

Children and Their Parents' Perceptions of Symptom Severity and Treatment Preference for Tourette Syndrome

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Objective: This study surveys children and their parents' perceptions, and their treatment preference of significant/bothersome symptoms in children with Tourette syndrome.

Methods: Thirty five children and adolescents who referred to an out-patient clinic of a Child Psychiatry Clinic were selected as subjects for this study. The children and their parents were interviewed about their perception of significant/bothersome symptoms of motor tics, vocal tics, learning difficulties, attention deficit disorder, hyperactivity, obsessions, compulsions, and rage attacks.

Results: About two thirds of the subjects had symptom of rage. Inattentiveness and hyperactivity were observed in more than half of the children. There was a statistically significant difference between parents and their children in frequency of motor tics and rage attacks. Children reported the necessity for controlling and management of these symptoms less than their parents.

Discussion: The rates of motor, vocal tics and rage attacks in the Iranian sample are similar to other studies. Rage attack is one of the most common significant/bothersome symptoms reported that should be treated. While motor tics were not rated among the most common features that should be treated in a study in Canada, it was the most common significant/bothersome symptom in Iran. Parents perceive motor tics and rage attacks as more significant/bothersome symptoms compared to children.

Keywords: Attitude, Child, Iran, Parent, Tourette syndrome

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Tics are only part of the picture of Tourette syndrome (TS). In TS, motor and phonic tics have persisted for at least more than a year. The age of onset for tics is usually between 5 and 6 years of age (1). The peak of tic severity is usually between 10 and 12 years of age (2). Another study reported that the age at the onset of tics was 7.6 ± 3.5 years, and the mean delay in diagnosis of TS was about 3.9 years (3). About 29% of the patients had anger control problem (3).

Of course, most patients with TS have only minimal symptoms that do not interfere with their daily functioning (4). In many children with TS, the associated behavioral problems are more impairing than their tics (5). A study on 12 children with TS suggests that rage attack is related to the presence of co-morbid disorders (6). Socially inappropriate behaviors, such as arguing or insulting others are more common in children with TS (7). Even children with TS-only have a broad range of behavioral problems and some of these problems are related to the severity

of tic symptoms (8). Aggressive behavior is independent of tic severity or age (4). In addition, about two-thirds of children with TS have co-morbid ADHD, conduct disorder, or oppositional defiant disorder (9). More aggressive behavior in children with TS is associated with co-morbid ADHD or OCD.

Therefore, the presence of explosive outbursts in children with TS should alert the clinicians to evaluate the presence of underlying co-morbid conditions (10).

A study on 138 children with TS showed that the rate of a specific learning disorder was 22%, and tics were not a predictor of academic problems. They reported that the school-related difficulties are associated with co-morbid attention-deficit hyperactivity disorder (11). Therefore, the co-occurring problems should be considered and managed in these children.

Tourette severity affects parenting stress (12). One of the most difficult problems to be controlled in children with TS is the outburst of rage (6). Parents report that problems related to ADHD and LD are the most difficult problems in TS (13). More than half of the

children with TS experience serious difficulties in emotional-behavioral interactions (14). Families often report that aggression (rage) is more disruptive than tics (13). Thus, parent-child interaction is not easy for the parents. Meanwhile, it is very important for children with TS to be understood and accepted by their family members (2). The parents of TS youngsters are under personal stress. They usually comment on their children's tics and may even punish their children for such behaviors as tics (15).

Moreover, administration of medication is dependent on the effect of tics and co-occurring symptoms on the child's life. Only one study was found on parents' perception of symptoms severity in TS (13). The current study compares parents' and children's perception of tic and its related symptoms in children with TS. In addition, it compares results with a similar study from Canada for studying cross cultural similarities and differences (13).

Materials and Methods

The participants were 35 children and adolescents with TS who referred to the out-patient clinic of Child and Adolescent Psychiatric Clinic affiliated by Shiraz University of Medical Sciences. The data were gathered along with a study on the behavioral problems and psychiatric disorders in children with TS (16). The diagnosis of TS was established using the DSM-IV-Text Revised diagnostic criteria (American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 4th ed., text revision (DSM-IVTR), 2002). All of the subjects and their parents were interviewed using the Farsi version of Schedule for Affective Disorders and Schizophrenia (K-SADS) by a child and adolescent psychiatrist (17, 18.)

The children and their parents were interviewed about their perception of symptom severity of tic and the co-morbid symptoms using a structured questionnaire used in a previous study (13). It included the symptoms of motor tics, vocal tics, learning difficulties, attention deficit, hyperactivity, obsessions, compulsions, and rage attacks. The interview was conducted by a bilingual child and adolescent psychiatrist. Parents and their children consented to participate in the study.

The collected data were statistically analyzed using SPSS. Cronbach's alpha was used to examine the

internal consistency of the questionnaire. Wherever it was applicable, Chi-Square tests or Fisher's exact test

were used. Statistical significance was defined at less than 5% level.

Results

Most of the children were boys (88.6%) with the mean age of 11.8 (SD=3.1; age range: 6 to 18 years). The tic onset age was about 9.1 (SD=2.9) years (16). Cronbach's alpha for the parent version of the questions was 0.92 , and it was 0.94 for questions asked from children. Table 1 demonstrates the frequency of symptoms and the importance of the symptoms in the view of children and their parents. 80% of the subjects were currently suffering from motor tics. About two thirds of the subjects had the rage attack symptom. In addition, inattentiveness and hyperactivity were observed in more than half of the children. There was a statistically significant difference between parents and their children regarding the importance of treatment priority for motor tics and rage attacks. Children reported motor tics and rage attacks to be less significant/bothersome symptoms than their parents.

The prevalence of co-morbid psychiatric disorders was presented elsewhere before (16). The most common psychiatric disorders were ADHD (68.6%), oppositional defiant disorder (28.6%), and Obsessive-compulsive disorder (28.6%).

Discussion

In the current study, the rates of motor and vocal tics at the time of conducting the study were 80% and 60% respectively. The rates in a similar study conducted in Canada were 98% and 91% for motor and vocal tics respectively. The sample characteristics of the Canadian study was very similar to the current study in Iran in terms of rate of girls (17.1% versus 11.4%) , and the mean age of the children (11(3.3) versus 11.8(3.) years), except for the mean age for the onset of tic (6.2(2.8) versus 9.1(2.9) years) respectively. Obsession and learning problem symptoms were the least frequent symptoms in both studies. The rates of rage attack in the Iranian and the Canadian studies were 66.6% and 59% respectively. These findings show that the rates of various co-occurring symptoms

Table 1. Percent of tic and related symptoms of Tourette disorder and importance of the symptoms by the children and their parents

Symptoms	significant/bothersome symptom in view of		Significance
	Childrenn(%)	Parentsn(%)	
Motor tic (n=28)	11(39.3)	20(71.4)	X2=5.8, df=1, P<0.01
Vocal tic (n=21)	4(20.0)	7(35.0)	X2=1.1, df=1, P= .2
Inattentiveness (n=20)	1(5.0)	2(10.0)	X2= .1, df=1, P=0.1*
Obsession (n=11)	0	4(36.4)	-
Hyperactivity (n=19)	1(5.3)	3(15.8)	X2=1.2, df=1, P=0.3*
Learning difficulty (n=9)	2(22.2)	2(22.2)	-
Rage (n=23)	6(26.1)	16(69.6)	X2=8.7, df=1, PP<0.003

in the two cultures are very similar. These similarities make it easier to compare the results of these two studies.

It is interesting that parents of the Iranian children reported motor tics and rage attacks as the most significant/bothersome symptoms that should be managed in their children.

This is somewhat different from the Canadian study that rage attack and attention problems were reported as the most significant/bothersome symptoms. In addition, the Canadian study reported that motor tics were not rated among the most serious features and it was the least important symptom.

It is very interesting that learning difficulties and attention problems were reported as the least significant/bothersome symptoms by the Iranian parents. These comparisons show that rage attacks are one of the most significant/bothersome symptoms in view of the parents of these two cultures. However, there is a considerable discrepancy between the parents' view of children with TS in each of these cultures.

The current study also compares the frequency of significant/bothersome symptoms between children and their parents; we did not find any study that had compared them. There was a significant difference between the parents and their children regarding the perception of the significance of motor tics and rage attacks. While these two symptoms were not usually important for the children, they were considered more important in the view of their parents. Tics are often done as a response to sensory tics or premonitory urges (19). These urges represent an inner buildup of tension that becomes extremely distracting and uncomfortable until temporarily relieved by expressing the tic. Many children with TS describe a constant internal battle to control these urges, which may have a compulsive component because the tics may need to be repeated until the urge is satisfied. The parents are often unaware of some but not all of them. It may be possible that the tics are the most visible symptoms by the parents. The premonitory urges may be underestimated by parents relative to children subjects. This is a subjective experience and may cause greater distress than the tics themselves (20). The high rate of tic importance might show that the tics have a great impact on their family. For example, the parents are embarrassed by the tics. However, it is possible that many parents who felt embarrassed for their children's tics have not already referred to clinics.

Rage attack behavior was one of the most common co-morbid behavioral problems in these children. Most of the parents and about one quarter of the children reported it as a significant/bothering symptom. Aggression in the children with TS is very frequent and severe. A previous study indicated that many families of these children are hostages to the possibility of a rage outburst (2). The finding that aggression was reported as one of the most important symptoms that

should be treated is in accordance with the study conducted in Canada (13). Less than one thirds of the children with TS had learning problems. Previous studies reported that 25% of children with TS have learning difficulties (21). Most of the children and parents with learning problems reported it as an unimportant problem. Parents and their children may think that learning difficulties are less disturbing than many other symptoms. It is possible that aggression more likely affects others but learning difficulties affect the patients themselves. Consequently, parents more than children reported rage attacks to be a significant/bothersome symptom.

The tics fluctuate in type, frequency, severity, and location over time. It is very important for children with TS to be understood and accepted by their families (2). This study shows that before administration of medication, it is necessary to talk to the children, adolescents and their parents to survey the degree of impact of tics and their related symptoms. This is much more important when we are aware that the treatments are purely symptomatic and do not improve the long-term prognosis.

In addition, it can be concluded that therapists should identify the symptoms that are most significant/bothersome to the patients and their children, and therapy should be directed towards improving these symptoms first. It is worth mentioning that cooccurring psychiatric disorders may be associated with rage attacks in Tourette syndrome (6). A previous study conducted many years ago indicted that Paroxetine may be effective for treating episodic rage in Tourette syndrome (22).

There are some limitations that should be considered. The sample size of children and adolescents was relatively small and they were recruited from a clinic. Therefore, generalization of the results to other samples is not guaranteed. In addition, it should be noted that the children were from a clinical sample. Most of the clinical sample comprised of children with ADHD symptoms (23). This may explain why the rate of inattentiveness and hyperactivity were more common than some of the other symptoms. Further, the lack of difference between parents and children for some of the symptoms might be related to error type II. Furthermore, this study compared the current sample with a group of historical controls from a study which examined parental perception of symptom severity in TS (13). One sample from Iran and one sample from Canada may not exactly distinguish the differences between the two cultures. In addition, most of the children with TS have at least another co-morbid psychiatric disorder (16). Further studies should include the severity of other co-morbid disorders and their association with the degree of tic symptoms perceived as bothersome. In other words, the significance of the tic symptoms might be somewhat associated with the other co-morbid disorders. Future studies should also consider the severity of TS and its

symptoms, degree of impairment in different aspects, age, gender of children, history of treatment, pattern of recurrence and remission, its chronicity; and some parental characteristics such as history of tic in parents, and psychiatric disorders of parents. Moreover, premonitory urges in TS is a neglected research area (20) that should be included in further studies.

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