Tourette Syndrome & Persons with Developmental Disabilities

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“I’m not bad....

I have
Tourette syndrome”

Tourette Syndrome (TS)

- A chronic neurochemical disorder that causes involuntary motor movements & vocalizations (sounds/words) called tics
- Occurrence: approximately 1 in 200 persons (some studies found 26% of children in special ed class had tics
- Occurs in males > females
History of TS
- 1825-Dr. Itard reported 1st case: Marquise de Dampierre
  - This noblewoman lived to the age of 86 & her case was also described by the French neurologist, Dr. Gilles de la Tourette
- Other famous people with TS include: Samuel Johnson, lexicographer & André Malraux, French author
- Recently Neve Campbell has become a spokesperson as she has a brother with TS

Tics
- Involuntary, rapid, sudden movements or vocalizations that occur repeatedly at irregular intervals
- Any attempts to inhibit these movements DO NOT WORK for most people
- Described as a sensation or uncomfortable feeling that is temporarily relieved when the tic is performed

Tics
- Onset: approximately 7 years of age
- Tics can wax & wane, can be mild to severe, from the subtle to the bizarre
- EXTERNAL TICS: movements that can be seen by an observer (facial grimacing, limb tics)
- INTERNAL TICS: not readily observable (breath holding, abdominal tensing)
Tics

- Tic suppression is NOT encouraged as it may lead to tic flurry (explosive outburst of tics & temper) later in the day (at recess or upon returning home).
- It also requires ++ concentration so will distract from learning & schoolwork.

Types of Tics

**Motor tics:**
- Simple motor
- Complex motor
- Copropraxia
- Echopraxia

**Vocal tics:**
- Simple vocal
- Complex vocal
- Coprolalia
- Palilalia
- Echolalia
- Speech atypicalities

Comorbidities?

- ASD, 6-22% (22% w/tic dx, 11% w/GTS))
  - + correlation btwn tics & severity of I/DD
- I/DD
  - 1235/5450 in TIC database (23%)
- FXS, cases reported (2008)
- DS, cases reported
Associated disorders: OCD

- Obsessions: unwanted, intrusive, repetitive thought, difficult to control. Often causing increased anxiety.
- Compulsions: repetitive, deliberate actions that occur in an attempt to relieve anxiety caused by obsessions, sometimes called rituals.

Examples of compulsive behaviors:

- Checking
- Counting
- Hoarding
- Touching
- Arranging
- Picking at self
- Repetitive questions
- Hand washing

Other OCD behaviors:

- “Looping” or perseveration: inability to stop thinking about a particular thought
- Reassurance seeking: needing constant reassurance about everything
- Chronic negativism: “glass is ½ empty”
- Ritualistic behavior: performing compulsions until it “feels right”
- Defensiveness: inability to tolerate constructive criticism, feels attacked by teacher or peers
**Associated disorders: ADHD**

- Regulatory problem of attention, activity level & impulse control
- An inability to filter out environmental stimuli & to resist distractions
- Characterized by impulsive behavior & unfocused attention
- 3 types:
  - Predominantly hyperactive & impulsive
  - Predominantly inattentive (Ø hyperactivity)
  - Combination of both

**Associated disorders: ADHD**

Other signs:
- Inability to organize/classify information
- Seeking sensory stimulation: fidgeting, tapping, touching people/things
- Losing things: pencils/erasers/homework
- Changing thoughts quickly
- Inability to complete tasks
- Speaking out of turn or shouting out answers to teacher
- Poor time management

**Other associated disorders:**

- Panic disorder
- Trichotillomania
- Mood disorders:
  - Depression
  - Bipolar disorder
Other associated disorders:

- Mood disorders:
  - Depression: look for common signs:
    - Crying, sadness
    - Altered sleep patterns
    - Agitation/irritability
    - Withdrawal from activities
    - Thoughts of death & suicide or self-harm
    - Low energy
    - Change in appetite
    - Vague physical complaints: headache, malaise

- Other associated disorders:
  - Mood disorders:
    - Bipolar disorder: may be misdiagnosed as ADHD
    - Signs include:
      - Extreme, unpredictable & frequent irritability
      - Explosive or irrational outbursts that last for hours
      - Intense rapid mood swings
      - Extreme impulsivity
    - Signs of mania: elevated mood, decreased need for sleep, pressured speech, grandiose delusions, poor judgment, increased physical/mental activity, excessive involvement in pleasurable but risky activities

Neuropsychological deficits:

- Executive dysfunction (EDF)
- Sensory Integration dysfunction (SIDF)
- Visual-perceptual-motor disabilities
- Social skills deficits
- Memory deficits
- Rage
Neuropsychological deficits:

- Executive dysfunction (EDF):
  - Problems with cognitive processes involving planning & organization
  - Difficulty starting & completing homework
  - Difficulty planning the assignment & breaking it down into manageable pieces
  - Difficulty determining deadlines for each part of the assignment
  - "often underestimating length of time required for each part or total assignment"

Neuropsychological deficits:
Sensory Integration dysfunction:

- Altered sensitivity to sensory stimuli (touch, smell, vision, sound):
  - Hyper-sensitive:
    - exaggerated awareness & response to sensory stimuli
    - May feel overwhelmed by environment & feel pain or threatened if touched lightly
  - Hypo-sensitive
    - Under-aroused response to sensory stimuli
    - May seek out stimulation

Neuropsychological deficits:
Visual-perceptual-motor disabilities

- Eye-hand coordination problems
- Poor handwriting
- Keeping up w/ teacher, trying to take notes is major problem
- Difficulty w/ organization of math problems
- Spacing issues in math calculations & handwriting
### Neuropsychological deficits: Social skills deficits

- (EDF) Difficulty picking up on social cues (voice tone & body language)
- (EDF) Difficulty being aware of own behavior & making inappropriate responses in conversation
- (ADHD) Missing subtle non-verbal communication: eye-contact, hand gestures & facial expressions (↑ voice)
- Low self-esteem develops from repeated social rejection

### Neuropsychological deficits: Memory deficits

- Deficits in:
  - Procedural memory: sequenced behaviors (procedures, long division)
  - Working memory: amount of auditory & visual info that can be temporarily stored (verbal instructions may be forgotten)
  - Strategic memory: using organizational strategies to perform memory task (mnemonics may help: roygbiv)
  - Strength in autobiographical memory

### Neuropsychological deficits: Rage

- Occurs most often in persons w/ TS + (TS + OCD or ADHD)
- Rage attacks = “neurological storms”
- Not tantrums, but look similar except:
  - Anger out of proportion w/ trigger
  - Different than their typical acting out behavior
  - Ear-splitting screams
  - May throw objects within reach
  - Frantically kick or flail entire body
  - NOT short lived
Neuropsychological deficits: Rage

- Cause not known, may be that increased energy is required to suppress symptoms during the day & one small thing can become “la goutte qui debord la vase”
- Intervention: let it run its course but try to move student to a private, quiet place
- Determine triggers & try to eliminate them to prevent future outbursts
- Collaborate w/ student & family to ID warning signs of impending rage

Summary of associated disorders & neuropsychological deficits

Tourette

- OCD
- Panic disorder
- ADHD
- Mood disorder
- Visual-perceptual-motor
- EDF
- SIDF

Treatments

- Medication
- Psychotherapy & alternative treatments
- Occupational therapy
- Treat most distressing problem:
  - tic?
  - OCD?
  - ADHD?
  - Mood disorder?
GENERAL Intervention strategies:

- Pep up presentations to appeal to all senses, esp. visual + auditory
- Post assignments in classroom (visual schedule)
- Ask them to restate instructions
- Patience & sense of humor!
- Educate & inform other staff about TS
- Transition between classes, recess, & beginning & end of day may be specifically stressful for students w/ TS
- *Create list of strategies for substitute staff

GENERAL Intervention strategies:

- Use + language (state clearly the behavior that is preferred; please do this...)
- Natural consequences: you can have X when you finish Y
- Stay calm & keep control – role model
- Don't take it personally
- Have a plan for physical episodes (consequences vs punishment)

CONSEQUENCES

- *practice: “please go back & close the door gently”
- Do chores to pay for a broken item or help to repair the item
- Come home earlier or stay home next time for a missed curfew
- Develop a better plan for the future
CONSEQUENCES

- Make consequences real world & short term
- Don’t get mad - teach a skill that’s missing
- Try to catch them before they do something wrong & help them to think & plan

Coprolalia & copropraxia

- Acknowledge that it’s a symptom of TS
- Do not punish for a neurological problem!
- Develop strategies w/ person & family
  - Cover mouth to muffle
  - Express modified version of word/gesture
  - Practice expressing portion of word/gesture
  - Lower volume of voice
  - Encourage them to leave the room to release symptoms

Coprolalia & copropraxia

- Educate all staff about these symptoms
- Help them develop skills & confidence to explain symptoms to those offended
- Educate peers about symptoms
- Validate peers concerns & reinforce that person also upset by this behavior. Brainstorm on how they can help
- Validate concerns of other parents & refer to local TS chapter/support group
Need for mobility

- Allow trips to BR or H2O fountain (if frequent, may need to investigate possible causes)
- Send them on errands when need for movement is obvious (make sure other staff aware of strategy)
- Allow them to stand at desk/work area
- Keep supply of soft squishy toys (stress balls) for student to fidget with
- Big therapy ball or Move n’ Sit pillow for seating
- Elastic stretch (Thera-band) bands around desk for legs, resistance exercises

Strategies vs tics

- Brainstorm w/ them for best results
- DO NOT punish for tics
- Allow for competing activities: chewing gum if tongue/mouth tics
- Box of tissues for spitting tics
- Provide buffer zone in room seating arrangement (larger area) if expansive motor tics
- Allow them to exit room to discharge tics as needed

Strategies vs tics...

- Students w/ vocal tics may be uncomfortable in library, offer alternatives
- Educate & inform other staff of these strategies
- Educate staff on TS
- Educate peers on TS (w/ person’s permission)
Strategies for educators

For compulsions affecting written work:
- Allow choice between cursive or printed handwriting for work
- Allow choice of pen/pencil
- Allow computer work
- Allow oral presentations
- Provide copies of teacher’s notes
- Corrections should be done on fresh paper to prevent obsession over X’s & repetitive erasing

For compulsions affecting reading:
- Books on tape
- Allow reading out loud or into tape
- Allow someone else to read to student
- Chunk reading assignments
- Highlight important sections of longer reading & have student read those sections
For compulsions affecting math:
- Use graph paper
- Try computer tutorials
- Reduce workload if symptoms are problematic
- Allow un-timed tests (allow extra time to complete exams)

Strategies involving math
- Reduce workload accordingly
- Calculator use
- Allow headphones to reduce distractions
- Teach mnemonics to remember math rules (Ex. for long division: Dirty Marvin Smells Bad: for divide, multiply, subtract & bring down)
- Tables/cheat sheets
- Number strip on desk to reduce number reversal or memory difficulties

For spelling
- Teach mnemonics
- Allow spell check to be used
- Grade on content not spelling
- Tape letters on desk for students who reverse letters or have memory difficulties
For handwriting

- Computer, oral presentations or taped homework
- Word-spacer: popsicle stick
- Bold line at left margin
- Teach use of highlighter to emphasize important text
- Ask for clarification if work illegible
- Reduce handwriting expectations (note form, bullets,

For sensory overload & fatigue

- Observe student's body language for signs of stress
- PRE-ARRANGE a signal between student & teacher to discreetly allow for time out
- Designate safe, quiet place for time-out
- Reduce or eliminate unnecessary distractions

For sensory overload & fatigue

- Provide alternate area for work
- Allow use of headphones for white noise, allow student to choose preferred music
- Allow for extra time to get from one class to the other or to leave 5 minutes earlier
- Adjust workload according to severity of symptoms
- Whenever possible/tolerated, adjust to a heavier workload
Other Sensory Interventions
Decrease sensory overload by:
- Changing the lighting
- Seat the person away from a window or door or any noisy, distracting area
- Noise-cancelling earplugs

More Sensory Interventions
Heavy work & proprioception
- Pushing/pulling activities, lifting heavy objects, deep pressure massage (backpack w/ 10% of body weight, groceries
- Being “squished”: Bearhug vest, weighted blankets
- Mouth muscles: straws (sucking pudding or applesauce thru a straw!), gum, crunchy/chewy foods, wine-tubing on pencils, fruit leather
- Vestibular: trampoline

Calming activities
- Slow, rhythmic mvmt
- Linear mvmt (back & forth)
- Continuous mvmt
- Deep pressure
- Sweet tastes
- Vanilla lavender scents
- Deep breathing : “smell the flower, blow out the candle”
- Chewing activities (see mouth exercises)
**Alerting activities**
- Quick mvmt, Start & stop mvmt
- Multi-directional mvmt
- Spinning
- Light or unexpected touch
- Extreme temperatures (cold)
- Sour, spicy, bitter flavours
- Strong lighting or changes in lighting
- Strong scents

**Need to cap off w/ deep pressure activity or may go “over the top”!**

**For “bad” behavior**
- DETERMINE causes & triggers
- KNOW YOUR STUDENT: behavior may be due to TS symptoms or coping responses
- STRESS (+/-) can exacerbate symptoms

**Considerations for “bad” behavior**
- Student may have difficulty verbalizing feelings. Help him to find the words to describe his feelings.
- Validate & support his concerns
- Discuss plan for escalation/crisis & include student
- Allow student time & space to calm down
- DO NOT take behavior personally
- Establish an adult ‘safe’ contact person for student
For Transitions

- Warn student in advance to prepare for transition
- Permit student to have 5 minute head start to prepare for transition
- Allow for extra time to gather related material
- Prepare student if a substitute teacher will be teaching any classes

For teasing & bullying

- Validate student concerns
- Educate peers about TS (w/ student permission)
- Model + & accepting attitudes towards student, classmates will follow
- Investigate all situations cautiously before establishing cause

To improve organization

- Color code binders & textbooks
- Or one large binder w/ subject dividers
- Set up time to tidy binders, schoolbag & remove irrelevant material (per semesters or completed sections)
- Work w/ student & family to store finished unit work in safe place for future test review
To improve organization

- Write due dates on assignments
- Keep extra supply of pens, pencils, etc. in class (supplied by parents)
- Praise student when he remembers to bring supplies
- Adhere to clearly established daily routine
- Discreet cues & reminders placed on desk or post-it note can be helpful

Schoolwork tips

- Reading:
  - Determine # pages to read
  - Divide total # pages into a daily allotted reading so book is completed by due date
  - Assign daily reading quota & check w/ student daily
  - Books on tape
  - Have student read out loud on tape
  - Headphones

Schoolwork tips

- Long-term assignments
  - Assign in manageable chunks
  - Be specific about due dates for each part
  - Provide feedback after each part is completed
  - Post plan in class & in student's agenda
  - Teach student to plot time-line
  - Use e-mail & websites to post homework so family can verify from home
  - Provide example of finished product (assignment)
Schoolwork tips

- Studying
  - Provide outline
  - Review notes, highlight important info
  - Provide practice questions
  - Teach student to find & record answer on tape, or tape teacher's review & then review for studying
  - Teach student how to break down info for studying
  - Encourage study sessions of 10-15 minutes
  - Encourage study buddies

Conclusion

- Work w/ student & family to create best intervention plan
- Maintain + approach
- Use any & all resources possible
- EDUCATE others
- Resources:
  - www.tourette.ca
  - http://www.tsa-usa.org/

References

- Medline articles on TS (available on request)
- Tourette Syndrome Foundation website (checklists & video clips)
- TSF book for educators
- TSF Ottawa Chapter, presentation on sensory issues by Jennifer Boggett Carsjens (OT at CHEO)
- CHEO tic clinic, Ottawa
- TS support group at Ste Justine Hospital in Montreal
- You Tube videos
- Dr. Duncan McKinlay, psychologist, video: “Life's a Twitch”