

Premonitory Tic Urges in Tourette Syndrome Patients with Comorbid Autism Spectrum Disorder

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ASD and TS

- In individuals with a **TS diagnosis**, co-morbid **ASD** ranges from **2.9 to 20%***
- In our clinic a recent audit showed **46%** of young people who attended for support / management of Tics had co-morbid ASD

* Cravedi, E., Deniau, E., Giannitelli, M., Xavier, J., Hartmann, A. and Cohen, D. (2017). Tourette syndrome and other neurodevelopmental disorders: a comprehensive review. *Child and Adolescent Psychiatry and Mental Health*, 11(1). doi:<https://doi.org/10.1186/s13034-017-0196-x>.

ASD and TS

- Not too much is established about the quality / nature of tics in ASD, nor about pre-monitory urges for Tics in ASD.
- Kahl et al. (2015) - 21 individuals with ASD and Tics compared to 16 individuals with TS w/o ASD, and they found that tics in ASD were indistinguishable from tics in TS and were similarly distributed, but less severe. Tic awareness was limited in ASD group.*

* Kahl, U., Schunke, O., Schöttle, D., David, N., Brandt, V., Bäumer, T., Roessner, V., Münchau, A. and Ganos, C. (2015). Tic Phenomenology and Tic Awareness in Adults With Autism. *Movement Disorders Clinical Practice*, 2(3), pp.237–242. doi:<https://doi.org/10.1002/mdc3.12154>.

ASD, sensory sensitivity and interoception

- In ASD – there are significant irregularities in the perception and processing of sensory modalities (Robertson & Baron-Cohen, 2017), e.g., visual, auditory, and tactile stimuli,and growing evidence that **interoception** may be similarly affected (DuBois et al., 2016).
- *Therefore, the characterization of premonitory urges and interoception is of particular relevance to TS individuals with comorbid ASD.*

Premonitory urge

- Sensations directly preceding tic expression.
- The current literature: those with TS possess **a lower degree of interoception** - accurate awareness of one's bodily sensations, relative to those who do not tic (Schütteler et al., 2023). Although within TS a heightened interoception is associated with more severe premonitory urges (Rae et al., 2019).

Primary question

- How does the experience of premonitory urges vary in someone with ASD?

Questionnaires used to collect data:

- The **PUTS** (Premonitory Urge for Tics Scale (PUTS), developed by Woods and colleagues in 2005, is a 10-item (9 of which are scored) questionnaire intended to assess the strength and sensory features of premonitory urges for individuals with tics (Openneer et al., 2020).
- PUTS regarded as a highly reliable measure with strong convergent and discriminant validity (Baumung et al., 2021).
- **Secondary:** for measuring interoception in children, the **Multidimensional Assessment of Interoceptive Awareness - Youth Version (MAIA-Y)** is the most widely recognized metric. The MAIA-Y is a 32-item, 8-factor questionnaire intended to assess a child's ability to perceive and understand their own physical sensations.

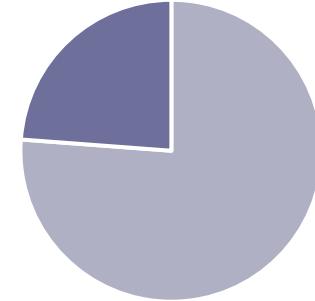
PUTS – Premonitory Urge for Tics Scale

- Scores on Individual Items (1-4 in order of increasing agreement):

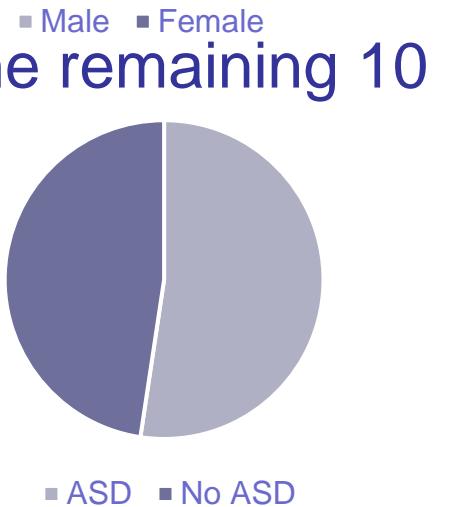
1. “Right before I do a tic, I feel like my insides are itchy.”
2. “Right before I do a tic, I feel pressure inside my brain or body.”
3. “Right before I do a tic, I feel wound up or tense inside.”
4. “Right before I do a tic, I feel like something is not ‘just right’.”
5. “Right before I do a tic, I feel like something isn’t complete.”
6. “Right before I do a tic, I feel like there is energy in my body that needs to get out.”
7. “I have these feelings almost all the time before I do a tic.”
8. “These feelings happen for every tic I have.”
9. “After I do the tic, the itchiness, energy, pressure, tense feelings or feelings that something isn’t ‘just right’ or complete go away, at least for a while.”
10. “I am able to stop my tics, even if only for a short period of time.”

Sample

- 21 patients, all of whom had a diagnosis of TS. 16 patients were male (76.2%) and 5 were female (23.8%).



- 11 patients had a comorbid ASD diagnosis (52.4%), while the remaining 10 patients (47.6%) did not.



Analysis of PUTS

- Patients grouped according to their ASD comorbidity status and compared via **independent samples t-test** on mean total PUTS score, as well as each of the 9 scored items.
- Across all items, these groups did not differ significantly **except** in mean scores on **item 4** ($t = -4.189$; $df=19$; $p<0.001$), **item 7** ($t = -2.842$; $df=19$; $p=0.005$), and **total PUTS score** ($t = -2.120$; $df=19$; $p=0.047$).
- Those with ASD scored higher on average for item 4 (mean = 3.36; $sd = 0.20$), item 7 (mean = 3.45; $sd = 0.21$), and total PUTS score (mean = 25.09; $sd = 0.93$) when compared to TS patients without comorbid ASD.

- **Total PUTS Score (out of 36; minimum 9)**
 - Scores on Individual Items (1-4 in order of increasing agreement):
 1. “Right before I do a tic, I feel like my insides are itchy.”
 2. “Right before I do a tic, I feel pressure inside my brain or body.”
 3. “Right before I do a tic, I feel wound up or tense inside.”
 4. **“Right before I do a tic, I feel like something is not ‘just right’.”**
 5. “Right before I do a tic, I feel like something isn’t complete.”
 6. “Right before I do a tic, I feel like there is energy in my body that needs to get out.”
 7. **“I have these feelings almost all the time before I do a tic.”**
 8. “These feelings happen for every tic I have.”
 9. “After I do the tic, the itchiness, energy, pressure, tense feelings or feelings that something isn’t ‘just right’ or complete go away, at least for a while.”
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Multidimensional Assessment of Interoceptive Awareness - Youth Version (MAIA-Y)

- Challenges for children with ASD to complete it !
- For the ASD group (n=11) We had only 5 completed MAIA-Y
- Overall these show lower interoception scores, but cannot really conclude based on 5 questionnaires

Conclusion

- The sample (n = 21) is small, nevertheless the analysis shows that TS patients with comorbid ASD may be more susceptible to increased severity and frequency of premonitory urges.
- Given the lack of matching number of **MAIA-Y (interoceptive awareness)** questionnaires we did not analyse these, but there appears to be lower scores on interoceptive awareness in ASD, which is in keeping with research.
- **Why did the ASD group have higher scores on PUTS, and specially on certain items ?**
- This has prompted us to collect similar and further data, in a larger sample – which we are continuing to do for every child after the initial assessment (for group attendance) and have over 75 children with this data. Will be happy to share our findings on this next year!