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# Stigma and Adults with Tourette's Syndrome: "Never Laugh at Other People's Disabilities, Unless they have Tourette's—Because How Can You Not?"

Melina Aikaterini Malli<sup>1,2</sup> · Rachel Forrester-Jones<sup>3,4</sup>

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## Abstract

Tourette's syndrome (TS) is a condition that has been stigmatised and mocked in contemporary society, yet little is known about the subjective experience of those directly affected by it. Guided by Public and Patient Involvement (PPI) a mixed method design was used for this study to explore the experience of stigma in adults living with TS in the UK. A total of one hundred and ninety-nine adults participated in a cross-sectional online survey using an adapted version of the Discrimination and Stigma Scale (DISC-12) and the Perceived Quality of Life (PQoL) scale, twenty of whom were also interviewed using a semi-structured interview schedule. Quantitative findings indicated that participants experienced discrimination in numerous life domains; most prominently in education (75.4%), social life (71.4%), public transport (60.8%) and employment (54.3.%). The PQoL of adults with Tourette's was found to be negatively correlated with both *Enacted* and *Anticipated Discrimination* from the DISC-12 scale. Qualitative findings illustrated the pervasive nature of TS stigma, which expanded beyond micro-interactions, and which could be observed at a structural level. The peculiar impact of disparagement humour in the construction and promulgation of "othering" individuals with TS was also highlighted. Concealment and self-stigma were mechanisms commonly utilised by individuals to manage their "spoiled identity", inhibiting active and collective responses to stigmatisation. The study highlights how TS stigma acts as a barrier to social and economic participation for adults with the condition and helps identify factors that need to be considered when developing anti-stigma strategies.

**Keywords** Tourette's syndrome · Stigma · Discrimination · Disparagement humour · Trivialisation

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✉ Melina Aikaterini Malli  
[melina.malli@phc.ox.ac.uk](mailto:melina.malli@phc.ox.ac.uk)

Extended author information available on the last page of the article

## Introduction

Tourette's syndrome (TS) is a neurological condition with childhood onset characterised by tics, involuntary unwanted movements and vocalisations that can vary in frequency, complexity and intensity (American Psychiatric Association, 2013). It presents a complex and multifaceted clinical picture as the tics have a waxing and waning course and, in most cases, they are accompanied by behavioural comorbidities such as Obsessive–Compulsive Disorder (OCD), Attention Deficit Hyperactivity Disorder (ADHD), anxiety disorders, and depression (Robertson, 2012). TS is estimated to have a prevalence of 0.30–0.77% in school aged children and it follows a remitting course, improving in late adolescence. Nevertheless, a sizable subset of individuals live with TS in adulthood (Gill & Kompoliti, 2020).

The condition has been portrayed as the 'swearing disease' within mainstream media (Calder-Sprackman et al., 2014; Fat et al., 2012) by virtue of the symptom of coprolalia (involuntary utterances of obscene words), although this feature of TS is fairly uncommon (Freeman et al., 2009). It has also been rendered as synonymous with unpredictable behaviour (Malli et al., 2016) and it has served as a pretext by a number of public figures within the entertainment industry and the political arena to hurl insults and offensive statements with impunity. Indicatively, in 2012 UK Prime Minister (PM), James Cameron, characterised the heckling of his opponent Ed Balls in parliament as "having someone with Tourette's sitting opposite you" (Chapman, 2012). The former PM's comment exemplifies how the condition is associated with metaphorical references to incoherent behaviour and instability. Previous research (Sontag, 1989) has shown how the misuse of conditions and illness metaphors reflect society's underlying stigmatising attitudes.

Despite the 'social meaning' of TS, the condition has mostly been examined through the lens of the medical model, which views the tics as a deficiency; a problem that needs to be cured so that those with it can function "normally" in society, whilst the perspective of those affected by Tourette's has been omitted from the literature (Malli et al., 2019). Diminished wellbeing of individuals with TS has mainly been attributed to individual traits and associated with clinical variables, such as severity of tics (Evans et al., 2016). This conceptualisation frames the individual as the problem, absolving society of any accountability; ignoring the role that ignorance, stereotypes and prejudice plays in prohibiting inclusion and social participation (Shakespeare, 2006). This medicalisation of the condition may account for why TS stigma has not adequately been addressed as a legitimate concern within care and practice. Similarly, research exploring the social determinants of TS have been sparse; the few studies that do exist indicate that misinformation and misconceptions around TS have led to stigmatisation and discrimination (Cox et al., 2019; Malli et al., 2016) and the narratives of individuals with TS are saturated with accounts of rejection, harassment and stigma (Malli et al., 2019; Smith et al., 2015).

Stigma has been characterised as "an attribute that is deeply discrediting", and that devalues individuals, depriving them of full social acceptance (Goffman,

1963, p.3). It has been highlighted that this “blemish” is not a trait intrinsic to the individual, but a social construct generated by social interactions. In other words, the “normal” and the stigmatised are not persons but perspectives (Crocker et al., 1998). Link and Phelan (2001) have defined the phenomenon as the co-occurrence of its components – labelling, stereotyping (negative evaluation of a label), separating those labelled from “us”, status loss, and discrimination. Discrimination is the behavioural component of stigma, but not all forms of discrimination are a result of stigmatisation. For the latter to occur, there needs to be a separation between “us” and “them”, namely, a form of “othering” and a power imbalance must exist between the stigmatised and the stigmatiser, with the latter in position of dominance. Stigma does not solely manifest in everyday interaction, and it is not the work of any single individual. Rather, it originates from broader social forces and may be systematically applied in practice by agencies, policies and institutions (Hannem, 2012; Hatzenbuehler, 2016). Many studies suggest that stigma is associated with diminished quality of life (Jacoby, 2002), and can deprive people and groups of their rightful life opportunities related to important life goals (Corrigan, 2014; Jacoby, 2002). It can also negatively impact their psychological well-being, including their self-esteem, self-perception and group-identification (Corrigan & Bink, 2005).

A systematic review by Malli et al. (2016) and the synthesis of Smith et al. (2015) highlighted the lack of comprehensive research that delves into the subjective, first-hand accounts of individuals suffering from TS stigma. Thus, although in some qualitative studies using an inductive research approach (Malli et al., 2019) stigma emerged as a finding, there is a dearth of qualitative or quantitative studies that have set out to examine the nature and impact of stigma. Consequently, the mechanisms underlying TS stigmatisation have remained largely unclear and due to the unique nature of the condition, mental illness stigma theories may not be relevant to this population. This might help explain why anti-TS stigma programs have been largely unsuccessful (Friedrich et al., 1996). As Sartorius (2008) has argued, interventions that combat stigma need to be rooted in the accounts of the population it affects, who can identify the most problematic aspects of their experiences that need to be addressed. The overall purpose of this research was therefore to provide an in-depth picture of the impact of TS stigma on the lives of individuals with TS, in order to inform current intervention practice. To this end, there were four aims:

1. to assess the extent and nature of stigma as experienced by adults with TS and to understand the influence of stigma on the participants’ quality of life;
2. to evaluate whether sociodemographic and clinical variables, such as age and the existence of co-occurring conditions, influence stigma;
3. to explore the everyday difficulties experienced by adults with TS as a result of stigma, as well as, what they perceived to be the drivers and core beliefs that perpetuate TS stigma;
4. to map the coping strategies adopted by individuals with TS to help manage stigma.

## Methods

### Study Design

A concurrent parallel mixed-method study was used, in which two sets of data (quantitative and qualitative) were collected and triangulated to gain a comprehensive understanding of the phenomenon (Cresswell et al., 2011). A pragmatic methodological approach was adopted to prioritise the research question over methodological disputes, and to accept both constructivism and positivism. Equal weight was put on both sets of methods of data in order to gain a deeper and broader understanding of the research topic (Tashakkori & Teddlie, 2010). Through a national online survey, we assessed the prevalence of stigmatisation amongst individuals with TS; the nature and the context in which discrimination manifests; whether sociodemographic and clinical variables, such as education, age, and comorbidities of the stigmatised influence discrimination; and we measured the impact of Tourette's stigma had on individuals' quality of life. This was followed by in-depth interviews, which provided a deeper and richer picture of the experience, the perceived causes and the way TS stigma manifests in the lives of those affected by the condition.

### Patient and Public Involvement

Our study was informed and guided by INVOLVE's definition of public involvement in research: doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public (<https://www.invo.org.uk/>). The first author regularly participated in Tourettes Action support groups; concerns, apprehensions and personal experiences expressed by many individuals with TS directly fed into the research question, agenda and design. Furthermore, an advisory group comprised of 18 people with TS collaborated with the researchers in all stages of the study, including the development of user-relevant and culturally appropriate participant information sheets, survey and interview questions. The group identified lines of inquiry, advised on the most appropriate interview style and helped keep the research on track. Many suggestions were made that significantly impacted the content and language of the text. Some advisory group members also took part in a short recruitment video outlining the purpose and nature of the study (see Recruitment and Procedure section). Post-analysis, five members from the Advisory group were asked to verify the findings. They were able to add their alternative perspectives and provided insightful interpretations of the data but also confirm that it also reflected their experiences.

### Recruitment and Procedure

Participants were recruited via short video-adverts (see <https://www.youtube.com/watch?v=XVQTO0wew8A>) posted with a link to the study (both survey and interview elements) on relevant social media platforms (e.g., Tourettes Action Facebook page) and through the Research Participation Registry of Tourettes Action,

a voluntary database of individuals willing to consider participating in research. Snowball sampling within the TS community was also used. To avoid potential recruitment bias, adverts emphasised that people did not have to have experienced stigma to take part. The online survey and interviews were fielded from May 2019 to April 2020.

Adults were eligible to participate in the online survey if they were residing in the UK and had received a formal diagnosis of TS at least one year prior to the study. Consent and autonomy/voluntariness were implicit by choosing to fill out the online survey. At the end of the online survey, there was an invitation to take part in a one-to-one telephone or video interview. Prior to commencing the interview, each participant was given a written outline, verbal description of the study and consent form. A £10 voucher was given to anyone who took part in the interview in recognition of their time and contribution to the research. The study was given a favourable opinion by the Tizard Centre Ethics Committee, University of Kent (REF: 11/2018).

## Data Collection

### Online Survey

The survey consisted of three sections. The first section aimed to establish the nature of the sample, exploring demographic questions such as age, ethnicity, marital status, education, other self-reported mental health diagnosis or developmental condition and age of tic onset.

The second section was an adapted self-completion 25-item version of the Discrimination and Stigma Scale (DISC-12) (Brohan et al., 2013), which has been used in different settings and clinical populations worldwide. It comprised of two subscales. Subscale 1, *Experienced Discrimination*, contained 21 questions that aimed to assess the degree to which people with TS experienced stigma and discrimination in their everyday lives. Thus, questions were related to work, relationships, parenting, housing, leisure and religious activities (e.g., “*due to Tourette’s syndrome, have you ever been treated unfairly by people in your neighbourhood?*”). Subscale 2, *Anticipated Discrimination*, comprised of four questions that focused on how far participants would limit their involvement in everyday social participation due to the fear of discrimination (e.g., “*due to Tourette’s syndrome have you stopped yourself from applying for work?*”). Participants rated their experiences on a 4-point Likert scale (from “0 not at all” to “3 a lot”) and a non-applicable option was also available. Analysis of the DISC-12 has found that it has good psychometric properties including inter-rater reliability (weighted kappa range: 0.62–0.95), internal consistency ( $\alpha=0.78$ ) and test–retest reliability (weighted kappa range: 0.56–0.89) (Brohan et al., 2013).

The third section of the survey was The Perceived Quality of Life scale (PQoL) (Patrick et al., 1988, 2000). It is a 20-item measure that aims to assess individuals’ subjective evaluation of their physical, social, and cognitive health and well-being. Participants rate their satisfaction with aspect of life on an 11-point scale from “0 extremely dissatisfied” to “10 extremely satisfied”. Scores below 7.5 are interpreted

as “Dissatisfied”, and scores 7.5 and higher are interpreted as “Satisfied”. The scale has demonstrated good internal consistency ( $\alpha=0.88\text{--}0.91$ ) and convergent validity (0.70) (Patrick et al., 2000).

## In-depth Interviews

A semi-structured interview schedule— developed from the authors’ previous studies and this study advisory group— was used to explore individuals’ lived experiences of being affected by Tourette’s and stigma, their perceptions about societal responses to TS, and their coping strategies in relation to discrimination and stigma. We also asked participants what they thought might help to reduce the stigma they suffered (see Table 1). All interviews took place via video or telephone and lasted between 30 to 90 min, using an active interview approach (Holstein & Gubrium, 1995). In contrast to traditional interviewing techniques, in which the participant is viewed as a “vessel of answers” (Holstein & Gubrium, 2003, p. 12) to whom the researcher directs their questions at, this approach allowed the interviewer and the participant to collaboratively build an inter-subjective account of social reality. Subsequently, the wording of questions and probes were unique to each interview. All interviews were digitally recorded and transcribed verbatim.

## Data Analysis

Statistical analysis was carried out using SPSS-25. Descriptive statistics were used to summarize the demographics, subscale scores and mean scores of rating scales. Non-parametric tests were chosen to account for skewed distribution. To address the first aim of the study, Spearman’s rank correlation coefficients were run to examine the strength of association between interval data (e.g., *Enacted Discrimination* and *Perceived Quality of Life*). The Mann-Whitney was used to address the second aim of the study and identify whether the mean score of *Enacted Discrimination* differed between participants based on categorical demographic characteristics. For ordinal dependant variables (e.g., education), the Kruskal-Wallis tests was used. Statistical significance was set at the level  $p < 0.05$ .

**Table 1** Indicative Interview Schedule for Semistructured interviews

1. Please tell me what Tourette’s syndrome and being affected by the condition means to you?
2. What has it given to you and what has it taken away?
3. How has Tourette’s impacted different aspects of your life?
4. Does the term stigma have any relevance to your life? When? Where? Can you give me some examples?  
How do those instances make you feel?
5. Why do you think people behave the way they do towards individuals with Tourette’s syndrome?
6. How do you think this sort of behaviour could be stopped or changed?
7. How do you deal with people stigmatising you? What mechanisms do you use?
8. What support in relation to stigma do you think would be useful?

The interview transcriptions were coded using NVivo-12 software and subjected to inductive thematic analysis using Braun and Clarke's (2006) six-phase approach in order to identify patterns, concepts and themes across the dataset, and to provide a rich insight into the experience of stigma. Validity and credibility were ensured through reflexivity, member checking, and independent coding by the two authors (Lincoln & Guba, 1985). A reflective journal was kept during the interviews, transcription and analysis by the first author. Furthermore, to assess the accuracy of the interpretation of the participants' accounts, member checking was conducted "on the spot" during the course and at the end of the interviews. Finally, all the transcripts were independently coded by the second author to establish inter-rater reliability.

Findings from the quantitative and qualitative data set were analysed separately and independently and integrated in the interpretation stage through the process of triangulation and complementarity. In the former, the results were compared and contrasted to identify data convergence and divergence and, in the latter, the two methodologies were used to elaborate and enhance the knowledge of this specific phenomenon in an attempt to provide a fuller and more accurate description (Greene et al., 1989).

## Results

### Research Population

Whilst 232 adults with TS completed the online survey, 43 individuals were excluded (3 identified as being younger than 18 years old and 40 lived outside the UK), leaving a total of 199 adults. The mean age of the sample was 31.95 (SD = 13), with a range from 18 to 73 years old. Over half the survey sample identified as *White British* and *Single* (see Table 2).

Additional, (one or more) mental health conditions or developmental disorders were reported by approximately three fourths % of the participants. These included, amongst others, Anxiety Disorder, OCD, ADHD and Autism Spectrum Disorder.

A total of 20 (14 males, 6 females) took part in the one-to-one interviews. Their age ranged from 20 to 71 (mean = 33.5) and the majority identified as *White British* (n = 19). Fifteen reported comorbid diagnosis, including OCD, Anxiety Disorder, Autism Spectrum Disorder, ADHD, and Eating Disorders.

### Online Survey Findings

Mean scores of the *Enacted* and *Anticipated Discrimination* scales are reported in Table 3. The global result of being discriminated to any degree ("a little", "moderate", "a lot") indicated that the life domains, which the participants were more affected were education (75.4%), social life (71.4%), making or keeping friends (68.3%), public transport (60.8%), family (57.8%), dating (57.3%) and getting a job (54.3%) (Table 4). Fewer individuals reported discrimination in relation to

**Table 2** Demographic participant information on gender, education, marital status and ethnicity, age of tic onset and co-morbid conditions

Variable	
Gender	
Male	88 (46.1%)
Female	92 (48.2%)
Rather not answer	10 (5.7)
Marital Status	
Single/ Unmarried	125 (65.4%)
Married	50 (26.2%)
Separated	3 (1.6%)
Divorced	11 (5.8%)
Widowed	2 (1%)
Highest level of Education	
Primary Education or less	9 (5%)
Secondary education	45 (24.9%)
Further education	56 (30.9%)
University degree (undergraduate)	43 (23.8%)
University degree (postgraduate)	16 (8.8%)
Other general education	12 (6.6%)
Ethnicity	
White British	130 (71%)
White Irish	10 (5.5%)
Any other white background	25 (13.7%)
White and Black Caribbean	1 (0.5%)
White and Asian	2 (1.1%)
Any other mixed Background	5 (2.7%)
Indian	1 (0.5%)
Pakistani	1 (0.5%)
Any other Asian Background	1 (0.5%)
Asian British	2 (1.1%)
Chinese	3 (1.6%)
Other ethnic Categories	2 (1.1%)
Age of tic onset	
0–3 years old	11 (6.4%)
4–8 years old	96 (56.2%)
9–17 years old	48 (28%)
18 years old or older	16 (9.4%)
Existence of comorbidities	
Yes	129 (73.7%)
No	46 (23.1%)
Co-morbid conditions	
ADHD	42 (21.1%)
OCD	74 (37.2%)
Autism Spectrum Disorder	33 (16.6%)
Social Phobia	24 (12.1%)

**Table 2** (continued)

Variable	
Anxiety Disorder	87 (43.7%)
Disruptive Behaviour	5 (2.5%)
Mood Disorders	64 (32.2%)
Somatoform Disorders	12 (6%)
Trichotillomania	11 (5.5%)
Eating Disorders	11 (5.5%)
Alcohol Abuse	7 (3.5%)
Abuse or dependency	17 (8.5%)
Schizophrenia	2 (1%)

medical treatment, housing, parenting or personal security and safety, and dealing with the police.

The vast majority of the respondents (75.4%) appeared to cope with stigma and discrimination by concealing their condition. Approximately half (53.8%) did not apply for jobs or educational opportunities (50.3%) for fear of discrimination (Table 5).

In terms of PQoL, participants had a mean score of 5.31 (SD=2.04) on the 11-point scale. These figures compared unfavourably with those reported by their US counterparts (mean = 6.6 SD = 1.7) (Conelea et al., 2013).

No differences concerning *Enacted Discrimination* were found for any demographic variable such as gender ( $U = 242$ ,  $p = 0.117$ ), education ( $\chi^2 (5) = 9.413$ ,  $p = 0.094$ ), ethnicity ( $\chi^2 (11) = 7.27$ ,  $p = 0.738$ ) and marital status ( $\chi^2 (4) = 5.415$ ,  $p = 0.247$ ). No significant association was found between *age* and *Enacted Discrimination* ( $r_s = -0.024$ ,  $p = 0.768$ ). However, individuals with comorbidities reported experiencing significantly more *Enacted Discrimination* ( $U = 179$ ,  $p = 0.012$ ) than those without any *co-occurring conditions*.

A significant negative correlation was found between the PQoL of the participants and *Enacted Discrimination* ( $r_s = -0.630$ ,  $p < 0.001$ ) (Fig. 1). Poorer quality of life was also observed to be moderately associated with *Anticipated Discrimination* ( $r_s = -0.553$ ,  $p < 0.001$ ). Finally, *Experienced and Anticipated Discrimination* were positively correlated ( $r_s = 0.557$ ,  $p < 0.001$ ).

## Interview Findings

Participants explained their experiences of stigma in various ways, which were encapsulated into three overall themes, namely: 1) Constructing and perpetuating

**Table 3** Mean scores of *Enacted Discrimination* and *Anticipated Discrimination*

	<i>N</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Mean</i>	<i>SD</i>
<i>Enacted Discrimination mean</i>	167	0	2.736	1.134	0.754
<i>Anticipated Discrimination mean</i>	160	0	3	1.730	0.956

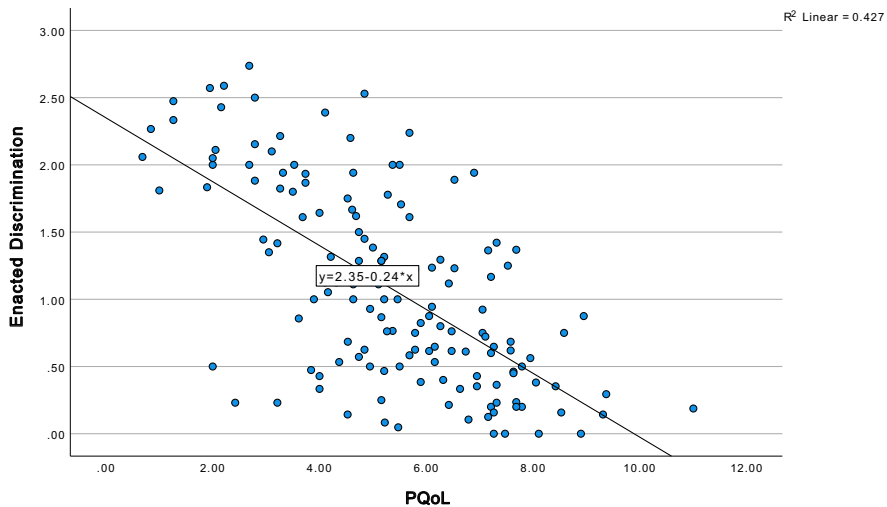
**Table 4** Responses for *Enacted Discrimination* by combined category

Item	Discriminated		No different treatment		Not applicable/missing	
	n	%	n	%	n	%
1. Making or keeping friends	136	68.3%	40	20.1%	23	11.6%
2. Neighbourhood	106	55.3%	66	33.2%	27	13.6%
3. Dating or intimate relationships	114	57.3%	41	20.6%	44	22.1%
4. Housing	75	37.7%	79	39.7%	45	22.6%
5. Education	150	75.4%	25	12.6%	24	12.1%
6. Marriage/ divorce	44	22.1%	46	23.1%	109	54.8%
7. Family	115	57.8%	55	27.6%	29	14.6%
8. Finding a job	108	54.3%	43	21.6%	48	24.1%
9. Keeping a job	95	47.7%	51	25.6%	53	26.6%
10. Public transport	121	60.8%	47	23.6%	31	15.6%
11. Welfare benefits or disability pensions	77	38.7%	36	18.1%	86	43.2%
12. Religious practices	43	21.6%	41	20.6%	115	57.8%
13. Social life	142	71.4%	27	13.6%	30	15.1%
14. Police	58	29.1%	53	26.6%	88	44.2%
15. Physical health	84	42.2%	72	36.2%	43	21.6%
16. Mental health staff	74	37.2%	74	37.2%	51	25.6%
17. Privacy	65	32.7%	72	36.2%	62	31.2%
18. Personal safety and security	74	37.2%	72	36.2%	53	26.6%
19. Starting a family or having children	54	27.1%	35	17.6%	110	55.3%
20. Role as a parent to your children	50	25.1%	25	12.6%	124	62.3%
21. Avoided or shunned by people	108	54.3%	53	26.6%	38	19.1%

TS stigma; 2) experiences of stigma, discrimination and exclusion; and 3) stigma management. Each theme comprised of at least two sub-themes (Fig. 2). The voices of adults with TS are reproduced verbatim in the data extracts to illustrate the identified sub-themes.

**Table 5** Responses for *Anticipated Discrimination* by combined category

Item	Stopping self		No difference		Not applicable/missing	
	n	%	n	%	n	%
22. Stopped self from applying for work	104	52.3%	43	21.6%	52	26.1%
23. Stopped self from applying for education or training	100	50.3%	44	22.1%	55	27.6%
24. Stopped self from looking for a close relationship	107	53.8%	39	19.6%	53	26.6%
25. Felt the need to conceal diagnosis	150	75.4%	10	5%	39	19.6%



**Fig. 1** Scatterplot depicting the relationship between *Enacted Discrimination* (DISC 12, subscale 1) and PQoL in adults with Tourette's syndrome

### Theme one: Constructing and perpetuating TS stigma

Participants identified two distinct yet interconnected factors – jokes and trivialisation — that construct an insidious form of stigma disguised in a veneer of light-heartedness, which perpetuate a normative culture and tolerance of Tourette's discrimination and stigmatisation.

#### Jokes and Tourette's Syndrome

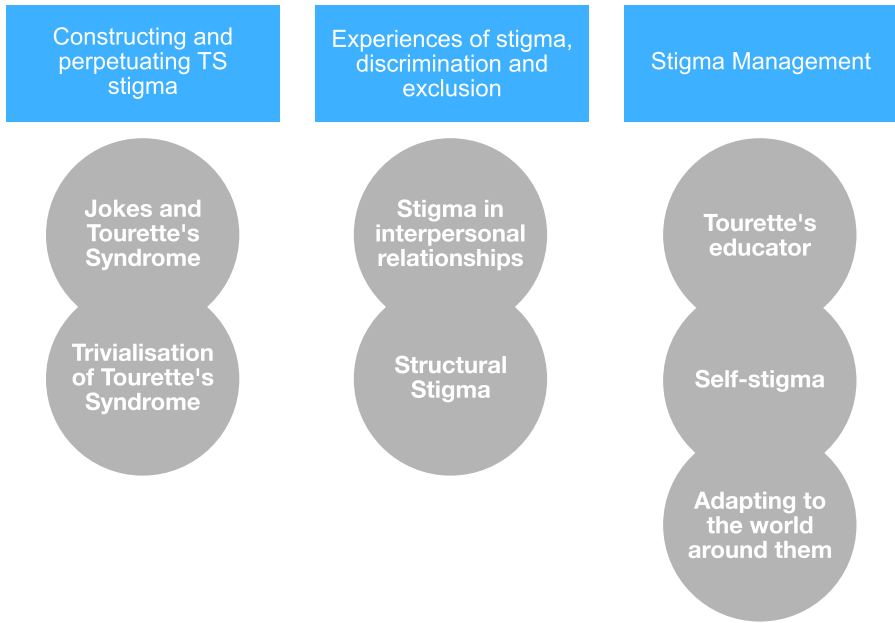
The majority of the participants suggested that jokes were used to demean and/or dismiss their experiences.

*"They see us as a joke- a haha joke. You know you see jokes, memes like 'Never laugh at other people's disabilities, unless you have Tourette's because how can you not?' How can we be taken seriously? (Participant 1)*

Participants understood this form of humour as creating a climate in which discrimination against people with TS was tolerated and permitted. Jokes did not merely cement stereotypes in the public's mind but also actively contributed to stigmatisation and the construction of "otherness":

*"Of course they can set me aside, because they don't take Tourette's seriously. They can laugh at us and take the mick and say, 'it's just a joke'. Because that's what Tourette's is for them, a joke" (Participant 19)*

According to many participants, jokes that ridiculed TS had yet to be effectively challenged by anti-stigma campaigns. Rather than them specifically targeting and contesting disparagement humour, which in their mind was largely ineffective, participants believed that if the Tourette's community took control of these jokes they



**Fig. 2** Themes and subthemes derived from thematic analysis of the semi-structured interviews with adults with Tourette's syndrome

could reclaim TS from its stigmatized form and educate the public about the complexity of living with Tourette's. Thus, humour could be used in a constructive way to raise awareness.

*“rather than it being something we try to squash (jokes about TS), which we won't be able to, it's something that the Tourette's community could use much more to get out there and to give support out to people”* (Participant 5)

### Trivialisation of Tourette's Syndrome

Comical depictions of TS were perceived by participants as contributing to the trivialisation of the condition (Pavelko & Myrick, 2016). Some participants expressed a concern that portrayals of TS in the media were oversimplified, causing the condition to be seen through a levity lens.

*“I think it's one of those disabilities where people use it as, like a joke, they'll use it as an example for someone who's got a potty mouth or something like that, but actually, that's not what it is at all.”* (Participant 12)

Many discussed the fact that coprolalia was being depicted as the only symptom of TS, when in fact it is only encountered by approximately 10% of the Tourette's population (Freeman et al., 2009). One participant, who had undergone a surgical procedure to alleviate his tics, highlighted the overuse of the term in everyday discourse:

"It's like Tourette's is only the f\*\*\* word, it's not the pain, not having to open your brain to make the pain go away. Just the swearing. And it's just kind of, you have Tourette's, I have Tourette's, everybody has Tourette's if they swear" (Participant 5)

Consequently, individuals felt that the public were failing to recognise the less observable co-morbidities and symptoms that were part of their complex everyday reality, or viewed it simply as an eccentric personality trait, or an idiosyncrasy:

"Because the bizarre, flamboyance nature of it... it's less tangible than paraplegia or cancer or whatever... It's seen as more about the oddness of the personality, which is at the very least oversimplification" (Participant 9)

Trivialisation then was regarded as impeding the general public from understanding the complexity of TS and its potential negative impact on their lives of people affected by it. They perceived this as creating an innate form of stigma that helped perpetuate discrimination.

## **Theme Two: Experiences of Stigma, Discrimination and Exclusion**

Participants' narratives provided vivid details about their experiences of stigma, discrimination and exclusion. Although there was a significant variation in their accounts, most reported numerous instances of overt and covert, micro and macro stigmatisation, suggesting its pervasiveness. Based on their accounts, we identified two dimensions of stigma and discrimination: stigma in interpersonal relationships, and structural stigma.

### **Stigma in Interpersonal Relationships**

The participants described an array of incidents that ranged from seemingly innocent and unintentional acts of "othering" to blatant discrimination.

Indirect or subtle forms of stigma included being stared at in public. Some participants described experiencing what Garland-Thomas (2009) termed as the "baroque stare"—a prolonged invasive and dehumanising stare. Participants discussed being shamelessly glared at in streets, shops, and restaurants. They described it as an intrusive gaze driven by curiosity that asserted power over them and "enfreaked" them:

"I always get those intense stares that tell me that I belong in a zoo or a freak show or something" (Participant 11)

Issues relating to subtle and perhaps unintentional expressions of stigma included microinvalidation (Sue et al., 2007). Participants believed that some observers were minimising and/or denying the visibility and impact the tics had in their everyday lives, just to avoid any form of discussion in relation to TS that could potentially make them feel uncomfortable. Participant 10 described:

*“I know that you know I have Tourette’s, and I know when you say I haven’t even noticed, I know that’s not true, because I’ve just done something at that moment. And when you say I haven’t noticed I’m kind of inwardly rolling my eyes. Like, OK, fine. Let’s all pretend I’m normal, it makes it easier”.*

A few participants described consistently being verbally victimised on public transport. People with disabilities are widely reported to have been experiencing hostility and hate crimes in public transport (Wilkin, 2019). It has been highlighted that this form of victimisation remains unaddressed in the public discourse, as well as in research as it so common that it has become socially acceptable. Participant 6 discussed his experience on buses, which led him to withdraw from using public transport to avoid exposure to verbal abuse.

*“People in buses they will start shaking their heads and If I ask them what’s wrong, they’ll say ‘it’s you, you’re obviously sick and you’re gonna get me ill’ and they just cover their mouths... I generally try not to go on the buses, cause I got sick and tired of trying to explain to people.*

In other occasions participants were asked to leave public places, due to the misconception that they were under the influence of an illegal substance. Participant 3 narrated:

*“There are a lot of occasion when I’ve been shut out of bars because they thought I’ve been on coke. And then they said to me things like ‘Mate, are you alright? You know. You look like you’ve been taking something’ and I was like ‘no, no, I’ve got Tourette’s and they were like ‘Are you taking the mick?’. And in the end, they ask me to leave.”*

The aforementioned instances endorse the notion that public spaces, despite the name of the term, are in fact not open to all (Gardner, 1991). They are restrictive, abounding in regulations imposed by those in social power. They are places that certain “others” can be excluded if they do not adhere to what is perceived as publicly acceptable behaviour.

## Structural Stigma

Participants recounted experiencing discriminatory practices in both public and private institutions. The interviews included many accounts of workplace discrimination in obtaining and maintaining employment. Some associated not being considered or rejected for employment due to their Tourette’s. Others described being denied access to work development opportunities, including training. Most commonly, individuals were not being provided with flexible work arrangements.

Some believed that the lack of these reasonable adjustments and the consequential difficulties created was the deciding factor for their job termination or for their contract not being renewed. Participant 4 shared his experience:

*“they basically said to me you can’t be on this medication and do this job. It’s another way of them saying you can’t do this job with Tourette’s. They said you have to stop taking it, without saying it... I did that and got really ill and basically they didn’t renew my contract cause of the sick days I had trying to get off the bloody stuff.”* (Participant 4)

Participants also disclosed being confronted with significant barriers in educational settings. Most commonly, they recollected not being provided with reasonable accommodation or adjustments, such as additional time for examinations and extensions of assignments. Some discussed feeling that the essence of Tourette’s was not comprehended or it was not viewed as a disability and, as a result, they received disciplinary action rather than support and accommodation for their learning from the school. Most surprising, three participants disclosed being unofficially excluded from school. Unofficial or informal exclusion occurs when parents are encouraged to remove their children from the mainstream classroom for reasons other than physical illness, without any formal record of the proceeding being kept on the school register (Brodie, 2001). Although official guidelines clearly state that it is an unlawful process, it continuous to take place and is associated with a range of damaging long-term outcomes for the pupils (Gill et al., 2017):

*“Basically they called my parents in, they said either you take your child out of the school by option and will keep him on our books and he can do his exams here or get him out, which is completely illegal. They basically broke the law, yeah.* (Participant 5)

Most participants also discussed victimisation in school settings. Many narrated being bullied by their peers but also by their teachers in school.

*“I was in a line with the rest of my class, and as we went in, he [teacher] singled me out. He said, can you stand there for a minute? OK, what have I done? That was my immediate reaction. And then once everyone else had gone in he said ‘stay there until you can behave yourself’. You know stop making these stupid noises”* (Participant 2)

Although these acts may appear as isolated incidents that could potentially be resolved through discussion, in the participants’ views they were in fact made possible and sustained due the schools’ rules and practices, and also by their indifference and tolerance towards them. As these incidents of bullying failed to be addressed and challenged by the head of the school, it indirectly contributed to sustaining a hostile environment for individuals with TS.

The participants’ narratives clearly indicated the existence of TS stigma within the healthcare system. According to Pugh (2015), structural stigma occurs in healthcare settings when people with a specific condition receive suboptimal quality of care because of a lack of resources, insufficient funding and lack of

access to specialised services. Indeed, this study sample described how general practitioners were unable to recognise the salient signs of Tourette's or had inaccurate and outdated beliefs regarding the condition leading to complicated referrals and delayed diagnosis. Participant 19 described her experience:

*"It wasn't straight forward at all. I went to the doctor, I think I had to go there three times, they didn't seem like they knew...they offered me counselling. I had to go back and say 'No, I want to see a specialist' And then I went on the Tourettes Action website, and they gave me a list of specialists... I had to tell the GP exactly who to refer me to, I had to say that quite a few times. He kept saying he couldn't make the referral. It was different when I went to another GP"*

The excerpt above also points out the inconsistency in clinical responses to Tourette's since there were no specific guidelines, leaving practitioners to make their own (sometimes ill informed) judgements.

Furthermore, some adults attested that they were not given the option of Behavioural Therapies, which according to European clinical guidelines are "the first line of treatment for tics for both children and adults" (Verdellen et al., 2011):

*"I went to see someone recently and [they] gave me just a bunch of links to things that I can do, workshop wise, courses and they're all weird like 'welcome of llamas' and 'learning from horses'. Basically, clean out their stables for free... So yeah, there's not much in support wise around at the moment."* (Participant 4)

Almost all of the participants discussed the media's role in shaping and perpetuating TS stigma corroborating Corrigan et al.'s (2005) article stating that the media can act as a powerful social structure that propagates stigma. Whilst some of the older participants highlighted how during the last few decades Tourette's had become more visible within mainstream culture, portrayals of the condition tended to endorse outdated myths and stereotypes about swearing, with little effort made to depict the condition with any degree of scientific accuracy. Furthermore, they highlighted that the public had contact with individuals with TS only through voyeuristic and sensationalised TV shows that followed the freak show blueprint (see for example the dating reality UK TV show 'The Undateables'). These depictions have focused on how individuals with TS differ from what is perceived to be the "norm" and perpetuate a 'pity' discourse that further widens the gap between "us" and "them".

*"You're using that person's disability to make money. If you want to help people with different issues find love, brilliant. But that's not what these shows are doing. These shows are showing two little dwarfs falling in love so the rest of the norms can go 'Ahhh' over it. It's disgusting. My main question is why are they segregating people with disabilities? Put them on Love Island."* (Participant 10)

## Theme Three: Stigma Management

Some participants reported a need to educate others and challenge negative stereotypes as a way of managing stigma. Others put all their effort into adapting themselves to make their condition as inconspicuous as possible to avoid being viewed as “other” and disrupting the existing social order. Many participants also claimed to have internalised public attitudes and endorsed stereotypes about themselves.

### Tourette’s Educator

A minority ( $n=3$ ) of our participants took on the role of the Tourette’s educator. This entailed individuals educating themselves more about the condition and passing that information on to their wider community. The need to raise awareness stemmed mainly from incorrect and insufficient information that was available to the public. Participants said that they approached people both in person and through online interactions. By providing information about the biomedical causes underpinning the condition, as well as dispelling myths about TS, the participants recalled sparking dialogues with others in the expectation of enlightening them and in turn, deflecting negative reactions.

*“I’m fairly clued up on the condition, I’ve done a fair amount of research, I’ve read books, I’ve read things on the internet because I think a lot of the time people need education in it [Tourette’s]. You get some really ignorant people saying some really horrible things, so it’s a case of trying to inform them and putting a positive spin on it” (Participant 14)*

However, the role of Tourette’s educator was all-consuming for some individuals, who felt that they could not simply ‘be themselves’ or present other elements of their identity in public:

*“I have become pretty damn good at explaining what Tourette’s is. But it’s draining and it’s like exhausting...I always have to be the ‘Tourette’s girl’” (Participant 20)*

### Self-Stigma

Some individuals reported adopting and absorbing stigma endorsed by society (Watson et al., 2007) with their narratives, revealing incidents of self-stereotyping, self-prejudice and self-discrimination. One participant attested to feeling inferior, agreeing with the public belief that people with disabilities have more undesirable attributes, skills and abilities and subsequently saw himself as having a devalued social identity:

*“Because I was different and because obviously it is not seen as normal, it is perceived as being something that makes you less intelligent and weak to be blunt. And I believed it to a certain extent.” (Participant 17)*

Many of the participants felt unable to deal with the exigencies of specific life goals, whilst others lacked the self-confidence to pursue their dreams. Participant 3 described what Corrigan et al. (2009) terms as “why try?” effect. He narrated giving up his personal goals, restricting his ambitions and future career aspirations:

*“I’d love to be an actor. Tourette’s stopped that dream. It’s just like no. You can’t be doing TV like EastEnders if you’re ticcing... Sometimes you do imagine yourself—I had to stop imagining myself because I know, it would be like—I could never do it.”*

### **Adapting to the World Around Them**

Most of the participants described not wanting to disrupt the social order and stigmatising landscape they lived in and recounted how, in an attempt to assimilate to the norm, they resorted to “supressing” their tics, a process they described as both physically, and emotionally exhausting. “Passing” (Goffman, 1963) was described as a process that required intensive self-monitoring and concentration as well as close observation of the onlookers’ reaction:

*“I just got really quite good at hiding it from people. So, if you’re having a conversation and, you know when one person looks away subconsciously in the end, I just know they’re looking away, and I’d fit all my tics in that particular moment in time” (Participant 3)*

Many described being motivated to suppress their tics by the need to minimise the discomfort of the norms while interacting with them. In these encounters, adults with TS had to undertake what Scully (2010) terms “hidden labour” to reduce the discomfort of the others by manipulating the presentation of their impairment.

*“They see a grown man, like me and to be honest, I do look a little bit like a bouncer – the bouncer making silly noises and it takes a little while to process. And they can’t deal with it. I think. A lot of it...yeah or it scares them” (Participant 2)*

Maintaining the interaction order was apparent in relation to requesting reasonable adjustments or accommodation within employment, with most participants reluctant to disclose their needs or request this legal requirement of employers. Due to the stigma and misconceptions surrounding TS, and the fear of job insecurity, individuals were hesitant to self-advocate for what they needed, such as more flexible work schedule or a closed as opposed to an open-plan office space. They felt the risk involved in requesting any form of adjustment was not worth taking:

*“In my line of work, open plan offices are the bane of my life. I would like, you know, to be able to say, can you put me in my own little office? ... My worry is if I push this ‘I want an office,’ I would be effectively on a short list so*

*that when the next time they're working out redundancies or whatever, I'll be on it"* (Participant 2).

Others feared that employers might perceive them as a liability and avoid hiring them in the future:

*"but again, it's one of those things; if you're on file as having caused lots of problems before, they're not going to re-employ you. It's just, that's the logic in that, you know?"* (Participant 5)

## Discussion

Despite growing awareness of the existence TS stigma, there is a paucity of research that focuses on its nature and consequences. The purpose of this study was to advance knowledge on TS stigma through assessing the extent and nature of it, and the impact it has on the quality of life of those affected by it. We also aimed to explore how it is perceived and managed by adults with TS.

Our findings suggest that stigmatisation is a real component of the social experience of living with TS, which negatively affects the quality of life of those affected by it. TS stigma is not significantly determined by age, level of education, gender or ethnicity, suggesting its precarious character. Individuals reported having endured high rates of discrimination and stigma in diverse settings, substantially similar –if not higher– to those of people with severe mental illness (Adeosun et al., 2014). Our study indicates that it is not simply observed at an interpersonal level but also manifest at a macro level, thus in employment, education, and healthcare settings leading to the social and economic exclusion of this population. The role of humour and jokes in constructing and perpetuating TS stigma was also highlighted, indicating the unique nature of TS stigma in relation to other condition (e.g., mental illness) and the need for new anti-stigma approaches to be developed to combat it. Furthermore, the study indicates that participants rarely engage in stigma resistance and are more prone to conceal, camouflage and suppress their tics, while leaving the social structure relatively intact. This, however, inhibits opportunities for collective stigma management, which is necessary for challenging and ultimately changing sociocultural norm.

The findings suggest that stigma is a powerful barrier to work participation for people with TS as 54.3% of our sample reported experiencing discrimination in finding a job and 47.7% in maintaining it. The findings also exemplified the way TS stigma operated within the domain of employment. Employers' negative attitudes towards hiring and supporting individuals with Tourette's, limited workplace accommodation, inflexible practices and protocols are some of the challenges the participants discussed. Although in some instances stigmatisation and discrimination were clearly a result of oversight and ineffective communication between employer and employee, it still highlights the lack of consideration for people with TS. Thus, although the UK Equality Act (2010) specifies that employers have a duty to make reasonable and necessary adjustments in the workplace, our findings suggest that the weight to adjust to the environment still largely falls on individuals with TS.

Our findings could partially explain the high rates of unemployment among adults with TS. Aldred and Cavanna (2015) reported that 29.2% of their 137 participants were unemployed compared to a 7.5% unemployment rate in the general population at the time of their study. Even higher rates were reported by Dodel et al. (2010), with 40% of their 200 participants being unemployed. Furthermore, individuals with TS have been found to occupy lower skilled jobs than would be expected based on their qualifications (Champion et al., 1988), were more likely to be receiving lower income than the median salary and be receiving government welfare (Yang et al., 2016). Future research needs to specifically explore the experiences of individuals with TS in the workplace and assess the challenges they face in order to develop better strategies to improve individuals with TS employment outcomes.

The study indicates that more than three quarters of the sample felt that they experienced discrimination within educational settings, and implicit and explicit exclusionary practices implemented undermined their educational attainments. This finding is concerning especially given the long history of inclusive education in the UK (Williams-Brown & Hodkinson, 2019). Participants reported schools and practitioners were not responsive to their additional and diverse needs despite inclusion policies. Furthermore, being target of bullying further impeded their sense of belonging. There has been research that has suggested a link between TS and lower educational attainment (Pérez-Vigil et al., 2018). Specifically, studies have indicated that TS is related to special education placement and children with the condition are at a higher risk of grade retention (Abwender et al., 1996) and absenteeism (Conelea et al., 2011), whilst their parents are more likely to be contacted about school problems (Bitsko et al., 2014). Studies indicate that poor academic achievements may influence subsequent employment, financial security and well-being (Hinshaw & Stier, 2008). However, in most cases the studies attempted to explain the relationship through a medicalised perspective and deficits within the individual. Thus, the tics and the effort to suppress them may distract and interfere with learning. Furthermore, executive memory deficits and fine motor dysfunction could result in academic underachievement (Como, 2001). The current findings indicate that the role of prejudicial attitudes towards individuals with TS should be considered as a contributing factor and further research needs to explore the mechanism by which it manifests.

The study also revealed the existence of TS stigma within the healthcare system. Half of the sample described experiencing discrimination from healthcare workers, and almost all interviewees reported poor awareness of Tourette's syndrome by General Practitioners, lack of clinical expertise, difficulty accessing specialist services, delays in receiving a diagnosis—all of which highlight the limitations of the healthcare system in managing Tourette's. That there are currently no guidelines by the National Institute for Health and Clinical Excellence (NICE) specific for the assessment and treatment of Tourette's to guide practice exacerbates these barriers to the provision of optimal health care to this group of individuals. NICE guidelines are a series of recommendations that are a product of multidisciplinary processes, strongly based on empirical evidence. Their absence could lead to a lack of standardization in assessment and care, with clinicians having to rely on their own judgment and knowledge, which could be out of date

or not sufficiently evidence based. Our findings indicate the need to introduce NICE guidelines to transform how Tourette's syndrome is treated in the UK.

The role of humour in constructing and perpetuating TS stigma was emphasised in the study. It is widely accepted that jokes are not always harmless and should not always be perceived as benign (Billig, 2005). They are imbricated in ridicule and derision, and can solidify existing power relationships and old belief systems, blocking social change (Holmes & Marra, 2002). The jokes used against people with TS reveal a form of disparagement humour that in participants' view has played an important part in forming perceptions about Tourette's syndrome in contemporary society. As many highlighted, TS jokes are so deeply embedded in popular culture that we may fail to recognise their precarious character. Similar to sexist (Bemiller & Schneider, 2010), racist (Weaver, 2011) and disablist humour (Shakespeare, 1999), disparagement jokes about TS encode contemporary perceptions and stereotypes, and encourage and facilitate tolerance of discrimination against disempowered segments of society (Ferguson & Ford, 2008). Jokes about TS, however, have not incurred severe social censure in contrast to jokes about other disabilities, race and gender, which are considered "politically incorrect". Indeed, over the last twenty years, intense debates have arisen about the ethical limitations of humour about people with protected characteristics (Lockyer & Pickering, 2001). Thus, there is still tension amongst those who aim to protect the freedom of speech of the comedians and those aimed at defending marginalised groups from "masked" stigmatisation. People with Tourette's are considered a politically and ethically more acceptable target than people with physical or even mental disabilities and, in many cases, Tourette's jokes have received a "moral amnesty". Despite our findings, humour in relation to TS is surprisingly understudied and findings illustrate the need to theorise what makes us laugh in relation to TS, why it is still considered fair play, and to explore its consequences and functions. Furthermore, we need to examine the role of TS humour in reproduction and circulation of stereotypes.

The current study highlights the need for public initiatives that counteract stigma. Hitherto, the main strategies that have been used by individuals with TS to manage their spoiled identity is schooling themselves to better manage the stigma pinned on them. However, our findings suggest that TS stigma is a multi-level phenomenon that needs to be tackled at an individual (intrapersonal), interpersonal and structural level concurrently. We posit three recommendations as follows:

Interventions at an intrapersonal level aim to reduce the impact of self-stigma on marginalised groups mainly through counselling and education. Cognitive Behavioural Therapy (CBT) and psychoeducational interventions have been identified as effective in reducing self-stigma in people with mental illness through altering stigmatised beliefs of the individual and enhancing their self-esteem and coping strategies (Heijnders & Van Der Meij, 2006). In the context of Tourette's, although many interventions focus on enhancing self-esteem and aim to improve skills to cope with the psychosocial consequences of their condition (Storch et al., 2012), no studies to our knowledge have assessed their effectiveness in reducing self-stigma. Practitioners need to pay greater attention to this and evidence-based interventions that tackle TS self-stigma need to be developed.

Intrapersonal anti-stigma interventions are geared towards eliminating social stigma in community groups mainly through education, intergroup contact and advocacy. Studies assessing the effectiveness of TS anti-stigma interventions on specific community groups (i.e., healthcare professional, secondary school children, college students) are scant and have proved to be generally unsuccessful (Malli, 2018). Furthermore, there is a lack of studies and practice pertaining to key actors in positions of power, such as employers, and school personnel. Such interventions need to be developed as our study indicates they are imperative to the well-being of this population.

Finally, at an institutional and structural level, anti-stigma initiatives aim to reduce stigma in institutions and organisations through training programs and policies (Cook et al., 2014). In addition, advertising and mass media interventions attempt to change public opinion on a large scale. To date, there have been very few TS mass media campaigns aimed at reconstructing public perceptions about TS in the UK and these have been mainly based on the protest strategy; challenging and condemning media representation of TS, attempting to change social values, and norms by discouraging the stigmatisation and trivialisation of TS, and demanding the removal of such depictions from the media (e.g. <https://www.takethetourettepledge.com>). Similar strategies have been used in the past to diminish negative public images of mental illness and have been shown to be of limited impact to changing the public's attitudes (Penn & Corrigan, 2002). However, as the participants in our study highlighted, TS is portrayed in a distinguishable way as a “joke condition” and the individuals affected by it are not depicted as demonic, violent and/or dangerous, they are the ‘butt of the joke’. The response to these ‘soft’ denigrating depictions should therefore be more complex and non-confrontational to avoid backlash. Protesting against this form of humour may result in the protestor being accused of being moralistic and humourless, and the ethical appeal for people to stop laughing at these jokes may result in a rebound effect, thus, “don’t tell me what to laugh at”. Characteristically, after Tourettes Action criticised a pun about Tourette’s that won the Edinburgh Fringe joke in 2019, the charity received a firestorm of criticism in social media, and particularly in Twitter. Hundreds of messages immediately accused the charity of being humourless, moralistic, lacking a sense of humour and failing to take a joke (Rosemurgey, 2019). Our participants suggested that humour and jokes that have been used as a tool of oppression for them should be used as an advocacy tool to challenge the systems of normalcy. Indeed, in the last decade, individuals with Tourette’s have been using Tourette’s as a form of advocacy to challenge society’s attitudes, present TS as a natural dimension of diversity and narrate their personal stories (Doward, 2020). Future anti-stigma interventions need to consider incorporating humour as an educational strategy that will simultaneously entertain but also allow the audience to reflect on their prejudice and stigmatising behaviours.

The combination of the aforementioned approaches could result in better outcomes due to the bidirectional relationship between the different interventions. It is well established that reduced stigma at the more structural level can have positive effects on the everyday lives of the stigmatised. Conversely, reduced self-stigmatisation can urge individuals to confront discrimination, minimise social withdraw and improve interpersonal contact. It might therefore ultimately affect structural stigma (Gronholm et al., 2017).

## Limitations

Whilst our online survey attracted a large community sample of demographically diverse individuals from different regions of the UK—and hence avoided a clinical sample biased toward more severely psychopathologically affected individuals—it may have been subject to volunteer effect; individuals with experiences of stigma finding the survey more relevant to them and who were more likely to respond (Eysenbach, 2005).

In many cases, the data were retrospective and entailed participants' memories. Although there has been criticism relating to the validity of retrospective accounts, in line with a constructivist position, adults with TS were giving an interpretative account of what happened to them and not an exact picture (Charmaz, 2006).

As researchers, we conducted the study as outsiders to the experience of having Tourette's syndrome and being stigmatised. Although this could result in misinterpretations and misunderstandings of the lived experiences of respondents (Link & Phelan, 2001), it was emphasised that it was in our interest as researchers to accurately illustrate the experiences of stigma using the voices of those with TS and our participants appeared to be comfortable narrating their stories to us (Wigginton & Setchell, 2016).

As the majority of participants had co-occurring conditions, it is difficult to evaluate the results within a condition-specific measurement approach. Thus, individuals with comorbid conditions were asked to report on the impact of a specific condition in their lives, but it is unclear to what extent they could untangle the effect of the different conditions.

## Conclusion

This study is the first to explore TS stigma in depth and provide a unique insight into how it unfolds in day-to-day life. The findings suggest that stigma is an issue of substantial concern for adults with TS. It manifests in various contexts and life domains, such as employment and education, and can dramatically impair people's quality of life and effect their self-worth. Jokes, humour and trivialisation were identified as factors that insidiously perpetuate discrimination, but also create a unique form of stigma that is disguised by a veneer of light-heartedness and allows societal inertia. Clinical practice should therefore not only focus on minimising the severity of the tics but also prioritise addressing the social complications linked to having TS.

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## Compliance with Ethical Standards

**Ethics Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Tizard Centre Ethics Committee, University of Kent (REF: 11/2018).

**Consent to Participate** Written informed consent was obtained from the participants.

**Consent to Publish** The participants have consented to the submission of the case report to the journal.

**Conflicts of Interest** The authors have no conflicts of interest to declare that are relevant to the content of this article.

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## References

- Abwender, D. A., Como, P. G., Kurlan, R., Parry, K., Fett, K. A., Cui, L., Plumb, S., & Deeley, C. (1996). School problems in Tourette's syndrome. *Archives of Neurology*, 53(6), 509–511.
- Adeosun, I. I., Adegbohun, A. A., Jeje, O. O., & Adewumi, T. A. (2014). Experiences of discrimination by people with schizophrenia in Lagos, Nigeria. *Journal of Public Mental Health* 13 (4), 189–196. <https://doi.org/10.1108/JPMH-06-2013-0038>
- Aldred, M., & Cavanna, A. E. (2015). Tourette syndrome and socioeconomic status. *Neurological Sciences*, 36(9), 1643–1649.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- Bemiller, M. L., & Schneider, R. Z. (2010). It's not just a joke. *Sociological Spectrum*, 30(4), 459–479.
- Billig, M. (2005). *Laughter and ridicule: Towards a social critique of humour*. Sage.
- Bitsko, R. H., Holbrook, J. R., Visser, S. N., Mink, J. W., Zinner, S. H., Ghandour, R. M., & Blumberg, S. J. (2014). A national profile of Tourette syndrome, 2011–2012. *Journal of Developmental and Behavioral Pediatrics: JDBP*, 35(5), 317.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brodie, I. (2001). *Children's Homes and School Exclusion: Redefining the Problem*. Jessica Kingsley Publishers.
- Brohan, E., Clement, S., Rose, D., Sartorius, N., Slade, M., & Thornicroft, G. (2013). Development and psychometric evaluation of the Discrimination and Stigma Scale (DISC). *Psychiatry Research*, 208(1), 33–40.
- Calder-Sprackman, S., Sutherland, S., & Doja, A. (2014). The portrayal of Tourette syndrome in film and television. *Canadian Journal of Neurological Sciences*, 41(2), 226–232.
- Champion, L. M., Fulton, W. A., & Shady, G. A. (1988). Tourette syndrome and social functioning in a Canadian population. *Neuroscience & Biobehavioral Reviews*, 12(3–4), 255–257.
- Chapman, J. (2012). Cameron sorry for Tourette's jibe at Ed Balls. *Daily Mail (London, England)*. <https://search.proquest.com/docview/914611346>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage.
- Como, P. G. (2001). Neuropsychological function in Tourette syndrome. *Advances in Neurology*, 85, 103–111.
- Conelea, C. A., Woods, D. W., Zinner, S. H., Budman, C. L., Murphy, T. K., Scahill, L. D., Compton, S. N., & Walkup, J. T. (2013). The impact of Tourette syndrome in adults: Results from the Tourette syndrome impact survey. *Community Mental Health Journal*, 49(1), 110–120.
- Conelea, C. A., Woods, D. W., Zinner, S. H., Budman, C., Murphy, T., Scahill, L. D., Compton, S. N., & Walkup, J. (2011). Exploring the impact of chronic tic disorders on youth: Results from the Tourette Syndrome Impact Survey. *Child Psychiatry & Human Development*, 42(2), 219–242.

- Cook, J. E., Purdie-Vaughns, V., Meyer, I. H., & Busch, J. T. (2014). Intervening within and across levels: A multilevel approach to stigma and public health. *Social Science & Medicine*, 103, 101–109.
- Corrigan, P. W. (2014). *The stigma of disease and disability: Understanding causes and overcoming injustices*. American Psychological Association.
- Corrigan, P. W., Larson, J. E., & Ruesch, N. (2009). Self-stigma and the “why try” effect: Impact on life goals and evidence-based practices. *World Psychiatry*, 8(2), 75.
- Corrigan, P. W., Watson, A. C., Gracia, G., Slopen, N., Rasinski, K., & Hall, L. L. (2005). Newspaper stories as measures of structural stigma. *Psychiatric Services*, 56(5), 551–556.
- Corrigan, P., & Bink, A. B. (2005). *On the stigma of mental illness*. American Psychological Association.
- Cox, J. H., Nahar, A., Termine, C., Agosti, M., Balottin, U., Seri, S., & Cavanna, A. E. (2019). Social stigma and self-perception in adolescents with Tourette syndrome. *Adolescent Health, Medicine and Therapeutics*, 10, 75.
- Creswell, J. W., Klassen, A. C., Plano Clark, V. L., & Smith, K. C. (2011). Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health*, 2013, 541–545.
- Crocker, J., Major, B., Steele, C., Fiske, S. T., & Lindzey, G. (1998). *Social stigma*. McGraw-Hill.
- Dodel, I., Reese, J. P., Müller, N., Münchau, A., Balzer-Geldsetzer, M., Wasem, J., Oertel, W. H., Dodel, R., & Müller-Vahl, K. (2010). Cost of illness in patients with Gilles de la Tourette’s syndrome. *Journal of Neurology*, 257(7), 1055–1061.
- Doward, J. (2020). Comedians with Tourette’s help to show it’s no laughing matter. *The Observer (London)*. <https://search.proquest.com/docview/2451710468>
- Equality Act 2010. (2010). Retrieved 11 January 2020, from <http://www.legislation.gov.uk/ukpga/2010/15/contents>
- Evans, J., Seri, S., & Cavanna, A. E. (2016). The effects of Gilles de la Tourette syndrome and other chronic tic disorders on quality of life across the lifespan: A systematic review. *European Child & Adolescent Psychiatry*, 25(9), 939–948.
- Eysenbach, G. (2005). Using the internet for surveys and research. In Anderson J.G. & Aydin C.E. (Eds), *Evaluating the Organizational Impact of Healthcare Information Systems*. *Health Informatic* (pp. 129–143). Springer.
- Fat, M. J. L., Sell, E., Barrowman, N., & Doja, A. (2012). Public perception of Tourette syndrome on YouTube. *Journal of Child Neurology*, 27(8), 1011–1016.
- Ferguson, M. A., & Ford, T. E. (2008). Disparagement humor: a theoretical and empirical review of psychoanalytic, superiority, and social identity theories. *Humor: International Journal of Humor Research*, 21(3), 283–312.
- Freeman, R. D., Zinner, S. H., Müller-Vahl, K. R., Fast, D. K., Burd, L. J., Kano, Y., Rothenberger, A., Roessner, V., Kerbeshian, J., & Stern, J. S. (2009). Coprophobia in Tourette syndrome. *Developmental Medicine & Child Neurology*, 51(3), 218–227.
- Friedrich, S., Morgan, S. B., & Devine, C. (1996). Children’s attitudes and behavioral intentions toward a peer with Tourette syndrome. *Journal of Pediatric Psychology*, 21(3), 307–319.
- Gardner, C. B. (1991). Stigma and the public self: Notes on communication, self, and others. *Journal of Contemporary Ethnography*, 20(3), 251–262.
- Garland-Thomson, R. (2009). *Staring: How we look*. Oxford University Press.
- Gill, C. E., & Kompoliti, K. (2020). Clinical Features of Tourettes Syndrome. *Journal of Child Neurology*, 35(2), 166–174.
- Gill, K., Quilter-Pinner, H., & Swift, D. (2017). Making the difference: Breaking the link between school exclusion and social exclusion. *Institute for Public Policy Research*.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Prentice-Hall.
- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis*, 11(3), 255–274.
- Gronholm, P. C., Henderson, C., Deb, T., & Thornicroft, G. (2017). Interventions to reduce discrimination and stigma: The state of the art. *Social Psychiatry and Psychiatric Epidemiology*, 52(3), 249–258.
- Hannem, S. (2012). Theorizing stigma and the politics of resistance: Symbolic and structural stigma in everyday life. In S. Hannem & Bruckert (Eds), *Stigma Revisited: Implications of the Mark*, (pp. 10–28). University of Ottawa Press.
- Hatzenbuehler, M. L. (2016). Structural stigma: Research evidence and implications for psychological science. *American Psychologist*, 71(8), 742–751.

- Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine*, 11(3), 353–363.
- Hinshaw, S. P., & Stier, A. (2008). Stigma as related to mental disorders. *Annual Review of Clinical Psychology*, 4, 367–393.
- Holmes, J., & Marra, M. (2002). Over the edge? Subversive humor between colleagues and friends. *Humor*, 15(1), 65–87.
- Holstein, J. A., & Gubrium, J. F. (1995). *The active interview*. Sage.
- Holstein, J., & Gubrium, J. F. (2003). *Inside interviewing: New lenses, new concerns*. Sage.
- Jacoby, A. (2002). Stigma, epilepsy, and quality of life. *Epilepsy & Behavior*, 3(6), 10–20.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27(1), 363–385.
- Lockyer, S., & Pickering, M. (2001). Dear shit-shovellers: Humour, censure and the discourse of complaint. *Discourse & Society*, 12(5), 633–651.
- Malli, M. A., Forrester-Jones, R., & Murphy, G. (2016). Stigma in youth with Tourette's syndrome: A systematic review and synthesis. *European Child & Adolescent Psychiatry*, 25(2), 127–139.
- Malli, M. A. (2018). *Adolescents' Perceptions of their Peers with Tourette's Syndrome: Does A Brief Anti-Stigma Intervention Help? (Publication No. 13875957). [Doctoral dissertation, University of Kent]. ProQuest Dissertations & Theses Global.*
- Malli, M. A., Forrester-Jones, R., & Triantafyllopoulou, P. (2019). "Tourette's Is a Lonely Place": An Interpretative Phenomenological Analysis of the Personal Experience and Identity of Adults with Tourette's Syndrome. *Journal of Developmental and Physical Disabilities*, 31(6), 819–845.
- Patrick, D. L., Danis, M., Southerland, L. I., & Hong, G. (1988). Quality of life following intensive care. *Journal of General Internal Medicine*, 3(3), 218–223.
- Patrick, D. L., Kinne, S., Engelberg, R. A., & Pearlman, R. A. (2000). Functional status and perceived quality of life in adults with and without chronic conditions. *Journal of Clinical Epidemiology*, 53(8), 779–785.
- Pavelko, R., & Myrick, J. G. (2016). Tweeting and trivializing: How the trivialization of obsessive-compulsive disorder via social media impacts user perceptions, emotions, and behaviors. *Imagination, Cognition and Personality*, 36(1), 41–63.
- Penn, D. L., & Corrigan, P. W. (2002). The effects of stereotype suppression on psychiatric stigma. *Schizophrenia Research*, 55(3), 269–276.
- Pérez-Vigil, A., de la Cruz, Lorena Fernández, Brander, G., Isomura, K., Jangmo, A., Kuja-Halkola, R., Hesselmark, E., D'Onofrio, B. M., Larsson, H., Mataix-Cols, D. (2018). Association of Tourette syndrome and chronic tic disorders with objective indicators of educational attainment: A population-based sibling comparison study. *JAMA Neurology*, 75(9), 1098–1105.
- Pugh, T., Hatzenbuehler, M., & Link, B. (2015). Structural stigma and mental illness. *Commissioned Paper for Committee on the Science of Changing Behavioral Health Social Norms, Mailman School of Public, Columbia University (August 2015).*
- Robertson, M. M. (2012). The Gilles de la Tourette syndrome: The current status. *Archives of Disease in Childhood-Education and Practice*, 97(5), 166–175.
- Rosemurgey, E. (2019, August 20) Tourette's Charity Apology Over 'Funniest Joke' of Edinburgh Fringe. *Unilad*. [https://www.unilad.co.uk/life/tourettes-charity-wants-apology-over-funniest-joke-at-edinburgh-fringe/?source=facebook&fbclid=IwAR00RbUv-SFd0aHzgRt0CruJKtNf3G28iYaS66RWmO\\_QA-wlptYbtZH0NI](https://www.unilad.co.uk/life/tourettes-charity-wants-apology-over-funniest-joke-at-edinburgh-fringe/?source=facebook&fbclid=IwAR00RbUv-SFd0aHzgRt0CruJKtNf3G28iYaS66RWmO_QA-wlptYbtZH0NI)
- Sartorius, N. (2008). The WPA Global Programme against Stigma and Discrimination because of Schizophrenia. In J. Arboleda-Flórez & N. Santorius (Eds), *Understanding the Stigma of Mental Illness: Theory and Interventions*, (pp.37–47). John Wiley & Sons, Ltd.
- Scully, J. L. (2010). Hidden labor: Disabled/nondisabled encounters, agency, and autonomy. *IJFAB: International Journal of Feminist Approaches to Bioethics*, 3(2), 25–42.
- Shakespeare, T. (1999). *Joking a Part. Body & Society*, 5(4), 47–52.
- Shakespeare, T. (2006). *Disability Rights and Wrongs*. Routledge.
- Smith, H., Fox, J. R., & Trayner, P. (2015). The lived experiences of individuals with Tourette syndrome or tic disorders: A meta-synthesis of qualitative studies. *British Journal of Psychology*, 106(4), 609–634.
- Sontag, S. (1989). *AIDS and its metaphors*. Farrar.

- Storch, E. A., Morgan, J. E., Caporino, N. E., Brauer, L., Lewin, A. B., Piacentini, J., & Murphy, T. K. (2012). Psychosocial treatment to improve resilience and reduce impairment in youth with tics: An intervention case series of eight youth. *Journal of Cognitive Psychotherapy*, 26(1), 57.
- Sue, D. W., Capodilupo, C. M., Torino, G. C., Bucceri, J. M., Holder, A., Nadal, K. L., & Esquilin, M. (2007). Racial microaggressions in everyday life: Implications for clinical practice. *American Psychologist*, 62(4), 271.
- Tashakkori, A., & Teddlie, C. (2010). Putting the Human Back in “Human Research Methodology” *Journal of Mixed Methods Research*, 4(4), 271–277.
- Verdellen, C., Van De Griendt, J., Hartmann, A., & Murphy, T. (2011). European clinical guidelines for Tourette syndrome and other tic disorders. Part III: behavioural and psychosocial interventions. *European Child & Adolescent Psychiatry*, 20(4), 197–207.
- Watson, A. C., Corrigan, P., Larson, J. E., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin*, 33(6), 1312–1318.
- Weaver, S. (2011). *The rhetoric of racist humour: US*. Ashgate Publishing Ltd.
- Wigginton, B., & Setchell, J. (2016). Researching stigma as an outsider: Considerations for qualitative outsider research. *Qualitative Research in Psychology*, 13(3), 246–263.
- Wilkin, D. (2019). *Disability hate crime: Experiences of everyday hostility on public transport*. Springer.
- Williams-Brown, Z., & Hodkinson, A. (2019). Development of Inclusive Education in England: Impact on Children with Special Educational Needs and Disabilities. In: *Papa R. (eds) Handbook on Promoting Social Justice in Education*. Springer, Cham. [https://doi.org/10.1007/978-3-319-74078-2\\_151-1](https://doi.org/10.1007/978-3-319-74078-2_151-1)
- Yang, J., Hirsch, L., Martino, D., Jette, N., Roberts, J., & Pringsheim, T. (2016). The prevalence of diagnosed Tourette syndrome in Canada: A national population-based study. *Movement Disorders*, 31(11), 1658–1663.

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## Authors and Affiliations

Melina Aikaterini Malli<sup>1,2</sup>  · Rachel Forrester-Jones<sup>3,4</sup>

Rachel Forrester-Jones  
rforre@uwo.ca

- <sup>1</sup> Nuffield Department of Primary Care Health Sciences, University of Oxford, Radcliffe Observatory Quarter, Woodstock Road, Oxford OX2 6GG, UK
- <sup>2</sup> Faculty of Health and Education, Manchester Metropolitan University, Brooks Building, 53 Bonsall Street, Manchester M15 6GX, UK
- <sup>3</sup> Centre for the Analysis of Social Policy, Department of Social Policy and Sciences, University of Bath, Claverton Down, Bath BA2 7AY, UK
- <sup>4</sup> School of Health Studies, Faculty of Health Sciences, Western University, London, ON N6A 3K7, Canada