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clinical care suffers

Item Type	Article (Accepted Version)
UoW Affiliated Authors	Whittaker, Daniel
Full Citation	Malli, M. , Whittaker, Daniel and Phoenix-Kane, D. (2026) When Tourette syndrome is reduced to a debate about offence, clinical care suffers. The BMJ, 392 (s473). pp. 1-2. ISSN 1756-1833
DOI/ISBN/ISSN	https://doi.org/10.1136/bmj.s473
Journal/Publisher	BMJ Publishing Group Ltd. The BMJ
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License	n/a
Link	https://www.bmj.com/content/392/bmj.s473

When Tourette syndrome is reduced to a debate about offence, clinical care suffers

Misunderstanding of Tourette syndrome is not confined to the media; it can shape recognition, delay diagnosis, and limit care, write Melina Aikaterini Malli, Daniel Whittaker, and Danni Phoenix-Kane

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Recent media coverage of the John Davidson's tics at the Baftas followed a familiar script.¹ What should have prompted understanding and awareness of Tourette syndrome became a debate about offence and public decorum, while the condition itself receded into the background.

When Tourette syndrome is discussed primarily through offence and acceptability, it becomes harder to recognise accurately how it manifests in everyday life, including in healthcare. The result is not just misunderstanding but a narrow and insufficient assessment of the whole person, poorer outcomes, and a greater burden on people with Tourette's to explain themselves and mask their condition.

Tourette syndrome is a neurodevelopmental condition marked by involuntary motor and vocal tics and commonly co-occurs with attention deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder. Yet public discussion tends to reduce Tourette syndrome to its most sensationalised form: swearing, spectacle, and loss of control. Coprolalia, commonly understood as involuntary swearing or obscenity, is only one possible symptom and only a minority of people with Tourette syndrome experience it.

This is not simply a representational problem but a clinical one. Research in UK primary care suggests gaps exist in recognising different types of tics, distinguishing them from other conditions, and knowing where to refer people for specialist support.² Negative stereotypes could also inhibit people coming forward for diagnosis, particularly in adulthood.³ This, in turn, might negatively affect reported prevalence rates, clinical exposure, and the level of support available. Two of us (DW and DPK) live with Tourette syndrome, and our different experiences show the barriers to accessing care, from avoiding seeking support because of the

fear that a less stereotypical presentation would be regarded as undeserving, to having a prolonged and difficult journey to diagnosis, beginning with being dismissed at first contact with primary care.

Care gaps are compounded by uneven clinical pathways. The UK National Institute for Health and Care Excellence (NICE) still has no single comprehensive clinical guideline for the diagnosis and management of Tourette syndrome. NICE notes variation in practice and defers to recommendations for broader tic disorders rather than a dedicated guideline for Tourette's. In practice, this can mean that care depends on whether someone with Tourette syndrome happens to encounter a clinician with sufficient experience and confidence.

Misunderstanding and stigmatisation are a substantial part of the condition's burden. Qualitative accounts, including our own research, describe long delays before diagnosis and encounters with general practitioners who did not recognise Tourette syndrome, were unfamiliar with its presentation, or relied on inaccurate, outdated assumptions. Others described a different but related problem: Tourette's was reduced to swearing, while their pain, fatigue, emotional distress, and co-occurring difficulties were overlooked.⁴ Such framing can lead people without coprolalia to distance themselves from the wider Tourette's community, while those with coprolalia are stigmatised.⁵

Narrow stereotyping will likely have a negative impact on clinical practice. Clinicians cannot control public commentary, but they can avoid reproducing its assumptions. Tourette syndrome is heterogeneous. Some will have more visible or disruptive tics; others may present with suppression, exhaustion, distress, or difficulties linked to the social consequences of living with Tourette's. People whose symptoms do not fit familiar expectations should not have to work harder to be believed.

A better clinical response begins with comprehensive assessment. Clinicians should ask about motor and vocal tics, but also about premonitory urges and mental tics, pain, fatigue, anxiety, mood, and the effect of symptoms on daily life. They should actively consider co-occurring conditions, which may be as impairing as the tics themselves. Language matters too. Narrow questions about swearing or responses that trivialise the condition can discourage future help seeking and undermine trust.

Healthcare systems need better training and clearer routes to care, since support is currently fragmented. A system that depends on chance encounters with informed professionals is failing people with Tourette syndrome. When stigma dominates public narratives, an understanding, non-judgmental clinician may be one of the few sources of

reassurance and guidance.^{4,6} Improving care means more consistent referral pathways, better professional education, and greater recognition that stigma is part of the clinical picture.

When Tourette syndrome is framed mainly through offence or spectacle, the damage does not end with bad reporting. It shapes recognition, narrows assessment, and leaves people carrying the burden of correcting other people's assumptions. The Baftas coverage could have improved public understanding. Instead, it reinforced stereotypes and, in satire, framed Tourette's as an "excuse" for deliberately inappropriate behaviour.⁷ Healthcare must be one place where that does not happen.

Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

¹ Johnson R, Horsburgh L. Baftas row "has sparked Tourette's negativity", mum says. BBC News 26 Feb

2026. <https://www.bbc.co.uk/news/articles/cj98z31pxrvo>

² Phoenix-Kane D, Keville S, Davies EB, Ludlow A. Making the shoe fit: a thematic analysis exploring the journey of adult tic recognition and acceptance in the United Kingdom. *Adv Ment Health* 2025;1-23. doi:10.1080/18387357.2025.2584410

³ Phoenix-Kane D, Keville S, Davies EB, Ludlow A. Experiences of self-identification, diagnosis and support for adults seeking a recognition of tic disorders in the United Kingdom. *Prim Health Care Res Dev* 2026;27:e23. doi:10.1017/S1463423626100905. PubMed

⁴ Malli MA, Forrester-Jones R. *Tourette's syndrome, stigma, and society's jests*. Palgrave Macmillan, 2025, doi:10.1007/978-3-031-83368-7

⁵ Zito RC. When you're (not) the stereotype: coprolalia stigma in the lives of adults with Tourette syndrome. *Deviant Behav* 2025. doi:10.1080/01639625.2025.2531145

⁶ Curtis-Wendlandt L. *Chasing Tourette's: time, freedom, and the missing self*. Springer, 2023. doi:10.1007/978-3-031-19104-6

⁷ Saturday Night Live criticised for "hurtful" Tourette's sketch. BBC News 2 Mar 2026. <https://www.bbc.co.uk/news/articles/c05v0ln6nq3o>