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

Tara Murphy
Consultant clinical psychologist
Great Ormond Street Hospital for Children
London, England
Tara.Murphy@ucl.ac.uk
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

Impact / differs
## Tic Severity Differs by Country

<table>
<thead>
<tr>
<th>Authors</th>
<th>N</th>
<th>Adult / Child</th>
<th>Highest rating at Baseline TTSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wilhelm et al, 2003</td>
<td>32</td>
<td>Adult</td>
<td>30.5</td>
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<tr>
<td>Verdellen et al, 2004</td>
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<td>Adult &amp; Child</td>
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<tr>
<td>Deckersbach et al, 2006</td>
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<td>Adult</td>
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<tr>
<td>Piacentini et al, 2010</td>
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<td>Child</td>
<td>24.7</td>
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<tr>
<td>Wilhelm et al, 2012</td>
<td>122</td>
<td>Adult</td>
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<tr>
<td>Yates et al, 2016</td>
<td>33</td>
<td>Child</td>
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<tr>
<td>Rizzo et al, 2018</td>
<td>110</td>
<td>Child</td>
<td>24.1</td>
</tr>
<tr>
<td>Nissen et al, 2018</td>
<td>59</td>
<td>Child</td>
<td>23.8</td>
</tr>
<tr>
<td>Andren et al 2021</td>
<td>74</td>
<td>Child</td>
<td>23.4</td>
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<tr>
<td>Zimmerman-Brenner et al, 2020</td>
<td>46</td>
<td>Child</td>
<td>24.8</td>
</tr>
<tr>
<td>Rachamim et al 2020</td>
<td>41</td>
<td>Child</td>
<td>22.7</td>
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<tr>
<td>Hollis et al, 2021</td>
<td>224</td>
<td>Child</td>
<td>28.4</td>
</tr>
</tbody>
</table>
...but restricted to a few High-Income countries
Tic Severity Differs by Country

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)
Reactions vary by country

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

(Stiede et al, 2021)
...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
Even in our small sample of countries, there is significant difference in impact.
<table>
<thead>
<tr>
<th>Impact / very different</th>
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</table>

Do very different countries have very different tic impacts?
There are no studies of tic impact in Low income countries
Proxy:
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)
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.
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?
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.
• 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