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# Tourettic Research of Tourette Syndrome: Some Reflections

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## Abstract

Tourette syndrome (TS) research is largely conducted by non-Tourettic stakeholders from a clinical and medical or external perspective. Reasons for this may include the ableist structures that exist for disabled and neurodivergent folk within academia. This article reflects on the authors' experiences of conducting research into TS as two early career researchers who have a confirmed diagnosis of TS themselves. The article maps our experiences through TS research, categorising experiences relating to *representation*, *additional labour*, and some specific reflections on *data collection*. In highlighting our distinct experiences, we hope to encourage more consideration of the embodied intricacies of conducting this kind of research as Tourettic researchers, and to encourage further discussions relating to access and inclusion in TS research spaces.

## Keywords

disability, neurodiversity, research methods, lived experience, Tourette syndrome

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## Introduction

Tourette syndrome (TS) research is largely conducted by non-Tourettic[1] stakeholders in TS. This includes, but is not limited to, healthcare or diagnosing professionals (doctors, psychiatrists and paediatricians) and those who are externally impacted (e.g., parents, family members, friends and partners). As such, there can be a clinical, medical or externally viewed predominance of research. There are many potential reasons for this, whether in the ableist structures that exist for disabled and neurodivergent folk within academia, the lack of academic journals that focus on the specific nuances and experiences of TS as a priority, or otherwise. Disabled experiences of academia have been extensively explored in recent years (cf. Brown & Leigh, 2018; Lourens, 2021; Price, 2024) shedding light on important factors such as comfort of disclosure in the face of stigma and the normative pressures to achieve exceptional academic performance. However, this article specifically addresses some of the distinct experiences that we as early-career TS researchers – who both have a diagnosis of TS (hence 'Tourettic') – have had, with particular focus on PhD-related reflections and our experiences as early career researchers.

At the time of writing, Daniel has recently completed his PhD based at Newcastle University, is conducting research into the embodied experiences of public spaces had by adults with a TS diagnosis. His work was based in the department of Geography, Politics and Sociology at Newcastle University and is particularly inspired by creative research methodologies and analysis through a spatial lens. Furthermore, he is currently a Research Associate at The University of Sheffield, working on a project surrounding anti-ableist research culture, focusing on research methods and accessible academic events. Danni, a self-funded third-year part-time PhD researcher based at the University of Hertfordshire, has dedicated her research to raising the profile and recognition of tics and Tic Disorders in adulthood. This devotion was sparked by her

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own recognition journey when diagnosed with TS in her 30s, and as such she aims to amplify adult voices of lived experience by her studies. Her work is based in the School of Life and Medical Sciences with a Psychology focus. Like Daniel, Danni has employed a diverse range of creative and cross-disciplinary methodologies – such as the creation of audiovisual installations and spectrogram and music-coded analysis – to explore experiential cognition of the condition. She is currently leading a study within an ArtSci Lab collaboration that examines everyday tics in adulthood. In this project, she has co-developed the research methodology and outcomes alongside participants and art specialists. This includes method-setting workshops, participant-led video capture, and participant interviews to gather responses to the results (Godman et al., 2024).

As researchers, we crossed paths through mutual colleagues and involvement in academic projects and spaces. We began talking about our experiences as adults with TS and how that plays a role in our research and the navigation of work as Tourettic TS researchers. Through discussions we came to realise that our experiences of TS research and its associated academic spaces were distinct from those of other researchers in the field. Furthermore, we found that our own research practices have been significantly shaped by our own Tourettic positionalities.

This collaborative reflective paper highlights the distinctive ways in which we, as Tourettic TS researchers, experience academia. We initially discuss the current representation in the field and its influence over our research motivations and positionalities. Next, we explore the additional hidden and emotional labour that is intertwined with conducting TS and Tic Disorder research as Tourettic researchers. Finally, we reflect on some specific considerations and challenges encountered while collecting data in qualitative, people-centred research on TS. Through these reflections, we ask 'who is the imagined researcher in TS?', aligning with some methodological literature about the tensions that exist between insider and outsider epistemologies (cf. Ademolu, 2024; Geirbo, 2019). We detail first-hand Tourettic experiences within academic spaces and provide valuable insights for established TS researchers and professionals, in a current landscape of calls for further Tourettic involvement in TS research.

## Representations

Within research and clinical settings, Tourettic adults are not so well represented. Much of the existing and ongoing literature surrounding TS specifically concerns children and young people experiencing the syndrome or concerns Tic Disorders in a broader non-specific age-based focus (cf. Andrén et al., 2021; Boudjouk et al., 2000). While interest and research on TS appears to be on the rise, there is still a gap in understanding the experiences of adults and life-long implications. Examples of valuable research that has been conducted in adulthood experiences are very limited, however there are a few instances that are key to note here. Conelea et al. (2013) discuss the significance of the avoidance of public spaces and the experiences of discrimination had by adults with a diagnosis of TS. Also considering the specific case of adulthood and TS, Malli et al. (2019) explore the ways in which Tourettic adults incorporate TS into their sense of self, and share that their adult participants shared meaningful experiences of social withdrawal and self-stigma additional to externally experienced stigma. However, it is fair to say that perhaps TS researchers need reminding that Tourettic children grow into Tourettic adults. While tics may fluctuate in severity and prominence, TS does not simply *disappear*. The significant focus on children and young people might be said to have contributed to the infantilisation of TS. Part of this is due to the restrictions in how external research councils and funding bodies approach their funding of TS research (Jones, 2023), but adult-focused research *does* exist – be it in Danni or Daniel's aforementioned research, or otherwise such as the work of Malli et al. (2019).

The predominant focus of TS as a childhood disorder researched in a clinical and medical way is something that we both have noticed in the professional spaces we occupy. We might walk into a TS conference and be assumed to be attending based on an idea that we are patient representatives due to the overt nature of tics. It is no secret that academia is not regarded as accessible for disabled or neurodivergent colleagues (Smilges, 2023) and this is only highlighted by specific working projects such as the *Anti-Ableist Research Cultures* project hosted by the University of Sheffield (2024). Conversations and moral panics in Higher Education-based literature have been happening in recent months regarding concern over accessibility accommodations 'going too far' (Levinovitz, 2024), and there have been multiple threads of conversation beginning to happen in response to this (Jones & Gauthier-Mamaril, 2024; Von Bergen, 2024). Academia has long been described as inaccessible, from both a student and an employee perspective (Brown & Leigh, 2018; Husson & Jones, 2023; Olsen et al., 2020). Additionally to navigating ableist academic accommodation loops, we as Tourettic non-clinical TS researchers unwillingly assume the role of underdog – an *academic rebel*. Simply, our presence in academic inaccessible spaces whereby we are assumed to exclusively fit the role of *patient* makes us seem confrontational before we even begin to communicate. Our positionality as Tourettic renders our involvement in these spaces and contexts *political*, making our engagement susceptible to scrutiny and potential criticism.

Within this representation section, we also want to recognise the impact of our own white privilege. Beyond considering the experiences of adults and women with TS, it's important to note the significant lack of diversity in TS representation. Currently, we believe there is a sparse lack of papers that consider global majority ethnic (GME) experiences of TS, much less those of GME Tourettic adult women. Despite these challenges, TS appears consistent across all ethnicities, cultures and social classes, though data highlighting GME experiences of TS is still significantly limited (Dy-Hollins et al., 2024). Even within England, there is a significant lack of consistency regarding the availability of TS service provision and treatment (National Steering Group for Tics & Tourette Syndrome, 2025). As white British researchers, we acknowledge that there is a representational and accessibility issue surrounding intersectionality in TS research, and here we want to call for this to be addressed within the field moving forwards.

## Additional and Hidden Labours

Although we may be seen as 'political', our commitment to social justice has been a driving force to be scholars in TS research. Our pursuit for representation results in additional hidden emotional labour that non-Tourettic TS researchers typically do not encounter. Hidden labour, defined by Scully (2010, p. 25) is labour '*carried out by disabled people to manage or manipulate the presentation of their impairment to others*'. Ahmed (2017, p. 135) similarly writes '*If you are not white, not male, not straight, not cis, not able-bodied, you are more likely to end up on diversity and equality committees. The more nots you are, the more committees you might end up on*'. Whilst Ahmed refers specifically to EDI work in Higher Education spaces, these scholars highlight key issues of how marginalised people are often the ones who end up *doing* the work to fix issues surrounding accessibility and representation. Historically, this might have been in disabled-led campaigning in 1980s England for equal education and housing rights, or in the formation of various disability action groups (Greater Manchester Coalition of Disabled People, 2010). Today, this might include – but is not limited to – the requirement of mobility-aid users to more carefully plan out step-free routes around the institution; feeling pressured to suppress tics when in professional academic environments as to not be deemed disruptive, or even the specific case of co-authoring this article as two Tourettic scholars ourselves who are frustrated with current TS research discourse.

It is key to highlight some of the specific hidden labour activities that we as Tourettic TS researchers ourselves take on. In addition to the emotional burden of being seen as an underdog in academic settings, we face extra challenges in operating in and occupying the same academic spaces as our non-Tourettic colleagues. Some of these challenges are common across academic environments, while others are TS specific.

Oftentimes, academic events are filled with expectations of being quiet and respectful in conference or symposium spaces. It is key to reiterate that tics are involuntary and impulsive. Some Tourettic people can employ tic suppression for a limited period, but tics inevitably surface, and the effort to suppress them can be especially exhausting. There is an additional labour for Tourettic researchers in attempting to suppress or redirect tics to not emphasise their Tourettic identity – to pass as acceptable, able-bodied and *capable* researchers. Tics can also be exasperated by witnessing others performing tics or tic-like behaviours. In TS specific academic spaces, there is a common practice to share videos of patients ticcing. This content can be particularly triggering and, due to the suggestibility of tics, may increase the effort needed to suppress or redirect them.

Moreover, our positionality often drives us to engage in participatory practices, and we sometimes face additional pressure from the TS or Tic Disorder communities. Many within the community have expressed frustration with the current discourse on TS, and we both have encountered instances where participants urge us to 'do well for the community' or express gratitude for our efforts on its behalf. While these sentiments are well-meaning, they add pressure and a sense of responsibility to ensure that we accurately represent the diverse range of experiences when researching, presenting and writing about TS.

From an intersectional perspective, Danni, as a Tourettic woman, may be subject to even more additional labours than Daniel in these spaces. Particularly in academia, women are underrepresented in prominent authorship positions (first or last author, dependent on academic discipline), encounter biases in peer review processes, receive fewer citations and less recognition, secure less research funding, and face limited opportunities for advancement to senior positions (Gruber et al., 2021; Llorens et al., 2021). Again, to use the words of Ahmed, the more 'nots' you are, the greater that additional labour you undertake is likely to be, regardless of the underrepresentation experienced. As *not* male, Tourettic women are more subject to stigmatisation in this regard (Coleman & Melia, 2024). Women also may experience later onset and peak severity of tics, with potentially more complex and varied co-morbid conditions than men, making it less likely for their symptoms to align with diagnostic norms (Garris & Quigg, 2021).

In addition to the range of micro-aggressions that people with visible and invisible disabilities may face, Olkin et al. (2019) identified two potential additional micro-aggressions experienced by women in their study. One was the disbelief or dismissal of their symptoms by medical professionals, who may be prone to attributing them to psycho-emotional factors – resulting in potentially disparate medical care and gatekeeping. Another mentioned was the perception that women would be perceived as 'too healthy' or 'too attractive' to have a disability, a stereotype that undermines their lived experience while subtly reinforcing gender inequalities. Notably, in recent years, Tourettic women in particular have been subject to particularly significant stigmatisation when considered in academic research, with suggestions of teenage girls *catching* TS through social media contagion via sites such as TikTok (Hull & Parnes, 2021; Muller-Vahl et al., 2022; Olvera et al., 2021; critiqued by Conelea et al., 2022) – which impacts on the way that Tourettic women are perceived in TS research spaces. Additionally, from our standpoint as white Britishness researchers, this additional labour exponentially increases with further intersectional considerations. For example, what for GME Tourettic populations who may feel that they are even less well represented than white Tourettic folks? How are race-based tics received by GME Tourettic people, comparatively to white Tourettic people who may have similar tics? We cannot speak to this from a position of personal experience, though this is something being explored in more depth within Daniel's forthcoming PhD thesis (Jones, forthcoming). Once more – the more 'nots' you are, the greater the additional labour.

## Data Collection (From Research Inception to Publication)

Following on from the broader narrative of representation and additional labour, there are specific points to highlight related to our research from inception to publication. Our individual research methodologies lead to the collection of empirical data, specifically in the collection of Tourettic experiences. This approach, along with our previous experiences and personal positioning, contributes to unique experiences that differ from those of non-Tourettic researchers in the same field.

For example, in the construction of aims and intentions for qualitative and quantitative research, our nuanced familiarity with TS and related conditions inspire us to undertake collaborative participatory research approaches, attempting to carefully consider how each research phase aligns with community need(s). This collaborative planning for the future beyond any smaller project timelines and the achieving if *change* that aligns with community needs are key in participatory action research (Pain & Francis, 2003; Pain et al., 2019), and as researchers with lived experience ourselves, we are particularly aware of the effects of our research and the value of participatory approaches. Like other researchers who do not have TS, each researcher draws upon their existing knowledge or understanding of the condition in the formulation of research intention. Therefore, our inquiries incorporate both experiential and informed elements, ideally providing fresh perspectives and new angles for investigation compared to traditional research approaches. For example, Danni's research, influenced by her personal experiences with TS as an adult, atypically concentrates on manifestations in adulthood. Additionally, our personal TS relationship may prompt us to particularly consider the ethical implications of research participation and the proposed methodologies employed on individuals, as well as to the debriefing and support mechanisms available to assist them.

A condition like TS also gives unique considerations regarding researcher interaction during data collection with participants. When conducting focus groups or interviews, there is an embodied physical and verbal distinctiveness in how Tourettic bodies might interact with each other. Tics can be suggestable, environmentally triggered and exacerbated particularly when witnessing similar symptomology (Efron & Dale, 2018). This potential transient exacerbation of tics may lead to increased likelihood of physical (e.g., pain) and emotional (e.g., embarrassment) stress in participation for both participant and researcher. Similarly, tics, particularly copropraxia and coprolalia, may raise concerns, inadvertently generate offence or conflicting ideology to expressed views, and consequently there may need to be more accommodations made (such as check-ins and clarifications of intention) during data collection discourse. During remote online interviews, both parties may have the option to manage their tic interruptions by utilising the mute function or opting not to display their camera. As such there is an additional multifaceted layer of interaction to disclose to participants prior to, and navigate during, data collection for Tourettic researchers.

Nevertheless, the involvement of Tourettic researchers in conducting TS research may also enhance the relationship between participants and researchers. These researchers may have a strengthened ability to establish an empathetic connection and inspire a sense of kinship and non-judgemental comfort with participants. Resultantly, participants may feel more inclined to share and reveal experiential information because of this connection, trusting that their accounts are being carefully considered and listened to. They may perceive the research process as more collaborative, feeling that it is being conducted 'with them' rather than 'at them'. Yet, the bond between researcher and participant can also introduce further hurdles in extracting detailed personal accounts, stemming from an assumption of shared understanding – 'you know what it's like…'. Tourettic researchers may also need to be wary, especially when conducting interviews that follow up or where clarifying questioning is not relating too much to participant experience or personal investment. Consequently, the Tourettic researcher may need to exert extra efforts to capture the participant's reality.

When transcribing collected data, the Tourettic researcher relives the embodied interaction between themselves and the participant. Daniel notes that as he watches the recordings, he finds himself experiencing more tics, not just due to the participant's tics but also his own. Danni shares similar experiences and ensures to take regular breaks during transcription. Another consideration encountered involves determining how to represent verbal tics within transcribed data or quotations used in research.

This necessitates careful reflection and deciphering what is and is not a tic during discourse. Although Tourettic researchers may be able to identify tics easier due to personal familiarity, it is not absolute, especially given the individualistic nature of tic experience and presentation. While certain tics might be confirmed during real-time discourse, one method employed by both authors involves transcribing suspected tics using square brackets. Depending on specific research objectives, researchers may allow participants the option to decide whether tics should be incorporated into the data. However, tic elimination carries the potential for censorship or loss of nuanced data and layering of meaning. Conversely, despite participant anonymity, participants may feel embarrassed and may be less inclined to participate in current and future research if their tics are included.

Furthermore, our Tourettic identity may influence our approach to carrying out data analysis. It may be influential in determining what we perceive as meaningful, relevant, and significant. In thematic analyses, the dynamic process of comprehending the participant's personal world is influenced by researcher preconceptions (Braun & Clarke, 2006). The same is true of any overview of literature, especially commentaries or unstructured systematic reviews we may undertake to understand the current landscape of our field (Gregory & Denniss, 2018). Some viewpoints may argue that adopting an observational stance from a distance, detached from the condition, could offer greater objectivity. However, it is important to note, especially as PhD students at the time of writing, that our research and conclusions are rarely, if at all, achieved in isolation. While undoubtedly relying on our interpretive resources, such as personal experiences, we aim to ensure the integrity of our potentially more contextualised latent interpretations by acknowledging our theoretic stance. This entails engaging in research supervision and member checks to validate our sense-making processes. By employing both a non-Tourettic and Tourettic scrutinisation of data, we endorse a higher standard of research outcomes that prioritise and authentically represent the voices of participants. This commitment aims to shift the scientific conversation surrounding the condition through educational research.

In the realm of research representation, we encounter an extra challenge when seeking publication. Unlike certain other co-occurring or neurodiverse conditions like autism, there are few journals available that acknowledge our findings without deeming TS too specialised. Furthermore, a significant proportion of researchers in the TS field are clinicians, rather than solely academic researchers. This exacerbates the challenge of navigating the political gatekeeping, fast-paced environment, and competitive landscape inherent in academia. However, as aforementioned, we hold the belief that our research contributions and promotion of our Tourettic stance enhances the existing body of knowledge and can coexist alongside other studies to promote holistic TS understanding.

## Some Concluding Remarks

Our experiences as Tourettic researchers of TS are complex and intersectional, and this furthers the evidence for the need for interdisciplinary approaches to neurodiversity and disability in research contexts (Shah & Holmes, 2023). Researching a stigmatised identity is difficult even prior to the added complexities of researcher lived experience that goes beyond parenting of Tourettic children. Our lived experience influences every part of the research process, from inception to data collection to research dissemination. Whilst the experiences listed above summaries some of our key reflections from our collective decade in TS research spaces, this list is by no means exhaustive. Here we urge further discussion and a deeper understanding of the ways in which researcher lived experience can influence the spaces we choose and are able to occupy and the research we conduct. The first-hand reflections provided in this article are significant as they clearly span multiple disciplinary backgrounds, and offer further nuanced consideration of Tourettic involvement in disability and neurodiversity research spaces. Considering our individual experiences here offers an entry point into broader questions about the imagined normative researcher that would be beneficial to explore in greater depth moving forwards. Non-Tourettic stakeholders in TS research can (and should) contribute meaningfully in allistic ways for Tourettic people, and the creation of collaborations between Tourettic and non-Tourettic TS researchers is just one way in which this might be done, aside from simply centring the most affected by TS – Tourettic people. In fact, this is something that both of us as Tourettic TS researchers are actively working towards, and hope to see much more of it moving forwards with the discipline. TS research can greatly benefit from Tourettic researcher contributions and collaborations. Whilst there are calls for further Tourettic involvement, we must continue to actively work towards this in the context of the existing barriers and nuances to Tourettic involvement with TS research that exist.

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## Note

1. We adopted the term ‘Tourettic’ as a self-descriptor and to describe others with TS, aligning with the usage outlined by Bervoets et al. (2023). This terminology aims to reframe experiences away from the pathological or medicalised connotations associated with ‘syndrome’ or ‘disorder’.

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