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ABSTRACT

Tourette Syndrome (TS) is a neurological disorder characterized by multiple, involuntary, and repetitive motor and vocal tics. This paper addresses the educational needs of students with TS noting that, without proper intervention and appropriate learning experiences, these children often experience personal distress, reduced self-esteem, social problems, and school failures. It reports on results of questionnaires in ongoing case studies of 15 Australian students (14 boys and 1 girl). Analysis of questionnaire responses is organized around four categories: (1) feelings about TS, (2) effects on learning, (3) treatment by others, and (4) management of tics. Most respondents described their initial feelings about life with TS as negative but predictions of life in the future were more positive. Fourteen of the students reported that TS affected their learning in such ways as reducing concentration and the distraction of obsessive thoughts. Students generally felt they were treated differently because of their TS, although they appeared to feel less of this in the classroom environment. Two-thirds of students indicated that they try to cover up their tics. Possible teacher and student actions are organized around the physical dimension, social/emotional dimension, the psychological dimension, and the medical dimension. (Contains 15 references.) (DB)

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**TOURETTE SYNDROME:
A CASE FOR ESTABLISHING THE
INDIVIDUAL NEEDS OF CHILDREN AT RISK**

Jeni Wilson and Bradley Shrimpton

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Tourette Syndrome: A case for establishing the individual needs of children at risk

Paper presented at the Australian Curriculum Studies Association Conference, Canberra, 2001

Dr. Jeni Wilson and Bradley Shrimpton

Abstract

Tourette Syndrome (TS) is a neurological disorder characterised by multiple, involuntary, and repetitive motor and vocal tics. ADHD and Obsessive Compulsive Disorders are often associated with Tourette Syndrome. TS is not discriminatory, it can occur across all races and socio-economic groups (Wodrich, 1998). The numerous medical characteristics (physical and psychological) are well documented in the literature and sensationalised in the media, but the complex and sometimes devastating experiences of individual sufferers is often reduced to numerical data. These data do not consider the feelings, perspectives and abilities of individuals and cannot portray the lives led by children with TS.

This paper is concerned about the educational implications for students with TS. It is commonly stated in the literature that children with TS represent the normal range of levels of intelligence, although some sources state that children with TS have average or above average intelligence (Carroll, Geffen, Comerford, Bailey and Morison, 2000). Despite this children with TS often experience personal distress, reduced self-esteem, social problems (Stefl and Milton, 1985) and school failure (Wodrich, 1998). Children with Tourettes do not have diminished intellectual capabilities but without proper intervention and appropriate learning experiences, they may be easily be categorised as learning disabled or are at risk of becoming learning disabled (Jones and Johnson, 1992).

Increased teacher awareness and public education (Lemons and Barber, 1991) are essential in order for these children to receive an appropriate education. This paper will discuss case study data about students with TS (aged 7-17years) and the educational implications.

Introduction

In 1984, Beazley stated that all children deserve the courtesy and grace of an appropriate education. No doubt this sentiment would be consistent with the beliefs of most educators but for TS sufferers this is very often not reality. The experiences of some of the students with TS in this study could never be described as dignifying or rewarding.

The complexities and feelings of Tourette Syndrome (TS) sufferers are not well known by teachers or indeed medical practitioners. Yet, without a sound understanding of the complexities of the condition how can educational practitioners expect to develop the potential of children with TS?

The prevalence of TS is difficult to determine because of poor knowledge and misdiagnosis of the condition. Estimated figures vary considerable from suggesting 1 in 2,500 (Carroll, Geffen, Comerford, Bailey and Morison, 2000) may suffer from this condition, to as many as 1 in 200 (Juan, 2001). Jones and Johnson (1992) have claimed that among special needs populations, as many as 1 in 4 children have been reported with TS. The figure quoted for boys is usually about four times as for girls.

What is Tourette Syndrome?

Tourette Syndrome was once thought to be a psychiatric condition, but it is now known to be a neurological disorder. It is caused by a chemical abnormality that disrupts messages between nerve cells in parts of the brain. TS is characterised by multiple, involuntary, and repetitive motor and vocal tics. Other symptoms can include repeating their own or other's words, or undesirable words. These wax and wane but TS cannot be outgrown. The symptoms are generally at their worst in the adolescent years.

This is a physical, not a psychological disorder with varying levels of severity. Tics can release a build up of tension in a child's body but can also cause pain when they are severe. ADHD and Obsessive Compulsive Disorders are often associated with the Tourette Syndrome and other medical problems may co-exist. There is no typical TS child: behaviors vary considerably.

What are some of the Implications of Tourette Syndrome?

Tourette Syndrome is not well understood. Children with TS are sometimes treated with rejection (Parker, 1985), ridicule (Lerer, 1987) and suspicion. Adults may believe that children are just "doing it to be naughty", and do not have control over their behaviour. The possibility of tic control is debatable, but generally tics are unwanted intrusions to people with TS. Other people's responses such as the above can also cause extreme anxiety.

TS can make many simple and routine activities like reading and writing more difficult. This is especially true if children are trying to suppress tics. Tic suppression requires much energy; therefore it is difficult to concentrate on classroom tasks. Children should not be told to suppress tics because this is difficult, it uses a lot of energy and distracts from academic concentration. But regardless of teacher support, students may try to suppress tics anyway because of the unwanted reactions of peers and others.

Frustration is another problem for children with TS. Imagine what it would be like with a disorder that never allows you to be still, where your life is constantly interrupted by your own body moving out of control. Imagine if your body always felt tense and hurt from persistent jerky movements of tics. Noisy situations and stress can aggravate tics – unfortunately these conditions are common in classrooms and schools.

Task avoidance is a real issue for anyone finding tasks difficult. Add to this self-consciousness about unpredictable behaviour and school can become a daunting place. Children with TS are not lazy; physically getting their work done can be overwhelming. Some planning and adjustments to classroom requirements could make the difference between motivation and feelings of failure.

There is little written about TS. The literature available is generally limited to explanations of symptoms, possible treatments or educational difficulties for TS students. Educational solutions are few or scantily outlined. Some generalisations about teaching approaches have been made but many seem unworkable in modern classrooms, for example, a suggestion to reduce noise, team tasks and exciting activities may be of detriment to motivation, sustained engagement and the development of many important skills. Some suggestions also fail to consider the diversity of individual needs.

Not surprisingly, Burd, Kauffman, Kerbeshian (1992) found that the most successful learning programs were able to accommodate students' individual needs. Case study material is rare but is desperately needed for a better insight into the educational needs and appropriate care of individuals. A case study approach is planned for this research. A research overview is now presented. The findings to date are summarised; these are supported by examples from the data.

Research Overview

The research aims to investigate the management of TS, particularly how self-instruction affects the frequency of TS behaviours. This research documents the complexity of the syndrome and linked educational needs. The data collection has not been completed.

Case study data, including interviews and self-reporting through questionnaires, will be used to examine the issues. It was hoped that sixty students from Years 3-8, approximately 20 parents and 20 teachers from Victoria and NSW would be involved in this study. The data presented in this paper represents analysed responses from Victorian volunteers 15 (14 boys and 1 girl) who have completed an extensive questionnaire. Only one interview has been conducted with a student so far. His parents and teacher will also be involved at a later date.

Nine students are currently on medication and 11 experience or have experienced side effects. Although the tic behavior of students varies for each child and over time, the frequency for this group of respondents was categorised as mainly high (per minute or hour) for all students. The students reported a wide range of behaviors that are ever changing, these included: Blinking (N=9), Vocals (e.g. clicking noises/throat clearing (N=9), twitching and jerky body movements (N=8), head nodding/jerking neck (N=7), sniffing (N=4), teeth grinding (N=2). Other behaviors included: finger licking, squatting, cracking toes and fingers, jaw dropping, grimaces, chewing, and ankle rolling. Other medical problems (such as ADHD and OCD) were not investigated.

Findings

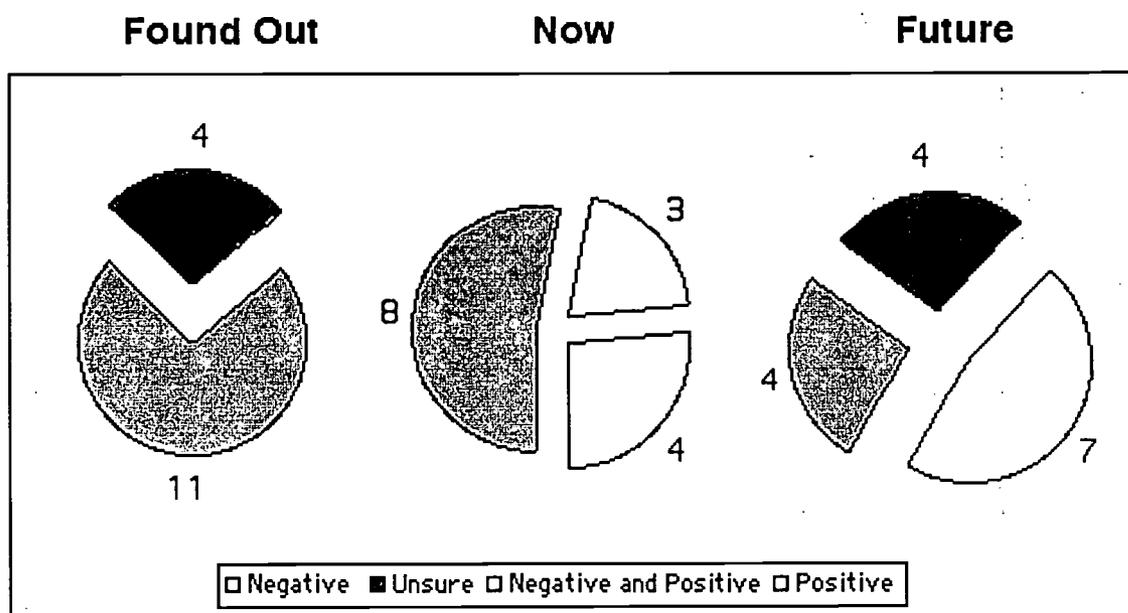
A large amount of data has been collected. The data presented in this paper has been organised under the following headings:

1. Feelings about TS
2. Effects on Learning
3. Treatment by Others
4. Management of Tics

1. Feelings about TS

Many of the student responses related to their feelings about having Tourettes reveal a progressive shift over time (see Table 1). Most respondents have described their initial feelings about life with TS as negative, but overall predictions of life in the future are more positive. In some instances, for example Case 2 (below) the need to accept and live with their condition was expressed.

Table 1. Feelings about TS



The following quotes were taken from two students (Neil and Amy) in response to three questions on the questionnaire asking students to describe:

- a. How they felt when they found out they had Tourettes,
- b. What their life with TS was currently like, and
- c. What they think their life will be like in the future.

Neil and Amy are cited at various stages throughout this paper as well as other students involved in this research.

Case 1. Neil

- a. 'I was devastated. I thought I was going to be a normal boy. But I'm not'
- b. 'My life is awful. I feel like they are controlling me and that I look stupid. I feel like I'm missing out on a lot of things because of my tics.'
- c. 'I will feel a lot better if my tics go. If they don't I will learn to put up with them.'

Case 2. Amy

- a. 'It was no different, but sometimes I felt like I was the odd one out.'
'My friends did things like sport and I really liked it too, but when I got excited I ticked a lot and didn't concentrate properly.'
- b. 'Well it's great! I mean I'm still the same person.'
- c. 'I have no idea. It's going to be whatever I make of it.'

Feelings About Themselves Generally

To explore the relationship between positive and negative self perceptions and tic behavior, students were asked to indicate on a scale their general self-image and their self-image when experiencing tics. Table 2 and 3 show that for a majority of students general feelings of self worth declined from 'good' or above, to just under two thirds rating their feelings as either low, or good/low during tic episodes.

Table 2. Feelings about Themselves Generally

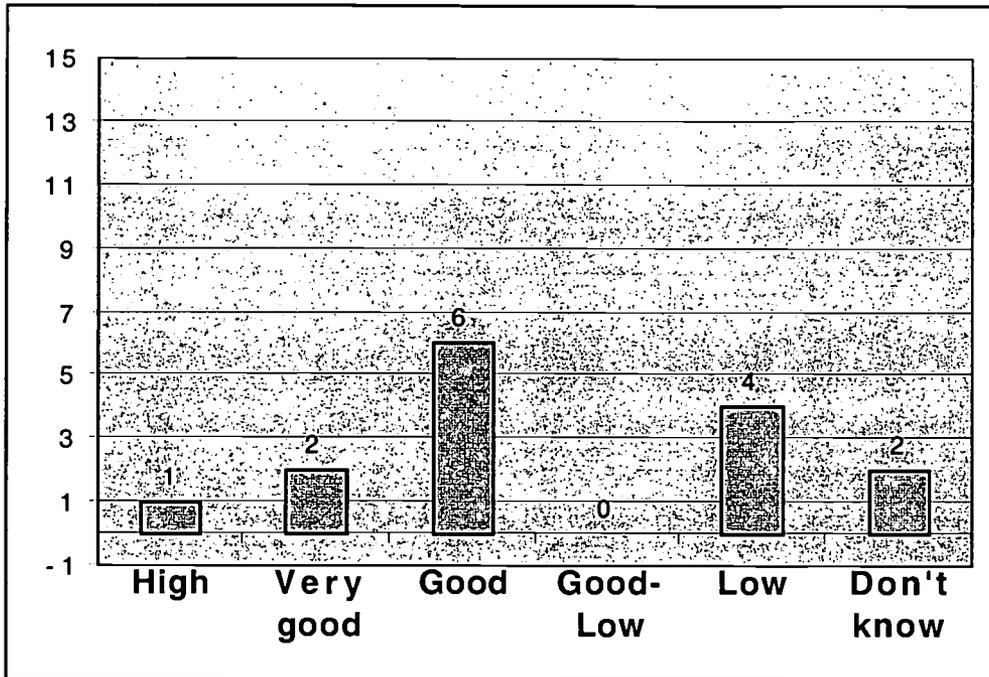
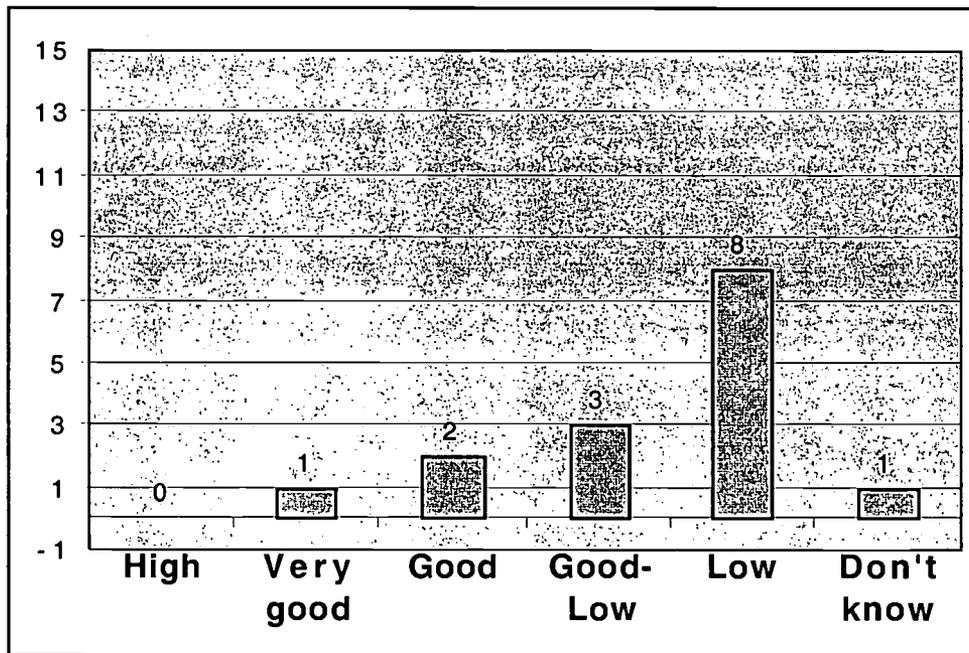


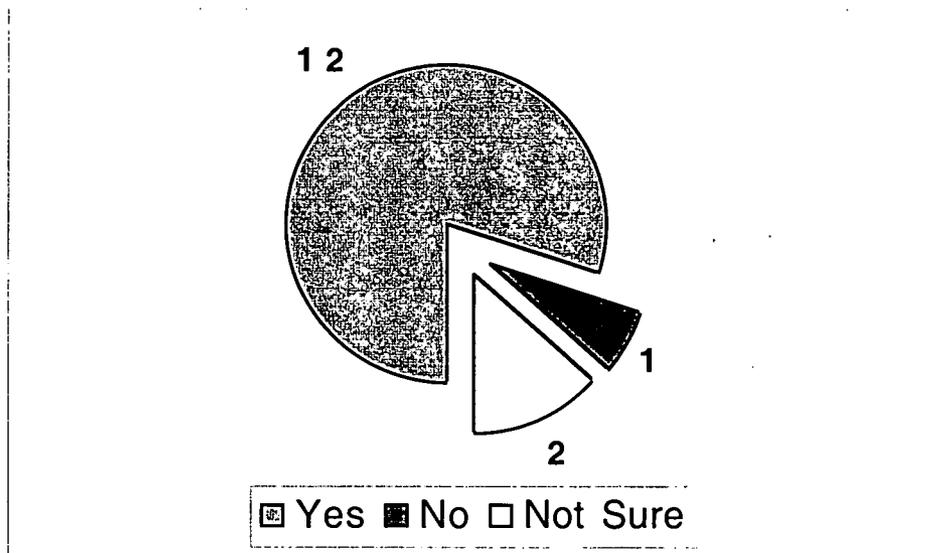
Table 3. Feelings about Themselves with Tics



2. Effects on Learning

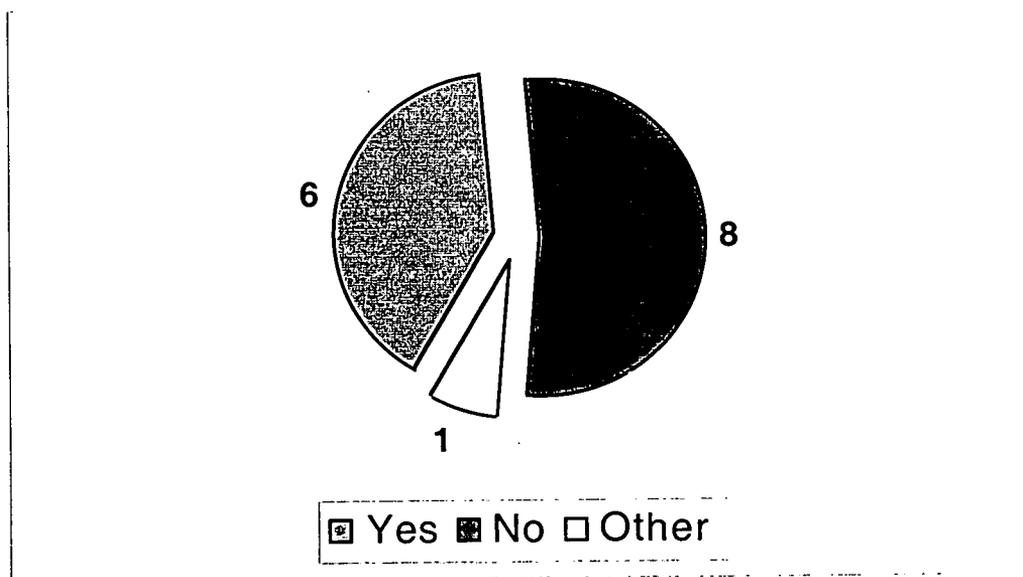
Student thoughts about the impact of living with Tourette Syndrome on their learning provide clear anecdotal evidence of the disruptive nature of Tourettes on learning. Twelve out of fifteen respondents (see Table 4) variously reported that TS reduced concentration, created obsessive thoughts that inhibited class participation, affected their friendship and caused vocals and twitches that disrupted collaborative learning and learning in general. For example Mason stated that 'Tourettes stops me doing things. When I want to do something, something comes up in my mind saying don't do it – it's really annoying.' Neil discussed a different problem: 'Yes, it affects my concentration as I make noises while the teacher is talking and miss some information. It really affects my friendships, as people don't really understand about my tics. Luckily I am a high achiever.'

Only one student felt that TS had not effected their learning. However, his parents indicated that their 11 year old son had yet to progress beyond basic reading and writing abilities. The two students who responded to this question as 'unsure' did not have parent comments to verify or deny their claim. It is possible that these students may be unaware of the disruption Tourette has on their learning. This aspect will be pursued in the interviews.

Table 4. Effects on Learning

3. Treatment by Others in Class

Eight out of the fifteen students of the study cohort reported they felt they were not treated differently by either teachers or fellow students in class as a result of their Tourettes (Table 5 below). This feedback however is not consistent with data recorded in Table 6 where ten students noted they believed they had been treated differently by people because of their TS. These comments may suggest that classrooms provide them a sense of security. What happens in class as compared with what happens in the playground or elsewhere, may be monitored and mediated by the teacher. Students may be more self-conscious in other environments such as home, in public and the schoolyard. Another possible explanation for the inconsistent data is that concern by family members may be more intense than concern shown at school, for example: 'Mum and Dad are always worried about me when I don't want them to be.' (Jess)

Table 5. Treatment by Others in Class

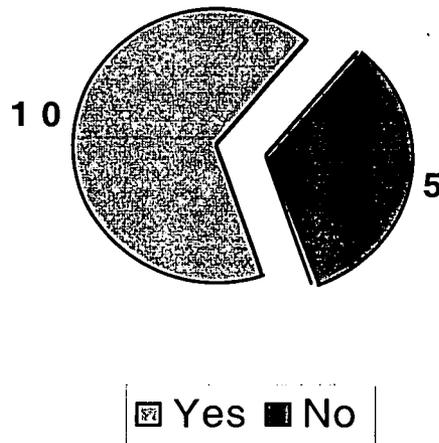
Interestingly, the responses by students about their treatment in class were not all negative. Many students commented on their favorable treatment by teachers. For example: 'My teacher treats me like an angel and manages my Tourettes really well. The other students try to be understanding as my teacher has told them all about TS. '(Neil) and 'No, I get treated like everybody else in my class, but I used to get treated differently by doing less amount of work, and being let off easier.' (Howard)

It is noted that while such teacher actions may be intended to support students and that students may accept them as favorable, in the long term such actions may not be of benefit to learning. Requiring less work and treating students differently may reinforce or create feelings of incompetence and difference.

However, some responses revealed disturbing school experiences. John reported on unrelenting harassment: 'I used to get asked why I blink all the time and everyone used to get angry at me because I couldn't help looking at them and I always get harassed.' In contrast Amy provides a humorous response

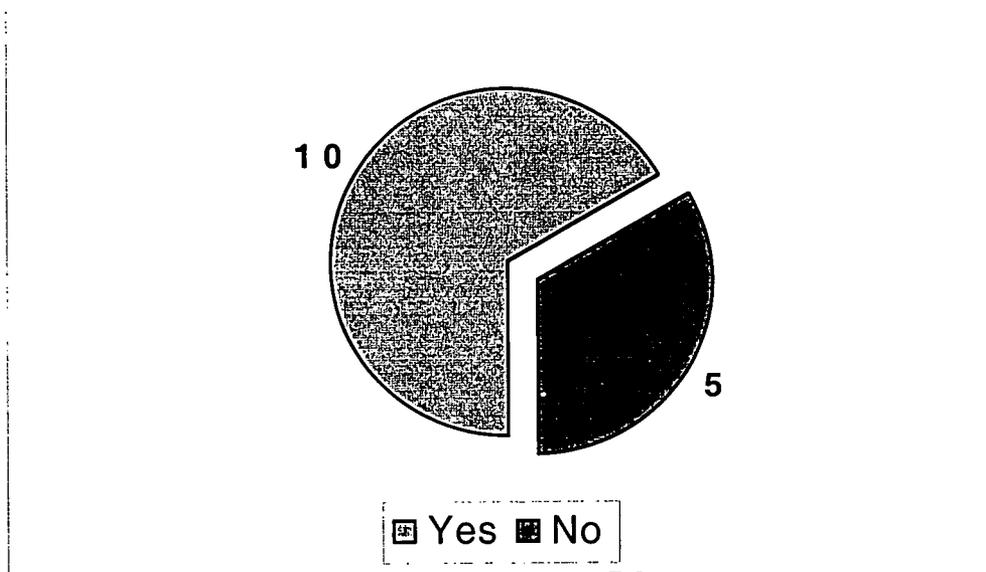
demonstrating her relaxed attitude to her condition: 'I do silly things, but my friends don't have TS and they do silly things too.' (Amy)

Table 6. Treatment by Others



4. Management of Tics

Two third of the students in this study indicated that they try to cover up their tics. Tic suppression is most likely to occur in public situations rather than at home. Many students expressed a difficulty in holding back or disguising their tics. For example: 'I try to cover my mouth to muffle my tics – but I have trouble trying to stop them.' (Neil) and 'All I really do is try to make it as less noticeable [as] I can. If I ever get seen doing tics then I just look away or pretend I was doing something else.' (Howard). Again Amy provides an alternative response to most: 'No - I just let them happen, because if I hold them back, they will build up, then start like an explosion!'

Table 7. Do You Cover Up Your Tics?

Students were asked to report on strategies that they used to stop or cover up their tics. The range of responses is another example of the uniqueness of TS characteristics and demonstrates the differences in ways individuals respond. In this cohort the most successful strategy used to cover up or stop tics was thinking about them but this was also one of the least successful strategies. Holding back was named as a most successful strategy for two students but three students included it as one of their least successful strategies.

Another successful strategy was named 'hide and disguise'. This is where students reported pretending they were doing something else, for example a mouth opening might be 'turned into' yawning, or a flinging arm might be made to look like an intentional wave. Some students such as Chris reported covering up their tics, for example: 'Putting my head down and covering my face'. Other examples of strategies and supporting quotes are given below in Table 8.

Table 8. Most/least successful ways to stop/cover up tics

Most	Least
Thinking 5 <i>'Try to keep you mind off it by doing or thinking of something different.'</i> (Howard)	Thinking 3 <i>'Sometimes if I think about them it makes them worse.'</i> (Sebastian)
Hide and Disguise 4	Hide and Disguise 1
Hold Back 2	Hold Back 3 <i>'To try to suppress them.'</i> (Neil)
Nothing Works 1	Nothing Works 1
Other: 1 <i>'Resting'</i>	Other: 3 <i>'Letting it happen'</i>

There is no evidence to suggest that people with TS take any pleasure in tics, or that they are deliberately used to attract attention. Quite the contrary, the findings indicate that tics cause children to be scared, anxious, angry and distressed over their unpredictable behavior. It appears that individual students have tried a range of strategies. The success of the strategies varies across students but can also vary for individuals according to circumstances. For example, thinking about tics might work well for some students in some situations but not in others.

In an evaluation of behavioral treatments for TS, Peterson and Azrin (1992) found that a range of procedures were effective for at least one of their subjects. They found that self-monitoring resulted in the largest reduction in tics in children but they did not note any ramifications for learning. They concluded by recommending self-monitoring as the initial behavioral approach.

Parent Responses

At the back of the questionnaire, space was provided for parental comment and some parents responded in detail. These require more analysis and will be useful in determining the extent of behaviors and management by families and others interacting with children with TS.

Preliminary analysis reveals that student accounts are not always the same as their parents, this is not surprising given the ages of the students and their ability to record their responses. However, while it is recognised that some reports may be incomplete this does not discredit the overall responses. Any study of this kind must include self-reporting. Follow up interviews with the students, parents and teachers will be more illuminating. Even with such a small sample size the trends are discernable and consistent with the literature.

The authors are not aware of other studies of TS that have included extensive parent responses. The parent responses (including parent questions and appeals) in the questionnaires are passionate, informative and crying out for support. They also show that parents are not always fully aware of the anxiety of their children or some of the perceived negative reactions of others until they read the questionnaires. Parent feedback through the planned interviews will no doubt be fascinating.

Discussion: Classroom Management

The knowledge and skills teachers have working with children with chronic medical problems; physical difficulties, etc also apply to helping children with TS. Children with TS can face physical, social, emotional, psychological and other medical difficulties. It is always important to first consider the abilities and needs of the children involved and to seek parental feedback. The assistance of other specialists, such as a psychologist or teaching aid could be advantageous. Support groups have also proved valuable in some cases.

It is quite clear that what teachers do and say makes a difference to children in their care. The teacher has an enormous impact on children through modelling and monitoring responses. Patience and empathy rather than annoyance and anger will demonstrate appropriate responses. It is worth remembering that children with TS get frustrated and embarrassed about their involuntary actions and noises as much or more than others do. Pointing out tics is counterproductive; the stress this may cause can heighten the symptoms and negatively affect self-esteem. Acceptance that the symptoms are not purposeful or 'naughty' is a good starting point to help children function at school.

Other disorders sometimes experienced by students with TS, for example OCD and ADHD cause bigger challenges to behaviour and learning. These disorders cause a wide range of difficulties, such as attention problems and impulse control difficulty, therefore each case and task expectations must be considered individually. Being flexible and adjusting expectations are most likely outcomes when teaching students with TS.

It is understating the task to say that catering for children with TS involves consideration of many related factors. A multi-faceted approach to planning learning for students with TS has been developed from these initial research. It recommends due attention to the following major dimensions: Physical, Social, Psychological and Medical. These dimensions are not mutually exclusive but are presented here as a list for clarity purposes. Within each dimension, the teacher and student can identify and act upon individual demands.

A Multi-faceted Approach to Learning with TS

The following dimensions are not stages or levels rather they provide a multi-faceted approach to learning with TS. Each dimension requires awareness and support by family, teachers and peers.

Physical Dimension

Identify the physical characteristics of TS that impede learning, for example, poor fine motor coordination, jerky movements may distract concentration.

Possible Teacher and Student Actions

- Identify behavior control methods that may diminish physical characteristics, for example, self-reflection, relaxation, time out.
- Remember that tic suppression techniques may have other negative effects on learning, for example, reduce energy and cognitive capacity to focus on the task at hand.

The focus at this dimension is on distinguishing between the physical characteristics of TS that impede learning as distinct from social consequences.

Social/Emotional Dimension

Identify the emotional development and social interactions of students with TS that impede learning, for example, easily frustrated, teasing by others, impulsive responses and being off task in cooperative groups.

Possible Teacher and Student Actions

- Organise integration aid support and procedures for time-out.
- Conduct class meetings (seek student approval).
- Identify coping strategies for social situations, for example managing negative self-concept and social reactions.
- When coping with students with TS, emotional responses of teachers can be triggered.

The focus at this dimension is on identifying the impact of social relationships within the classroom and outside the classroom on learning.

Psychological Dimension

Identify the psychological characteristics of TS that impede learning, for example feelings of insecurity might manifest in constantly seeking reassurance, asking for directions to be repeated a number of times or withdrawal.

Possible Teacher and Student Actions

- Seek support about resilience training and counseling services.
- Identify coping strategies necessary for living with a disability.

The focus at this dimension is on supporting students who are experiencing psychological ramifications as a result of the physical and social/emotional dimensions of TS on learning.

Medical Dimension

Identify other medical conditions often associated with TS (such as ADHD and OCD). These can have more impact on their learning than TS. The side effects of medication can also negatively effect learning, for example, tiredness, school avoidance or phobias.

Possible Teacher and Student Actions

- Seek advice on the implications of each medical condition.
- Liase with parents about the side effects of medication.

The focus at this dimension is on identifying other medical conditions and medication that might impact on learning.

Having underlined the importance of designing individual learning plans for students, there are some problems commonly experienced by TS sufferers. These may include attention difficulties, language, writing, spelling and written

mathematics problems. Dornbush and Pruitt (1995) provide a comprehensive handbook of suggestions for each possible learning difficulty associated with TS, ADHD and OCD. It is noted that teacher and teaching actions often suggested in texts may not always be possible within some classroom settings.

Conclusion

Australian qualitative research on the learning implications of TS is rare. Although this research is in the preliminary stages of data collection and analysis of only fifteen students, it provides rich, thought provoking data about students as individual people with individual abilities and needs. The research aimed to investigate the management of TS behaviors and in particular the impact of self-instruction. It has partly achieved this aim but interview data will be useful in illuminating the usefulness of reflective thinking.

Data so far supports the anecdotal claims that many children with TS endure unfavorable, unwanted and unfair treatment by others. It also recognises teacher efforts. The unexpected outcomes of the data provide further questions about the role of the teacher and the nature of effective interactions with families. Teacher interviews may highlight details of teacher actions necessary for successful educational progress.

A supportive educational environment is crucial to contribute to the future success of children (Parker, 1985 and Lemons and Barber, 1991) so that they can operate as confident, capable and active social beings. Teachers have an opportunity to positively or negatively impact upon these children's fragile 'sense of themselves' (Bronheim, 1991). The task is not easy, but it is essential to develop the educational potential of children who are at risk.

Educational advancement for children with TS can only be achieved when teachers understand the emotional, social and psychological consequences of TS, and if they are able to support the individual needs of students. It is hoped that this paper will raise awareness, interest and insights into this multi-faceted

disorder. This is vital to promote understanding, open-mindedness and empathy for people with TS.

We want to conclude by revisiting the voices of two students who have Tourettes. They demonstrate the range of emotions uncovered in the research so far and, although saddening, present a glimmer of hope that human compassion and support can make a real difference.

'I was devastated [when I found out I had TS]. I thought I was going to be a normal boy. But I'm not. My life is awful. I feel like they [tics] are controlling me and that I look stupid. I feel like I'm missing out on a lot of things because of my tics. I will feel a lot better if my tics go. If they don't I will learn to put up with them'.

(Neil)

'I felt like I was the odd one out. My friends did things like sport and I really liked it too, but when I got excited I ticked a lot and didn't concentrate properly. [But now] it's great! I mean I'm still the same person. I have no idea [of what my life will be like in the future], it's going to be whatever I make of it. (Amy)

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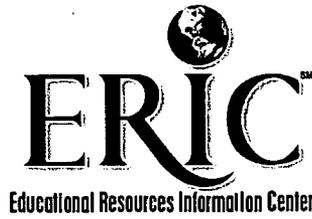
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