

Science-society rifts on tics, compulsions, and Tourette’s: Perspectives of a panel of Tourettic persons and Tourette’s researchers

Diana Beljaars, Swansea University, UK, **Kassandra Cooke**, School of Psychology, Healthy Autistic Life Lab, Deakin University, Australia, **Jaleesa Jenkins**, Independent advocate, USA, **Daniel Jones**, Newcastle University, UK, **Jo Bervoets**, Antwerp University, Belgium, **Devon Oship**, GE Healthcare, USA, **Christine Conelea**, University of Minnesota, USA

Background / Problem statement

In recent years, the societal context in which Tourette has been experienced and studied has undergone significant changes, including increased diversity in patient groups (Heyman et al. 2020), emergence of internet-based platforms for information dissemination, representation of tics and compulsions via social media (e.g. Twitter, YouTube, TikTok, and Instagram) (Conelea et al. 2022), and adoption of neurodiversity-inspired views around treatment and self-determination (Bervoets et al., 2023). *These changes risk the creation of rifts between Tourette scientists and Tourette’s advocates, such that alignment of interests, contingencies, and motivations between these groups will be important for ensuring that research outcomes meet the needs of the Tourette community.* Person-centred research has addressed this issue in other areas of health and disability. In this framework, individuals with lived experience, family members, community clinicians, and other key stakeholders fully collaborate in all stages of the research process, including identification of research questions, study design, and interpretation of results. *In this poster, we describe key themes that emerged from a transdisciplinary person-centred panel discussion focused on identifying areas of mis-alignment between Tourettic advocates and researchers.*

Methodology

Panel members consisted of Tourettic and non-Tourettic advocates and researchers, including human geographers, psychologists, and a philosopher. Panellists provided their unique professional and/or personal perspectives on recent research on Tourette’s and tics. To identify what concerns were shared, a public broadcasted discussion session was held during the Northern Network for medical Humanities Research congress in April 2023. Whilst individual circumstances and experiences are of equal importance, the three points below are the key shared perspectives of the panel.

“The fact of the matter is that if we listen to Tourettic people, we will see that it’s *us* who contribute to their hardship and who cannot see added value in a neurodivergent way of being. *We* need to do better instead of merely focusing on making *them* better. Maybe it complicates our science, but it is the only way we can uncomplicate Tourettic lives.” – Jo Bervoets

Point 1: **CONTEXT:** Tourettic people hold an important perspective regarding how they are impacted by social media and online communities.

Researchers have identified possible contributions of social media to an increase in tic-related referrals during the pandemic. Discourse has typically focused on potential adverse impacts of increased visibility of Tourette/tics on social media. Whilst well intended, such discourses do not align with a person-centred approach and can undermine personal agency. *Panellists identified positive benefits, including:*

- *Better representation of Tourettic lives built by online communities;*
- *Supportive connection and communication between Tourettic people unmediated by third parties;*
- *New insights into similar struggles in adjacent diagnoses.*

Finally, when support is difficult to come by, social media is often the only first line of support. *Panellists therefore identified the need to comprehensively study the impact of social media on Tourettic lives from appropriate social scientific and humanities perspectives.*

Point 2: **EXPERIENCE:** Possibilities for research to be informed by the Tourettic community and their diverse lived experiences.

Panellists highlighted ways in which Tourette’s advocates have begun to share novel views on the manifestations and phenomenology of Tourette. These include experiences of non-tic specific challenges (e.g., involuntary behaviours “in opposition to” personal values, fatigue) and differential social experiences related to the intersection of tics with other social identities. For example, it was noted that people with tics who are BIPOC, gender-marginalised, or multiply disabled often have adverse experiences in healthcare settings and are less likely to be actively recruited to partake in research. *The panel identified how concerted efforts to engage groups underrepresented in prior Tourette research would facilitate an improved scientific understanding of Tourette and enable efforts to correct systemic barriers that contribute to healthcare disparities.*

Point 3: **COLLABORATION:** Tourette research is likely to benefit from person-centred approaches that recognize and value the expertise of lived experience.

Panellists discussed the benefits of levelling historical hierarchies between researchers, clinicians, and Tourettic persons. This would enable ethical, representative, and scientifically sound research that more comprehensively addresses the full experience of those in the Tourette community. Panellists identified concrete ways they have done this, including

- *Informal discussions between researchers and Tourette’s advocates;*
- *inclusion of advocates as research collaborators in studies and on grant proposals;*
- *co-authoring scientific manuscripts, co-presenting in both academic and community settings (e.g., conferences, podcasts, webinars);*
- *helping to establish supportive environments when those with tics become researchers themselves.*

The importance of authentic, equitable, and mutually beneficial partnership was emphasized to deliver on the promises of patient emancipated research. Partnerships done well offer a new wave of expertise that deserves fundamental embedding in the knowledge base of Tourette syndrome.

“It wasn’t until I went online that I found an amazing tic community who understood my experience and accepted me for who I am. Because of the difficulty of my experience, I decided to self-advocate for others who may feel ashamed because of their tics, or those who feel alone because their presentation doesn’t align with the classic Tourette profile”. – Kassandra Cooke

Results & Conclusions

1. Person-centred approaches that facilitate equitable and generative partnership between researchers and members of the Tourette community are needed to advance research and ensure it is designed and disseminated in ways that maximally benefit people with tics.
2. Tourette’s research should be informed by Tourettic people and reflect community values and take note of shared concerns of research implications, for instance through participative methods throughout the research process.
3. Research that comprehensively examines social media engagement and its impacts on the Tourette community are needed, including research that considers possible benefits of these platforms.
3. Concerted efforts on the part of researchers are needed to understand and address the needs of those in the Tourette community who are most marginalized, underrepresented in prior

References

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