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Supporting students with Tourette syndrome in secondary school: a survey of staff views

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Key words: Tourette syndrome, special educational needs, inclusion.

Tourette syndrome is a neurological condition involving involuntary movements and sounds (tics) and is thought to affect as many as 1% of school-aged children. Some young people with Tourette syndrome experience educational difficulties and social difficulties. Current clinical guidelines suggest educators can play an important role in maximising learning potential and reducing the negative impact of this condition on students' social adjustment. Secondary school staff (N = 63) with responsibilities for special educational needs or disabilities completed a survey about support strategies for students with Tourette syndrome. Participants were first asked to suggest potentially helpful strategies and then rated how easily 17 recommended strategies could be implemented in school. The survey participants suggested a range of support strategies that were categorised as (1) promoting knowledge and understanding in school, (2) helping the student to cope with his/her tics, (3) supporting the student's learning and (4) providing social and emotional support. All the recommended support strategies were rated as being easy to implement (or already in place) by the majority of respondents (e.g., increasing staff awareness and regular communication with home). The strategies that were identified as being least easy to implement were those requiring extra staff input (support from teaching assistants and individual/small group working). Additional challenges to providing support were also identified by the participants (e.g., getting input from outside agencies).

Tourette syndrome (TS) is a neurological condition in which an individual has involuntary movements and vocalisations ('tics') for a period of 12 months or more. TS is thought to affect as many as one in every hundred school-aged children (Robertson, 2008a), but many children will have only mild symptoms that cause minimal impairment and some will not have received a diagnosis (Robertson, 2008b). Other children with TS have more frequent and severe tics. Symptoms of TS typically appear during the primary school years (4–6 years) and reach peak severity in secondary school (11–14 years), before becoming less

severe by adulthood (Leckman et al., 2006). Boys are around four times more likely to have TS than girls (Freeman et al., 2000).

Tics are sudden, rapid and uncontrollable sounds and movements. Tics fluctuate in type, severity and frequency and can sometimes, with effort, be suppressed or delayed for short periods of time (Leckman et al., 2006). Tics vary in how complex and purposeful they appear to be, from blinking or throat clearing to jumping and uttering words or phrases. Coprolalia, the involuntary expression of socially inappropriate utterances, is seen in just 19% of males and 14% of females with TS (Freeman et al., 2009). Environmental and emotional factors such as anxiety can worsen tic frequency (Conelea and Woods, 2008); therefore, schools can potentially play an important role in reducing the negative impact of TS on educational and psychosocial adjustment by attending to these factors. TS often co-occurs with other conditions, particularly attention deficit hyperactivity disorder (ADHD) and obsessive–compulsive disorder. Although TS does not intrinsically affect intellectual ability, the prevalence of learning disabilities in this population is estimated to be 23% (Burd et al., 2005).

TS can have a significant impact on educational attainment and the school experience. In studies in clinical settings, around 50% of children with TS have educational difficulties necessitating support (Abwender et al., 1996; Debes, Hjalgrim and Stov, 2010). Children with additional diagnoses such as ADHD are more likely to have educational difficulties and social or emotional problems in school (Kadesjö and Gillberg, 2000). Tics can be a barrier to learning by causing difficulties with concentration, with performance on time-limited tasks and with reading or writing (Packer, 2005; Shady, Fulton and Champion, 1988). Children with TS can also exhibit aggression and other behavioural problems, and these can cause disagreement between school staff and between staff and parents (Chowdhury and Christie, 2002; Christie and Jassi, 2002). TS can also affect peer relationships, with a quarter of young people with TS reporting peer victimisation or peer rejection (Packer, 2005; Storch et al., 2007; Zinner et al., 2011).

Research indicates that students with TS can experience a range of challenges in school, related to academic work,

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relationships with others and managing emotions. Therefore, some students with TS will require and/or benefit from additional support and accommodations in school. However, empirical work examining ways to support students with TS is limited. A US survey found 72% of children with TS (6–17 years old) received some type of accommodation for tics in school and, on average, they received four different accommodations (Packer, 2005). The most common and helpful accommodations (reported by parents) were that teachers ignore tics, having permission to leave the classroom as needed, preferential seating and extended time on classwork and tests.

A small number of US studies have evaluated the effects of specific TS strategies, particularly peer education. A recent review suggests that peer education about TS (using films, workshops or vignettes about TS) results in more positive attitudes towards an individual with TS, but there is less evidence that it leads to a change in behaviour towards an individual with TS (Nussey, Pistrang and Murphy, 2013). These studies were conducted in laboratory settings but more recently, a classroom TS presentation was found to improve the knowledge and attitudes of the classmates of primary school children with TS in the UK (Nussey, Pistrang and Murphy, 2012). Also, one small study looking at teacher education found a small but significant increase in teacher knowledge following a 2-hour TS workshop (White et al., 2011).

In a recent Canadian study, 30 students with TS, their parents and teachers were asked to rate the usefulness of 84 learning and behavioural strategies that had been identified by teachers with experience of children with TS (Thomas et al., 2012). Students endorsed fewer strategies than teachers or parents and there was little agreement between informants regarding the most useful strategies. Using computers for work and assigning an appropriate amount of homework were the only educational strategies endorsed by all three informant groups. In addition to the lack of agreement concerning helpful strategies, some of the strategies included were vague and thus not very informative as to how they could be implemented (e.g., ‘The student paying attention and being informed’ – highly endorsed by parents). Furthermore, this study included students aged between 8 and 17 years and who were therefore being taught in a range of educational environments (elementary, middle and high school). However, not all strategies will be relevant or appropriate in these different school settings.

Most research examining TS-related school difficulties and support has been conducted in North America, where educational provision is different to the UK. The present study addresses this gap by surveying staff with responsibilities for students with special educational needs or disabilities in mainstream secondary schools in England. As tic severity reaches its peak between 10 and 12 years (Leckman et al., 1998), the transition into secondary education is a potentially difficult time. The secondary school environment presents novel experiences and challenges to students with TS. The aim of this study was to identify support strategies

used in schools that could help a student with TS, to determine the ease with which a set of recommended strategies could be implemented in schools and to identify any barriers to providing this support.

Method

Online TS survey

The survey was created online and included both closed- and open-ended questions. The survey respondents were first asked whether they currently had any students with TS or had previously had a student with TS, in order to identify those working in schools with some experience of the condition. The survey consisted of two main sections. The first presented participants with a fictional case example of a student with TS (‘Adam’):

Adam is an 11-year-old who has recently started in Year 7. He has Tourette syndrome, a condition that involves involuntary motor tics (he jerks his head suddenly and forcefully to the left and he rolls his eyes) and vocal tics (he makes a high pitched ‘eh’ sound). Adam’s Key Stage 2 results suggest that he is at the expected level academically (level 4). Adam tries hard not to let his tics out at school but rarely gets through a lesson without making the movements or sounds.

Adam finds it difficult to concentrate in class because he is focusing so hard on controlling his tics. He sometimes does not finish his work. Although Adam works well in lessons he can struggle with written work and organisation. When Adam gets home after school he is usually very tired and his tics come out a lot more.

Although most of his teachers ignore his tics, some teachers have told him to ‘be quiet’ or to ‘stop it’, which upsets him. Adam has a good group of friends from primary school but sometimes other students will make an unkind comment about his behaviour or copy him, which he finds very upsetting.

This description was followed by the open-ended questions ‘How would you support a student like Adam in the classroom/at other times in school?’ with a text box for respondents to type their answers. The aim was to identify support strategies that special educational needs or disabilities (SEND) staff thought they could provide and that they felt were appropriate, before they were given a list of recommended strategies in the second section of the survey. The responses to the open-ended questions were analysed by coding the suggested strategies into categories (example codes include ‘examination accommodations’ and ‘support from teaching assistants’). These specific codes were then organised into superordinate themes reflecting the more general type of support suggested (e.g., ‘supporting the students’ learning’).

The second section of the survey presented a list of 17 support strategies and respondents were asked ‘how easy do

you think it would be to implement each strategy in your school?' The list of recommended strategies for supporting a student with TS was developed by (1) reviewing relevant literature including empirical papers (as cited in the Introduction) and clinician recommendations (Chowdhury and Christie, 2002; Chowdhury and Zaman, 2010; Kepley and Conners, 2007; Robertson and Cavanna, 2008; Zinner, 2004), (2) consulting with the UK charity Tourettes Action and (3) discussions with young people with TS, their parents, clinicians and educators. Four response options were available: 'impossible, this could not be done in my school'; 'difficult, this could be done with some difficulty in my school'; 'possible, this could be done quite easily in my school'; and 'we already do this in my school'. Participants were also given the opportunity to explain why any strategies could be difficult or impossible to put in place in school (open-ended response).

Participants

Staff with responsibilities for SEND in mainstream secondary schools were invited to take part in the survey. A set of schools were selected to be invited to take part in the survey. This set of schools was representative of mainstream secondary schools in England in terms of school size and percentage of students eligible for free school meals (FSM) – with the aim of recruiting respondents from a broad range of schools. The 3310 mainstream secondary schools in the 2011 School Census (Department for Education, 2011) were categorised according to size using pupil headcount data and according to percentage eligible for FSMs. The schools were then split into six strata (or groups) and a proportional number were selected randomly from each stratum to be invited to take part (proportionate stratified random sampling). The link to the survey was emailed to the school special educational need (disability) coordinator (SENCo) directly, or via the schools' point of contact (usually the school office) with a request to pass it on to SEND staff in the school.

SEND staff from 1004 mainstream secondary schools in England were invited to take part in the survey. The response rate was 9.3% with responses from 93 individuals. Of these respondents, 63 SEND staff from different secondary schools had contact with a student with TS currently or in the past. Data for these 63 respondents from schools with experience of educating a student with TS are presented in this paper. Over half of the participants (36/63) who completed the survey were SENCos or SENDCos. The remainder were teaching assistants (TAs)/learning support

assistants, learning support/SEND managers or other staff with responsibility for SEND.

Data for the participants' schools on student headcount and percentage of students eligible for FSMs were taken from the 2011 School Census (Department for Education, 2011). Schools were classified as small (1–799 students), medium (800–1099 students) or large (1100+ students), with categories based on previous literature (Johnson et al., 2008). Schools were categorised as having below or above average percentage of students eligible for FSMs (based on the national average, below average FSM = less than 15.9%, at or above average FSM = 15.9% or more). Data on FSMs is often used as an index of low parental income or material disadvantage in the school's locality (Gorard, 2012). Data for the 63 schools are given in Table 1 and the percentage data for all mainstream secondary schools in England from the 2011 School Census are also given for comparison. The schools whose staff completed the survey were not representative of secondary schools in England. There were fewer responses from staff in small schools and from schools with a below average percentage of students eligible for FSMs.

Results

Support strategies identified by SEND staff for a student with TS

Specific strategies suggested by the participants as ways to support a student with TS are given in Table 2. Four superordinate themes relating to the broad support type were identified: improving knowledge and understanding in school, strategies to help the student manage tics, strategies to support the student's learning and providing social and emotional support. These themes are not mutually exclusive, for example, strategies to promote TS understanding in school may also support the student socially and emotionally. Nonetheless, these themes are helpful in framing the main challenges and support requirements a school may encounter. As well as dealing with the actual tics in school, there is a need to educate others about TS. Furthermore, TS can be a barrier to learning and may be associated with social and emotional difficulties which affect the student in school.

Most of the strategies suggested by participants, and certainly those most frequently suggested, were also included in the list of recommended strategies (Table 3). Thus, many of strategies (e.g., informing staff of TS and student's needs, breaks from lesson and a safe place to go, making

Table 1: Characteristics of participating schools

School characteristic		Percentage for sample (n = 63)	Percentage for England (n = 3310)
School size (student headcount)	Small (1–799)	22.2	32.8
	Medium (800–1099)	33.3	30.4
	Large (1100+)	44.4	36.8
Percentage students eligible for free school meals	Below national average (less than 15.9%)	55.6	61.2
	Above national average (15.9% or more)	44.4	38.8

Table 2: Support strategies suggested by SEND staff for a student with TS

Support strategy (frequency)	Examples (if appropriate)
Improve knowledge of TS	
Inform staff about TS and the student's needs	Staff training about TS , individual education plans (IEP), card about TS for student to show to staff
Educating other students about TS	Talks within tutor group, year group or whole group assembly
Information about TS from parents	
Information about TS from outside agencies	Child and Adolescent Mental Health Services (CAMHS)
Strategies to help student manage tics	
Provide student with a safe place to tic/to use	
Allow student short breaks from lessons	Using a 'time out card'
^a Appropriate seating of student in class	
Allow student to fiddle with an object/doodle	
Encouraging staff not to respond to tics	
Strategies to support student's learning	
Adjustments to classwork	Extra time, printed worksheets, scribes or laptops
Use of teaching assistants	
Adjustments to homework	Reduced amount of homework or attend homework club
Examination accommodations	Providing extra time or a separate room
^a Reduced student's timetable	
Providing social and emotional support	
^a Use of programmes to support social relationships	Peer mentor/'buddy' system or small social skills group
Providing a trusted individual for the student to talk to	Keyworker or mentor

^aDenotes strategies not specifically included on the recommended strategy list. SEND, special educational needs or disabilities; TS, Tourette syndrome.

Table 3: Ease of implementing recommended strategies for a student with TS

Strategy	Percentage rated as 'already do/possible'	Percentage rated as 'difficult/impossible'
Provide personalised information about student's needs for student to give to staff	100.0	0.0
Allow student to fiddle with an object such as a tangle toy in class	98.4	1.6
Seek an agreement with parents/carers and student so that s/he is not disciplined for tics but conduct issues can be managed appropriately	98.4	1.6
Provide a named person as point of contact for student to discuss his/her needs	98.4	1.6
Make staff aware of student's tics and how to respond (e.g., ignore tics)	98.4	1.6
Provide extra time and/or a separate room for examinations or assessments	98.4	1.6
Arrange regular communication between school and home (e.g., through diary, meetings)	96.8	3.2
Seek specialist input from outside agencies (e.g., Child and Adolescent Mental Health Services, Educational Psychology Service)	93.7	6.3
Seek training for a member of staff on Tourette syndrome	90.5	9.5
Give information to students about Tourette syndrome	90.5	9.5
Allow student to have breaks from lessons	88.9	11.1
Reduce amount of homework or have flexible deadlines	88.9	11.1
Provide a safe area for student to release tics	88.9	11.1
Reduce amount of written work (e.g., worksheets, written instructions, break down tasks)	88.9	11.1
Educate all school staff about Tourette syndrome	87.3	12.7
Give option for individual or small group work away from the main classroom	82.5	17.5
Provide student with support from teaching assistants	79.4	20.6

Note: Strategies are listed in descending order from most highly rated to least highly rated. TS, Tourette syndrome.

adjustments to classwork and using TAs) are accommodations that many schools are able and willing to provide (i.e., within the school's arsenal of support and recognised as potentially helpful to a student with TS). These findings therefore corroborate the recommended strategy list. A small number of support strategies suggested by staff were not included in the recommended strategy list. These were the use of programmes to support peer relationships in school, preferential seating and reducing the student's timetable.

Feasibility of using the recommended TS strategies

Only a small number of participants gave the difficult or impossible response options; therefore, the responses were collapsed into two categories: possible/already implemented versus difficult/impossible (Table 3). For all strategies, 79% or more of the participants indicated that it would be possible to implement or that the strategy was already in place in school (either for a student with TS or for other students).

The more difficult strategies to implement, with around 20% rating them as difficult or impossible to do, would require extra staff to supervise and work with the student (support from TAs and individual or small group work). Six strategies were rated as impossible to implement by one or more respondents: individual/small group work (4), teaching/learning support assistants (3), breaks from lessons (2), providing a safe area (1), seeking help from outside agencies (1) and educating all staff (1).

Challenges to implementing strategies

Sixteen participants provided open-ended responses as to why some strategies may be difficult to implement in school. Six respondents cited barriers related to staff: having limited staff to support students, staff unwilling to be flexible regarding classwork given to students and staff not following guidance consistently. Getting help and expert input from outside agencies such as Child and Adolescent Mental Health Services (CAMHS) was also seen as difficult by six participants. Student-related barriers were also noted, including the need for the student to have a statement of special educational needs and concerns over the student missing classwork (6). Lack of funding (3), time (3) and space (2) were also potential barriers. Two participants stated that the culture of the school (rigid approach to behaviour management and an emphasis on results) could be problematic.

Discussion

SEND staff identified a number of support strategies that they thought may be useful for a student with TS. These were strategies aimed at promoting knowledge and understanding of TS in school, helping the student to cope with his/her tics, supporting the student's learning and providing social emotional support. This is in line with current treatment strategies for young people with TS, which aim to maximise their potential in school and in social functioning, rather than trying to eliminate tics (Du et al., 2010). SEND staff were also asked to rate how easily 17 recommended

strategies could be implemented in their schools. All the recommended strategies were rated as being easy to implement (or already in place) by around 80% or more respondents. This is an encouraging finding given that approximately 50% of children with TS receiving clinical support are expected to experience some kind of difficulties with learning in school (Abwender et al., 1996; Debes et al., 2010; Kadesjö and Gillberg, 2000; Packer, 2005).

Promoting understanding of TS in schools can play a key role in improving the experiences of students with TS in secondary school. Reports of negative or unhelpful experiences with staff (e.g., being disciplined for uncontrollable vocalisations) suggest that support for TS in schools can fall down at this first hurdle (Chowdhury and Christie, 2002; Shady et al., 1988). Improving understanding and empathy towards students with TS can also address difficulties students with TS can encounter with peers (e.g., victimisation and/or rejection). Strategies such as educating staff and students about TS are contingent upon on the student being willing to 'go public' about their condition. Seeking advice or training from parents and/or agencies such as CAMHS is also advised. As noted by Chowdhury and Christie (2002), increasing staff awareness of TS is not only beneficial to those staff but can also have long-term positive benefits for the well-being of the student with TS. European clinical TS guidelines emphasise the need to improve understanding of the condition in schools (Verdellen et al., 2011).

Students with additional diagnoses, of ADHD for example, are likely to have significantly more educational problems (Debes et al., 2010). Nonetheless, students with TS, regardless of the presence of other conditions, may benefit from support that helps them to manage their tics. The specific strategies that the student will find helpful will depend on the student and the nature of his/her tics but a common suggestion in this survey was allowing the student to take a short break from lessons (and having a safe place to go during these breaks). Refraining from commenting on or responding visibly to tics and modelling acceptance have recently been identified as two of the most helpful strategies that school staff can use (Pruitt and Packer, 2013). Contextual factors have been found to worsen tics, such as stressful/anxiety-provoking events, certain social situations and fatigue (Conelea and Woods, 2008). Tics can also change in nature and severity over the course of the school day/week/term. Therefore, schools and families can usefully share information regarding a student's current tics and factors that can worsen tics (e.g., stressors).

Research with both clinical and community samples suggest that a significant proportion of students with TS will have difficulties with learning that require support (Abwender et al., 1996; Debes et al., 2010; Kadesjö and Gillberg, 2000; Packer, 2005; Shady et al., 1988). Concentration problems are frequently reported in individuals with TS and children with increased attentional problems may be less able to successfully control or suppress their tics (Himle and Woods, 2005). Often, appropriate strategies to support learning will not be specific to TS and SEND staff

will have experience in using such techniques with other students with learning needs. This survey suggests that a student whose TS or other conditions disrupt learning may benefit from adjustments being made to written work, homework and/or examinations/assessments. Small group work or one-to-one with TAs may also be useful, although these may be more difficult to implement due to limited resources and if the student does not have a statement of special educational needs.

The SEND staff surveyed suggested that students with TS may also benefit from social and/or emotional support. Around a quarter of children with TS are reported to be rejected or victimised by peers (Packer, 2005; Storch et al., 2007; Zinner et al., 2011) but a larger number may encounter teasing (e.g., name-calling and mimicry) or poor social acceptance (Cutler et al., 2009). Problems with peers and emotional symptoms such as anxiety and anger can have a detrimental impact on quality of life in school. Students may find it helpful to have an individual identified as a point of contact (e.g., keyworker). Although the use of established social programmes was not included in the recommended list of strategies, they were suggested by survey respondents in the open-response section. Such schemes (e.g., 'circle of friends') may be useful if the student appears to be socially isolated or is finding social interactions difficult to manage. The development of close supportive friendships is an important task in adolescence (Berndt, 1982; Paul and White, 1990) and secondary schools tend to be the main setting for such relationships. Qualitative research suggests adolescents with TS can develop such supportive relationships during their time in secondary school (Wadman, Tischler and Jackson, 2013).

This is the first survey of UK SEND staff regarding TS support and it has been useful to examine the types of support strategies that experienced staff would consider to be appropriate when supporting a student with TS. Unfortunately, the response rate was poor and as such, the responses received may not reflect the wider community of SEND staff. The use of an online survey and an illustrative vignette is an appropriate methodology to use with participants with limited time to give. However, the extent to which the findings reflect actual behaviour in everyday practice cannot be assessed here. Further research is needed to identify the effective ways of improving understanding and management of TS in the secondary school setting.

In this study, SEND staff indicated that a range of strategies for supporting a student with TS (identified as useful by clinicians, educators, young people with TS and a TS support organisation) were appropriate and feasible. Many of the recommendations are strategies that schools already employ with other students with learning, behavioural or socioemotional needs. Schools are therefore in a good position to support a student with TS by helping them cope with having tics in school, and if needed, supporting learning and social development. TS is a complex condition and has often been misleadingly portrayed in the media as simply involving obscene verbal outbursts. For this reason, increas-

ing knowledge about TS in schools is an extremely important strategy in supporting students with TS.

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