

In motion, out of place: the public space(s) of Tourette Syndrome

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Abstract

According to Doris Humphrey, “Nothing so clearly or inevitably reveals the inner man [sic] than movement and gesture...the moment you move you stand revealed, for good or ill, for what you are” (*The dance notebook*, 1984). Tourette Syndrome, characterized by motor and vocal tics, elicits stigma for just this reason: the tics and movements it causes have revealed Touretters as something beyond the ‘normal.’ This paper examines the ways Touretters are perceived and received in public spaces, using published illness narratives and film documentaries to address the question of why the reactions TS invokes are so severe. We will demonstrate how the stigma surrounding the disorder stems from the perception of Touretters as disruptive to the order and health of public spaces. To describe the production of stigma and the violent reactions to TS individuals, we draw upon theories of bodies and performativity from feminist studies, Catherine Waldby’s work with the imaginary anatomy, and geographical perspectives on the social construction of space. The geographic studies of space are used to illuminate discussions of people’s life experiences by showing how body movements associated with illness produce stigma by transgressing the unwritten codes that govern particular public spaces. Our intention in this paper is not to introduce new empirical data, but rather to analyze the mechanisms of stigma formation produced by the complex relationships between the functioning of social spaces and individuals’ experiences of illness.

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Nothing so clearly or inevitably reveals the inner man than movement and gesture. It is quite possible, if one chooses, to dissimulate behind words, or paintings, or statues or other forms of human expression, but the moment you move you stand revealed, for good or ill, for what you are. (Doris Humphrey, cited in *The Dance Notebook*, 1984.)

In Michigan, a grocery store bagger with Tourette Syndrome (TS) is fired for cursing in front of customers. The Michigan Court of Appeals finds that the supermarket was well within their rights, because the bagger violated the store’s policy against abusive language. A

seminary student sues the school that blocked him from finishing his studies and becoming a minister, for similar reasons. These two legal battles stem from (mis)perceptions of TS. Both the bagger and the student suffer from the condition, and both cases result from their TS symptoms. Both feel they have been discriminated against.

Representations of the “cursing disease” have become commonplace in the mainstream media and entertainment industries. Celebrities casually call themselves Touretters¹ when they misspeak or are held accountable

¹ We invoke the term “Touretters”, first coined by Oliver Sacks, as an alternative to the clumsy “individual with TS”. Like any collective label, many people with TS use the term, while others find it offensive. We intend no disrespect to the condition or the people affiliated with it through the use of the term.

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for excessive cursing. *Not Another Teen Movie*, a film that spoofs the teen film craze, includes a cheerleader with TS, and other films, such as Rob Morrow's *The Maze* and Gary Winick's *The Tic Code* depict characters with the condition. Touretters have appeared as television characters on *L.A. Law*, *Quincy*, *Ally McBeal*, and *Ellen*. But despite all the publicity the condition is receiving, and despite the Tourette Syndrome Association's educational crusade, Touretters often live in a divided world, a world where privately their bodies are accepted and acceptable, but publicly they are not.

This paper examines the ways Touretters are perceived and received in public spaces to address the question of why, despite the fact that TS has drawn so much attention from the media, the reactions it invokes remain so severe. We will demonstrate how the stigma surrounding the disorder stems from the perception of Touretters as disruptive to the order and health of public spaces. To describe the production of stigma and the violent reactions to TS individuals, we draw upon theories of bodies and performativity from feminist studies, Catherine Waldby's work with the imaginary anatomy, and geographical perspectives on the social construction of space. The geographic studies of space are used to illuminate discussions of people's life experiences by showing how certain behaviors associated with illness produce stigma by transgressing the unwritten codes that govern particular public spaces. In this paper we consider published illness narratives, film documentaries, and other representations of TS. Our intention in this paper is not to introduce new empirical data, but rather to analyze the mechanisms of stigma formation produced by the complex relationships between the functioning of social spaces and individuals' experiences of illness.

A cursing marquise: the history of Tourette Syndrome

TS, although known most commonly by the tendency of sufferers to curse spontaneously and uncontrollably, is actually categorized as a collection of symptoms, ranging from minor motor tics (uncontrollable movements of the extremities), to echolalia (the repeating of words or phrases), to the infamous coprolalia (cursing), which occurs in only a minority of cases. Howard Kushner, in his book *A Cursing Brain? The Histories of Tourette Syndrome*, describes the contested history of TS. The condition was named after Gilles de la Tourette, who, in 1885, described a collection of symptoms he refers to as "maladie de tics", based on the Marquise de Dampierre who was infamous for cursing inappropriately and exhibiting other tics. Tourette, however, never met the Marquise or examined her. He based his account on Jean Marc Gaspard Itard's published record of the Marquise, who only examined her briefly. Yet the

syndrome is still discussed today, and still retains the name of the man who is thought to have "discovered" it. According to Kushner (1999), "It is fair to say that almost all discussion of the often-cited and emblematic case of Gilles de la Tourette Syndrome [the case of the Marquise de Dampierre], rests on an 1885 partial reproduction of an 1825 publication in a language inaccessible to many commentators who cite it". These inauspicious circumstances gave birth to a syndrome that has remained controversial into the new millennium.

TS is classified as a syndrome because of its unknown etiology. The debate over whether the causes are psychological or biological still rages, although it is now more commonly thought of, particularly in the United States, as a genetic disposition that is triggered in an individual's lifetime by a variety of factors. Most Touretters have a complex system of tics, both vocal and motor, that prove disruptive to daily life, often-attracting attention and hostility to the TS individual. The difficulties of such a condition are obvious: uncontrollable sounds and movements that occur inappropriately lead to stigma and disruption in both the Touretter and their environment. Treatment of TS usually consists of a combination of drug therapy and behavioral therapy. Because the syndrome is comorbid with both Attention Deficit Hyperactivity Disorder and Obsessive Compulsive Disorder, much success can be achieved through replacing specific behaviors with more acceptable ones.

Although people have become more aware of TS because of the media and publicity campaigns established by the Tourette Syndrome Association, the syndrome is still perceived as rendering life difficult for people who have it. Oftentimes, this is the case. While many with milder symptoms lead a "normal" life, many of the memoirs and documentaries available depict the hardship of acting in a way that is nearly unanimously viewed as inappropriate, or even rude. In a world so focused on the visual, on appearances, Touretters are often stigmatized by their behavior.

Many factors play into this stigma, such as inappropriate behavior in particular spaces, or at improper times. Because TS patients exhibit some level of control over their tics by either holding them in until there is a more appropriate opportunity to release them, or by channeling the movements into gestures that simulate more "normal" actions like scratching or stretching, and since tics worsen and lessen regularly, to the point of nearly disappearing in situations that demand the person's complete attention, Touretters can be faced with the accusation of "doing it on purpose". The visual impact of the movements themselves is also powerful; the Touretter appears to be out of control, another problem in societies where self-control is valued and expected.

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