



Occupational Therapy in Tourette Syndrome and Tic Disorders

Presented By:

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Learning Objectives

1

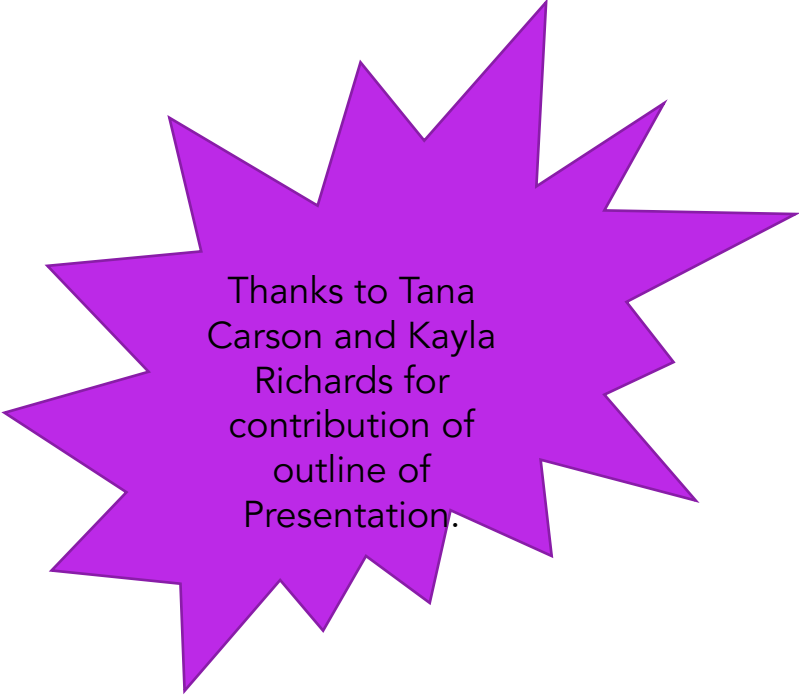
Learning Objective 1: Attendees will adequately understand the role of occupational therapy in managing tic disorders.

2

Learning Objective 2: Attendees will identify resources on further training and resources for occupational therapists in the community to better serve people living with tics.

Disclosures

Heather Simpson and Jan Rowe are paid consultants of the TAA



Thanks to Tana
Carson and Kayla
Richards for
contribution of
outline of
Presentation.

Diagnostic Indicators (DMS-V)

- ▶ Transient Tic Disorder (F95.0)
- ▶ Persistent (Chronic) Motor or Vocal Tic Disorder (F 95.1)
- ▶ Tic Disorder (F 95.9)
- ▶ Tourette's Disorder (F 95.2)

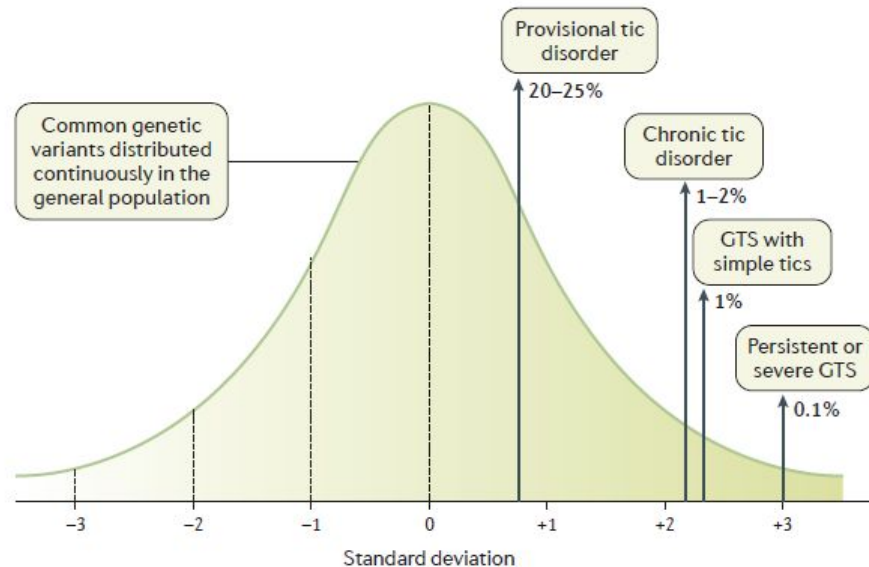


Figure 3 | Genetic architecture of Gilles de la Tourette syndrome and related developmental tic disorders. In the polygenic risk model, in which genetic risk arises

(Robertson, et al. 2017)

Prevalence of Tic Disorders



1 in every 50 school aged children have tics



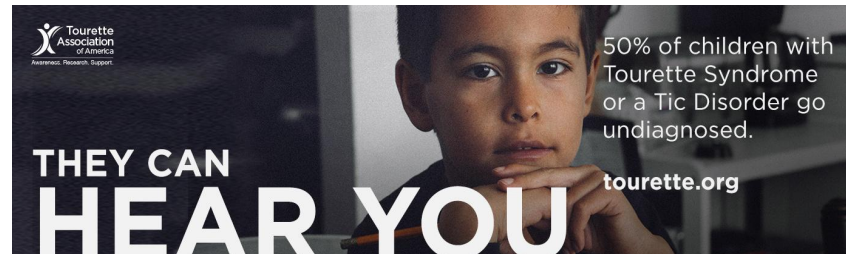
CDC estimates 1.4 Million people are living with TS



The prevalence of current TS is lower in adults (rule of thirds)



More common in males (4:1)



(Woods et al., 2008)
(CDC, 2023)
(TAA, 2017)

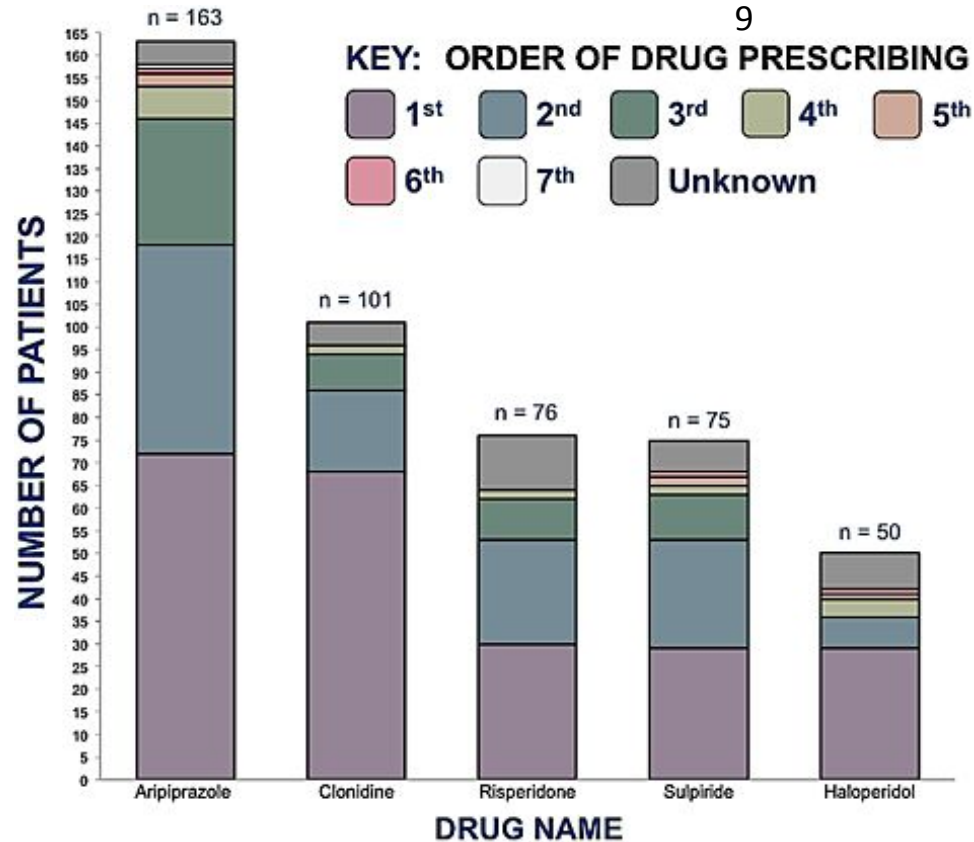
Traditional Tourette Syndrome Care

Traditional Providers

- Primary Care Provider
- Psychiatry
- Psychology
- Neurology
- Social Workers

Typical Medication

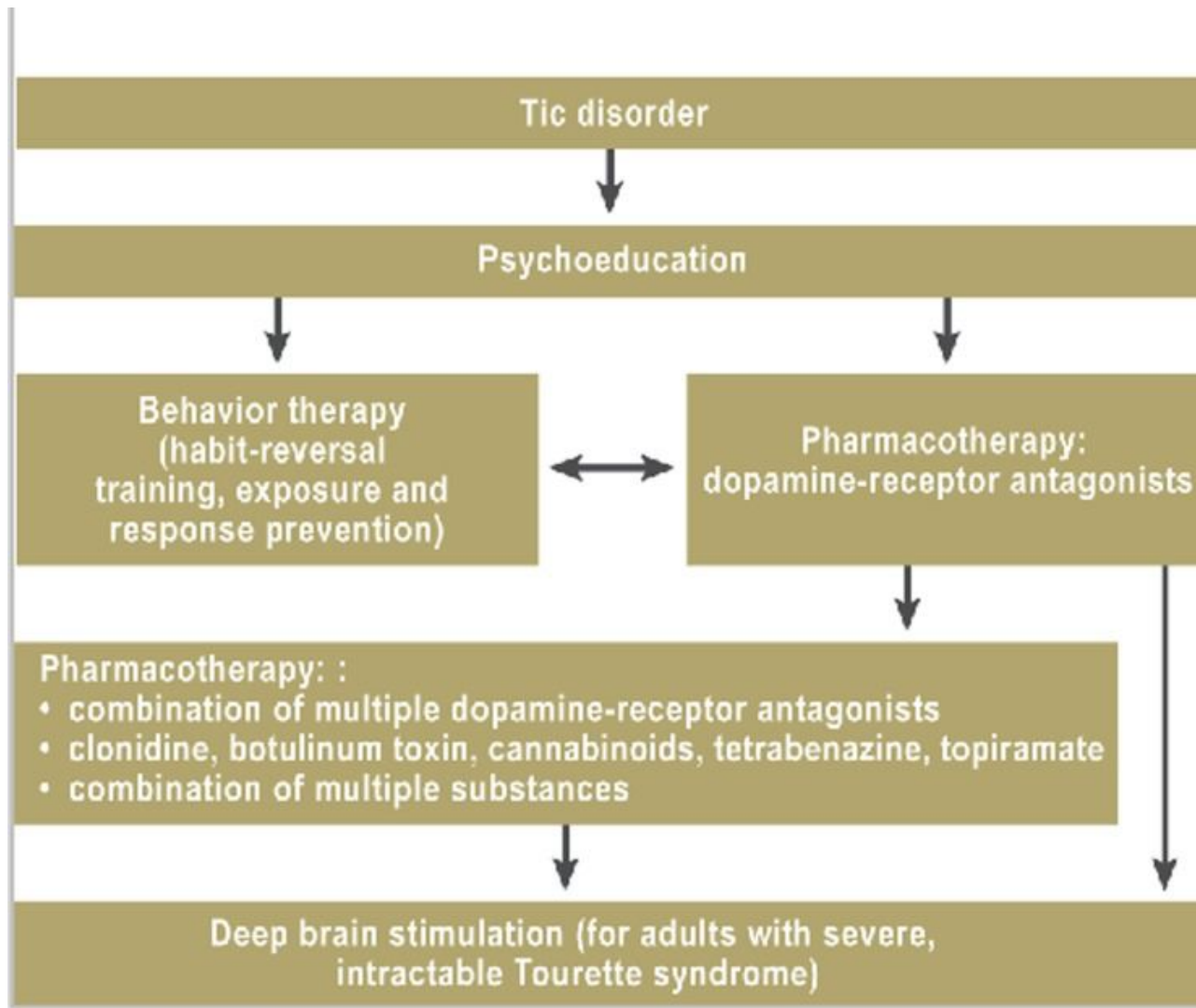
Figure 9



(Farag et al., 2015)

Treatment Decision Tree

(Ludolph et al., 2012)



What is an Occupational Therapist?



What is an Occupational Therapist?

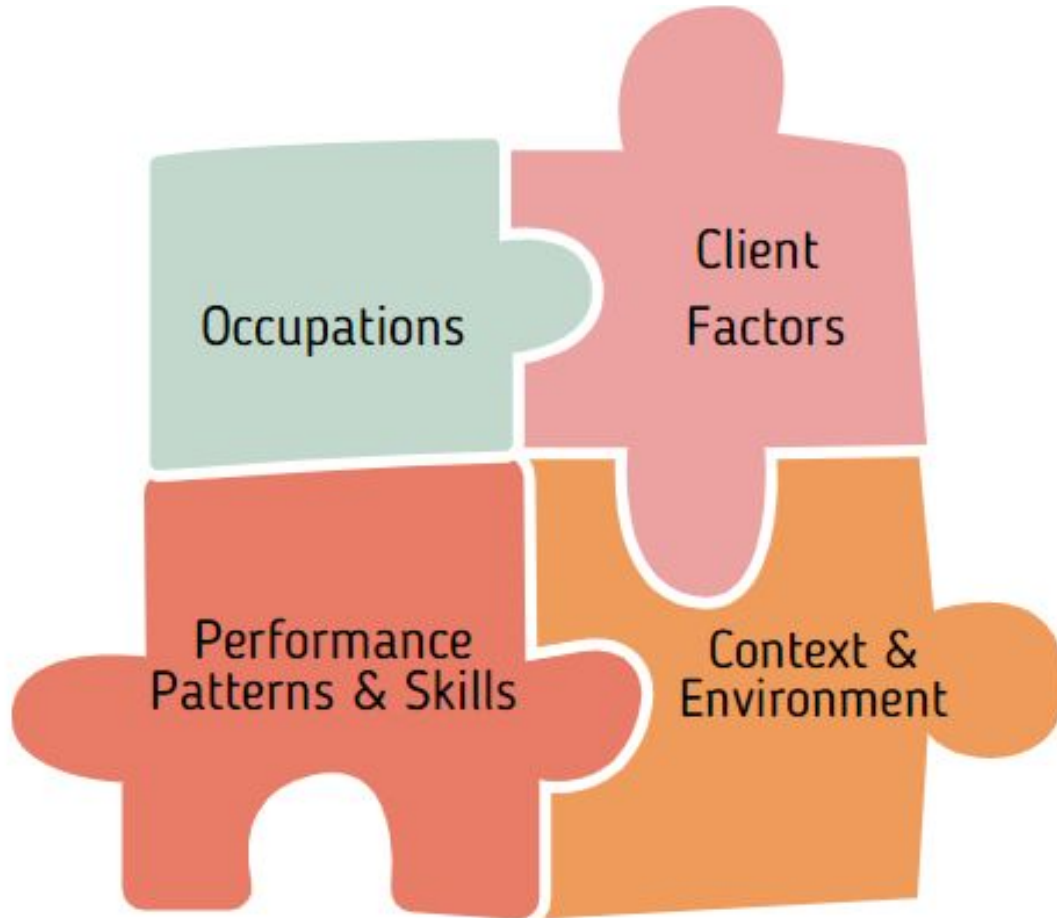


<https://makeameme.org/meme/to-independence-and>

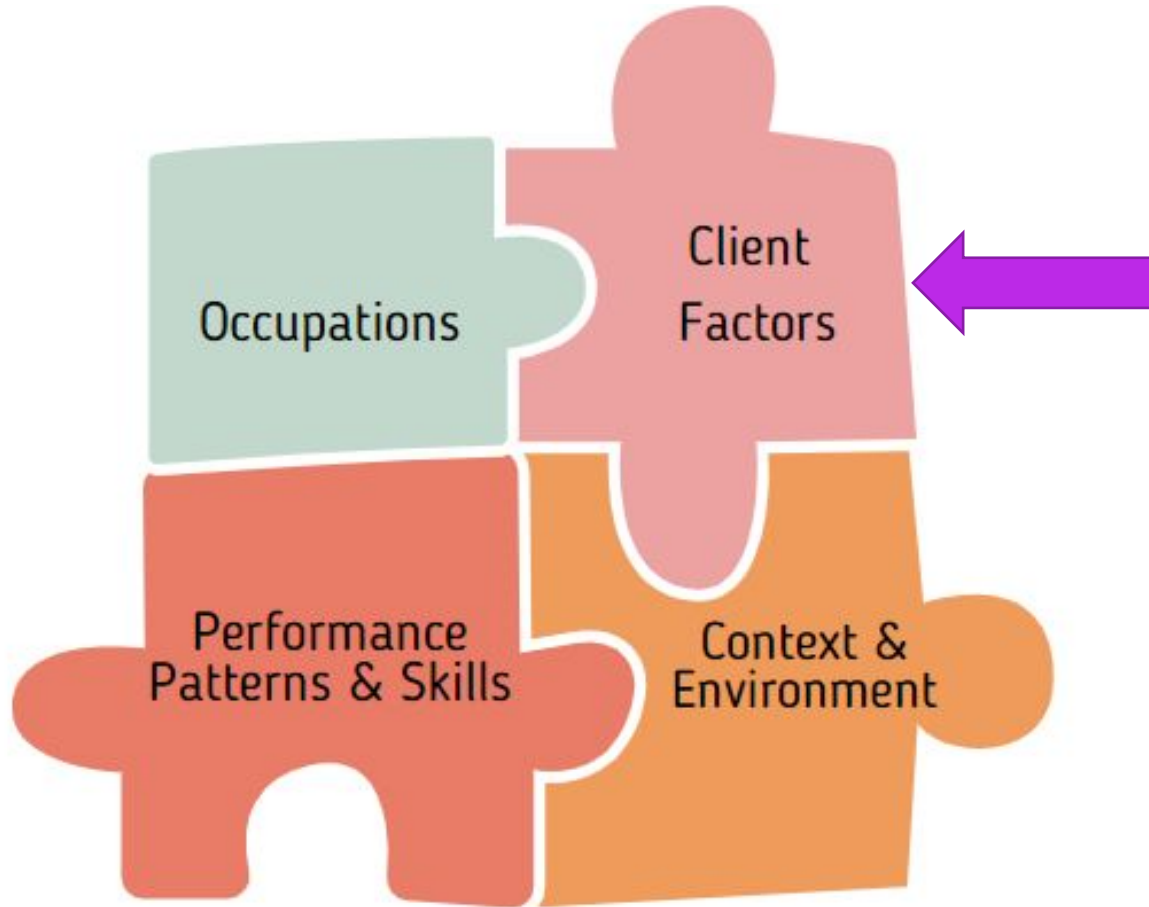
- + “*occupational therapy* is defined as the therapeutic use of everyday life occupations with persons, groups, or populations (i.e., the client) for the purpose of **enhancing or enabling participation**”
- + “Occupational therapy is the only profession that helps people **across the lifespan** to do the things they want and need to do through the therapeutic use of daily activities (occupations).”
- + “In occupational therapy, *occupations* refer to the everyday activities that people do as individuals, in families, and with communities to occupy time and bring meaning and purpose to life. **Occupations include things people need to, want to and are expected to do**”

(AOTA, 2014)
(AOTA, n.d.)
(AOTA, 2020))

Occupational Therapy Intervention



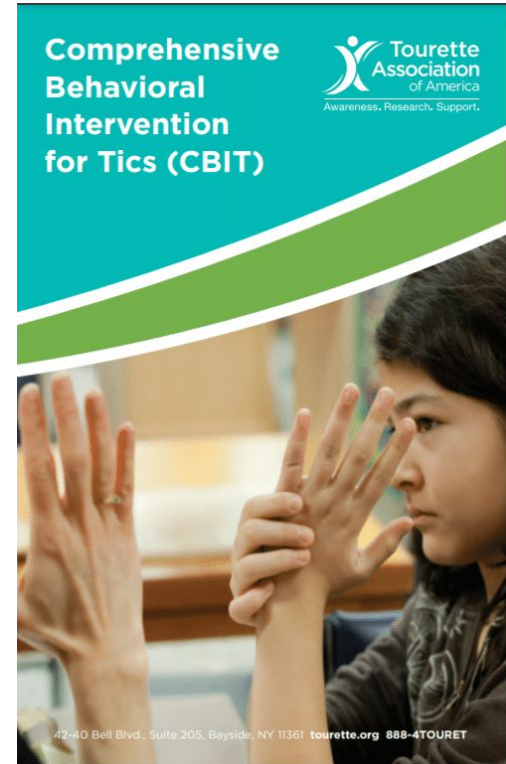
Client Factors



Tic severity can impact level of functional impairment (Liao, 2015)

Comprehensive Behavioral Intervention for Tics

- Gold Standard in the treatment of tic disorders
- A behavioral intervention based on habit reversal training
- Teaches individuals how to manage tics



Comprehensive Behavioral Intervention for Tics



Two parallel RCT comparing behavior therapy to Standard therapy



Child Study (2010): 52.8% improved; maintained over 6 months (compared to 18.5%)



Adult Study (2012):38% of those improved; maintained over 6 months



Improvements in tic severity, intensity, anxiety and QoL



10 year follow-up from this study showed maintained gains (2019)

(Woods et al., 2008)
(McGuire et al., 2015)
(Piacentini et al., 2010)
(Wilhelm et al., 2012)
(Woods et al., 2019)

History of OT and CBIT

Comprehensive Behavioral Intervention to Improve Occupational Performance in Children with Tourette Disorder

- Significant reduction in the number of tics and **function based** on the subjective data collected
- At conclusion, 1/3 were tic free and 1/3 exhibited only one tic
- CBIT helps enhance participants' self-perceived occupational performance as indicated by their improvement in scores on the COSA

Comprehensive Behavioral Intervention to Improve Occupational Performance in Children With Tourette Disorder

Jan Rowe, Hon K. Yuen, Leon S. Dure

MeSH TERMS

- activities of daily living
- behavior therapy
- tic disorders
- Tourette syndrome
- treatment outcome

OBJECTIVE. We evaluated the efficacy of a comprehensive behavioral intervention for tics (CBIT) program to reduce tic severity and improve occupational performance in children with tic disorder using a one-group pretest–posttest design.

METHOD. Thirty children with tic disorder completed an eight-session CBIT program. The program focused on habit reversal, relaxation training, and function-based approaches to address how the environment and social situations (antecedents and consequences) sustain or influence tic severity.

RESULTS. We observed significant reduction in the number of tics and improvement in scores on the Parent Tic Questionnaire, Subjective Units of Distress Scale, and Child Occupational Self Assessment after CBIT compared with scores at baseline.

CONCLUSION. Findings provided support that CBIT reduced the number of tic expressions, tic severity, and level of distress associated with tic and improved these children's self-perception of their competence in and importance of performing everyday activities (i.e., occupational performance).

Rowe, J., Yuen, H. K., & Dure, L. S. (2013). Comprehensive behavioral intervention to improve occupational performance in children with Tourette disorder. *American Journal of Occupational Therapy, 67*, 194–200. <http://dx.doi.org/10.5014/ajot.2013.007062>

(Rowe et al., 2013)



Components of CBIT

Education about tics/
TS

Self awareness

Habit reversal

Function based
approach for
environment and social
situations

Relaxation training

The Future Is Bright

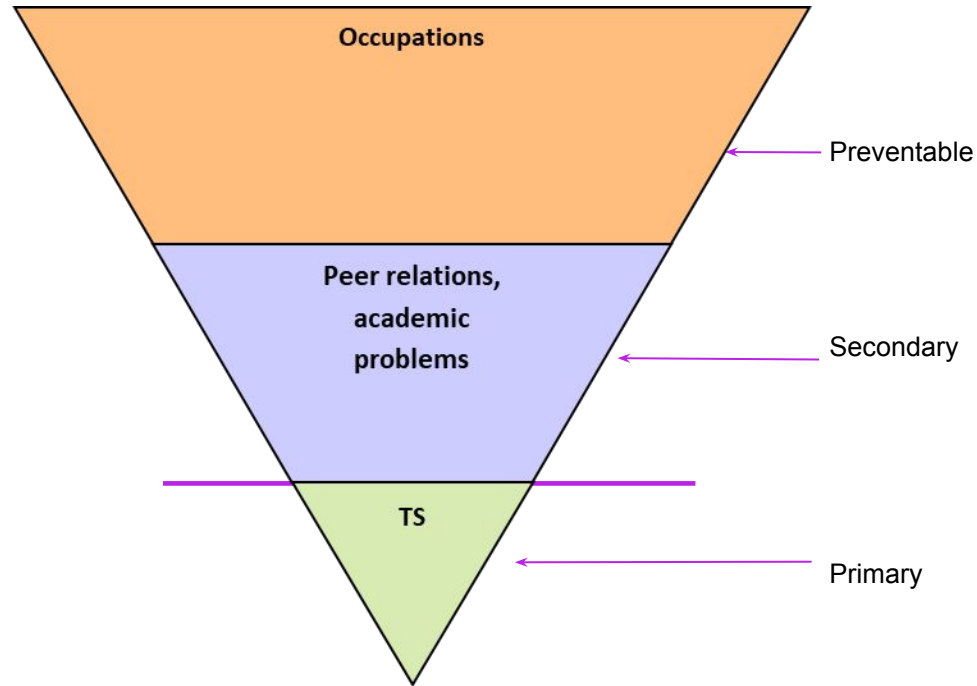
- CBIT Training for OTs easily accessible
- Number of OT providers trained in CBIT increasing each year
- American Occupational Therapy Association (AOTA) recognizes efficacy
- Increase in OT-related CBIT research
- Increase in student training

Do Occupational Therapists have to be trained in Tics to effectively work with those living with tic disorders?



<https://tenor.com/view/no-no-gif-9670945>

Burden of TS Disability



(modified from Juncos, 2013)



**WHAT DOES THIS
MEAN?**

**HOW CAN
OCCUPATIONAL
THERAPISTS HELP?**

Occupational Therapy Practice Framework (3rd ed.)

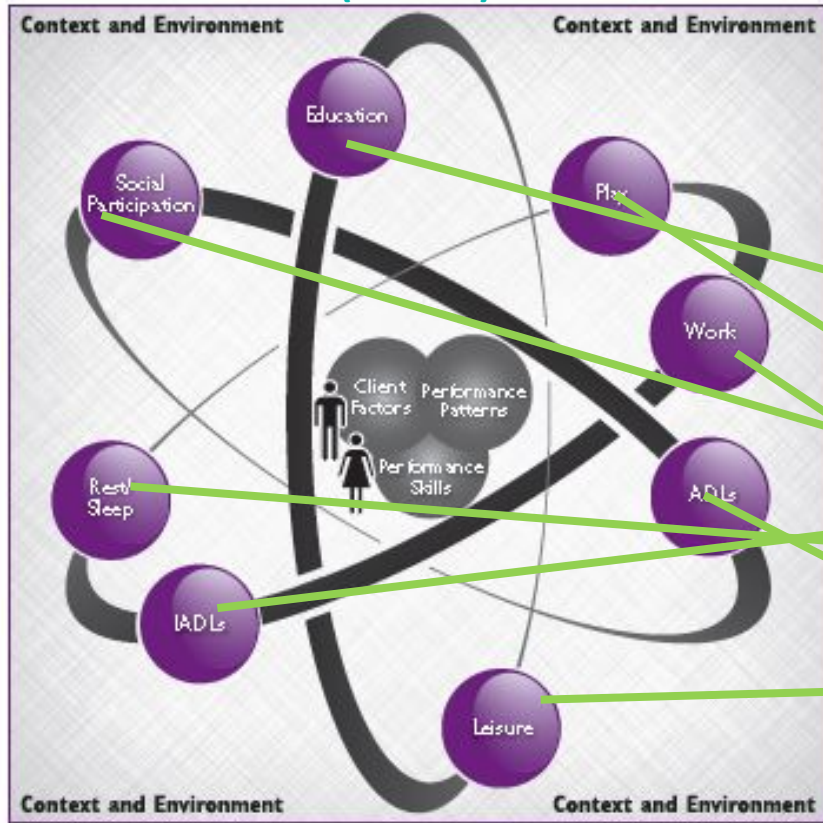


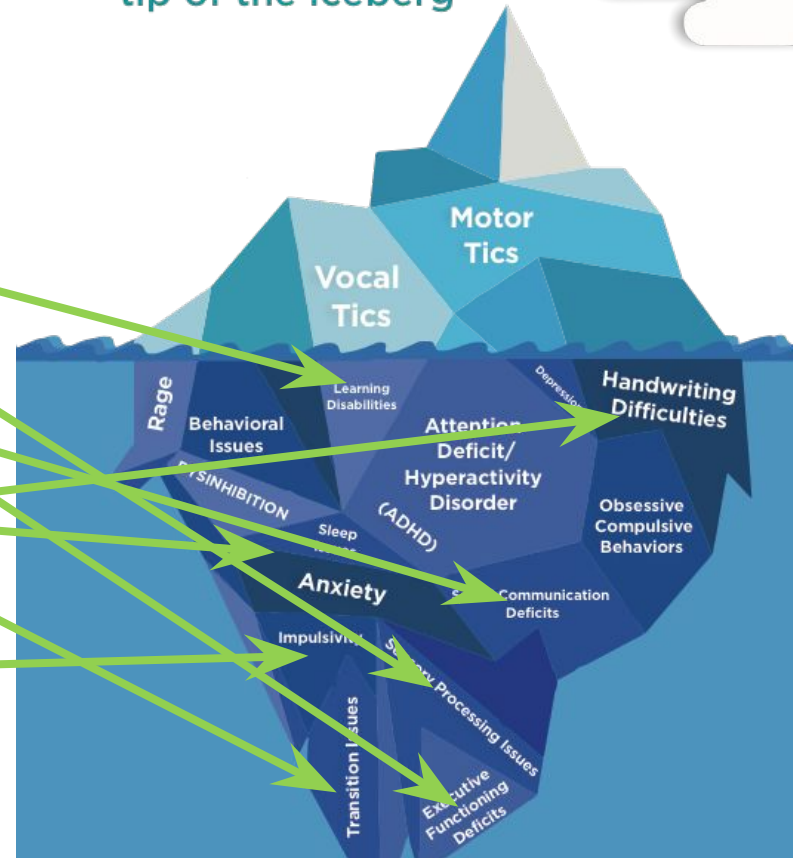
Figure 1. Occupational therapy's domain.

Note. ADLs = activities of daily living; IADLs = instrumental activities of daily living.

(AOTA, 2014)

TOURETTE SYNDROME

Tics are just the tip of the iceberg



(TAA, 2017)



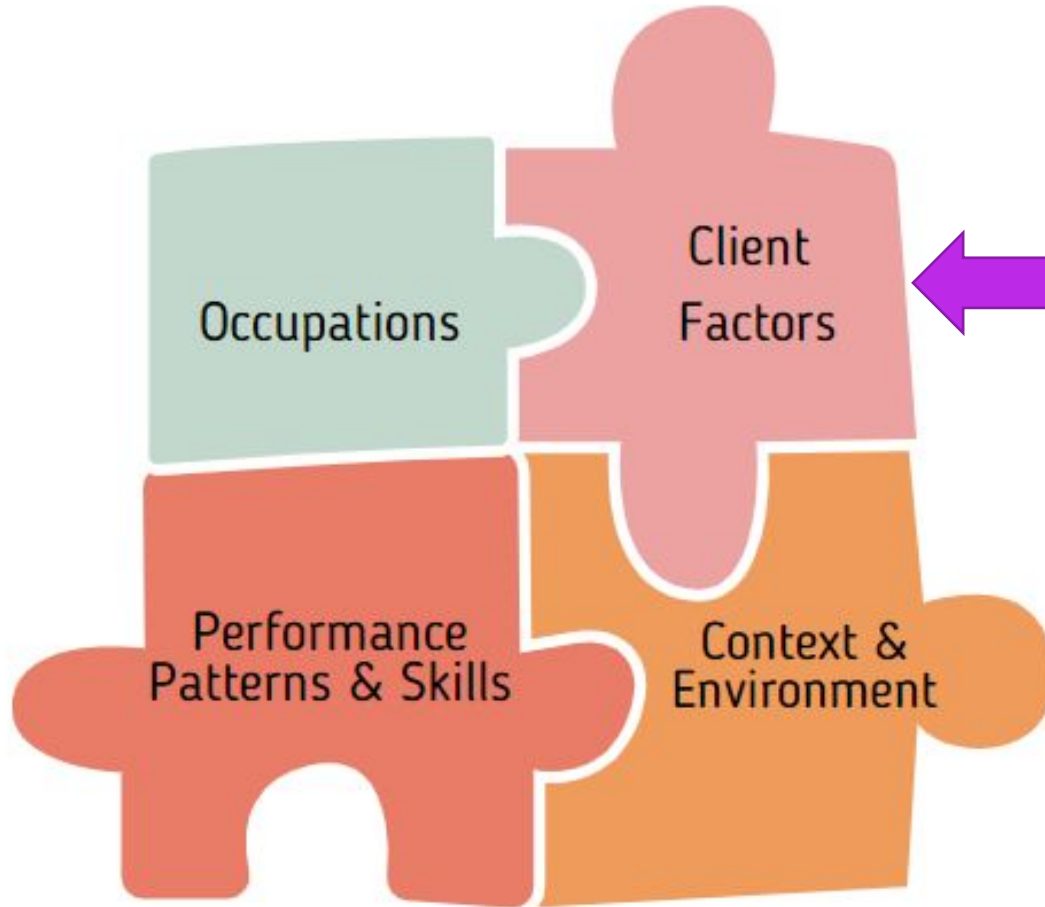
Occupational Therapists in Tic Disorders

Tics impact many occupations and domains that OTs already treat.

	OT	PT	SLP
Executive Functioning	●		●
Sensory Integration	●		
Attention Training	●		
Pain Management		●	
Social Skills & Pragmatic	●		●
Activities of Daily Living	●		
Handwriting	●		
Sleep Hygiene	●		
Assistive Devices	●		
Stuttering			●
Pelvic Health Issues		●	
Incoordination	●	●	
Fine Motor	●		
Gross Motor		●	
Reading Comprehension			●
Dyslexia			●
Vocational Skills	●		●
Oculomotor or Vision	●		
Feeding Aversion	●		
Driving Readiness	●		
Arousal & Impulse Control	●		●

(TAA, 2017)

Client Factors



“Specific capacities, characteristics, or beliefs that reside within the person and that influence performance in occupations”
(AOTA, 2020)

Executive Functioning (EF)

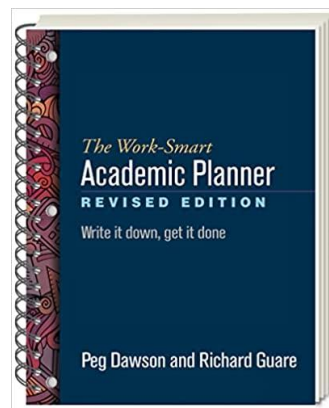
What is EF in Tourette's

- Examples of executive dysfunction in TS
 - Difficulty with organization
 - Difficulty with making decisions
 - Difficulty with problem-solving
 - Difficulty with time management
 - Difficulty with inhibition
 - Difficulty with working memory
 - Difficulty with arousal and emotional regulation
- Children with TS were rated as having clinically significant executive functioning difficulties in the everyday environment compared to their peers

(Hovik et al., 2017)
(Jeter et al., 2015)

How OT Can Help

- Functional training related to:
 - Daily schedule
 - Use of planner
 - Time management



Arousal and Emotional Regulation

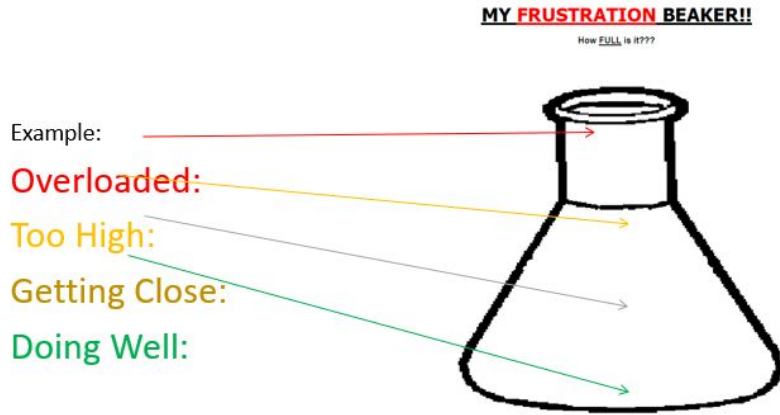
- ~70% of those with TS report difficulty with emotional outburst and difficulty controlling anger
- Related to:
 - Difficulties with executive dysfunction
 - Poor emotional regulation related to the basal ganglia and the frontal cortex
- Children with Tourette Syndrome may demonstrate:
 - “Rage” Attacks
 - Excessive Emotional Outbursts
 - Low Frustration Tolerance
 - Difficulties with peers
 - Self-abusive behaviors (non-tic based)
 - Increased delinquency



Arousal Programs Used in TS

CPRI Leaky Brakes

TS-specific arousal program designed by OTs and psychologists



(CPRI, 2010)

Alert Program

Pilot program with modified 3-session Alert Program and tics demo improvements in YGTSS, PTQ and SP2

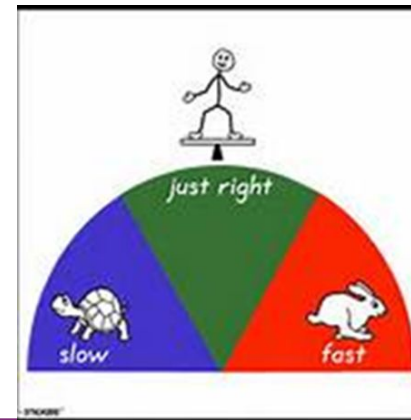


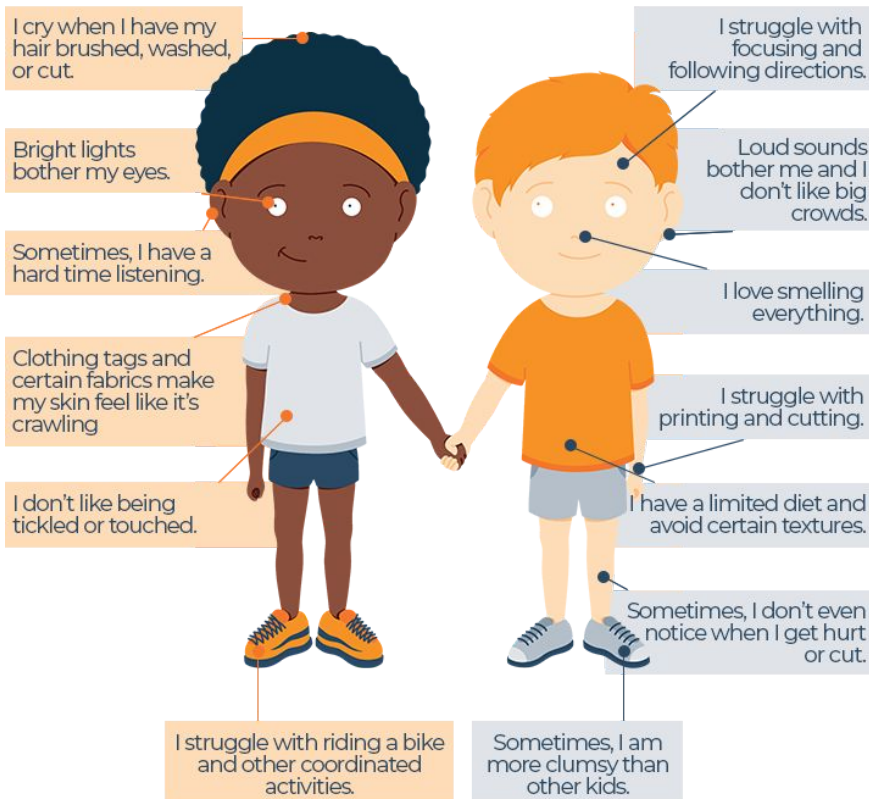
Figure
24

(Williams & Shellenberger, 1996)
(Soler et al., 2019)

Sensory Processing and Tourette

Do You Know Me?

It's hard for me to fall asleep at night and I am often the first one up.



Sensory Processing in Tourette's

- Heightened sensitivity in all senses
 - Particularly with repetitive/constant, faint and external input
- Tactile Sensitivity
 - Hypersensitivity
 - Seeking preference
- Exacerbated by co-occurring conditions

Sign of Sensory Processing Disorder			
Sensory Modulation Disorder	Sensory Discrimination Disorder	Postural-Ocular Disorder	Dyspraxia
<p>Definition: A problem in regulating responses to sensory inputs resulting in withdrawal or strong negative responses to sensations that do not usually bother others.</p>	<p>Definition: A problem in recognizing/ interpreting differences or similarities in qualities of stimuli.</p>	<p>Definition: A problem with control of posture or quality of movements seen in low muscle tone or joint instability and/ or poor functional use of vision. It is often seen with vestibular and proprioceptive problems</p>	<p>Definition: A problem with planning, sequencing & executing unfamiliar actions resulting in awkward & poorly coordinated motor skills typically seen with a sensory processing deficit. It is usually seen with difficulty doing new activities or those that are done infrequently. (May-Benson, Teasdale, & Koomar, 2006)</p>
<p>Common Signs ★</p> <ul style="list-style-type: none"> • Easily distracted by noises • Overly sensitive to sounds • Dislikes nail/ hair cutting • Dislikes clothing of certain textures/ fits/ or styles • Upset about seams in socks • Difficult time falling or staying asleep • Reacts defensively to tastes/ textures of food • Easily distracted by visual stimuli 	<p>Common Signs</p> <ul style="list-style-type: none"> • Jumps a lot on beds • Bumps or pushes others • Grasps objects too tightly or uses too much force • Frequently drops things or knocks things over • Mouths, licks, chews, or sucks on non-food items • Craves movement, e.g. likes to spin self around • Afraid of heights/ swings or slides • Has poor balance 	<p>Common Signs</p> <ul style="list-style-type: none"> • Seems weaker than other children • Fatigues easily • Frequently moves in and out of seat • Slumps while sitting • Difficulty making eye contact/ tracking with the eyes, e.g. reading • Falls and tumbles frequently • Feels heavier than anticipated when lifted • Has flat feet 	<p>Common Signs</p> <ul style="list-style-type: none"> • Problems with daily life tasks like dressing or using utensils • Eats in a sloppy manner • Difficulty following multistep directions • Strong desire for sameness or routines • Has an awkward pencil grasp • Has poor handwriting • Dislikes or reluctant to participate in sports

How OTs Can Help

- + Specialized sensory evaluation
- + Sensory diet
- + Strengthening spatial awareness
- + Reflex Training
- + De-sensitization Therapy
- + Arousal training



<https://yourkidstable.com/sensory-integration-therapy/>



<https://www.theottoolbox.com/how-to-help-kids-with-sensory-issues-with-clothes/>

Sensory & Arousal level

Tic worsening correlated with TOO MUCH or TOO LITTLE sensory stimulation in the environment

Too Much

Overexcitement

Anticipation

Watching TV

Playing video-games

Multi-tasking

Too Little

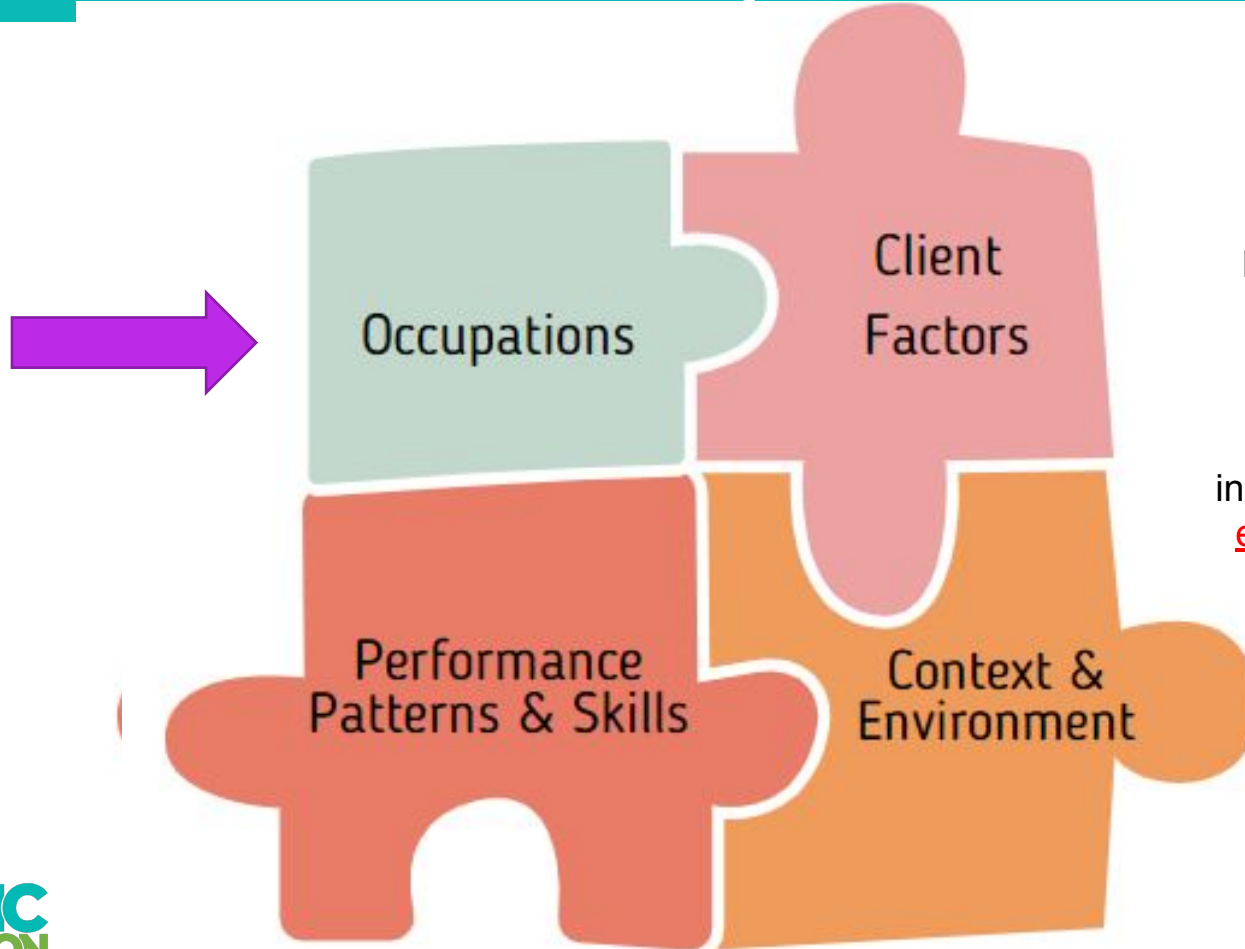
Boredom

Under-stimulation

Trying to fall asleep



Occupations



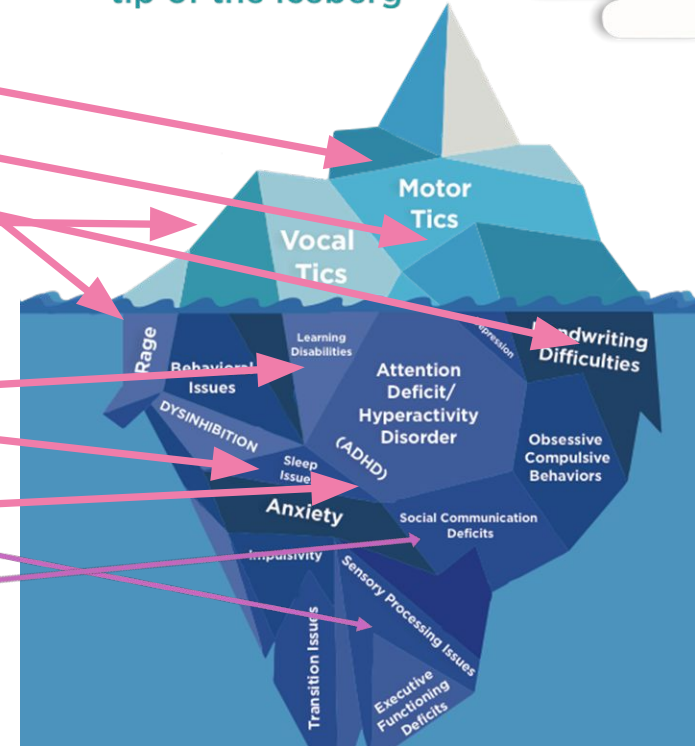
Activities of daily living (ADL) functional performance will vary before, during and after a **waxing** period. Those with tics report significant reported impacted occupations include dressing, rest, sleep, education, play, organized activities and functional mobility. (Liao, 2015)

What are Occupations for Children with Tourette

- ▶ Self-care
- ▶ Driving
- ▶ Handwriting
- ▶ Social and Emotional Health Promotion
- ▶ Symptom and Condition Management
- ▶ Medication Management
- ▶ Sleep
- ▶ Education
- ▶ Employment
- ▶ Play/Hobbies
- ▶ Friendship and Intimate Relationships

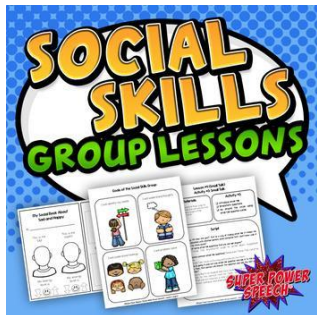
TOURETTE SYNDROME

Tics are just the tip of the iceberg



How OTs Help with Occupations

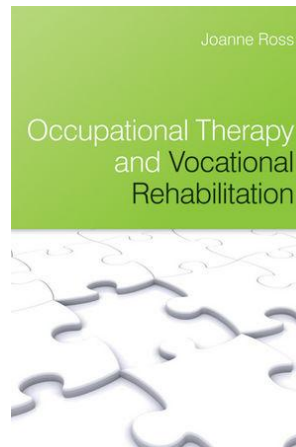
Occupational Intervention and Functional Training is addressed in many ways



<https://www.teacherspayteachers.com/Browse/Search:occupational%20therapy%20social%20skills>



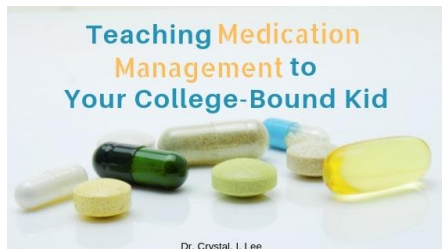
<https://www.altedAustin.com/blog/teaching-driving-readiness-to-young-teens>



<https://www.wiley.com/en-us/Occupational+Therapy+and+Vocational+Rehabilitation-p-9781118709764>

Shoelace tying!	
	Spread laces out wide
	Use your nipper fingers
	Cross one lace over and loop one under the hole
	Pull each side of the lace tight. You have made your first knot.
	Hold the lace in the middle and then bring it back to the centre. Make one bunny ear.

<https://fremantlecd.wa.edu.au/occupational-therapy-news-shoelace-tying/>



Dr. Crystal, I. Lee

<https://laconciergepsychologist.com/blog/teaching-medication-management-to-your-college-bound-teen/>



<https://www.youtube.com/watch?v=-rg7FVpJ3yI>



Handwriting Skills

Handwriting in OT

Dysgraphia in TS has many components

- Impaired postural control
- Motor planning & coordination (sensory-based)
- Oculomotor skills
- Mild visual-motor deficits
- Increased handwriting time, case substitution errors
- Tics that physically occur with handwriting

How OTs Can Help

- + CBIT for handwriting tics
- + Dysgraphia training
- + Strength training
- + Adaptive strategies/assistive technology

Four men and a jolly boy came out
of the black and pink house quickly to
see the bright violet sun, but the sun
was hidden behind a cloud.

Four men and a jolly boy came
out of the black and pink
house quickly to see the bright violet
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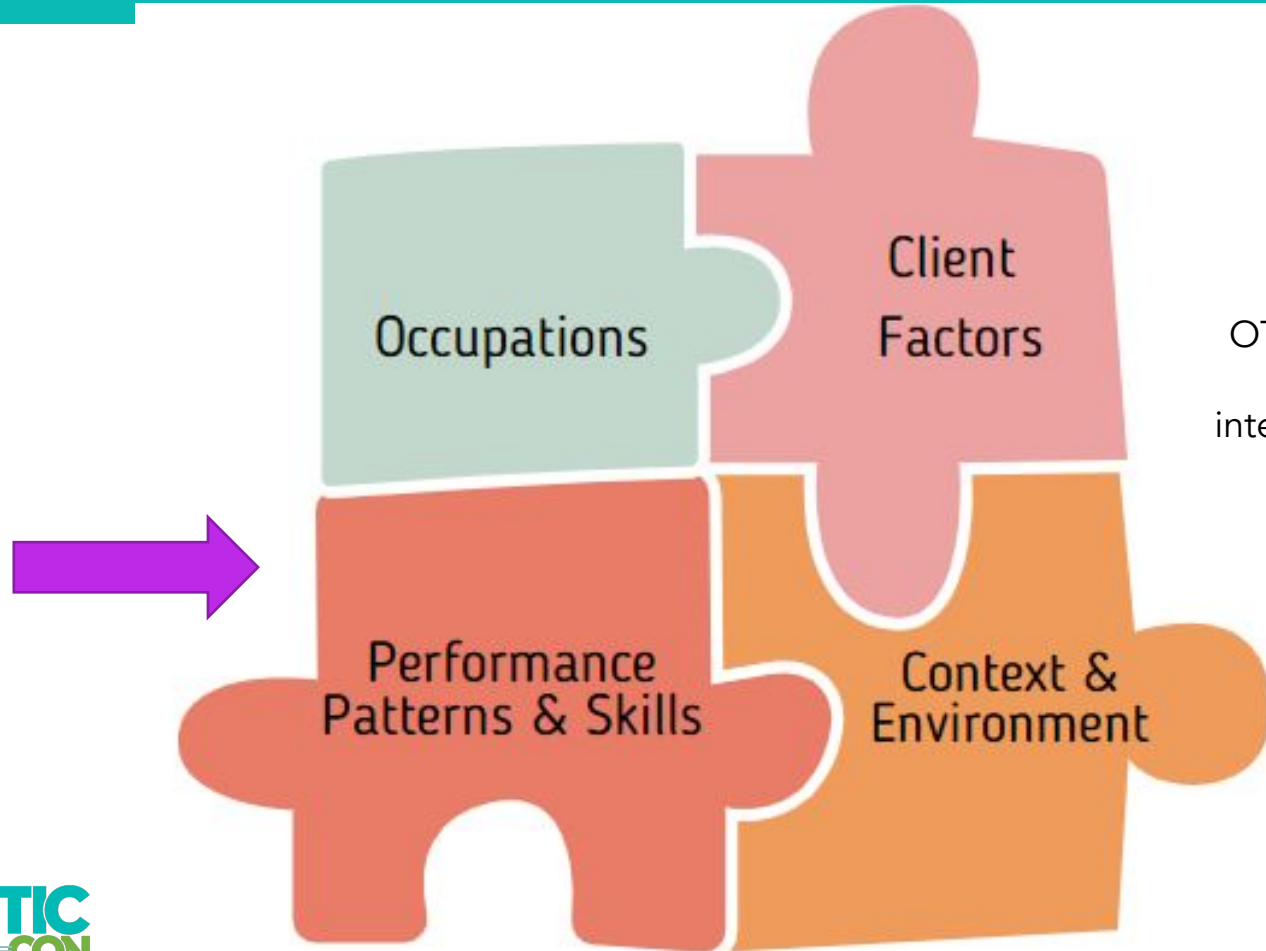
(Liao, 2015)

(Sulkowski, McGuire & Tesoro, 2016)

(Zanaboni et al., 2016)

(Simpson et al, 2020)

Performance Patterns & Skills



OTs can address the biological changes of TS through intervention of performance skills & patterns (Liao, 2015)

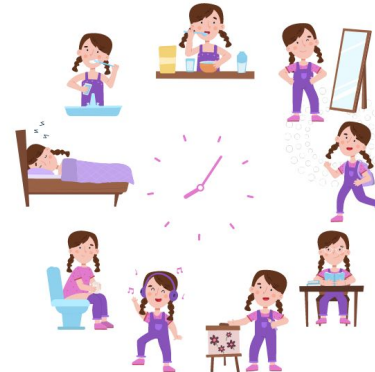
Daily Routine Management

Routine and Tics

- Structure allows for decreased exacerbation of tics due to the:
 - Decreased stress
 - Decreased anticipation of the unknown
 - Improved transitions
 - Improved executive functioning & planning

How OTs Can Help

- Daily Schedule
- Visual Schedules
- Healthy leisure exploration



<https://www.brilliantmindspsychology.com.au/occupational-therapy/>

(Eaton et al., 2017)

2023 TIC-CON | touretteconference.org

Assistive Technology

What is Assistive Technology

“any item, piece of equipment or product system whether acquired commercially, modified, or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities.”



(Goodrich & Garza, 2015)



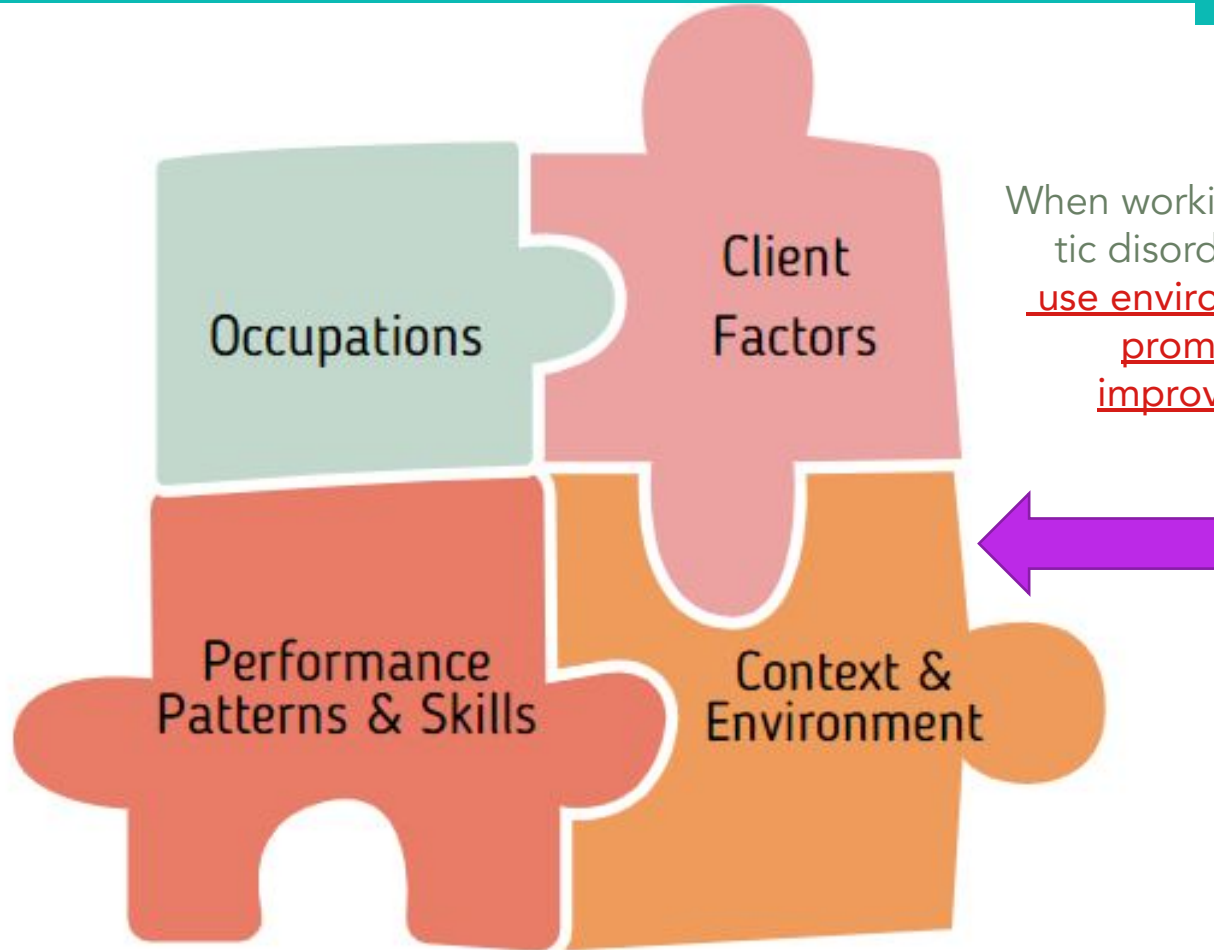
How OTs Can Help



https://youtu.be/6M_OVN0qmF8



Context and Environment



When working with those living with tic disorders, it is important to: use environmental modifications, promote resilience and improve the quality of life

Environmental Factors Related to Tics

Influence of Environmental Consequences & Internalizing Symptoms on Children's Tic Severity

Eaton et al., 2017; Herrmann et al., 2019; Iverson & Black, 2022

	Antecedents	Consequences
Internal	<ul style="list-style-type: none"> • Urge • Loneliness • Acute Stress • Anxiety • Thinking About Tics • Boredom • Fatigue • Paying attention to tics • Feelings of: <ul style="list-style-type: none"> ○ Anticipation or excitement ○ Fear ○ Sadness ○ Anger/frustration 	<ul style="list-style-type: none"> • Relief of the urge • Holding in the tic • Being aware of being observed
External	<ul style="list-style-type: none"> • Watching TV • Playing video games • Socialization • Holidays • Returning to school • Physical restraint (not being able to use body in the way you want to) • Anticipation of social events • Sudden loud sounds • Fear conditioning procedures (trauma situations, needles, etc.) • Loss of sleep • Activities that engage or promote Overstimulation or understimulation • Social Conflict 	<ul style="list-style-type: none"> • Attention to tics <ul style="list-style-type: none"> ○ Being told to stop ticcing ○ Receiving attention from others when ticcing <ul style="list-style-type: none"> ▪ Laughing, starting • Allowing child an opportunity to escape typical responsibilities when exhibiting tics • Being allowed to take breaks from tasks they were completing while ticcing • Being asked to leave are while ticcing

Tic
Severity



Things that have been shown to IMPROVE tics: rewards for tic management, musical performance and exercise



Tourette Syndrome At School Review

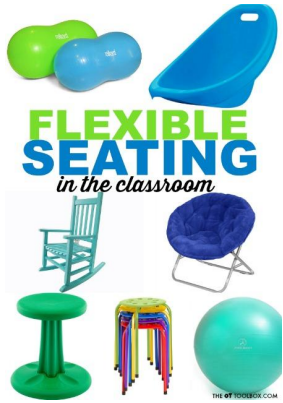
- Academic difficulties associated include:
 - School work more difficult due to tics
 - Mental fatigue
 - Negative response from staff or peers
 - Difficulties managing emotions
 - Difficulties with concentration
 - Difficulties with specific school activities including:
 - Homework
 - Exams
 - Handwriting
 - Anxiety
 - Managing anger
 - Speaking in class

80% of children felt that tics negatively impacted their school experience



(Wadman, Tischler, & Jackson, 2013)
(Evans, Seri & Cavanna, 2016)
(TAA, 2022)

OTs Role in the School



<https://www.theottoolbox.com/flexible-seating-in-the-classroom/>

- Important providers within the education support team
- Support a student's ability to participate in desired daily school **OCCUPATIONS** and **ROLES**
- Can be incorporated into 504 plan/IEP
- Aid learning through promotion of “positive behaviors” and adaptive skills needed to have academic success
- Assist in school-based intervention to improve knowledge of TS of peers & teacher

Occupational Therapy Tips
for Homework Success



(AOTA, 2013)
(Eapen et al., 2016)

Summary

Getting Plugged In

+ **WHERE** CAN I GET OCCUPATIONAL THERAPY?

Occupational therapy practitioners work in a variety of settings

- + Hospitals/health care facilities,
- + Schools,
- + clinics,
- + Community centers
- + Home health
- + skilled nursing facilities

+ **HOW** DO I SCHEDULE AN OCCUPATIONAL THERAPY VISIT?

Ask your physician about a referral for occupational therapy services

Talk to your child's teacher about the need occupational therapy services at school

+ **FIND** out more

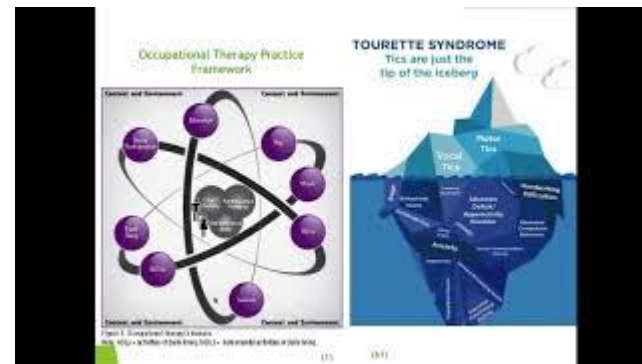
American Occupational Therapy Association

<http://www.aota.org>

What if You Are an OT?

- Stay informed: Don't be scared or shy away from treating kids (or adults) with tics
- Address the co-morbid conditions (ADD, anxiety, OCD, executive functioning deficits)
- Facilitate eligibility for a 504 plan or an IEP when Tourette impacts the educational environment
- Functional Assessment and environmental modifications
- Set-up family with resources and support
- Troubleshoot before problem occurs
- **ADVOCATE**: The public misunderstands this disorder and labels as **BAD BEHAVIOR**
- Consider getting CBIT certified

Resources



Benefits of Occupational Therapy for Tourette Syndrome

Ask the MAB

Jan Rowe, Dr. OT, OTR/L, FAOTA is Coordinator, Tourette syndrome and Tic disorders program at Children's of Alabama and is a member of the TAA Medical Advisory Board.



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