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ORIGINAL ARTICLE

Exploring the Impact of Chronic Tic Disorders on Youth: Results from the Tourette Syndrome Impact Survey

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Abstract Prior research has demonstrated that chronic tic disorders (CTD) are associated with functional impairment across several domains. However, methodological limitations, such as data acquired by parental report, datasets aggregated across child and adult samples, and small treatment-seeking samples, curtail interpretation. The current study explored the functional impact of tics among youth in a large, "virtual" community sample. An Internet-based survey was completed by families with children who had CTD.

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The sample included 740 parents and 232 of their children (ages 10–17 years). The survey assessed impact across five functional domains: physical, social, familial, academic, and psychological. Health-related quality of life and perceptions of discrimination resulting from tics were also assessed. Results suggest that (1) youth with CTD experience mild to moderate functional impairment, (2) impairment is generally positively correlated with tic severity, (3) children with CTD plus one or more co-occurring psychiatric conditions tend to have greater functional impairment, and (4) a notable portion of youth with CTD experience discrimination due to tics. Implications and limitations of these findings are discussed.

Keywords Tourette syndrome · Chronic tic disorder · Tic · Functional impact · Quality of life

The Impact of Chronic Tic Disorders in Youth: The Tourette Syndrome Impact Survey

Chronic tic disorders (CTD), including Tourette Syndrome (TS) and chronic motor/vocal tic disorders (CMVTD), are neuropsychiatric conditions characterized by the presence of motor and/or vocal tics for a minimum duration of 1 year [1]. TS is estimated to have a childhood prevalence of 3–8 per 1,000 [2, 3] and often co-occurs with other psychiatric diagnoses, including Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive Compulsive Disorder (OCD) [4].

Research on the functional impact of TS provides some support for the notion that TS is associated with impairment across several domains. In a recent study, Storch et al. [5] examined tic-related functional impairment in a clinic-based sample of youth with TS. Parents rated the degree to which tics interfered with their children's school, home, and social functioning, as defined by multiple "problem areas" within each of these three functional domains. The majority of the sample reported tic-related impairment in at least one significant problem area; 37% reported two or more significant problem areas.

In the Storch et al. [5] study, the most frequently endorsed areas of impairment were related to school and social functioning, domains often reported to be adversely impacted by TS. A variety of school-related difficulties have been reported secondary to tics [6]. Common educational problems include difficulty concentrating or paying attention, performing well on time-limited tasks, and writing, as well as avoidance of reading aloud, asking questions, or doing homework [7, 8]. Parents typically rate tic-related academic impairment as mild [5] to moderate [7].

Social difficulties have also been reported in youth with TS. Peer victimization, such as bullying and teasing, occurs at higher rates in youth with TS than controls and is positively correlated with loneliness, anxiety, and internalizing symptoms [9]. Youth with TS are viewed by peers as being more withdrawn, more aggressive, and less popular than same-sex class members [10, 11]. Evidence also suggests that youth with TS are rated by their peers less positively [12] and as less socially acceptable [13] than those children without tics. Social impairment, as rated by parents, has ranged from mild [5] to moderate [7].

Physical and family functioning may also be impacted. Specifically, tic performance may result in neuropathic pain or tissue damage (e.g., headaches, neck and shoulder pain, stress fractures) [14, 15]. Adverse effects on the family can include high caregiver strain [16, 17] and stress [18, 19].

The degree to which functioning is adversely impacted by TS alone or by co-occurring conditions, such as ADHD and OCD, remains unclear. For example, Storch et al. [5] asked parents to rate separately, tic and nontic impairment. Results showed 70% reported at least one problem area seemingly unrelated to tics, whereas fewer (52.1%) reported at least one problem area related to tics alone. Research comparing youth with both TS and ADHD to those with TS alone found that those with both disorders had significantly more behavior problems, poorer social adaptation, and worse quality of life, suggesting that some functional impairment may be accounted for by the presence of a co-occurring condition [20, 21]. Negative impact on family functioning may also result primarily from comorbid disorders [19, 22].

The relationship between functional impairment and tic severity remains unclear as well. Some research has yielded significant positive correlations between tic severity and functional impairment [5, 9, 17, 19], while other research has failed to demonstrate a significant relationship [10, 11, 20, 22].

Most existing data have relied on parental report or clinician report [e.g., 22], with just two studies gathering the youth's perspective [24, 25]. Storch et al. [25] found no significant agreement between youth (aged 12–17 years) and parent reports of quality of life, suggesting that collection of both parent and youth perspectives may be useful, even necessary, for a comprehensive assessment of impairment. Additional limitations to existing research include poor generalizability due to small treatment-seeking samples, which may exclude youth with mild tics, those who experience financial or geographic barriers to diagnosis and treatment, and those who choose not to seek clinical care (e.g., parents do not want to draw attention to condition, do not recognize symptoms or misattribute them to other causes, are opposed to medication or medical intervention, or prioritize treating other conditions due to psychosocial and/or cultural factors). In addition, TS studies using large samples tend to combine adult and youth data [e.g., 23, 26, 27], making it difficult to disentangle functional impairment in youth alone. An enhanced understanding of the impact of TS on youth would improve existing treatment and assessment efforts and help prioritize future developments in these clinical areas.

The advent of the Internet has availed new strategies to overcome the aforementioned sampling limitations, providing opportunities to maximize sample size and enhance generalizability of results. For example, Woods et al. [28] successfully recruited 1,697 individuals reporting on the functional impact of trichotillomania via an anonymous Internet-based survey. Consequently, these researchers were able to demonstrate the significant impact of trichotillomania on social, psychological, academic, and occupational functioning. Importantly, research comparing data collected in person versus over the Internet has demonstrated that results are similar across administration formats, consistent with results from studies using traditional methodology, and without adverse impact by repeat or false responders [29, 30]. Internet-based data collection may possibly have additional advantages over in-person collection, such as an increased sense of privacy/anonymity, ease of response, and avoidance of conflict with the youth as a result of direct examination.

The current study sought to address some of the gaps and limitations in the current youth TS literature by examining the clinical characteristics and functional impact of CTD in a large sample using Internet survey methods. Given some inherent limitations of Internet-based research, the current study was conceived as an opportunity to collect preliminary data and generate hypotheses about the impact of CTD in youth to guide future research employing more traditional methodology.

Method

Participants

The current study was approved by the Institutional Review Board at the University of Wisconsin-Milwaukee. A link to the study survey was posted on the home page of the national Tourette Syndrome Association (TSA; www.tsa-usa.org), a large non-profit membership organization supporting research and advocacy related to TS. Recruitment emails directing participants to the survey were sent by the TSA to patient members, and a study announcement was placed in one nationally distributed TSA newsletter.

Parent Sample

A total of 1,135 parents or guardians consented to participate in the study. Parents were included in data analyses if they (1) reported that their child was age 17 years or younger and (2) reported that their child had been formally diagnosed with either TS or CMVTD (participants who did not complete enough of the survey items to indicate diagnosis were excluded as well). Of the parents who consented to participate, 1,113 had a child age 17 or younger, and, of these, 740 reported that their child had been formally diagnosed with a CTD. Thus, a total of 740 parents met inclusion criteria and were included in data analyses. In the analyses described below, differences in sample size reported on individual items and measures are due to missing data resulting from skipped items or early termination of participation.

Youth Sample

Youth between the ages of 10–17 years whose parents consented and met the inclusion criteria described above were included (N = 438). The age range was restricted for the youth portion of the survey as older children were assumed more capable of articulating their perspective independent of parent bias. Of 438 possible youth, 421 provided assent to participate in the study and 232 answered survey questions. A total of 232 children were included in data analyses.

Materials

Tourette Syndrome Impact Survey for Children

The Tourette Syndrome Impact Survey for Children (TSIS-C) was designed to gather a wide range of information about youth with TS. The TSIS-C was created specifically for this study and developed across multiple stages. First, the authors modeled the format and structure of the TSIS-C upon the Trichotillomania Impact Survey and the Trichotillomania Impact Survey for Children, which are Internet-based surveys designed to examine similar research questions in different community samples [28, 31]. Next, the first two authors (CC, DW) modified survey questions, conceived new questions specifically targeting areas of interest, and chose standard measures to assess TS symptoms, anxiety, depression, family functioning, and quality of life. Measures that were free or low-cost with published demonstration of good psychometrics, prior inclusion in similar research, and easy adaptation to online administration were given greater consideration than similar existing measures. The remaining authors (SZ, LS, CB, TM, SC, JW, LD), who are TS experts, were then provided with the survey draft and submitted suggestions and feedback regarding content. Based on their feedback, a final version was prepared and approved by all authors. Finally, the TSIS-C was posted on www.surveymonkey.com, an Internet-based survey administration website. A link to the website was placed on the national TSA homepage. The online TSIS-C (available from the second author) contained both parent- and youth-report sections.

TSIS-C Parent Section

The parent section assessed basic demographics and tic impact. “Demographic” questions centered on the parent (relationship to child, age, ethnicity, education, marital status, number of children, household income) and affected child (age, gender, ethnicity, education, diagnosis of other psychiatric conditions). “Impact” questions centered on tic interference in four domains of child functioning, including (1) physical (e.g., “Has your child ever had tics that caused pain or physical damage?”), (2) social and familial (e.g., “In the last 12 months, how much do you believe your child’s tics interfered with his/her social life”), (3) academic (e.g., “In the last 12 months, how much do you think tics interfered with your child’s academic life?”), and (4) psychological (e.g., “Does your child feel different or abnormal because of his/her tics?”; “Do you think your child’s tics have ever led to another emotional disorder, such as depression, anxiety, etc.?”). Impact in these domains was rated on a 10-point Likert scale (range 0–9), with lower scores indicating less impact. Parents were also asked whether their child had encountered discrimination as a result of tics (e.g., “Has your child ever been treated differently because of his/her tics?”, “Has your child been discriminated against or treated rudely by a business because of his/her tics?”).

Parents were instructed to try to rate only the impact of tics with the instructions, “Please only comment on how the tics impact your child’s life. Try to exclude from these ratings how much OCD, ADHD, or other problems interfere”. The parent section of the survey also included several standardized measures to assess these and other domains of functioning, as described below.

TSIS-C Youth Section

The youth section included questions assessing the functional impact of tics across three domains: (1) social/familial, (2) academic, and (3) psychological. Questions were designed to parallel the impact questions on the parent section in terms of content area and time frame but modified slightly to fit a lower reading level (e.g., “In the last 12 months, how much do you think your tics get in the way of doing fun things with other people, like hanging out with friends, going shopping, or going out places?”) or omitted from the youth section altogether when not strongly relevant to a youth’s response (e.g., “Did your family avoid going on vacation as a result of your child’s tics?”). Youth who reported using tobacco products, illegal drugs, or alcohol were also asked about their efforts to cope with premonitory urges or the adverse effects of tics by using substances (e.g., “Do you drink alcohol to help get rid of some of the bad feelings [sadness, guilt, shame] you get because of your tics?”). The child section of the survey also included several standardized measures to assess these and other domains of functioning, as described below.

Parent Tic Questionnaire [32]

The Parent Tic Questionnaire (PTQ) is a parent-report measure designed to assess the presence, frequency, and intensity of motor and vocal tics during the previous week. Parents identify whether or not each of 14 common motor and 14 common vocal tics occurred and indicate the intensity and frequency of each tic endorsed. Frequency and intensity are separately rated on Likert scales ranging from 1 to 4, with greater scores indicating greater frequency and stronger intensity. A score for each tic is calculated by summing its frequency and intensity, yielding a score ranging from 0 (tic absent) to 8 (tic has maximum intensity and frequency). Individual tic scores are summed to yield a total tic severity score (Range = 0–224), and separate motor and vocal tic severity scores can be calculated by summing the scores for all motor and vocal tics, respectively (Range = 0–112). In a clinic sample, the measure showed acceptable internal consistency ($\alpha = .90$), temporal stability (ICC = .84), and convergent and discriminant validity [32].

Child Tic Questionnaire

The Child Tic Questionnaire (CTQ) is an unpublished child self-report measure developed for the purposes of this study. The CTQ was designed to parallel the PTQ and included identical items and rating scales. Total tic severity, motor tic severity, and vocal tic severity were calculated following the same procedures as the PTQ.

Spence Child Anxiety Scale [33]

The Spence Child Anxiety Scale (SCAS) is a self-report measure that assesses anxiety symptoms in children and adolescents. The measure consists of 44 items; 38 reflect specific anxiety symptoms and 6 are positive filler items designed to reduce a negative response bias. The SCAS yields a total score and six empirically derived subscales designed to evaluate symptoms of generalized anxiety, separation anxiety, social phobia, OCD, panic-agoraphobia, and fears of physical injury. Items are rated using a 4-point scale ranging from 0 (“never”) to 3 (“always”). Ratings are summed for the 38 anxiety items to yield a total possible score of 114, where higher scores reflect greater anxiety. Mean total scores in normative samples have ranged from 14.3 (SD = 10.5) [34] to 28.6 (SD = 16.5) [33]. The scale has demonstrated good internal consistency ($\alpha = .92$), temporal stability ($r = 0.6$), and convergent and divergent validity [33].

Spence Child Anxiety Scale for Parents [35, 36]

The Spence Child Anxiety Scale for Parents (SCAS-P) closely parallels the SCAS but does not include positive filler items, yielding 38 items on the scale. Items on the SCAS-P were rephrased to ask parents to rate each item on a scale of 0 (“never”) to 3 (“always”). The measure yields the same possible total score as the SCAS, and confirmatory factor analysis has supported the same six subscales [35]. Reported mean scores for the SCAS-P total score are 14.2 (SD = 9.7) in normal controls and 31.8 (SD = 14.1) in children with anxiety disorders [35]. The SCAS-P has demonstrated good internal consistency ($\alpha = .89$)

and convergent validity [35]. Parent–child agreement has been found to range from 0.23 to 0.60.

The Short Mood and Feelings Questionnaire [37]

The The Short Mood and Feelings Questionnaire (SMFQ) is a 13-item child and adolescent self-report measure assessing depression. The SMFQ was designed for use in epidemiological studies and has been shown to have a unifactorial structure. Items describe various affective and cognitive symptoms of depression rated on a three point scale (0 = not true, 1 = sometimes, 2 = true). Items are summed to yield a total score, where higher scores are indicative of greater depression. The SMFQ has demonstrated good internal consistency ($\alpha = .90$).

Family Impact Questionnaire [38]

The Family Impact Questionnaire (FIQ) is a 50-item questionnaire that asks parents to rate the impact of their child's behavior upon the family compared to others' children of the same age (e.g., "My child is more stressful"). Items are rated on a 4-point scale ranging from 0 ("not at all") to 3 ("very much"), where higher scores indicate more negative family impact. Items are summed according to 6 empirically derived subscales, 5 of which measure perceptions of the child's negative impact on parenting feelings (impact on social life, negative feelings toward parenting, impact on finances, and, if applicable, impact on the marriage, and impact on siblings). The sixth subscale measures perceptions of the child's positive impact on parenting feelings. Previous research has reported good internal consistencies for the positive impact score ($\alpha = .81$) and a combined negative impact score ($\alpha = .92$) [39].

Pediatric Quality of Life Inventory: Short Form Generic Core Scales, Version 4.0 [40]

The Pediatric Quality of Life Inventory: Short Form Generic Core Scales, Version 4.0 (PedsQL-SF15) is a 15-item scale that measures a child's health related quality of life. The PedsQL-SF15 includes parallel child self-report and parent-report formats, as well as versions for children (ages 8–12) and adolescents (13–18). In the current study, 4 different versions of the PedsQL-SF15 were administered depending on the respondent (parent or child) and the child's age (child or teen). All items on these versions are essentially identical and differ only in pronoun (first or third person) and in the use of the word "child" versus "teen". Respondents are asked to rate how often a particular item has been a problem during the past month using a 5-point scale ranging from 0 ("never a problem") to 4 ("almost always a problem"). Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), such that higher scores are indicative of better quality of life. The average of all items yields a Total Scale Score and two health summary scores (Physical and Psychosocial) that have been recommended for use in secondary analyses. Mean total scores for healthy samples have ranged from 83.0 (SD = 14.90) [5] to 86.1 (SD = 11.2) [40]. Storch et al. [5] also reported mean scores of 72.2 (SD = 12.7) in a psychiatric sample and 71.9 (SD = 16.2) in a CTD sample. The measure has demonstrated good internal consistency ($\alpha = .85$ child, .89 parent) and good construct validity [40].

Procedure

Data Collection

The survey was available online for 6 consecutive months (July 2008–January 2009). The first page was an informed consent document, which advised parents (ages 18 years and older) of the study's purpose to examine the impact of TS and other CTD on the lives of youth ages 17 and younger. Parents were instructed to complete the first part of the survey and to ask the affected youth between the ages of 10–17 years to complete the second portion. Parents consented to participate by checking "Yes, I agree to participate". Practice administrations with undergraduate research assistants suggested that the parent portion of the survey took approximately 45 min to complete.

After providing consent, parents were asked, "Is your child between the ages of 10–17?" Parents who checked "no" were directed to the start of the parent survey and completed the parent portion only. Parents who checked "yes" were first directed to a child assent page and told to ask their child to read the assent document. Youth gave their assent to participate by checking "Yes, I agree to be in the study". Parents subsequently completed the parent portion of the survey. Following the parent portion, parents with children aged 10–17 were instructed to leave the room and allow the affected youth to complete the youth portion alone. On the first screen of the youth portion, children were instructed to ask for adult help only if questions or confusion arose. Based on practice administrations with undergraduate research assistants, it was estimated that the youth portion of the survey took approximately 45 min to complete.

Survey responses were automatically stored on a password protected account on www.surveymonkey.com. At the end of the data collection phase, responses were downloaded and transferred into a statistical program (SPSS software, version 17.0; SPSS Inc., Chicago, IL.). To ensure participant anonymity, computer IP addresses were not collected. An attempt to identify repeat responders was conducted by searching for respondents who matched on several key demographic variables (gender, age, ethnicity, income, marital status, number of children, education). Of the participants who met inclusion criteria, none were identified as repeat responders.

Analytic Strategy

Study analyses were conducted with the goal of describing the parent and youth samples across several domains. Based on research suggesting that some of the functional impairment experienced by youth with TS may be better accounted for by a co-occurring condition [e.g., 5, 20] the parent and youth samples were each split into two groups: CTD-Only and CTD-Plus. The CTD-Only group consisted of youth who only had a parent-reported formal diagnosis of a CTD (parent sample CTD-Only: N = 361, youth sample CTD-Only: N = 107), while the CTD-Plus group consisted of youth who had an additional parent-reported formal psychiatric diagnosis (parent sample CTD-Plus: N = 375, youth sample CTD-Plus: N = 125). These diagnoses included ADHD, OCD, other anxiety disorders (e.g., Social Phobia), disruptive behavior disorders (i.e., Oppositional Defiant Disorder, Conduct Disorder), depression, Bipolar disorder, somatoform disorder, eating disorders, trichotillomania, learning disabilities, pervasive developmental disorders, and mental retardation.

To determine if impairment was related to tic severity (defined as PTQ total tic score for the parent sample and as CTQ total tic score for the child sample), Pearson's correlation coefficients were calculated for interval data and point-biserial correlation coefficients were calculated for dichotomous variables (i.e., yes/no questions).

The percentages reported in the results section were calculated based upon the number of responses to each question and thus exclude missing responses. Missing data procedures were implemented for several measures. On the PTQ and CTQ, motor or vocal subscales missing two or fewer items were included in analyses. Missing data were interpolated by calculating the average score for a particular domain of tic severity (either frequency or intensity). Tic severity scores for a particular tic were only included if the tic reportedly occurred within the past week. For the following measures, missing data procedures described in the measure's instructions were followed. On the SCAS, measures missing four or fewer items were included in analyses. Missing data were interpolated by calculating the average item score for the measure. SMFQs missing two or fewer items were included, and missing scores were interpolated using the average item score. FIQ subscales missing less than 10% of items were included. Missing items were replaced with the average item score for that subscale. Finally, on the PedsQL-SF15, subscales missing less than 50% of items were included, and missing values were replaced with the mean score for the relevant subscale.

Results

Basic Demographics

Parent Sample

The parent sample was predominately comprised of biological mothers (87.3%, N = 646) and also included biological fathers (4.9%, N = 36), adoptive mothers (4.3%, N = 32), adoptive fathers (0.3%, N = 4), and small numbers of other types of legal guardians (e.g., grandparents). Parent ethnicities included white/Caucasian (90.8%, N = 672), Hispanic/Latino (3.1%, N = 23), multiracial (2.2%, N = 16), Asian (1.6%, N = 12), and African-American (0.9%, N = 7). Parents had a mean age of 41.1 years (SD = 6.4, range = 18–76). The sample had a modal household income of greater than $75,000 and a modal education level of a bachelor's degree. Eighty-seven percent of parents (N = 644) were currently married, 9.4% (N = 70) were separated or divorced, 2.7% (N = 20) were single and never married, and 0.5% (N = 4) were widowed.

Basic demographic information for the youth as described by the parent sample is presented in Table 1. Approximately half had been diagnosed with one or more additional psychiatric disorders. Reported comorbid diagnoses were OCD (34.5%, N = 255), ADHD (34.5%, N = 255), non-OCD anxiety disorders (24.1%, N = 178), depression (11.1%, N = 82), learning disorders (10.7%, N = 79), disruptive behavior disorders (6.8%, N = 50), skin picking (5.7%, N = 42), PDD (5.5%, N = 41), bipolar disorder (3.5%, N = 26), eating disorders (1.1%, N = 8), trichotillomania (1.1%, N = 8), mental retardation (0.8%, N = 6), and somatoform disorder (0.3%, N = 2).

Youth Sample

Basic demographic information for the youth sample, based on parent-report, is presented in Table 1 (note that only parents were asked to report demographic information). Approximately half of the youth who provided date in this study had been diagnosed with

Table 1 Demographic characteristics

Characteristic	Children of parent sample (N = 740)	Child sample (N = 232)
Gender, % (N)		
Male	80.7% (N = 597)	82.8% (N = 192)
Female	19.3% (N = 143)	17.2% (N = 40)
Age, mean (SD)	10.6 (SD = 2.9, N = 733)	12.4 (SD = 2.2, N = 230)
Range	4–17	10–17
Ethnicity, % (N)		
White/Caucasian	86.7% (N = 634)	86.0% (N = 197)
African American	0.8% (N = 6)	1.7% (N = 4)
Hispanic/Latino	3.3% (N = 24)	3.1% (N = 7)
Asian	1.5% (N = 1 1)	1.7% (N = 4)
Multi-racial	6.6% (N = 48)	5.7% (N = 13)
Other	0.8% (N = 6)	1.7% (N = 4)
Unspecified	1.2% (N = 9)	1.3% (N = 3)
Grade level completed, mode	4th grade (N = 109)	6th grade (N = 46)
Age of parent-reported tic onset, mode	Birth to 3 years old (N = 189)	Birth to 3 years old (N = 232)
Parent-reported formal TS diagnosis (%)	97.3% (N = 720)	99.1% (N = 230)
Parent-reported formal CMTD diagnosis (%)	2.7% (N = 20)	0.9% (N = 2)
Parent-reported formal CVTD diagnosis (%)	0% (N = 0)	0% (N = 0)
Parent-reported formal diagnosis of another psychiatric disorder (%)	50.9% (N = 377)	53.9% (N = 125)

one or more additional psychiatric disorders, the most common being OCD (39.2%, N = 91), ADHD (37.1%, N = 86), other non-OCD anxiety disorders (25.9%, N = 60), and mood disorders (18.1%, N = 42).

Current Tic Symptoms

Parent Sample

PTQ scores were available for 256 parents following missing data exclusions. The mean PTQ Total Severity Score for the entire parent sample was 39.2 (SD = 23.2), similar to a previously reported clinical sample mean [32]. Motor tics were reported to be more severe than vocal tics (Total Motor Severity Score: mean = 27.2, SD = 15.4; Total Vocal Severity Score: mean = 12.3, SD = 12.0). The PTQ demonstrated strong internal consistency across all items ($\alpha = .95$) and acceptable levels in the motor ($\alpha = .73$) and vocal ($\alpha = .72$) subscales. The mean PTQ Total Severity Score was significantly higher in the CTD-Plus group (mean = 42.5, SD = 24.4) than in the CTD-Only group (mean = 36.2, SD = 21.2; t (254) = 2.2, $p = .03$).

Youth Sample

CTQ scores were calculable for 88 youth; the remainder of the sample exceeded missing data criteria described above. The mean CTQ Total Severity Score for the entire youth sample was 39.8 (SD = 31.8), which is similar to the mean PTQ score reported for a clinical sample (mean = 39.9, SD = 28.8) [32]. This score was significantly and positively correlated with the PTQ as completed by the youth's parent ($r = .56$, $p < .000$), suggesting similar reports of tic severity from youth and parents. Motor tics were reported to be of greater severity than vocal tics (Total Motor Severity Score: mean = 26.5, SD = 19.3; Total Vocal Severity Score: mean = 13.9, SD = 14.8). The CTQ demonstrated good internal consistency across all items ($\alpha = .81$) and across the items on the motor ($\alpha = .83$) and vocal ($\alpha = .76$) subscales. The CTD-Only sample had a mean score of 42.1 (SD = 33.5), and the CTD-Plus sample had a mean score of 37.4 (SD = 30.2). These means were not significantly different, t (85) = .69, $p = .49$.

Impact of Tics

Ratings of functional interference related to tics are presented in Table 2 for parents and in Table 3 for youth.

Physical Impact

Parent Sample

The majority of respondents reported that their child had at least one tic that caused pain or physical damage, although parents in the CTD-Plus group were 1.8 times more likely than parents in the CTD-Only group to endorse this item. As noted in Table 2, tic severity scores were significantly associated with tic-related pain/physical damage.

Social Interference

Parent Sample

Overall, parents reported that tics moderately interfered with their child's social functioning in the past 12 months (Table 2). Significant positive correlations were found between item responses and tic severity for all social interference items. Compared to parents in the CTD-Only group, the CTD-Plus group reported that their children experienced significantly greater interference with their social lives, family relationships, friendships, private leisure, and completion of household tasks, as well a greater tendency to avoid vacation, social events, public places, and group activities. However, parents in both groups reported some avoidance due to tics.

Youth Sample

The overall child sample reported mild to moderate interference with social functioning in the past 12 months (Table 3). Significant positive correlations were found between tic severity and all social interference items. The CTD-Plus group reported significantly higher interference than the CTD-Only group for social lives, family relationships, and

Table 2 Parent sample: functional interference caused by tics in the past 12 months

Domain	Overall sample		CTD-only	CTD-plus	
	Item Mean or Percent Endorsed	Correlation with PTQ Tic Severity Score (Pearson's *r*)	Item Mean or Percent Endorsed	Item Mean or Percent Endorsed	CTD-Only versus CTD-Plus
Physical interference					
Tic that caused pain or physical damage (%)	64.3% (N = 428)	.28**	56.9% (N = 182)	71.1% (N = 246)	χ^2 (1) = 13.8**
Tic-related hospitalization or urgent medical attention (%)	8.3% (N = 55)	.09	6.6% (N = 21)	9.9% (N = 34)	χ^2 (1) = 1.7
Social interference					
Interference with social life, mean (SD)[a]	4.5 (2.6, N = 663)	.35**	3.8 (2.5, N = 320)	5.1 (2.6, N = 343)	*t* (661) = 6.1**
Interference with family relationships, mean (SD)[a]	2.5 (2.3, N = 651)	.34**	2.0 (1.9, N = 312)	2.9 (2.5, N = 339)	*t* (649) = 5.0**
Interference with friendships, mean, mean (SD)[a]	3.8 (2.7, N = 654)	.37**	3.1 (2.6, N = 315)	4.4 (2.7, N = 339)	*t* (652) = 5.9**
Interference with private leisure, mean (SD)[a]	3.7 (2.6, N = 654)	.39**	3.2 (2.5, N = 316)	4.1 (2.6, N = 338)	*t* (652) = 4.2**
Interference with household tasks, mean (SD)[a]	2.9 (2.5, N = 652)	.40**	2.3 (2.1, N = 314)	3.4 (2.7, N = 338)	*t* (650) = 4.6**
Avoided going on vacation because of tics (%)	16.0% (N = 105)	.28**	11.3% (N = 36)	18.4% (N = 270)	χ^2 (1) = 10.4**
Avoided social events or entertainment activities because of tics (%)	42.7% (N = 282)	.35**	32.3% (N = 103)	47.5% (N = 162)	χ^2 (1) = 27.2**
Avoided public places because of tics (%)	37.5% (N = 248)	.29**	30.1% (N = 96)	44.4% (N = 152)	χ^2 (1) = 15.4**
Avoided group activities because of tics (%)	44.5% (N = 293)	.34**	34.3% (N = 109)	54.0% (N = 184)	χ^2 (1) = 25.6**
Academic interference					
Interference with academic life, mean (SD)[a]	4.5 (2.8, N = 662)	.34**	3.9 (2.7, N = 300)	4.9 (2.8, N = 324)	*t* (622) = 4.6**
Days of school missed because of tics, mean (SD)	3.3 (1.3, N = 499)	.29**	2.6 (16.4, N = 320)	4.0 (16.2, N = 247)	*t* (497) = .95
Days of school tardy because of tics, mean (SD)	1.5 (5.8, N = 502)	.13	0.9 (3.4, N = 251)	2.1 (7.5, N = 251)	*t* (345) = 2.3*
Days of school with unscheduled breaks because of tics, mean (SD)	13.6 (36.7, N = 444)	.21**	7.7 (28.1, N = 221)	19.6 (42.8, N = 223)	*t* (382) = 3.5**
Psychological impact					
Feel different or abnormal because of tics (%)	74.7% (N = 482)	.27**	65.7% (N = 203)	83.0% (N = 279)	χ^2 (1) = 24.7**
Child development of another disorder (%)	59.5% (N = 275)	.33**	49.4% (N = 155)	77.6% (N = 236)	χ^2 (1) = 48.1**

Table 2 continued

Domain	Overall sample		CTD-only	CTD-plus	
	Item Mean or Percent Endorsed	Correlation with PTQ Tic Severity Score (Pearson's *r*)	Item Mean or Percent Endorsed	Item Mean or Percent Endorsed	CTD-Only versus CTD-Plus
Parental development or exacerbation of emotional disorder (%)	35.3% (N = 229)	.18**	26.6% (N = 83)	43.5% (N = 146)	χ^2 (1) = 21.4**
Parent treatment for reaction to tics (%)	39.7% (N = 258)	.19**	30.0% (N = 94)	48.7% (N = 164)	χ^2 (1) = 23.2**
SCAS-P total, mean (SD)	27.3 (15.9, N = 301)	.37**	24.5 (18.5)	28.1 (17.8, N = 318)	*t* (615) = 6.7**
SCAS-P separation anxiety, mean (SD)	5.3 (3.7, N = 302)	.24**	3.8 (4.1)	4.4 (3.8, N = 318)	*t* (617) = 3.7**
SCAS-P social phobia, mean (SD)	6.0 (3.9, N = 302)	.33**	5.2 (3.7)	6.0 (4.0, N = 318)	*t* (618) = 5.3**
SCAS-P obsessive compulsive, mean (SD)	3.9 (3.5, N = 301)	.40**	4.4 (4.0)	5.1 (3.9, N = 318)	*t* (601) = 7.4**
SCAS-P physical injury fears, mean (SD)	3.5 (2.6, N = 302)	.14*	3.2 (2.9)	3.2 (2.5, N = 318)	*t* (619) = 2.5*
SCAS-P panic and agoraphobia, mean (SD)	2.9 (3.6, N = 301)	.31**	3.3 (4.3)	4.1 (4.8, N = 318)	*t* (588) = 5.7**
SCAS-P generalized anxiety, mean (SD)	5.5 (3.2, N = 301)	.26**	4.5 (3.8)	5.2 (3.6, N = 318)	*t* (617) = 5.6**

CTD Chronic Tic Disorder, *PTQ* Parent Tic Questionnaire, *SCAS-P* Spence Child Anxiety Scale for Parents, *ns* non-significant

* Significant at $p < .05$

** Significant at $p \leq .01$

[a] Rated on a 1 (mild interference) to 9 (severe interference) point scale. A score of $\geq$4 indicated moderate interference

Table 3 Child sample: functional interference caused by tics in the past 12 months

Domain	Overall sample		CTD-only	CTD-plus	CTD-Only versus CTD-Plus
	Item mean or percent endorsed	Correlation with CTQ tic severity score (Pearson's *r*)	Item mean or percent endorsed	Item mean or percent endorsed	
Social interference					
Interference with social life, mean (SD)[a]	3.6 (2.6, N = 203)	.53**	3.0 (2.3, N = 95)	4.1 (2.7, N = 108)	t (200) = −3.0**
Interference with family relationships, mean (SD)[a]	2.7 (2.3, N = 201)	.23**	2.2 (1.8, N = 93)	3.2 (2.6, N = 108)	t (194) = −3.3**
Interference with friendships, mean (SD)[a]	3.8 (2.7, N = 204)	.49**	3.3 (2.6, N = 96)	4.2 (2.8, N = 108)	t (202) = −2.6*
Interference with private leisure, mean (SD)[a]	3.3 (2.4, N = 203)	.53**	2.9 (2.3, N = 95)	3.6 (2.5, N = 108)	t (201) = 1.7
Interference with household tasks, mean (SD)[a]	2.9 (2.6, N = 203)	.58**	2.7 (2.5, N = 95)	3.2 (2.6, N = 108)	t (201) = 1.4
Academic interference					
Interference with school or school work, mean (SD)[a]	4.4 (2.8, N = 205)	.57**	4.0 (2.6, N = 96)	4.7 (2.8, N = 109)	t (203) = 1.8
Tics make it hard to study (%)	65.0% (N = 132)	.32**	58.3% (N = 56)	71.0% (N = 76)	χ^2 (1) = 3.6
Tics make it hard to do well in classes (%)	59.6% (N = 121)	.37**	53.7% (N = 51)	64.8% (N = 70)	χ^2 (1) = 2.6
Psychological interference					
Feel different or abnormal because of tics (%)	62.1% (N = 126)	.33**	56.3% (N = 54)	67.3% (N = 72)	χ^2 (1) = 2.6
SCAS-C total, mean (SD)	26.3 (18.1, N = 198)	.55**	24.5 (18.5, N = 94)	28.1 (17.8, N = 104)	t (196) = 1.3
SCAS-C separation anxiety, mean (SD)	4.1 (3.9, N = 199)	.39**	3.8 (4.1, N = 94)	4.4 (3.8, N = 105)	t (197) = .9
SCAS-C social phobia, mean (SD)	5.6 (3.9, N = 198)	.43**	5.2 (3.7, N = 94)	6.0 (4.0, N = 104)	t (196) = 1.3
SCAS-C obsessive compulsive, mean (SD)	4.7 (4.0, N = 198)	.53**	4.4 (4.0, N = 94)	5.1 (3.9, N = 104)	t (196) = 1.3
SCAS-C physical injury fears, mean (SD)	3.1 (2.7, N = 200)	.16	3.2 (2.9, N = 94)	3.2 (2.5, N = 106)	t (198) = .3
SCAS-C panic and agoraphobia, mean (SD)	3.7 (4.5, N = 198)	.59**	3.3 (4.3, N = 94)	4.1 (4.8, N = 104)	t (196) = .9
SCAS-C generalized anxiety, mean (SD)	4.9 (3.6, N = 200)	.50**	4.5 (3.8, N = 94)	5.2 (3.6, N = 106)	t (198) = 1.5
SMFQ, mean (SD)	7.4 (6.1, N = 206)	.35**	7.0 (5.9, N = 97)	7.6 (6.1, N = 109)	t (204) = .9

CTQ Child tic questionnaire, *SCAS-C* Spence child anxiety scale, *SMFQ* Short mood and feelings questionnaire, *ns* non-significant

[a] Rated on a 1 (mild interference) to 9 (severe interference) point scale. A score of ≥4 indicates moderate interference

* Significant at $p < .05$

** Significant at $p \leq .01$

friendships. In contrast to parent-rated data, there was no differential interference between the youth groups for leisure activities or completion of household tasks.

Academic Interference

Parent Sample

Parents reported that their children experienced moderate interference with academic life due to tics (Table 2). A positive significant correlation was found between this item and tic severity. Parents in the CTD-Plus group reported significantly more academic interference than the CTD-Only group. Youth in the CTD-Plus group experienced significantly more tardy school days, unscheduled breaks, and days of decreased productivity attributed to tics than did those in the CTD-Only group.

Youth Sample

The overall youth sample reported moderate academic interference due to tics over the past 12 months, which was significantly and positively correlated with tic severity (Table 3). The majority of the overall youth sample responded “yes” to the questions, “Do your tics make it hard for you to study?” and “Is it harder for you to do well in your classes because of your tics?” Reported academic interference did not differ between the CTD-Plus and CTD-Only groups.

Psychological Interference

Parent Sample

The majority of parents in the overall sample and both subgroups reported that their child felt different or abnormal because of tics (Table 2). Parents in the CTD-Plus group were more likely to report that their child felt different/abnormal because of tics, that their child’s tics led to the development of another emotional disorder, that their child’s tics led them or their spouse to develop or exacerbate an emotional disorder, and that they sought professional help regarding their reaction to their child’s tics. Tic severity was significantly correlated with feeling different or abnormal and with child development of another disorder.

In the overall parent sample, the SCAS-P mean total score was higher than the mean reported for children from the community (mean = 11.2, SD = 8.9) but lower than the mean for children with anxiety disorders (mean = 29.7, SD = 14.9) [41]. Tic severity was generally significantly and positively correlated with anxiety symptoms. The SCAS-P total score and all subscale scores were significantly higher in the CTD-Plus group than in the CTD-Only group.

Youth Sample

The majority of youth reported feeling different or abnormal because of tics (Table 3). An affirmative response was significantly correlated with CTQ tic severity.

A small minority of the entire youth sample reported using alcohol, tobacco, or illegal substances (2.2%, N = 5). Of these, 3 reported using tobacco and 3 reported using illegal drugs in an attempt to reduce adverse emotional reactions occurring as a consequence of tics (e.g., sadness, embarrassment, shame). Use of tobacco (N = 1) or illegal drugs (N = 1) to reduce premonitory urge sensations was rare.

The mean total score of the SCAS for the overall youth sample was higher than the mean reported for a community sample (mean = 17.7, SD = 11.9) but lower than the mean reported for children with anxiety disorders (mean = 35.8, SD = 17.5) [41]. Tic severity was significantly and positively correlated with the SCAS total score. The CTD-Only and CTD-Plus groups did not significantly differ on the SCAS total score or on any measure subscales.

The mean total scores for the SMFQ in the overall youth sample, CTD-Only, and CTD-Plus groups were similar to the mean reported for a child outpatient treatment-seeking sample (mean = 7.1, SD = 5.2) [37]. Significant positive correlations were found between the SMFQ and the CTQ. SMFQ scores did not significantly differ between the CTD-Only and CTD-Plus groups.

Discrimination

The majority of parents reported that their child had been treated differently by others, and notable portions of the sample indicated that they had been treated in a rude or discriminating manner by a business, asked to leave a school setting, and/or asked to leave a public place (Table 4). Discrimination items were significantly and positively correlated with tic severity, suggesting that increased tic severity may put youth at a higher risk of encountering tic-related discrimination. Parents in the CTD-Plus group were significantly more likely to report that their youth had experienced tic-related discrimination.

Family Functioning

Scores on the FIQ subscales and their correlations with the PTQ are shown in Table 5. Scores on all negative scales (i.e., adverse family impact) were significantly higher in the CTD-Plus group, suggesting greater impairment in family functioning for families with youth who have both CTD and a comorbid condition. Compared to previous research, scores on the negative impact scale in the overall sample were similar to those reported for young adults (ages 16–26) with cerebral palsy (mean = 21.3, SD = 12.1) and higher than those with Down Syndrome (mean = 16.5, SD = 8.0). Scores on the negative impact scale in the CTD-Plus group were similar to scores reported for intellectual disability (mean = 24.5, SD = 11.2) but lower than for autism (mean = 28.9, SD = 9.0) [42]. Most FIQ scores were significantly positively correlated with tic severity, suggesting that more severe tics are associated with more negative impact on family functioning.

Quality of Life

PedsQL-SF15 scores for the two age groups were combined, yielding total scores for the parent sample and the youth samples regardless of youth age. Scores on the PedsQL-SF15 and their correlations with tic severity are presented in Table 6. Note that lower scores indicate poorer quality of life.

Parent Sample

The mean total score of the overall parent sample is lower than that reported by parents of youth with TS recruited in a clinic based study, a psychiatric sample, and healthy controls

Table 4 Discrimination experienced as a result of tics as reported by parent sample

Item	Overall sample		CTD-only	CTD-plus	CTD-only versus CTD-plus
	Percent endorsed	Correlation with PTQ tic severity score (Pearson's r)	Percent endorsed	Percent endorsed	
Treated differently	75.0% (N = 480)	.29**	64.9% (N = 203)	84.3% (N = 84.4)	χ^2 (1) = 31.9**
Asked to leave a public place	13.5% (N = 88)	.39**	8.6% (N = 27)	18.0% (N = 61)	χ^2 (1) = 12.6**
Asked to leave a school setting	20.6% (N = 134)	.23**	13.7% (N = 43)	26.9% (N = 91)	χ^2 (1) = 16.3**
Discriminated against or treated rudely by a business	20.0% (N = 130)	.33**	13.5% (N = 42)	26.0% (N = 88)	χ^2 (1) = 16.5**

PTQ Parent tic questionnaire

** Significant at $p < .05$

Table 5 Parent sample: family impact questionnaire

FIQ Score	Overall sample		CTD-only	CTD-plus	CTD-only versus CTD-plus
	Mean (SD)	Correlation with PTQ Tic severity score	Mean (SD)	Mean (SD)	
Negative impact[†]	21.2 (10.9, N = 604)	.34**	17.4 (9.7, N = 295)	24.8 (10.9, N = 309)	*t* (598) = −8.8**
Negative feelings toward parenting	11.7 (4.7, N = 601)	.29**	10.1 (4.7, N = 293)	13.2 (4.5, N = 308)	*t* (599) = −8.3**
Social relations	9.6 (7.4, N = 602)	.32**	7.3 (6.3, N = 295)	11.7 (7.7, N = 307)	*t* (583) = −7.7**
Finances	5.6 (4.8, N = 598)	.26**	3.6 (3.9, N = 292)	7.5 (4.6, N = 306)	*t* (587) = −11.1**
Marriage	6.8 (4.6, N = 529)	.21**	5.8 (4.0, N = 263)	7.7 (5.0, N = 266)	*t* (501) = −4.6**
Siblings	5.6 (4.2, N = 499)	.34**	4.2 (3.5, N = 247)	6.9 (4.4, N = 252)	*t* (475) = −7.6**
Positive impact	11.4 (4.4, N = 602)	−.04	12.4 (4.4, N = 294)	10.4 (4.2, N = 308)	*t* (600) = 5.7**

PTQ Parent tic questionnaire, *FIQ* Family impact questionnaire

* Significant at $p < .05$

** Significant at $p \leq .01$

[†] The negative impact score is a sum of the negative feelings toward parenting and social relations

Table 6 Quality of life as reported by the parent and child samples

PedsQL-SF15 score	Overall sample		CTD-only	CTD-plus	CTD-only versus CTD-plus
	Item mean (SD)	Correlation with tic severity score[a] (Pearson's *r*)	Item mean (SD)	Item mean (SD)	
Parent sample					
Total score	58.3 (20.9, N = 515)	−.32**	69.2 (19.9, N = 238)	54.8 (18.1, N = 277)	*t* (513) = 8.8**
Psychosocial health score	53.9 (21.7, N = 515)	−.36**	62.6 (21.1, N = 238)	46.4 (19.1, N = 277)	*t* (484) = 9.2**
Physical Health Score	76.7 (24.6, N = 515)	−.10	82.5 (21.8, N = 238)	71.7 (25.8, N = 277)	*t* (513) = 5.1**
Child sample					
Total score	67.1 (19.8, N = 196)	−.43**	72.5 (18.5, N = 93)	62.3 (19.6, N = 103)	*t* (198) = 3.6**
Psychosocial health score	52.4 (20.4, N = 196)	−.39**	58.0 (19.7, N = 93)	47.3 (19.8, N = 103)	*t* (197) = 3.8**
Physical health score	76.8 (25.0, N = 195)	−.22	7.0 (5.9, N = 93)	7.6 (6.1, N = 102)	*t* (197) = 2.3*

PedsQL-SF15 Pediatric Quality of Life Inventory: Short Form

* Significant at $p < .05$

** Significant at $p \leq .01$

[a] PTQ Tic Severity Scores were used in correlations for the parent sample; CTQ Tic Severity Scores were used in correlations for the child sample

[25]. Increased tic severity was found to be associated with decreased quality of life. The CTD-Plus group had significantly lower scores on the PedsQL-SF15 than the CTD-Only group.

Youth Sample

Results in the youth sample were similar to those in the parent sample and lower than those reported by Storch et al. [25]. CTQ total severity scores were significantly negatively correlated with the PedsQL-SF15 total score, suggesting that increased tic severity is associated with decreased quality of life. Lower quality of life was reported by the CTD-Plus group than by the CTD-Only group.

Discussion

The current study assessed demographic characteristics and tic-related functional impairment in a large sample of youth and their parents using Internet survey methodology. As will be discussed, this methodology inherently presents several limitations. However, to our knowledge, the present investigation includes the largest samples of youth with CTD and parents of youth with CTD who have responded to parallel questions about the functional impact of tics.

The current study suggests that (1) youth with CTD experience mild to moderate adverse impact on various domains of functioning and (2) are treated differently and experience discrimination due to tics; (3) higher tic severity is generally associated with greater functional impairments across multiple domains, including general quality of life; (4) anxiety, depression, family functioning difficulties, and quality of life dissatisfaction are greater in those with CTD as compared to the general population but roughly equal to levels reported in other psychiatric populations; and (5) the presence of a co-occurring psychiatric condition increases the likelihood of experiencing functional impairment and discrimination, avoiding activities/settings, and having a lower quality of life. These data are consistent with previous research from smaller clinic-based samples suggesting that youth with chronic tics are likely to experience functional impairment [5].

Previous researchers have suggested that the presence of a co-occurring psychiatric condition may account for functional impairment experienced by youth with TS [20]. The results of the current study support the claim that the presence of a co-occurring condition may be associated with elevated reports of functional impairment, even when respondents are asked only to rate tic-associated impairment. However, it appears that youth with CTD whose parents do not report another psychiatric disorder also experience notable impairment and that the degree of impairment experienced is related to the perceived severity of the child’s tics. Why youth in the CTD-Plus group were viewed as more functionally affected in ways specific to tics is unclear. One possibility is that respondents had difficulty discriminating tic-specific impairment from impairment more likely caused by a related condition (e.g., ADHD) or that the presence of a comorbid condition has a synergistic effect on functioning. It is also possible that respondents or parents of youth with CTD-plus are generally more distressed and thereby more likely to negatively elevate responding. Results also indicate that impairment ratings significantly differed between the CTD and CTD-Plus groups more frequently in the parent sample than in the youth sample. To what extent this discrepancy is a function of respondent characteristics (e.g., parents may be better able to identify deficits in functioning) or study methodology (e.g., different sample sizes, age group of youth) is unclear. Future research using more rigorous methodology, such as structured diagnostic interviewing in person or via the internet to confirm the presence of a co-occurring condition, would help clarify effects on functional impairment.

Other limitations reflect our method of data collection. Given the use of an anonymous Internet survey, CTD diagnoses and symptom severity could not be confirmed. Also, we cannot confirm whether parents followed the instructions to let the youth complete the youth portion independently. Parental involvement may have also resulted in inaccurate youth responses to sensitive questions (e.g., about substance use) despite assurance of confidentiality. The time frame of assessment used for different domains of functioning and survey measures may have influenced the degree to which certain domains were assessed negatively. For example, psychological and physical impact of tics was rated based on lifetime experiences, while social and academic impact was based on the previous 12 months. It is possible that certain demographic and psychiatric comoribidity characteristics made some respondents more or less likely to complete an online survey. For example, parents and children with moderate to severe ADHD or depression and those in disadvantaged socioeconomic circumstances may have been less likely to respond to an Internet survey, meaning that the current sample may represent a healthier, more functional segment of the CTD community. Indeed, data suggest that the current sample is biased in that parents were older, mostly Caucasian, and had more education and higher income than the average family. Overall, in terms of generalizability, it appears that these results generally cohere with previous research; however, the current findings may not generalize to community TS populations who do not have Internet access, are treatment-seeking, or are not connected or choose not to be connected to the TSA (e.g., membership and interest in advocacy may reflect a greater negative impact of CTD relative to those with CTD who are not members). Still, the benefits of an Internet-based research survey (i.e., large sample size and cost-efficiency) provide an advantage to otherwise customary research limitations in rare, chronic conditions such as CTD.

One of the goals of the current study was to generate hypotheses that could be addressed in future research. As tic severity was generally significantly and positively correlated with various measures of functional impairment, reductions in tic severity may be associated with decreased social, academic, and psychological impairment; improved family functioning; and improved quality of life. Tics perceived as severe may appear more disruptive or socially conspicuous and may be more closely associated with functional impairment and experiences of discrimination. It is also possible that early, effective tic management may reduce functional impact, the development of mood or anxiety symptoms, and/or discrimination. Similarly, strategies such as including a child's teachers and peers in psychoeducation programs about CTD, which have been shown to reduce negative perceptions of tics [43], may prevent or reduce academic and social impairment. Conversely, it is also possible that in some circumstances, diagnosis and treatment may introduce stigmatization (e.g., receiving mental health care) or side effects (e.g., cognitive dulling or weight gain from medication) that contribute to functional impairment or discrimination, supporting the importance of identifying specific sources of impairment. Notable portions of the parent sample reported distress related to their child's tics. Improvements in family and/or parental functioning may occur when parents engage in adequate psychoeducation and support. Close examination of those youth with TS who are not experiencing tic-related functional impairment may help future research determine if these factors (e.g., early intervention, psychoeducation, family support) or others predict high resilience or well-being. For example, 13% (N = 69) of PedsQL-SF15 total scores in the current parent sample were above a reported mean for a healthy sample (86.1) [40], suggesting that a notable portion of youth who have CTD may function quite well. Identification of the factors that best predict well-being in those who live with TS may lead to improved treatment and advocacy efforts.

Summary

Children with TS are thought to experience functional impairment across several domains. However, research in this area has been limited by reliance on parent or clinician report, small treatment-seeking samples, and reports of data aggregated across youth and adult samples. To address these limitations, 740 parents of youth with CTD and 232 of their children (ages 10–17 years) were surveyed regarding the functional impairment of tics across several domains (physical, social, familial, academic, and psychological), health-related quality of life, and perceptions of discrimination resulting from tics. The results of this study support the notion that youth with CTD experience notable functional impairment as a result of tics, that increased impairment is generally associated with increased tic severity, and that those with an additional co-occurring condition(s) tend to have greater functional impairment. Although the current results are limited due to confounds associated with Internet survey methodology, these preliminary findings suggest that future research efforts may need to focus on identifying how clinicians, families, and patient advocacy groups can most effectively improve the functioning of youth affected by CTD.

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