

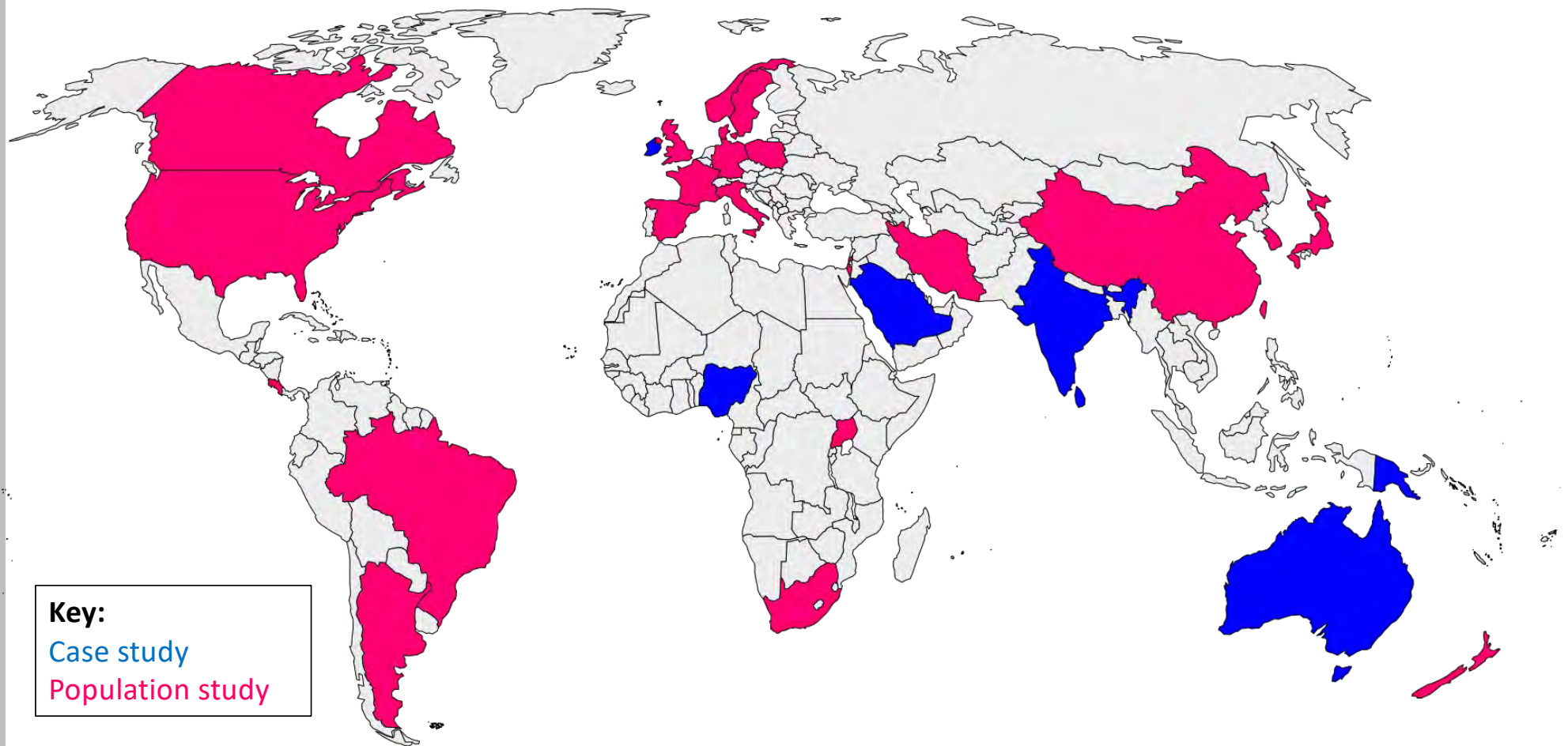
Ticking the wrong box

a global look at why we don't
know what works in tic
education and how we can
find out

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Tics

Tics are evenly distributed (in places we have looked)



Tics are similar

- Similar age of onset, tic severity, prevalence of co-occurring conditions, gender distribution
- Need to consider health seeking behaviours, sample selection methods, instruments used etc (Robertson et al, 2009)

Tourette's syndrome is seen in every race, every culture, every stratum of society –
Oliver Sacks

Impact

Impact differs by country

What is impact?

How tics effect:
Daily Function
Quality of Life



ORIGINAL ARTICLE
Tic Disorders Associated With Lower Child and Parent Quality of Life and worse Family Functioning
Jennifer Vermilion, MD, Erika Augustine, MD, MS, Heather R. Adams, PhD, Edwin van Wijngaarden, PhD, Tanya K. Murphy, Correspondence information about the author Erika Augustine, MD, MS
Published: December 26, 2019 DOI: <https://doi.org/10.1016/j.pediatrneurol.2019.12.003>



Calidad de vida y comorbilidades psiquiátricas en pacientes pediátricos con síndrome de Gilles de la Tourette

G. Solís-García, A. Jové-Blanco, A. Chacón-Pascual, M. Vázquez-López, P. Castro-De Castro, J.J. Carballo, L. Pina-Camacho, M.C. Miranda-Herrero

Association of Chronic Tic Disorder With Violent Assault and Criminal Convictions

David Mataix-Cols, PhD, Suvi Virtanen, PhD, [...], and

> BMC Psychiatry. 2016 Jan 20;16:14. doi: 10.1186/s12888-016-0717-9.

Difficulties experienced by young people with Tourette syndrome in secondary school: a mixed methods description of self, parent and staff perspectives

Ruth Wadman¹, Cris Glazebrook², Charlotte Beer³, Georgina M Jackson⁴

European Child & Adolescent Psychiatry

The effects of Gilles de la Tourette syndrome and other chronic tic disorders on quality of life across the lifespan: a systematic review

Joel Evans, Stefano Seri, and Andrea E. Cavanna

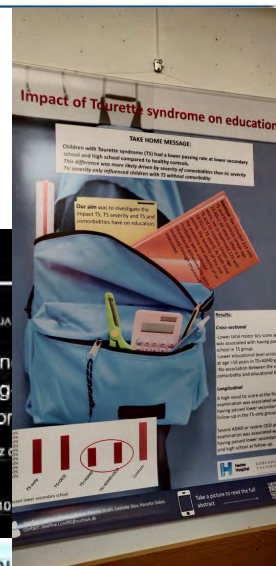
Movement Disorders

CLINICAL PRACTICE

RESEARCH ARTICLE

Driving with Tic Disorders: An International Survey of Lived Experiences

Lorena Fernández de la Cruz, PhD,¹ Helene Ringberg, MSc,² Seonaid Anderson, PhD,³ Jeremy S. Stern, FRCP,^{4,5} and David Mataix-Cols, PhD^{1,6}



JAMA Neurology













American Medical Association

Association of Tourette Syndrome and Chronic Tic Disorders With Objective Indicators of Educational Attainment

A Population-Based Sibling Comparison Study

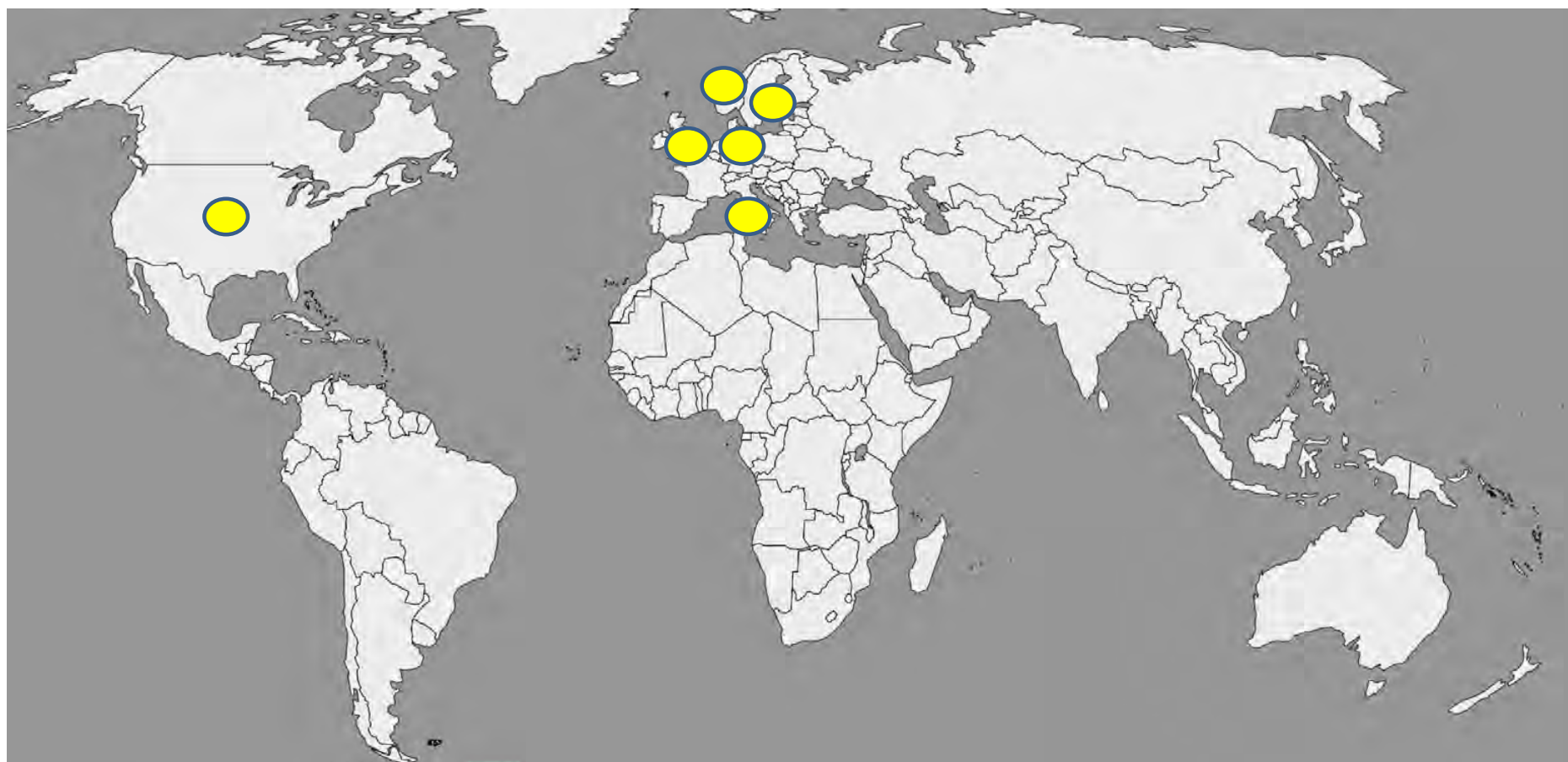
Ana Pérez-Vigil, MD, Lorena Fernández de la Cruz, PhD, [...], and David Mataix-Cols, PhD

Tic Severity Differs by Country

Authors	N	Adult / Child	Highest rating at Baseline TTSS	
Wilhelm et al, 2003	32	Adult	30.5	
Verdellen et al, 2004	43	Adult & Child	26.1	
Deckersbach et al, 2006	30	Adult	29.3	
Piacentini et al, 2010	126	Child	24.7	
Wilhelm et al, 2012	122	Adult	24.0	
Yates et al, 2016	33	Child	29.0	
Rizzo et al, 2018	110	Child	24.1	
Nissen et al, 2018	59	Child	23.8	
Andren et al 2021	74	Child	23.4	
Zimmerman-Brenner et al, 2020	46	Child	24.8	
Rachamim et al 2020	41	Child	22.7	
Hollis et al, 2021	224	Child	28.4	

Impact / differs

...but restricted to a few High-Income countries



Tic Severity Differs by Country

Primary Care Companion to The Journal
of Clinical Psychiatry

Physicians Postgraduate Press, Inc.

Clinical Correlates of Tourette's Disorder Across Cultures: A Comparative Study Between the United Arab Emirates and the United Kingdom

Valsamma Eapen, Ph.D., F.R.C.Psych., F.R.A.N.Z.C.P. and

Mary M. Robertson, M.D., D.Sc., F.R.C.P. (U.K.),

F.R.C.P.C.H., F.R.C.Psych.

Compared 35 patients in UK & United Arab Emirates

- Rates of OCD, ODD, CD & ADHD were similar
- Severity / Copro were higher in the UK (specialist clinic)

Reaction varies by country



(Stiede et al, 2021)

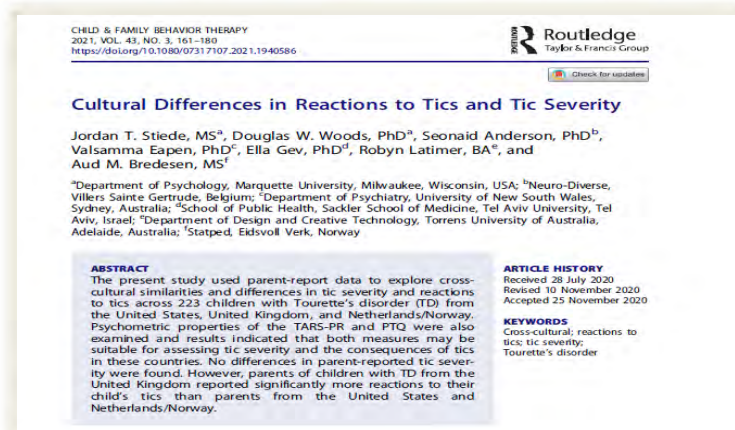
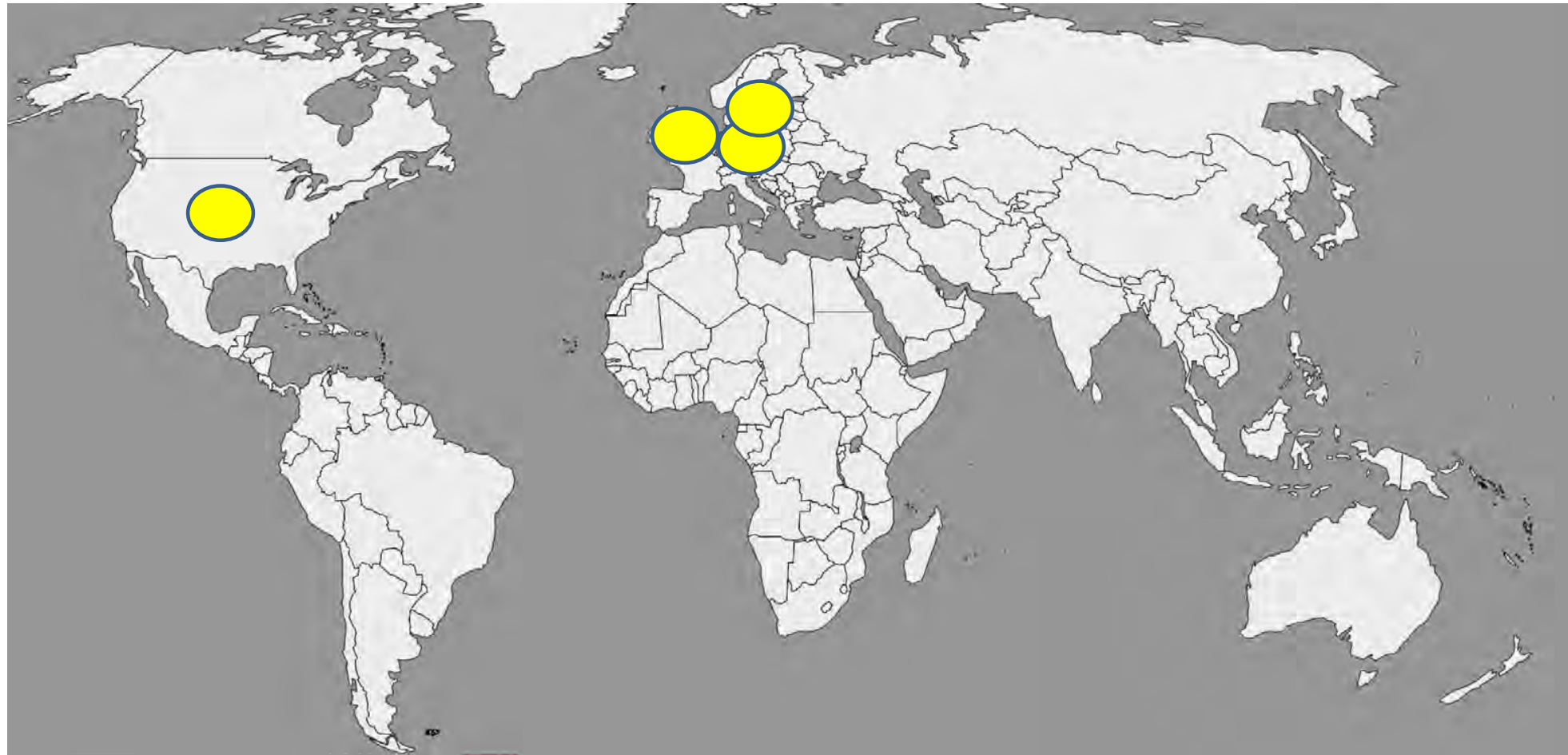


Table 3. TARS-PR sample items.

TARS-PR subscale	Sample items
School	He/she cannot fully complete schoolwork He/she cannot participate fully in a fun school activity He/she has to leave school for the day
Home	He/she has to stop playing a videogame or watching TV He/she is left out of family activities
Other	A parent tells him/her to stop ticcing An adult other than a relative tells him/her to stop ticcing He/she has to stop playing a sport or outdoor game He/she is asked to leave a public place
Attention	A parent verbally comforts him/her Another kid asks if he/she is ok
Aversive	An adult asks him/her questions about tics Another kid teases him/her An adult laughs at him/her
Escape	He/she is left out of family activities A parent or sibling completes a chore or task for him/her He/she does not go to school at all for the day He/she does not complete homework

- Parent online reports N=223
- 25 countries (UK, US, Netherlands & Norway)
- No difference in severity of tics
- Stronger (negative) reactions in UK parents = stigma?

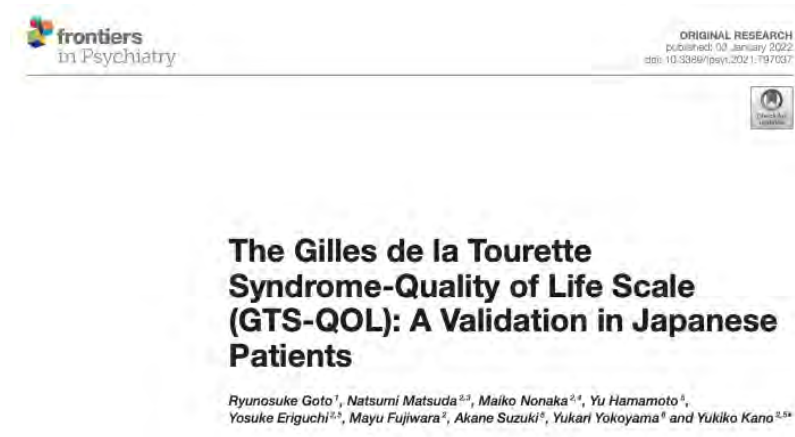
...but that study was restricted to a few HI countries



QoL varies by country

Japanese (N=102) vs UK data
(Goto et al, 2022) (TTSS 20.4
vs 26.8)

GTS – QoL scores poorer in
Japan



Impact varies by country

N= 85 Costa Rican cohort
similar tic severity but
reported low impact



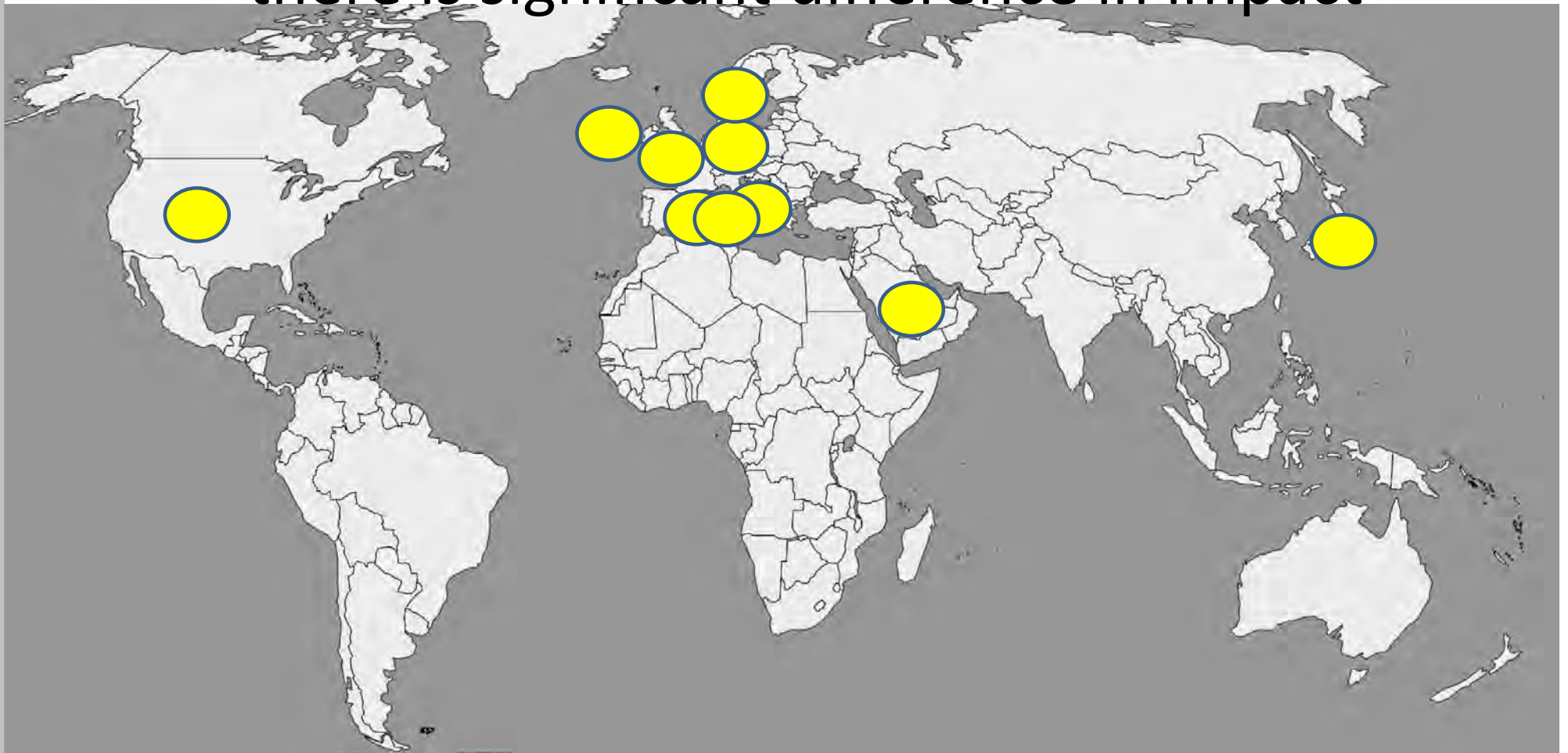
Articles

Cultural Influences on Diagnosis and Perception of Tourette Syndrome in Costa Rica

CAROL A. MATHEWS M.D.,[✉] LUIS DIEGO HERRERA AMIGHETTI M.D.,
THOMAS L. LOWE M.D., BEN J.M. VAN DE WETERING M.D., PH.D., NELSON
B. FREIMER M.D., VICTOR J. REUS M.D.

Even in our small sample of countries,
there is significant difference in impact

Impact / differs



Do very different countries have
very different tic impacts?

There are no studies of tic impact in Low income countries

Impact is enough to make a patient organisation

Even though there are no studies, there are case studies that show tics do have impact (we just don't know how much)

Received: 5 April 2019 | Revised: 5 November 2019 | Accepted: 19 November 2019
DOI: 10.1111/jan.14279

ORIGINAL RESEARCH: CLINICAL TRIAL



Effectiveness of a modified comprehensive behavioral intervention for tics for children and adolescents with tourette's syndrome: A randomized controlled trial

Chia-Wen Chen Doctoral Student¹ | Huei-Shyong Wang MD, Medical Doctor² |
Hsiu-Ju Chang PhD, Professor¹ | Chang-Wei Hsueh MD, Division of Pediatrics, Director³

Behavior Therapy for the Treatment of Tourette's Disorder in India: A Patient Series from an Indian General Hospital Psychiatric Unit

Natarajan Varadharajan, Subho Chakrabarti, [...],
and Srinivas Balachander

[Additional article information](#)



ACTA SCIENTIFIC PAEDIATRICALS (ISSN: 2581-883X)

Volume 4 Issue 2 February 2021

Case Report

Gilles de la Tourette Syndrome - A Severe Case in an 8 Year-Old Nigerian Male

Dr Christian Chukwukere Ogoke^{1*} and Dr Emeka Charles Nwolisa²

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²Department of Paediatrics, Federal Medical Centre, P.M.B 1010, Owerri, Nigeria.

***Corresponding Author:** Christian Chukwukere Ogoke, Paediatric Neurology Unit, Department of Paediatrics, King Fahad Central Hospital, Abu Arish, Jazan, Saudi Arabia.

Received: August 08, 2020

Published: January 22, 2021

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Professional understanding?

Uganda

(Rodin et al, 2021)



Assessed knowledge in 162 health professionals, 6 interviews:

- Majority good awareness of diagnostic criteria and co-occurring conditions
- Minority had diagnosed / treated a patient with TS
- 52% had misdiagnosed a patient with tics
- Treatment: drugs and cognitive behavioural therapy / family therapy
- 30% were confident in diagnosis

Themes: challenges faced by professionals, cultural factors in help seeking behaviours and limited capacity in clinical care

Saudi Arabia

(Alalwan et al, 2022)



Assessed medical knowledge in 375 GPs and medical students:

- 66% describe diagnostic criteria; knowledge about co-occurring condition
- Minority had diagnosed / treated a patient with TS
- Limited experience of treating tics
- Treatment: 46% considered anticonvulsants and antipsychotics; 25% had heard of HRT and 15% understood the principles
- Appetite to learn more

Proxy: Global Google searches for 'Tourettes'

Searches - June 8 2021- June 8 2022



Variation exists even though the web is universal

Global impact: the pandemic shows that when a society becomes different, it has a large impact on tics

Journal of Paediatrics and
Child Health

doi:10.1111/jpc.15932

ORIGINAL ARTICLE

Rapid onset functional tic-like behaviours in children and adolescents during COVID-19: Clinical features, assessment and biopsychosocial treatment approach

Velda X Han^{1,2}, Kasia Kozłowska^{3,4,5}, Kavitha Kothur,¹ Michelle Lorentzos,¹ Wui Kwan Wong^{6,1}, Shekeeb S Mohammad^{1,4}, Blanche Savage,³ Catherine Chudleigh⁷ and Russell C Dale^{1,4,6}

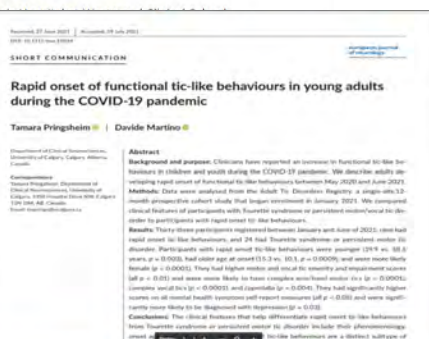
¹Kids Neuroscience Centre, The Children's Hospital at Westmead, Faculty of Medicine and Health, ²The Children's Hospital at Westmead, ³Westmead Child Health Research Centre, ⁴Westmead Child Health Research Centre, ⁵Westmead Child Health Research Centre, ⁶Westmead Child Health Research Centre, ⁷Westmead Child Health Research Centre



RESEARCH ARTICLE

TikTok Tics: A Pandemic Within a Pandemic

Caroline Olvera MD, Glenn T. Stebbins PhD, Christopher G. Goetz MD, Katie Kompolti MD



Viewpoint

COVID-19 related increase in childhood tics and tic-like attacks

Isobel Heyman¹, Holan Liang,¹ Tammy Hedderly²

EXPLOSION OF TICS

Since the onset of the COVID-19 pandemic, paediatricians and child mental health practitioners have noticed an increase in tic symptoms in some children and adolescents already diagnosed with tic disorders.¹ Interestingly, clinicians have also seen a marked increase in new-onset

disorder (ADHD). Distinguishing these two subtypes can be challenging; however, the likelihood is that in either case the precipitating factor for symptomatology and impairment is anxiety (probably in part COVID-19 related), and importantly, the same management strategies are suggested for both of these groups.

has at least a partial component of functional neurological disorder that have been identified as functional tics and tic-like attacks.²⁻³ Neurological examination reveals no focal abnormalities, and investigation is unremarkable, as is the case in Tourette syndrome. The adolescents present acutely, and they and their families are invariably distressed and frightened, may have presented to emergency services and sought multiple opinions about the new symptoms. It is hypothesised that this unusual presentation is related to lockdown, change in usual structure and routine, social media related events/bullying and pandemic-related stress in vulnerable adolescents. Some



CASE SERIES

Tics and TikTok: Functional Tics Spread Through Social Media

Mariam Hull MD, Mered Parnes MD

First published: 17 June 2021 | <https://doi.org/10.1002/mdc3.13267> | Citations: 4

My experience is that different countries do have different impact from tics



Uganda

Butabika National
Referral Hospital

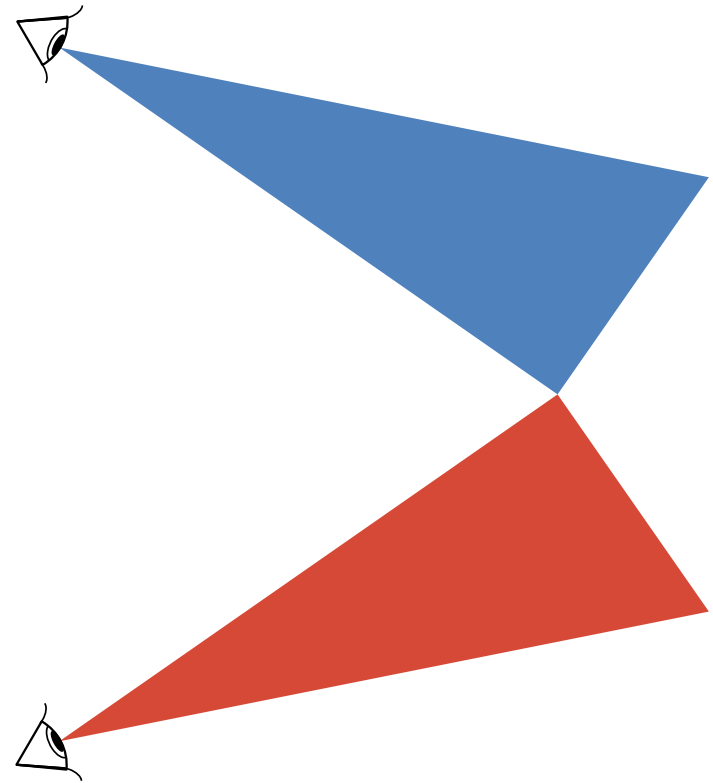
Why does impact differ?

Other hypotheses why tics may have less impact

- More exercise (Reilly et al, 2018; Kim et al, 2018; Pringsheim et al, 2021)
- More sunshine (vitamin D – Bond et al, 2021 – not supportive for reduced tics)
- Less emphasis on disability / normalcy (Malli, 2016; 2017)
- Healthier diet (Ludlow & Rogers, 2018)
- Bigger concerns / threats in health
- Reinforcers differ / are fewer (Eaton et al, 2017)
- Focus on function

Is impact genuinely lower in some Low and Medium countries?

- From outside perspective, it's easy to see what LMI countries could improve
- From an inside perspective, why do tics seem to have a low impact? What could we learn?



What we do currently

Practice Guideline > Eur Child Adolesc Psychiatry. 2022 Mar;31(3):403-423.
doi: 10.1007/s00787-021-01845-z. Epub 2021 Jul 27.

European clinical guidelines for Tourette syndrome and other tic disorders-version 2.0. Part II: psychological interventions

Per Andrén ¹, Evgeni Jakubovski ², Tara L Murphy ³, Katrin Woitecki ⁴, Zsanett Tarnok ⁵, Sharon Zimmerman-Brenner ⁶, Jolande van de Griendt ⁷, Nanette Mol Debes ⁸, Paula Viefhaus ⁴, Sally Robinson ⁹, Veit Roessner ¹⁰, Christos Ganos ¹¹, Natalia Szejko ¹² ¹³ ¹⁴, Kirsten R Müller-Vahl ², Danielle Cath ¹⁵, Andreas Hartmann ¹⁶, Cara Verdellen ¹⁷

Affiliations + expand

PMID: 34313861 PMCID: PMC8314030 DOI: 10.1007/s00787-021-01845-z

Review > Eur Child Adolesc Psychiatry. 2022 Mar;31(3):425-441.
doi: 10.1007/s00787-021-01899-z. Epub 2021 Nov 10.

European clinical guidelines for Tourette syndrome and other tic disorders-version 2.0. Part III: pharmacological treatment

Veit Roessner ¹, Heike Eichele ² ³, Jeremy S Stern ⁴, Liselotte Skov ⁵, Renata Rizzo ⁶, Nanette Mol Debes ⁵, Péter Nagy ⁷, Andrea E Cavanna ⁸, Cristiano Termine ⁹, Christos Ganos ¹⁰, Alexander Münchau ¹¹, Natalia Szejko ¹² ¹³ ¹⁴, Danielle Cath ¹⁵, Kirsten R Müller-Vahl ¹⁶, Cara Verdellen ¹⁷ ¹⁸, Andreas Hartmann ¹⁹ ²⁰, Aribert Rothenberger ², Pieter J Hoekstra ²², Kerstin J Plessen ²³ ²⁴

European clinical guidelines for Tourette syndrome and other tic disorders-version 2.0. Part IV: deep brain stimulation

Natalia Szejko ¹ ² ³, Yulia Worbe ⁴ ⁵, Andreas Hartmann ⁶, Veerle Visser-Vandewalle ⁷, Linda Ackermans ⁸, Christos Ganos ⁹, Mauro Porta ¹⁰, Albert F G Leentjens ¹¹, Jan-Hinnerk Mehrkens ¹², Daniel Huys ¹³, Juan Carlos Baldermann ¹³, Jens Kuhn ¹³ ¹⁴, Carine Karachi ⁵ ⁶ ¹⁵, Cécile Delorme ⁶, Thomas Foltynie ¹⁶, Andrea E Cavanna ¹⁷, Danielle Cath ¹⁸ ¹⁹, Kirsten Müller-Vahl ²⁰

Affiliations + expand

PMID: 34605960 PMCID: PMC8940783 DOI: 10.1007/s00787-021-01881-9

Psychoeducation

(Wu & McGuire, 2018)

Causes of tics

Clinical course of tic disorders

Factors that influence tic expression

Common problems with tics

Psychoeducation about interventions

The Neurobehavioral Model

Myths and misconceptions

School, workplace, extended system.....

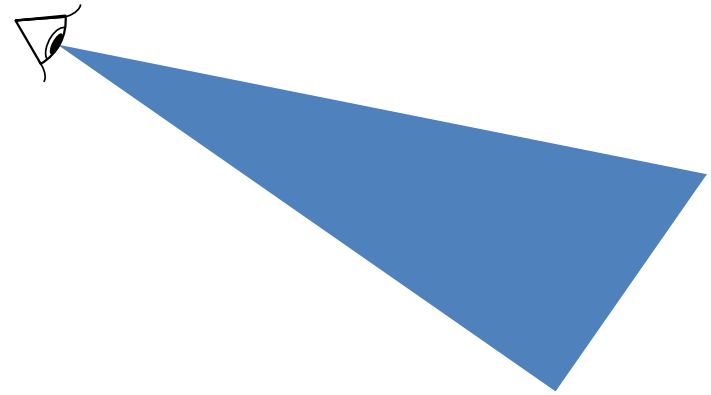
**How to create
environments where tic
impact is low?**

What can *they* do?

Factors discovered

Enhance understanding in society
and skill up professionals

Evidence-based interventions seem
to benefit beyond context
developed



What could *we* do?

What can we learn from places where tic impact seems low?

- Change societal viewpoint - if society doesn't see tics as a problem, the individual may not either
- If people ignore the tics, they seem to have less impact on the individual's life
- Create supportive communities (Perkins et al, 2020)
- Emphasise strengths & function



Are we starting to do things differently?

Letting Tourette's be?

Jo Bervoets*(1), Diana Beljaars (2), Hanne De Jaegher (3,4,5)

* Corresponding author: joberv@gmail.com

- (1) NeuroEpigenEthics project, Philosophy Department, University of Antwerp
- (2) Department of Geography, Swansea University
- (3) IAS-Research Centre for Life, Mind, and Society, University of Basque Country
- (4) Department of Psychology, University of Sussex
- (5) Peter Wall Institute for Advanced Studies, University of British Columbia

Abstract:

Tourette Syndrome is almost exclusively seen through the lens of disruptive tics. The most relevant clinical question seems to be: how to combat tics? In line with emerging calls from those diagnosed, we argue for a more positive approach focused on the Tourettic person, rather than on disruptions flowing from tics. This change of focus is ethically motivated but has important theoretical implications. As an exercise in 'letting be' (i.e. of finding out what something is on its own terms, through sensitively interacting with it), it brings out the basic relationalities of Tourette's with both the non-human and the social environment. Echoing Tourettic lived experience, disruptive tics then emerge as the tips of icebergs consisting of spontaneous, even playful, interactions with the environment. A more nuanced view emerges in which problems experienced by those diagnosed are no longer located in individual brains but require comprehensive study of how tics situationally develop. Listening attentively to lived experience reports leads to a dramatic shift away from the classical 'lack of inhibition' model, to reveal a constant pressure to inhibit actions that one feels strongly and spontaneously compelled to do. This inhibition is dependent on what is signaled as disruptive by others and is therefore suppressed for their sake. The Tourettic person's distress or felt impairment seems more tied to an onlooker's focus on their tics, than on the severity and frequency of their tics. We conclude that 'letting be' is an attitude towards Tourette's that is worth considering, both clinically and theoretically. In fact, we believe that the overall good prognosis as to felt impairment correlates with finding trusted environments where one is 'let be' (without being 'let go of') instead of living under constant scrutiny.



Health & fitness Women Men Love & sex Beauty Home & garden Money Cars

'I had to tape my fingers together to stop me tearing the skin': the reality of living with Tourette syndrome



- Much of modern medicine comes from traditional remedies
- **Maybe we can learn from societies that seem to have lower impact from tics**
- **Collaboration**

Thank you for listening

Comments, queries, questions