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INVITED REVIEW

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

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Abstract

The most common clinical research question regarding Tourette syndrome focuses on tic reduction, which follows from classical 'lack of inhibition' models. Rooted in views about brain deficits, this model suggests that with higher severity and frequency, tics are necessarily disruptive and should therefore be inhibited. However, emerging calls from people with lived experience of Tourette syndrome suggest that this is too narrow a definition. This narrative literature review analyses issues with brain deficit views and qualitative research on tic context and feelings of compulsion. The results suggest the need for a more positive and encompassing theoretical and ethical position on Tourette's. The article puts forward an enactive analytical approach of 'letting be', that is, approaching a phenomenon without forcing preconceived reference structures onto it. We suggest using the identity-first term 'Tourettic'. Prioritizing the perspective of the 'Tourettic patient', it urges attentiveness to the everyday issues diagnosed people encounter and how these are embedded in further life. This approach highlights the strong relationship between the Tourettic persons' felt impairment, their adoption of an outsider's perspective, and feeling under constant scrutiny. It suggests that this 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'.

Tourette syndrome is defined as a neurodevelopmental condition characterized by repetitive, non-rhythmic, involuntary movements and vocalizations defined as motor and vocal tics.[1] Tourette's is diagnosed if a person has had at least two motor tics and one vocal tic for more than a year, with onset before the age of 18 years.[2] The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition defines tics as sudden, rapid, recurrent, non-rhythmic movements or vocalizations usually appearing in bouts while waxing and waning in frequency, intensity, number, complexity, and type.[2] In addition to Tourette syndrome, this paper uses 'Tourette's' because it is a common shortening of Tourette syndrome used both colloquially and in the scientific literature. While Tourette syndrome is a less negative term than Tourette's disorder, both qualify Tourette's as primarily negative. Therefore, using the terms Tourette's and Tourettic people helps reflect a more nuanced understanding away from primarily pathological terms, such as syndrome or disorder; such an understanding is also preferential in the autism debate by those diagnosed.[3] This narrative literature review 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[4-8] and by ethical pointers underpinning the neurodiversity paradigm, this article 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. Extending these considerations as used in autism research[9] to Tourette syndrome research and clinical practice, this article raises fundamental questions about problem definition in Tourette syndrome research. In doing so, the article combines clinical and neuroscientific research into Tourette's with social

sciences and medical humanities research on Tourette's and neurodiversity.

BIOMEDICAL DEFINITIONS OF TOURETTE SYNDROME

Certain types of tics are relatively easy to recognize, for instance, short motor tics in the face and torso, such as eye blinking and head nodding, and short vocal tics, such as sniffing and throat scraping. Contrary to how Tourette's is often presented in the popular media, the uttering of obscene words (coprolalia) has an estimated prevalence range of 10% to 30%.[10] The tendency towards exhibiting non-obscene socially inappropriate behaviour is well documented[11] and often impacts social relations and quality of life.[12] 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.[13,14] A recent population study estimated the prevalence of Tourette syndrome at around 1% in the general population.[15] In most cases, onset is before the age of 10 years but the timing of the diagnosis varies widely; sometimes diagnosis is not sought.[16] The development of Tourette syndrome into adolescence is also highly variable, yet remission of tic symptoms and reduced felt impairment in young adulthood are common.[17] Moreover, the strong heterogeneity of tics is related to 90% of people with Tourette syndrome having one or more comorbid diagnoses, such as obsessive–compulsive disorder, attention-deficit/hyperactivity disorder, and autism, often also including mood disturbances and anxieties.[15] Therefore, suggestions have been made for a Tourette syndrome–obsessive–compulsive disorder 'spectrum' based on genetic,[18] behavioural,[19] and neurological[20] findings.

The tentative understanding of Tourette syndrome as a neurological disorder resulted from the rejection of a psychogenic approach based on psychoanalysis in the 1970s.[21] This shift was catalysed by a coalition between doctors and parents, among others, to remove the stigma of 'overprotective mothers (who) infantilized their (overwhelmingly male) children' and remove the 'blame' that was often still placed on the way the child was reared.[21(p. 116)] The focus on tics as neurological symptoms led to the conceptualization of Tourette syndrome as primarily the manifestation of a brain impairment, understood as 'deficit', particularly in the basal ganglia. This impairment causes a lack of inhibition of bodily action leading to behaviour at odds with societal expectations.[22] Although this tic-centred problem definition is increasingly being questioned by researchers and clinicians,[23] a biomedical view of Tourette syndrome as neurological dysfunction causing disturbing tics predominates in the literature.[24,25]

Despite biomedical consensus on the origin of Tourette syndrome, debates continue about the underlying pathophysiological mechanisms[26] and genetic predisposition.[27] Despite initial success with pharmacological treatments,[21] the value of psychoeducation as first-line management is still preferred over forms of pharmacological and neurosurgical therapy.[28] Nonetheless, the Comprehensive Behavioral Intervention for Tics is recommended as the first-line treatment in both the European Union and USA,[29] suggesting that clinical and research practices are open to move beyond brain deficit models in their understanding of Tourette's.

What this paper adds

- Its theoretical position allows a more holistic view of Tourette's, integrating tics with oft-overlooked complex compulsions.
- The 'letting be' position also allows us to view why the presentation of Tourette's is likely to vary with gender and age of onset.
- 'Letting be' is a promising approach to improve a clinical understanding of Tourettic well-being over and above tic severity and frequency.
- It integrates quantitative research on Tourette syndrome in the neurosciences with qualitative neurodiversity literature in the medical humanities.
- It integrates ethical frameworks as developed in enactive philosophy with the conceptualization and treatment of tics and compulsions.

ISSUES WITH BRAIN DEFICIT VIEWS OF TOURETTE SYNDROME

Because clinical scholarship is heavily based on biomedical research of Tourette's with a focus on the brain, other types of research into Tourette syndrome cannot be readily brought into clinical scholarship and practice. Therefore, this section explores the challenges of brain deficit views of Tourette's, specifically in the context of defining what is the most relevant factor for clinical interventions for individuals with a diagnosis of Tourette syndrome.

One of the most important merits of research in Tourette's focusing on a brain deficit can be summarized by the philosophical and ethical analysis outlined by Schroeder.[22] Schroeder argued that 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. At the same time, a brain deficit view creates a categorical difference between the Tourettic and non-Tourettic brains, which serves as an anchor for exculpation. Brain deficit views suggest that tackling this deficit could rid the individual *of* their Tourette syndrome. Indeed, the conceptualization

of Tourette's as a brain deficit explains how individuals cannot be blamed for having tics because these are unrelated to willpower while highlighting a specific locus for treatment. Despite such a view having clear benefits, as yet there is no validated scientific foundation.[26]

The first issue with the brain deficit view of Tourette syndrome is related to phenomenology. Lived experience reports emphasize the importance of context on tics, that is, how they surface as inappropriate in the context of particular social environments.[10] Another common feature in lived experience reports is compulsion, that is, tics being experienced as responses to an urge that demands being acted on despite one's better judgement.[30] An analogy often used is that of an urge to scratch when feeling an itch. Stress negatively affects how acutely such a compulsion is felt and the threshold at which one feels one must 'give in'[30] with, as a combined effect, a varying ability to 'suppress' tics by not performing them. 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.[31] Consequently, some experienced spaces improve tics while others worsen them.[13] Tic intensity and frequency change from minute to minute and over longer periods; this waxing and waning is related to how stressful or soothing the environment is perceived to be.[32]

These elements of context and compulsion point to a sociospatial context of doing a tic that requires more research complementing a strict neurological focus.[31] Both elements suggest that a fruitful direction of study requires a focus on environmental factors. Qualitative research investigating lived experiences may yield valuable insights. The sociospatial context of tics has been studied qualitatively with regard to how the urge and tic experience are informed by the bodily environment.[13,14] Complementing Leckman et al.[33] and based on interviews, participant observations, and mobile eye tracking, a study by Beljaars[34] showed that central to the urge and tic experience is feeling compelled to engage actively with one's surroundings, such as by touching or ordering objects in specific ways to make them feel 'just right'. Not giving in leads to more intense urge sensations; inhibiting such touching or ordering leads to an ever-greater awareness of the element that is 'not just right'. Ultimately, the mounting tensions often become unbearable. Such premonitory urges are highlighted in autobiographical reports (for instance, Bliss[35] and Seligman and Hilkevich[36]) and they are linked to tic severity.[37]

A second issue with the brain deficit view of Tourette's concerns the asserted categorical difference between Tourettic and non-Tourettic brains. Research shows that constructing such differences has adverse social implications. It unduly creates hierarchies of people,[38] exacerbates societal stigmatization, and worsens the mental health of those diagnosed. Indeed, several studies[39,40] found that biomedical views of mental illness essentialize mental disorders and lead to a 'dehumanization' of those diagnosed. As in the review by Malli et al.,[41] the stigmatization of people with Tourette syndrome based on biomedical views is a major element of the Tourettic lived experience.

As discussed by Bervoets et al.,[42] and drawing on the framework developed by the philosopher P. F. Strawson, essentializing psychopathology as a static biological category may require adopting 'the objective attitude to another human being (…) to see him [sic], perhaps, as an object of social policy, as a subject for what, in a wide range of sense, might be called treatment, as something certainly to be taken account, perhaps precautionary account, of; to be managed or handled or cured or trained.'[43(p. 9)] Such '[a] sustained objectivity of inter-personal attitudes, and the human isolation which that would entail'[43(p.11)] produces a socio-ethical problem: suppressing tics puts pressure on Tourettic people to pretend they do not have tics and 'pass for normal'. A qualitative study by Malli and Forrester-Jones[44] 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.[12] To increase the quality of life of Tourettic people, it is crucial to make room for positive self-identification.[45]

While clinical practice does not solely rely on the brain deficit model, it makes a difference to consider the main challenges reviewed here. Relaxing brain deficit views of Tourette's to brain *difference* views shows that an experientially more authentic understanding of Tourette's can only emerge by integrating insights from other empirical and scholarly disciplines referred to as the medical humanities. The complementary nature of neurological and social scientific evidence is crucial in autism research and is compatible with the tenets of the neurodiversity movement.[9] Seeing Tourette's, like autism, as an entanglement of social and neurological factors and as the meeting point of brain difference and societal expectations, holds promise for Tourette's research. This would allow including a broader set of elements of the Tourettic lived experience.[46] It also allows a theoretical view of Tourette's in line with contemporary enactive and embodied views in cognitive science.[47] Finally, a brain difference view also allows seeing Tourette's more holistically, thus reducing stigmatization.[48] Based on lived experience reports, Tourette's as a neurodiverse way of being is then characterized as a 'surplus of sensitivity' to the physical and/or social environment.

Addressing issues created by brain deficit views with qualitative research thus requires Tourette's research to provide valuable complementary views useful for clinical scholarship and interventions in Tourette syndrome as happening within a social context. The next section investigates how social sciences and medical humanities research can address neglected aspects of the Tourettic lived experience beyond a strictly pathological view of Tourette's, in line with autism-based neurodiversity views,[9] to improve clinical means of support and improve quality of life.

EXPANDING TOURETTE'S RESEARCH BEYOND PATHOLOGY

Many practitioners are sympathetic to the brain difference and neurodiversity views expanded at the end of the previous section. Nonetheless, Tourette syndrome continues to be 'produced' *only* as a pathological problem that is in turn reduced to observable tics. 'Produced' is deliberately chosen here over 'conceived as' to indicate that the pathological focus on Tourette syndrome and tics is an active choice rather than a matter of 'merely neutral scientific discovery'. Hollenbeck[49] 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.' Hollenbeck emphasized the problem formulation as being strongly related to the social symbolism of tic movements. 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.[50] While the previous section highlighted how brain deficit views developed a relatively narrow conceptualization of Tourette's, this section considers the possibilities for expanding it.

As mentioned earlier, qualitative research into the lived experience of Tourettic people can clarify how tics occur when one's surroundings feel '(not) just right'.[14] Such research provides a more detailed understanding of the felt urge–tic relationship. Resembling autobiographical reports, this relationship consists of a rising sensation, that is, a tingling or an itch that urges the individual to do a tic that would help them feel 'just right' again.[35,49] Diagnosis and research based on quantifying the tic count of typical or 'classic' upper body tics observed in standardized laboratory or diagnostic conditions are narrow in the tic variation they can record. In contrast, lived experience research in Tourette's records phenomena that fall outside the category of the limited set of classic tics most conspicuous to an observer. Expanding the clinical and research focus from tics to a broader range of symptoms that encompasses 'complex' tics involving multiple muscle groups take longer to complete and can appear intentional in their interaction with bodily surroundings.[13,14] Such expansion repositions 'complex tics', such as ordering, touching, or aligning, as more central to the breadth of Tourettic experiences. Likewise, it allows integration of key aspects that are associated with Tourette syndrome, for instance, the compensatory or masking strategies often conceptualized as 'cognitive tics', such as 'counting tics'.[51] Moreover, these aspects predominate in felt impairment reports[17] because they can tie into compulsions bordering on the obsessive, such as rituals of cleaning or leaving the house.[19] Furthermore, a better integration of complex tics in Tourette's research may help to put into focus 'internalized' tics that are more often performed by girls, women, and non-binary Tourettic people;[52] it may also shed light on the tic-related clinical issues that have surged during the COVID-19 pandemic and those related to increased social media use.[53]

Thus, the production of Tourette syndrome as primarily a brain pathology simultaneously erases important aspects of the lived experiences of Tourette's and renders tic complexity beyond analytical reach. This criticism echoes enactive approaches to psychiatry; for instance, de Haan[54] explained that this approach falls within the remit of the biopsychosocial model. Enactive theory is an empirically informed approach affiliated with the 4E trend of embodied, enactive, ecological, and embedded research in cognitive science. For enactive theory, an understanding of the phenomena of the mind cannot be reduced to the neurological make-up of an individual but always resides in a relational interplay between embodied individuals and their (physical and social) environment.[47] This means that 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. This research direction has been advanced in the case of autism.[55,56]

The 'lack of inhibition' approach to Tourette's clearly lacks some compatibility with the Tourettic lived experience. A 'neurogradualist' approach could help integrate the brain difference model with lived reality. In such an approach, the sensorimotor sensitivities of Tourettic individuals are different in degree rather than being categorically different from neurotypical individuals.[57] In the case of Tourette's, suggestions in the direction of such a solution have already been made. Indeed, Singer and Augustine[26] highlighted the following as one of the key questions for the field to address: 'Are tics due to excess excitation or deficient inhibition?' This suggestion is put even more directly by Beste and Münchau[58] who propose 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. It would not only avoid the stigma born out of essentializing the psychiatric category[39,40] but also—via a dimensional or neurogradualist conception—positively contribute to the inclusion of neurodivergent Tourettic people.[48] First and foremost, however, it would do justice to the efforts of Tourettic people to try to make their difference intelligible based on common human sensitivities. This entails aspects of the phenomenology of bodily sensations akin to itches[35] and aspects of obsessive thoughts.[36]

The expansion of how Tourette's can be viewed and studied is demonstrated empirically via interviews held with four Tourettic people in a participatory research context. Interviews were conducted by the first author over Skype and face to face, with written notes taken during the interviews. In line with participatory research practice guidelines outlined by Fletcher-Watson et al.,[59] the four interviewees were involved in cocreating the Tourette

syndrome-related research questions with the first author. Ethical approval for the use of these quotations was obtained from the Antwerp University Ethics Committee for the Social Sciences and Humanities (No. SHW_19_65 dated 13th December 2019); explicit written informed consent from each of the interviewees was obtained for the quotations and the context in which they are placed in this article. The interviewees were aged between 18 and 30 years and were recruited independently from each other in three north-western European countries. They were all diagnosed in childhood or early adolescence and had persistent motor and vocal tics at the time of interviewing. When asked about how they characterized living with Tourette's, they stated the following:

> I remember very distinctly that, when I was young, I wanted to go to an ice-skating event. When we got there it was very crowded of course, I was acutely aware that I could not do my arm tic so my hands started tingling of course. I enjoyed the race, I had longed so hard to see it live. The energy in my arms however built and built but I could not release it because that would ruin it for everybody and for myself as well of course. When we got out of the stadium and out of the crowd I could finally 'let it out'. The tics were so violent I fell flat on the floor when we were going to our car. It was a wonderful day (Lydia).

> Whenever I need to present for an audience I take some time to 'straighten myself out'. I know being nervous to present to strangers brings out my tics but I cannot let them out, certainly not at such a time. I don't want to be seen as the guy that made a great presentation despite his Tourette's or something. That is just the way I see it but if you'd ask what hinders me most about it: well, that I need to spend so much energy in not ticcing, because, you know, it is energy I cannot spend in doing those things I want to do well, like presenting and stuff (Joseph).

> People rarely notice my tics. I don't want them to. I'll sit on my hands and stiffen up my whole body. Maybe count in my head or something like that. Anything really that diverts energy away from being able to do the tics. My father has it as well. He says I should 'let it out', that it's not healthy 'to keep it in' but I feel responsible not to bother others with it. Sometimes I really get obsessed with my diversion tactics. That can be scary too (Linda).

> Exams are really hard situations for me because they put me in front of an impossible choice: either to disturb others with my tics or to disturb myself by inhibiting them (Penny).

While these quotations can only indicate a part of the lived experience reported, they illustrate how much quality of life issues for Tourettic people[12] relate to an ever-present pressure to inhibit tics when faced with social reactions and stigma. Even if the reality of problematic, often painful, tics is present outside of social circumstances, this social reality of Tourette's is very salient in the Tourettic lived experience and was brought up by the interviewees without specific prompting. Qualitative research by Malli and Forrester-Jones[44] reflects this emphasis. As an integral part of Tourettic lived experience, it is a reality to be taken into account in holistic pictures of Tourette's. Briefly, 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. Based on this, the final section of this review considers a radically new position towards Tourette's in research and in the clinic.

LETTING TOURETTE'S BE

This review pointed out challenges and offered new research directions for addressing some of the realities of life with Tourette syndrome beyond tics. Indeed, there are many more kinds of compelling tics than currently considered in research on Tourette's. However, the tics seen as problematic and in need of inhibition are those that Tourettic people feel they get into the most trouble for, thus highlighting the social core of Tourette's problems. This section considers the premise for tackling this social aspect of Tourette's.

The lived experience reports of Tourette's emphasize a constant pressure to inhibit actions that one feels strongly and spontaneously compelled to do. This shift is reminiscent of the case of autism where the original 'lack of empathy' model was revised under the pressure of lived experience reports of individuals with autism.[50] Neurodiversity scholars argued that this original deficit model constituted a 'double empathy problem'[60] with onlookers being unable to empathize with autistic ways of being. A change of focus towards the Tourettic lived experience is not only ethically necessary to include the testimony of those diagnosed but has important theoretical implications.[9]

Such a change of focus has already been explored in the case of autism as an exercise in 'letting be'.[61] De Jaegher and Di Paolo started from a specific enactive view in which human meaning-making is grounded in 'participatory sense-making'.[62] In this enactive view, an intersubjective breakdown cannot be attributed to a deficit in communication in one of the participants,[63] but attention ought to be paid to both parties (re)establishing inclusive communication. This approach is uniquely positioned to do justice to the issues and opportunities that are raised in this review. Specifically, within the neurodiversity context, Maclaren calls attention to the phenomenological concept

of 'letting be'.[64] Letting be is finding out what something is and can become on its own terms by neither over- nor underdetermining it, while sensitively interacting with it.[65] In other words, it means approaching a phenomenon without forcing preconceived reference structures onto it. In the case of Tourette's, as in autism, this means being attentive to the everyday issues diagnosed people encounter without losing sight of how these problems are embedded in their further life. Merely seeing Tourettic people through the lens of their tics overdetermines them while at the same time underdetermining them by not relating to positive (and negative!) aspects related to their overall experience of Tourette's. In a clinical setting 'letting be' leads to the familiar weighing of therapeutic options starting with the holistic assessment of a Tourettic person.[25] Such an enactive view is moreover in line with the biopsychosocial model.[54] The key to letting be in this context is to start from the view of a Tourettic person by focusing on their felt impairment within their social environment rather than just on tic severity since these aspects do not correlate.[17]

Tourette's should no longer be seen and treated only from a detached onlooker point of view with a *sole* focus on disruptive tics; clinical scholarship *also* ought to be even more sensitive to the issues Tourettic people experience in their everyday lives. Taking away this single focus and making an effort to understand Tourette's from its lived experience beyond tics, allows Tourettic persons to express their way of being and allows them to relate to it in a more holistic way. They then do not have to formulate their experience only in terms of standardized and quantifiable tics, which are most visible to and found disturbing by onlookers. Letting be does *not* mean 'letting Tourettic persons go' in the sense of not caring about the difficulties they face. It simply means that to make new progress for the well-being of people with Tourette's, the research methodology of the social sciences and medical humanities are not only crucial but complementary to those of the neurosciences.

DATA AVAILABILITY STATEMENT

The interview data that support the findings of this study are available on request from Jo Bervoets. The data are not publicly available due to privacy or ethical restrictions.

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