SMC Research Summary
the latest research evidence underpinning our practice

Tourette syndrome

December 2021

What Is Tourette syndrome?

Gilles de la Tourette syndrome - more commonly known as Tourette syndrome - is a condition characterised by persistant motor and vocal tics that are present for over 12 months, with onset prior to 18 years. Tics are involuntary and are preceded by an intense urge and associated tension that is released once the tic has been performed. This creates a feedback loop where the person associates relief with a tic being performed (Leckman et al, 1993; Woods et al., 2005). Tics characteristically have a waxing and waning course – with frequency of tics and the nature of specific tics changing over the natural course of the condition. Tics typically increase in frequency when children are tired, stressed, anxious, or upset. Drawing attention to tics (e.g. during clinical consultations) often also increases tic frequency.

Common examples of 'simple' motor tics include eye blinking, eye rolling, facial movements, shoulder shrugging, or head or neck jerking. Complex motor tics involve several muscle groups, and examples include touching people or objects, adjusting clothing, or twisting around. Common examples of 'simple' vocal tics include throat clearing, sniffing, coughing, grunting, and humming. 'Complex' vocal tics can involve animal sounds, words, and unusual changes of pitch and volume. Coprolalia – tics involving offensive language – are relatively rare and occur in only 10-15% of cases of Tourette syndrome (Eapen & Usherwood, 2021).

Tics in childhood are very common, with at least **one in five** children experiencing tics at some stage during childhood (Eapen & Usherwood, 2021). In most cases, tics are transient – lasting only weeks to months. A diagnosis of Tourette syndrome can be made when a child has exhibited both vocal and multiple motor tics for over a year with onset prior to the age of 18 (Robertson et al., 2017). Behaviours such as rage, self-injurious behaviours and socially inappropriate comments or actions can also be exhibited by those with Tourette syndrome (Eapen & Robertson, 2015).

Tourette syndrome occurs in 1% of school-aged children with an average age of onset of 6-7 years old (Robertson, 2015). The intensity of symptoms will typically reach its peak at 10-12 years old with improvements generally occurring during adolescence (Bloch et al, 2006). Tourette syndrome is more common in males with a male to female ratio of 4:1 (Jancovic & Kurlan, 2011).

There are many factors which can contribute to the development of Tourette syndrome with genetics playing a large role. Family and twin studies have shown that Tourette syndrome is highly heritable (Mataix-Cols et al., 2015). Environmental factors before and after birth are also implicated, with factors including smoking, exposure to infection, psychosocial stressors, and birth complications being associated with an increased likelihood of Tourette syndrome in childhood (Eapen et al., 2013). Neurobiologically, dopamine excess in the corticostriatal circuitry is implicated in the development of Tourette syndrome (Eapen & Usherwood, 2021).

Common Strengths

A supportive family network has been shown to improve the child's long-term quality of life (Eapen et al., 2016). Therefore, ensuring that families and the child have all the information they need about the trajectory of Tourette syndrome is vital.

Please cite this as: Eapen & Montgomery., (2021). *Tourette syndrome: A Brief Summary of Key Research*. Salvesen Mindroom Centre, Edinburgh, UK.

People around the child particularly need to be aware that although brief suppression of tics is possible, that the child is ultimately unable to control the noises or sudden movements that they make (Eapen & Usherwood, 2011). Children and families benefit from being linked with national and international Tourette Syndrome associations and local support groups (Eapen & Usherwood, 2021).

Common Challenges

There are several other conditions which often accompany a diagnosis of Tourette syndrome, and most people with a diagnosis of Tourette syndrome will have at least one or more additional diagnoses. In many cases, the co-occurring conditions can cause more problems than the tics themselves. The most common co-occurring conditions include attention deficit hyperactivity disorder (ADHD), and obsessive-compulsive disorder (OCD), or obsessive-compulsive behaviours (OCB) not meeting full diagnostic criteria for OCD (Freeman et al., 2000). Only about 10% of people with a diagnosis of Tourette syndrome will have isolated Tourette Syndrome, with no other associated diagnoses (Eapen & Robertson, 2015).

The unusual and distracting nature of tics can result in children experiencing difficulties socially as well as academically, and can impact upon mental health (Eapen et al., 2016). Children with a diagnosis of Tourette syndrome can often be seen as disruptive within the classroom and experience embarrassment due to vocal or motor tics (Dornbush & Pruitt, 1995). It is important that teachers are provided with information about Tourette syndrome so that they are made aware that tics are involuntary (Eapen & Usherwood, 2021). Children can often be distracted from their learning, by attempts to supress tics. With mental effort, children can successfully supress tics for a period, but this can result in heightened inner tension and a subsequent flurry of increased tics when they later stop suppressing (Elstner et al., 2001).

The Evidence on Supports

Lifestyle factors, such as improving sleep quality and reducing stress, can decrease tic frequency. If warranted, referral to a psychologist can also be of benefit to assist with behaviour modification techniques (Capriotti et al., 2014; Piacentini et al., 2010).

Medication can also assist those struggling with tics and symptoms associated with Tourette syndrome or co-morbidities such as ADHD or OCD. It is important to ascertain which symptoms are causing significant distress or disruption and tailor the medication choice accordingly (Eapen & Usherwood, 2021).

What's Next in Research?

Ongoing research is focusing on identification of more effective medications and other treatments for individuals living with Tourette syndrome. Although not currently used in children, particularly refractory and complex adult cases that have shown limited response to past treatments may be eligible for treatment with deep-brain stimulation, though this treatment has had variable outcomes (Martinez-Ramirez et al., 2018).

References

Eapen V, Usherwood T. Tourette syndrome in children. Australian Journal of General Practice [Internet]. 2021;50(3):120-125.doi: 10.31128/AJGP-10-20-5700

Leckman JF, Walker DE, Cohen DJ. Premonitory urges in Tourette's syndrome. Am J Psychiatry 1993;150(1):98–102. doi: 10.1176/ajp.150.1.98.

Woods DW, Piacentini J, Himle MB, Chang S. Premonitory urge for tics scale (PUTS): Initial psychometric results and examination of the premonitory urge phenomenon in youths with tic disorders. J Dev Behav Pediatr 2005;26(6):397–403. doi: 10.1

Robertson MM. A personal 35 year perspective on Gilles de la Tourette syndrome: Prevalence, phenomenology, comorbidities, and coexistent psychopathologies. Lancet Psychiatry 2015;2(1):68–87. doi: 10.1016/S2215-0366(14)00132-1.

Bloch MH, Peterson BS, Scahill L, et al. Adulthood outcome of tic and obsessivecompulsive symptom severity in children with Tourette syndrome. Arch Pediatr Adolesc Med 2006;160(1):65–69. doi: 10.1001/archpedi.160.1.65.

Jankovic J, Kurlan R. Tourette syndrome: Evolving concepts. Mov Disord 2011;26(6):1149–56. doi: 10.1002/mds.23618.

Kurlan R. The differential diagnosis of tic disorders. In: Martino D, Leckman JF, editors. Tourette syndrome. New York, NY: Oxford

Mataix-Cols D, Isomura K, Pérez-Vigil A, et al. Familial risks of Tourette syndrome and chronic tic disorders. A population-based cohort study. JAMA Psychiatry 2015;72(8):787–93. doi: 10.1001/ jamapsychiatry.2015.0627.

Eapen V, Perkes I, Goff R. (2013) Pathways from genes to symptoms in Gilles de la Tourette syndrome (GTS). In: Martino D, Leckman JF, editors. Tourette syndrome. New York

Robertson MM, Eapen V, Singer HS, et al. Gilles de la Tourette syndrome. Nat Rev Dis Primers 2017;3:16097. doi: 10.1038/nrdp.2016.97

Eapen V, Robertson MM. Are there distinct subtypes in Tourette syndrome? Pure-Tourette syndrome versus Tourette syndrome-plus, and simple versus complex tics. Neuropsychiatr Dis Treat 2015;11:1431–36. doi: 10.2147/NDT.S72284

Freeman RD, Fast DK, Burd L, Kerbeshian J, Robertson MM, Sandor P. An international perspective on Tourette syndrome: Selected findings from 3,500 individuals in 22 countries. Dev Med Child Neurol 2000;42(7):436–47. doi: 10.1017/s0012162200000839.

Eapen V, Cavanna AE, Robertson MM. Comorbidities, social impact, and quality of life in Tourette syndrome. Front Psychiatry 2016;7:97. doi: 10.3389/fpsyt.2016.00097.

Dornbush MP, Pruitt SK. Teaching the tiger: A handbook for individuals involved in the education of students with attention deficit disorders, Tourette syndrome, or obsessive-compulsive disorder. Carol Stream, IL: Hope Press, 1995.

Elstner K, Selai CE, Trimble MR, Robertson MM. Quality of life (QOL) of patients with Gilles de la Tourette's syndrome. Acta Psychiatr Scand 2001;103(1):52–59. doi: 10.1034/j.1600- 0447.2001.00147.x.

Capriotti MR, Himle MB, Woods DW. Behavioral treatments for Tourette syndrome. J Obsessive Compuls Relat Disord 2014;3(4):415–20. doi: 10.1016/j.jocrd.2014.03.007.

Piacentini J, Woods DW, Scahill L, et al. Behavior therapy for children with Tourette disorder: A randomized controlled trial. JAMA 2010;303(19):1929–37. doi: 10.1001/jama.2010.607

Martinez-Ramirez D, Jimenez-Shahed J, Leckman JF, et al. Efficacy and safety of deep brain stimulation in Tourette syndrome: The International Tourette Syndrome Deep Brain Stimulation Public Database and Registry. JAMA Neurol 2018;75(3):353–59. doi: 10.1001/ jamaneurol.2017.4317