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European Society for the Study of Tourette Syndrome



Tourette syndrome: myths, misconceptions, and ways forward

Andreas Hartmann

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Tourette Greece, Scientific Advisor



SYNDROME GILLES DE LA TOURETTE

TOURETTE

CENTRE DE RÉFÉRENCE, PARIS

Disclosures

Consultant for:

- Noema Pharma
- Synendos
- SciSparc

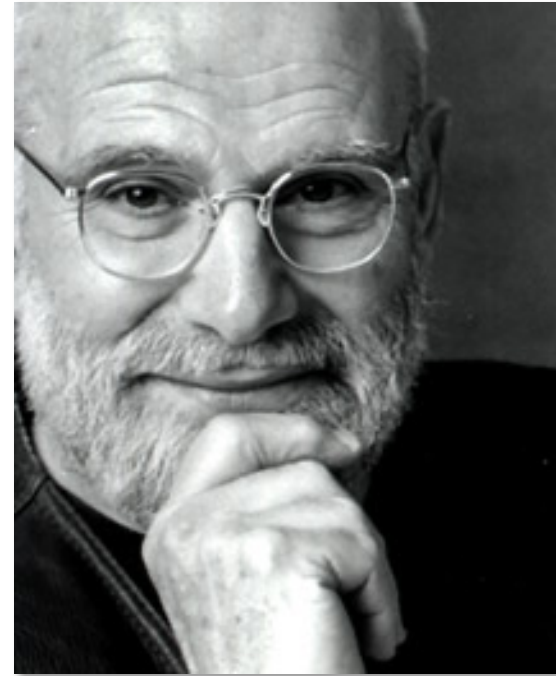


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“This is truly of tremendous importance.

Any understanding of such a syndrome must vastly broaden our understanding of human nature in general...

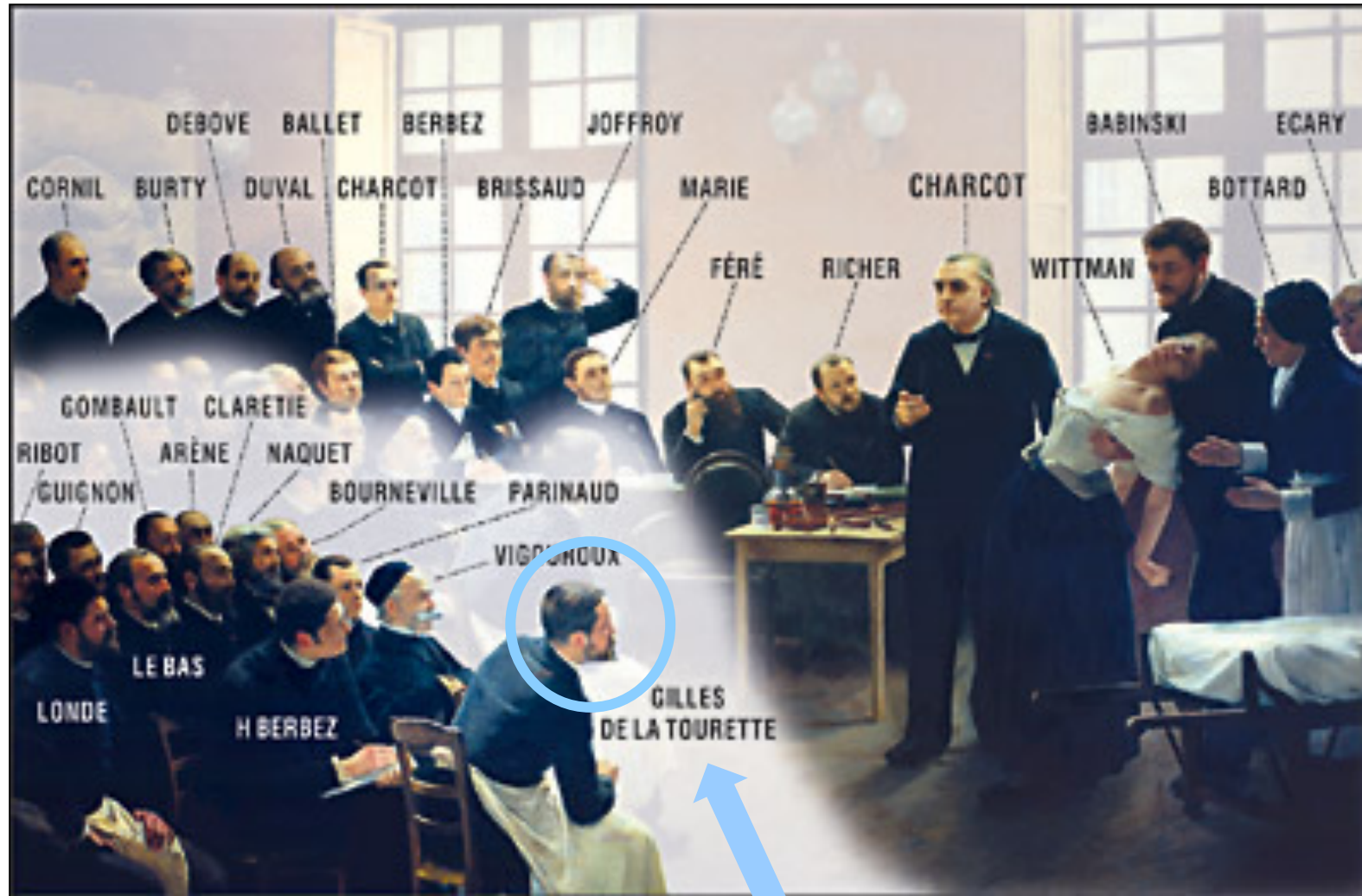
I know of no other syndrome of comparable interest.”



A.R. Luriiia – O. Sacks (1977)



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L. Brouillet, Une Leçon Clinique à la Salpêtrière (1887)

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- Itard (1825), Gilles de la Tourette (1885) et la Marquise de D...
- La 'maladie des tics'



Tics are only passing...

SCIENTIFIC REPORTS

OPEN

Provisional Tic Disorder is not so transient

Soyoung Kim¹, Deanna J. Greene^{1,2}, Emily C. Bihun¹, Jonathan M. Koller¹,
Jacqueline M. Hampton³, Haley Acevedo¹, Angela M. Reiersen¹, Bradley L. Schlaggar^{4,5,6} &
Kevin J. Black^{1,2,3,7}

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Motor and vocal tics are common in childhood. The received wisdom among clinicians is that for most children the tics are temporary, disappearing within a few months. However, that common clinical teaching is based largely on biased and incomplete data. The present study was designed to prospectively assess outcome of children with what the current nomenclature calls Provisional Tic Disorder. We identified 43 children with recent onset tics (mean 3.3 months since tic onset) and re-examined 39 of them on the 12-month anniversary of their first tic. Tic symptoms improved on a group level at the 12-month follow-up, and only two children had more than minimal impairment due to tics. Remarkably, however, tics were present in all children at follow-up, although in several cases tics were apparent only when the child was observed remotely by video. Our results suggest that remission of Provisional Tic Disorder is the exception rather than the rule. We also identified several clinical features present at the first examination that predict one-year outcome; these include baseline tic severity, subsyndromal autism spectrum symptoms, and the presence of an anxiety disorder.

Provisional Tic Disorder 307.21 (F95.0)

- A. Single or multiple motor and/or vocal tics.
- B. The tics have been present for **less than 1 year since first tic onset**.
- C. Onset is before age 18 years.
- D. The disturbance is not attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., Huntington's disease, postviral encephalitis).
- E. Criteria have never been met for Tourette's disorder or persistent (chronic) motor or vocal tic disorder.
- Specifiers:
 - The “motor tics only” or “vocal tics only” specifier is only required for persistent (chronic) motor or vocal tic disorder.

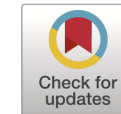
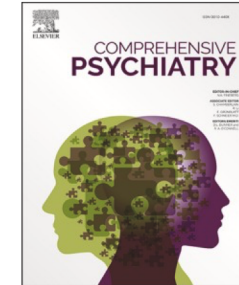




Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Comprehensive Psychiatry

journal homepage: www.elsevier.com/locate/comppsy



We've all been wrong about provisional tic disorder

Sarah C. Gossen^a, Amanda L. Arbuckle^b, Emily C. Bihun^b, Jonathan M. Koller^b,
David Y. Song^a, Angela M. Reiersen^b, Bradley L. Schlaggar^c, Deanna J. Greene^d, Kevin
J. Black^{e,*}

^a Departments of Psychiatry and Neurology, Washington University in St. Louis, St. Louis, MO, United States of America

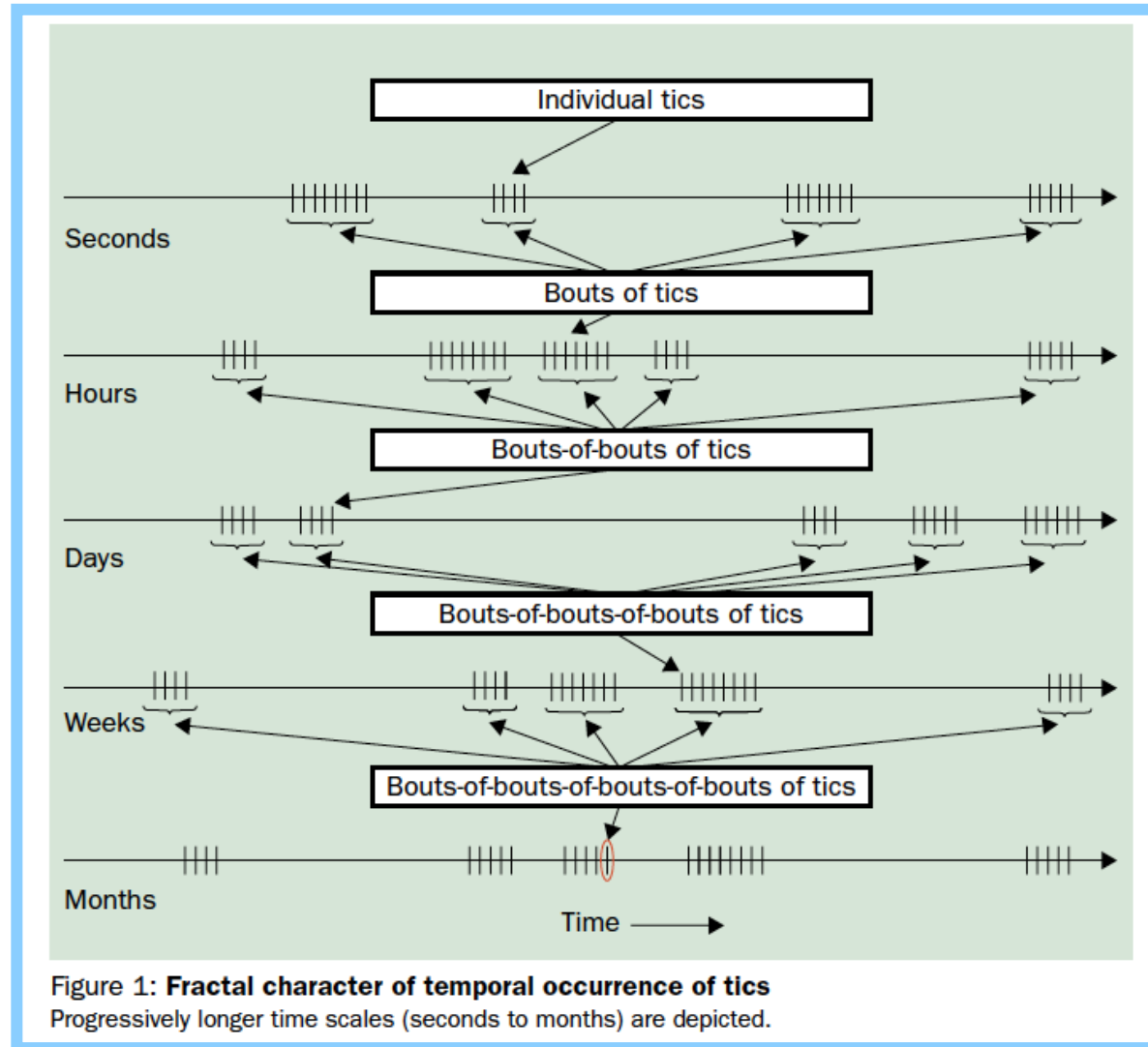
^b Department of Psychiatry, Washington University in St. Louis, St. Louis, MO, United States of America

^c Kennedy Krieger Institute, Baltimore, MD, and Departments of Neurology and Pediatrics, The Johns Hopkins University School of Medicine, Baltimore, MD, United States of America

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Tics are invisible...



Seminar

Tourette's syndrome

James F Leckman

Lancet 2002; 360: 1577–86

Diagnostic delays and auto-diagnosis

Neuropediatrics 2008; 39(2): 101-105

DOI: 10.1055/s-2008-1081457



Original Article

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Limited Knowledge of Tourette Syndrome Causes Delay in Diagnosis

N. M. M. Mol Debes¹, H. Hjalgrim¹, L. Skov¹

¹Pediatric Department, Glostrup University Hospital, Glostrup, Denmark



Diagnostic delays and auto-diagnosis

REVUE NEUROLOGIQUE 181 (2025) 544–555



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Original article

The diagnostic and therapeutic journey of Tourette syndrome: Thematic analysis of the difficulties experienced by parents of patients



Z. Breton ^{a,b,1}, P. Denis ^{c,1}, V. Goussé ^d, A. Hartmann ^{e,*}

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^b Lyv Healthcare, Nantes, France

^c Laboratoire Psychologie Sociale (EA 849), Université d'Aix Marseille, Marseille, France

^d Université de Nîmes, 30021 Nîmes, France

^e Centre de Référence National Maladie Rare: « Syndrome Gilles de la Tourette », Département de Neurologie, DMU Neurosciences, AP-HP, Sorbonne Universités, Groupe Hospitalier Pitié-Salpêtrière, 75651 Paris Cedex 13, France

Somatic conditions

- Ophthalmological (conjunctivitis or dry eye syndrome)
- Otolaryngological (allergy)
- Gastroesophageal reflux
- Stuttering



TS is a benign disease

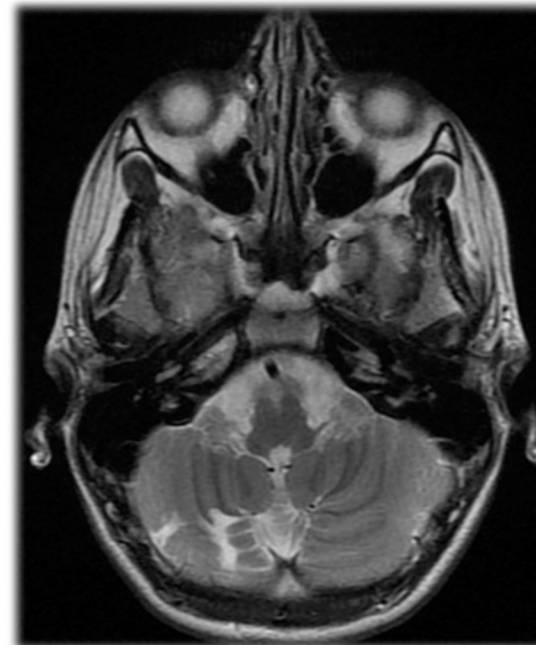
Malignant Tourette Syndrome

Min-Yuen Cynthia Cheung, BS, Joohee Shahed, MD, and Joseph Jankovic, MD*

Parkinson's Disease Center and Movement Disorders Clinic, Department of Neurology, Baylor College of Medicine, Houston, Texas



Movement Disorders
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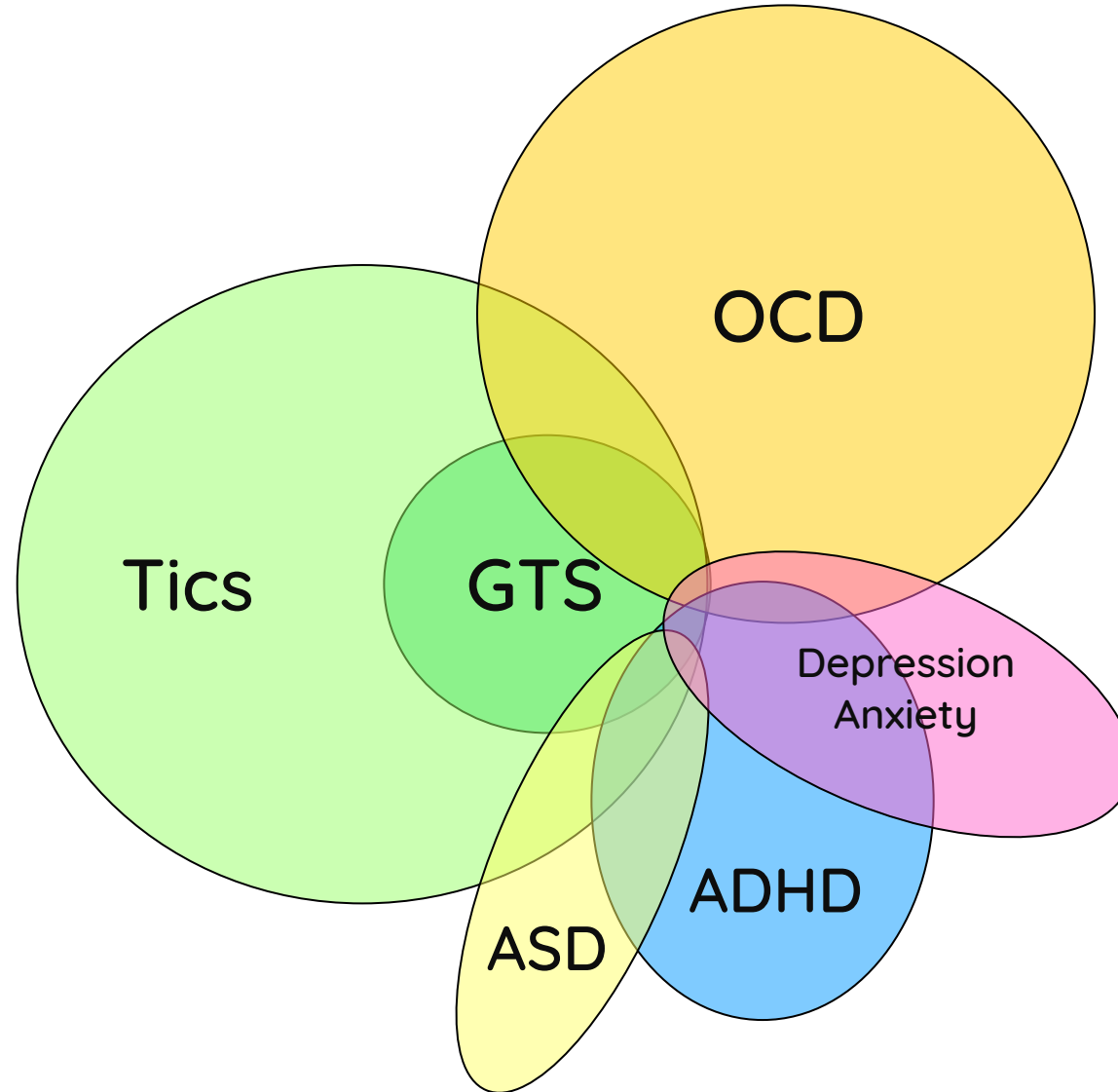


Pain in Tourette Syndrome: A Comprehensive Review

Bryan Green, MD,¹ Allison Waters, PhD,² and Joochi Jimenez-Shahed, MD³



Tics are simple to recognize



Original Investigation

Lifetime Prevalence, Age of Risk, and Genetic Relationships of Comorbid Psychiatric Disorders in Tourette Syndrome

Matthew E. Hirschtritt, MD, MPH; Paul C. Lee, MD, MPH; David L. Pauls, PhD; Yves Dion, MD; Marco A. Grados, MD; Cornelia Illmann, PhD; Robert A. King, MD; Paul Sandor, MD; William M. McMahon, MD; Gholson J. Lyon, MD, PhD; Danielle C. Cath, MD, PhD; Roger Kurlan, MD; Mary M. Robertson, MBChB, MD, DSc(Med), FRCP, FRCPC, FRCPSych; Lisa Osiecki, BA; Jeremiah M. Scharf, MD, PhD; Carol A. Mathews, MD; for the Tourette Syndrome Association International Consortium for Genetics

JAMA Psychiatry. 2015;72(4):325-333. doi:10.1001/jamapsychiatry.2014.2650

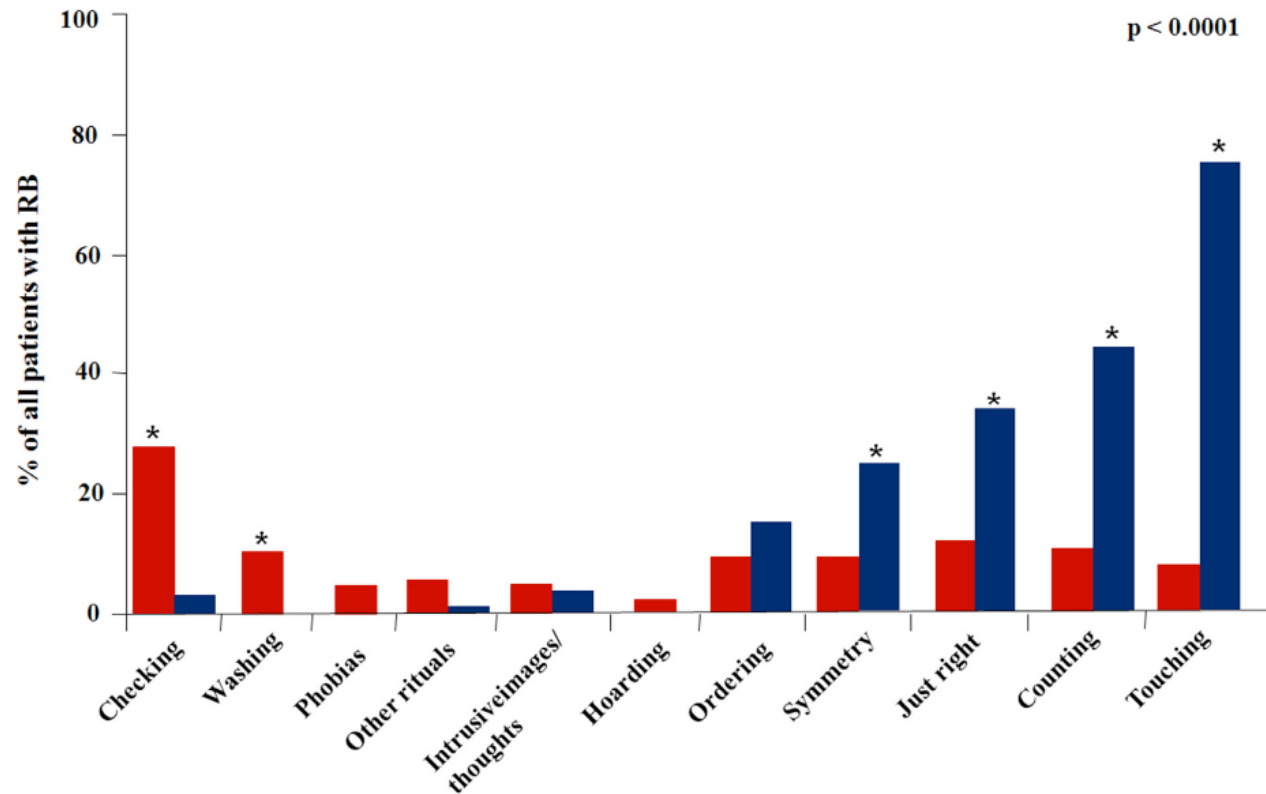
Table 1. Lifetime Prevalence of Psychiatric Disorders by Sex

Comorbid Disorder	No./Total No. With Available Data (%)			P Value ^a
	All TS-Affected Participants	Sex		
		Male	Female	
Obsessive-compulsive spectrum ^b	904/1368 (66.1)	645/1001 (64.4)	259/367 (70.6)	.03
Attention-deficit/hyperactivity	713/1314 (54.3)	564/962 (58.6)	149/352 (42.3)	<.001
Mood ^c	277/930 (29.8)	184/690 (26.7)	93/240 (38.8)	<.001
Anxiety ^d	343/949 (36.1)	225/703 (32.0)	118/246 (48.0)	<.001
Disruptive behavior ^e	185/622 (29.7)	157/493 (31.8)	28/129 (21.7)	.03
Eating ^f	19/937 (2.0)	2/693 (0.3)	17/244 (7.0)	<.001
Psychotic ^g	7/931 (0.8)	5/689 (0.7)	2/242 (0.8)	.88
Substance use ^h	59/948 (6.2)	42/701 (6.0)	17/247 (6.9)	.62
Elimination ⁱ	108/668 (16.2)	90/531 (17.0)	18/137 (13.1)	.28



Semiologic overlap

OPEN ACCESS Freely available online



Repetitive Behaviours in Patients with Gilles de la Tourette Syndrome: Tics, Compulsions, or Both?

Yulia Worbe¹, Luc Mallet¹, Jean-Louis Golmard², Cécile Béhar¹, Franck Durif³, Isabelle Jalenques^{4,5}, Philippe Damier⁶, Pascal Derkinderen⁶, Pierre Pollak⁷, Mathieu Anheim⁷, Emmanuel Broussolle⁸, Jing Xie⁸, Valérie Mesnage⁹, Karl Mondon¹⁰, François Viallet¹¹, Pierre Jedynak¹, Mouna Ben Djebara¹, Michael Schüpbach¹, Antoine Pelissolo¹², Marie Vidailhet¹, Yves Agid¹, Jean-Luc Houeto⁹, Andreas Hartmann^{1*}

Figure 1. Percentage of different types of repetitive behaviours in our GTS patients sample. Red columns: 'OCD-like' RB; blue columns:

'tic-like' RB. * p < 0.0001.

doi:10.1371/journal.pone.0012959.g001

Semiologic overlap

Neurological Sciences (2024) 45:477–483
<https://doi.org/10.1007/s10072-023-07095-y>

REVIEW ARTICLE

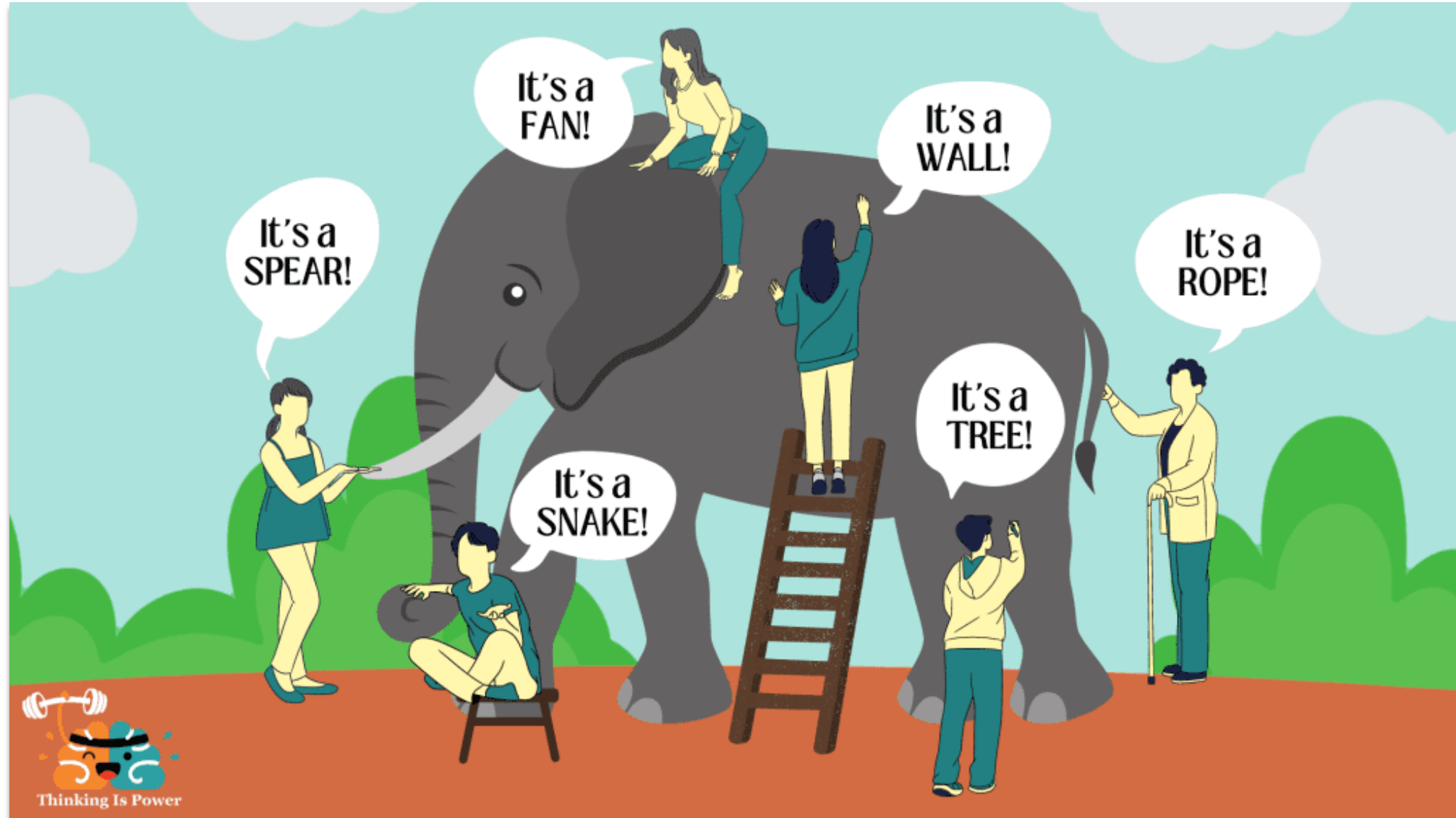
Co-morbid tics and stereotypies: a systematic literature review

Andrea E. Cavanna^{1,2,3,4}  · Giulia Purpura⁴ · Anna Riva^{4,5} · Renata Nacinovich^{4,5}

Received: 18 March 2023 / Accepted: 24 September 2023 / Published online: 29 September 2023
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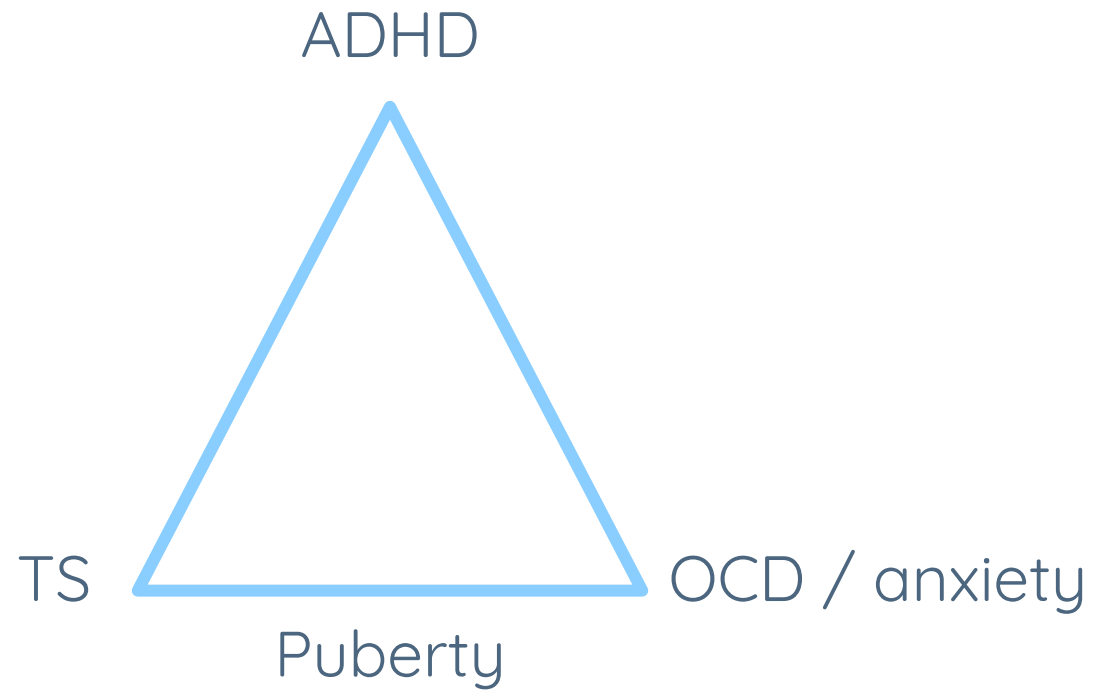


TS explains everything

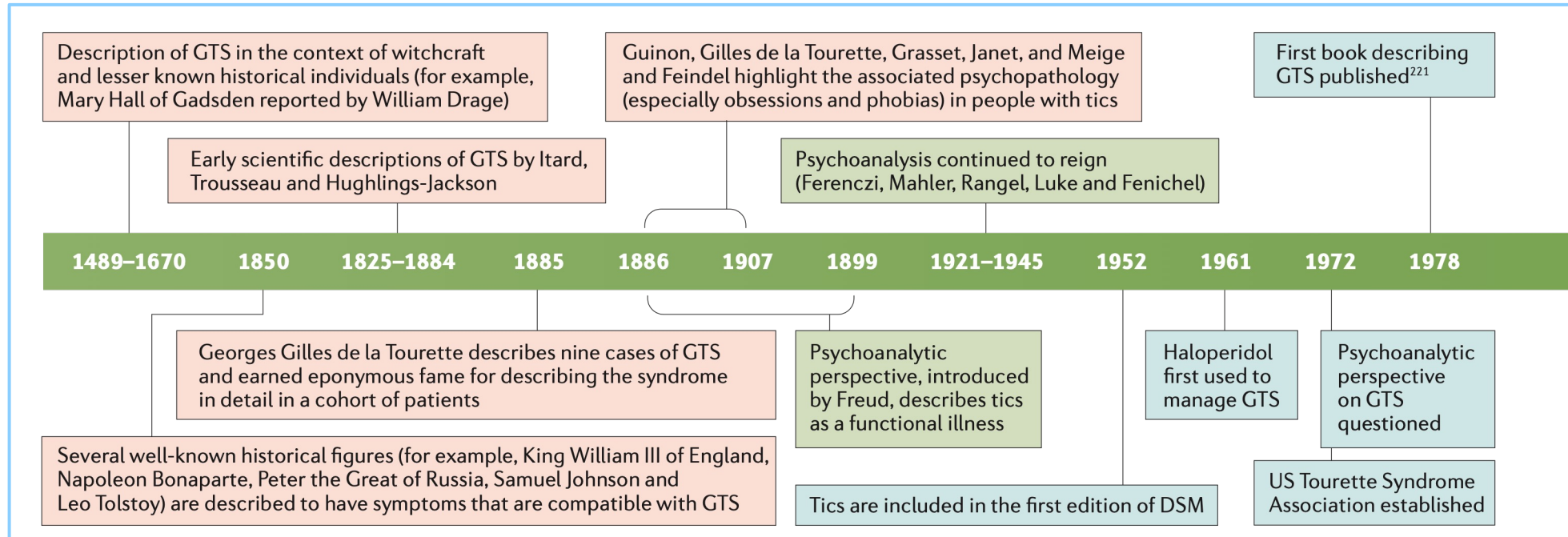


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TS=behavioural problems



Tics are “functional”

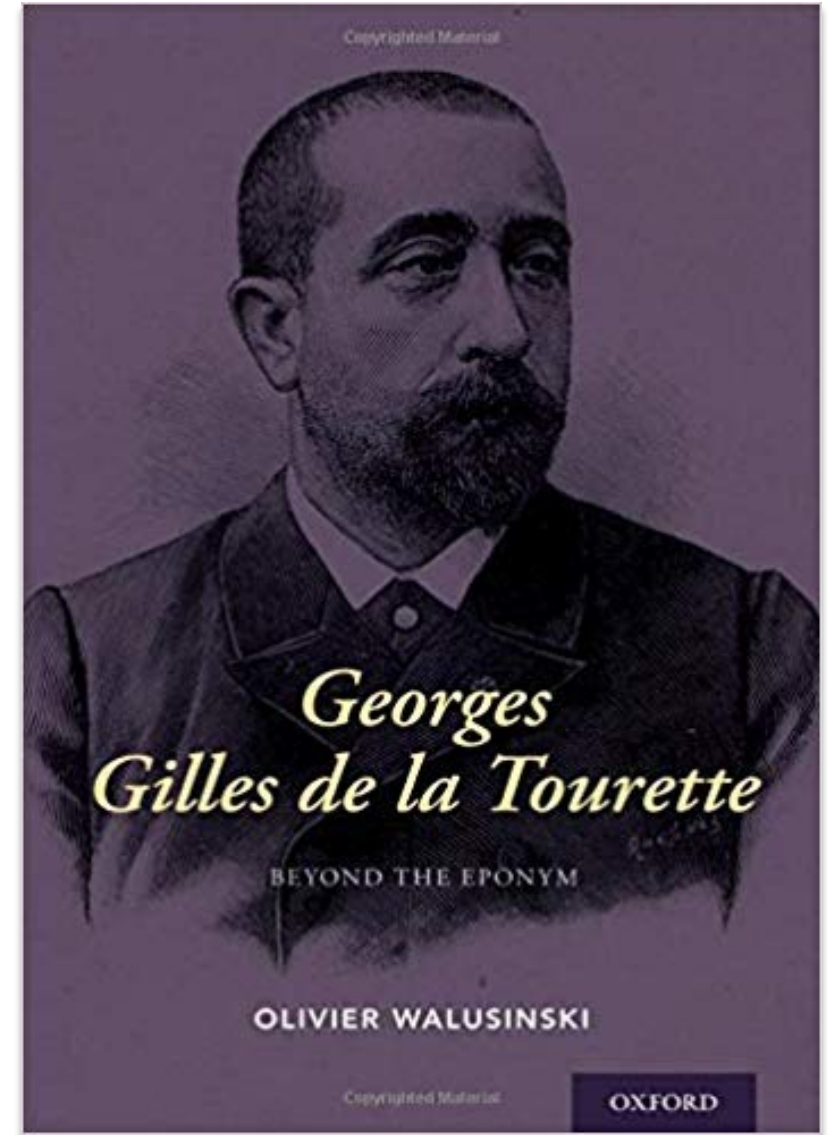
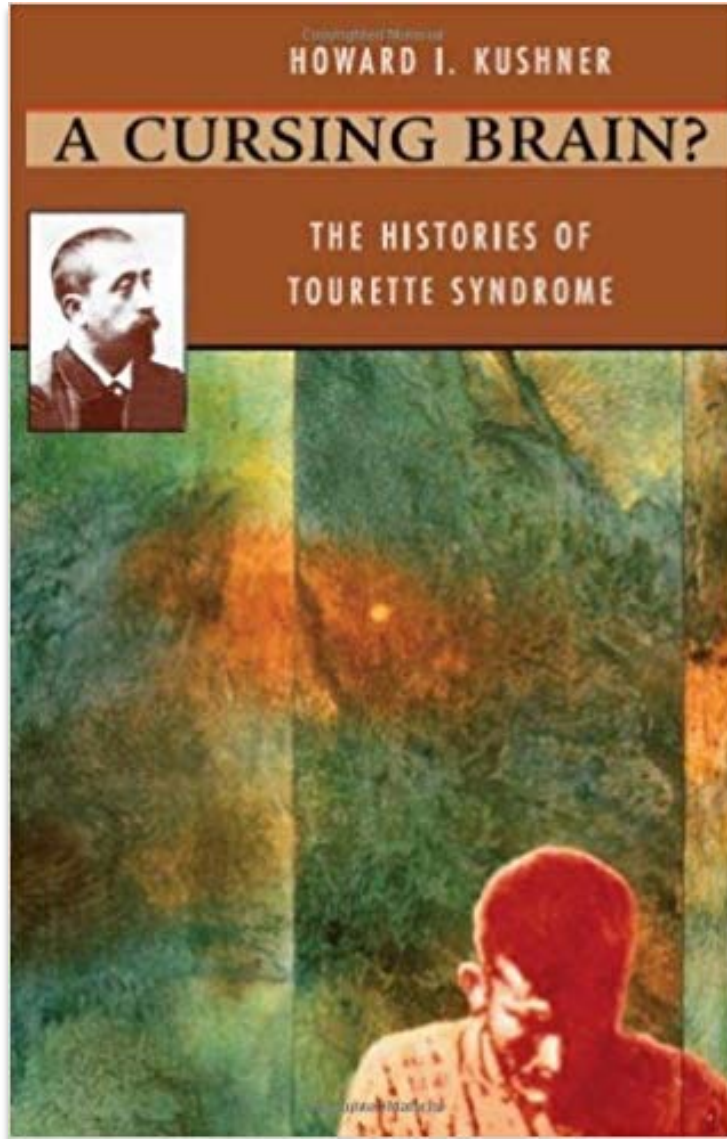


Gilles de la Tourette syndrome

Mary M. Robertson^{1,2}, Valsamma Eapen^{3,4}, Harvey S. Singer⁵, Davide Martino⁶, Jeremiah M. Scharf^{7–9}, Peristera Paschou^{10,11}, Veit Roessner¹², Douglas W. Woods¹³, Marwan Hariz^{14,15}, Carol A. Mathews¹⁶, Rudi Črnčec^{3,4} and James F. Leckman¹⁷



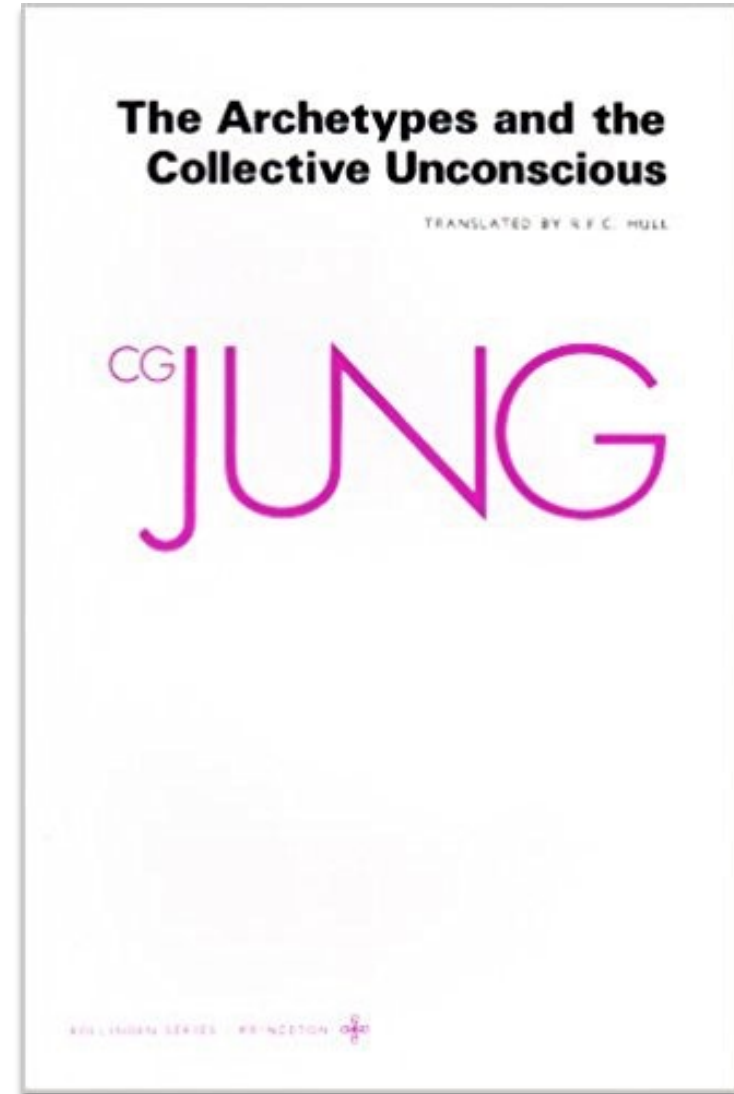
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Causes, triggers and parental guilt

- Psychological / pedagogic
- Organic: stress, divorce, infections, genes...

TS=coprolalia



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Holding Two Valid Truths:

Tourette, the BAFTAs, and the Space Between Pride and Pain,
Where Lived Experience Meets Clinical Science



Maria Shea



Paul Stevenson



Andreas Hartmann



video

A discussion about what Tourette Syndrome is neurologically, what coprolalia is and *is not*, and why tics are not chosen, intentional, or reflective of belief. At the same time, we acknowledge the real impact that certain words can have.



CLINICAL PRACTICE

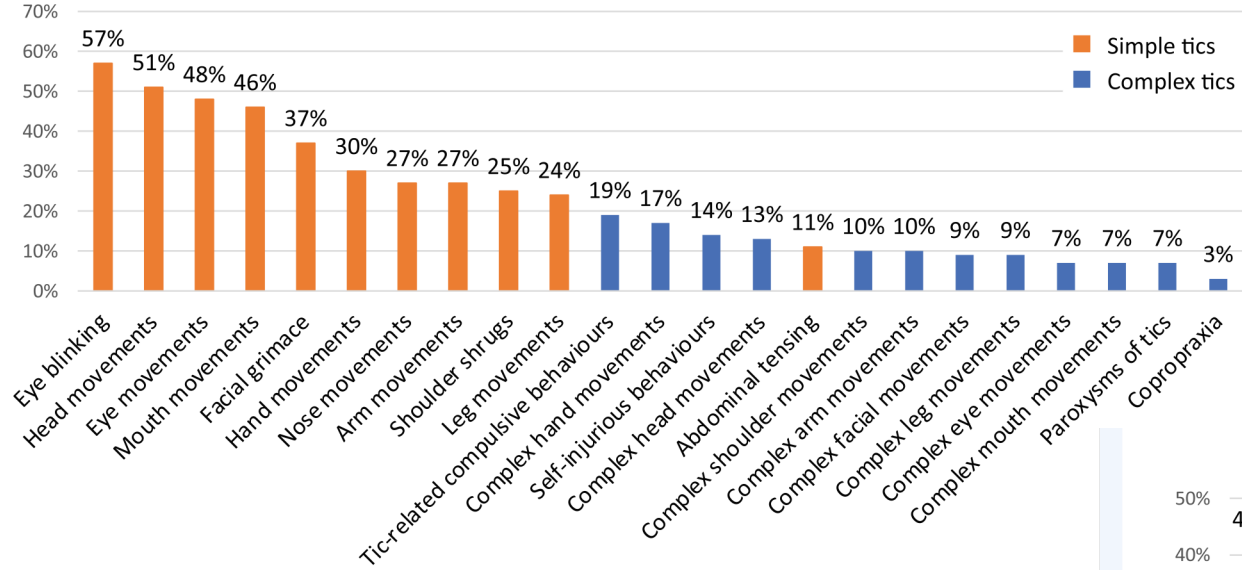
Have We Forgotten What Tics Are? A Re-Exploration of Tic Phenomenology in Youth with Primary Tics

Christelle Nilles, MD,¹  Davide Martino, MD, PhD,^{2,3,4}  Julian Fletcher, BA,² and Tamara Pringsheim, MD^{1,2,3,4,*} 

MOVEMENT DISORDERS CLINICAL PRACTICE 2023; 10(5): 764–773. doi: 10.1002/mdc3.13703



Prevalence of motor tics by type/location



Prevalence of phonic tics by type

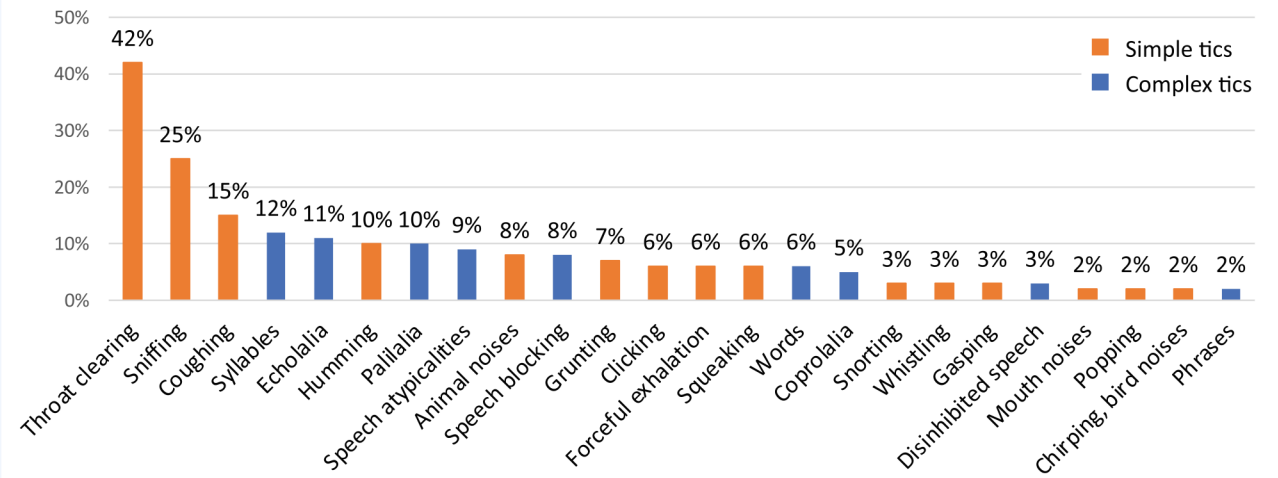


FIG. 1. Prevalences of both simple and complex motor tics and phonic tics in youth with primary tic disorders at first clinical assessment.



Original Article

Public Perception of Tourette Syndrome on YouTube

Mary Jane Lim Fat, BSc¹, Erick Sell, MD^{1,2},
Nick Barrowman, PhD^{1,3}, and Asif Doja, MD^{1,2}

Journal of Child Neurology
27(8) 1011-1016
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DOI: 10.1177/0883073811432294
<http://jcn.sagepub.com>



Abstract

We sought to determine public perception surrounding Tourette syndrome through viewers' responses to videos on YouTube. The top 20 videos on YouTube for search terms *Tourette's*, *Tourette's syndrome*, *Tourette syndrome* and *tics* were selected. The portrayal of Tourette syndrome was assessed as positive, negative, or neutral. Top 10 comments for each video were graded as "sympathetic," "neutral," or "derogatory." A total of 14 970 hits were obtained and 41 videos were retained, with an average of 590 113 views (1369 to 13 747 069) and 1761 comments (0 to 35 241). Twenty-two percent of videos retained portrayed Tourette syndrome negatively, 20% were neutral and 59% positive. Negative portrayals were significantly associated with more views (Spearman correlation $\rho = -.46$, $P = .003$) and comments (Spearman correlation $\rho = -.47$, $P = .002$). Although excellent examples of Tourette syndrome are available on YouTube, the popularity of negative portrayals may reinforce existing stigma in society.

Keywords

Tourette syndrome, tics, social media



Functional tic-like behaviours (FTLB)



Functional tic-like behaviours (FTLBs)



Video 1



Video 2



Received: 26 October 2022

Accepted: 17 December 2022

DOI: 10.1111/ene.15672

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 of neurology
the official journal of the european academy of neurology

ORIGINAL ARTICLE

European Society for the Study of Tourette Syndrome 2022 criteria for clinical diagnosis of functional tic-like behaviours: International consensus from experts in tic disorders

Tamara Pringsheim¹  | Christos Ganos² | Christelle Nilles¹ | Andrea E. Cavanna^{3,4,5} |
 Donald L. Gilbert^{6,7} | Erica Greenberg⁸  | Andreas Hartmann⁹ | Tammy Hedderly¹⁰ |
 Isobel Heyman¹¹ | Holan Liang¹¹ | Irene Malaty¹² | Osman Malik¹³ | Nanette
 Mol Debes^{14,15} | Kirsten Muller Vahl¹⁶ | Alexander Munchau¹⁷ | Tara Murphy¹¹ |
 Peter Nagy¹⁸ | Tamsin Owen¹⁰ | Renata Rizzo¹⁹ | Liselotte Skov²⁰ | Jeremy Stern²¹ |
 Natalia Szejko²²  | Yulia Worbe²³ | Davide Martino¹ 

Download:



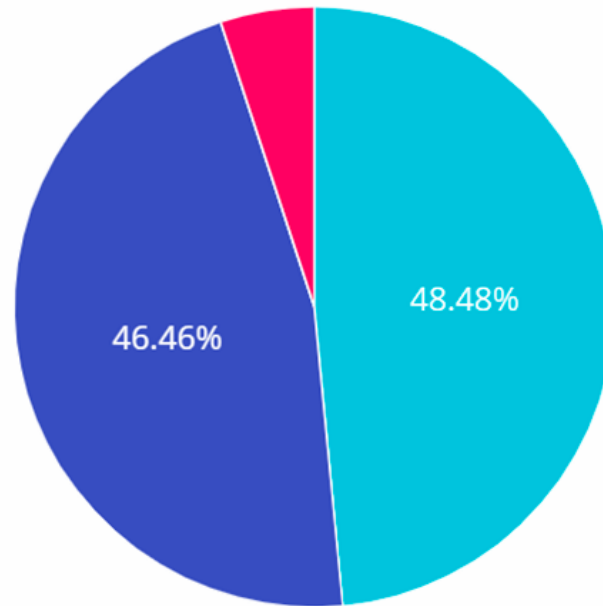
open

To “T” or not to “T”?

Survey: Is it time to rename Tourette ?

Controversy: Pro/con discussion with the audience followed by a poll.

ESSTS Conference, Hannover 2019









● Yes ● No ● It's all the same to me



CLINICAL PRACTICE

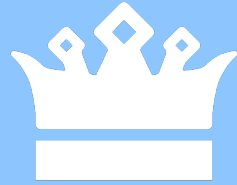
Tic-Talk: Voices on Tourette's Labelling

Giulia Raffaele, BSc,^{1,*}  Osman Malik, MD,² Seonaid Anderson, PhD,³ Lauren Corcoran, BN,⁴ Andreas Hartmann, MD,⁵ Davide Martino, MD, PhD,^{6,7}  Nanette Mol Debes, MD, PhD,^{8,9} Kirsten R. Müller-Vahl, MD,¹⁰  Christelle Nilles, MD,¹¹  Tamara Pringsheim, MD,⁶  Sara Sopena, PGDip, MSc, DClin,⁴  Natalia Szejko, MD, PhD,^{6,10,12} Owen Tasmin, DClinPsy,⁴ Kinga K. Tomczak, MD,¹³ and Tammy Hedderly, MD^{1,4,*}

MOVEMENT DISORDERS CLINICAL PRACTICE 2025. doi: 10.1002/mdc3.70110



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**KEEP
CALM**

**IT'S ONLY TOURETTE
IT'S NOT CONTAGIOUS
YOUR IGNORANCE IS**

TOURETTE



Thank you for your attention!

andreas.hartmann@aphp.fr

