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SHARED CONSCIOUSNESS: A SOCIAL HISTORY OF TOURETTE SYNDROME  
AND ITS TREATMENTS

By

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B.A., University of Montana, Missoula, MT, 2006

Thesis

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Shared Consciousness: A Social History of Tourette Syndrome and its Treatments

Chairperson: Jeff Wiltse

This study tracks how treatments and personal management strategies for the medical condition Tourette syndrome have changed over time. Additionally, the purpose of this research is to discover the shared experiences that influence the treatment choices of American adults with the condition. Clinical theories about the causes of Tourette syndrome have directed the treatment of the disorder and its symptoms for many years. Recent patient discontents with side effects from medications have led many people with the disorder to practice complementary and alternative therapies. While some of these alternative interventions continue to rely on the guidance of a standard health care professional, several individuals with Tourette syndrome, often referred to as Touretters, have formulated treatments of their own. Many therapies that Touretters practice today are often based on certain idiosyncrasies of an individual's condition. As a result, a variety of different treatment methods have been used by Touretters in recent years.

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## INTRODUCTION

### Transitions

“FOR THIS REASON, I FEEL THAT IT IS IMPORTANT TO PRESENT A VIEW FROM WITHIN THE PATIENT’S MIND...”

Rick Fowler, *The Unwelcome Companion*

The defining experiences of individuals with a shared medical disorder can inspire their therapeutic measures. Throughout history, the style of treatment used for a particular syndrome has been mostly guided by clinical opinion about its etiology or the meaning of certain symptoms. As the medical label of a condition changes, conventional treatments which correspond with that condition can be altered as well. For individuals with Tourette syndrome, a condition characterized by sudden involuntary movements and vocalizations called tics, scientific theories about causal factors have greatly impacted social, public, and therapeutic experience.<sup>1</sup> However, Touretters and researchers have recently formulated many different coping strategies for tics by responding to the variety of symptom triggers and physical sensations reported by patients. Contemporary treatment methods practiced by people with the syndrome have become increasingly unconventional and based less on empirical scientific understanding of the condition and more on personal knowledge and testimony. As a result, ticing people have taken a diversity of therapeutic avenues in recent years. This study tracks how treatments and personal management of Tourette’s has changed over time and relates the collective experiences that have inspired the therapeutic choices of American adults with the condition.

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<sup>1</sup> See Howard I. Kushner, *A Cursing Brain?: The Histories of Tourette Syndrome* (Cambridge: Harvard University Press, 1999).

Since what we now know as Tourette syndrome first began to be recognized by the European medical community in the late nineteenth-century, clinical and cultural outlooks of the disorder have almost entirely determined how recorded cases of involuntary motion and vocalizations have been treated.<sup>2</sup> After the psychoanalytic era of American medicine that occurred during the first half of the twentieth-century, pharmaceutical experimentation of the 1960s and 1970s resulted in wide-spread acceptance of motor and vocal tics being grouped together into one disorder with a single physiological causal factor. Thereafter, the conventional treatment for Tourette syndrome, as it came to be known, became pharmaceuticals. Particularly within the past ten years, a surge in complementary and alternative therapy practice has been evident among Americans with the disorder. After so many years of medication being the dominant form of treatment, the growing presence of non-drug therapies has been under-recognized and the reasons why these interventions began to replace conventional methods and their significance have remained largely unexplored. A historical inquiry into this issue should then be guided by asking what experiences shared by people with Tourette syndrome have inspired so many with the condition to practice complementary and alternative therapies?

A substantial number of patients have found that unwanted side effects accompany prescription medications. Telling of his experience with neuroleptic drugs, one former patient revealed, “I was like a walking zombie.”<sup>3</sup> Common side effects have ranged from unwanted weight gain to psychological and existential trauma. While Touretters offer a number of reasons for using alternatives to drug intervention, the issue

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<sup>2</sup> Ibid., 5-9.

<sup>3</sup> Interview with Sean, 22 July 2010.

of side effects stands out as the most common reason for the rising popularity of other treatment options. Unsatisfactory experiences with pharmaceuticals and the emergence of more promising alternatives have led an increasing number of people with Tourette syndrome in recent years to abandon prescription medications in favor of unconventional substitutes.

Alternative medicine is any variety of therapeutic systems or techniques that traditional health care practitioners do not consider to be conventional treatment.<sup>4</sup> Some patients occasionally use such methods as a supplement to conventional medicine, in which case they are considered to be complementary measures. Others apply them as complete replacements to conventional interventions. In the case of Tourette syndrome, medication acts as the traditional form of treatment from which many patients either abandon or compliment with unconventional therapies. These alternative methods include, but are not limited to Comprehensive Behavioral Intervention for Tics (CBIT), Habit Reversal Training (HRT), Neurofeedback, dietary restrictions, physical exercise, and relaxation techniques. These practices differ greatly in their application and intent, and also in how patients arrived at using them.

While scientific knowledge of Tourette's and etiological theories continue to influence the development of some alternative methods, actual patient awareness about the idiosyncrasies of their condition has inspired several self-formulated treatment systems. After more than a century of records indicating the importance of clinical thought in tic therapy, tourettic individuals have often practiced clinical autonomy in dealing with their symptoms in recent years. Observing this trend gives rise to additional

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<sup>4</sup> National Center for Complementary and Alternative Medicine, *What is CAM?*, <http://nccam.nih.gov/health/>, accessed 17 July 2011; Tova Navarra, *The Encyclopedia of Complementary and Alternative Medicine* (New York: Facts on File, Inc., 2004), 6.



historical questions. How is it, that during experiences with such an unusual and misunderstood condition, has the American Tourette's population began to arrive at strikingly similar conclusions about how they invent therapeutic strategies? Furthermore, why have some chosen unconventional management of their symptoms using clinical approaches while others have formulated their own methods?

Touretter frustration with limited scientific research and understanding about their condition accounts for many unilateral treatment decisions. Historian Howard Kushner has noted that "one day's medical certainty gives way to more compelling explanations and interventions. Nowhere has this been more true than in the history of Tourette syndrome."<sup>5</sup> This has had a monumental impact on those with the condition, as ambiguities that still often characterize Tourette's diagnosis, symptoms, and treatment has motivated numerous practitioners of certain alternative coping strategies to proceed without the advice of a clinician.<sup>6</sup> Additionally, after years of unsatisfactory experiences with pharmaceutical interventions, individuals have widely chosen to attempt alternative ways of controlling tics based on personal observations such as how symptoms can worsen with stress and anxiety or the sensory urges that often precede involuntary actions. The decision to consult medical advice about symptom relief or not has played a large part in contemporary Tourette's treatment. Consequently, the latest complementary and alternative approaches can be efficiently investigated through a division into two main styles.

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<sup>5</sup> Kushner, *A Cursing Brain?*, xii.

<sup>6</sup> For a brief discussion about Touretter skepticism towards clinical research and suggestion about treatments, see Tourette Syndrome Association, *TSA's Statement on Unsubstantiated Reports of Alternative Therapies for Tourette Syndrome*, [http://www.tsa-usa.org/news/Unsubstan\\_Altern\\_Ther\\_TS.html](http://www.tsa-usa.org/news/Unsubstan_Altern_Ther_TS.html) (December 2009).

Alternative clinical approaches to Tourette's treatment are specific methods that require the guidance of a standard health care professional. Although drugs do not have to be involved in such methods, alternative clinical approaches can be practiced either as a complete alternative to medications or complementary to them. Popular interventions that patients have used most frequently in the past ten years include CBIT and HRT, which focus on retraining the brain and behavioral habits. Since these therapies tend to focus primarily on the mind rather than the brain, their efficacy in certain cases has caused some people to question the involuntary nature of tics. Yet regardless of opinions about underlying causal factors, clinicians have continued to administer these treatments to tourettic patients. Needless to say, many people with the disorder have continued to rely on the latest clinical advice for controlling their tics. Even though further scientific experimentation is required for full endorsement of these therapies by the larger medical community, patient involvement in them has increased due to an effort to find new interventions that do not result in negative side effects.

Alternative energetic approaches to Tourette's treatment do not require clinical assistance and are usually personally formulated methods. This diverse set of therapies works with the body, its energy sources, or with tourettic energy often by engaging in an activity that simultaneously involves body and mind. Many who have interpreted their individual cases through daily observation of their symptoms have resorted to a variety of energetic therapies. Due to autonomous decisions regarding their coping strategies, certain individuals cannot be accurately referred to as "patients." For example, several Touretters have discovered that exercise and relaxation techniques relieve much of the physical and mental stress that can exacerbate tics. Musicians with the condition

frequently tell of how their symptoms lessen or vanish during performances. Activities that require strict mental focus have also proven valuable. Regardless of physiological explanations about why practice of these interventions might be useful, several people with the disorder have applied them in recent years. Unilateral decisions favoring personally formulated ways to deal with tics have corresponded directly with energetic treatment approaches.

\* \* \*

Recognizing that Touretters have preferred a variety of different treatments in recent years reveals a historically and sociologically meaningful theme shared by people with the condition. That is, after years of medications being virtually the only form of intervention available to patients, contemporary Touretters have experienced personal choice in treatment. This is not to suggest that ticcing people during decades past had never practiced adaptive strategies for their condition. Indeed, individual testimonies dating back several years would prove otherwise. However, at no other point in history has a substantial part of the collective whole been involved in supplementing or rejecting the conventional form of therapy for their condition. Current interventions for tics are therefore best described as preferred rather than administered.

The diversity of tourettic experience also shows how many claims made about tic therapy should be considered as generalized statements. To suggest, for instance, that every individual has taken a similar path of action concerning treatment would be neither fair nor accurate. Since no two cases of the condition are completely alike, an unquestioned, all-inclusive intervention does not exist. Keeping in mind that therapeutic goals might also differ from person to person, individuals have reported varying degrees

of success with both conventional and alternative treatments. In essence, a socio-historical study about ticcing people and their therapy decisions should not take interest in the overall efficacy of a treatment, but rather the choices of individuals.

A Tourette's decision to medicate is commonly influenced by the role of side effects, but also by many other factors such as severity of symptoms and satisfaction with alternative methods.<sup>7</sup> Due to mild tics or plain indifference to their condition, some choose not to take part in any treatment model or might discontinue treatment after experiencing a natural remission of symptoms.<sup>8</sup> However, a therapeutic method does not always correspond with the severity or frequency of one's tics. Speaking of the personality of the individual, physician Gerald Erenberg commented, "I am continually amazed by individuals who bear with grace, symptoms that others would find devastating, while other individuals cannot endure symptoms that an outsider sees as tolerable."<sup>9</sup> The tics, or involuntary actions caused by Tourette syndrome, are differentiated between motor and vocal manifestations.<sup>10</sup> Though symptoms vary greatly from case to case, common motor tics include head jerks, flailing of limbs, eye blinking, full body contortions, and grimacing facial expressions. Common vocal tics are yelping,

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<sup>7</sup> Tourette Syndrome Association Newsletter, Vol. 27, No. 2 (Fall 1999), 1; Tourette Syndrome Association Newsletter, Vol. 29, No. 1 (Summer 2001), 1, 7; Marcia Angell, "The Truth About the Drug Companies," Public Lecture, The University of Montana, 19 October 2009. In her lecture Dr. Angell, although not speaking specifically about Tourette syndrome, noted that many people with non-fatal conditions who experience a rise in symptoms while attempting alternative therapies commonly revert back to medication use.

<sup>8</sup> Mitzi Waltz, *Getting Older with Tourette Syndrome*, <http://www.tsa-usa.org/People/LivingWithTS/GettingOlderWithTS.html>, accessed 14 July 2011; American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> ed., Text Revision (Washington, DC: American Psychiatric Association, 2000), 112-13.

<sup>9</sup> Tourette Syndrome Association Newsletter (Fall 1999), 1. Dr. Erenberg continues by stating, "the ultimate decision-maker is the patient, with the physician acting as an advisor providing information about medication options and side effects."

<sup>10</sup> Many people with Tourette's have also reported experiencing a range of involuntary thought processes or mental images. For one example, consult Adam Ward Seligman, "In the Blink of an Eye," *Don't Think About Monkeys: Extraordinary Stories Written by People with Tourette Syndrome*, eds. Adam Ward Seligman and John S. Hilkevich (Duarte: Hope Press, 1992), 53.

barking noises, repetitive sniffing or clearing of throat, tongue clicking, stuttering, and prolonged screeching.<sup>11</sup> One patient described his uncontrollable urge to tic as, “an intense feeling that unless I tic or twitch I feel as if I am going to burst. Unless I can physically tic, all of my mental thoughts center on ticcing until I am able to let it out.”<sup>12</sup> Symptoms of Echolalia and Echopraxia, where one repeats the words or mimics the behavior of another, are occasionally exhibited in the disorder. Contrary to popular belief, only a small number of people with the disorder ever have symptoms of Coprolalia, a term that denotes involuntary cursing or unsociable comments.<sup>13</sup> The presence of tics alone or a diagnosis of Tourette’s in any varying degree of intensity has not always indicated which interventions might best fit a particular case.

The placement of a rigid scientific label on a particular set of symptoms has impacted the ability of ticcing people to choose a therapy that is appropriate for their situations. As with any clinical syndrome construction, researchers have grouped certain symptoms together and classified them as Tourette syndrome.<sup>14</sup> Although this is standard scientific practice, it can result in simplifying the management of a more complex issue, as some health care providers have been inclined to make the individual fit the treatment rather than make the treatment fit the individual. Because the American scientific community continues to debate over the disorder’s official medical classification and

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<sup>11</sup> Tourette Syndrome Association, *Facts About Tourette Syndrome: Answers to Most Commonly Asked Questions*, [www.tsa-usa.org](http://www.tsa-usa.org), accessed 15 February 2010; American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> ed., Text Revision, 111.

<sup>12</sup> James Leckman, “Phenomenology and Natural History of Tourette Syndrome: The Self Under Siege,” Powerpoint Presentation, 2004 Tourette Syndrome Association National Conference.

<sup>13</sup> Tourette Syndrome Association, *Facts About Tourette Syndrome*; James Miller, “The Voice in Tourette Syndrome,” *New Literary History*, Vol. 32, No. 3 (Summer 2001): 519-36; Kushner, *A Cursing Brain?*, 2-4. Although coprolalia is an uncommon tourettic symptom, historian Howard Kushner intelligently warns against the risk of scientifically and culturally segregating Coprolalics from people with less florid forms of Tourette’s in *A Cursing Brain?* (221-22).

<sup>14</sup> Kushner, *A Cursing Brain?*, 5.

which symptoms and signs to include among the diagnostic features, the manner in which a patient is treated can differ from physician to physician.<sup>15</sup> This shows how historic themes of misdiagnosis and clinical misunderstanding are still present today. An inquiry into Touretters and their treatments therefore has the unique ability to uncover historical lessons useful to many who are directly or indirectly affected by the disorder.

The rapid increase of Tourette's diagnosis in the United States and the growing recognition of disabilities studies by historians suggest the relevance of this topic to a greater number of people. Since medical opinions about certain attributes and indicators that should constitute a diagnosis of the syndrome still vary, estimates concerning the prevalence of tics and Tourette's differ. Still, recent studies have even argued that minor motor and vocal tics are a common occurrence among Americans, but it is often noted that approximately 200,000 people in the nation have very visible cases.<sup>16</sup> Regardless of diagnostic accuracy, the disorder "represents one of the fastest growing diagnosis in North America."<sup>17</sup> Similarly, current historians and other scholars have concentrated their studies more frequently on people with physical and mental "disabilities."<sup>18</sup> Writing on the significance of disabilities studies, historian Catherine Kudlick contends that the subject "occupies a place comparable to gender and race in defining the human condition."<sup>19</sup> Commenting on the topic of Tourette's, Kudlick continues by stating that

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<sup>15</sup> Tentative proposals have been made to classify Tourette syndrome as a "Neurodevelopmental disorder" in the next edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V). For details about the current debate over Tourette's classification, consult Tourette Syndrome Association Newsletter, Vol. 38, No. 3 (Winter 2010), 12.

<sup>16</sup> National Institute of Neurological Disorders and Stroke, *Scientists Discover First Gene for Tourette Syndrome*, [http://www.ninds.nih.gov/news\\_and\\_events/news\\_articles/news\\_article\\_Tourette\\_gene\\_121505.htm](http://www.ninds.nih.gov/news_and_events/news_articles/news_article_Tourette_gene_121505.htm) (December 2005); Tourette Syndrome Association, *Facts About Tourette Syndrome*.

<sup>17</sup> Kushner, *A Cursing Brain?*, 4.

<sup>18</sup> For an excellent discussion about disability historiography, see Catherine J. Kudlick, "Disability History: Why We Need Another 'Other'," *The American Historical Review*, Vol. 108, No. 3 (June 2003): 763-93.

<sup>19</sup> *Ibid.*, 767.

histories of the disorder “could greatly enhance our understanding of medical practices...while giving the people with Tourette’s themselves more agency by including their perspective.”<sup>20</sup> This study aims to place those with the syndrome at the center of their own history. In the event that trends of increased diagnosis and scholarly consideration of the condition continue, the value of historical inquiry into the social history of Touretters and their preferred treatments can be placed at a high level of importance.

Current treatment circumstances and privileges shared by people with Tourette syndrome today represent a monumental shift from situations found in prior years. A thorough investigation into the disorder’s social and clinical past must then precede an analysis of current therapeutic trends. This historical backdrop reveals public and personal similarities to current situations and locates the origins of medical treatments for tics. A subsequent review of the psychogenic theories of etiology and corresponding treatments that characterized much of the twentieth-century will be necessary to draw essential parallels with recent alternative therapies. After Tourette’s was established as a physiological condition primarily during the 1970s, individual choice in treatment remained narrow as medication became the dominant form of tic intervention until around the turn of the twenty-first century. Thereafter, the growing preference of alternative and supplemental therapies that has become apparent among Americans with Tourette syndrome will be explored in depth. This historic phenomenon will be examined from Touretter viewpoints that favor either clinical consultation for therapeutic measures or unilateral decision-making. And yet, the variety of coping strategies people have preferred in recent years illustrates how the social history of the condition is far

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<sup>20</sup> *Ibid.*, 775.

from black and white. Those who have chosen to use medication or practice alternative treatment methods with or without the support of a clinician or apply any variety of techniques or lifestyle choices in dealing with their symptoms construct the social whole of people affected by the condition. The complicated nature of the disorder's history paired with how little is still known about it makes for a complicated past, but one certainly worth understanding.



CHAPTER ONE  
Lack of Control: Demons, Doctors, and Early Ticking People

“WHEN I WAS EIGHT YEARS OLD I WIGGLED MY NOSE. LIKE A RABBIT. I  
SNIFFED AND I BLINKED TOO.

‘DON’T DO THAT,’ MY MOTHER COMMANDED.

‘I CAN’T HELP IT,’ I ANSWERED.

‘CURL YOUR TOES INSTEAD,’ SHE SAID. ‘THAT WAY NO ONE WILL SEE  
YOU.’”

Elaine Fantle Shimberg, *Living with Tourette Syndrome*

A well-rounded understanding of recent trends in tic management and their significance requires an investigation of the disorder’s long-term history. Nineteenth and early twentieth-century physicians, psychologists, and much of the general public incorrectly assumed that tics were caused by insanity, inadequate or abusive parenting, or even lack of willpower.<sup>1</sup> Essentially, clinicians and patients had few indications about the cause of involuntary vocalizations and motor movements. To complicate matters, no documentation can prove that the cases analyzed in the first studies about tics during the nineteenth-century or many subsequent cases through the twentieth-century exhibited the same medical condition we know today as Tourette’s.<sup>2</sup> Several people who might have had “Tourette syndrome” prior to its current status as a neuropsychiatric disorder had no clinical outlet or organization to learn more about themselves.

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<sup>1</sup> Tourette Syndrome Association Newsletter, Vol. 29, No. 4 (Spring 2002), 1.

<sup>2</sup> Throughout its approximate 187-year-long medical history, the symptoms that fit today’s diagnostic criteria of Tourette’s had been known by other terms for more than half the time. However, many historical cases reflect modern Gilles de la Tourette syndrome even centuries ago. For examples, consult Arthur K. Shapiro et al., *Gilles de la Tourette Syndrome* (New York: Raven Press, 1978), 14-19; Donald R. DeGlopper, “18<sup>th</sup> Century Touretter,” *Science News*, Vol. 138, No. 9 (September 1990): 131, 139; Ruth Dowling Bruun and Bertel Bruun, *A Mind of Its Own: Tourette Syndrome, A Story and a Guide* (New York: Oxford University Press, 1994), 153-58.

Medical research, cultural perception, and the social history of Tourette syndrome and its treatments are in many ways inseparable.<sup>3</sup> The way clinicians and public observers viewed the cause of tics directly influenced the manner in which people were treated. Researchers had arrived at an improved understanding of tics and Tourette's before many individuals began to make their own decisions about how to best handle their symptoms. Yet before formal clinical research into the cause of tics began, there were no conventional therapies available to people who experienced such symptoms. Initial scientific investigations about tics mark the beginning of the disorder's long journey towards physiological classification which allowed for greater levels of creativity and choice in managing one's condition.

### **An Inner Disturbance**

The misunderstanding of tics reaches far back into the past and extends into recent times as well. As early as the fifteenth-century, some people have associated tics and involuntary movements with demonic possession. One account portrays an otherwise rational and normal behaving priest who suspected that he was possessed by the devil because he would unwillingly stick out his tongue and contort his body. The priest testified, "I cannot help myself at all, for so he [the Devil] uses all my limbs and organs, my neck, my tongue, and my lungs, whenever he pleases, causing me to speak or

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<sup>3</sup> These three interwoven topics serve as the basis for historian Howard I. Kushner's book *A Cursing Brain?: The Histories of Tourette Syndrome* (Cambridge: Harvard University Press, 1999). He writes, "the interpretation of clinical cases both influences and reflects clinicians' identification and treatment of Tourette syndrome...a history of Tourette syndrome must, therefore, simultaneously explore three distinct but overlapping stories: that of the claims of medical knowledge, that of patients' experiences, and that of cultural expectations and assumptions." (9) As readers of this thesis will come to understand, the factors of self-understanding and self-awareness are elements in the social history of Tourette syndrome not to be disregarded, particularly in recent years.

cry out...I am altogether unable to restrain them.”<sup>4</sup> Five centuries later people still held similarly confused understandings of tics and involuntary movements. In 1949, an east coast teenage boy experienced prolonged violent outbursts, motor activity, and growling vocalizations. His parents took him to see Catholic Priests, who concluded he was possessed by demons.<sup>5</sup> In both cases, five centuries apart in time, the diagnosis was based on guesswork informed primarily by cultural assumptions.

As a consequence of this historical misunderstanding, people who have exhibited involuntary movements and vocalizations have been subjected to unnecessary treatments. In the cases of the fifteenth-century priest and the mid-twentieth century teenager, both were subjected to exorcisms.<sup>6</sup> In other instances, individuals with physical and verbal tics were assumed to be insane and incarcerated in mental institutions. Others have been isolated from society and bled by leeches.<sup>7</sup> All these examples show that before a modern clinical understanding of tics existed, public and cultural interpretation of symptoms largely determined the measures taken in response to unexplained movements. Additionally, early assumptions about the causes of tics epitomize the variety of misconceptions that people have made about tics throughout history. These allegations have profoundly impacted people’s treatment experiences.

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<sup>4</sup> J. Sprenger, *Malleus Maleficarum* (1489), trans. Montague Summers (London: Pushkin Press, 1948), taken from Shapiro et al., *Gilles de la Tourette Syndrome*, 15.

<sup>5</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 15; Rick Fowler, *The Unwelcome Companion: An Insider’s View of Tourette Syndrome*, rev. ed. (Cashiers: Silver Run Publications, 1996), 54-55. After investigating the personal memoirs of one of the priests and conducting personal interviews, the boy’s story has been retold by Thomas B. Allen in *Possessed: The True Story of an Exorcism* (New York: Doubleday, 1993). See esp. pages viii, 213, 233, 259.

<sup>6</sup> The teenage patient, who was allegedly hospitalized at Georgetown University, was labeled with Tourette’s disorder by psychiatrists some time afterwards. William Blatty, author of *The Exorcist*, reportedly studied this case and used it as the basis for his book and film. See Shapiro et al., *Gilles de la Tourette Syndrome*, 15; Fowler, *The Unwelcome Companion*, 54-55.

<sup>7</sup> Bruun and Bruun, *A Mind of Its Own*, 32, 135. See esp. Tourette Syndrome Association Newsletter, “The History of TS Treatment,” Vol. 29, No. 4 (Spring 2002), 1. In this article, Dr. Ruth Bruun testifies, “I’ve had some older TS patients who were diagnosed as schizophrenic and spent time in mental institutions. I’d assume that in early times there were more of them.”

Scholars have provided different interpretations about the role of supernatural forces in public observations of tics.<sup>8</sup> Writers such as H. Sidky observe that the same uncontrolled twitching, shaking, and vocal outbursts that are symptomatic of Tourette syndrome and tic disorders were at one time also indicative of witchcraft or evil spiritual activity. In a revisionist look at European witchcraft entitled *Witchcraft, Lycanthropy, Drugs, and Disease*, Sidky discusses the possible function of drugs and disease in early witch hunts. Among other factors, Tourette syndrome is offered as a possible explanation for the odd behavior that led to such accusations.<sup>9</sup> A number of psychiatrists and researchers have attributed historical instances of madness and witchcraft to modern diseases and syndromes.<sup>10</sup> Essentially, people who appear to have experienced ticcing actions in earlier periods have been labeled with a newer pathology long past their own time. Other scholars have disputed the idea of a link between the supernatural and medical conditions.<sup>11</sup> Erik Midelfort, for example, contends that clinical explanations for those accused of witchcraft are far too complex and take away from the real meanings behind witchcraft and demonic possession by “hiding them under layers of clinical jargon.”<sup>12</sup>

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<sup>8</sup> Historian Howard Kushner briefly touches upon the topic of attributing odd movements to witchcraft in *A Cursing Brain?* He writes, “Itard described seven men and three women, all of whom displayed bizarre behaviors not unlike those who in earlier centuries were believed to have been enchanted by diabolical forces.” (14)

<sup>9</sup> In a book review, Sidky was criticized for not having “pursued more fully” this topic of relating witchcraft to certain diseases. See William T. Walker, “Review: *Witchcraft, Lycanthropy, Drugs, and Disease: An Anthropological Study of the European Witch-Hunts*” by H. Sidky, *The Sixteenth Century Journal*, Vol. 30, No. 2 (Summer 1999): 563-64.

<sup>10</sup> For a listing of such figures, see Erik Midelfort, “Madness and the Problems of Psychological History in the Sixteenth Century,” *The Sixteenth Century Journal*, Vol. 12, No. 1 (Spring 1981): 10, note 23.

<sup>11</sup> See Kathleen R. Sands, “Word and Sign in Elizabethan Conflicts with the Devil,” *Albion*, Vol. 31, No. 2 (Summer 1999): 242, note 20; Michael MacDonald, *Mystical Bedlam: Madness, Anxiety, and Healing in Seventeenth-Century England* (Cambridge: Harvard University Press, 1981), esp. xii-xiii.

<sup>12</sup> Midelfort, “Madness and the Problems of Psychological History in the Sixteenth Century,” 11.

Touretters themselves have figuratively described their uncontrollable movements as the result of supernatural seizure.<sup>13</sup> Rick Fowler, Touretter and author of *The Unwelcome Companion*, makes a comparative description of his disorder and demonic possession. In his book, he gives a fictional portrayal of his experiences with the condition. “The tourettic demon,” as he imagines, is an accurate narrative since many people with the syndrome feel as if an “unwanted entity lives inside the brain.”<sup>14</sup> He also writes that in past years “people who made strange noises or bizarre gestures were usually thought to be either mentally unstable, completely insane, or possessed by demons.”<sup>15</sup> Fowler’s descriptions, though not meant in a literal sense, show how assumptions about tics being caused by evil manifestations have also been present in a first person point-of-view.

Regardless of whether modern movement disorders were present in some historic cases of demonic possession, certain examples show how outsider interpretation can affect the intervening measures of a given set of symptoms where the causal factors are unknown. In addition, archaic notions of involuntary movements represent the beginning of misconceptions about tics. Misinformed public explanations and assumptions about tics and Tourette’s have existed for years and remain today. “I know what it’s like to be discriminated against,” reports one Touretter, who shared an experience with a friend being falsely accused of substance abuse by a police officer.<sup>16</sup> Bystanders have

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<sup>13</sup> Reports of actual children and adults with Tourette’s feeling as if they are being controlled by the devil or having latent evil ambitions can be found in Bruun and Bruun, *A Mind of Its Own*, 120-21.

<sup>14</sup> Fowler, *The Unwelcome Companion*, 52, 53.

<sup>15</sup> *Ibid.*, 17. Author Mitzi Waltz also writes that tics and odd behaviors were “occasionally blamed on possession by evil spirits or demons” in *Tourette’s Syndrome: Finding Answers and Getting Help* (Sebastopol: O’Reilly & Associates, 2001), 2. Although Fowler, Waltz, and others give convincing arguments about the role of Tourette’s in witchcraft accusations and related issues, citations of actual case studies and historic evidence remain narrow.

<sup>16</sup> Interview with Eric, 20 May 2010.

associated disruptive vocalizations and spastic movements with things like irrational behavior, drug use, and other forms of social deviancy.<sup>17</sup> Inadequate medical understanding and cultural prejudgment of tic symptoms have restricted the treatment options and lifestyles of many ticcing people.

### **The Advent of Medical Inquiry and Treatments**

The actual investigation of tics and Tourette syndrome from a clinical perspective has its roots in the French physician Jean Marc Gaspard Itard's famous 1825 study of the "cursing marquise." Being twenty-six-years-old at the time, the noblewoman known as the Marquise de Dampierre was notorious for her sudden impulse to shout out obscenities and unsociable comments during conversation. She also experienced a variety of motor and vocal tics.<sup>18</sup> Itard became convinced that her chronic swearing was involuntary in nature. He reported that the more severe and offensive that certain words were, "the more she is tormented by the fear that she will utter them, and this preoccupation is precisely what puts them at the tip of her tongue where she can no longer control it."<sup>19</sup> Although Itard wrote on the marquise extensively, he only studied her condition for a brief period in 1825, and never followed up afterwards with treatment.

Itard's examination of two other ticcing women shows how preconceived clinical assumptions have affected the treatment experiences of people with involuntary movements and vocalizations. Relating his patients' symptoms to his previous studies

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<sup>17</sup> Elaine Fantle Shimberg, *Living with Tourette Syndrome* (New York: Simon & Schuster, 1995), 109-12. See esp. Fowler, *The Unwelcome Companion* (5-6) for an emblematic story concerning public assumption of a Touretter being intoxicated.

<sup>18</sup> For descriptions of the Marquise de Dampierre, consult Kushner, *A Cursing Brain?*, 10-12; Bruun and Bruun, *A Mind of Its Own*, 8-9; Shapiro et al., *Gilles de la Tourette Syndrome*, 15-16.

<sup>19</sup> Jean M. G. Itard, "Mémoire sur Quelques Fonctions Involontaires des Appareils de la Locomotion, de la Préhension et de la Voix," *Archives Générales de Médecine*, 8 (1825): 385-407, quote from 405, trans. Howard I. Kushner, taken from Kushner, *A Cursing Brain?*, 10-11.

about the role of experience in speech development, the French physician concluded that his female subjects felt a “domestic unhappiness” that resulted in brain irritations. This physical damage in turn weakened their will and therefore caused tics and uncontrollable cursing.<sup>20</sup> In his view, a weakened will could be strengthened through a form of “moral treatment” which included public shaming. In addition to traditional interventions of long baths, a blistering agent, and periodic trials of leeches, Itard recommended that his first patient be isolated from the alleged domestic causes of her condition. Itard also bled and administered the application of leeches and long baths to his second patient who experienced extended bouts of howling noises and other vocalizations. As the primary part of her therapy, however, Itard required that the young woman take escorted walks in public, believing that the embarrassment she felt about her symptoms would help to cure her.<sup>21</sup> Itard’s own perception of his patients’ conditions determined the intervening measures they underwent. Although the two women appeared intellectually fit, Itard intended his moral treatments, supplemented with other customary measures, to nourish an underdeveloped will.

In 1885, the case of the Marquise de Dampierre, as reported by Itard, became the centerpiece of a study made by a young Parisian neurologist named Georges Gilles de la Tourette. He worked under the direction of his mentor Jean-Martin Charcot, chief physician of the Salpêtrière Hospital in Paris, who assigned him to record and interpret cases of motor and vocal tics.<sup>22</sup> During his observations, he formulated an idea about

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<sup>20</sup> Kushner, *A Cursing Brain?*, 14-15. As for his seven male patients with tics, Itard concluded that their symptoms were the result of organic brain damage. He actually performed his main study about the origins of language and speech development while attempting to educate a displaced child named Victor, whose famous case also became known as the “Wild Child of Aveyron.”

<sup>21</sup> *Ibid.*, 15-16.

<sup>22</sup> Kushner, *A Cursing Brain?*, 27. Although Gilles de la Tourette and Charcot are most frequently labeled as “neurologists,” nineteenth-century medicine saw no clear division between psychiatry and neurology, as

involuntary tics that had never been thought of before. In his published article “Study of a Nervous Affliction,” he argued that the variety of odd vocalizations, cursing and twitching symptoms displayed by the marquise and others were all connected to a single underlying cause.<sup>23</sup> Like Itard, he concluded that these actions were involuntary. This new pathological model known as “maladie des tics” (also called convulsive tic illness) centered on neurology and included hereditary aspects. It would also become the most complete early representation of today’s diagnostic criteria and clinical understanding of Tourette syndrome.

There is no proof, however, that the people diagnosed by Gilles de la Tourette as having his convulsive tic illness exhibited what is known today as Tourette syndrome. Similar to many researchers of that age, Charcot and his promising young intern only reinterpreted the case of the Marquise de Dampierre from Itard’s writings. Neither one ever actually met with or treated her.<sup>24</sup> In addition, out of nine case histories interpreted by Gilles de la Tourette, only the one noblewoman’s symptoms fit the narrow set of characteristics found in *maladie des tics*.<sup>25</sup> It remains questionable whether the six patients that he actually met with experienced the disorder described in his essay. Gilles de la Tourette was hardly different from several other scientists who used the marquise’s example to help legitimize their preconceived clinical notions. This resulted in certain symptoms being placed above others in diagnostic importance, and therefore altered the

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“physicians” in whole investigated and treated a variety of conditions believed to relate to both body and mind. See *Ibid.*, 17, note 21; Bruun and Bruun, *A Mind of Its Own*, 32.

<sup>23</sup> Kushner, *A Cursing Brain?*, 20-25; Shapiro et al., *Gilles de la Tourette Syndrome*, 17-18; Bruun and Bruun, *A Mind of Its Own*, 9.

<sup>24</sup> Although some sources claim that the marquise was an actual patient of Charcot and only observed by Gilles de la Tourette (e.g. Shapiro et al., *Gilles de la Tourette Syndrome*, 18), Howard Kushner proves in his 1999 history *A Cursing Brain?* that “Charcot never had any direct contact with the marquise, let alone any physician-patient relationship.” (20)

<sup>25</sup> Kushner, *A Cursing Brain?*, 24.



experiences of Touretters in later years. Nonetheless, the condition labeled as *maladie des tics* clearly reflects modern descriptions of Tourette syndrome, which is named after the late nineteenth-century physician.

According to Gilles de la Tourette's task as an intern, his study was primarily concerned with distinguishing the diagnostic symptom criteria of the newly constructed illness from other movement disorders rather than finding treatments for ticcing people. His belief that no intervention could provide any lasting relief for convulsive tics also helps to explain his lack of focus on the matter.<sup>26</sup> The physician's recommended therapeutic measures were limited to rest and isolation.<sup>27</sup> Clinical and cultural perceptions of uncontrolled movements would continue to evolve after the formulation of *maladie des tics*, as would treatments for such symptoms. But more significant than any interventions Gilles de la Tourette administered to his patients in the late nineteenth-century is the impact that the scientist's theories had on patients around the mid-twentieth century and after. That is, his original ideas concerning pathological origins inside the brain and the grouping of several symptoms under one underlying source inspired modern clinical thought about Tourette syndrome and therefore how many with the condition came to be treated. Oddly, in later years he regretted his contentions of a physiological etiology in convulsive tic illness and adhered closer to popular psychogenic theories of his time instead where mental degeneration was thought to contribute to the cause of tic disorders.<sup>28</sup> Still, in accordance with our current understanding, Gilles de la Tourette appeared to be correct during his crucial years. His study was the beginning of

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<sup>26</sup> *Ibid.*, 23; Shapiro et al., *Gilles de la Tourette Syndrome*, 21.

<sup>27</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 22.

<sup>28</sup> *Ibid.*, 21; Bruun and Bruun, *A Mind of Its Own*, 10.

the neurological single-causal factor theory of etiology that eventually led to the widespread use of pharmaceutical treatments for Tourette syndrome.

CHAPTER TWO  
Altered Meanings: Etiological Theories of the Early Twentieth-Century and Social Consequences

“ONE DOES NOT HAVE TO KNOW THE CAUSE OF A FIRE TO PUT IT OUT.”  
Dr. Will Menninger, in *Time: The Weekly Newsmagazine*, October 25, 1948

Not long after Georges Gilles de la Tourette described *maladie des tics*, treatment of tic symptoms was caught in the rage of psychoanalytic thought during the early and mid-twentieth century. The widely reviewed “Study of a Nervous Affliction” encountered immediate criticism shortly after its publication in 1885 and faded from clinical influence for around fifty years.<sup>1</sup> In the American and European medical world, accepted scientific truths were often based less on empirical observation and more on theoretical postulates and personal biases. Ticking people were affected by this larger theme in the history of medicine. As psychogenic theories overruled evidence supporting a neurological etiology for convulsive tics, patients diagnosed with the disorder became caught in the middle of a theoretical debate of the most complex and confusing nature. Consequently, the few patients with recorded treatment histories during this time became subject to psychoanalytical therapies and limited drug intervention. Not until attention was given to more practical scientific research that pointed to a physiological causal factor would pharmaceuticals begin to replace psychoanalytical treatments as the most common intervention administered to Touretters.

Amidst a multitude of different theories about etiology, people with motor and vocal tics as well as more florid symptoms were exposed to the treatment model

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<sup>1</sup> Howard I. Kushner, *A Cursing Brain?: The Histories of Tourette Syndrome* (Cambridge: Harvard University Press, 1999), 26, 102-03.

formulated by the physician or psychologist they encountered. In our current day, intervening measures for tics are best described as *chosen* by patients rather than *administered* to them. A variety of therapies are now available under the discretion of the patient, as well as they are created by Touretters themselves. Yet evidence only reveals this distinction as of late. During the first half of the twentieth-century, fewer clinicians were involved in the study and treatment of movement disorders and often created their own brand of tic management.<sup>2</sup> The treatments given to people with *maladie des tics* or a similar diagnosis were also at times unnecessary or inhumane. Such interventions were present since researchers often concluded that tics were the result of repressed masturbatory urges, sexual perversion, aggressive behavior, and other voluntary influences. Treatments frequently coincided with the suspected causal factor, and were still administered strictly from the judgment of the acting medical authority.

### **Early Psychogenic Theories and Drugs**

Immediately following Gilles de la Tourette's formulation of *maladie des tics*, the complicated debate about the new movement disorder began. Distinguished clinicians started to question and reject the idea that a group of ticcing symptoms had a neurological origin. The dominance of psychology seen in early twentieth-century Europe and North America instead became the defining influence on etiological notions of chronic tic

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<sup>2</sup> Between 1885 and 1965, only about 50 cases of chronic tic illness were actually reported in medical literature. See Arthur K. Shapiro et al., *Gilles de la Tourette Syndrome* (New York: Raven Press, 1978), 4. The authors of this important publication conducted an exhaustive search for every piece of literature pertinent to tics and Tourette's prior to the late 1970s. Less than five hundred clinical studies and articles are cited compared to over three-thousand that exist today in the National Institute of Health's on-line medical library *PubMed* since 1960. Fewer than half of the citations in *Gilles de la Tourette Syndrome* are dated during the established psychoanalytic period and before.

disorders.<sup>3</sup> This marked a significant step away from the Parisian doctor's theory of a biological causal factor as reported in "Study of a Nervous Affliction" and therefore limited the use of medication. In addition to continuing ideas of hysteria and choreas, hereditary degeneration and behavioral issues became longstanding explanations for movement disorders before the twentieth-century, during which time physicians did commonly administer drugs to ticcing patients.

Although drug therapy was infrequent between 1900 and the 1950s, there were more instances in previous years. The physicians who examined and treated the first recorded North American case of Gilles de la Tourette's disease (maladie des tics) prescribed chemical interventions.<sup>4</sup> The twelve-year-old male they described in an 1886 volume of the Journal of Nervous and Mental Disease was, after first being "soundly and systematically punished," administered bromides and arsenic.<sup>5</sup> Similar to other cases involving convulsive tics around this time, the patient's physicians did not give him medication as a result of their suspicion of an underlying neurological pathology. Rather, the boy's disorder was viewed as a consequence of familial degeneration that had no physiological cause.<sup>6</sup> The chemotherapy was intended to suppress the symptoms rather than address the cause, and was reported to be effective by the boy's clinicians. As in most case histories of this period, patient testimony was not recorded.

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<sup>3</sup> Kushner, *A Cursing Brain?*, 39, 65; Shapiro et al., *Gilles de la Tourette Syndrome*, 4-6; Ruth Dowling Bruun and Bertel Bruun, *A Mind of Its Own: Tourette Syndrome, A Story and a Guide* (New York: Oxford University Press, 1994), 32.

<sup>4</sup> Kushner, *A Cursing Brain?*, 40.

<sup>5</sup> C.L. Dana and W.P. Wilkin, "On Convulsive Tic with Explosive Disturbances of Speech (So-Called Gilles de la Tourette's Disease)," *Journal of Nervous and Mental Disease*, Vol. 13, No. 7 (July 1886): 410, 412. Bromides have also been used in treatment of epilepsy to act as a sedative and arsenic is a poisonous substance.

<sup>6</sup> *Ibid.*, 412. Dana and Wilkin write: "As to the pathology of the disease... we can exclude any organic lesion... it is apparent that it belongs to the neuro-degenerative disorders."

Ten years after the first North American case, a Philadelphia pediatrician named J.C. Wilson assigned sedatives to a fifteen-year-old male with tics known as “Z.” Although Wilson recognized that Z.’s case reflected several people described by Gilles de la Tourette in 1885, he eventually settled on the presence of a psychological condition characterized by a deteriorating mental state as an explanation for Z.’s condition.<sup>7</sup> By initially focusing on sedatives for tic management, it is again likely that the patient’s symptoms were the target of intervention instead of the cause.

Reversing the postulate of later psychoanalysts, Wilson argued that Z.’s twitches and vocalizations worsened with the patient’s alleged masturbatory habits.<sup>8</sup> The corresponding measures he administered to Z. in association with this idea were first surgery and then physical restraints. When circumcision failed to permanently stop the tics, Z. was placed into splints at night.<sup>9</sup> Z.’s situation exemplifies the questionable nature of interventions that physicians formulated from a theoretical perspective of tic etiology.

Drug intervention was occasionally the single choice given to patients with tics even when a physiological source was declared absent. Both Z. and the patient examined just one year after the publication of “Study of a Nervous Affliction” took sedatives, and most likely for symptom reduction rather than to target the mental decay deemed present by their treating physicians. A similar instance occurred in 1901 when a middle-aged German immigrant underwent different medication trials that included bromides. Disregarding evidence that supported the presence of a physical causal factor, the

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<sup>7</sup> Kushner, *A Cursing Brain?*, 42.

<sup>8</sup> *Ibid.* Subsequent psychoanalysts involved in or influential to tic treatment such as Sandor Ferenczi would argue that tics were the expression of repressed masturbatory urges as opposed to tics being aggravated by the act itself.

<sup>9</sup> *Ibid.*

patient's physician determined his condition to be caused by a weakened will.<sup>10</sup> Unlike the weakened willpower that Itard attached to his female patients around 1825, this physician contended that the man's alleged degenerative situation was the result of masturbatory infatuation rather than of unfulfilled gender role.<sup>11</sup> He suspected a psychological causal factor after observing the failure of medication to have a lasting impact on the condition. Such histories reflect researchers Arthur and Elaine Shapiro's description of Tourette's disorder during much of the twentieth-century that "when in doubt it is psychological."<sup>12</sup>

The use of chemicals such as bromides and arsenic for tic suppression would create a patient experience similar to future instances involving neuroleptic medications. That is, these drugs frequently had the effect of simply tranquilizing the patient rather than correcting some imbalance in brain chemistry. Among other unintended side effects, this stands as a primary reason why Touretters have commonly begun to stray from pharmaceuticals in recent times.

However, prior to drug treatments even becoming the central form of tic management, their distribution was intended to suppress symptoms or possibly interfere with a speculated psychological causal factor. Whatever success physicians professed to have encountered with medication did not lead them towards a physiological construct of etiology. With prevalent clinical thought becoming steadily anchored in psychoanalysis after the beginning of the twentieth-century, clinical prescription of chemical therapy

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<sup>10</sup> Ibid., 43.

<sup>11</sup> Ibid. When compared with prior examples, a common trend that appears in popular medical thought during this time is the attachment of tics to gender or sexual issues, that which would become full-blown with the rise of classic Freudian psychoanalytic techniques. Kushner notes that "masturbation resulted from and led to a series of degenerative mental disorders."

<sup>12</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 5.

became far less common. Psychogenic theorizing survived well into the following decades with new studies and articles that adhered to this growing paradigmatic status quo.

### **Therapeutic Confusion**

At the forefront of alternative explanations for Gilles de la Tourette's disease was Henry Meige and E. Feindel's *Les Tics et leur Traitement (Tics and their Treatment)*. This 1902 publication, which emphasized a psychological origin of tics, "became the standard for diagnosis and treatment of motor and vocal tics for the next half century."<sup>13</sup> After late nineteenth-century contentions that frequently related tics to hysteria and choreas, *Tics and their Treatment* placed tic symptoms deeper into a behavioral category.<sup>14</sup> Consequently, many people who experienced involuntary movements and vocalizations during this period were subject to a wide variety of interventions aimed at correcting what were supposed to be willful bad habits. Patients treated under the authors' theories were frequently placed into physical restraints to forcefully stop the alleged voluntary mannerisms or made to perform exercises leading one to believe that their symptoms were purposeful actions.<sup>15</sup> A sharp decline in the use of drug therapies and an increase in psychotherapy and behavioral interventions followed Meige and Feindel's ideas, as did a great deal of diagnostic and therapeutic confusion among treating practitioners and their patients.

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<sup>13</sup> Kushner, *A Cursing Brain?*, 45.

<sup>14</sup> *Ibid.*, 48; Shapiro et al., *Gilles de la Tourette Syndrome*, 30. It is important to note at this time that people who might have identified with a multiplicity of known modern movement disorders, including Tourette syndrome, would have been affected by the authors' assumptions.

<sup>15</sup> These treatment methods endorsed by Meige and Feindel are best illustrated in the first chapter of their publication that describes the representative case of "O." See Henry Meige and E. Feindel, *Tics and their Treatment* (New York: William Wood and Company, 1907, Reproduced by BiblioBazaar, 2009), 1-24.



Similar to Gilles de la Tourette who used the Marquise de Dampierre as the central model of his study, Meige and Feindel sought a patient example that fit their preexisting etiological belief.<sup>16</sup> Although citing other patient cases as well, their preconceived ideas were cast upon a single subject as they discovered the “perfect compendium of almost all the varieties of tic.”<sup>17</sup> Explicitly focusing on one patient subsequent to forming an etiological theory suggests the speculative nature of their interventions. With a 1907 English translation of *Tics and their Treatment* by famed British Neurologist S. A. Kinnier Wilson, the emerging psychopathological construct of tic illness perpetuated by Meige and Feindel became the most influential theory for American physicians.<sup>18</sup>

Many researchers who subsequently authored articles hypothesizing a behavioral cause of tics also had only one patient, and at times none at all. Providing no case study of his own, Hugh T. Patrick argued in 1905 that tics were sensory in origin. He viewed them as willful acts carried out to gain relief from a psychic sensation.<sup>19</sup> In 1906, Boston physician Morton Prince described an adult male patient whose bodily convulsions and unpredictable vocalizations often stemmed from a kind of “fear psychosis.”<sup>20</sup> Although careful to recognize the involuntary nature of the patient’s disorder, he still described the collective symptoms as purposive and relating to a variety of possible causal factors. He provided an extensive view of tic etiology designed from the example of one person. A German physician, J. Sadger, based his theories about the causes of tics on a single

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<sup>16</sup> Kushner, *A Cursing Brain?*, 49.

<sup>17</sup> Meige and Feindel, *Tics and their Treatment*, 1.

<sup>18</sup> Kushner, *A Cursing Brain?*, 58; Shapiro et al., *Gilles de la Tourette Syndrome*, 36.

<sup>19</sup> Hugh T. Patrick, “Convulsive Tic,” *Journal of the American Medical Association*, Vol. 44, No. 6 (1905): 437-42; Shapiro et al., *Gilles de la Tourette Syndrome*, 32.

<sup>20</sup> Morton Prince, “Case of Multiform Tic Including Automatic Speech and Purposive Movements,” *Journal of Nervous and Mental Disease*, Vol. 33, No. 1 (January 1906): 29-34.

female patient in 1914. Although suspecting organic factors as having initially caused the woman's condition, he speculated that her movements were at present voluntary compulsions made in an effort to preserve latent erotic pleasures from childhood. Since Sadger deemed her actions to be willful, he prescribed psychoanalysis.<sup>21</sup> Despite lacking a substantial number of patients with like symptoms from which to base etiological claims, several physicians were confident about coming to firm conclusions about the nature and treatment of a movement disorder. Reports that appeared in journal publications had the potential to inspire a number of others to view and deal with ticcing patients in a similar fashion.

The real triumph of the psychoanalytic perspective of tic etiology and treatment came from Hungarian psychoanalyst Sandor Ferenczi, whose 1921 publication "Psycho-Analytical Observation on Tic" addressed only a single case, and it was a case that he had read about in a separate publication.<sup>22</sup> A close follower of Sigmund Freud, founder of traditional psychoanalysis, Ferenczi reinterpreted the borrowed case to substantiate his idea that tics were a symbolic form of repressed masturbatory urges.<sup>23</sup> For Ferenczi, this meant that all tics were behavioral and stemmed from the unconscious part of one's psyche that often hid destructive childhood sexual conflict. Convulsions and vocalizations could then be mitigated or cured by bringing such conflicts to the surface of

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<sup>21</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 39.

<sup>22</sup> *Ibid.*, 40; Kushner, *A Cursing Brain?*, 58-59; Tourette Syndrome Association Newsletter, Vol. 38, No. 3 (Winter 2010), 12. This separate publication was in fact Meige and Feindel's *Tics and their Treatment*. Ferenczi reassessed the case of their patient "O." within his own psychoanalytical framework.

<sup>23</sup> Kushner, *A Cursing Brain?*, 59; Shapiro et al., *Gilles de la Tourette Syndrome*, 40. Freud, who took limited interest in the debate on tic etiology, had a profound influence on psychiatry and many who were involved in the study of tic illnesses. His psychoanalytic notions with strong emphasis on childhood sexuality made their way into the thinking of prominent researchers of convulsive tics such as Ferenczi. See André E. Haynal, "In the Shadow of a Controversy: Freud and Ferenczi 1925-33," *International Journal of Psychoanalysis* 86 (2005): 457-66; Kushner, *A Cursing Brain?*, 60-62; *TIME: The Weekly Newsmagazine*, Vol. 52, No. 17 (25 October 1948), 65-66.

one's conscious. As Ferenczi's conclusions became "the official psychoanalytic view of tics," patients began to encounter psychoanalytic techniques.<sup>24</sup>

The publications of Ferenczi, Meige and Feindel did not remain completely unquestioned. Varying mixtures of psychogenic and biological explanations for tic symptoms surfaced between the 1920s and the 1950s. Although the practice of psychoanalysis would overcome this opposition, the founding of several different scientific theories offered physicians a chance to formulate their diagnostic conclusions according to their own beliefs and medical opinions.<sup>25</sup> Such circumstances placed ticcing people deeper within an already confusing array of treatments and etiological explanations.

Disagreement with Ferenczi's model began the same year his paper was published. While Ferenczi argued that tics and psychosis had the same root as narcissistic disorders, another observer by the name of Abraham quickly contested this assertion. Without citing any supporting evidence, he declared instead that tics and compulsive habits were linked, a distinction Ferenczi had allegedly overlooked.<sup>26</sup> Years later in 1945, researcher O. Fenichel offered a kind of synthesis between Ferenczi and Abraham. Perceiving tics to be the end result of conversion, he saw both narcissistic and compulsive forces acting as the causes of unwanted motor movements and vocalizations.<sup>27</sup>

A similar instance occurred when S. A. Kinnier Wilson, the English translator of Meige and Feindel's book, encountered resistance towards his psychogenic framing of

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<sup>24</sup> Kushner, *A Cursing Brain?*, 59, 62-64. This often meant the practice of free association and dream interpretation.

<sup>25</sup> *Ibid.*, 80.

<sup>26</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 40-41.

<sup>27</sup> *Ibid.*, 41-42.

tics. During a 1927 medical conference Jean-René Cruchet demonstrated, with limited acceptance of the observers, the probability of a physiological basis of movement disorders. He contended that sound-minded ticcing people who had a healthy genetic history illustrated the involuntary nature of unexplained motor actions, and that a causal factor could probably be found in the brain due to a reaction from a previous infection.<sup>28</sup> His neurological theory of etiology was, as many such theories are, connected with a belief in medications, some of which he argued would actually target the supposed cause rather than just sedate the patient. Cruchet's arguments were anomalous in an otherwise psychoanalytically focused debate. London physician W. Russell Brain added yet another interpretation between Wilson and Cruchet by separating tics into different etiological categories. In a 1928 essay, he divided tics into physiological and behavioral types, creating only further confusion for the greater medical community instead of making more sense of existing contradictions.<sup>29</sup>

Claims of a post-infectious causal factor of tics that arose even before Ferenczi's publication led to a temporary increase in surgical interventions. Operating from only a single bacterial experiment performed by a colleague, influential professor of medicine Frank Billings promoted the idea that infection could act as the cause of tics and the removal of certain infected organs could relieve them.<sup>30</sup> As the president of the American Medical Association and the Association of American Physicians, his ideas inspired practitioners in the United States to perform operations on ticcing patients in spite of contrary psychogenic viewpoints. Among those was Laurence Selling, whose

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<sup>28</sup> Kushner, *A Cursing Brain?*, 73-75.

<sup>29</sup> *Ibid.*, 76-77.

<sup>30</sup> *Ibid.*, 77-78. The corresponding surgical procedures to this theory usually involved the removal of sinuses or tonsils.

1929 paper synthesized the work of Billings and two other physicians.<sup>31</sup> Until it faded from medical literature during the 1930s, the infectious scenario under the Billings model represented a physiological challenge to the dominating psychogenic paradigm that did not encourage the use of medication.

For a short while in the 1930s, constant disagreements about the etiology of tics and Gilles de la Tourette's disease led much of the scientific community to abandon the search for a cause and focus on comprehending the symptoms themselves.<sup>32</sup> Nevertheless, psychoanalytic treatments persisted among ticcing patients and continued well into the next couple of decades. During and after the Second World War, psychoanalytic-oriented psychiatry would dominate much of the American medical realm.<sup>33</sup> "Psychoanalysis," as professor Howard Kushner reports, "thrived during the war and overwhelmed all other ways of understanding vocal and motor tic symptoms in the postwar world."<sup>34</sup> *TIME* magazine, however, painted a slightly different picture of late 1940s' psychiatry. In a 1948 issue, only one-tenth of all American psychiatrists were reported to be "out and out psychoanalysts."<sup>35</sup> Yet, other points of discussion in the article pertaining to personal psychoanalytic testing as a degree requirement for doctors and extensive discussion of Freudian terminology and therapeutic methods reveal the prominence of such thought in mid-century psychiatry.

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<sup>31</sup> *Ibid.*, 77-79.

<sup>32</sup> *Ibid.*, 82, 84-87. During this time, the amount of medical literature pertaining to Gilles de la Tourette's disease severely declined. Kushner provides convincing evidence showing that many cases of convulsive tics were probably misdiagnosed as other movement disorders.

<sup>33</sup> See esp. M. Wilson, "DSM-III and the Transformation of American Psychiatry: A History," *American Journal of Psychiatry* [Abstract] Vol. 150, No. 3 (March 1993): 399-410.

<sup>34</sup> Kushner, *A Cursing Brain?*, 94. Similar to scholars from many disciplines who left Europe during the rise of Nazi occupation, psychoanalysts who came to the United States were able to share ideas with like-minded practitioners.

<sup>35</sup> *TIME* (25 October 1948), 69. This statement most likely refers to the 4,432 psychiatrists reported to belong to the American Psychiatric Association at the time.

Psychiatrists as depicted in *TIME* were also said to be “not always sure just how or why their techniques work, but so long as the patient gets better, they are content to plug away at the techniques and let the theories wait.”<sup>36</sup> When this statement was written, most physicians still believed that tics represented mental illness, particularly described as any of several forms of psychosis or neurosis.<sup>37</sup> Seeing that patients deemed mentally ill were the central focus of psychiatrists, it is logical to conclude that American Psychiatric Association president Will Menninger’s position that a “cure is more important than exact diagnosis” applied directly to many ticcing people.<sup>38</sup> Even though physicians and researchers quickly returned to looking for a cause, the theme of treating the symptoms rather than the cause of a disorder remains common in psychiatry today.

During the reign of psychoanalytical thought, some persisted in promoting physiological explanations for tics. In the 1940s psychoanalyst Margret Mahler offered a sort of middle ground between two central etiological arguments. In a series of articles, she postulated that while physical factors were present in causing tics, repressed psychological familial conflicts acted as the triggering mechanism for the symptoms.<sup>39</sup> Mahler’s influential publications affected clinical outlooks of tics, shifting popular notions about causal factors from psychogenic to psychosomatic.<sup>40</sup> Since the actual

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<sup>36</sup> *Ibid.*, 65.

<sup>37</sup> Bruun and Bruun, *A Mind of Its Own*, 32. The authors write: “Although psychiatry and neurology never fully separated from each other, for many years the field of psychiatry was dominated by psychoanalytic theory... psychoses and neurosis were left to the psychiatrists, who concentrated their efforts largely on psychotherapy.” In the above 1948 issue of *TIME*, psychiatry was noted to recognize psychosis and neurosis as the two main types of mental illness, both of which “can be cured.” (64)

<sup>38</sup> Quote from *TIME* (25 October 1948), 69. As a result of this stance, ticcing people would have often been subject to a variety of psychoanalytic therapies applied in the classic styles set down by Sigmund Freud.

<sup>39</sup> Kushner, *A Cursing Brain?*, 102, 104; Shapiro et al., *Gilles de la Tourette Syndrome*, 44-46. In her first paper which appeared in 1943 Mahler, like many preceding authors, initially used a single-case study as a prime example for her psychosomatic theory of tics.

<sup>40</sup> Kushner, *A Cursing Brain?*, 98, 102-04, 119; Shapiro et al., *Gilles de la Tourette Syndrome*, 42, 46. For a synopsis of several subsequent reports about ticcing patients that also described intervening measures influenced by Mahler’s psychosomatic theories, see *Gilles de la Tourette Syndrome*, 50-62.

underlying emotional struggles that Mahler claimed to activate involuntary motor movements were the focus of her patients' treatment, psychoanalytic methods persisted as the most common intervention for tics.<sup>41</sup> Her studies therefore represented another twentieth-century etiological postulate with limited physiological elements that did not include medication as an associated therapy.

After a long absence from medical literature, the term "Gilles de la Tourette's disease" reappeared in Mahler's essays under the psychosomatic label of "tic syndrome."<sup>42</sup> Although having actually conducted follow-up analysis with several patients, Mahler and her co-authors often provided ambiguous criteria for inclusion in the studies that varied as their theories of tic syndrome developed.<sup>43</sup> "In selecting cases for follow-up study," wrote Mahler in a 1946 article concluding treatments and prognosis, "we discarded many in which there was either accompanying proven organic involvement (choreo-encephalitis, etc.) or proved psychosis, of which the tic syndrome seemed to be only a complicating factor."<sup>44</sup> These constant fluctuations proved to be thematic in Mahler's papers. By the 1960s, a defined set of diagnostic criteria for Gilles de la Tourette's disease had still not been established, and left the disorder open for reinterpretation by another clinical viewpoint that would become widely accepted and carry its own signature treatment.

Examining the nearly incomprehensible mixture of competing clinical ideas about tic illnesses shows that people with involuntary motor and vocal symptoms used therapies

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<sup>41</sup> Kushner, *A Cursing Brain?*, 102-06, 119-21. For an overview of the psychotherapeutic interventions carried out with many of Mahler's patients, see Margaret Schoenberger Mahler and Jean A. Luke, "Outcome of the Tic Syndrome," *Journal of Nervous and Mental Disease*, Vol. 103, No. 5 (May 1946): 433-45.

<sup>42</sup> Kushner, *A Cursing Brain?*, 102.

<sup>43</sup> *Ibid.*, 113-14, 117; Shapiro et al., *Gilles de la Tourette Syndrome*, 42-45.

<sup>44</sup> Mahler and Luke, "Outcome of the Tic Syndrome," 433-34.

that had no relation to their condition. As doctors became too preoccupied with psychogenic hypothesizing from what was often a single case, treatments for tics based on empirical scientific studies and multiple patient analysis were delayed for many years. In reference to this period, psychiatrist Arthur Shapiro writes: “The tendency to burden medicine with overdeveloped theories has always impaired medical progress, interfered with the treatment of patients, and led to fruitless years of treatment and hardship for many afflicted patients.”<sup>45</sup> People who displayed symptoms of Gilles de la Tourette’s disease were either examined without any prescribed therapeutic measures or only had the choice of their physician’s interventions that were formulated from an incomplete view of tic etiology.<sup>46</sup>

### **Caught in the Middle**

During this period of mixed clinical messages about tics, there exists no significant record describing individuals who practiced personally formulated therapies for their condition. This does not negate any possibility that some patients did personally discover helpful measures of their own. However, with a severely limited number of actual patient testimonies from the first half of the twentieth-century, it is difficult to uncover the extent of ticcing people’s efforts to seek unconventional means of dealing with their condition. For this reason, their shared treatment experiences can best be understood through the lens of clinical history. Physicians and researchers did not arrive

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<sup>45</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 5.

<sup>46</sup> Most key figures in this debate viewed tics as coming from a single pathological entity. These figures include Meige and Feindel with a hereditary degenerative explanation, Ferenczi theorizing about repressed masturbatory urges, Billings arguing that tic symptoms occurred subsequent to a focal infection, and Mahler observing repressed psychosexual conflicts about family. For a short period during the 1930s, different types of tics became increasingly reassigned under individual causal factors.



at a consensus about the causal factor(s) of or proper therapies for tic symptoms. Instead, patients encountered a setting where the different explanations for unexplained movements and speech included familial degeneration, weakened will, chronic masturbation, sexual perversion, childhood trauma, willful bad habits, narcissism, and psychotic disturbances of all kinds. The stories and case records that are available tell of the central themes beneath the social history and treatment history of Gilles de la Tourette's disease largely from a second-person point of view.

With the exception of frequent psychoanalytic theories and therapies, no single overriding theme can characterize the history of tic treatment during the first half of the twentieth-century. A twenty-seven-year-old man named Paul fell under this theme, and underwent psychoanalytic intervention in the early 1920s. After first being diagnosed and unsuccessfully treated as a hysteric, the patient visited psychiatrist Charles Trepsat. Deciding that Paul's tic symptoms related to suppressed psychosexual fantasies, Trepsat felt that word association and dream interpretation would strip the patient's hidden wishes from his unconscious mind and cure him.<sup>47</sup> This early 1920s individual participated in therapies that were probably inspired by the work of Ferenczi. Although his treating physician reported success with the interventions, the view of the patient remains unknown.

After being sent to an asylum for motor and vocal tic symptoms and severe pain, a twenty-one-year-old woman named Blanche also encountered psychoanalytic therapy in 1920. Blanche's psychiatrist, Raymond de Saussure, avoided labeling her a hysteric and hence rejected the validity of her previous physician's practice of hypnotism. He formed his own etiological theories from her case alone and determined that a previous illness

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<sup>47</sup> Kushner, *A Cursing Brain?*, 67-68.

was linked to weakening her mental constitution and resulted in tics.<sup>48</sup> This conclusion that Blanche's condition was an issue of the mind and not the body helps explain why she later went through psychoanalysis rather than medication or any other therapy. Many treating clinicians who suspected that tics had some origin in physiology nevertheless redirected their opinions and interventions towards a psychological matter of some kind.

Three adults who went through psychoanalytic trials in the mid-1940s were told that their tic condition was related to stress. M. W. Gerard, a psychoanalyst, concluded that the observed convulsive movements were triggered during a prior traumatic experience and became ingrained into the psyche and surfaced in anxious circumstances.<sup>49</sup> In these cases, visiting an actual psychoanalyst would likely conclude with the practice of associated treatments. Due to many psychoanalysts' fixations with their own etiological beliefs and intervening measures, encountering a variety of therapeutic choices was not probable during consultation.

Patients whose physicians assumed that an infection had caused their tic symptoms could also witness this same circumstance. In 1928, a fourteen-year-old male with a medical history of tics and sinus infections underwent a sinus removal procedure. The one who carried out this measure was Laurence Selling, who had presented a strong argument denying psychogenesis in tics and instead recognized evidence supporting the role of focal infection as a cause.<sup>50</sup> Regardless of his stance that favored a physiological etiology, clinical history relating to tics at this time suggests that certain aspects of a patient's symptom course could easily have been favored or ignored depending on the

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<sup>48</sup> Ibid., 69-71. Hypnotism was the central corresponding intervention administered to people diagnosed as hysterics.

<sup>49</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 51-52.

<sup>50</sup> Kushner, *A Cursing Brain?*, 79-80; Shapiro et al., *Gilles de la Tourette Syndrome*, 37.

background and opinions of the treating practitioner. The fourteen-year-old was presented the single intervening option that corresponded with the assumed causal factor of his condition. In all above cases, whether tics were thought to stem from a psychological or biological source, medication remained largely absent from the treatment portrait.

A successful businessman identified as “O.” was one of the first persons subjected to treatment methods formulated from biased or incomplete psychogenic observation of tic symptoms. Singled out as exemplary of convulsive tics by Meige and Feindel and later given a psychosexual interpretation by Ferenczi, O. was administered intervening measures that were the direct product of behavioral notions of tic etiology.<sup>51</sup> The practice of physically immobilizing his limbs followed by conducting willful movement of ticcing muscle groups was intended to correct what O. was led to believe to be habitual motor outbursts.<sup>52</sup> Additional therapy included mirror drills and breathing exercises. With mirror drills, O. repeated motor spasms voluntarily in a mirror, which was supposed to help him gain mental awareness of his symptoms.<sup>53</sup> The act of prolonging the hold of a deep breath twice daily simultaneous with flowing arm movement targeted some limited physiological connection between movement and thought.<sup>54</sup>

During the course of his symptoms, O. recorded the social and public hardships that followed his condition, which revealed his willingness to trust his treating physicians

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<sup>51</sup> Meige and Feindel, who observed and treated O., were the authors of the period’s defining publication about tic treatments. As a result, the interventions he underwent reflect those of other ticcing patients of his time.

<sup>52</sup> Kushner, *A Cursing Brain?*, 55-56. Meige and Feindel adopted the described method of habit tic reversal from Édouard Brissaud, an early critic of Gilles de la Tourette’s disease who argued that the associated symptoms were a variable form of chorea that was linked to mental degeneration.

<sup>53</sup> *Ibid.* Henry Meige created this particular exercise.

<sup>54</sup> *Ibid.* This specific breathing discipline was invented under the theoretical postulate of Albert Pitres, who was a contemporary of Gilles de la Tourette’s mentor Jean-Martin Charcot.

and adhere to certain prescribed remedies. He wrote, “in regard to my tics, what I find most insupportable is the thought that I am making myself ridiculous and that everyone is laughing at me.”<sup>55</sup> Without his testimony, one might question the reasons why O. would agree to practice certain interventions that intended to make him conscious of his symptoms when he was obviously well aware of them in the first place. The answer lies within his expressed desire to conceal his symptoms using any accessible measure.<sup>56</sup> Perhaps also in lacking other outlets of support and information, O. welcomed the medical attention that he had the opportunity to receive.

Particularly when confronting difficult challenges with their condition, many ticcing patients past and present naturally seek clinical advice and become accepting of their physician’s opinions and recommendations. Today, scientifically supported and universally accepted ideas about the etiology of certain symptoms ease the process of diagnosis and treatment. But like several people during this earlier period who had few means of questioning their physician’s views of tic etiology, O. evidently remained interested in correcting his “bad behaviors” through Meige and Feindel’s interventions. Observation of this fact should not create a negative impression of clinical consultation, but rather simply represent that no historical record indicates a large-scale movement towards patient autonomy or individually formulated coping strategies until more recent times. As the alleged causal factors of tic symptoms varied from researcher to researcher, people diagnosed with *maladie des tics* and related disorders were still linked to problematic etiological paradigms and subject to corresponding treatment models.

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<sup>55</sup> Ibid., 55, taken from Henry Meige, “La Genèse des Tics,” *Journal de Neurologie* (5 June 1902): 17.

<sup>56</sup> Kushner, *A Cursing Brain?*, 55.

During the mid-twentieth century, growing acceptance of a modified version of Gilles de la Tourette's original disease construct altered popular medical notions and thus the shared treatment circumstances of tourettic peoples.<sup>57</sup> Evidence supporting neurological origins of certain tic symptoms was extensively published by psychiatrist Arthur Shapiro and psychologist Elaine Shapiro and eventually gained world-wide recognition. As this new etiological design gradually overcame once prominent psychogenic theories, patients encountered a dramatic increase in the use of pharmaceutical treatments, particularly with the drug Haloperidol.<sup>58</sup> Although chemical therapies had already been used in a few cases dating back to the late nineteenth-century, they had never before in the history of convulsive tics been the primary treatment. As progressive ideas about causal factors gave pharmacotherapy a forceful shove into conventionality, psychiatric observation of Gilles de la Tourette's disorder transitioned from many etiological theories with many associated treatment structures to one central etiological theory with a single signature intervention.

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<sup>57</sup> The evolved version we know today described by doctors Arthur and Elaine Shapiro, the Tourette Syndrome Association, and the latest *Diagnostic and Statistical Manual of Mental Disorders* does not stress symptoms of echolalia as much as "Study of a Nervous Affliction," nor does it include negative prognosis about inevitable debilitation or insanity over time and the unavoidable development of cursing. Consult Shapiro et al., *Gilles de la Tourette Syndrome*, 254; Ruth D. Bruun and Arthur K. Shapiro, "Differential Diagnosis of Gilles de la Tourette's Syndrome," *Journal of Nervous and Mental Disease*, Vol. 155, No. 5 (November 1972): 328-34; Tourette Syndrome Association, *Facts About Tourette Syndrome: Answers to Most Commonly Asked Questions*, [www.tsa-usa.org](http://www.tsa-usa.org), accessed 15 February 2010; American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> ed., Text Revision (Washington, DC: American Psychiatric Association, 2000), 111-13.

<sup>58</sup> The history of convulsive tics up to this point shows how symptoms being thought of as either voluntary or involuntary is vital to a patient's treatment experience.

CHAPTER THREE  
Beneath the Mask: Origins of Pharmaceutical Dominance in the Treatment of  
Tourette Syndrome

"ALL I KNEW WAS THEY FINALLY FOUND A NAME FOR WHAT I HAD AND I  
WAS TAKING MEDICATION."

Tourette quoted in the *Chicago Tribune*, July 6, 1981

The nineteenth-century physiological understanding of convulsive tics that began with Georges Gilles de la Tourette reappeared in an updated form in the second half of the twentieth-century. During the 1950s and 60s, several clinicians began exploring the effects of neuroleptic medications on ticcing patients, which commonly appeared to decrease symptoms. Encouraging results with pharmaceuticals led many researchers to suspect that certain drugs balanced disrupted brain chemistry. Consequently, Gilles de la Tourette's disease became less frequently associated with mixed psychogenic theories and publications. The clinical and therapeutic confusion of prior years began to be lifted when researchers Arthur and Elaine Shapiro established specific diagnostic criteria for a structured pathological framework and supported the creation of a nationwide support group for the "Gilles de la Tourette syndrome" that we know today. These historic occurrences placed an official neurological label on the condition that in turn triggered an outbreak of mass-distribution of medication for its treatment. Pharmaceuticals, especially the antipsychotic drug Haloperidol (Haldol), became the primary form of clinical intervention for the modern version of the disorder. However, while some physicians and reporters celebrated the efficacy of certain prescription drugs, patients and other physicians recognized that many medications had harmful side effects.

## From Psychoanalysis to Pharmacology

As medical outlooks on the origins of tics began to refocus on the brain rather than of the mind, the number of purely psychoanalytic papers about Gilles de la Tourette's disease started to decrease by the 1960s. Simultaneously, the use of pharmacotherapy to treat the condition in conjunction with psychotherapy increased.<sup>1</sup> Whether Margaret Mahler's psychosomatic paradigms directly inspired the treatment of certain pre-1970s cases or not, ticcing people commonly found themselves under this dual form intervention. However, it was not long after physicians began experimenting with antipsychotics such as Haldol and Chlorpromazine, which helped control the symptoms of other psychiatric disorders, that their perceptions of appropriate clinical treatment of ticcing patients gradually transitioned to the strict use of medication.<sup>2</sup> The increased attention that many health practitioners gave to the physical origins of tics, particularly the multi-case studies of the Drs. Shapiro, would eventually place patients into a medical setting concentrated on pharmacology.

Initially, many psychiatrists used medications only to supplement the primary treatment of psychoanalysis. One of the first efforts to manage tic symptoms using both drugs and psychotherapy in America occurred in 1959 and involved an adult and two

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<sup>1</sup> Consult Arthur K. Shapiro et al., *Gilles de la Tourette Syndrome* (New York: Raven Press, 1978), 55-62. Although dominant modes of clinical thought about tics and Tourette's reflect the shared treatment circumstances of patients, it is important at this time to keep in mind the diversity of etiological ideas and treatments that survive along with the prominent paradigm.

<sup>2</sup> For a history and descriptions of these two important drugs, see Howard I. Kushner, *A Cursing Brain?: The Histories of Tourette Syndrome* (Cambridge: Harvard University Press, 1999), 130-42. An interesting point Kushner makes is that while the impact of chemical agents on involuntary tics immediately led most European physicians (with the exception of Tourette syndrome's native country of France) to question psychological origins of the symptoms, many clinicians in the United States continued to fall back on psychoanalytic assumptions of etiology during the 1960s.

teenage males.<sup>3</sup> Since the patients' physician believed their conditions were related to a schizophrenic pathology stimulated by mental conflict, he treated them primarily with psychoanalysis. He also administered Chlorpromazine, a neuroleptic medication used in the treatment of schizophrenia, to the patients to assist in psychotherapy by sedating them to a point where their tics did not interfere with the process.<sup>4</sup> Even though the patients' provider reported that psychoanalysis alone had minimal effect, Chlorpromazine was still used only to gain better access to their unconscious.

Soon, however, medication would begin to take on a more direct role in treatment. One doctor prescribed a forty-two-year-old woman Haldol in 1967 for her uncontrollable motor and coprolalic vocal tics after a diagnosis of Tourette's disorder had been overlooked for nearly twenty years.<sup>5</sup> Due to certain traumatic childhood experiences, she had developed severe emotional issues which she felt were satisfactorily addressed by psychotherapy. After explaining that her lasting "jerks and swearing seem to be something else," her physician looked for other possible explanations for the tics and eventually settled on a diagnosis of what he referred to as Tourette's syndrome.<sup>6</sup> Speculating that malnutrition and "fearful stress" brought about by disturbing events early in her life caused the symptoms to surface physically, the physician administered Haldol in conjunction with psychoanalysis.<sup>7</sup> The suspected link between physiological and emotional elements involved in the symptoms explains the mixed interventions of

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<sup>3</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 55.

<sup>4</sup> Ibid.

<sup>5</sup> Eugene G. Goforth, "A Single Case Study: Gilles de la Tourette's Syndrome, a 25-Year Follow-Up Study," *Journal of Nervous and Mental Disease*, Vol. 158, No. 4 (April 1974): 306-09.

<sup>6</sup> Although Goforth labeled the patient's condition as "Tourette's syndrome" in 1974, his expressed etiological beliefs for this particular case show that his use of the term does not coincide with the inherent neurological classification that it is given during this decade.

<sup>7</sup> Ibid., 306, 308-09.



emotional therapy and medicine.<sup>8</sup> The drug caused side effects, although the doctor reported that they were minimized by proper dosage. The patient's unique case involving childhood emotional trauma and convulsive tics was treated psychosomatically for several years.

Some patients underwent exclusive medication trials after physicians initially administered them drugs as a compliment to behavioral and emotional therapies. Such was the case of "Larry S." who visited a psychologist as a child and was subsequently sent to military school for unsociable comments and yelling. During his teenage years, a psychiatrist provided Larry with psychotherapy accompanied by small amounts of Chlorpromazine and carbon dioxide treatments.<sup>9</sup> Two other psychiatrists later treated Larry as an adult using only heavy doses of Chlorpromazine. In their report on the case, they noted that "it was not until the advent of psychotropic drugs that demonstrable progress began to be made in the control of the clinical manifestations of Tourette's disease."<sup>10</sup> As the authors intended to review the efficacy of different drugs that had been previously used for ticcing patients, the references cited in this 1968 article well illustrate the increasing use of pharmaceutical trials for such cases. Their description of Larry represents a single-case study that drew upon other like sources for direction on how to manage their own patient's symptoms.

Similar to the example of Larry S., a team of four clinicians from the University of Pennsylvania encountered a thirty-eight-year-old man who had been intermittently treated with psychotherapy and medication during the 1960s. This patient, who also

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<sup>8</sup> This therapeutic model closely reflects those created by Margaret Mahler, whose 1946 publication was among the few references cited in this 1974 article by Goforth.

<sup>9</sup> Bernard S. Levy and Eduard Ascher, "Phenothiazines in the Treatment of Gilles de la Tourette's Disease," *Journal of Nervous and Mental Disease*, Vol. 146, No. 1 (January 1968): 36-40.

<sup>10</sup> *Ibid.*, 36.

visited a psychologist during childhood and continued psychotherapy during some of his adult years, eventually reached doctors who understood pharmaceuticals to be the emerging form of Tourette's treatment.<sup>11</sup> After observing inconsistent results with Haldol, the medical team briefly prescribed the patient Chlorpromazine, later supplemented with L-Dopa, until continuing trials with Haldol. The physicians concluded that the man's unfavorable reaction to Chlorpromazine and L-Dopa could be useful in etiological studies and recommended continued use of Haldol despite the unavailability of long-term follow-up studies with the drug.<sup>12</sup>

A striking similarity between these four cases is that medical practitioners relied solely on one patient to formulate their treatment plan.<sup>13</sup> Although citing other studies about touretic conditions, each researcher operated from the perspective of a single patient example. A comparison of two articles illustrates the problematic nature of attempting to understand a syndrome by using such a method. The physicians who treated Larry S. wrote in a synopsis of their article that, "it is the purpose of this paper to present a case report of a patient with Gilles de la Tourette's disease who has been successfully treated through the use of large doses of Chlorpromazine."<sup>14</sup> On the contrary, the combined psychiatrist and neurologist team who studied the thirty-eight-year-old ticcing man around the same time record, "this case report suggests that...treatment with L-Dopa and Chlorpromazine is ineffective in this syndrome."<sup>15</sup>

Observing that the effectiveness of medication influenced etiological theories about tics,

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<sup>11</sup> Joseph N. DiGiacomo et al., "A Case with Gilles de la Tourette's Syndrome: Recurrent Refractoriness to Haloperidol, and Unsuccessful Treatment with L-Dopa," *Journal of Nervous and Mental Disease*, Vol. 152, No. 2 (February 1971): 115-16.

<sup>12</sup> Ibid.

<sup>13</sup> For other case studies made during the waning years of psychogenic theorizing that follow this clinical theme, see Shapiro et al., *Gilles de la Tourette Syndrome*, 50-62.

<sup>14</sup> Levy and Ascher, "Phenothiazines in the Treatment of Gilles de la Tourette's Disease," 36.

<sup>15</sup> DiGiacomo et al., "A Case with Gilles de la Tourette's Syndrome," 115.

the direct disagreement over the impact of Chlorpromazine on tourettic symptoms demonstrates how multiple-patient scenarios were needed to substantiate ideas about a neurological causal factor.

### **The Official Label**

Some years after the first studies describing the use of Haldol for tic symptoms appeared, psychiatrist Arthur Shapiro and psychologist Elaine Shapiro of the Cornell University Medical Center in New York published reviews of several Tourette syndrome patients that they treated with the drug.<sup>16</sup> In their articles, the Shapiros criticized the use of single-case studies in understanding the disorder and assaulted the psychogenic theorizing of involuntary tics.<sup>17</sup> Others before them had actually reported successful treatment of ticcing patients with medications such as Haldol while suspecting the presence of a physiological causal factor, and even attached the term “syndrome” to Gilles de la Tourette’s name.<sup>18</sup> However, Arthur and Elaine Shapiro and the Tourette Syndrome Association (TSA) they helped create would act as the driving forces behind the formulation of a permanent neurological label for the French physician’s original disease description and the exclusive use of medication.

In 1965, a colleague of Dr. Arthur Shapiro referred a twenty-four-year-old female patient to him and recommended psychotherapy for her treatment. Since her youth, the

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<sup>16</sup> See esp. Arthur K. Shapiro, Elaine Shapiro, Henriette Wayne, “Treatment of Tourette’s Syndrome with Haloperidol, Review of 34 Cases,” *Archives of General Psychiatry*, Vol. 28, No.1 (January 1973): 92-97.

<sup>17</sup> See esp. Arthur K. Shapiro and Elaine Shapiro, “Clinical Dangers of Psychological Theorizing: The Gilles de la Tourette Syndrome,” *Psychiatric Quarterly*, Vol. 45, No. 2 (1971): 159-71.

<sup>18</sup> For example, see Janice R. Stevens and Paul H. Blachly, “Successful Treatment of the Maladie des Tics: Gilles de la Tourette’s Syndrome,” *Am. J. Dis. Child.*, Vol. 112, No. 6 (1966): 541-45. The authors, who reported on a single case, noted that the condition had “long rested in the shadowy borderland between neurology and psychiatry,” and was “highly resistant to psychotherapy.” (541) See also Kushner, *A Cursing Brain?*, 134-37; Shapiro et al., *Gilles de la Tourette Syndrome*, 7.

woman experienced twitching of her arms and head, full-body convulsions, and barking and grunting vocalizations. Without any prior knowledge of Gilles de la Tourette's disease, Shapiro observed that the patient's symptoms, although frightfully bizarre, were clearly involuntary and could not be explained by developmental history or psychological assessment.<sup>19</sup> Realizing that clinical observation of the woman's symptoms "did not fit the theoretical postulates" and that she "could not be characterized as psychotic or as having an underlying psychosis," he decided to investigate other explanations.<sup>20</sup> After reading available literature, the psychiatrist diagnosed her with Gilles de la Tourette's disease.

As Arthur Shapiro began to take further interest in the disorder, he undertook an investigation into its clinical and treatment history. In realizing the "unfortunate error" of psychogenic hypothesizing, he concluded that the symptoms exhibited by the patient had to be caused by organic factors.<sup>21</sup> Subsequent to explaining this to his patient, Shapiro and the ticcing woman decided that the best approach to treatment involved trials with different drugs that had been reported to be effective in reducing tics. Arthur Shapiro's description of an agreement between doctor and patient about medication is suggestive of one of the first documented incidences of patient input in the treatment of tics. Following

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<sup>19</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 1-2. Ten years before the Shapiros published this seminal book on the topic in 1978, they described the patient's case in a March 1968 journal article that appeared in the *British Journal of Psychiatry*.

<sup>20</sup> *Ibid.*, 2-3.

<sup>21</sup> *Ibid.*, 3-4. It is important to note that at the time of Shapiro's inquiry the term "organic," as opposed to the term "functional," described medical conditions that were characterized by having "defined pathological lesions" and could be illustrated by empirical scientific experimentation. The physician's consultation with his first tourettic patient occurred around a time where the field of psychiatry was becoming more linked with neurology after decades spent within psychoanalytic frameworks. In 1994, the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) dismissed the terms "organic" and "functional" and established the more wide-ranging term "mental disorder." Terms such as "neurological," "physiological," and "neuropsychiatric" are therefore more fashionable and appropriate descriptions of the condition today. For a description of this shift in terminology and the criteria for inclusion of "mental disorders," consult Shahul Ameen, *Organic Mental Disorders*, <http://www.psyplexus.com/neuropsychiatry/introduction.htm>, accessed 12 May 2011.

experimentation with thirty-six different drugs which caused side effects that “interfered with functioning,” the doctor discovered the use of Haldol in five other case reports of Tourette’s disease.<sup>22</sup> This inspired him to prescribe it to his own patient. The neuroleptic had side effects, but Shapiro declared that they became tolerable after finding proper dosage.

Although the Shapiros began with a single case, they expanded the scope of their studies to hundreds of patients, many who they treated with Haldol and other drugs.<sup>23</sup> This led to their identification of a neurological syndrome. Like Mahler before them, they redefined Gilles de la Tourette’s disease, but this time as a physiological condition rather than a psychosomatic one. In a 1972 article titled “Differential Diagnosis of Gilles de la Tourette Syndrome” Arthur Shapiro, co-authoring with Cornell University colleague Ruth Bruun, set out to clarify tourettic symptomatology and establish specific diagnostic criteria.<sup>24</sup> Multiple case studies were conducted for the first time since Mahler’s formulation of “tic syndrome,” totaling thirty-four patients who Shapiro had followed up with for six years. The consistency of patient inclusion standards and positive reports about interventions specifically set the Shapiros’ studies apart from Mahler’s.<sup>25</sup> By 1976, the Shapiros had authored or co-authored over twenty articles

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<sup>22</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 6-7.

<sup>23</sup> In *Ibid.*, the doctors claim their report to be based on “experience in diagnosing, treating, and studying over 500 patients with Tourette syndrome.” (v)

<sup>24</sup> Ruth D. Bruun and Arthur K. Shapiro, “Differential Diagnosis of Gilles de la Tourette’s Syndrome,” *Journal of Nervous and Mental Disease*, Vol. 155, No. 5 (November 1972): 328-34. Confirming their interest in the condition’s unique qualities, the authors describe Tourette syndrome as “a rare but fascinating movement disorder.” (328)

<sup>25</sup> See Margaret Schoenberger Mahler and Jean A. Luke, “Outcome of the Tic Syndrome,” *Journal of Nervous and Mental Disease*, Vol. 103, No. 5 (May 1946): 435, 440-41. In this article, the authors vacillate between proper criteria for diagnosis. See also Kushner, *A Cursing Brain?*, 114-15.

relating to Tourette syndrome and its treatments.<sup>26</sup> An accessible text describing their neurological perspectives of the condition and administration of Haldol to patients was entitled *Gilles de la Tourette Syndrome* and published in 1978. This comprehensive overview of Tourette's studies included specific criteria for diagnosis of the disorder and inspired the description that appeared in the *Diagnostic and Statistical Manual of Mental Disorders* published by the American Psychiatric Association.<sup>27</sup>

The Shapiros' syndrome construction was intertwined with the founding of the Tourette Syndrome Association (TSA) in 1972.<sup>28</sup> After certain media sources reported on the updated understanding of the strange tic condition, concerned parents of affected children held meetings to decide what measures needed to be taken to find proper treatments and a possible cure for the condition, to educate clinicians, and to increase public awareness. Arthur Shapiro was asked to serve as an advisor for the group.<sup>29</sup> Essentially, the TSA aimed to create an outlet for continued medical research while providing social advocacy for Touretters. Their current mission statement expresses its goals as "to identify the causes of, to control the effects of and to find the cure for Tourette syndrome through education, research and service."<sup>30</sup> By way of the cooperative endeavors between the Shapiros, their colleagues, and the TSA, varying psychogenic notions of Tourette's symptoms became increasingly unfashionable.

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<sup>26</sup> For a comprehensive list of articles published by Arthur and Elaine Shapiro up to this date, see Shapiro et al., *Gilles de la Tourette Syndrome*, 414, 423-24.

<sup>27</sup> The "criteria for diagnosis of chronic multiple tic or Gilles de la Tourette syndrome" appears in *Ibid.*, 254. The DSM-IV includes Arthur Shapiro among their list of advisors about "disorders usually first diagnosed during infancy, childhood, or adolescence." American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> ed. (Washington, DC: American Psychiatric Association, 1994), 853.

<sup>28</sup> Historian Howard Kushner recognizes the dependent relationship between the Shapiros and the TSA in *A Cursing Brain?* (178), writing, "the Shapiros played such a central role in the formative years of the Association that it is impossible to separate their views on the etiology and treatment of Tourette's from those of the Association's."

<sup>29</sup> *Ibid.*, 177; Shapiro et al., *Gilles de la Tourette Syndrome*, 410-11.

<sup>30</sup> Tourette Syndrome Association Newsletter, Vol. 38, No. 3 (Winter 2010), 13.

Following the foundation of the TSA, the Shapiros' contentions of physiological etiology gained the attention of researchers in the United States and around the world. Articles published between 1972 and 1979 that discussed Gilles de la Tourette syndrome appeared in German, Polish, Hebrew, and Chinese. Earlier 1970s references to Tourette's disease or *maladie des tics* could be found in French, Dutch, Romanian, and Czech.<sup>31</sup> Comparing the publication dates of articles citing a "disease" prior to the founding of the TSA with those that used the term "syndrome" after its establishment shows the association's swift global influence.<sup>32</sup> This was confirmed during the First International Gilles de la Tourette's Symposium in May 1981 that welcomed almost three hundred researchers from around North America, Europe, and Asia.<sup>33</sup> "Tourette syndrome is everywhere, all around the globe," writes a Norwegian man discussing the shared public experiences of people with the disorder.<sup>34</sup> The TSA continues to provide financial support for researchers from several different nations.<sup>35</sup>

Current research on the origins of Tourette's largely continues to investigate and support the conclusion that the syndrome is caused by a chemical imbalance in the brain.<sup>36</sup> However, the neurological label that the Shapiros originally placed on their reconstruction of the syndrome seemed to be motivated just as much by opposition towards psychoanalytic theorizing as it did by empirical scientific evidence. Although their 1978 book provides compelling analysis about how psychoanalytic techniques were

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<sup>31</sup> PubMed search: "Tourette Syndrome Treatment," 27 April 2011.

<sup>32</sup> Although this distinction is suggestive of the TSA's influence, inability to interpret articles in many different languages limits precise understanding of their content and exact premises.

<sup>33</sup> Kushner, *A Cursing Brain?*, 185.

<sup>34</sup> Christian Melbye Jr., "Min Egen Lille Verden," *Don't Think About Monkeys: Extraordinary Stories Written by People with Tourette Syndrome*, eds. Adam Ward Seligman and John S. Hilkevich (Duarte: Hope Press, 1992), 159.

<sup>35</sup> See esp. Tourette Syndrome Association, "Medical and Scientific Programs: Research Awards 2010-2011."

<sup>36</sup> Ibid.

“unfortunately imposed” on patients, their reviews of prior studies appear more concerned with faulting such methods than discussing the efficacy of medication.<sup>37</sup>

While the effect of neuroleptics helped authenticate a physiological cause of tics, this did not provide any concrete proof of this claim. Anti-psychotics such as Haldol block the transmission of dopamine, which is the brain chemical commonly associated with tourettic symptoms.<sup>38</sup> Therefore, some researchers contended that the mitigating effect these drugs had on an individual’s tics was convincing evidence of a chemical imbalance. Arthur Shapiro, on the other hand, only knew that the drug acted as a major tranquilizer and most likely tackled the symptoms rather than acted on the cause.<sup>39</sup> While the Shapiros first largely celebrated the use of Haldol they, as well as their patients, became aware of the danger of side effects.<sup>40</sup>

Despite the limited support that medication could provide for the existence of a neurological causal factor, the Shapiros both disputed and set themselves apart from psychodynamic theorizations and research methods that characterized much of the twentieth-century. First, instead of relying on single-case studies to determine the origins of tics and establish conventional treatment, the Shapiros and their colleagues conducted

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<sup>37</sup> See Shapiro et al., *Gilles de la Tourette Syndrome*, 39-64, quote from 63. See also Kushner, *A Cursing Brain?*, 173-74.

<sup>38</sup> Norman L. Keltner and David G. Folks, *Psychotropic Drugs*, 2<sup>nd</sup> ed. (St. Louis: Mosby-Year Book, Inc., 1997), 69, 365. A mention of common side effects follows the authors’ discussion of Haldol and other anti-psychotic drugs.

<sup>39</sup> The etiological opinions that the use of Haldol inspired amidst the syndrome’s continued unknown causal factor(s) is mentioned in Richard D. Sweet et al., “Neurological Features of Gilles de la Tourette’s Syndrome,” *Journal of Neurology, Neurosurgery, and Psychiatry* 36 (1973): 1-9. The authors (including the Shapiros) report: “Tourette’s syndrome responds best to treatment with haloperidol...it has been suggested that a dopamine excess may underlie Tourette’s syndrome (Snyder, Taylor, Coyle, and Meyerhoff, 1970), but the actual anatomical or pathophysiological abnormality which might cause Tourette’s syndrome and can be controlled by haloperidol is still unknown.” (1) See also Kushner, *A Cursing Brain?*, 133-34, 173, 187.

<sup>40</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 257, 288-89, 311, 316-24, 395. For descriptions about side effects that Touretters experienced while taking Haldol and other drugs, consult Ruth Dowling Bruun and Bertel Bruun, *A Mind of Its Own: Tourette Syndrome, A Story and a Guide* (New York: Oxford University Press, 1994), 140-46.



several different surveys that included dozens of patients. In “Neurological Features of Gilles de la Tourette’s Syndrome,” the authors wrote that, “since subtle neurological abnormalities and clinical correlations may escape notice in a few patients, or in a group of patients examined by various physicians, we thought it worthwhile to report the findings in a large series of patients with Tourette’s syndrome.”<sup>41</sup> Second, unlike many other ticcing patients who received short-term psychoanalytic interventions, those under the Shapiro model continued contact with their treating clinician and had follow-up appointments. The Shapiros’ formulation of specific diagnostic criteria based on observation of hundreds of patients over a prolonged period changed the medical experiences of people with Tourette syndrome.

### **Social Implications**

The neurological syndrome theory promoted by the Shapiros and the TSA that distanced tic symptoms from psychogenic explanations eased certain treatment-related challenges shared by people with involuntary tics. These challenges included misdiagnosis, exile, incarceration, and the expense of tic therapies. Such concerns remain in some Touretter situations today, and commonly act as the reasons for seeking alternative methods of treatment. Although these difficulties are illustrated in many cases, treatment with medication and frequent reports of side effects are apparent in nearly every recorded example during the post-psychogenic era. The progression of personal events in Tourette syndrome cases that appeared in the 1970s and 1980s is quite predictable. Most individual stories reveal a common pattern beginning with confusion about symptoms, then followed by initial psychological testing, then discovering

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<sup>41</sup> Sweet et al., “Neurological Features of Gilles de la Tourette’s Syndrome,” 1.

information about Tourette's through media sources, and finally the administration of medication and frustration with side effects.

Clinical misunderstanding about tic symptoms left many patients with mixed messages about the cause of their condition. In *The Unwelcome Companion*, Rick Fowler recalls his 1974 visit to a doctor's clinic, once again seeking an explanation for his uncontrollable motor movements. Doubting the physicians' claim that there was no physical cause behind his symptoms, he continued to search for another opinion. Due to repeated misdiagnosis, Fowler remained confused about his disorder for several years. After a friend brought a magazine article to his attention that described Tourette syndrome, Fowler consulted a neurologist who diagnosed him with the disorder. "That doctors have actually treated thousands of patients with similar symptoms seemed unbelievable to me," he wrote.<sup>42</sup> Other physicians had previously prescribed him tranquilizers and Ritalin for what they thought were nervous habits. After his Tourette's diagnosis, he again pursued medication trials for his tics, but this time with improved results. Despite the improved efficacy, his new prescriptions initially created side effects that left him "unable to function in everyday life."<sup>43</sup>

Since many people at one time did not understand their condition as Tourette's disorder, they did not receive clinical treatment. "Many go through life without ever having their disorders diagnosed," observed Ronald Kotulak, a journalist who reported on Tourette's cases in the 1970s. "If an effective treatment is available, they may never get

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<sup>42</sup> Rick Fowler, *The Unwelcome Companion: An Insider's View of Tourette Syndrome*, Rev. ed. (Cashiers: Silver Run Publications, 1996), 10-15, quote from 15.

<sup>43</sup> *Ibid.*, 40.

it.”<sup>44</sup> Frank Brancaccio, for example, did not discover that his involuntary tic symptoms matched the description of Tourette syndrome until 1975 at the age of thirty-four. The New York man later began trials with Haldol, which had become the “drug of choice” for the disorder.<sup>45</sup> He later began experiencing strange emotions and “completely withdrew from the world,” though he remained uncertain about whether the depression was caused by the neuroleptic or not.<sup>46</sup> His experience exemplifies that of several other ticcing people who were prescribed medication after receiving a diagnosis of Tourette syndrome and experienced possible side effects.

Adults who grew up without any explanation for their tics or under the impression that they had a mental illness were often later diagnosed with Tourette’s due to greater media coverage of the condition and widespread acceptance of the neurological syndrome construct among physicians. A woman in her fifties who had previously been told that her tics were the result of anxiety noted, “I always thought I was a very nervous person.”<sup>47</sup> As Tourette’s was beginning to be understood as a physiological disorder Richard, a father of three tourettic children, became perplexed about his own lifelong experience with obsessive compulsions when his oldest son began mimicking his actions. Subsequent to clinical observation of the boy that concluded with the finding of Tourette syndrome, he and his younger sister encountered negative experiences with medication. The boy’s neurologist, who labeled him as being demented in spite of a diagnosis of Tourette’s, “poured medications down him without comprehending what their results

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<sup>44</sup> Ronald Kotulak, “Tempo: The Agony of Those Obscure, Sorry-No-Cure Afflictions,” *Chicago Tribune*, 12 June 1978, B1.

<sup>45</sup> Frank Brancaccio, “Subway People,” *Don’t Think About Monkeys*, 29. Quote taken from Elaine Fantle Shimberg, *Living with Tourette Syndrome* (New York: Simon & Schuster, 1995), 54.

<sup>46</sup> Brancaccio, “Subway People,” 31.

<sup>47</sup> Tourette Syndrome Association Newsletter, Vol. 37, No. 1 (Summer 2009), 14.

might be,” according to his father.<sup>48</sup> Richard’s daughter’s trials with medications “created more problems and solved few,” as any effect they had on her symptoms were teamed with dizziness, blurred vision, drowsiness, and mental incoherency.<sup>49</sup> This instance, where a parent with tics was not diagnosed with Tourette’s until the surfacing of his children’s symptoms, reflects the frequency of clinical misunderstanding of tics in previous years and also illustrates the problem of side effects with medication during early pharmaceutical trials.

An article that appeared in the *Chicago Tribune* after the founding of the TSA described an example where clinicians administered drug treatments to a patient after years of misdiagnosis. Tim, a twenty-five-year-old Wisconsin man, had been grimacing, clearing his throat, making barking sounds, and thrashing his limbs since he was a child. His parents took him to many physicians, but received no satisfactory explanation for their son’s actions. During his early twenties, Tim’s mother read and informed him about an article that discussed a condition with similar symptoms. Physicians later diagnosed him with Tourette’s. Not knowing quite how to react, Tim refrained from speaking about the matter for a while. “All I knew was they finally found a name for what I had and I was taking medication,” Tim commented.<sup>50</sup>

Clinical misdiagnosis, particularly connected with schizophrenia and other psychosis, prevented many people from understanding their disorder as Tourette syndrome. Physicians and other authorities who figured tics to be caused by mental conflict sometimes incarcerated ticcing people in mental institutions or placed them in hospitals where psychiatrists occasionally administered psychotherapy or no treatment at

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<sup>48</sup> Richard Stickann, “The Family Tourette,” *Don’t Think About Monkeys*, 101-20, quote from 113.

<sup>49</sup> *Ibid.*, 108.

<sup>50</sup> Sandy Battin, “Child’s Twitch, Barking May Be Neural Disorder,” *Chicago Tribune*, 6 July 1981, A4.

all.<sup>51</sup> In one instance during the late 1980s, a twenty-six-year-old man was released after spending ten years in a state mental institution when a clinician changed his diagnosis of schizophrenia to Tourette syndrome.<sup>52</sup> Recent examples of misdiagnosis reveal the extent to which outdated conceptions of tics and Tourette's tend to surface even decades after they slip behind the times.

Some parents encountered blame for being the cause of their child's condition upon initial clinical consultation.<sup>53</sup> Having grown up with involuntary tics in the 1960s without knowledge of Tourette's disease, Marilyn was surprised when two out of her three sons exhibited like symptoms during their youth. Medical attention to their situation was delayed due to problems with insurance coverage. Marilyn's feelings that she had passed her own compulsions to her children were not comforted when the boys' psychologist reinforced her fears. Sometime during her sons' visits with the psychologist, she noticed a short article published by the TSA and requested further information from the organization. Her inquiry eventually led to an appointment with a pediatric neurologist who diagnosed one of the boys as having Tourette's. The physician's prescription of Clonidine, a drug used for high blood pressure, produced

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<sup>51</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 129, 175. In *TIME: The Weekly Newsmagazine*, Vol. 52, No. 17 (25 October 1948), it is reported that "the mass of mentally ill...have nowhere to go but the state institutions," but "because of a lack of money, modern psychiatry [in 1948] is an all-too-rare visitor in the state hospitals." (72)

<sup>52</sup> Tourette Syndrome Association Newsletter (Summer 2009), 13-14. In an interview, the man's new physician mentioned "many of my older patients have spent years in psychoanalysis' being erroneously treated for what their doctors believed to be psychological problems that were causing their TS symptoms."

<sup>53</sup> The blame that physicians often placed on parents for their child's tics is largely what led to the creation of the TSA. See Tourette Syndrome Association Newsletter (Winter 2010), 13; Kushner, *A Cursing Brain?*, 167. Influential psychosexual views of tic etiology professed by Margaret Mahler prior to the formation of the TSA were largely responsible for parental blame of tics.

undesirable consequences. After the mother and patient decided that “the cure was worse than the disease,” the trial was discontinued.<sup>54</sup>

Due to frequent public and scientific misinterpretations of tic symptoms, a number of Touretters before the 1970s spent much of their time in social isolation. As a result, they often did not receive treatment for their condition. Before being treated with Chlorpromazine, Larry S., for example, “mostly stayed at home” as a child because of the social awkwardness of his coprolalia and did not seek medical assistance.<sup>55</sup> Upon understanding that their tics were not related to some unconscious mental instability, several individuals came out of hiding after the condition gained greater publicity and were prescribed medication.<sup>56</sup> A young woman named Nancy, for example, took Haldol for intense episodes of involuntary cursing that previously kept her largely isolated from social settings. Since the offensive nature of Nancy’s condition drove her to seclusion from the public, her doctor, in spite of understanding the potential for side effects, celebrated the impact that the drug had on her symptoms.<sup>57</sup> The reclusive behavior practiced by many during these years perhaps accounts in some part for the lack of descriptions of actual tourettic cases prior to the 1970s.

The expense of many treatments posed another challenge for patients. Before ticcing people had a common biological explanation for their symptoms, they commonly accumulated large medical costs after attempting different psychological interventions for their unknown disorder. During what is considered to have been the first TSA meeting in

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<sup>54</sup> This story appeared in Marilyn Johnson, “Cycles of Misery,” *Don’t Think About Monkeys*, 121-32.

<sup>55</sup> Levy and Ascher, “Phenothiazines in the Treatment of Gilles de la Tourette’s Disease,” 36. Larry’s parents were also initially blamed for the presence of his symptoms.

<sup>56</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 8-9, 409; Ronald Kotulak, “New Drug Aids Victims of Rare Cursing Illness,” *Chicago Tribune*, 17 September 1972, 26.

<sup>57</sup> Kotulak, “New Drug Aids Victims of Rare Cursing Illness,” 26.

June of 1971, the Drs. Shapiro and others learned that “thousands of dollars had been spent by many people for unnecessary psychotherapy.”<sup>58</sup> One couple persisted with clinical consultation for eight years trying to find an explanation for their son’s tics. Following many unproductive doctor visits for their son that cost thousands of dollars, they finally found a newspaper article describing a syndrome that matched his condition.<sup>59</sup> Like many at the time, the boy was later prescribed Haldol.

The similar experiences of Tourette’s authors Adam Seligman and Lowell Handler reveal actual instances where clinical treatment for tics seemed to have been directly impacted by economic forces. Around 1980 Seligman and Handler, having each struggled with the undesired effects of Haldol, conveyed satisfaction with the use of a less potent antipsychotic medication called Pimozide (also Orap) which presented significantly fewer side effects.<sup>60</sup> The drug, however, was not approved by the Food and Drug Administration (FDA) at the time, and Seligman’s efforts to smuggle supplies of Pimozide in from Canada failed at the border.<sup>61</sup> By chance, both men were invited by a mutual friend, Abbey Meyers of the TSA, to advocate for the legal status of the drug at public hearings in Washington, DC. The Orphan Disease Act that would follow addressed concerns about the lack of economic incentives for pharmaceutical companies

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<sup>58</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 5-6, 409, quote from 409. A 1948 issue of *TIME* magazine also discussed the “staggering” cost of psychoanalysis in post-war America for mentally ill patients, suggesting that people with a variety of uncommon disorders with psychogenic labels encountered difficulties with medical costs and proper treatment. *TIME* (25 October 1948), 71-72.

<sup>59</sup> Kotulak, “Tempo: The Agony of Those Obscure, Sorry-No-Cure Afflictions,” B1.

<sup>60</sup> Lowell Handler, *Twitch and Shout: A Touretter’s Tale* (Minneapolis: University of Minnesota Press, 2004), 48-49, 52-53; Adam Ward Seligman, “In the Blink of an Eye,” *Don’t Think About Monkeys*, 38, 43-45. Pimozide, although not pharmacologically related to Haldol, also acts as a dopamine inhibitor. See Keltner and Folks, *Psychotropic Drugs*, 365.

<sup>61</sup> Seligman, “In the Blink of an Eye,” 45; Handler, *Twitch and Shout*, 52-53, 56. Although the drug was illegal in the United States at the time and therefore not obtainable by normal prescription, Seligman reported that his mother once successfully smuggled supplies in from Canada and France while Handler, who was under the care of Dr. Arthur Shapiro, was temporarily able to gain legal access to the drug through the Investigational New Drug Program (IND) which allowed physicians access to medications that were under current FDA consideration.

to create medications for uncommon disorders. Its approval provided tax credits for pharmaceutical companies that developed drugs for rare conditions, and allowed for drugs such as Pimozide to be available and affordable for people with Tourette syndrome.<sup>62</sup> However, Seligman wrote that after the battle for Pimozide was won, he was continually bothered by side effects from medication.<sup>63</sup>

Regardless of the accuracy behind claims that the effects of Haldol indicated an organic pathology, updated clinical perceptions of Tourette's disorder had a tremendous impact on the lives of people with involuntary tics and placed them under an entirely new therapeutic framework. A variety of patient testimonials and publications that appeared after the Shapiros' articles and the founding of the TSA show how Touretters everywhere were being medicated for their condition. Touretters during this period were still very dependent on physicians for therapeutic measures. As treatment options were restricted to the use of medication and researchers attempted to uncover further details about the syndrome, opportunities for creativity and choice in finding coping strategies for tics remained limited.

As patient histories show, medications frequently generated a host of undesired results. Understandably, many individuals who saw some change in their symptoms while on medication were relieved to find an intervention that could make public interaction less stressful or comfort their fears of being psychotic or schizophrenic. Still, nearly every piece of history and literature that relate to the use of drugs for the treatment

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<sup>62</sup> Seligman, "In the Blink of an Eye," 47-49; Handler, *Twitch and Shout*, 53-63; Ronald Kotulak, "'Orphan' Diseases Now In From Cold as Reagan Signs Law Aiding Victims," *Chicago Tribune*, 9 January 1983, 6. Seligman's case was highlighted in this 1983 newspaper article.

<sup>63</sup> Seligman, "In the Blink of an Eye," 49.



of Tourette syndrome include some mention of side effects. Among other reasons, the common appearance of unanticipated consequences during medication trials have inspired many people with the condition in more recent years to seek out alternative means of symptom management.

## CHAPTER FOUR

### Shared Initiatives: The Rising Use of Complementary and Alternative Therapies

“LIKE BAD PHYSICIANS, THEY THOUGHT TO CURE THE DISEASE BY REMOVING THE SYMPTOMS...”

Jacob Burckhardt, *The Civilization of the Renaissance in Italy*

Years of living with a case of severe Tourette syndrome left a young man confused about the best way to deal with his condition. After several disappointing trials with medication Kyle (a pseudonym) decided to explore other possibilities in managing his symptoms. “I tried enough of them [medications] to where I had a pretty good idea that they weren’t going to work,” he explained.<sup>1</sup> For a short time, he thought the narcotics he was prescribed might have been making a difference, but side effects became intolerable, and Kyle grew worried about developing a high level of tolerance to them and how they were affecting his overall health. While in consultation with physicians about finding another treatment, he discovered a variety of other options and was eventually approved for an innovative new surgical procedure called Deep Brain Stimulation (DBS). It had been designed mostly for Parkinson’s disease but could also be used to treat the symptoms of other neurological movement disorders.<sup>2</sup> As an experimental procedure, the outcome of his participation remained unknown. But out of a need to find a non-medicinal approach to calm his harmful symptoms, Kyle pursued the opportunity to have the surgery. He recently underwent a successful operation with positive results.

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<sup>1</sup> Interview with Kyle, 25 April 2011.

<sup>2</sup> National Institute of Neurological Disorders and Stroke, *NINDS Deep Brain Stimulation for Parkinson’s Disease Information Page*, [http://www.ninds.nih.gov/disorders/deep\\_brain\\_stimulation/deep\\_brain\\_stimulation.htm](http://www.ninds.nih.gov/disorders/deep_brain_stimulation/deep_brain_stimulation.htm), accessed 17 October 2011.

Eric (also a pseudonym) also discovered alternative methods of controlling his symptoms. During his adolescence, he was frequently on medication due to severe tics. Though uncertain about what affect most of the pharmaceuticals had, he especially recalls being “zoned out” on one particular drug.<sup>3</sup> Throughout his life Eric, similar to many others like him, had realized that nervousness or stress made his symptoms worse. In high school, his mother informed him of an on-line article relating to exercise and Tourette syndrome. After reading the article and contemplating how a relative with a related condition felt relief while swimming, Eric decided to increase his physical activity. His exercise routine, which included running every morning, proved to be effective. After finding that running decreased feelings of stress and anxiety that worsened his symptoms, he decided to maintain the consistency of his training. “It tired me out in a good way,” he said.<sup>4</sup> During college, he formulated his class schedule so that he could participate in an exercise course every semester. In addition to seeing benefits in exercise, he was relieved to see his involuntary actions begin to wane naturally while coming into adulthood. The lessening of tic severity after high school made Eric decide that he didn’t need medication anymore, but he continued to exercise as a way to manage his lighter symptoms.

The experiences of these two Touretters are representative of many with the condition today. While previous Touretters such as Adam Seligman and Lowell Handler often labored to find better medications, the contemporary generation has been more willing to pursue alternative treatments. Current knowledge and perceptions of the syndrome have allowed for a greater degree of creativity and choice in managing tic

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<sup>3</sup> Interview with Eric, 20 May 2010.

<sup>4</sup> Ibid.

symptoms. “Today, we benefit from a much better understanding of TS,” writes the TSA in a recent newsletter, “and therefore we are able to apply various therapeutic strategies to better treat individuals with the condition.”<sup>5</sup> Medication remains the dominant form of treatment administered to people with the disorder, but there has been a strong and undeniable trend of complementary and alternative treatments during this century. The frequent side effects from pharmaceuticals along with the rise of new alternative therapies have recently inspired many people with Tourette syndrome to replace medications with unconventional practices.

The growth of complementary and alternative treatments among Touretters within the last decade marks a fascinating new turn in the history of Tourette syndrome in that it occurred without the formulation of a new etiological theory. Large numbers of people with tourettic symptoms and their physicians have, often with minimal regard to causal factor, sought unconventional forms of therapy. In addition, many people have also taken the leading role in their own symptom management by creating alternative ways of relieving tourettic stress and tension. The demarcation between individuals who seek clinical consultation and those who formulate coping strategies for themselves is a significant new theme in Tourette’s treatment. This chapter will examine the reasons why many Touretters have chosen alternative therapies. The following two chapters will detail Touretters’ experiences with these practices.

### **A Common Trend**

Over the past ten years, many people with Tourette syndrome have gradually reduced their use of pharmaceuticals and turned instead to alternative therapies. While

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<sup>5</sup> Tourette Syndrome Association Newsletter, Vol. 38, No. 3 (Winter 2010), 12.

several individual cases illustrate decisions to stray from medication, critical studies and patient support outlets that represent significant numbers of Touretters reveal the scope of the trend. The Tourette Syndrome Association, although consistently advocating for new and better medications, has recently published an official statement on alternative therapies for the disorder. It begins by stating, “The TSA frequently receives reports from individuals or practitioners that they or their patients have uniquely benefited from a new or different treatment for the symptoms of Tourette syndrome or co-occurring conditions.”<sup>6</sup> The report mentions that people who tell of successes with unconventional treatments frequently have a past record of failed trials with standard medical care. Unsatisfactory results that many encounter with pharmaceuticals was the topic of another statement made by the organization in a 1999 newsletter:

Few topics provoke more passionate opinions than the subject of medications for the treatment of TS. Convictions vary from adamant stances against all medications to ardent desires to find the right medication in doses that reduce TS symptoms while minimizing the impact of side effects...the aversion to medication-and its side effects-remains an important factor in medical decisions for both children and adults.<sup>7</sup>

These statements made by the TSA, which deals with and represents thousands of people with the condition nationwide, substantiate the increasing deviation from pharmaceuticals.

The Association for Comprehensive NeuroTherapy (ACN) is a non-profit organization focused on studying alternative treatments for Tourette’s and related neurological disorders. It functions to educate the public about tics and Tourette’s and

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<sup>6</sup> Tourette Syndrome Association, *TSA’s Statement on Unsubstantiated Reports of Alternative Therapies for Tourette Syndrome*, [http://www.tsa-usa.org/news/Unsubstan\\_Altern\\_Ther\\_TS.html](http://www.tsa-usa.org/news/Unsubstan_Altern_Ther_TS.html) (December 2009).

<sup>7</sup> Tourette Syndrome Association Newsletter, Vol. 27, No. 2 (Fall 1999), 1.

acts as a network of discussion between medical practitioners and other interested parties. The presence of this recently formed organization involved in finding new methods of managing Tourette's and related conditions further indicates the development of an alternative medicine movement. The association reports that "large numbers of individuals are dissatisfied with results of and/or side-effects of available medications."<sup>8</sup> As the 1970s saw the founding of the TSA, which advocated for the use of medication for treatment, the ACN, which was born since the turn of the century, focuses entirely on natural alternative therapies. Although the ACN does not operate on the same scale as the TSA, its recent establishment is reflective of growing attitudes about the importance of general health in managing tourettic symptoms and represents the rise of different ideas about the best ways of dealing with them.

The Gale Encyclopedia of Alternative Medicine has also noticed the growing use of alternative treatments for Tourette's. "Although there is no cure for TS," the encyclopedia reports in its 2005 edition, "many alternative treatments may lessen the severity and frequency of the tics...most TS patients do not need to take drugs."<sup>9</sup> Although this publication focuses on the use of alternative medicine and therefore might favor such practices, the notion that medication is only necessary when symptoms interfere with quality of life is shared by other important references.<sup>10</sup> Associations and references such as the ACN and The Gale Encyclopedia of Alternative Medicine have

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<sup>8</sup> Sheila J. Rogers, *Association for Comprehensive NeuroTherapy*, <http://www.latitudes.org/about.html>, accessed 26 February 2010.

<sup>9</sup> Belinda Rowland and Rebecca J. Frey, "Tourette Syndrome," *The Gale Encyclopedia of Alternative Medicine*, ed. Jacqueline L. Longe. Vol. 4, 2<sup>nd</sup> ed. (Detroit: Gale, 2005), 2028.

<sup>10</sup> See, for example, Joseph Jankovic, *Tourette Syndrome*, [www.uptodate.com](http://www.uptodate.com) (May 2010), 4; Food and Drug Administration, *Orap (Pimozide) Tablets*, [www.accessdata.fda.gov/drugsatfda\\_docs/label/2009/017473s041lbl.pdf](http://www.accessdata.fda.gov/drugsatfda_docs/label/2009/017473s041lbl.pdf), last updated January 2008, 2.

shown strong opposition to the use of pharmaceuticals in treating Tourette's and reflect a growing desire for non-drug approaches in handling the disorder.

Considering that the suspected causal factor of tics and Tourette's has determined patient treatment during past centuries, this evolving shift in non-medicinal therapy models with no new etiological paradigm is a crucial point in the history of the condition. The social and clinical histories of Tourette's disorder, which have proven to be quite inseparable, have recently begun to separate as many Touretters have slowly discovered useful alternative therapies with limited regard to an underlying causal factor. In addition, while clinical treatment was once explicitly administered, contemporary sources indicate that patients today are primarily able to choose among different interventions. In other words, unlike prior eras when doctors told patients what measures to take for symptom management, Touretters are now given a chance to decide which strategy or model might fit them. This illustrates how self-awareness is now undeniably playing a critical part in many people's decisions about how they deal with their condition.

### **Shared Motives**

Touretters have chosen to pursue alternative treatments for several different reasons. And yet, some reasons are more common than others. Though side effects remain as the central explanation for growing interest in complementary and alternative methods, other common reasons include lack of therapeutic effect, issues with cost of treatment or health insurance, clinical unawareness about the disorder, and the simple presence of more promising coping strategies.

As seen since the 1960s, side effects commonly appear in many instances of drug usage for Tourette syndrome and are a significant issue in the disorder's treatment history. After physicians conducted several different case studies with Haldol, it quickly became known that severe undesired results frequently accompanied use of neuroleptics.<sup>11</sup> Ever since the 1970s, the TSA had been receiving letters from members describing the depression and lethargy caused by Haldol.<sup>12</sup> Reports about the drug's unbearable side effects or lack of functioning appeared in publications such as the *Wall Street Journal*, *Good Housekeeping*, and *Today's Health*.<sup>13</sup> One former patient of Dr. Arthur Shapiro claimed that patients, regardless of other side effects, were turned into "zombies."<sup>14</sup> Similarly, the TSA revealed that "many adults in their thirties and forties recall childhood experiences as 'zombies,' over-medicated with doses of neuroleptics."<sup>15</sup>

The absence of medications that do not cause intolerable side effects can result in continued dissatisfaction with the conventional form of intervention. Mark (a pseudonym) who choose to quit after exhaustive trials with pharmaceuticals that produced constant side effects, said "it almost literally stole ten years of my life."<sup>16</sup> He describes arboring, or tree climbing, as a new creative outlet for his perfectionist habits that he feels accompanies his condition. Former chair of the TSA Medical Advisory Board Ruth Bruun observes, "it is clear that each of the medications now in use, helpful as they may be, carry their own price in the form of side effects. The search for more

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<sup>11</sup> For details about Haldol and general warnings of side effects, consult Food and Drug Administration, *Haldol Brand of Haloperidol Injection*, [www.accessdata.fda.gov/drugsatfda\\_docs/label/2008/015923s081018701s0561bl.pdf](http://www.accessdata.fda.gov/drugsatfda_docs/label/2008/015923s081018701s0561bl.pdf), last updated February 2008. More specific warnings pertaining to side effects that some Tourette's patients experience while taking Orap can be found at Food and Drug Administration, *Orap (Pimozide) Tablets*. Haldol and Orap continue to be the only FDA approved drugs for Tourette's treatment.

<sup>12</sup> Kushner, *A Cursing Brain?*, 190.

<sup>13</sup> *Ibid.*, 189-91.

<sup>14</sup> *Ibid.*, 189.

<sup>15</sup> Tourette Syndrome Association Newsletter (Fall 1999), 1.

<sup>16</sup> Interview with Mark, 3 September 2010.



effective treatments, especially with less severe and fewer side effects, therefore continues.”<sup>17</sup> This 1994 statement is illustrated today in the TSA’s recent cooperation with Psyadon Pharmaceuticals Inc. to discover the possible use of the drug Ecopipam for Tourette’s intervention.<sup>18</sup> The role of undesirable consequences from medications is apparent in Tourette’s treatment today and continues to drive many patients to seek alternative therapy methods.

Touretters have also found that some drugs simply do not work for them. “As people with TS know, medication doesn’t work all the time,” writes author Mitzi Waltz. “There is no magic pill for TS.”<sup>19</sup> Aside from side effects, some Touretters look towards non-medicinal therapies due to a drug having little or no impact on their symptoms. In one example, doctors first prescribed neuroleptics and other medications to a Touretter named William (a pseudonym). William noted that it didn’t take long for him to recognize that they each had either bad side effects or were plainly ineffective.<sup>20</sup> Eventually William turned to exercise and cognitive retraining therapy as replacements for medication.

The cost of certain treatments or fiscal inability to obtain medication has also caused some Touretters to practice personalized coping strategies. Laura, for example, expressed awareness about the minimal financial burden that nutritional monitoring for tic therapy requires. In an interview, she noted, “there are simple things to do that don’t

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<sup>17</sup> Ruth Dowling Bruun and Bertel Bruun, *A Mind of Its Own: Tourette Syndrome, A Story and a Guide* (New York: Oxford University Press, 1994), 146.

<sup>18</sup> “Tourette Syndrome Association and Psyadon Pharmaceuticals to Collaborate on a Drug Trial for Tourette Syndrome Treatment,” *Clinical Trials Week*, 23 May 2011, 209.

<sup>19</sup> Mitzi Waltz, *Tourette’s Syndrome: Finding Answers and Getting Help* (Sebastopol: O’Reilly & Associates, 2001), 92.

<sup>20</sup> Interview with William, 7 May 2011.

cost a thing, such as staying away from sugar and choosing decaffeinated drinks.”<sup>21</sup>

Insurance cost and eligibility have also created difficulties for Touretters in being able to access medication and standard health care.<sup>22</sup> In an interdisciplinary study about adults with the condition, one researcher notes that many “have limited access to health care due to lack of health insurance.”<sup>23</sup> According to Ruth Bruun, part of the limited access Touretters encounter with health insurance can be explained by continuing confusion about the disorder’s medical classification. “Most people wonder why TS is treated both by neurologists and psychiatrists,” Dr. Bruun writes about treatment availability. “If it is truly a neurological disorder, why are psychiatrists involved at all? The answer is complicated, but because the neurology versus psychiatry dilemma is also encountered when applying for insurance coverage, it is important to understand it in some depth.”<sup>24</sup>

Although a defined etiological theory and associated treatment method has been established for Tourette’s, clinical unawareness about the condition continues to be a challenge for many patients today. The fact that the disorder is still “frequently misunderstood by the public and often misdiagnosed medically” can create difficulty for patients in finding treatment and can also sustain existing confusion about their symptoms.<sup>25</sup> Professor Peter Hollenbeck of the TSA Medical Advisory Board comments on the issue, saying, “early diagnosis and access to a good clinician” are necessary to

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<sup>21</sup> Tourette Syndrome Association Newsletter, Vol. 34, No. 4 (Spring 2006), 3.

<sup>22</sup> For a description about the challenges many Touretters encounter with obtaining insurance coverage, see Mitzi Waltz, *Health Insurance Issues for Persons with Tourette Syndrome*, <http://www.tsa-usa.org/People/LivingWithTS/Insurance.htm>, accessed 14 July 2011.

<sup>23</sup> Shlomit Ritz Finkelstein, “Adults with Tourette Syndrome” [Abstract] (PhD diss., Emory University, 2009).

<sup>24</sup> Bruun and Bruun, *A Mind of Its Own*, 31-32.

<sup>25</sup> Quote taken from “Tourette Syndrome Association and Psyadon Pharmaceuticals to Collaborate on a Drug Trial for Tourette Syndrome Treatment,” 209.

“make a good decision about whether to medicate or not.”<sup>26</sup> Michael, a man diagnosed as an adult with Tourette’s, published his story of medical challenges in *The Week* magazine. He writes, “I was shuttled from neurologist to neurologist and medication to medication. Eventually, I lost any faith in my doctors’ ability to actually understand my disease and found myself hoping only for a treatment that would make it better.”<sup>27</sup>

Opportunities to pursue new non-drug therapies for Tourette syndrome, whether provided by a standard health care professional or not, have attracted many individuals to test their efficacy. People often discover alternative interventions through a self-awareness effort that results in finding a more fitting approach to managing their condition without the use of pharmaceuticals.<sup>28</sup> Amy, for example, once took medication for her tics. Since her symptoms often caused her to feel socially awkward, she chose to take medication, but without much enthusiasm for it. After an attempt to discontinue the treatment in college, her stress in law school worsened her symptoms, and she resumed trials with prescription drugs. As an active twirler of batons as a creative outlet, she trained frequently with gymnastics, jazz, and ballet. Upon noticing that stress in any form exacerbated her symptoms and twirling helped relieve her stress, she decided to make twirling her central coping mechanism.<sup>29</sup>

A comparison between outdated concepts about tics and how Touretters are interpreting their symptoms today reveals a new method that many have practiced in formulating interventions. In essence, a number of individuals have changed what

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<sup>26</sup> Tourette Syndrome Association Newsletter, Vol. 37, No. 1 (Summer 2009), 13.

<sup>27</sup> Michael Barthel, “A Compulsion to Do What You Shouldn’t,” *The Week*, 10 December 2010, 52.

<sup>28</sup> Rising interest in complementary and alternative therapies can be attributed in part to information found on the internet. Gerald Erenberg et al., “Complementary and Alternative Medicine for Tourette Syndrome: A TSA Medical Publication,” (March 2006), 1.

<sup>29</sup> Tourette Syndrome Association Newsletter, Vol. 32, No. 2 (Fall 2004), 3.

component they focus their therapeutic efforts on. Quite similar to Margaret Mahler's psychosomatic treatment tradition, recent case examples have centered less on tics as the focus of treatment and more on the actual factors that they recognize to cause them. For example, in Mahler's theorizing, psychosexual issues involved with family stress causes tics. In accordance with her psychosomatic notions, these underlying issues that caused tics were the target of treatment rather than the tics themselves. In cases such as Amy's, a particular exercise relieves stress. As a result, it has become her coping strategy or personalized therapy, and stress is the causal factor addressed through her activity. Although a parallel between the two appears evident, they still cannot be equated. While Mahler saw repressed familial issues as the actual underlying mental cause of tics, contemporary ticcing individuals appear to see factors such as stress only as an element that noticeably worsens symptoms that is unrelated to etiology. They manage the issues that affect their tics in a way that is instead self-serving and gained not from an alleged etiological construct but through the power of self-observation.

The establishment of Tourette syndrome as a physiological condition led to further understanding and acceptance of the disorder that resulted in a higher level of control over one's situation. Common experiences with medications, clinical consultation, and triggering factors for tics have inspired patients to discover new alternative therapies. Around the turn of the last century, a Touretter's experience with seeking clinical guidance slowly changed from encountering one etiological theory and one treatment option to the same etiological theory with many corresponding treatments. A number of these new therapies, whether dependant on physician guidance or not, focus

on using the mind to influence physiological activity. Since alternative interventions are practiced either with or without the guidance of a standard health care provider, they can be best understood as clinical and energetic approaches to the treatment of Tourette syndrome.

## CHAPTER FIVE

### New Traditions: Alternative Clinical Approaches to Treatment

“IN RECENT YEARS, A NUMBER OF CLINICIANS HAVE DEVELOPED A NOVEL APPROACH THAT DEPARTS FROM CONVENTIONAL MEDICATIONS...”

Tourette Syndrome Association letter to supporting members, November, 2009

Many alternative methods of Tourette syndrome treatment sought by patients in recent years are actually older clinical therapies provided by doctors and other licensed practitioners. Although physicians have used the most popular of these methods for years in the treatment of other conditions, their role in Tourette’s therapy is relatively new. This chapter examines alternative clinical treatments for Tourette’s, while the next chapter examines the more personal energetic therapies.

Alternative clinical approaches to treatment can be defined as therapeutic methods that require the assistance of a standard health care professional but have not become conventional medicine for Tourette syndrome. There are currently a number of such interventions available to Tourette’s patients.<sup>1</sup> Although physicians show varying degrees of approval for these methods, lack of sufficient scientific research on them prevents more widespread endorsement from the TSA and health care providers.<sup>2</sup> Nevertheless, out of a desire for safe and effective interventions without the unintended effects of medication, patients have continued to use new procedures offered by certain

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<sup>1</sup> Descriptions of the diverse therapeutic methods that licensed health care providers can currently administer to Tourette’s patients can be found in Joseph Jankovic, *Tourette Syndrome*, [www.uptodate.com](http://www.uptodate.com) (May 2010). See also Gerald Erenberg et al., “Complementary and Alternative Medicine for Tourette Syndrome: A TSA Medical Publication,” (March 2006), 4-6; Belinda Rowland and Rebecca J. Frey, “Tourette Syndrome,” *The Gale Encyclopedia of Alternative Medicine*, ed. Jacqueline L. Longe. Vol. 4. 2<sup>nd</sup> ed. (Detroit: Gale, 2005), 2028.

<sup>2</sup> Tourette Syndrome Association, *TSA’s Statement on Unsubstantiated Reports of Alternative Therapies for Tourette Syndrome*, [http://www.tsa-usa.org/news/Unsubstan\\_Altern\\_Ther\\_TS.html](http://www.tsa-usa.org/news/Unsubstan_Altern_Ther_TS.html) (December 2009). See also David Volk, “Not Your Ordinary Workout: Handle Institute Creates Unusual Exercises to Treat Attention Deficit Disorder, Autism,” *Puget Sound Business Journal*, Vol. 18, No. 2 (May 1997): 12A.

medical practitioners. The relationship between patient demand, investigation into alternatives by researchers, and physicians prescribing these treatments is very complex and not always clear. In short, many patients have either directly or indirectly led clinicians and researchers to investigate, provide, or recommend unconventional interventions for tics. What is certain is that patients have arrived at practicing a variety of non-medicinal therapies through different avenues, and a wide array of clinical therapy choices exists for Touretters today that present different ways of treating the same disorder.

Strangely, behavioral therapy that characterized much of the psychogenic era of Tourette's has strongly reappeared in modernized versions. Similar to how etiological debates of the early twentieth-century aroused fervent opinions on different sides, behavioral therapies, though proving effective for many, have caused some people to question their perceptions about how the disorder should be classified. Since these interventions focus on using the mind to overcome physical symptoms, some patients and physicians feel that their practice presents a challenge to the idea of tics being involuntary actions. For the most part, however, Touretter involvement in such therapies has increased. Three particular methods that have stood out above the rest as popular alternative clinical treatments are Comprehensive Behavioral Intervention for Tics, Neurofeedback, and Deep Brain Stimulation.

### **Behavioral Interventions**

Clinical attitudes about the utility and legitimate role of behavioral interventions in the treatment of Tourette syndrome have altered significantly since the condition was

given a neurological label. In 1978, Arthur and Elaine Shapiro along with colleagues Ruth Bruun and Richard Sweet argued that “until adequate evidence has accumulated supporting the effectiveness of behavior therapy in the treatment of tics or Tourette syndrome, it should be used only as an experimental therapy.”<sup>3</sup> Writing in 1994, Drs. Ruth and Bertel Bruun reiterated their skepticism about behavioral interventions in the disorder’s treatment. “Although there are a few reports of successful behavior therapy for tics,” they observed, “the efficacy of this treatment, in our experience, is doubtful.”<sup>4</sup> By the twenty-first century, however, the opinion of some leading researchers had changed. Prior to the 2010 TSA National Symposium in Washington, DC, a notice on the association’s website read: “Free Training Program: Comprehensive Behavioral Intervention for Tics (CBIT).”<sup>5</sup> Among the presenters was University of Wisconsin professor of psychology Douglas Woods, a leading figure in the advancement of the innovative therapy for Tourette’s patients. Woods’ experimentation with a non-pharmacological intervention for tics demonstrates an effort to provide an effective alternative or complementary approach without harmful side effects, and reflects the increasing trend towards the use of behavioral intervention for a large number of other disorders as well.<sup>6</sup>

Similar to medications for Tourette’s, Cognitive Behavioral Therapy (CBT) was originally intended to treat other psychiatric conditions. It was developed by Dr. Aaron

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<sup>3</sup> Arthur K. Shapiro et al., *Gilles de la Tourette Syndrome* (New York: Raven Press, 1978), 359. The authors also argue that this suggestion should “apply equally to the claims for the effectiveness of psychotherapy, family therapy, hypnosis, surgery, and chemotherapy with haloperidol as described previously.”

<sup>4</sup> Ruth Dowling Bruun and Bertel Bruun, *A Mind of Its Own: Tourette Syndrome, A Story and a Guide* (New York: Oxford University Press, 1994), 147.

<sup>5</sup> Tourette Syndrome Association, Public Bulletin, [www.tsa-usa.org](http://www.tsa-usa.org), accessed 1 February 2010.

<sup>6</sup> For a discussion about the increase in behavioral therapy use in other conditions, see Melissa Healy, “Talk Therapy Helps Adults with ADHD,” *Los Angeles Times*, 25 August 2010.



T. Beck in the 1960s and was first used for the treatment of depression. Initially trained as a psychoanalyst, Dr. Beck centered the therapy on the patient recognizing and evaluating spontaneous mental activity called “automatic thoughts.”<sup>7</sup> By doing so, the patient aims to develop a more balanced thought process and thereby relieves depressive symptoms. In a repeat of the historical trend of borrowing treatments from other conditions, a revised form of CBT has become a common alternative treatment for Tourette’s.

Professional researchers have reformulated CBT according to Tourette descriptions of their symptoms and used it much more often in the past ten years to treat the condition.<sup>8</sup> Habit Reversal Training (HRT), which can be provided by trained psychologists, neurologists, and nurse practitioners, acts as the main component of the tailored version of CBT known as Comprehensive Behavioral Intervention for Tics (CBIT). In this process, individuals are taught to recognize the sensory urges that can often occur before a tic. In an effort to retrain cognitive responses to these premonitory sensations, a Tourette will choose a voluntary action known as a “competing response” to focus on in place of an involuntary tic, and therefore gain a sense of control over the situation.<sup>9</sup> “This puts you in the position of being an active agent,” noted Peter Hollenbeck, TSA scientific advisory board chairman and Purdue University professor of biological sciences.<sup>10</sup> A patient’s level of focus and control over their physical

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<sup>7</sup> Beck Institute for Cognitive Behavior Therapy, *The History of Cognitive Therapy*, <http://www.beckinstitute.org/what-is-cognitive-behavioral-therapy/cognitive-therapy/history-of-cbt/>, accessed 4 November 2011.

<sup>8</sup> Jeannine Stein, “Behavioral Therapy Effective in Treating Tourette Syndrome,” *Los Angeles Times*, 18 May 2010.

<sup>9</sup> Tourette Syndrome Association, “Medical and Scientific Programs: Research Awards 2009-2010,” 21. The presence of premonitory urges in tic symptoms is noted as a telling detail in the actual diagnosis of Tourette’s in Tourette Syndrome Association Newsletter, Vol. 37, No. 1 (Summer 2009), 1.

<sup>10</sup> Stein, “Behavioral Therapy Effective in Treating Tourette Syndrome.”

premonitory urges creates a link between emotional and situational responses and tics, which explains the logic behind using cognitive behavioral methods as a form of Tourette's treatment.<sup>11</sup>

CBIT and HRT require greater patient discipline than conventional treatments. Unlike medications, the potential efficacy of behavioral interventions requires consistent work and concentration. As Hollenbeck explains, "opposed to saying, 'sit back and take your [medication] and hope for the best,' this is a set of skills to learn."<sup>12</sup> Naturally, the desire to undertake such a task depends on the preference of the individual. Similar discipline is also required of other popular complementary and alternative coping strategies for tic symptoms.

The increasingly common use of CBIT for Tourette's patients has gained the attention of many researchers and media sources.<sup>13</sup> One scholarly journal article that reviewed recent literature on the disorder placed cognitive-behavioral approaches on the same level of importance as pharmaceuticals. While noting the need for more effective medication options, the authors state that "recent data has demonstrated both the safety and efficacy of non-pharmacological approaches."<sup>14</sup> Many reports favor the new behavioral method as a positive alternative or complementary intervention to medication,

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<sup>11</sup> Drs. Arthur and Elaine Shapiro described past behavioral therapies that use concentrated efforts to suppress tics as "red herring[s]" or "blind alley[s]" to Tourette's treatment in Shapiro et al., *Gilles de la Tourette Syndrome*, 274.

<sup>12</sup> Stein, "Behavioral Therapy Effective in Treating Tourette Syndrome." Author Charles Barber also touches upon the role of discipline in cognitive behavioral therapies in *Comfortably Numb: How Psychiatry is Medicating a Nation* (New York: Pantheon Books, 2008), 166.

<sup>13</sup> For an important example, see John Piacentini et al., "Behavior Therapy for Children with Tourette Disorder," *Journal of the American Medical Association*, Vol. 303, No. 19 (May 2010): 1929-37.

<sup>14</sup> Michael Bloch, Matthew State, Christopher Pittenger, "Recent Advances in Tourette Syndrome," *Current Opinion in Neurology*, Vol. 24, No. 2 (April 2011): 119-25. The authors also observe that "treatment studies have underscored the importance of cognitive-behavioral as well as pharmacological interventions for the treatment of tic disorders."

which could help explain the increase in its practice.<sup>15</sup> In the American Medical Association's *Family Medical Guide*, the authors listed behavioral interventions before medications in the description of treatment options for Tourette syndrome.<sup>16</sup> In this example, behavior modification techniques are placed above pharmaceuticals in order to help patients and families discover whether a person's tics can be controlled through simple habit reversal before resorting to more acute forms of treatment. A physician reporting on CBIT in *Chicago Life* magazine went so far as to title his article "Medical Mystery Solved."<sup>17</sup> His review described a recent study conducted by Douglas Woods and his colleagues and highlighted the degree of symptom control that patients obtained without experiencing side effects. In recognizing the varied severity and nature of Tourette's cases seen throughout the condition's social history, a reader might still be left confused about the author's concluding statement that "above all, Tourette's is a manageable disorder."<sup>18</sup>

The presence of behavioral retraining therapies for Tourette's has resulted in skepticism about the involuntary nature of the disorder's symptoms. Treatments such as CBIT and HRT, though applied to what is now understood as a biological condition, stress a form of habitual retraining comparable to the outdated psychotherapies of the early twentieth-century. In the case of "O.", for instance, Henry Meige and E. Feindel suspected that their patient's movements were "habit tics" and assigned him to practice

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<sup>15</sup> Out of three recent media reports about behavioral therapies and Tourette's, each report discussed the issue of side effects during medication use. See Ellin Holohan, "Behavioral Therapy May Reduce Tourette Tics, Symptoms; Adult Brain is More Flexible Than Once Thought, Researchers Say," *Consumer Health News*, 21 April 2011; Catharine Skipp and Arian Campo-Flores, "Taking on Tourette's: A New Approach to Stopping Tics Before they Happen Offers Hope to Thousands Who Live with the Disorder," *Newsweek*, 3 September 2007, 53; Stein, "Behavioral Therapy Effective in Treating Tourette Syndrome."

<sup>16</sup> American Medical Association, *Family Medical Guide*, 4<sup>th</sup> ed. (Hoboken: John Wiley & Sons, Inc., 2004), 412.

<sup>17</sup> Cory Franklin, "Medical Mystery Solved," *Chicago Life Magazine*, November 2010, 24-25.

<sup>18</sup> *Ibid.*, 25.

mirror drills as a cognitive strategy to become aware of his condition through voluntary re-expression of his tics. Contemporary researchers have therefore, knowingly or unknowingly, adopted therapeutic methods that are very similar to those used by earlier medical providers but are compatible with existing etiological beliefs. CBIT particularly operates from the notion that, as one researcher described, “psychotherapy can modify cerebral activation.”<sup>19</sup> Although some Touretters celebrate such treatments, others still oppose them on the grounds that they convey a false message about the causes of the disorder and the nature of tics.

Certain individuals with the condition have been offended by the idea of practicing behavioral therapies for their uncontrollable symptoms. Leonard Misner, a thirty-nine-year-old man with Tourette’s, is critical of the use of such interventions for the disorder. Since the efficacy of CBIT and HRT in many cases can cause people to doubt that tics are completely involuntary, he believes that some regression in public and institutional understanding of the disorder has occurred.<sup>20</sup> “We in the Tourette’s community have fought hard to get insurance companies to understand that this is a genetic neurological disorder,” said Misner in an interview with *Newsweek*.<sup>21</sup> This statement reflects how the use of CBIT and HRT can influence public understanding of Tourette’s and perhaps even impact those who do not practice them by misleading insurance companies about the nature of the condition. From a clinical perspective, neurologist Roger Kurlan, having not seen “any effect on the underlying condition,”

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<sup>19</sup> Holohan, “Behavioral Therapy May Reduce Tourette Tics, Symptoms.”

<sup>20</sup> For a discussion about the confusion many people encounter with the meaning of behavioral therapy use in Tourette’s and how CBIT is supposed to function in the treatment of tics, see B. Duncan McKinlay, *Tourette Syndrome*, [www.lifesatwitch.com](http://www.lifesatwitch.com) (July 2011).

<sup>21</sup> Skipp and Campo-Flores, “Taking on Tourette’s,” 53.

favors the prescription of medication for his patients.<sup>22</sup> Like others, he contends that any conscious effort to suppress tic symptoms is unhealthy.

Many contemporary Touretters are not concerned with etiological debates so long as an intervention proves to be effective and produces minimal side effects. Thirty-four-year-old Touretter David Retano, for example, supports new behavioral therapies. For years, Retano experienced florid and self-injurious tic symptoms that affected his quality of life. He claims that HRT has given him a degree of control over his symptoms that he had not possessed before.<sup>23</sup> Those who experience positive results with particular coping mechanisms such as HRT after years of ineffective or no treatment often reveal that causal factor theories are of minimal importance to them.

Behavioral interventions of the early twentieth-century and these current alternative methods, though having distinct parallels, still cannot be equated with one another. Arthur and Elaine Shapiro wrote a cautionary note about behavioral therapies in 1978, warning that, “another means by which old ideas can persist is to reintroduce them in a seemingly new and radical but essentially disguised format of previous ideas.”<sup>24</sup> In observing the behavioral focus of newer therapies such as CBIT and HRT, it is difficult to argue that this quote does not apply to the current situation. However, unlike earlier habit-reversing treatments that were intended to correct a suspected psychological disturbance, providers of current methods mostly believe that CBIT and HRT can improve neurological imbalances by using the power of the mind to influence brain

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<sup>22</sup> Ibid.

<sup>23</sup> Ibid.

<sup>24</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 64.

activity.<sup>25</sup> In essence, this indicates a growing belief in the natural link between thought and physiology, or that concentration of the mind has an impact on the body as well. Dr. Alan Peterson for example, who researches HRT, operates under the assumption that Tourette syndrome and other related conditions can stem from an underlying physiological cause and still be influenced by psychological forces.<sup>26</sup> Consequently, behavioral treatments might be effective in some patients by taking a psychiatric angle-of-entry towards a biological cause. Therefore, the presence of cognitive approaches in current Tourette's intervention cannot be explained as a resurgence in archaic perspectives of and therapies for the disorder, but rather as an increase in popularity of thought about the mind-body connection in syndrome treatment.

### **Neurofeedback**

Similar to CBIT, a method of cognitive retraining called Neurofeedback also relies on connections between the body and the mind. Though the technique does not have the ability to reveal tourettic neurological activity, it does work directly to retrain brainwave patterns.<sup>27</sup> Also known as an Electroencephalograph (EEG), Neurofeedback uses a special machine to translate brain waves to a computer monitor to show the fluctuation of neuro-electrical activity while electrode sensors are attached to the scalp. The patient is supposed to read into what sensations or emotions they feel during different levels of activity in order to learn more about how their brain waves react to various mental states. The intended result is to eventually gain greater control of their

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<sup>25</sup> For a discussion about the role of mindfulness in Cognitive Behavioral Therapy, see Barber, *Comfortably Numb*, 160-67.

<sup>26</sup> Skipp and Campo-Flores, "Taking on Tourette's," 53.

<sup>27</sup> Autism-Home.com Neuro/Biofeedback Center, *What is Neurofeedback?*, [www.autism-home.com/neurofeedback.shtml](http://www.autism-home.com/neurofeedback.shtml), accessed 30 August 2009.

physiology through visual observations of their own neurofunctioning.<sup>28</sup> Neurofeedback is a form of biofeedback, which encompasses many forms of self-monitoring. Through different biofeedback techniques, the patient aims to obtain command over things like muscle tension, heart rate, and stress.<sup>29</sup>

Tracing its origins to the 1920s when German psychiatrist Hans Berger used electrodes to monitor and categorize brain waves, Neurofeedback was not initially intended to treat Tourette syndrome. It began as an assistive coping strategy for stress and is currently used for a variety of mental conditions. After Berger invented the EEG, it became more readily available in the 1970s in the current treatment format that rewards a patient for concentration.<sup>30</sup> Although the treatment may be attempted by anyone who possesses the proper equipment, the most common providers of the therapy include clinical psychologists and neuropsychologists.<sup>31</sup> Similar to CBIT and HRT, Neurofeedback involves discipline. In creating more balanced brainwave patterns through observation and focus, the brain is supposed to remain in its new, more comfortable state for long periods of time after comprehensive training. A single Neurofeedback session would do little to achieve long-term results.

Although not as commonly used for Tourette's treatment as behavioral therapies, Neurofeedback has been practiced as an alternative to medications. Since no pharmaceutical treatments have been specifically created for Tourette's or its symptoms, some health care practitioners have looked to Neurofeedback as a new way of "providing long-term results with minimal side effects" according to one Neurofeedback information

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<sup>28</sup> Biofeedback Therapy, *Neuro Biofeedback*, [www.biofeedbacktherapy.net/neurobiofeedback.php](http://www.biofeedbacktherapy.net/neurobiofeedback.php) (2007).

<sup>29</sup> Biofeedback Therapy, *What is Biofeedback Therapy?*, [www.biofeedbacktherapy.net/](http://www.biofeedbacktherapy.net/) (2007).

<sup>30</sup> Blaine Greteman, "Train: How Neurofeedback Can Help Reduce Stress, Enhance Creativity and Improve Mental Health," *ODE* (March 2009), 46.

<sup>31</sup> *Ibid.*, 49.

center.<sup>32</sup> As medication continues to serve as the conventional treatment method for many neurological conditions, patients from different backgrounds who are dissatisfied with undesirable side effects or limited effectiveness of pharmaceuticals seek this intervention as an alternative to standard treatment.<sup>33</sup> While in high school, Adam, for example, sought treatment for his tics due to the difficulties they presented during school and social settings. At times, he was taking as many as six medications. Although the drugs appeared to help at first, frequent instances of elevated tic severity led him and his family to seek out other coping strategies. He decided to try Neurofeedback after hearing the suggestion from a psychiatrist, who noted that the therapy was “unconventional.”<sup>34</sup> Having also seen a television show about the treatment, Adam found it to be an effective approach. After several sessions with the intervention, he felt “calmer and more in control than he had in a long time.”<sup>35</sup>

While more studies are being undertaken on the technique, Neurofeedback began with very limited acceptance in the medical community.<sup>36</sup> That has begun to change. “We’ve reached a tipping point...it’s becoming much more difficult for mainstream medicine to ignore [Neurofeedback]. No one can say any longer that there is no science behind it,” commented James R. Evans, editor of the *Handbook of Neurofeedback*.<sup>37</sup> As clinicians and patients continue to seek effective non-drug treatments without harmful

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<sup>32</sup> Autism-Home.com Neuro/Biofeedback Center, *Tourette’s Syndrome Treatment with Neurofeedback, EEG Biofeedback*, [www.autism-home.com/tourettes-syndrome.shtml](http://www.autism-home.com/tourettes-syndrome.shtml), accessed 30 August 2009.

<sup>33</sup> Peter Jaret, “Can You Retrain Your Brain?: A Bold New Therapy is Helping People with ADHD, Anxiety, and Other Brain-Related Disorders Get their Lives Back on Track,” *Alternative Medicine*, 25 May 2004, 2.

<sup>34</sup> *Ibid.*, 1.

<sup>35</sup> *Ibid.*, 2.

<sup>36</sup> For a recent clinical study that investigated the role of Neurofeedback in Tourette’s treatment, see National Institute of Neurological Disorders and Stroke, *Investigation of Neurofeedback with Real-Time fMRI in Healthy Volunteers and Patients with Hyperkinetic Movement Disorders*, [http://clinicalstudies.info.nih.gov/detail/A\\_2009-N-0118.html](http://clinicalstudies.info.nih.gov/detail/A_2009-N-0118.html), accessed 11 November 2011.

<sup>37</sup> Greteman, “Train,” 46.



unanticipated effects, patient participation in certain interventions and further scientific investigation will determine the conventional status of this and other therapies.

Insurance eligibility and cost of treatment are factors that can impact Tourette choices about using alternative clinical therapies such as Neurofeedback. Some of the same challenges Touretters have encountered with insurance payments for medications are also present with certain unconventional interventions. Since the use of Neurofeedback for Tourette's is controversial, many insurance companies do not cover the costs of Neurofeedback. Additionally, they almost always require documentation from applicants with neuropsychiatric conditions showing that the intervention is being provided by a certified therapist.<sup>38</sup> In many instances, treatment for Tourette syndrome might not be covered in general due to the disorder being labeled as a pre-existing condition.<sup>39</sup> Furthermore, as Leonard Misner pointed out in his testimony concerning HRT, insurance companies who question the use of cognitive retraining approaches for Tourette's might refuse to provide coverage on the grounds that the condition is behavioral. Current patient issues with insurance coverage illustrate the continued importance of syndrome classification, and also might explain some of the motivation behind many peoples' decisions to formulate their own therapeutic methods.

Similar to CBIT and HRT, Neurofeedback also presumes a connection between body and mind. Although it employs cognitive retraining methods as well, patients have not expressed like concern about the implications it has for Tourette's etiology. Perhaps this can be partially explained by the presence of the term "neuro" in Neurofeedback and the presence of the words "behavioral" and "habit" in CBIT and HRT. Additionally,

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<sup>38</sup> Ibid., 51.

<sup>39</sup> Mitzi Waltz, *Health Insurance Issues for Persons with Tourette Syndrome*, [www.tsa-usa.org/People/LivingWithTS/Insurance.htm](http://www.tsa-usa.org/People/LivingWithTS/Insurance.htm), accessed 14 July 2011.

Neurofeedback has not received the same level of publicity as other behavioral interventions. No matter the reason, people with Tourette syndrome who in recent years have resorted to alternative clinical interventions such as Neurofeedback, CBIT, and HRT appear less concerned with how they work and more concerned with finding an efficacious, drug-free therapy that, regardless of why it functions, does not come with so many negative unintended results.

### **Deep Brain Stimulation**

Annette “began believing in the power of medicine” when she was informed about the first case of Tourette syndrome successfully treated with a new experimental surgical procedure.<sup>40</sup> Although she began experiencing tic symptoms as a child during the 1960s and 1970s, Annette was among the many during that period who were not diagnosed with Tourette syndrome until adulthood. Frustrated with prior clinical consultation where therapists advised her to engage in more “daring” sex and to remove her clothes to let her “inner child break out into a scream,” Annette remained confused about the nature of her condition.<sup>41</sup> After she was diagnosed with Tourette’s, dissatisfaction with the “drool-promoting drugs” that she was prescribed had a demoralizing effect on her belief in functional treatment.<sup>42</sup> Hearing of how another very severe case of the disorder found relief in Deep Brain Stimulation (DBS) inspired her to seek out the procedure herself.

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<sup>40</sup> Annette Racond, “Seeking the Beauty of Stillness: Sufferer of Tourette’s Syndrome Hopes for Advances in Research and Treatment of the ‘Orphan’ Condition,” *New York Times*, 10 August 2004, F5.

<sup>41</sup> Ibid.

<sup>42</sup> Ibid.

First used for Parkinson's disease, DBS surgery uses electrodes that are implanted into the Basal Ganglia regions of the brain to receive electronic pulse signals by wire from a pacemaker that is placed inside the chest.<sup>43</sup> Conditions where imbalanced neurochemical activity is the suspected causal factor have been treated more commonly with DBS in recent years. People with Tourette syndrome who undergo the procedure usually have, like Annette, a very severe case that has not responded favorably to other interventions.

Just as has been the case with CBIT, the TSA has given greater attention to DBS within the past few years. A German research team intending to further investigate the procedure appeared on the organization's 2010-2011 list of grant recipients.<sup>44</sup> In addition, the establishment of the TSA International Database for Deep Brain Stimulation Studies in Tourette Syndrome was announced in the Fall of 2010.<sup>45</sup> In response to the growing number of clinical reports about the use of DBS for Tourette's, the TSA created the database in order to gather reports about the surgery in cases with "severe and drug-refractory presentation of the condition."<sup>46</sup> Although DBS has been a controversial procedure, its use for treatment of refractory Obsessive-Compulsive Disorder (OCD) gained FDA approval in 2009 and its use as an alternative therapy option for particularly severe cases of Tourette's has steadily increased.<sup>47</sup>

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<sup>43</sup> Ibid. See also National Institute of Neurological Disorders and Stroke, *NINDS Deep Brain Stimulation for Parkinson's Disease Information Page*, [http://www.ninds.nih.gov/disorders/deep\\_brain\\_stimulation/deep\\_brain\\_stimulation.htm](http://www.ninds.nih.gov/disorders/deep_brain_stimulation/deep_brain_stimulation.htm), accessed 17 October 2011; "Deep Impact: A Way a Switching Depression Off," *The Economist*, 5 March 2005, 78-79.

<sup>44</sup> Tourette Syndrome Association, "Medical and Scientific Programs: Research Awards 2010-2011," 8.

<sup>45</sup> Tourette Syndrome Association Newsletter, Vol. 38, No. 2 (Fall 2010), 9.

<sup>46</sup> Ibid.

<sup>47</sup> Alicia Ault, "Deep Brain Stimulator Wins Approval from FDA for Severe OCD," *Clinical Psychiatry News*, Vol. 37, No. 5 (May 2009): 6. For a discussion of ethics related to Deep Brain Stimulation, consult Emily Bell, Ghislaine Mathieu, Eric Racine, "Preparing the Ethical Future of Deep Brain Stimulation," *Surgical Neurology*, Vol. 72, No. 6 (December 2009): 577-87.

The first large-scale effort to monitor post-operative results of Touretters treated with DBS gained publicity in the *Los Angeles Times*. In the formal study, a British surgical team led by Dr. Andrea Cavanna performed the experimental operation on eighteen adult patients who were not using other treatments. While realizing that the surgery's "underlying mechanisms are still not fully understood," the team was able to follow-up with fifteen of the patients, who cumulatively reported positive results with the procedure.<sup>48</sup> "Our findings hold promise for helping people with severe Tourette syndrome, who are in need of new treatment options to improve their quality of life," noted Dr. Cavanna.<sup>49</sup>

DBS is different from alternative interventions such as CBIT, HRT, and Neurofeedback in three main ways. First, with the possible exception of healing and occasional check-ups with the internal equipment, it does not require the same kind of continual practice from the patient to achieve the desired results. Second, it does not assume a link between thought and physiology. Functioning entirely on the physical level, the surgery does not directly work with cognitive retraining, the premonitory physical sensations of particular symptoms, or any other element gathered from personal observation of one's condition. Third, as a result of these properties, DBS does not challenge the neurological theory of Tourette's etiology. In fact, due to its effectiveness working strictly with the brain, it might even substantiate the idea of a neurological causal factor.

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<sup>48</sup> Thomas H. Maugh II, "Booster Shots: Deep Brain Stimulation Eases Tics in Tourette's Syndrome," *Los Angeles Times*, 26 October 2009.

<sup>49</sup> *Ibid.*

As is evident with the growing presence of unconventional clinical treatment models such as CBIT, Neurofeedback, and DBS, patients in the American Tourette syndrome community have pushed medical research towards finding new functional, non-pharmaceutical therapies. This effort is shared in part by the TSA who, despite continuing to advocate for new and better medications, states in its official research mission that “increased knowledge of the basic underpinnings of Tourette Syndrome (TS) will lead to improved medical treatments with fewer side effects.”<sup>50</sup> Although many of these treatments have existed for decades, only in recent years have they begun to be used in Tourette’s therapy. The issues surrounding some mentally focused interventions such as HRT have suggested the possibility of a moderate regression back towards psychogenic notions of the condition. Yet a closer examination of the ideas behind current cognitive and behavioral therapies for tics does not imply renewed acceptance of outdated theories and interventions, but rather shows a heightened clinical and patient consciousness about the connection between body and mind. In such methods, the balancing of brain chemistry is attempted through mental activity and personal observations of elements like brain wave patterns and premonitory sensations.

The self-awareness involved in popular alternative clinical treatments is also of critical importance for Touretters who practice non-clinical treatment methods. Naturally, many individuals with Tourette syndrome continue to rely on standard health care professionals for guidance about the treatment of their condition. However, there are many who, through personal observations, have decided to formulate therapeutic strategies of their own.

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<sup>50</sup> Tourette Syndrome Association, “Medical and Scientific Programs: Research Awards 2010-2011,” back cover.

## CHAPTER SIX

### A Common Way: Alternative Energetic Approaches to Treatment

“BUT FOR THOSE WHO CANNOT BE PHARMACOLOGICALLY ‘CONTROLLED’ – OR WHO, PERHAPS, AS ADULTS, MAY DECIDE THEY DO NOT WISH TO BE – THERE IS, FINALLY, BEYOND MERE ‘COPING’ OR ‘ACCEPTANCE,’...”

Oliver Sacks, foreword in Adam Ward Seligman and John S. Hilkevich, eds.,  
*Don't Think About Monkeys*

American adults with Tourette syndrome have practiced a range of unconventional substitutes for medication that involve minimal clinical intervention. Often after unsatisfactory experiences with pharmaceuticals, they have discovered their own ways of dealing with their condition that limit side effects, specifically target the cause of the symptoms, and are tailored to their individual viewpoints of health and well-being.<sup>1</sup> In addition to the alternative clinical treatments detailed in the previous chapter, many Touretters have also recently adopted coping strategies independent of standard medical services or guidance. Physical exercise, dietary restrictions, meditation, massage, and musical performance have all been used to mitigate or control tics and tourettic symptoms. Lots of these activities are comparable to unconventional clinical approaches to tic treatment that employ awareness and self-observation as part of their functionality. Practitioners of energetic methods have also responded to characteristics of their disorder, such as symptom remittance during focused tasks, to create a therapeutic model. Consequently, an important mind-body connection remains present in many forms of energetic practice.

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<sup>1</sup> See Gerald Erenberg et al., “Complementary and Alternative Medicine for Tourette Syndrome: A TSA Medical Publication,” (March 2006), 1; Tourette Syndrome Association, *TSA's Statement on Unsubstantiated Reports of Alternative Therapies for Tourette Syndrome*, [http://www.tsa-usa.org/news/Unsubstan\\_Altern\\_Ther\\_TS.html](http://www.tsa-usa.org/news/Unsubstan_Altern_Ther_TS.html) (December 2009).

Alternative energetic approaches to treatment are therapeutic methods that do not require the assistance of a standard health care professional and function by either working with the body and its energy sources or by releasing or relieving tourettic energy through activity that simultaneously involves body and mind. Although these diverse health practices share common attributes, they can differ in their application and intent. Some act as an intervention to lessen symptom severity and frequency. Others are best described as coping strategies that operate as a lifestyle choice or adaptive method. Therapies are frequently made to fit one's interests, values, or routines and work to achieve different ends. James, for example, felt as if he were being controlled by medications while he was growing up. At age sixteen, he decided to discontinue use of them.<sup>2</sup> He instead discovered singing as a useful activity, including performing in televised competitions. "When I sing, it just all goes away," James explained, "I don't have a care in the world."<sup>3</sup> Each energetic approach represents a non-traditional and often personally formulated way to deal with the allied symptoms of Tourette syndrome.

Numerous personal statements suggest that Touretters commonly make alternative treatment decisions without clinical guidance. A recent survey in the medical journal Movement Disorders involving one hundred children and adults with the condition revealed that eighty percent of people who used complementary or alternative therapies did not inform their physician about their choice. In addition, researchers who conducted the survey argued that "in recent years CAM use has increased."<sup>4</sup> According

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<sup>2</sup> Hal Boedeker, "James Durbin Rebounds from Surprise 'American Idol' Ouster," *Los Angeles Times*, 13 May 2011.

<sup>3</sup> Michelle Healy, "Singing Through Tourette Syndrome: 'American Idol' Finalist Brings Spotlight Onto the Misunderstood Condition," *USA Today*, 9 March 2011, D7.

<sup>4</sup> K. Kompoliti, W. Fan, S. Leurgans, "Complementary and Alternative Medicine Use in Gilles de la Tourette Syndrome," [Abstract] *Movement Disorders*, Vol. 24, No. 13 (October 2009): 2015-19. Out of

to *The Encyclopedia of Complementary and Alternative Medicine*, people with a variety of conditions who use alternative therapies commonly do so without consulting their doctor or another health professional.<sup>5</sup> The encyclopedia reveals several factors that can explain this phenomenon. First, it is uncommon for contemporary American physicians to discuss or recommend complementary or alternative medicine with their patients. As a result of this lack of communication about the issue, patients generally perceive their non-traditional practices to be disconnected from their conventional treatments and do not talk about them with their physician. Second, many believe that their doctors would view their ideas about alternative medicine as nonsensical or unrealistic. In such instances, the patient rarely brings up the subject during clinical consultation. Third, a number of physicians lack faith in the efficacy and safety of unconventional interventions that have not undergone empirical scientific experimentation.<sup>6</sup> Clinical skepticism towards such treatments has been particularly strong when dealing with Tourette's patients.<sup>7</sup>

Touretters have also made autonomous decisions regarding therapy because they have formulated adaptive strategies tailored to themselves based on a detailed understanding of their condition. For example, lots of individuals notice how exercise reduces the stress that worsens their tics. Consistent activity with a chosen fitness model then becomes a method of controlling tics for that person. Some people realize that their symptoms improve during focused activity in music or athletics and continue their

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one hundred patients, sixty-four used some form of complementary or alternative medicine, ranging from prayer and meditation to diet alterations and hypnosis.

<sup>5</sup> Tova Navarra, *The Encyclopedia of Complementary and Alternative Medicine*, foreword. Adam Perlman (New York: Facts On File, Inc., 2004), x.

<sup>6</sup> Ibid.

<sup>7</sup> See Mitzi Waltz, *Tourette's Syndrome: Finding Answers and Getting Help* (Sebastopol: O'Reilly & Associates, Inc., 2001), 175-77; Tourette Syndrome Association, *Alternative/Complementary Therapy for TS Symptoms*, <http://www.tsa-usa.org/Medical/alternative.html>, accessed 30 September 2010.



performance as a therapy in addition to an interest. Others remove particular food products from their diets after realizing that an excess of certain nutrients such as carbohydrates and sugars exacerbate their tics. This kind of self-awareness has led many to make unilateral decisions regarding how they deal with their condition.

The increasing use of energetic coping strategies in recent years marks an important historical shift. For the first time in the documented treatment history of tics, many Touretters have taken the management of their condition into their own hands. This indicates that the social and clinical realms of the disorder have, to a certain extent, become separated. Although Touretters have created and practiced a variety of methods other than those offered by physicians, lots of energetic therapies share similarities with alternative clinical interventions.

### **Individual Etiology?**

Some popular energetic approaches to treatment work directly with the body or the body's energy sources and are supposed to target the specific cause of an individual's tourettic symptoms. While some Touretters practice complementary or alternative medicine with little concern about the causes and triggers of their condition, others choose a therapeutic method according to how it corresponds with the assumed source of their tics. People who address their own tic-inducing internal agents such as allergy, stress, and tension commonly use measures like dietary restrictions, exercise, and massage as symptom deterrents. Such examples illustrate continued interest in the etiology of tics and Tourette's, but by Touretters on a personal level instead of by doctors and researchers on a clinical level.

After altering his diet for health problems unrelated to his Tourette syndrome, Jim (a pseudonym) found that his symptoms improved, and he subsequently began to monitor his eating habits as a way to reduce his tics. Initially, a reduction of refined foods and red meat along with eating more raw fruits and vegetables appeared to lessen his symptoms. Following the elimination of foods that contain corn syrup from his diet, Jim noticed that his symptoms “almost entirely disappeared.”<sup>8</sup> Sheila Rogers, author of *Natural Treatments for Tics and Tourette's*, notes that while the number of people who use dietary restrictions for tic treatment is unknown, this method is among the most frequently reported observations to the Association for Comprehensive NeuroTherapy (ACN).<sup>9</sup> Convinced that his updated eating habits improved his condition, Jim formulated a personalized treatment by observing the cause of his symptoms.

Touretters have commonly reported that dietary restrictions and certain nutrition measures can be effective alternatives to medication.<sup>10</sup> In *A Mind of Its Own*, published in 1994, the authors note that, “for many years patients and their families, exasperated with the failure or the side effects of conventional medications, have turned to alternative treatments in the form of dietary changes or homeopathic products.”<sup>11</sup> Ashley (a pseudonym) asserts that for her condition, dietary management is a safer and more helpful treatment choice than pharmaceuticals. Since her former medication was ineffective and had “horrible side effects,” she chooses to manage her symptoms by

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<sup>8</sup> Sheila J. Rogers, *Natural Treatments for Tics and Tourette's: A Patient and Family Guide* (Berkeley: North Atlantic Books, 2008), 74.

<sup>9</sup> *Ibid.*, 17. Disciplined avoidance of certain allergens is also mentioned among the most frequently described tic management techniques reported to the ACN.

<sup>10</sup> See Belinda Rowland and Rebecca J. Frey, “Tourette Syndrome,” *The Gale Encyclopedia of Alternative Medicine*, ed. Jacqueline L. Longe. Vol. 4, 2<sup>nd</sup> ed. (Detroit: Gale, 2005), 2028; Erenberg et al., “Complementary and Alternative Medicine for Tourette Syndrome,” 3.

<sup>11</sup> Ruth Dowling Bruun and Bertel Bruun, *A Mind of Its Own: Tourette Syndrome, A Story and a Guide* (New York: Oxford University Press, 1994), 146.

regulating her eating habits.<sup>12</sup> Upon noticing how refined sugar and other nutrients can worsen her tics, Ashley removed them from her diet.

Many Touretters notice how certain environmental or situational factors, often referred to as “triggers,” affect their symptoms. These triggers are diverse, ranging from stress to caffeine to cell phone use.<sup>13</sup> “Food allergies are definitely a trigger for me,” stated Frank, who reached this conclusion while researching nutrition and holistic approaches to treatment.<sup>14</sup> According to some sources, Touretters who experience more severe symptoms when consuming certain foods do not have allergies, but rather are sensitive to particular foods that might interfere with bodily function.<sup>15</sup> Since researchers have given minimal attention to the link between food allergies and Tourette’s, using dietary changes as an effective alternative to medication is not a standard recommendation among treating clinicians.<sup>16</sup> As a personal trainer and health food entrepreneur, Frank’s choice to monitor his diet as a tic prevention measure coincides with his values and lifestyle. He also includes spirituality and physical exercise, another common energetic approach, in his tic management system.

Stress is among the most commonly reported triggers for tics.<sup>17</sup> In order to alleviate tourettic symptoms caused by stress, many individuals have found exercise that

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<sup>12</sup> Rogers, *Natural Treatments for Tics and Tourette’s*, 71-72.

<sup>13</sup> For a discussion about different triggers encountered by people with tics and Tourette’s, consult Rogers, “ACN’s Survey on Tic Triggers,” and “Understanding Survey Results,” in *Natural Treatments for Tics and Tourette’s*, 59-70.

<sup>14</sup> Tourette Syndrome Association Newsletter, Vol. 36, No. 4 (Spring 2009), 3.

<sup>15</sup> See Waltz, *Tourette’s Syndrome*, 210; Erenberg et al., “Complementary and Alternative Medicine for Tourette Syndrome,” 3.

<sup>16</sup> Rogers, *Natural Treatments for Tics and Tourette’s*, 65.

<sup>17</sup> In *Natural Treatments for Tics and Tourette’s* (62), a 2003-2004 survey that involved 1,794 respondents with tics showed stress to be the most commonly reported triggering factor. See also Bruun and Bruun, *A Mind of Its Own*, 24; Waltz, *Tourette’s Syndrome*, 204.

involves both body and mind to be effective therapy.<sup>18</sup> Josh, who uses weightlifting and strength training techniques as a coping strategy for his condition, encourages others to find fitness practices that build strength and reduce stress and tics.<sup>19</sup> “I got into lifting weights during a decade-long battle with Tourette’s syndrome,” Josh wrote describing his personalized way of dealing with the disorder. “This distraction became my passion, my entire way of living and viewing life.”<sup>20</sup> Josh’s testimony illustrates an example where exercise and fitness act as a lifestyle choice as much as a tic therapy. Although there is no clinical study that explores the use of exercise for Tourette’s treatment, several people have found a physical activity approach to dealing with the condition through self-observation.

The use of exercise to alleviate the stress that exacerbates tic symptoms stands among the common alternatives to pharmaceuticals. Michael, who became frustrated after trying “every medication in the book,” decided to discontinue drug treatments because they turned him into a “zombie.”<sup>21</sup> Having grown up during the advent of prescription medication for Tourette’s, Michael was placed on Haldol, which he felt interfered with his academic pursuits. In order to help deal with tic-causing stress, Michael now chooses to exercise and eat healthy, stating “diet, exercise, and allergy neutralization - which helps build immunity to allergies - are what I do now.” “It’s not for everyone,” he adds, “but diet control and exercise really work for me.”<sup>22</sup>

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<sup>18</sup> See Mitzi Waltz, *Exercise, Sports and Tourette Syndrome*, <http://www.tsa-usa.org/People/LivingWithTS/Exercise.htm> (April 2010); Waltz, *Tourette’s Syndrome*, 204-05; Rogers, *Natural Treatments for Tics and Tourette’s*, 238.

<sup>19</sup> Tourette Syndrome Association Newsletter, Vol. 37, No. 3 (Winter 2009), 13.

<sup>20</sup> Josh Hanagame, *About World’s Strongest Librarian*, <http://worldsstrongestlibrarian.com/about/> (July 2011).

<sup>21</sup> Tourette Syndrome Association Newsletter, Vol. 32, No. 3 (Winter 2004), 3.

<sup>22</sup> *Ibid.*

Similar to Michael, Megan also focused part of her coping strategy for tics on stress management following unsatisfactory results with medication. After deciding that pharmaceutical intervention “didn’t work out,” Megan stopped drug treatment and included physical exercise as a component in how she handles her symptoms.<sup>23</sup> Although exercise is an important part of her lifestyle and method of dealing with stress, her work and studies in crisis management and conflict resolution have largely inspired the techniques she uses to calm anxiety that can produce tics. Megan’s example shows how internal elements such as stress or tension often become the focus of tic therapy after medication is disregarded.

Massage, acupuncture, and relaxation techniques have also been common replacements or supplements to conventional treatments.<sup>24</sup> Laura, who received a late diagnosis for her condition at the age of seventeen, found that cranial facial massage helped by alleviating tic-causing anxiety. While aware of the ability to use unconventional therapies as compliments to medication, she noted that her own treatment choices act as complete alternatives to pharmaceuticals, saying “nutrition, acupuncture, massages – these alternative therapies truly work for me.”<sup>25</sup> Her decision to not take prescription drugs for her disorder was inspired by her profession as a spa/wellness center director. While therapies such as massage and acupuncture have existed for hundreds of years and are becoming more widely accepted within traditional medicine as a treatment

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<sup>23</sup> Tourette Syndrome Association Newsletter, Vol. 34, No. 3 (Winter 2006), 3.

<sup>24</sup> Consult Kompolti, Fan, Leurgans, “Complementary and Alternative Medicine Use in Gilles de la Tourette Syndrome.” Out of sixty-four patients who used some form of complementary or alternative medicine, eight had explored acupuncture and nineteen had used massage. See also Rowland and Frey, “Tourette Syndrome,” 2028; Erenberg et al., “Complementary and Alternative Medicine for Tourette Syndrome,” 5; Rogers, *Natural Treatments for Tics and Tourette’s*, 234.

<sup>25</sup> Tourette Syndrome Association Newsletter, Vol. 34, No. 4 (Spring 2006), 3.

for other illnesses, their place in documented cases of Tourette's intervention has appeared only recently.<sup>26</sup>

Similar to Laura, Casey also did not receive a diagnosis of Tourette's until her late teens and had to "learn how to manage stress" in order to deal with her condition.<sup>27</sup> As part of her coping strategy for stress, she acquires a monthly massage, which can relieve body tension caused by multiple tics. Since she did not understand her disorder as Tourette syndrome for many years, Casey did not receive clinical treatment during her youth and personally explored ways to control her tics. During this time, she discovered that meditative breathing was useful. Like lots of others, song and music also act as two of her primary methods of stress relief.

Several sources published since the mid-1990s indicate that different forms of meditation, relaxation techniques, and prayer are common practices for coping with an increase in stress-related tic symptoms.<sup>28</sup> In *Tourette Syndrome: The Facts*, the authors note that Touretters have often used relaxation training in the form of deep breathing and deliberate muscular tensing then relaxing in conjunction with other treatments.<sup>29</sup> *The Gale Encyclopedia of Alternative Medicine* lists relaxation techniques and Yoga as potentially beneficial complementary methods for tic treatment because they lower stress.<sup>30</sup> In order to release tic-inducing stress experienced at work, Ed, for example,

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<sup>26</sup> The increasing presence of massage and acupuncture in traditional medicine is discussed in Navarra, *The Encyclopedia of Complementary and Alternative Medicine*, xvii, xx.

<sup>27</sup> Tourette Syndrome Association Newsletter, Vol. 33, No. 2 (Fall 2005), 3.

<sup>28</sup> See Kompoliti, Fan, Leurgans, "Complementary and Alternative Medicine Use in Gilles de la Tourette Syndrome"; Erenberg et al., "Complementary and Alternative Medicine for Tourette Syndrome," 5; Rogers, *Natural Treatments for Tics and Tourette's*, 234-35, 237-38; Waltz, *Tourette's Syndrome*, 204, 206; Bruun and Bruun, *A Mind of Its Own*, 42; Elaine Fantle Shimberg, *Living with Tourette Syndrome* (New York: Simon & Schuster, 1995), 132-34.

<sup>29</sup> Mary M. Robertson and Simon Baron-Cohen, *Tourette Syndrome: The Facts* (New York: Oxford University Press, 2002), 34-35.

<sup>30</sup> Rowland and Frey, "Tourette Syndrome," 2028.

enters a meditative state of prayer as a way to “let the tics out.”<sup>31</sup> After unsatisfactory experiences with medication followed his diagnosis at the age of thirty-eight, he chose to rely on prayer, relaxation, and music for refuge from his symptoms.

The above cases show that Touretters have developed therapeutic measures according to the observed cause(s) of their symptoms. In turn, it is useful to recall how etiological theories have almost exclusively directed the clinical treatment of tics ever since Jean Itard’s first years of clinical inquiry into unexplained motor movements and vocalizations. In recent years, many Touretters have formulated their own energetic treatments under a similar logic. Though recognizing a neurological causal factor associated with their disorders, individuals have concluded that there are certain elements that cause their own bodies and minds to tic. Since things like allergies, stress, and tension trigger or worsen their tourettic symptoms, they have applied interventions such as dietary restrictions, physical exercise, massage, acupuncture, and meditation in place of or with medication. Each example shows the unique qualities of the individual case. Additionally, they reveal how self-awareness motivates decisions to autonomously practice personalized therapies.

### **Artistic Expression**

Focused activities have also worked to reduce or eliminate tics. Touretters have described music, arts, and certain lifestyle choices as having the ability to create a refuge from tics, providing a sense of symptomatic relief. Noticing the effects that these pursuits have on their symptoms, many Touretters have used them as therapeutic measures. Frequent reports of artistic, athletic, and also personalized ways of handling

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<sup>31</sup> Tourette Syndrome Association Newsletter, Vol. 35, No. 3 (Winter 2007), 3.

tics appear in newspaper articles, books, biographical accounts, and TSA newsletters.

When examined closely, these energetic therapies appear to function similarly to certain alternative clinical interventions that rely on focused instruction to retrain or improve cognitive ability.

Throughout the history of tic disorders, focused activity has been noted to reduce symptoms. In 1886, Georges Guinon, a critic of Gilles de la Tourette's original disease classification, described an Italian ballet dancer who possessed the ability to control his odd involuntary movements during performance, but whose symptoms returned when the act was completed.<sup>32</sup> While observing the case of "O." in 1902, Henry Meige wrote, "his devotion to billiards, or to such exercises as fencing or rowing, is never interfered with by an unruly tic. He is a great fisher, and...he will remain motionless indefinitely."<sup>33</sup> Meige also noted that O.'s tics would return if he lost concentration on his activity. In 1922, Charles Trepasat wrote of his patient Paul's tic condition, noting that he could sit still for up to half an hour when immersed in his work.<sup>34</sup> Margaret Mahler and Jean Luke even noted in a 1946 study that different forms of physical and artistic activity served as helpful tic treatment measures: "Performance activity of the small as well as the large muscles of the body is useful, and, wherever possible, artistic outlets should be encouraged."<sup>35</sup> Since many ticcing individuals in the past evidently experienced a withdrawal of symptoms during focused activities, it is conceivable that they might have formulated their own adaptive strategies for their condition, particularly during times of

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<sup>32</sup> Arthur Shapiro et al., *Gilles de la Tourette Syndrome* (New York: Raven Press, 1978), 24.

<sup>33</sup> Henry Meige, "La Genèse des Tics," *Journal de Neurologie* (5 June 1902): 10-11, taken from Howard I. Kushner, *A Cursing Brain?: The Histories of Tourette Syndrome* (Cambridge: Harvard University Press, 1999), 54.

<sup>34</sup> Kushner, *A Cursing Brain?*, 67.

<sup>35</sup> Margaret Schoenberger Mahler and Jean A. Luke, "Outcome of the Tic Syndrome," *Journal of Nervous and Mental Disease*, Vol. 103, No. 5 (May 1946): 445.



mixed etiological theories. Still, no available evidence reveals a large-scale attempt by people to control their tics through concentrated efforts until recent years.

Instances where tourettic symptoms recede during intense mental occupation are seen in many documented cases today. During very serious situations, Christian notices that his tics reduce to an unnoticeable level. “Its always been that way for me,” he commented, adding that he uses physical exercise to help deal with stress.<sup>36</sup> Similarly, Stephen often experiences a remission in his symptoms while he is preaching or teaching. As an active person, he feels that involuntary movements seldom occur when constantly preoccupied with things like work, school, and athletics. Having come across adverse effects from medications during adolescence, Stephen later concluded that pharmaceuticals were not necessary for treating his condition. “I think the medications have come a long way since then...I still opt not to take medication, I’d rather just deal with the tics,” he noted.<sup>37</sup> Although individual conditions vary in nature and severity, the ability to gain a sense of relief from tic symptoms by centering one’s attention on a single task can be seen in contemporary examples.

In the original criteria for Tourette syndrome diagnosis described in the influential 1978 publication *Gilles de la Tourette Syndrome*, one identifying requirement out of seven actually stated that “Nonanxious concentration or preoccupation is associated with decrease in symptoms.”<sup>38</sup> This description relates closely to many who participate in athletics and exercise for tic therapy, but also those who play music to break away from

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<sup>36</sup> Tourette Syndrome Association Newsletter, Vol. 37, No. 2 (Fall 2009), 3.

<sup>37</sup> Tourette Syndrome Association Newsletter, Vol. 35, No. 1 (Summer 2007), 3.

<sup>38</sup> Shapiro et al., *Gilles de la Tourette Syndrome*, 254. This attribute, however, does not appear in the most up-to-date diagnostic description of Tourette syndrome. Consult American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> ed., Text Revision (Washington, DC: American Psychiatric Association, 2000), 111.

their symptoms. In the recent publication *Musicophilia*, neurologist Oliver Sacks explores the different reactions Touretters have to listening to and playing music. Though personal testimony reveals that listening to different kinds of music can have positive or negative effects on a person's tics, playing music as a hobby can possess therapeutic value for tourettic musicians.<sup>39</sup> "I think that initially music was an escape for me," mentioned Scott, who began playing the guitar after realizing the beneficial affect it had on his condition. "When I do perform, all of my tics subside completely."<sup>40</sup> Jason, an opera performer, recalled his experience growing up with music as a refuge from tics, saying, "When I was singing I'd stop ticcing and knew that there was something healing in the experience of singing."<sup>41</sup>

The intense concentration required during singing and musical performance causes tics to subside in several individuals.<sup>42</sup> As a result, this phenomenon has been the inspiration for personalized tic therapies that are used in place of or a supplement to conventional treatment. Chris (a pseudonym), for instance, claims that he does not tic during a song performance. After encountering undesired results such as headaches while taking medication as a child, he discovered that the act of singing possessed therapeutic qualities. During an interview, he commented, "If you're focused on what you're doing, it is as if your brain blocks out the tics. That's what singing and performing does for me."<sup>43</sup> Luke, a musician and composer, echoed Chris' statement, saying, "For some, making music can be therapeutic. For me, it's the level of

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<sup>39</sup> Oliver Sacks, *Musicophilia: Tales of Music and the Brain*, rev. ed. (New York: Vintage Books, 2008), 247-53; Tourette Syndrome Association Newsletter, Vol. 32, No. 2 (Fall 2004), 1, 8.

<sup>40</sup> Tourette Syndrome Association Newsletter (Fall 2004), 1.

<sup>41</sup> Tourette Syndrome Association Newsletter, Vol. 38, No. 3 (Winter 2010), 3. At the end of a "twelve-year-long search for a remedy," Jason practices a multi-factorial treatment model including performance, exercise, dietary restrictions, homeopathy, and prayer.

<sup>42</sup> See Bruun and Bruun, *A Mind of Its Own*, 42.

<sup>43</sup> Tourette Syndrome Association Newsletter, Vol. 38, No. 1 (Summer 2010), 3.

concentration and the serious intent of the music...music uses all your faculties – tactile, visual, aural – all the neurotransmitters are at work.”<sup>44</sup> Such comments illustrate Tourette awareness about the neurological and mental impact that intense concentration teamed with musical rhythms can have on the condition. At a young age, Luke also took several medications, which he chose to discontinue in his adult years. During adolescence when his disorder was most severe, Luke found that musical expression acted as the single outlet where he “had freedom from the tics.”<sup>45</sup>

While refuge from tics is commonly sought in music, some tourettic musicians and athletes have addressed their condition in a manner that acts less as a mechanism for reducing tics and more of an adaptive strategy that attempts to utilize tourettic energy for purposes of enhancing artistic expression or athletic talent. Such approaches are more suggestive of using tics to help an activity than they are of using an activity to help tics. For example, during his time playing the piano, an English musician with severe tics named Nick experiences a remission of visible symptoms. However, he contends that his condition is actually a critical component of playing the piano as his symptoms become “harnessed and focused” in his performance.<sup>46</sup> In this and other like instances, tic therapy cannot be accurately described simply as a way to relieve symptoms. Since many individuals place some effort towards applying or adapting their symptoms to a particular creative end, it is important to explore examples that thoroughly describe such efforts as a central part of a lifestyle or therapeutic model.

A classical music composer named Tobias described the disappearance of noticeable tic symptoms while writing. While concentrated on musical creation, Tobias

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<sup>44</sup> Tourette Syndrome Association Newsletter, Vol. 34, No. 2 (Fall 2006), 3.

<sup>45</sup> Ibid. In addition to musical activity, Luke also looks towards exercise as a way to relieve stress.

<sup>46</sup> Sacks, *Musicophilia*, 251-52.

retains the ability to be still. However, he contends that his sporadic mental tourettic energies contribute to his music by inspiring creativity in his composition. Claiming that he has “harnessed its [Tourette’s] energy,” Tobias reveals a deliberate effort to apply the forces of his condition to his profession as one way of controlling his symptoms.<sup>47</sup>

The application of Tourette’s as a source of physical energy is seen in the example of Sean (a pseudonym), a drummer/percussionist who encourages others to express themselves through music. After encountering poor experiences with medication due to side effects, Sean turned to nutrition and exercise to improve his symptoms. He decided to follow such measures as therapeutic strategies that coincide with his general lifestyle. Although his situation determines the outlet he chooses to alleviate tic-inducing stress, drumming acts as a central method. Primarily, Sean reports that the freestyle aspect of drumming paired with the study of sheet music results in mental and physical strengthening that offers relief from his condition. In addition to relief, he asserts that drumming provides a creative outlet of tourettic expression, as his actions during practice are occasionally inspired by his tics. His study of percussive instrumentation denotes the use of music as a vehicle to relieve stress as well as it represents an effort to use Tourette’s as a source of energy to enhance his abilities.<sup>48</sup>

David, also a drummer, reveals his journey towards self-control during drumming experimentation in the collection of stories *Don’t Think About Monkeys*.<sup>49</sup> While playing music largely during the 1970s, he did not understand his motor tics and compulsive percussive habits as Tourette syndrome until many years later. As a result, he attempted

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<sup>47</sup> Ibid., 252.

<sup>48</sup> Interview with Sean, 22 July 2010.

<sup>49</sup> David R. Aldridge, “Rhythm Man,” *Don’t Think About Monkeys: Extraordinary Stories Written by People with Tourette Syndrome*, eds. Adam Ward Seligman and John S. Hilkevich (Duarte: Hope Press, 1992), 173-82.

to understand the nature of his condition through the urge he had to drum on different objects. Following an initial effort to hide his movements with tactics such as hand drumming on a table, he discovered that such actions produced a sense of control over his tics. “This newly found masking movement actually harnessed my unbounding energy,” David wrote, “directing it into an orderly flow.”<sup>50</sup> Over the next several years, he experimented with ways of channeling his explosive tendencies towards drumming and achieving “a perfectly controlled flow of unrestrained energy.”<sup>51</sup> His effort to redirect involuntary motor movements onto drums is an early example of a unique personally adapted strategy to release and understand tourettic energy through music.

Having not discovered a medical term for his unexplained sensory urges to flinch and blink his eyes until he was sixty, John (a pseudonym), who still exhibits a moderate level of tic symptoms, uses tourettic energy in his vocational and athletic pursuits. As he never took medication for his condition, John learned to utilize and adapt to his movements over time. “I always felt comfortable with what I had. I never knew what I had, so I had to work with my symptoms,” he revealed in an interview.<sup>52</sup> While involved in a business atmosphere, John claims that high-stress situations can accelerate his already rapid speed of thought, which he attempts to channel towards problem solving. Balance, he says, is the key word in his Tourette’s, meaning that certain compulsions and urges to move must be satisfied before he can disregard them. While at work, certain tasks and obstacles become the target of his compulsive intensity and focus. Like Sean, he also uses his condition as a source of physical energy. During a basketball game, he

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<sup>50</sup> Ibid., 174.

<sup>51</sup> Ibid., 181.

<sup>52</sup> Interview with John, 8 June 2011.

summons lots of energy since he finds that “a [body] part is always moving.”<sup>53</sup> John’s methods of managing his symptoms do not function to lessen tic frequency or severity but rather act as ways of channeling tourettic action towards useful purposes.

The various concentrated efforts Touretters practice to control tics show a link between certain alternative clinical interventions and energetic coping strategies. For example, in Habit Reversal Training (HRT), which is the central component of Comprehensive Behavioral Intervention for Tics (CBIT), self-awareness and focus play critical roles in the functioning of treatment. Practitioners of certain energetic therapies also utilize these two elements but in different ways. Touretters such as Ed, who in times of stress looks to relaxation and prayer for relief, are attentive to the anxious feelings that cause tics rather than premonitory urges to actually tic. Casey, in the same manner as an HRT patient, applies mental focus to redirect her attention towards meditative breathing when feeling tense. This effort then transforms an unwanted compulsion into a productive, deliberate action. Both HRT patients and practitioners of meditation, music, and exercise aim to become the “active agents” of tourettic energy.<sup>54</sup>

Musical approaches to tic management and Neurofeedback technique are also alike in intent and application. Essentially, the concentrated efforts made by musicians to control tourettic energy appear to operate in the same manner as the focused instruction involved in the initial phases of Neurofeedback. In both treatments, strict attention to an activity helps to manipulate or gain authority over tics, directing either brainwaves or the symptoms themselves into what David referred to as an “orderly flow.” During a Neurofeedback procedure, however, cognitive retraining through focused activity is

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<sup>53</sup> Ibid.

<sup>54</sup> Quote taken from Jeannine Stein, “Behavioral Therapy Effective in Treating Tourette Syndrome,” *Los Angeles Times*, 18 May 2010.

specifically meant to lessen tic severity and frequency over time. In musical therapies, different individuals either report temporary or lasting relief from symptoms or work towards utilizing tourettic energy. With each exercise, practitioners commonly experience a return of symptoms when a loss of focus occurs. “If you’re focused on what you’re doing, it is as if your brain blocks out the tics,” Chris commented, denoting the methodology behind Neurofeedback and musical intervention for tics. In many ways, Touretters who autonomously use things like music, relaxation techniques, and meditation to control tic symptoms intend to accomplish the same internal results that Neurofeedback or HRT patients do.

Largely in response to the unwanted side effects from medication, a number of Touretters, clinicians, and researchers have created new therapeutic measures based on the personal experiences of Touretters. After significant efforts have been made to establish Tourette’s as a neurological rather than a purely psychological disorder, many clinical and energetic alternative therapies seem to deal more with the mind than they do with the body.<sup>55</sup> The use of thought and focus to control physical sensations has added to the continued elusiveness of the exact nature of the disorder. In addition, such practices suggest that individuals are commonly more concerned about knowing which treatments work for their own condition than with assigning a descriptive clinical label to it.

More important than the historic argument about etiology is the central reason behind the varied manner in which Touretters have managed their symptoms in recent years. While patient dissatisfaction with medications largely explains the growing use of

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<sup>55</sup> Therapeutic methods that use different ways of applying mental focus to reduce or control tics include CBIT, HRT, Neurofeedback, musical activity, meditation styles, and physical exercise.

complementary and alternative treatments, the power of self-awareness accounts for many newer tic management strategies. In HRT, patients are taught to be conscious of their premonitory urges to tic and respond to them. Neurofeedback requires patients to be attentive to how their brain wave patterns respond to different circumstances. Those who practice nutrition and dietary management are concerned with the effect that certain foods and environmental factors have on their symptoms. Participants in physical exercise, meditation, and massage tend to be aware that stress has a negative impact on their disorder, and individuals who find refuge or control in music simply understand that their symptoms improve or might even be utilized during concentrated performance.

Such varied interventions show how each case, though evidently rooted in the same causal factor, is unique and can respond differently to particular therapies. In recognizing the limitations of dividing known conditions into diverse categories, the DSM-IV notes that in syndrome classification, there should be “no assumption that all individuals described as having the same mental disorder are alike in all important ways.”<sup>56</sup> After over a century of fierce etiological debate that inspired popular interventions, the historical record reveals that people with tics and Tourette syndrome have recently obtained a wide range of choice in dealing with their symptoms. Energetic therapies, for example, are preferred simply because they appear to have a positive effect on symptoms, match one’s lifestyle, and minimize undesired results. Many treatment decisions that Touretters make tailor to the individual condition.

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<sup>56</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> ed. (Washington, DC: American Psychiatric Association, 1994), xxii.



## CONCLUSION

### Patterns of Meaning

"FOR THE INDIVIDUAL TO MAKE HEALTH CARE DECISIONS THAT HE OR SHE FEELS ARE IN HIS OR HER BEST INTEREST, THAT INDIVIDUAL MUST TAKE THE RESPONSIBILITY OF BEING FULLY INFORMED. THIS APPLIES WHETHER THE TREATMENT IS CONVENTIONAL OR ALTERNATIVE."

Adam Perlman, foreword in Tova Navarra, *The Encyclopedia of Complementary and Alternative Medicine*

The diversity of touretic experience throughout history conveys valuable lessons useful in our current day and offers insights into the human condition. The personal circumstances of ticcing people and their individual treatment choices have varied so extensively that generalizations must be formed and viewed with care. With this in mind, shared patterns of experience do exist within the social whole. A common trend apparent in recent years is that Touretters have increasingly chosen alternative interventions. These choices have been inspired and informed by growing self-awareness about the particularities of their condition. Given that the disorder and its causes still puzzle doctors and researchers, the testimony of Touretters themselves can offer the most valuable insight. In addition, the presence of behavioral interventions for tics, the limits of scientific knowledge, autonomy in therapy practice, and the act of labeling a medical condition are all critical points of discussion which reveal valuable lessons that can be drawn from a social history of Tourette syndrome and its treatments.

The increasing use of cognitive and behavioral therapies has the potential to complicate clinical and public understanding of the disorder. Psychological implications involved in treatments such as CBIT and HRT have caused some to reconsider their

views about the origins of tics.<sup>1</sup> As a result, their practice can affect a patient's self-perception, ability to receive insurance coverage, and the response of outside observers. Before the work of Arthur and Elaine Shapiro and the TSA in the 1970s, Touretters also more frequently encountered clinical misinterpretation of their symptoms and social isolation. People with the disorder could experience some resurgence of these challenges if patients, doctors, families, and insurance companies do not understand current beliefs about the underlying functionality of cognitive and behavioral therapies. Recent clinical efforts to expand the availability of such interventions for people with the condition place this issue at a heightened level of importance.<sup>2</sup> Many concerned patients and advocates have begun to educate essential individuals and institutions about the mind-body connection involved in certain therapies in order to further validate their practice and avoid the possible reappearance of historic difficulties. Such efforts have been made largely in response to public confusion about the use of behavioral interventions for a neurological disorder.

The social history of Tourette syndrome and its treatments illustrates how scientific knowledge about the condition cannot always ensure a greater quality of life for those who live with it. Needless to say, certain empirical investigations into the causes of the disorder have resulted in significant benefits for Touretters within the past several decades and have unquestionably helped to ease shared cultural burdens. A number of

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<sup>1</sup> For an insightful discussion about the implications and consequences of labeling certain disorders as "mental" or "physical," consult American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> ed. (Washington, DC: American Psychiatric Association, 1994), xxi-xxii.

<sup>2</sup> See Tourette Syndrome Association, "Medical and Scientific Programs: Research Awards 2009-2010," 21; David Volk, "Not Your Ordinary Workout: Handle Institute Creates Unusual Exercises to Treat Attention Deficit Disorder, Autism," *Puget Sound Business Journal*, Vol. 18, No. 2 (May 1997): 12A; National Institute of Health, *Developing New Treatments for Tourette Syndrome: Clinical and Basic Science Dialogue*, [http://www.ninds.nih.gov/news\\_and\\_events/proceedings/new\\_treatment\\_for\\_ts\\_09262006.htm](http://www.ninds.nih.gov/news_and_events/proceedings/new_treatment_for_ts_09262006.htm), last updated March 2011.

patients and families continue to show an interest in scientific research about the syndrome by financial contributions and fundraising.<sup>3</sup> However, historical studies have demonstrated how easily biased information can spread and become widely accepted among medical practitioners.<sup>4</sup> More importantly for contemporary ramifications is the indifference many other patients have about the discovery of a “cure” and growing discontent about medication. “If I had been medicated, I don't think I would have ever learned this tic management,” mentioned a twenty-six-year-old woman. “If there were a pill to cure my Tourette, I wouldn't take it.”<sup>5</sup> In the past, researchers and medical professionals listened to patient testimonies far less often than today.<sup>6</sup> The advent of new interventions based on sensory urge awareness suggests that clinical attention to patient descriptions has begun to inspire prescribed therapy. The choices that Touretters have made in recent years indicate that clinicians have given greater attention to their patients' personal descriptions and combine insights gained from their testimony with the best of scientific understanding when researching new safe and effective treatments. Yet in many instances medical practitioners still attempt to address their ticcing patient's therapeutic needs through scientific understanding alone.

Especially with those who take an energetic approach towards handling their condition, the effectiveness of the intervention and how it relates to personal values or interests is more important to the person than the neurobiological reason behind why it

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<sup>3</sup> See Tourette Syndrome Association Newsletter, Vol. 39, No. 2 (Fall 2011), 14; Kat Zeman, “Step Out for a Good Cause at Run for the Roses,” *Daily Herald*, 10 May 2004, 1.

<sup>4</sup> Elaine Fantle Shimberg, *Living with Tourette Syndrome* (New York: Simon & Schuster, 1995), 64. See esp. Howard I. Kushner, *A Cursing Brain?: The Histories of Tourette Syndrome* (Cambridge: Harvard University Press, 1999).

<sup>5</sup> jspring, comment on “Tourette Syndrome – Now What?” Blog, last updated October 8, 2007, <http://tourettenowwhat.tripod.com/>.

<sup>6</sup> Writing in 1999, historian Howard Kushner observes, “even today, influenced by the success of pharmacological agents for symptom control, practitioners often neglect to listen carefully to the particular experiences that patients and their families report” in *A Cursing Brain?*, 220.

helps control their symptoms.<sup>7</sup> Many self-formulated coping strategies have not only served as a therapeutic method designed to control symptoms but also as means of self-discovery and exciting exploration into one's own internal complexities. While discussing the limitations of science, author Charles Barber observes, "no matter how much progress neuroscience makes, there will always be something that remains ineffably mysterious and unknowable about ourselves...there will never be a one-to-one correspondence between neuroscience and lived experience."<sup>8</sup> Touretters' expression of their energy in a variety of arts and athletics often entertains the mystifying side of themselves in a way that helps to control symptoms that do not produce undesired side effects. "One thing TS probably does help with is my singing and performances," stated Jeff in an interview about his single-minded concentration while on stage that he suspects is the product of a tourettic compulsion. "If it is, it is a good thing for the purpose of my becoming a better performer."<sup>9</sup> Since it is likely that we will never arrive at a concrete scientific understanding about what causes many people to tic, patients will always rely to some extent on their own intuitions in dealing with their situation. Still, some clinicians and support groups are reluctant to accept the informed use of many unconventional treatments.

Despite any reluctance from outside influences, individuals commonly practice autonomy in their treatment decisions. Since people with the condition often decide the best ways to manage their symptoms through personal insight, science alone cannot

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<sup>7</sup> For a discussion about Touretter reactions to medical research, consult Adam Ward Seligman and John S. Hilkevich, eds., *Don't Think About Monkeys: Extraordinary Stories Written by People with Tourette Syndrome* (Duarte: Hope Press, 1992), 197-200.

<sup>8</sup> Charles Barber, *Comfortably Numb: How Psychiatry is Medicating a Nation* (New York: Pantheon Books, 2008), 222-23.

<sup>9</sup> Tourette Syndrome Association Newsletter, Vol. 32, No. 2 (Fall 2004), 1.

determine which therapies are effective or safe. Unlike many cases that were treated with pharmacotherapy, current testimonies have not revealed a strong pattern of risks involved with certain interventions such as dietary management, exercise, and meditative techniques. Virtually no article, study, review, or book ever discusses medications without mentioning or warning about side effects. This provides an important indication about the nature of their usage and places the safety of pharmaceuticals into equal question as most alternative therapies. Also, by listening to patient experiences and examining the recent social history of the condition, clinicians and researchers can discover how many unconventional ways of dealing with tics are methodologically the same as other mind-body therapies that are gaining greater approval within the medical community. Patient and physician awareness of this important mind-body relation between popular clinical and energetic interventions might even result in deeper insights into the nature and treatment of Tourette's and related conditions. Doctor and patient communication about complementary and alternative therapies can also provide an informed view of the patient's treatment preferences.

The emergence of multiple therapeutic avenues taken by Touretters in recent years is a direct result of the idiosyncrasies involved in each case of the disorder. An investigation of different individual examples reveals that, as observed by Oliver Sacks, "it is never the same in any two people."<sup>10</sup> As a consequence, many patients and advocates agree that no single treatment model is useful for everyone with the condition. "The uniqueness of each person's symptoms makes it impossible to treat TS – and many other disorders – in a rigid 'one size fits all' manner" writes Elaine Shimberg, a Touretter

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<sup>10</sup> Seligman and Hilkevich, eds., *Don't Think About Monkeys*, i.

and mother of children with the condition.<sup>11</sup> This contention is shared by two organizations that speak for large numbers of people with Tourette's but represent different spectrums of treatment for the disorder. The TSA, while showing moderate approval of alternative clinical approaches to tic therapy, views medication as the primary means of treatment. And yet, a recent TSA newsletter acknowledged that, "there is no one treatment for everyone with TS. Doctors and patients must work together to make the right choices."<sup>12</sup> In advocating for more natural methods of Tourette's therapy Sheila Rogers, Director of the ACN, writes: "We do not have answers for every person with a tic disorder or an accompanying condition, yet remarkable progress has been made in defining new ways to approach prevention and treatment."<sup>13</sup> She further describes the natural treatment of many tic conditions as an "important movement" towards discovering interventions other than traditional medications, which can cause side effects.<sup>14</sup> Although organizations advocate certain therapies based on what members and outside sources tell them, they continue to remain sensitive to the diversities of touretic experience.

Medication continues to be a crucial factor in the treatment choices of people with Tourette's. The social history of the syndrome has shown that the level of side effects present in pharmacotherapy serves as an important indicator for most people about a drug's usefulness. Depending on individual interpretations about the best way to manage their condition, Touretters have entertained many different reasons for acceptance of or opposition to conventional treatment. Paige, for example, feels that drug intervention is

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<sup>11</sup> Shimberg, *Living with Tourette Syndrome*, 51.

<sup>12</sup> Tourette Syndrome Association Newsletter, Vol. 37, No. 1 (Summer 2009), 14.

<sup>13</sup> Sheila J. Rogers, *Natural Treatments for Tics and Tourette's: A Patient and Family Guide* (Berkeley: North Atlantic Books, 2008), xiv.

<sup>14</sup> *Ibid.*, xv.

an effective way of coping with some of her symptoms that can be physically painful. Although she does not take large amounts of medication, Paige noticed that regulated doses allow her to function better as a classical music composer.<sup>15</sup> After twenty-one years of trying different prescription drugs, Bruce also felt that he finally arrived at a satisfactory combination. “Some of the medications stopped my tics, but the side effects were horrendous,” Bruce revealed. “I had to find a balance between tics and side effects...I’m on Risperdal now, and take a very small amount, just enough to take the edge off.”<sup>16</sup> Tim, a professional soccer player, chooses to disregard medication out of concern that it might dull his senses and therefore affect his athletic abilities. During moments of intense focus, Tim reports that his tics become unnoticeable.<sup>17</sup> Similarly, Dominique practices her own style of adaptive strategies in dealing with her condition that does not involve pharmaceuticals. “Having never been medicated for my tics, I learned myself how to adapt and work with it. With meds, I might not have been able to do that.”<sup>18</sup> Regardless of whether one chooses to medicate their condition or not, many individuals display awareness of their goals in treatment while deciding what works for them. With “a disorder as diverse as life itself,” people with the condition have commonly tailored therapeutic strategies to personal values, lifestyles, and the nature of their own unique situation.<sup>19</sup>

Touretters today often make informed decisions when faced with the challenge of understanding which treatments might best fit their individual situation. Oftentimes, case

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<sup>15</sup> Tourette Syndrome Association Newsletter, Vol. 32, No. 1 (Summer 2004), 3-4.

<sup>16</sup> Tourette Syndrome Association Newsletter, Vol. 30, No. 4 (Spring 2003), 3.

<sup>17</sup> CBS News 60 Minutes, “Shutting Out Tourette’s Syndrome,” 11 February 2009.

<sup>18</sup> Dominique, comment on “Tourette Syndrome – Now What?” Blog, last updated October 8, 2007, <http://tourettenowwhat.tripod.com/>.

<sup>19</sup> Quote taken from Seligman and Hilkevich, eds., *Don’t Think About Monkeys*, back cover.

reports show how this is not a simple matter of preference but rather an intense process of experimentation involving self-awareness and exploration of different therapeutic directions. Furthermore, informed decisions tend to be based less on suspected causal factor theories or the biological way a treatment functions than about how well it actually works without resulting in undesired side effects. A specific case that this observation might bring to mind is Arthur Shapiro's first tourettic patient in 1965 where Haldol was used experimentally. Although Shapiro's subsequent trials with Haldol for Tourette's patients helped substantiate a neurological theory of etiology, the target cause was less the actual object of treatment as the patient and psychiatrist remained uncertain about how exactly the drug worked to stop tics.

Just as the underlying functionality of medication has been unclear in the past, the same is true with many alternative treatments. For instance, most health care providers currently understand CBIT to balance brain functioning through habitual training, but our understanding of its successes and failures in terms of neurology, psychology, or a placebo effect could very well change in coming years.<sup>20</sup> The same can be said of Neurofeedback techniques, which have existed for over forty years without professionals understanding how people are actually able to control their brain wave patterns.<sup>21</sup> One study involving eighteen Tourette's DBS patients was carried out even though the essential mechanisms of the surgery are "still not fully understood."<sup>22</sup> Since the exact etiology of Tourette's is unknown, the way in which associated treatment methods work

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<sup>20</sup> For a discussion about the possible role of the placebo effect in many current complementary and alternative treatments, consult R. Barker Bausell, *Snake Oil Science: The Truth About Complementary and Alternative Medicine* (New York: Oxford University Press, 2007).

<sup>21</sup> Blaine Greteman, "Train: How Neurofeedback Can Help Reduce Stress, Enhance Creativity and Improve Mental Health," *ODE*, March 2009, 50.

<sup>22</sup> Thomas H. Maugh II, "Booster Shots: Deep Brain Stimulation Eases Tics in Tourette's Syndrome," *Los Angeles Times*, 26 October 2009.



remains largely unsolved. Particularly in recent years, a sense of self-awareness has guided individual choices about managing tic symptoms more than has scientific understanding of a treatment. In addition, Touretters' decisions to practice alternative interventions reveal that patients measure the therapeutic success of pharmaceuticals not by their ability to completely eliminate tics but rather by how well they mitigate symptoms without producing harmful side effects.

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People who exhibit a like set of symptoms and are placed under the same medical label can nonetheless be fundamentally different from each other in how they choose to manage their condition. Yet in their unique situations, contemporary Touretters have often practiced or created unconventional therapies that respond to the defining features of their disorder, such as tic disappearance during focused activities, symptom escalation with feelings of stress and tension, the effect of consuming certain nutrients, or the sensory urges that often precede a tic. This does not mean that a historically deterministic end is pushing Tourette's treatment towards more natural, non-medicinal methods of intervention. Instead, it reflects similar thinking among a great number of individuals with Tourette syndrome. Several people within the collective whole have displayed a sharp mindfulness about their disorder and have subsequently used therapeutic measures based on their personal understanding of particular internal attributes. Their common choices reveal the presence not only of a common condition but a shared consciousness.

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## DISSERTATIONS

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