entries/turing-test/. A recent book, *The Most Human Human: What Artificial Intelligence Tells Us about Being Alive* chronicles one man's quest to be crowned the "Most Human Human" at an annual Turing Test competition held by the artificial intelligence community (Christian 2012).

technologies experience them as mundane and transparent in their everyday lives. As unusual as brain implants are, many of the people with them say they are grateful for their benefits. From their perspective, these benefits are restorative of previously valued functions, unproblematically related to their experience of embodiment and identity.

In his book *The Singularity is Near* (2005), Kurzweil outlines the trajectory of technologies and their development. Based on the exponential growth of computing resources, and the declining cost of computer hardware and scientists' constantly increasing knowledge of the brain's neural circuitry and pathways, he predicts both an emerging consciousness from computing machines and a merging of these technologies with human bodies. For Kurzweil, this computing power ultimately leads to artificial intelligence within computers whose processes successfully simulate human cognitive and emotional capacities. These capacities approximate human consciousness so closely that Kurzweil takes them to be functionally equivalent.

Kurzweil's research on the dynamics of information technology has lead to a worldwide following of transhumanists, celebrities, and businesspeople. The film *Transcendent Man: The Life and Ideas of Ray Kurzweil,* follows the futurist as he brings his vision of the Singularity to audiences worldwide (Ptolemy 2009). During a recent Technology, Entertainment, and Design (TED) talk (2009), Kurzweil announced Singularity University, a venture that educates small numbers of innovators in the exponential growth of technology and its applications across a number of domains, including education and health care. Co-founded by Kurzweil and Peter Diamandis, an engineer and entrepreneur who founded the X Prize for innovation in space, Singularity University is housed at a NASA

facility and has received funding from Google. A heady mix of big ideas, vast resources, and optimism about the future pervades the public persona of both Kurzweil and Singularity University[2].

One of Singularity University's major initiatives is FutureMed, an annual conference focused, according to its website, on how exponentially developing technologies will shape the future of health and medicine. In his April 2011 talk at TED Maastricht, FutureMed Executive Director Daniel Kraft reviewed current technologies such as portable ultrasound devices. These tools, Kraft claimed, mimicked the diagnostic tricorder carried in Star Trek[3]. Referencing the exponential growth in technologies along with declining costs, Kraft emphasized the links to be made between massive amounts of personal behavior and genomic data, new treatment modalities that are smaller and cheaper, and new monitoring devices that could identify the earliest symptoms of disease.

Kraft's presentation mirrors Kurzweil's optimism. The argument for prosthetic and cyborg enhancement beyond the medical context is that alterations to the human body and brain's capacities for pattern recognition and understanding will only increase as the world becomes more interconnected and thus more complex. When Kurzweil reviews the trajectory of technologies and their development and strives to live a healthy and active life in order to remain alive long enough to see the Singularity for himself, Kevin Warwick in the UK has started to augment his own capacities using neural implants.

An engineer and professor at the University of Reading in the UK, Professor Warwick's media appearances and self-experimentation with implants connecting his arm to

2 See singularityu.org.
3 See http://futuremed2020.com/daniel-kraft-md-on-the-future-of-health-medicine/ for a copy of this video.

his spinal cord have led many to call him the first cyborg. His book, *I, Cyborg* (2004) supports this claim while chronicling his media appearances and near-celebrity status. While most of his work focuses on computer science and applying cybernetics to prosthetics and other devices to help people with disabilities regain a measure of function, Warwick remains a controversial, and some would say self-promoting, figure.

In social-scientific and professional writing circles, discussion of current and possible future configurations of human bodies with digital devices, prosthetics, and other technological treatments and enhancements tends to be more nuanced and perhaps more cautious. Many of these discussions blend the concepts from cybernetics and biotechnology to discuss transhumanism. As a concept, transhumanism describes the relation between developing sciences and technologies and human capacities. As a movement, transhumanism is devoted to harnessing the power of science and technology to improve human potential by overcoming common difficulties such as aging, cognitive disabilities and involuntary suffering[4].

Generally grouped into libertarian transhumanism, democratic transhumanism, and neo-Luddite groups, scholars and activists (with considerable overlap between the two groups) have written a flurry of books and articles since the late 1990s and early 2000s reflecting their views. For the libertarian transhumanists, Ronald Bailey's work *Liberation Biology: The Scientific and Moral Case for the Biotech Revolution* (2005) remains an important text on the argument for allowing adults to modify their capacities and the capacities of their children. As a writer for *Reason* magazine and a committed libertarian,

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4 See http://humanityplus.org/philosophy/transhumanist-declaration/.

Bailey sees little need for government intervention or limits on the application of current or future technologies, save for their safety and efficacy. Philip Santa-Maria, writing in the interdisciplinary journal *Nebula*, also takes a techno-libertarian approach to enhancement technologies (2007). Under this approach, government interference with personal enhancement technologies is reduced to an absolute minimum, while individuals are free to alter their bodies to any degree possible.

Sociologist and transhumanist James Hughes has written two books and many essays, articles, and book chapters arguing for a "democratic transhumanism" to counter Bailey and Santa-Maria's libertarian ideals. For Hughes (2004), use of emerging technologies to enhance human capacities is reasonable only within a society that is committed to liberty, equality, and solidarity—a social democratic polity. For Hughes, the freedom to use human enhancement demands effective democratic governance. Further, this democratic transhumanism should be embraced by advocates for reproductive rights, transgender rights, gay and lesbian rights, disability rights advocates, and people with disabilities.

Speaking for the critics of enhancement through biotechnology, former chairman of the President's Council on Bioethics Leon Kass (2003) worries that thinking about ourselves as "creatures of our chemists" or "turning ourselves into bionic tools designed to win and achieve in inhuman ways" is a threat to our very humanity (xvii). Asking biotechnology companies to fulfill our deepest desires for longer lives, happier affect, better athletic performance and ever-more-perfect children, Kass suggests, leads to an overly instrumental view of human life and, ultimately, degrades the wonderful unpredictability of (currently-available) human nature.

My investigation of deep brain stimulation (DBS), the name for a therapy, and medical device implanted within the body and brain, is embedded within and connected to this larger context of debates over the line between treatment of human illness and disease and enhancement of human capacities. Ultimately, I think that the arguments over how far biotechnology can and should go in restoring or enhancing human capacities are really about the form and boundaries of human nature. What binds Bailey, Hughes and Kass is their shared concern with identifying the characteristics of human kind. For some, the meaning of human life is to gain more and more control over our environment, and ultimately, our physical and mental abilities. For others, the potential disadvantages of blurring the line between treatment and enhancement include a rejection of family, community, and the moral boundaries that, for these scholars, allow for a more expansive notion of human flourishing beyond individual desires. What's more, these scholars recognize that the very categories of disease and human problem are subject to change such that a relatively minor problem, a minimally important characteristic today, could become a target for intervention tomorrow. They fear that, if we have a tool (biotechnology) to solve a problem (say, left handedness), eventually that tool will be understood as appropriate for the problem as defined by biotechnology. The argument is that biotechnologies should not drive the definition of certain human traits, even "abnormal" ones, as deviant or requiring biotechnical intervention.

As a social scientist seeking to understand human experience by empirically investigating human beliefs, actions, and their consequences, I think that studying the world of deep brain stimulation has significant advantages. The first advantage is empirical. By investigating the practices that lead to candidacy for deep brain stimulation surgery, I

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uncover how doctors construct acceptable patients, "do-able" surgeries (Fujimura 1987). Talking with patients before their surgeries helped me understand the impact of symptoms on their home, work, and leisure. Follow-up interviews post-surgery allowed me to investigate how "good" treatment outcomes were created, and the often-disappointing persistence of issues untouched by a "miracle" treatment.

The second advantage to this approach is relational—I illustrate how the perspectives of doctors and patients are mutually constructed within the context of unequal power between the two sets of actors. While doctors control patient access to deep brain stimulation surgery, patients exert some measure of control over their self-presentation within the clinic. Many patients enter the clinic with long experience with medications and armed with first-person accounts of deep brain stimulation from the Internet and patient advocacy groups such as the National Parkinson Foundation.

The third advantage to my approach is its account of the stakes of surgery for patients. The stakes are high, as being denied surgery means continued struggle with disease symptoms and the prospect of certain decline in body control. Movement disorder symptoms, and the progression of illness made future suffering inevitable without surgical intervention. Although the impact of being denied surgery was surely significant, nearly all of the people I spoke with characterized their decision to undergo surgery as a non-event, one lacking a clear turn from "no" to "yes." Speaking of this lack of choice, many recipients said, "You don't pick them [doctors], they pick you [for surgery]."

I witnessed this suffering first-hand during an early interview with a white, married,

professional man named James[5]. I had arrived at James' house in a leafy suburb just south of

Memphis early one evening. My plan was to interview James and return to Memphis for

some barbecue before the best places closed for the night. When I admitted to not having had

dinner just after joining him in the family kitchen, he invited me to dinner. I mentioned my

hope to try Memphis barbecue, and James knew just the place. He drove me to his favorite

local spot, an outpost of a local 'cue chain. His wife, also a professional, met us there.

On the twenty-minute ride back to his home, the medications James took every three

hours for his advanced Parkinson's disease (PD) started "wearing off." I had read about the

"on" and "off" cycles PD patients undergo as their medications work for a time, then

gradually lose effectiveness until the next dose may be taken. Most PD medications lose

effectiveness over time, and higher doses are required more frequently. Patients are often

caught between doses. Too much medication leads to unwanted treatment effects[6] that mimic

the tremor of PD itself—a condition called dyskinesia.

As he drove, James' right hand began to tremor at a slow, then progressively faster,

rate. Then his left foot began to rhythmically tap the floorboard, the motion of his foot

bringing his whole leg into motion. As his limbs slowly left his conscious control, James

narrated their progression to me, said he was embarrassed by his lack of control. His right

hand and arm now useless for steering, James hugged it close to his chest. There, his left

elbow pinned the arm down, his left hand on the steering wheel. He apologized for the way

he looked, control over his limbs slipping away as we sped towards home. With his left hand,

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5 James is a pseudonym. The proper names of all interview subjects and movement disorder conference
personnel have been changed. Eastwood Hospital is also a pseudonym.
6 I am placing both "therapeutic" and "non-therapeutic" effects of drugs and other treatments together here, and
using "treatment effects" to describe them. Treatment effects cover a broad range of behavioral, psychological,
and social outcomes of taking drugs and/or using other forms of therapy for illnesses like James'.

James reached into his trouser pocket and produced a small pillbox. Opening it, he popped a quick-release version of his regular medicine, Sinemet, into his mouth. I sat, mostly silent, fascinated by what I was witnessing—a man losing control of his arm and leg as we sped down the highway at 60 miles per hour. What if James had forgotten his pillbox at home or work? Would I need to drive us home, a stranger entrusted with James and his truck, making my way through an unfamiliar city? Descriptions of "wearing off" now felt all too real and consequential. The stakes of surgery for James became startlingly clear. With it, he could drive, work, and play golf without fear of his medications wearing off. Without it, he might be forced out of his career and off the golf course. By the time we reached his house, James' right-hand tremor had quieted, but not disappeared.

In the chapters that follow, I introduce the reader to the social world (Clarke and Star 2008; Strauss 1978) of deep brain stimulation; from the meeting room where neurologists and surgeons discuss and decide which patients will be offered deep brain stimulation surgery to conversations with patients before and after their surgeries. Throughout, I offer a new perspective on the transparency of technology, the invisibility of symptoms, and the struggles patients undergo to become "good candidates." I add the concept of chronic treatment to the vocabulary in medical sociology and expand on the notion of technoscientific identity. Working from a symbolic interactionist perspective, I analyze the deep brain stimulator itself as a unique kind of boundary object, one that does its work inside the human body.

My findings are inconsistent with both libertarian transhumanism and present a vision less dire than so-called neo-Luddites such as Kass. Although Kass worries that

biotechnologies will enhance human capacities in ways that disregard community life, I find

that people "enhanced" or, treated, with deep brain stimulation often seek treatment in order

to re-engage with community life. Among people who report successful treatment, many

rejoin valued social circles. Others extend their time with such groups by undergoing surgery

before their symptoms limit their social engagements.

Contrary to Kurzweil's visions, and Warwick's new world of technologically

enhanced bodily capacities, the people who actually live with advanced technological devices

within their bodies and brains usually find them to be unremarkable. In their unremarkability,

devices like deep brain stimulators join a growing number of interventions designed to work

within the human body in ways that are invisible to others and transparent to their users. The

concepts invisibility and transparency are two of the concepts I use to understand patient

experiences with deep brain stimulation devices within this world.

Device makers and their representatives, neurologists, neurosurgeons, and the patients

themselves collectively accomplish the work of producing this transparency. Transparency is

the result of a series of consultations, discussions, and patient education that ultimately

serves to naturalize the deep brain stimulation treatment as a normal part of everyday

treatment for PD and other movement disorders. Without overwhelming their patients with

technical details, neurologists, neurosurgeons, and ultimately patients build a nonthreatening

persona for the device, relating it to other treatments already well known to the social world

of movement disorder patients. One patient recalled her doctor characterizing the DBS

device as "Pure Sinemet," a commonly-prescribed PD medication.

Patients do the work of rendering their device invisible to others, only rarely, and

selectively, revealing their status as person-with-device, usually on a "need to know" basis.

When the device is working well, its invisibility offers the promise of stigma-free social

interactions and a form of repaired motor function that many patients suggest is liberating

and almost miraculous.

Introducing Deep Brain Stimulation

In operating rooms throughout the US and around the world, people diagnosed with

Parkinson's disease, essential tremor (ET), dystonia, and other conditions are undergoing

deep brain stimulation surgery to implant electrodes deep inside their brains[7]. These

electrodes, powered by a small generator typically implanted below the patients' collarbone,

deliver electrical pulses in order to alter neuron and neurochemical activity, reducing PD and

other movement disorder symptoms.

The DBS device has four essential components. In the simplest cases, surgeons

implant one lead through the patient's skull and into his or her brain. These surgeries are

called "unilateral." In more complex surgeries, neurosurgeons implant two leads, one for

each hemisphere of the brain. These surgeries are called "bilateral." In some cases of surgical

"revision" a new lead is placed near an existing one. A lead is the bundle of wires bound

together in a protective sheath, extending from just outside the skull to the target area of the

brain. At the bottom of the lead are four electrodes, each about a millimeter and a half long.

The lead is attached to the pulse generator, also called a neurostimulator, by an "extension"

wire. This wire extends from the top of the skull, where it attaches to the lead, under the

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7   Online resources, such as WebMD, often feature schematic drawings of the DBS device when implanted.
    See
    http://img.webmd.com/dtmcms/live/webmd/consumer_assets/site_images/articles/health_and_medical_refer
    ence/brain_and_nervous_system/BrainStimulation.jpg for one such image.

patient's skin, down his or her neck, and into the patient's chest. There, the extension is connected to the neurostimulator. The neurostimulator regulates the distribution and power of electric current as it flows into the brain though the extension and out one or more of the electrodes. The DBS device is thus implanted entirely within the body of the patient.

Once the DBS device is implanted, neurologists program the device using a specialized control panel and an antenna that communicates with the neurostimulator wirelessly. They place the antenna on the patient's chest, just above the implanted stimulator. The antenna relays instructions from the sophisticated control panel to the neurostimulator. Some patients are allowed to control their level of stimulation and turn the device on and off using a small "remote" with a grey, flexible, and rubber-covered antenna that also communicates to the neurostimulator through the patient's skin.

Thousands of Americans live with these medical devices, which silently and often unobtrusively allow patients to regain voluntary control of their own movements. These devices aim to restore a portion of what most people consider normal movement to the patient. Instead of conjuring images of technologically enhanced human-machine hybrids, media coverage of DBS has focused on the miracle of restoring once taken-for-granted movement[8].

Before examining doctors' and patients' engagement with DBS and its consequences, I describe the more general features and epidemiology of Parkinson's disease, essential tremor, and dystonia. By providing these brief accounts, I contextualize the current and

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8 Videos like this one from the Mayo Clinic, have provided over 32,000 people a glimpse inside the operating room. Comments on this video run onto a second page: http://www.youtube.com/watch?v=M_fjiEOb40M. ABC's nightly "World News" program also profiled the surgery: http://abcnews.go.com/WN/WorldNews/cutting-edge-treating-tremors-deep-brain-stimulation/story?id=10138705.

potential reach of DBS as a treatment, and characterize the need for future intervention.

The Parkinson's Disease Foundation reports that over 30,000 people worldwide have received DBS implants (2012). Although global statistics are difficult to obtain, it seems likely that over 50,000 people have received these implants across their applications in PD, essential tremor, dystonia, and mental illnesses such as depression and obsessive-compulsive disorder. While estimates vary, the Parkinson's Disease Foundation reports that approximately 1 million Americans live with PD, and there are about 7 to 10 million cases worldwide (2010). It has been nearly 200 years since James Parkinson described this disease, which bears three cardinal features: tremor, rigidity, and akinesia (absence or poverty of muscle movements) (Lang and Lozano 1998a). Diagnosis of PD is made on the basis of clinical criteria, including a neuropathological examination. There is no biologic marker that confirms the diagnosis. The best medical knowledge to date shows that PD causes progressive death in several different populations of neurons. Among these neurons are dopamine-producing cells in several regions of the brain, but not all areas are equally impaired (Lang and Lozano 1998a). Since its description, PD has been treated primarily with drugs such as levodopa. Despite this drug's discovery over 40 years ago, none of the currently available treatments have been proven to slow the progression of PD (Lang and Lozano 1998b). The most common sites for DBS surgery in PD patients are the internal segment of the globus pallidus and the subthalamic nucleus (surgeons and neurologists typically choose one or the other). The subthalamic nucleus is "deeper" into the brain relative to the globus pallidus, and as its name suggests, is below the thalmus.[9]

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9 For a visual representation of the subthalamic nucleus and globus pallidus, see:
http://commons.wikimedia.org/wiki/File:Basal_ganglia_circuits.svg ; For a visual of the ventral intermediate

The Essential Tremor Foundation estimates that 10 million Americans have this progressive condition (2012). Essential Tremor is characterized by rhythmic shaking in the hands, usually between 4 to 12 times per second. This disorder can also affect the head, voice, trunk and legs. These tremors usually occur when the affected person tries to use his or her hands for everyday activities like eating, drinking, writing, tying shoes, and so on. These tremors are often the cause of social embarrassment, frustration, and many people with ET suffer social isolation. Over time, tremor symptoms usually progress to other parts of the body, affecting head, leg, trunk movements and weakening the voice. Because tremors occur when the person attempts to complete a task or perform an action, ET is often characterized as an "action tremor" to distinguish it from resting (tremor when a person is relaxed) and intention (tremor when a limb approaches its target) (Louis 2001).

Like PD, ET diagnosis is also clinical, and Louis cautions clinicians to carefully assess tremor characteristics to avoid misdiagnosis. Some pharmaceuticals have been used to improve function and reduce embarrassment that often accompanies ET symptoms. Louis reported that somewhere between 25 and 55 percent of patients show no response to drugs (2001). Researchers are not sure why response to medication varies widely. Because of this, patients are often prescribed one drug, then another, until a helpful drug is identified, or available drugs are exhausted. There is also evidence that ET is a heterogeneous condition, with some sub-types more likely to occur earlier in life, while others develop in people over 70 years of age. The most common site for DBS surgery in ET patients is the ventral intermediate nucleus of the thalamus, which plays a key role in regulating movement.

The Dystonia Medical Research Foundation suggest that over 300,000 North

nucleus of the thalmus, see: http://commons.wikimedia.org/wiki/File:Thalamus-schematic.svg.

Americans are effected by one of the 13 different types of this disorder (2010). Coined by

Oppenheim in 1911, dystonia, "describes a disorder causing variable muscle tone and

recurrent muscle spasm... Dystonia is a movement disorder that causes sustained muscle

contractions, repetitive twisting movements, and abnormal postures of the trunk, neck, face,

or arms and legs" (Tarsy and Simon 2006). Resulting from involuntary muscle contraction of

muscles overflowing into adjacent muscles, dystonic movements can be slow or rapid, and

may change during different activities or postures. These postures can become fixed in

advanced cases. Like ET, some cases are characterized as "action dystonia" when dystonic

features occur during voluntary activity. Other dystonias are localized in one area of the body

and may respond to "sensory tricks" such as a light touch to the affected body part (Tarsy and

Simon 2006). the causes of dystonia are unknown, although certain genetic mutations are

thought to be associated with generalized dystonia (Tarsy and Simon 2006). Aside from some

cases effectively treated with levodopa, there is no specific drug for dystonia. Patients may

be treated by botulinum toxin (botox) via injection into dystonic muscles. These injections

reduce muscle spasm, and studies show that these injections provide benefit in 70 to 90

percent of patients (Tarsy and Simon 2006). The most common site for DBS surgery in

dystonia patients is the globus pallidus, which is located above the subthalamic nucleus. Both

are part of the brain's dopamine system.

PD, ET, and Dystonia Share Common Features that Make them Amenable to DBS

Parkinson's disease, essential tremor, and dystonia share their origins within the brain,

and all are chronic. In addition to being currently incurable, doctors and researchers have yet

to identify a set of mechanisms and causes for PD and ET. Researchers now think that

genetics plays some role in both conditions. Drug treatments are available for PD (most commonly, levo-dopa), but their effectiveness declines over time. Like many treatments for chronic illness, drugs for PD mask its symptoms while the disease continues to erode the brain's dopamine system in the brain region called the thalamus. As the U.S. population ages, it is likely that PD will pose an even greater burden on health care spending (de Lau and Breteler 2006). Doctors and researchers have used DBS to treat movement disorders for about twenty years, and new uses of the device for obsessive-compulsive disorder and refractory depression are currently being developed. The causes of dystonia remain mysterious, although some cases are the result of traumatic accidents and other injuries.

Negotiating medications and social life

In addition to these medical factors, people with these movement disorders shared a set of experiences that included encounters with doctors, drugs, strangers, relatives and friends. During my interviews, people with PD, ET, and dystonia shared their experiences of seeking treatment, trying multiple rounds of pharmaceuticals, and their frustration with the ever-contracting "on" time when their medications are working. Several discussed dreading "off" periods, when their medications no longer controlled movement disorder symptoms but the next dose of medication remained out of reach by hours. Still others noted that taking too much of a drug could cause PD-like involuntary movements and tremors. As with many unpleasant and unwanted discomforts, the people I interviewed faced the problem of finding an explanation for their disordered bodily symptoms. Facing a disruption in their ability to control their bodies, whose unwanted tremor, rigidity, and stiffness caused multiple physical and social limitations, several of the people I spoke with discussed their struggle to find

stability and give order to their lives.

Many discussed altering their social lives, reducing trips to visit relatives and friends, embarrassed by their physical limitations. Deep brain stimulation is one of many treatments for chronic illness that seek to reduce or eliminate disease symptoms without affecting the underlying disorder. Such treatments are, to be sure, the best available at this time, and their efficacy can relieve much of the day-to-day struggles that people with chronic illness, like PD and ET, face. Symptom treatments like DBS have an important social function as well: they can eliminate outward signs of illness that often mark people living with chronic physical conditions, allowing them to "pass" as normal. Passing as unremarkable, as being an "ordinary" person, Sacks wrote, is a form of work that does not just happen, but is the result of sustained effort (1984).

Hybridity and Self-Identity

I draw on recent developments in medical sociology and science and technology studies in order to understand human-device hybridity and its implications for human identity. The hybridity concept has origins in agriculture, through the creation of new biological life by grafting one plant onto another (Nederveen Pieterse 2007). As I use the term, hybridity references both mixing of previously distinct objects, and Haraway's (1996) concept of the cyborg, combinations of humans and new technologies (see also Downey and Dumit 1997).

Following past research on chronic illness and self, I embrace a symbolic interactionist approach to the study of self-identity. The interactionist approach allows me to treat all objects, persons, events and social settings as acquiring their meaning over time,

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through human understanding and interpretation (Karp 1996). This standpoint allows me to treat human and nonhuman objects equally because both have meaning for the people who deal with DBS devices and the symptoms of illness everyday. I agree with Karp, who writes, "My view is that to really understand a human experience, it must be appreciated *from the subjective point of view of the person undergoing it*" (1996:11). In the chapters that follow, I seek to move beyond statistical inference, correlations and rates in order to give an account of ordinary people trying to make the uncertain and messy reality of chronic illness sensible.

For symbolic interactionists, objects, including people, collect meaning based on an observer's response to them. That response is an ongoing process, subject to revision and continued interpretation. This concern for the iterative construction of the self has its grounding in Mead (1934), who argued that each person experiences herself as an object, but only indirectly, from the standpoints of other members of her social group. Reflecting on herself, she becomes an object to herself as other people are objects to her. As a result, self, and self-identity, are only possible through social experience. It follows, then, that we come to know ourselves through experience, not from a transcendental subject position. This experience of self is necessarily embodied. Recent philosophical writing suggests that embodiment is the fundamental ground for meaning (Johnson 2007). Linking Mead's conception of the self as an effect of social experience with Johnson's account of the body as the ground for meaning allows both phenomenological and sociological leverage when interpreting the words, gestures and emotions of patients and their doctors. Mead's insight into the ways we create meaning about ourselves through interaction with others may also be extended to our interactions with other meaningful objects, including devices like the DBS.

Mead's conception of the human person as a social relation means that every person is necessarily a product of his or her location in space and history. Because of this, certain kinds of selves are made possible in relation to social position. Holstein and Gubrium (2000) reviewed the sociological literature on the social sources of self with this in mind. Taking the self and society to be in dialectical relation, Holstein and Gubrium (2000) found that early theories of self and society tend to view society as a source of socialization and positive moral values. There was a darker side, however, as others lamented the ways in which the individual, "private" self was under attack, overly concerned with pleasing others. For Riesman, this was the "other-directed" man of the bureaucratic corporation, in contrast to the masculine ideal of rugged individualism idealized in American culture, if unattainable in practice (1950). These masculine stereotypes of the 1950s and pre-industrial economies, respectively, are conspicuously light in their treatment of women, whose contribution to the social self is either taken for granted as "free" labor or simply forgotten. The over-conforming self, many scholars feared, was subject to propaganda, emotional appeals lacking rigor or logic, and popular passions that would undermine rational democratic decision making.

This kind of social self may be under attack, but Holstein and Gubrium argue that the self is flexible, responsive to social influence, and reflexive. In its production, they argue, selves are both, "artfully agentic and culturally circumscribed" (2000:12). Holstein and Gubrium blend Foucault's archaeology with their form of symbolic interactionism. In his studies of asylums and the hospital, Foucault uses a method he calls archeology to describe historical development of systems of thought and knowledge (1994, 1995). These systems

operate below the consciousness of individuals and define the set of conceptual possibilities available within thought within a domain at a certain period of time. Foucault argues that selves are constructed within the boundaries of these systems of thought, which he calls epistemes or discursive formations. Holstein and Gubrium suggest that Foucault's archeology should be supplemented by analyzing the actual process of self-construction using what they call analytic interpretive practice (2000). Analytic interpretive practice allows these authors to analyze:

> ... the going concerns of society's members, who artfully put discourses to work to constitute their subjectivities. It's an analytics that orients to the different subjectivizing discourses at play in everyday life, whose institutionalization offers up, but does not fully determine, our identities for all practical purposes in the local scheme of things (2000:96).

Holstein and Gubrium conceptualize self as a project of discursive formation within everyday life, mobilizing many identities and "selves" in use under various social conditions (2000). These selves both motivate action and provide stories that justify actions taken. This definition of the social self is consistent with theories that understand human identity as fluid and multiple, dependent upon both time and place, consistently acting and reflecting on its actions. Following from American pragmatist philosophy, this is *not* a transcendental ego, but rather an embodied, active, everyday sort of self. This study innovates theoretically by examining the creation and maintenance of identities with technologies that operate within the body (Howard 2000, Powell and Owen 2007). Here, I analyzed interview transcripts for examples of how patients work to discursively form themselves within the conversation, and in dialogue with their social conditions.

Although pharmaceuticals and their role in medicalization remain the most researched

treatment among medical sociologists (see Conrad 1992, 2005, 2007 and Loe 2004 for

examples), medical devices have only recently received much needed attention (Faulkner

2009). The Advanced Medical Technology Association (AdvaMed 2012), the medical device

maker's lobbying group, reports that the $200 billion industry includes over 6,000 US

companies. Artificial joints and pacemakers have become the standard of care for some

bodily conditions. I offer an in-depth study of how patients make meaning from their

experiences with the deep brain stimulation device, contrasting that with the reflections of

cardiac pacemaker recipients. Like pacemaker patients, DBS recipients confront a form of

hybridized embodiment in which a medical device operates within the body. Rather than

regulate the heart these electrodes manipulate electricity within the brain. Patients may

experience changes in their self-identity as a result of using this device. Some patients may

experience themselves as a kind of cyborg, a human-device hybrid. With this new cyborg

identity, a patient may act in ways that are consistent with a new understanding of self,

marking differences through activism or public display. Others may personify the device,

conduct "dialogues" with the device, turning it on and off throughout the day as social

setting, work, and social obligations require. In my research, I found one patient who

"trades" one set of symptoms for another as the DBS device lessens some symptoms but not

others. For some tasks, the DBS is more helpful when it does not operate. Still others might

consider the DBS an "illness minder," something that blocks the illness and prevents its

intrusion into daily life. These patients may feel that the device is more similar to a

pharmaceutical than others who actively manage their device by turning it on and off. My

work aims to specify how these devices matter to the people who use them, and the cultural

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and organizational conditions under which these different meanings arise.

Examining the role that brain implants have in the construction of technoscientific identities is also important because their use speaks to a number of social and demographic facts that have emerged in the recent past. From the mid-twentieth century to the present, Americans have enjoyed advances in medical science and technology that have increased average life spans. Along with longer lifetimes have come changing patterns of disease, especially chronic conditions that, while not always fatal, significantly lower quality of life for those who live with them. While medical science and pharmaceutical companies have brought us drugs that lessen the pain and some symptoms of these chronic illnesses, they have provided few cures. The limits of pharmaceuticals are becoming increasingly clear, and their effectiveness, even their worth, are being questioned for some conditions, (Healy 2004; Kramer 1997; 2005).

Contributing to STS with Interactionist Medical Sociology

DBS, and the relative invisibility that it has for patients, what I call its remarkable unremarkability, is of general interest in the sociology of science, technology, and medicine. Much of the literature on new biomedical technologies and patients has focused on processes of biomedicalization (e.g. Clarke et al. 2003; Clarke et al. 2010) and biosociality (Rabinow and Rose 2006; Rose 1999). For Adele Clarke and her colleagues, the new regime of biomedical knowledge reconfigures the terms and sites on which power relationships are contested. They, along with Nikolas Rose (1999) have noted the role thatmedical practices, and the medical community in general (from doctor-approved diet plans to self-help psychology gurus) has come to play in the reconfiguration of identities and social

relationships. Groups formed on the basis of technoscientific knowledge and identity are called biosocial, and engage in a form of collective action called "biosociality" (Rose and Novas 2005; Rabinow and Rose 2006). Forming collective identity and common purpose around new biological categories, risk profiles, and genetic predispositions is a new way of becoming community based not on our values or our interests, but on the basis of our biological endowment, a new organizing principle. The cyborg represents a kind of implosion of boundaries; Rabinow (1992) suggests that biosociality is another. This concept helps us think about "nature" as a manufactured object that is no longer outside society.

One strategy for understanding the new social configurations that have emerged with biomedical technologies is the analysis of the "cyborg" in the sense of the implosion of previously stable cultural categories of nature and culture. At the social and cultural level, hybrid identities and human-device hybrid relations can be unsettling. These configurations challenge received binaries such as subject/object, nature/culture, and human/machine. New forms of human life shaped with technology have been discussed on the cultural level through Haraway's concept of the cyborg (Haraway 1996), one form of hybridity that is often public and visible. From this perspective, the DBS device is an invisible cyborg technology, further engaging scholars in theorizing the boundary between the human and nonhuman[10].

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10 Some scholars within the sociology of science have undertaken studies of the connection between scientific knowledge and medical practice. Star (1989), followed the controversy between diffusion and localization theories regarding the brain's function. Current views on brain activity show that the brain does act in certain ways both electrically and chemically. Since the brain is not simply "a lump of meat with a few electric channels strung through it" (Star 1995:20), an empirical question, then, concerns how the DBS device alters what is seen to be the "natural" functioning of the brain. More important sociologically is the way in which the implantation and maintenance of the device alters the way patients, neuroscientists, psychiatrists, and others understand what the brain is and how it "works." If a neurostimulator can affect a person's emotions, and can cause depression in people with Parkinson's disease (Weaver et al. 2009, Deuschl 2009), then distinguishing between "true" and "false" depression can be exceedingly difficult.

Issues of hybridity and cyborgs can also be conceptualized from the perspective of the meanings attributed to nonhuman objects (e.g. Dumit 2004; Joyce 2008; Latour 1987, 2005; Preda 2006). Whereas interactions between human pairs can be said to occur in between two people in their language, gestures, and other symbols, the interaction between human and nonhuman object are also symbolic, but take place within the self of the human. For example, Preda's study of the stock ticker as an important socio-technical artifact that carries meanings and is provided with agency by stockbrokers provides an example of sociological work that takes nonhuman objects seriously (2006).

Scholars in the interactionist tradition, such as Casper (1998), Fujimura (1996), Mamo and Fishman (2001), Mamo and Fosket (2009) and others, have discussed how human and nonhuman objects are given meaning through social processes and relationships with fetuses, cancer genetics, Viagra and other pharmaceuticals. These scholars present multiple perspectives on these technologies and interventions, arguing for a sociology that recognizes differences in power and knowledge. Sociologists trained in the symbolic interactionist tradition (Clarke and Fujimura 1992; Clarke and Montini 1993; Star 1991) have added that studies of human-object relations should also focus on inequalities and power relationships. These scholars often provide compelling feminist insights into their research, challenging researchers to make visible the "invisible" work often done by women (Star and Strauss 1999). Star and Strauss (1999) argue that "articulation work," the invisible work of preparation, coordinating materials, and soothing emotions is often overlooked, and thus undervalued. At the same time, articulation work allows other, more high profile (and thus better paid, high status "male" work such as that of doctors) to proceed without costly delays.

This study contributes to work on new biomedical technologies and the sociology of human-technology relationships by examining, what, if anything, is different or unique about these relationships when the object is embedded or inside the body. Symbolic interactionist studies of human-object relations have been significantly limited in their focus on nonhuman objects outside the body. With their roots in Mead's pragmatist theory of human object relations, these studies examine the processes through which meanings are created, shared, and sustained over time (1934, 1936). Mead did not strongly distinguish between human and nonhuman objects in this regard. My work follows in the interactionist tradition and innovates by considering the role of nonhuman objects that work within human bodies. My findings are broadly important for scholars interested in identity transitions, and the relationship between medical innovations and human capacities.

Nonhuman objects that are designed to work within the human body are less frequently studied relative to objects that exist outside the body. Scholarly attention to these objects is important for several reasons. First, paying attention to nonhuman objects within the human body recognizes one important difference within the category of nonhuman objects. Because these objects do their work within the body, the meanings that humans make from them may be significantly different from those made from objects that are outside the body. Alternatively, recipients may come to understand the device as part of their body, re-imagining them as organic. This research aims to contribute to sociological theories of nonhuman objects by examining the meanings people make from nonhuman objects within their bodies. My research suggests a general argument: the relationship with objects embedded in the body tends to become invisible to others, and transparent to the user, so that

objects become absorbed into standard identities as part of the body and not the self. However, the relationship is unstable, and occasionally this transparency and associated invisibility breaks down as the objects re-emerge.

Relatively few studies have examined how people live as a human-device hybrid. Some research has taken up the relationship of humans to their devices, such as cell phones (see Turkle, ed. 2008) and computers (Turkle 1984, 1995), but the majority of studies deal with technologies that work outside the body. Thinking about the visibility or invisibility of devices and other aids for people with chronic illnesses will produce new insights into the types of work people who have these devices do in order to manage difficult conversations, or to "pass" as normal (Coleman 2006)[11]. In the disability studies community, several authors have discussed the implications of Cochlear implants for children and adults (Lane 2006). In his memoir *Rebuilt,* Chorost (2005) argues that his Cochlear implant made him *more* human, contradicting critical scholarly accounts (Davis 1999). These perspectives are just as, if not more, important to examine as they relate to the brain and the brain's connection to each person's identity.

My dissertation also engages the growing field of narrative medicine (Charon 2006). This field applies the tools of literary analysis to medical practices in order to enhance the listening and healing skills of doctors. My approach innovates by utilizing patient narratives, which are often overlooked, but not entirely absent, from most narrative medicine. More often, scholars in literature approach narrative medicine by teaching novels, short fiction and poetry to convey the meanings of illness. From this research, doctors may inform future

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11 A few studies have outlined the effects cardiac defibrillators have on an individual's understanding of death (Pollock 2008).

patients about the likely consequences of receiving the implant beyond its effects in reducing

disease symptoms. Listening to stories of illness and treatment can help doctors become more

sensitive to the effects their interventions have on their patients' lived experience.

The Experience of DBS: A Symbolic Interactionist Approach

Goffman's work on stigma (1963a), defined here as a deeply discrediting attribute that

reduces the status of the person with that attribute, suggests that people with bodily variations

such as PD or ET often engage in strenuous efforts to control information, retaining their

social and moral status as full persons worthy of respect. For people with visible symptoms

of Parkinson's disease or essential tremor, this work is perhaps more complex and fraught, as

their bodies repeatedly fail the test of unremarkability in both public and private space. While

riding home with James, I witnessed the struggle that people with movement disorders

undergo when they begin to lose control of their hands and arms. His attempts to minimize

the symptoms, and his apologies, reinforced my own understanding of the stakes riding on

his surgery and the embarrassment that bodily stigmas like tremors often cause.

Before undertaking this research, I had assumed that people with DBS devices and by

extension other medical implants invisible to the naked eye might undergo change in their

self-concept, or self-identity. That a relationship between selves and devices is possible is a

fundamental tenet of symbolic interaction. Foundational work by Blumer (1969), offers a

general statement explaining human action in relation to both human and nonhuman objects.

For Blumer, people act of the basis of meanings that objects have for them. These meanings

derive from social interaction, and are modified by their interpretations in practice. Because

the deep brain stimulator is an object much desired by movement disorder patients, and the

subject of deliberation and debate within the patient, doctor, and medical device communities, I suggest that these relations are worthy of investigation.

Previous research (Charmaz 1993; Frank 1995, 2002; Karp 2006) reports that the experience of chronic illness often forces people to elaborate re-statements of self-identity. These statements, together, are woven into illness narratives that give shape and meaning to the experience of chronic illness (Kleinman 1988). These narratives can center on the ways that a long-term illness disrupts one's social location, experience of embodiment, and often increases the need for valued resources while limiting the ability to reciprocate and support others (Bury 1982). Taken together, these dislocations force re-assessments of valued activities and life goals. Other sociologists have identified the collective sources of commitment to individual and collective illness identity separate and apart from previous forms of identity (Barker 2002). At stake is how people undergoing illness and treatment experiences understand those experiences and make them meaningful within their own lives. The implications of such understandings can influence current and future patients' own actions and intentions towards their illness.

Past research has also suggested that alterations in self-identity while living with DBS may be common precisely because these devices work within the brain (Rehel & Morrison 2008). Recent research on deep brain stimulation has highlighted the questions implants like these raise about personal identity, agency and free will. In their provocative article, Lipsman and Glannon (Forthcoming) understand DBS to be a novel third actor in relations between agency and personal identity. Because the DBS has ability to directly modify behavior and mood, these authors argue that it can represent a perceived threat to a patient's experience of

control. This threat, they argue, is more acute than threats perceived by people with cardiac pacemakers for arrhythmia. This intervention may diminish the amount of control patients feel they have over their behaviors because the DBS device is actively involved in modifying those behaviors. I understand the brain to be distinctly different from other parts of the body such as the hip or knee because of the way we conceptualize the relation of our brain to the self. In many ways, the brain is often taken to be the locus of our self-identity and agency. Thinking about disorders within the brain, and the addition of electrodes and brain-altering electricity to the brain reinforces the kind of reflexive self-thinking that is a hallmark of human identity and its study (Thoits and Virshup 1997).

The recent introduction of DBS devices that treat movement and a growing list of other disorders allow sociologists to understand the human-object relationship from the perspective of patients themselves. Although Blumer's tenets of symbolic interaction provide a necessary starting-point for studies of human-object relationships and their impact on identity, sociological theory has not clearly addressed how we should conceptualize these hybrid human-object relationships in which the object is within the body. Hybrid forms of human life such as this force us to reconsider the connections between technologies and the social construction of individual selves.

I came to the conclusion that people with brain implants understand them to be relatively unremarkable and not especially challenging to previous conceptions of self by addressing several questions. In the chapters to follow, I ask: How do patients relate to their brain implant, how they think about and interact with it, and what meanings do they make from these interactions? In what ways, if any, do brain implants impact a person's sense of

self-identity? How do doctors and others create eligible patients? What happens when DBS

devices, and surgeries, fail? Finally, what insights might the experiences of people with

cardiac pacemakers add to our understanding of human-device interactions?

Research Methods

To understand this complex world of objects, illness, and medical practice, I gathered

ethnographic and interview data both inside and outside a major research university's

neurological surgery unit. Through these methods, I develop a rich and nuanced description

and understanding of patients' interactions with their implants, and the effects these

interactions have on patient identity. I gained access to the neurologists, neurosurgeons,

device maker representatives, and other health professionals using professional networks

within the research university's hospital and clinics. The appropriate institutional authorities

approved this research, which was conducted from October 2009 until June 2012.

During this time, I recruited patients who had been approved for treatment by the

interdisciplinary medical team. I also observed this team during their monthly case

conferences as they determined which patients would be offered surgery and which would be

diverted. I interviewed 11 patients before and after their surgeries and 11 patients only after

their surgeries. In total, I conducted a total of 33 interviews with 22 patients. Because the

neurosurgery team evaluates patients from a multi-state region in the mid-South, I

encountered many obstacles in my attempts to contact, speak with, and interview DBS

patients whose requests for surgery were approved. Eventually, I decided to focus on

collecting as many complete pre- and post-surgery interview sets as possible. I describe these

respondents' basic demographic characteristics below. All patients who were offered DBS

surgery accepted, and thus I was unable to interview patients who elected not to pursue DBS

surgery. Table 1 summarizes the gender, age, diagnosis, interview dates and residence for

each person I interviewed.

Table 1: Select Demographic and Diagnostic Characteristics of Interview Subjects

Patient Number	Gender	Age	Diagnosis	Pre-Surgery Interview	Post-Surgery Interview
1	F	65	Essential Tremor	06/22/10	10/19/10
2	F	68	Parkinson's	06/29/10	09/22/10
3	M	56	Parkinson's	07/08/10	10/20/10
4	F	61	Parkinson's		07/23/10
5	M	75	Essential Tremor		07/26/10
6	M	76	Essential Tremor		07/29/10
7	F	59	Parkinson's		07/30/10
8	M	58	Essential Tremor		08/02/10
9	F	77	Essential Tremor	08/03/10	10/26/10
10	F	68	Parkinson's		08/18/10
11	F	65	Parkinson's		08/20/10
12	F	70	Parkinson's		09/17/10
13	M	77	Essential Tremor	10/05/10	03/09/11
14	F	61	Parkinson's	09/16/10	03/11/10
15	M	56	Parkinson's	09/16/10	03/11/10
16	M	57	Parkinson's	11/17/10	04/13/11
17	M	69	Parkinson's		12/09/10
18	F	61	Dystonia		12/10/10
19	M	62	Parkinson's		01/12/11
20	F	66	Dystonia	11/30/10	03/07/11
21	F	38	Tremor/MS	11/26/10	04/26/11
22	M	55	Dystonia	10/21/10	07/01/11

Twelve of the DBS recipients interviewed are women, the rest men. The interviewees averaged just under 64 years of age. Twelve respondents reside in Tennessee, seven in Kentucky, two in Mississippi, and one in Arkansas. I was able to interview each of these people in person, except for respondent 10, a woman who lives in the Little Rock, Arkansas area. Respondent #21, a 38 year-old woman from rural East Tennessee is somewhat of an outlier in my data. Janet was diagnosed in the medical record as having a tremor disorder, not ET or PD. Due to difficulties in in scheduling interviews and the logistics of travel, some follow-up interviews were conducted up to six months after implant adjustment.

Aside from the telephone interview I conducted with one person in Little Rock, I traveled over 1,000 miles, meeting each respondent in person. I interviewed most respondents in their homes, although a two interviews (with the same person) took place at a local restaurant. I interviewed one woman at her workplace. I found that visiting the everyday spaces of people considering, or living with, DBS implants helped me understand the multiple and interlocking strategies they employed to create a sense of control over themselves within the context of illness. For example, Respondents 14 and 15 had fitted a special handrail to the side of their bathtub. This rail allowed both entering and exiting the tub without fear of losing their balance, preventing falls. I noted how stairs had been replaced by ramps. Many hours were devoted to controlling, as best they could, physical safety and mental tranquility. Respondents discussed their efforts to reduce stress and anxiety by refusing to tolerate complaining from fellow patients and ending relationships with unhappy people. Many recounted declining stamina, reduced exercise and less time spent with favorite hobbies.

In pre-surgery interviews, I asked patients to recall when they first noticed movement disorder symptoms and when they first sought help from medical professionals. In order to understand their trajectories through treatment, I asked respondents to tell me about the medications they have tried, how effective these medications were, and what impacts the medications, and the illness, has had on their lives, careers and families. As the interview progressed, I narrowed the focus to deep brain stimulation, asking patients when they first heard about the treatment, and what their initial reactions were, the impact of brain implants on their daily lives, and the impact of these devices on their illness. Many people were eager to tell their stories of illness, troubles with getting an accurate diagnosis, and difficulties with medication. By listening to patients tell their stories of illness, therapy, surgery and treatment, I gain greater insight into how patients construct their own versions of technoscientific identity in chronic illness, or reject these new identities. Patient references to him- or herself, stories that elicit emotions such as sorrow or those that refer to qualities of self that are either newly present, absent, or as part of a "previous self" before illness were marked as relevant to uncovering patients' views of self-identity.

In post-DBS interviews, I asked patients to recall their lives prior to the surgery, including the ways in which thinking about, or having the device implanted, has changed how they feel about themselves. Patients' stories often reference the advice their doctors offered, media accounts, and information gleaned from Internet sources like WebMD and online patient forums. Many of these stories took a rather conventional and even mundane form, mimicking the structure of ordinary, even acute illness narratives, normalizing an uncommon sequence of events (Sacks 1984). Collecting these ethnographic and interview

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data has become standard practice within symbolic interactionist and science and technology studies because these methods reveal the novel and complex ways people make sense of their social and technological lives.

I also examined the process of constructing patients as eligible for DBS surgery by observing 30 Movement Disorder Case Conferences (conference) from October 2009 to June 2012. The conference was usually held once per month. There were certain exceptions. For example, conference was rescheduled when both neurosurgeons were away from the hospital, an exceedingly rare event. I gained access to conference through a key informant, Dr. North. Introduced to the conference of about 20 neurologists, neurophysiologists, trainees and representatives from a device manufacturer as "A student who is here to help us understand the social aspects of our work with patients" by the senior neurosurgeon, Dr. Clark, I discussed my project and gained consent from the group before conducting formal observations. Spending this time "in the field" offers an in-depth look at the social and biomedical considerations that are at work in selecting the right candidates for the surgery. This work also allows me to investigate how medical teams incorporate error and mistakes into their ongoing practices. The social repair of mistakes is the subject of a second chapter using this ethnographic data.

Finally, I reviewed existing popular literature on patient experiences with cardiac pacemakers written by pacemaker recipients and a historian of pacemaker technology. Investigating patient experiences with another implant technology will help me identify the features of human-device interactions that carry across boundaries and locations within the body. Consistent with the literature on chronic illness and biographical disruption, the

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narratives I reviewed focused on acute disruptions and their aftermath. Robert Pensack's memoir of his experience with a congenital disorder that causes thickening of the walls of his heart is a rich and moving account of the pain, fear, and existential crises that attend his illness. While the historian Kirk Jeffrey does not have the same flair for drama, his account of the ongoing development and revision of pacemaker technology shows us just how contingent and unstable a seemingly settled piece of medical technology can be. In each substantive chapter to follow, I outline my research process, providing some insight into the process of collecting and analyzing the presented data.

Analytic Strategy and Chapter Outlines

Inspired by interactionists like Karp (1996, 2006), Charmaz (1993) and the in-depth qualitative and narrative work of Frank (1995, 2002), I have employed a basic thematic and narrative analysis to the interview and ethnographic data. As you will see, in the chapters to come, I analyze the rhetorical and interactive work of doctors and patients as they create and participate within the social world of deep brain stimulation.

Chapter Two reports on my observations of the interdisciplinary medical team that meets monthly to discuss all movement disorder patients who are candidates for DBS surgery. In order to receive the implant, each patient must show declining response to existing drugs, and volunteer to undergo the procedure. In these meetings, doctors and scientists review medical charts, watch videos, and discuss scores on standard movement disorder inventories for up to twenty patients. Together, they try to determine whether or not a particular patient is a reasonable candidate for surgery, and if so, what type of surgery. I find that this team meeting is a critically important site for defining the project of DBS at this

center, and for determining which patients exhibit symptom profiles, dispositions, and social supports necessary to create a "do-able" surgery. One of the first attempts to look at interdisciplinary, team-based decision-making processes has implications for medical sociologists' understanding of how doctors collectively create and use categories of inclusion and exclusion in practice, a contribution to the literature on medical gatekeeping. In this chapter, I profile the processes, both social and biomedical, that lead to decisions supporting, and denying, surgery.

My fieldnotes from these team meetings reveal the multiple forms of evidence that doctors and neurologists use when determining eligibility for the DBS implant and, by extension, for the human-device relationship central to this project. I sought to determine, as much as possible, the ways in which doctors understood key concepts such as quality of life, and how they deployed these concepts in order to strengthen, or diminish, the likelihood of offering surgery to a particular patient. I found that neurologists construct a patient's history and profile, often using quality of life justifications for a recommendation to offer the patient DBS surgery. Over time, patterns in the deployment of quality of life justifications and stories emerged from the data. Doctors often tried to match their understanding of each patient's quality of life to an existing version of the DBS device. These stories resonated with marketing materials from device manufacturers, anecdotes collected from previous patients, standardized scores on symptom measurements, quality of life indexes, and doctors' own "gut" feelings about the procedure. By observing these meetings and collecting field note data on the ways in which team members conceptualize the implant, its actions, patients and movement disorders themselves, I examined the process patients undergo when moving from

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person-with-chronic illness to person-with-device. Interviews with patients helped clarify their decision-making process around DBS and its consequences.

In chapter three, I stay with the medical team to examine patterns of talk and action that frame doctors' beliefs about the need for revisions to DBS surgeries. Here, I describe how doctors come to see revision as necessary. Some revisions become necessary when surgical sites develop infections, either on the scalp or near the implanted generator. Other revisions are required when the implant's leads cannot be adjusted to the patients' and doctors' satisfaction. These situations often require repositioning, or removal and repositioning, of DBS leads. Generally, this work involved the process of discovery, attempts to correct the problem without surgical intervention, discussions of causation and assigning responsibility, and finally, decisions to revise or to leave the implant as-is.

In this chapter I introduce an analytic framework of symptom visibility and implant transparency in order to evaluate doctors' decision-making practices. The typology captures for analytic purposes the interactive processes that occur between the implant, patient, and his or her doctors. This chapter balances the somewhat ideal view of DBS surgery that is depicted in future chapters and recognizes that mistakes are made.

In chapter four, I use a form of thematic narrative analysis to document the ways DBS recipients construct normality both in their embodiment and discourse. I find that my respondents have a complex and often contradictory understanding of "normal" that both recognizes the device's intrusiveness and downplays its significance. For many DBS recipients, the device is symbolically absent, even invisible. I analyze how this invisibility is sustained, and theorize its meaning for DBS recipients.

In chapter five, I analyze transcripts from interviews with DBS recipients in order to further specify Clarke et al.'s concept of "technoscientific identities" (2003). Technoscientific identities, these authors argue, are forms of human subjectivity constructed on the basis of technoscientific objects and human bodies. Because DBS recipients experience an unusual, though rapidly expanding, form of embodiment, their reports of identity maintenance and change are a source for insights into the lived experience of hybridity. Their unique position as persons-with-device allows us to understand how boundaries between human and object are essentialized, erased, or deployed (Nederveen Pieterse 2007).

In these chapters, I make connections between patient reports of self-identity and the cultural and social sources of these reports as captured within the interviews and from my ethnographic field notes. Keeping in mind the social locations each recipient inhabits, and is shaped by, helps me represent the complex and multi-layered worlds that intersect in the experiences of patients with brain implants. These chapters help demonstrate the impact of cultural and organizational contexts on technology and social identity.

Chapter six develops a comparison with the cardiac pacemaker. Since the DBS is often called "the pacemaker for the brain,"[12] a comparison of patient experiences with the devices seems warranted. Although the DBS is certainly a "cutting edge" technology, the current generation of cardiac pacemakers often include automatic fibrillation, and are thus more cybernetic, in the sense that these implants sense action within the heart and respond to it. This means that cyborg implants have been used to maintain cardiac health and prevent

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12 See the *Scientific American* article on DBS for PD: http://www.scientificamerican.com/article.cfm?id=sparking-recovery-with-brain-pacemakers and the Johns Hopkins Health System's Newsletter "NeuroLogic" for an example of this usage to treat epilepsy: http://www.hopkinsmedicine.org/news/publications/neurologic/neurologic_spring_2011/a_pacemaker_for_the_brain.

death for many years. Perhaps ironically, less "advanced" devices like the DBS roil our imagination while older, more familiar technologies are more sophisticated.

In this chapter, I examine the narratives of three men whose lives depend on the continued functioning of these devices. As with the narratives of DBS recipients, I approached the stories of pacemaker recipients thematically, paying special attention to the accounts of their sense of embodiment with the implant. While analyzing their stories, I came to understand that these pacemaker recipients often focused their attention on both the outward and inner signs of their pacemaker. In their accounts, pacemaker recipients highlighted the connections between changes to their bodies, and their sense of embodiment, and the meanings about themselves and their lives that reflections on these uncovered.

In chapter 7, I very briefly summarize the lessons I think medical sociologists, science and technology studies scholars, and perhaps biomedical ethicists can take from this study. Stepping back from the individual chapters, I reflect on, and integrate, insights across the work. Here, I suggest that much medical sociology has neglected the stories behind the statistics. A great deal of medical sociology is focused on illustrating the unequal distribution of health and wellbeing in society. Much of this work is methodologically rigorous. For all their power to describe rates, predict morbidity and document the stress process, these approaches leave us without a sense of what it is like to experience chronic stress, to be subject to the health effects of race, gender, and class-based inequalities.

At its most basic, this project relies on a social worlds perspective. Social worlds are defined as "universes of discourse" (Strauss 1978) through which individuals and groups of people create meaning through interaction. They create meaning in shared discursive spaces,

as they work with overlapping sets of tools, objects, and technologies. As social worlds grow, they often segment into multiple worlds that intersect others as they share common interests, objects, and people. When these social worlds develop conflicts, viewpoints, careers, and other types of difference, the whole can be analyzed as an arena. (Clarke and Star 2008). Social worlds are bounded in that only certain people share the forms of discourse, knowledge, and skills that operate in any particular world, even though each person occupies multiple social worlds of family, workplace, sports team, and role-playing fantasy game (Fine 1983). This project allows the reader particular vantage points on the deployment of, and daily life with, a relatively new medical technology.

This approach integrates data such as interviews, participant observation and ethnography, inviting a more nuanced and complex analysis of the social worlds under study. By specifying relationships among the elements in the situation, analysts can achieve "thick analyses" of the full set of elements in the situation under study, analogous to Geertz's (1973) "thick descriptions" (Clarke 2005).

CHAPTER I

MAKING THE CASE: HOW DOCTORS CREATE "DO-ABLE" PROBLEMS AND

RETAIN AUTHORITY IN CASE CONFERENCES[13]

The objective facts of contemporary social life are primarily embedded in texts, including case histories and other 'personal' files. Those texts consequently limit an individual's claims, and hence limit her person. For example, the individual who encounters someone who is in possession of her file also encounters a chorus of others who have left marks in the file. Those disembodied others communicate with the possessor of the file, but not with the individual, throughout the interaction between the two. And because much of what they communicate through the file has been subjected to rituals of truth, it tends to carry more weight than anything she might do or say to the possessor of the file. She may challenge the veracity of those who 'speak' through the file but at the risk of casting doubt upon her own veracity and, perhaps, upon her 'self' possession. Or, she may attempt to convince the possessor of the file that she is no longer the person whom the file constructs and whom she once was. Her person presentational options are clearly limited. (Cahill 1998: 143).

I quote Cahill on the ways files and charts limit an individual's claims about herself

because this chapter is about the moments that lead to these inscriptions on medical files.

Cahill is not so much concerned with how a person's characteristics make their way into the

files—how disorders, personality types, illness narratives, symptom scales, and chief

complaints become matters of fact for the purposes of clinical and social action. Cahill's

point above is that in an age when social life is embedded in texts and files, individuals who

seek to challenge the textual presentation of themselves face difficult set challenges to their

agency. Embedded within the structure and content of the files are interpretive schema that

provide experts with consequential diagnoses, suggesting certain kinds of therapy and ruling

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13 The title of this chapter refers to a part of Fujimura's scholarship (1987) on how cancer researchers construct "do-able" research problems.

out others

In medical contexts, there are situations in which the medical history of the person, including his or her disease, cannot be challenged by the patient—places where patients are not allowed to go, and thus are not allowed to challenge the judgments made by doctors. Case conference is the place where disease entities are presented, contested, ratified and made objects for intervention with DBS. Approximately 20 people regularly attend case conference: about 5 neurologists, two neurosurgeons, one physical therapist, one neuropsychologist, one technologist, one surgery coordinator, two patient care coordinators, a neurosurgery nurse, three neurosurgery interns, two medical students, one MedCorp representative, and myself.

The case conference is thus a key site in the transition from person-with-illness to person-with-brain implant. It is here where actors beyond the patient's immediate neurologist and consulting neurologist are enrolled (Latour 2005), where the "conveyor belt" from community to conference as "hub" happens. This is where some important individual and collective work is done, objectifying the boundary object (Star and Griesemer 1989; Star 2010) (Parkinson's disease, essential tremor or Dystonia) that is also a work object. Enactment is a key concept here—as is representation. What's called upon in these meetings is an individual and collective imagination, filling in the gaps of the stories, often with other stories, other narratives of and about patients. The task of representing the patient and his or her condition falls to a medical professional, and the patient lacks any significant level of control over this presentation. Indeed, doctors take patients' efforts to highlight certain of their concerns as forms of deception and perhaps mental instability. During the course of my

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observations, I noticed that doctors resist patients who seem overly eager to undergo surgery. Sometimes, these patients "help" their symptoms by exaggerating their severity during standard tests of movement disorder severity. Any attempt to modify their symptoms, including "faking" or "assisting" symptoms, consciously manipulating the appearance of their severity is coded as dissembling by doctors. These inscriptions doctors make inside the medical record ultimately place people into one of three categories: "surgery," "not a candidate," and "re-evaluate."

Doctors face the challenge of discerning the difference between exaggerated and "real" symptoms in their interactions with patients. How stable are symptoms as objective, quantifiable things? The issue of stability in symptoms that doctors intend to treat and patients intend to be delivered from is a core feature of DBS conference work. If the symptoms are not stable, how are they to be treated? It is simply the case that symptoms are expressed more or less severely for many patients on a daily, even hourly basis. These fluctuations are often due to medications "wearing off" or losing effectiveness before they can be replaced. Symptoms may also vary according to patient diet, variation in physical activity, and exposure to stress. Controversies, then, over what symptoms really are, and how the reality of each patient's experience is represented, are repeated again and again. Doctors struggle to articulate and defend their positions, marshaling both evidence and support for their interpretations of available evidence. This evidence includes standardized symptom scale scores, clinical (but, doctors aver, never "anecdotal"), and patient self-reports. These kinds of knowledge have varying truth values, with scale scores and clinical judgment often ranking higher than patient self-reports. I sat in on these meetings in order to determine how

decisions were made within movement disorder case conferences.

Goals for this Chapter

This chapter has four main goals: First, to outline the major components of the ethnographic scene, focusing primarily on the conference as a case-making venue; second, to describe the representational processes whereby patient profiles, complaints, and factors the team label "social" are condensed into a plan of action (or inaction); third, to uncover the ways in which surgeons and neurologists work together to maintain and enhance their authority in determining these plans of action through selective and partial readings of "quality of life" for their patients. I will show these processes at work through the presentation and analysis of three cases: one "easy" case that quickly led doctors to offer surgery, one "easy" case that ultimately resulted in the patient being denied surgery, and finally one "difficult" case that called on doctors to do a significant amount of work in determining a patient's suitability for DBS. By comparing these cases, we get a nuanced and rich picture of deliberative processes in an age of evidence-based medicine, and the enduring ways that doctors occasionally use privileged knowledge and clinical experience to override the "evidence" in ways that enable them to retain their authority in offering patients surgery, or denying the same. Finally, I want to briefly highlight a few instances in which the world "outside" patient care came into the foreground in these discussions in order to illustrate the ways in which assumed differences between activities "inside" and "outside" medical practice are always already central to the work of presentation, diagnosis, and treatment.

Entering the Field

This chapter is built on my observation of 30 Movement Disorders Case Conferences

(hereafter "conference/s") from October 2009 to June 2012. Conference was generally held once per month, and rescheduled only in case of significant scheduling conflicts for doctors, and specifically surgeons[14].

I gained access to conference through one of my key informants, Dr. North[15], one of the two neurosurgeons. I was publicly introduced as "A student who is here to help us understand the social aspects of our work with patients" by the senior neurosurgeon, Dr. Clark. Clark was obliged to introduce me because his younger colleague, North, was out of town. I presented my project to the conference, careful to distinguish my role as a sociologist from any "help" I might provide members of the conference, or the conference as a whole. After I described my project, I asked for questions and comments.

Dr. Davenport asked me to state my hypothesis. I said that as a qualitative researcher, I think that starting research with hypotheses to be tested can unduly blind the researcher to important social processes that were not apparent before deep engagement with the scene. Any hypotheses that may be developed during the course of fieldwork should be based on familiarity with a scene or problem. As the reader will see, I was able to develop a theory about the meaning and deployment of "quality of life" as a key component of the presentation of expertise for members of the conference, and the conference itself. In that moment, I was able to tell Dr. Davenport and the rest of the group that my work is qualitative, and thus inductive and theory-generating rather than theory testing. Dr.

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14 My email address was inadvertently dropped from the invitation list during the summer of 2010. When I returned to conference two months later, I discovered this was simply an oversight. The person who sends out agendas and meeting reminders was quite apologetic for failing to include me on the list of conference participants. I had missed two meetings. Scheduling difficulties prevented me from attending another two meetings.
15 The names of all conference participants and patients have been changed.

Davenport did not seem convinced. He said that doctors are a highly reactive group and that I might not get the kinds of data I sought. I kept this in mind as I sat in the back of the conference room through the next seventeen months[16]. Davenport is a neurologist, a very famous one, and a full professor. He leads several of the studies that involve DBS patients, and he is also extremely quick witted. He will be one of the first to joke, and nearly always the first to joke about Dr. Halter, a gregarious and often funny man. His standards for presentation and history on patients are extremely high—he seems to want as full a story as is possible, and he practically demands it of his colleagues.

Dr. Halter is an associate professor of neurology, and is probably the least organized, but the funniest, person in the room. From a country in Europe, Dr. Halter often turns an interesting phrase, using language that betrays his background as a non-native English speaker. Sometimes, he forgets which patient he is discussing, chalking this up to his heavy workload—how can someone remember every patient? The heartiest laughter in the group comes from his clever, or seemingly clueless, turns of phrase. In my observations of this group, I have tried to quote Dr. Halter extensively, because his language is often some of the least technical in the room. Halter has the reputation, in conference, as being the most likely to recommend and even "push" DBS for his patients. Two key incidents illustrate his reputation as a proponent of DBS. First, in conversation with Dr. North, I learned that Halter often advocates for surgery outside the conference. Halter sometimes advocates for patients whom North believes are not yet suitable candidates. Second, during my field work, I noticed

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16 I followed IRB-prescribed protocol by obtaining verbal consent from conference attendees. I opted for verbal consent because I think it provides a greater level of anonymity for members of the group. By not recording their names in my field notes, I have mitigated any potential harm that might result from the loss or improper distribution of my notes.

Halter's tendency to contradict or question test results from Ms. Steele (Steele is the physical therapist whose testing quantifies movement disorder symptoms) when they conflict with his clinical impression of the patient.

The person who seems most enthusiastic about surgery during conference is one of the more circumspect participants in the Operating Room. Patients are always accompanied in the Operating Room by their Eastwood neurologist. In surgery, the neurosurgeon manipulates the DBS device settings, both stimulation frequency and voltage. The neurologist manipulates the patient's arms and legs. These tests give doctors an sense of the symptom relief patients might expect when their DBS device is fully functional[17]. Dr. North, the neurosurgeon, for example, reports that, during surgery, Dr. Halter will never say that patients' rigidity has been reduced more than 80%.

I always found a place at the back of the room—a location that allowed me to see the faces and behavior of nearly all conference participants. I was also able to see the large screen upon which a neurologist would project a patient's electronic medical record. These images were almost always joined by videos of patients as they completed tests of their ability to move in various ways. The videos were taken by Ms. Steele, as they went through tests that aim to quantify the degree of impairment caused by their movement disorder. To this end, each file/presentation included one video that captured the patient "on" medication, the other "off" medication.

During the first few sessions I attended, I sat behind the neurosurgeons, who were placed at the "bottom" of the U-shaped set of heavy, darkly stained tables that defined the room as a place for deliberation (see Figure 1). In subsequent meetings, I sat to the right of

17 This time varies for each patient, with healing and surgery format the two main factors.

the "bottom" of the U. In this position, I was able to stay out of the main aisle within the conference room and take notes without other members of the conference sitting near me. I think this may have made my notes, and my note-taking, less obtrusive to members of the conference. It is difficult to know exactly how reactive the doctors were. When they joked about patients, and about the foibles of Dr. Halter, I sensed that they generally placed me in the category of "med student" or "trainee"--someone who was there to listen and learn, not contribute. This impression may have been helped by the fact that during fieldwork, I was approximately the same age as medical residents and interns. In addition, I tended to dress business casual, distinguishing me from MDs and PhDs, who often wore lab coats, or scrubs. The student role also played by one, but sometimes two or three medical students. Judging by the way members of the conference joked with each other, I think that my presence was minimally disruptive.

There were two occasions when members of the team spoke to me directly. Dr. Frank, a PhD technologist who rarely spoke in conference excitedly approached me to say that the team was now allowing patients to bring in their favorite movies and videotapes to watch while in surgery. This, Frank said, was a great innovation, because patients must be awake during their surgeries. Often, Frank said, they get bored as the surgeons go about their work. Watching videos, he said, would help patients relax, and focus on something besides their neurosurgery. Doctors would then alert patients when their full attention is needed.

Figure 1: Eastwood Hospital Movement Disorders Conference

Projection Screen

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2

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6

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Conference table

8   9 10 11 12 13 14 15 16 17 18 19
    27 28 29 30 31 32 33 34 35 36 37 38 39

26

25   46

24   45

23   44

22   43

21   42

20   41

40

Key:
Numbers represent chairs in the room. The table at right describes the most common occupant of each chair.

Chairs not assigned were either unoccupied or occasionally occupied by medical students. I sat in chairs 38 and 39 for most of my fieldwork.

Food table

Doorway

1 Podium (Neurologist)	10 Neurologist
2 Physical Therapist	13 Neurosurgeon
3 Neurologist	14 Neurosurgeon
4 Neuro-psychologist	17 Neurosurgery Nurse
5 Neurologist	20-22 Neurology Interns
6 Surgery Coordinator	23 Neurologist
7 Patient Care Coordinator	24 Technologist
8 Patient Care Coordinator	26 Medtronic Representative

I found this conversation curious, first, because I had never interacted with Dr. Frank for more than a few moments, at most simply a hello, or acknowledging him briefly. I think this indicates that, for at least this one member of the conference, my presence was not "invisible." I was being treated more like an interested outsider, or perhaps a trainee with little clinical experience. As the person who is interested in "the social" aspects of the work conference members do, any change in the patient's experience was supposed to be important to me. In fact, I may have come to represent, for this doctor, the eyes of the world "outside" the clinic, a person whose loyalties were not solely with the medical team, but someone whose sympathies were thought to be more in line with patients than doctors. This latter interpretation lines up with Dr. Davenport's assertion that doctors are "reactive" to being the subjects of outside scrutiny.

Another event supports this interpretation of my student status within the conference came during the moments just before the start of conference. Ms. Dougherty, a nurse who works in neurosurgery, asked Ms. Lawton who I am. Lawton said that I was working on a study. As I was close by, she motioned towards me, introducing me to Dougherty, whom I'd already met in the clinic at the Eastwood neurosurgery center. I re-introduced myself to Dougherty and briefly explained that I am interviewing patients pre- and post-surgery to find out how they understand the process of DBS, what their expectations are and how they are doing post-implantation. I also said that, as part of this work I was observing this group and seeing how they work. She seemed to accept this definition of my presence, and of this situation (the conference) as a site where this type of fieldwork could take place or at minimum is authorized. In addition, I often wore business casual clothing during these

meetings. Since many of the doctors wore business professional attire, this, and my age, might have made me seem more like a medical student to conference members.

The Scene, October 2009-June 2012

The Dean's Conference Room is in use. Neurologists, the surgery coordinator, physical therapist, a neurosurgeon, and the MedCorp representative wait, tapping their toes. There is almost-whispered talk of patients and about the conference agenda, such as "What do we have today?" Lighter moments are shared too, as the conference has the feel of professional a monthly reunion, with its regular rituals and protocols. Children are inquired after, small kindnesses acknowledged. One neurologist thanks a neurosurgeon for allowing her father to observe a DBS surgery, and the neurosurgeon replies that the father is welcome any time. The MedCorp representative, Mr. Block, greets neurologists and staff members alike, cheerfully. Although he rarely speaks in conference, Block does answer technical questions about MedCorp products and provides brief training sessions on using the DBS remote control to the "non-specialists," patient care coordinators, who often receive phone calls from patients. Block is often the best dressed, wearing suits and ties to each conference. He most often comments on insurance billing and approval issues and answers occasional questions about products. Block is an elite member of the MedCorp sales team, and is present at each surgery where MedCorp products are used.

A group of three or four non-technical, non-physician administrative professionals make up Block's primary audience. They include a surgery coordinator, two patient care coordinators, and sometimes other "non-specialists" who interact with patients regularly. These non-specialists are Block's audience because they are the first line of contact for

patients, many of whom call the neurosciences office with questions about their remote

control device and how to use it effectively. When MedCorp introduces a new deep brain

stimulator, or DBS control device[18], Block will ask for some time with these staff members

after the meeting to discuss the controller, the questions patients have about it, and the many

ways they can "troubleshoot" patient use of the controller from a distance. This has the effect

of, first, providing some form of technical training for "low" level staff members; second

enhancing the status of these workers—who get to be experts in an area that the surgeons

they work with are often not; third, offloading work from Block, who, although he gives each

patient his personal cell phone number, is in actuality seldom contacted by the patients I

spoke to. Finally, this training shores up relationships between Block, MedCorp, and the

team. Block's business relies on good relationships with the team, and Block has offered to

buy the group's lunch on at least one occasion. This group does have a budget for these

expenses, but occasionally the budget runs low. This is when Block attempts to step in with

MedCorp's largesse. These overtures have been rebuffed, as the patient coordinator he asked

said no, referencing concerns over conflicts of interest.

The group currently delaying DBS Movement Disorders Conference, as it is officially

known, has brought in Krispy Kreme doughnuts and a coffee carafe to share. It seems as if

the two groups do not know each other. The hospital is a multi-billion dollar enterprise,

employing tens of thousands of people, and thus it is not unusual to share spaces with other

medical professionals without knowing their names, or their area of practice. This tends to

manifest itself in a casual civility that permeates the use of shared spaces, where questions

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18 Like many large device makers, MedCorp invests heavily in research and development. The company has
     several devices under development now.

such as "How are you doing?" are briefly asked and answered.

Both the carafe and doughnut box are empty as the neurostimulation group ambles inside.

Two members of the office staff[19] move between the kitchen adjacent to the conference room and the hallway, attending to sandwiches, ice, Diet Coke cans, and water bottles. It is 10:30 a.m., but that qualifies as lunch time here, since doctors and nurses start their days in the wee hours of the morning, prepping for clinic and surgical duties long before many of us pour our first cup of coffee. Food is always provided during these conferences. Occasionally, offerings go beyond sandwiches from the hospital-owned cafe or from national chains. In the fall of 2010, a thanksgiving type meal, with turkey, dressing, gravy, rolls and iced tea was served on china, along with real silverware, with the support of two catering staff members.

This particular conference room measured about 15' by 25', with one creek-rock and cement wall and three walls in dark wood paneling. Inside, deep brown tables are set in what event planners call open conference (U-shaped). The room is located next to the hospital's executive suites. At the front of the room a large screen is lowered, on which images of patient charts (via the Hospital's electronic medical record) will be displayed, as well as images of scans and movies of patients both "on" and "off" medications. About 20 rolling black leather armchairs with worn brass rivets ring the outside of the open conference tables, which are built of solid hardwoods and feature glass tops. On the perimeter of the external and back sides of the room sit an additional 15 chairs, enough room for visitors, trainees, and overflow doctors and clinic staff.

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19 This may be an example of the "invisible work" (Star and Strauss 1999) that is often performed by administrative professionals, often women, as part of their unofficial duties providing comfort and hospitality to doctors and other higher-status professionals.

This conference has its own set of processes, heuristics, shorthand, and cast of characters. These processes were built over time, as the group gathered experience and members. Dr. Clark, the senior surgeon, has played an important role in editing the "Movement Disorders Conference" template within the Electronic Medical Record. The "skeleton" of each person's story is written into the assumptions about patients, their symptoms, illnesses and complaints of the template.[20] Dr. Clark is the senior surgeon on the team. He is the driving force behind the DBS surgery program at Eastwood, and is widely regarded as one of the most gifted and accomplished surgeons in the neurosurgery program. A tenured full professor, Dr. Clark mentors Dr. North. He also formally and informally guides the conference meeting, often taking charge of editing a patient's medical record on his ever-present laptop, summarizing the discussion and, sometimes, offering a final judgment about the type of surgery to be performed. He has been recognized as a top doctor by a national magazine, and he has been featured on several television and Internet-based programs discussing, and even videotaping, DBS surgeries. Dr. Clark is tall, and has a commanding presence and deep voice. He holds both a PhD and an MD. Dr. Clark's major project involves improving the program's digital "Atlas" program, which maps brain structures in three dimensions and helps these two neurosurgeons "hit" the right spot(s) in the brain with their electrodes to affect the optimum symptom reduction in their patients. Dr. Clark has been working on this neurosurgery team conducting DBS surgeries for over 10 years. Conference is one site where the medical record's skeleton acquires its connecting tissue, as professionals meet to create a narrative of illness and perhaps treatment for each

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20 The electronic medical record has been understood as an important technology in its own right, and scholars have noted the ways in which the EMR is used in practice (Hartswood et al. 2003).

patient. Not all narratives are equally complete or coherent. But the major task of the conference is to ensure that a minimal coherence in understanding and future work is achieved.

Dr. North is the junior neurosurgeon on the team, having just completed his fifth year at Eastwood. With an undergraduate degree from an Ivy league school, medical school training at a prestigious medical school, and residencies in the US northeast and Canada, Dr. North's research has focused on applications of DBS for several conditions, including the movement disorders under study here. He has trained with some of the most recognized names in DBS treatment and research. A full service neurosurgeon, Dr. North has completed hundreds of brain surgeries, including lesioning procedures such as those Michael J. Fox has undergone for the treatment of his Parkinson's disease. On the tenure track, Dr. North's future at the hospital relies on his research productivity, grants activities and his clinical and surgical work. Dr. North generally waits to speak until his senior partner, Dr. Clark has had a chance to weigh in on any particular case. He asks more questions of the neurologists than he answers.

Dr. Philos is a neurologist who handles many, if not most, of the cases seen in DBS conference. An associate professor with tenure, Dr. Philos is one of two female neurologists currently on the team. Early in my observation period, a younger neurologist, Dr. Walker, left the hospital and is now employed by another institution. Another, Dr. Strong, took her place. Dr. Philos is also the neurologist working with Dr. North's patients with obsessive compulsive disorder. Dr. Philos is one of the more outspoken members of the team, and often has the most extensive case presentations prepared. Dr. Philos, like other neurologists,

presents the patient's diagnosis, major complaint, a bit of history, as well as family situation and some of the details of the patient's life situation.

Dr. Tomarro is also an associate professor of psychiatry and a neuropsychologist. He oversees and/or conducts all of the neuropsychological testing on each and every patient who is evaluated for movement disorder DBS at the hospital. Dr. Tomarro is always consulted in each case presentation, and his opinion on the patient's cognitive abilities are central to whether or not a patient is approved for DBS surgery. If Tomarro finds that the patient meets the criteria for MCI (mild cognitive impairment), or worse (dementia or Alzheimer's), he will indicate that in the patient's chart. Once this determination is made, the most likely outcome for MCI patients is to delay the surgery and re-test cognitive abilities in six months. If cognitive impairment is worse, as in a case of dementia or a more serious condition, the surgery is unlikely to be approved at any time by this center.

I sit in the back right-hand side of the room, under the portrait of Mr. Dean, the conference room's namesake. To my left is a "telephone room," a place for doctors to duck out briefly while they take cell phone calls from their residents and other members of their clinic. Conference meetings are frequently interrupted by these calls; sometimes a neurologist who is supposed to present his or her "case" is on the phone in the back room. It seems to happen more frequently with Dr. Halter than with the other neurologists on the team.

The set-up of this room is important because its arrangement tells us something important about the differences in role and status played by those within the scene. The chart and videos of the patient have a place of ritual prominence in the center of the room, while a

neurologist off to the side "drives" the computer, whose screen is projected onto a large canvas. The patient's chart, and representations of his or her symptoms are the objects to be queried, the reality to be understood. Placing two forms of patient representation on the central screen as putative object of inquiry and interpretation might give observers the impression that the action is on screen. It is clear that the way in which symptoms are expressed in videos of patients, and the written record of neuropsychological and other forms of testing, plus the patient's medications and other "history" are important [to whom?]. The power within the room, however, is primarily held by two neurosurgeons, who sit directly opposite the screen. These surgeons have their records of success and failure on the line with each new patient. Such records are the "files" for surgeons, tallies of successful procedures and satisfied patients, useful in evaluating performance, granting tenure, securing reputation within the hospital and increasing the likelihood of future referrals. Surgeons ask—is this patient worth the risk? Since DBS can be applied in at least three areas of the brain, why this surgery, for this person, at this time?

Observing these conferences has lead me to conclude that the videos and medical record are both important, but that the stories they contain are not decisive for placing patients in one of the three disposition categories. It is the representational work done collaboratively by neurologists and surgeons that create a decisive outcome in the conference's standard, perhaps even ritualistic, form of moving patients from candidates for surgery to approval, deferral, or denial. Case conferences are thus rituals of truth as much as occasions for scientific judgment (Foucault 1995). Placing representations of patients "front and center" in the conference adds to the rhetorical work that is accomplished through

interactions between video and textual artifact, neurologists, neurosurgeons, and the psychologist. The conference is a site where rituals of truth are observed, auguries made, and future courses of action set.

The setting is also important because the location's material and symbolic resources hold important meanings for the conferencing work itself. From the sociology of science literature, in particular its ethnographic and micro-sociological branch, we know that important insights occur when we study how scientific beliefs take shape in the daily practice of scientists (Knorr-Cetina 1981; Fujimura 1987, cited in Berg 1992). These types of studies show how the shape of knowledge results from negotiations between scientists, funders, instruments, materials, etc., and that scientists are interactionally trying to establish what it means for an experiment, or a scientific practice, to "work." These negotiations take place in a "highly preconstructed reality" (Berg 1992) as Knorr-Cetina states (1983:119). In these work settings, typically laboratories, each item within the lab has been constructed from a seemingly endless array of choices, from the instruments in the lab to the chemicals used. Earlier choices enable and constrain future ones. Berg states, "the setting in which the negotiations occur pre-structures their course towards the production of a 'scientific fact'. The contingent, locally dependent character of these earlier choices implies that scientists' construction work can only be understood by referring to this situated, contextual nature" (Berg 1992: 152-3).

As with science, so too with medicine? This chapter takes the setting, material tools, as well as technical and linguistic (otherwise known as socio-technical) resources as important aspects in the specification of processes and interactions that occur within medical

case conferences. The data on the prevalence of these conferences is sparse. To my knowledge, there is no "registry" of case conferences of the type I observed at Eastwood Hospital. One might think, however, that social and epidemiological conditions are right, in this moment, for the proliferation of case conferences. This is because, first; in a tertiary medical center such as Eastwood, patient cases are, on average, more complex than might be seen in a community health center; second, the state of medical knowledge, and professional specialization, calls for patients' diseases (but not their illnesses) to be "managed" by multidisciplinary teams. It is not uncommon for a patient with diabetes to be "managed" by a nephrologist, dialysis technician/insulin pump manager, dietician, physical therapist, and/or other quasi-medical professionals. These professionals may, or may not, meet to discuss any particular patient's case. Finally, in a teaching and research institution like Eastwood, students are trained and research is conducted. These meetings allow doctor-scientists to share current research findings, demonstrate their expertise to peers, educate fellows and medical students, and forge research partnerships for future studies (and share funding and grantsmaking activities and resources).

As Berg (1998) noted, often medical data or doctors' impressions override reports from patients. But this is not always the case, and sometimes the medical data or the accuracy of an assessment of physical symptoms is called into question. Sometimes a particular patient's symptoms do not match well with the standared assessment, and especially when this is coupled with "scores" that are close to, but not within, the guidelines that the team typically uses to determine eligibility for surgery. Patients whose scores do not meet the standards face one of three outcomes. They may be denied surgery. Alternatively, their

neurologist might make a persuasive argument that the scores do not adequately reflect the patient's true quality of life deficit. The final option, and perhaps the most critical of biomedicine, is when the test upon which the score is based is challenged as inadequate to represent the patient's "true" symptoms. Sometimes, "clinical judgment" trumps technical examinations as the basis for inclusion or exclusion. "Purely" medical considerations are *not* the sole, nor even sometimes the main, criteria. The next section describes the typical sequence of events that give common form to the team's examination of patient records.

Throughput in the Conference System

The interdisciplinary movement disorders conference can be characterized as a set of information exchanges, where perspectives on the "facts" of the case are voiced and debated. Some are included in the official medical record. These exchanges occur often, but not always, in routine order. The exchanges are less liturgical in their ordering and more like freestyle ice skating: certain elements must be articulated and discussed (certain jumps attempted, artistic elements included), but these discussions may occur in any order. Members of the team, approximately 20 participants, gather one morning each month to discuss about 10 patients each time. These conferences bring together the neurologists, neurosurgeons, neuropsychologist, and a physical therapist, each of whom has a stake in the process of evaluating people for DBS surgery to treat one or more of their movement disorders.

It is a discursive, textual, and visual feast, with case discussions, images of patients both "on" and "off" their medications, as well as images of each patient's electronic medical record. Participants are asked to attend to the neurologist making case presentation, the

questions asked and answered, and the images of patients in at least two different videos. These videos are often synced together so that one can see the person undergo these tasks when their medicines are supposed to be maximally and minimally effective. Neurologists may stop during their case presentation to verbally interpret the symptoms visualized on the screen.

The tests that Ms. Steele, the physical therapist, conducts with patients are intended to assess and record several types of movement, each meant to simulate a task of daily life. For each disease, a corresponding motor test is available. For Parkinson's, it is the Unified Parkinson's disease Rating Scale (UPDRS). For Essential Tremor, it is the Washington Heights-Inswood Genetic Study of essential tremor(WHIGET), and for Dystonia, it's Twisters. Ms. Steele has been doing this a long time out of a privately run clinic, and she is in each "on" and "off" patient video, leading patients through a series of activities that are then used to measure motor function. Of course, these simulations aren't the real thing, and short of observing each patient in his or her home, it's difficult for participants to get a sense of how a patient's environment and illness interact. As sociologists know, environments enable and constrain, and with certain types of social support, people with significantly limiting illnesses such as Parkinsons may be less functionally limited than others with seemingly less significant illnesses. The images of patients might be helpful to doctors on one level, but when combined with scores, may be a somewhat misleading form of reality. What is given in standardization is then taken away in specificity and context for the particular patient under inspection. It is just this type of truth construction that the conference has as its goal.

Opening and Closing Cases

The case presentations in DBS conference differ from those profiled by Anspach (1988), in terms of both authorship and setting. Whereas Anspach conducted her ethnographic work in two neonatal intensive care units, observing a small group of residents, interns, and attendings, my setting is quite different. Largely this is because of changes over time, and the type of illnesses scholars like Anspach studied—severe, and acute. Today's case conferences, especially for interdisciplinary medical teams managing chronic and progressive illnesses seem significantly different. In these cases, the doctors assemble, and the patient is absent—literally not seen, only represented by the combination of electronic medical record, video, and occasionally, medical imaging such as MRI[21]. Indeed, previous sociolocal accounts of case conferences seems to be done at the bedside or just outside the patient's room, as doctors and trainees "round" through the wards.

Representing a patient's history is always a complex act of storytelling. Since there are usually 3-5 neurologists in the room, and at most two neurosurgeons, this work takes on the character of "presenting" a patient's history, test scores, and neuropsychological results to the surgeons and other neurologists for evaluation. With about 10 patients to discuss and evaluate for each conference, and each conference scheduled for 105 minutes (1 hr 45 min), minus introductory and concluding remarks from members of the team, each patient receives on average 10 minutes of discussion.

Most often, case presentations have standard "openings" and "closings" with analysis of the patient's neuropsychological testing and its interpretation in between. In the next three brief sections, I describe the general structure of case presentations; their openings, middles,

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21 See Renee Anspach (1988) on case presentation.

and ends. These features were discerned throughout the 17 case conferences I observed

during fieldwork. Ms. Aleander's case is representative. Following this section, I analyze

three cases in more depth to illustrate how "quality of life" discourse helps doctors retain

authority.

"Opening" a Case

In April of 2010, Dr. Philos begins her discussion of a patient with essential tremor

this way:

> Ms. Aleander is a 50 year-old woman with tremor since childhood. She is
> having difficulty with her ADLs [Activities of Daily Living]. Her neck dystonia
> does not bother her. The question here is not whether or not to do the surgery,
> but rather what type of surgery to do (fieldnotes, 4/2/2011).

Dr. Philos starts her discussion of Ms. Aleander by reviewing features of the case that

should be familiar to conference members. A few days before to each conference, one of the

surgery coordinators emails a copy of the conference agenda to members of the team.

Features on the agenda include the patient's record number, name, age, diagnosis, the names

of his or her doctors, and the dates of the patient's visits for neuropsychological and motor

symptoms testing. Outcomes of these tests are generally not widely known until each patient

is presented during conference. The agenda provides members with a sense of the "case load"

for the month, and an outline of which neurologist will present each case.

Philos highlights the long duration of Ms. Aleander's illness and her major complaint:

difficulty with ADLs. ADLs stand in for a great number of practical actions that constitute a

person's routine. The contents of Ms. Aleander's routine are left unspecified, yet taken for

granted as meaningful for her and for the team's evaluation of her candidacy for surgery. A

restriction in the ability to perform ADLs often leads to a discussion, or at least the evocation,

of "quality of life" as a key consideration in deciding whether or not a patient will be offered DBS surgery.

This particular patient's cluster of symptoms is somewhat problematic, since her condition includes neck dystonia. This complicates the doctors' decision-making and introduces the element of time ordering vis-a-vis treatment selection. Dr. Philos minimizes this problem by reporting that Ms. Aleander is not bothered by her neck dystonia. She hedges by opening the door to one or more types of surgery, yet practically insists that this particular patient is qualified to receive at least one surgical intervention.

In the next section of Ms. Aleander's time in the spotlight, Dr. Clark picks up the conversation and offers a solution to the choice between surgeries: Dr. Clark argues that we need to tackle the essential tremorfirst, then go to the dystonia after about a year. Further, he says that they usually estimate regained function as somewhere between 85 and 90%, but that in this case, they should say 60% (fieldnotes, 4/2/2011). Here, Clark narrows the conversation, making essential tremor the focal disorder, whose symptoms are subject to intervention. Taking into account Ms. Aleander's co-occurring dystonia, Clark hedges his estimate of success, lowering it between 25 and 30%. Overlapping patterns of symptoms can sometimes be reduced through DBS, as other portions of my fieldnotes show. Here, however, Clark narrows his definition of success, perhaps indicating that Dr. Philos should prepare her patient for less benefit than she might otherwise expect.

Widening the scope of the conversation, and showing his own command of the neurological landscape, Dr. Davenport suggests that many other centers are dealing with patients who show signs of both essential tremorand dystonia. Passing over this comment and

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responding to Dr. Clark, Dr. Philos responds that it is hard to capture tremor in these circumstances. Here, "capture tremor" means to relieve, or reduce, symptoms of essential tremor and dystonia using DBS.

The Middle Portion of Case Presentations

The middle of case presentations are usually marked with a "call for scores" and a brief analysis of neuropsychological testing. A member of the team, often, but not always, a neurosurgeon, calls on Ms. Steele to report on the assessment of motor functioning she conducted with the focal patient. Neurosurgeons are often "in" the chart, altering the conference notes as it goes on, keeping a minimal record of the group's discussions and findings. These reports are then used as the basis for future action, and their construction is often constrained by factors that some may consider external to patient care[22]. Someone calls for scores. Ms. Steele reports the patient's WHIGET scores, 15 on her right, 11 on her left.

The importance of scores varies across disease entity. For Parkison's Disease, this group likes to see at least a 30% difference in a patient's "on" versus "off" score[23]. For essential tremor, the standards are less specific. In part, this is due to the fact that the difference is that scores for Parkinson's patients are essentially an index of how well medications work for patients whereas essential tremorsymptoms often do not respond, even slightly, to medications. For Parkinson's patients, better medication response seems to lead to better DBS response. Since very few, if any, drugs work for essential tremorpatients, there are no "on" or "off" scores for them, and thus the WHIGET scores are simply indexes of severity. The WHIGET score goes from 0 to 25 or 26. Scores are also used in dystonia cases,

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22 Doctors are concerned about what goes into the medical record because it is the "official" story given to insurance companies for payment. The record is also audited by the FDA in certain circumstances.
23 More about these heuristics in a later case example.

but they are also less prohibitive when compared to the use of scores in Parkinson's.

In Ms. Aleander'scase, neuropschological test results did not prevent her from surgery. Neuropsychological testing did not reveal any cognitive or emotional difficulties. (Below, I review a case in which Dr. Mark Tomarro's assessment of a patient's cognitive status did play a significant role.)

Closing a Case Presentation

If a patient's scores are acceptable, (or if they have been made suspect through claimsmaking within the conference) and neuropsychological testing is "passed," the conference moves on to consider what type of surgery warranted. This can happen very quickly. In Ms. Aleander's case, once the scores are read, Dr. Clark says that they will do DBS mapping for VIM, implantation, then future planning for possible additional surgeries. Several quick moves are made here. First, the senior neurosurgeon follows up on his previous commitment to treating Ms. Aleander's essential tremoras the primary concern. Second, he outlines a technical procedure, DBS mapping, a system that combines brain images to model a person's brain in three dimensions. This program, called Atlas, helps Clark determine exactly where to place the DBS electrodes within the patient's brain. Atlas is accurate to about 1 cubic millimeter. Finally, Clark leaves the possibility of reconsidering Ms. Aleander for more interventions should she wish to be treated for the neck dystonia that Dr. Philos said was not a current concern. It is assumed that Dr. Philos will report this decision to Ms. Aleander. Now the decision has picked up both authority and power, in that it has the imprimatur of the conference, and it has the power to authorize future types of actions, including resource allocation.

Distinguishing Easy from Difficult Cases

In this section, I present and analyze three cases. The first is an "easy" case for surgery, filled, characterized by long pauses as team members reflect on the severity of Mr. Wolff's symptoms. The second is an "easy" case against surgery. Here, Mr. Fork is judged ineligible due to cognitive difficulties. The last case is most complex, and engagedmembers of the conference in an ongoing discussion of movement disorder symptoms, insurance, cognitive status, "conversion," social support, and attention-seeking. The case illustrates a key fact that emerged from my fieldwork, namely that the meanings raised by case conferences go far beyond symptom inventories and standard diagnostic categories. In cases like these, doctors venture far beyond their disciplinary toolkits, reaching into what Dr. Clark calls his "back pocket clinical gestalt" (fieldnotes, Sept. 2011) for insight into human motivation.

"Easy" Cases for and Against Surgery

Dr. Halter presents the case of Erving Wolff: "Scores are 45 and 9, Mr. Wolff is taking 33 Sinemets a day. He is an ideal candidate. He needs help." Halter leads with Wolff's scores, emphasizing that Wolff's symptoms dramatically respond to drug therapy. The unstated, but shared understanding about DBS treatment for Parkinson's disease is that response to drug therapy is a strong predictor of DBS response. Still, Dr. Clark raises a procedural issue: "He would not be able to stop taking drugs at 6 the night before surgery. When do you tell him to stop taking meds? Staged?" Tomarro reports that he is fine cognitively. With scores this high, Dr. Clark asks, "What did he do for work?" Halter says, "He is on disability now." Clark marvels, "He must fall a lot." Halter replies, "He lays down a lot. The first time (I saw him in

clinic) I almost called a code (Wolff was lying down in the exam room for relief from his symptoms). Ms. Steele says that he also reclined during his movement test. She reports: "He said, 'I couldn't take it any longer.'"

The air is heavy now as conference members pause. There is a sense of sadness as they consider this patient's case. His symptoms are so severe that it is perfectly clear the benefits he could derive from treatment with DBS. The group seems to be responding to his suffering and are keen to get this patient in for surgery as soon as possible. This sense speeds the rest of the discussion along, and the group agrees to STN stimulation bilaterally. They quickly move to the next patient (fieldnotes, 9/10/2010).

Dr. Halter has just arrived to October's conference. The team started without him, and are taking patients out of order. By the time Halter arrives, the team has discussed half of the day's patients. As Mr. Fork's medical record is called up and projected on the screen, Halter's voice booms, "I didn't get a sense of his dementia [in his clinic visit]!" Halter has read Dr. Tomarro's evaluation of his patient, Dale Fork. Both Halter and Tomarro know what the rest of the team is just learning: that Mr. Fork has failed his neuropsychological evaluation and no longer qualifies for DBS. Fork "failed" his evaluation, and Tomarro has labeled him with dementia. Hearing Halter's confession, Tomarro shoots back, "How long have you had neurotic guilt?" The conference erupts in laughter, as Tomarro has used his psychiatric expertise to make a joke at Halter's expense. To this point, the details of Mr. Fork's neuropsychological testing have not been clearly stated. Someone calls for scores, and Ms. Steele reports that they are, 42 and 15—scores that would qualify an otherwise mentally intact person with Parkinson's disease for surgery. Tomarro rounds out the picture on Dale

Fork's mental status: "Let me tell you want happened. The technician did the tests, a full battery, but he failed. Got confused. Tasks completed were very poor. He has visual hallucinations. You've got the whole shooting match here." Halter follows: "Probably should just treat him for dementia. I didn't get that sense of dementia at the bedside." He seems genuinely surprised. Dr. Clark, the senior surgeon, steps in: "We saved you from making a very expensive[24] mistake, and this is why we [the medical team] do testing."

In this brief statement, Clark provides a justification for the work of this conference—to call upon the expertise of many disciplines in piecing together a more complete, but still incomplete, picture of a patient's condition. He is also reminding Halter, and the rest of the team that they must carefully attend to their patients' mental status during clinic visits. Once Mr. Fork is given the label "demented" he is no longer considered eligible for surgery. The team may be concerned that Fork's mental status prohibits him from consenting to surgery. The team may also be concerned that a person with dementia is unlikely to be able to use the remote control to monitor and adjust his DBS implant. It could also be that doctors have determined that his quality of life would not improve significantly should he be given DBS.

These two "easy" cases follow the general format of openings, middles, and closings, as outlined above. Openings typically consist of a brief patient history, with age, years diagnosed, diagnosis and something of the patient's "social" character—job and family life. Middles include movement disorder testing results from Ms. Steele, and neuropsychological test results from Dr. Tomarro. Closings focused on discussion of these results, arguments over the meaning of symptoms, the patient's quality of life, the likelihood of benefit from

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24 DBS surgery is expensive. Although reimbursement to Eastwood hospital varies, the cost of a similar procedure for obsessive compulsive disorder, self-pay, is approximately $140,000.

DBS, and treatment site choice (where the electrodes would be placed in the patient's brain) in the case of a decision to proceed with surgery. The "easy" cases were presented once, and the "disposition" of each was handled entirely within that day's conference.

Other cases stretch over multiple case conferences. There are two primary reasons for this. The main barrier, after one "passes" movement disorder testing, is neuropsychological evaluation. Should a patient "fail" neuropsychological testing, or should questions be raised concerning the patient's mental status, then that patient will most likely be deferred for six months and asked to re-take neuropsychological testing at that time. The concern with neuropsychological testing in cases of mild cognitive impairment (MCI) (something that is quite normal in elders) is that some cognitive impairment is associated with the progression of Parkinson's disease. Experiencing (MCI) only disqualifies a deferred patient if his or her second test reveals greater cognitive impairment than the first. Tomarro often interprets these cognitive declines as associated with Parkinson's disease. Progressive cognitive decline disqualifies these patients from further consideration for DBS, a practice that can be frustrating for neurologists. These doctors sometimes comment that they could have helped these patients if only they had sought DBS treatment before the onset of (now Parkinson's-related) cognitive impairment.

A "Difficult" Case

Most meetings flow smoothly from patient to patient, neurologist to neurologist. Movement Disorder Conference notes are entered into the patient's electronic medical record, and the team reaches consensus without sharp conflict or hard feelings. Observing these meetings, I came to see how collegiality and esprit de corps infused the conference, as the

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neurologists, neurosurgeons, and other staff worked together. Occasionally, the team grappled

with cases that test the limits of their typical procedures and heuristics. Sue Ellen Twitty

represents one such case, and her case raises questions about equity, trust in patient self-

reports, and the core goals of the DBS for movement disorders treatment program at

Eastwood Hospital.

Dr. Philos presents the case of Sue Ellen Twitty, who suffers from generalized

dystonia. Philos outlines the case:

> Sue Ellen Twitty has generalized dystonia with severely limiting abdominal
> symptoms. She is the daughter of a patient from earlier today. At 36 years old,
> she has severely limiting abdominal symptoms. Very limited in ADLs, and she
> has young children. She has had no meaningful response to botox injections.
> Her scores are 37 out of 120 on the BFM. She has trouble swallowing, she
> chokes. Voice changes. She also has an insurance issue with physical therapy
> and evaluation of symptoms. She was previously referred to Washington
> University in St. Louis (but they were not able to help her).

To this point, Twitty's case seems similar to that of Ms. Aleander, above. Soon the picture

gets less clear, as the relatively simple picture of a disorder complicating daily activities for a

young mother is complicated. Dr. James Adams has been intently watching the videos from

his place at the computer. He speaks up: "I am concerned that this patient has psychosomatic

issues and is exaggerating her symptoms." Here, Adams is making the argument that Twitty's

symptoms can not possibly be as debilitating as she reports[25], given his assessment of her

video—she simply does not seem as impaired as she claims. Dr. Adams is an assistant

professor of neurology. He often runs the computer, videos and patient charts during these

meetings. He serves as a kind of hub, responding to requests from the more than 20 people

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25 I wondered if Dr. Adams has ever attempted to raise young children while suffering generalized dystonia.
Dystonia is characterized by repetitive muscle contractions that often cause jerking or twisting movements. In
Twitty's case, these movements were confined to her abdomen.

present. These requests are almost always made by a neurologist or neurosurgeon, rarely from a technician or other staff member. Dr. Adams has many of the same duties as Dr. Philos, and he also tends to give more extensive patient histories, often including some storytelling about how the patient's disease has impacted his or her quality of life. Adams exemplifies this tendency here.

Dr. Tomarro responds: "Neuropsych (the department) does not routinely do personality testing to see if someone has a conversion disorder." Without a standing order for personality testing, the team has no way to move confidently forward in the face of Dr. Adams' accusation. At this point, the question of whether or not Sue Ellen Twitty is presenting a "conversion" disorder or "genuine" symptoms is lively. With no evience at hand to help them determine what is truly dystonia and what is conversion, the group decides to require Twitty to undergo a personality test before they move forward with surgery (fieldnotes 2/5/2010).

Twitty is re-presented to conference in March. This time, the fears of a converstion disorder gain strength. Tomarro recounts his interactions with Twitty, and reports that he gave her the Minnesota Multiphasic Personality Inventory (MMPI) to complete at home. This month, Dr. Tomarro plays an active role in shaping the group's interpretation of Twitty's mental state. Tomarro and the rest of the teem seem to assume that the MMPI measures stable personality traits, an assumption that social scientists have queried in a variety of contexts (Hacking 1995; Martin 2007; Rose 1998). Tomarro reports that Twitty scored "extreme" on the defensiveness scale on the MMPI. He suggests that a neurologist present her with the idea that she is not accurately reflecting her symptoms. Tomarro says that he

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spoke with this patient and gave her lots of options, including psychiatry. He said, "She seems naïve, she's doing these things in a very transparent way. She may want the surgery so bad that she 'helps' her own symptoms by exaggerating them."

Turning from his impressions of her interpersonally, Tomarro reports that Twitty is cognitively normal, but fragile and suggestible, lacking sophistication. He seems to suggest that she is invested in her illness, what some sociologists call illness identity. Tomarro and others are concerned that her mother's success in securing DBS treatment has made Twitty overly optimistic about her chances for the therapy. It may be that her mother's experience made Eastwood her hospital of choice. All of this seems to indicate that the team is troubled by this patient and her circumstances. This is the second time conversion has been mentioned with respect to this patient. The doctors get no closer to a resolution, and decide to reconsider her case next month, after she has completed a second round of movement tests with Ms. Steele the physical therapist (fieldnotes, 3/5/2010).

Sue Ellen Twitty appeared on the agenda in April 2010 as well. Dr. Philos reviewed her story, noting that Twitty is the daughter of a current patient, and that she showed defensive responding in her personality test. Dr. Philos reports that she had a frank conversation with Twitty, and Twitty reported that her symptoms were worse, not exaggerated during the previous visit, but not this one. The newest video shows a head tilt to the left, whereas previous videos also displayed show greater impairment. Ms. Steele: "She was scored on Twisters and has trunk issues."

Dr. Philos responds, providing some "social" history: "Her mom is interesting, had writer's cramp and a double mastectomy. She had surgery April 14." Dr. Adams is still

skeptical: "Has she really had treatment without psychogenic conditions? I'm inclined to try botox again, and medicines by mouth." Adams raises the possibility that Twitty's scores, indeed her presentation of symptoms, might not be authentic. Tomarro contributes, supporting Adams' suggestion: "If we wait, we can try her on meds and get a bit more history and build a relationship. It is hard to engage her in psychiatric treatment. She does have a strong support system." Philos interjects: "The difficulty is insurance coverage. It is hard for me to treat her with botox. Right now, I can see her because she is being evaluated. She's been see at the University of Arkansas, and seen good people." Dr. Davenport asks, "Do we have permission to share these two videos with Arkansas?" Twitty's insurance status, her distance from Eastwood, and her lower-middle class status may combine in this conversation, allowing doctors to take her less seriously than some of their higher-status, professional class patients.

The conversation has once again reached a dead end. The patient's videos are not equivalent. One shows severely debilitating symptoms, while the other is much less severe. This is reflected in the scores Ms. Steele reports: On the first twisters, she scored 37. On the second, 14. Her generalized score (the BFM) is 18 for cervical dystonia.

Following this news, the neurologists and neurosurgeons hold an extended discussion about how to deal with the fact that this patient exaggerated her symptoms in the first evaluation. They seem to have decided that the severe symptoms captured in the first video were fictitious, and they are trying to now evaluate the truth value of the second video as well as the patient's orientation towards treatment. They are trying to answer a question about the reality of this patient's situation by discovering why there is so much difference between the

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two videos. An ontological question is raised here: is there any "there" there? Dr. North asks, "In the absence of a clear series of drug trials, how much do we believe our patients? If they say they don't respond, do we believe them? Generally yes. But if the group has concerns, how do we evaluate this?" He offers, "We may treat the mom and the daughter gets better." Adams interjects: "You may be treating DBS a lot like (psycho)therapy, instead of a second-line therapy for dystonia." Philos compares this patient to others: "This is an issue of equity to other patients. If they say they have no response or no meaningful response, then we implant these patients." Here, doctors have reached the murky territory at the center of conference: how to evaluate evidence when the "truth" about a patient's symptoms are not transparent to external observers. This case bedevils doctors because the disease entity and the person with the disease are unsteady. The taken for granted stability of Ms. Steele's symptom scales, and the presumed purity of patient self-reports have been shaken.

North broaches a compromise by adding new data: "I saw her" he said, "And her overlay isn't extreme now. She has mild dystonia." Tomarro agrees: "I didn't see any exaggerating of symptoms." North tries to bring the conversation to a close: "If we keep doing this, we chase our tails." Tomarro summarizes: "We saw a bit of acting, but with direction, she turned this around. She is attention-seeking, and dependent." Davenport tries to reframe Twitty's condition: "We could do a soft tissue MRI to compare cervical musculature. The non-embellishment video seems reasonable for dystonia."

With this detour under consideration, Block comments: "She had so much invested in this treatment. Her mother was all jazzed up over the visit. They view DBS as the last resort. They went to St. Louis (for DBS evaluation) maybe they've been elsewhere." Here, Block

raises the possibility of doctor shopping, without naming this as a possibility. I read Block as both sympathizing with the patient, and her mother's plight while identifying with this team in its struggle to understand the sequence of events. Dr. Black says: "To what extent do we think this treatment will help? Our success rate is lower than doctors expect. But patients are happy.[26] To what extent will this be helpful? The extent of "overlay" in dystonia patients is hard to judge. Factor in her top (more recent) video." Black continues: "We feel like ET and PD work well (that is, DBS works well for these conditions, as applied by this team). We don't have so much evidence for dystonia. So we need to collect data on dystonia." I read Dr. Black's comment as attempting to bring the focus back to the extent to which this team can ensure that DBS treatment is effective, and their ongoing attempts to both quantify and qualify the extent to which DBS will help patients increase their quality of life. Here, Black collapses the multiple tasks of the doctors and surgeons around the table: to both help *this particular patient* and to conduct research for the benefit of *future* patients and the larger evidence base upon which they seem to rest their practice.

As the conversation came to a close, Philos and North agreed to meet with Twitty one more time on the day before her mother's surgery. The goal of the meeting was to review the findings of the conference and re-present options for her to consider. As of summer 2010, Twitty had not yet received DBS from this center (fieldnotes 4/2/2010).

Fortunately, not every case has the long duration of Sue Ellen Twitty's. Nor do many cases spark the extensive discussion of authenticity in patient performances of their disease,

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26 This medical team rarely mentions the cost of the surgery directly. The major concern members of the team articulate is over insurance reimbursement, and their strategies to "make the case" that DBS treatment is medically necessary for patients whose scores do not meet standard criteria. One company in particular seems to raise the most issues. Medicare does not.

commitments to that performance, and intimations of mental illness and "overlay."

The Back Pocket Clinical Gestalt

If you ask Dr. Clark what the purpose of DBS treatment is, he will often say that it is to improve the quality of life patients enjoy. For many medical sociologists, successful treatment of a patient's symptoms is synonymous with improvements to that patient's quality of life. . Functional improvement is often the goal of people with chronic illnesses. In the face of progressive declines in health, social life and activity, regaining even small amounts of motor function can improve the quality of life for many patients. Introducing quality of life as an important standard for evaluating whether a patient should or should not qualify for surgery may be a new set of criteria that doctors in other groups and centers, use to evaluate patients for surgical and other forms of treatment.

As a general rule, this team requires a score of at least 30 on the UPDRS scale for Parkinson's patients to qualify for DBS. That score has its origins in insurance companies, not from a clinical trial, or even consensus among neurologists and neurosurgeons. Its origin was raised in a February 2011 conference, in the context of considering Dee Carter who recently underwent knee replacement. Her score was a 26. Dr. North asked, "Do we buy 30 as the cut-off? I know insurance likes 30, but have we adopted it?" Ms. Steele had just mentioned that this particular patient was teary during her testing, saying that she really wanted surgery[27]. Philos responds to North, saying, "I think we have in general." Halter

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27 By most definitions, DBS is an "elective" procedure (although many of my patient respondents strongly argued that there was nothing voluntary about seeking DBS treatment—it was, for them, absolutely necessary). Since it is not curative, and not yet the standard of care for all Parkinson's, Essential Tremor, and Dystonia patients, DBS remains an option. As with many procedures in today's US healthcare system, "elective" procedures are not always approved by insurance companies. Since most patients cannot afford the $140,000 surgery, the team is focused on ensuring that their work will be compensated.

confirms: "We've basically said 30." In resolving this dilemma, the doctors craft a work-around that they hope will give this patient's symptoms the chance to become, ironically, more debilitating. Philos raises the possibility of waiting six months and re-testing this patient. Halter agrees, saying, "We can always say that she needs to recover from knee surgery." This shifts the justification for delay from what doctors might consider an untenable reason (adopting an arbitrary cut-off based on insurance company reimbursements) to a medical one, the need for orthopedic rehabilitation.

In Ms. Carter's case, we saw how quantification of symptoms may not capture the patient's perspective, or her desire, for DBS treatment. In other cases, doctors' judgments concerning quality of life provided the needed justification when the score was closer to 30. Dr. Black presented a case where a person with Parkinson's disease scored a 29 on the UPDRS scale. He reviewed her case—terrible wearing off dystonia[28], taking levodopa every 2-3 hours. In this case, Dr. North said it was reasonable to approve GPi stimulation. In an uncharacteristic move, Block intervened, saying, "There is a 10% chance that Blue Cross Blue Shield might balk at a score of 29 (it is too low)." Tomarro jests, "How about rounding up?" [laughter throughout the room]. More seriously, Block suggests, "It would be ideal if this could be noted in the conference note." He is speaking of the doctors' opinion that this patent's "true" score was at least 30. Dr. Clark emphasizes their judgment: "We are *sure* her off is over 30." When a neurologist's presentation of a patient's symptoms and that patient's scores on a standardized symptom inventory do not match, some important rhetorical and

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28 "Wearing off" refers to the cycle of symptom reduction and re-emergence that characterizes drug treatment for patients with Parkinson's disease. Symptoms re-emerge as drug effects "wear off" before a patient's next dose of medication is taken. Patients must be careful not to take too many medications, due to side effects that mimic Parkinsonian symptoms, and the drug's destructive effects on the dopamine system within the brain.

perhaps ontological work is undertaken in order to fit the patient into the "surgery" category. In another context, Steve Woolgar and Dorothy Pawluch (1985) call this kind of work "ontological gerrymandering." I think that ontological gerrymandering is the major work produced by the conference. When doctors construct quality of life arguments, they gerrymander patients from category to category. My fieldnotes include instances of diagnoses contested, movement tests questioned, each a gerrymandering strategy. These gerrymanders move patient outcomes from one category to another, shifting the grounds of decision-making from "official" measures and diagnoses to what Dr. Clark called the back pocket clinical gestalt.

The back pocket clinical gestalt helps neurologists and neurosurgeons retain their authority within the routinized practices that lead patients to conference. Patients can be shifted towards surgery when doctors make, support, and secure consensus around a patient's "true" symptoms, and their effect on that patient's quality of life. These arguments are often made by discounting certain aspects of the videotaped evidence, or reflecting on impressions made during consultation with patients, the "clinical gestalt" that doctors get when interacting and creating a shared reality with patients. To take the scores at face value, to understand them as determining patient outcomes is to miss the key construction of truth that is formed when technical expertise, clinical experience, and past practices come together. Practices such as "following the scores" have a logic that pushes doctors towards pre-determined outcomes, sets of heuristic decision rules that are often followed in the typical, and easiest, cases. Doctors make their most significant contributions to a patient's course of treatment when they deviate from these ready-made bins, questioning other professionals'

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assessments (movement testing was the most frequent target). Questioning Ms. Steele's standard symptom inventories allowed higher-status neurologists and neurosurgeons to retain some decision making capacity outside the heuristics. When her work was challenged in this way, Steele referred to the test as standardized and inflexible. She would often agree that this or that test was not intended to quantify every symptom that this or that patient experienced.

In a 1992 study of medical disposals, Berg found that historical and examination data are not pre-existing facts that the doctor needs to reveal, contrary to previous studies that ruled out social sciences approaches to understanding and explaining medical knowledge. The history of medical sociology is replete with scholarship that did not question doctors' judgment or question how doctors came to diagnoses, courses of treatment, or other "scientific" aspects of medical practice. This work has often been reduced to critiques of functionalist medical sociology, usually criticizing scholars such as Parsons (1951). In contrast to this tradition, Berg explains that medical criteria and disposal options are not scientific and fixed "givens" (1992:155). Berg describes how doctors up- or downgrade accounts of patients in case conferences: "[during case]... meetings the weight of data can be up- or downgraded by referring to e.g. the patient's story as 'typical' or 'classical' or, respectively, 'atypical' or 'incoherent.' Equally, the weight of examination data can be modified by referring to the excellent or poor quality of the performer of the examination, the worth of the examination technique, etc." (1992:159).

What Berg saw, and what I often witnessed in the medical team meetings, is the differential valuing of lay and medical knowledge at different times and under different conditions. As Berg (1998) noted, often medical data or doctors' impressions override reports

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from patients. But this is not always the case, and sometimes the medical data or the accuracy of an assessment of physical symptoms is called into question.

Conclusion

This chapter focused on the work conducted during a series of Movement Disorder Conference meetings. At these monthly gatherings, approximately 20 medical professionals, support staff members, and trainees met to determine which patients would be offered DBS, denied the procedure, or placed on the "waiting list" and deferred six months. Here, I outlined the major components of the ethnographic scene, and focused on the conference as a case-making venue. Second, I described the forms of representation used by the team in their work. These are the processes through which patient profiles, complaints, and factors the team label "social" are condensed into a plan of action (or inaction). Third, I described and discussed the ways in which surgeons and neurologists work together to maintain and enhance their authority in determining these plans of action through selective and partial readings of "quality of life" for their patients.

Using this ethnographic and participant observation data, I showed how representational practices work through the presentation and analysis of three cases: one "easy" case that quickly led doctors to offer surgery, one "easy" case that ultimately resulted in the patient being denied surgery, and finally one "difficult" case that called on doctors to do a significant amount of work in determining a patient's suitability for DBS. Through this comparison, we get a nuanced and rich picture of deliberative processes in an age of evidence-based medicine. We also are given access to the ways in which doctors occasionally use privileged knowledge and clinical experience (the "back pocket clinical gestalt") to

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override the "evidence" of standard movement disorder tests. These knowledge practices enable them to retain their authority in offering or denying patients surgery. I also discussed previous research that connects my ethnographic findings to medical disposals in general, and examined the discursive strategies doctors use when weighing their own forms of knowledge over and against their patients' embodied knowledge of movement disorder symptoms and their impact on quality of life. This chapter demonstrates the social and biomedical processes that construct eligibility for treatment with DBS implants for movement disorders. Once patients have qualified for DBS surgery, they are one step closer to developing a relationship with their implant. As I will demonstrate, this relationship is often characterized by implant transparency.

CHAPTER II

REVISIONS: PROBLEM RECOGNITION AND ORIENTATIONS TOWARD ACTION

The nurse said Dean's surgery went perfectly. He left the Portland, Oregon hospital with high hopes for this, his third open-head surgery to reduce the symptoms of Parkinson's Disease. Dean understood that adjustments to the DBS were normal and that it could take up to a year for his neurologist to determine just which settings produced the greatest symptom relief with the fewest unwanted effects. After the first appointment, Dean writes, "I was flirting with disappointment when I left… because my voice had started to weaken and swallowing felt strange. But I kept the faith my body would adjust" (Crumpacker 2009:2). His body did not adjust. Each month, Dean returned to be "re-programmed" by his neurologist. Each adjustment brought benefits lasting just a few days. Dean's voice became nearly inaudible and he had difficulty swallowing. His doctors referred Dean to a speech therapist.

While Dean struggled to speak audibly and swallow, his left side progressively lost strength. Then, Dean began losing dexterity in his left hand and arm. That arm hung from his shoulder, mostly useless. Dean's symptoms, he reports, seemed to be accelerating at a rapid pace.

Dean's doctors were concerned that the DBS device was not working for him. Yet his tremors increased when the DBS was turned off, so the device must have been providing some treatment benefits. Dean returned to his neurologist every month, hoping for an adjustment that would eliminate his difficulties in speech, swallowing, and the use of his left arm. Eventually Dean was told that the programming specialist had achieved "optimum" settings, and that no further improvement could be made.

Dean still experienced nearly inaudible speech. Eating and drinking were both uncomfortable and dangerous, since his swallowing reflex was unreliable. Dean's left hand and arm were practically worthless. Confined to a wheelchair, his left side was so weak that someone else had to push him from place to place. These troubles left Dean exhausted both mentally and physically, and he questioned the doctors, searching for another treatment, anything to reduce or eliminate his many problems.

His doctor eventually sat Dean down and told him that he needed, " to face the fact that I had advanced Parkinson's and learn to live with it" (Crumpacker 2009:2). At this point in his illness career, Dean's three surgeries had left him in a condition he describes as, "more debilitated than I'd been before the surgery" (Crumpacker 2009:2).

During this time, Dean's sister was at work on the Internet, researching DBS surgery results and searching for options. She found a licensed DBS programmer in Washington State, and encouraged Dean to make an appointment. That DBS programmer, Sierra Farris, scheduled Dean for a three-day series, testing Dean's symptoms, his DBS system, and ordering a CT

scan. Farris and the center's medical director checked Dean's DBS settings and noted when increased stimulation brought unwanted treatment effects.

The CT scan showed that the device was intact, but in the wrong spot. Dean reports that Farris said, "If you have to turn the settings up to a point that you experience debilitating side-effects, the probes are not in the target area" (Crumpacker 2009:4). And so it was: Dean's symptoms were not signs of progressing Parkinson's disease, but rather unnecessary side effects of the DBS itself. After more tests by speech therapists, occupational therapists, and a speech and language pathologist, Farris and the rest of the team sent his medical records to a surgeon at the University of Washington for an evaluation.

That Washington neurosurgeon suggested that Dean undergo surgery "revision." The CT scan revealed that the electrode on the right side of Dean's brain was not positioned correctly and would need to be removed and replaced with another, this time in the proper location. This neurosurgeon, Dr. Hebb, felt strongly that Dean's condition could be improved.

The surgery involved removing some of Dean's existing wires, his implantable generator, and the misplaced electrode, and replacing them with new hardware. The effects of these changes were almost immediate, with improvement in Dean's voice and swallowing. His left arm function returned within the next two weeks. After a month spent healing and resting from the stress of brain surgery on his brain, Dean returned to Farris, the DBS programmer for another round of adjustments. This time, the electrodes were better positioned, and Farris was able to find settings that calmed Dean's tremor and eliminated the speech and swallowing problems[29].

Other patients experience unwanted treatment effects, or display unusual behavior without requiring surgical intervention and surgery "revision." Whatever problems they experience after surgery can either be resolved, or accommodated with less intense interventions such as re-programming the DBS device or altering medications and their dosages. For example, when Brent Peterson, former associate coach with the National Hockey League franchise in Nashville, TN, finished his series of DBS surgeries, the effects were remarkable. Peterson jumped on a treadmill the day after his implant was turned on and adjusted. He was said to be full of energy (Cooper 2012). His symptoms changed, but so did

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[29] The names of doctors and the names patients give themselves in published newspaper reports and online forums discussed in this chapter are unchanged, as is the grammar and spelling of their postings. Mr. Crumpacker's story is adapted and shortened for presentation here.

his affect:

> The electrodes caused him to become overly emotional. He said he would cry watching a football team score a touchdown. Or he would laugh at a joke that wasn't funny. He also went on a spending spree, including buying a $3,000 necklace for his wife… 'I was crazy. I emptied out our checking account' Peterson said. 'It was too much energy in my head' (Cooper 2012).

After some investigation, neurologists determined that Peterson's stimulation levels could be adjusted, and the overactive emotions and excessive spending stopped. Even with these improvements, Peterson still struggles with his balance, cannot skate, and fears falling. He still takes Parkinson's medication daily, although fewer pills today than before DBS.

The previous chapter welcomed the reader into the world of neurologists, neurosurgeons, and others as they work together to shape patient stories and symptoms while creating eligibility for DBS surgery. Becoming eligible is just one of many steps in the trajectory from diagnosis through surgery and eventual, if temporary, outcome(s) for patients. As we will see in the chapters that follow, patients who chose surgery at Eastwood spoke highly of their surgical team and often described their surgery as a "success." Despite this, several patients expressed concerns over new symptoms, symptoms that were not treated by the surgery, and symptoms not resolved by adjustments to the power or frequency of stimulation.

Doshi (2011), using Medtronic data, reported that over 75,000 DBS procedures have been performed worldwide for various indications. Like many surgeries, DBS treatment carries risk. Known complications from the surgery include intracranial hemorrhage, seizure, confusion, dysarthria, lead migration, lead breakage and system infection (Bhatia, Sanjay, Oh, Angle, and Whiting 2010). This chapter recounts several occasions in which this team re-

examined the results of past surgeries performed at Eastwood and other hospitals. This was a rare occurrence at Eastwood. Although I observed thirty case conferences, only a handful of "revision" cases surfaced during that time. Often, these revision cases were patients dissatisfied with the effects of surgeries performed at other treatment centers. Patients returning to Eastwood after surgeries conducted by Dr. North or Dr. Clark were less common. One reason for this could be that neurologists on this team were well versed in the art of adjusting stimulation levels so that patients who did experience problems were never seen in conference. Another reason could be that neurologists and neurosurgeons *expect* implant programming to take about a year of monitoring and adjustment in order for any particular patient to receive optimal benefit from the device. Finally, it might be the case that certain patients do not return to this center for follow-up or regular DBS programming, and are thus "lost to follow-up" from this program. It was often the case that Eastwood would handle the evaluation of DBS candidates, surgery, and initial programming, while the patient's referring neurologist, or another center, would conduct follow-up programming.

In order to more fully understand the range of DBS patient experiences, I also conducted a targeted search of popular Internet message boards and public web forums and web logs ("blogs") to increase the number and variety of patient stories I present in this chapter. Many such message boards exist, and I chose to focus on the most popular outlets, including sites such as HealthUnlocked.com, neurotalk.psychcentral.com, and forum.parkinson.org.

While many patients' stories of DBS and their thoughts about symptoms that persist, or appear, after the treatment are relatively well developed, others must be pieced together

over time, as messages on Internet message boards build and contributors elaborate. Some

cautionary tales about DBS are second-hand, while others are barely sketched. For example,

in a thread titled "DBS – would you do it again?" DJM1, a member at

neurotalk.psychcentral.com reported that a friend had extraordinarily bad results:

> She has had frequent problems with her DBS ever since she had the first surgery 9 years ago. I can't tell you what all has happened to her over the years, but I can say that within the past year, she developed an infection that resulted in her DBS system having to be removed. The PD symptoms held at bay by the DBS came flooding back only now she's 9 years further along in the progression of the disease! She is trying to be patient as she waits for to have the DBS done yet again. This is someone who has had many, many problems with the system while it was working yet still finds the less than stellar response she has to it better than her state of advanced PD without it. It's a Quality of Life issue where, for her, the QOL though flawed with DBS is far superior than without it. (2/26/2012, http://neurotalk.psychcentral.com/thread164119-3.html)

Just as people with Parkinson's and other movement disorders become "cases" inside

the DBS conference, people whose DBS treatment effects cause, or are thought to cause,

problems also become cases. Their situations become problems the team agrees to discuss.

Conversations about surgery revision at Eastwood generally occurred as the result of troubles

patients experienced with their implant, troubles whose origin was often unclear when the

patient initiated contact with the medical team. The issue seemed to be determining whether

the set of troubles were caused by the "natural course" of the patient's illness, difficulty with

the implant's settings, the location(s) of implanted electrodes, or perhaps trouble with

medications and dosing. Neurologists' efforts to reprogram and reconfigure the DBS' settings

were not always successful. Even if the DBS electrodes were sited incorrectly, the team was

asked to determine whether or not the unwanted treatment effects patients experienced were

severe enough to warrant a second surgery. Like Dean, many of these patients underwent

"revision" surgeries.

The movement disorders team worked potential revision cases into their regular monthly meetings, effectively making their "cases" no more or less significant than any new or returning patient. Prominent research in medical sociology has shown that certain aspects of medical practice, such as morbidity and mortality conferences (Bosk 2003) are sites for the policing of locally established, socially constructed moral boundaries for trainees. Observing practicing neurologists and neurosurgeons well into their careers gave me the opportunity to understand the many ways attributions of "cause" were developed and deployed. Each opportunity to discuss revising the position of electrodes, or remove and replace DBS hardware, was de facto an opportunity to investigate a type of wrongdoing and apportion responsibility. In some cases, this responsibility was not threatening to the team (as they had not conducted the original surgery). In other cases, the team worked together to mitigate the potential harm to personal and surgical reputations. This next section describes several revision cases and how the team managed the potential for negative moral judgment from their in-room peers.

Management of DBS Failures in the Medical Literature

Neurosurgeons, neurologists, and others have investigated in incidence of suboptimal results from DBS surgery. An early study on the incidence of complications during and after DBS surgery from one treatment center found that 6% of the 86 patients whose cases were analyzed developed persistent neurological problems (Beric et al. 2001). Although this may seem low, these authors report that the incidence of adverse effects, "in our experience is higher than that reported for thalamotomy and pallidotomy" (2001:77). Twenty-six of the 86

patients who received DBS implants in this study experienced some unwelcome event. Altogether, these authors report a serious complication rate of 21% among their 86 patients, and among 12% of the 149 electrodes implanted (Beric et al. 2001).

A more recent, two-center study on the management of suboptimal results from 41 DBS surgery patients with movement disorders reported the cause of complications and efforts to improve treatment effects from DBS and medications (Okun, Tagliati, Purfar, Fernandez, Rodriguez, Alterman and Foote 2005). Of the patients evaluated, 46% had misplaced electrodes; 17% had no access, or poor access to programming; 20% required local follow-up and 37% of patients held DBS devices that were inadequately programmed. Over 70% of patient required movement disorder medication changes (Okun et al. 2005:1251-2). Of these 41 patients, 51% had "good" outcomes with medical or surgical management, while another 15% showed modest clinical improvement. The remaining 34% "failed to improve" (Okun et al. 2005:1252). Okun and colleagues recommend improvements in triage, screening, operative procedure, follow-up programming and medication changes in order to eliminate the need for expensive and time consuming revision and reprogramming.

A study of hardware failure and infections over eleven years from a single center (Bhatia et al. 2010) reports an infection rate of 9.3% (25 of 270 patients). Nearly all infections occurred within a year of implantation (Bhatia et al. 2010). Calling infectious complications:

> some of the most serious and difficult to manage… Infection is a serious and frustrating complication that can lead to long-term intravenous antibiotic administration, multiple hospitalizations, multiple surgeries and, often, removal of the hardware and loss of benefit of stimulation, not to mention increased economic consequences (Bhatia et al. 2010:147).

In addition to their analysis of infection incidence, these authors analyzed infection rates over time. Finding that infection rates declined, the authors suggest that improved technology, and improved surgical practice, account for declining infection rates.

These authors also analyzed their ability to "save" DBS hardware despite infection. Less than 50% of patients with infections in this study had their DBS hardware completely removed. Just over 30% all patients with infections kept all their DBS hardware, and another 21% kept part of it (Bhatia et al. 2010:152).

Finally, a recent study of long-term surgical and hardware complications from DBS surgery performed by a single surgeon (Doshi 2011). This study of 153 patient cases and 298 electrode placements revealed a complication rate of 15.6%. Overall, 4.5% of patients experienced either lead erosion or infection at this center compared to a range of 1 to 8.3% in reviewed studies (Doshi 2011:93). This study concludes that DBS is a relatively safe surgical procedure.

A Typology of Treatment Effects

In order to deal analytically with the complex web of causes and consequences borne by DBS patients and made objects of inquiry by their doctors, I created a typology of treatment effects. Here, I bring together both wanted and unwanted (commonly called "side") effects of surgical and medical treatment. Taking a closer look at the connection between symptom visibility and implant transparency helps us understand the pathways DBS recipients might take from "successful" treatment to surgical revision and device manipulation. Table 1 illustrates the relevant categories.

Table 1: Typology of Treatment Effects by Implant Transparency and Symptom (In)Visibility

		Transparency of implant from the perspective of the patient	
		Low	High
Visibility of movement symptoms from the perspective of the patient	Low	DBS treatment effects that generally alter behavior, not motor symptoms	DBS and medication work together in an ideal way
	High	Problems with the implant that exacerbate motor symptoms	DBS works as well as possible, but symptoms remain bothersome

Low Transparency, Low Visibility Cases

      Cases in this category feature unwanted treatment effects that do not mimic the traditional symptoms of the target movement disorder. Unwanted or unusual behaviors, including excessive spending, excessive laughter or crying, and other uncharacteristic behaviors fall into this category. Here, movement disorder symptoms have diminished, or are practically non-existent. Because movement disorder symptoms are relatively quiet, symptom visibility is low. These effects often indicate to patients that there is something amiss with their otherwise high-performing DBS device. Some DBS recipients may, for a time, enjoy these unintended effects, as when recipients experience heightened mood and more expressive behaviors. However, these effects are understood to be "out of character" for the patient, and therefore problematic. Other cases that fall into this category are generally the result of infection or other complications resulting from surgery. Patients can experience repeated and severe infections, often requiring invasive and continuous treatment with antibiotics. In severe cases, all DBS components must be removed from the patient's body.

I place cases like Brent Peterson's in cell one, low implant transparency and low visibility of movement symptoms. For Peterson, the often stigmatizing and embarrassing movement symptoms of PD were replaced by unwelcome, manic behaviors. Visibility of his movement disorder symptoms declined, and he was able to continue many, if not all, of his previous activities. The transparency of his implant, on the other hand, was low. Because manic behaviors were not a well-known part of Peterson's life before DBS, or before PD, his free spending was considered a sign that something was wrong with his device. After some investigation, Peterson's doctors determined that the settings on his device were causing the problem, and new settings alleviated his "manic" behavior.

Early in my observations, a case for revision was made at the close of the meeting. Although his case was not on the pre-circulated agenda, his situation was dramatic enough to break the team's routine. A 60-year-old male had developed what team members described as "hypersexual" behaviors after implantation. Currently described as manic, he had cancelled his last two appointments with Eastwood neurologists and has reportedly stopped taking all medications. Although his surgeon and neurologist described his surgery as 'a runaway success' these symptoms are said to be beyond his personality—he was not hypersexual or inappropriately focused on sexual behavior before implantation. His neurologist reported that family members complained that he had spent well beyond his financial means and had taken to mowing lawns at 3:00 a.m. I was not able to record dialogue from this case, as the discussion was short and moved from description to decision in a very short time. Like Peterson, this man's symptoms made his implant highly salient. Alterations to the DBS' settings were unsuccessful, and the team scheduled him for revision of his lead placement at

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the first available moment.

For some DBS patients, revision surgeries are the result of problems endemic to surgery: infection. Despite antiseptic and aseptic operating rooms, aftercare from the surgery can be uneven, the potential for infection present at all times. In this situation, patients whose devices are working well (and thus are most often transparent) and whose symptoms are well controlled (thus their visibility is low) are nonetheless subject to revision due to infection. HealthUnlocked.com member NoStringsAussie presented his story on the Parkinson's Movement site[30]:

> *in late 2010… I was short tracked for the DBS in-plant. Then in April 2011… DBS* in plant. Amazing results. Initially there was euphoria as it appeared to fix everything,then stability around Oct. I was back to fulltime work in June 2011 and killing it. By Nov. 2011, the DBS doc's said I had a non-healing wound but I felt great. By Jan 18th 2012, they made the decision to go in and revise the incision and found a sub-cranial infection at the same time. The left side… was removed during the revision surgery on 18th of Jan 2012. I have been without DBS since then and back to relying on meds.
>
> I don't tolerate the meds well but they work. On the other hand the DBS is a miracle. I was so lucky to have a great response to surgery. … on April 10 2012… I am getting my left side DBS put back in! I just can't wait. I certainly appreciated the DBS last time around but it took a while to not take advantage of having the clock wound back 20 years. … We are much stronger today as a family because of DBS. Facing the 3rd surgery doesn't seem so intimidating (2012).

While NoStringsAussie stresses his appreciation for the DBS' treatment effects, his story reminds us that treatment experiences with DBS are often dynamic, with unforeseen events and subtle, developing issues resulting in chronic problems that require intensive intervention. A treatment experience that began in category three slowly developed problematic features, turning it into a category one situation. Once his DBS was removed, we could re-categorize his situation as category two, in which the low transparency of his

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30 I have kept all original grammar and spelling in this and all other quotations from the Internet.

implant (in this case, the fact that not having the benefits of a well-functioning implant) and the high visibility of his movement disorder symptoms without the device. Although drug therapy remains an option for him, unstated reasons prevent their use over the long term.

This patient's experience with infection also occurred for at least one patient at Eastwood. Betty Seaver, 70, a white woman on Medicare and Medicaid of Tennessee, developed an infection after the leads connecting her implanted generator to the deeply seated electrodes eroded after just two years. This brought the Eastwood team into a discussion of post-operative wound care and the need to reduce infection rates among their patients. The decision to remove the useless electrodes and replace them was made quickly. After her DBS hardware was removed in the fall of 2009, her wounds were cleaned. In January of 2010, Seaver went back into the operating room to receive new hardware, electrodes and leads.

Some national, non-profit research and education organizations have created space on their websites for patient dialogue and support. The National Parkinson Foundation hosts an "Ask the Surgical Team" forum for current and prospective DBS patients. Patients are thus allowed access to some of the most highly ranked doctors without an appointment. On this forum, Dr. Okun[31], a University of Florida neurologist and National Medical Director of the National Parkinson Foundation, answers most surgical questions. In October 2010, Sewgood750[32] brought his or her case to the forum:

> I was diagnosed with Parkinson and put on sinemet in August of 2000 at the age of 57.

31Dr. Okun and his collaborator Dr. Foote presented their work with DBS patients at a TEDx event at the University of Florida. A video of their presentation can be found here: http://mdc.mbi.ufl.edu/research/tedx-talk-on-deep-brain-stimulation-by-dr-michael-okun-and-dr-kelly-foote
32 Format in the original.

- February 2008. Stimulator and generator was placed on my left side.
- Sept 2008 DBS placed on right side
- March 27, 2009 removed all hardware on my right side due to a skin infection and wire exposed
- Feb 15, 2010 replaced stimulator on my right side
- March 22, 2010 developed an external fluid leak at incision under cap of stimulator site, Either Spinal fluid or Serous Fluid, surgery for wound Repair
- April 6, 2010 Developed leak again and had stitches from March 22 surgery removed by surgeon and replaced with 6 stitches (In Doctor office without benefit of numbing)
- April 21, 2010 developed another lead; surgery required, removed stimulator and was told by one doctor I had a Infection under cap and exposed wire by another surgeon. The generator was not removed.

…

The generator and wires up the back of my neck has not been removed from the right side. I still have a problem with the spinal fluid leaking under the skin on the right side. Should I be concerned about either of these issues? Will the leaking ever stop? What do I do now.

In light of Sewgood750's extensive account, Dr. Okun recommends:

… Sitting with your neurologist and neurosurgeon and discussing how much the DBS has helped and whether the devices are well placed and whether a revision of placement or improving programming can help. When devices are well placed they usually provide excellent benefit in well-selected patients. If hardware continues to be the issue, another option may be subthalamotomy, or making lesions through 'well-placed' DBS leads.
I would also recommend also potentially seeking a second fresh opinion just to be sure you have all the options on the table. As for leaking and other hardware issues, usually they can be treated or addressed in person by an expert team. ("Ask the Surgical Team", 26-28 October 2010).

Like Betty Seaver, Sewgood750's situation involved an unwelcome effect of surgery:

infection and a complication with an exposed DBS wire. Like her, this person's trajectory

through DBS treatment resulted in the removal of leads and generator on the right side of the

body once, the leads on the right removed twice, and an ongoing spinal fluid leak. This

patient's treatment experience foregrounds the problems that people with implanted medical

devices can have even when their surgeries are "successful" and DBS treatment results in

some significant symptom relief. It is the implant itself that has become problematic, apart from its effects in reducing movement disorder symptoms. Although leaking spinal fluid seems to be this person's main concern, Okun addresses this last. His first suggestion is an open, honest discussion with this person's current doctors that both describes the patient's experience with the DBS. This conversation, Okun suggests, will help to clarify the status of leads, and determine if they are indeed ideally placed. This statement links the concern about leaking spinal fluid to lead placement—a somewhat odd connection, given that a leak from the skull would not occur from the location of a lead, but from the site where the burr hole was drilled that allowed access to the electrode's destination in the first place. The brain, remember, is cushioned within the skull by spinal fluid. In other words, placement of the lead and its pathway to placement are different. After approaching the topic of revision, Okun then turns to other surgical options and the idea of pursuing a second opinion with an "expert" team.

Given the chronic nature of DBS treatment, patient trajectories through the typology I have outlined can vary quite dramatically. Consider the cases of Bill Heiser of Longwood, Florida and a man who calls himself Lightning94 on the HealthUnlocked.com "Parkinson's Movement" website. Heiser corresponded with Dr. Okun through the National Parkinson Foundation's website. He wrote:

> I just read in the article in the Washinton Post that some of the side effects of DBS are slurred speech and falling. Im on my second go round as the first time an infection set in and the surgeon went in three times to clean and apply anti-bioctics. The fourth time he pulled everything out. Because he trimmed the skin each time I had to little skin to close good and two weeks ago I had a plastic surgeon redo the area. Have your tuning experts been able to get rid of the falling problems? Because this time I have both slurred speech and falling issues. I was supposed to see you this comimg Monday or Tuesday but because of the

new wound I put off until August.

Okun responds:

> Slurred speech and falling are very difficult to treat using DBS.
>
> They can be side effects of the DBS surgery itself meaning if they don't change when you turn the device on or off they may be permanent. The most common issue that this occurs after DBS is verbal fluency (getting words out of the mouth). Other common issues after DBS are slurred speech and soft speech.
>
> If it gets better when off DBS, then sometimes it can be re-programmed, but often it cannot (reprogramming strategies may be using bipolar configurations, turning one side off or reducing pulse width (as examples).
>
> Falling is very hard to treat with DBS. Usually falling occurs as a result of disease progression. Occasionally the DBS is placed in a region important to motor function (e.g. the internal capsule) and moving the lead or reprogramming may help. Falling also may occur as a result of over-aggressive reduction in medications.
>
> These are complex issues and can be hard to treat, as they may occur just from disease progression.
>
> Hope that helps.

From there, Bill picks up the conversation:

> Thank you Dr. Okun, last week my wound opened again after a plastic surgeon supossedly repaired it. So it was two days wide open, I kept it covered and it only developed a mild infection which infectious diesease doc is monitoring. I have picc line and recieve one bag of antibioctics daily. Dr. Razack is the surgeon and he is thinking that unless the skin is replaced in that area on my head, it might not seal again, and then there is the fact that this is the second one that been put in. The first one developed an infection imediately, and everything was pulled after 3 months. Waited until Jan of this year and tryed to reimplant and Dr. Razack used two battery units just incase. Well they took out the left side (which was the infected side the first time). When I woke up in post op my speech was almost 100% better and once I took a pill and it kicked in my walking was approx 90% better. I still have appt. with you set for August 6. I will fill you in on all all I've been through with this. At present with out meds adjusted to compansate for missing unit I am talking normal and walking with no walker or cane and no falling just like before 2nd DBS. I will give you my email just in case you only want to respond to me. Thank you and looking forward to

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seeing you in August . I' m in no hurry to put unit back in head (battery pack
still in chest) because my head on that side has been opened up 10 times in
 past 18 months. Hopfully your tuners can make best out of what I have.

Thank you
Bill Heiser
(April 16, 2012: http://forum.parkinson.org/index.php?/topic/12623-ted-talk-
on-deep-brain-stimulation-dbs-for-parkinsons-and-other-neuropsychiatric-
disorders/)

In August of 2011, Lightning94 responded to a question from a new DBS recipient

who had called for stories of post-DBS life. He recalled:

Yes I had bilateral DBS surgery last December.. Everything went very smooth
during the operation and the first tuning session. Everyone was very pleased.
Then on about the third week an infection became apparent and the surgeon put
me on some very strong antibiotics orally. The infection didn't get any better but
it didn't get worse either/ So he put on a total of 4 weeks of antibiotics and we
waited. In the meantime I gad a total of 3 tuning sessions and had dropped from
a total of about 2100 mg of carbadopa down to 675mg. I could get up and walk
the minute I woke up. It was totally amazing. However the oral antibiotics didn't
get rid of the infection so everything came out and I was put on 24/7 IV
antibiotics. Fortunately, this knocked it out. I'm coming up on 6 months and the
doc said that should be enough time for any swelling to go down and everything
to heal properly. He placed it right on the money the fist time, I hope he can do
again this second time.
(August 21, 2011 http://parkinsonsmovement.healthunlocked.com/blogs/41841/
Deep-Brain-Stimlation-DBS)

Although he does not clearly state this, Lightning94 had his first, bilateral DBS removed

after developing an infection (as he notes, below). On the cusp of his second DBS surgery,

Lightning94 expressed optimism about the potential for a new DBS implant, with the hope of

avoiding future infections. By July of 2012, his trajectory had changed again:

… I have had my 2nd DBS, the first worked perfectly, however I developed
on infection in my left side brain leads. Long story short, they (docs) pulled
everything. I had bi-lateral with one battery. 10 months later they put everything
back in with two batteries. As soon as tuner turned it on my speech went to
sounding as if I were drunk and I tried to move every wall in the house by falling

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into them. Because the 1st time th edoc went into that one side too clean the infection my skin will no longer heal. So they sent me to a plastic surgeon, and he didn'tdo anything to help. The wound opened up again(you could see the mice running around in there) and my doc said its been compromised and pulled the left brain lead. I woke up in post-op and could speak normally and once my meds kicked in I could walk normal. Now I had dropped a lot of meds, but my life my life sucked. The docs have no explaination but they say it is doubtful. They will able to put another unit back in there. I would never go through this again (now this is just my case, I've heard many wonderful endings with DBS)
(July 7, 2012 http://parkinsonsmovement.healthunlocked.com/blogs/353969/post-dbs#354605).

Both Bill Heiser and Lightning94's movement disorder symptoms were well controlled with DBS implants. It was an unexpected consequence of surgery, and the particular way that his surgeon approached opening his skin, that led to their situation. From two leads to no leads, then re-implantation ten months later and a second infection that cost him his left lead, Lightning94's case has transitioned from category one to arguably category two, low transparency and high visibility. Unfortunately, symptoms on his right side can no longer be controlled by the DBS, and he must rely on medications. Even after employing a plastic surgeon and attempting to cover the offending incision, this patient has rejected further DBS treatment beyond his existing, right-brain implant and generator. His speech problems went away when the second (perhaps misplaced?) lead was removed and his medications were effective.

Both Bill and Lightning94 sought treatment for problems, like falling, that are not generally well controlled by DBS. Their difficulties with infections may obscure an important aspect of their stories: they expect something from DBS that it is not likely to provide. Thus Dr. Okun's response to Heiser focused on helping him determine whether the problem, as Heiser defined it, was the result of improper DBS lead placement, improperly

aggressive reductions in medication, or simply the result of disease progression that cannot be helped with DBS surgery. In situations like these, revision of DBS leads is often unlikely.

Low Transparency, High Visibility Cases

Outcomes in cell two also feature low implant transparency, but are coupled with high visibility of movement disorder symptoms. Cases of low transparency and high visibility may be most obvious candidates for revision. Here, patients returning to Eastwood (and who shared their stories online) spoke of surgeons about recurring movement disorder symptoms. Since the majority of revision cases seen at Eastwood were from other centers, patients in this category gave members of the conference the opportunity to directly compare some "results" from other, and in their estimation, less competent, centers than their own. The group at Eastwood is not alone in questioning the value of other centers offering DBS surgery.

Okun and colleagues suggest that since the Food and Drug Administration approved the procedure in 1997 (HHS News 1997), the number of centers offering the surgery has surged (2005). Offering an optimistic, if unhappy perspective, Okun et al. write, "As the prevalence of DBS therapy increases, implanting centers are becoming more experienced. We are hopeful that this experience… will result in global improvement in the outcomes of DBS surgery" (2005:1255). The meaning of "experience" here is clear: as other centers get better at placing DBS leads, our center (the focus of their study documenting reasons patients sought their help for unhelpful surgeries) will have fewer cases to "revise." Taken together, these efforts should result in fewer expensive revision and replacement surgeries.

In cases of high visibility and low transparency, the implant's leads may be

inappropriately positioned and thus are unable to "capture" (in medical team parlance) movement symptoms. In January 2010 the team considered the case of a white man in his early 70s from northern Mississippi. Diagnosed with essential tremor, the neurologist presenting his case suggested that surgeons in Memphis misplaced one of the two implanted electrodes. Drawing a connection between the misplaced lead and rapidly draining battery within this man's IPG, the neurologist suggested surgery revision. The neurophysiologist, Dr. Tomarro, reported that this patient showed difficulty in staying focused during neuropsychological testing as well as cognitive and memory issues. One neurologist suggested that this patient's response to surgery revision would be minimal.

January 2012 brought a potential revision case to the group. The case, unlike the other fifteen discussed that morning, was scheduled for the end of the meeting and marked "discussion only" on the team's agenda. Mark Angelo, a white male high school football and baseball coach in his early 50s underwent surgery at Eastwood the previous spring. The name of the treating neurosurgeon is not listed on the agenda. His Eastwood neurologist, Dr. Begin, unpacked his story:

> Mr. Angelo was implanted in the spring of 2011. We have had programming issues with this 51 year old male. He can't really walk. Amplitude is at .8 to 1. Because he is having so many problems I cannot push the amplitude. He has bilateral STN place-ment for PD (fieldnotes, 1/13/2012).

Hearing this, Dr. Adams opens up Mr. Angelo's medical record and, finding an immediate post-operation CT scan and opening the file for display on the large projection screen, the group begins to discuss their impressions of the lead placement and surgery.

Dr. North and Dr. Clark, the two neurosurgeons, have the most to say. North says that he was a difficult patient in the operating room, a football coach who felt like he was getting

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high during the surgery. North asks Begin to describe Angelo's symptoms. Begin said, "He has several symptoms. His feet will turn in, face will pull, his speech is altered." Hearing this, North begins to discuss options. One is to go for an alternate target, perhaps GPi. Begin said that he has tried all programming options, running "all four contacts" in an attempt to show some treatment benefit. Dr. Philos says that she remembered him cursing in the operating room. In response, North suggests offering Angelo a sleep GPi surgery "If it's not working for him." Another option, North offers, is to move the left lead into the GPi from the STN. Clark asks: What is the most significant feature you want to fix? Begin says that his walking and speech are impaired at high amplitudes. North then suggests a "harlequin" surgery, moving the right lead deeper into the brain while leaving the left in place. As the discussion winds down, no decision is made. Begin will discuss the group's conversation with Mr. Angelo at his next appointment, and the team leaves the possibility of a revision surgery open until Angelo and Begin determine the next step in his treatment.

The surgeons do not seem surprised about Mr. Angelo's surgical outcome. To be sure, they are concerned, but not surprised. Evidence of this comes from an encounter no more than five minutes later. After discussing the next patient, Philos said, "Quiet group." Clark immediately responded: "We are still shocked that the perfect lead didn't lead to the perfect result!" The group erupted in laughter at Clark's quip. Doctors in this group expect a certain level of problems with implants and programming to occur. This comment meant that everyone understood the uncertainty inherent in this kind of brain surgery. The comment may have also underscored the fact that, unlike other brain surgeries in which interventions are permanent (such as thalamotomy, where small portions of the brain are "lesioned" or

destroyed), DBS surgeries can be revised and potentially improved.

The next month, Dr. Clark addresses a patient he has added to the agenda for the day. Joe Lock is 64 years old, a white man diagnosed with Parkinson's Disease. Clark brought his case to conference in order to discuss possible revision of his leads. Clark begins, "I'm trying to put a story together. We implanted him in 2009 and we never got the super results we wanted. He is questioning the placement of the implant. He is hitting side effects." Halter asks, "What are his side effects?" Dr. Strong says, "Dysarthria[33]."

Reviewing the CT scan that he has pulled up on his laptop, Clark says, "One is real high on the left, the other is in the normal position on the right." Clark asks Strong about the opinion of Dr. Davenport, a senior-level neurologist who is not present at this meeting. She says, "Bob says that if it can be revised, then it should be." Clark tells the group that he wishes they could see a view of the lead positions, but that it is difficult to load: "It would be nice to show you the pictures, it would be easy to pull that lead one millimeter." At this point, the decision to revise Lock's DBS surgery is answered, and the team starts planning for a revision surgery that will revise the left lead. Clark finishes this discussion by saying "The lead is so high we are getting thalamic effect on that left side" (fieldnotes 2/3/2012).

Lock's symptoms could be mistaken for problems associated with normal disease progression. Dean's symptoms, his soft, barely audible voice and weakness on his left side, were mistaken for "normal" or natural disease progression, untouched and unavailable to intervention with DBS. Perhaps because Strong's statement labeling these problems

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33 Dysarthria is a motor speech disorder that results from neurological injury to the muscular component of speech. In other words, it is a condition of the muscles that allow a person to talk. People with dysarthria have difficulty in the audibility, naturalness, intelligibility and efficiency of speech.

dysarthria was so short and definitively stated, and because a senior neurologist approved her diagnosis, it was accorded a prominent position in the discussion of causality. The unequal placement of the leads, confirmed by post-operative CT scan, also lent credibility to the conclusion that a return to the operating room was required.

High Transparency, Low Visibility Cases

As an analytic device, the typology I developed includes a category that doctors do not typically see for revision—those defined as successful by patients. Including this type of treatment outcome in the typology helps us understand that outcomes may shift over time as diseases progress, DBS devices break or batteries wear out, or as devices are calibrated and re-calibrated with the aim of reducing movement disorder symptoms. Because so many of the people I spoke to in this research consider they have benefitted greatly from their treatment, I will reserve their stories for chapters four and five.

High Transparency, High Visibility Cases

Some cases feature high visibility of movement disorder symptoms in the absence of evidence suggesting DBS failure, maladjustment or inappropriate positioning. For some patients, DBS treatment simply cannot capture some troubling movement disorder symptoms. Patients whose cases fall into this category often undergo repeated "programming" sessions in an attempt to reduce problems with posture, voice strength, and other concerns. These outcomes were the subject of some discussion in my interviews with DBS recipients. Many patients in this category felt their DBS device was usually transparent, and did not require the degree of discussion required by recipients in categories 1 and 2, yet some symptoms they associated with their illness were not removed, or reduced, by the

conjoint action of their device and medication therapies. People with symptom profiles in this category are often not eligible for surgery revision, either because their symptoms are controlled to the greatest extent possible by current DBS settings (and well-positioned leads). Some types of symptoms, such as balance problems, soft speech, and others, are unlikely to be effected by the DBS implant, no matter how well placed. The device simply is not able to mitigate those movement disorder symptoms. Another set of causes for cases in this category can be raised: disease progression (as cited by doctors in the movement disorders clinic). It may be the case that the implant's stimulation levels (the amount of electric power going to the electrodes and out into the brain) without resulting in other treatment effects that are intolerable for the patient.

Sophia Marrs was added to a DBS movement disorder conference in early 2012. Only 38 years old and diagnosed with dystonia, this white woman was described as "mute and severely mentally disabled." Her neurologist, Dr. Teresa Strong said, "This patient had viral meningitis at four years old, and has lots of brain damage. She was implanted in 2009 at [Eastwood]. She is mute and severely mentally disabled. She hurts her mother, lashes out" (fieldnotes 2/3/2012). The two currently share living quarters. While Strong speaks, Dr. Adams projects the image of Marrs, whose body thrashes across the screen, her head bobbing up and down violently, not unlike the "headbanging" style of dancing popular among certain young people listening to high tempo, loud, raucous music.

Dr. North speaks: "She had lesional surgeries, a palladotomy, then bilateral GPi DBS." He continues, describing some of her symptoms (but, by implication, not all) as dystonic. He says that Marrs' mother has made multiple therapeutic attempts, advocating for

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her daughter's treatment. He said that Mother would come in with lots of medical literature, information she put together. North stated that it would be a big mistake to operate, and he suggested that the team might have done too much already.

Dr. Halter suggests that Marrs' mother may need a psychiatrist in order to deal with the stress of seeking care for her daughter. Dr. Tomarro, the neuropsychologist, suggests that the mother has multiple issues, and asks the room if Ms. Marrs has autism. Halter responds that she had encephalitis, but that it was secondary. Begin then suggests treatment with DBS, with the nuclear (nucleus) accumbens as a preferred site. He said that this location has worked in cases of traumatic brain injury.

North said, "Her brain is damaged because of neurosurgeons poking in her brain. Her mother's goal is to keep her out of a state facility. I promised that I would give it to the group to decide." Halter then says that he doesn't know her, or the case, but that it might be Munchausen by proxy (syndrome). Dr. Clark intervenes here, suggesting that the mother has "guilt issues" from having her daughter institutionalized previously. He says, "Mom has talked to Oliver Sacks, Mom will go to no end. I have a handwritten note from Sacks on this patient." Halter then says, "He wants to write Awakenings 2. Gweneth Paltrow will play her." Clark responds, "We've exhausted our options here." North then returns to the conversation, saying that if you test what she (the mother) really wants, she wants complete remission. On the patient, I think the symptoms are behavioral, and she needs operant conditioning." Halter responds: "What is her IQ like?" To which Tomarro responds, "I don't know" and Strong follows, "You were unable to test her." Clark has some of the last words in the conversation, saying, "She's profoundly impaired."

The conversation about Sophia Marrs ends and the group seems to take a deep breath. There is a sense of sadness for Marrs and her mother. In addition, there may be some sense that Dr. North is right, the team has over-intervened, and crossed the boundary of appropriate treatment. North's suggestion of behavior modification through operant conditioning both reveals the inadequacy of this therapy for some complex constellations of symptoms and social relations and calls into question previous surgeries, focused as they were on altering brain anatomy and function through lesioning and stimulation. Post-meeting minutes, distributed to the group via email note that Marrs' mother (and, by extension, her daughter) requested a meeting with Dr. Clark. The minutes suggest that Dr. Clark can choose to accept, or decline to meet with the women.

Thumbpick, a member of the HealthUnlocked forum, also experienced unwanted effects of the DBS treatment. He writes:

> I had bi-lateral DBS surgery in 9/10 and emerged virtually tremor free!!! Also, my though it's not supposed to help the other symptoms, my swallowing has been almost 100% cured, and I don't freeze when walking at all. AND, although I am a self-diagnosed pain wimp it was virtually painless!
> …
> I got my life back. Not w/o [without] some problems … it left me w/some slurred speech and almost indecipherable handwriting (have great difficulty even reading my own writing). But, I've had several years of speech therapy, the latest (and most effective) being the LSVT method, and it's been very helpful. Most days I'm pretty intelligible, others not so much. … The tremors on my right side (which was always the worst) have come back a little, but zero on the left. And, I'm due for another "adjustment" of the controller/battery pack soon. Meds seems to have little effect on anything. Although I have some tremors, I can eat and drink like an (almost) normal person. I also used to have pretty good skills on the computer keyboard, but now I type a work and often there will be 5 or 10 characters repeated which I did not type (at least not Internationally)... a string of S's of A's, or O's, etc. (July 7, 2012: http://parkinsonsmovement.healthunlocked.com/blogs/377471/Gonna-Do-DBS-in-September-I-think)

Thumbpick is sharing his or her experience with DBS treatment effects that are unwanted,

and, in this case, difficult but manageable difficulties in writing and speech. Sharing

experiences and tips, such as offering LSVT speech therapy as an effective method, lends the

forums at HealthUnlocked a friendly, helpful tone. Thumbpick advances a "well-known" fact

about DBS surgery—that it is not supposed to improve swallowing and unspecified other

symptoms. His or her speech, however, has been slurred, and Thumbpick attributes this to

DBS surgery and current DBS settings, not medication effects or disease progression. The

same can be said for his or her indistinct handwriting.

Conclusions

While most health care consumers tend to think of surgical interventions as either

successful or unsuccessful, considering DBS surgery outcomes in terms of symptom

visibility and implant transparency offers a different perspective. By analytically capturing

possible outcomes, we can begin to ask questions about how patients navigate through the

elements of the typology, and the social and biological forces that shift their relative

location(s). In addition, we might use this typology to order future research on chronic illness

and treatment, particularly for cases in which treatments are more or less transparent to their

users.

Thinking about surgery revisions for DBS leads us to consider how different centers

understand both error and success. One measure, as we have seen, is how certain centers, like

Eastwood, receive patients whose unwanted treatment effects lead them to seek care beyond

their place of implantation. For doctors at Eastwood, these patients provided an opportunity

to burnish their own pride of purpose and suggested that their outcomes were in some

respects better than others. When patients did return for revision after implantation at

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Eastwood, the team emphasized the highly technical and uncertain nature of their practice, arguing that these kinds of events happen to all professionals at the leading edge of medical and surgical practice. By refusing to name Mr. Angelo's neurosurgeon, I suspect that the surgery coordinators, and, by extension, the team, sought to reduce the share of blame held by that neurosurgeon, sharing it more widely throughout the group.

The patient experiences shared in the movement disorder conference, online, and in aggregate inside the medical literature provide a helpful counterpoint to media portrayals of near-miracles that so often appear nightly network news broadcasts and Good Morning America[34]. Some recipients may describe their treatment with DBS as miraculous, but I found that this enchantment with the device and its effects, if present, were short lived. Most DBS patients, even those with self-reported excellent outcomes, characterized their device as transparent and forgettable.

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34 See this story from Good Morning America:
http://abcnews.go.com/GMA/AheadoftheCurve/story?id=5941480&page=1#.UGkG1vk5wi4

CHAPTER III

Natural Movement by Unnatural Means: Transparency and Invisibility in Narratives of DBS

Recipients

> "whenever you go deep hanging out you get it that folks' lives, even in the
> worst of conditions, aren't done, they're not through. You have got to be at
> risk for getting at how people's lives aren't done, they're not just flattened
> ever, even in the worst of conditions, but they're burdened"
> (Haraway, quoted in Gane 2006:152).

> "Anytime you fool with your brain, it's serious. And I can't believe I didn't
> think any more about it than that. But I just wanted something to cure
> Parkinson's" (Alice, 592-3 interview 011b).

> I just thought at first that it was an awful easy way [for] somebody to mess
> your head that way. It would be an easy way to pass on out of here. So I thought,
> well, it's worth a try. I'd just about as soon meet the day as be the way I was. I
> couldn't even, I read all the time. I couldn't hold a book still with my hands. I'd
> shake so that I couldn't hold a book and read anything. Now I read all the time.
> … it's always a funny feeling in your head or in your brain or whatever when
> you know that somebody's gonna put something in your brain, they're gonna
> actually open up your head to put something in your brain. … I, I had some
> thoughts about it, like I say, but I'd just about as soon be dead as to be shaking
> like I was when I couldn't do anything anyway (Thomas, 176-187 interview 005b).

Reflecting on her "Cyborg Manifesto" twenty-one years after its publication, Donna

Haraway's quote leads this chapter. Each person's story, the narrative arc of each partial story

of illness and treatment recorded here remains unfinished. Their experiences of illness and

treatment, and their stories about those experiences, are not yet complete. The risk, as

Haraway describes it, lies in acknowledging that our work is always partial. There is a

temptation to seek a full and complete story, taut and sealed as if in amber, perfectly

preserved. Joining people in the midst of their process of illness and treatment offers a view

of their experience, partial but nevertheless more clear for the viewing. The people I

interviewed are lively, and in-process, just as their implanted devices are, as Haraway puts it,

"lively too" (Gane 2006:141).

In the second quote, Alice acknowledges the high stakes that come with brain surgery, stakes that she now reports only briefly considering before the movement disorders team offered, and she accepted, deep brain stimulation surgery. She, like so many other people I interviewed, desired a cure for Parkinson's disease. She was struck by her own lack of reflection—she didn't "think it through" in any sustained way. She did not deliberate or rationally consider her option *not* to have DBS surgery. Her desire for an effective treatment for the intrusive symptoms of Parkinson's seems to have overridden any other concerns.

In this chapter, we hear from people who have received deep brain stimulation implants talk about how they relate to their implant. Their words reveal much about how they think about and interact with their device, and the meanings they make from these interactions. I asked people with brain implants to talk with me about their device and how they were getting along after deep brain stimulation surgery. I found that many deep brain stimulation recipients use a rhetoric of the natural or normal body. This rhetoric, I argue, is productive in both neutralizing and minimizing the distinction that they might have drawn between their organic body and the inorganic implant. Some DBS recipients' accounts suggest that they forget the device's presence within their bodies and brains. Forgetting is a meaningful response to life with a brain implant because forgetting produces a kind of normality unavailable upon reflection, a normality that my respondents most desire and value. Consistent with Sacks' discussion of doing being ordinary (1984), many DBS recipients framed their trajectory through illness and treatment as "what anyone" would do in their situation.

By engaging in a forgetful rhetoric of normality, these DBS users deal with the blurry

boundary between nature and culture. DBS recipients report "forgetting" the technology that works to sustain their re-created natural or normal embodiment. Here, I offer a partial answer to one set of questions that motivate my research: How do patients relate to their brain implant? How do they think about and interact with it, and what meanings do they make from these interactions? How is device use a social event similar to, or different from, drug-taking? Regarding the nature of treatment for chronic mental illness, Karp writes, "drug-taking is a social event that extends well beyond the pill and the person taking it" (2006:54). If Karp is right, is living with a device different? Guided by these questions of action and interaction, I set out to understand the forms of engagement people with DBS implants have with those devices. This chapter contributes to the growing scholarship on biomedical treatment within medical sociology and interactionist social psychology.

Below, I briefly review what medical anthropologists and sociologists call the voice of the lifeworld, as distinguished from the voice of medicine. Next, I discuss Kleinman's early work on illness narratives, and contrast this with more recent interactionist medical sociology that I am calling the sociology of treatment (Karp 2006; Denzin 1987). Then, using excerpts and narratives from in-depth interviews I conducted, the focus shifts to people with deep brain stimulators. To preview, I find that many of the people I spoke with report forgetting about, or rarely reflecting upon, their implant. I argue that this finding is due, in part, to characteristics of the device, its design and placement. I think this finding also reflects something fundamental about a certain type of treatment experience (often "successful" in the recipients' own terms) and ambivalence in recipients' descriptions of their lives with the device. For many, their implant that did not deliver the total remission of symptoms that they hoped to achieve. In addition, I find that most DBS recipients defer

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authority over adjustments to their implant to doctors, out of fear of making an error, coupled with a sense of awe around the technology that works inside the body. With few exceptions, the patients I heard expressed either amazement or confusion over the DBS' effects. Reflecting on these forms of patient experience opens for investigation the issue of embodiment and authority, especially considering the ability to raise and lower stimulation levels and the sense of "freedom" this is intended to give patients over their device.

The Voice of Medicine and the Voice of the Lifeworld

In the chapter on medical team meetings, I illustrated how doctors and surgeons use quality of life language in part to retain authority over DBS allocation. In an environment of uncertainty over the criteria that doctors should apply when considering a patient for DBS surgery, arguments over and judgments about quality of life become an important resource in creating persuasive appeals. In their meetings, 'quality of life' is discursively created as an object independent of its practice in particular human lives. This is "quality of life" as viewed through the voice of medicine.

The voice of medicine, Mishler (1984) argues, is the dominant voice within doctor-patient interactions. It is the voice of disease entities, categories at a high level of abstraction compared to any one patients' experience of that disease. The voice of medicine is also the voice of quantification and calibration. To critics, the voice of medicine values precision without understanding and accuracy without reflection (Mishler 2009, 1984; Olin Lauritzen and Hydén (2007) but see Barry et al. (2001) for a qualification of Mishler's dichotomy. The voice of medicine, these critics argue, overpowers the patient's description of how his or her life has been affected by the illness experience, what Mishler calls the voice of the lifeworld. The voice of medicine is most common in acute care situations in which the "problem"

seems straightforward and easily treated. The voice of medicine may be particularly problematic when applied to patients with chronic illness because chronic ailments, by definition, have longer histories than acute ones. This longer history leads to relatively more complex and lengthy patient "histories" and thus require a more extensive medical interview. From the perspective of the voice of medicine, the chronically ill can become problem patients who, by definition, "fail" to recover quickly and without significant resources in time and care. In previous chapters, I described doctors on the deep brain stimulation team, and their efforts to determine course(s) of treatment for patients who have "failed" traditional therapies.

Drawing upon Habermas' notions of system and lifeworld, Mishler recognized the similarities between these notions and medical practices that often ignore or downplay the significance of a person's experience of illness and its effects on daily living. The voice of the lifeworld conveys a patient's subjective understanding of, and explanation for, their experience of illness. The voice of the lifeworld includes the limitations and opportunities of illness experience that are left unrecognized and often untreated by doctors whose primary, and perhaps only tools, are from the voice of medicine. Because doctors and patients are speaking in two different voices, conflicts arise, and inhumane and less than ideal treatment is often the result. These conflicts arise, in part, when doctors fail to adequately reflect on their own interpretive processes when confronted with patients' subjective accounts of illness (Kleinman 1988:16-17).

Mishler's analysis of the conflict between the voice of medicine and the voice of the lifeworld has been tremendously productive within the social sciences of medicine, and his work remains some of the most highly cited within qualitative medical sociology. In many

ways, Mishler's work provided a language that opened up discourse about the personal, social, and cultural dimensions of medicine that echo from the clinical encounter through the social and cultural meaning of illness. Studies based on Mishler's distinction between the two voices often relied on in-depth interviews with patients, eliciting the voice of the lifeworld by analyzing stories patients tell about their experiences (Kleinman 1988; Frank 1995, 2002).

Whereas Mishler focused on conflicts that may arise in patient-provider interactions, Kleinman's work added a cross-cultural dimension, focusing on the meaning of the experience of illness, and the tools for telling that patients employ and doctors often ignore. Taking up patients' illness narratives as important to the process and practice of care for chronically ill people, Kleinman argues, "Legitimating the patient's illness experience— authorizing that experience, auditing it empathetically—is a key task in the care of the chronically ill, but one that is particularly difficult to do with the regularity and consistency and sheer perseverance that chronicity necessitates" (1988:17). Attending to the stories that accompany illness, listening to the voice of the lifeworld, can be effective in treating that illness (Barry et al. 2001). Illness is personal as well as cultural in its significance and meaning. Certain diseases bear dreadful and shameful meanings for a culture in a particular time and place, only to be renamed, or become less prevalent over time (the renaming of leprosy as Hansen's disease, for example). At the same time, illnesses that carry little stigma in one country or culture may be highly stigmatized in another. Kleinman's work argues that the social and cultural significance of illness, and the subjective and cultural stories told about it, are important resources for health professions seeking to reduce human suffering.

Disease vs. Illness

The distinction between illness and disease often travels with Mishler's voice of

medicine versus lifeworld. Disease is defined as a biomedical phenomenon, albeit one strongly affected by social forces. From this distinction sociologists have studied the experience of illness, and the distribution of disease across class, race, sex, ethnicity, education, and other social factors. Whereas illness is experienced and described differently by different people at various places and times, disease categories are often assumed to be without ambiguity.

Diseases, as abstract entities, are then diagnosed under specific material and cultural circumstances (Jutel 2009). The Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association is one example of a diagnostic system with disease categories defined and organized into a more or less coherent system that is to be applied to particular cases of illness for the purposes of diagnosis and subsequent treatment of mental disorders (Bowker & Star 1999). The International Classification of Diseases (ICD) is another such effort to codify the diverse group of physical illnesses into discrete categories (Brown 1995, Kleinman 1988).

Illnesses are matters of personal and collective definition. They define some states of the body and mind as disordered, or deviant. From the first sign of a cold, or the throbbing of a headache, symptoms must be noticed and be seen as problematic in order to be defined as abnormal. Sociologists have studied the subjective and intersubjective experience of abnormal body (and mind) conditions among lay persons, often utilizing interview and ethnographic research methods to represent the personal and collective experience of illness within particular times, places, and cultures (Brown 1995, Karp 1996, Kleinman 1988). Social forces shape our understanding of and actions toward health, illness, and healing (Brown 1995).

Like Mishler's, Kleinman's work on illness narratives has been tremendously productive and influential in areas of social science that take medicine, health, and illness as their objects of study. In addition to Kleinman's sensitive anthropology of illness narrative and illness experience, many sociologists and symbolic interactionists have also sought to uncover the meanings patients, groups, and societies make of certain forms of illness. Examples of this line of work across include Charmaz's work on chronic illness and time (1991) to Karp's work on people with depression (1997), Frank (1999; 2002) on cancer and chronic illness, Epstein (1996) on HIV/AIDS activism have presented personal and collective struggles with illness, often contests between the medical professions and lay people, activists, and the sick.

The Turn to Diagnosis and Treatment

Recent medical sociology has recognized that, like illness, treatment is a co-construction of the patient and doctor. Brown writes , "In constructing their definition of an illness, people also construct what they consider appropriate ways to treat it" (1995:47). At this point in the social construction of disease, doctors often prescribe a treatment not solely based on medical criteria, but also upon a patient's family responsibilities, work life, and other factors. This negotiation, if handled appropriately, often leads to higher rates of "compliance" with medical treatment. At the political level, disease has been affected by the decision *not* to treat particular groups of patients, often on the basis of the social construction of the disease. Brown cites the Tuskegee Syphilis experiment as an example of the way in which the Public Health Services' construction of Black men as inferior made them subject to experimentation (1995).

I think that treatment with DBS is an excellent example of the co-construction that

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Brown discusses. The DBS case is perhaps more complex than the situations Brown had in mind because recipients often navigate relationships between doctors, devices, and drugs. Although Brown's understanding of treatment negotiations between doctors and patients seems to include devices, he leaves them out of his analysis. Too often, then, leading medical sociologists begin by excluding an important form of treatment from their analytic frame, rendering these technologies invisible within the literature. Downplaying or bracketing medical technology's role in diagnosis and subsequent treatment might lead to neglecting the construction, and reconstruction, of mental and physical conditions that are only "visible" technologically (Dumit 2004).

In addition to this empirical oversight, many sociologists mention the personal and interactive meaning-making processes in determining diagnoses, but rarely empirically examine them, or seek to understand these processes from the patient or doctors' point of view. Thus, we get somewhat abstract, if grand, discussions of widespread social processes such as medicalization, biomedicalization, and the sociology of diagnosis. What is needed, then, is an investigation of the subjective and interactive processes that patients devise when making meaning from their status as DBS recipients. This chapter begins that investigation.

Chronic Illness and Chronic Treatment

Since Charmaz' pathbreaking work on the self and chronic illness (1991), interactionists and some medical sociologists have recognized that people with chronic illness spend a considerable amount of time thinking about and dealing with their illnesses. Some scholars have characterized the time and energy required by chronic illness as a kind of work (Star 1991; Star and Strauss 1999), amounting to a career (Strauss et al. 1985, Karp 2006). The career of a person with chronic illness often revolves around consultations: with

primary doctors and specialists, with the medical literature, and with support groups both in person and on the Internet. Some of the people I interviewed described their disease and drug therapies. Others elected not to study their illness, nor to become lay experts on their disease and potential treatments.

These forms of knowledge and degrees of engagement seem to impact DBS recipients' understanding of, and willingness to experiment with, medications and ultimately, their device. The sociological research on "adherence" or "compliance" with doctors' orders often focuses on "the symbolic meanings attached to aspects of treatment, including medications" (Karp 1996:30). In his book on the sociology of drug taking for depression, Karp uncovered three general stories told by people who take anti-depressant medication.

In the first general story, people taking antidepressants are ambivalent towards their use, reluctant to rely upon the drugs, and often move from drug to drug in search of more positive and less negative treatment effects. This is a narrative of partial success, one in which many people come to accept that they will be taking drugs for depression indefinitely. The second general story is one of repeated attempts to find relief in medications, but continued setbacks and struggles. This group of trajectories through illness helps us understand the courage needed to sustain repeated drug trials in the face of unrelenting mental illness. People who tell this story often reconcile themselves to a lifelong struggle with illness. Finally, for a third, and smaller, group, medications seem to work very well. In many ways, this is the ideal, and the vision that pharmaceutical companies, device manufacturers, and marketers want the public, and potential patients, to carry. Yet Karp found this to be the least common narrative among the people he interviewed. Their treatment was so successful that people with this story tend to characterize their ongoing treatment with

drugs as a cure (Karp 2006).

Other scholars have also picked up on the idea that treatment is an important area of inquiry. For example, psychiatrist David Healy has written two books (1998, 2004) on the history, phenomenology, and political economy of anti-depressant medications. His work is perhaps a precursor to sociological investigations of the social psychology and phenomenology of medical treatment that Karp (2006) has published, and I undertake here.

In the remainder of this chapter, I outline and provide evidence for three main findings. Where Karp found that few patients described themselves as "cured," I found many more whose treatment effects patients described as reaching, or coming close to, that level of success. The second category, patients who describe their DBS treatment as a "mixed blessing" are similar to Karp's respondents who struggle with marginally effective drug treatments. The third category of DBS recipients is perhaps the most unique. Although people with depression can reduce, or increase, the amount of medication they take, the effects of these medications develops over time. DBS recipients may have a different relationship to their implant, since they can control their device's actions by raising and lowering stimulation levels for immediate relief of unwanted treatment effects. Only one DBS recipient interviewed adjusted his implant settings regularly. These findings are based on post-implantation interviews with twenty-two deep brain stimulation patients. In each section, I present the finding, provide a sense of its limits and qualifications, and then proceed to document, describe, and interpret the stories DBS recipients tell about their lives with devices implanted within their brains and bodies. These stories provide us with the first glimpses of everyday life with brain implants.

Forgetting About their Devices, DBS Recipients Obscure the Distinction Between Self and

Device

Haraway's "Cyborg Manifesto" (1996) helped feminist, cultural studies, and other scholars develop a vocabulary to both document and begin to understand practices in techno-scientific and medical contexts that challenged previously clear distinctions between nature and culture, the organic and mechanic. Haraway pointed out that people make objects, and these objects shape and re-shape people. Today, medical care is a key site where human and nonhumans interact—where the body's agency, chemical, and material objects' activities are put to use to treat illness and disease. Recursive relationships like these may be a hallmark of contemporary treatments for chronic illness, as well as key sites in the creation of biosocial identities, personal and collective (Hacking 2006a, 2006b; Rabinow 1996). Without resorting to techno-bliss (Gane 2006) or techno-terror, Haraway called for, and continues to investigate, sites where the human and nonhuman intersect, how humans and nonhumans collaborate, communicate, and construct joint actions. Haraway discussed these interactions in her *Companion Species Manifesto* (2003).

Whereas Karp (2006) interviewed a small number of people who told stores of cure, this type of story was more common among the people I interviewed. Recipients often say that the DBS device is so helpful in reducing their symptoms that they feel it comes close to curing their condition. Although almost all of the Parkinson's and dystonia patients I spoke to continue to take some form of medication for their symptoms, most of them report forgetting about, or rarely reflecting upon, their implants. This finding points to a key difference between drug-taking and device implantation: namely, that devices, once set at optimal levels, may be less manipulated than prescription drugs. Control over the implant and alterations to its settings is a somewhat unique aspect of treatment with DBS, compared to

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drug treatment(s). Neurologists at Eastwood often "governed" the manipulability of their

patients' DBS device, limiting the amount of variation between highest and lowest levels of

stimulation and frequency. The ability to control the DBS does not always translate into

practice. Unlike people who develop long-term relationships with drugs, many people with

devices report forgetting about them. Amelia and Thomas' stories helpfully illuminate many

of these themes, suggesting that transparency and invisibility often characterize the human-

device relationships that are at the core of this project.

Amelia, a 69 year old from Kentucky contrasts her life with drugs and with device:

"You know, I tried every medication I think there was. And none of them quite worked the

way that this one does now. And that's a big big thing. I have a lot less drug side effects"

(002b, lines 346-349). Trying to get to the core of Amelia's relationship with her DBS device,

I asked her how she relates to the device and whether or not she thinks about its presence.

Amelia said:

> [I can tell that] the leads [are there], occasionally. But no, it's basically not
> there. Which   is what I like. I don't want to be aware of it. Now when we go to
> the next level of programming and see I'm only at the first level. I don't know
> what the next level will be like. But that, it may, when I can fiddle with it more
> then I may related to it more. Who knows? But right now I can just forget that
> it's there. … If I thought about it I would be likely to obsess about it. Is it
> working right? Could it be working better? But I don't. I can see somebody
> doing that, if I wanted to get myself into it, but I don't.

The fact that she carries a brain implant is brought to her active consciousness on few

occasions. Other people have spoken about the ways they felt their implant leads and under-

the-collarbone generator when buckling their seat belt, or playing with their grandchildren[35].

Amelia holds open the possibility of more interaction and "fiddling" with her DBS's settings

in the future, when she reaches the next level of programming, and presumably, a higher

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35 See, for example, Emily Hill's description below of her grandson pressing down on her chest, where the
implanted controller resides.

level of stimulation. People like Amelia describe DBS treatment is described as a sort of respite between two phases of their trajectory—a place that, while being within the arc of Parkinson's, is somehow set apart. Many people I interviewed understood that their illness would inevitably progress, with more trips to the hospital, and more adjustments to medications and the DBS device. Living within the respite from often debilitating symptoms seems to both stall time, seen in the desire to extend the respite period as long as possible, and to increase the value of relationships nurtured and developed during this time. Amelia describes the difference: "Part of that was knowing that it was just going to be consistently downhill. And that feeling is gone now. I, you know it doesn't feel like it felt anywhere else" (002b, 325-6). Thomas (introduced below and quoted above) focuses on bodily control that he now feels with the DBS: "it was such a good feeling to know that you was in control of yourself again" (005b, 282).

Since the DBS devices are programmable to one-one hundredths of a volt of electrical impulse, and the stimulation frequency also varies widely, patients and their doctors have an almost endless variety of settings to try when programming the device. Because DBS therapy is relatively new compared to drug therapy, and because a theory of its effectiveness has yet to be finalized, adjustments to the device can be very narrowly tailored. With up four electrodes per lead, and the ability to adjust stimulation levels and frequency on each electrode, many settings are possible. In this way, the device does differ from drug treatment. Pills often come in standard "strengths." Because of this, doctors can prescribe a certain timetable of dosage, including time between dosing. They intend for their patients to take these drugs on a consistent basis, although in practice, doctors do ask patients to self-manage their medications. Doctors and patients often describe drug and device treatments as two

different modalities in service of one goal: maximal symptom reduction and minimal

unwanted effects. Amelia reports that changes to the device's settings are on the way, as her

illness progresses and the symptoms become more pronounced. At this point, however, her

stiff and slow movements are now loosened and fluid.

Amelia said that she does not want to think about, obsess over, or consider the

implant at all. When I asked her to talk about the physicality of the DBS, Amelia says she

has:

> No feeling. That is the wonderful thing about it. The thing that's most
> concerning is some of the sutures haven't healed right. But that's outside. So
> I've got a couple of stitches that didn't quite do what they were supposed to
> do in the dissolving process. … But having a device in my body? No problem
> (002b, 363-371).

I asked how it felt mentally or psychically to have a medical device in her brain and body.

Amelia said:

> mentally I've very glad it is, it's there. Because it's having a very good positive
> effect. Psychically, rephrase that and say spiritually, I'm also very glad it's there.
> I think it's a gift. I think God provides technology as well as, miracles happen in
> a lot of forms (002b, 374-376).

For people whose DBS treatment has allowed them to recover some, if not all, of their

mobility, the device is often described as a technological miracle. In my discussions with

DBS recipients, the theme of magic, miracle, amazement, and transformation expressed a

sense of wonder mixed with joy. The "miracle" narrative was most often linked with a

curious type of invisibility that cloaked the implant and its activities for DBS recipients.

For Thomas Moore, a 76-year-old white man from rural Tennessee, the DBS implant

is also practically invisible. Thomas had DBS surgery on the left side of his brain (which

coordinates right-side movement) to treat the symptoms of essential tremor. He tells a

technological miracle story: "I couldn't do anything with my hands. Shake so much I couldn't

do anything with them. And it's surely been a miracle, sure enough, after the operation"

(005b, 45-46). Thomas is thankful, and a bit amazed, by the action of his implant. To him, the

implant is all but invisible:

> I never think about it. It's just there and I know it and it's doing what it was
> put there for   and that's all I know and it's never bothered me in my head at
> all. Not one bit. And ah I don't know. The wires run down to this thing in my
> chest. They really didn't, that's the only thing that really bothered me was the
> wires [that] run down through there. … But it, now I don't even notice it
> anymore... I don't see how in the world they did it, but they did... I don't even
> notice it being there, at all. The only time I know it's there is when I turn it on
> and off (005b, 238-242, 254-257).

His implant is invisible, in part, because it does not bother him "in his head." Like

other DBS recipients, the portion of the implant inside his brain is the part he has the least

consciousness about. The more "external" components, like the generator and wires under his

skin and up to his skull gather the most attention. Thomas said, "[It] works perfect 'til I shut it

off. And I'd already turned it off of course it acts like the left one, shakes" (005b, 126-127).

Because he has the DBS implant on only one side of his brain, but experiences symptoms on

both sides, Thomas has a "built in" check on the effectiveness of his DBS implant. Should he

choose, he can turn the DBS implant off and "check" its effects by comparing his hands and

against his experience with the device turned on. I asked Emily, a 62- year-old woman

Kentucky, how her DBS device was working for her. She said, "It's been doing great. I don't

have the tremors at all" (004b, 144). Linking the device to her symptoms, Emily later

described her feelings about the device: "it's been so good to me the symptoms that I had that

I don't even think about it very much. I just don't really know. It must be working well

[laugh]" (004b, 175-6). Here, Emily corrects her description of what the device has done for

her and for her *symptoms*. This collapse of self into illness is a cardinal feature of many

illness narratives within the medical sociology and symbolic interaction literatures. Self

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becomes illness and illness, self. Because of the intimate connections between patients' sense of self and their experience of illness, positive changes in symptoms become treatments for self. As I document more fully in chapter five, some aspects of Sulik's (2009) technoscientific illness identity may operate within the lives of DBS recipients, including thinking of oneself through the categories of illness, or in this case, treatment.

People with brain implants may not ponder their devices, and the meaning of their life with their device for several reasons. Some of these have to do with the device itself, its location, and the work it does to lessen the outward symptoms of a movement disorder. Emily told a short story that captures a situation when her device became salient:

> The only time I think about the batteries, my little grandson will get up in my lap or something and he puts his hand where it is and mashes down really hard because he doesn't realize what it is. And other than that, I don't even notice that I have anything there. Except the wires are on this side of my neck and sometimes I can feel those if I turn my had a certain way or something then you can feel where the wires are and I'll get a little tingling or something, but not much... I can feel something (004b, 180-189).

The picture of a little boy pressing on his grandmother's chest, exploring the curve of the DBS generator, pressing on a foreign object within this 62 year old woman was unique enough to be worthy of the telling. The wires that snake up her neck and down into her brain can be brought to mind. Yet in general, she doesn't think about the device and its presence: "When I run my hands down through what little hair I have now I can feel the spots where they have worked on the wires are down, they have like a ridge there where all those are still there. And I can tell that they're there but as a rule I don't even think about it" (004b, 215-7). Like Emily, Thomas also describes a lack of consciousness about his implant. In talking about the implant's action, Thomas recalled this story:

> I don't know how it's working myself. I know it's there but I never feel nothing in my brain or my head. … I don't know what it's doing but it's doing something

right. That's all I know. I know it keeps my right hand from shaking. That's really a treat from the way it was. I remember one time I was eating at the table. My little granddaughter was on the other side of the table from me and of course I was trying to pick things up, I couldn't get them in my mouth, I was shaking them out. And she said, 'Grandpa don't play with your food, eat!' I was doing the best I could (227-232).

Thomas is not troubled by his lack of knowledge about the mechanism through which the DBS does its work to minimize the symptoms of his essential tremor. He expressed his amazement about the implant's effects: "I don't know, just unbelievable really what that little implant in my brain can do" (005b, 330). His short story speaks to the embarrassment that many people with movement disorders feel when the limited control they have over their body is not politely ignored, as described in Goffman's work on civil inattention (1963b). While in public, most adults are likely to recognize Thomas' limitations and politely ignore them as a matter of civil inattention, a type of face engagement wherein one gives another visual notice that he appreciates the other's presence, then immediately withdraws attention so as to assure that the person noticed is not of particular importance or in need of special scrutiny. On the contrary, Thomas' lack of full bodily control constitutes a stigma in Goffmanian terms (1963a). Thomas' granddaughter had yet to learn this interactional skill, and interpreted the shaken food as a sign of playfulness, not disability. The very same symptom can be interpreted in multiple and often conflicting ways, occasioning stories like this, which were told for comedic effect during many of my interviews with DBS recipients.

The stigma of movement disorders like Parkinson's is often reduced, or even eliminated in the cases I studied. As the symptoms of PD and ET become relatively invisible, they lose some of their symbolic power to spoil identity. There is a physiological reason for why patients are unable to feel their implants within their brain. This is because the brain's neurons are not sensitive to touch, so no signals of discomfort can be felt. Once the

electrodes leave the brain and become wires, however, patients can often feel them run from the crown of their heads just under the skin's surface, down the neck and into the upper chest. The implant wires, which connect the electrodes to the generator, are the most likely source of discomfort.

Another reason people might not reflect on the presence of the DBS device is that the device does not have to be monitored or adjusted, turned off or on for most people with Parkinson's and dystonia. Since symptoms of these conditions extend throughout the day, people with implants are encouraged to check their device only weekly. For people who are free from prescription drugs, the former schedule of drugs three to five times per day is now unnecessary and thus is not available as a reminder of their ongoing disease. For those who continue taking drugs, their routine stays the same, but their symptoms improve. The essential tremorpatients I spoke to all report turning their DBS devices off at bedtime and on in the morning. They do this because ET's symptoms are absent during sleep, and many DBS recipients expressed the desire to extend the life of their implant's battery.

A lack of reflection on the activities of the implant is, in itself, a form of treatment experience that should not be overlooked. For many people, the DBS is a technological miracle because its actions remove a portion of the burden that comes with thinking about one's symptoms, drug dosages, and the struggle to maintain valued social and personal activities. People who receive positive treatment experiences should not be overlooked by medical sociologists who seek to understand the experience of health and illness from the patient's point of view.

Mixed Blessings

While for some patients the DBS device is an unequivocal good, many people

experience the device as a mixed blessing. For these patients, the promise of DBS surgery remains somewhat unfulfilled. Their imagined recovery out of reach, patients whose treatments are only marginally successful express frustration. For many of these patients, the implant is highly visible and salient for their everyday lives. For example, Jeff Stark, a retired Pentecostal minister, lamented the loss of his strong tenor voice after his DBS surgery. Others noted that they had gained mobility while losing some stability or balance, and still others expressed confusion over what the DBS surgery entailed or meant for their body and memory. Still others describe the DBS as offering partial, but far from full, relief from their movement disorder symptoms. This group of eight interviewees, slightly fewer in number with those who told their technological miracle stories (14) and includes some stories from patients whose discussions included both "miracle" and "mixed blessing" accounts. Like Jeff, for Emily, the benefits from DBS are not complete. She spent quite a while discussing aspects of her Parkinson's disease that were not helped by the DBS, discursively splitting her disease from her treatment, even though the two are tightly bound together throughout her experience of Parkinson's disease. After describing the complete cessation of her tremors, Emily said, "there's been two things that have bothered me quite a bit since then [DBS surgery]. One is my voice, and the other is my legs. I've had quite a bit of soreness in my legs so Dr. Philos has me seeing a physical therapist now" (004b, 144-146). She continues, "I used to be able to yell really loud when my children were small and things like that. Not anymore" (004b, 266-267). With her DBS, Emily expresses her *lack* of thinking about, planning or coordinating motions that, prior to her surgery, were effort full: "there's so many little things now that I do without thinking. Sometimes I get down in the floor and play with my little grandson now and I wasn't able to do that before. But too, sometimes if I'm falling,

I'll have a few bad days sometimes that I fall" (004b, 290-292).

The medical professionals I worked with during this study were aware of the limits to DBS therapy. Some call the device "pure Sinemet" because the DBS' effects mimic so well the effects of the drug. Because of this, people who have a good experience with Sinemet are usually good candidates for DBS. The similarity in treatment effects for DBS and Sinemet raise the question of what, exactly, is added when patients are implanted with the DBS device. The justification for the implant, then, is based on what will *not* happen, or what will be forestalled, if the device is implanted. Sinemet and other drugs that alter the brain's dopamine system reduce that system's effectiveness when they are used continuously, whereas the DBS uses a different mechanism for a similar result. This therapy, then, aims to forestall the need for higher and higher doses of medications, and the unwanted effects (such as dyskinesia) that accompany larger doses of drugs. It is as if the DBS changes the character of a disease entity assumed (by medical professionals) to be static (and viewed in just that way during movement disorders conferences) but is actually quite variable in its daily expression and impacts.

Controlling the Implant to Maximize Effectiveness and Minimize Symptom Expression

Now that DBS patients have received their implant, how do they control its actions? As I noted above, doctors have a virtually unlimited array of choices when "programming patients" following DBS surgery (this is how doctors talk about creating optimal DBS settings). Some of these choices may be programmed into a patient's control pack, allowing him or her to raise or lower stimulation power and/or frequency. Some patients are given preset levels and frequency of stimulation, and can choose from two or more such settings. Many patients vest authority over the settings for their DBS device in their doctors. Although

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patients were allowed to make changes in the implant's settings, few took advantage of this opportunity. Reasons for this deference vary, and include fear of making mistakes, lack of training, and an "if it's not broke, don't fix it" attitude. This fear is often connected to a sense of awe over the technology that works inside their body. In several interviews, DBS recipients discussed the control pack as a "remote," linking the small, grey box to a common household item, the channel changer. Steven Cox, a 76 year old white male who lives in the Chattanooga, TN area, linked his progress following the surgery to his DBS control pack. When I commented on how strong he looked post-surgery, he said, "Well, I've got that little thing right in here [motioning to the generator in his chest]. I've got that little motor right there. Ah, turn it off at night, and I turn it on in the morning' and motor on!" (006b, 245-248). Referring to his generator as a little motor, and separating its generative capacity from his brain, where the electrical pulses have their effects, Steven uses a machine metaphor to describe both himself as a human-machine and the generator as a motor for his electrodes. Turning it off at night and on each morning saves the battery. When asked about the control pack, Steven offers a loose story about what it does, avoiding any explanation of how the control pack works with the generator and electrodes. He said: "[I] open my shirt, put it right there, and push it. And sometimes this top button will come on. Sometimes that one and that one both will come on. Why, I don't know. I'm not that smart" (006b, 920-923).

John, a 58-year-old white man's experience of working with his DBS control pack is somewhat different from the rest of the people I interviewed. John found that the digital and radio equipment he operated for a Tennessee mountain town's police department interfered with the signals of his DBS. Here is how he described the situation:

> it's a combination between what the stimulator was putting out and what they
> put out. It was just too much. And I, my speech was really slurred, real bad. And

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I had to go back and have it reset. And then the doctor, she finally set it up to where I could control it. And that helped a lot. Because, some days at work, ah I've got it turned up higher than I do other days. So it, it helps a lot (008b, 378-383).

Because his workplace includes several overlapping magnetic and radio frequency fields, John went back to his doctor and was given the ability to raise and lower his stimulation levels. At first, John was afraid of his own power to control the implant's actions: "I wasn't real thrilled about having to control is. I didn't want to fry my brain or something [chuckles] getting too high. But obviously you can't do that but it won't go that high... They had to set it and it stayed on a specific setting. But now I've got it to where I can control it. I can increase it or decrease it, whatever I need" (008b, 383-392). John was one of the most excited users of his DBS implant. He reported being fascinated by the DBS surgery. Due to the position of some in-Operating Room video cameras, John was able to observe his own surgery as it happened. He shared his knowledge of the DBS with me:

John: Let me get it and show it to you. You've got this little thing here that actually is a setting of it and this is an antenna. [You] put the antenna over where the generator is and turn it on. And it tells you with the check mark, it tells you that it's on and that the battery is okay and what each side is set on.

Morrison: Okay. So 2.5 on one and 2.1 on the other. I don't have any idea what that means.

John: That's voltage. Two point. Two and a half volts on the left side and two point ten volts on the right side.

Morrison: And then you select a side and then to hit, punch it up and down.

John: Yep. It, which ever side you want, you select in and then it, hit either side here if you want to go up or you want to go down.

Morrison: So you say you turn it up and down on different days at work for various reasons. What are some of those times where you?

John: Well it just depends on how many of the radios are going, what we have going on. Whether I'm doing a lot of computer work or not. Some days I can

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turn it up, the highest I've had it is two point seven five. But I keep it around two ten, two twenty most of the time. That usually works best for me.

Morrison: So if you're doing more computers, do you think it's higher, so you can do more typing or something?

John: No, actually, if I'm around the radio, we've got more radios going than normal, more computers, I have to turn it down because of the field they're putting out (008b, 394-419).

Here, John describes his work environment, and the accommodations he makes to this environment with his DBS device. The radios and computers at his workplace generate electrical fields and these fields interfere with the regular operation of his DBS device, increasing his stimulation levels. When there are many electrical fields, John must turn his device down to avoid the slurred speech he mentions above. For John, the workplace can alter implant's settings and thus to the treatment effects he relies upon to do his job well. John reports monitoring his DBS device and adjusting its settings much more frequently than many of the people I interviewed. John's story is intriguing because his DBS device settings in his workplace stand in for his symptoms. In the excerpt above, John focuses on the action of the implant, and the effects of electrical fields in his workplace. John's unique relationship to technology and electrical fields within his workplace, may indicate the development of a technoscientific identity, described by Sulik (2009) as understandings of self formed by and in relationship with, technoscientific means. These means would include devices such as DBS.

Conclusion

Stepping back from individual stories of patient-device interactions raises deeper questions of embodiment, control, and the meaning of movement for DBS patients within their multiple social roles. When some patients defer authority to alter the settings of their

DBS device, they simultaneously reject some of the responsibility for self-management. As long as their symptoms are well controlled, this may not be problematic. The ability to alter the amplitude and frequency of DBS stimulation, when used well, can free patients from unwanted and intrusive symptoms, as in John's case. Adjustments can be made within a few minutes, and might provide a sense of control and comfort for patients who accept this responsibility. It is precisely this ability to finely manipulate the treatment that is so unusual, and this ability is lost when patients defer authority.

As Goffman (1963a, 1963b) and others have shown, body control is fundamental aspect of smoothly functioning social relations, of fulfilling expected and prescribed roles in nearly all forms of interaction. The assumption that adult humans have control over their bodily movements is a basic aspect of sociality in the contemporary United States. Thomas summarizes this view: "I'll tell you it's great to be able to use your body again like used to. Not be controlled by something that you can do something about, that's the thing... It's great to be able to feed myself and do the things I used to do" (005b, 735-739). We think people are rude when they step on our toes and fail to apologize, or unintentionally push or tap us with their arm, hand, or foot. Part of being a civilized person is respecting interpersonal bodily boundaries, and the deficits that people with movement disorders bring to the public sphere help us see this unspoken, yet powerful, aspect of embodiment and its connection to social life more generally. The DBS device is active in the management of Thomas' symptoms, and those of many other DBS recipients. The electrical pulses, frequent and focused, returns some level of body control to many patients. For Thomas, the control lies not in the device, but in himself, a stark contrast from his lack of control over ET symptoms prior to DBS. This self-control approximates the ability many people without movement

disorders take for granted. People with DBS implants, like Thomas, suggest the invisibility of

his implant contributes to the fluidity of his movement.

CHAPTER IV

TECHNOSCIENTIFIC TREATMENT IDENTITY: CONFIRGURING NORMAL BODIES
AFTER DEEP BRAIN STIMULATION

> Sixty years old with iridescent white hair, Lauren had been living with her
> DBS for about three months. Lauren's movements, once halting and tenuous,
> were now fluid and seemingly effortless. She bounded down the pressure-
> treated stairs and set off across the gravel parking surface between her mobile
> home and her nearby garage and recreation building. I walked alongside,
> impressed by her agility.
>
> We were preparing to play table tennis before I left her Paducah, Kentucky,
> area home after a three-hour interview session, our second since her deep brain
> stimulation surgery. As we moved toward the building she smiled and said, "It's a
> good thing you're here today. I'm already forgetting that it [the deep brain
> stimulator] is there. The pain is really going away, and I can forget about it now.
> I don't consider that I have Parkinson's anymore." By this time, Lauren and I had
> spent about ten hours together, talking about her journey from diagnosis to deep
> brain stimulation. Claiming a kind of freedom from her symptoms of PD, and
> from the disease itself, marks a welcome disruption within her career of illness
> and treatment.

In this chapter, I draw upon my interviews with DBS recipients, deepening the

analysis I began in chapter four. This chapter stands apart, however, because it focuses on

interpreting patient stories of illness and treatment through the theoretical lens of

technoscientific identities. These identities, I suggest, are ways of understanding self as a

result of engagement with medical treatment. Statements like Lauren's suggest the distance

between her sense of self and the Parkinson's disease that, until recently, had restricted her

mobility. There is a kind of freedom expressed in her words and actions, the ability to

coordinate her movements without concern about her medications suddenly wearing off. The

freedom Lauren expressed is closely tied to her DBS treatment. Defining technoscientific

identities, Clarke and colleagues write:

> *Technoscientific identities* is our generic term for the new genres of risk- based,

genomics-based… and other technoscience-based identities. The core criterion is that such identities are *constructed through technoscientific means*. That is, techno-scientific identities produced through the application of sciences and technologies to our bodies directly and/or our histories or bodily products including images (Dumit 1997). These new genres of identities are frequently inscribed upon us, whether we like them or not… (2003:182).

Clarke and colleagues' discussion of technoscientific identities applies to identities formed in relation to predictive and diagnostic tests (for example, BRCA analysis, genetic testing for Down Syndrome) and for identities formed in relation to technoscientific treatments. These authors suggest that, on the individual level, technoscientific identities are selectively taken on, and are most likely to be taken up when accepting the identities seems beneficial. Benefits may accrue especially to recipients of seemingly miraculous treatments, and technoscientific identities may be strategically accepted to achieve certain goals—but they they may also be refused in favor of other identities. Each technoscientific identity, then, is subject to ongoing negotiation both individually and inter-personally (Clarke et al. 2003). Defining technoscientific identities broadly, Clarke et al. open up multiple sites for empirical study, including identities that result from technoscientific treatments like deep brain stimulation.

Below, I report on a number of themes found in my interviews with twenty-two deep brain stimulation recipients. My findings concern the shape of technoscientific identities among these DBS recipients, and these run counter to both utopian and dystopian visions of cyborg selves and hybrid identities described in some more theoretically-based accounts of human-object or human-computer relationships (Haraway 1996, Hayles 1999, Nederveen Pieterse 2004). This work furthers our understanding of the impacts of technologies on self and social relations. Before answering this question, I review the symbolic interactionist perspective on human-object relationships and outline my analytic process.

Interactionist Approaches to Human-Object Relations

The early interactionist literature on objects forcefully held that their *meanings* were of central importance to the many social worlds that individuals and groups both create and inhabit (Clarke and Star 2008). The social worlds framework allows researchers to investigate how working with objects provides occasion for groups of actors to create meaning. These processes work at both the individual and group level. For example, Blumer (1969:11) memorably noted that the nature of any object "consists of the meaning that it has for the person for whom it is an object" . For Blumer, anything that may be referred to is an object, material (like chairs), persons (as social objects), and the non-material, such as maxims or principles. Thus understanding the role of human and nonhuman objects has often been the focus of interactionist work on the "conversation of gestures" and the ways in which lines of action are coordinated. Individuals often learn ways of regarding new objects, like the DBS, by observing others within their group and fitting their own interactions with the object in ways that are consistent with group norms (Blumer 1969).

Part of Blumer's genius was his understanding of process and change, which included the development of new material and non-material objects. I argue that people with deep brain stimulation implants are at the vanguard of constructing meaning around the role of implants in the ongoing (re)construction of self. Like all symbolic interaction, this activity occurs both within the individual's own ongoing conversation with self and among individuals, medical professionals, and significant others. Today, sociological and interactionist approaches to self and illness focus on the ways in which long-term chronic illness influences personal and collective identity. These works often focus on the transition from "external" labeling (often with associated stigma) to "internal" labeling. This move has

often been understood as both empowering for groups (Brown, Adams, Morello-Frosch, Senier and Simpson 2010; Epstein 1996, 2007) and restrictive for some individuals (Sulik 2009). Such self-labeling can result in patient activism (Epstein 1996), or embodied health social movements (Brown, Zavestoski, McCormick, Mayer, Morello-Frosch and Gasior 2004).

Chronic Illness and Identity

Charmaz was one of the first to carefully attend to the ways in which chronic illness alters the self (1997). Since her landmark book, many interactionists have explored the subjective aspects of illness, including the role that new medical science has played in the development of illness identities, ways of self-understanding that incorporate an individual's experience of illness and its impacts.   Writing about the integration of biomedical knowledge and information into breast cancer survivor's identities, Sulik described the process whereby biomedicalization and biomedical uncertainty encourage the development of a new form of illness identity based on associations with and knowledge of science and technology. She called this identity "technoscientific identity" (TSI). For Sulik:

> The development of TSIs involves four central processes: (1) individuals seek and become immersed in professional biomedical knowledge; (2) they use this professional discourse to locate themselves within a technoscientific framework; (3) individuals receive support for the emerging TSI from professional discourse and∕or positive reinforcement from doctors, medical staff, or other validated support systems; and (4) they prioritise their biomedical classifications over their suffering, thereby creating a somatic self. Those who fully incorporate technoscientific classifications align their lay knowledge and embodied experience with professional knowledge. When participants did not have a deep understanding of biomedical technoscientific information, held beliefs that conflicted with prevailing medical discourse, or experienced suffering that prohibited them from suppressing their embodied experiences, they were less likely to use biomedical technoscience as the frame for their illness identity (2009:1072).

> This form of identity transfers biomedical information and characteristics directly to

the person. Sulik writes, "The TSI functions as a means to manage biomedical uncertainty and increase a sense of control over the experience of illness, uncertainty, and risk" (2009:1063). Contrary to the idea of applying a classification to a person, the technoscientific identity encourages the person to think of herself in terms of the classification (2009). Thus the distance that some people diagnosed with breast cancer put between themselves and their illness is diminished, blurring the line between self and illness. Faced with an uncertain outcome when diagnosed with breast cancer, many women turn to the biomedical literature, and to other laypersons with similar diagnoses, to both understand their status as a person with cancer. These actions, Sulik (2009:1063) argues, grant priority to the discourse of biomedical and technical experts, "limiting the full range of discourses available to patients while increasing their reliance on medical authority and technoscience" .

Sulik's application of the technoscientific identities concept focused on women's responses to breast cancer diagnoses and their changing relationship to expert knowledge. The medical literature for breast cancer lead many women to think of themselves as always at risk for recurrence (if their cancer was in remission, or had been removed surgically). Because of this risk, women with TSIs often engaged in surveillance practices and screenings, including testing for genetic mutations known to be associated with breast cancer. Even after their cancer has been "cured," many women undergo annual or semi-annual testing in order to ensure they are cancer-free.

Although Clarke and colleagues' (2003) discussion of technoscientific identities often focuses on genetics, genomics, and statistical analyses of risk, other dimensions are possible. These authors specifically mention the application of science and technologies to human bodies. Within the interactionist tradition, scholars such as Karp (1996, 2006), Frank (1995,

2002)*, and Denzin (1987) have focused on *treatments* as scientific and technological interventions worthy of study in their own right. Some people diagnosed with depression express ambivalence about their need for psychoactive drugs (Karp 2006). Transitioning from a self free of such drugs to a self in need of them can be difficult. In a number of patients, identifying as a person who takes drugs for mental health issues is simply too great a change in self-understanding. Others accommodate drug use, trading some symptom relief with unwanted treatment effects. Frank's work has taken a narrative direction, focusing on how storytelling helps many people in their journey through illness and towards recovery from chronic conditions like cancer. Denzin's approach in *The Recovering Alcoholic* brought our attention to the social sources of both alcoholism and recovery through his ethnography of Alcoholics Anonymous.

Despite the work of these scholars and others, and the fact that chronic illnesses often feature chronic treatment, the study of treatments remains understudied. Although subordinated to the meanings of illness, the meanings of treatments, for both physical and mental illnesses, are subject to the same processes of meaning construction that scholars have chronicled for illnesses. Studying the contests over the meanings of treatments helps to complete our picture of the processes guiding illness and treatment experiences, especially for those with chronic conditions. The effects of these treatments on risk, surveillance, information, and patients' quality of life and satisfaction with life are worthy of study. These effects are more than the "other side" of the illness coin. In the context of highly technical and multidisciplinary treatments, studying them links scholarship on illness experience with science, technology, and medicine studies. Focusing on treatments, I argue, also provides insight into the experience of a significant portion of people with chronic illnesses whose

symptoms are well treated by conventional and novel therapies. In contrast with patients who may be subject to recurrence of conditions like cancer[36], with only episodic (though long-lasting) treatment regimens, many people live with progressive, debilitating diseases and are subject to life-long treatments through pharmaceuticals, modern technoscientific devices and other therapeutic practices. Thus, people with chronic illnesses and treatments may be forced to live with chronic (even if successful) treatments with little hope of cure. In order to describe the identity work undertaken by patients in relationship to their deep brain stimulation device, I introduce the term technoscientific treatment identity (TSTI). In my view, the TSTI covers the discursive construction of self that may result from advanced technoscientific interventions like DBS. These interventions share all the cardinal features of technoscience, and could lead to individual and community identification. We might consider online communities devoted to discussion and support for DBS patients and potential patients as one source of TSTIs.

Technoscientific Identities and Treatment

Turning our attention to the scientific and technical aspects of treatment fills a relative neglect in research on the social aspects of recovery and repair. Classic work by Denzin (1987) and recent work by Talley (2008) has focused on the social, technical, and personal consequences of treatment and risk. This work provides a valuable portrait of life amongst people with debilitating and chronic illnesses, and/or stigmatized bodies, conditions that constitute a certain kind of deviance (Parsons 1951). Although the focus on illness has been productive, focusing on the signs and symptoms of illness may neglect investigation of

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36 To my knowledge, Clarke et al.'s (2003) technoscientific identities concept has been somewhat neglected within their larger argument reframing medicalization in a more technological direction. Sulik's 2009 article is one of the most well-developed responses. Cancer seems to be the best-studied illness with a chronic course and potential for recurrence.

treatment, even while being in conversation with the perspectives of doctors, care-givers and significant others. Illness and its treatment may be two sides of the same experience for people with acute and chronic illness. The voice of the life world for patients (Mishler 1984) most certainly includes both symptoms and treatments. In the following sections, I illustrate the importance of treatments for technoscientific identities through a series of brief stories as told by DBS recipients.

Previous research on technoscientific identities focused on the types of identities formed in relation to the results of genetic testing. Often, this genetic testing confers a type of risky status, one that places individuals and groups in a new category as pre-diseased persons. For example, Frank (2012) studied posts to an online forum for carriers of the BRCA1 and BRCA2 genetic variations known to increase breast cancer risk among women. Many "previvors," people surviving with a predisposition to breast cancer, come to identify with this status. The "previvor" identity, Frank argues, encourages women to understand their breasts and ovaries as nonessential parts of their femininity, sexuality, and reproductive selves, leading to prophylactic surgeries to remove these body parts. Frank illustrates how an identity formed in relation to technoscientific test results can motivate action. A focus on genetics and genetic testing as one source of identity creation is only the most well-developed possibility. Several patients discussed significant changes in self-understanding and identification in the absence of a community of risk—indeed, in the absence of co-located illness community. Amelia's case is similar to many others I interviewed who had recently received the DBS implant. After initial DBS programming, Amelia, a woman with Parkinson's disease, actively engages the work of recovery, negotiating the boundary between the DBS' treatment effects and her own desire for increased physical and social activity. I

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recount her story below.

This chapter follows up on Clarke et al.'s (2003) concept of technoscientific identities as well as Sulik's (2009) account of these identities among breast cancer survivors. Here, I argue that the concept of technoscientific identities can be broadened to include identities formed at the individual level under conditions of treatment and repair. Using the concept of technoscientific treatment identities to account for patients who experience a return to some version of pre-illness identity. These changes are of such significance that they may necessitate a new theoretical vocabulary to capture the experience of individuals who continue to suffer from chronic illnesses while simultaneously receiving significant relief from their symptoms. Technoscientific treatment identities amongst people with chronic illnesses may be significantly different than those subject to risk and surveillance. Not quite cured, but also not as significantly impaired, people-with-devices such as deep brain stimulators occupy a space that is, like risk, liminal—but one that is also based on a relationship between self, body and treatment. People with chronic illnesses do not face risks of recurrence; they face risks of declining physical abilities that take an uncertain and uneven course. Extending Sulik's (2009)work on technoscientific illness identity, I add a focus on the dynamics of self in relation to highly technical treatments like DBS with the TSTI concept . This modest contribution helps sociologists understand the many patients who experience technoscientific treatments as restorative without the hallmarks of technoscientific illness identity. Many patients report that the DBS helps reconstruct a version of normal life that, without the device, seemed unlikely.

Taking the concept of technoscientific identity (TSI) and bringing it into realms of treatment expands the scope of our inquiry into the range of technoscientific treatment

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practices and their impacts on human identity and self-understanding. Expanding the TSI vocabulary opens up the space to recognize that many chronic illnesses do have treatments, and queries effects these treatments have on individual and collective identities. In addition, underscoring the technological aspects of treatments, and their status as a material objects rather than a component of the patient's body, adds an additional layer of interpretive and relational complexity. Genes, and their expression, are components of the individual's body, in certain ways inextricably linked to the self of the person within whose body they compose, enable and constrain. Compared to genes, medical devices such as deep brain stimulation implants are surgically implanted within the body, "foreign" objects that serve a therapeutic purposes. The notion of TSTIs, then, aims to provide some analytic leverage for these situations.

Devices such as the DBS serve somewhat different functions, and share some characteristics with prosthetic devices (objects that augment, or replace, impaired bodily functions) such as cochlear implants and other electronic devices that have external components often visible to outside observers (see Chorost 2005 on cochlear)[37]. Yet DBS devices are also similar to other medical implants, including pacemakers and spinal cord stimulators, both devices whose work is accomplished entirely within the body of the recipient. In this case, the DBS enables a more "normal" presentation of one's body while simultaneously altering organic functions, in this case, the cycle of dopamine use within certain areas deep within the brain of the user. The DBS device, then, is wholly other to the patient *and* embedded within the patient. Here, I unpack the concept of technoscientific

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37 I consider DBS devices to be significantly different from visible prosthetics like Cochlear implants. While some Cochlear hardware is implanted within the body of its recipient, many components are publicly visible. Current models of these implants must have an external component because the device picks up sound waves that are external to the body (i.e. the speech of others). In order to "hear" a sound wave external to the body through a prosthetic, that prosthetic must reside outside the body.

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identity by attending closely to the experiences and meanings of the recipients of these brain altering devices themselves.

Understanding the diverse interpretations and understandings of self-identity, including possible technoscientific identities, requires engaging recipients in dialog. Methodologically, this requires in-depth conversations with DBS and other device recipients. Here, I ask DBS recipients to reflect on the meaning of their illness and treatment, focusing on their introduction to and experience with the DBS device. I analyzed the interview transcripts, seeking to capture the range of human meanings from experience while keeping the social, interpersonal and contextual aspects of the interview situation in mind. Interpreting patient experiences in this way may help sociologists discover previously hidden layers of meaning that are both personal and shared, embedded in subjective experience.

The focal technology here is the deep brain stimulation device. In taking the DBS device as a particular object of interest, I want to inquire beyond its form and its functions to the meaning of the object for the person who lives with it. DBS recipients both own the device as an object and are intimately bound together with it. The device is *theirs* in a way that another's DBS isn't, and that DBS devices or other medical devices in general are not, either.

Many researchers in cultural, medical, and other areas of sociology take a qualitative approach when investigating the status afforded to particular objects in the lives of the people and populations they study. Often, sociologists find that significant communities do cohere around objects, practices, and events. For example, Clawson (2011) studied sacred harp singing groups, an intensely visceral and collective musical genre, and the foundations of this diverse community. We might expect that DBS recipients would form relationships with the

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objects that work within their own bodies as well. If these processes occur in reference to objects external to the body, must they also happen for objects within the body?

Analytic Techniques

In this chapter, I utilize narrative analytic techniques (Riessman 1990) to develop our knowledge of technoscientific identities (Clarke, Shim, Mamo, Fosket and Fishman 2003; Clarke, Mamo, Fishman and Shim 2010). Recently, medical sociologists have renewed their commitment to in-depth studies of the social and technological processes that result in new forms of knowledge and claims-making (Dumit 2004, Joyce 2008) as well as new forms of biopolitics and health activism (Clarke and Olesen 1999, Epstein 1996, 2007, Klawiter 2008). Biopolitics, a term these scholars take from Foucault (1978), refers to the ways power is exercised on and through individual and collective bodies within a state. Multiple streams of research have developed to explore this concept. Lemke (2005) suggests that the term has been productively used in the science and technology studies, feminist science studies, and gender studies for inquiries into the multiple ways that living bodies are understood as artificial and thus open to decomposition and recombination. While not all of these scholars take a narrative approach, many of these studies have reinvigorated debates over medicalization in professional practice, and its multiple effects on patient experience (Clarke et al. 2010).

Since medicine is increasingly characterized by the interaction of highly technological and scientific practices, these practices must be theorized in both their meanings and their material forms. According to Clarke and colleagues (2003), these practices include corporeal transformations and their manifestations, taking both technoscientific forms of knowledge, treatments, and practices and the body as co-constituitive. Although recent scholarship has

focused on risk, and its foundation in new genetic testing, other formations are possible.

Analysis of pre- and post-implantation interviews suggests that DBS recipients do engage in identity work (Strauss et al. 1982). This work results in establishing a new normality as people seek continuity with previous forms of self rather than an identity closely tied to medical technology. The validity of this claim can be tested by its resonance in the experience of other people who have received DBS. In contrast with some other descriptions of technoscientific identities, including those Sulik (2009) described, the people I spoke to only rarely described deep and lasting changes in their own self-understanding. It seems that, while self-descriptions and narratives of self can be fluid and change across time, many people seek narrative continuity across time (Holstein and Gubrium 2000). Radical breaks with previous forms of self may be less common than the literature suggests. When such breaks occur, they may be in the service of re-establishing narrative continuity with a previously valued identity and told in a form that maximizes an individual's sense of a coherent self. Although this finding may be controversial to many who subscribe to a strong constructionist view of the self, such as Butler (2005).

Developing a chronic illness like Parkinson's, Essential Tremor, or dystonia is almost without exception disruptive and life-altering (Charmaz 1993, Frank 2002). In the face of ongoing impairment, the need to gain control of self and illness experience is paramount. As Reissman (1990) suggests, people who have experienced disruptive life events often attempt to construct positive images of self through discourse, telling stories that bolster self esteem and diminish stigmatized aspects of their situation. Their stories aim to secure morally worthy status, often by emphasizing their success in highly valued roles such as father, employee, and husband, from the perspective of their audience.

Sociologists have made significant strides in their empirical analysis of chronic illness by attending to the work patients do in constructing their stories. Far from simple, verbatim accounts of events, these stories give people the opportunity to reconstruct their own lives during serious disruption and in its aftermath (Frank 1995). Sociologists have considered the work of storytelling, including the motivations for any particular storytelling event, the structure of the story, and the work that storytelling does for the storyteller and his or her audience (Riessman 2008). In the analysis that follows, I construct a thematic narrative analysis of patients' stories of their lives with DBS treatment (Riessman 2008). Thematic narrative analysis focuses on the most common experiences and understandings relayed in the content of interviews, rather than the form this content takes. I follow Riessman's (2008:6) understanding of personal narrative as "long sections of talk—extended accounts of lives in context." The stories below describe in general terms, what effects living with a DBS device have on everyday life activities such as walking, taking medication, at work and at play. I argue that this analysis of patient narratives of their experiences with illness and treatment expands our knowledge of the subjective and intersubjective aspects of life with chronic illness. Narrative analysts, such as Riessman, help other researchers understand the ways in which stories are told, and the settings in which they are told, elicit certain types of narratives and relay aspects of these experiences that are held in common among members of a particular group. Thus, sociologists and interactionists may uncover important layers of meaning in their discussions of chronic illness and treatment that are common to the experience itself while simultaneously understanding that this knowledge is always partial (Morrison and Bliton 2011).

Connecting individual stories with a sociological perspective on narratives allows

scholars access to resources and analytic tools from both symbolic interactionist thought and literary/narrative analytics. I think that this intersection is a fruitful one for analyzing self-stories of people undergoing chronic illness and treatment—precisely because these illnesses, and their associated treatments disrupt previously valued lines of action, occasioning the re-telling of self-stories.

I intended my questions to lead respondents toward narrating their trajectory from illness through treatment. I expected DBS recipients to tell some stories, but was unprepared for the extent to which their responses to my questions took a story form. Respondents relayed their experiences to me in stories, sometimes brief vignettes, sometimes in extensive detail. Many plotted their experiences in sequence, noting key events, turning points, meaningful events and interactions—including receiving approval from doctors, securing payment for the surgeries, and consulting with friends and relatives. Occasionally, a respondents' story was told with the help of another's story, acknowledging solidarity with others' struggle through chronic illness. Far from solipsistic, as Frank (2010) argues, stories *do* things—they act on us, with us, and on behalf of us—stories carry the past, envision the future and provide scripts for human action without determining it.

In his most recent book, Arthur Frank (2010) suggests that sociologists should turn their attention towards stories and the work they do for individuals and communities. He argues that this, a "storied sociology" would recognize the social sources of stories and storytelling. For Frank (2010:14), no one ever thinks a story that is wholly original, and that no one ever thinks a story alone. Frank (2010) draws a distinction between story and narrative. Stories are individual, local, and specific, often describing ongoing projects and activities. Narratives, on the other hand, are the resources from which people build the stories

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they tell, and are key resources for the intelligibility of those stories (Frank 2010). Analyzing stories allows interactionists to recognize the ongoing lines of action in any individual's life are essentially stories about the way in which the world works. The extent to which any particular story is intelligible testifies to its location within an existing narrative system. Frank (2010:14) writes, "people's stories, however personal they are, depend on shared narrative resources." Since stories are individual accomplishments with collective sources, they include agency as well as structure.

By definition, chronic illnesses are long-lasting, with the prospects for cure exceedingly low. Understanding aspects of experiences people with movement disorders who are considering (and ultimately receive) treatment with deep brain stimulation provides us with an important window into the processes many people undergo when considering their shift from illness to treatment. This study asks: How do identities, including technoscientific identities, shift when confronted with chronic treatments? Through an in-depth thematic analysis of 22 in depth interviews, I distinguish three genres of narratives that help people with chronic treatment understand themselves in light of their new status as person-with-brain implant. Examining the treatment narratives of people with DBS is crucially important for our understanding of the human side of highly technoscientific medical treatments, technologies that often alter our basic biological processes.

Three Narrative Genres

My thematic analysis yielded three widely used narratives that provide a framework for understanding patient stories on their trajectory through illness and treatment. These narratives are also touchstones in understanding the forms of technoscientific treatment identities, identities formed in relation to advanced, in this case, medical, technologies. The

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stories shared here the result of self-described successful surgeries and the resulting, positively evaluated, treatment experiences. Future research should investigate the forms of technoscientific treatment identity that develop in response to negatively evaluated DBS treatment. Each narrative genre shares an overriding concern with reducing, or eliminating bodily stigmas. Navigating the new relationship between self, device, and illness is a continuing concern for patients whose stories take each narrative form. The first narrative, negotiating a new normal, covers accounts that focus on learning the limits of the DBS device's treatment effects, and corresponding changes to each patient's version of self with the device "on board." The second narrative, normality as sameness, represents one kind of blurring the distinction between pre- and post-DBS implantation. Patients whose stories reflect this narrative suggest that the DBS has become an unremarkable form of treatment, similar to drug therapies and integrated into daily routines. The final narrative, treatment as positive disruption, replaces a mundane or invisibility with the notion that the DBS device constitutes an important alteration to self and illness career. Although I am separating these narratives for analytic purposes here, some people I interviewed told stories from more than one narrative genre. This suggests that DBS recipients can be flexible in presenting their self-stories, adapting them to suit their own purposes.

Negotiating a new normal

Amelia, introduced in the last chapter, has lived with Parkinson's disease for over 10 years. We spoke for a second time about two months after her DBS surgery. She is a white, intelligent and articulate former medical writer living in one of the oldest homes in her rural Kentucky county. She and her roommate Rachel are supported solely by Social Security disability payments. Relying on Rachel, Amelia ventures out of her house for appointments

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with her doctors, the Social Security office, to the grocery, and to her place of worship. In this excerpt, Amelia explains one of the unexpected effects of her treatment with DBS.

> Morrison: How has the device been working for you?
>
> Amelia: Very well. [I] went through a period of about a week when I was getting more exercise than [I] used to. And I was, it was shutting, going to off, not the device turning off but going to the off state very suddenly. So that was, that was learning how to titrate activity against the device. And that is one of the things I will be talking to Dr. Adams [her neurologist] about. Because I haven't been pushing activity. I don't think she wants me to. So that's, that's been the difficulty. I also have discovered, I had been, this is strange. They say there is no relationship with what you eat. I'm finding that I really can't eat beef. If I do it turns the reaction off. I go very suddenly and quite unpleasantly into the off state and I have to wait for the beef to wear off rather than waiting for the drug to wear off (002b, 148-155).

At this point in her treatment, Amelia recounts a story of coming to an understanding of the limits of DBS treatment effects. After surgery, Amelia's tremor in her arms subsided, and she was able to walk with the fluidity and stamina that she had not enjoyed for several years. She was now able to walk up and down her long driveway, an activity she had all but abandoned prior to DBS. To her surprise, her increasing activity caused pain and trembling in her arms, which she describes as going from an "on" state to an "off" state. The language of "on" and "off" is typical of people with Parkinson's disease. Since the effects of drug therapy tend to wax and wane on a somewhat predictable schedule, people like Amelia often discuss these states, and their efforts to avoid long periods in the "off" state, before more drugs may be consumed. In order to avoid sudden "off" periods, Amelia has reduced her exercise in order to balance her activity level with the effects of the device and her medications. Instead of blaming the DBS for failing to consistently reduce her PD symptoms, she praises the device's activity while noting its shortcomings. It is Amelia who must change her desired activities, reducing the amount of exercise she takes. The contradiction between praise for the

device and frustration and surprise regarding its limits goes unremarked. The ability to exercise for any sustained period of time is marked as a success for the device.

Amelia's story is one of many I heard in which people with DBS devices moderate their activities. Most DBS recipients are used to choreographed days that balance activity and rest, drug benefits and the threat of "wearing off." What was once a balance between activity and drug treatment effects has now become a more complex, three-way interaction between drugs, device, and vigilant attention to her PD symptoms. In Amelia's case, the sudden loss of treatment effects leads to a reconsideration of her desire for physical activity, the actions of the DBS and the effects of medication. Amelia could use the hand-held controller to alter the settings on her DBS device, raising or lowering the frequency and/or amplitude of electric pulses within pre-set ranges. Although the controller is relatively easy to use, with just a few buttons, she chose not to alter her DBS' effects, or her medication. Instead, Amelia reduced her physical activity and consulted her neurologist in the hope that she will be able to extend her physical activity without the sudden loss of treatment effects.

The management of device, drugs, and activities is also evident in Amelia's developing relationship to high-protein foods like beef. Before DBS surgery, Amelia was able to eat beef without incident. This new configuration of self, drugs, and device makes this activity problematic and potentially risky. She must learn a new way to "titrate" her meal selections against the joint actions of her DBS and continuing drug regimen. An optimal DBS configuration (one in which stimulation reduces as many PD symptoms as possible) means changing Amelia's bodily capacities. Amelia steadily works through her daily life, moderating her activities to match her drug and device effects, changing her routines in order to accommodate an increased, but still sub-optimal, level of relief from her Parkinson's

symptoms.

In the excerpt below, Amelia discovers that she does not have diabetic neuopathy. Amelia has lived with diabetes for years, and was told that the symptoms she experienced in her feet were caused by that illness. After receiving the DBS implant, Amelia's foot problems seemed to miraculously disappear.

> Amelia: I also discovered that something that I thought was independent [is connected to PD]. I have diabetic neuropathy in my feet. I discovered a lot of the symptoms of diabetic neuropathy are actually Parkinson's. And they respond to taking Sinemet now. Which they didn't before. And I mentioned that to her [Dr. Adams] over the phone and she said, "Oh yes, that's one way we distinguish between neuropathy and Parkinson's." So she wasn't at all surprised on that one (002b, 172-176).

This except illustrates how the addition of a functioning DBS alters both the symptoms previously determined to be Parkinson's related and those thought to be independent or comorbid, forcing Amelia to think differently about a concurrent illness. In the balance between DBS, drugs, and disease, the DBS' effects allowed Sinemet to alter a PD symptom that was previously unresponsive to any form of treatment. Amelia mobilizes her experience and knowledge of her body and its problems to fashion an explanation for her disappearing symptoms. This explanation combines DBS effects and drug effects, repositioning this ailment under the rubric of Parkinson's instead of diabetic neuropathy. Amelia's understanding of her body and its processes are thus altered by the addition of the DBS device to her body, an insight that she would not have gained without it—and one that was unavailable to her doctors as well.

Normality as sameness

Some respondents reported a form of sameness that carried across their trajectory of illness and treatment. This form of identity maintenance is least consistent with the idea of

technoscientific treatment identity as formed as the result of becoming a DBS implant user.

The group of DBS recipients whose stories shared this theme included included several

respondents like Amelia who experienced both significant improvement in their symptoms,

and many those whose symptoms remained remarkably consistent both before and after their

implantation. I interviewed John, a 58-year -old white man who has had essential tremor for

many years. We spoke at his home on the outskirts of an East Tennessee mountain town

where John lives with his wife and two chihuahuas. Although he often struggles with pain in

his arms and consistent fatigue, John continues his work as a police desk officer, a position

he has held in two states. John spoke with me in a Southern accent, slowly and melodically,

several months after his DBS surgery. His story blurs the distinction between his self-identity

before and after DBS.

> Morrison: How does it feel, physically, to have a device in your brain and
> body?
>
> John: You don't know it's there.
>
> Morrison: Can you forget about it?
>
> John: Yeah. Yeah. There's times I didn't know whether or not I had it on or not
> actually... You know... sometimes I'll turn it off of a night when I'm not using it
> to save on this battery. And ah, I'll forget to turn it off, or forget to turn it back
> on sometimes the next day. You just, you don't know it's there. Until you go to
> do something, and then it will tell you whether it's on or off by what you can do.
>
> Morrison: Yeah.
>
> John: That's the only way you'd know.
>
> Morrison: So in the morning, let's say you've left it off. What's the first thing that
> you might do ...
>
> John: Ah, well I've got other medication I take, you know, for my restless leg
> syndrome that I have to take, and I have to take my heart medication. When I go
> to take my medication I'll know by trying to take the lid off the bottle, or 'Yep,
> better go turn it on.' You know (008b, 512-527).

When asked about how it feels to have a device in his brain and body, John's response focused on his interactions with the device, turning it on and off via the small remote-control device that each DBS patient receives in order to check the device's battery life and stimulation levels. For John, and for a significant minority of my respondents, the DBS device becomes less relevant to their daily illness experience. While the electrical stimulation alters brain chemicals, dampening the symptoms of essential tremor, Parkinson's disease and dystonia, its user remains mostly unaware of this work.

Emily, 61, a white, middle class woman, often forgets about her device. When I asked her to describe how her DBS device works within her brain, she responded:

> Well, it's been good to me. The symptoms that I had [now] I don't even think about it very much. I just really don't know. It must be working very well with the symptoms that I had because it's to the point now that I don't even think about it (004, 173-174).

Elaborating, Emily describes situations that activate her awareness, making the DBS problematic, if temporarily:

> The only time I think about the batteries, my little grandson will get up in my lap or something and he puts his hand where it is and mashes down really hard because he   doesn't realize what is. And other than that, I don't even notice that I have anything there. Except the wires are on this side of my neck and sometimes I can feel those if I turn my head a certain way or something then you can feel where the wires are and I'll get a little tingling or something, but not much. It's not really a tingling, that's probably not the right word, but I know that they're there, and I can feel something.

[From here, Emily tells me about her recent visit to the neurologist for a DBS check-up. We return to our discussion.]

> Morrison: But as an everyday kind of thing you don't really think about it?

> Emily: No. When I run my hands through what little hair I have now I can feel the spots where they have worked on and the wires are down, they have like a ridge there where all those are still there. And I can tell that they're there but as a rule I don't even think about it. I don't feel anything, really (004b, 210-218).

Steven, a 76-year-old white man, suggested that the implant's wires were the most visible

part of the device. When I asked him to describe how the device is working inside his brain,

Steven responded:

> It must be working fine. Only thing I reach back here and feel where it goes
> down and down to my neck right there [runs his hand along the base of his
> skull down his neck, tracing the path of the electrical leads]. And then it goes
> on into my shoulder I guess (006b, 308-310).

I pursued this line of questions with Steven, asking him to articulate just how he understands

and interacts with his implant. Notice how Steven integrates a future haircut into his

discussion of the implant wires and their impact on the shape of his head. He does not seem

concerned about the implant or its actions:

> Morrison: not everyone has one of these things inside their bodies and brains,
> so I can only ask you what that's like. So, how do you relate to the device? Do
> you think about it at all?
>
> Steven: Not until time to hook it up of a morning and turn it off at night. Now
> I think more about where it's hooked up right through here [pointing to his neck]
>
> Morrison: Okay, just at the base of your, the top of your neck
>
> Steven: and the place on the back of my head right there. It's kind of, well it's
> a little, sticks out more than the rest of my head. Of course, I don't have much
> hair left anymore so. In fact, the next time I go to the barber shop I'm just going
> to have him cut the whole thing off.
>
> Morrison: Is that right? Just all of it. All of it, or just the top?
>
> Steven: Well, have it cut short like I have [now]. I don't want to have to get near
> as many haircuts.
>
> Morrison: I understand that. I understand that. So you say the only time you
> really think about the device is when you turn it on in the morning and turn it
> off at night. Is there any other way that you would be able to tell that it's there?
>
> Steven: Not really, I can't (006b, 334-348).
>
> For Steve, the implant is transparent during the day, and unnecessary during the night

(people with essential tremor do not exhibit symptoms when asleep). His morning routine includes turning his device on, and this is perhaps similar to the routine that Parkinson's patients develop when taking their daily medications on schedule. Many patients could not account for the device's effects or explain how the DBS device works, both adding to their sense of wonderment and distancing themselves from detailed knowledge. Although many DBS recipients were unable to provide an account, those patients who remained employed, or who held upper-middle and professional class occupations, were most likely to express a deeper understanding of their device.

John, Emily, and Steven's descriptions of life with the DBS often focused on their ability to conduct themselves "normally" or to manage mundane behaviors without the fear of stigma or public embarrassment. For example, when I asked Steven to describe how his daily life has changed since DBS, he responded:

Oh, I do about the same things now that I always done.

[His wife, Vicki, quickly countered: But when you go to the bank you can sign whatever.]

Steven: Well yeah, I can

Vicki: You can eat

Steven: I can use my right hand for about anything I need.

Vicki: You can button your shirt.

Morrison: Was that a problem before, buttoning shirts?

Vicki: Yes, because his hands were just so bad.

[Steven and Vicki go back and forth, her mentioning tasks Steven can now perform, him agreeing. Then Steven tells a story:]

Steven: I've got a little grandson that's going on four. And when he comes over here, he just lives right back there. [motions behind his home] He wants

a sucker or a piece of bubble gum or, and I always have it.

Vicki: You can pick him up and play with him, pick him up and hold him.

Morrison: So you can play with your grandson now?

Steven: Oh yeah.

Morrison: Were you able to hold him before?

Steven: Not as well as I'd like to.

Morrison: And you can pick out a piece of candy for him, or gum, or

Steven: Oh yeah.

Vicki: Yeah, help him go to the bathroom, help him get his pants pulled
back up. Little things (006b, 423-452).

Like many objects in our environment, the DBS device becomes salient in the

thoughts and actions of recipients when it is *not* working as it should, or when its recipient

neglects to turn his or her stimulator "on." Like many objects in our various social worlds,

the DBS only captures our attention, or "stands out" to us at moments that disrupt the normal

flow of daily events (Garfinkel 2002). It is precisely this form of mundane work, reliance on

and interaction with devices like DBS, that interactionists should consider when attempting

to understand the role of highly technical objects in contemporary health care.

Treatment as positive disruption

Although many DBS recipients indicated sameness and continuity in their self-

understanding, these accounts were not always consistent. John avows a significant change in

self-understanding and social relationships since his DBS surgery. The addition of the DBS

implant to John's brain and body provided significant relief from the rhythmic shaking in his

arms that plagued his life with essential tremor. The shaking was painful and prevented John

from activities most consider unremarkable, like tying shoes and buttoning shirts. Before

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DBS, John declined invitations to hunt and fish, limiting his outdoor and public activities.

When I asked him to tell me more about what has remained consistent across his pre- and

post-DBS experience, John enthusiastically reports that he has made a radical break from his

life with essential tremor.

> Morrison: So you said you're able to do a lot more things now that you've
> had the DBS and it's working pretty well. In what ways do you feel the same,
> what has stayed the same in your experience with essential tremor between now
> and before you had DBS?
>
> John: I don't think anything is the same. Because before the DBS it was, you
> know I could do about anything, but it just took so long, and if I messed
> something up it was frustrating because I had to start over, where now I don't
> have that problem. So I don't think anything is the same. It's all better now.
>
> Morrison: Okay. In what ways do you feel the same? Are there any ways that
> you feel the same?
>
> John: No. It makes, it just, it's, well just like that, a lady told me the day I went
> in to have my surgery, she'd had it done and she told me, she said, 'This is a life-
> altering experience for you. You don't realize it yet, but it is.' And she was right,
> it is.
>
> It [DBS] changes everything, and for the better. So you know, you can't
> compare ah, well you can compare the bad to the good, but nothing, nothing is
> the same. It literally is a life altering experience for anybody that has it done.
>
> Morrison: So in what ways do you feel different since the surgery?
>
> John: Well obviously off the medication I've got more energy, more pep. I feel
> like I've lost a lot of weight since I've been off of it. Because before, you know,
> you're not getting [exercise], you don't move.
>
> Morrison: Right.
>
> John: And I go fishing now a couple of days a week, and take these two
> knuckleheads [dogs] walking of a morning before I go to work. It's just,
> drastically different. You know, now I look forward to my days off where before
> I didn't, I didn't care. I look forward to getting up, moving, and just doing things,
> because now I can do things that I couldn't do before. It's literally a life altering
> experience (008b, 832-858).

[A few minutes later in our conversation, John returns to the theme of life-altering difference,

contrasting his current abilities with his previously self-imposed confinement:]

> John: It's [essential tremoris] not painful by any means, it's just, you're so, well I guess you confine yourself because you don't want other people to see how you are and it, it's just terrible. It's a terrible way to live. And like the lady said, and I agree with her, it's a life-altering experience having it done (008b, 895-897).

John's story may seem inconsistent: Is his self-understanding, his identity significantly different, or has he remained the same throughout his experience with essential tremorthat culminated in DBS? This apparent contradiction can be reconciled by considering John's version of the device's ontology, its being within his body, and his interpretation of the device's effects on his essential tremor symptoms.

Considering the device's existence, John sees no separation between himself and his device, as it practically disappears with its use. It is only when the device's effects are disrupted that its status as a "foreign" object within his body comes to his consciousness. It is then that John may reflect on his status as a person-with-device and the meaning of the device for his identity. The quotes above illustrate John's ongoing symbolic interaction within the triad of self, illness, and device, as John credits the DBS for the life-changing experience of restored motor function. John's experience of the DBS' treatment effects enables a more active and publicly engaged lifestyle, one in which he, like Amelia, is able to return to some level of previously valued activities.

Embedded within this excerpt is John's account of a chance meeting with another DBS recipient. Here, John recalls another attempt to frame the significance of the DBS' effects. These effects are significant at multiple levels of an individual's interior and public life, including relationships with significant others. John tells us that he has more energy, which makes him available for a more active presence within his community, fewer sick days

at work, and a return to valued outdoor activities. John's inclusion of another story within his reveals one way that interpretations of experience are transmitted. This transmission takes place with and through the language and interpretive resources of others, always through interaction.

Conclusion: The Work of Normal

Regardless of where their stories fit in the themes outlined above, most of the stories DBS recipients told me shared a focus on the work of repair, the ways in which people who experience chronic and progressive movement disorders interpret their struggle with drugs and device. Taken together, these three types of stories share the work of discursively constructing a new "normal," responding to the problem of device implantation within the body and brain. These themes illustrate once again the range of interpretations possible for our understanding of medical devices from the perspective of users themselves. Taking this approach to the study of self and object reminds interactionists that distinctions between self and object are less stable than they appear, that previously external objects may be integrated in a way that seems effortless. Yet the account of effortless integration often masks the difficult work that people like Amelia engage with—testing the limits of the DBS, reaching those limits, and recalibrating activity. For DBS recipients like Lauren, a technoscientific treatment identity can take the form of a self that is dramatically different from the Parkinsonian illness identity, closer to a pre-Parkinsonian self, and yet never a post-Parkinsonian self. This form of treatment identity, the TSTI, relies on a highly technical, risky surgery with long-lasting consequences that follow a patient throughout his or her career as a person with a movement disorder. By studying the human experience of illness and treatment with DBS patients helps interactionists create a more nuanced picture of

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people who are helped, but not cured, by technoscientific advances.

When sociologists approach technoscientific visions of the future, whether of humans with enhanced cognitive and physical abilities, or of human-computer hybrids, they should be careful to separate facts from fictions and utopian futures from current complex arrangements of suffering and treatment. This chapter has argued that, contrary to many visions of human-device hybrids in which the non-human element is central to the construction of human identity, only a few of my respondents with DBS devices reported radically different notions of self after implantation. The work of storytelling, for these patients, has been focused on constructing continuity rather than radical change. Relations between self and illness were reconfigured, however, and respondents commonly reported *integrating* the brain implant into their sense of self, often "forgetting" its presence while simultaneously relying on its effects. Future research on human-device relations should continue to investigate the multiple layers of human experience medical implant recipients report, and could take up the technoscientific treatment identity concept, applying it to future cases.

CHAPTER V

CARDIAC AND BRAIN-COMPUTER INTERFACES

"There is no Moore's Law for human beings."

-- Michael Chorost, *World Wide Mind: The Coming Integration of Humanity, Machines, and the Internet*. p 8. (2011, New York: Free Press).

There is no delusion more damaging than to get the idea in your head that you understand the functioning of your own brain. Once you acquire such a notion, you run the danger of moving in to take charge, guiding your thoughts, shepherding your mind from place to place, *controlling* it, making lists of regulations. The human mind is not meant to be governed, certainly not by any book of rules yet written; it is supposed to run itself, and we are obliged to follow it along, trying to keep up with it as best we can. It is all very well to be aware of your awareness, even proud of it, but never try to operate it. You are not up to the job.

– Lewis Thomas, "The Attic of the Brain" p. 141 in *Late Night Thoughts on Listening to Mahler's Ninth Symphony.* (1983, New York: The Viking Press).

In this chapter, I compare the reflective accounts of people with pacemakers to the interview data I collected from DBS recipients. I find that memoirists and the DBS recipients I spoke with share a quest to return to a sense of normality that had eluded them in the past. I also find that both groups strive to make meaningful use of the signs and symptoms of their illnesses. Sometimes, this takes the form of reflection upon their own suffering. As others (Leibing 2009) have reported, many patients seek to interpret the effects of pharmaceutical and device treatment. Following Cromby (2011), I call this type of attention to and interpretation of the body's signs embodied meaning.

The notion of comparing the pacemaker for the heart to the "pacemaker for the brain" seems obvious. The Medtronic Corporation, a pioneering medical technology firm whose co-founder, Earl Bakken, was one of the first to develop the external cardiac pacemaker, features

the link between the two technologies (Medtronic, Inc. 2012a). Framing the DBS device as an extension of an older, now reliable and even common medical device might reduce any anxieties potential recipients hold about placing electrodes into their brain. Both devices are completely implanted within the body. Both use electrodes, batteries, and electric current to stimulate specific regions of the heart and brain, respectively. Both technologies require ongoing monitoring by doctors and patients. The comparison seems apt, and perhaps the DBS will follow a trajectory similar to the cardiac pacemaker: from external to partially internal to completely internal; from unreliable and easily broken to well designed, light weight, durable and unobtrusive.

There are important differences. Aside from the obvious differences in placement, the most important is likely the life-sustaining features of the cardiac pacemaker for those who require continuous pacing. Originally used for complete "heart block" or absence of normal heart rhythm, the pacemaker is a technology aimed at forestalling death (Jeffrey 2001). Many early pacemaker recipients died when their pacemaker battery unit lost power, was damaged, or leaked. Broken electrodes, insecure attachment to the heart, and many other troubles plagued early cardiac pacing. The earliest pacemakers were external, relying on hospital power and extension cords (Jeffrey 2001). Cardiac pacing is required to sustain many patients' lives. Today's pacemakers are quite well advanced, with well-understood procedures for implantation, programming, and monitoring. In 1963, "demand" pacemakers were invented. They provided electrical stimulation to the heart only when patients whose hearts failed to pump correctly, saving battery power, extending the lifespan of the device, and avoiding competition with naturally occurring heart rhythm (Jeffrey 2001).

In contrast, DBS is not life-sustaining (or life-saving), the doctors I worked with

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describe it as elective. Yet elective does not mean optional for many patients, as each of my respondents who received the implant attest. These recipients felt that their condition absolutely required DBS treatment. These people vigorously argued that their conditions required DBS treatment, and they offered a variety of reasons why their case made the treatment necessary. While not strictly necessary for the maintenance of one's life, the effects of DBS are, for many recipients, critically important for the quality of one's remaining years. Discussions of life quality were a central pillar of each patient's case for DBS implantation and treatment.

These two devices, each continually subject to innovation in their design, capabilities, and uses, share a common history in electrophysiology and biomedical engineering (Channell 1991). These devices either replace or assist normal, naturally-occurring processes in the brain and heart. These and other interventions have, "raised questions concerning the distinction between the human and the machine. As each of these mechanical [or digital] devices becomes a functioning part of a human, it becomes more and more difficult to characterize the assimilated object as a human or as a machine" (Channell 1991:129). These innovations, and the questions they raise, are often characterized by the term cyborg, with complex meanings and interpretations. (Channell 1991; Haraway 1991).[38] Minimally, the term cyborg names a unique relation between the human and the machine, "'needs to function without the benefit of consciousness, in order to cooperate with the body's own autonomous homeostatic controls'" (Clynes and Klines 1960, as cited in Channell 1991:129). More recent work within the medical community on brain-computer interface (BCI) devices has described treatment studies for Alzheimer's dementia and depression (Tierney, Sankar &

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38 For a contemporary, and constantly expanding trove of writing on the relations between people and technologies from social scientific perspectives, see http://thesocietypages.org/cyborgology/.

Lozano 2011). Benabid and colleagues (2011) report on new electrodes, and are advancing techniques for intravenous delivery of DBS electrodes.

One goal of this dissertation is to provide readers with insight into the experience of living a cyborg life, being a person with a brain-computer interface. The philosophical questions about dividing the organic from the inorganic, the body from the device, look somewhat different from this perspective. Instead of asking what the implantation of devices within the human body means for human life in its broadest sense, we might do well to consider the practice of life with these devices. Thus, my project asks questions of people living with DBS devices so that the scholarly community might gain a new perspective on life with such brain-computer interfaces. Asking people with DBS implants to reflect on their experience with their devices reveals the sense- and meaning-making practices that may soon be required, or desired, to reduce human suffering.

In my view, Haraway's work on the cyborg is neither a celebration of human capacity nor dystopian vision--it's vividly and creatively descriptive of practice while anticipating change. Some forms of practice may lead to liberation, others to oppression for some people at some times and with some technologies (1991). As social scientists, our central concern is often to investigate the situation, and Kurt Wolff's plea to investigate with openness seems to resonate well with Haraway's call for inquiry (1976).

In the epigraph above, Chorost refers to Gordon Moore's famous 1965 prediction that the number of components on an integrated circuit microchip would grow very quickly, thus the price for the integrated circuit would decline. The prediction proved helpful in defining the possibilities for silicon-based microchips, and CalTech professor Carver Mead enhanced Moore's fame by labeling the prediction "Moore's Law" (Computer History Museum 2007;

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Intel Corporation 2005). Chorost knows the strengths and limitations of Moore's Law

personally. His 2005 book *Rebuilt: How Becoming Part Computer Made Me More Human*

vividly illustrates the author's journey through hearing impairment, hearing loss and eventual

recovery with cochlear implants. Chorost's hearing was not literally recovered, however, but

replaced by the implant's 280,000 transistors. These transistors stimulate Chorost's auditory

nerves, but the signals that result do not replicate the depth and nuance of his natural hearing.

Chorost had to re-learn how to hear, that is, how to interpret the stimuli that his implant

received, translated into digital signals, transferred to the thousands of transistors, which in

turn stimulated his auditory nerves. For Chorost, choosing a cochlear implant opened up

difficult and important questions about the role of technologies in replicating, and potentially

enhancing, native human senses. Ultimately, Chorost argues that by becoming a cyborg, a

human-device hybrid, he grew more humane; more caring, compassionate, better able to

understand others, less self-serving.

In his new book, Chorost (2011) investigates current technologies and envisions

future brain-computer hybrids. Combining science journalism with his own philosophical

reflections, he notes that many currently-available devices that may be implanted invite

questions about the division between what is biological, internal and human and what is

external, technological and thus foreign to the human. Profiling a nanowire system tracking

neuron firing, communicating those pulses to others, and receiving others' brain firing data

for the purposes of communication, he writes:

> For most people the body is In Here and the computer is Out There. In our
> technology-saturated lives, the only remaining computer-free zone is our own
> warm, wrinkly sacks of skin and bone. The body is the last redoubt, the one
> aspect of human life that computers have not changed. Sacrosanct, pristine,
> untouched. A neural implant changes all that. In my case, when I got my
> cochlear implant all of a sudden the computer was In Here, taking up

permanent residence, enforcing new rules. All of a sudden, I had to pay
attention to software and batteries as a matter of my body's own functioning.

A cochlear implant gives me an inkling of what it would be like,
psychologically, to accept such an electronic enfolding. But just an inkling. I
had only machinery to deal with, not other minds. For that reason, my cochlear
implant didn't fundamentally challenge my sense of autonomy and selfhood.
(2011:60).

Chorost's book invites non-specialist readers to reconsider the distinction between

inner and outer that so often seems to structure our understanding of, and participation within

the world. I take his capitalization of "In Here" and "Out There" to mean that these

distinctions are more than ways of knowing the world for many people. They are often

understood to be metaphysical, having the status of transcendent truth. Although the

inner/outer, self/other distinctions are relied upon by many, understanding the world in this

way neglects the more fundamental truth of relationship and interaction that makes these

distinctions possible. Our bodies are actually within the scene that appears to be "outer", in

front of, behind, to the left or right of us. The meaning of what is around us is, from the

perspective of the actor, always relative to our embodiment within our immediate

environment. Philosophers within the phenomenological tradition and symbolic interaction

schools of sociology have built their understanding of social life based on the concept of

relation between self and other(s), including nonhuman objects (Johnson 2007; Blumer

1969). Neural implants, Chorost reports, breach this boundary and thus disrupt our

understanding of our bodies and, potentially, ourselves. Chorost makes the case that, to a

much greater extent than many contemporary Americans believe, our thoughts, actions,

habits and dispositions are the result of social networks, understood as webs of relationships

that communicate and create meaning. For example, Christakis and Fowler (2009) report on

the power of social networks to predict behavior, influence health and spread violence.

Brain computer interfaces, such as cochlear implants, deep brain stimulators, and other technologies also invite reflection on the inner/outer distinction. How is the distinction deployed, or challenged, when devices work within the body? What difference might location of the implant, or its effects, make in these discussions? In the quote above, Chorost explores the disruption in his taken-for-granted view of his body and inner world, focusing on the implant's new rules and its need for maintenance, care, and feeding through battery monitoring and replacement. Suddenly, checking and maintaining a device, with its internal and external components, is part of a body routine, akin to showering or brushing one's teeth. This is a relatively new set of requirements and circumstances, particularly when we think about computer-brain interfaces, mostly developed since the middle of the twentieth century. New interfaces are currently under development and led by the inventor of the DBS in France (Benabid et al. 2011).

For Chorost, living with a cochlear implant helps him envision a future in which nanowires record brain activity and modify it through electrical pulses. And because the cochlear implant's actions do not directly connect him with other minds, he claims it did not change his sense of autonomy or self-hood. Although the distinction between self and implant had been reduced, or even eliminated, his sense of autonomous selfhood remained stable.

In what follows, I briefly review the features, design and function of the most recent cardiac pacemakers. Next, I discuss patient experiences that lead to pacemaker implantation, focusing on the embodied meaning (Cromby 2011) these devices have for recipients. These experiences were captured through the memoir, *Raising Lazarus*, and still unfinished *Bert's Box*, a vignette in *Machines in Our Hearts*, as well as collected essays from Lewis Thomas.

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With these brief narratives as background, I offer representations of movement problems, collected from my interviews with DBS patients pre- and post-implantation. Comparing the themes from written accounts with my own interviewees' stories, this chapter adds depth and complexity to the often facile comparisons of the two technologies in many popular media.[39]

The Pacemaker: Indications, Design, Function

Today's pacemakers are used most often to correct irregular heartbeats, or arrhythmias, by stimulating the heart to contract appropriately and consistently. Regardless of how a particular arrhythmia is caused, a pacemaker is often required for persistent problems regulating the heartbeat. There are two types of arrhythmias: tachycardia (abnormally fast heartbeat) and bradycardia (abnormally slow heartbeat). Normally, a bundle of cells in the right ventricle, called the sinus node, is responsible for initiating and regulating heartbeat (National Heart, Blood and Lung Institute 2012; American Heart Association 2012; Mayo Clinic 2012).

The pacemaker itself is a small device, its pulse generator about the size of a pocket watch. The generator is essentially a small computer with batteries that monitors the heart and regulates the frequency and intensity of electric current that supports heart rhythm. Flexible, insulated leads that are commonly attached to the right ventricle and right atrium deliver the current. The pacemaker then monitors the patient's heartbeat and assists when necessary. Today's models from Medtronic commonly weigh between 27.1 and 31.3 grams (Medtronic Inc. 2012b). The company currently sells five different models of internal pacemakers, and one external model. One model is made in ten variations, another in four. The rest are stand-alone, one model affairs. Each model is intended to suit different

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[39] For an example of how the body's electrical properties have been investigated, and sensationalized, see "Mad Science" at *The Huffington Post* here: http://www.huffingtonpost.com/2012/05/15/mad-science-giovanni-aldini_n_1519723.html.

conditions, and with greater or less complexity. For example, some pacemakers are now compatible with magnetic resonance imaging, and other models feature programming software with built-in summaries of relevant research. Doctors often monitor patients and their pacemakers by reviewing a modified electrocardiogram trace by telephone. Patients use a special device to record his heartbeat and transmit this data to the doctor's office (Jeffrey 2001). With these electrocardiogram readings, doctors can monitor pacemaker activity, identify problems, and estimate remaining battery life.

By the early 1960s, a standard internal pacemaker design had been established within the marketplace. Jeffrey reports that these devices:

> ... embodied physicians' choices on three crucial points: first, the device would be fully implanted inside the patient's body so as to reduce the risk of infection and the risk that patients or others might mess something up by manipulating the external part of the device; second, the battery would not be rechargeable because this would require the patient to present himself every few days at a charging station, and because the longevity of nickel-cadmium batteries had not been shown to surpass that of mercury batteries; third, the pacemaker would abandon the idea of AV [atrium and ventricle] synchrony by ignoring the atrium and pacing the ventricle only. All of these fundamental choices were intended to reduce the number of ways the device could fail, to minimize the doctor's or the hospital's responsibility for managing the case after implantation, and to foil the patient's interest, if any, in playing doctor (Jeffrey 2001:106).

The DBS is fully implanted, and today, rechargeable models are available. Unlike those earlier implanted cardiac pacemakers, today's rechargeable DBS devices must be recharged daily or weekly. Some patients are allowed to control the level of stimulation they receive from the implant. For example, one man demonstrated the function of his DBS for essential tremorfor me. Hopping out of his rocker-recliner to grab the controller and antenna, he deactivated the DBS. Slowly, a rhythmic tremor returned to his hands. Because the DBS device is "dumb" and even the most advanced DBS devices cannot sense the patient's need

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for more or less stimulation, the patient, and his or her neurologist, must decide what level and frequency of stimulation is most helpful.

Cardiac Pacing and Embodied Meaning

Earl Bakken's experience in the early days of external pacemaking devices showed him that, for many, the pacemaker benefited the whole personality of the patient, "effecting a mental and spiritual as well as a physical restoration" (Jeffrey 2001:81). Patients were able to return to their normal routines, and some patients were quite memorable. "Bakken particularly recalled a patient who resided at the Veterans Administration hospital in south Minneapolis. 'They would release him every weekend to go home to Bemidji [in northern Minnesota], and he was an avid square dancer, that was his big love of life. He'd go dancing... and he'd break his wire and then he'd retract to a slow heart rate, would have to sit down, get back to the VA, and I'd be called invariably on Mondays to come out and solder his wires back together'" (Bakken interview, as cited in Jeffrey 2001:81).

When Bakken developed cardiac pacing, he was focused on a relatively well-defined problem that had frustrated doctors and surgeons. From the patient's perspective, however, Bakken's invention was much more than a device to support heart rhythm. For the square dancer from Bemidji, the pacemaker seems to have had a sort of embodied meaning (Cromby 2011), for it allows him to participate in a social scene organized around body performance and bodily interaction.

Dr. Pensack

Dr. Robert Pensack's book *Raising Lazarus* is a memoir recounting his, and his family's, struggle with IHSS, Idiopathic Hypertrophic Subaortic Stenosis. Now called Hypertrophic Cardiomyopathy (HCM), this condition is usually genetically inherited. IHSS

is a slowly progressive disease of the muscle of the heart which causes thickening of the walls. this thickening obstructs blood flow into and out of heart chambers. Over time, the heart's walls usually thicken, and this thickening leads to shortness of breath and ultimately heart failure. Pensack reports that Hank Gathers, the college basketball player who died on the court had been diagnosed with HCM (Pensack and Williams 1994:46).

During medical school during the mid-1970s and 25 years old, Pensack's condition worsened to such an extent that surgeons at the National Institutes of Health conducted surgery to trim the size of his overgrown heart muscle. During the course of that surgery, his surgeon damaged his heart's natural pacemaking system, the sinus node. Although his doctors hoped that his heart would heal and natural rhythms would be restored, the damage was too severe, and his external pacemaker was replaced with an internal model. Pensack describes the device:

> … I am taken to surgery where a permanent pacemaker is implanted into my abdomen just to the left of the belly button. It is the size and shape of a tin of snuff, suspended just under the skin like a can of Skoal in the hip pocket of a pair of tight jeans. I learn that the damaged electrical system of my heart has revealed itself as being... undependable (1994:122).

Pensack's pacemaker, implanted snugly below his skin, keeps his heart from damaging arrhythmia. Adding a pacemaker to his body seems to immediately alter Pensack's sense of himself:

> For the next few days I sense I've changed. My hands shake, my concentration is nonexistent, a pile of magazines sits neat and dusty on the nightstand as I lie wakeful and alert through a wilderness of sights and sounds. ... Questions arise, both medical and ontological, having to do with my sanity and the nature of this terrible new awareness. The mind doesn't work with the familiar pattern that it did just a few weeks ago (Pensack and Williams 1994:122).

This feeling of unease and lack of concentration eventually passed, as Pensack sought the help of a psychiatrist. Together, they discovered that Pensack's symptoms were related to

his repeated brushes with his own death, as well as his mother's death from IHSS. His experience with a genetic condition, and his implantation with a pacemaker at such a young age, make him somewhat different from the stereotypical pacemaker patient today, someone in mid- to late-life suffering from heart block not due to solely genetic factors. Like Chorost with his cochlear implant, Pensack's body had been altered. This medical student with a new girlfriend recounted exploring his newly-acquired scars while recovering from open-heart and pacemaker surgery:

> … I slip into my parents' former bedroom and stand naked to the waist before a full-length mirror, taking in the scars, the bulge of the pacemaker, the disfigured breast-bone. I hear myself gasp, an audible breath of shock. Then I don't move or make any sound... I stand before the mirror mesmerized, horrified, full of the disbelief that what I am observing is a reflection of my body, a picture of my own flesh and bone. I stare closely at the misshapen contours of the pacemaker, the crescent incisional scar, then the T-scar where I observe the barely perceptible pulse of my heart against my wounded chest. All sounds die, I mouth the words, *I am twenty-five years old.* My hands and feet tingle as I run my fingers along the purple seams. For what must be fifteen minutes I stand there, lost in the history of the wounds... (1994:124-125).

The bump of the pacemaker, the scars marking the visits of surgeons into his chest are both private and shared. In order to really see his body, Pensack used a mirror, an instrument of both truth and judgment. He describes the scars as seams, the pacemaker's outline misshapen, not simply unattractive, ugly. His reaction is both emotional and analytic, describing an incisional scar, and the horror he felt when observing his chest, sewn together with a purple T. Regarding himself seems to alter Pensack's feelings about his body. His scars now make public swimming pools, and private intimacies fraught. His wounds mark difference, a kind of suffering that begs the unspoken question: why has this happened to me? The question of suffering seems to animate this memoir, just as it motivated other writings and provided an often quiet undertone in my conversations with Parkinson's,

essential tremor, and dystonia patients, both before and after their surgeries.

After about a year and a half with his pacemaker, Pensack returns to the NIH and requests a new, bipolar pacemaker that will eliminate muscle twitching in his abdomen, a side effect of unipolar stimulation. Allowed to watch his own surgery while under local anesthesia, Pensack dispassionately examines, in an almost detached way, his body opened:

> I am now both identifying and empathizing because I know it is me
> beneath the knife in the mirror, my own flesh and blood... After a few
> graceful lacerations into the valley of the wound the titanium casing of the
> pacemaker is revealed and I see for the first time that machine that has
> become part of me (Pensack and Williams 1994:150).

A sense of detachment at observing his body being opened is followed by affiliation with his pacemaker, the device he describes as being a part of himself. The pacemaker is not a mere tool, but an object full of what might be called embodied meaning (Cromby 2011). Following Ruthrof's phenomenological account of the body and experience. Ruthrof argues:

> "the continuously embodied character of experience means that the
> linguistic signs with which qualitative health research more usually engages
> are *always and already* bound up with and suffused by these other, *embodied*
> signs, which we know as sensations or feelings. The signs of language are never
> separate from the signs of the body: what we speak and what we hear is always
> influenced by how we feel, and vice-versa: meaningful signs arise directly
> through and within the body, as well as through and in language
> (Cromby 2011:85).

Pensack's experience of watching his own pacemaker being removed is of an example of embodied meaning, a scene of language and emotion, as Cromby writes, always and already bound together. The notion of embodied meaning allows us to acknowledge the physicality of language without sacrificing a robust understanding of language as also always social and interactive.

His new dual-lead pacemaker monitors his heart rate and provides assistance only when needed for just a few months. Soon, Pensack is in complete heart block, his body

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completely dependent on the pacemaker for normal heart rhythm. Because his pacemaker is set for a maximum of 70 beats per minute, without his normal heartbeat, Robert's heart cannot respond to strenuous activity with greater blood circulation. As a result, Pensack is sluggish and weary, particularly when exercising. About the moment when he realizes that his heart, and his life, are now dependent upon his pacemaker, Pensack writes, "My heart's own conduction system is not working. I am now and forever dependent upon the pacemaker for every heartbeat... My life now depends on this little clock keeping my heart beating for the rest of my life" (Pensack and Williams 1994:154-155).

Battling periodic arrhythmias and the limited flexibility of his pacemaker, Pensack returns to the hospital and once again observes his own pacemaker surgery. Out of surgery, his heart goes into atrial flutter, a type of arrhythmia. His new, improved pacemaker is adjustable through an electromagnetic programmer. Dr. Rosenberg, Pensack's surgeon, is adjusting the pacemaker's settings with the programmer held to Robert's chest, and the reader is brought into the memory of a hospital room:

> The procedure is called atrial burst pacing and was done in the operating suite prior to the advent of this pacemaker. Rosenberg lowers the device over my chest and begins turning the dials in a seemingly random fashion. For a moment he grows impatient with the machine that isn't behaving predictably at his command. Then as he continues to work, I feel the effects of magnetism on my pacemaker... the pace of my heart warbles too the wildly varying pitch of the programmer. Then, with terrifying suddenness, I feel my heart die in my chest and sense the old familiar fading of consciousness (Pensack and Williams 1994:174).

Dr. Rosenberg is able to adjust Pensack's pacemaker and he returns to consciousness. Pensack is both furious and incredulous--his heart was in asystole and had completely stopped beating. Turning to his father, a terrified and angry Pensack declares, "Dad, they turned my heart off in here... Then they turned it back on. That's not all right" (Pensack and

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Williams 1994:175). Dr. Rosenberg's intervention caused Pensack to experience a brief

period of dissociation from his body, depersonalizing the process of losing consciousness, the

pathway towards death.

The second half of his memoir chronicles the progression of his disease, medications

taken, difficulties and struggles overcome, until a heart transplant is required. Pensack went

on to earn his medical degree from the University of Colorado, and practiced psychiatry in

the state. He did receive a heart transplant from a young man who died in Texas. His

recovery is thick with emotional, mental, and physical troubles and turmoil. As part of

monitoring the body to ensure his body does not reject the transplanted heart, Pensack

undergoes a series of heart biopsies, first every two weeks, then every month, and finally

once every three months. He can feel each tug the catheter makes as it takes a small bite out

of his heart muscle. At the close of the text, Pensack's body begins to reject the heart, and

this rejection is counteracted with increasing doses of prednisone. Currently counteracting

rejection with a new immunosuppressant, Pensack is now free of organ rejection, and has

regained strength (Pensack and Williams 1994:315). He lives with his wife and children in

Steamboat Springs, Colorado.

Randy Hunt

The Internet has allowed people with chronic illness and their family members to

connect and share their illness and treatment stories across space and often asynchronously

(Heaton 2011; Josefsson 2005; Liebing 2009). Heaton's chapter reviews the many uses of the

Internet for health communication, including electronic medical records, prescribing, and

communication between and among patients and their doctors (2011). Josefsson identifies

patient online communities as key sites for communicating both scientific and subjective or

personal knowledge about illness, and the infrastructure, capabilities, and social

characteristics of these groups (2005). Liebling's article analyzes how patients and caregivers

struggle to find good treatment for the symptoms of Parkinson's disease. She finds that

patients legitimate their claims about the efficacy of certain medications through an

"embodiment of information" on a health information email list (2009).

Taking the theme of online communication and shared knowledge further, Randy

Hunt is currently using the Internet to solicit donations for his memoir *Bert's Box*. Starting in

March 2012, Hunt has posted the introduction and selections from four chapters on his

website. Hunt plans to complete the memoir in January 2013. Born with a heart condition,

this former "Blue Baby" describes his pounding heartbeat, and the internal cardiac

pacemaker and defibrillator that shocked his heart into rhythm:

> It's summer 2006. My heart takes off like an avalanche. I look down and see
> my T-shirt fluttering over the pounding in my chest. There's a crackling in my
> head, like pitchy wood in a fireplace, and I can't remember where or who I
> am. I go to my knees, sit on my heels and topple to the floor.
>
> ...
>
> All I ever think about is the metal box inside me. I can feel it in my flesh, can
> see the grotesque bulge below my left shoulder pulling the skin taut.
>
> It is a Ventritex model #115C implantable defibrillator/pacemaker, a battery-
> operated computer encased in a hard plastic shell to keep my juices out.
> …
> If the rhythm is within certain parameters, the box sends low-voltage electrical
> impulses into the muscle, which produces a pulse that fits in between the
> galloping heartbeats. The therapy lasts for brief seconds and the result is a
> normal heartbeat.
>
> If an outlaw rhythm exceeds those limits, the box jumps into emergency mode.
> If my heart takes off at 200 or more beats per minute, if its cadence is wildly
> irregular, if the beat stops altogether, the box will send a mad jolt into the
> muscle, confusing it back into a normal rhythm.
> (Hunt 2012).

Hunt's heart seems to perform much better than Pensack's, yet his jarring experience of terror and anxiety are similar. Unlike Pensack, whose pacemaker ultimately replaced his own heart's capacities to maintain a steady rhythm, Hunt's pacemaker monitors his heart, responding to faster-than-normal rhythms with either traditional pacing or much more powerful defibrillation.

While Pensack seemed to regard his pacemaker as part of himself, Hunt describes the metal box as grotesque, the hard plastic shell protecting a fragile computer from his body's warm and salty environment. Unlike many of the DBS recipients I spoke with, Hunt thinks about his implant quite often, although its salience, and the degree to which his heart problems and the pacemaker's actions force themselves into his awareness are likely to vary throughout the day depending upon how strenuously his heart muscle works.

This glimpse of Hunt's story lacks some of the depth and complexity of Pensack's 300-page memoir, but perhaps future chapters, and the final book, will fill in important details. For now, I want to note the embodied meaning of the pacemaker/defibrillator for Hunt. Simultaneously a lifeline and a grotesque, unfeeling metal box, Hunt seems both attracted to and repulsed by what the device can do. Although he is not perfectly clear in this passage, I suspect that Hunt's pacemaker went into emergency mode and sent a strong pulse of electric current into his heart, restoring it to rhythm, and him to consciousness.

Elmer Braun

Kirk Jeffrey's fascinating account of the history and development of the pacemaker, *Machines in Our Hearts* (1991) outlines the circuitous history of this device, from early work in locating the sinus node (the heart's natural pacemaker, located in the right atrium) to animal model experiments, external, and temporary, cardiac pacing to today's "smart"

pacemakers, devices that sense a person's needs. This complex history of device

construction, testing, development and widespread use of the pacemaker lies well beyond the

scope of this chapter. Jeffrey's book does give us these short narratives of patient experience,

starting with Elmer Braun, who received his first pacemaker in the early 1980s:

> … while walking his dog one fall day, Braun noticed that he was short
> of breath. That afternoon he went to a local clinic to see a cardiologist, who
> put him into a wheelchair and pushed him across the street to the hospital:
> his heart rate had fallen from the normal range of 60 to 100 beats per minute
> to 39. Two days later, a pacemaker team consisting of a surgeon and a
> cardiologist made a small incision in Braun's upper chest and opened a vein,
> threaded a wire lead down into his right ventricle, and connected it to a pulse
> generator that 'looked like the original Zippo lighter' and weighed 95 grams.
> Together, the generator and the lead constituted a cardiac pacemaker. Powered
> by a solid-state lithium battery, the device fired tiny electrical stimuli into his
> heart muscle to trigger regular contractions. It was set to deliver 72 impulses
> per minute, but would withhold its stimuli unless Braun's normal heartbeat
> fell below that rate. The generator, product of three decades of invention on
> two continents, did not stay outside Braun's body but went inside. The
> surgeon created a pocket beneath layers of skin and fat but above the pectoral
> muscles, attached the end of the lead to the generator, positioned the generator
> in the pocket, and, layer by layer, closed the wound. Braun requested that the
> generator be implanted in his left chest because 'I didn't want it to interfere
> with my golf swing'." (Jeffrey 2001:1-2).

> …

> Braun's experience as a pacemaker patient in the 1980s was representative
> on a number of counts. First, he had a slow heart rate but was not in extremis
> and convulsing in a hospital emergency room. The pacemaker saved him that
> experience; had it not been available, he might later have encountered far more
> terrible symptoms than shortness of breath. For this patient, the entire
> experience of receiving a pacemaker was a fairly mild one: three days in the
> hospital; an implantation procedure lasting about an hour and requiring only
> local anesthesia; a quick return to everyday life. Most of the earliest
> pacemaker patients, those on whom the technology of pacing was first tried
> back at the end of the 1950s, had been pacemaker-dependent. In contrast, the
> typical candidate for an implanted pacemaker today is not device-dependent:
> he or she would not die suddenly if the device were to fail for some reason
> (Jeffrey 2001:3).

> In 1995, one of the leads connecting Braun's pulse generator to his heart developed a

crack in its insulation. His cardiologist replaced the damaged lead, but, fearing damaging the

heart, left the old lead in his body, disconnected from the generator. In 1997, another faulty

lead. Again, Braun was implanted with a new lead and new generator. Jeffrey spoke with

Elmer Braun after these procedures, when Braun was on his fourth pacemaker. He had two

"good leads" and two dysfunctional ones. Jeffrey writes, "The lead failures seem not to have

troubled him: 'Everything is fine,' he reported. 'I feel great.' He recently had lens implants

for cataracts and was about to be fitted with new glasses. He told me, 'I'm like an old car --

you replace the muffler, replace this, replace that, and it keeps on running" (Jeffrey 2001:13).

Lewis Thomas

Lewis Thomas was a well-known doctor, biologist, essayist, etymologist and poet. He

wrote frequently for the *New England Journal of Medicine* and *Discover*. An independent

medical researcher at Tulane University's School of Medicine, Thomas artfully chronicled

his own need for a cardiac pacemaker:

> I woke up, late one Friday night, feeling like the Long Island Railroad
> thumping at top speed over a patch of bad roadbed. Doctor-fashion, I took
> my pulse and found it too fast to count accurately. I heaved out of bed and
> sat in a chair, gloomy, wondering what next. A while later the train slowed
> down, nearly stopped, and my pulse rate had suddenly dropped to 35. I
> decided to do some telephoning (1983:45).

Later, in the intensive care unit, Thomas interpreted his own electrocardiogram

(ECG), which tracked the irregularity of his heart rhythm on a paper graph. Skipped beats,

long stretches with no activity, then many short bursts of activity. His doctors tried a series of

drugs aimed to restore normal cardiac rhythm, but these failed. Thomas writes, "The

cardiovascular surgeon at the foot of my bed was explaining that it would have to be a

pacemaker, immediately, Sunday late afternoon. What did I think? (1983:46). Thomas

continues, "What I thought, and then said, was that this was one of the things about which a

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man is not entitled to his own opinion. Over to you, I said" (1983:46).

Like many of the people I interviewed, Thomas does not understand the surgeon's question as offering him a choice for or against having the pacemaker implanted. The need for the pacemaker is clear, as Thomas' capacities have been greatly diminished by the wildly fluctuating rhythm of his heart. The DBS recipients I spoke with did not characterize their decision to receive the device as a choice. Rather, the decision to request evaluation for the device is the major turning point in each person's process. Once a patient becomes a potential candidate for surgery, the medical team is then responsible for determining whether to accept or reject the patient's request for surgery. Thus, when I asked patients why they had chosen to undergo DBS, they most often read the question as insensible--having the DBS surgery was not a choice for them. In just this way, Thomas understood the choice to implant a pacemaker as being beyond his capacity for opinion.

Thomas' pacemaker set a floor for his heart rate: 70 beats per minute. When needed, the pacemaker would respond to exertion or stress and increase his heart rate, but never allow it to dip below 70. In a couple of days, Thomas reports that he was back up and around, doing whatever he felt like, pushing furniture and climbing stairs, then returning to work and normal daily routines.

Once again, Thomas' desire for everyday activities, and his lack of interest or curiosity in his pacemaker (see below) are mirrored in many of my respondents' words. The DBS devices implanted today are "dumb" in comparison to Thomas' pacemaker and contemporary models. Thomas' device monitors his heart and responds with higher levels of stimulation, and more beats per minute, when he is under stress or strain, such as when exercising or lifting furniture. The uneven path to developing a pacemaker that could sense

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the body's need for a quicker pace is outlined in Jeffrey's excellent history of the cardiac pacemaker, *Machines in Our Hearts* (1991). In contrast to Thomas' pacemaker, current models of the DBS device do not sense when the body and brain "need" more stimulation, nor do they respond to levels of anti-Parkinson medications. These devices are adjustable in terms of amplitude (strength of electrical output) and frequency (pulses per minute).

Despite his own scientific and technical background, it is not the pacemaker that fascinates him--it's his own heart. Thomas writes:

> I had come into the presence of a technological marvel, namely me. to be sure, the pacemaker is a wonderful miniature piece of high technology, my friend the surgeon a skilled worker in high technology, but the greatest wonders is my own pump, my myocardium, capable of accepting electronic instructions from that small black box and doing exactly what it is told. I am exceedingly pleased with my machine-tooled, obedient, responsive self. I would never have thought I had it in me, but now that I have it in me, ticking soundlessly, flawlessly, I am subject to waves of pure vanity (1983:46-7).

In fact, Thomas shows no interest in knowing the details of his heart ailment, nor is he curious about how his pacemaker works:

> I do not want to know very much about my new technology. I do not even want to have the reasons for needing it fully explained to me. As long as it works, and it does indeed, I prefer to be as mystified by it as I can. This is a surprise. I would have thought that as a reasonably intelligent doctor-patient I would be filled with intelligent, penetrating questions, insisting on comprehending each step in the procedure, making my own decisions, even calling the shots. Not a bit of it. I turn out to be the kind of patient who doesn't want to have things explained, only to have things looked after by the real professionals. Just before I left the hospital, the cardiologist brought me a manila envelope filled with reprints, brochures, the pacemaker manufacturer's instructions for physicians listing all the indications, warnings, the things that might go wrong. I have the envelope somewhere, on a closet shelf I think, unexamined. I haven't, to be honest, the faintest idea how a pacemaker works, and I have even less curiosity (1983:47).

His orientation towards the pacemaker, knowledge of its operation, and possible problems, is curious to Thomas. He writes about lectures and publications he has authored

about medicine's over-reliance on technology and its consequences. He writes, "I have been critical of what I called 'halfway technologies,' designed to shore things up and keep flawed organs functioning beyond their appointed time. And here I am, enjoying precisely this sort of technology, eating my words" (1983:48). Yet Thomas' heart relied on just such a half-way technology.

DBS Recipients on their Treatment

Like cardiac pacemakers, deep brain stimulators are also a half-way technology, meant to reduce the patient's reliance on drugs like Sinemet in order to prolong drug treatment effects, eliminate dyskinesias caused by over-reliance on these drugs, and give more "on" time each day. As outlined in previous chapters, patients with DBS devices use a number of strategies, including selective inattention, when interacting with the implant.

Both cardiac pacemaker and DBS recipients share an uncommon experience of living with a device wholly within their bodies. Like all manufactured goods, these devices are subject to decline and decay, and require periodic, ongoing maintenance. When these devices are working well, we might expect recipients to reflect upon their activities, to seek knowledge of their operation. The people I interviewed do not, for the most part, spend much time considering, much less marveling, at the technical achievements that restored some level of normalcy to their bodies and thus their everyday lives.

It is in moments of acute crisis that their hybrid status as person-with-device becomes immediately and pressingly salient. For patients with cardiac pacemakers and chronic heart conditions such as Dr. Pensack, periodic crises lead to extended hospitalization. For DBS recipients such as Amelia, working with the implant has meant titrating her activity against the work of her implant and her medications. Fearing a sudden and dramatic loss of motor

control in public, Amelia carefully monitors the balance between drugs, device, and disease. Rebalancing these is a continuing challenge as the disease progresses, while Amelia and her doctor adjust the treatments.

Following DBS patients who negotiate the disease, drug, and device trio has lead to an insight on the visibility and invisibility of the work patients to to understand their body's signs and symbols. Thinking through this challenge has also highlighted the importance of the inside/outside distinction for medical treatments.

Inside and Out

Developed in the early 1960s, battery powered pacemakers were still partially external to the patient's body. While some patients continued to be paced by a wire that breached their skin, others were implanted with devices that could be controlled by radio frequency, without the risk of infection endemic to all short- and long-term skin wounds. The radio frequency pacemakers worked by transmitting pacing rate and amplitude information to a coil inside the body and on to the leads inside the heart muscle. These devices were ultimately unsuccessful in the marketplace, Jeffrey comments, because doctors' control of the system was compromised. Patients could see and touch part of the pacing system (2001). Because they could see and touch the system, patients could also modify it, with potentially disastrous consequences.

On top of concerns about continual pacing with radio frequencies, and the need for weekly transmitter cleaning, in 1963, Harold Siddons, a British surgeon, observed the effects of this technology on his patients' psychology: "'Psychologically the arrangement is not ideal, as patients find it hard to forget their condition and are apt to keep on fingering the small transmitter and belt'" (Jeffrey 2001:89). Another surgeon is quoted as saying that

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patients were always, "'obliged to remember that his life depends on this device'" (Jeffrey 2001:90). To this, Jeffrey comments, "Under the circumstances, the patient could hardly put this thought out of his mind for long" (Jeffrey 2001:90).

Contemporary pacemakers and implanted cardiac devices are fully implanted within the body, removing the risk of infection from skin breach. When some portion of the pacemaker is external to the body, many patients developed a kind of physical and psychological relationship to the device, keeping the pacemaker's generator close to the body. The presence of the generator at their hip led to a kind of physical intimacy that may be absent from the experience of most pacemaker recipients today.

For some patients, the fact of their mortality without cardiac pacing was continually visible, and their reminder travelled with them in the form of the external generator. The wires from the generator to the implanted radio receiver constituted a lifeline. Because the generator was external and is now implanted, it is difficult to imagine that many recipients of pacemakers today have this same relationship with their pacemakers. My inquiry into the memoirs of people with pacemakers does not show an equally prominent interest in the generator, nor do the memoirists mention reminding themselves of the device's presence through touching the implant site.

The psychological and social terms upon which the interaction between the patient and his or her pacemaker seem to have changed. Without an external object to reflect upon, it may be more difficult for patients to remember that their life depends upon the device. But perhaps more importantly, the market for cardiac pacemakers has expanded to reach many more disorders of the heart, and thus patients with less than complete heart block are now receiving pacemakers. Earl Braun is a good example of this: without his pacemaker, Braun's

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heart still operates, albeit in a far from ideal manner. Due to improved pacemaker

monitoring, extended battery life, and pacemakers that monitor the heart and only fire when

needed, Braun's pacemaker does not seem to intrude on his thoughts or produce habitual

checking as was reported by Dr. Siddons in the early 1960s.

Conclusion

In this chapter, I focused on re-presenting the stories of men with cardiac pacemakers.

These memoirs are among the very few patient-centered accounts of life with these half-way

devices in the popular literature. Placing their experiences alongside those of DBS recipients,

we begin to fill out our picture of human interaction with medical implants. Like many

patients in previous chapters, Lewis Thomas has rejected in-depth knowledge of his implant,

preferring to rely on its effectiveness and diminish, to some extent, the responsibility he

might feel towards the device.

The accounts here remind us of the many ways our bodies can fail, and the potentially

devastating results of such failure. If Johnson (2007) is correct, then the care and

maintenance of our body's capacities to continue moving through the world is of highest

importance in developing meanings from our world.

Finally, in this chapter I suggested that medical devices, and treatments outside the

body, may have a higher degree of importance for identity work compared to devices within

the body. Social psychological theory might suggest that this is the case because important

objects for medical treatment, like visible insulin pumps, hearing aid devices, and the

external apparatus of the cochlear implant may attract, and hold the attention of others. As

Mead (1934) suggested, the meaning of objects to the individual is the result of the reactions

others have to that object. Thus, when DBS and cardiac pacemaker recipients are able to

effectively conceal the presence of the implant, and the associated illness, the possibility of others discovering and continuing to attend to the device is remote. The work of concealing bodily stigmas that attend movement disorders like PD, however, remains.

CONCLUSION

I began this dissertation by noting the influence of futurists and technologists like Ray Kurzweil and Kevin Warwick in addressing questions of human and computer consciousness, bodily enhancement, and human lifespan. The possibilities might seem terrifying, liberating, or both, as the technological ability to alter biology reframes the body as a work object (Hogle 2005). Predictions about the future notwithstanding, I have shown how people considering, undergoing, and then living with advanced medical implant technologies accommodate these devices into their everyday lives. In doing so, many people with movement disorders have sought and often found relief from their most troublesome symptoms. Others discovered that the device did not meet expectations and encountered problems in programming, with infections, or with unwanted treatment effects such as soft speech. Although the clinical literature has an approach to the topic, such as quality of life measures (e.g. Weaver et al. 2012) on a formal scale, I suggest that there is also much to be gained from an ethnographic perspective anchored in symbolic interactionism.

This dissertation is a modest contribution to qualitative medical sociology and science and technology studies. Using the tools of ethnography and in-depth interviewing, I sought to bring some clarity to the situation of people with Parkinson's disease, essential tremor and dystonia who sought the most technologically advanced treatment currently available. Throughout my research, I found that people with brain implants actively work to reestablish the appearance of a normal body, and that this normative body often reinvigorates previously valued versions of self.

At the center of this study is a longstanding concern for symbolic interactionists: how

is the meaning of an object determined through engagement? Bringing this question into realms of medical treatment raises concerns about the constitution of disorder and efforts to reduce or eliminate them. Both the identification of a disorder and our efforts to treat them are based on our understanding of suffering, normality and pathology (Karp 2006). In turn, these concepts are useful for social control. By defining certain bodily states as pathological and in need of medical care, action is indicated and efforts are made to normalize the body's movements through interventions like DBS. It is certainly the case that the patients I spoke with, and those whose stories I encountered through the Internet, deeply desired medical treatment, including cure, for their disease symptoms. The issues DBS patients struggled to live within with were not newly-defined as "medical" in nature, but rather had been identified as medical problems for over a century.

Heather Talley recently suggested that within certain circles of critical medical sociology it has become fashionable to argue for non-intervention for impairments like facial disfigurement, certain cosmetic surgeries, and other conditions. She writes, "In the last two decades, it has become almost theoretically cliché to interrogate bodily intervention and conclude that social institutions and discursive structures inspire intervention and thus intervention should cease" (Talley 2008:263). In these critiques of medical intervention, the stories of people with difficult body problems like Parkinson's disease are often left out, or considered to be "cultural dopes" whose true interests would be served by investing in efforts for social change that would redefine bodily differences that result from conditions like PD as unremarkable (Rubenstein 2001). Without denying the struggles of living with such a condition, these critics argue for a broad-based strategy of social support and care giving that would provide for the daily activities of people with movement disorders.

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That critical work, and its orientation towards social change, seems both necessary and vital. It also comes at a cost, leaving people currently undergoing illness without treatment options in the here and now. Such views could stigmatize the search for medical intervention. In the case of DBS for movement disorders, there is surely another path, one that recognizes patients' desires for unremarkable bodies in public spaces and efforts to destigmatize all forms of bodily difference.

The medical literature suggests that, medical interventions like DBS are judged "successful" more often than not. For example, a recent article summarizing 36-month outcomes of 159 patients from a randomized trial of DBS for PD showed improvement in scores on the most common motor skills inventory (Weaver et al. 2012). The authors of this study also found that quality of life scores on the PDQ-39 (the 39-item Parkinson's disease Questionnaire) improved over the first 6 months following DBS surgery, then declined slightly.[40]

Like the life stories of my respondents, this dissertation has changed over time. My two-year engagement with DBS patients, and my observations with their doctors illustrates that the depth of human experience with medical treatment is ultimately the stuff of life itself: relationships, interaction, connection, suffering, and movement. To date, there have been no sustained, long-term studies of DBS recipients from the standpoint of patients themselves, where their voices, struggles, triumphs and fears are given narrative form. This dissertation is a modest down-payment on that study, and one step towards my continuing examination of patients and their lives with complex technoscientific objects.

The story of DBS is also unfinished, since Medtronic and other DBS manufacturers

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40 More information about the PDQ-39 may be found at: http://www.isis-innovation.com/outcomes/cns/pdq.html.

continue to innovate the device's format, size and features. New applications are also being

tested, with DBS for treatment-resistant depression being piloted in six patients (Mayberg,

Lozano, Voon**,** McNeely**,** Seminowicz**,** Hamani**,** Schwalb, and Kennedy 2005) and 15

patients (Malone Jr., Dougherty, Rezai, Carpenter, Friehs, Eskandar, Rauch, Rasmussen,

Machado, Kubu, Tyrka, Price, Stypulkowski, Giftakis, Rise, Malloy, Salloway, and

Greenberg 2009). Other recent studies described the use of DBS for obsessive-compulsive

disorder in three patients (Gabriëls, Cosyns, Nuttin, Demeulemeester, and Gybels 2003) and

in a case report (Aouizerate, Cuny, Martin-Guehl, Guehl, Amieva, Benazzouz, Fabrigouls,

Allard, Rougier, Bioulac, Tignol and Burbaud 2004). The application of DBS for mental

health conditions seems a fruitful place for future research that queries the construction of

normative affect and the discursive and scientific resources brought to bear to make device

intervention possible. While neurosurgeons, neurologists, and device makers work on new

applications, use of the DBS device in other areas, such as epilepsy, continues (Andrade,

Zumsteg, Hamani, Hodaie, Sarkissian, Lozano, and Wennberg 2006; Loddenkemper, Pan,

Neme, Baker, Rezai, Dinner, Montgomery, Jr., and Lüders 2001).

      The illness narratives of the DBS recipients and the cardiac pacemaker memoirists I

have presented and reviewed here help point medical sociologists to key features of therapies

and the meaning of therapies for patients. In the case of DBS, these pages also illustrate the

work patients do to achieve "normal" bodily expression and normal body movement. For

cardiac pacemaker-dependent patients, the work of normal is also an embodied type of work,

often focused on monitoring heart function and limiting stressful environments and strenuous

physical activity. As Sacks (1984) helpfully illustrated, "normal" is not the absence of an

activity, but the presence of a particular kind of activity that takes work to complete. Normal

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requires an audience who attributes normal motives and goals, as well as normal means and resources to these actions. When telling a mundane story, or making a mundane trip to the store, we rely on habituated forms of talk and action that are sociologically important, if less interesting, than the bizarre and exceptional (see Brekhus 2000).[41]

As patients told me their stories of diagnosis and trajectories through treatment and finally implantation with the DBS device, I became aware of the intense and effortful work required to qualify for the treatment. After undergoing symptom diagnostic exams and an intense neuropsychological test, patients were qualified for surgery, delayed, or denied the treatment. At the end of their journey to DBS treatment, another odyssey started, and patients were faced with the challenge of determining just what, if anything, being a person with a brain implant meant to them. For some, who felt the implant to be transparent, integrating the device into previous versions of self seems relatively unproblematic. When movement disorder symptoms remain stubbornly visible to the patient and others, this transparency is unavailable. The device remains problematic and can become a center of concern.

Patients whose implants are not adjusted properly, or those who develop infections, tend to experience their implants as lacking the transparency of "successful" cases. For this group, working with the device, seeking second opinions and searching for competent, caring help can become a constant occupation. Surgeons, neurologists, and other professionals at Eastwood Hospital struggled to determine the source of these complications.

Comparing the DBS case to more familiar cardiac implant technologies suggests a relationship between medical technologies that work within the patient's body, the expression of illness, and the transparency of that technology for the patient herself. The general argument is that the relationship of patients to technologies within the body tends to become

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41 See Brekhus (2003) for the "grammar of social identity" among gay men in suburbia.

transparent to their user and invisible to others. These objects become integrated into standard, often pre-existing, forms of identity as part of the body and not the self. This relationship remains unstable, as the transparency of the implant, and thus the invisibility of the symptoms, can break down as objects re-emerge. In the interaction between patient, device, and others, invisibility and transparency are two sides of the same coin.

Sherwin Nuland once wrote, "We are all united in the commonality of effort called healing" (2008:13). Throughout this dissertation I have told stories of patients and doctors as they engage one another in the work of treating progressive, debilitating movement disorders. The ultimate goal of healing such conditions remains elusive. By examining the social world of deep brain stimulation, I reveal a complex set of interlocking persons, professions, desires, capacities, and resources that are shaped in a context of high technology and the promise of mastery through biomedical technologies. Advances in device-based treatments continue, and we are likely to see non-human devices supplement, and perhaps replace, body capacities in ways currently unimagined. Such work should be empirically examined for its effects on patients, medical practices, and the future of human life. In my future research, I plan to do just that: continue to track the relationships between humans and their technologies.

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