Psychological interventions for tics

Dr. Eve McAllister
Tic Disorder Service, Great Ormond Street Hospital
Plan

• Discuss views of children and parents with tics

• European clinical guidelines on psychological interventions for Tourette syndrome and other tic disorders

• Psychological treatments for tics
  • Psychoeducation
  • Behavioural interventions for tics
    • Habit Reversal Therapy/Comprehensive Behavioural Intervention for Tics
    • Exposure and Response Prevention
Perceptions of treatment for tics

• Online survey with parents and individual interviews with young people in UK (Cuenca et al, 2015)
  • N= 295 parents
  • N= 42 interviews with young people

• Medication common
  • 54.8% young people interviewed had taken medication for tics (median 1, range 1-5)
  • 54.7% of parents in survey mentioned that their child had taken medication for tics

• Access to behavioural interventions for tics was limited
  • 19.0% young people interviewed had received some form of behavioural treatment for tics
  • 25.9 % of parents in survey
Need for access to informed and expert care:

‘Perceived lack of understanding of TS among health professionals’

• Health professionals have insufficient knowledge to recognise TS
• Professionals have limited training in providing adequate treatment
• Children had to attend different health services to receive treatment for tics because many of the services they visited had a poor understanding of their condition.

“...most of the places we have been to about my Tourettes like it seems like no one actually knows about it, like we know more than them... when we go there they usually ask us about it more than we ask them”
‘Accessing or maintaining care’

Difficulties in receiving specialist treatment:

- Delays
- Cancellations
- Insufficient funding
- Little or no information about TS and tics from their health professionals

‘Importance of receiving informed specialist care’

Young people who had received specialist advice spoke about:

- Feeling understood and more confident
- Considered that knowledgeable health professionals could help them to better understand their condition.
Medication

‘Concerns and limitations about taking medication for tics’
- Adverse effects or limited impact: Young people reported side effects (e.g. drowsiness, tiredness, weight gain)
- Parents’ shared young people’s concerns regarding adverse effects of medication.
- 46% of parents felt that the drug had mod or severe adverse effects.

‘Positive experiences of medication for tics’
- Positive effects were noted amongst young people in relation to gaining more control over tics
Positive experiences and perceptions of Behavioural interventions

‘Bl are a ‘natural’ intervention that could be incorporated into daily life’

‘Positive experiences of behavioural interventions for tics’

“...it took me a while but now it works more... I don’t have to think oh I must bite my lip I just do it without thinking, but at the time I was just like oh this isn’t going to work but it got better.”

‘Perceived potential helpfulness of behavioural interventions for tics’

Seems to involve learning and practising behaviours similar to those they have used to control their tics
Negative experiences and perceived challenges

‘Negative experiences’
Some young people felt that it was difficult to execute competing responses for motor or vocal tics or in one case that this led to a substitution of tics

‘Perceived potential challenges of behavioural interventions for tics from those who have not accessed these’
Take long, considerable effort from their part or much support from others
Key findings

• Young people with TS and parents have had difficulties getting a diagnosis of TS and appropriate information

• Most parents would like behavioural tic treatments for their child (76% of parents in survey)

• There is limited availability of behavioural tic treatments

• Results of the parent survey and the interviews with young people suggest that many children may not receive sufficient “dose” of behavioural intervention (>5 sessions)

• Young people hold positive perceptions of behavioural tic treatments as ‘natural’ interventions

• Young people who hold negative perceptions of behavioural interventions seem linked to the motivation and effort needed to practise the treatment, rather than to adverse effects
What do patients know and prefer? USA


- Survey among 672 TS adults and 740 parents of TS children
- 83% of TS adults and 76% of TS children had not received BT

- A lack of knowledge of what BT is and where to find this treatment
- A lack of trained therapists
- Concerns of negative effects of BT, such as rebound following suppression and development of new tics (misconceptions)
What do patients prefer and get?

Verdellen & Van de Griendt (2014)

Survey among Dutch TS adults (n=55) and parents of TS children (n=88)

74% (n=41) of adults and 84% (n=74) of children received treatment for tics.

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<tr>
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<th>What do you want?</th>
<th>What do you get?</th>
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| **Children** | Behavior therapy (76%)  
Medication (11%) | Behavior therapy (41%)  
Medication (49%) |
| **Adults**   | Behavior therapy (54%)  
Medication (19%) | Behavior therapy (38%)  
Medication (58%) |
Ideas moving forward

• Increase professionals knowledge in relation to tics and TS

• Provide children and families with access to information and psychoeducation about tics

• Increase availability of behavioural tic interventions/train more professionals

• Challenge misconceptions about behavioural interventions, e.g. regarding effort, rebound or tic substitution (Scahill L et al. 2013)
European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part II: psychological interventions


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First steps in CAMHS input

• Comprehensive CAMH assessment and diagnose tic disorder and other co-occurring disorders if present

• Provide psychoeducation about tics to young people and families

• Offer treatment of co-occurring disorders
Direct to appropriate self-help resources and organisations (e.g. Tourettes Action)
Psychoeducation through focused meetings & direct teaching at school

Child and Adolescent Mental Health

Does it help to talk about tics? An evaluation of a classroom presentation about Tourette syndrome

Claire Nussey, Nancy Pistrang, Tara Murphy


Abstract

Background

Tourette syndrome (TS) is a poorly understood condition characterised by motor and vocal tics. It may affect children’s social functioning at school. This study examined the impact of a psychoeducational intervention (classroom presentation) from multiple perspectives.
Forms of PE

• Documentaries
Psychoeducation: What we offer to families

• Information about tic disorder is shared with the child and their family verbally at assessment.

• Parents are informed about sources of psychoeducation and support

• Children and their parents are offered the opportunity to attend a psychoeducation group
Remote Tourette’s syndrome psychoeducation session

- 120 minute remote session for young people and their families

Run monthly (primary and secondary ages)

- 10-12 families invited

Aim to make it as interactive as possible
Content of the group

• providing information about tics
• supporting young people and parents to feel confident in talking about tics
• promoting resilience and discussing positive role models with tics
• answering young people and parents’ questions
Example of info from the group
For lots of people (not everyone) tics will follow this pattern.....
Stars in their field ✔️ Got tics ✔️
Key strategies

• Educate everyone

• Practice your ‘I have tics phrases’

• Remind everyone: ignore and avoid commenting on tics

• Get smart on seating
I have Tourette syndrome. This is a medical condition which means I make noises and movements that I can’t help. I’m sorry if my tics cause you any offence. I would be grateful for your understanding and empathy. If you would like any more information about Tourette syndrome, you can visit:

https://www.gosh.nhs.uk/medical-information/search-medicalconditions/tourettesyndrome/tourettesyndrome-information-pack
Behavioural interventions for tics

When psychoeducation alone is insufficient, then behavioural tic treatments are recommended as first line interventions:

- Comprehensive Behavioural Intervention for Tics (HRT)
- Exposure and Response Prevention
Behavioural tic treatments

The rationale for using BT for treating tic disorders is based on the fact that tics can be suppressed for various lengths of time. Factors that can influence tics include:

- Premonitory urges (tic alerts)
- Internal (e.g. emotional) states
- Environmental factors (e.g. specific situations or activities, stress-inducers, social reactions)

The goal of behavioural therapies is to provide tic-specific behavioural techniques to enhance self-control and decrease factors that worsen or maintain tics.
Who provides behavioural tic treatments:

- Often these are provided by clinical psychologists and CBT therapists with expertise in behavioural interventions in CAMHS teams or specialist services

What do they involve:
- 8 or more sessions have been recommended for CBIT
- 12 for exposure and response prevention (ER)
What we currently offer?

- Online psychoeducation groups
- Online exposure with response prevention groups
- Individual CBIT/HRT or ERP for Tics in person or online
- Consultation with local therapist delivering behavioural tic treatments
Which children are they suited to?

• Children who are bothered by their tics and want to learn strategies to gain greater control over them

• Children and families who will be able to engage in the practice tasks

• Children with classic tics (limited evidence re usefulness for children with functional tics)
Behavioural tic treatment manuals

Managing Tourette Syndrome: A Behavioral Intervention for Children and Adults Therapist Guide
Douglas W Woods, John Piacentini, Susanna Chang, Thilo Deckersbach, Golda Ginsburg, Alan Peterson, Lawrence D Scahill, John T Walkup, and Sabine Wilhelm

Cara Verdellen, Jolande van de Griendt, Sanne Kriens, Ilse van Oostrum
Habit Reversal Training (HRT)

- **Theory:**
  - Awareness of the tic
  - Incompatible response to interrupt or prevent the tic

- **Intervention:** multi-component (Azrin & Nunn, 1973; CBIT Woods et al., 2008)
  - Awareness training
  - Training the incompatible response
  - Relaxation training
  - Social support
  - Generalisation
Does HRT work?

Several Randomized Controlled Trials:

- HRT > Wait List (WL), Massed Practice (MP), Supportive Therapy (SP)
  - Azrin & Peterson, 1990 (WL; N=10)
  - Azrin, Nunn, & Frantz, 1980 (MP; N=22)
  - Wilhelm ea, 2003 (ST: N=32)
  - Deckersbach ea, 2006 (ST: N=30)
  - Piacentini, Woods ea, 2010 (CBIT-ST: N=124)
  - Wilhelm, Peterson ea, 2012 (CBIT-ST: N=122)

- HRT = HRT + Cognitive Behavioural Treatment (CBT)
  - O’Connor, Gareau, & Borgeat, 1997 (N=14)

- HRT = HRT + Acceptance and Commitment Therapy (ACT)
  - Franklin, Best, & Wilson, 2011 (N=13)
Does HRT work?

- HRT = Exposure and response prevention (ERP)
  - Verdellen, Keijsers, Cath, & Hoogduin, 2004 (N=43)

- Group HRT > PsychoEducation (PE)
  - Yates, Edwards, King, Luzon, Evangeli, Stark, McFarlane, Heyman, Ince, Kodric & Murphy, 2016 (N=33)

- Behaviour Therapy (BT) > PE
  - Rizzo, Pellico, Silvestri, Chiarotti & Cardona, 2018 (N=110)

- Group HRT/ ERP = individual HRT/ERP
  - Nissen, Kaergaard, Laursen, Parner & Thomsen, 2019 (N=59)
Comprehensive Behavioural Intervention for tics / Habit Reversal Training

- Tic Description
- Awareness Training
- Competing Response Training
- Social Support
- Functional analyses
- Motivational strategies
Make a Tic Hierarchy

- Use the YGTSS list of tics
- Select the **most bothersome** tic from the list
- Understand why it is bothersome to the patient
Tic Description

➢ Purpose

  • Ensure therapist and patient are clear on the tic
  • Process

Get the patient to describe the tic in a high level of detail

Where is the urge?

What happens first?

Then what happens?

Have we missed anything?
Tic Detection

- Therapist simulated practice (if necessary)

- Client practice
  - Client tics → client acknowledges → Praise client
  - Client tics → client doesn’t acknowledge → prompt
  - Continue until at least 80% correct

- Have client simulate tics if s/he is not ticcing

- Practice these procedures following the urge
Competing Response Training

- **Purpose**
  - A behaviour to do that is physically incompatible with the tic or that allows the person to do something while they do not tic

- **Three techniques**
  - Choosing the Tic blocker
  - Therapist tries competing response
  - Patient practices competing response to mastery
Choosing the Tic Blocker

- **5 Rules -**
  1. Incompatible w/ tic
  2. Less socially noticeable than the tic
  3. Patient can **do CR almost** anywhere
  4. **Maintain** CR for longer than one minute
  5. Use **no props** (‘naked in the desert’)

- **Choosing a TB should be a decision b/w patient and therapist**
Tic Blocker for Motor tics

- Shoulder-Jerking
  - Shoulders Depressed

- Head-Shaking
  - Tensing Neck

- Shoulder-Jerking
  - Shoulders and Hands Pressure

- Elbow-Flapping

- Head-Jerking
  - Tensing Neck
## Vocal tics

<table>
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<tr>
<th>Sounds</th>
<th>Breath in and out through the nose without a pause</th>
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<tr>
<td></td>
<td>Whistle</td>
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<tr>
<td></td>
<td>Swallow</td>
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| Sniffing              | Breath in and out through the mouth without a pause |

| Cursing               | Breath in and out through the nose without a pause; hold lips tight |
|                       | her                                                 |
Therapist demonstrates tic blocker

- Therapist demonstrates action to patient
- Patient correctly implements to mastery
  - Contingent on tic urge or warning sign
  - Held for 1 min or until urge goes away, whichever is longer
Patient Practices

- Have patient demonstrate tic blocker and provide corrective feedback
- Have patient practice implementing tic blocker contingent on actual tic (or simulated tic)
- Therapist should prompt and praise as appropriate
Helpful tips

- Work towards generalisation: go to park; visit a shop; play games in session; read a book; look at the computer
- Build a hierarchy of places where the child is motivated to control their tics.
- Start with the easiest places and work through the hierarchy
- Train the parent as you train the child
- List to the patient and hear what they find works well for them
- Eye tics are hard to treat
Concerns about HRT?

- Onset of new tics HRT / PS
  - 1.25 new tics in each group
- Adverse outcomes
  - No difference between groups
- Worsening of co-occurring conditions
  - No difference at EoT, CBiTS fewer symptoms at 6 months
    (Peterson et al, 2016; Behavior Therapy)
- Patient groups concerns around ‘tic suppression’

**BT is for mild tics only**

Success is reported in mild and severe tics/TS cases
(Piacentini et al., 2010; Verdellen et al., 2004; Wilhelm et al., 2012)
What is exposure and response prevention

• Young person is exposed to their tic-alert (premonitory urge) whilst controlling their tics

• They practice not ticcing when they have the urge to tic in sessions and at home with parents

• As they become more skilled at ERP this is made increasingly challenging through introducing tic triggers
ERP: The cycle of tics

URGE (ITCH) → TIC (SCRATCH) → RELIEF

[Diagram showing the cycle with an insect illustration and a prohibition symbol]
Inhibitory learning
Video of ERP
What we cover in the ERP group

• Recap on psychoeducation about tics
• Explain exposure and response prevention
• Provide opportunities to practice
• Support young people to practise with their parents at home
• Build motivation and confidence in regards to tic practice.
• Increase a young person’s ability to control tics when exposed to ‘tic triggers’ that make them want to tic
Involving parents and children:
Work with children to set achievable goals in the group alongside their parents.

ERP: Set goals

**GOALS!**
WHAT DO YOU HOPE TO GET FROM COMING TO THE GROUP?
Goals

Better control tics

Increase confidence about tics

To be able to control tics in a certain situation (e.g. in school or when playing football)
ERP: Discuss aims and possible outcomes

• Over the next few sessions we will teach you the skills to manage tics when you want.

• Evidence has shown that this approach helps to reduce tics by up to 40-50% when young people do lots of practice. Like any skill this takes practice but don’t worry we will call you to help you build your skills.
Help young people understand that learning ERP requires practice
MYTHBUSTING

• If I control tics then they rebound and get worse when I stop controlling

• If I control tics then new tics will come in their place

• ERP only works for mild tics
Practicing response prevention

TRY AND STOP ALL YOUR TICS
IF YOU EXPRESS THE SAME TIC 3x IN A ROW:
FOCUS ON ONLY THAT TIC UNTIL YOU CAN CONTROL IT FOR 5 MINS THEN GO BACK TO CONTROLLING ALL TICS

https://www.timeanddate.com/stopwatch/
Exposure and Response Prevention

• The key ingredient in ERP is tolerating the urge while you control your tics.

• With practice this will get easier

• We are going to get you to make the tic alert (also known as the urge) really strong until you get used to the feeling without ticcing

• We are working on all tics at the same time rather than one at a time
Involving parents

Have parents as co-therapists

Discuss and support them in their role as coach and cheerleader
HOW DID LAST WEEKS PRACTICE GO?

- Any personal records broken?
- What went well?
- Anything that was hard?

HOW YOU CAN KEEP YOUR CHILD MOTIVATED

- Link practice to their future goals regarding tics e.g. if you practice now you will find it easier when answering a question in class.
- Use lots of praise and encouragement – remember it is really difficult.
- Don’t force your child to practice – negotiate times for tic practice.
- If you spot your child practising at other times, point this out to them subtly and show them that you are proud of them.
- Consider the use of rewards or things which may motivate your young person.
Tic Triggers

• What have you noticed makes your tics less or more frequent?

• Any surprises?

• Can you rank the triggers?

• Discuss in small groups what makes the tic signal stronger.
Some of the most common TIC triggers are...
EXAMPLE OF A TIC TRIGGERS LADDER?

1. Practising ERP without talking
2. ERP whilst talking about my tic urges
3. ERP whilst others are ticcing or acting out tics
4. ERP in a noisy place whilst talking about tics
5. ERP whilst in a lesson I find difficult
Involving children

• Getting inventive when increasing the level of difficulty. Some things we have tried:
  • Children in group/therapist acting or saying a tic whilst the child resists
  • Using a mirror. Having self view off or on using this zoom function
  • Answering times tables
  • Playing guitar whilst on zoom with others listening

NEXT LEVEL CHALLENGE...

★ Practice ERP in breakout rooms
Involving children

PRAISE AND ENCOURAGEMENT

SURPRISE THEM—WHAT DID THEY THINK THEY WOULD BE ABLE TO DO AND WHAT COULD THEY DO

PRAISE MUTUAL SUPPORT

PREPARE FOR PERSONAL BEST TIMES TO DROP DURING PERIODS WHEN TICS ARE AT A PEAK OR WHEN INCREASING THE LEVEL OF DIFFICULTY
ERP in triggering situation
Why have we been offering ERP in groups

ERP addresses multiple tics simultaneously in contrast to HRT/CBITs, which treat one tic one at a time.

- Those accessing our clinic tend to present with more severe symptoms and multiple varied tics.
- Treatment effects of ERP for tics are comparable to that of HRT (Verdellen et al., 2004)

Why group format?

- to access as many children as possible.
- Opportunities for children with tics to meet and work with other children
- There is preliminary evidence that ERP can be effective in a group format (Heijerman-Holtgrefe et al. 2020)
- Own pilot data showed high attendance rate and positive outcome
Problem solving

Child doesn’t seem as engaged in behavioural tic treatment?

Questions to think about:
• Are tics bothering the child at present?
• Do they understand the approach?
• Who are the tics a problem for?
• How is practice going in sessions and at home?
• Is it currently a challenging period for tics?
• Are they having challenges in engaging due to mode of delivery (group/online)?
• Are other challenges more of a priority?
Training opportunities

Psychoeducation Day on Tourette Syndrome

FOR NHS TRUSTS AND CLINICIANS

A 1-day training course for professionals from disciplines such as Psychology, Nursing, Occupational Therapy, Psychiatry and Neurology.

Booking Information:
Per Delegate: £150

This training is for professionals working with children and young people with tics. The course will include a wealth of material frequently used to provide psychoeducation to young people and their families.

The course contains a review of the literature, background information on Tourette syndrome, including symptom trajectory and management, practical materials to help attendees discuss the condition with young people and their families.

For queries, please contact:
PGME.Education@gosh.nhs.uk

Behavioural Treatment for Tics (CBIT)

FOR NHS TRUSTS

A 2-day training course for professionals from disciplines such as Psychology, Nursing, Occupational Therapy, Psychiatry and Neurology.

Booking Information:
Per Delegate: £210

The course will include theoretical approaches and practical training in Exposure and Response Prevention (ERP) and Habit Reversal Therapy (HRT) as behavioral treatments for Tourette syndrome.

Included in the training is the opportunity for two online group consultation sessions where clinicians can bring cases for discussion and reflect on ways to further improve the delivery of treatment. The supervision will need to be completed within 6 months of the training.

For queries, please contact:
PGME.Education@gosh.nhs.uk
Books

For adults and professionals:

• Tic Disorders: A Guide for Parents and Professionals – Uttom Chowdhury and Tara Murphy
• Challenging Kids, Challenged Teachers: Teaching Students with Tourette’s, Bipolar Disorder, Executive Dysfunction, OCD, AD/HD and More - Leslie E. Packer
• A Family's Guide to Tourette Syndrome – John T Walkup, Mink, Black et al
• An Unlikely Strength: Tourette Syndrome and the Search for Happiness in 60 Voices Paperback by Larry Barber
Books

For young people:

- I Tic – Abby Hargrove (6 yrs +)
- Can I tell you about Tourette syndrome? - Mal Leicester (recommended 9 yrs +)
- The Tourette’s Survival Kit: Tools for Young Adults with Tics - Tara Murphy and Damon Millar. (15 yrs +)
- Nix your tics – B. Duncan McKinlay (15 yrs +)
- Welcome to Biscuit Land: A Year in the Life of Tourettes hero – Jessica Thom, a YouTuber with Tourette’s Syndrome (adults)
- Coping with Tourette Syndrome: A Workbook for Kids with Tic Disorders – Sandra Buffolano (workbook, 10 yrs +)
Resources for Clinicians

Books

• The Clinician's Guide to Treatment and Management of Youth with Tourette Syndrome and Tic Disorders 2018 by Joseph F. McGuire et al

• Managing Tourette Syndrome: A Behavioral Intervention for Children and Adults Therapist Guide 2009 by Woods and Piacentini

• Tics - Therapist Manual & Workbook for Children by Verdellen et al 2016

Great Ormond Street Hospital Specialist clinic have drawn together a comprehensive Tourette syndrome information pack

www.gosh.nhs.uk/medical-information/search-medical-conditions/tourette-syndrome/tourette-syndrome-information-pack
Useful resources for professionals

• Join European Society for the Study of Tourette Syndrome
• Specialist list for Tourette Action / Tourette Scotland
• Sign up for the NeuroDiverse Newsletter https://tinyurl.com/bzd57n9f
• TAA webinars
  • https://tourette.org/resources/taa-webinars/
• ACAMH podcasts
  • https://www.acamh.org/blog/tics-and-the-pandemic/
Websites

Tourette associations of American, Canada and the Uk-based Tourette action

https://tourette.org/resources/overview/

https://tourette.ca/about-tourette-syndrome/questions-answers/

https://www.tourettes-action.org.uk/64-resources.html
Thank you: Questions