

Tourette’s Syndrome

Identification and diagnosis

In order to appropriately diagnose TS at least one vocal tic and multiple motor tics must be present and observed for at least 12 months (Gill and Kopoliti, 2019). Diagnosis is obtained by a GP referral to a specialist, however there are challenges to being diagnosed (NHS, 2021). Currently, there are no TS specialists in Wales that treat children, however, children’s neurodevelopmental services are set to improve and increase by March 2022, therefore children may be able to access the support they need for a better quality of life (Welsh Government, 2021).

Challenges

- Tics can be easily imitated and impersonated therefore may create difficulty in producing an accurate diagnosis due to uncertainty of whether tics are deliberate or involuntary (Leckman, No Date).
- Tics are not uncommon for children to demonstrate for several months before ending (NHS, 2021).
- Symptoms may be disregarded as allergies or bad habits (Chichioco and Thom, 2016; Meyers, 2016).
- Parents in denial will refuse to acknowledge a child's additional learning need for fear of stigmatisation (Logsdon, 2020).
- Often occurs as a comorbid disorder with Attention Deficit /Hyperactivity Disorder and Obsessive-Compulsive Disorder resulting in a higher risk of misdiagnosis as symptoms can be misinterpreted as compulsions (Centers for Disease Control and Prevention, 2021; Cavanna, 2013).

Benefits

- Gain access to support services in order to develop an understanding of the disorder and methods to manage the symptoms (Tourette’s Action, 2022).
- Preparation of an Individual Development plan within 12 weeks in order to provide children with the optimum support for their additional learning need (Welsh Government, 2018).

Introduction

Tourette's Syndrome (TS) is a genetic, childhood, neurological disorder that is presented by urges resulting in sudden, involuntary vocal expressions and movements known as tics (Tourette's Action, 2015; Kahl *et al.* 2021). Symptoms usually begin around the age of five and affect 1 in 100 school children (Hallet, 2015; Tourette’s Action, 2017). The disorder occurs in all ethnic cultures and males are more frequently diagnosed and affected than females (Tourette Association of America, No Date; Garris and Quigg, 2021; NHS, 2021).

Symptoms

National Institute of Neurological Disorders and Stroke (2021) state that symptoms of TS are assorted as mild to severe and categorised as simple or complex motor and vocal tics. Tourette’s Action (2022) states that complex motor tics include the use of several muscle groups in a recognisable pattern and simple motor tics are brief, sudden and repetitive. Some examples can be seen below.

	Motor	Vocal
Simple	• Blinking • Eye rolling • Shrugging • Jerking • Grimacing	• Throat clearing • Sniffing • Coughing • Barking • Grunting
Complex	• Jumping • Touching other people • Obscene gestures • Repeating viewed gestures • Twirling	• Using obscene language • Using socially unacceptable words/insults • Repeating sounds

Barriers

Damaging media portrayals have allowed societal perceptions of TS to result in misunderstanding, stigmatisation and stereotypical attitudes in which patients are viewed as having an eccentric personality trait whereupon exhibiting involuntary swearing and obscene language are considered the main symptoms; However, only 10% of TS diagnosis actively display these symptoms (Calder- Sprackman, Sutherland and Doja, 2014; Elliott, 2016; Meyers, 2016; Malli and Forrester-Jones, 2021). Children with tics are more likely to experience bullying, resulting in poor mental health with an increase in low self-esteem, depression, suicidal thoughts and school avoidance (Claussen and Bitskov, 2015). Additionally, stressful and anxious emotions enhanced through bullying can increase tic severity, symptoms and urges (Zinner *et al.* 2012). Furthermore, affecting academic ability and social development through underperformance and poor school adjustment (Tourette’s Action, 2020; Kaloeti, 2021).

Strategy

There are treatments available to help manage tics. The predominant form of treatment is medicinal; however, no medicinal treatments have been proven to be reliably effective for long term improvement of tics (Eddy, Rickardson and Cavanna, 2011), and often have adverse effects (Cuenca *et al.* 2015). Habit Reversal Therapy (HRT) is an alternative treatment provided by specially trained therapists to manage tics. The primary components of the therapy are awareness training, competing response training and social support; Children are taught to notice the sensation of a tic’s preliminary urge and use an alternative, socially acceptable response (McGuire *et al.* 2015; Coffey, 2022). This is achieved by the child identifying their tics and selecting which to improve consecutively in which they are supported by a therapist to increase the sense of awareness of when the tic will occur. The child is then supported to conduct a deliberate competing response to avoid the tic occurring (Murphy, 2017). Study findings indicate that HRT has displayed considerable improvements to quality of life and in the reduction of tic severity. Additionally, learning to manage their tics without the need of medication can enable children to feel empowered and have a sense of control over their bodies (Dutta and Cavanna, 2013; Viefhaus *et al.* 2018; Coffey, 2022).

Conclusion

Achieving a diagnosis for TS can prove extremely challenging due to comorbid disorders, broad range of symptoms and limited knowledge within the education and health service. Similarly waiting 12 months for a diagnosis could prove stressful to children, thus making their symptoms worse. However, early intervention and access to HRT could significantly improve the quality of life for children, provide additional support within schools and reduce the risk of victimisation, although the lack of specialists in Wales could be problematic and hinder necessary support.

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