

Clarifying the “life-saving” online community building in Tourette Syndrome

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Background

In recent years, there has been a growth in concern over social media sites such as TikTok and their implied impact on tics and Tourette Syndrome (Müller-Vahl, 2022). However, some have sought to critique these claims (Conelea *et al.*, 2022). My PhD research inquired into the embodied experiences of public space had by adults with Tourette Syndrome, inclusive of online public spaces such as social media sites. Attending to online publics was incredibly and distinctly important in the case of Tourette Syndrome, particularly for Tourettic adults who felt that there were no spaces of support or community that existed for them. Additionally, the in-person support of Tourettic adults was heavily critiqued for focusing solely on supporting non-Tourettic stakeholders of Tourette Syndrome (i.e. non Tourettic parents of Tourettic children), and as a result the value of online support and community was found to be especially significant. This paper highlights three of the key three arguments relating to the use of online public spaces found in the research, and encourages us to question existing discourse surrounding TS and social media.

“Sometimes I don’t feel safe at support groups because of comments being made by non-Tourettic people. It’s a shame when it’s someone who hasn’t got Tourette’s coming to a Tourette’s meeting and making someone with Tourette’s uncomfortable. That’s weird.”

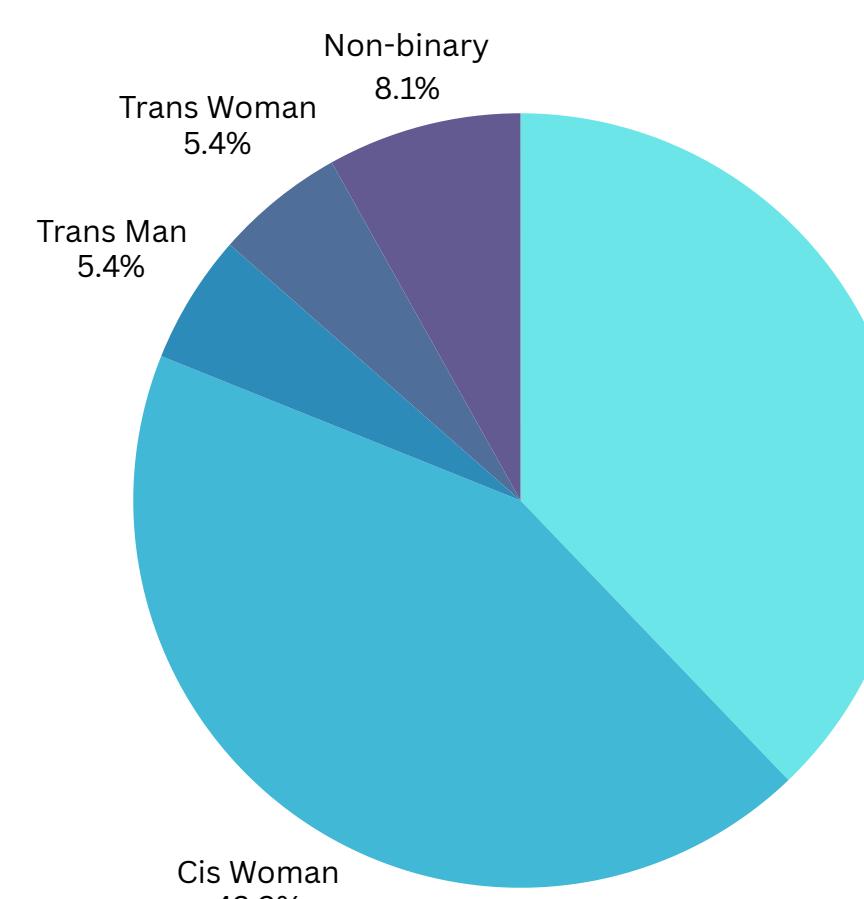
- Bella, Interview 1

“I can’t even go to the doctors without being asked if I use TikTok”
- Yebby, Interview 2

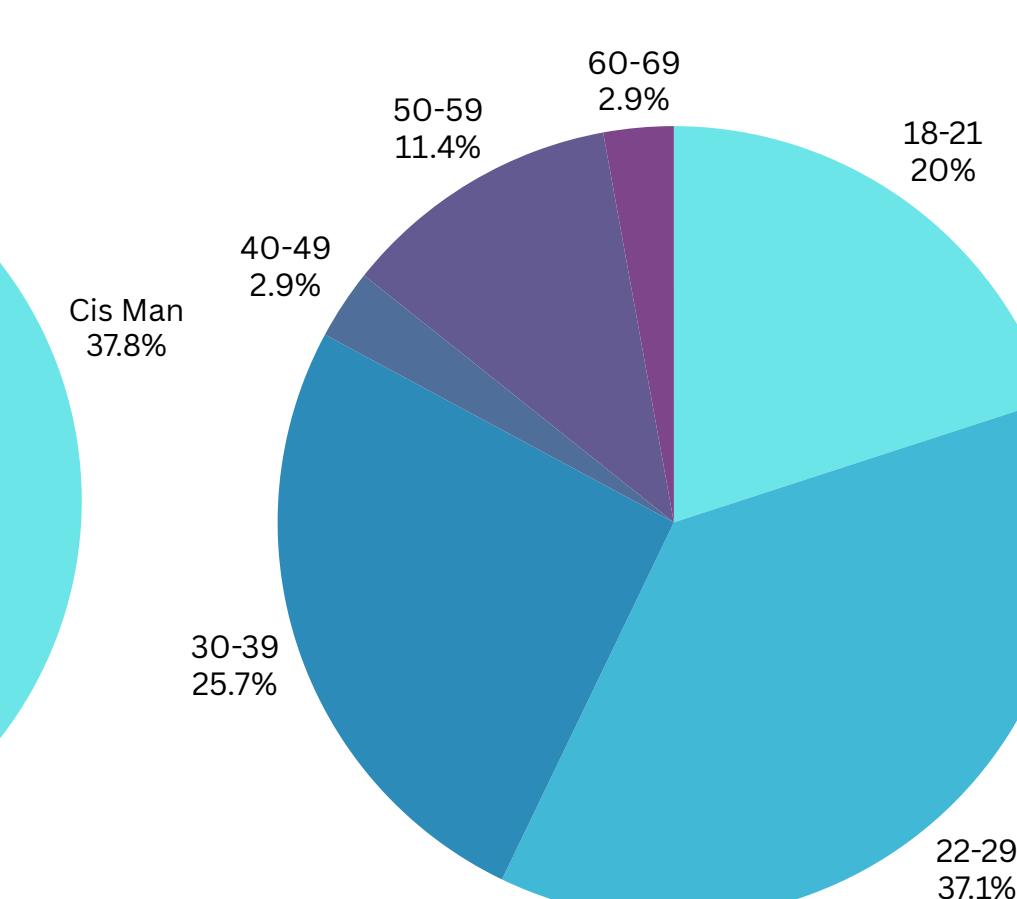
Methodology

The research consisted of international advisory focus groups (n=2) to set the tone for the research. These were followed up with individual interviews with adults diagnosed with Tourette Syndrome (n=38) and a Zineing workshop (cf. Jones, 2024) for participants. The research was conducted in collaboration with charity ‘TIC-Hull’, and was facilitated in a participatory manner (Kindon, Pain & Kesby, 2007). Data was analysed through qualitative coding in NVivo, and in consultation with participants and ‘TIC-Hull’ as a collaborative partner organisation.

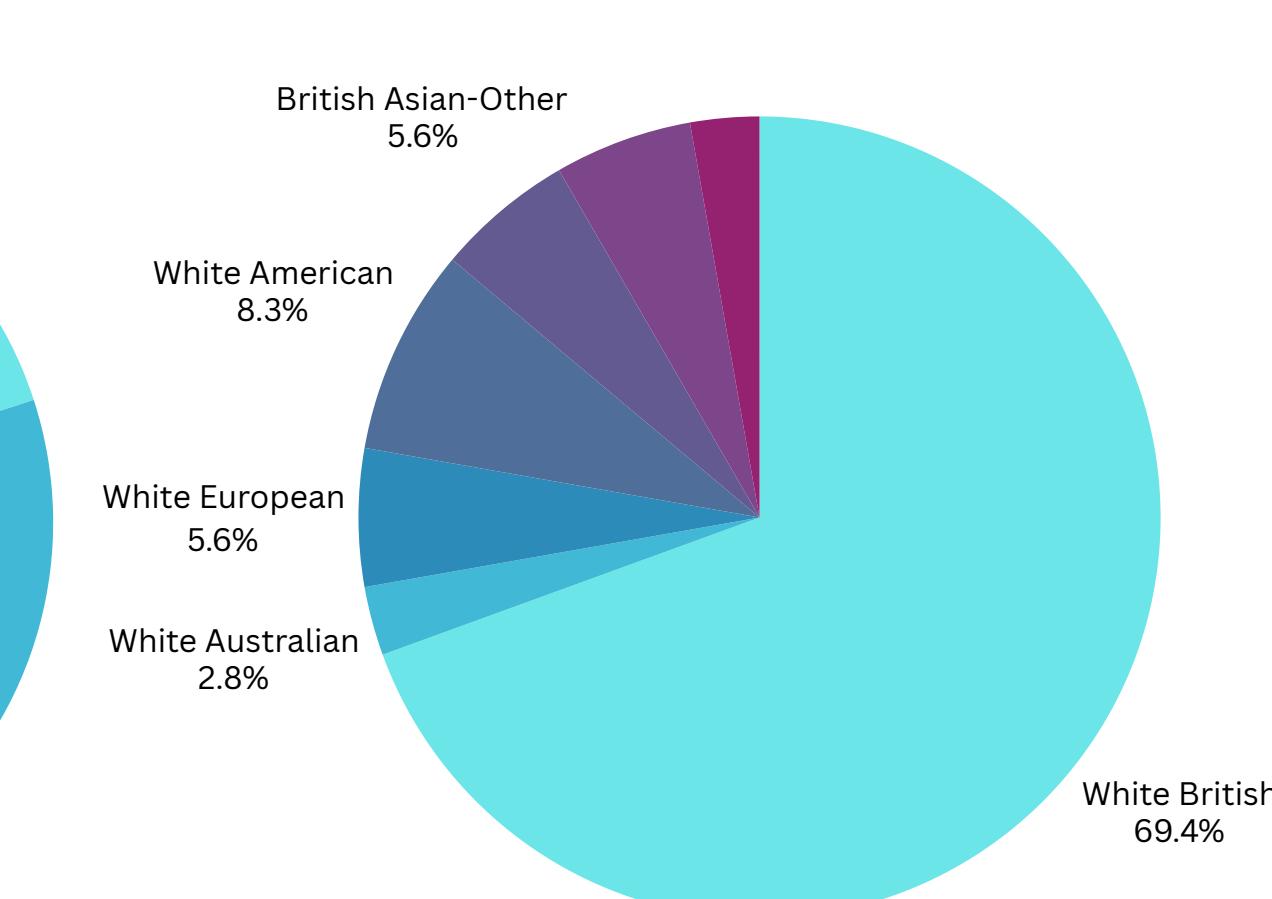
Participant Gender



Participant Age



Participant Ethnicity



Main Finding 1: The lack of support for Tourettic Adults

All participants expressed that there was a significant lack of support available for Tourettic adults, with one participant summarising this by saying that “once you turn 18 you just fall off the map, and nobody cares about you”. In the rare instances where adulthood support was offered, the group was not run as it was advertised: “The adult group was parents who wanted reassurance that their kids were not going to have terrible lives. I went hoping to get support myself, but they just were looking at me as the support pariah”. Significant distress seemed to arise from non-Tourettic stakeholders in TS ‘taking over’ spaces intended for Tourettic people, rendering already limited available support as inadequate. The lack of adequate support has led many Tourettic adults to seek out community in online spaces including private forum spaces and social media sites. The majority of participants stated that without social media they would feel no sense of community or belonging related to Tourette Syndrome.

Main Finding 2: The dangers of demonizing social media

A large majority of participants had experienced negative encounters in public spaces as a direct result of stigma surrounding Tourette Syndrome and social media. One participant stated: “I can’t even go out in public without somebody telling me I spend too much time on TikTok because of the stigma... I don’t even use TikTok!”. Many participants outlined experiences of verbal abuse and hate crime which they attributed directly to stigma perpetuated by TikTok tics narratives and documentaries published by popular broadcasting outlets. Many participants also expressed concern about using social media because they were being increasingly subject to accusations surrounding the faking of Tourette Syndrome. This is particularly concerning given the digital shift in the ways that Tourettic people are seeking out support.

Conclusion, Recommendations & Next Steps

Researchers have a responsibility to not further the stigmatisation of Tourettic people by demonising social media use. In the landscape of particularly limited quantity and quality of Tourette Syndrome support and service provision for Tourettic adults, adding a layer of stigmatisation to Tourettic activity in online publics such as on social media works to further the othering that Tourettic adults feel, and actively contributes to the distinct experiences of loneliness and isolation in Tourette Syndrome. Similarly, service providers need to consider the value of digital and online service provision relating to community and a sense-of-belonging, particularly when it comes to multiply minoritised Tourettic adults. We need significantly more research into the multiply minoritised experiences of Tourette Syndrome in order to ensure that we are providing safe community spaces for them. Online spaces of community, inclusive of social media sites, have the potential to be life-saving, and to facilitate greater connection and solidarity within the Tourettic community.

Main Finding 3: The value of digital spaces

The value of digital spaces was a key theme that arose time and time again in the research. Digital spaces allowed Tourettic adults to feel some sense of belonging and community, as they were able to connect with others who shared similar experiences of TS as them. For many, online spaces were an important stepping stone to allowing them to feel comfortable and confident enough to attend in-person support, and was key in helping them come to terms with their diagnosis.

Additionally, online spaces were referred to as “life-saving” by many, particularly those who are multiply minoritised in their identity (i.e. Tourettic and trans, queer, global majority ethnicity, etc). Tics are suggestible (Efron & Dale, 2018), and contexts and identity characteristics influence verbal tics. Online spaces were the only place where multiply minoritised Tourettic adults felt safe to explore Tourettic community and belonging in many situations.

References

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