

## **OCD and Tourette Syndrome: Re-examining the Relationship**

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At the outset of this article I would like to thank the hundreds of kids whom I have seen professionally in my more than twenty five years of clinical practice. They were as much my teachers as my patients, in that they opened my eyes to numerous insights, some of which are outlined here. Many were indulgent enough to describe their experience with OCD and related problems in such exquisite detail that they shaped my thinking--and re-thinking--of what I thought I knew about OCD, Tourette Syndrome (TS) and the multitude of clinical features that often presented within the same young packages. Some just had OCD in its familiar forms, and others just tics. But many had a hodge-podge of clinical features--OCD and TS and ADHD (attention deficit hyperactivity disorder) and LD's (learning disorders) and ODD (oppositional defiant disorder) and ... you name it. I had innumerable opportunities to learn about their first-hand experiences so near to the genesis of their own disorders. As a result, a picture began to emerge that was consistent with their descriptions but often at odds with orthodox views. Here I will briefly outline several perspectives that derive from a re-examination of the relationship between OCD and TS based on that picture.

### **OCD vs. Tics and TS (T/TS)**

It is useful to start by examining some of the commonly accepted views of OCD and tic disorders, with more attention to tic disorders, since readers of this article are likely to be more familiar with OCD.

OCD is characterized by obsessions--frequent, unwanted, upsetting and maladaptive thoughts or images that a person can't get out of consciousness. These are often associated with ritualized overt or covert behaviors (compulsions) that the person feels compelled to perform in response to his/her obsessions. Typically, these are designed to reduce distress and/or to prevent a feared event. Tics are sudden, repetitive, stereotyped movements or phonic emissions that are usually seen as involuntary and are sometimes preceded by urges. Tics can occur in flurries and tend to wax and wane in severity and intensity over time. They can be simple--sudden, brief and meaningless (e.g. eye blinks, head jerks, facial grimaces, coughs, barks, snorts, etc.) or complex--slower, and more purposeful (e.g. smelling things, touching things, shouting obscenities, counting things, tracing objects, "evening up" objects repeating heard words or phrases, etc). Simple tics often appear first with complex tics developing later. Tourette syndrome is diagnosed when multiple motor tics and one or more phonic tics are present during the course of the disorder.

OCD can begin at any age but most typically it begins in early adulthood in females and somewhat earlier in males. The course of the disorder can vary greatly from individual to individual, but in most cases OCD persists into adulthood, though waxing and waning in severity. Among the more common comorbid conditions are depression, other anxiety disorders, eating disorders, and TS.

Tic disorders typically begin in mid-childhood and peak during early adolescence, and, like OCD, usually wax and wane in severity over the years. By adulthood tics tend to abate or be absent entirely. In 15% of adults tics continue to present moderate problems, and 10% experience severe problems with tics. Prediction of the course of the disorder in any individual child is impossible. While the tics themselves can be problematic enough, many individuals with tics and most people

with TS have features associated with a wide variety of other disorders. Among the more common features appearing in conjunction with tics are: impulsivity, inattention, hyperactivity and restlessness associated with ADHD; the behaviors and obsessive compulsive thoughts associated with OCD; the difficulties in learning associated with LD's; the emotional liability, irritability, anger and aggression associated with mood disorders and oppositional defiant disorder; the fearfulness, avoidance and clinginess associated with anxiety disorders; the guilt and helplessness associated with depression; and the sensory integration issues (e.g. oversensitivity to textures, smells, noises, light) associated with sensory processing problems. The majority of children with TS have symptoms of one or more associated conditions. Those children are said by some experts to have "TS Plus".

OCD and TS exist as separate entities according to the current Diagnostic and Statistical Manual of Mental Disorders (4th Edition) -- DSM-IV. OCD is classified as an anxiety disorder while tic disorders including TS are among "Disorders Usually First Diagnosed in Childhood". The currently favored treatment approaches, both pharmacological and psychological, for OCD vs. T/TS also differ. For OCD the psychological treatments of choice are the cognitive behavior therapy (CBT) techniques of exposure and response prevention (ERP) and cognitive therapy (CT), while pharmacological treatment favors the serotonin reuptake inhibiting family of antidepressants, selective and non-selective (SSRI's, SRI's) and a variety of augmenting medications. Tics/TS, on the other hand, tend to be treated by the CBT techniques of contingency management, relaxation training and habit reversal training (HRT). Medications favored for treatment of T/TS are standard neuroleptics (e.g. haloperidol, pimozide) and atypical neuroleptics (e.g. risperidone, olanzapine) and alpha-2 agonists (e.g. clonidine, guanfacine). OCD and T/TS have also been viewed as distinctly different entities on the basis of differing courses as well as presumed etiologies.

Yet despite the distinctions outlined above, there is substantial evidence that OCD and T/TS overlap in ways that suggest a much closer relationship. The frequent concurrence of symptoms of both disorders in the same individual is one strong clue. Up to 60% of TS sufferers have been reported to have OCD symptoms, 50% of children with OCD are reported to have had tics and 15% met criteria for TS. Also, evidence from family studies and lines of genetic research suggest that the disorders are etiologically linked.

Moreover, at the clinical level, distinguishing between OCD and T/TS symptoms can be difficult and at times impossible. Even seasoned experts can be hard put to distinguish complex tics from compulsions. This can present a significant dilemma for clinicians attempting to make a differential diagnosis (tic or compulsion?) under such circumstances. This is not a small point. Besides influencing treatment decisions, the diagnosis holds important implications for the predicted course of the patient's disorder, the likely choice of treatment and the expected prognosis for the individual.

So at this stage of the clinical science and art, there are strong indications of an interplay between OCD and T/TS, suggestive of a tantalizing relatedness. Yet there continue to be formal barriers to a clearly elucidated conceptual framework that would clarify the relationship between these disorders and that would provide pathways for practical solutions to frequently encountered clinical problems. In the remainder of this article I will offer perspectives on the relationship between OCD and T/TS based upon years of clinical experience with these disorders. I and my colleagues at the Behavior Therapy Center of Greater Washington are convinced that our adoption of perspectives

described here has greatly facilitated our understanding of the nature of the problems confronting our patients and our efforts to provide the most effective treatment possible. My hope is that broader efforts to understand OCD and its variants and to develop more effective methods to help sufferers and their families might be enhanced by consideration of these views. Moreover, I have seen patients and their families struggling to understand the perplexing array of symptoms that can occur at the interface of OCD and T/TS, take comfort in the perspectives outlined here. It is my hope that others might similarly benefit if these ideas were more widely dispersed. Finally, I hope that the broader scientific effort to understand OCD in all of its manifestations may benefit from these insights drawn from clinical observation and practice.

### **Tourettic OCD (TOCD):**

Current conceptual formulations regarding the OCD and T/TS relationship provide minimal practical utility for clinicians, especially for non-specialists, in everyday clinical practice. As mentioned above, boundaries between symptoms of OCD and T/TS can be blurry, especially with regard to differentiating complex tics from compulsions in cases where actions are repeated specific numbers of times, according to prescribed rules, or until a "just right" feeling is achieved. This symptom cluster is not uncommon, yet it is often peripheral to discussions of OCD and its treatment. Ascertaining a personal or family history of tics can be useful. The clinical significance of "tic-related OCD" has been well described by James Leckman and his colleagues at Yale. Yet in clinical practice reliable information of that sort can be difficult to get. Moreover, clinical decision-making in the treatment of such clients has yet to be clearly elucidated. Categorical thinking (tic or compulsion?) and the absence of a coherent and unified perspective on these phenomena can unnecessarily limit treatment options and thereby impede the development of more effective treatments.

In an effort to address some of these shortcomings in the OCD and T/TS literature, my colleague, David Keuler and I have proposed elsewhere (Mansueto & Keuler, 2005) that there exists a clinical subgroup of individuals frequently seen in treatment who present with a distinguishable cluster of symptoms that represent a blend of OCD and T/TS features. We argued that these individuals can be readily identified by their characteristic clinical presentation whether or not a personal or family history of T/TS can be verified. We call this subtype "Tourettic OCD" (TOCD) and suggest that it is distinct from "purer" forms of OCD because it is heavily influenced by features usually associated with T/TS.

### **Distinguishing Features of TOCD**

Because it is closely akin to T/TS, symptoms of TOCD, like those of many tics are preceded by prodromal sensations characterized by somatic discomfort, not anxiety. Unlike true OCD, in which cognitions (obsessions) lead to an emotional (affective) state, typically fear of the content of the obsession, TOCD sufferers report discomforting sensory experiences such as physical discomfort in body parts such as hands, eyes, stomach etc. or a diffuse psychological distress or tension, for example, "in my head" or "in my mind." These localized or general discomforts in the TOCD sufferer tend to be relieved by varieties of motor responses including "evening things up," doing things to certain numbers, positioning items, touching and retouching things, doing things symmetrically and so on, typically with the requirement that these actions are performed "just so" or "just right" in order to alleviate the somatic/psychological discomfort. Unlike reports of subjective experiences associated with classic forms of OCD, individuals describe a relative absence of fear or concerns about catastrophic consequences occurring should the required actions not be

performed. Instead there are likely to be concerns that the discomfort might be intolerable or unending if the actions were left undone or done poorly. Some TOCD sufferers may report a vague sense that "something bad might happen" if required actions are not performed but they typically lack the more elaborate obsessional features of the typical OCD sufferer. Also, the required actions do not function in the modulation of anxiety and/or prevention of catastrophic consequences typical of compulsions in OCD. TOCD characteristic symptoms can appear alone or can exist in combination with classic OCD symptoms. Other writers have noted such clusters of symptoms in clinical populations and have variously referred to them as "cognitive tics," "sensory-based rituals," "sensory fulfillment," and "Factor II OCD."

### **Historical Indicators of TOCD**

It is not uncommon for TOCD to have been preceded by certain "historical indicators": early signs of sensory hypersensitivity (e.g. tactile-defensive reactions to clothing tags, seams, scratchy fabrics, confining clothes, etc.); multiple comorbid disorders, particularly attention deficit disorder, learning disorders, impulsivity and emotional self-control issues; a weak response or no response to SSRI monotherapy and a weak response, no response, or an anomalous response to exposure and response prevention (ERP) therapy. Sometimes, but not typically, symptoms include intrusive sexual, aggressive or gruesome images.

### **Clinical Implications of TOCD**

The TOCD perspective opens the door to a broader range of treatment possibilities than that drawn from an orthodox categorical perspective. Patients with TOCD are seen in our clinic with regularity. Instead of being constrained by the usual treatment recommendations our patients are likely to receive a mix of therapeutic approaches drawn from both the OCD and T/TS "tool kits." ERP and cognitive therapy are frequently augmented by relaxation training, substitution strategies like HRT in which required responses are discouraged by practice of responses that are incompatible or by channeling their urges in directions of less disruptive or bothersome responses. Patients utilizing these techniques are encouraged to suppress the unwanted responses for longer and longer intervals. On the medication side of the board, the highly knowledgeable medical professionals with whom we collaborate regularly are willing to augment SSRI medications with alpha-2 agonists or with typical and atypical neuroleptics with greater confidence, even when the practice seems to cross the boundaries of standard diagnostic prescription. They are methodical and judicious in their approach to the addition of other medications, particularly stimulants because of their potential to initiate or exacerbate tics, in some cases.

We have used ERP for years with our patients, even those who were primarily identified as T/TS patients, and have observed what recent research has begun to confirm: that this approach doesn't necessarily result in the rebound effect that would be expected when response suppression tactics are applied to apparent tics and that the repetitive responses often respond favorably to these techniques. By applying a broader range of therapeutic techniques to our TOCD patients we have had increasing success in helping these individuals achieve greater degrees of mastery over their symptoms. I recommend that other clinicians adopt the TOCD perspective in efforts to help such patients.

### **Helping Patients and Families Make Sense of the "Alphabet Soup Syndrome"**

Communication regarding the nature of their problems to patients and their families is a crucial, early step in therapeutic practice. Many of patients come to us because OCD has been detected among a complex of other diagnoses. I have come to refer to the perplexing array of diagnoses that are so often affixed to the children who enter our offices as the "Alphabet Soup Syndrome." Tics or TS may, or may not be in the diagnostic mix, but among the commonly co-diagnosed conditions are attention deficit disorder (ADD), learning disabilities (LD's), oppositional defiant disorder (ODD), often at least one diagnosis designed to explain the child's emotional "meltdowns" (Depression or Mood Disorder NOS are typical), and recently, the unofficial diagnosis of sensory processing disorder (SPD). These children and their parents want to know how they developed so many things wrong with them. Often, by the time I see them the child and parents are "doctored out", bewildered and far from convinced that they are yet on the right therapeutic path. Questions about the appropriate diagnoses, the proper therapeutic approach(es) and the role of medication are foremost in their minds.

A large proportion of these patients (certainly not all—there are other routes to Alphabet Soup) have hallmark features of TOCD along with the array of associated conditions that occur so often in conjunction with a nervous system that is prone to developing tics, but may not manifest the kind of simple tics that are easiest to identify. Previous visits to mental health professionals typically fostered the view that the child suffered from a seemingly unrelated cluster of disorders. At our clinic we view the situation differently—we see it as an array of problems resulting from a developing nervous system from which clinical features emerge that cut across a range of diagnostic categories. The "tourettic" nervous system is "hair triggered"—easily aroused, and hard to settle. This suggests that excitatory mechanisms within their nervous systems, those which initiate and energize actions and feelings generally function well, but that complementary inhibitory mechanisms that modulate these functions are not up to the task. This asynchrony can certainly present challenges for parents, teachers, family members and peers. The particular mix of features makes it difficult for the child to adapt to the requirements that society establishes for children, for example, to "sit still in class, pay attention to the teacher, and learn the material," "wait your turn," or "put away your toys and come to the table."

Since conceptually TOCD is linked with a "tourettic nervous system" (but not necessarily with tics per se), the array of "disorders" can be viewed as the cluster of associated conditions common to T/TS. As in cases of "TS Plus" there is likely to be improvement in many of the neurological symptoms through maturation alone. The developing nervous system achieves greater harmony and balance as characterized by the diminution or disappearance of tics in most sufferers by adulthood. The idea that time may very well be "on our side" can be comforting to the individual and family who feel battered by the problems that led them to therapy. The therapeutic endeavor becomes a group effort with the greater goal of keeping the child out of trouble and on track toward a hopeful future.

Language used to describe the clinical conditions matters too. Children can feel like "damaged goods" when told that they have neurological disorders. They respond in notably positive ways, however, when described as "extra alive", with "supercharged" nervous systems, "brimming over with energy that is almost impossible to contain—spilling out in bursts of behavior, emotions and spontaneity." A metaphor can make a world of difference! They drive a Ferrari through life, while most others drive a Toyota. The engine may be cranky, the handling may be skittish and quirky,

and driven carelessly it is an accident or speeding ticket waiting to happen. But when you know how to handle it is the most impressive vehicle on the road. (If that seems too macho then instead it can be the image of a skittish and often hard- to-control thoroughbred race horse among a herd of "Old Nellies.") Little chests puff out with pride, and parents see their child in a new light. That still leaves a significant challenge given the often formidable array of problems that must be addressed in important spheres of the child's life and the uncooperative nature of the nervous system underlying those problems. Battles must be chosen wisely, and it is useful for the therapist to remain humble in setting goals for treatment, resisting bold plans to "fix the kid".

But with proper education and support for significant individuals (parents, siblings, other family members, teachers, friends, coaches, etc.) and with orchestrated individual, family and (whenever possible) school interventions drawn from empirically-supported cognitive-behavioral principles, there is an excellent chance to help the child stay on course. A positive perspective is invaluable since, in many cases, the course of treatment can be rough. It helps to point out that while the course of treatment can be very challenging, children like these can have wonderful potential. Many lively, energetic, funny, creative, fun-loving, exuberant, innovative, empathic, tireless, passionate, curious, feisty, formidable, relentless adults arose from these shaky foundations. With energies channeled in the right direction, these naturally energetic, "extra alive" nervous systems can supercharge a formidable young adult.

### **Understanding and Short-Circuiting a Developmental Form of OCD**

Over the years of dealing with children who inhabit the TOCD and alphabet soup world, I have had innumerable opportunities to observe kids at every possible stage of experiencing and coping with OCD, T/TS and TOCD in all their manifestations, combinations and permutations. Among the "Eureka" moments was the realization that the underpinning of a tourettic nervous system can, with the passage of time, evolve into a classic adult form of OCD, sometimes with reverberations of the tourettic features but often without a trace of their origins. How might this happen? Let me outline the steps:

- Phase 1: A child is born with a tourettic nervous system
- Phase 2: Associated secondary clinical features emerge; simple tics emerge (optional)
- Phase 3: TOCD features (compulsions/complex tics emerge)
- Phase 4: Cognitive elaborations are attached to complex tics/compulsions
- Phase 5: Classic (cognitive/affective) OCD develops, tourettic features diminish or disappear (but may persist in some individuals).

In this scenario, foundations for a tourettic-developmental form of OCD are set when a child is born with "tourettic" nervous system: quick to excite, slow to quiet, irritable, highly arousable, with inhibitory mechanism developmentally not up to the task of effectively keeping impulses in check. (Note: It is possible that these nervous system characteristics may be acquired through mechanisms such as "PANDAS" - Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection). While tics may emerge in some, many children will exhibit various combinations of associated behavioral/psychological characteristics associated with the tourettic nervous system (attentional problems, impulsivity, explosiveness, sensory processing problems

etc.) without any discernable tics. Tourettic OCD features emerge and generate behavioral "demands" on the individual (in concerns with symmetry, "just right" or "just so" requirements, evening up, ordering, touching, etc.) driven by localized physical tension, generalized somatic discomfort and diffuse psychological distress (but not obsessions and anxiety as in classic forms of OCD). In time, however, primitive cognitive attributions become associated with these recurrent efforts to end distress (... "or something bad might happen"). The cognitive "overlays" can become more specific and further elaborated upon to evolve into classic OCD concerns such as: "harm will come to my parents", "God will be angry at me" or "I may get sick". Since these are anxiety-provoking ideas, a classic cognitive-affective OCD emerges out of the tourettic raw materials and continues to coexist with the sensory-motor components or to outlast these elements as the nervous system matures and tourettic features disappear. The classic OCD features are then the familiar, chronic, debilitating OCD that does not characteristically abate or disappear with passage into adulthood. One very important implication may be drawn: successful early intervention with TOCD sufferers can short-circuit the formation of classic OCD with its potential to be a life-long affliction.

### **Conclusion: Conceptual Integration of TS and OCD**

The ideas and perspectives presented here, while derived from extensive clinical experience, much reflection and deductive reasoning, range from somewhat to highly speculative. Time will tell which and how many of these ideas will receive the empirical validation necessary for widespread acceptance by the clinical and scientific communities. At this early stage of efforts to comprehend the relationship between OCD and TS, and to develop effective treatments for these disorders, the conceptual viewpoints presented here do have potential advantages. First, they describe interactions between two frequently comorbid, and curiously related, conditions. Second, they describe the functional relationships between subjective experiences common to individuals in these clinical groups and the problematic repetitive behavior patterns that they exhibit. Third, they provide for a wider range of treatment options for effectively addressing a challenging clinical subgroup. Fourth, they point to a potential mechanism in which OCD etiology is traced to tourettic origins. Fifth, they provide for conceptual unification of seemingly disparate, but commonly co-existing clinical phenomena.

#### Reference:

Mansueto, C.S. and Keuler, D.J. (2005) Tic or Compulsion?: It's Tourettic OCD!. *Behavior Modification*, 29, 784-799.

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