



# Tourette's: Syndrome, disorder or spectrum? Classificatory challenges and an appraisal of the DSM criteria



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## ARTICLE INFO

### Article history:

Received 29 March 2014

Received in revised form 29 April 2014

Accepted 25 May 2014

### Keywords:

DSM-5

Classification

Diagnosis

Tics

Neurodevelopmental disorder

Tourette Syndrome

## ABSTRACT

The fifth version of the Diagnostic and statistical manual of mental disorders (DSM-5) was released in May 2013 after 14 years of development and almost two decades after the last edition DSM-IV was published in 1994. We review the DSM journey with regards to Tourette Syndrome from the original publication of DSM 1 in 1952 till date. In terms of changes in DSM 5, the major shift has come in the placement of Tourette Syndrome under the 'Neurodevelopmental Disorders' alongside other disorders with a developmental origin. This review provides an overview of the changes in DSM-5 highlighting key points for clinical practice and research along with a snap shot of the current use of DSM as a classificatory system in different parts of the world and suggestions for improving the subtyping and the diagnostic confidence.

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## 1. Introduction

### 1.1. The history of Gilles de la Tourette Syndrome (GTS) – where the DSM and America are situated

DSM was initiated in 1952 with the publication of DSM-1. Since then there have been several editions which have been numerically named or designated (DSM-1 to DSM-5), with several text revisions (e.g. DSM-III-R; DSM-IV-TR). DSM-5 was published in May 2013 and was not only eagerly awaited internationally, but has drawn much comment from practitioners since publication.

Before discussing DSM (or indeed any diagnostic criteria for Gilles de la Tourette Syndrome [GTS], e.g. the WHO ICD or the Chinese Criteria one must acknowledge that GTS is not a unitary condition as was once thought (see below for details) and there is no diagnostic test for GTS either, unlike other disorders (e.g.

Huntington's Disease, Dystonia, cystic fibrosis). As such, it is more difficult to be 100% certain what the syndrome is and who does or does not have it (for full discussion see below).

Regier et al. (2013) suggest that DSM-5 changes have been driven by (i) advances in neuroscience (ii) clinical and public health needs (iii) inherent problems in DSM-IV (iv) need for better alignment with the upcoming ICD-11 of the WHO. Blumenthal-Barby (2013) suggests that the main changes in DSM-5 include (i) expanded nosology (ii) taking into account the role of claims about societal impact in changes in nosology (iii) categorisation nosology to spectrum nosology. Nemeroff et al. (2013) examined the changes, controversies and future directions of the DSM criteria. There have been numerous letters and papers about the DSM-5 and they include some specific "syndromes, disorders, spectrum disorders". For example, in the case of Autism Spectrum Disorder (ASD), there have been significant changes in DSM-5 leading to numerous comments and discussions about the DSM-5 approach to autism and ASD (e.g. Volkmar and McPartland, 2013; Guthrie et al., 2013; Hazen et al., 2013). With regards to GTS, the diagnostic criteria are quite similar to DSM-IV-TR and work well.

What the DSM (APA, 1952, 1968, 1980, 1987, 1994, 2000, 2013) first called "tics" and now calls Tourette's Disorder (TD) was in fact established first as a "European syndrome"; the first descriptions being from the Salpêtrière and allied hospitals in Paris, France. In

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1825 the French physician Itard is highly likely to have first documented what we know as GTS today, writing his observations of a French noblewoman the Marquise de Dampierre in: “Memoire sur quelques fonctions involontaires des appareils de la locomotion, de la prehension et de la voix” (Itard, 1825). Sixty years later, George Eduard Brutus Gilles de la Tourette described nine cases of the syndrome in 1885, earning him eponymous fame (Gilles de la Tourette, 1885). Soon after, Guinon (1886) also from France described “Sur la maladie des tics convulsifs”. In this paper and that of a fourth Frenchman, Grasset, as well as another paper of Gilles de la Tourette (translated by Robertson and Reinstein, 1991), the tic phenomenology and early psychopathological features were exquisitely described including obsessions and compulsions, which were suggested to be integral to and an essential part of the syndrome. The World Health Organization has referred to it as a “syndrome – de la Tourette syndrome” (ICD-10, 1993, F95.2) and has thus remained consistent for over 20 years. The only stipulations were that (i) multiple motor and one or more vocal tics must have been present at some time during the disorder, but not necessarily concurrently (ii) the frequency of tics must be many times a day, nearly every day, for more than 1 year, with no period of remission during that year lasting longer than two months (iii) onset is before the age of 18 years. Numerous papers from predominantly Europe marked the beginnings of GTS documentation and research, with British John Corbett contributing substantially.

The first American to publish in the area of GTS was Stevens (1965) and Stevens and Blachly (1966) including the suggested treatment of GTS and also describing the “Jumping Frenchman of Maine” (Myriachit, also described by others in USA/Canada). It was perhaps after the Frenchman physician Seignot (1961) description of the successful use of haloperidol in GTS that the physical “treatment” of GTS “took off” and in this regard the USA took the lead, with papers by Chapel et al. (1964, haloperidol), Lucas (1964, 1967, phenothiazines, haloperidol) and Shapiro and Shapiro (1968, haloperidol). The evolution of the study of GTS was then “fathered” (our word) in the main, by the well known American pioneers (Arthur and Elaine Shapiro [PubMed publications 1968–1992], including the first book (Shapiro et al., 1978), Arnold Friedhoff [publications 1966–1977], Donald Cohen [publications 1978–2003]), all of which led the way to GTS becoming an “American led syndrome”. Ruth Bruun of the Shapiro group, also a pioneer, still works in the New York area [publications starting from 1972]. Other noted American neurologists in the field were Tom Chase [publications 1984–2002] and then those who still actively contribute such as Joseph Jankovic [publications starting from 1983] and the Harvard geneticist David L. Pauls (also from the Yale Child Study Centre “stable” [publications starting from 1981] and Bradley Peterson, the latter two working on the genetic and neuro-anatomical substrates of GTS. Importantly the notable clinician-researchers from the “Yale Stable” who in fact really led the way included the mentor Donald Cohen, as well as James Leckman, Lawrence Scahill and Robert King. James F. Leckman “succeeded” Donald Cohen at the Yale Child Study Centre taking over the clinical and academic “reign” of GTS, and is currently the highest international publisher [publications 1982–2013;  $n = 195$ ] on this subject. In a recent paper entitled “The most cited works in Tourette Syndrome” (Mariam and Cavanna, 2012), no less than 72% were authored solely by American groups. Thus understandably America has taken the lead, and that is why the American Psychiatric Association (APA) criteria (DSM) and their history with regards to GTS are important to know and understand.

When discussing the DSM criteria for GTS, it might be worth mentioning the important role of the American Tourette Syndrome Association (TSA) in the development of the notion of the phenotype of GTS. The TSA, while located in the USA, always

tried to emphasise the international perspectives of GTS, including both clinical work and the basic sciences. This was undertaken in several forums including the sponsoring and holding of international GTS scientific meetings (the first held in New York City in 1981), international scientific consortia for research (e.g. the TSA International Genetic Consortium) and also the awarding of substantial competitive scientific grants, which are given to many members of the international community, and who then conduct important GTS research world-wide. The TSA also published the proceedings of the conferences as a book after each major International Meeting: the first in the “GTS Advances Journey” was Advances in Neurology in 1982 (Volume 35; edited by Arnold J Friedhoff and Thomas N Chase Raven Press, NY) which was followed by Volumes 58 (1992), 85 (2001) and 99 (2006), covering all aspects of GTS, for example clinical phenomenology, co-morbid disorders (ADHD OCD, depression, behavioural disorders), new findings in basic sciences of GTS, neuroimaging and neurophysiology of GTS, genetics and molecular biology, immunology, epidemiology, and advances in treatment in GTS. It is easy to see how all this influenced the developing notion of GTS, its recognition world-wide and thus helping understand the GTS phenotype and almost certainly influencing the DSM–GTS debate.

## 2. The DSM criteria: a critical appraisal

The American Psychiatric Association (APA) drew up criteria (DSM) for GTS, as did the World Health Organization (WHO), but for the ease of comparing research data with the majority of publications which were from the USA, DSM criteria became the preferred classificatory system for GTS research internationally.

### 2.1. DSM-I

In 1951 the American Psychiatric Association (APA) was first established and the following diagnoses relevant to our current knowledge of GTS were included as diagnostic categories (DSM-1 APA, 1952): “echolalia” (326.2), “interjectional speech” (326.2), “habit spasm” (780.4), “spasm nutans” (nodding of the head, 780.4), and “tic” (irregular muscle contraction, 780.4). Interestingly from an historical perspective, other “disorders” in category 780.4 included athetosis, choreoathetosis, combined forms of involuntary movements, dystonic movements, hemiathetosis, hemiballismus, myoclonus and neurotic excoriations, Trichotillomania and other obsessional disorders were included in 313.

### 2.2. DSM-11

In 1968 DSM-11 was published and tic was included under 306.2 (special symptoms not classified elsewhere).

### 2.3. DSM-111

DSM-111 was published in 1980 and with it the “birth” of Tourette’s Disorder (307.23) and the specification of diagnostic criteria and essential features. The diagnostic criteria included (a) age at onset between 2 and 15 years (b) presence of recurrent, involuntary, repetitive, rapid, purposeless motor movements affecting multiple muscle groups (c) multiple vocal tics (d) ability to suppress movements voluntarily for few minutes to hours (e) variations in the intensity of the symptoms over weeks or months (f) duration of more than one year.

It must be noted that the upper age limit at onset was suggested to be 15 years. It was noted that tics typically involve the head and, frequently, other parts of the body, such as the torso and upper and lower limbs. The vocal tics include various sounds such as clicks, grunts, yelps, barks, sniffs, coughs and/or words. Coprolalia, an

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