

# Changes in Socio-Emotional and Behavioral Functioning After Attending a Camp for Children with Tourette Syndrome: A Preliminary Investigation

Cyd K. Eaton<sup>1</sup> · Julia LaMotte<sup>1</sup> · Ana M. Gutierrez-Colina<sup>1</sup> · Patricia Kardon<sup>2</sup> · Ronald L. Blount<sup>1</sup>

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**Abstract** Children and adolescents with Tourette syndrome are at risk for social, emotional, and behavioral difficulties that may negatively influence feelings of self-competence and attitudes toward having this diagnosis. Attending a camp for children with Tourette syndrome may facilitate improvements in overall socio-emotional and behavioral functioning and self-perception. The current study obtained data from 37 campers (76 % male, 24 % female) and 47 caregivers of campers to investigate changes in children's emotional and behavioral functioning, self-perception (i.e., social and general), attitudes towards having Tourette syndrome, and how different they felt from peers after attending a 1-week summer camp for youth with Tourette syndrome using a pre-post design. Results indicated that campers endorsed a significantly improved sense of social self-competence and more favorable attitudes toward having Tourette syndrome post-camp. Campers also tended to endorse feeling less different than peers at camp versus peers in general. Caregivers endorsed significantly less severe symptoms associated with Tourette syndrome for campers after attending camp. No pre-to-post-camp changes were observed for campers' levels of anxiety or obsessive-compulsive symptoms. These preliminary findings suggest that attending camp or having other opportunities to interact with similar peers may promote better perceptions of social self-competence, more favorable attitudes toward

having Tourette syndrome, and a stronger sense of affiliation with peers for children with Tourette syndrome.

**Keywords** Tourette syndrome · Camp · Socio-emotional functioning · Behavioral functioning

Tourette syndrome (TS) is a neuropsychiatric disorder with childhood onset characterized by the presence of motor and vocal tics (American Psychiatric Association [APA], 2013). TS is diagnosed in approximately 3–8 per 1000 children, with higher rates in males (APA, 2013). Children with TS often present with comorbidities, including attention-deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), separation anxiety, oppositional defiant disorder, depression, and learning disorders (Center for Disease Control [CDC], 2009). Children with TS have also demonstrated higher rates of social functioning deficits (Güler et al., 2015).

Given the risk of socio-emotional and behavioral difficulties, children with TS may benefit from protective experiences that enhance social and emotional functioning. In other pediatric populations, attending specialty camps with peers with similar diagnoses has been associated with more positive self-perceptions (i.e., self-competence, self-esteem, self-concept; Odar et al., 2013), social interactions (Cushner-Weinstein et al., 2007), and attitudes toward having a chronic condition (Briery and Rabian, 1999), as well as lower overall anxiety symptoms (Bultas et al., 2013). Campers attending a pediatric oncology camp endorsed feeling less different than peers at camp compared to peers in general (Meltzer and Rourke, 2005). Findings from pediatric camp literature suggest that camp attendance has a positive influence on emotional and social functioning and helps children develop connections with peers affected by similar challenges related to having a chronic condition.

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✉ Cyd K. Eaton  
cydeaton@uga.edu

<sup>1</sup> Department of Psychology, University of Georgia, 125 Baldwin Street, Athens, GA 30602, USA

<sup>2</sup> Tourette Information Center and Support (TICS) of Georgia/Camp Twitch & Shout, 2462 Jett Ferry Road, Suite 400-156, Dunwoody, GA 30338, USA

A prior study conducted at a camp for children with TS identified higher pre-camp levels of depression as a risk factor for having poorer experiences at camp and more negative attitudes toward having TS post-camp (Eaton et al., 2015). No studies have examined pre-to-post-camp changes that may facilitate positive adjustment in children with TS. The experience of attending a camp for children with TS may lead to improvements in socio-emotional functioning (e.g., anxiety, attitude toward having a TS, self-competence), similar to those observed at camps for children with other diagnoses. However, the potential stress of being in a new environment may have negative implications, manifested through increased severity of symptoms associated with TS (Conelea and Woods, 2008). Research examining pre-to-post changes in socio-emotional and behavioral functioning is needed to determine how camp attendance affects children with TS, and potentially offsets risk for psychological and social problems associated with TS diagnoses.

This preliminary investigation used a pre-post design to answer questions about how socio-emotional and behavioral functioning in children with TS changes after attending a pediatric specialty camp. Based on results from prior research on the effects of attending pediatric camps, it was hypothesized that from pre-to-post-camp: (a) campers' anxiety symptoms would decrease, (b) levels of perceived self-competence (social and general) and attitudes towards having TS would improve, (c) severity of symptoms associated with TS would increase, and (d) campers would report feeling less different compared to peers at camp versus in general. Exploratory analyses examined pre-to-post changes in obsessive-compulsive symptom severity and correlations between study variables and change scores to suggest potential mechanisms and relationships between the degrees of observed changes.

## Method

### Participants

The current sample included 37 children with TS ( $M$  age = 12.32,  $SD$  = 2.56; range 8–18) and 47 caregivers of campers ( $M$  age = 42.98,  $SD$  = 6.40; range 18–47). The majority of campers were male (76 %) and identified as White/Caucasian (94 %). Comorbid diagnoses included ADHD (59 %), OCD (59 %), depression (15 %), and anxiety (47 %). Sixteen campers (43 %) were first-time camp attendees. Caregivers were primarily female (94 %) and identified as White/Caucasian (94 %). The majority of caregivers identified as biological parents of campers (92 %) and were married (85 %). See Tables 1 and 2 for additional demographic details.

**Table 1** Camper Demographic Information

Factor	$M$	$SD$
Age (years)	12.32	2.56
	Frequency	%
Sex		
Male	28	76
Female	9	24
Race		
White/Caucasian	35	95
Black/African American	2	5
Comorbid diagnoses		
ADHD	20	59
OCD	20	59
Depression	5	15
Anxiety	16	47

$N = 37$ . *ADHD* Attention-deficit/hyperactivity disorder; *OCD* Obsessive compulsive disorder

### Setting

Participants were recruited from a summer camp in the United States for children ages 7 to 18 years with TS. The 1-week camp was designed to create an environment for children to build social relationships with other children with TS and

**Table 2** Caregiver Demographic Information

Factor	$M$	$SD$
Age (years)	42.98	6.40
	Frequency	%
Sex		
Male	5	11
Female	42	89
Race		
White/Caucasian	44	94
Black/African American	2	4
Asian-East Indian	1	2
Family income		
Less than \$10,000	3	6
\$10,000–24,999	3	6
\$25,000–49,999	7	15
\$50,000–74,999	5	11
\$75,000–99,999	7	15
\$100,000–149,999	16	34
Prefer not to say/choose not to report	6	13
Marital status		
Married	40	85
Single, never married	2	4
Divorced	5	11

$N = 47$

engage in typical camp activities (e.g., archery, capture the flag, swimming, rock climbing) without concern for how others will react to their TS diagnosis and display of tic behaviors. As such, there were no interventions administered for reducing tics (e.g., comprehensive behavioral intervention for tics [CBIT]; Woods et al., 2008) or other co-occurring behavioral, emotional, or social problems. Staff members included paid employees who managed the facility for this and other pediatric camps, as well as unpaid volunteers (e.g., counselors, medical and mental healthcare providers).

## Procedures

Procedures were approved by the Institutional Review Board of the investigators' university. Approximately 1–5 weeks prior to attending camp, all registered campers and their caregivers were invited to participate in the study (Time 1) via email. Caregivers and campers followed a secure link to an online data collection service (Qualtrics®) to provide informed consent and assent and complete study measures. The average time from the baseline assessment to the start of camp was 15 days for campers and 19.91 days for caregivers. Campers who agreed to participate completed a second set of paper and pencil measures on the last full day of camp (Time 2). Caregivers completed post-camp measures immediately or up to 4 weeks after camp ended via an emailed link (Time 2), with an average completion time of 19.28 days post-camp. Campers received a \$2 incentive to use at the camp store. Caregivers were not compensated for completing the study.

## Measures

**Demographic Information** Campers and caregivers completed a demographics form to provide information about themselves and their household (e.g., sex, race, age). Caregivers reported on campers' comorbid psychological diagnoses.

**Perceived Competence Scale for Children (PCS)** Campers completed the Social and General subscales of the PCS (Harter, 1982), a self-report measure of children's self-competence (i.e., perceived level of functioning in various domains). The Social subscale assesses competence related to peer interactions (e.g., "Kids seem to really like me") and the General subscale assesses how good children feel about themselves, overall (e.g., "I am happy with the way I am"). Campers reported on how similar they felt to items using a Likert-scale ranging from *Not at all* to *A whole lot*. The Social and General self-competence subscales demonstrated good internal consistency in the current sample (Social: Time 1  $\alpha = 0.82$ , Time 2  $\alpha = 0.84$ ; General: Time 1  $\alpha = 0.82$ , Time 2  $\alpha = 0.86$ ).

**Children's Attitude Towards Illness Scale (CATIS)** Campers completed an adapted version of the CATIS (replacing "illness" with "Tourette syndrome;" Austin and Huberty, 1993). Campers reported how favorably or unfavorably they felt about having TS (e.g., "How often do you feel sad about having Tourette syndrome?"). The CATIS was developed with a sample of children with epilepsy and asthma (Austin and Huberty, 1993). In the current sample, the CATIS had good to excellent internal consistency (Time 1  $\alpha = 0.88$ , Time 2  $\alpha = 0.91$ ).

## Multidimensional Anxiety Scale for Children (MASC)

Campers completed the Social Anxiety and Separation Anxiety subscales of the MASC (March, 1997), a self-report measure assessing childhood anxiety symptoms. Campers responded to items using a Likert-scale ranging from *Never true about me* to *Often true about me*. Raw scores were converted to age-normed T-scores. Both subscales demonstrated good internal consistency in the current sample (Social Anxiety: Time 1  $\alpha = 0.88$ , Time 2  $\alpha = 0.90$ ; Separation Anxiety: Time 1  $\alpha = 0.78$ , Time 2  $\alpha = 0.81$ ).

**Peer Comparison** Campers responded to two adapted items (Meltzer and Rourke, 2005) to assess their sense of feeling different compared to peers in general and at camp. Before attending camp, campers reported on how different they felt compared to peers in general. At the end of camp, campers reported on how different they felt compared to peers at camp. The five response options ranged from *Very different* to *Not at all different*.

## Tourette's Disorder Scale-Parent Rated Version (TODS-PR)

Caregivers completed the TODS-PR (Shytle et al., 2003), a measure assessing overall severity of children's symptoms associated with TS (e.g., tics, hyperactivity, inattention, obsessions, compulsions). Caregivers rated statements on how much their child was bothered by each symptom using a Likert-scale ranging from *Not at all* to *Extremely*. Responses were summed to create a total severity score, ranging from 0 to 150, with higher scores indicating more severe TS symptoms. The TODS-PR was validated in a similar sample of youth with TS (Shytle et al., 2003). The TODS-PR had excellent internal consistency in the current sample (Time 1  $\alpha = 0.92$ , Time 2  $\alpha = 0.94$ ).

## Spence Child Anxiety Scale for Parents (SCAS-P)

Caregivers completed the Separation Anxiety, Social Anxiety, and OCD subscales from the SCAS-P (Spence, 1998) to assess perceptions of campers' symptoms. Caregivers rated the occurrence of symptoms from *Not at all* to *Always*. The selected subscales of the SCAS-P demonstrated good internal consistency in the current sample (Time 1  $\alpha = 0.80$ – $0.86$ , Time 2  $\alpha = 0.79$ – $0.86$ ).

## Statistical Analyses

Descriptive statistics were calculated for study variables. Paired sample *t*-tests were used to evaluate changes in mean levels of all study variables from Time 1 (pre-camp) to Time 2 (post-camp). The null hypothesis was rejected if the *p*-value was less than 0.05. Cohen's *d* was calculated to determine effect sizes for mean differences. Post-hoc correlations were calculated to determine how within-reporter variables demonstrating pre-to-post-camp changes covaried from Time 1 and Time 2 to suggest potential mechanisms of changes and to examine relationships between absolute change scores for variables demonstrating pre-to-post-camp changes. Change scores were calculated by taking the absolute value of differences between Time 1 and Time 2 scores.

## Results

### Did Campers' Self-Reports of Socio-Emotional Functioning Change After Attending Camp?

Results of paired samples *t*-tests indicated that, after attending camp, campers endorsed significantly higher mean levels of social self-competence and more favorable attitudes towards having TS. There were no significant changes from pre-to-post-camp for campers' mean levels of general self-competence or social and separation anxiety symptoms. See Table 3 for more details.

### Did Campers Feel Less Different from Peers at Camp Versus Peers in General?

Compared to peers in general, campers tended to feel more different. The most frequently endorsed pre-camp responses were *Very different* (28 %) and *A little different* (25 %).

Compared to peers at camp, campers tended to feel less different. The most frequently endorsed post-camp responses were *Not at all different* (33 %) and *Not too different* (25 %). Campers responded as feeling significantly less different than peers at camp versus peers in general,  $t(35) = -2.61, p = 0.010, d = -0.53$ . See Table 4 for more details.

### Did Caregivers' Proxy-Reports of Campers' Emotional and Behavioral Functioning Change After Attending Camp?

Results of paired samples *t*-tests indicated that after attending camp, caregivers endorsed significantly lower mean levels of symptoms associated with TS for campers. There were no significant changes from pre-to-post-camp for campers' mean levels of social anxiety, separation anxiety, or OCD symptoms. See Table 5 for more details.

### Post-hoc Correlations Between Variables Demonstrating pre-to-Post-Camp Changes

Results indicated that feeling more similar to peers in general at Time 1 was positively correlated with social self-competence ( $r = 0.43, p = 0.009$ ) and attitude toward having TS ( $r = 0.57, p < 0.001$ ) at Time 2. Social self-competence at Time 1 was positively correlated with social self-competence ( $r = 0.89, p < 0.001$ ), attitude towards having TS ( $r = 0.46, p = 0.005$ ), and feeling more similar to campers ( $r = 0.56, p < 0.001$ ) at Time 2. Attitude toward having TS at Time 1 was positively correlated with social self-competence ( $r = 0.51, p = 0.001$ ) and attitude toward having TS ( $r = 0.86, p < 0.001$ ) at Time 2. No other significant correlations emerged including among absolute change scores.

**Table 3** Changes From Pre-to-Post-Camp for Camper-Reported Socio-emotional Functioning

Variable	Pre-Camp		Post-Camp		<i>t</i>	df	<i>d</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Social self-competence	1.80	0.69	1.97	0.66	-2.71*	35	-0.25
General self-competence	2.03	0.67	2.05	0.70	-0.31	35	-0.03
Attitude towards having TS	3.43	0.89	3.64	0.82	-2.79**	36	-0.25
Social anxiety symptoms	9.86	6.79	9.14	7.15	0.82	36	0.10
Separation anxiety symptoms	7.89	5.24	7.38	5.16	0.82	36	0.10

TS Tourette syndrome. Higher scores for self-competence and attitude towards having TS indicated better self-competence and more favorable attitudes. Higher scores for social anxiety and separation anxiety symptoms indicated greater symptom severity. Social and General self-competence were measured with the Perceived Self-Competence Scale (PCS); Attitude towards having TS was measured with the Children's Attitude Towards Illness Scale (CATIS); Social and Separation anxiety symptoms were measured with the Multidimensional Anxiety Scale for Children (MASC)

\* $p < 0.05$ , \*\* $p < 0.01$

**Table 4** How Different Campers Felt Compared to Peers in General and at Camp

Response	Compared to peers in general <i>n</i> (%)	Compared to peers at camp <i>n</i> (%)
1 - Very different	10 (28)	4 (11)
2 - A little different	9 (25)	6 (17)
3 - In between	5 (14)	5 (14)
4 - Not too different	4 (11)	9 (25)
5 - Not at all different	8 (22)	12 (33)
Mean ( <i>SD</i> ) per item	2.75 (1.44)	3.53 (1.40)

The numbers listed before the response anchors are the numeric, Likert-scale values assigned to each response descriptor

**Discussion**

The aim of the current study was to provide preliminary data on whether children with TS experienced changes in socio-emotional and behavioral functioning after attending a pediatric specialty camp. As hypothesized, campers endorsed higher levels of social self-competence and more favorable attitudes towards having TS after camp. Campers reported feeling significantly less different than peers at camp compared to peers in general. Improvements in social self-competence and attitudes towards having TS were consistent with findings that children with chronic conditions experience post-camp improvements in self-perception (Odar et al., 2013), social interactions (Cushner-Weinstein et al., 2007), and attitudes toward having a chronic condition (Briery and Rabian, 1999). Prior research has also supported feeling less different compared to fellow campers after attending a pediatric camp (Meltzer and Rourke, 2005).

Post-camp changes in more favorable perceptions of social self-competence and attitudes toward having TS may reflect the environment fostered at camp, which encouraged socialization and self-confidence about having TS. Campers’ endorsement of feeling less different compared to peers at camp may have reflected opportunities to interact with peers facing similar TS-related challenges. Due to the nonexperimental study design, it cannot be determined if differences in ratings

occurred as a result of attending camp. Additionally, effect sizes were small, suggesting that improvements may not be consistent across campers or be large enough to generalize to broader areas of functioning (e.g., social skills, self-confidence). The co-occurrence and directionality of these changes (i.e., more favorable perceptions of social self-competence and attitudes towards having TS, feeling less different compared to peers at camp) tentatively suggest possible benefits of camp attendance and socialization experiences for children with TS. These findings lay the groundwork for prospective longitudinal investigations to examine whether these changes mitigate the risk for future socio-emotional problems in children with TS.

Contrary to hypotheses, there were no pre-to-post-changes in campers’ general self-competence. This finding was inconsistent with prior research indicating overall improvements in self-perception for children with other chronic conditions (Odar et al., 2013). The null findings may have been due to subscale items, which related to overall self-perception (e.g., “I am pretty sure of myself”), and may have been less affected by camp experiences than items on the Social subscale (e.g., “I have a lot of friends”). The small sample size, variability in data collection methods from Time 1 to Time 2 (online versus in person), and relatively large age range for campers are other plausible explanations for null findings.

**Table 5** Changes From Pre-to-Post-Camp for Caregiver Proxy-Reported Socio-emotional and Behavioral Functioning

Variable	Pre-Camp		Post-Camp		<i>t</i>	df	<i>d</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Symptoms associated with TS	73.81	29.98	65.35	29.69	2.61*	46	0.28
Social anxiety symptoms	5.89	3.16	6.34	3.74	-1.20	46	-0.13
Separation anxiety symptoms	4.68	3.47	4.17	3.38	1.84	46	0.15
Obsessive compulsive symptoms	4.62	3.99	3.98	3.42	1.90	46	0.17

TS Tourette syndrome. Higher scores for symptoms associated with TS, social anxiety symptoms, separation anxiety symptoms, and obsessive-compulsive symptoms indicated greater symptom severity. Symptoms associated with TS were measured with the Tourette’s Disorder Scale-Parent Rated Version (TODS-PR); Social anxiety, separation anxiety, and obsessive compulsive symptoms were measured with the Spence Child Anxiety Scale for Parents (SCAS-P)

\**p* < .05

There were no pre-to-post-changes in campers' social and separation anxiety or obsessive-compulsive symptoms. Findings related to social and separation anxiety were inconsistent with research suggesting that campers experience decreases in anxiety symptoms after attending a pediatric camp (Bultas et al., 2013). Hypotheses were based on prior findings, though none of these camps provided psychological or psychiatric intervention to address anxiety symptoms. Without targeted, empirically-supported intervention, anxiety and obsessive-compulsive symptoms should not be expected to improve by attending camp. Inconsistencies in findings may relate to the population (e.g., cardiac conditions versus TS). The current sample's psychological comorbidity rate was higher than base rates in the general child population (e.g., Costello et al., 2005). This sample likely reflected more severe symptomatology than prior studies', and, therefore, would not change after brief engagement in camp activities.

Unexpectedly, severity of symptoms associated with TS decreased, rather than increased, after camp. The initial hypothesis was guided by the theory that increased stress due to environmental and possible emotional changes associated with camp attendance (i.e., fatigue, anxiety) would increase the severity of symptoms associated with TS (Conelea and Woods, 2008). The current findings may have been influenced by caregivers rating the severity of symptoms associated with TS up to 4 weeks after camp. Symptoms may have attenuated due to a period of relaxation following high activity levels at camp. Alternatively, campers may have returned home feeling better about their social self-competence and having TS, translating into more positive emotions. Increased positive emotions post-camp may have protected against the risk for symptoms associated with TS. Prospective studies should examine how long post-camp decreases in symptoms last and measure positive emotionality to determine whether camp attendance is a protective experience for children with TS.

Post-hoc analyses showed that having positive attitudes towards having TS, higher social self-competence, and feeling similar to peers at Time 1 was associated with better socio-emotional and behavioral functioning after camp. Results were intended to provide future directions to identify potential mechanisms of changes (e.g., social self-competence mediating pre-to-post-camp improvements in attitudes towards having TS). A larger sample size and more rigorous research design is needed to determine mechanisms of change. Additionally, absolute change scores were not significantly correlated, suggesting that change among one set of variables (e.g., attitude towards having TS) may not covary with change among another set of variables (e.g., social self-competence).

The current study had limitations. A larger sample size would support broader generalization, increase statistical power, and likely enhance participant diversity (e.g., the current sample had a relatively high family income). This

study relied on self-report measures and did not include in vivo behavioral measures at camp. Future researchers should consider having study personnel present at camp to obtain observational data (e.g., social interactions), and determine if behavior changes over the course of camp. The TODS-PR included symptoms of tics and common comorbidities associated with TS. By grouping these symptoms, it is possible that decreases in mean scores reflected the aggregate of symptoms included on the TODS-PR and not just tics. Future investigations should include a separate measure of tic severity to clearly delineate comorbidities from potential changes in tic severity. The study design was nonexperimental and there was no control group, limiting the ability to explain why changes occurred from pre-to-post-camp. Other explanations for changes include the passage of time, separation from parents, or change in settings. The current study utilized mixed methods for data collection (i.e., online, in person). This design was selected out of necessity for collecting pre-camp data from families living across the United States but introduced method variance issues when interpreting results.

Replication and adding a control group would help validate these results and identify mechanisms of changes in socio-emotional and behavioral functioning. Utilizing a true experimental design would further support the notion that attending a specialty camp helps children with TS develop positive perceptions about having TS and social self-competence. Results suggest that levels of anxiety or obsessive-compulsive symptoms should not be expected to decrease in the absence of targeted intervention. Additional research is needed to clarify how camp attendance influences the severity of symptoms associated with TS, particularly given the reduction in overall symptoms found in this investigation. This preliminary evidence suggests that children with TS benefit from socializing with similar peers in a safe and supportive environment. Further research is needed to determine whether improvements are maintained in the long-term, and if they offset risk for socio-emotional and behavioral problems often seen in children with TS.

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#### **Compliance with Ethical Standards**

**Conflict of Interest** All other authors have no conflicts of interest to disclose.

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