



**Should we still use the YGTSS, or GTS/tic-QOL scales to measure tic severity and the impact of tics on day-to-day life ?**

**Arguing pro traditional assessment**

DAVIDE MARTINO



# The AV Gestalt of tics

“Tics could operationally be defined as extra movements (EM) or extra vocalizations (EV), i.e., spontaneously occurring non-goal-directed movements (or sounds) in a context where movements (or sounds) are not required or should not occur”.

[Bartha et al., Ann Neurol 2023]

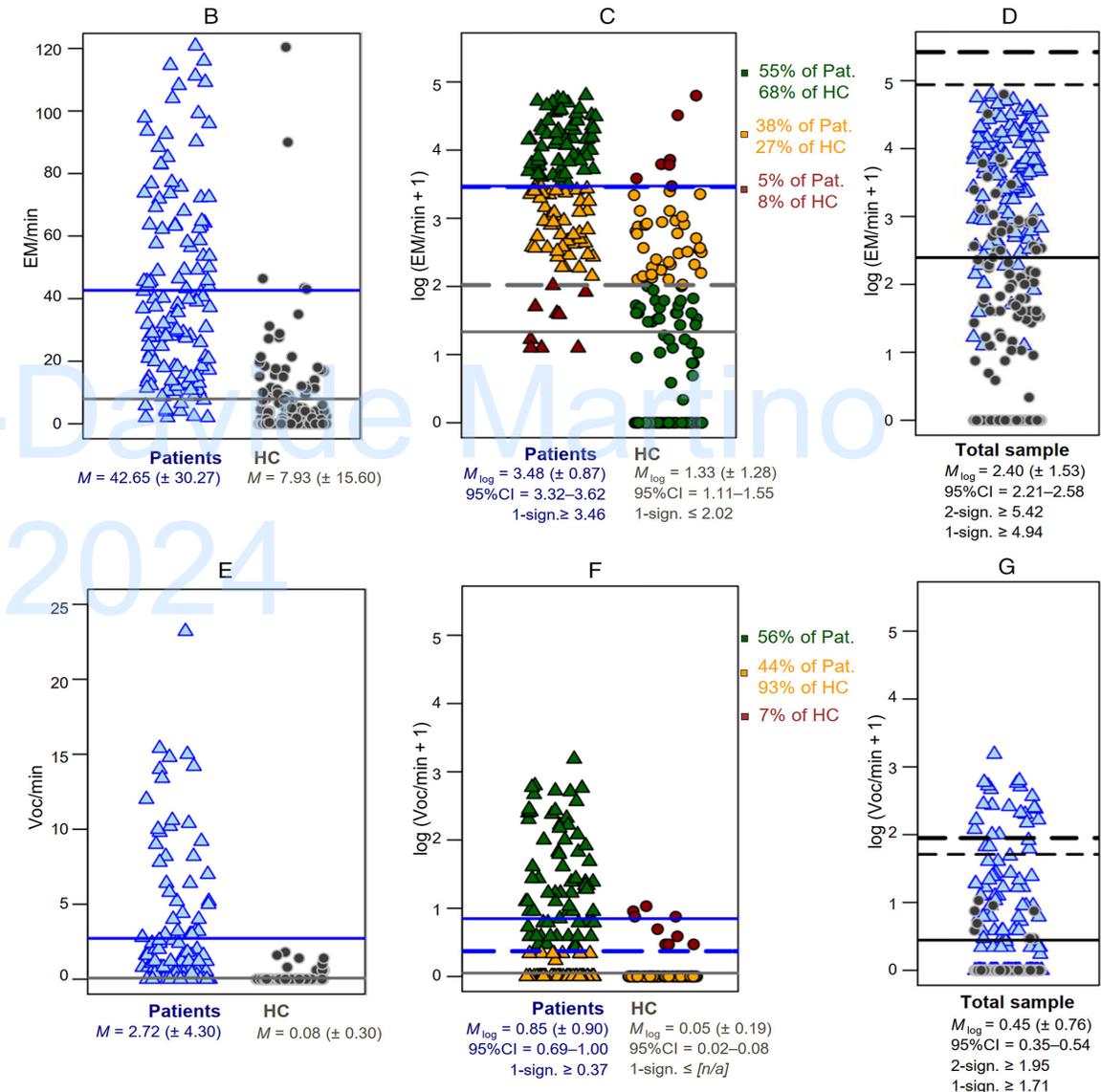
➤ People with tic disorders present with a higher number of EM/EV than controls without tic disorder

← B, E

➤ Individuals with and without a tic disorder cannot be differentiated only based on the frequency of EM

← D, G

➤ Other qualitative features, other than frequency, such as repetitiveness, are more important to differentiate tics reliably



# The Rush Video-Based Tic Rating Scale-Revised: A Practice-Oriented Revision

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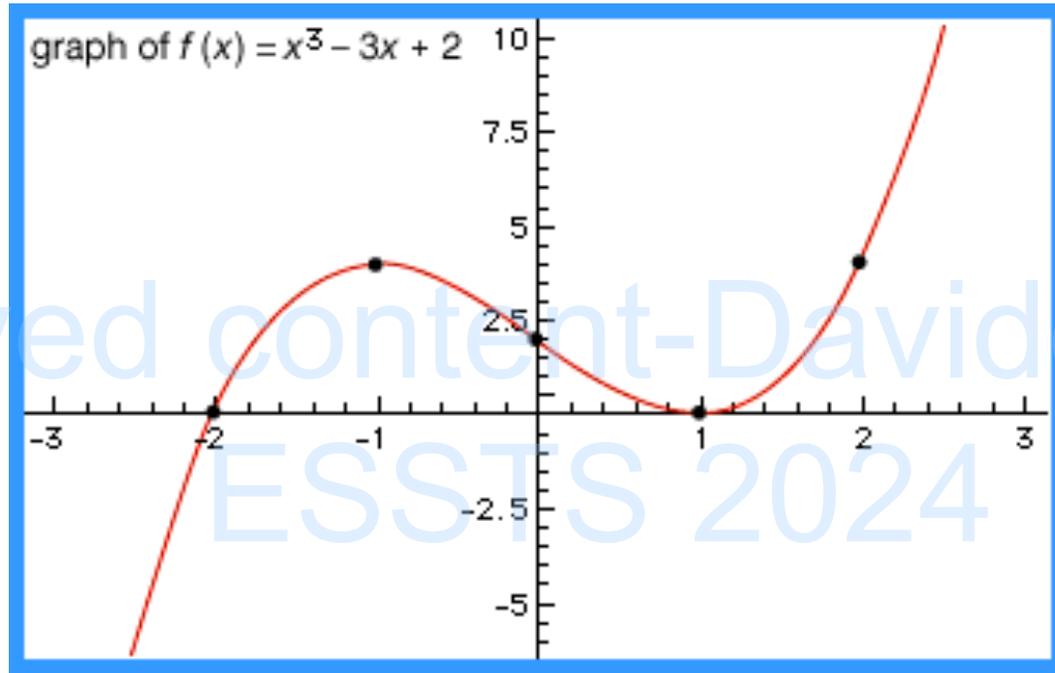
# ALGORITHM

FALLING IN LOVE WITH THE ALGORITHM

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# The manifestation of tics is a function of factors acting in opposite directions



- Intensity of premonitory urges → intensity of tics → likelihood of tic manifestation
- **Entirely subjective**
- Can we measure urges without influencing urges?
- Urges matter in behavioral therapy

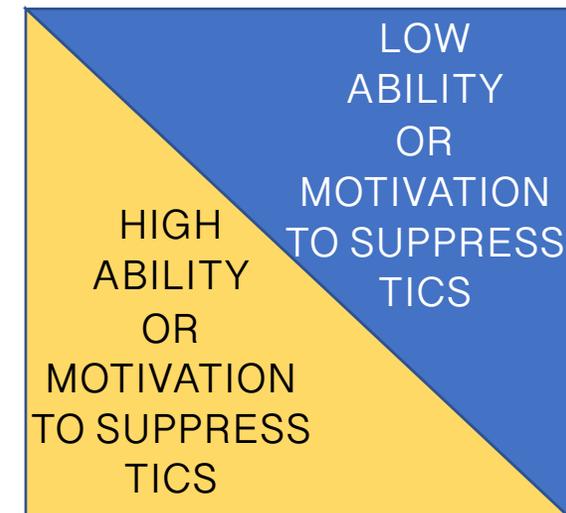
# The subterranean forces of the «urge-tic phenomenological complex»

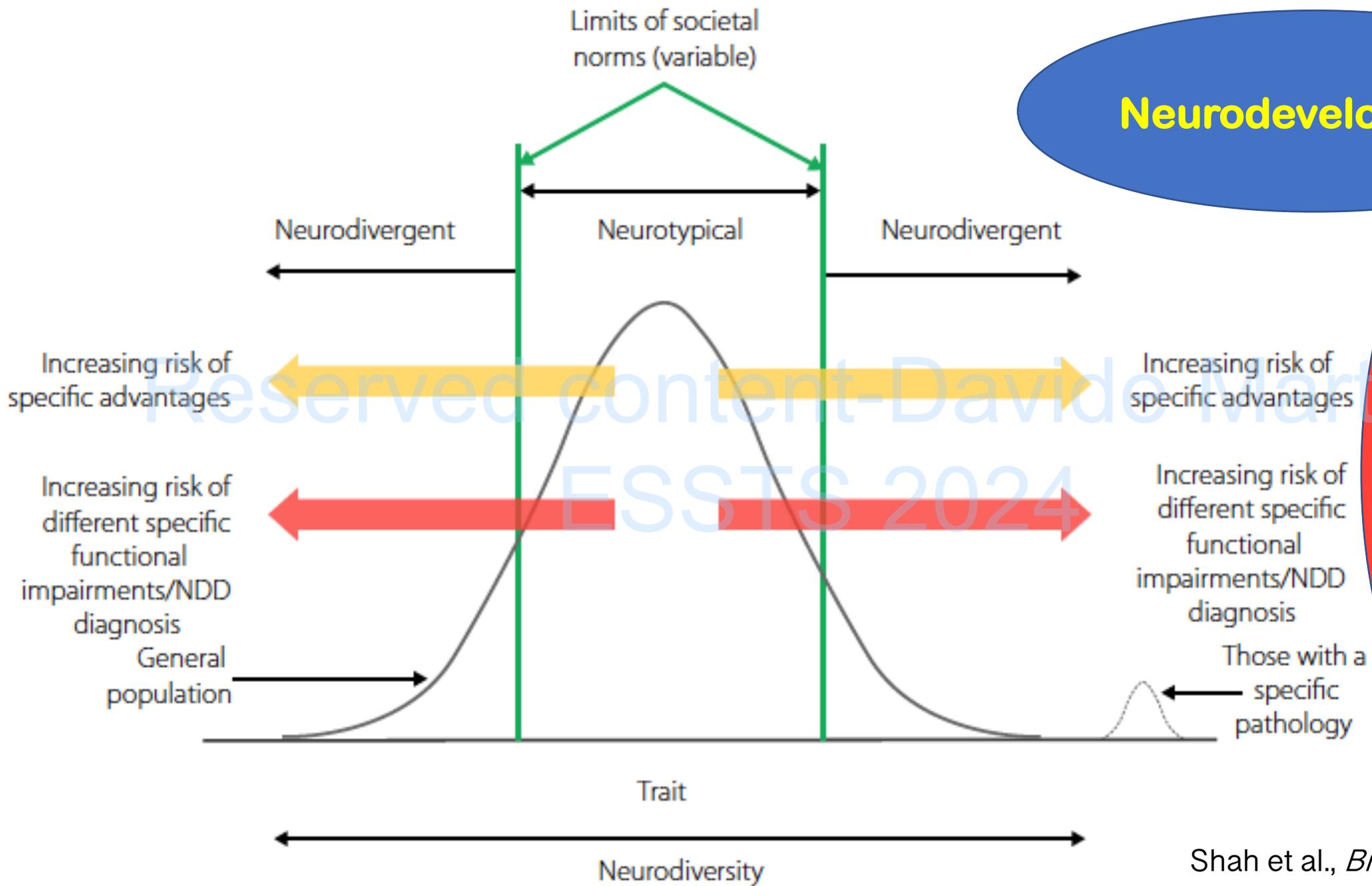


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**ASSESSING TICS  
GOES BEYOND  
«COUNTING» TICS**





- Executive functions
- Regulating
- Learning
- Attention
- Emotions
- Impulses
- Sensory Processing
- Motor execution
- Social Behaviours

# Could AI quantify all domains of tic severity?

**NUMBER** ✓

	Motor	Phonic	
<b>NONE.</b> No tics present.	0	0	0
<b>MINIMAL.</b> Single tic present.	0	0	1
<b>MILD.</b> Multiple discrete tics (2-5).	0	0	2
<b>MODERATE.</b> Multiple discrete tics (>5).	0	0	3
<b>MARKED.</b> Multiple discrete tics plus at least one orchestrated pattern of multiple simultaneous or sequential tics, where it is difficult to distinguish discrete tics.	0	0	4
<b>SEVERE.</b> Multiple discrete tics plus several (>2) orchestrated paroxysms of multiple simultaneous or sequential tics, where it is difficult to distinguish discrete tics.	0	0	5

**FREQUENCY** ✓

	Motor	Phonic	
<b>NONE.</b> No tics present.	0	0	0
<b>MINIMAL.</b> Specific tics are usually present on a daily basis, but there are long tic-free intervals during the day. Bouts of tics may occur on occasion, but are not sustained for more than a few minutes at a time.	0	0	1
<b>MILD.</b> Specific tics are present on a daily basis. Tic free intervals as long as 3 hours are not uncommon. Bouts of tics occur regularly, but generally limited to a single setting.	0	0	2
<b>MODERATE.</b> Specific tics are present virtually every waking hour of every day. Bouts of tics are common and may not be limited to a single setting.	0	0	3
<b>MARKED.</b> Specific tics are present every waking hour. Bouts of tics are common and may occur in multiple settings.	0	0	4
<b>SEVERE.</b> Specific tics are present virtually all the time. Tic free intervals are difficult to identify and do not last more than 5 to 10 minutes. Bouts of tics are very common and occur in multiple settings.	0	0	5

**INTENSITY** ✗

	Motor	Phonic	
<b>NONE.</b> No tics present.	0	0	0
<b>MINIMAL.</b> Tics not visible or audible (based solely on patient's private experience), or tics are less forceful than comparable voluntary actions and are typically not noticed because of their intensity.	0	0	1
<b>MILD.</b> Tics are not more forceful than comparable voluntary actions or utterances, and are typically not noticed because of their intensity.	0	0	2
<b>MODERATE.</b> Tics are more forceful than comparable voluntary actions, but are not outside the range of normal expression for comparable voluntary actions or utterances. They may call attention to the individual because of their forceful character.	0	0	3
<b>MARKED.</b> Tics are more forceful than comparable voluntary actions or utterances and typically have an "exaggerated" character. Such tics frequently call attention to the individual because of their forceful and exaggerated character.	0	0	4
<b>SEVERE.</b> Tics are extremely forceful and exaggerated in expression. These tics call attention to the individual and may result in risk of physical injury (accidental, provoked, or self-inflicted) because of their forceful expression.	0	0	5

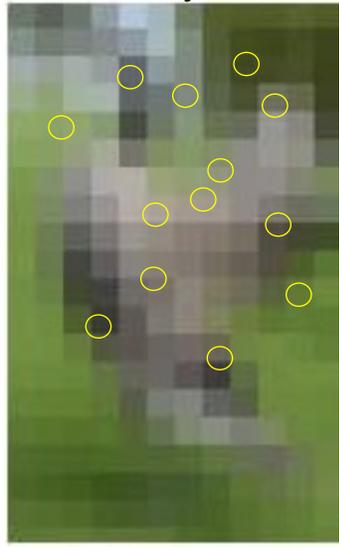
**COMPLEXITY** ?

	Motor	Phonic	
<b>NONE.</b> No tics present.	0	0	0
<b>MINIMAL.</b> If present, all tics are clearly "simple" (sudden, brief, purposeless) in character.	0	0	1
<b>MILD.</b> Some tics are not clearly "simple" in character.	0	0	2
<b>MODERATE.</b> Some tics are clearly "complex" (purposive in appearance) and mimic brief "automatic" behaviors, such as grooming, syllables, or brief meaningful utterances such as "ah huh" or "hi" that could be camouflaged.	0	0	3
<b>MARKED.</b> Some tics are more "complex" (more purposive and sustained in appearance) and may occur in orchestrated bouts that would be difficult to camouflage, but could be rationalized or "explained" as normal behavior or speech (tapping, saying "you bet", "honey", "FF", "sh", or brief echolalia).	0	0	4
<b>SEVERE.</b> Some tics are very "complex" in character and tend to occur in sustained orchestrated bouts that would be difficult to camouflage and could not be easily rationalized as normal behavior or speech because of their duration and/or their unusual, inappropriate, bizarre or obscene character (a lengthy facial contortion, touching genitals, echolalia, speech atypicalities, bouts of copropraxia, self-abusive behavior, coprolalia).	0	0	5

**INTERFERENCE** ✗

	Motor	Phonic	
<b>NONE.</b> No tics present.	0	0	0
<b>MINIMAL.</b> When tics are present, they do not interrupt the flow of behavior or speech.	0	0	1
<b>MILD.</b> When tics are present, they occasionally interrupt the flow of behavior or speech.	0	0	2
<b>MODERATE.</b> When tics are present, they frequently interrupt the flow of behavior or speech, but do not disrupt intended behavior or speech.	0	0	3
<b>MARKED.</b> When tics are present, they frequently interrupt the flow of behavior or speech, and they occasionally disrupt intended action or communication.	0	0	4
<b>SEVERE.</b> When tics are present, they frequently disrupt intended action or communication.	0	0	5

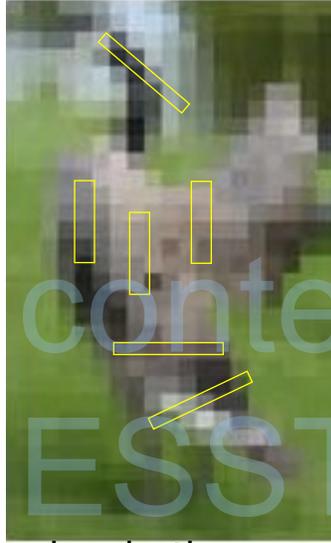
Chorea- or myoclonus-like



ONSET

complexity

END OF PUBERTY



simple tics



complex tics

TICS

More complex and patterned  
Quasi-purposeful or voluntary behaviours

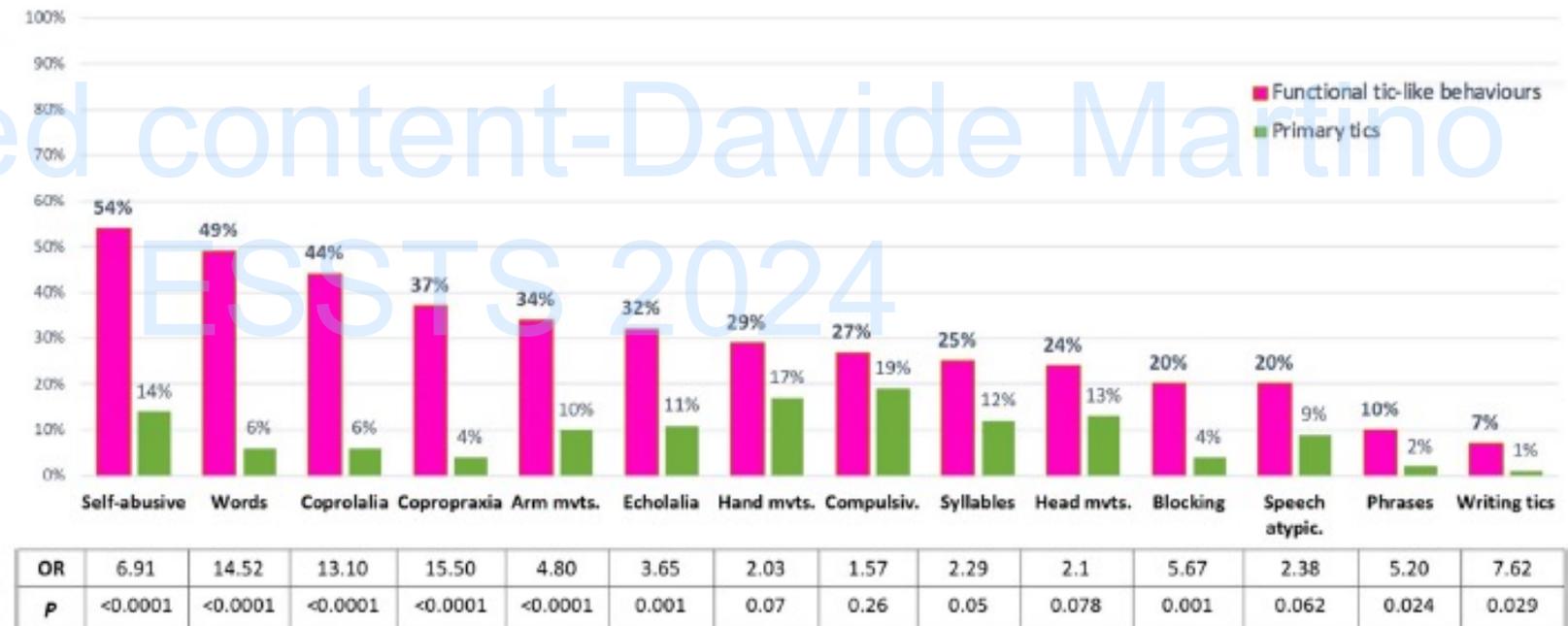


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# Making progress towards 'positive supportive' signs of FTLBs

## SPECIFICITY OF POTENTIAL SUPPORTIVE CRITERIA

- AGE >12 YEARS: 94.2%
- $\geq 2$  COMPLEX MOTOR AND  $\geq 1$  COMPLEX PHONIC BEHAVIOUR AT FIRST VISIT: 96.2%
- NR COMPLEX TIC-LIKE BEHAVIOURS > SIMPLE TIC-LIKE BEHAVIOURS AT FIRST VISIT: 89.7%



[Nilles, Martino...Pringsheim *Mov Disord Clin Pract* 2024  
Nilles, Martino, Pringsheim *Eur J Neurol* 2024]

# What are we asking AI to do here?

- So why do we want to use AI? To count tics on videorecordings? It's a no brainer, let's do it

BUT

- Are videorecordings even a good way to measure the number of tics? Can we record patients most of their days?
- The problem of “knowing to be videorecorded”

The Rush Video-Based Tic Rating Scale is a “laboratory test”

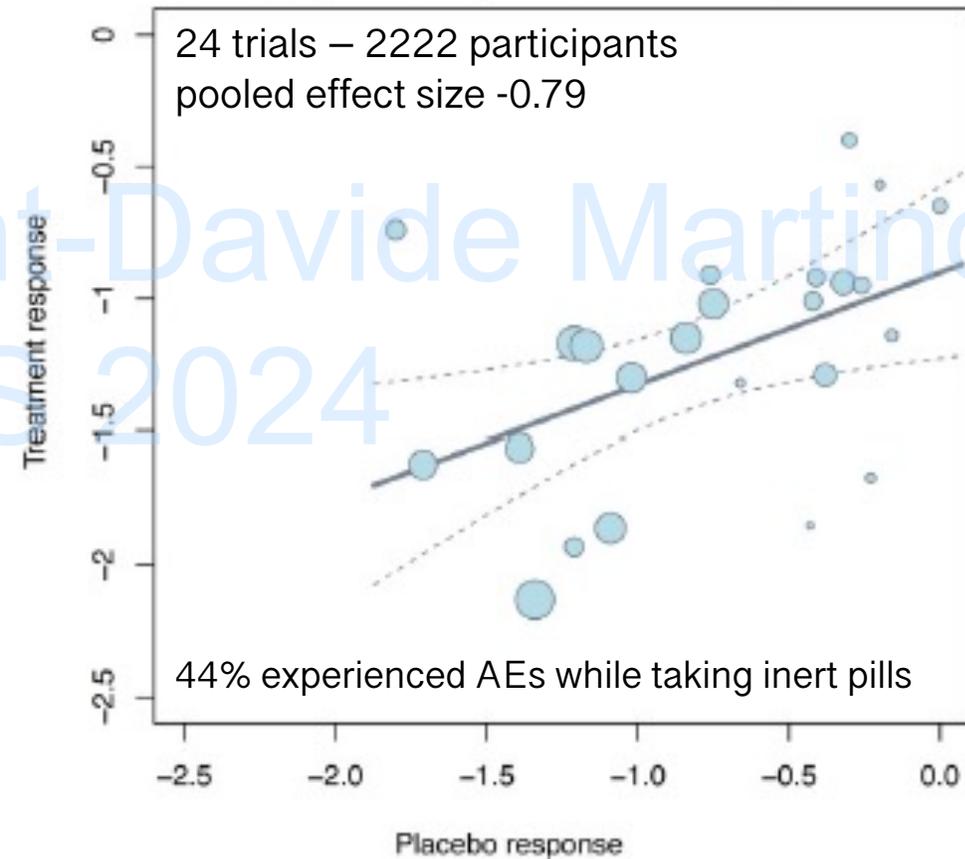


# What are we asking AI to do here?



"How did you get past the motion sensor?"

a Association between placebo response and treatment response



[Wang...Han *Mov Disord* 2024]

# Heisenberg's Principle

$$\Delta x \cdot \Delta p \geq \frac{h}{4\pi}$$

position                      momentum

$\Delta x$	$\uparrow$	$\Delta p$	$\downarrow$
$\Delta p$	$\uparrow$	$\Delta x$	$\downarrow$

## APPLIED TO TIC TRACKING

«There is a limit to the precision with which certain pairs of tic properties, such as location and timing, can be simultaneously known»

# To summarize...

- Tics can be influenced by the context, but also by the subject or method of observation
- The assessment of tics is a nuanced process that aims to summarize a period in the patient's life, not a fleeting snapshot of how tics appear in an artificial setting
- Tics are multiform, and complex tics can be very hard to separate from voluntary behaviors (not to mention functional tics)
- Patients and families care more about how tics influence functioning and quality of life than the number or the type of tics per se
- ...AI and digital tic tracking will have to put these aspects at the centre of its future development goals.....and then we'll truly fall in love with the algorithm