

Caregiver Perspectives on the Health Care System for Tic Disorders: Utilization and Barriers

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ABSTRACT: Tic disorders (TDs) can cause considerable functional impairment and are often associated with comorbid conditions, resulting in difficulty managing symptoms. Although several effective evidence-based interventions are available, previous research has found that caregivers of children with TDs often experience substantial burden navigating the health care system to address their child's tics. **Objective:** This study aimed to understand health care experiences among a sample of caregivers of children with TDs to inform future directions for improving the health care system. **Methods:** We conducted a survey of caregivers of youth with TDs and used descriptive statistics and quantitative analyses to characterize the health care utilization practices of the sample. **Results:** The majority (70%) of families first consulted their pediatrician/primary care provider, and caregivers reported receiving care in line with current best practice guidelines. However, caregivers in the current sample perceived a lack of knowledgeability on the part of their first providers, which significantly predicted more providers seen and also reported difficulty finding specialty providers (63% of the sample reported difficulty finding a treatment provider who understood tics). **Conclusion:** Results suggest that improving caregiver satisfaction with early health care experiences for their child's TD may help to relieve the burden on families and the health care system more broadly, along with continued efforts to increase the number of specialty providers available.

(*J Dev Behav Pediatr* 44:e581–e589, 2023) **Index terms:** tic disorder, Tourette disorder, health care utilization, primary care, mental health.

Tic disorders (TDs [Studies have not been consistent in their inclusion/exclusion of specific TD diagnoses, and given the large phenomenological overlaps in these samples, we will use “TD” to refer to studies both wherein participants had any TD (most were largely Tourette disorder) or participants exclusively had Tourette disorder diagnoses. Use of “Tourette syndrome” applies only to specific study and group names.]) are a class of childhood-onset neurodevelopmental disorders

characterized by involuntary, rapid, repetitive movements and/or vocalizations (i.e., motor and vocal tics).¹ Persistent TDs (i.e., persistent motor/vocal TD or Tourette disorder) affect approximately 0.5% to 1% of school-aged children^{2,3} and involve the presence of motor and/or vocal tics that have been present for at least 1 year. Provisional TDs affect an additional 3% of children and involve motor and/or vocal tics that have been present for less than 1 year.² Tics typically emerge in early childhood and wax and wane in severity over time, peaking in severity in adolescence.⁴ Some individuals report symptom improvement beginning in early adulthood,⁵ but complete remission is rare.⁶ Although some children are not bothered by their tics, many experience impaired functioning^{7,8} and reduced quality of life.⁹ Up to 85% of children with TDs experience comorbid psychopathology, which can interact with tics to increase impairment and complicate treatment decision making.^{10,11}

Several evidence-based interventions exist for individuals with TDs. Recently published practice guidelines from the American Academy of Neurology (AAN)¹² recommend “mindful monitoring,” psychoeducation, and healthy lifestyle behaviors for children whose tics are not bothersome. For children whose tics are causing impairment, Comprehensive Behavioral Intervention for Tics (CBIT)¹³ is recommended as a first-line intervention when available.¹² CBIT is an evidence-based intervention that teaches skills to improve voluntary tic control¹³ and

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has shown to be more effective than supportive psychotherapy in large randomized controlled trials of children and adults.^{14,15}

Medication is another option in the treatment of TDs. The most effective medications have side-effect profiles that limit their use¹² but may be warranted when immediate tic reduction is needed (e.g., if tics are causing physical harm).

Although effective treatment options exist, caregivers and patients with TDs report substantial health care burden,¹⁶ including delayed diagnosis^{8,17} and increased caregiver strain.¹⁸ In 2010, Woods and colleagues¹⁹ conducted the Tourette Syndrome Impact Survey (TSIS) to examine caregiver-reported barriers to receiving care. They found that the most commonly endorsed barriers were finding a knowledgeable treatment provider (42%), the financial cost of treatment (41%), and the side effects of treatment (36%). However, this survey predated the publication of the seminal CBIT trials and subsequent AAN treatment guidelines. The purpose of the current study was to provide a 10-year update to the TSIS¹⁹ and evaluate the extent to which a sample of caregivers of pediatric patients with TD reported having received care consistent with current best practice recommendations and whether care was being implemented efficiently (i.e., pediatricians manage care for those who do not require treatment and provide referrals for behavioral therapy or medication for patients whose tics are impairing).^{20,21} Specifically, the current study aimed to quantitatively describe caregiver perspectives on (1) their health care help-seeking history and experiences with providers, (2) the relationship between help-seeking history/experiences and overall health care burden, and (3) barriers and challenges to receiving appropriate services.

METHOD

Population and Recruitment

Caregivers of children with TDs were invited to participate in an online survey examining TD-related health care system experiences.

Inclusion Criteria

Caregivers were included if they reported that their child had either (a) been previously diagnosed with a TD by a qualified medical professional or (b) demonstrated motor and/or vocal tics consistent with a *DSM-5* diagnosis of a TD.

Exclusion Criteria

(a) Child older than 18 years and (b) residence outside of the United States.

Recruitment

A study description and survey link were e-mailed to members of the Tourette Association of America and associated support groups and were posted to TD-related online groups. It is not possible to know how many people viewed the information but did not follow the link. Caregivers were directed to an online consent form before

beginning their participation. The survey was open for 2 years (September 2018–September 2020). Participants were not compensated.

Survey

The survey used in this study was a composite caregiver questionnaire administered online through RED-Cap²² and designed to gather a wide range of information about experiences caring for a child with a TD.

Sample Characterization

The demographic portion of the survey asked about child and family background characteristics. Caregivers were asked to specify their child's TD diagnosis, report on *DSM-5* TD diagnostic criteria, TD-related medication status, any previous diagnosis of a *DSM-5* psychiatric disorder, and medication status (Table 1).

Parent Tic Questionnaire

The Parent Tic Questionnaire (PTQ) was used to characterize tic²³ severity. The PTQ is a 27-item caregiver self-report measure designed to assess for the presence of common motor and vocal tics. For each tic, the frequency and intensity are rated on a 4-point scale (higher scores = higher severity symptoms). Overall severity scores are calculated by summing frequency and intensity scores for each tic, yielding possible total scores ranging from 0 to 216. The PTQ has demonstrated good reliability and validity in measuring tics.²⁴

Caregiver Strain Questionnaire–Short Form 7–Tic Specific

The Caregiver Strain Questionnaire–Short Form 7–Tic Specific (CGSQ-SF7)²⁵ is a self-report questionnaire measuring caregiver strain associated with a child's illness. The CGSQ-SF7 contains 7 items assessing the illness impact on both objective caregiver strain (e.g., finances) and subjective caregiver strain (e.g., worry) in the past 6 months. Item responses rated on a 5-point Likert scale are summed and divided by the number of questions, yielding scores from 1 to 5. The original questionnaire demonstrated good psychometric properties for evaluating the child's illness impact on their caregivers²⁵ and was adapted in the current study to be used specifically for tics by substituting the word "illness" for "tics" (e.g., "interruption of personal time resulting from your child's tics"). The authors of the CGSQ-SF7 mention basing qualitative descriptors of severity ratings on interquartile ranges (<25% = low, 25%–75% = medium, and >75% = high).

Health Care Help-Seeking Behaviors and Related Experiences

The survey asked the number of different providers seen for tics (response options: 1–5, more than 5) and the child's age when first sought treatment for tics. A series of questions to gather information about their initial provider (i.e., first provider they consulted or sought treatment from) and overall providers (i.e., all providers that they reported having consulted) were also included. Caregivers indicated what type(s) of

Table 1. Demographic Information

	n (%)
Respondent relationship	
Mother	173 (93)
Father	7 (4)
Others	6 (3)
Child gender (male)	121 (65)
Taking medication for a TD	96 (52)
Taking medication for a comorbid disorder	82 (45)
Total	186
Diagnosis	
Tourette disorder	160 (86)
Provisional TD	8 (4)
Do not know	8 (4)
Persistent motor TD	5 (3)
Persistent vocal TD	2 (1)
No official diagnosis	2 (1)
Total	185
Household income	
\$14,999 or less	2 (1)
\$15,000–\$34,999	11 (6)
\$35,000–\$49,999	16 (9)
\$50,000–\$74,999	27 (15)
\$75,000–\$99,999	33 (18)
\$100,000–\$149,999	40 (22)
\$150,000 or more	50 (28)
Total	179
Race	
American Indian or Alaskan Native	2 (1)
Asian	2 (1)
Black	1 (<1)
Multiracial	13 (7)
White	166 (90)
Others	1 (<1)
Total	185
Ethnicity (Hispanic) ^a	12 (6)
Diagnosed with at least 1 additional psychiatric disorder	112 (62)
Anxiety disorder	80 (44)
ADHD	79 (44)
Obsessive-compulsive disorder	59 (33)
Other externalizing (not including ADHD)	41 (23)
Mood disorder	33 (18)
Learning disorder	21 (12)
Sleep problems	19 (10)
Obsessive-compulsive spectrum (hair pulling and skin picking)	13 (7)
At least one other disorder (<5% each)	43 (24)
Total	181

Other disorders included posttraumatic stress disorder, eating disorder, pervasive developmental disorder, sensory integration disorder, autism spectrum disorder, and coordination disorder. ^aTotal N for this analysis = 185. ADHD, attention-deficit/hyperactivity disorder; TD, tic disorder.

provider(s) they saw (discipline/degree/specialty), what the providers recommended and/or what services they provided (selected from options, including recommendations, referrals, and interventions), and their perception of the providers' knowledge of TDs (rated on a 9-point Likert-type scale ranging from 1 = "not at all knowledgeable" to 9 = "expert in TDs"). For analyses, answers to the *first providers'* questions were analyzed descriptively and then combined with later providers to form an *overall providers* category, which was analyzed similarly. All questions are listed with results in Table 2.

Perceived Barriers and Challenges

Several items from the 2010 TSIS¹⁹ were used to assess barriers and challenges related to receiving treatment for TDs, administered in a format identical to the original survey. Caregivers were asked what had made receiving treatment difficult (multiple selections and write-ins permitted). All participants were prompted to endorse reasons for difficulty accessing behavioral treatment for tics on a 9-point Likert scale (1 = "not true" to 9 = "very true"), regardless of whether or not they had received behavioral treatment. Finally, caregivers were asked to rank-order (from 1 to 3) a list of potential solutions (established by the authors based on clinical experience and results from the TSIS¹⁹) to improve the health care system for TDs. Potential solutions were reverse scored (e.g., first rankings were coded as 3 points) and summed such that higher scores indicated more strongly endorsed items (Table 3).

Statistical Analyses

We used quantitative descriptive procedures to outline sample demographics, clinical characteristics, health care help-seeking behaviors and experiences, barriers, and challenges. We used proportions, means, and SDs as measures of central tendency. To provide insight into descriptive results, we defined several parametric and nonparametric statistical tests a priori to use to compare differences in subgroupings within the sample for study variables of interest. All analyses were completed using R Studio Version 1.4.²⁶

Ethical Considerations

All research procedures were approved by the Institutional Review Board at the University of Utah before study initiation. No personal identifying information was collected. Before survey participation, participants read an online informed consent document and indicated their consent to participate.

RESULTS

Sample

Three hundred thirty caregivers consented to participate in the study. Participants were excluded from analyses if they did not provide adequate information to evaluate inclusion/exclusion criteria (n = 113, 34%). Of the remaining 217 participants, exclusions occurred if

Table 2. First Provider Characteristics and Recommendations

	n	%
When you first sought consultation for tics, how long did you have to wait to see this provider?		
Under a month	74	45
1–3 mo	64	39
4–6 mo	17	10
6 mo or more	9	5
What type of provider did you first tell about your child's tics or first recognized tics?		
Pediatrician/PCP/family doctor	116	70
Neurologist	27	16
Psychiatrist	9	5
Psychologist	4	3
Other provider (<2% each)	9	5
Interventions/information received ^a		
They said my child's tics will almost surely go away and indicated that we shouldn't worry	33	20
They said my child's tics will probably go away and to mindfully monitor them	33	20
They provided information about tics	37	22
They prescribed medication	27	16
They provided support	17	10
They provided an incorrect diagnosis (allergies, eye problems, or ADHD) ^b	17	10
They provided behavioral treatment	9	5
They said my child was too young for treatment but to mindfully monitor tics	6	4
Referrals provided ^a		
They referred me to a neurologist (i.e., for consultation or medication)	66	40
They referred me to a psychiatrist (i.e., for consultation or medication)	18	11
They referred me to a social worker/psychologist/therapist/occupational therapist for behavioral therapy	18	11
They referred me to a social worker/psychologist/therapist/occupational therapist for support	10	6
Total	165	

^aOther responses were endorsed at a rate of <5% each. ^bThis response was a compilation of write-in responses and was not included in the original survey. ADHD, attention-deficit/hyperactivity disorder; PCP, primary care provider.

their responses indicated that their child did not meet *DSM-5* criteria for a TD ($n = 3$, 1%), the child they were reporting on was older than 18 years ($n = 3$, 1%), they lived outside of the United States ($n = 18$, 8%), or were duplicate responses (determined by searching for matches across 8 demographic variables; $n = 7$, 3%). Final analyses included 186 participants.

Missingness

On the PTQ, if participants were missing more than 2 items for either frequency or intensity ratings, their responses were excluded from analyses ($n = 2$, 1%). Remaining item-level missing data were interpolated by using the average score for that type of response (i.e., intensity or frequency) from the other questionnaire responses ($n = 19$, 10%). For the CGSQ-SF7-TD, 1 participant missed 1 item, which was interpolated similarly to the PTQ. Some participants terminated survey participation early (subsamples reported per analysis in tables and results). To determine whether missingness was at random, we compared noncompletion ($n = 55$, 30%) and

completion groups ($n = 131$, 70%) on child age, gender, family income, medication status, PTQ score, and CGSQ-SF7-TD score and found no differences between groups. Given that missingness appeared to be at random and the descriptive nature of the study, results are only reported for individuals who completed the applicable portions of the survey.

Sample Characteristics

Sample demographic and diagnostic information is described in Table 1. The mean PTQ score in our sample was 34.92 ($SD = 27.57$, $n = 184$), which is similar to the average PTQ score found in treatment-seeking samples with moderate tic severity²⁴ (mean = 36.11). The mean CGSQ-SF7-TD score was 3.00 ($SD = 0.98$, $n = 138$), indicating medium levels of TD-related family strain.²⁵

Caregiver-Reported Initial Health Care-Seeking Behaviors and Experiences

Descriptive Analyses

One hundred sixty-six caregivers (96%) reported consulting at least 1 health care provider regarding

Table 3. Total Providers and Interventions

	n	%
How many different providers have you seen in total for your child's tics?		
1	9	6
2	42	26
3	48	30
4	31	19
5	10	6
6+	21	13
Total	161	
What types of provider(s) have you seen to help with tics? ^a		
Pediatrician/primary care physician/family doctor	137	86
Neurologist	136	85
Psychologist	61	38
Psychiatrist	60	38
Social worker/therapist/counselor	38	24
Nurse practitioner	24	15
Occupational therapist	22	14
Physician's assistant	8	5
Interventions/information received overall ^a		
They provided information about tics	110	67
They prescribed medication	101	61
They provided support for my child	74	45
They provided behavioral therapy	56	34
They said my child's tics will probably go away and to mindfully monitor them	49	30
They said my child is too young for treatment but to mindfully monitor tics	12	7
Total	173	

^aAdditional responses were endorsed at a rate of <5% each.

their child's tics. The child mean age at the first appointment was 6.53 years (SD = 2.99). One hundred thirty-eight caregivers (84%) reported that they waited 3 or fewer months to see a provider. The highest endorsement for first consultation was pediatrician/primary care provider (PCP; n = 116, 70%). The most highly endorsed care by first providers included referral to a neurologist (n = 66, 40%) for medication or further consultation, providing education regarding tics (n = 37, 22%) and "mindful monitoring" (n = 33, 20%). Full results are described in Table 2.

First Provider Statistical Comparisons

Results from a one-way between-subject analysis of variance showed that specialist medical doctors (neurologists or psychiatrists) were perceived as significantly more knowledgeable about TD than pediatricians/PCPs ($F [1149] = 40.56, p < 0.001$). A series of χ^2 tests demonstrated that pediatricians/PCPs were more likely to provide a referral ($\chi^2 = 4.57, p = 0.032, N = 151$), and specialists were more likely to prescribe medication for tics ($\chi^2 = 22.14, p < 0.001, N = 151$). However, there were no differences between pediatricians/PCPs and specialists in their referral for behavior therapy ($\chi^2 = 0.163, p = 0.687, N$

= 151). Results from linear regression analyses demonstrated that caregivers who rated their first provider as less knowledgeable about TDs consulted a greater number of providers overall ($b = -0.129, p = 0.004, N = 159$); however, caregiver-rated first provider knowledge of TDs did not predict the number of treatments they reported having tried for tics overall ($b = -0.125, p = 0.129$). A higher percentage of participants in the "any comorbidity" group were taking medication for tics ($\chi^2 = 13.34, p < 0.001, N = 186$) and had tried therapy for tics ($\chi^2 = 3.85, p = 0.049, N = 153$) compared with those without comorbidity.

Health Care Burden

Descriptive Statistics

One hundred fifty-two caregivers (94%) reported consulting more than 1 health care provider about their child's tics (modal number seen = 3). Full results are presented in Table 3. The most endorsed provider seen was a neurologist (N = 137, 86%). The most highly endorsed interventions caregivers reported ever receiving were psychoeducation (n = 110, 67%),

Table 4. Barriers to Accessing Care**Is there anything that has made receiving any treatment hard for your child, you, or your family?**

	n (%)	
Difficulty finding a treatment provider who understood tics	90 (63)	
Not having a specialist close to us who provides treatment for tics	70 (49)	
The financial cost of treatment	60 (42)	
Time commitment involved in receiving treatment	56 (39)	
The side effects of the treatment my child received	38 (37)	
Total	143	
Getting behavioral treatment has been difficult because...		
	<i>M</i>	<i>SD</i>
No one near me to get treatment from	5.72	3.05
Issues with insurance (e.g., high deductible, preferred provider is not covered)	5.01	3.31
Nearby providers have long waitlists	4.8	2.99
No time due to school or other activities	3.91	2.6
No time due to commitments for parents	3.91	2.84
Cannot afford it	3.86	2.86
No time due to commitments for other children	3.36	2.6
No time due to other health care appointments	2.54	2.31
Do not have the required transportation	1.21	0.706
Total	140	
Overall, what would you say the 3 most important improvements would be to the health care system for TDs?		
		Score (rank)
Family doctors know more about tics		196 (1)
More therapists know behavioral treatment/behavioral treatment is easier to find		168 (2)
More specialty doctors specialize in treating tics/specialty doctors are easier to find		164 (3)
Specialty doctors know more about tics		111 (4)
Therapists know more about tics		95 (5)
Behavioral treatment for tics is cheaper		55 (6)
Behavioral treatment for tics is less time consuming		25 (7)
Total		140

The score was calculated by reverse scoring rankings (1–3) and then summing all responses. TD, tic disorder.

child had tried medication than behavior therapy. In addition, our results do not indicate that recent efforts to increase knowledge about, and access to, behavior therapy have been particularly effective.¹⁹ Thus, in addition to improving early health care experiences, continued efforts to increase the number of available CBIT therapists and diminishing access barriers (e.g., leveraging advancements in telehealth technologies) could be a promising way to increase access to evidence-based treatments.

Addressing Health Care–Related Challenges and Implications for Practice

When caregivers were asked to rank the most important solutions to care access challenges, they ranked them as follows: (1) family doctors know more about tics, (2) increased availability of therapists trained in behavior therapy, and (3) increased availability of specialized medical

providers. Given that most caregivers in this sample first consulted their pediatricians, one important long-term focus for research and structural change is pediatrician training. However, given that our data do suggest that pediatricians are generally providing recommendations consistent with AAN guidelines, incremental improvement from these trainings would depend on their content. It may be beneficial to focus trainings on *how* pediatricians deliver information. For example, although advice to ignore/“mindfully monitor” tics and healthy lifestyle recommendations are consistent with practice recommendations, such advice could leave caregivers who are concerned about their child’s symptoms feeling frustrated and discouraged. Providing sufficient reassurance and psychoeducation along with these recommendations may improve initial health care experiences and, in turn, improve health care–related satisfaction and reduce burden. Leveraging integrated care structures could also fit very

well with the health care needs of individuals with TDs.¹⁶ For example, brief consultations with a mental health professional during a pediatrician visit to determine the impact of tics and assess for potential comorbidity before making referrals could further improve the efficiency and effectiveness of care.

Limitations

The current sample was relatively small and not demographically representative. Given that the sample was predominately White and non-Hispanic, conclusions cannot be made about the experiences of families with more underserved racial identities, especially because these populations are likely to have unique barriers to accessing care and adverse experiences with health care providers/system.^{30,31} Furthermore, it will be relevant for future research to examine health care-seeking experiences in families with lower socioeconomic status (SES). Accessing appropriate care is likely even more difficult for these populations because lower SES both increases saliency of logistical barriers and has been associated with higher tic severity.³² However, even in this relatively socioeconomically and culturally privileged sample, caregivers report significant TD-related health care burden. Another limitation is that the results described in the current study are based on caregiver report of diagnoses, symptoms, behaviors, and experiences, and the study could not directly diagnose or evaluate tic symptoms and related diagnoses, so results may be subject to recall bias. Our recruitment methods also likely resulted in biases common in caregiver-reported surveys, such as toward those who have higher personal health literacy.

CONCLUSION

The current study suggests that caregivers of children with TDs typically first consult their pediatrician/PCP about their child's tics, most often resulting in a "mindful monitoring" approach or a referral to a specialist. Pediatricians/PCPs were generally accessible to caregivers, and misdiagnosis was rare. However, despite recent efforts to disseminate accurate information about TDs, lack of accessible and knowledgeable providers remained caregivers' most highly endorsed barrier to accessing care. Although caregivers reported receiving advice and care that is generally in line with best practice guidelines, they consulted a large number of providers, which was correlated with health care burden. Future efforts to address these barriers should focus both on improving communication between early providers and caregivers and continued efforts to make evidence-based interventions, such as behavior therapy, more available. Additional efforts to understand barriers that uniquely affect patients and communities that are known to experience health care disparities are also imperative.

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