

# Prediction of Functional Impairment and Quality of Life in Youth with Tourette's Syndrome

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## Introduction

While development of tics during childhood for a short period of time is fairly normative (Kurlan, Behr, & Medved, 1988), youth with full-blown Tourette's Syndrome (TS) experience a wide range of functional impairments and behavioral difficulties. These typically include school-related problems (Abwender et al., 1996; Erenberg, Cruse & Rothner, 1986), difficulty coping with TS (Ernberg, Cruse, & Rothner, 1987), social interactions (Storch et al., in press), and a lower overall quality of life than their peers without TS (Elstner, Selai, Trimble, & Robertson, 2001). In addition, highly disruptive behavior (Sukhodolsky et al., 2003) and anxiety and mood disturbance (Robertson, Banerjee, Eapen, & Fox-Hiley, 2002) are very common in youths with TS. Consequently, there is a high comorbidity between TS and other psychiatric disorders, including attention-deficit/hyperactivity disorder (ADHD; 50-75% of cases; Robertson et al., 2002) and obsessive-compulsive disorder (OCD; 50% of cases; Robertson, 1995). Little research, however, has been conducted to examine what factors are predictive of current functional impairment and quality of life in youths with TS. The factors examined in the current exploratory study are demographic variables, such as age, gender, and race, current emotional and behavioral difficulties, and the specific type of TS symptoms possessed.

## Method

### Procedure

Prior to study onset, the University of Florida institutional review board granted relevant ethical permissions. Written parental consent and child assent was obtained for each participating youth before administering measures (consent rate = 91%; 59/65). Participation was voluntary, and families were compensated \$.50 for their participation with funds being given to the consenting parent for distribution. Measurement administration was counterbalanced with approximately 50% of families being administered the YGTSS before completing child- and parent-report measures. A trained research assistant provided instructions for each measure and was available for assistance. Masters or doctoral level clinical psychology trainees, trained in administration by the first author, administered the YGTSS to both the child and parent jointly in a private clinical office. YGTSS training consisted of an instructional meeting about the YGTSS, four practice interviews, and four directly observed interviews.

### Measures

Youth and their parents completed a series of questionnaires that included a demographic questionnaire, the Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989), Child Behavior Checklist (CBCL; Achenbach, 1991), the Schwartz Peer Victimization Scale (SPVS; Schwartz, Farver, Change, & Lee-Shin, 2002), Child Tourette's Syndrome Impairment Scale - Parent Report (CTIM-P; Storch et al., 2007), and the Pediatric Quality of Life Inventory version 4.0 (PedsQL; Varni, Seid, & Rode, 1999).

### Participants

The sample consists of 59 children and adolescents ( $n = 11.4$  years,  $SD = 2.6$  years, range = 8-17, males = 41) with a diagnosis of Tourette's Syndrome who presented to a specialty outpatient clinic. Although the age of tic onset and illness duration were not systematically collected, by virtue of our inclusion criteria of TS or a chronic tic disorder, youth had tics for at least one year prior to presentation (without a tic-free period of greater than three months). The most prevalent co-morbid diagnoses for the current sample were Attention Deficit Hyperactivity Disorder ( $n = 28$ ) and OCD ( $n = 25$ ), with other co-morbid diagnoses in the population including Generalized Anxiety Disorder ( $n = 7$ ), Major Depression ( $n = 6$ ), Oppositional Defiant Disorder ( $n = 6$ ), Asperger's Disorder ( $n = 3$ ), Social Phobia ( $n = 2$ ), and Panic Disorder ( $n = 1$ ).

## Results

### Impairment due to Tics

There was a wide range of endorsement on particular types of impairments, but the majority of the sample reported significant functional problems in one or more areas (52.1%), with 37.5% of the sample reporting significant problems in two or more areas. The areas where parents reported the highest percentage of impairment (defined as a rating of 'pretty much' or 'very much' on CTIM-P) due to tics were primarily school related, such as writing during class (24.6%), doing homework (21.9%), concentrating on work (21.8%), and being prepared for class (18.5%), or social activity related, such as being teased by peers (17.5%) and making new friends (15.8%). There was a wide range of endorsement on particular items, but the majority of the sample reported significant problems in one or more areas (52.1%), with 37.5% of the sample reporting significant problems in two or more areas. Across broad categories of impairment, 35.6% of children were reported as having at least one significant problem area in school, 23.7% were reported to have at least one significant problem area at home, and 25.4% were reported to have at least one problem area in social activities. Of those children with significant problems, 10.2% reported at least one problem area in each domain (school, home, and social activities).

### Behavioral and Emotional Functioning

Table 1 gives the means and standard deviations for the various measures of behavioral and emotional functioning in the current study, as well as the Pearson product moment correlations between the measures.

**Table 1**  
Pearson product moment correlations for various measures of psychological functioning.

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
(1) CTIM-P-Tics	1.00	.370*	.433**	.513**	.513**	.288*	.081	.450**	-.422**	-.321*	.077
(2) YGTSS Motor		1.00	.565**	.707**	.824**	-.040	-.123	-.030	.048	-.190	.153
(3) YGTSS Phonic			1.00	.710**	.842**	-.174	.098	.195	-.184	-.331*	-.282*
(4) YGTSS Impairment				1.00	.566**	.214	.170	.338*	-.247	-.394*	.462**
(5) YGTSS Total					1.00	.162	.063	.240	-.181	-.369*	.383**
(6) CBCL Externalizing						1.00	.679**	.581**	-.636**	-.309*	.243
(7) CBCL Internalizing							1.00	.514**	-.669**	.491**	.397**
(8) CBCL Social Problems								1.00	.651**	-.590**	.502**
(9) PEDI-QI Parent									1.00	.647**	-.427**
(10) PEDI-QI Child										1.00	-.653**
(11) SPVS											1.00
Mean	12.41	13.39	7.91	18.21	39.52	11.56	12.81	3.83	71.78	71.93	8.61
Standard Deviation	15.91	6.40	7.33	13.90	24.73	8.86	9.89	3.33	16.28	16.18	3.83

Note. CTIM-P = Child Tourette's Syndrome Impairment Scale - Parent Report; YGTSS = Yale Global Tic Severity Scale; CBCL = Child Behavior Checklist; PEDI-QI = Pediatric Quality of Life Scale; SPVS = Schwartz Peer Victimization Scale.  
\* $p < .05$ . \*\* $p < .001$ .

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## Results (cont.)

### Regression Analyses

Stepwise multiple regression analyses were used to examine the relationship between severity of tics, internalizing and externalizing problems, social problems, peer victimization, and degree of impairment due to tics as measured by the CTIM-P (see Table 2). On Step 1, gender and age were entered on the first step to control for demographic effects and accounted for 15.9% of the variance. The Social Problems scale of the CBCL entered on step two, accounting for an additional 12.9%, with Phonic scale of the YGTSS added on step three and adding 6.8% to the model. On the last step, the total of the SPVS was entered, accounting for a total adjusted  $R^2$  to .408 for the total model ( $p = .023$ ).

Two more stepwise multiple regressions were used to examine prediction of quality of life, as reported by both parents and children. For the first analysis, examining prediction of parent-reported QoL (see Table 3), gender and age were entered on step one and accounted for 1.3% of the variance. The CBCL Internalizing scale entered on step two and accounted for 46.3% of the variance in parent-reported QoL. The Social Problems scale of the CBCL entered on the final step of the model, bringing the total adjusted  $R^2$  to .570 for the model ( $p = .001$ ).

To predict child-reported quality of life, another analysis was run. As before, gender and age were entered on step one to control for demographic effects, with an adjusted  $R^2$  of .042. On step two, the SPVS total score entered and accounted for 32.9% of the variance in child-reported QoL. CBCL Social Problems entered on the final step of the model, bringing  $R^2$  to .484 for the total model ( $p = .001$ ).

**Table 2**

Stepwise Multiple Regression Analyses for Prediction of Impairment Due to Tics

Variable	Multiple R	R <sup>2</sup>	Adjusted R <sup>2</sup>	F change	Significance of F
Step 1 Gender, age	.435	.189	.159	6.19	.004
Step 2 + CBCL Social Problems	.571	.326	.288	10.59	.002
Step 3 + YGTSS Phonic	.634	.402	.356	6.49	.014
Step 4 + Schwartz Peer Victimization Scale	.680	.462	.408	5.54	.023

Note: CBCL Internalizing, CBCL Externalizing, YGTSS Motor, and YGTSS Total did not enter into the equation.

**Table 3**

Stepwise Multiple Regression Analyses for Prediction of Parent-reported Quality of Life

Variable	Multiple R	R <sup>2</sup>	Adjusted R <sup>2</sup>	F change	Significance of F
Step 1 Gender, age	.220	.049	.013	1.35	.267
Step 2 + CBCL Internalizing	.710	.505	.476	47.90	<.000
Step 3 + CBCL Social Problems	.775	.601	.570	12.33	.001

Note: CBCL Externalizing, SPVS, YGTSS Motor, YGTSS Phonic and YGTSS Total did not enter into the equation.

**Table 4**

Stepwise Multiple Regression Analyses for Prediction of Child-reported Quality of Life

Variable	Multiple R	R <sup>2</sup>	Adjusted R <sup>2</sup>	F change	Significance of F
Step 1 Gender, age	.278	.077	.042	2.21	.119
Step 2 + Schwartz Peer Victimization Scale	.637	.406	.371	28.74	<.000
Step 3 + CBCL Social Problems	.722	.521	.484	12.34	.001

Note: CBCL Externalizing, CBCL Internalizing, YGTSS Motor, YGTSS Phonic and YGTSS Total did not enter into the equation.

## Discussion

Tourette's Syndrome can be a devastating illness to youth, with impairments seen across a wide range of areas. Understanding what factors are most predictive of impairments and quality of life in TS youths can allow for more targeted interventions and improvements. Contrary to what may be expected, the results of the current study do not implicate severity of tics as the major contributing factor to a decrease in either functional impairment or quality of life. For example, the amount of social problems were found to be the most predictive index of parent-reported functional impairment, with degree of phonic tics and peer victimization contributed further predictive validity to the model, for a total of 41% of the variance in functional impairment accounted for by those factors. Similar results were found for parent- and child-reported quality of life, in that social problems were a significant predictor in each. For parent-reported QoL, however, the most predictive factor was the presence of high levels of internalizing behaviors, with social problems completing the model and account for a total of 57% of the variance in QoL. For child-reported QoL, amount of peer victimization was the most significant predictor, with the addition of social problems totaling 48% of the variance in QoL.

These results point to the impact of social environment and the reactions of individuals in the environment to the youth's tics, rather than the degree of tic, on functioning and quality of life. Based on the current results, clinicians may need to spend more time assessing the amount of difficulties in social problems and interactions with peers, instead of spending as much time assessing number and severity of tics, when seeing youth with Tourette's for therapy. Developing social skills and increasing coping abilities for these youth in conjunction with standard treatment for controlling tics (e.g., habit reversal training) may assist in improving treatment outcomes.

