Tic-Talk: Voices on Tourette Labelling

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Background:

Tourette Syndrome (TS) is a neurodevelopmental disorder characterized by involuntary motor and vocal tics. The diagnostic label assigned to TS holds significant implications for individuals living with the condition, as well as their caregivers and healthcare providers. However, there is limited research examining the perspectives on TS labelling and the terminology used to describe the condition. This study aims to fill this gap by investigating the current attitudes towards TS labelling among patients, caregivers, and healthcare professionals.

Methods:

Three distinct survey forms were developed to capture the perspectives of patients, caregivers, and healthcare professionals. Each form included questions about demographic information, such as age, age of diagnosis, and current location. Participants were asked to provide their interpretation of the term "Tourette" and rate their sentiment towards it on a happiness scale. Additionally, respondents were presented with a list of terms for TS and asked to indicate their preferences. An open-ended section allowed participants to share any additional comments or concerns regarding labelling.
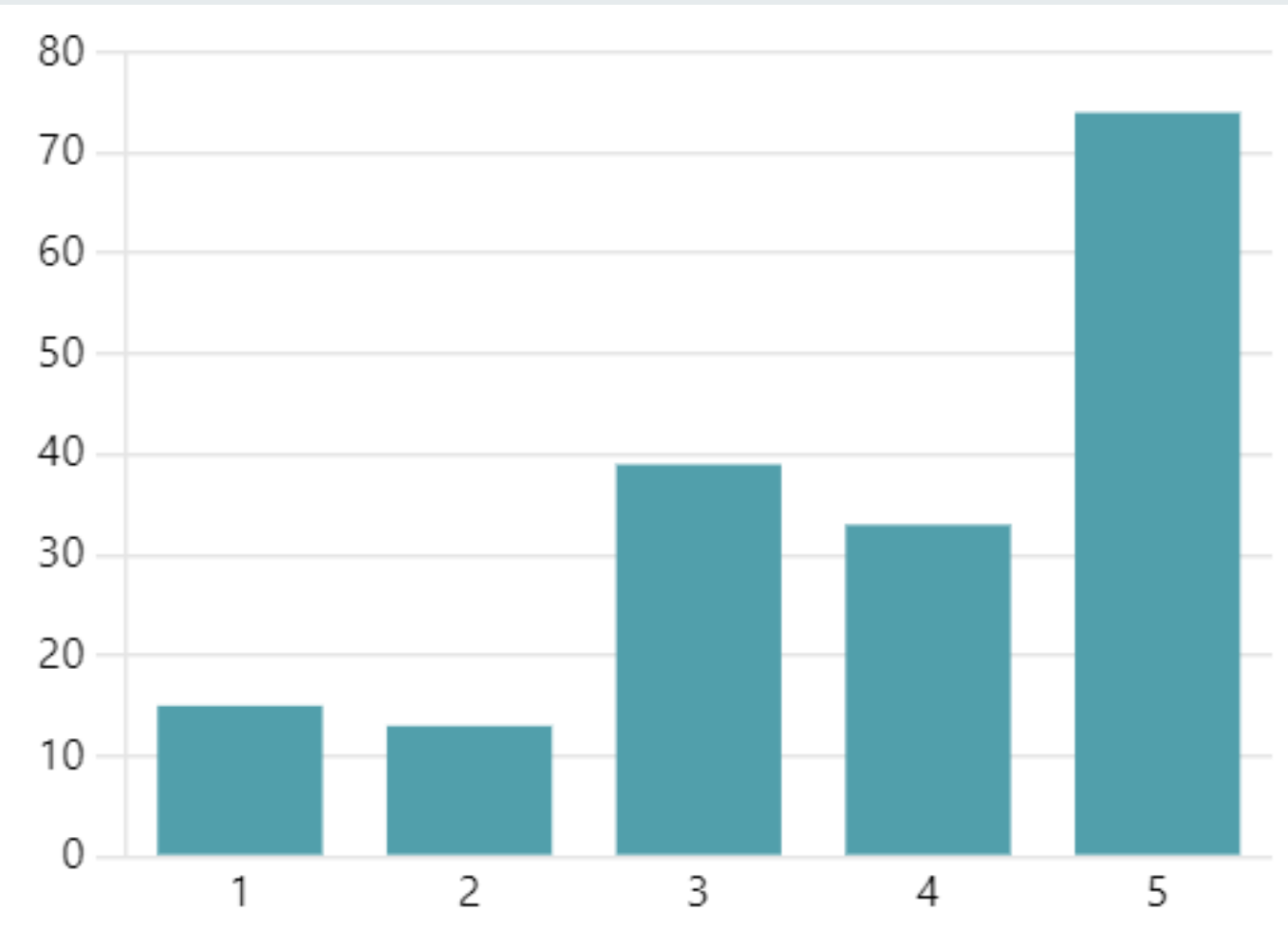
> Tourette's Syndrome is the word we have and have built knowledge, community, and identity around.

> Changing names can be important but also causes more confusion and ignorance in others. Changing something like this feels like steps backwards in awareness drives.

> Getting a Tourette's diagnosis has been crucial to me. It finally explained the "weird little habits" (tics) I've had since I was very young, which no one thought to address or find answers for. It has given me information, vocabulary, and a community of similar people.

> We need language that comes from those with Tourette's & describes our internal experiences rather than the language of medical professionals that often is based on external observations of us.
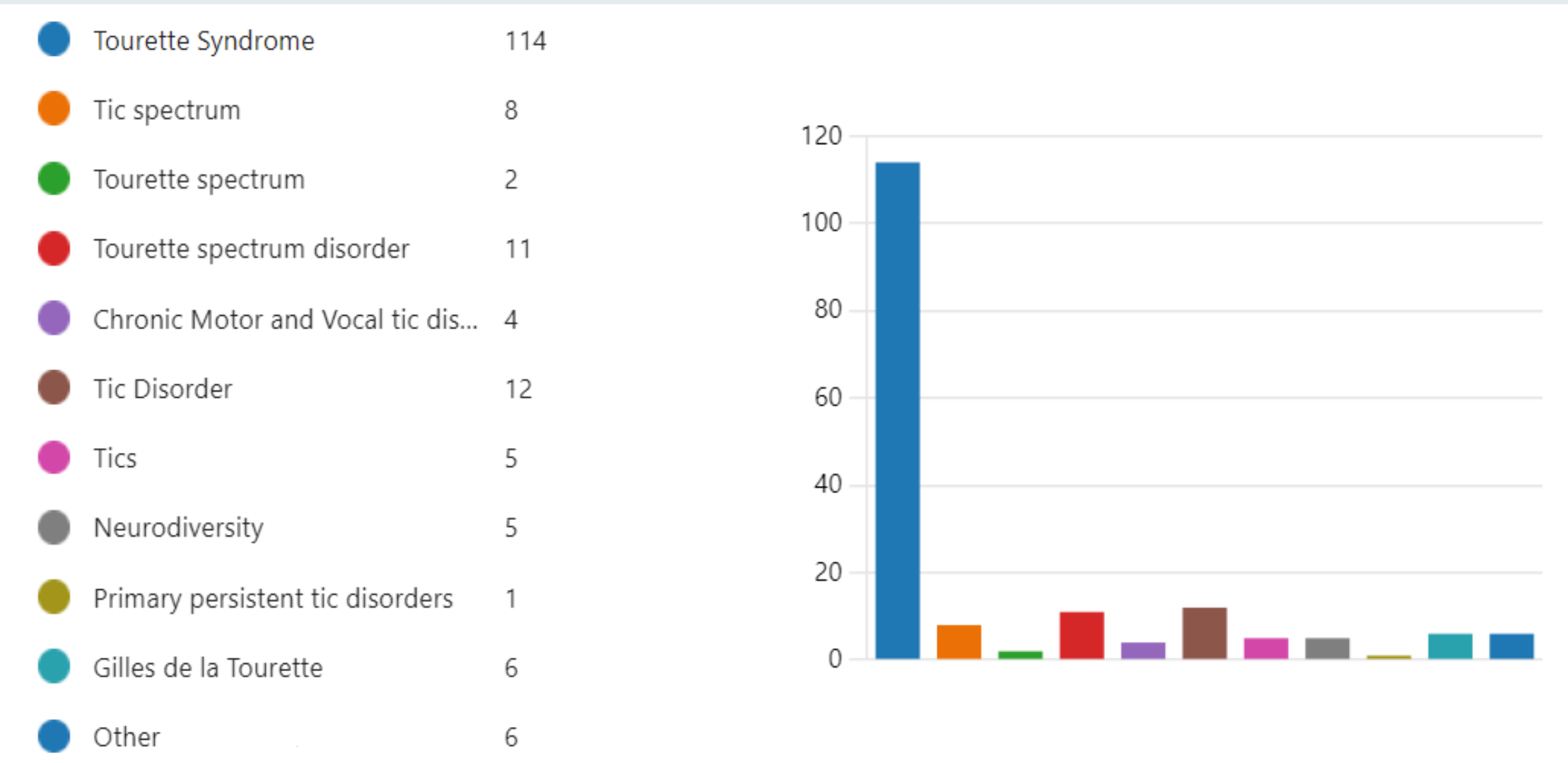
Figure 2 | *Comments left by the responders.*

Figure 1 | Patients' satisfaction score with the term *Tourette's syndrome.* *(1 = Not satisfied at all, 5= Completely satisfied.)*

Results:

This study analyzed responses from 421 individuals: 174 patients, 160 carers, and 87 healthcare professionals, with 51% of patients from the UK. Most patients (25%) were in the 18-24 age bracket, while carers/parents completed surveys for younger patients (0-17). Half of the respondents were diagnosed between ages 8-17. Patients and carers rated the term Tourette Syndrome highest, with average ratings of 3.79/5 and 3.74/5, respectively, while healthcare professionals rated it 3.11/5. Among 61 patient comments, 82% opposed changing the term due to identity and community ties. Conversely, some healthcare professionals and carers highlighted stigma and supported a new term. Overall, 65.5% of patients and 52.5% of carers preferred Tourette Syndrome, compared to 28.7% of healthcare professionals.

Figure 3 | *Preference levels between the proposed terminology among patients.*

Conclusions:

The results indicate variations in current attitudes towards TS labelling among patients, caregivers, and healthcare professionals. Notably, patients and carers exhibit a strong positive disposition towards the diagnostic term "Tourette Syndrome". Most patients reported that changing terminology would create confusion and consequential disinformation around TS and would rather channel resources into educational and informational campaign that would offer support.
In addition, patients feel strongly about the sense of identity and relief that this diagnosis has given them. **This findings highlight the importance of directly involving patients in discussions surrounding diagnostic labelling and language choices.**