

Letting Tourette's be: The importance of understanding lived experience in research and the clinic

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1. Background

This poster is a narrative literature review that explores the possibilities for nuancing views of Tourette's in clinical practice and theory. Tourette syndrome is often viewed primarily through the lens of disruptive tics and clinical research is most commonly aimed at reducing tics. Inspired by emerging calls from those so diagnosed (1-5) and by ethical pointers underpinning the neurodiversity paradigm, this poster explores the possibility of an approach that focuses on the personal experience of people diagnosed as having Tourette syndrome instead of on disruptions of the flow of voluntary bodily movements caused by tics. The poster raises fundamental questions about problem definition in Tourette syndrome research.

Tourette's is not only a neurological phenomenon but must also be seen as a particular mediation between an individual's sensorimotor atypicality and a social environment that is optimized for neurotypical individuals and invites neurotypical behaviour.

3. Biomedical definitions of Tourette syndrome

The conceptualization of Tourette syndrome as neurological disorder focuses on tics as neurological symptoms. Tics are considered to manifest a brain impairment, particularly in the basal ganglia which is understood as 'deficit'. This impairment causes a lack of inhibition of bodily action leading to behaviour at odds with societal expectations (6). Tics tend to resemble typical behaviours but are more sudden, frequent, and unexpected. The frequency and type of tic vary with environmental factors because activities and spaces tend to have an associated sensory load (e.g. touch, olfaction, vision); for instance, clearing the dishwasher in the kitchen can evoke many particular tics (7,8). Tics often impact social relations and quality of life (9). Nonetheless, **Although this tic-centred problem definition is increasingly being questioned by researchers and clinicians (10) a biomedical view of Tourette syndrome as neurological dysfunction causing disturbing tics predominates in the literature (11,12).**

4. Issues with brain deficit views of Tourette syndrome

Clinical scholarship is heavily based on biomedical research of Tourette's with a focus on the brain. This problematises other types of research into Tourette's to be brought into clinical scholarship and practice. **Localizing the cause of problematic tics in the brain creates grounds to 'excuse' the person diagnosed with Tourette syndrome. Their lack of inhibition is seen as outside their control (6).** Nonetheless, context influences not only the content of tics but also their intensity and frequency as well as shaping one's potential to concentrate to suppress (13). Additionally, central to the urge and tic experience is feeling compelled to engage actively with one's surroundings in specific ways to make them feel 'just right' (Beljaars, 2018). A qualitative study by Malli and Forrester-Jones (14) showed that Tourettic people compound their suffering by being fully focused on suppressing tics, leading to feeling a pressure of being under constant scrutiny. These pressures increase the probability of a negative self-image thereby reducing quality of life (15,16). **Relaxing brain deficit views of Tourette's to brain difference views shows that an experientially more authentic understanding of Tourette's can emerge by integrating insights from other empirical and scholarly disciplines referred to as the medical humanities.**

2. Methodology

This paper the poster reflects on is based on a literature analysis of the portrayal of tics in neuropsychiatric literature, the underlying ethical principles of deficit approaches employed in the consideration of Tourette's as a human condition, and the uptake of context and compulsion in the formulation of the main problem that Tourette's incites. It is also based on four interviews with Tourettic people on the salience of tics in their quality-of-life evaluation.

5. Expanding Tourette's beyond pathology

Peter Hollenbeck (17) argued that, from a Tourettic perspective, '*Tourette's (...) is largely a disease of the onlooker. When I tic I am usually not the problem. You are.*' He emphasized the problem formulation as being strongly related to the social symbolism of tic movements. Beste and Münchau (18) who proposed viewing, analysing, and treating Tourette syndrome as a *surplus of sensitivity* to environmental stimuli in comparison to the neurotypical norm. Such suggestions take away a need for categorically separating a pathological Tourette syndrome from 'healthy' individuals (19,20). **Relying exclusively on the positivist methodology of quantifying disruptive tics not only produces Tourette syndrome as a disease but risks erasing the wider lived experience of Tourettic people.** Moving away from such a tic-centred view of Tourette's as primarily a disorder is a precondition to putting lived experience knowledge on equal footing with quantitative findings in an improved understanding of experiential differences as already shown in autism research (21). Four interviewees illustrate how much quality-of-life issues for Tourettic people relate to an ever-present pressure to inhibit tics when faced with social reactions and stigma (22). **Qualitative research that honours the lived experience and context of the Tourettic phenomena beyond tics can spearhead research that develops the social realities of Tourette's and offers new possibilities for clinical support.**

The felt impairment of tics can be reduced by creating a physical and social environment in which the person is 'let be' but not 'let go of'

6. Conclusions: Letting Tourette's be

Letting Tourette's be is an emancipative approach to restructure of clinical Tourette's research and practice, heeding calls from progressive patient and neurodiversity perspectives. Rooted in enactive philosophy and employed in autism research, *letting be* means approaching a

phenomenon without forcing preconceived reference structures onto it (23). In line with the biopsychosocial model (24), it consolidates always seeing Tourettic people beyond disruptive tics and being fully attentive to everyday issues and the embedding of Tourette's related problems in further life. *Letting Tourette's be* allows Tourettic persons to express their way of being and allows them to relate to it

in a more holistic way. It avoids them having to formulate their complex, dynamic experiences only in terms of standardized and quantifiable tics, which are most visible to and found disturbing by onlookers. **In a clinical setting *letting be* would lead to the weighing of all therapeutic options to assemble an individualised management approach (12) that would involve focusing on their felt impairment within**

a Tourettic person's social environment. The *letting be* approach opens up new ways to foreground the wellbeing of people with Tourette's, following the research methodology of the social sciences and medical humanities, as these are not only crucial but complementary to those of bio- and clinical medicine.

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