"One of the negative things about having TS is the way that people react": An Interpretative Phenomenological Analysis (IPA) Investigating Stigma in Tourette Syndrome

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Abstract

Tourette Syndrome (TS) is a highly stigmatised condition linked to poor quality of life and socio-ecological barriers. Previous studies on TS have proposed various interventions, however there is a paucity of research on the subject. This study aimed to add to the literature by exploring how people with TS experience stigma, the socio-ecological barriers it creates and what they think is necessary to reduce it. 16 previously written blogs from the Tourette's Action website were analysed using interpretative phenomenological analysis. The study found people with TS experienced extrinsic and self-stigma, which creates barriers in their

relationships, education, employment, and in healthcare. Interventions, such as raising awareness, support groups and reframing their perception of TS were suggestions made by the bloggers confirming previous findings. Easing tics instead of suppressing them was also suggested, which requires further investigation.

Background

Over 300,000 adults and children in the UK live with Tourette's syndrome (TS) (Tourette's Action, 2024), a neurodevelopmental condition characterised by the presence of motor movements or vocalisations (Malli and Forrester-Jones, 2021; Perkins et al, 2020). TS is a highly stigmatised condition associated with poor quality of life (QOL) and creates barriers to accessing help through various domains of the people who live with it (Cox et al, 2019; Cuenca et al, 2015; Storch et al, 2007; Subu et al, 2021). Stigma has been defined as an attribute that discredits the individual, disqualifying them from full social acceptance (Goffman,1963). Despite declining for other diseases, stigma has remained stable for mental illness (Best and Arseniev-Koehler, 2022) and can originate from a lack of awareness and education, particularly if odd behaviour and violence are in its nature (Shrivastava et al, 2012).

Studies exploring the perception of TS illustrate how manifesting odd behaviours can elicit negative attention. Friedrich et al (1996) were one of the first to research perceptions of TS and investigated peer responses to a child with TS and a child without. Their attitudes and behavioural intentions were more favourable towards the child without TS. These findings were supported by studies conducted by Storch et al (2007) and Katona (2013) that compared perceptions of people with TS compared to people with other conditions (diabetes type 1 and epilepsy, respectively). Their results showed more positive results for the other conditions than TS. Although they highlight the

negative perception of TS, the samples used in these studies of children and healthcare students inhibit the ability to generalise the findings. However, looking at a wider and more diverse sample, Fat et al (2012) investigated public perceptions of TS by analyzing responses to YouTube videos featuring someone with TS. Videos portraying the condition negatively or focusing on coprolalia (involuntary obscene language) for humour received more likes and comments than positive portrayals. Although these results are from one social media platform, they exhibit the entrenched nature of stigma towards TS.

People with TS can be affected by stigma that occurs externally, internally and pervades throughout various domains in their lives. Bronfenbrenner's (2005) socio-ecological model illustrates the complexity of the social and environmental influences where stigma can diminish the QOL of people with TS, from the individual and micro (interpersonal) levels through to the macro (broad cultural) levels. Malli and Forrester-Jones (2021) conducted a mixed method study and found stigma results in barriers to health care, education, and employment, although the impact of comorbidities on the results was not clear. Parents reported their children with TS experience higher rates of bullying and discrimination from their peers resulting in struggles to develop and maintain friendships (Eapen et al, 2016; O'Hare et al, 2016). From an individual perspective, Shiu et al (2023) found interpersonal stigma made up 90% of enacted stigma through traumatic events (teasing, or exclusion); confrontations; and subtle mistreatments (unwanted questions). Subtle forms of stigma that are considered as trivial by those who enact it, have been found in studies by Malli et al (2019) and Malli and Forrester-Jones (2017) where home is a key site, and peers patronise or enhance their own self-esteem by comparing themselves to a worse situation in a downward social comparison (Festinger, 1954). When individuals embody the negative perceptions of others to the extent it affects their self-concept, including one's identity, roles, attitudes (Pring et al, 2023; Silvestri, et al, 2017) it can delay those with TS accessing health care (Vieira et al, 2023). Subu et al (2021) explored mental health stigma through interviews with healthcare professionals in Indonesia. Although the

sample is one hospital, their findings give a good insight and postulate clinicians need to be aware of self-stigma and the resulting shame, isolation, and powerlessness. Malli and Forrester-Jones (2019) used interpretative phenomenological analysis (IPA) on telephone interviews with adults with TS, which they found to be less intrusive than face-face. The analysis allowed them deeper insight into how people with TS perceive their condition and discovered participants did not identify with TS in a positive way because of stigma and tried to minimise its influence in their lives, or distance themselves from it. (Malli and Forrester-Jones, 2019). Knowing how the individual with TS experiences stigma can help provide pivotal insight to improve the care they receive.

The omnipresent nature of stigma for people with TS makes finding interventions crucial, therefore, it is necessary to understand the roots of these negative beliefs. Many studies propose the media has a strong influence on the negative perceptions of TS (Cox et al, 2019; Happich et al, 2012; Malli et al, 2015). Calder-Sprackman et al (2014) conducted qualitative analysis of movies, television programs and shorts that featured TS or tic disorders and showed TS was misrepresented, heavily focused on the negative aspects, and was produced for entertainment rather than education. Findings from previous studies show people are more entertained by the negative portrayals of TS, which they find humorous (Fat et al, 2012) and this is important considered with results from studies that show some adolescents and teachers find their information about TS from the media (Ludlow et al, 2022; Malli and Forrester-Jones, 2017). Misunderstanding the cause of the odd behaviour has also been postulated to fuel stigma in TS (Bervoets et al, 2022; Stofleth, 2022). Ben-Ezra et al (2017) recorded stigma responses after watching a clip of a person with TS or nature and found greater stigma responses to the clip of TS with a positive association between stigma and level of education. This suggests people with TS evoke stigma even when being portrayed with status because they are assumed to have a level of control over their tics. Stofleth et al (2022) investigated this further by interviewing adults with TS to explore other people's responses to their behaviour and found stigma was elicited when people with TS were held responsible for their tics. Due to the

sampling of these studies the findings cannot be generalised, however, they offer a basis for more research. A study by Bervoets et al (2022) advises caution when attributing cause to tics as some bio-medical attributions evoked stigma, therefore it is important to explore the nuances of attributions in TS.

Various interventions to alleviate the effects of stigma have been mentioned in the literature. People with TS have expressed a desire for more understanding (Happich et al, 2012), and education about the condition was stated to combat the media misconception and help raise self-concept of people living with it (Cox et al, 2019; Eapen et al, 2016; Nussey et al, 2014). Stacy et al (2023) highlight the importance of increasing knowledge about TS in their survey of clinicians and caregivers of TS whose concern about the condition did not convert to an adequate assessment of the needs of the patients. They posit educating clinicians about TS can help improve the care they give (Stacy et al, 2023). Brook and Boaz (2007) spent months educating adolescents about TS and found education can help to increase tolerance and positive perceptions in their classmates. These findings were corroborated by Nussey et al (2014) who discovered that not only did education improve the attitude and responses of the classmates of the child with TS, it also improved the self-concept of the child leading to greater acceptance of the condition. Improving the self-concept of people with TS can diminish the effects of stigma, as interviews with adolescents with TS showed those who could identify positive attributes about TS that made them unique and creative constructed resilient self-concepts and had more positive hopes for the future (Happich et al, 2012). As these studies are all focused on children and adolescents, research investigating the effect of education on adults' perceptions of TS would be beneficial. Other interventions to alleviate stigmatizing effects have been posited in the literature, however there is a paucity of research to support these suggestions. Online support groups have been found to help those with TS feel empowered and less isolated (Perkins et al, 2020; Soos et al. 2022) and a review of TS posit hobbies and using humour to their advantage can help to improve the QOL of those with TS (Eapen et al,

2016). Further research is needed to investigate the different ways that can ease the effects of stigma for people with TS.

Reviews of the literature have discovered a paucity of research into stigma in TS (Pring et al, 2023). A review on stigma in TS by Malli et al (2015) found no research had been done to that point. They suggested research was needed to understand the perception of people with TS, and propose qualitative research is required to obtain rich data exploring the nuances of stigma (Malli et al,2015). In 2023, a scoping review of the literature into TS stigma found research had been conducted that showed stigma was still prevalent through all socio-ecological levels, including interpersonal relationships, education and employment, health care, policies, and practices. However, the number of studies was still low (Pring et al, 2023). The authors posit much more research into the complex nature of stigma is needed and agree qualitative studies were necessary for greater understanding of the nuances of stigma to develop targeted interventions through all socio-ecological levels (Pring et al, 2023). To address the need for qualitative research of the complexities of stigma in TS and necessary interventions, this study aimed to explore the lived experiences of individuals with TS, using interpretative phenomenological analysis (IPA) on blogs written by people who live the condition to investigate the research question how do people with TS experience stigma, and sub-questions which social-ecological domains are affected by stigma, and what interventions people with TS believe are necessary to reduce stigmatizing effects.

Analysis and discussion

This study adds to the literature investigating stigma in TS by providing evidence to explore how entrenched stigma is in the lives of people with TS, which socio-ecological domains are affected by it, and the interventions people with TS suggest to reduce stigmatising effects. Three superordinate themes were drawn from the data analysis: 'Impact of stigma on the lives of people with TS', 'Socio-ecological barriers created by stigma' and 'Interventions'

Figure 1:

Thematic map
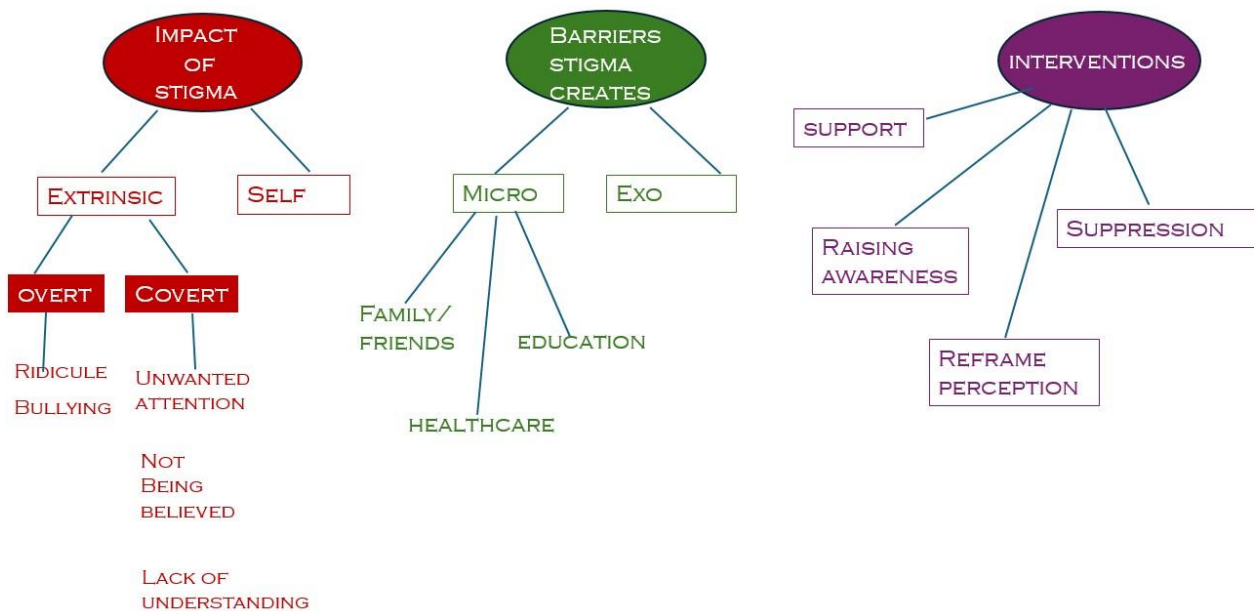
Theme 1: Impact of stigma on the lives of people with TS

The data analysis showed that stigma played a significant role in the lives of the bloggers. Two subthemes emerged from the analysis.

Extrinsic stigma

All the blogs referenced some kind of extrinsic stigma. The variety of ways extrinsic stigma occurred created two subthemes divided into categories.

Overt Stigma

Five bloggers described overt stigma, which generated two subthemes.

Ridicule

Studies have shown a unique link between humour and TS (Malli and Forrester-Jones, 2021). Evidence confirming this association was found in the data. One blogger referenced being mimicked because of the condition.

> *'I've had people mimic me in pubs, I've had people laugh, I've had people point as they're telling their mate that the girl who is just trying to enjoy her wine is a little odd!' Blog 1: Line 39-40.*

The tics manifested by the bloggers were a source of ridicule to others, confirming findings by Shrivastava et al (2012) that stigma is associated with odd behaviour. However, some bloggers report being able to laugh at their tics, defining a difference between humour that mocks, and humour that breeds acceptance.

> *'I can tic some pretty funny things, and I prefer for people to laugh at those things if they think they are funny. Personally, it's all about whether you are laughing with me or at me; it's never nice to be laughed at … Me blinking rapidly isn't funny, and me shouting chicken really loudly does get boring, but when my tics are contextual and its appropriate to, nothing helps more than having a little laugh about it.' Blog 3: Line 22-24 and42-43.*

Using humour to their advantage has been posited in the literature to help people with TS better cope with and adapt to the condition (Eapen et al, 2016). However, as suggested by blogger 3, it is

best to take the lead of the person with TS as it is not always appropriate to laugh depending on the type of tic and the person who is ticcing. A review of stigma in mental health postulate responses to stigma are personal depending on how it is perceived (Shrivastava et al, 2012), therefore, any guidance that is offered to help people live with TS should advise caution when using humour with the individual, as this is subjective.

Bullying

Two bloggers wrote about being bullied because of TS, describing it as debilitating, having a damaging effect on their mental health.

'I cannot leave my flat alone partly due to my Tourette's, but also because of the abuse I get outside.' Blog 10: Line 30.

'This confrontation of the truth [his diagnosis] *along with some bullying spiralled me down the stairs to the hole of depression. My next two years went by in a severe depressive state of potential suicide and full isolation from society by not leaving the house.' Blog 13: Line 12-14.*

These extracts show how damaging the nature of this type of stigma can be and yet people with TS have reported higher rates of bullying and discrimination than their peers because of their tics (Friedrich et al, 1996; Eapen et al, 2016). Shiu et al (2023) posit these types of traumatic events are the most distressing stigma people with TS can experience, with consequences such as social isolation and severe negative mental states. A study by Malli and Forrester-Jones (2017) has shown peers of people with TS can see a pronounced difference between themselves and individuals with

TS, which can be one explanation of the cause of bullying. More research into the causality of bullying is crucial to finding the right interventions to address it.

Covert Stigma

Overt discrimination is debilitating; however, Malli and Forrester-Jones (2019) posit they are not tolerated publicly and not as frequent as more subtle forms of stigma which are treated as trivial and not recognised as being stigma (Malli and Forrester-Jones, 2019). When analysing the data for this study covert forms of stigma were frequently mentioned in the blogs. Three categories emerged from the data.

Unwanted attention

Unwanted attention occurred as stares, unwanted questions or comments. The bloggers differed in the way they described this kind of attention, suggesting its impact was variable (Shrivastava et al, 2012). Some did not like the extra attention being drawn to them because of their tics, whereas others were exhausted by it, possibly due to it happening so frequently. There were suggestions of resignation in some accounts, indicating they reluctantly accepted this was the nature of living with TS. Others did not mind the questions and encouraged them if they were generated by genuine concern or a desire for greater understanding.

> *'Are you alright? Are you having a fit? Why did you do that? You've had hiccups all day! Would you like some water? These are just some of the comments I receive. I won't lie, it gets tiresome.' Blog 1: Line32-37.*

I've had more questions than a TV show about my condition! … for most of the public, this is no fault of their own as they are just curious, and I guess struggling to comprehend what is going on and may even be concerned for me.' Blog 6: Line 39-42.

Those who disliked the extra attention given to them because of their tics support findings by Stofleth and Parks (2022) that people with TS experienced distress because of unwanted attention and posit this may differ from other conditions, therefore deserves more attention. However, some attention may have genuine intent as Malli and Forrester –Jones (2017) found their adolescent participants had a genuine desire to understand how their peers were affected by TS and the complexities of the condition. Although it was not clear if the participants would have had this desire if it was not for the study, it does show that exposure to the condition can generate curiosity and desire for increased knowledge, which should be considered when suggesting interventions to address stigma.

Not being believed

Another type of covert stigma was not being believed that their behaviour was caused by TS. Blog 7 writes about not being believed that her behaviour is a tic because it is not swearing, and not being believed when she does have a swearing tic and getting in trouble.

'I ticced 'f**k off' and a security guard told me to watch my language, so I tried to explain that I have TS and he thought I was lying and said 'yeah right' … This whole situation is one that has really stuck with me for a few reasons. One of them being that I was really enjoying my holiday and then after that interaction I felt like I needed to suppress my tics and honestly, I just wanted to go home and hide in my house.' Blog 7: LIne 13-14 and 25-27.

Not being believed occurred to a few of the bloggers with family members, friends, teachers and clinicians. Research has shown misunderstanding the cause of TS can result in negative attitudes and increase stigmatising behaviours towards people with the condition (Malli and Forrester-Jones, 2017; Cox et al, 2019; Stofleth and Parks, 2022). Blog 9 illustrates the importance of attributing the cause of TS behaviour by using his blog to explain how most of what his brain does is without his input. However, Bervoets et al (2021) caution against using simplified explanations for attribution, as they found neurological explanations reduced blame attribution, but could generate stigmatising effects. Instead, it is suggested a mixture of neurological and psychosocial attributions with an epigenetic explanation can reduce effects of stigma (Bervoets et al, 2021). Seeing TS as a brain difference rather than a brain deficit has been suggested as it may initiate a more accurate understanding (Bervoets et al, 2023). Future studies exploring the impact different attributions have on perceptions of TS would be beneficial.

Lack of understanding

A common feature in the blogs was lack of understanding with teachers and clinicians resulting in the bloggers not receiving necessary help.

'she diagnosed me with Tourette's and sent me on my way without any help or any advice on where to go for outside help.' Blog 5: Line7 and 8-10.

'Teachers lacked understanding and the proper training to prepare them to deal with a kid with TS.' Blog 14: Line 16-17.

These extracts illustrate knowledge and understanding of TS are lacking in healthcare and educational settings. A study among healthcare students found TS stigma remained in their attitudes with only a small familiarity of the condition (Katona, 2013). More recently Stacy et al (2022) found

gaps in the diagnostic and tic management process that needed improving and propose physicians need more education to improve TS patient care. There are not many studies regarding educators, however, a recent study by Ludlow et al (2022) propose education is needed as they found British teacher's knowledge of TS was limited and although they knew they could access knowledge when needed, they sought it from sources like the media, where TS can be misrepresented (Calder-Sprackman et al, 2014). The evidence in this study add weight to past proposals that targeted education is needed for professionals involved with the care of people with TS.

Self-Stigma

All blogs reported intrinsic stigma, where they embodied the negative perceptions of others (Pring et al, 2023). Many struggled with symptoms that caused them to do or say things they did not want them to. Some bloggers expressed worry and fear at displaying these symptoms in front of others in case they reacted badly, pre-empting negative reactions due to past experiences. One referenced being depressed because of the tics and other's reactions.

> *'I was still absolutely terrified to let any of my classmates know because I had already seen how people who were "different" were treated.' Blog 16: Line 25 – 26.*

> *''After the diagnosis came a life change. My confidence fell to the ground ... it's not because I was ticcing that made me less confident, it's what people would think of me that made my confidence shatter.' Blog 8: Line 11 and 15-16.*

These findings confirm negative beliefs of others can be internalised causing shame, embarrassment, greater risk of mental health problems and lower self-esteem (Eapen et al, 2016; Vieira et al, 2023). Subu et al (2021) suggest these processes are automatic and implicit, occurring without any known effort on the part of the person experiencing it, which needs to be considered when trying to

alleviate self-stigma. It has been proposed self-confidence grew as they got older for some people with TS (Pring et al, 2023), however the evidence in this study suggest more is needed for this to happen, therefore further exploration into what reduces the embodiment of stigma is integral.

Theme 2: Socio-ecological barriers created by stigma

The data analysis generated evidence showing the discrimination felt by the bloggers pervaded throughout the socio-ecological levels (Bronfenbrenner, 2005). The impact on self has already been discussed, therefore this theme generated two sub themes

Micro level

Barriers at the micro-level were referenced in most of the blogs, generating three categories.

Family and friends

Although home has been found to be a key site for stigma in TS (Malli et al, 2019), a few bloggers in this study mention their parents were the catalyst for seeking help and home was where they could finally express their tics. Stigma did occur with siblings through not believing their tics were tics, or teasing.

'My siblings soon found out they could wind me up and trigger my "twitch" as we called it by leaving light switches on or just repeating the word "twitch" over and over.' Blogger 16: line 11-12.

Friends were mentioned in the blogs as having a significant impact on the blogger's ability to cope with the condition and stigma. However, one blogger discarded some friends because they did not believe her tics, and blog 13 states 'kids were mean' (line16) at school. Studies have shown people

with TS are viewed differently and more negatively than their peers (Friedrich et al, 1996; Brook and Boaz, 2006), which can provide an explanation for difficulties when establishing supportive friendships and can also explain why there are challenges with siblings. It has been found that 40% of adolescents with TS struggle to make friends, and this number increases to 70% in adulthood (Pring et al, 2023). It is important to look further into barriers with relationships as they have been found to be essential to long term social and emotional stability (Eapen et al, 2016).

Healthcare

Hesitancy about going to the doctors was mentioned in the data. One blogger expressed worry about what the outcome of the appointment would be, others worried about not being taken seriously.

'A lot of the professionals I went to see raised their eyebrows at me… the other half merely raised their eyebrows to question if maybe I was a little anxious and stressed at work.' Blog 8: Line 4-6.

A few blogs mentioned lack of knowledge from clinicians restricted the support they received, which adds to findings that people with TS had to be educators for the professionals who were dismissive. The diagnostic process was also long and traumatic (Pring et al, 2023). Blog 1 described the difference a supportive professional made who helped her understand TS and took 'the weight' of living with the condition, demonstrating how awareness and understanding are crucial to improve care for TS patients. Currently, there are no NICE guidelines for TS specifically, which has been suggested as an explanation for the lack of awareness and expertise in healthcare (Malli and Forrester-Jones, 2021). Providing guidance and education on TS to healthcare professionals is essential for improved care of TS patients.

Education and employment

Lack of knowledge about TS and lack of adequate support made school and work challenging for most bloggers.

'Some didn't really care because they were not very educated about TS, and other teachers tried to understand but still did not really grasp some of the access needs that were put in place to help me get through the day without going home.' Blogger 5: line 19-21.

In school, some bloggers mentioned they worried about the reaction of others or being a distraction, which led to suppressing their tics. Suppressing or hiding tics was mentioned in the workplace too. One blogger made frequent trips to the bathroom to let his tics out, others lost their job because of TS or had their job 'stripped back'. These findings support the mixed methods study investigating the experience of stigma in adults with TS by Malli and Forrester-Jones (2021) that schools and employment did not accommodate for additional needs expecting people with TS to adjust (Malli and Forrester – Jones, 2021). Blogger 17 states a good SEN department and supportive teachers set him up for future employment and it has been found children with TS can embrace their condition if schools provide knowledge about TS and have strategies to improve attitudes about the condition (Eapen et al, 2016). These findings suggest more needs to be done to improve understanding of TS in educational and employment settings so the right support can be provided.

Exo level

At the exo level, two blogs detailed how stigma in the media can cause problems that seep through all the socio-ecological levels. Blogger 2 described how ratings take precedence over TS education, and how challenging it is to provide a clear picture of the variability of the condition. Both

blogs mention the over-representation of coprolalia and misinformation in the media, confirming findings in the review by Calder-Sprackman et al (2014) that the primary goal of the media is to entertain which results in misrepresentation and exaggeration of TS. The effect the media has on people's perceptions of the condition was mentioned.

> *'It only takes one stupid comment from someone famous and you can see how much more work is needed to properly raise awareness ... someone makes a very tired, lazy joke equating Tourette's with swearing or vocal outbursts ... it's become a default term for outbursts or saying the wrong thing ... too much time and effort is still spent undoing the use of tires stereotypes and misinformation.' Blogger 2: Line 76-79 and 91-92.*

The significance of the impact of the media is highlighted by research that found adolescents based their perceptions of TS from what they learned in the media (Malli and Forrester-Jones, 2017) and teachers who needed to learn more about their students with TS would go to the media as a source (Ludlow et al, 2022). With the vast audience the media has, it can be used as a tool to raise awareness. Participant 6 described how seeing a boy on TV with the same condition helped him understand what was going on with him and gave him something to relate to, which shows the good that the media can do, therefore the media should take more responsibility when portraying TS.

Theme 3: Interventions

Almost all blogs wrote about what they think is necessary to address stigma and alleviate its effects, generating 4 subthemes.

Support

Most bloggers found the right support made a notable difference to their experience, as discussed previously, with friends and family, healthcare, education, and employment. A few of the blogs referenced how beneficial the support they found from TS communities was.

'I allowed every tic and every urge to exist, and it felt good. I thought I would be exhausted,
as *I'm always exhausted, but I was surprisingly fine. As if ticcing is less tiring than suppressing*
(how *surprising!) ... It was a phenomenal experience to see everyone being able to be themselves*
without any judgement.' Blogger 15: line 11 –14 and 34.

TS communities were a place the bloggers felt they were accepted and free to tic. Those who mentioned it described relief. No other studies were found that investigated the impact in-person TS communities had, although some studies found local community support was lacking (Perkins et al, 2020; Pring et al, 2023). Research has been conducted for online TS support communities and found people with the condition could obtain needed information and support from them that they could not offline, which relieved social isolation and improved psychological wellbeing (Perkins et al, 2020; Soos et al, 2022). The evidence so far indicates TS support groups have great success improving stigmatising effects, but more investigation into the impact of in-person groups is needed to improve this service.

Raising Awareness/Education

The intention of the blogs was to share their experience to raise awareness of TS or help others who live with it. Many referenced a need for more awareness.

'There is still so much that others need to learn about Tourette's and what people living with Tourette's go through ... People need to be educated and have an understanding on what Tourette's is.' Blog 8: line 26 and 28-29.

However, blogger 2 warns '*Awareness … doesn't equal understanding*' (line 11-12). As discussed previously, a lack of training for educators and clinicians was highlighted in the data and recent research confirms more knowledge about TS is needed to improve the care and support that professionals and caregivers can provide (Stacy et al, 2023). Targeted education has improved knowledge, attitudes, and behaviours towards those with TS, which enhanced awareness in classmates, teachers and parents and helped to improve the self-concept of the person with TS (Brook and Boaz, 2007; Nussey et al, 2014). This study confirmed other findings that bloggers had a desire for others to understand the condition (Happich et al, 2012). This desire with the benefits of targeted education provides a strong argument towards greater education to reduce stigma.

Reframing how they view TS

A few of the blogger's mention embracing and seeing the positive about TS helped improve self-concept and alleviate stigmatising effects.

'a close friend once described my tics as 'the representation of all the hard times and how you've got through them.' I liked that … It may have taken me 9 years to get here, but I finally accept that I have something that's a little different' Blog 1: line 14-15 and 59-60.

They suggest this was achieved by supportive others, medication, achieving things they did not think possible and increased understanding of the condition. However, another blogger mentions seeing TS positively is not easily achieved, warning against 'toxic positivity', claiming this does not help TS awareness as it is not realistic. Blogger 10 also shares a 'brutally honest account' that includes pain, isolation, and bullying. The severity of tics appears to be the cause of their inability to change their perception, which goes against studies where self-perception was related more to comorbid disorders, parenting style and poor peer relationships than tic severity (Cox et al, 2019; Silvestri et al, 2017). As the nature of this study meant that no additional information about the participant could

be obtained, future research could benefit from looking into the nuances of self-perception to ascertain how this can be improved.

Suppression

Almost all bloggers mentioned suppressing tics as an intervention to avoid negative reactions. However, suppressing was described as painful, exhausting and leading to tic attacks.

'People don't realise how much energy and concentration is needed to suppress your tics. This resulted in tic attacks and fatigue that made my lessons and even friendship impossible.' Blog 16: line 20-21.

Suppression is a component in treatment of TS (Kim et al, 2019, yet experiences from this study suggest tic suppression exacerbates symptoms. Some studies corroborate these findings stating suppression is physically and mentally exhausting and associates with worsening of symptoms, low self-concept and low QOL (Cox et al, 2019; Pring et al, 2023). Some bloggers mentioned hobbies/passions enabled them to ease their tics into something they enjoy which felt relieving rather than exhausting. Eapen et al (2016) have referenced this topic but it has not been explored. As suppression has such debilitating consequences, it would be worthwhile to explore the impact hobbies/passions can have on alleviating tics.

Limitations

Writing blogs enabled honest and candid accounts of the bloggers experience and using IPA allowed rich ideographic insight into it. However, as the blogs were previously written, no extra information was available, which restricted the exploration of certain topics, including the impact of comorbidities and tic severity on stigma. This risk was minimised by using a larger sample than is recommended in IPA. Bias towards TS support groups may have occurred as the blogs were from the

Tourette's Action charity website. However, it could be argued that they would not have mentioned the groups if they did not want to, so the benefits of their involvement in TS groups can be assumed genuine. As it is a qualitative study, there is a risk of bias through the researcher's interpretation of the data. Although the author tried to be aware of this, another researcher may draw different conclusions.

Conclusion

An IPA of blogs written by people with TS illustrated stigma was an entrenched part of their lives with debilitating consequences. Overt stigma, such as bullying and ridicule, was most distressing causing issues with mental health and social isolation. Humour was a way some bloggers coped with this, but this strategy should be led by the individual, as a difference between humour that mocks and humour that supports was defined. Covert stigma was more frequently mentioned as unwanted attention, lack of understanding and not being believed. Stigma led to barriers in sibling relationships, and accessing help in education, employment and healthcare. Adequate support helped the bloggers embrace the condition and manage the symptoms. Raising awareness through education on the condition could alleviate the effects of stigma and improve support and the media could be good source for information. However, it misrepresents TS so future representations of TS in the media need to be responsible for checking its accuracy. Caution should also be taken when attributing a cause to TS behaviour as some explanations have generated stigma responses (Bervoets et al, 2021). Further investigations into TS attributions are needed so as not to exacerbate stigmatizing effects. Improving the self-perception of TS helped some bloggers, but tic severity made this challenging for others, which differs from previous findings that report comorbidities had a greater impact on self-perception (Silvestri et al, 2017). Therefore, more research exploring which factors affect self-perception in people with TS could be beneficial. Suppressing tics was the intervention that the bloggers used to avoid stigma resulting in pain,

exhaustion, and exacerbation of symptoms, however, easing tics into hobbies was found to be

relieving. No research could be found to support this, so this could be an aim for future studies.

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