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British teachers' knowledge and awareness of Tourette syndrome in children attending mainstream school

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Mainstream primary and secondary schools are increasingly committed to the inclusion of students with Tourette Syndrome (TS). This qualitative study explores teachers' perceptions of factors that have contributed to, or hindered, their success in creating an inclusive environment for children with Tourette Syndrome (TS). Eight teachers (two males, six females) from mainstream primary and secondary schools in the United Kingdom (UK) took part in semi-structured interviews to ascertain their knowledge, training and experience of TS during their professional careers in the UK. Thematic analysis of the transcripts revealed three main themes: teachers' lack of real knowledge and awareness of TS; training provision and marginalisation of TS; and finding solutions and building alliances. Although many of the teachers described their mainstream school as an inclusive environment, many still believed they lacked the professional training to adequately understand the disorder. By enhancing teacher training related to TS, improvements may be seen in the communications between the teachers and parents, and opportunities to educate children and the wider community will also result in a more inclusive environment, reducing specific and generic stressors for children with TS.

Introduction

Tourette syndrome (TS), also known as Tourettes disorder, is characterised by involuntary, repetitive and non-rhythmic motor and vocal tics, with a typical onset between 6 and 7 years (American Psychiatric Association (APA), 2013). When symptoms involve more persistent motor or vocal tics, a diagnosis of persistent (chronic) motor or tic disorder (symptoms more than a year) is given (APA, 2013). Although the prevalence rates for

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children diagnosed with TS and/or a chronic tic disorder are estimated to make up around 3% of all children in mainstream schools (Chowdhury and Christie, 2002), the number of children showing other types of tic disorder are much higher. For example, provisional tic disorder is a condition in which a person makes one or many brief repeated, movements or noises (tics). These movements or noises are involuntary and occur in around 25% of healthy children (Efron and Dale, 2018), with one review of the literature suggesting all children will have a tic at some point in time (Black, Black, Greene, et al., 2016). Furthermore, since the start of the COVID-19 pandemic, there has been a significant increase in the severity and frequency of tics for those who already have a diagnosis of a tic disorder (Conte, Baglioni, Valente, et al., 2020), and cases of new and sudden onset of severe tics and 'tic-like' attacks seen by clinicians (Heyman, Liang, and Hedderly, 2021). Many mainstream educators will face educating adolescents showing such tic-like attacks, often for the first time; consequently, understanding and appropriately managing this within the classroom seem crucial for the inclusivity agenda in mainstream schools and in line with international legal commitments (UN, 2016).

One of the difficulties for children with TS involves the variability in the types of tics displayed, which can include involuntary movements and sounds. Simple motor tics can include behaviours such as eye blinks, shrugs and grimaces; more complex tics can include the touching of objects and/or people. Whereas simple vocal tics can include coughs and grunts, more complex vocal tics might involve repetition of their own speech (palilalia) or someone else's (echolalia) (Zinner, 2004). In addition to the motor and vocal classification of tics, there is some unpredictability surrounding the symptoms. For example, the body parts affected by tics, and the frequency and severity of the tics can change over time (Singer, 2005).

Although a diagnosis of TS may not directly affect intelligence, in about 23% of cases the co-occurrence of tics with Attention Deficit Hyperactivity Disorder (ADHD) or Obsessive-Compulsive Disorder (OCD) can negatively

impact on cognitive functioning (Burd, Freeman, Klug, et al., 2005). Such attentional and cognitive deficits can then impact the learning process. It is estimated that up to 50% of children with TS have difficulties with their learning requiring additional educational support (Abwender et al., 1996; Debes, Hjalgrim, and Skov, 2010). Furthermore, children with TS experience fatigue and are embarrassed and anxious at the prospect that their tics might materialise during the school day (Edwards, Mendlowitz, Jackson, et al., 2017). Such anxiety can further increase the frequency and severity of tics (Conelea and Woods, 2008). Consequently, some children will explicitly find their tics a barrier to learning, impacting on their general concentration, writing and reading ability and performance under time constraints (Packer, 2005).

Additionally, children with TS can struggle with emotional and social difficulties in school (Kadesjö and Gillberg, 2000), and some may exhibit aggressiveness (Chowdhury and Christie, 2002). Finding their tics are not understood or accepted during social interactions with others and can be just as debilitating as the academic challenges they face (Lee, Wang, Chen, et al., 2018). Indeed, many children with TS are teased (Debes, Hjalgrim, and Skov, 2010), victimised or rejected by their peers (Packer, 2005; Storch, Merlo, Lack, et al., 2007; Zinner, Conelea, Glew, et al., 2012). Crucially, a recent study identified a staggering three-quarters of adults with TS had experienced stigma in education settings (Malli and Forrester-Jones, 2021). Therefore, children with TS's ability to socialise and make friends at school can be just as demanding as the academic aspects they encounter.

Within mainstream schools, interrelationships between learning, social and emotional development are central to the experience of inclusivity for children with TS; teachers can play an important role in a child's education experience. Although a substantial amount of research has addressed the inclusion of young children with special needs in classrooms (Odom and Diamond, 1998), much of this has focused on the beliefs and attitudes of regular and special education teachers (Vidovich and Lombard, 1998) and recommendations on inclusivity enhancing practices (Blenk and Fine, 1995). However, there has been limited research addressing mainstream teacher's understanding and inclusion of TS in the classroom, with discrepancies noted. For example, teachers are implementing good practice in mainstream schools with 80% of 17 recommended strategies for teaching children with TS noted by teachers as being easy to implement in their school or already in place (Wadman, Glazebrook, Parkes, et al., 2016). Yet parents of children with TS have expressed concern around inadequate support and services available for their children, struggling to have their learning needs met at school (Ludlow, Brown, and Schulz, 2016). Parents have further noted barriers around teachers' understanding of the nature of a tic disorder,

consequently disciplining a child for tic related behaviours (Jones and Ramphul, 2018).

Conversely, children are at their happiest and most productive when teachers are understanding and respectful of their needs and feelings (Grace and Russell, 2005). Yet, students worrying or even thinking about tics can lead to their onset (O'Brien, Harris, Beckman, et al., 2014); thus, teachers attempting to reduce tics will not improve the student's learning ability (Kalsi, Tambelli, Aceto, et al., 2015); in contrast, it may worsen it if tics are exacerbated. Instead, evidence suggests that symptoms of TS are less problematic when children are engaged in school activities in a non-pressurised environment (Kepley and Conners, 2007), or when adaptations are made to accommodate their difficulties. Such adaptations can include more time, alternative ways of delivering their work (Zinner, 2004), reduced amounts of homework (Packer, 2005) and providing scheduled breaks (Kepley and Conners, 2007).

There is limited research addressing education provision for children with TS and teachers' role in inclusion; as classroom teachers are the ones who are directly responsible for implementing most of the day-to-day practices of inclusivity (Sardo-Brown and Hinson, 1995), this study aimed to explore mainstream primary and secondary school teachers' experience, knowledge and understanding of teaching children with TS.

Materials and methods

Design

Qualitative research offers a valuable approach to capturing complexities and exploring meaning and subjective experiences in-depth. As thematic analysis (TA) has flexibility in identifying and analysing patterns of meaning (Braun and Clarke, 2006), this was used to analyse semistructured interviews with teachers working in mainstream schools across the UK.

The second author devised a semi-structured interview schedule through consultations with the first author, adults with lived experiences of TS and the literature. Ouestions included:

- Please can you tell me what you know about Tourette's Syndrome?
- What professional expertise have you received (during and after your professional training) to enable you to provide help and support for a child with Tourette's Syndrome?
- How would you accommodate the needs of children with Tourette's Syndrome?
- How do (or how would) you go about talking to the class about Tourette's Syndrome?

- If you have taught children with Tourette's Syndrome, how have you engaged with their family to understand their particular difficulties?
- What is your school policy on children with special needs and those with Tourette's Syndrome?
- Is there any information or support you feel you need/would like on the topic of Tourette's Syndrome?

Participants

An opportunity sampling method was used to recruit eight qualified teachers (two male and six female) from different mainstream primary and secondary schools across the UK (see Table 1). Participants had to be a qualified teacher for at least 2 years and initially trained as teachers in the UK. Teachers were aged between 29 years and 62 years (M = 46.25 years; SD = 9.74) with teaching experience that ranged from 5 years to 41 years (M = 19.75 years; SD = 10.50). Five participants were also their schools' Special Educational Needs Coordinator (SENCO).

Data collection

During recruitment 193 schools were contacted *via* email or telephone within England, Scotland and Wales; eight schools (4%) agreed to participate and were sent participant information sheets outlining the study aims. Interested teachers independently contacted the researcher to find out more about the study; all those who agreed to participate were interviewed face to face in a quiet room on school premises at the beginning, end or during their working day. Interviews lasted between 45 and 60 minutes.

Ethical considerations

Ethical approval was granted by the University of Hertfordshire Ethical Advisory committee (protocol number: LMS/PGT/UH/02813), and the research was performed in accordance with the Declaration of Helsinki. Participants were provided with information sheets and informed consent obtained. Participants were made aware of interviews being recorded, deleted on transcription and anonymised data used in a publication. After the interviews,

participants were thanked for their participation and provided with a debrief sheet which gave details of supportive organisations offering emotional support, as well as details of the charity Tourette's Action who provide information and support regarding TS to individuals with the condition, their families, health professionals and the wider community.

Data analysis

Rather than being theory-driven, the second author analysed the data inductively exploring surface-level meanings, alongside reflecting on underlying assumptions and issues. The analysis involved moving backwards and forwards between the phases of TA (Braun and Clarke, 2006): familiarisation of the data was conducted during the transcription process; initial overarching codes were generated, and an audit trail used to quantify the number of times initial shared themes arose; a re-read of all transcripts honed the themes into refined themes; themes were defined and reviewed to ensure distinction, representation of participants words and that they reflected the data set and codes. Themes were further explored for links and commonalities resulting in the final theme table.

Quality assurance

To ensure credibility, quality criteria were applied throughout the study (O'Brien, Harris, Beckman, et al., 2014; Treharne and Riggs, 2015), including reflexive conversations between first and second authors, member checking of the final themes to ensure rigour and analysis of the findings; and agreement of all authors in the final themes and quotes presented in this paper. Further, to minimise bias during the acquisition, analysis and interpretation of the collated data, the second author made self-reflective notes throughout the process discussing ideas and clarifying differences (Braun and Clarke, 2019).

Results

Three main themes emerged from the analysis: teachers' lack of real knowledge and awareness of Tourette

Table 1: Demographic information for teachers

| Participant | Age | Sex | Ethnicity | Nationality | Teaching qualification | Teacher training location (UK) | Current school | Teaching experience years (& if taught children with tics) | SENCO training undertaken |
|-------------|-----|--------|-----------|-------------|------------------------|--------------------------------|--------------------|--|---------------------------------|
| Prisha | 42 | Female | Indian | British | PGCE | South East England | South East England | 14 (Yes ^b) | Yes |
| David | 53 | Male | White | British | B.Ed | Midlands | Midlands | 22 (Yes) | No |
| Geoff | 52 | Male | White | British | PGCE | East Anglia | Eastern England | 13 (No) | Yes |
| Brigid | 29 | Female | White | British | QTS | Midlands | Eastern England | 5 (No) | Yes |
| Rachel | 43 | Female | White | British | PGCE | London | Eastern England | 19 (No) | No |
| Janet | 62 | Female | White | British | C.Ed | East Midlands | South East England | 41 (Yes ^a) | Yes |
| Rose | 46 | Female | White | British | B.Ed (Hons) | North England | Midlands | 24 (Yes ^b) | Yes |
| Lisa | 43 | Female | White | British | B.Ed | East Midlands | South East England | 20 (Yes ^a) | No |

^aTeacher had previous experience of children with suspected TS when working in a special school. ^bChild formerly diagnosed with TS.

syndrome; training provision and marginalisation of Tourette syndrome; and finding solutions and building alliances.

Teachers' lack of real knowledge and awareness of Tourette syndrome

Six teachers highlighted their lack of prior knowledge of TS, with five teachers stating their interpretation of this condition was mainly drawn from other sources, such as the media, searches of reputable organisations on the internet (three teachers) or speaking with other professionals with expertise or experience in TS (two teachers). Seven teachers in this sample described symptoms as verbal tics, including the expression of profanities (three teachers). For example, when asked to explain what they knew about TS:

From what I have seen advertised in newspapers and TV it is sudden outbursts of noises or tics or shouting, occasionally swearing.

(David, Teacher)

Just four teachers were aware that tics could manifest as repetitive, jerky physical movements; and four teachers also acknowledged that TS symptoms could be exacerbated by stress or anxiety, for example:

What I have seen is very limited. It's mainly been from TV programmes and I've had no personal experience of it. As far as I believe it is people who find it difficult to control their speech or when they feel anxious they can repeat words or shout out involuntarily, or move involuntarily and not have control over their body. (Brigid, SENCO Teacher)

Four teachers with previous experience of children with TS learned to recognise that such stress and anxiety exacerbated tic symptoms, for example:

...at times of heightened anxiety these tics can be worsened.

(David, Teacher)

It was more about his anxiety building, and he was finding it hard to come down as it would just escalate into natural verbal and physical outbursts.

(Prisha, SENCO Teacher)

Five teachers reported teaching experience for children with tics, yet only three teachers were aware children with TS had co-occurring disorders of ADHD or ASD; when directly asked to explain what they knew about TS, seven teachers did not express any awareness of the onset, prevalence or treatments for TS. Where children with tics did not have a formal diagnosis for their condition, or where their symptoms only became apparent when they were at school, teachers discussed their stance for instigating enquiries as reactive, based on a need-to-know basis:

It would only be if we had someone specifically that was diagnosed with TS that we would do the training, or if we'd got a particular interest for a personal reason.

(Janet, SENCO Teacher)

We work on the basis that diagnosis is only necessary if it's going to help you understand or help your child rather than it equals money therefore do it. (Rachel, Teacher)

Brigid aired concern about the potential ramifications this lack of awareness might have when initiating support for children with suspected TS:

Because I have so little understanding or experience [in TS] I initially would be concerned that I wouldn't know how to deal with it, how to support them without exacerbating the problem...because if it all happened tomorrow, I think we would be underprepared. (Brigid, SENCO Teacher)

Training provision and marginalisation of Tourette syndrome

Although seven teachers described their mainstream school as an inclusive environment and four teachers stated their school accepted and accommodated differences or diversity among children with specific needs, most teachers revealed their professional training did not adequately prepare them to understand children with special needs:

I think the initial teacher training could include a much bigger remit, I mean special educational needs is completely minimalized.
(Lisa, Teacher)

Indeed, irrespective of the initial teacher training undertaken, six teachers reported their course did not adequately equip them to anticipate or identify undiagnosed children with TS; they could not even recollect TS being mentioned at all, and the other two teachers noted the topic of TS was marginalised. Further, five teachers did not know whether there had been undiagnosed children with TS in their class during their teaching career, creating a quandary:

Because I have so little understanding or experience [in TS] I initially would be concerned that I wouldn't know how to deal with it, how to support them, without exacerbating the problem.

(Brigid, SENCO Teacher)

Such ignorance meant that the instigation of help for a child with TS was largely reactive where issues might escalate to crisis point before action was taken:

When they're in crisis, that as a school, as a mainstream school we're not equipped to do, we've trained ourselves, but we've had to go out there and try and find the training, and then access that training. (Prisha, SENCO Teacher)

The decision to initiate conversations with families or appropriate members of staff regarding children with TS also revealed a less systematic process often based on personal interest:

We don't honestly have a lot of training [in TS]. We have a lot on dyslexia and dyspraxia, the more common problems we come across in a regular primary school but it would only be if we had someone specifically that was diagnosed with TS that we would do the training, or if we'd got a particular interest for a personal reason

(Janet, SENCO Teacher)

The five teachers with additional responsibility as a SENCO assumed overall responsibility for the management of SEN needs of children within their school. A SENCO teacher commented on the inadequacy of the training for SEN disorders in general:

I did the SENCO course and got the qualification for that but that was more about the management of special needs, coordinating outside agencies and things like that rather than trying to describe to people the individual difficulties.

(Janet, SENCO Teacher)

The one teacher who had completed the induction aspect to the SENCO training and the four teachers who had previously completed the course, all reported their training in TS was inadequate:

I've done the induction to SENCO course this year and attended lots of cluster meetings and extra training on top, but TS has not been covered in any way, shape or form.

(Brigid, SENCO Teacher)

It seemed the lack training provision marginalised children with TS, yet the teachers seemed willing to find solutions.

Finding solutions and building alliances

Although teachers lacked coherent knowledge of TS, five felt confident in their ability to elicit sufficient information as well as support and advice from different people to accommodate a child with TS in their school. These teachers also felt competent in obtaining consent from the family to implement tailored care management plans to suit the needs of the child and discuss this with other children in the school. For example, one

teacher listed a series of actions she and her school would do:

We would hope to collaborate with the parents, and work with the whole class to help explain and understand what TS is and how it manifests itself. Work with whole group of children to enable them to have strategies themselves for helping that child manage their own behaviour. Empower children at an early age to help them learn to deal with it in the same way I hope outside of the school environment the adults would.

(Lisa, Teacher)

Where there was agreement between teachers and families for adjustments to be made to accommodate the needs of a child with TS, implementation was more productive:

When he first came to us we had to very quickly put in place an adult to support him so he had one-to-one support full-time, and that was to help him cope with his learning, to give him options, limited choice with his learning, to give him overload breaks.

[Prisha, SENCO]

One teacher expressed limitations of school procedures when implementing adjustments, suggesting this might be out of kilter with parental wishes, which was clearly viewed as a difficulty:

I think our difficulty as a school would be where a parent's idea of how you might manage or deal with it might differ from the school's own system.

(Lisa, teacher)

Two teachers also recognised the necessity to acknowledge the impact of a child's tics on other children in the class and their families. For example: Lisa stated: 'The wider community is a lot more nervous [of children] with TS'. This extended to an awareness that teachers were limited by wider ignorance around TS, limiting acceptance:

I think the only concern that some senior leaders [teaching staff] will have is other parents' perceptions of how you're not dealing with inappropriate behaviour...because parents are very protective of their own children and if their child is subject to hearing abusive language that they find offensive themselves and which they are trying to protect their children, that is probably the biggest concern...because children are actually much more accepting than adults, so it's developing that wider understanding and eradicating ignorance among the wider community. That's the biggest challenge.

(Rose, SENCO Teacher)

Two teachers noted occasions when parents were unwilling to access wider support limiting teachers' ability to implement whole-class or whole-school strategies to indirectly support a child with TS:

The parent did not want any outside agency involvement and doesn't want any support but I have made contact with her and let her know we've support if she needs it...so my role has been a bit different, making sure the anxiety for that child within school isn't an issue.

(Rose, SENCO Teacher)

Discussion

To ascertain the extent to which children with TS were accommodated in mainstream school, this is the first qualitative research study exploring teachers' experiences of TS in terms of their acquisition of knowledge, training and experience. Although the inclusion of TS as part of teacher training was highlighted as lacking in all accounts, even for the SENCO's, teachers still reported their schools as having an inclusive environment.

The findings suggest that teachers received little or no information on TS during their professional teacher training. This is in direct conflict to recent European clinical guidelines emphasising the importance of educating schools about TS, in addition to providing clinical behavioural interventions for young people with TS (Mathews, 2021). Instead, the teachers acquired much of their comprehension of TS via the media, often presenting a distorted view. For example, most of the teachers described the manifestation of tics as the vocalisation of inappropriate words (Calder-Sprackman, Sutherland, and Doja, 2014). However, this represents a limited understanding of TS, and Claussen, Bitsko, Holbrook, et al. (2018) have argued that students with TS are best supported when their teachers and caregivers are better aware of the diverse challenges associated with the condition.

Some teachers generally understood that stress and anxiety worsened tic symptoms. One strategy to manage this involves removing a child with TS from the main classroom, to complete their work in a less pressurised environment. Although a different learning environment may help children with TS cope with their symptoms (Kepley and Conners, 2007), it also misses the opportunity for the main classroom setting being made more conducive to the learning experience of children with TS, such as through psychoeducation with their peers (Rizzo, Pellico, Silvestri, et al., 2018). Indeed, this separation of children might serve to fracture relations between both parties and highlight differences for children with TS, limiting their sense of belonging to their social group (Choi, Schuck, and Imm, 2022). Instead, teachers need to remain sensitive to the needs of the child with tics, while ignoring the tics themselves, and facilitate a child to briefly leave the classroom to relieve the tic(s) given this can reduce tic suppression (Packer, 2005). Conceptually, to reinforce this as an inclusion strategy, it seems important the child is facilitated in instigating this; any abrupt or unsignposted removal of a child by a teacher could be counterproductive, inadvertently fostering a sense of exclusion.

In cases where children had a formal diagnosis of TS, teachers were often reactive to the situation and were able to work with parents and other professionals to create interventions tailored to the needs of each child. However, where children with tics did not have a diagnosis, teachers displayed a reluctance to commence enquiries with the children's parents unless it negatively affected the child's learning in school (Sciutto, Terjesen, and Frank, 2000); this can exacerbate stress and anxiety within school contexts for a child with tics who remains undiagnosed. Therefore, simply enhancing teacher training related to TS may lead to a more consistent and effective referral process where teachers may help secure a formal diagnosis (Polirstok and Gottlieb, 2006). This is particularly important for children whose tics manifest in the classroom or at school only, beyond parental/carer awareness, limiting the ability of parents/carers themselves to observe the behaviours and instigate a referral.

Teachers in the current study mainly described their school as supportive and inclusive, where children with SEN were accepted and accommodated, corroborating previous findings (Wadman, Glazebrook, Parkes, et al., 2016). Where children had a diagnosis of TS, and there was a good rapport between their family and teachers, psycho-education interventions and a reduced curriculum were implemented to help reduce stress and anxiety. Importantly, among staff who had no prior exposure to TS, an assumption was made that they would know when a child with TS presented and would access relevant information when needed. However, as noted, many teachers were unaware of the diversity of tics and were accessing only partial information, potentially missing important cues.

There was also an assumption that, with parental consent, a programme of psychoeducation interventions for other children within the school community could be implemented (Nussey, Pistrang, and Murphy, 2014). In practice, teachers in this sample noted that parents sometimes declined offers of help for their child's tics; this could be for a range of reasons, such as parental avoidance as a coping strategy, fear of their child being stigmatised or a general unawareness of the options open to them (Ohan, Seward, Stallman, et al., 2015). It could also be due to school specific TS presentations with a child presenting differently at home. Regardless, it could mean the needs of a child with TS remain unmet in school. Teachers also

discussed their need to manage parental expectations, a potentially challenging area for both parents and teachers, because tics wax and wane, due in part to the different demands and stresses for the child, meaning tics may manifest differently in a school *versus* a home environment (Cohen, Leckman, and Bloch, 2013). Therefore, teachers and parents are likely to have different accounts of a child's condition, and this may create some confusion over the needs of the child and how best to meet them.

Importantly, common to all reports among the teachers was the absence of initial teacher training in the prevalence, diagnoses, symptomology and treatments of SEN disorders. In most cases, teachers could recall no mention of TS during teacher training, suggesting TS is not fully recognised among the teaching profession as a SEN despite its inclusion in the DSM-5 (American Psychiatric Association, 2013). Teachers with an additional SENCO qualification also reported a lack coverage of TS during their course, irrespective of when that training took place. Instead, the SENCO programme took a transdiagnostic approach to the management of SEN with a generic focus on logistical arrangements with external agencies relating to any SEN, rather than a holistic approach on each disorder that may present within schools (Gini, Knowland, Thomas, et al., 2021). Given stress and anxiety exacerbate TS, it is crucial that better understanding and recognition occur for all manifestations of the condition, to enable children with TS to access appropriate help and support, including more direct management of stressors.

Although the sample in this research was small, it did encompass teachers with different levels of experience of TS, providing a more nuanced understanding of lived experience, through case-to-case transfer generalisation (Treharne and Riggs, 2015). Furthermore, the wide variation in where teachers had completed their initial teacher training was quite broad and in different settings, enabling the researcher to ascertain that there had been little or no information taught on TS nationally. However, there are several limitations of the study, for instance, during recruitment, 193 schools were contacted via email or telephone within England, Scotland and Wales, yet only eight schools (4%) agreed to participate. The sample in this study may, therefore, represent highly conscientious schools and their teachers towards children with TS, slightly biasing these findings. In view of the low uptake of schools engaging with this exploratory study, it is important to ascertain the experiences of a large sample of teachers from all over the UK; thus, quantitative research using an anonymous online questionnaire to capture teacher's knowledge, training and experience of TS within the whole of the UK is proposed. A separate exploratory qualitative study, using semi-structured oneto-one interviews, could also consider education experiences directly with children with TS.

In summary, although teachers believed they could access relevant resources for a child with TS when needed, knowledge was limited; there is an urgent need to review teacher training programmes and systematically introduce core information and treatment strategies for TS within them. These tic-like behaviours appear to develop and peak in severity within hours to days, causing significant functional impairment (Pringsheim and Martino, 2021); thus, this implementation is essential in such changeable current times, given many mainstream educators will now be faced with educating adolescents showing such tic like attacks. Furthermore, to help mitigate prejudice and stigmatisation towards individuals with TS, treatment strategies for this disorder should also extend to psychoeducation programmes for the wider school community and external agencies. Short teacher training workshops have been shown to be effective for teachers with limited knowledge of developmental disorders, such as TS and ADHD (White, Sukhodolsky, Rains, et al., 2011). This would help address any misconceptions that exist of TS and ensure the equilibrium of an inclusive school environment in mainstream schools is maintained.

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Conflict of interest

All other authors declare no conflict of interest.

Data availability statement

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

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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), pp. 509–511. https://doi.org/10.1001/archneur.1996.00550060051016

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders*, 5th edn Arlington, VA: American Psychiatric Association.

- Black, K. J., Black, E. R., Greene, D. J. & Schlaggar, B. L. (2016) 'Provisional tic disorder: What to tell parents when their child first starts ticcing.' *F1000Research*, 5, p. 696. https://doi.org/10.12688/f1000research.8428.1
- Blenk, K. & Fine, D. L. (1995) *Making School Inclusion Work: A Guide to Everyday Practice* Cambridge, MA: Brookline Books.
- Braun, V. & Clarke, V. (2006) 'Using thematic analysis in psychology.' *Qualitative research in psychology*, 3 (2), pp. 77–101. https://doi.org/10.1191/1478088706QP063QA
- Braun, V. & Clarke, V. (2019) 'Reflecting on reflexive thematic analysis.' *Qualitative Research in Sport, Exercise and Health*, 11 (4), pp. 589–97. https://doi.org/10.1080/2159676X.2019.1628806
- Burd, L., Freeman, R. D., Klug, M. G. & Kerbeshian, J. (2005) 'Tourette syndrome and learning disabilities.' *BMC Pediatrics*, 5 (1), 34. https://doi.org/10.1186/1471-2431-5-34
- Calder-Sprackman, S., Sutherland, S. & Doja, A. (2014) 'The portrayal of Tourette syndrome in film and television.' *Canadian Journal of Neurological Sciences*, 41 (2), pp. 226–32. https://doi.org/10.1017/S0317167100016620
- Choi, S., Schuck, R. K. & Imm, K. (2022) 'Redesigning deficit-laden assessments for Neurodivergent students.' In: Williams, R.D. (Ed.) *Handbook of Research on Challenging Deficit Thinking for Exceptional Education Improvement*. USA: Hunter College &CUNY, pp. 179–206. IGI Global.
- Chowdhury, U. & Christie, D. (2002) 'Focus on practice: Tourette syndrome: A training day for teachers.' *British Journal of Special Education*, 29 (3), pp. 123–6. https://doi.org/10.1111/1467-8527.00254
- Claussen, A. H., Bitsko, R. H., Holbrook, J. R., Bloomfield, J. & Giordano, K. (2018) 'Impact of Tourette syndrome on school measures in a nationally representative sample.' *Journal of Developmental and Behavioral Pediatrics*, 39 (4), pp. 335–42.
- Cohen, S. C., Leckman, J. F. & Bloch, M. H. (2013) 'Clinical assessment of Tourette syndrome and tic disorders.' *Neuroscience & Biobehavioral Reviews*, 37 (6), pp. 997–1007. https://doi.org/10.1016/j.neubiorev. 2012.11.013
- Conelea, C. A. & Woods, D. W. (2008) 'The influence of contextual factors on tic expression in Tourette's syndrome: A review.' *Journal of psychosomatic research*, 65 (5), pp. 487–96.
- Conte, G., Baglioni, V., Valente, F., Chiarotti, F. & Cardona, F. (2020) 'Adverse mental health impact of the COVID-19 lockdown in individuals with Tourette syndrome in Italy: An online survey.' *Frontiers in Psychiatry*, 11, p. 1325. https://doi.org/10.3389/fpsyt. 2020.583744
- Debes, N., Hjalgrim, H. & Skov, L. (2010) 'The presence of attention-deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder worsen psychosocial

- and educational problems in Tourette syndrome.' *Journal of Child Neurology*, 25 (2), pp. 171–81. https://doi.org/10.1177/0883073809336215
- Edwards, K. R., Mendlowitz, S., Jackson, E., Champigny, C., Specht, M., Arnold, P., et al. (2017) 'A qualitative exploration of the experiences of children and adolescents with Tourette syndrome.' *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 26 (1), pp. 39–44.
- Efron, D. & Dale, R. C. (2018) 'Tics and Tourette syndrome.' *Journal of paediatrics and child health*, 54 (10), pp. 1148–53. https://doi.org/10.1111/jpc. 14165.
- Gini, S., Knowland, V., Thomas, M. S. & Van Herwegen, J. (2021) 'Neuromyths about neurodevelopmental disorders: Misconceptions by educators and the general public.' *Mind, Brain, and Education*, 15 (4), pp. 289–98. https://doi.org/10.1111/mbe.12303
- Grace, R. & Russell, C. (2005) 'Tourette's syndrome and the school experience: A qualitative study of children's and parents' perspectives.' *Australasian Journal of Special Education*, 29 (1), pp. 40–59. https://doi.org/10.1017/S1030011200025239
- Heyman, I., Liang, H. & Hedderly, T. (2021) 'COVID-19 related increase in childhood tics and tic-like attacks.' *Archives of Disease in Childhood*, 106 (5), pp. 420–1.
- Jones, K. S. & Ramphul, K. (2018) *Tourette Syndrome* and *Other Tic Disorders*. Treasure Island, FL: StatPearls Publishing.
- Kadesjö, B. & Gillberg, C. (2000) 'Tourette's disorder: Epidemiology and comorbidity in primary school children.' *Journal of the American Academy of Child* & *Adolescent Psychiatry*, 39 (5), pp. 548–55. https:// doi.org/10.1097/00004583-200005000-00007
- Kalsi, N., Tambelli, R., Aceto, P. & Lai, C. (2015) 'Are motor skills and motor inhibitions impaired in Tourette syndrome? A review.' *Journal of Experimental Neuroscience*, 9, pp. 57–65. https://doi. org/10.4137/JEN.S25095
- Kepley, H. O. & Conners, S. U. S. A. N. (2007)
 'Management of learning and school difficulties in children with Tourette syndrome.' In: Woods, D.W., Piacentini, J.C. & Walkup, J.T. (Eds.) Treating Tourette Syndrome and Tic Disorders: A Guide for Practitioners, pp. 242–64. New York: Guilford Press.
- Lee, M. Y., Wang, H. S., Chen, C. J. & Lee, M. H. (2018) 'Social adjustment experiences of adolescents with Tourette syndrome.' *Journal of Clinical Nursing*, 28 (1-2), pp. 279–88. https://doi.org/10.1111/jocn. 14564
- Ludlow, A. K., Brown, R. & Schulz, J. (2016) 'A qualitative exploration of the daily experiences and challenges faced by parents and caregivers of children with Tourette's syndrome.' *Journal of Health Psychology*, 23 (14), pp. 1790–9.

- Malli, M. A. & Forrester-Jones, R. (2021) 'Stigma and adults with Tourette's syndrome: "Never laugh at other People's disabilities, unless they have Tourette's —Because how can you not?".' *Journal of Developmental and Physical Disabilities*, pp. 1–27. https://doi.org/10.1007/s10882-021-09829-2
- Mathews, C. A. (2021) 'Treating Tourette syndrome and other chronic tic disorders: Updated guidelines by the European society for the study of Tourette syndrome (ESSTS).' European Child & Adolescent Psychiatry, 1-2, pp. 375–6. https://doi.org/10.1007/s00787-021-01892-6
- Nussey, C., Pistrang, N. & Murphy, T. (2014) 'Does it help to talk about tics? An evaluation of a classroom presentation about Tourette syndrome.' *Child and Adolescent Mental Health*, 19 (1), pp. 31–8. https://doi.org/10.1111/camh.12000
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A. & Cook, D. A. (2014) 'Standards for reporting qualitative research.' *Academic Medicine*, 89 (9), pp. 1245–51. https://doi.org/10.1097/ACM. 00000000000000388
- Odom, S. L. & Diamond, K. E. (1998) 'Inclusion of young children with special needs in early childhood education: The research base.' *Early Childhood Research Quarterly*, 13 (1), pp. 3–25.
- Ohan, J. L., Seward, R. J., Stallman, H. M., Bayliss, D. M. & Sanders, M. R. (2015) 'Parents' barriers to using school psychology services for their child's mental health problems.' *School Mental Health*, 7 (4), pp. 287–97. https://doi.org/10.1007/s12310-015-9152-1
- Packer, L. E. (2005) 'Tic-related school problems: Impact on functioning, accommodations, and interventions.' *Behavior Modification*, 29 (6), pp. 876–99. https://doi.org/10.1177/0145445505279383
- Polirstok, S. & Gottlieb, J. (2006) 'The impact of positive behavior intervention training for teachers on referral rates for misbehavior, special education evaluation and student reading achievement in the elementary grades.' *International Journal of Behavioral Consultation and Therapy*, 2 (3), pp. 354–61. https://doi.org/10.1037/h0100789
- Pringsheim, T. & Martino, D. (2021) 'Rapid onset of functional tic-like behaviours in young adults during the COVID-19 pandemic.' *European Journal of Neurology*, 28 (11), pp. 3805–8.
- Rizzo, R., Pellico, A., Silvestri, P. R., Chiarotti, F. & Cardona, F. (2018) 'A randomized controlled trial comparing behavioral, educational, and pharmacological treatments in youths with chronic tic disorder or Tourette syndrome.' *Frontiers in Psychiatry*, 9, 100. https://doi.org/10.3389/fpsyt.2018. 00100

- Sardo-Brown, D. & Hinson, S. (1995) 'Classroom Teachers' perceptions of the implementation and effects of full inclusion.' *ERS Spectrum*, 13 (2), pp. 18–24.
- Sciutto, M. J., Terjesen, M. D. & Frank, A. S. B. (2000) 'Teachers' knowledge and misperceptions of attention-deficit/hyperactivity disorder.' *Psychology in the Schools*, 37 (2), pp. 115–22. https://doi.org/10.1002/(SICI)1520-6807(200003)37:2
- Singer, H. S. (2005) 'Tourette's syndrome: From behaviour to biology.' *The Lancet Neurology*, 4 (3), pp. 149–59. https://doi.org/10.1016/S1474-4422(05) 01012-4
- Storch, E. A., Merlo, L. J., Lack, C., Milsom, V. A., Geffken, G. R., Goodman, W. K. & Murphy, T. K. (2007) 'Quality of life in youth with Tourette's syndrome and chronic tic disorder.' *Journal of Clinical Child and Adolescent Psychology*, 36 (2), pp. 217–27. https://doi.org/10.1080/15374410701279545
- Treharne, G. J. & Riggs, D. W. (2015) 'Ensuring quality in qualitative research.' In P. Rohleder & A. Lyons (eds), *Qualitative Research in Clinical and Health Psychology*, pp. 57–73. London: Red Globe Press.
- United Nations. (2016). General Comment No. 4 on the right to inclusive education (CRPD/C/GC/4).
- Vidovich, D. & Lombard, T. P. (1998) 'Parents', teachers' and administrators' perceptions of the process of inclusion.' *Educational Research Quarterly*, 21 (3), p. 41.
- Wadman, R., Glazebrook, C., Parkes, E. & Jackson, G. M. (2016) 'Supporting students with T ourette syndrome in secondary school: A survey of staff views.' *Journal of Research in Special Educational Needs*, 16 (4), pp. 226–33. https://doi.org/10.1111/1471-3802.12077
- White, S. W., Sukhodolsky, D. G., Rains, A. L., Foster, D., McGuire, J. F. & Scahill, L. (2011) 'Elementary school teachers' knowledge of tourette syndrome, obsessive-compulsive disorder, & attention-deficit/ hyperactivity disorder: Effects of teacher training.' *Journal of Developmental and Physical Disabilities*, 23 (1), pp. 5–14. https://doi.org/10.1007/s10882-010-9209-x
- Zinner, S. H. (2004) 'Tourette syndrome—Much more than tics.' *Contemporary Pediatrics*, 21 (8), pp. 22–49
- Zinner, S. H., Conelea, C. A., Glew, G. M., Woods, D. W. & Budman, C. L. (2012) 'Peer victimization in youth with Tourette syndrome and other chronic tic disorders.' *Child Psychiatry & Human Development*, 43 (1), pp. 124–36. https://doi.org/10.1007/s10578-011-0249-y