Parent perceptions of symptom severity in Tourette's syndrome

J M Dooley, P M Brna, K E Gordon

Abstract

The families of 66 consecutive children with Tourette's syndrome were surveyed for their perception of symptom significance using a questionnaire. Families considered attention deficit and learning difficulties to be most significant, while motor and vocal tics were least important. When present, episodic rage was the most impairing symptom. Physicians must be aware of the significance of these comorbid symptoms for patients with Tourette's syndrome.

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Tourette's syndrome is a chronic neurobehavioural disorder characterised by a spectrum of neurological, behavioural, and cognitive symptoms and signs. Although the criteria for diagnosing Tourette's syndrome are based on the presence of motor and vocal tics,¹ symptoms of comorbid neurobehavioural disorders are also frequently present. Attention deficit hyperactivity disorder (ADHD) is reported in 50-75%² and obsessive compulsive behaviours (OCB) are found in 20-60%² of Tourette's syndrome patients. Episodic aggression or rage attacks² and learning difficulties³ are also frequent.

Medical attention is usually focused on the dramatic phenomena of motor and vocal tics, although there is evidence that the comorbid behavioural symptoms, such as ADHD and OCB, can have a detrimental impact on cognitive, educational, and psychosocial function.³ There are few data on the importance of these related symptoms from the perspective of families of patients with Tourette's syndrome.

Subjects and methods

The families of 66 consecutive Tourette's syndrome patients who met DSM IV diagnostic criteria¹ completed a questionnaire regarding their perception of symptom severity. The patients were all seen by one of the authors (JD) during a six month period. Each family completed a questionnaire that listed the symptoms of motor tics, vocal tics, learning difficulties, attention deficit, hyperactivity, obsessions, compulsions, rage attacks, and "other", which allowed families to add other perceived problems. The families were asked to rate how "significant/bothersome" they found each symptom on the following scale:

Table 1 Number (%) of Tourette's syndrome patients with various symptoms at time of questionnaire completion

Symptom	Number	Per cent
Motor tics	65	98
Vocal tics	60	91
Attention deficit	56	85
Compulsions	52	79
Learning difficulties	45	68
Hyperactivity	44	67
Obsessions	42	64
Rage	39	59

Table 2 Importance of symptoms ranked by the entire group

Importance	Symptom	% of families
Most important	Learning difficulties	18
	Attention deficit	18
Second most important	Attention deficit	18
	Other	16
Third most important	Vocal tics	18
	Compulsions	18

- (1) does not apply
- (2) not at all
- (3) just a little
- (4) pretty much
- (5) very much.

Finally, they listed the three most significant/bothersome problems in order of perceived severity. Data were entered and analysed using Epi Info version 6.04.⁴

Results

Families of 55 boys and 11 girls with Tourette's syndrome completed the questionnaires. The mean (SD) age of tic onset was 6.2 (2.8) years and the mean age at assessment was 11 (3.5) years. The mean duration of symptoms at the time of assessment was 4.7 (3.4) years.

At the time of completion of the questionnaire, motor tics were the most prevalent symptom (table 1). Using the median age of the group (10 years) as the cut off, there was no correlation between symptoms and age, with the exception of learning difficulties, which were more common in the older group ($p = 0.008$; χ^2).

Learning difficulties and attention problems were cited equally as the most significant/bothersome (table 2). Importantly, motor tics were not rated among the three most serious features.

Some characteristics may be infrequent but important when present; therefore, symptom significance was analysed for those reporting each feature. In this analysis episodic rage was the most important manifestation while both motor and vocal tics were ranked as the least important (table 3).

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Table 3 Percentage of families ranking symptom as very important, when symptom present

Symptom	%
Rage	36
Attention deficit	29
Learning difficulties	24
Obsessions	21
Hyperactivity	16
Compulsions	14
Motor tics	9
Vocal tics	7

Discussion

Approximately 3% of children have Tourette's syndrome⁵ and the disorder has a wider clinical spectrum than previously recognised. Physicians who care for patients with Tourette's syndrome must recognise that the requirements of patients and families extend beyond our previous focus on "tics and twitches". The more flamboyant phenomena of coprolalia and copropraxia, which have previously received so much attention, were not reported by any of our patients or families.

The Canadian health care system permits universal access to tertiary level care. Within this system, children with Tourette's syndrome are more likely to consult a child psychiatrist when behavioural problems are paramount, while those with other predominant symptoms tend to see paediatric neurologists. We studied consecutive patients with Tourette's syndrome who were referred to a paediatric neurologist; therefore, it is possible that our sample was biased towards children with comorbid Tourette's syndrome related symptoms and signs.

Attention deficit problems were frequently present and were ranked as the most important difficulty. More than half of the children had episodic rage, and, when present, this was considered the most important problem for these families. Motor and vocal tics were universally rated as being least important.

Learning difficulty was the only symptom related to age. This may reflect that learning problems are more easily recognised as academic demands become more complex in older children. The equal representation of the other associated symptoms in the younger and older patients suggests that, when they occur, these features tend to present early in the course of the disorder.

Therefore, the prominence and perceived importance of comorbid symptoms mandates that physicians who care for children with Tourette's syndrome must address these needs and must offer appropriate counselling and behavioural or pharmacological interventions.

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