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Systematic Literature Review on Public Health Impacts of Persistent Tic Disorders Health Care Needs and Health Care Use

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INTRODUCTION

Approximately 1 in 50 children has a persistent tic disorder (PTD), including Tourette syndrome (TS).¹ A PTD diagnosis requires the presence of motor and/or vocal tics before age 18 years that persist for at least 1 year and are not due to another medical condition.² Although PTD symptoms may lessen in severity or resolve by young adulthood, they can persist throughout the lifespan.³ PTDs are associated with negative outcomes across the lifespan related to education, family and social functioning, quality of life, and engagement in health risk behaviors.⁴⁻⁶ Public health can play a role in supporting individuals with PTDs through the provision of the 10 essential public health services, which include monitoring health status, diagnosing and investigating health problems, and ensuring the availability of essential health services.⁷

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DISCLAIMER

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DISCLOSURE

The authors have nothing to disclose.

PTD outcomes can be improved by early identification of PTDs and receipt of evidence-based treatment when needed.^{8,9} Approximately half of children with TS are undiagnosed.¹ Underdiagnosis of TS may be more common in Black and Hispanic populations,^{4,10} suggesting possible disparities in health care access. Among US children diagnosed with TS, half saw at least 3 health care providers before being diagnosed.¹¹ A lack of knowledge or comfort in the identification and treatment of tic disorders may contribute to underdiagnosis.^{12,13}

Identification of PTDs requires access to health care, and treatment of PTDs often necessitates access to specialty health care.^{8,9} Professional organizations in the United States, Canada, and Europe have published diagnostic and treatment guidelines that describe evidence-based practice for caring for children and adults with PTDs.^{8,9,14,15} The guidelines each describe the assessment of PTDs, recommend psychoeducation about PTDs for individuals with these disorders and their families, and review the evidence base for behavioral and pharmacologic treatments as well as deep brain stimulation.

To inform improved health and well-being among individuals with PTDs, the authors conducted a systematic literature review focusing on health-related indicators and outcomes associated with tic disorders (herein referred to as outcomes) addressable through public health activities.¹⁶ This article summarizes the literature related to health care access, health care needs, and health care use among children and adults with PTDs compared to those without PTDs. The information from this review can inform future research, practice, and policies to improve identification and treatment of tic disorders.

METHODS

Literature Review

We conducted a broad literature search to identify outcomes associated with PTDs; the full search is described here, as well as findings related to health care; other outcomes will be summarized in future studies. The literature search was conducted on July 6, 2023, using Medline, Embase, PsycInfo, Cochrane library, CINAHL, and Scopus. Although we proposed several a priori associated outcomes of interest (eg, health care, social, education), our search was intentionally broad to capture emergent outcomes in the literature. The Medline search terms were “tic disorders/OR TS/OR Tics/ OR (Tourette* OR tic disorder* OR tics OR (involuntary ADJ2 [twitch* OR movement* OR sound* OR vocalization* OR noise* OR gestur*])).ti,ab,kf. AND (Public health OR epidemiolog* OR surveillance OR survey* OR “quality of life” OR QoL OR cost* OR impact* OR burden).ti,ab,kf,hw. OR ep.fs OR px.fs” (Table 1 specifies all search terms). The search was limited to English language publications with no restrictions on year of publication, age of individuals with PTDs, or geographic location, and identified 6510 articles.

Title and Abstract Screening

The titles and abstracts of all 6510 articles were screened in Covidence by 2 independent reviewers, with disagreements adjudicated by a third reviewer. No automation tools were used to identify articles for inclusion or exclusion. Articles were excluded using the

following criteria: (1) the study involved nonhuman participants; (2) the title or abstract explicitly stated that the article was a research protocol only; (3) the article focused on nonrelevant “tics” retrieved by the search terms (eg, tick, trauma-informed care [TIC]); (4) the article focused on tardive dyskinesia, Parkinson’s disease, schizophrenia, Huntington’s disease, dystonias, functional tics, psychogenic tics, transient tics, or provisional tics, rather than PTDs; (5) the article was a book review, video, poster, slide, or personal account; (6) the article was not peer reviewed (eg, dissertations); (7) the article reported on a study with less than 10 participants; and (8) conference abstracts. This resulted in the exclusion of 4076 articles (Fig. 1).

Full-text Screening

The research team conducted full-text screening on the remaining 2434 articles. Eligible outcomes were those identified as potentially modifiable through public health activities (Fig. 2). Overarching categories and examples of eligible and ineligible outcomes within the health care needs and use category were identified based on existing knowledge and continuously refined over the course of the review. All changes were then retrospectively applied to all previously screened articles. Exclusion criteria at this stage included those applied to the title and abstract review and (1) articles with no eligible outcomes (see below and Fig. 2); (2) reviews and meta-analyses; and (3) surveys of health care providers or educators about their experiences with PTDs. We also excluded articles focusing on prevalence of co-occurring mental, behavioral, and developmental disorders (MBDDs), and symptoms of these disorders (eg, behavioral problems, executive function), among individuals with PTDs to avoid duplication with the substantial literature documenting the prevalence of these disorders among individuals with PTDs.^{8,9,14,15} One exception was that we included studies of substance-use disorders and substance use as eligible health risk behaviors. Examples of other ineligible outcomes included studies on the knowledge of tic disorders, instrument psychometrics, prevalence of PTDs, neurobiology of tic disorders, and studies focused on characteristics of tic disorders (eg, type of tic, severity). Most articles were reviewed by 2 reviewers, including in all cases where these exclusion criteria were not clearly present.

We excluded 1826 articles at this stage. As part of this review, we identified 5 additional eligible articles that were missed in the initial literature search or screened out in an earlier stage; these articles were identified by reviewing methodology papers cited by articles during full-text review. This resulted in 613 articles for potential extraction.

Full-text Extraction

Full-text extraction focused on studies with comparison groups without PTDs from any geographic location published in 2003 or later. Two reviewers conducted extraction in Covidence; a third reviewer conducted a consensus review. Data extracted included study location, year(s) of data collection, whether the sample was recruited from a tic disorder specialty clinic, types of PTDs (eg, TS only), how PTDs were identified including which assessments and diagnostic criteria were used, type of comparison group (eg, general population, normative data), source of data for outcome measures (eg, parent-report,

administrative data), type of study (eg, cohort, case-control), participant characteristics (eg, age, sex, race/ethnicity), and eligible outcomes.

Several decisions for extracting data consistently across articles were documented. Treatment prevalence was included when it was a key study outcome and not when it was included as part of the sample description. In articles with multiple comparison groups, the group that was most similar to the general population was selected. In articles with multiple PTD groups (eg, TS only, TS and ADHD, ADHD only), we coded TS only compared to a comparison group or, if no true comparison group, compared with the co-occurring condition only (eg, ADHD only) group. We included studies with PTDs and transient tic disorders that could not be disaggregated and refer to these as PTDs; groups are shown in Table 2. Cross-sectional studies and studies where the outcomes were measured after the PTD diagnosis were included, while studies where the eligible outcome was a predictor of tic onset or severity and measured before tic onset were excluded. For example, articles examining cross-sectional association of infections and PTDs were included,¹⁷ but if the infection was documented before tic onset or a change in tic severity, the article was excluded.¹⁸ We focused on prevalence estimates when available, or unadjusted (or least adjusted) results for comparability across studies.

During this stage, we also excluded 6 articles with substantial or complete overlap of participants and eligible outcomes; in these cases, we kept the articles with larger sample sizes or with the most representative PTD and comparison groups (eg, not stratified by an additional variable). This resulted in 167 articles for inclusion. Fifteen of these articles reported on outcomes related to health care (eg, access, treatment) and are summarized here.

CURRENT EVIDENCE

Characteristics of the 15 articles are summarized in Table 2 and Table 3. All studies were from North America (7 from United States, 1 from Canada) or Europe (3 United Kingdom, 2 Spain, 1 France, 1 Sweden). Only 2 studies included adults.^{19,20} Seven studies assessed clinical criteria for PTDs, 3 identified PTDs using medical records or claims data, and 5 identified PTDs based on caregiver or self-report of a previous diagnosis. Thirteen studies reported the sex distribution for individuals with PTDs; of these, the PTD group was at least 75% male in 6 studies. Of the 6 studies that reported on race or ethnicity, over 80% of the PTD group was White in 5 of the studies; in the sixth study, race/ethnicity was only reported for the full sample using health care claims data.²¹ Seven of the 15 articles included only TS, while the other 8 articles included a combination of tic disorders. Two studies reported findings for TS and chronic tic disorder separately.^{21,22} Outcomes were measured using parent-report or self-report in 12 studies, data from health care records in 2 studies, and a combination of parent-report and self-report and health care records in one study (see Table 3). Four studies from North America were nationally representative, and a fifth included health care claims data from multiple US states; 5 studies were population-based with recruitment from schools (n = 2) or the community (n = 3), 4 were clinic based, and one used a convenience sample to complete an online survey. Nine studies included less than 100 individuals with PTDs and only one included more than 200 individuals with PTDs.

The studies are summarized in 6 outcome categories: routine care, specialty mental health care, other specialty care, medication use, nutritional supplements and special diets, and quality and satisfaction with care.

Routine Care

Based on four studies in the United States and Europe, children with and without PTDs had similar access to, and use of, routine care.

North American (United States) Studies

A. Bitsko, 2013: Nationally representative sample, 2007²³

Children with current TS and a comparison group of children who never had TS or asthma had similar prevalence of having a usual source of sick care (94.7% vs 92.9%).

B. Bitsko, 2014: Nationally representative sample, 2011 to 2012⁴

1. A similar percentage of children with and without TS received preventative medical care in the past year (96.6% vs 94.6%).
2. The percentage of children with TS with an unmet medical need in the past year was lower than that for children without TS, although the difference was not statistically significantly (19.3% vs 45.4%).

European Studies

A. Khalifa, 2005: Community-based study (Sweden)²²

A small percentage of children with TS, 4% (n = 1), had no contact with medical care, although a higher percentage of children with chronic vocal tics (50%) or chronic motor tics (67%) had no contact with medical care. This was compared to 88% of children with transient tics with no contact with medical care.

B. Jalenques, 2017: Community-based study (France)²⁴

1. A similar percentage of children with and without TS were “followed by” a general health practitioner (69.3% vs 72.0%).
2. A smaller percentage of children with TS were “followed by” a pediatrician compared to children without TS, although the difference was not statistically significant (4.0% vs 13.3%).

Specialty Health Care Use: Mental Health

Five North American and 2 European studies reported on mental health service needs and use; one of the 5 North American studies included adults with TS in Canada.²⁰ Indicators included mental health service use in general, mental health consultation, in-patient and out-patient care, and emergency mental health care. These studies consistently reported that individuals with PTDs needed and used more mental health services compared to those without PTDs.

North American Studies of Mental Health Care Use

- A.** Scahill, 2006: Community-based study (United States)²⁵
- The percentage of children with any tic disorder who used mental health services was twice that of the comparison group, although the difference was not statistically significant (33.3% vs 15.5%).
- B.** Olfson, 2011: Health care claims data for children (United States)²¹
- Percentage of children with claims for mental health care services over one calendar year was higher for those with PTDs (TS and chronic tic disorders [CTD]) compared to children without PTDs, including claims for
1. Mental health assessment for publicly insured (10.5% TS, 6.6% CTD, 1.6% no PTD) and privately insured children (24.0% TS, 15.5% CTD, 2.8% no PTD);
 2. Psychotherapy for publicly insured (16.7% TS, 10.1% CTD, 2.4% no PTD) and privately insured (35.5% TS, 20.1 CTD, 4.0% no PTD);
 3. Inpatient mental health care for publicly insured (7.3% TS, 3.3% CTD, 0.5% no PTD) and privately insured (3.5% TS, 1.5% CTD, 0.3% no PTD);
 4. Emergency mental health care for publicly insured (8.7% TS, 6.5% CTD, 0.7% no PTD) and privately insured (2.6% TS, 2.4% CTD, 0.4% no PTD);
 5. Psychiatrist visits for privately insured (30.0% TS, 15.9% CTD, 2.1% no PTD; not reported for publicly insured).
- C.** Bitsko, 2013: Nationally representative sample, 2007 (United States)²³
- Children with TS were more likely than the comparison group of children without TS or asthma to
1. (Currently) have an emotional, developmental, or behavioral problem for which they needed counseling (56.0% vs 8.2%);
 2. (Currently) need or use more medical care, mental health care, or educational services (63.6% vs 11.6%, respectively);
 3. Have received treatment or counseling from a mental health professional in the past year (57.2% vs 8.9%).
- D.** Bitsko, 2014: Nationally representative sample, 2011 to 2012 (United States)⁴
- Children with TS were more likely than children without TS to
1. Receive treatment or counseling from a mental health professional in the past year (54.7% vs 11.3%);
 2. Have an unmet mental health care need in the past year (41.7% vs 15.1%).
- E.** Yang, 2017: Nationally representative survey (Canada)²⁰

Adolescents and adults with TS were more likely to consult a health professional regarding mental health issues in the past year compared to the general population (36.6% vs 12.5%).

European Studies of Mental Health Care Use

- A. Jalenques, 2017: Community-based study of children (France)²⁴
A larger percentage of children with TS compared to without TS were (currently) followed by a psychiatrist (45.3% vs 4.0%) or a psychologist (37.3% vs 4.0%).
- B. Zinna, 2021: Clinic-based study of children (United Kingdom)²⁶
Among children admitted for inpatient mental health care, children with PTDs had significantly longer stays compared to those without PTDs (mean 207.3 vs 135.1 days).

Specialty Health Care Use: Other than Mental Health

Five North American and 2 European studies reported on specialty care other than mental health; one study from the United States included adults with tic disorders.¹⁹ Types of specialty care included neurology, hospitalization, and therapy (such as physical or speech). Individuals with PTDs were generally more likely to use specialty health care services compared to children without PTDs. Underserved groups with PTDs may also experience difficulties accessing specialty care clinics. One exception was that there was no difference in the number of hospitalizations between children with PTDs compared to children with asthma.²⁷

North American (United States) Studies of Specialty Care other than mental health

- A. Gadow, 2009: Clinic-based study of children²⁸
Children with “chronic multiple tic disorder” and ADHD (CMTD; n = 66 including 62 with TS) were more likely than children with ADHD only to have ever been hospitalized for a nonpsychiatric medical condition (40% vs 20%).
- B. Olfson, 2011: Health care Claims data for children²¹
Percentage of children with claims for visits with a neurologist in one calendar year was higher for publicly insured children with PTDs than without PTDs (33.3% TS, 36.5% CTD, 0.9% no PTD; not presented for privately insured).
- C. Bitsko, 2013: Nationally representative sample of children in 2007²³
Children with TS were more likely than the comparison group of children without TS or asthma to
 - 1. (currently) need special therapy (25.0% vs 6.9%);
 - 2. Have seen a specialist other than a mental health professional in the past year (53.2% vs 21.4%).
- D. Bitsko, 2014: Nationally representative sample of children in 2011 to 2012⁴

Children with TS were more likely to have seen a specialist other than a mental health professional in the past year than children without TS (40.9% vs 23.6%).

E. Giacobbe, 2021: Clinic-based study¹⁹

This study focused on underserved (defined as those with Medicaid insurance or using self-pay) children and adults with movement disorders, including tic disorders.

1. Among children and adults with tic disorders, in a 15 year time period, 41.8% received rehabilitation, 1.5% (n = 1) received deep brain stimulation, and none received botulinum treatment. This compares to 34.4%, 6.5%, and 11.5%, respectively, for all underserved patients with any movement disorder (including tic disorders).
2. The median distance to a movement disorder center of excellence for individuals with a tic disorder was 69.66 km (across the 12 included movement disorders the distance ranged from 6.01 to 226.28 km).
3. A much smaller percentage (5.2%) of the individuals included in the study with movement disorders, including tic disorders, accessing specialty care met the underserved definition compared to 19.5% with Medicaid and 14.9% uninsured in the general population of Florida.

European Studies of Specialty Care other than mental health

A. Cooper, 2003: Clinic-based study of children (United Kingdom)²⁷

Children with TS had fewer previous hospitalizations compared to children with asthma (mean = 1.04 vs 5.92), although the difference was not statistically significant.

B. Jalenques, 2017: Community-based study of children (France)²⁴

A larger percentage of children with TS compared to without TS were followed by a neurologist (58.7% vs 2.7%).

Medication Treatment

Three US studies and 4 European studies reported on medication treatment among children with PTDs (no studies included adults). Studies reported on any medication use and/or specifically on psychotropic medication use. In the US studies, more children with PTDs used medications compared to children without PTDs; one finding in a smaller clinic-based study reported a significant result forever, but not current, use of medications. Two school-based studies from Spain found similar estimates of children with and without PTDs receiving medication, while a clinic-based study found that children with TS had fewer prescriptions compared to children with asthma. In a study of medication use at the time of admission to (and discharge from) mental health inpatient care, more children with PTDs than children without PTDs received medication.

North American (United States) Studies

A. Gadow, 2009: Clinic-based study²⁸

More children with PTD+ ADHD had ever taken a psychotropic medication compared to children with ADHD only (45% vs 6%); however, the difference was not significant for current psychotropic medication use (4% vs 0%) or for use of non-psychotropic medication (16% vs 15%).

B. Olfson, 2011: Health care Claims data for children²¹

More children with PTDs had claims in one calendar year for psychotropic medications compared to children without PTDs (public insurance: 85.1% TS, 62.0% CTD, 11.2% no PTD; private insurance: 73.3% TS, 48.9% CTD, 7.8% no PTD).

C. Bitsko, 2013: Nationally representative sample of children in 2007²³

Compared to children without TS, children with TS

1. Were more likely to currently need or use medicine prescribed by a doctor, other than vitamins (52.4% vs 17.1%);
2. Had taken medication for difficulties with emotions, concentration, or behavior, including for ADHD in the past year (42.6% vs 7.1%).

European Studies**A. Cooper, 2003: Clinic-based study of children (United Kingdom)²⁷**

Children with TS had fewer prescription medications than children with asthma (mean = 2.04 vs 3.12).

B. Cubo, 2013: School-based study (Spain)²⁹

A similar percentage of children with and without PTDs had a need for pharmacologic treatment (12.3% vs 9.4%).

C. Cubo, 2017: School-based study (Spain)³⁰

Pharmacologic treatment was similar among children with and without PTDs (6.6% vs 7.1%).

D. Zinna, 2021: Inpatient-clinic-based study (United Kingdom)²⁶

At the time of admission to inpatient mental health treatment, children with PTDs more often received medication compared to children without PTDs (72.1% vs 52.0%); this finding persisted at the time of discharge (93.0% vs 76.0%).

Nutritional Supplements and Special Diets

In one online study from the United Kingdom,³¹ children with TS were more likely to take nutritional supplements compared to children without TS (56% vs 15%) and were also more likely to have ever adopted a special diet (35% vs 6%).

Health Care Quality and Satisfaction with Care

Four studies were identified that addressed aspects of quality (eg, having a medical home,³² being prepared for transition for adult health care) and satisfaction with health care for children with PTDs (no studies were included for adults). Three US studies examined aspects of the medical home and health care transition using nationally representative data. Children with TS were less likely than children without TS to have care coordination or a medical home (the finding for medical home was not significant based on 2007 data)^{4,23} and had similar or better indicators of being prepared for transition to adult health care.³³ The fourth study from the United Kingdom found no differences between children with and without TS in satisfaction with inpatient mental health care.

North American (United States) Studies

Two of the studies presented on aspects of the medical home based on the US National Survey of Children's Health (NSCH).

A. Bitsko, 2013: Nationally representative sample, 2007²³

Compared to children without TS and asthma, in the past year, children with TS

1. Were less likely to have care coordination (43.7% vs 69.3%);
2. Had lower but not statistically different estimates for receipt of family-centered care (56.3% vs 64.5%);
3. Had lower but not statistically different estimates for having a medical home (38.9% vs 55.0%).

B. Bitsko, 2014: Nationally representative sample, 2011 to 2012⁴

Compared to children without TS, in the past year, children with TS

1. Were less likely to have care coordination (36.6% vs 65.7%);
2. Were less likely to have a medical home (33.7% vs 52.6%).

C. Leeb, 2020: Nationally representative sample, 2016 to 2017³³

Compared to children without a mental, behavioral, or developmental disorder, children with TS

1. Had a similar estimate of meeting criteria for a composite measure of health care transition planning (12.4% vs 14.2%);
2. Were more likely to have time alone with the provider, in the past year (48.9% vs 36.8%);
3. Were more likely to work with their provider to gain health management skills or understand health care changes (74.1% vs 59.7%).
4. Had a similar estimate of having had a conversation with their provider about the transition to adult health care (48.8% vs 50.8%);

European Studies

A. Zinna, 2021: Inpatient-clinic-based study (United Kingdom)²⁶

There were no differences in satisfaction with inpatient mental health care between children with and without PTDs and their parents.

DISCUSSION

The current evidence shows that children with PTDs have similar access to, and use of, routine care as children without PTDs, but that children and adults with PTDs generally need and use more specialty health care, including mental health services. Children with PTDs may be more likely to use medications than children in the general population but may not be compared to children with other chronic health conditions. Children with PTDs also had unmet mental health care needs and underserved groups may experience difficulties accessing specialty clinics. Based on a limited number of indicators, children with PTDs generally received similar quality of health care but were less likely to receive care coordination and somewhat less likely to have a medical home than children without PTDs. Based on nationally representative data for US children, approximately 2 in 5 children (43.7% in 2007, 36.6% in 2011–2012) had care coordination, and less than 2 in 5 had a medical home (38.9% in 2007, 33.7% in 2011–2012).^{4,23} Although the composite measure of health care transition planning did not differ between children with TS and children without MBDDs, the overall estimate was very low for both groups (12.4% TS vs 14.2% for children without MBDDs).³³

Although the identified literature documented more health care needs and specialty health care use among children with tic disorders than the general population, we identified several gaps in the literature. First, only 15 studies were identified that were published since 2003 and included a comparison group, and these studies were limited to North America and Europe. Most (10) of the included studies used data from 2000 to 2013, and only one study included data on over 200 individuals with PTDs. Among these studies there were limited data on adults, most included a majority of White participants, and only one stratified results by sociodemographic characteristics (Medicaid vs private insurance),²¹ which prevented summarizing the disparities beyond comparison to individuals without tic disorders. Only 2 studies included data stratified by tic disorder type (TS and chronic tic disorder).^{21,22} Most of the studies relied on parent or self-report; while these data may reflect individuals' experiences, additional data with objective measures (eg, medical records) would allow for validation of these findings. In addition, limited data were available on the use of behavioral therapy, and most indicators of mental health treatment were not specific (eg, use of psychotropic medication or psychotherapy) limiting inferences on whether treatments were evidence based (ie, specific medications and behavioral treatments recommended by professional guidelines). Only one study was available on health care transitions from adolescence to adulthood and no studies reported on costs associated with tic disorders. Future studies could prioritize recruitment of diverse populations, including comparison groups of individuals without PTDs, with large enough sample sizes to stratify by sociodemographic characteristics to document health disparities in access to and use of health care among individuals with PTDs. Ongoing documentation of health care needs

and health care use can inform future programmatic work to improve identification and treatment of PTDs.

The higher co-occurrence of mental disorders among children with PTDs compared to those without and professional guideline recommendations for behavior therapy and psychotropic medications as evidence-based treatments for tic disorders reflect the increased needs for these services for the long-term health and well-being of individuals with PTDs.^{8,9,14,15} Individuals with PTDs and co-occurring neurobehavioral or mental health disorders may experience more challenges with school, lower quality of life, and greater tic severity.^{4,11,20} Although co-occurring mental disorders are common among children with PTDs, findings based on US health care claims data in 2000 to 2007 reported a low percentage of children with TS and public insurance who had a mental health assessment (10.5%) or psychotherapy (16.7%); the corresponding numbers for privately insured children with TS were 24.0% and 35.5%.²¹ In addition, nationally representative data for US children in 2011 to 2012 showed that, based on parent report, just over half of children with TS received treatment from a mental health professional in the past year, and 2 in 5 had an unmet mental health care need in the past year.⁴ Together these data suggest possible unmet mental health care needs among children with PTDs.

Given the underdiagnosis of PTDs in the United States¹ and the findings reported here suggesting children with PTDs often have access to routine health care,^{4,22-24} improving identification and management of PTDs in primary care settings may improve specialized health care access for individuals with PTDs. Public health approaches that leverage policy and systems changes to improve population-level mental health care access have been described.^{34,35} The US Department of Health and Human Services Roadmap for Behavioral Health Integration can support opportunities for improved access to mental health services within primary care settings.³⁶ Telehealth is an approach that has been expanded since the coronavirus disease 2019 pandemic and may increase access to specialty care and evidence-based treatments among individuals with PTDs in underserved communities; although research on and quality guidelines for this population are limited.³⁷ Community health workers may also play a role in identification of tic disorders.¹⁰ To address providers self-reported lack of knowledge and comfort related to PTDs,^{12,13} provider trainings on the identification and management of PTDs, inclusive of co-occurring conditions, were developed and are available through the Tourette Association of America (TAA)^a and the American Academy of Pediatrics^b. In addition, TAA's Centers of Excellence^c are hubs for tic disorder coordinated care and specialist services; expansion of the expertise and referral networks from the Centers of Excellence to increase local provider capacity could help address gaps.

SUMMARY

In summary, this review documents specialty health care needs and health care use, including mental health care, among individuals, mostly children, with PTDs. There are

^a<https://tourette.org/resources/provider-webinar-series/>.

^b<https://www.aap.org/Tourette-Syndrome-Course-Series>.

^c<https://tourette.org/about-tourette/overview/centers-of-excellence/>.

numerous gaps in the literature that preclude conclusions on disparities in accessing needed health care among individuals with PTDs. Future studies with recruitment focused on inclusion of diverse populations of individuals with PTDs could help to address these gaps. The findings reported here can be used to inform public health activities and clinical supports for increasing access to care around priority needs for individuals with PTDs.

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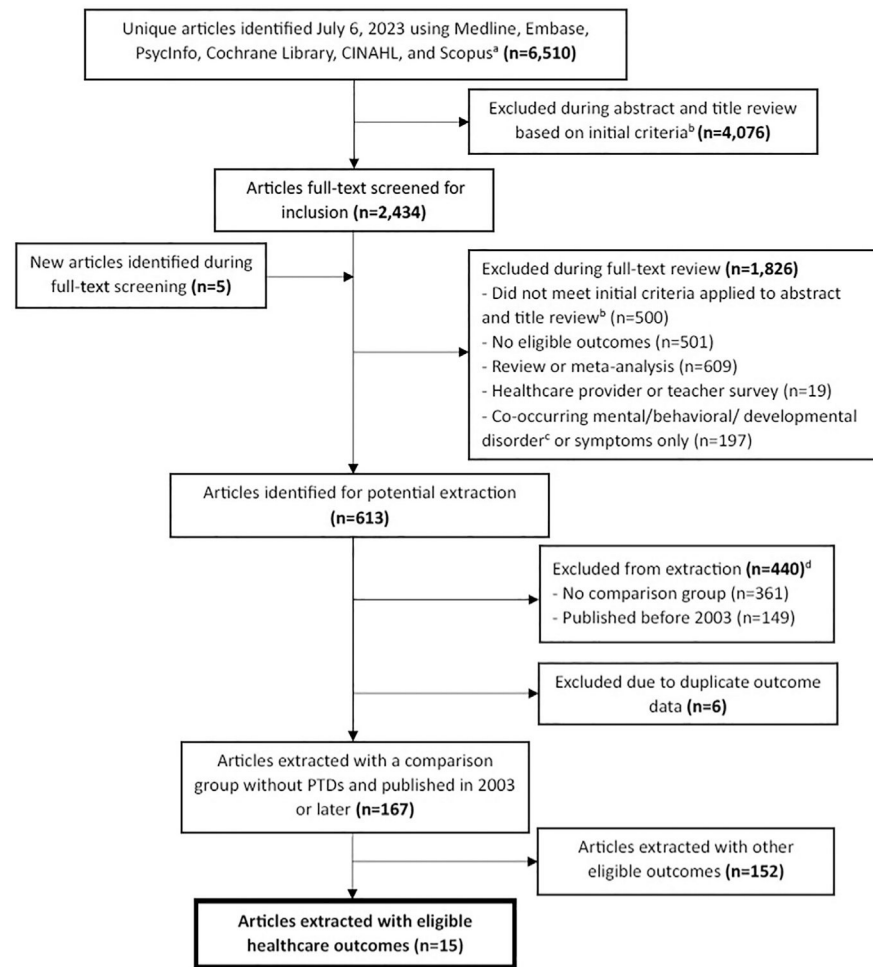
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KEY POINTS

- Most children with persistent tic disorders (PTDs) have access to routine health care, similar to children without PTDs.
- Children with PTDs use more specialty care including mental health care compared to children without PTDs.
- The literature on health care use among individuals with PTDs that have comparison groups without PTDs is limited, particularly for adults. Additionally, only one of the included studies examined health care needs or use by sociodemographic characteristics.

CLINICS CARE POINTS

- Clinicians can consider implementing integrated behavioral health care, by leveraging expanded opportunities as described in the Health and Human Services (HHS) Roadmap Behavioral Health Integration.
- Access to specialty care, especially in under-resourced areas, may also be increased through telehealth and initiatives that expand the reach and referral networks of PTD specialty care to increase local provider capacity.
- Training on identification and management of PTDs is available through the TAA and the American Academy of Pediatrics.

**Fig. 1.**

Flowchart of identified, excluded, and included articles in the systematic literature review on health-related indicators and outcomes associated with persistent tic disorders (PTDs), including health care-related outcomes. ^aAll search terms listed in Table 1. Exclusion criteria for title and abstract screening: (1) the study was with nonhuman participants; (2) the title/abstract explicitly stated the article was a research protocol without results; (3) the only mention of “tic” was a different tic (eg, tick, trauma-informed care); (4) the article focused on tardive dyskinesia, Parkinson’s, schizophrenia, Huntington’s, dystonias, functional tics, psychogenic tics, transient tics or provisional tics rather than persistent tic disorders; (5) the article was a book review, video, poster, slide, or personal account; (6) the article was not peer reviewed (eg, dissertations); (7) the article was a case study or case series with less than 10 participants, (8) conference abstracts. ^cSubstance use and substance-use disorders were included as indicators of health risk behaviors. ^dCategories are not mutually exclusive.

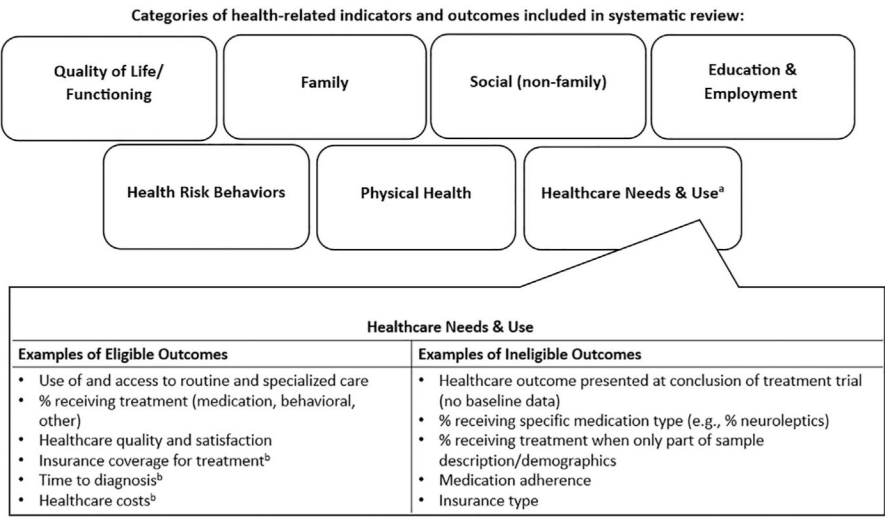


Fig. 2. Overarching categories of health-related indicators and outcomes included in the systematic review and examples of eligible and ineligible outcomes within the health care needs and health care use category. ^aCategory reviewed for inclusion in this article. ^bNo studies met inclusion criteria for these outcomes.

Table 1

Search strategies to identify public health impact outcomes associated with tic disorders, by database (July 6, 2023)

Database	Strategy
Medline (OVID) 1946–	tic disorders/OR tourette syndrome/OR Tics/OR (Tourette* OR tic disorder* OR tics OR (involuntary ADJ2 (twitch* OR movement* OR sound* OR vocalization* OR noise* OR gestur*))).ti,ab,kf. AND (Public health OR epidemiolog* OR surveillance OR survey* OR "quality of life" OR QoL OR cost* OR impact* OR burden).ti,ab,kf,hw. OR ep.fs OR px.fs Limit to English Language; Abstract Available
Embase (OVID) 1974–	tic/OR Gilles de la tourette syndrome/OR (Tourette* OR tic disorder* OR tics OR (involuntary ADJ2 (twitch* OR movement* OR sound* OR vocalization* OR noise* OR gestur*))).ti,ab,kw. AND (Public health OR epidemiolog* OR surveillance OR survey* OR "quality of life" OR QoL OR cost* OR impact* OR burden).ti,ab,kw,hw. OR ep.fs Limit to English Language Remove Medline Records Abstract Available
PsycInfo (OVID)	tic disorders/OR tourette syndrome/OR Tics/OR (Tourette* OR tic disorder* OR tics OR (involuntary ADJ2 (twitch* OR movement* OR sound* OR vocalization* OR noise* OR gestur*))).ti,ab,id. AND (Public health OR epidemiolog* OR surveillance OR survey* OR "quality of life" OR QoL OR cost* OR impact* OR burden).ti,ab,sh,id. Limit to English Language; Abstract Available
Cochrane Library	[mh "Tourette Syndrome"] OR [mh "tic disorders"] OR [mh Tics] OR (Tourette* OR "tic disorder" OR "tic disorders" OR tics OR (involuntary NEAR/2 (twitch* OR movement* OR sound* OR vocalization* OR noise* OR gestur*))) AND ("Public health" OR epidemiolog* OR surveillance OR survey* OR "quality of life" OR QoL OR cost* OR impact* OR burden):ti,ab,kw Abstract Available
CINAHL (EBSCOHost)	(MH "Tourette Syndrome") OR (MH "Tic") OR (Tourette* OR "tic disorder*" OR tics OR (involuntary N2 (twitch* OR movement* OR sound* OR vocalization* OR noise* OR gestur*))) AND (TI ("Public health" OR epidemiolog* OR surveillance OR survey* OR "quality of life" OR QoL OR cost* OR impact* OR burden)) OR (AB ("Public health" OR epidemiolog* OR surveillance OR survey* OR "quality of life" OR QoL OR cost* OR impact* OR burden)) OR (SU ("Public health" OR epidemiolog* OR surveillance OR survey* OR "quality of life" OR QoL OR cost* OR impact* OR burden)) Limiters - English Language; Exclude MEDLINE records; Abstract Available
Scopus	TITLE-ABS-KEY(Tourette* OR "tic disorder*" OR (involuntary W/2 (twitch* OR movement* OR sound* OR vocalization* OR noise* OR gestur*))) AND TITLE-ABS-KEY("Public health" OR epidemiolog* OR surveillance OR survey* OR "quality of life" OR QoL OR cost* OR impact* OR burden) AND NOT INDEX(medline) Abstract Available

Characteristics of studies included in the systematic review on health care needs and health care use among individuals with persistent tic disorders

Table 2

Author, Year	Tic Disorders Included, PTD Assessment/PTD Criteria (Number of People in the Study with PTD)	Comparison Population (n)	Age at Outcome (years)	Male (%)	Race/Ethnicity (% or n)	Sample Type, Years of Data Collection (Country)
Bitsko et al, ²⁵ 2013	Current TS; parent report (147)	Children without TS or asthma (57,416)	6–17	TS: 78.9% Comparison: 50.4%	TS: 82% W; 9.2% H Comparison: 73.6% W; 19.6% H	Nationally representative survey, NSCH 2007 (U.S.)
Bitsko et al, ⁴ 2014	Current TS; parent report (153)	Children without TS (~65,000)	6–17	TS: 128 male, 25 female	TS: 114 W(NH), 6 B(NH), 13 h Total: 43,075 W(NH), 6168 B(NH), 8051 h	Nationally representative survey NSCH 2011–2012 (U.S.)
Cooper et al, ²³ 2003	Current TS; Assessed using National Hospital Interview Schedule, DSM-III-R (26)	Children with asthma (26)	7–16	TS: 76.9% Comparison: 61.5%	TS: 100% W Comparison: 42.3% W, 57.7% O	Tourette specialty clinic, nd (UK)
Cubo et al, ²⁹ 2013	Current TS, chronic motor/vocal, transient tic disorders; Diagnostic assessment, DSM-IV-TR (162)	Children without tics (245)	6–16	TD: 68.5% Comparison: 60.7%	TS: 92.5% W Comparison: 88.4% W	School-based, 2007–2009 (Spain)
Cubo et al, ³⁰ 2017	Current TS, chronic motor/vocal, transient, nonspecific tics; Diagnostic assessment, DSM-IV-TR (61)	Children without tics and who had grade retention since 2013 study (156)	11–17	TD: 55.4% Comparison: 55.4%	NR	School-based, 2010–2014 (Spain)
Gadow et al, ²⁸ 2009	Current CMTD + ADHD; YGTSS, GTRS, direct observation, family history, assessment of research criteria (66, including 62 TS & 4 CMTD)	Children with ADHD only (66)	Avg (SD) 8.6 (1.8) CMTD+ADHD 8.0 (1.4) comparison	CMTD+ ADHD: 77% ADHD only: 89%	CMTD+ ADHD: 88% W, 12% O ADHD only: 89% W, 11% O	Psychiatry clinic, community clinic, schools, media, parent-support groups, nd (U.S.)
Giacobbe et al, ¹⁹ 2021	Current Tic disorder; medical record review for diagnosis (67)	Underserved (Medicaid insurance or self-pay) patients with movement disorders, includes tic disorder group (355)	Avg (SD) 19.9 (11.6) tics, 44.4 (20.5) total	TD: 67.2% Total: 50.4%	NR	Academic tertiary movement disorders clinic, 2002–2017 (U.S.)
Jalenques et al, ²⁶ 2017	Current TS; Previous diagnosis, clinical assessment, DSM-IV-TR (75)	Children without TS (75)	12–18	TS: 60% Comparison: 60%	NR	Community-based, 2010–2013 (France)
Khalifa et al, ²² 2005	Current TS (25), chronic motor (34), chronic vocal (24); Clinical assessment, DSM-IV	Children with transient tics (25)	7–15	NR	NR	Community-based, nd (Sweden)
Leeb et al, ³³ 2020	Current TS; parent-report (107)	Children with no MBDD (21,664)	12–17	NR	NR	Nationally representative survey, NSCH 2016–2017 (U.S.)
Olfson et al, ²¹ 2011	Current TS, Chronic tic disorder; ICD-9 codes from health care claims (Publicly insured: 5414 TS, 787)	Children without tic disorders; (Publicly insured: 10,237,261;	4–18	Publicly insured: 51.1%,	All publicly insured: 34.6% W, 28.7% B,	MarketScan Research Databases, Medicaid Analytic Extract File (health

Author, Year	Tic Disorders Included, PTD Assessment/ Criteria (Number of People in the Study with PTD)	Comparison Population (n)	Age at Outcome (years)	Male (%)	Race/Ethnicity (% or n)	Sample Type, Years of Data Collection (Country)
	CTD; Privately insured: 8071 TS, 1642 CTD)	privately insured: 16,102;562)		Privately insured: 51.1%	29.1% H, 7.6% O (NR for privately insured)	care claims), 2000–2007 (U.S.)
Scahill et al., ²⁴ 2006	Current TS plus CTD plus transient/provisional; DSM-III-R, Clinical assessment (DISC-R) (21)	Children without TS or other psychiatric disorder; (43)	6–12	TD: 61.9% Comparison: 51.1%	NR	Community-based, 1991 (U.S.)
Smith et al., ³¹ 2023	Current TS; caregiver report (42)	Typically developing children; (34)	5–17	TS: 78.6% Comparison: 29.4%	NR	Anonymous online survey, nd (U.K.)
Yang et al., ²⁰ 2017	Current TS; self-report (122)	Total population-based sample, includes TS group; (122,884)	≥ 12	TS: 74.7% Comparison: 49.3%	NR	Nationally representative survey, CCHS 2010–2011 (Canada)
Zinna et al., ²⁷ 2021	Current TS plus CTD; ICD-10 codes from medical records (43)	Children without TS; (175)	≤ 13	PTD: 67.4% Comparison: 50.9%	NR	Psychiatry/neurology/psychology clinic based, 2009–2019 (U.K.)

Race/ethnicity: B ,black; H, Hispanic; NH, non-Hispanic; NW, non-White; O, other; W, White.

Abbreviations: CCHS, Canadian community health survey; CMTD, chronic multiple tic disorder (terminology used by Gadow et al., 2009, includes 62 TS and 4 “CMTD”); CTD, chronic tic disorder; DISC-R, diagnostic interview schedule for children, revised; DSM, Diagnostic and Statistical Manual of Mental Disorders (III-R = third edition, revised; GTRS, global tic rating scale; ICD, international classification of diseases; IV-TR, fourth edition, text-revised); MBDD, mental, behavior, or developmental disorder; nd, no date (years) presented for time of data collection; NR, not reported; NSCH, National Survey of Children’s Health; PTD, persistent tic disorder, including TS, chronic tic disorders, and persistent tic disorders; TD, tic disorders, including transient/provisional; TS, Tourette syndrome; U.K., United Kingdom; U.S., United States; YGTSS, Yale global tic severity scale.

Outcomes included in the systematic review on health care needs and health care use among individuals with persistent tic disorders

Table 3

Author, Year	Mode of Data Collection for Included Outcomes	Outcomes Included		
		Routine Care (RC), Mental Health Care (MH), Other Specialized Care (SC), Medication (MS), Nutritional Supplements and Special Diets (NS), and Quality and Satisfaction (QS)		
Bitsko et al, ²⁶ 2013	P	• RC: Has a usual source for sick care ("a place the child usually goes when he/she is sick or you need advice about his/her health") • MH: Had an emotional, developmental, or behavioral problem for which he/she needs counseling • MH: Received treatment or counseling from an MHP • MH: Needs or uses more medical care, mental health, or educational services • SC: Needs or gets special therapy	• SC: Had seen a specialist other than MHP, past year • MS: Currently need or use medicine prescribed by a doctor, other than vitamins • MS: Had taken medication for difficulties with emotions, concentration, or behavior, including for ADHD • QS: Received effective care coordination • QS: Received family-centered care • QS: Had a medical home	
Bitsko et al, ⁵ 2014	P	• RC: Received preventive medical care, past year • RC: Had an unmet medical need, past year • MH: Had an unmet mental health care need, past year • MH: Received treatment or counseling from an MHP, past year	• SC: Had seen a specialist other than MHP, past year • QS: Received family-centered care, past year • QS: Received effective care coordination, past year • QS: Had a medical home, past year	
Cooper et al, ²⁴ 2003	P	• SC: Number of previous hospitalizations • MS: Number of prescribed drugs		
Cubo et al, ³⁰ 2013	P	• MS: Had a need for pharmacologic treatment		
Cubo et al, ³¹ 2017	P	• MS: Pharmacologic treatment		
Gadow et al, ²⁹ 2009	P	• SC: Ever hospitalized for a nonpsychiatric medical condition • MS: Were currently taking medication; Had ever taken medication; ever or current psychotropic medication		
Giacobbe et al, ²⁰ 2021	Existing health care records over 15 y time period	• SC: Distance to nearest movement disorder clinic • SC: Received rehabilitation	• SC: Received deep brain stimulation • SC: Received botulinum treatment	
Jalenques et al, ²⁷ 2017	C & P	• RC: Were followed by a general practitioner and/or a pediatrician (reported separately) • MH: Were followed by a psychiatrist and/or a psychologist (reported separately)		

Author, Year	Mode of Data Collection for Included Outcomes	Outcomes Included Routine Care (RC), Mental Health Care (MH), Other Specialized Care (SC), Medication (MS), Nutritional Supplements and Special Diets (NS), and Quality and Satisfaction (QS)
		• SC: Were followed by a neurologist
Khalifa et al, ²³ 2005	P	• RC: Had no contact with medical care
Leeb et al, ³⁴ 2020	P	• QS: Composite score for health care transition planning • QS: Had time alone with a PCP, past year; Had a PCP work with the adolescent; Had a PCP discuss the transition
Olfson et al, ²² 2011	Existing health care records (claims for one calendar year)	• MH: Mental health assessment • MH: Psychotherapy • MH: Inpatient mental health care • MH: Emergency mental health care • MH: Visit with psychiatrist • SC: Visit with neurologist • MS: Psychotropic medications
Scahill et al, ²⁵ 2006	P	• MH: Used mental health services
Smith et al, ³² 2023	P	• NS: Used nutritional supplements • NS: Used special diets • NS: Used nutritional supplements to reduce tic symptoms • NS: Used special diets to reduce tic symptoms
Yang et al, ²¹ 2017	Self-report	• MH: Had consulted a health professional regarding mental health issues in the past year
Zinna et al, ²⁸ 2021	C and P, health care records	• MH: Length of time of hospital admission in days • MS: Received medication on admission to inpatient mental health unit • MS: Received medication on discharge from inpatient mental health unit • QS: Inpatient mental health care satisfaction questionnaire

Outcome reporter: C = child report; P = parent report.

Abbreviations: GTS, Gilles de la Tourette syndrome; MHP, mental health professional; PCP, primary care provider; SHCN, special health care needs.