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ABSTRACT

This paper examines the educational implications for students with Tourette syndrome (TS) and outlines a multi-dimensional approach for improving their education. It presents data from two qualitative studies in Australia. TS is a debilitating neurological disorder that causes involuntary vocal and motor tics. The first study investigated the management of students with TS, particularly how self-reflection and instruction affects the frequency of TS behaviors. Results revealed a need for educational management approaches. The second study focused on improving the learning and teaching of these students. Data from approximately 70 people (students, teachers, counselors, parents) were tracked over two years and analysis is reported on students' treatment at school, effects of TS on learning, self and teacher management, and home-school relationships. The recommended multi-faceted approach is charted showing physical, social/emotional, psychological, and medical dimensions with identified learning foci, observable behaviors, and teacher/parent/student actions for each dimension. An appendix lists specific classroom strategies for attention difficulties and tic behavior, language problems, writing/spelling problems, and written mathematics. (Contains 34 references.) (DB)

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Increasing the effectiveness of education for students with Tourette Syndrome.

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Abstract

Tourette Syndrome (TS) is a debilitating neurological disorder that causes involuntary vocal and motor tics. Children with TS represent the normal range of levels of intelligence, yet these children often experience personal distress, reduced self-esteem, social problems (Stefl and Milton, 1985) and school failure (Wodrich, 199). Research reveals a lack of teacher knowledge and confidence in dealing with students and families with Tourettes. This paper examines the educational implications for students with TS and will outline a multi-dimensional approach for improving the education of these students at risk.

Introduction

The complexities and feelings of Tourette Syndrome (TS) sufferers are not well known by teachers or medical practitioners. As a result misunderstandings and lack of adequate support for students with TS, their families and teachers is commonplace. Communication amongst families and between sufferers and teachers is often minimal. Even in cases where families are satisfied with home-school relationships, misunderstandings are often present and inhibit confidence and achievement.

The literature available on TS is generally limited to explanations of symptoms, possible medical treatments or descriptions of educational difficulties experienced by students with TS. Management of TS is rarely discussed in a wholistic way and this is reflected in the feelings of helplessness reported by some families and appeals for assistance by many teachers. Some of the suggested approaches to teaching students with TS fail to recognise the individual and changing needs of this group, and the effect of any one aspect of learning, such as social interactions, on a student's overall learning success.

This paper will present data from two qualitative studies (from 4 states of Australia) about students with TS (aged 7-17 years) and the educational implications of Tourette Syndrome. The focus will be on a multi-dimensional approach for improving the education of these students at risk.

What is Tourette Syndrome?

Tourette Syndrome is a neurological disorder characterised by multiple, involuntary, and repetitive motor and vocal tics. Other symptoms can include repeating their own or other's words, or undesirable words. The latter is often cruelly sensationalised in the media. ADHD

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and Obsessive Compulsive Disorders are often associated with Tourette Syndrome and other medical problems can co-exist. Tourette Syndrome was once thought to be a psychiatric condition, but it is now known to be is a neurological disorder. It is caused by a chemical abnormality that disrupts messages between nerve cells in parts of the brain. The symptoms are generally worse in the adolescent years. These wax and wane but TS cannot be outgrown.

Tourette Syndrome is a physical, not a psychological disorder with varying levels of severity. Tics release a build up of tension in a child's body but can also cause pain when they are severe. The changing nature and complexity of the syndrome sometimes raises doubt in the minds of teachers and the public about the involuntary nature of TS. The impact of such disbelief on the sufferer can have a range of undesirable consequences, for example, further undermine an already low self esteem.

There is no typical TS child. The range of TS behaviours displayed by children is wide. These vary amongst individuals and sometimes from day to day for individuals. One tic may be recurrent, for example, eye blinking, head jerking or shoulder shrugging. Others might appear and disappear unpredictably. Some examples of symptoms are listed in Table 1.

Motor Symptoms		**Vocal Symptoms**	
Eye rolling	Inhaling/exhaling	Barking	Animal noises
Facial grimacing	Knee knocking	Blowing	Moaning
Finger tapping	Lip licking	Clicking	Screeching
Foot dragging	Nose twitching	Gasping	Sniffing
Hair tossing	Picking self	Grunting	Snorting
Hand clenching	Pulling clothes	Hissing	Throat clearing
Hitting self/others	Teeth grinding	Honking	Yelping

Table 1. Examples of Symptoms of Tourette Syndrome

The prevalence of TS is difficult to determine because of poor knowledge and misdiagnosis of the condition. It is common for sufferers to be repeatedly misdiagnosed and to eventually find out about their condition through sources other than medical practitioners. 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 four times higher than for girls.

Diversity and Doubt

Tics must be released because, like a sneeze, they are 'irresistible' (Jeffreys, 2001) and cannot be held back forever (Parker, 1985). This 'inner tension' (Singer and Walkup, 1991) is relieved by ticcing whereas suppression causes discomfort and sometimes pain. The

energy required to stop tics makes concentration very difficult, and the act of masking tics can also create extreme self-doubt and anxiety, which in turn increases tics. Although ticcing is involuntary some children can suppress tics for short periods of time (Bronheim, 1991).

The unpredictable and irregular nature of ticcing can cause some teachers to believe a student is 'just behaving that way to be naughty' and many teachers respond accordingly. But children do not just 'put them on' (Robertson and Baron-Cohen, 1998) and non-supportive reactions to tics and associated TS behaviors are felt intensely by the child. Our research has confirmed that children do not enjoy ticcing, other Tourette behaviours nor the attention these attract.

The range of symptoms of TS and therefore the range of needs is diverse. The most successful learning programs are those that accommodate students' individual needs (Singer and Walkup, 1991). A learning plan should consider the many dimensions of TS, including: physical, social-emotional, medical and psychological needs. Ideally this learning plan is best developed collaboratively with children, parents, teachers and sometimes counseling providers (see the Multidimensional plan for learning, page 12).

Some Common School Challenges

Children with TS represent the normal range of levels of intelligence but despite this often experience personal distress, reduced self-esteem (Jones, 1992), social problems (Stefl and Ruben, 1985), stress (Nash, 1993) and school failure (Wodrich, 1998). According to Stefl and Ruben: 'the degree and frequency of problems experienced by TS students in the classroom is striking' (1985 : 74). For example, tasks can be physically difficult, students may be fatigued and suffer side effects of medication, lack confidence and experience social and emotional challenges. Some of these are related to TS symptoms that disrupt learning and interfere with attention (Singer and Walkup, 1991), others can be associated with related dimensions (see page 12) or comorbid medical conditions. Without proper intervention and appropriate learning experiences, TS students may easily be classified as learning disabled.

TS can make many simple and routine activities like reading and writing more difficult (Robertson and Baron-Cohen, 1998). The syndrome causes excessive movement, interruptions, tension and pain from persistent jerky movements of tics. Frequent ticcing, called 'neurological chaos' by Dornbush and Pruitt (1995), is very disruptive for learners and physically getting their work done can be overwhelming. This is especially true if children are trying to suppress tics. Tic suppression requires much energy and can cause stress which may interfere with a student's ability to concentrate on classroom tasks.

It is the above reasons that it is not advisable to tell children to suppress tics (Jones and Johnson, 1992). Other people's negative responses to tics can cause anxiety, which in turn increase tics and generate self-doubt. However, regardless of teacher acceptance of tics, students may still try to suppress tics regardless because of the concern for unwanted reactions of peers and others. One study participant Mason (8 yrs) explained: *'People don't like to look at it.'*

In general, children with Tourettes are not disruptive students but can be labeled as naughty and weird. Some behavior is a direct consequence of having a stigmatizing disorder (Singer and Walkup, 1991). Where basic management of tics is considered unsatisfactory, other explanations for aggressive behaviour, (particularly if rage attacks occur) should be sought. This sort of behaviour may signal that students are not coping with their TS, that they are not coping with the secondary consequences of the syndrome and co-morbid conditions (such as ADHD, ADDD, OCD), or may be due to Oppositional Defiant Disorder. The existence of Obsessive Compulsive Disorder/anxiety disorders can also create additional problems for students particularly in completing tasks.

Not surprisingly, frustration is another problem for children with TS (Cohen, Bruun and Leckman, 1988) and some degree of emotional difficulties can be expected including increased anxiety and depression (Bruun and Bruun, 1994; Carter, O'Donnell, Schultz, Scahill, Leckman and Pauls, 2000; Haerle, 1992; Parker, 1985). Social isolation can also be a disturbing result of tic behavior (Stefl and Ruben, 1985) and sadly, some children have no friends (Zamula, 1988). These social and emotional difficulties can be more problematic on a day to day basis than the tics. This is often due to the people's reactions to the vocal and motor tics.

Roberts and Lindell (1997) are convinced that peer acceptance has a fundamental impact on social and emotional health of students with disabilities. Teasing and misunderstandings amongst peers at school can impact on self confidence and then cause other learning difficulties. This can be particularly challenging for TS students whose condition is likely to be at its most extreme during adolescence when most young people just want to 'fit in'.

Task avoidance is another real issue for anyone finding tasks difficult. Add to this self-consciousness about unpredictable behaviour and noisy classroom situations which can aggravate tics, and school can become a daunting place for children with TS. Frequent calls for some planning and adjustments to classroom requirements are found in the literature. These modifications can make the difference between motivation and feelings of failure.

Challenges for students, parents and teachers are common when trying to plan for learning and teaching with TS. Effective interaction and communication between all parties is essential. Parental involvement in the education process is considered highly desirable although this can be difficult for parents. The high level of parental stress associated with dealing with schools, particularly in relation to modifying teaching practices to better cater for their child's needs, was recently reported by Brock and Shute (2001). The teacher's responses and the impact on class members can be highly significant (Byers, 2001) and their ability to foster effective communication is a key to helping students cope (Parker, 1985).

Research Overview

This paper reports on two separate but related research studies on Tourette Syndrome. The first research project aimed to investigate the management of TS, particularly how self-reflection and instruction affects the frequency of TS behaviors. The results revealed a need

for educational management approaches. Subsequently, the second research project focused on improving the effectiveness of learning and teaching students with Tourette Syndrome.

Case study data about students with TS has involved over seventy people (students, teachers, student counsellors and parents) making the work the largest qualitative study of TS students in Australia. The first project involved data from over sixty people, some of which have also participated in the second project. Data collection for the second project is in the final stages.

Background Information

Approximately half of the students with TS are currently on medication, most of whom experience or have experienced side effects (see Awaad, 1999). For example, restlessness, lethargy, cognitive dulling, weight gain, anxiousness, depression, school refusal and phobias. Although the tic behavior of students varies for each child and over time, the frequency for the majority of children in this study was categorised as mainly high (per minute or hour). The students reported a wide range of behaviors that are ever changing, these included: twitching and jerky body movements, vocals, for example: clicking noises/throat clearing; head nodding/jerking neck; blinking, sniffing and teeth grinding. Other behaviors reported: finger licking; squatting; cracking toes/fingers; jaw dropping; grimaces; chewing and ankle rolling.

Although no students reported anger outbursts, these were reported by some parents. Other medical issues (such as ADHD and OCD) were not the focus of this investigation but many of the students involved in this study did have a range of medical problems.

Many of the student responses related to their feelings about having Tourettes and reveal a progressive shift over time. This is consistent with what might be expected when children and their families learn to cope with a chronic illness (see Eiser, 1993). 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 the need to accept and live with their condition was expressed, for example Ron (12 yrs) said: *'No fairies going to wave a magic wand and make it better'*. In some cases though, children believe that their condition will go away and even though this is not true, parents knowingly do not dispute this hope. Students indicated that their feelings of self worth declined during tic episodes.

The following two quotes demonstrate two quite different perspectives on finding out about and living with TS.

> *'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, 9yrs)*

'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 ticced 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, 15 yrs)

Despite the optimism prevalent in the second of these two quotes a later interview with Amy's mother has documented her annoyance that teachers had dampened Amy's dream of completing her VCE. Amy dropped out of school and has just moved back home after living in the streets for some time.

Research Findings

A large amount of data has been collected covering all aspects of the lives experienced by TS students and their families. Research data spanning two years has allowed tracking of changes in TS symptoms and educational progress. This paper reports on treatment at school, effect on learning, self and teacher management, home-school relationships and a multi-faceted plan for learning.

Treatment at School

About half of the students of the study cohort reported they felt they were treated the same as others by either teachers and/or fellow students in class. Of the group who said they were treated differently at school, these responses were not always negative. Many students commented on their advantaged treatment by teachers. For example one participant reported that:

'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, 9 yrs)

One parent was also very complimentary of the efforts made by a school:

'He gets more help because he needs it. His teacher tries to make it easy as possible to cope with schoolwork. He put his needs first before anyone at that school. Every teacher treats him like a prince. They all love him – he just smiles and they fall for him.'

However, 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 inadequacy or 'learned helplessness' (Carter, et al, 2000), disadvantaging TS students academically or otherwise in the long term. According to Wehmeyer, Sands, Doll and Palmer (1997) it is important for students with disabilities to become more self-sufficient and self-determined.

In contrast to favorable school experiences, some students describe disturbing school experiences. Lyle (9 yrs) has Aspbergers and Tourette's Syndrome, he says he feels like he's in prison when he is at school. John (14 yrs) provided comments about reveal unrelenting harassment:

> 'I *used to get asked why I blinked all the time and everyone used to get angry at me because I couldn't help looking at them and I always get harassed.'*

Exclusion by peers is a reality for many students. As one insightful nine year explained: *'They just don't understand and they never will.'* Another explains: *'They think of me as a freak of nature. They call me a freak. These kids think I am not one of them!'*

A parent's extreme frustration with the daily torment experienced by their child at school is reflected in this quote:

> *'I asked the Education Department on their exact policy to stop the bullying. They haven't stopped bullying but they do come down on anyone retaliating. So I suggested to the teacher that maybe I could come in there and slap her across the face, or kick her in the shins and laugh while she has to sit there and <u>not</u> retaliate. 'You can't do that' she said. I said: 'You expect my son to put up with it so if that's the case I expect you to as well.'*

Reported treatment outside the classroom and school was less positive than within classrooms. Such 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 more positive because of teacher 'protection'. Students may also be more self-conscious in other environments such as in public and the schoolyard.

Effects on Learning

Student thoughts about the impact of Tourette Syndrome on their learning provide clear anecdotal evidence of the disruptive nature of Tourettes. For example, students said that TS reduced concentration, created obsessive thoughts that inhibited class participation, affected their friendships and caused vocals and twitches that disrupted collaborative group work and learning in general. Mason and Neil are high achievers, but they discuss different problems. *'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.'*(Mason 8 yrs) and '*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.'* (Neil 9 yrs).

Some students report that TS has not affected their learning. However, comments made by parents suggest that their children's perceptions are not always accurate. For example, a parent noted that although their child said it hadn't affected his learning, their 11 year old son had yet to progress beyond basic reading and writing abilities. Another sat alone in class while all other students sat together in groups. Despite the differences in opinions, parents

do not openly challenge children's misconceptions for fear of dampening their positiveness or creating further educational problems.

Student Self-Management of Tics

Students were asked to report on strategies they have 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 to the syndrome. Tic suppression is often advised by medical practitioners, teachers and parents (less often) to disguise tics. But the underlying message for TS sufferers is that the behavior is not acceptable, it is wrong and it is not normal. But because tics are involuntary the advice to suppress them can be very confusing for students.

Two thirds of the students in this study indicated that they try to cover up their tics, some have stopped trying. Tic suppression is most likely to occur in public situations rather than at home. Many students go to great lengths to 'disguise' their tics to avoid ridicule and embarrassment but expressed a difficulty in holding back or covering up their tics. For example: *'I try to cover my mouth to muffle my tics – but I have trouble trying to stop them.'* (Neil, 9 yrs) 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, 14 yrs). 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!'* A number of students described this inevitable result of tic suppression in a similar way.

Tic suppression strategies (used by less than half of students) include thinking about something else or self-talk. For example: *'Don't do it'* and *'Concentrate.'* Other examples of self-talk included attempts to reduce anxiety: *'Calm down,' 'Be quiet.'* Tic suppression can include actions where children pretend they are doing something else (hide and disguise), 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 report covering up their tics, for example*: 'Putting my head down and covering my face.'* 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. Sam says to himself (out loud*) 'Stop, Shut up and the 'f' word' but it doesn't help.'* He says he still does it anyway *'because it lets the anger out.'*

There is no evidence to suggest that people with TS take any pleasure in tics, that they do this on purpose or that they are deliberately used to attract attention. Quite the contrary, tics can cause children to be anxious, angry and distressed over their unpredictable behaviour.

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 to tic control. Mc Dougall (1998) also concluded that self-monitoring

and self-management could improve student on-task behavior and productivity, and according to Reid (1996), could be easily incorporated in to classroom programs. But Prins and Hanewald (1999) found that anxious children may not know how and when to use self-talk effectively. Our results were inconclusive therefore we recommend that the utilisation of self-talk with students with disabilities requires further research.

Students with TS were asked what advice they would give to other students with TS. They mainly related to perserverence and confidence, for example:

- *'Ignore it when others look at you and explain your problem'*
- *'Just take it calmly, take it quietly and don't be scared of new things. That's how I started it. I wasn't scared'*
- *'If you have a tic attack just lay down, if you have bad jerks just take a break, if you have a bad neck or bad fists just rest them'*
- *'Just don't worry about it. Have a go. If it's too hard get some help'*
- *'Try to control your tics and don't let anyone put you down'*

Effective Home-School Relationships and Classroom Communities

Most parents reported that they did not know what tics were displayed at school or if teachers were using any particular management techniques. This is surprising given that parents in this study (who had informed teachers about their child's TS) spent and continue to spend considerable hours raising teacher awareness about TS.

The most likely explanations for parent lack of knowledge of school behavior and management is related to parents' own feelings of anxiousness about discussing TS with teachers. They may fear of the consequences for their own children (see Brock and Shute (2001). For example, one parent shared her reluctance about approaching schools: *'The teachers he likes speak highly of him but teachers he doesn't like think 'Oh here comes that mother'.* Another parent was confronted with a teacher's comment: *'Isn't there a pill you can give her!'* This was offensive to the parents because the child had suffered many side effects of medication for years and was trying to cope without medication.

In most cases teachers did not approach parents about what was happening at school unless there were major (behavioral or learning) problems. This means that often parents are largely unaware of teachers concerns and visa versa. Where teachers have expressed a willingness/ interest to discuss TS, parents have always been grateful. A feeling of satisfaction by children, parents and teachers is generally the result.

Parents were asked what suggestions they could offer teachers in regards to facilitating the education of students with TS. They frequently wanted TS and the associated difficulties to be acknowledged (not disbelieved), raising the issue of trust for effective home-school relationships. Some examples of parent comments are included below:

- *'Realize that it is a real condition needing special attention even though it is not always obvious'*
- *'The way you treat and teach a child is so important. Encourage students to be positive, ignore tics and realize they have TS before handing down punishments'*
- *'Be flexible'*
- *'Understand the loss of concentration that comes with Tourettes and the impact this has on their schooling and how they feel about themselves'*
- *'Understand that Tourette children need a bit more one-on-one to help them keep on a level with the classroom'*
- *'If the child with TS requests extra time for completing work don't think it's an excuse. Look at it compassionately. Put yourself in their situation. It's not as straight forward as for a normal child. What's two or three days more?'*

Classroom Management by Teachers

The findings of Stefl and Ruben (1985) eighteen years ago are unfortunately similar to those found in this study. Although some educators may show empathy to students with TS, most are not very knowledgable about TS. It is clear from the data collected that the teachers (like parents) need advice about classroom strategies and support for their management of students with TS. Most teachers have no previous experience with a child with TS and therefore their management techniques can be haphazard and unplanned. In our research many of the parent and teacher management techniques had not been planned but were used as 'hope for the best' crisis control strategies as needed. This reveals the uncertainty of parents and lack of support for the condition.

There was a range of responses by teachers about their management strategies. Some had not discussed management with children or parents at all (mostly in low level TS cases). Some suggested deep breathing and relaxing for children when they are distressed or 'badly' behaved. Others had devised behavioral intervention strategies such as time out or a private place for tic release (the latter is frequently suggested in the literature). Wodrich (1998) suggests that a 'release room' is advisable for social and humanitarian reasons.

Another classroom strategy sometimes used was for students to sit at the back of the room. This was used to reduce attention on tics or to increase chances of concentrating. Unfortunately these good intentions were not necessarily communicated to parents and children and as a result were sometimes considered undesirable. Parents very rarely communicated their concerns or unhappiness about teacher's strategy choices. Parents understood that teachers faced challenges when dealing with their children with Tourettes, but teachers rarely acknowledged the difficulties faced by children and parents in the education process.

Jones and Johnson (1992) recommended that teachers should inform class members about the conditions and possible symptoms. In the cases where class members were educated about the syndrome, students with TS in our research felt that the situation improved for them (see Wilson, 2002 and Zamula, 1988). This is consistent with the findings of Lemons

and Barber (1991) who claimed that there is less likely to be misunderstandings and ridicule if people around a child with TS know what to expect.

When asked about their advise for teachers, young people with TS rarely commented on aspects of curriculum, but frequently suggested that teachers should be more empathetic. For example:

- *'Try to understand what it would be like for the student. Try and understand what they have got'*
- *'Understand what behaviors also come with TS'*
- *'Advise other students in the class about what TS is'*
- *'I would like teachers to be more assertive and not yell because it's intimidating and we tick more'*
- *'Be patient, help them as much as you can, don't give up on them. If they need a break from class let them go to a quiet place so they can finish off their work. If there is a test let them do it in a private study area'*
- *'Don't push them too hard and give them time'*

In classrooms where the child and parents are extremely happy, the teachers have shown compassion and flexibility. These two factors are considered crucial for accommodating TS students in the mainstream system (Zamula, 1988). Similarly, Stefl and Ruben (1995) have commented on the need for making accommodations for students and the importance of this for their psychosocial and education success. In one classroom, the teacher reported that: *'I don't treat him differently than anyone else.'* In her room the teacher works hard at creating a caring, 'family like' environment where everyone is treated with dignity.

The following factors were stated by teachers, parents and/or students as important for education satisfaction:

- Regular three way communication
- Increased self esteem of students
- Consistent rules and clear expectations that are *'livable for everybody'* (teacher)
- Individual needs are accounted for
- Recognition of everyone's rights
- Time out plans

Teachers who have taught students with TS suggested that wholistic understanding of student needs was important. They also reflected on how to modify the program to cater for individual requirements such as social problems. Teachers offered a range of useful suggestions for educating children with Tourette Syndrome including:

- *'Get to know the students. Determine their feelings about TS and how they cope with it'*
- *'Let the TS student give an explanation to the teacher of what they experience with TS so the teacher can see the syndrome through the student's eyes'*

- *'Be aware of both student and parent frustrations'*
- *'Modify expectations without reducing child's self esteem'*
- *'Establish with the student a Learning Management Plan that will assist both of you'*
- *'Maintain effective communication with the student's home. Parents should be involved in the development of student contracts so they have a clear idea of school expectations'*
- *'Inservice all staff'*
- *'Don't let the student be isolated from other students'*
- *'Because of the teasing that can occur in the yard consider establishing a team of students that support the TS student in the yard and the classroom'*

Discussion

In general, the knowledge and skills required of teachers working with students with other chronic medical problems and learning disabilities also apply to helping children with TS. It is always important to first consider the abilities and needs of the children involved and to seek parental feedback. Children with TS can face physical, social, emotional, psychological and other medical problems that can be ignored by schools. These dimensions provide a framework for teacher and support staff and family decision making.

It is quite clear from our data and the literature that what teachers do and say makes a difference to children with TS (Carroll and Robertson, 2000). The teacher has an enormous impact on children through modelling (Jones, 1992) and monitoring student 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 and the stress this may cause can heighten the symptoms and negatively affect self-esteem and their desire to learn.

A multi-faceted and integrated approach to planning learning for students with TS has been developed from this initial research. It is recommended that due attention is given to the following major dimensions: physical, social/emotional, psychological and medical as a starting point for planning. Uncovering the shroud of TS secrecy that often pervails is an important starting point for open communication and educational success.

A Multi-Faceted Approach to Planning Learning

The following dimensions are not stages or levels, rather they provide a multi-faceted approach to learning with TS. Each dimension requires awareness, open communication and support by family, teachers and peers. These dimensions are not mutually exclusive, they provide a framework for teacher decision making. Within each dimension, the teacher, parent and student can identify individual needs and act together to create classroom conditions that enhance learning (see Wilson and Shrimpton, 2001). When planning for learning, 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, teaching aide or support groups can be advantageous.

LEARNING DIMENSION	OBSERVABLE BEHAVIORS	Teacher, Parent and Student Actions
PHYSICAL DIMENSION		
Focus: identifying physical characteristics of TS that impede learning.	For example, poor fine motor coordination and movements that may distract concentration or discourage learning.	✓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 learning task. ✓Provide **alternatives** for some tasks, for example: an aide, computer, tape recordings, extended time for tests.
SOCIAL/EMOTIONAL DIMENSION		
Focus: identifying the impact of emotional development and social relationships (within and outside the classroom) on learning.	For example, easily frustrated, teasing by others, impulsive responses, behavior problems and being off task.	✓Organise **integration aid support** and procedures for time-out. ✓Conduct **class meetings** (seek student approval) to discuss effects of TS. ✓Identify **coping strategies** for social situations, for example managing negative self-concept and social reactions. Note: When coping with students with TS, emotional responses of teachers can be triggered.
PYSCHOLOGICAL DIMENSION		
Focus: supporting students who are experiencing psychological ramifications as a result of TS on learning.	For example, feelings of insecurity might manifest in constantly seeking reassurance, asking for directions to be repeated a number of times or withdrawal.	✓Seek support from **counseling services**. ✓Identify **coping strategies** necessary for living and learning with a disability. ✓Develop **self-esteem**
MEDICAL DIMENSION		
Focus: identifying other medical conditions and medication that might impact on learning.	Other medical conditions often associated with TS (such as ADHD and OCD) 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.	✓Seek **advice** on the implications of each medical condition. ✓**Liase regularly** with parents about the side effects of medication (e.g. communication book) ✓Check the school if they have a **medication policy.** This may conflict with parent preferences for medicating.

Table 2. Multi-Faceted Planning Grid

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 and impulse control difficulty. Therefore each student and task expectations must be considered individually. Being flexible and adjusting expectations are the most likely pre-requisites for teaching students with TS. For example, some students are exhausted when they get home from school and they cannot complete homework. A few students in our research needed to go to bed soon after they got home from school and slept until it was time to go to school the next morning.

Having underlined the importance of designing individual learning plans to accommodate the needs of students, there are some problems commonly experienced by TS sufferers. These may include attention difficulties, reading, 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 (See Appendix for classroom strategies for common problems). It is noted that teacher and teaching actions often suggested in texts may not always be possible within some classroom settings.

Conclusion

Despite advances in knowledge and treatment, tic disorders generally remain poorly understood. As a consequence, students with TS and their families can experience considerable extra burdens and school life can be challenging, if not distressing. The multi-faceted plan has been designed to assist with ideas for management and, most importantly, offer ways of working towards the healthy development of the whole child. This recognises the importance of open communication, self-esteem and constructive relationships for learning and living within and beyond formal education.

In the typical lives of TS sufferers, it is common for them to be:

- misdiagnosed
- considered a behaviour problem
- embarrassed and frustrated by their condition
- lacking confidence and suffer years of self doubt
- isolated from friends and family
- disbelieved about their lack of ticcing control
- facing on-going stressful situations
- discouraged from academic and sporting pursuits

Students with Tourette Syndrome, like all children, have enormous potential when wholistic support is based on individual needs and when they experience success. Children with TS should not feel as nine year old Mason does:

> *'If there were two of me and I looked myself in the eye, I'd feel sorry for myself – because it's just not normal'.*

Knowledge about TS and the ramifications is generally very limited. It is an indictment on our system that parents should feel as bitter as the following parent who says her family live an isolated life for survival:

> *'It's a relatively unknown syndrome but horrendous. It needs to be talked about. Some people, particularly teachers are the least educators, they don't have the right attitude.'*

It is hoped that this paper will raise awareness, interest, promote open communication, empathy and approaches to this fascinating, multi-faceted disorder. The results of this research raise interesting questions and challenges about educational approaches for managing teaching and learning for students with Tourette Syndrome. Certainly home-school relationships, and in particular communication processes, deserve further research.

A supportive educational environment and comprehensive individualized programs are required (Singer and Walkup, 1991, Burd, Kauffman and Kerbeshian, 1992) to enable students to experience success (Parker, 1985 and Lemons and Barber, 1991) and so that they can operate as confident, capable and active social beings. It is essential to promote understanding, open-mindedness and empathy for people with TS and to develop the educational potential of these children who are at risk.

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Dedication

For Madison and Ethan whose lived daily experiences enrich the insights of others.

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Appendix: Specific Classroom Strategies

The following list indicates some common problems for TS sufferers and some possible actions. It is acknowledged that these may not always be possible because of classroom set up and routines. These should be considered in light of particular difficulties that children face in conjunction with the Multi-dimensional approach. Please also note that while many classroom conditions may need to be modified, the level of work should still be appropriately challenging.

Attention Difficulties and Tic Behaviour

- If children are not using their energy to suppress tics they may be more focussed on the task
- Provide access to a private room for tension and tic release
- Offer short breaks
- Break long assignments into smaller parts
- Sit child in front of the teacher
- Avoid disruptive seating arrangements, such as by the door or window
- Develop work contracts
- Have an 'on task' reminder system. For example, tap on the shoulder
- Allow movement around the room
- Eliminate unnecessary materials from desks to avoid distractions
- Give time warnings
- Try to ignore tic behaviours that are not seriously disruptive
- Have a signal for time out, for example, a fictitious note to go to the office
- Have a rest/safe area for example, a beanbag
- More time might need to be allowed on timed tests and with deadlines particularly where physical difficulties make work difficult to complete

Language Problems

- Provide visual and auditory instructions
- Give step by step directions
- Restate instruction patiently
- If children are getting stuck on words or numbers, give them short breaks to break the cycle
- Allow oral presentations to be tape recorded
- Have a parent/carer scribe work
- If a child loses their place in a book suggest using a ruler

Writing and Spelling Problems

- Modify or reduce task requirements because some things take a lot longer for children with TS
- Distribute instructions rather than requiring children to copy copious instructions

- Allow longer time to complete timed tests
- Provide word processors and spell checkers
- Do not discriminate work on the basis of handwriting, always consider the effort

Written Mathematics

- Provide calculator
- Provide grid paper so that column work is easier
- See other relevant instructions above

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