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# Prevalence of Tourette syndrome among children and adolescents in the United States, 2016–2022

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## Abstract

**Background** Tourette syndrome (TS) is a neurodevelopmental disorder. The prevalence of TS in 2016–2017 has been reported; however, little is known about the current prevalence and trend in children and adolescents with TS. This study aimed to estimate the prevalence and trend of Tourette syndrome (TS) among US children and adolescents aged 0–17 years from 2016 to 2022.

**Methods** We analyzed data from a nationally representative sample of 278,472 children and adolescents aged 0–17 years who participated in the 2016–2022 National Survey of Children's Health (NSCH), a nationwide, population-based, cross-sectional survey of US children and adolescents. TS was defined as the affirmative response in the questionnaire completed by a parent or guardian.

**Results** Among the 278,472 children and adolescents enrolled, 754 had been diagnosed with TS, with an overall prevalence of 0.23% in all children and adolescents aged 0–17 years. The weighted prevalence by age group was lower than 0.01% in children aged 0–2 years, 0.05% in children aged 3–5 years, 0.28% in children aged 6–11 years, and 0.38% in adolescents aged 12–17 years. There were significant sex and racial/ethnic differences in the overall prevalence of diagnosed TS (i.e., 0.35% in boys and 0.11% in girls, 0.22% in Hispanics, 0.28% in non-Hispanic whites and 0.16% in non-Hispanic blacks). There was no significant change in the estimated prevalence of TS from 2016 to 2022.

**Conclusion** Based on nationally representative data, this study found that the national prevalence of TS among the US children and adolescents differed by sex and race/ethnicity but remained stable from 2016 to 2022.

**Keywords** Tourette syndrome, Prevalence, Developmental disorders, National Survey of Children's Health

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## Introduction

Tourette syndrome (TS) is a neurodevelopmental disorder characterized by multiple motor tics and at least one vocal tic lasting more than 1 year [1]. Although TS often improves in older teens/young adulthood, roughly three-quarters of children with TS still have tic symptoms in early adulthood [2, 3]. Several adverse outcomes have been associated with TS. Individuals with TS, including children, adolescents, and adults, are reported to experience mild-to-moderate functional impairments in areas of physical, psychological, academic, family, and social functioning [4–7]. Children with TS undergo



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more victimizing and perpetrating bullying than children without TS [8]. A prospective study found that individuals with TS were at a higher risk for premature death [9]. Moreover, multiple comorbidities, including anxiety, attention-deficit hyperactivity disorder (ADHD), and obsessive-compulsive disorder (OCD), have been reported in patients with TS, resulting in additional adverse outcomes [10, 11].

While previous studies have reported the national prevalence of some neurodevelopmental disorders, such as autism spectrum disorders (ASD) and ADHD, among children in the US and other countries [12–15], limited data are available on the estimates of the prevalence of TS in children [16–18]. In the US, the 2007 National Survey of Children's Health (NSCH) is the first national, population-based survey of people under 18 years of age concerning questions of TS [19]. According to 2007 NSCH data, it is estimated that 0.30% of American children and adolescents between the ages of 6 and 17 years have been diagnosed with TS [20]. Subsequent analyses using NSCH data from 2011–2012 and 2016–2017 estimated that the prevalence of TS among US children and adolescents between the ages of 6 and 17 years was 0.28% and 0.30%, respectively [8, 21].

In recent years, the onset and diagnosis of TS have increased among children under six years of age [22, 23]. Additionally, as two common comorbidities of TS, the prevalence of ADHD has been increasing in recent years [12], and the prevalence of OCD varies across regions [24]. Therefore, we also wanted to know whether TS prevalence has changed in recent years. In the present study, we analyzed nationally representative data from 2016–2022 NSCH annual surveys to estimate the most recent prevalence of TS among US children and adolescents aged 0–17 years. Additionally, we aim to examine whether the estimated TS prevalence has changed over those years.

## Methods

### Study population

The NSCH is an annual health survey sponsored and guided by the Health Resources and Services Administration Maternal and Child Health Bureau [25]. The NSCH was conducted periodically by the National Center for Health Statistics until the 2011–2012 cycle and annually by the US Census Bureau since 2016 with a change in survey design [26]. The NSCH provides rich data related to children's physical and mental health, and it is considered a valuable source to measure children's health and related healthcare systems in the US. The National Center for Health Statistics Research Ethics Review Board approved all data collection procedures for the survey. More information about the NSCH can be found elsewhere [27].

### Data collection

Information on TS among children and adolescents aged 0–17 years was collected in the NSCH data from 2016 to 2022. TS was defined by a parent/guardian's affirmative answer to the question [21, 27]: "Has a doctor or other health care provider ever told you that this child has Tourette syndrome?". Among the NSCH participants, 99.59% responded to this question. Information on age, sex, race/ethnicity, household income, and the highest level of education of the parent living with the child was collected using a standardized questionnaire. Race and Hispanic ethnicity were classified based on the 1997 Office of Management and Budget Standards. Household income levels were classified as less than 1.0, 1.0 to 1.9, 2.0 to 3.9, and 4.0 or higher than the Census Bureau's family poverty threshold according to the survey year-specific household income to poverty ratio guidelines.

We also collected information about the comorbidities of TS, including ADHD, anxiety, depression, ASD, behavioral problems, developmental delay, intellectual disability, learning disability, and speech or language disorder. OCD is also a common comorbidity of TS but was not included in the NSCH.

### Statistical analysis

In all the data analyses, we considered survey weights, strata, and primary sampling units to account for the complex survey characteristics, including unequal probabilities of selection, oversampling, and non-response. We estimated the national prevalence of TS based on demographic characteristics, including age, sex, race/ethnicity, parental education, and household income to poverty ratio. Chi-square tests were used to calculate *P*-values for overall differences in prevalence or percentages of different stratifications. With year as a continuous variable, a weighted logistic regression model was used to test trends in prevalence over time, adjusting for age, sex, and race/ethnicity. All analyses were performed using the survey procedures in SAS version 9.5 (SAS Institute, Cary, NC). Two-sided *P* < 0.05 was considered statistically significant.

### Results

This study included a nationally representative sample (*n* = 278,472) of children and adolescents aged 0–17 years (mean age 9.05 ± 5.27 years, 144,056 boys [51.73%]). Among these children, 754 had ever been diagnosed with TS, and the overall weighted TS prevalence was 0.23% from 2016 to 2022 (Table 1). TS prevalence did not differ significantly regarding parental education and family income. However, significant differences were found between boys and girls, as well as among different age and racial/ethnic groups (Table 1).

**Table 1** Characteristics of the participants with TS among the US children and adolescents aged 0 to 17 years, 2016–2022

Characteristic	Participants, No. (%) <sup>a</sup>			P Value <sup>c</sup>
	Overall	With TS	TS Prevalence, % <sup>b</sup>	
Overall (0–17 years)	278 472	754	0.23	
3–17	238 603	750	0.28	
5–14 years	119 172	363	0.29	
6–17 years	188 807	727	0.33	
Age, y				
0–2	39 869	4	< 0.01	< .0001
3–5	49 796	23	0.05	
6–11	82 081	228	0.28	
12–17	106 726	499	0.38	
Sex				
Boys	144 056	557	0.35	< .0001
Girls	134 416	197	0.11	
Race/ethnicity				
Hispanic	36 054	85	0.22	0.02
Non-Hispanic white	187 626	564	0.28	
Non-Hispanic black	17 482	35	0.16	
Other	37 310	70	0.18	
Highest household education				
Less than High School	6 902	19	0.19	> 0.05
High School graduate	35 766	107	0.24	
More than High School	234 617	627	0.24	
Family income to poverty ratio				
< 1.0	22 410	70	0.18	> 0.05
1.0–1.9	32 528	103	0.27	
2.0–3.9	71 259	169	0.22	
≥ 4.0	101 408	287	0.24	

<sup>a</sup> The numbers of participants overall and with TS were unweighted

<sup>b</sup> Prevalence estimates were weighted

<sup>c</sup> P values for overall differences in prevalence by stratum

Boys were more likely to have TS than girls (0.35% vs. 0.11%,  $P < 0.05$ ). TS prevalence increased as the children's age increased. Adolescents aged 12–17 years had the highest TS prevalence (0.38%), and children aged 0–2 years had the lowest TS prevalence (less than 0.01%). Non-Hispanic whites were more likely to have TS than non-Hispanic blacks (0.28% vs. 0.16%,  $P < 0.05$ ) (Table 1). Anxiety and ADHD were the two most common comorbidities for TS, with a prevalence of 52.04% and 49.11%, respectively (Fig. 1).

For the trend analysis, although there were swings in some years, there was no significant change in the estimated prevalence of diagnosed TS among US children

and adolescents from 2016 to 2022 ( $P$  for trend  $> 0.05$ ) (Fig. 2). The prevalence of TS among adolescents ( $\geq 12$  years) was higher than that among children aged 0–11 years (Fig. 3). There was significant increasing trend for three comorbidities of TS ( $P$  for trend  $< 0.05$ ) (Supplementary Fig. 1).

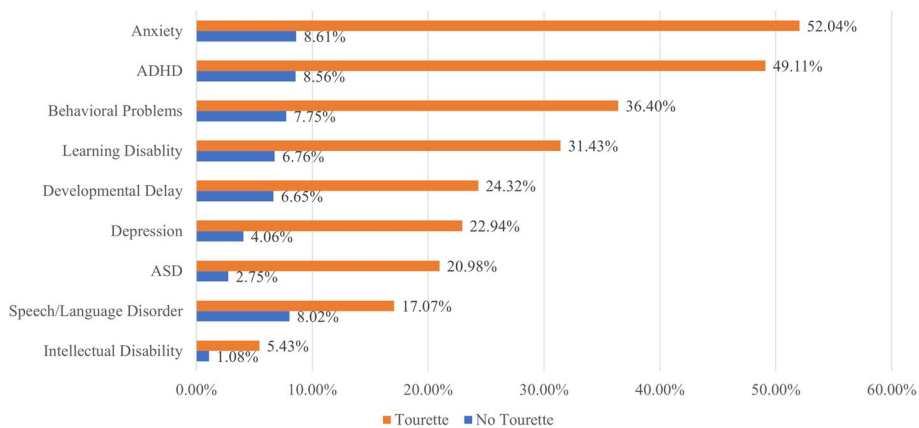
## Discussion

In this nationally representative sample of US children and adolescents, we found that the prevalence of diagnosed TS was 0.23% from 2016 to 2022, and the prevalence did not change significantly during the 7 years.

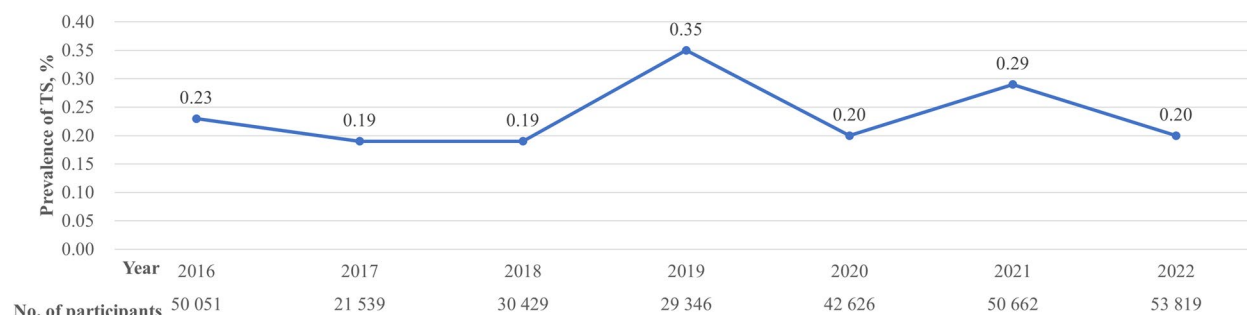
In this study, TS prevalence estimates were 0.33% for children aged 6–17 years, which was similar to the prevalence estimates reported in two previous studies for children in this age range (0.30% and 0.28%, respectively) [20, 21], using different cycles of NSCH data. This suggests that although the survey was re-designed after 2016 [27], TS prevalence from the national population survey was relatively stable.

Although TS prevalence estimates did not change significantly in different cycles of NSCH data, there has been an argument that survey data often rely on parental reports of previous diagnoses, which can lead to recall bias and miss individuals who have not been diagnosed [18]. For example, two partially overlapping systematic reviews and meta-analyses reported much higher TS prevalence, 0.77% [16] in children aged 5–14 years and 0.70% [28] in children aged 0–17 years, respectively. Considering 0.29% for children aged 5–14 years and 0.23% for children 0–17 years in our study, half of children with TS did not receive a formal diagnosis if these estimates from meta-analyses were reliable. Besides possible recall bias in population survey data, several reasons might also be considered for this difference. First, the two meta-analyses included studies from different countries across North and South America, Europe, and Asia. Prevalence variability in those countries might contribute to the difference. Second, both meta-analyses included studies across a long period, from the 1990s to the 2010s. Therefore, the diagnostic criteria varied across the studies. For example, three versions of the DSM and ICD systems were used in the included studies. Third, it could be challenging to distinguish TS, other persistent tic disorders, and functional tic-like behaviors. Children with other tic disorders or functional tics might be misdiagnosed as TS, which could lead to a higher estimate of TS prevalence.

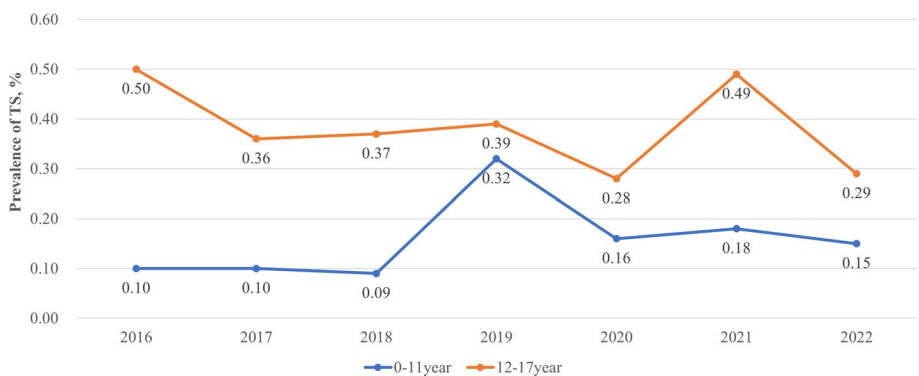
Although the prevalence of common comorbidities of TS, including ADHD and ASD, has continued to increase over the past two decades [12, 13], no significant change was found in the prevalence of TS in our study. The reason remains to be understood. Biological and genetic



**Fig. 1** Prevalence of comorbidities of TS among children and adolescents aged 0 to 17 years, 2016–2022



**Fig. 2** Trend in the prevalence of diagnosed TS among the U.S. children and adolescents aged 0 to 17 years, 2016–2022 ( $P > 0.05$ )



**Fig. 3** Trends in the prevalence of diagnosed TS among the U.S. children and adolescents aged 0 to 17 years, 2016–2022 ( $P > 0.05$ )

factors might play a more important role in TS etiology than environmental factors, compared to ASD and ADHD.

This study has several strengths. First, this study provides up-to-date information on TS prevalence among US children and adolescents aged 0–17 years using nationally representative data. Second, using a series of nationwide population-based surveys, we were able to assess trends

in the prevalence of TS over the past seven years. Third, a large sample from various communities allowed us to compare TS prevalence among groups with different population characteristics. There are also two limitations. First, TS diagnosis history was reported by parents, which may have been affected by recall bias. Second, from 2016 to 2022, the highest survey response rate was 43.1%, so non-response

bias could exist. Further studies with other data resources are warranted to validate the results of this study.

## Conclusion

In a nationwide population-based study of US children and adolescents, we found that the overall TS prevalence from 2016 to 2022 was 0.23% for 0–17-year-olds and 0.33% for 6–17-year-olds. No significant change was found over the 7 years.

## Abbreviations

TS	Tourette syndrome
ADHD	Attention-deficit hyperactivity disorder
ASD	Autism spectrum disorders
NSCH	National Survey of Children's Health

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12889-024-20216-2>.

Supplementary Material 1: Supplementary Figure 1. Trends in the prevalence of diagnosed ADHD, anxiety, and ASD among the U.S. children and adolescents aged 0 to 17 years, 2016–2022 ( $P < 0.05$ ).

## Acknowledgements

Not applicable.

## Authors' contributions

GX conceptualized and designed the study, had full access to all of the data in the study, and took responsibility for the integrity of the data. YX and GX drafted the manuscript. YX, MO'B and GX carried out the data analyses and interpreted the data. WY, XZ, WB critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

## Funding

None.

## Availability of data and materials

The dataset used in this study is the 2016–2022 National Survey of Children's Health, which is publicly available from the websites of the Health Resources and Services Administration (<https://www.childhealthdata.org/browse/survey>) and the Data Resource Center for Child and Adolescent Health (<https://www.childhealthdata.org/>).

## Declarations

### Ethics approval and consent to participate

The National Survey of Children's Health data collection was approved by the US National Center for Health Statistics Research Ethics Review Board and the Associates Institutional Review Board.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

Received: 28 January 2024 Accepted: 27 September 2024

Published online: 03 October 2024

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