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A National Profile of Tourette Syndrome, 2011–2012

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Abstract

Objective—To provide recent estimates of the prevalence of Tourette Syndrome among a nationally representative sample of US children, and to describe the association of Tourette Syndrome with indicators of health and functioning.

Method—Data on 65,540 US children aged 6–17 years from the 2011–2012 National Survey of Children's Health were analyzed. Parents reported whether a health care provider had ever told them their child had Tourette Syndrome or other neurobehavioral or chronic health conditions, and whether their child had current Tourette Syndrome.

Results—Based on parent report, 0.19% of US children had Tourette Syndrome; the average age of diagnosis was 8.1 years. Children with Tourette Syndrome, compared to those without, were more likely to have co-occurring neurobehavioral and other health conditions, meet criteria for designation as having a special health care need, receive mental health treatment, have unmet mental health care needs and have parents with high parenting aggravation and parents who were contacted about school problems; they were less likely to receive effective care coordination or have a medical home. After controlling for co-occurring neurobehavioral conditions, the findings on parents being contacted about school problems and children having unmet mental health care needs were no longer significant.

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Conclusion—TS is characterized by co-occurring neurobehavioral and other health conditions, and poorer health, education and family relationships. The findings support previous recommendations to consider co-occurring conditions in the diagnosis and treatment of Tourette Syndrome. Future research may explore whether having a medical home improves outcomes among children with Tourette Syndrome.

Key Terms

Epidemiology; prevalence; health care; comorbidity; parenting

Tourette Syndrome (TS) is a tic disorder characterized by motor and phonic tics, usually emerging between 5–8 years of age, with tics persisting for at least one year.¹ Prevalence estimates of TS among children vary widely, ranging from 0.4%–5.0% in community samples.² The first prevalence estimate based on a large, nationally representative sample of non-institutionalized US children, the 2007 National Survey of Children's Health, reported that 0.3% of US children aged 6–17 years had ever been diagnosed with TS.³ TS is a chronic condition, with tic severity generally peaking between ages 10–12 years, and often diminishing by early adulthood.^{4, 5} Given the age of presentation, children with tics may first present to primary care physicians and are often co-managed with subspecialists, such as developmental and behavioral pediatricians, psychologists, neurologists and psychiatrists. TS often co-occurs with one or more other neurobehavioral conditions, including attention-deficit/hyperactivity disorder and obsessive-compulsive disorder.^{1, 5, 6} Tics and symptoms of co-occurring conditions can both independently, and concurrently, impact family and peer relationships, education and health, including increased parent aggravation and health care needs, problems making friends or being teased, and problems in academic performance including with reading, speaking and concentration.^{5, 7–9} However, previous studies examining the impact of TS have been limited by small sample sizes, no control groups, or clinic or convenience samples with limited generalizability to larger populations. Given the chronicity of TS, the presence of co-occurring conditions, and its impact across a number of settings (school, health, peers, family), children with TS may benefit from coordinated care within a medical home.¹⁰ One study found that children with TS and a co-occurring mental disorder are less likely than children without TS to have a medical home.⁷

Our study provides a broad overview of TS among a nationally representative sample of US children by providing the recent estimates available for the prevalence of TS and co-occurring conditions, the association of TS with indicators of health, parenting aggravation and academic functioning, and the relationship between the presence of a co-occurring condition and TS severity with health and functioning among children with TS.

METHODS

Data were analyzed from the 2011–2012 National Survey of Children's Health, a cross-sectional telephone survey of US households conducted by the National Center for Health Statistics as a module of the State and Local Area Integrated Telephone Survey, using a random-digit-dial sample of landlines and cell phones.¹¹ A parent or guardian (n= 95,677) reported on one randomly selected child aged 0–17 years. The interview completion rate

(the proportion of households known to include children whose parent completed the interview) was 54.1% and 41.2% for landline and cell-phone samples, respectively. The overall response rate, including all non-response such as households that were never successfully screened for the presence of children and telephone lines that rang with no answer, was 23.0%. Consistent with the usual age at onset of Tourette Syndrome (TS), analyses were restricted to 65,540 children aged 6–17 years, with valid data on TS status and sex.

Parents reported whether a health care provider ever told them their child had any of a list of selected health conditions including TS (Table 1), and if yes, whether their child currently had the condition(s). If the child currently had TS, parents were asked whether TS was mild, moderate or severe. Parents also reported the child's age when first diagnosed with TS. Special health care need status was assessed based on parents' responses to a series of questions regarding the presence of chronic conditions resulting in functional limitations or service use or need beyond that generally required by children the same age as their child.¹² Variables reflecting aspects of the child's health care (in the past 12 months) included how many times their child saw a doctor, nurse, or other health care provider for preventive medical care, if their child received treatment or counseling from a mental health professional, and whether their child needed to see a specialist other than a mental health professional. Multiple survey questions were used to determine whether the child received effective care coordination,¹³ had a medical home,¹³ or had any kind of unmet health care need, and if so, about specific unmet health care needs including mental health.

A past-month parenting aggravation indicator (high/low) was calculated from parents' reports of how often they felt: angry with their child; their child was harder to care for than most children his/her age; and, that their child did things that really bothered them.⁸ Academic functioning was assessed by whether: the child had repeated a grade other than kindergarten; or a parent had been contacted within the past year about school problems.

Sociodemographic characteristics examined included: child's sex, age, race, Hispanic ethnicity, household income (later categorized relative to the federal poverty level) and highest education level achieved by the parent(s) living with the child.

SAS-callable SUDAAN (Version 10.0.1, RTI International, Cary, NC) was used to account for the complex sampling design, allowing for estimates generalizable to non-institutionalized US children 6–17 years of age. Household income was imputed for those without valid income data (9.3%). Weighted percent estimates, prevalence ratios, and 95% confidence intervals (CI) for all estimates and prevalence ratios were calculated; all data in tables 3 and 4 are weighted estimates. Logistic regression was used to calculate adjusted prevalence ratios controlling for child's sex, age (6–11 vs. 12–17 years), and race and ethnicity (white non-Hispanic vs. other); analyses on health and functioning were further adjusted for co-occurring neurobehavioral conditions.

RESULTS

Among US children aged 6–17 years, 0.19% (weighted estimate representing approximately 95,000 children) had current TS, by parent report. Similar to the findings based on the 2007 National Survey of Children's Health data, 0.28% (representing approximately 138,000 US children) had ever-diagnosed TS (compared to 0.3% in 2007).³ Current TS was more common in boys, children aged 12–17 years, and among white non-Hispanic children compared to Hispanic or black non-Hispanic children, but did not differ by parent education or household poverty level (Table 2). Demographic patterns across all groups were similar for ever-diagnosed TS. Among children with ever-diagnosed TS, the average age of diagnosis was 8.1 years (CI: 7.3–8.8, range 0–16). Parents rated current TS mild (63.1%; CI: 49.5–74.9) more often than moderate or severe (36.9%; CI: 25.1–50.5).

After adjusting for sex, age and race/ethnicity, children with current TS were 3 times as likely as children without TS to have ever had any co-occurring neurobehavioral condition ($p < 0.001$); 86.5% of children with current TS had at least one co-occurring neurobehavioral condition (Table 3). Children with current or ever-diagnosed TS were more likely to have ever had each neurobehavioral condition studied compared to children without TS (all $p < 0.01$).

Children with TS were more likely to have ever had a co-occurring chronic health condition compared to children without TS ($p = 0.02$); specifically, children with current TS were 2.9 times as likely to have had bone, joint or muscle problems ($p < 0.01$) (Table 3). Children with ever diagnosed TS (but not the subgroup with current TS) were 2.6 times as likely to have had a brain injury or concussion ($p = 0.02$). TS status was not associated with hearing or vision problems or asthma.

Eighty-one percent of children with current TS met criteria for children with special health care needs (Table 4). After controlling for age, sex, and race/ethnicity, compared to children without TS, children with TS were more likely to have a parent with high parenting aggravation ($p < 0.001$). Compared to children without TS, children with current (or ever) TS were more likely to have received treatment or counseling from a mental health professional and to have an unmet mental health care need, but less likely to have received effective care coordination or have a medical home (all $p < 0.02$). TS status was not associated with receiving preventive care, seeing a non-mental health specialist, or having an unmet medical need (Table 4).

After further controlling for the presence of a co-occurring neurobehavioral condition, current TS remained positively associated with meeting criteria for children with special health care needs, high parenting aggravation and receiving mental health services, and negatively associated with having effective care coordination or a medical home.

TS severity was generally associated with worse outcomes (e.g. parenting aggravation, academic functioning, health care needs); however, the estimates generally had high relative standard errors, and therefore, the data are not presented. The only significant, stable finding was that among children with TS, severity was associated with receiving mental health treatment (aPR = 1.9; 95% CI: 1.2–2.9).

DISCUSSION

Based on parent report among a nationally representative sample, in 2011–2012, 0.19% of US children aged 6–17 had current Tourette Syndrome (TS), representing 73% of children ever-diagnosed with TS. The average age of TS diagnosis was 8.1 years. In agreement with previous studies,^{2–5} TS was more common among boys and white non-Hispanic children, increased with age and was often mild.

The prevalence of TS reported here is similar to that reported using 2007 National Survey of Children's Health data (0.2% for current TS),¹⁴ but estimates from community-targeted studies that include previously undiagnosed cases are often double the estimates reported here and from clinic-based studies.² This discrepancy suggests that as many as half of pediatric TS cases remain undiagnosed, possibly more so among Hispanic and black non-Hispanic populations where the prevalence was half that observed among white non-Hispanic children. However, the data reported here leave uncertain whether the differences reported here are valid racial and ethnic differences in TS prevalence, or if the differences reflect under-recognition of TS among non-white children in the US.

The high prevalence of co-occurring neurobehavioral conditions reported here agrees with previous reports.^{1, 5, 6} Based on data from the National Survey of Children's Health, the prevalence of autism spectrum disorders (35%) among children with current TS in 2011–2012 was higher than that observed from the 2007 data (13.4%)⁷ and was substantially higher than previous estimates of co-occurring Asperger's disorder or other autism spectrum disorders that ranged from 1–5%.^{6, 15} This may be at least partially associated with recent increases in the prevalence of autism spectrum disorders, as estimated using the National Survey of Children's Health data.¹⁶ Previous research has documented shared genetic risk for autism spectrum disorders and TS.¹⁷

The findings here also show high co-occurrence of parent-reported learning disability, developmental delay, intellectual disability, and speech and language problems among children with TS. A large international study of children and adults with TS found that 22% had a learning disability, 3.4% had intellectual disability, 4.6% had a pervasive developmental disorder and 7.1% had stuttering.¹⁸ Other studies of smaller populations have noted varying ranges of these conditions (7–37% for learning disability, 4.5%–10.2% for pervasive developmental disorders, 3–27% for intellectual disability and 15–30% for stuttering or other speech disorders).^{6, 15, 18–23} Evolution in condition terminology as well as definition overlap may partially explain these variations. Children with TS were also more likely to have bone, joint or muscle problems, and those who were ever diagnosed with TS were more likely to have a brain injury or concussion. Such co-occurrence may be related to the tics themselves, as tics may be associated with self-injury, head-banging, headaches or general pain.^{24–26} Alternately, co-occurring depression or anxiety may be associated with a heightened awareness or reporting of pain, or a result of chronic pain,²⁷ while impulsivity and risk-taking behaviors of attention-deficit/hyperactivity disorder may increase the risk for injury.²⁸ Rarely, tics may result from traumatic brain injury.²⁹

In agreement with previous findings, TS was associated with many aspects of health and functioning for children and their families, including health care needs, parenting stress, and educational outcomes.^{7, 8} Our finding of 14.9% of children with TS repeating a grade (compared to 6.7% of children without TS) was similar to 12% previously reported in a sample of children with TS.¹⁹ In agreement with 2007 findings from the same survey, children with TS were equally likely as those without TS to receive preventive care, but were more likely to receive treatment from a mental health professional and less likely to receive coordinated care or have a medical home.⁷ In addition, children with TS were more likely to have an unmet mental health care need. While 86% of children with TS had a co-occurring neurobehavioral disorder, only 55% of children with TS received mental health treatment or counseling. Aspects of the medical home model have been shown to be associated with improved health and related outcomes among children with special health care needs.³⁰ Specifically, it has been suggested that improving care coordination – a component of the medical home – may be of particular benefit to children with TS given the complexity of the condition and high prevalence of co-occurring conditions.^{10, 31}

The reported findings are subject to certain limitations. The overall response rate for the 2011–2012 National Survey of Children's Health was low.¹⁶ Although the data were weighted to account for bias associated with non-response, it is possible that some non-response bias remains. However, the findings reported here are within the range of previous studies on the prevalence and epidemiology of TS.² The survey relies on parent report without any clinical examination. However a recent study found very similar prevalence estimates of attention-deficit/hyperactivity disorder based on parent-reported diagnosis on the National Survey of Children's Health and health claims data, providing some convergent validity for the parent-report methodology.³² Nevertheless, children without access to care who were not diagnosed are not included in diagnosis-based enumeration of prevalence. Furthermore, mis-diagnoses cannot be detected, and may contribute to the high co-occurrence of TS and ASD reported here. Finally, since this is a broad survey on children's health, specific data relevant to TS including the prevalence of co-occurring obsessive-compulsive disorder and specific treatment types were not available.

Given the prevalence and impact of co-occurring neurobehavioral conditions among this nationally representative sample of children with TS, these findings support the recommendations in the European clinical guidelines and among general expert opinion, that diagnosis and treatment of TS should include continued assessment of the presence and impact of co-occurring conditions.^{33, 34} A medical home including care coordination across medical, community and education services and in partnership with the family is recommended for all children to improve their care, health, and functioning.¹³ Future research is needed that addresses the existing knowledge gap regarding the extent to which effective care coordination in a medical home impacts functional improvements for children with TS.

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Table 1

Neurobehavioral and other chronic health conditions included* in the 2011–2012 National Survey of Children's Health

Neurobehavioral Conditions	Other Chronic Health Conditions
Tourette Syndrome (TS)	Hearing problems or vision problems that cannot be corrected with standard glasses or contact lenses
Attention-deficit/hyperactivity disorder	Asthma
Behavioral or conduct problems, such as oppositional defiant disorder or conduct disorder	Bone, joint, or muscle problems
Depression	Brain injury or concussion
Anxiety problems	Diabetes**
Autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder	Epilepsy or seizure disorder**
Learning disability	Cerebral palsy**
Developmental delay	
Intellectual disability or mental retardation	
Speech or other language problems	

* Parents were asked if a doctor or other health care provider (or a teacher or school official for learning disability) ever told them their child had the specified conditions.

** Estimates of these conditions, including diabetes, epilepsy or seizure disorder and cerebral palsy were considered unreliable due to their low prevalence of co-occurrence with TS and were not included.

Table 2

Prevalence of children aged 6–17 years with parent-reported current Tourette Syndrome (TS), by selected characteristics - National Survey of Children's Health, 2011–2012

Characteristic	No. in Sample (unweighted)	No. with current TS (unweighted)	Weighted prevalence % (95% CI)	Prevalence Ratio of weighted estimates (95% CI)
Total	65,540	153	0.19 (0.15–0.25)	---
Sex				
Male	33,949	128	0.32 (0.24–0.42)	5.3 (2.8–10.1)
Female*	31,591	25	0.06 (0.03–0.11)	1.0
Age (years)				
6–11*	31,007	63	0.14 (0.10–0.21)	1.0
12–17	34,533	90	0.24 (0.17–0.34)	1.6 (1.0–2.7)
Race/Ethnicity				
White non-Hispanic*	43,075	114	0.29 (0.21–0.39)	1.0
Black non-Hispanic	6,168	6	0.04 (0.02–0.11)***	0.1 (0.1–0.4)
Hispanic	8,051	13	0.10 (0.04–0.24)***	0.3 (0.1–0.9)
Highest Household Education*				
High school diploma or less	31,423	76	0.17 (0.11–0.25)	0.7 (0.4–1.2)
At least some college or technical school*	30,408	69	0.23 (0.16–0.33)	1.0
Federal poverty level (FPL)				
200% FPL	20,515	56	0.19 (0.12–0.29)	1.0 (0.6–1.7)
>200% FPL*	45,025	97	0.19 (0.14–0.27)	1.0

CI: Confidence interval

* Referent group

** Education of parents or adult respondent.

*** Relative standard error is 30–50%; the estimate should be interpreted with caution.

Table 3
Prevalence of parent-reported co-occurring neurobehavioral and other chronic health conditions among children aged 6–17 years with and without Tourette Syndrome (TS) - National Survey of Children's Health, 2011–2012

Ever-diagnosed conditions	Condition Co-occurring with Current TS		Condition, but No TS	
	% (95% CI)	aPR (95% CI)	% (95% CI)	% (95% CI)
Neurobehavioral Conditions	86.5 (75.8–92.9)	3.0 (2.6–3.5)	23.5 (22.8–24.2)	
Attention-deficit/hyperactivity disorder (ADHD)	63.0 (50.0–74.3)	4.2 (3.2–5.5)	12.2 (11.6–12.7)	
Behavioral problems**	26.4 (16.8–38.8)	4.2 (2.6–6.9)	4.8 (4.5–5.2)	
Depression	25.0 (15.9–37.0)	4.2 (2.6–6.8)	4.8 (4.5–5.3)	
Anxiety problems	49.3 (36.6–62.0)	6.2 (4.4–8.8)	6.3 (6.0–6.7)	
Autism Spectrum Disorder	35.4 (23.8–49.1)	9.3 (5.9–14.8)	2.4 (2.2–2.7)	
Learning Disability	47.4 (34.7–60.6)	3.1 (2.2–4.4)	12.0 (11.4–12.6)	
Developmental Delay	30.0 (19.2–43.6)	4.1 (2.5–6.8)	5.7 (5.3–6.0)	
Intellectual Disability	12.0 (4.9–26.6)*	7.5 (3.0–18.8)	1.4 (1.2–1.6)	
Speech/language problems	29.2 (18.8–42.3)	2.4 (1.5–3.9)	8.9 (8.4–9.3)	
Other Chronic Health Conditions	42.6 (30.7–55.4)	1.5 (1.1–2.1)	25.8 (25.1–26.6)	
Hearing or vision problem	12.8 (6.6–23.3)	2.0 (1.0–4.1)	5.5 (5.1–5.9)	
Asthma	27.5 (18.0–39.7)	1.5 (0.9–2.3)	17.5 (16.8–18.1)	
Bone, joint or muscle problems	12.4 (6.6–22.0)*	2.9 (1.5–5.7)	3.8 (3.5–4.2)	
Brain injury or concussion	9.4 (4.1–20.2)*	1.9 (0.8–4.7)	3.4 (3.1–3.7)	

CI: Confidence Interval; aPR = prevalence ratio adjusted for age, sex and race/ethnicity.

* Relative standard error is 30–50%; estimates should be interpreted with caution.

** Behavioral or conduct problems such as oppositional defiant disorder or conduct disorder.

Table 4
 Association of Tourette Syndrome (TS) among children aged 6–17 years with and without parent-reported TS with selected indicators of health and functioning - National Survey of Children's Health, 2011–2012

Selected Indicators of Health and Functioning	No TS		Current TS		aPR ^{††} (95% CI)
	% (95% CI)	% (95% CI)	% (95% CI)	aPR [†] (95% CI)	
Meets criteria for children with special health care needs	23.8 (23.1–24.5)	80.9 (68.2–89.4)	3.2 (2.7–3.8)	2.1 (1.5–2.9)	
High parenting aggravation	7.9 (7.4–8.4)	26.2 (16.6–38.8)	3.4 (2.1–5.3)	2.0 (1.2–3.4)	
Repeated a grade in school other than kindergarten	6.7 (6.2–7.2)	14.9 (7.2–28.2)*	2.1 (1.0–4.4)	1.1 (0.5–2.7)	
Parent contacted about a school problem	31.6 (30.7–32.4)	58.0 (44.8–70.2)	1.8 (1.4–2.3)	1.2 (0.8–1.7)	
Received preventive medical care in past year	94.6 (94.2–95.0)	96.6 (90.6–98.8)	1.0 (1.0–1.1)	1.0 (1.0–1.1)	
Received treatment or counseling from a mental health professional	11.3 (10.8–11.9)	54.7 (41.8–67.1)	4.2 (3.1–5.5)	2.0 (1.4–2.7)	
Seen a specialist (other than mental health)	23.6 (22.9–24.3)	40.9 (29.0–54.0)	1.4 (1.0–2.0)	1.2 (0.8–1.9)	
Receives effective care coordination	65.7 (64.5–67.0)	36.6 (24.5–50.6)	0.5 (0.3–0.7)	0.7 (0.5–0.9)	
Has a medical home	52.6 (51.7–53.5)	33.7 (22.7–46.7)	0.5 (0.3–0.8)	0.7 (0.5–1.0)	
Has an unmet medical need	45.4 (42.2–48.7)	19.3 (7.0–43.2)*	0.5 (0.2–1.2)	0.5 (0.2–1.3)	
Has an unmet mental health care need	15.1 (13.2–17.3)	41.7 (20.4–66.6)*	2.4 (1.3–4.4)	1.7 (0.9–3.3)	

CI = confidence interval; aPR[†] = prevalence ratio adjusted for age, sex and race/ethnicity; aPR^{††} = prevalence ratio adjusted for age, sex, race/ethnicity, and co-occurring neurobehavioral conditions including attention-deficit/hyperactivity disorder, behavioral or conduct problems, depression, anxiety problems, autism spectrum disorder, learning disability, developmental delay, intellectual disability, and speech or language problems.

* Relative standard error is 30–50%; estimate should be interpreted with caution.