Tics disorders: a MDT Perspective and Pathways for care

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Overview of Talk

• Why an MDT?
• What would an MDT look like?
• Pathways
• Current and future work
• Can you put your professional background in the chat please.
DSM – 5 Classification

- Neurodevelopmental disorders – motor disorders
- Onset before age 18 years, not due to any other medical condition/substance

- Provisional tic disorder
  - Tics less than one year

- Persistent motor/vocal tic disorder
  - Either motor or vocal tics for more than one year

- Tourette’s disorder (TS)
  - At least two motor tics and one or more vocal tics at least one year
  - Often other symptoms and comorbidity

- Tic disorder not otherwise specified
  - Criteria are not met for one of the specific tic disorders
  - E.g., onset >18 years
ICD – 11 Classification

• Disease of the Nervous system

  Motor Disorders

• 8A05.0 Primary tics or tic disorders
  • In order to be diagnosed as Tourette syndrome, both motor and vocal tics must have been present for at least one year, although they may not manifest concurrently or consistently throughout the symptomatic course.

  • Kept the terms ‘chronic’ and ‘transient’
Percentage of children with and without Tourette syndrome and another mental, behavioral, or developmental disorder.

Compulsive tics/tic-like behaviours and impulsive tics
Self-injurious behaviours
Quality of life in TS
OCD and ADHD
Autism spectrum disorder
Rage attacks
Neuropsychological impairments
Other hyperkinetic movements (e.g. dystonia, myoclonus and chorea)
Stereotypies
Functional movement disorders and vocalisations
Somatic conditions
PANS/PANDAS
Functional tics (FND)
Other areas to consider

- Sleep (Ricketts et al, 2018)
- Pain (Malek et al, 2022)
- Headache (Ghosh, 2015)
- Allergies (Huang et al, 2022)

- High rates of psychopathology in mothers (25%) and fathers (18%) (Leivone et al, 2017)
What is the impact?

How tics effect:

Difficulties experienced by young people with Tourette syndrome in secondary school: a mixed methods description of self, parent and staff perspectives

Ruth Wadman 1, Cris Glazebrook 2, Charlotte Beer 3, Georgina M Jackson 4

Association of Tourette Syndrome and Chronic Tic Disorder With Violent Assault and Criminal Convictions

David Mataix-Cols, PhD, Suvi Virtanen, PhD, [...], and Antti Latvala, PhD

The effects of Gilles de la Tourette syndrome and other chronic tic disorders on quality of life across the lifespan: a systematic review

Jose Evans, Stefano Seti, and Andrea E. Cavanna

Association of Tourette Syndrome and Chronic Tic Disorders With Objective Indicators of Educational Attainment

A Population-Based Sibling Comparison Study

Ana Pérez-Vigil, MD, Lorena Fernández de la Cruz, PhD, [...], and David Mataix-Cols, PhD
Suggested management algorithm for children with tic disorders.

Psychoeducation

(Wu & McGuire, 2018)

Causes of tics

Clinical course of tic disorders

Factors that expression

Common problems with tics

Psychoeducation -intervention

The Neurobehavioral Model

Myths and misconceptions

School, workplace, extended system........
UK Opinions (Cuenca et al, 2015)

Online survey in UK N= 295 & N= 42 interviews

Difficulties in receiving specialist treatment:

● Delays
● Cancellations
● Insufficient funding
● Little information about tics diagnoses from health professionals

“...After I got diagnosed two years after that, that’s when I started to get
information about it. ...I would have liked it to have been just more of a frequent
Thing when I actually needed the help more. Some sort of like guidance on
things I could do, instead of just finding out that I had to deal with it all on my own.”
Lack of understanding

- Health professionals have insufficient knowledge
- Health professionals have limited training
- Families had to attend different health services to receive treatment

“...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”
UK Opinions

- Medication was common and young people / parents described benefits.
  - Adverse effects were described and meds stopped

- Access to behavioural interventions for tics was limited
  - 76% of parents wanted this for their child

- Young people had reservations about BTs
  - Effectiveness
  - Practicality
Positive experiences

• Young people who had behavioural interventions felt that it helped them to recognise, control and / or manage their tics

• The treatment involved learning and practising behaviours similar to some of the behaviours they have used to control their tics, and they were described as “natural”.

“...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.”
Working together

- GP
- Medical consultant (Paediatrician, Neurologist, Psychiatrist)
- Psychologist
- Speech and language therapist
- Occupational therapist
- Nurse
- Educators
- Mental Health Specialist
- Family therapists
Tics and neuro-developmental movements (TANDeM)

Caring for children and young people with tics and neuro-developmental movement disorders.

What is the TANDeM service?
The TIC and Neuro-Developmental Movement (TANDeM) team provides services for children and young people, up to the age of 18, with tics and other movement difficulties.

Our clinic is part of the children’s neurosciences centre at St Thomas’ Hospital, the largest children’s neurosciences service in Europe.

We provide a ‘stepped care’ approach to treatment, meaning that your child’s treatment will be matched to their needs. We offer a range of treatment options, including:

- child and parent/carer therapy groups (habit reversal, mindfulness)
- psychoeducation
- school liaison
- medication reviews
- individual psycholinguistics
- neuropsychology

We work as part of the multidisciplinary team, and specialists.

In order to provide the best care, we work closely with local and adolescent mental health teams.

The Tic Disorder Service

The Tic Disorder Service at Great Ormond Street Hospital (GOSH) is a multi-disciplinary clinic headed by Dr Helen Liang (Child and Adolescent Psychiatrist), Dr Sara Shavel-Jesop (Consultant Paediatric Neuropsychologist) and Dr Tara Murphy (Consultant Paediatric Neuropsychologist).

The Tourette syndrome clinic is a national specialist service that cares for children and young people up to 17 years of age. We have a specialist multi-disciplinary team that works closely with other departments within GOSH, and with neurology, in particular. The care of children is always shared between local services and the specialist service here at GOSH.

There is a strong research collaboration between GOSH and the other Tourette syndrome clinics in the UK, and we have an international reputation for clinical research into psychological treatments for Tourette syndrome, including cognitive (learning) profiles as well as studies of the genetics of tic disorders and the role of infection.
Multidisciplinary Telemedicine Care for Tourette Syndrome: Minireview

Shan-shan Cen 1,2, Jun Yu 1, Qiao Wang 2, Wissam Deeb 1,4, Kai-liang Wang 3, Aparna Wagle Shukla 1, Irene Malaty 1, Adolfo Ramirez-Zamora 1, Jian-guo Zhang 2, Wei Hu 1* and Fan-gang Meng 2,5*

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Tourette syndrome (TS) is a childhood-onset, chronic neuropsychiatric disorder characterized by multiple motor and vocal tics. TS poses a considerable burden on both patients and health care providers, leading to a major detriment of educational success, occupation, and interpersonal relationships. A multidisciplinary, specialist-driven management approach is required due to the complexity of TS. However, access to such specialty care is often dramatically limited by the patients' locations and the specialists' geographic clustering in large urban centers. Telemence uses electronic information and communication technology to provide and support health care when distance separates participants. Therefore, we conducted this mini-review to describe the latest information on telemedicine in the assessment and management of TS and discuss the potential contributions to care for TS patients with a multidisciplinary approach. We believe that telemedicine could be a revolutionary method in improving medical access to patients with TS.
BUT....

Pathways are complicated & inconsistent
Many regions:
  have no pathway for tics
  won’t / cannot accept referrals
  either seen in paediatrics or psychiatry

Limited access to behavioural therapy for tics, psychological care for commonly co-occurring conditions
Gold Standard

- Clear referral pathway from primary to tertiary care
- Framework such as NICE guidelines
- Assessment within a multi / interdisciplinary team
- Emphasis on evidence-based intervention
- Clear commissioning routes
- Links between health and education and social care
Currently

- Pathways being developed in St Helens, Merseyside, Cornwall CCGs
- Consultation with MPs
- Tourette Action
Future Survey

• Associate Professor Maddie Groom, UoN
• Experiences of healthcare professionals
• Consult experts to develop a recommended service model
• Invitation in next 12-24 months
• Survey requests to recruit a representative sample from across specialities
Summary

- Children with TS rarely just have needs with TS
- MDT for assessment and intervention
- Telemedicine
Thank you for listening

Comments, queries, questions