CHANGES IN PERCEIVED KNOWLEDGE OF CONDITION, ATTITUDES TOWARD TICS, AND OVERALL CONSUMER SATISFACTION AFTER ADOLESCENTS WITH TOURETTE SYNDROME ATTEND THE TIM HOWARD LEADERSHIP ACADEMY

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Abstract

The Tim Howard Leadership Academy (THLA) was a three-day summer program for adolescent participants and young adult mentors with Tourette Syndrome. Among others, a few of the goals of the program were to improve participants’ self-leadership capabilities, enhance their understanding of their conditions, and to improve participants’ overall quality of life. Past studies showed that youth with TS have uniquely negatively impacted peer relationships and decreased quality of life. Few studies have shown the effects of group programs on youth with TS. Those that have been conducted showed promising outcomes. The present study was conducted to examine the potential psychosocial benefits of the 2016 THLA program. This information will inform future THLA programming and can provide data relevant to the development and/or modification of similar, outside programming. The present study analyzed the impact of attending the 2016 THLA on its adolescent participants. The study used archival survey data, collected via an online program (Qualtrics). All participants were voluntary, from the pool of 2016 THLA adolescent attendees. The 2016 THLA adolescent attendees were 13-18 year olds with TS. Research questions included: 1) In what way, if any, did THLA attendance alter the participants’ attitudes toward tics?, 2) Did participants gain knowledge and/or better understanding of their conditions after attending THLA? and 3) Were participants satisfied with their experiences at the THLA and why? Hypotheses regarding these questions were as follows: 1) Participants will report improved attitudes toward tics (e.g. more positive) after attending THLA; 2) Participants will report that they have gained knowledge of their condition after attending THLA; and 3) Participants will report high consumer satisfaction with their experience at THLA. Data were analyzed
using descriptive statistics, pre- and post- t-tests, and classical qualitative analysis. The t-test analyses of “knowledge gained” and “attitudes toward tics” indicated consistency with the hypotheses, including that participants exhibit more positive attitudes toward tics after attending THLA and greater perceived knowledge of conditions after attending THLA. The qualitative analyses concluded that participants reported overall consumer satisfaction with THLA programming, highlighting many factors that contributed to a positive consumer experience. Further research is needed to duplicate the findings of this study, to inform future THLA programming and similar outside programming, and to potentially provide alternatives to the resource-intensive individual therapies (e.g. HRT) that are currently the gold standard interventions for TS+.
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Chapter I: Introduction

Overview

This dissertation study was an evaluation of changes in perceived knowledge of condition, attitude toward tics, and overall consumer satisfaction with the Tim Howard Leadership Academy (THLA) on adolescents with Tourette Syndrome (TS) and comorbid, associated disorders (TS+). Information about THLA is provided below (see “background information.”) The reason for this evaluation was that this program has not previously been evaluated. Analyses of 2016 THLA data are able to inform future programming and have the potential to inform the development and/or improvement of similar programming for adolescents with TS+. In the present study, the potential psychosocial benefits that such a program can provide to its participants were examined. Utilizing retrospective data review, this dissertation aimed to assess THLA participants’ attitudes toward TS, knowledge of their condition, and how these attitudes and knowledge changed following participation in the 2016 THLA. In addition, participants’ satisfaction with THLA, after participation in THLA, was evaluated. Data were collected at baseline (pre-THLA), immediately post-THLA, and at 9 months post-THLA programming.

Background Information and Key Terms

Tourette Syndrome

Tourette Syndrome (TS) is a neurodevelopmental condition characterized by motor and vocal tics. Diagnostic criteria include the chronic presence of at least two motor tics and one vocal tic, since childhood (APA, 2013). Tics are defined as involuntary, sudden, rapid, recurrent, non-rhythmic movements (motor tics) and
vocalizations (vocal or phonic tics) (APA, 2013). There are many comorbid disorders thought to be associated with the etiology of Tourette Syndrome, including OCD, ADHD, and trichotillomania (Sheppard et al., 1999).

**Tim Howard Leadership Academy**

The New Jersey Center for Tourette Syndrome and Associated Disorders (NJCTS) is a non-profit organization that offers various programming to individuals with TS+ and their families. Among this programming are group-based opportunities and leadership experiences for youth with TS. Tim Howard partnered with NJCTS to begin the Tim Howard Leadership Academy (THLA). Tim Howard is a professional soccer goalie (with a $10 million + net worth) with diagnoses of TS and ADHD. In his autobiography, Tim Howard described the adversity he faced as a child and how he overcame many obstacles, including his TS and ADHD symptoms, in order to become a world-renowned soccer player. As such, Tim Howard serves as an important role model for many children with TS+. His story is one that instills hope and inspires readers to overcome their own obstacles, including the impact of their own symptoms. Tim Howard is originally from North Brunswick, NJ, making him an especially accessible role model for children in the tri-state area. As the name suggests, THLA is meant to inspire participants to hone their leadership abilities.

The New Jersey Center for Tourette Syndrome and Associated Disorders (2018) wrote on their website that “people of all ages with TS may experience a higher degree of social isolation, stigmatization, bullying, and discrimination. For children, the effects of Tourette Syndrome and its associated disorders create a disruption of typical childhood development and experiences, particularly in their social and academic lives. A view of
one’s self as successful, capable, and having possibilities, a feeling of social relatedness and connectedness are basic human needs which build resilience and are critical components of a positive outlook on life. For all young people, but especially for those who face TS and its inherent challenges, resilience is key.

The NJCTS Tim Howard Leadership Academy is designed to develop self-leadership, advocacy skills, and resilience in teens with Tourette Syndrome (TS) and its associated disorders. The program aims to increase participants’ understanding of their disorders and provides opportunities and a safe environment to explore and identify their strengths, challenges, needs, and skills. The four pillars of THLA are: “self-leadership, self-advocacy, resilience, and grit” (NJCTS, 2018). The goals of NJCTS and THLA are consistent with tenants of psychosocial wellbeing, which are particularly relevant for adolescents with TS who are at an increased risk for decreased psychosocial functioning. THLA provides participants with mentorship, education, and leadership training (NJCTS, 2018). Due to its unique offerings, the THLA attracts participants from other states and even other countries (e.g. Texas, New York, Canada, and Australia).

**TS, Quality of Life, and THLA**

TS and the associated disorders have been shown to affect psychosocial aspects of functioning, particularly quality of life, in a number of ways including increased social isolation, increased peer victimization, increased familial stress and discord, and negative self-esteem (Bawden et al., 1998; Carter et al., 2000; Conelea et al., 2011; Eapen et al., 2016; Eddy et al., 2011; McGuire et al., 2015; Robertson et al., 1995; Storch et al., 2012; Cavanna et al., 2013; Cutler et al., 2009; O’Hare et al., 2016; Rivera-Navarro et al., 2014; Storch et al., 2007; Zinner et al., 2012). There are very few research studies or treatment
programs that focus on the impacted quality of life in youth with TS. Those treatments that do exist often require ample resources (e.g. few locations, significant financial commitment, long-term nature) and can be difficult to access. The THLA was created in response to the psychosocial impact of having TS and its potential negative effect on youth’s aspirations and life trajectories. The present study evaluated aspects of the THLA program experience and its effects on participants, including participants’ perceptions of attitude changes toward their tics, knowledge gained, and consumer satisfaction.

*Child Attitude Toward Illness Scale Adapted for TS (CATIS-Tics)*

In 1993, Austin and Huberty (see references) developed the Child Attitude Toward Illness Scale (CATIS). During its development, this scale was tested on children (ages 8-12) with diagnoses or epilepsy or asthma. The researchers recognized that children with chronic physical conditions have difficulty adjusting that is at least in part related to their attitudes toward their illness. The original study found good internal consistency and test-retest reliability. The researchers measured how favorable or unfavorable participants’ attitudes were toward their given illness. The rating scale is comprised of 13 self-report questions that are summed for a total mean score. To determine whether there was consistency in responses, the researchers included the same item twice, with a reversed Likert scale. In 2000, Heimlich and colleagues provided further psychometric validation of the CATIS. Their tests yielded excellent internal consistency reliability and good test-retest reliability and demonstrated that CATIS scores correlated moderately with self-esteem and mastery demonstrating the measure’s construct validity. Although the CATIS was originally validated for children with epilepsy and asthma, the language of the items were adapted for a population with tics.
and/or Tourette Syndrome. The Attitude Toward Tics (CATIS-TICS) has not been validated for this population and further research is needed to create a psychometrically sound measure for this population. In the present study, the survey measure used includes the entire CATIS-TICS (13 total questions) with the language adapted (e.g. “How good or bad do you feel it is that you have Tourette Syndrome/tics?” rather than “How good or bad do you feel it is that you have epilepsy?”).

**Purpose of Study**

There are few programs that focus on evaluating or improving the quality of life of adolescents with TS and its comorbidities (Storch et al., 2007). The evidence-based programs in existence (e.g. Habit Reversal [Woods, 2008]; pharmacotherapy) require ample time and monetary resources to access and sustain participation. Programs such as the THLA provide an intensive, brief, and accessible experience for adolescents with TS+. THLA is a community program developed by a local, non-profit organization (NJCTS). Establishing the effectiveness of such a program will inform future THLA programming, will support the implementation and continuation of similar programs and has potential to improve outcome measures of psychological treatments for adolescents with TS+. The results of the present study may provide additional rationale for such programming, which could increase availability of funding for programs. This has the potential to ensure better psychosocial outcomes for adolescents with TS. The purpose of the present study is to conduct a research formative evaluation of survey data from participants of the 2016 cohort of THLA. This evaluation will assess participants’ satisfaction with THLA programming, assess knowledge gained after attending THLA, and will examine how participants’ views of themselves and their diagnoses changed, if at all, after attending THLA.
Research Questions

1.) In what way, if any, did THLA attendance alter the participants’ attitudes toward tics?

2.) Did participants gain knowledge and/or better understanding of their conditions after attending THLA?

3.) Were participants satisfied with their experiences at the THLA and why?
Chapter II: Review of the Relevant Literature

Defining Tourette Syndrome

According to the DSM-5, Tourette Syndrome (TS) is characterized by the presence of multiple motor tics and at least one vocal tic for the duration of one year. TS is estimated to affect 3-8 out of every 1,000 school-aged children, with males more commonly affected than females by a ratio of 2:1 – 4:1 (APA, 2013). In their 2013 article, Cavanna and Seri define Tourette Syndrome as “a neurodevelopmental condition characterized by multiple motor and vocal tics, which appear in childhood and are often accompanied by behavioral symptoms.” Tourette Syndrome was originally described by a French physician called Georges Gilles de la Tourette in 1885. Since that time, TS was thought of as a rare condition, until later epidemiological studies showed that 0.3-1% (Cavanna & Seri, 2013) of school-aged children meet the diagnostic criteria for TS. This does not include the rest of the school-aged children with tic disorders who do not meet criteria for TS (e.g. who may experience tics in one category, either vocal or motor, or experience temporary or transient tics). Cavanna and Seri write that “although it is estimated that about two thirds of patients with [TS] improve by adulthood, the syndrome affects health related quality of life.”

Common Comorbidities

Tourette Syndrome is a complicated disorder, with 80-90% of those diagnosed with TS experiencing at least one comorbid disorder (O’Hare et al., 2016). The etiology and relationship between TS and its comorbidities is not yet well understood (O’Hare et al., 2016). TS is thought to be at least partially genetically based, with unknown environmental factors contributing to its etiology. It is believed that TS and its
Comorbidities are genetically linked (Wang et al., 2018). Common comorbidities include attention-deficit hyperactivity disorder (ADHD) and disruptive behaviors, obsessive-compulsive disorder (OCD), and autism spectrum disorder (ASD), and coexistent problems include anxiety, depression, and low self-esteem, which can all lead to poorer psychosocial functioning and quality of life (Eapen et al., 2016). Packer (1997) also notes that mild to moderate learning disabilities are a common comorbid concern in children and adolescents with TS. Comorbidities such as ADHD, LD, and OCD can uniquely impact quality of life based on the academic impact and social impact of symptoms related to these diagnoses. In a study examining the impact of TS on young people’s quality of life, Cutler and colleagues (2009) used focus groups and questionnaire data to measure quality of life. They found that quality of life in children with TS was significantly worse than that of children in the normative sample. Poorer quality of life was associated with increased tic severity and the presence of ADHD and OCD symptoms.

A behavioral neurologist conducted a review of common comorbidities of TS and found that the most common comorbidities also include “rage attacks” and sleep disturbance in addition to those previously listed (Mol Debes, 2013). These comorbidities affect psychosocial, educational, and neuropsychological functioning and the presence of more comorbid concerns indicate higher risk for the development of conduct disorder (Mol Debes, 2013).

Previous case studies also suggest the possible presence of comorbid depression, OCD, and self-injurious behavior. In two cases, the co-occurrence of TS and these related problems led to suicide in young adulthood (Robertson et al., 1995). These case studies
were published with the intent to raise awareness that thorough evaluation, regular monitoring, and an understanding of psychosocial difficulties associated with TS are necessary in order to prevent TS and its comorbidities from resulting in suicide and other adverse outcomes. These case studies demonstrate how social stigma and the burden of multiple disorders can result in hopelessness and severe depression. Some of the factors reported as contributing to suicide were social stigma, restrictions on autonomy, illness or treatment disrupted normal functioning, limited opportunity for social activities (isolation), and burden on families.

**Impact on Quality of Life**

Literature on TS and quality of life shows an overwhelming consensus that TS negatively affects quality of life in youth. Specifically, TS can result in physical limitations, restricted social engagement, psychological stress, familial stress and discord, negative impact on well-being, and limitations in typical occupational activities (e.g. academic performance) due to physical, psychological, and/or emotional problems related to TS and emotional difficulties related to perceptions of one’s own health (Conelea et al., 2011).

Bawden et al. (1998) found children with TS to have poorer peer relationships when compared to healthy classmates and when compared to a group of same-age children with a different chronic illness. Wadman et al. (2016) found that tic severity is not always an accurate indicator of occupational difficulties that youth experience as it relates to their TS. These studies, and several others like them, point out the importance of assessing and treating psychological and psychosocial impacts of TS rather than simply targeting a reduction in tics (e.g. Habit Reversal Training; Woods et al., 2008).
Some of the psychological characteristics associated with resilience (providing a buffer for the psychosocial impact of TS) include: self-advocacy, self-leadership, and self-empowerment (Packer, 1997; Christner, 2008).

**Functional impairment across domains**

In 2011, Conelea and colleagues published the results of an Internet survey that they had distributed to 232 youth with tics and their families (740 parents in total). The survey assessed the impact of chronic tics across five functional domains: physical, social, familial, academic, and psychological. Results of this survey suggest that youth with chronic tics experience mild to moderate functional impairment; impairment is positively correlated with tic severity; children with chronic tics plus one or more comorbidity tend to have increased functional impairment; and children and adolescents with chronic tics experience discrimination due to their tics. In opposition to the Carter (2000) study, this study found that higher tic severity is positively correlated with impairment. Both studies came to consensus that TS+ creates risk for increased functional impairment when compared to TS only or to healthy controls.

**Quality of life and psychosocial impact**

Eddy and colleagues (2011) wrote that quality of life is adversely affected by behavioral symptoms associated with TS. Their study compared youth with TS to healthy controls and youth with epilepsy. They measured quality of life, anxiety, depression, and behavioral symptoms. They found a positive correlation between severity of tics and impact on quality of life. Participants with TS only presented with increased depression and lower quality of life. Those with TS and OCD presented with lower quality of life in the domains of relationships. The presence of OCD and ADHD comorbid with TS
resulted in poorer quality of life across domains. In another study examining the impact of TS on quality of life, Cutler and colleagues (2009) found that quality of life in children with TS was significantly worse than that of children in the normative sample. They used focus groups and questionnaire data to measure self-reported quality of life. Poorer quality of life was associated with increased tic severity and the presence of comorbidities (e.g. ADHD and OCD symptoms).

**Peer relationships**

In 1998, a research study was conducted to better understand peer relationships of children with TS. Bawden and colleagues found that children with TS had uniquely poor peer relationships when compared to their healthy classmates and when compared to a group of children with diabetes. Those with TS were also more likely to have “extreme scores” reflecting increased risk for peer relationship problems on a measure of social behavior when compared to a group of children with diabetes. The purpose of this study was to identify both whether children with TS experience more peer relationship problems, and whether these problems are generically related to having a chronic condition or unique to having a TS diagnosis. The findings suggest that extreme peer relationship problems are not unique to TS. Additionally, they found that children with co-occurring TS and Attention-Deficit Hyperactivity Disorder (ADHD) were at increased risk for poor peer relationships when compared to the healthy classmates (control group), and to the diabetes group (chronic condition control group).

Similarly, in 2000 Carter and colleagues studied a group of 72 children ages 8-14 years. This sample consisted of 33 children with TS and ADHD, 16 with TS only, and 23 without any psychiatric diagnoses. They found that children with TS and ADHD
demonstrated externalizing and internalizing behaviors and poorer social adaptation than those with TS only and the control group. Children with TS only were found to exhibit more internalizing symptoms than the healthy controls. Tic severity was not shown to have an impact on social functioning. This provides further evidence that there are unique, negative psychosocial effects of TS that are not related to the severity of tic symptoms and that TS+ can significantly compound psychosocial difficulties.

Storch and colleagues (2007) compared a group of children with chronic tics to a group of children with diabetes and a healthy control group. Children with tics displayed higher rates of peer victimization than health controls and a group of children with diabetes. Peer victimization was positively correlated with internalizing symptoms, tic severity, loneliness, symptoms of anxiety, and parent reports of child internalizing symptoms. These findings highlight the importance of the assessment and treatment of psychosocial aspects of having chronic tics and TS, including social functioning and peer relationships.

O’Hare and colleagues (2016) gathered data from 86 parents of children with TS. They found that TS, as compared to its comorbid disorders (e.g. OCD and ADHD), was associated with impaired social functioning and peer relationship problems. When comorbidities were taken into account, TS+ was associated with impaired emotional functioning (as indicated by increased emotional symptomatology) and impaired school functioning (as measured by a “Strengths and Difficulties” questionnaire).

Zinner and colleagues (2012) studied peer victimization in youth with TS, using child self-report and parent-report measures. Data showed that 26% of a group of 211 children reported being bullied. Peer victimization was associated with greater tic
severity, explosive outbursts, internalizing symptoms, and lower quality of life. Anticipatory guidance and bullying education are indicated for children with chronic tics.

In 1996, Friedrich and colleagues conducted a study of children’s attitudes and behavioral intentions toward a boy with symptoms of TS. They showed children a video of a boy with or without TS and studied the children’s responses. Children (grades 3-5) rated the peer with TS less positively than the peer without TS. There were no significant differences found across behavioral intention measures.

**Social stigma**

Eapen and colleagues (2016) conducted a review of the literature to examine co-occurring issues in children with TS. They aimed to understand how social stigma and misperceptions about symptoms lead to discrimination against those with TS. In their review, they found that TS co-occurs with anxiety, depression, and low self-esteem. Each of these co-occurring concerns can result in poorer psychosocial functioning and, relatedly, poorer quality of life. They found that those with TS experience social stigma, social maladjustment, social exclusion, bullying, and discrimination due to misperceptions of the disorder by the environment (e.g. educators, peers, community). Rivera-Navarro (2014) had similar findings, noting that others’ misperceptions of TS led to increased impairment in quality of life.

Malli and colleagues (2016) conducted a review of the literature on social stigma in youth with TS. Youth without diagnosis showed unfavorable attitudes toward individuals with TS as compared to typically developing peers. Youth with TS perceived devaluation from others as a response to their TS. Children also adopted
negative views about themselves. Parents expressed guilt in relation to their child’s TS and reported social isolation as a result of their child’s TS.

**Social cognition**

In 2004, Channon and colleagues conducted a study of adults with TS. They found that adults with uncomplicated TS (i.e. no comorbid diagnoses) demonstrated impaired inhibitory functioning but did not differ from matched healthy controls on tasks of social cognition (such as theory of mind and empathy). Inhibitory functioning deficits can result in impaired focus, attention, and behavioral responses. Inhibitory control is important for the suppression of actions (e.g. inappropriate social behavior) and for maintaining focus in the presence of irrelevant stimuli (Richardson, 2008).

**Academic functioning**

Children with TS are more likely to have special education needs and to require accommodations (Packer, 1997). Many children do not present with tics at their doctor’s office, which can result in underestimation of impairment associated with tics. Packer outlines how education and advocacy are necessary to improve outcomes for children with TS and its comorbidities.

**Summary**

The research consensus is that TS significantly impacts children and adolescents’ quality of life, most clearly related to domains of social and educational functioning. To address the impact of TS on social and educational functioning, Christner & Dieker (2008) suggests a collaborative approach that involves students, families, and teachers in order to increase knowledge and to dispel misconceptions about TS. This can improve the academic and social experiences of children with TS.
Programs to Address Quality of Life and TS

Few programs exist that directly target the quality of life in youth with TS. Those that have been piloted (e.g. Eaton et al., 2015; Khomenko, 2017; Marcks et al., 2007; McGuire et al., 2015; Yates et al., 2015) have not been replicated. There is a need for increased awareness and implementation of these promising programs for youth. These group programs may reduce social isolation, increase self-advocacy, and produce better personal and interpersonal outcomes for youth with TS.

Eaton et al. (2015) studied changes in functioning after children with TS attended a camp program. They found that children and adolescents with TS are at risk for lower self-competence and negative attitudes toward their TS diagnosis. They studied data from 37 campers and 47 caregivers to investigate how the campers’ emotional and behavioral functioning, self-perceptions, and attitudes toward having TS were impacted after attending a 1-week summer camp program for children and adolescents with TS. They found that campers reported significant improvements in self-competence and improved attitudes toward their TS after attending the camp. One limitation of this study was that the design included only pre- and immediately post-camp data, without a later follow-up to see if participation in the camp had any lasting effects on self-competence and attitudes toward TS. The findings of this study suggest that opportunities to interact with similar peers can positively impact outcomes for children and adolescents with TS.

Marcks et al., 2007 studied the effects of disclosure about TS on peer perceptions and social functioning. The results are promising, suggesting that proactive disclosure of TS may reduce social rejection, minimize others’ concern, and decrease misattributions of behavior to drug- and alcohol-related problems. McGuire et al. (2015) conducted a
pilot study of a treatment protocol called “Living with Tics” which combines targeting tic reduction (e.g. Habit Reversal Therapy; Woods, 2008) with identifying and implementing coping strategies to address stress and problems related to having TS. Findings suggest that the Living with Tics protocol improves quality of life for children and adolescents (ages 7-17 years) with TS and that it reduces tic related impairment. Limitations to this research include that it is an intensive, ten-week program. There are foreseeable concerns in accessibility including lack of treatment providers that specialize in Habit Reversal Training (Woods, 2008).

Yates et al. (2016) evaluate the effects of Habit Reversal Training group treatment as compared to educational groups about TS. This study was a randomized control trial that included children and adolescents (ages 9-13 years). They found that the youth in both treatment groups demonstrated improvements in quality of life but that the HRT group demonstrated greater reductions in motor tic severity. Both treatment groups demonstrated reductions in overall tic severity. These findings suggest that educational group treatments may improve quality of life and overall treatment outcomes for children with TS. Implications for this research include cost-effective, accessible treatment programs to specifically target quality of life in youth with TS, albeit less specialized than HRT.

Interestingly, Holtz & Tessman (2007) piloted an intervention focused on peers of children with TS. In their study, they provided video-based education to children without TS with the hope of increasing peer knowledge of TS and fostering positive attitudes toward a child with TS. They recognized that TS can be confusing and stigmatizing and that many children with TS experience social rejection and negative experiences in the
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classroom. They found that children who were shown the educational video showed increased knowledge about TS, more positive attitudes toward a peer with TS, and positive behavioral intentions toward the peer with TS as compared to the control group. Implications for this research include that a cost-effective, accessible educational video may have potential to reduce social rejection for children with TS.

The Tim Howard Leadership Academy

The NJCTS Tim Howard Leadership Academy program was formed by NJCTS with assistance from the TS Program at Rutgers-GSAPP. The Tim Howard Leadership Academy takes place in the Rutgers University dormitories every August for a total of three days. There are between 20-40 attendees per year. Additionally, a small group of young adult “coaches” (THLA alumni) serve as mentors for small groups of attendees (approximately 5-6 adolescents per group). Each summer, the THLA “empowers a new set of leaders and advocates” (NJCTS, 2019). The Tim Howard Leadership Academy addresses a number of quality of life factors specific to adolescents with TS. For instance, THLA addresses social isolation by connecting adolescents with same-age peers with TS, many of whom live near each other. Additionally, a main focus of the THLA is the teaching of leadership qualities and self-advocacy (NJCTS, 2019).

The Importance of Self-Advocacy

Children and adolescents with TS require strong self-advocacy skills, not only to survive the social aspects of their daily lives but also to obtain and consistently receive appropriate school based services and accommodations (Packer, 1997). TS can result in impaired academic functioning (due to physical and/or emotional impairment associated with TS) and may require the use of academic accommodations. Youth with TS
experience higher rates of co-occurring learning disabilities as compared to typically developing peers. In order to navigate special education services and academic accommodations, adolescents must learn to be self-advocates as they become increasingly independent from their parents and eventually age out of the school system.

“Self-advocacy” is a term that is often used in legal situations regarding a disability, handicap, or special education need. Becoming a self-advocate means understanding and effectively communicating your needs to others. The skills of self-advocacy aims to address the impaired educational and social functioning in youth with TS, as a result of others’ misunderstanding or misperceptions of TS symptoms. Additionally, when adolescents learn to advocate for themselves, they are able to educate others, to assert themselves appropriately, and to demand academic accommodations and services. Christner & Dieker (2008) highlight the importance of student empowerment, self-advocacy, and proactive attempts (on the part of the child and the family) to educate others about their diagnosis of TS. This kind of proactive education and self-advocacy has the potential to lead to improved social and academic outcomes for children with TS.

Children and adolescents with TS require strong self-advocacy skills, not only to survive the social aspects of their daily lives but also to obtain and consistently receive appropriate school based services and accommodations (Packer, 1997). TS can result in impaired academic functioning (due to physical and/or emotional impairment associated with TS) and may require the use of academic accommodations. Youth with TS experience higher rates of co-occurring learning disabilities as compared to typically developing peers. In order to navigate special education services and academic
accommodations, adolescents must learn to be self-advocates as they become increasingly independent from their parents and eventually age out of the school system.
Chapter III: Method of Investigation

THLA Programming

The NJCTS Tim Howard Leadership Academy (THLA) program was formed by NJCTS with assistance from the TS Program at Rutgers Graduate School of Applied and Professional Psychology. The TS Program is a community sliding-scale clinic that provides HRT and other evidence-based interventions to individuals with TS+. The first data collection at THLA was a pilot study of anonymous aggregate data in 2015. The TS Program then received IRB approval for continued data collection (i.e. human subjects research with an informed consent and assent process, which began in 2016). THLA takes place at Rutgers University Busch Campus, in the Busch Engineering Science and Technology Hall. For the duration of the program, participants stay overnight in the dormitories, supervised by NJCTS staff, a registered nurse, and their young adult coaches.

History of Data Collection at THLA

In 2015 an anonymous pilot study was conducted via paper surveys given to THLA participants who volunteered to participate. This survey measure was determined to be robust and was used in subsequent years. In 2016, IRB approval was granted to evaluate the THLA program. Data for the present dissertation study were sourced from the existing archive of data from the August 2016 cohort of THLA participants. Information regarding the consent process is outlined below (see “Recruitment and consent process”). The 2016 data were collected using a Qualtrics survey, sent to voluntary participants via an emailed link. This survey was a compilation of pre-existing measures (including the Tourette Syndrome Impact Scale and the adapted Child Attitude
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Toward Illness Scale for tics -- see References and Appendix B for more information on these measures) and questions that the director of the Rutgers TS Program created. This survey measure has not yet been submitted for reliability analysis. From the original survey, items were selected to answer the research questions for the present study in conjunction with NJCTS, in an effort to gain feedback on THLA programming. These items are listed in Appendix A.

**Population Studied**

All participants (30) who attended the 2016 NJCTS THLA were invited to participate in the Qualtrics survey. Participants included approximately 30 adolescents, aged 14-18 with pre-existing diagnoses of Tourette Syndrome who were selected by the NJCTS to participate in the 2016 THLA. Candidates submitted an application to the NJCTS and were selected based on their interest and demonstrated readiness to develop skills of leadership and self-advocacy. From this population, a voluntary sample was selected (see *Sample size*).

**Sample Size**

All THLA attendees were selected by NJCTS to participate in THLA via an application and review process. Candidates were selected based on their interest and demonstrated readiness to develop skills of self-leadership and advocacy, as determined by NJCTS staff. All THLA attendees were sent an e-mail describing that NJCTS and the TS Program at Rutgers planned to collect data about the THLA experience and asked for volunteers. The present sample included 23 adolescent participants from THLA 2016, ages 15-18 years.
Respondents

There were 23 responses to the 2016 THLA survey baseline (pre-THLA), 18 responses at the immediately-post THLA collection, and 10 responses at the 9-month follow-up collection. Approximately 7 attendees at THLA declined participation in the study.

Methods for Data Collection

1. Subjects were recruited from the entire pool of adolescent participants in THLA.
2. Data were collected immediately prior to, immediately following the conclusion of, and at 9 months following the conclusion of THLA via secure, online survey software (Qualtrics).
3. Participants were asked to participate in the research study from July 2016 to May 2017. Following the attainment of written consent and assent, consenting participants were contacted via email through Qualtrics and invited to complete a survey at each of the three time points. The first page of the Baseline (pre-THLA) Qualtrics survey included an assent form. The first pages of the Post and Follow-Up surveys reminded participants that they can discontinue participation at any time or skip any questions they do not wish to respond to. The last page of each of the three surveys included a debriefing statement and provided resources to participants, should they have questions or concerns regarding the research and/or their participation in the study.
4. Baseline surveys were sent out on 7/5/2016 and participants had one month (until 8/3/2016) to complete them prior to the start of THLA. Post-THLA surveys were sent on 8/8/2016 and participants had one month (until 9/8/2016) to complete
them. Follow-up surveys were sent on 4/8/2017 and participants had one month (until 5/8/2017) to complete them. Automated survey reminders were sent out two times during each month-long survey period, via Qualtrics.

5. During the data collection period, all identifying information (specifically informed consent forms with participants’ email addresses) were kept in a locked cabinet in the office of the primary investigator at Rutgers University. These data are to be kept for a total of five years under the original IRB (until 2021). De-identified, electronic data from Qualtrics were stored in a password-protected Excel file on the primary investigator’s password-protected computer, in her office at Rutgers University. Five years after the completion of the study (in 2021), all informed consent documents will be shredded and electronic files will be destroyed.

6. During the archival data analysis period, the password-protected Excel file with de-identified survey data was coded and exported to SPSS for analysis. None of the identifying information was accessed for the present dissertation study.

Recruitment and Consent

A consent form (see Appendix E) was mailed to the home of every potential participant (attendees of THLA), accompanied by a letter (see Appendix H) with instructions for completion. For participants under 18 years of age, an equivalent parental consent form was mailed (see Appendix F). The letter instructed participants to review the consent form, to contact the principal investigator with questions, and if interested to return the signed consent form directly to the research team at Rutgers, and to specify an email address for future correspondence. Following the attainment of written consent,
consenting participants were contacted via email through Qualtrics and were invited to complete the survey at each of the three time points. At each time point, participants were reminded that they could stop responding, skip questions, or discontinue their participation at any time.

Parental consent forms, accompanying information and instructions were mailed to participants’ homes by an NJCTS staff member who was identified and pre-approved by the Rutgers IRB. This was to keep mailing addresses confidential, so the research team did not have access to these addresses prior to obtaining consent. Mailing occurred after participants were accepted into THLA so that participants did not feel coerced to participate in the study. The parental consent form (see Appendix F) emphasized that participation in the study was voluntary and would not impact the family’s standing with NCJTS nor with THLA. Contact information for the principal investigator was provided on the consent form should parents or participants have any questions. Parents or participants were instructed to return signed consents, with initials on each page, directly to the research team so that NJCTS would not be aware which families agreed or declined participation in the study.

For all participants, an assent form (see Appendix G) was embedded into the first page of the Qualtrics survey at the baseline assessment. Participants were provided a review of study procedures and had the choice to select “voluntarily agree to participate” or “please exit me from this survey.”

**Internal Validity**

The original study was developed to provide a preliminary evaluation of the NJCTS THLA. The study was submitted as an open pilot in order to assess the feasibility
of conducting further research. This data collection was used to determine whether changes needed to be made to the survey questions to gather desired information about THLA. Internal validity was limited due to the lack of a control group. A control group was not feasible given the goals of the original research study. An additional threat to internal validity was the concern that participants may feel pressure to respond in a desirable way (i.e. to provide positive feedback regarding THLA). This threat to internal validity was limited by administering the survey through secure online software and emphasizing to participants that all data, as well as potential participants’ decisions whether or not to participate, would be sent directly to the Rutgers research team and that this information would not be shared with NJCTS. The sample studied included adolescents who decided to apply to THLA, therefore any findings may not be generalized to the general population of adolescents with TS. These threats to external validity are tolerable given the purpose of this research is to provide support for the effectiveness of NJCTS THLA programming.

Measures

The original Qualtrics survey (see Appendix A) included 58 questions at Baseline, 75 questions at Post, and 73 questions at Follow-Up. These sets of questions at each of the time points included the Child Attitude Toward Illness - Adapted for Tics (CATIS-Tics; See Austin & Heimlich, 1993) and the Tourette Syndrome Impact Survey (TSIS; see Conolea, 2011; see Appendix B). The surveys also included self-report questions formed by the principal investigator, which intended to assess the unique population and psychological constructs associated with TS. These included attitudes toward tics, impact of tics on quality of life, and participants’ internal experiences related to tics.
Additionally, the principal investigator was interested in participants’ consumer satisfaction with THLA programming.

From the larger surveys, items that queried about three variables of interest: 1) attitudes toward tics, 2) knowledge gained, and 3) consumer satisfaction were selected and analyzed. Repeated measures were used (pre, post, and at 9-months follow-up) to assess change over time in relation to participation in the NJCTS THLA.

**Research Questions and Predicted Trends**

1.) In what way, if any, did THLA attendance alter the participants’ attitudes toward tics?
   a. Prediction: Participants’ attitudes toward tics will become less negative after attending THLA (pre- to post-).

2.) Did participants gain knowledge and/or better understanding of their conditions after attending THLA?
   a. Prediction: Participants’ perceived knowledge of conditions will increase after attending THLA (pre- to post-).

3.) Were participants satisfied with their experiences at the THLA and why?
   a. Prediction: Participants will have positive feedback regarding their experiences at THLA due to forming new social bonds, spending time with adolescents facing similar concerns, gaining knowledge of their conditions, and learning self-advocacy and leadership skills.

**Methods for Data Analysis**
The data were analyzed using a mixed methods design to examine binary data, gradient scale (1-4 and 1-5) data, and qualitative data (text responses to survey items). All data were previously de-identified and stored in a password-protected Excel database.

Quantitative methods included descriptive statistics for each of the three variables of interest, encompassing responses to each item at each of the three time points; paired samples t-tests to determine changes in responses between time points (pre- to post-) and tests of statistical significance to determine the significance of any changes across time points.

**Steps to quantitative analysis**

1. For Research Question #1 ("In what way, if any, did THLA attendance alter the participants’ attitudes toward tics?"); mean scores from the 13-item CATIS-Tics were compared at pre and post. Mean scores are reported in “descriptive statistics” and paired samples t-tests of these mean scores analyzed changes from pre to post.

2. For Research Question #2 ("Did participants gain knowledge and/or better understanding of their condition after attending THLA?"); two items were included that directly queried about knowledge ("How much do you know about TS as a neurobiological condition?" and “How well do you understand your TS and how it affects you?"). These items were on a gradient scale, the scores of which ranged from 1-4 with 1 representing “Not at all,” 2 representing “Not much,” 3 representing “Some,” and 4 representing “A lot.” Means of these scores were used in paired samples t-tests to analyze changes from post and follow-up.

3. For Research Question #3 ("Were participants satisfied with their experiences at the THLA and why?"); 8 gradient Scale items and 2 free text items at post, and 6 gradient
Scale items and 2 free text items at the 9-month follow-up. The quantitative items at post were as follows: 1) How much has your experience at the Academy increased your overall confidence? 2) How much has your experience at the Academy helped you to better understand your strengths and skills? 3) How much has your experience at the Academy helped you to better understand your challenges and needs? 4) How much did you feel the climate of the Academy was respectful and accepting? 5) How much did you feel that the Academy presentations were relevant and helpful? 6) How much did you feel that the Academy activities were relevant and helpful? 7) How much did you feel that your coach demonstrated leadership and resilience? 8) How much did you feel understood and supported by your coach? At follow-up, the same items were repeated with items 5 and 6 omitted due to irrelevance at the 9-month follow-up time point.

Classical qualitative analyses of text responses to survey items examined consumer satisfaction, knowledge gained, and changes in attitudes toward tics. See details for qualitative methods below:

**Steps to qualitative analysis**

1. First, qualitative items were isolated from the original survey at each of the three time points of data collection (pre, post, and follow-up). Items were grouped by topic and responses were grouped by initial themes that emerged in the text, based on vocabulary used.

2. Second, the first reviewer created index cards that listed each survey item and each response.

3. Third, the initial themes that emerged were grouped subjectively (again, by the first reviewer) into broader, overarching categories.
4. Fourth, each response was examined to determine if responses were consistent with each other within each category and across time points (pre-THLA, post-THLA, 9 months follow-up THLA). This resulted in the first reviewer re-sorting the cards into categories, refining the original category delineations.

5. Fifth, a second reviewer, committee member Dr. Daniela Colognori who specializes in clinical interventions for individuals with TS+, examined the cards and grouped the responses into categories.

6. Finally, both reviewers came to a consensus regarding response categories. These categories were used in the final tally of responses.

For the variable *Consumer Satisfaction*, the qualitative items were: 1) “What do you expect might change for you following your experience at the 2016 Academy?” and 2) “Any additional comments or feedback?” in which participants were given a text box to type a response.
Chapter IV: Results

Introduction

The purpose of this study was to evaluate the experiences of a sample of adolescents with Tourette Syndrome who attended the Tim Howard Leadership Academy (measured by changes in perceived knowledge of condition, attitudes toward tics, and overall consumer satisfaction) at the 2016 Tim Howard Leadership Academy (THLA). Participants included adolescents with Tourette Syndrome (TS) and comorbid, associated disorders (TS+) who attended the 2016 THLA. Data were collected via an online (Qualtrics) survey which was sent out to voluntary participants immediately pre-THLA, immediately post-THLA, and 9 months following the conclusion of the THLA.

Descriptive Statistics

Variables

1. Perceived knowledge: Participants were asked two items that were included in the “perceived knowledge of condition” variable (1. “How much do you know about your TS as a neurobiological condition?” and 2. “How well do you understand your TS and how it affects you?”). In the paired samples t-test for perceived knowledge, means of the gradient scale scores were used to compare responses at pre and post. The gradient scale response options were as follows: 1=Not at all, 2=Not much, 3=Some, 4=A lot. Higher scores in response to these items indicated higher levels of perceived knowledge.

2. Self-esteem: At pre and post, there were five gradient scale items, four binary (Yes or No) items, and two qualitative (free text) items related to the variable of self-esteem. Items selected to respond to the research question about self-esteem
were, like the other research questions, chosen by the researcher using subjective methods of isolating items that query about factors related to self-esteem (e.g. confidence, level of comfort in discussing tics/TS, and acceptance of condition). The items included in the measurement and analysis of the “self-esteem” variable were as follows: Gradient Scale items: “How accepting do you feel toward your tics/TS?”; “How comfortable do you feel explaining TS in your own words to other teens?”; “How confident are you that you can be successful socially…with your TS and related conditions?”; “How confident are you that you can be successful academically with your TS and related conditions?”; “How confident are you that you can be successful overall in the future?”. The gradient scale range for measuring these was: 1=Not at all, 2=Not much, 3=Some, 4=A lot.; Yes/No items: “Do you feel different or abnormal because of your tics?”; “Do you feel special in a good way because of your tics?”; “Do you joke with others about your tics?”; “Do you tell other people ahead of time that you have tics?”; and Free text response items: As a follow-up question to the item Do you tell people ahead of time that you have tics, there are two items: “Why?” and “What do you tell them?”

3. Attitudes toward tics (CATIS-Tics): The 13 items included in the “attitudes toward tics” variable were from the CATIS-Tics. The CATIS was originally developed to measure how favorable or unfavorable participants’ attitudes were toward their given chronic illness (e.g. epilepsy). The rating scale is comprised of 13 self-report questions that are summed for a total mean score. The language
used in the CATIS was adapted for tics. Detailed descriptions of each item and its gradient scale are listed in Tables 1-3.

Table 1. Descriptive Statistics (Pre)

Summary: Descriptive statistics for quantitative data across three variables of interest: perceived knowledge of condition, self-esteem, attitudes toward tics (CATIS-tics) at baseline (“pre”) are presented in Table 1.

Perceived knowledge: At pre, responses to the item “How much do you know about your TS as a neurobiological condition?” ranged from 2-4, with the majority of participants (12 out of 23 total participants) endorsing 3 (“Some”); 10 endorsed 4 (“A lot”) and one participant endorsed 2 (“Not much”). The mean score at pre was 3.39. At post, 15 of the 18 total participants endorsed 4; two participants endorsed 3 and one participant (the same participant from pre who endorsed a “2”) endorsed 2. The mean score at post was 3.78. These results indicate that the majority of participants experienced a perceived increase in how much they know about their TS as a neurobiological condition. In response to the item “How well do you understand your TS and how it affects you?” the gradient scale was the same as for the previous knowledge-related item above. At pre, responses ranged from 3-4. 14 participants endorsed 4 (“A lot”) and 9 participants endorsed 3 (“Some”). The mean response at pre was 3.61. At post, 14 out of 18 total participants continued to endorse 4 and three participants endorsed 3. One participant endorsed 2 (“Not much”), indicating a perceived decrease in their understanding of their TS and how it affects them. The mean response at post was 3.72. These responses indicate that from pre to post, participants’ perceived understanding of their TS and how it affects them increased overall, although when examined at the
response level some responses stayed the same across time. It is noteworthy that five participants stopped responding from pre to post, therefore those participants’ potential changes in endorsed scores were not included in the overall perceived increase in knowledge.

**Self-esteem:** At pre and post, there were five gradient scale items (1-4), four binary (Yes or No) items, and two qualitative (free text) items related to the variable of self-esteem. Endorsed responses ranged from 2-4 at pre. Higher scores indicated more positive self-esteem. Yes/No items were coded as 0 or 1, respectively. In response to the binary items, the average responses at pre were as follows: “Do you feel different or abnormal because of your tics?” Average response = Yes; “Do you feel special (in a good way) because of your tics?” Average response = Yes; “Do you joke with others about your tics?” Average response = Yes; and “Do you tell other people ahead of time that you have tics?” Average response = No.

**Attitudes toward tics (CATIS-Tics):** At pre, participants responses on the gradient scale ranged from 1-5, endorsing the full range of the gradient scale. On the CATIS-Tics, the gradient scale for the items “How good or bad do you feel it is that you have tics/TS?” and “How bad or good do you feel it is that you have tics/TS” is as follows: 
1 = Very good, 2 = A little good, 3 = Not sure, 4 = A little bad, 5 = Very bad. At pre, the mean response to this item was 2.77. For the item “How fair is it that you have tics/TS” the gradient scale is as follows: 
1 = Very fair, 2 = A little fair, 3 = Not sure, 4 = A little unfair, 5 = Very unfair. At pre, the mean response to this item was 2.82. For the item “How happy or sad is it for you to have tics/TS?” the gradient scale is as follows: 
1 = Very happy, 2 = A little happy, 3 = Not sure, 4 = A little sad, 5 = Very sad. At pre, the mean response was 3.05.
CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

For the remainder of the 13 items, which query about the frequency of feeling certain ways about tics/TS, the gradient scale is as follows: 1=Never, 2=Not often, 3=Sometimes, 4=Often, 5=Very often. Mean responses to these items are listed in Appendix D.

Table 1. Descriptive Statistics (Pre)

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Min.</th>
<th>Max.</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you know about TS as a neurobiological condition? (Knowledge)</td>
<td>23</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.39</td>
<td>.583</td>
</tr>
<tr>
<td>How well do you understand your TS and how it affects you? (Knowledge)</td>
<td>23</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.61</td>
<td>.499</td>
</tr>
<tr>
<td>How accepting do you feel toward your tics/TS? (Self-esteem)</td>
<td>23</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.78</td>
<td>.518</td>
</tr>
<tr>
<td>How comfortable do you feel explaining TS in your own words to other teens? (Self-esteem)</td>
<td>23</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.57</td>
<td>.507</td>
</tr>
<tr>
<td>How confident are you that you can be successful socially (with friends, peers in school, peers in your activities) with your TS and related conditions? (Self-esteem)</td>
<td>23</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.43</td>
<td>.662</td>
</tr>
<tr>
<td>How confident are you that you can be successful academically (in school) with your TS and related conditions? (Self-esteem)</td>
<td>23</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.39</td>
<td>.583</td>
</tr>
<tr>
<td>How confident are you that you can be successful with your TS and related conditions overall in the future? (Self-esteem)</td>
<td>23</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.57</td>
<td>.507</td>
</tr>
<tr>
<td>How good or bad do you feel it is that you have tics/TS? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>5 (1-5)</td>
<td>2.77</td>
<td>1.066</td>
</tr>
<tr>
<td>Question</td>
<td>n</td>
<td>Range</td>
<td>Mean</td>
<td>SD</td>
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<td>------</td>
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<td></td>
</tr>
<tr>
<td>How fair is it that you have tics/TS? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>5 (1-5)</td>
<td>2.82</td>
<td>1.368</td>
</tr>
<tr>
<td>How happy or sad is it for you to have tics/TS? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>5 (1-5)</td>
<td>3.05</td>
<td>1.133</td>
</tr>
<tr>
<td>How bad or good do you feel it is to have tics/TS? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>5 (1-5)</td>
<td>3.05</td>
<td>1.174</td>
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<tr>
<td>How often do you feel that your tics/TS is your fault? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
<td>1.45</td>
<td>.671</td>
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<tr>
<td>How often do you feel that your tics/TS keeps you from doing things you like to do? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>4 (1-5)</td>
<td>2.36</td>
<td>1.002</td>
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<tr>
<td>How often do you feel that you will always be unhealthy because of your tics/TS? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
<td>1.68</td>
<td>.780</td>
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<td>How often do you feel that your tics/TS keeps you from starting new things? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>4 (1-5)</td>
<td>1.95</td>
<td>.950</td>
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<td>How often do you feel different from others because of your tics/TS? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>5 (1-5)</td>
<td>3.36</td>
<td>1.293</td>
</tr>
<tr>
<td>How often do you feel bad because you have tics/TS? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>4 (1-5)</td>
<td>2.14</td>
<td>.990</td>
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<tr>
<td>How often do you feel sad about having tics/TS? (CATIS)</td>
<td>22</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
<td>2.14</td>
<td>.834</td>
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<tr>
<td>How often do you feel happy even though you have tics/TS? (CATIS)</td>
<td>22</td>
<td>2 (1-5)</td>
<td>5 (1-5)</td>
<td>4.05</td>
<td>.899</td>
</tr>
<tr>
<td>How often do you feel just as good as other people your age even though you have tics/TS? (CATIS)</td>
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<td>2 (1-5)</td>
<td>5 (1-5)</td>
<td>4.18</td>
<td>.795</td>
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<td>Do you feel different or abnormal because of your tics? (Self-esteem)</td>
<td>22</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
<td>.36</td>
<td>.492</td>
</tr>
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CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

Table 1 Continued (2)

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<th>Question</th>
<th>N</th>
<th>0 (0-1)</th>
<th>1 (0-1)</th>
<th>p</th>
<th>( \beta )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel special (in a good way) because of your tics? (Self-esteem)</td>
<td>22</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
<td>.45</td>
<td>.510</td>
</tr>
<tr>
<td>Do you joke with others about your tics? (Self-esteem)</td>
<td>22</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
<td>.45</td>
<td>.510</td>
</tr>
<tr>
<td>Do you tell other people ahead of time that you have tics? (Self-esteem)</td>
<td>22</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
<td>.64</td>
<td>.492</td>
</tr>
</tbody>
</table>

Table 2. Descriptive Statistics (Post)

Summary: Table 2 lists the range of responses endorsed, mean response, and standard deviations in response to items that query about knowledge, attitudes toward tics, and self-esteem at post.

*Perceived knowledge:* The gradient scale response options were as follows:

1 = *Not at all*, 2 = *Not much*, 3 = *Some*, 4 = *A lot*. Higher scores in response to these items indicated higher levels of perceived knowledge. At post, responses to the item “How much do you know about your TS as a neurobiological condition?” were as follows: 15 of the 18 total participants endorsed 4; two participants endorsed 3 and one participant endorsed 2. The mean score for this item at post was 3.78. In response to the item “How well do you understand your TS and how it affects you?” the gradient scale was the same as for the previous knowledge-related item above. At post, 14 out of 18 total participants endorsed 4, three participants endorsed 3, and one participant endorsed 2.

*Self-esteem:* Endorsed responses on the gradient scale items ranged from 3-4 at post, with higher scores indicating more positive self-esteem. In response to the binary (Yes/No) items, the average responses at post were as follows: “Do you feel different or abnormal because of your tics?” Average response = No; “Do you feel special (in a good way) because of your tics?” Average response = Yes; “Do you joke with others about
your tics?” Average response = Yes; and “Do you tell other people ahead of time that you have tics?” Average response = Yes.

**Attitudes toward tics (CATIS-Tics):** At post, participants responses continued to range from 1-5 but the average trended toward more positive attitudes based on increases in the amount of “1s” and “2s” and less “4s” and “5s.” On the CATIS-Tics, the gradient scale for the items “How good or bad do you feel it is that you have tics/TS?” and “How bad or good do you feel it is that you have tics/TS” is as follows: 1=Very good, 2=A little good, 3=Not sure, 4=A little bad, 5=Very bad. At post, the mean response was 2.29. For the item “How fair is it that you have tics/TS” the gradient scale is as follows: 1=Very fair, 2=A little fair, 3=Not sure, 4=A little unfair, 5=Very unfair. At post, the mean response for this item was 2.47. For the item “How happy or sad is it for you to have tics/TS?” the gradient scale is as follows: 1=Very happy, 2=A little happy, 3=Not sure, 4=A little sad, 5=Very sad. At post, the mean response was 2.59. For the remainder of the 13 items, which query about the frequency of feeling certain ways about tics/TS (see Appendix C), the gradient scale is as follows: 1=Never, 2=Not often, 3=Sometimes, 4=Often, 5=Very often. Mean responses to these items are listed in Appendix D.

**Table 2. Descriptive Statistics (Post)**

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Min.</th>
<th>Max.</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you know about TS as a neurobiological condition? (Knowledge)</td>
<td>18</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.78</td>
<td>.548</td>
</tr>
<tr>
<td>How well do you understand your TS and how it affects you? (Knowledge)</td>
<td>18</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.72</td>
<td>.575</td>
</tr>
<tr>
<td>How accepting do you feel toward your tics/TS? (Self-esteem)</td>
<td>17</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.88</td>
<td>.332</td>
</tr>
</tbody>
</table>
Table 2 Continued (1)

<table>
<thead>
<tr>
<th>Question</th>
<th>Participants</th>
<th>Answers</th>
<th>Median</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>How comfortable do you feel explaining TS in your own words to other teens? (Self-esteem)</td>
<td>17</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.76</td>
<td>.437</td>
</tr>
<tr>
<td>How confident are you that you can be successful academically (in school) with your TS and related conditions? (Self-esteem)</td>
<td>17</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.76</td>
<td>.437</td>
</tr>
<tr>
<td>How confident are you that you can be successful with your TS and related conditions overall in the future? (Self-esteem)</td>
<td>17</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.82</td>
<td>.393</td>
</tr>
<tr>
<td>How much do you feel that your TS and related conditions interfere with goals that you set for yourself in life? (Self-esteem)</td>
<td>17</td>
<td>1 (1-4)</td>
<td>3 (1-4)</td>
<td>1.94</td>
<td>.659</td>
</tr>
<tr>
<td>How much has your experience at the Academy increased your overall confidence? (Satisfaction)</td>
<td>17</td>
<td>1 (1-4)</td>
<td>4 (1-4)</td>
<td>3.59</td>
<td>.795</td>
</tr>
<tr>
<td>How much has your experience at the Academy helped you to better understand your strengths and skills? (Satisfaction)</td>
<td>17</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.59</td>
<td>.618</td>
</tr>
<tr>
<td>How much has your experience at the Academy helped you to better understand your challenges and needs(Satisfaction)</td>
<td>17</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.59</td>
<td>.507</td>
</tr>
<tr>
<td>How much did you feel the climate of the Academy was respectful and accepting? (Satisfaction)</td>
<td>17</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.82</td>
<td>.529</td>
</tr>
<tr>
<td>How much did you feel that the Academy presentations were relevant and helpful? (Satisfaction)</td>
<td>17</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.41</td>
<td>.618</td>
</tr>
</tbody>
</table>
Table 2 Continued (2)

<table>
<thead>
<tr>
<th>Question</th>
<th>N</th>
<th>Min-Max</th>
<th>Mean</th>
<th>SD</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much did you feel that the Academy activities were relevant and helpful? (Satisfaction)</td>
<td>17</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.71</td>
<td>.588</td>
</tr>
<tr>
<td>How much did you feel that your coach demonstrated leadership and resilience? (Satisfaction)</td>
<td>17</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.88</td>
<td>.485</td>
</tr>
<tr>
<td>How much did you feel understood and supported by your coach? (Satisfaction)</td>
<td>17</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.88</td>
<td>.485</td>
</tr>
<tr>
<td>How good or bad do you feel it is that you have tics/TS? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>4 (1-5)</td>
<td>2.29</td>
<td>1.047</td>
</tr>
<tr>
<td>How fair is it that you have tics/TS? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>4 (1-5)</td>
<td>2.47</td>
<td>1.179</td>
</tr>
<tr>
<td>How happy or sad is it for you to have tics/TS? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>4 (1-5)</td>
<td>2.35</td>
<td>.862</td>
</tr>
<tr>
<td>How bad or good do you feel it is to have tics/TS? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>4 (1-5)</td>
<td>2.59</td>
<td>.939</td>
</tr>
<tr>
<td>How often do you feel that your tics/TS is your fault? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
<td>1.18</td>
<td>.529</td>
</tr>
<tr>
<td>How often do you feel that your tics/TS keeps you from doing things you like to do? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>4 (1-5)</td>
<td>1.88</td>
<td>.857</td>
</tr>
<tr>
<td>How often do you feel that you will always be unhealthy because of your tics/TS? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
<td>1.59</td>
<td>.618</td>
</tr>
<tr>
<td>How often do you feel that your tics/TS keeps you from starting new things? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
<td>1.82</td>
<td>.951</td>
</tr>
<tr>
<td>How often do you feel different from others because of your tics/TS? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>5 (1-5)</td>
<td>3.12</td>
<td>1.111</td>
</tr>
<tr>
<td>How often do you feel bad because you have tics/TS? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
<td>1.82</td>
<td>.636</td>
</tr>
</tbody>
</table>
CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

Table 2 Continued (3)

<table>
<thead>
<tr>
<th>Question</th>
<th>N</th>
<th>Range (Min-Max)</th>
<th>Mean (Range)</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you feel sad about having tics/TS? (CATIS)</td>
<td>17</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
<td>1.76</td>
</tr>
<tr>
<td>How often do you feel happy even though you have tics/TS? (CATIS)</td>
<td>17</td>
<td>3 (1-5)</td>
<td>5 (1-5)</td>
<td>4.18</td>
</tr>
<tr>
<td>How often do you feel just as good as other people your age even though you have tics/TS? (CATIS)</td>
<td>17</td>
<td>3 (1-5)</td>
<td>5 (1-5)</td>
<td>4.29</td>
</tr>
<tr>
<td>Do you feel different or abnormal because of your tics? (Self-esteem)</td>
<td>17</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
<td>.65</td>
</tr>
<tr>
<td>Do you feel special (in a good way) because of your tics? (Self-esteem)</td>
<td>17</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
<td>.29</td>
</tr>
<tr>
<td>Do you joke with others about your tics? (Self-esteem)</td>
<td>17</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
<td>.29</td>
</tr>
<tr>
<td>Do you tell other people ahead of time that you have tics? (Self-esteem)</td>
<td>17</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
<td>.47</td>
</tr>
<tr>
<td>How confident are you that you can be successful socially (with friends, peers in school, peers in your activities) with your TS and related conditions? (Self-esteem)</td>
<td>17</td>
<td>2 (1-4)</td>
<td>4 (1-4)</td>
<td>3.71</td>
</tr>
</tbody>
</table>

Table 3. Descriptive Statistics (Follow-Up)

Summary: The range of responses endorsed, mean response, and standard deviations in response to items that query about knowledge, acceptance, and self-esteem at the 9-month follow-up are presented in Table 3. Many of these results were not used in the analysis and interpretation due to a lack of responses at 9-month follow-up (see Discussion).
### Table 3. Descriptive Statistics (Follow-Up)

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Min.</th>
<th>Max.</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you know about TS as a neurobiological condition? (Knowledge)</td>
<td>10</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.70</td>
<td>.483</td>
</tr>
<tr>
<td>How well do you understand your TS and how it affects you? (Knowledge)</td>
<td>10</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.90</td>
<td>.316</td>
</tr>
<tr>
<td>How accepting do you feel toward your tics/TS? (Self-esteem)</td>
<td>10</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.70</td>
<td>.483</td>
</tr>
<tr>
<td>How comfortable do you feel explaining TS in your own words to other teens? (Self-esteem)</td>
<td>10</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.60</td>
<td>.516</td>
</tr>
<tr>
<td>How confident are you that you can be successful socially (with friends, peers in school, peers in your activities) with your TS and related conditions? (Self-esteem)</td>
<td>10</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.90</td>
<td>.316</td>
</tr>
<tr>
<td>How confident are you that you can be successful academically (in school) with your TS and related conditions? (Self-esteem)</td>
<td>10</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.70</td>
<td>.483</td>
</tr>
<tr>
<td>How confident are you that you can be successful overall in the future? (Self-esteem)</td>
<td>10</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.70</td>
<td>.483</td>
</tr>
<tr>
<td>How much do you feel your TS and related conditions interfere with goals that you set for yourself in your life? (Self-esteem)</td>
<td>10</td>
<td>1 (1-4)</td>
<td>3 (1-4)</td>
<td>2.10</td>
<td>.568</td>
</tr>
<tr>
<td>How much has the Academy increased your overall confidence? (Satisfaction)</td>
<td>9</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.89</td>
<td>.333</td>
</tr>
<tr>
<td>How much has the Academy helped you to better understand your strengths and skills? (Satisfaction)</td>
<td>9</td>
<td>3 (1-4)</td>
<td>4 (1-4)</td>
<td>3.78</td>
<td>.441</td>
</tr>
</tbody>
</table>
### Table 3 Continued (1)

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean</th>
<th>SD</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much has the Academy helped you to better understand your challenges and needs? (Satisfaction)</td>
<td>3.44</td>
<td>.527</td>
<td></td>
</tr>
<tr>
<td>How much did you feel the climate of the Academy was respectful and accepting? (Satisfaction)</td>
<td>4.00</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>How much did you feel that your coach demonstrated leadership and resilience? (Satisfaction)</td>
<td>4.00</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>How much did you feel understood and supported by your coach? (Satisfaction)</td>
<td>4.00</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>How good or bad do you feel it is that you have tics/TS? (CATIS)</td>
<td>2.33</td>
<td>.500</td>
<td></td>
</tr>
<tr>
<td>How fair is it that you have tics/TS? (CATIS)</td>
<td>2.44</td>
<td>1.014</td>
<td></td>
</tr>
<tr>
<td>How happy or sad is it for you to have tics/TS? (CATIS)</td>
<td>2.33</td>
<td>.707</td>
<td></td>
</tr>
<tr>
<td>How bad or good do you feel it is that you have tics/TS? (CATIS)</td>
<td>2.56</td>
<td>.882</td>
<td></td>
</tr>
<tr>
<td>How often do you feel that your tics/TS is your fault? (CATIS)</td>
<td>1.22</td>
<td>.441</td>
<td></td>
</tr>
<tr>
<td>How often do you feel that your tics/TS keeps you from doing things you like to do? (CATIS)</td>
<td>2.00</td>
<td>.866</td>
<td></td>
</tr>
<tr>
<td>How often do you feel that you will always be unhealthy because of your tics? (CATIS)</td>
<td>1.33</td>
<td>.500</td>
<td></td>
</tr>
<tr>
<td>How often do you feel that your tics/TS keeps you from starting new things? (CATIS)</td>
<td>1.33</td>
<td>.500</td>
<td></td>
</tr>
</tbody>
</table>
### Table 3 Continued (2)

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you feel different from others because of your tics/TS? (CATIS)</td>
<td>9</td>
<td>1 (1-5)</td>
<td>5 (1-5)</td>
</tr>
<tr>
<td>How often do you feel bad because you have tics/TS? (CATIS)</td>
<td>9</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
</tr>
<tr>
<td>How often do you feel sad about having tics/TS? (CATIS)</td>
<td>9</td>
<td>1 (1-5)</td>
<td>3 (1-5)</td>
</tr>
<tr>
<td>How often do you feel happy even though you have tics/TS? (CATIS)</td>
<td>9</td>
<td>3 (1-5)</td>
<td>5 (1-5)</td>
</tr>
<tr>
<td>How often do you feel just as good as other people your age even though you have tics/TS? (CATIS)</td>
<td>9</td>
<td>3 (1-5)</td>
<td>5 (1-5)</td>
</tr>
<tr>
<td>Do you feel different or abnormal because of your tics? (Self-esteem)</td>
<td>9</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
</tr>
<tr>
<td>Do you feel special (in a good way) because of your tics? (Self-esteem)</td>
<td>9</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
</tr>
<tr>
<td>Do you joke with others about your tics? (Self-esteem)</td>
<td>9</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
</tr>
<tr>
<td>Do you tell other people ahead of time that you have tics? (Self-esteem)</td>
<td>9</td>
<td>0 (0-1)</td>
<td>1 (0-1)</td>
</tr>
</tbody>
</table>

### Quantitative Results

**Variable: Attitude Toward Tics**

**Table 4. Paired Samples T-Tests of Attitudes Toward Tics (CATIS Total)**

The results of the Paired Sample T tests are presented in Table 4. 13-item CATIS-Tics mean differences based on total scores at pre and post, standard deviation, standard error of the mean, 95% confidence interval of the upper and lower, reported t, degrees of freedom, and test of statistical significance. The 13 items included in the “attitudes toward tics” variable were from the CATIS-Tics. The CATIS was originally developed to
measure how favorable or unfavorable participants’ attitudes were toward their given chronic illness (e.g. epilepsy). The rating scale is comprised of 13 self-report questions that are summed for a total mean score. The language used in the CATIS was adapted for tics. On the CATIS-Tics, the gradient scale for the items “How good or bad do you feel it is that you have tics/TS?” and “How bad or good do you feel it is that you have tics/TS” is as follows: 1=Very good, 2=A little good, 3=Not sure, 4=A little bad, 5=Very bad. For the item “How fair is it that you have tics/TS” the gradient scale is as follows: 1=Very fair, 2=A little fair, 3=Not sure, 4=A little unfair, 5=Very unfair. For the item “How happy or sad is it for you to have tics/TS?” the gradient scale is as follows: 1=Very happy, 2=A little happy, 3=Not sure, 4=A little sad, 5=Very sad. For the remainder of the items, which query about the frequency of feeling certain ways about tics/TS the gradient scale is as follows: 1=Never, 2=Not often, 3=Sometimes, 4=Often, 5=Very often. Mean responses to each of these items are listed in Appendix D.

**Table 4. Paired Samples T-Tests of Attitudes Toward Tics (CATIS Total)**

<table>
<thead>
<tr>
<th>Pair</th>
<th>Paired Differences</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
<th>95% CI of the Difference - Lower</th>
<th>95% CI of the Difference - Upper</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-CATIS and Post-CATIS</td>
<td>.22596</td>
<td>.52509</td>
<td>.13127</td>
<td>-.05384</td>
<td>.50876</td>
<td>1.721</td>
<td>15</td>
<td>.106</td>
</tr>
</tbody>
</table>

**Variable: Self-esteem**

**Table 5. Paired Samples t-tests of Self-Esteem**

The changes in mean responses of self-esteem items from Baseline to Post (based on total means from items that queried about self-esteem) are presented in Table 5. This includes the mean paired difference, standard deviation, standard error, 95% confidence interval of the upper and lower, reported $t$, degrees of freedom, and statistical
significance. The five gradient scale items that queried about self-esteem included: “How accepting do you feel toward your tics/TS?”; “How comfortable do you feel explaining TS in your own words to other teens?”; “How confident are you that you can be successful socially…with your TS and related conditions?”; “How confident are you that you can be successful academically with your TS and related conditions?”; “How confident are you that you can be successful with your TS and related conditions overall in the future?”. The gradient scale range for measuring these was: 1=Not at all, 2=Not much, 3=Some, 4=A lot. The measure of self-esteem also included four yes/no items: “Do you feel different or abnormal because of your tics?”; “Do you feel special in a good way because of your tics?”; “Do you joke with others about your tics?”; “Do you tell other people ahead of time that you have tics?” These items were used to create a measure of self-esteem at pre and post.

Table 5. Paired Samples t-tests of Self-Esteem

<table>
<thead>
<tr>
<th>Pair Differences</th>
<th>Paired Differences</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
<th>95% CI of the Difference - Lower</th>
<th>95% CI of the Difference - Upper</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre self-esteem and Post self-esteem</td>
<td>-.24706</td>
<td>.37769</td>
<td>.09160</td>
<td>-.44125</td>
<td>-.05287</td>
<td>-2.697</td>
<td>16</td>
<td>.016</td>
</tr>
</tbody>
</table>

Variable: Perceived Knowledge

Table 6. Paired t-tests of Items Regarding Perceived Knowledge

Table 6 includes paired differences in mean responses at pre and post, for two separate items that queried about changes in perceived knowledge. This table includes paired differences of means, standard deviation, standard error, 95% confidence interval of the upper and lower, reported t, degrees of freedom, and statistical significance. Two items that queried about one’s perceived knowledge of their condition included “How
much do you know about TS as a neurobiological condition?” and “How well do you understand your TS and how it affects you?” These items were asked at pre and repeated at post and the mean responses were used to conduct the t-test.

Table 6. Paired t-tests of Items Regarding Perceived Knowledge

<table>
<thead>
<tr>
<th>Pair</th>
<th>Paired Differences</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
<th>95% CI of the Difference - Lower</th>
<th>95% CI of the Difference - Upper</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you know about TS as a neurobiological condition? (Pre- and Post-)</td>
<td>-.333</td>
<td>.485</td>
<td>.114</td>
<td>-.575</td>
<td>-.092</td>
<td>-2.915</td>
<td>17</td>
<td>.010</td>
</tr>
<tr>
<td>How well do you understand your TS and how it affects you (Pre- and Post-)</td>
<td>-.111</td>
<td>.471</td>
<td>.111</td>
<td>-.346</td>
<td>.123</td>
<td>-1.000</td>
<td>17</td>
<td>.331</td>
</tr>
</tbody>
</table>

Qualitative Results

Variable: Attitudes Toward Tics

Do you tell people ahead of time that you have tics?
Why?

In response to the item “Do you tell people ahead of time that you have tics?” participants had the option to respond “Yes” or “No.” For those who responded “Yes” to this item, there are two follow-up questions: “Why?” and “What do you tell them?”

At pre 8 participants responded Yes, 14 responded No; at post, 9 participants responded Yes, 8 responded No; at follow-up, 5 participants responded Yes while 4 responded No.
In response to the follow up item “Why?” several themes emerged in participants’ responses, in which they had the freedom to submit a text response. For this item, the following themes emerged:

<table>
<thead>
<tr>
<th>Themes:</th>
<th>“Why?”</th>
<th>“What do you tell them?”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Control the situation and/or reduce judgment</td>
<td>1. Name of condition</td>
</tr>
<tr>
<td></td>
<td>2. Socially appropriate</td>
<td>2. What to expect</td>
</tr>
<tr>
<td></td>
<td>3. Raise awareness about tics/TS</td>
<td>3. List of my tics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Definition of terms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Invitation for questions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. How to help</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Tics are involuntary</td>
</tr>
</tbody>
</table>

At baseline, five responses were coded 1) control the situation/reduce judgment; one response was coded 2) socially appropriate, and two responses were coded 3) raise awareness. At post, three responses were coded 1) control the situation/reduce judgment; four were coded 2) socially appropriate; and two were coded 3) raise awareness. At follow-up, three responses were coded 1) control the situation/reduce judgment; two were coded 2) socially appropriate; and none were coded 3) raise awareness.

What do you tell them?

In response to the follow up question “What do you tell them?” several themes emerged in participants’ responses, in which they had the freedom to submit a text response. At baseline, eight responses included 1) name of condition; three responses included 2) what to expect; four responses included 3) list of my tics; five responses included 4) definitions of terms; one response included 5) invitation for questions; one response included 6) how to help; two responses included 7) tics are involuntary. At post, nine responses included 1) name of condition; one response included 2) what to expect; two responses included 3) list of my tics; three responses included 4) definitions of terms; one response included 5) invitation for questions; one response included 6) how to help;
and one response included 7) tics are involuntary. At follow-up, four responses included 1) name of condition; four responses included 2) what to expect; one response included 3) list of my tics; one response included 4) definitions of terms; one response included 5) invitation for questions; two responses included 6) how to help; and two responses included 7) tics are involuntary.

Table 8. Themes for the Item “What do you tell them?”

<table>
<thead>
<tr>
<th>General Psychoeducation Regarding Tics/TS:</th>
<th>Individualized Psychoeducation Regarding Tics/TS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of condition (#1)</td>
<td>What to expect (#2)</td>
</tr>
<tr>
<td>Definition of terms (#4)</td>
<td>List of my tics (#3)</td>
</tr>
<tr>
<td>Invitation for questions (#5)</td>
<td>How to help (#6)</td>
</tr>
<tr>
<td>Tics are involuntary (#7)</td>
<td></td>
</tr>
</tbody>
</table>

From these themes, responses were categorized as either “General Psychoeducation Regarding Tics/TS” (which included themes #1, 4, 5 and 7) or “Individualized Psychoeducation Regarding Tics/TS” (which included themes #2, 3, and 6). Within a single participant’s response, text could be coded into multiple categories. At baseline, 16 responses were coded as General Psychoeducation and 8 responses as Individualized Psychoeducation. At Post, 14 responses were coded as General Psychoeducation and 4 responses were coded as Individualized Psychoeducation. At Follow-Up, 8 responses were coded as General Psychoeducation and 7 responses were coded as Individualized Psychoeducation.

Variable: Consumer Satisfaction

What do you expect might change for you/what has changed for you following your experience at the 2016 Academy?

In the post measure, additional qualitative items were added to the survey: “What do you expect might change for you following your experience at the 2016 Academy?” This item was repeated in the follow-up measure as “What has changed for you about the way you feel or think about your TS (if anything) since attending the 2016 Academy?”
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In response to the items “What do you expect might change for you following your experience at the 2016 Academy?” (post) and “What has changed for you about the way you feel or think about your TS (if anything) since attending the 2016 Academy?” (follow-up), several themes emerged. These themes were as follows:

1. Friendship
2. Improved social skills
3. Increased knowledge of condition
4. Empowerment
5. Self-advocacy
6. Grit
7. Self-confidence
8. Gained coping skills
9. Attitude change
10. Resilience
11. Academic success

At Post, four responses were coded 1) friendship, one response was coded 2) improved social skills, five responses were coded 3) increased knowledge of condition, one response was coded 4) empowerment, four responses were coded 5) self-advocacy, one response was coded 6) grit, two responses were coded 7) self-confidence, three responses were coded 8) gained coping skills, two responses were coded 9) attitude change, and two responses were coded 11) academic success.

At Follow-Up, one response was coded 1) friendship, two responses were coded 2) improved social skills, one response was coded 3) increased knowledge of condition, one
response was coded 4) empowerment, one response was coded 5) self-advocacy, zero responses were coded 6) grit, three responses were coded 7) self-confidence, zero responses were coded 8) gained coping skills, four responses were coded 9) attitude change, one response was coded 10) resilience, and zero responses were coded 11) academic success. From these themes, the following categories were derived:

Table 9. Themes for the Item “What do you expect might change for you/what has changed for you following your experience at the 2016 Academy?”

<table>
<thead>
<tr>
<th>Overarching Categories:</th>
<th>Socialization</th>
<th>Knowledge</th>
<th>Empowerment</th>
<th>Resilience</th>
<th>Academic Success</th>
</tr>
</thead>
<tbody>
<tr>
<td>Themes:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friendship; Social skills</td>
<td></td>
<td>Increased knowledge of condition</td>
<td>Self-advocacy; Empowerment; Grit; Self-confidence</td>
<td>Coping skills; Attitude change; Resilience</td>
<td>Academic success</td>
</tr>
</tbody>
</table>

At Post, five responses were coded as socialization, five responses were coded as knowledge, eight responses were coded as empowerment, seven responses were coded as resilience, and two responses were coded as academic success.

At Follow-Up, three responses were coded as socialization, one response was coded as knowledge, five responses were coded as empowerment, five responses were coded as resilience, and zero responses were coded as academic success.

*Any additional comments or feedback?*

Participants were provided a space to enter any additional comments or feedback at the end of the survey. The following themes emerged among the responses coded as “positive experiences”:

1. General indication of a positive experience
2. Planning to attend THLA multiple times
3. Felt safe and accepted
4. Gained knowledge
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At Post, there were 11 total responses to this item. 10 of these responses generally indicated positive experiences at THLA while one respondent indicated a negative experience. Three responses specifically indicated plans to attend THLA again in the future, one response explicitly stated the feeling of safety and acceptance at THLA, and three responses indicated that they gained knowledge at THLA. At Follow-Up, there were four responses to this item (out of ten total respondents at Follow-Up). Two of these responses specifically indicated plans to attend THLA again in the future and one response explicitly stated the feeling of safety and acceptance at THLA.

Missing Data

From the baseline data collection (pre-THLA), to immediately post-THLA, to 9-months follow up, some participants stopped responding to the survey. From pre- to post-, there were 18 total respondents (of the 23 at baseline) whose data are reflected in the statistical analyses reported below. Of the 18 participants who continued to respond, one of these neglected to respond to the CATIS-Tics at post- and again at follow-up.

Statistical Analyses

Descriptive statistics and paired samples t-tests of mean values were used to analyze the data set. Statistical significance was tested for responses to few items in which there were enough responses. See Appendix D for a full report of descriptive statistics (including each survey item, the number of responses to each, the range of responses to each item, mean responses, and standard deviations). See Appendix D for the results of the paired samples t-tests.

Summary
This study was an evaluation of the consumer experience at the 2016 THLA, which examined whether the THLA accomplished its goals in terms of benefitting its participants and explores how satisfied participants were with their experience. The study examined changes in perceived knowledge of condition, changes in self-reported self-esteem, changes in attitudes toward tics and overall consumer satisfaction. Participants included adolescents with Tourette Syndrome (TS) and comorbid, associated disorders (TS+) who attended the 2016 THLA. Data were collected via an online (Qualtrics) survey which was sent out to voluntary participants immediately pre-THLA, immediately post-THLA, and 9 months following the conclusion of the THLA.

Changes in the mean scores for each item (see Tables 1 and 2 for Descriptive Statistics at pre and post) suggest trends toward increases in perceived knowledge, improved attitudes toward tics, and increased self-esteem from pre to post. These trends are examined more carefully using paired samples t-tests (see Tables 4, 5 and 6). Based on these paired samples t-tests, perceived knowledge from baseline to post-THLA significantly increased. Self-esteem significantly increased from baseline to post-THLA. Attitudes toward tics improved from baseline to post-THLA, however results were underpowered and therefore not significant (see Table 6). These findings are discussed in detail in the Discussion section.

Upon examining the qualitative results, it is evident that participants’ responses to attitudes toward tics items trended away from general psychoeducation and toward individualized psychoeducation. This suggests that participants were better equipped to provide individualized psychoeducation about their tics/TS to others after attending THLA. Additionally, responses to consumer satisfaction items indicated overwhelming
satisfaction with THLA programming, plans to attend THLA again in the future, and participants endorsed feelings of safety and acceptance.
Chapter V: Discussion

Introduction

The purpose of this study was to evaluate the experiences of a sample of adolescents with Tourette’s Syndrome who attended The Tim Howard Leadership Academy (measured by changes in perceived knowledge of condition, attitude toward tics, and overall consumer satisfaction) at the 2016 Tim Howard Leadership Academy (THLA). The NJCTS Tim Howard Leadership Academy program was formed by NJCTS with assistance from the TS Program at Rutgers-GSAPP. The Tim Howard Leadership Academy takes place in the Rutgers University dormitories every August for a total of three days. There are between 20-40 attendees per year. Additionally, a small group of young adult “coaches” (THLA alumni) serve as mentors for small groups of attendees (approximately 5-6 adolescents per group). Each summer, the THLA “empowers a new set of leaders and advocates” (NJCTS, 2019). Additionally, a main focus of the THLA is the teaching of leadership qualities and self-advocacy (NJCTS, 2019).

Participants for this dissertation study included adolescents (ages 13-18 years) with Tourette Syndrome (TS) and comorbid, associated disorders (TS+) who attended the 2016 THLA. Data were collected via an online (Qualtrics) survey which was sent out to voluntary participants immediately pre-THLA, immediately post-THLA, and 9 months following the conclusion of the THLA. The study analyzed the impact of attending the 2016 THLA on its adolescent participants.

Research questions included: 1) In what way, if any, did THLA attendance alter the participants’ attitudes toward tics?, 2) Did participants gain knowledge and/or better understanding of their conditions after attending THLA? and 3) Were participants
satisfied with their experiences at the THLA and why? Predicted findings were as follows: 1) Participants will report improved attitudes toward tics (e.g. more positive) after attending THLA; 2) Participants will report that they have gained knowledge of their condition after attending THLA; and 3) Participants will report high consumer satisfaction with their experience at THLA. Data were analyzed using descriptive statistics, paired samples t-tests (for pre- and post-), and classical qualitative analysis. This dissertation study was an evaluation of changes in perceived knowledge of condition, attitude toward tics, and overall consumer satisfaction with the Tim Howard Leadership Academy (THLA) on adolescents with Tourette Syndrome (TS) and comorbid, associated disorders (TS+). The reason for this evaluation was that this program has not previously been evaluated. Analyses of 2016 THLA data was intended to inform future THLA programming and the development and/or improvement of similar programming for adolescents with TS+. Establishing the effectiveness of THLA has the power to improve outcome measures of psychological treatments for adolescents with TS+.

**Research Questions and Predictions**

1. In what way, if any, did THLA attendance alter the participants’ attitudes toward tics?
   a. Prediction: Participants’ attitudes toward tics will become less negative after attending THLA (pre- to post-).

2. Did participants gain knowledge and/or better understanding of their conditions after attending THLA?
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a. Prediction: Participants perceived knowledge of conditions will increase after attending THLA (pre- to post-).

3. Were participants satisfied with their experiences at the THLA and why?
   a. Prediction: Participants will have positive feedback regarding their experiences at THLA due to forming new social bonds, spending time with adolescents facing similar concerns, gaining knowledge of their conditions, and learning self-advocacy and leadership skills.

Method of Study

From the larger surveys, items that query about 1) attitudes toward tics, 2) knowledge gained, and 3) consumer satisfaction were selected and analyzed. Repeated measures were used (pre, post, and at 9-months follow-up) to assess change over time in relation to participation in the NJCTS THLA.

Revisiting Rationale for the Present Study

Tourette Syndrome and its comorbidities are associated with functional impairment in youth. It is believed that TS and its comorbidities are genetically linked (Wang et al., 2018). Common comorbidities include attention-deficit hyperactivity disorder (ADHD) and disruptive behaviors, obsessive-compulsive disorder (OCD), and autism spectrum disorder (ASD), and coexistent problems include anxiety, depression, and low self-esteem, which can all lead to poorer psychosocial functioning and quality of life (Eapen et al., 2016). Packer (1997) also notes that mild to moderate learning disabilities are a common comorbid concern in children and adolescents with TS.
Based upon literature there is increased functional impairment (e.g. educational, peer related, physical impact, and familial stress) in youth with TS and its comorbidities, as compared to healthy controls and youth with other chronic health conditions (Conolea et al., 2011; Eddy et al., 2011; O’Hare et al., 2016). In particular, there is increased psychosocial impairment in youth with TS (e.g. decreased quality of life, negatively impacted peer relationships, increased social isolation, increased bullying, and increased peer and teacher misperceptions of symptoms) (Carter et al., 2011; Bawden et al., 1998; Eapen et al., 2016; Malli et al., 2016). Others’ misperceptions of TS and its symptoms led to discrimination, bullying, social rejection, and ultimately a decreased quality of life.

There are numerous potential benefits of group treatment for adolescents with TS, compared to individual treatment. Group treatments may be less costly, less resource-intensive for the providers, accessible for clients, and groups provide an opportunity for youth to interact with similar peers (McGuire et al., 2015). THLA was created with the intention of targeting adolescents’ leadership and self-advocacy skills (NJCTS, 2019). Research shows that providing others with education about TS (provided to peers) can reduce negative stigma, social rejection, and negative attitudes toward youth with tics (Holtz & Tessman, 2007).

**Major Findings and Interpretations**

The results of t-tests for 1) knowledge gained, 2) self-esteem, and 3) attitudes toward tics (CATIS-Tics total scores) are presented in Tables 4, 5, and 6. Paired samples t-tests for two response time points (pre to post or post to follow-up) were selected due to lack of responses (N=10) at the 9-month follow-up measure. Knowledge gained from baseline to post-THLA significantly increased (see Table 4). Self-esteem increased from
baseline to post-THLA (see Table 5). Results were significant. Attitudes toward tics improved from baseline to post-THLA, however results were underpowered and therefore not significant (see Table 6). Note: The CATIS-Tics total scores (which measured attitudes toward tics) involved reverse scoring, therefore a lower number score indicated more positive attitudes toward tics.

**Attitudes Toward Tics (CATIS-Tics)**

The 13 items included in the “attitudes toward tics” variable were from the CATIS-Tics (see Appendix C). At pre, there were 23 total participants. Of these, one participant did not respond to the CATIS-Tics items. Similarly, at post, there were 18 total participants. Of these, one participant did not respond to the CATIS-Tics items (see Appendix D – Descriptive Statistics). Based on the total participants that were the same from pre to post for all other items (18 total), the CATIS-Tics ended up being underpowered due to the participant who stopped responding on certain items. Lower scores on the CATIS-Tics indicated more positive attitudes toward tics. At pre, participants responses on the gradient scale ranged from 1-5, endorsing the full range of the gradient scale. At post, participants responses continued to range from 1-5 but the average trended toward more positive attitudes based on increases in the amount of “1s” and “2s” and less “4s” and “5s.” The means for total CATIS-Tics scores were used in the paired samples t-test “CATIS” (see Table 4). On the CATIS-Tics, the gradient scale for the items “How good or bad do you feel it is that you have tics/TS?” and “How bad or good do you feel it is that you have tics/TS” is as follows: 1=Very good, 2=A little good, 3=Not sure, 4=A little bad, 5=Very bad. At pre, the mean response to this item was 2.77. At post, the mean response was 2.29. Since lower values indicate more positive attitudes,
the mean change from pre to post indicates that participants felt “more good” that they have tics/TS at post. For the item “How fair is it that you have tics/TS” the gradient scale is as follows: 1=Very fair, 2=A little fair, 3=Not sure, 4=A little unfair, 5=Very unfair. At pre, the mean response to this item was 2.82. At post, the mean was 2.47. These means indicate that participants felt that it was more fair that they have tics/TS at post versus pre (indicating a trend toward more positive attitude toward tics). For the item “How happy or sad is it for you to have tics/TS?” the gradient scale is as follows: 1=Very happy, 2=A little happy, 3=Not sure, 4=A little sad, 5=Very sad. At pre, the mean response was 3.05. At post, the mean response was 2.59 indicating a trend toward more happiness. For the remainder of the items, which query about the frequency of feeling certain ways about tics/TS (see Appendix C), the gradient scale is as follows: 1=Never, 2=Not often, 3=Sometimes, 4=Often, 5=Very often. Mean responses to these items are listed in Appendix D.

**Self-Esteem**

At pre and post, there were five gradient scale items, four binary (Yes or No) items, and two qualitative (free text) items related to the variable of self-esteem. Items selected to respond to the research question about self-esteem were, like the other research questions, chosen by the researcher using subjective methods of isolating items that query about factors related to self-esteem (e.g. confidence, level of comfort in discussing tics/TS, and acceptance of condition). The items included in the measurement and analysis of the “self-esteem” variable were:

**Gradient Scale items:** “How accepting do you feel toward your tics/TS?”; “How comfortable do you feel explaining TS in your own words to other teens?”; “How
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confident are you that you can be successful socially…with your TS and related conditions?”; “How confident are you that you can be successful academically with your TS and related conditions?”; “How confident are you that you can be successful with your TS and related conditions overall in the future?”; Yes/No items: “Do you feel different or abnormal because of your tics?”; “Do you feel special in a good way because of your tics?”; “Do you joke with others about your tics?”; “Do you tell other people ahead of time that you have tics?"; and Free text response items: As a follow-up question to the item Do you tell people ahead of time that you have tics, there are two items: “Why?” and “What do you tell them?” The same questions were asked at pre and again at post. The gradient scale range for measuring these was: 1=Not at all, 2=Not much, 3=Some, 4=A lot. Endorsed responses ranged from 2-4 at pre and from 3-4 at post, indicating a trend toward increased self-esteem (see Table 2 and “Descriptive Statistics” in Appendix D). In response to the binary items, the average responses at pre were as follows: “Do you feel different or abnormal because of your tics?” Average response = Yes; “Do you feel special (in a good way) because of your tics?” Average response = Yes; “Do you joke with others about your tics?” Average response = Yes; and “Do you tell other people ahead of time that you have tics?” Average response = No. Endorsed responses ranged from 3-4 at post. In response to the binary items, the average responses at post were as follows: “Do you feel different or abnormal because of your tics?” Average response = No; “Do you feel special (in a good way) because of your tics?” Average response = Yes; “Do you joke with others about your tics?” Average response = Yes; and “Do you tell other people ahead of time that you have tics?” Average response = Yes. This demonstrates a change in the average response to two items: 1. Do you feel
changes after adolescents with TS attend THLA

different or abnormal because of your tics? changed from Yes to No (pre to post); 2. Do you tell other people ahead of time that you have tics? changed from No to Yes (pre to post). In response to the follow-up item “Why?” At baseline, five responses were coded 1) control the situation/reduce judgment; one responses was coded 2) socially appropriate, and two responses were coded 3) raise awareness. At post, three responses were coded 1) control the situation/reduce judgment; four were coded 2) socially appropriate; and two were coded 3) raise awareness. At follow-up, in response to the item “Why?”, three responses were coded 1) control the situation/reduce judgment; two were coded 2) socially appropriate; and none were coded 3) raise awareness (see Table 7).

Although these items lack responses at follow-up, there is evidence to suggest that fewer respondents were concerned with controlling the situation/reducing judgment. In response to the follow-up item “What do you tell them?” 14 responses were coded as General Psychoeducation at post and 4 responses were coded as Individualized Psychoeducation at post. At Follow-Up, 8 responses were coded as General Psychoeducation and 7 responses were coded as Individualized Psychoeducation. This shows an increase in participants who began to offer individualized psychoeducation to others regarding their tics/TS. At post, two of these items showed trend changes in the average response: 1. “Do you feel different or abnormal because of your tics?” At post, the average response was No; and 2. “Do you tell other people ahead of time that you have tics?” The average response at post was Yes. This shows that on average, participants felt less different/abnormal because of their tics after attending THLA. In addition, participants changed their behavior from not telling other people ahead of time
that they have tics, to endorsing that they do tell people ahead of time that they have tics after attending THLA.

**Perceived Knowledge**

Participants were asked two items that were included in the “perceived knowledge of condition” variable (1. “How much do you know about your TS as a neurobiological condition?” and 2. “How well do you understand your TS and how it affects you?”). In the paired samples t-test for perceived knowledge, means of the gradient scale scores were used to compare responses at pre and post. The gradient scale response options were as follows: 1=Not at all, 2=Not much, 3=Some, 4=A lot. Higher scores in response to these items indicated higher levels of perceived knowledge. At pre, responses to the item “How much do you know about your TS as a neurobiological condition?” ranged from 2-4 (see Appendix D), with the majority of participants (12 out of 23 total participants) endorsing 3 (“Some”); 10 endorsed 4 (“A lot”) and one participant endorsed 2 (“Not much”). The mean score at pre was 3.39. At post, 15 of the 18 total participants endorsed 4; two participants endorsed 3 and one participant (the same participant from pre who endorsed a “2”) endorsed 2. The mean score at post was 3.78. These results indicate that the majority of participants experienced a perceived increase in *how much* they know about their TS as a neurobiological condition.

In response to the item “How well do you understand your TS and how it affects you?” the gradient scale was the same as for the previous knowledge-related item above. At pre, responses ranged from 3-4. 14 participants endorsed 4 (“A lot”) and 9 participants endorsed 3 (“Some”). The mean response at pre was 3.61. At post, 14 out of 18 total participants continued to endorse 4 and three participants endorsed 3. One participant
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endorsed 2 ("Not much"), indicating a perceived decrease in their understanding of their TS and how it affects them. The mean response at post was 3.72. These responses indicate that from pre to post, participants’ perceived understanding of their TS and how it affects them increased overall, although when examined at the response level some responses stayed the same across time. It is noteworthy that five participants stopped responding from pre to post, therefore those participants’ potential changes in endorsed scores were not included in the overall perceived increase in knowledge.

In addition to these quantitative items that directly queried about perceived knowledge of condition, two of the free text response items revealed more information about participants’ perceived knowledge gained after THLA: 1. What do you expect might change for you/what has changed for you following your experience at the 2016 Academy? And 2. Any additional comments or feedback? In response to these items, five responses indicated at the post measure that they predicted that something that might change for them following the Academy was their [perceived] knowledge of their condition. At the follow-up measure (9 months later), one participant endorsed maintaining the perception that their knowledge of their condition had changed. This finding suggests that perceived knowledge of condition increased from pre to post, but that these perceived gains were largely not maintained at follow-up. At post, three responses indicated a belief that they had gained knowledge of their condition in response to the item “Any additional comments or feedback?” At follow-up, only four respondents continued to provide additional comments and none of these endorsed maintenance of knowledge gained. The follow-up data should be interpreted with caution given the overall lack of responses at follow-up.
Participant Satisfaction

The participant satisfaction variable included 8 gradient Scale items and 2 free text items at post, and 6 gradient Scale items and 2 free text items at the 9-month follow-up. The quantitative items at post were as follows: 1) How much has your experience at the Academy increased your overall confidence? 2) How much has your experience at the Academy helped you to better understand your strengths and skills? 3) How much has your experience at the Academy helped you to better understand your challenges and needs? 4) How much did you feel the climate of the Academy was respectful and accepting? 5) How much did you feel that the Academy presentations were relevant and helpful? 6) How much did you feel that the Academy activities were relevant and helpful? 7) How much did you feel that your coach demonstrated leadership and resilience? 8) How much did you feel understood and supported by your coach? At follow-up, the same items were repeated with items 5 and 6 omitted due to irrelevance at the 9-month follow-up time point. The gradient scale response options for these items ranged from 1-4: 1=Not at all, 2=Not much, 3=Some, 4=A lot. At post, responses to Item 1 ranged from 1-4 (mean=3.59); responses for Item 2 ranged from 2-4 (mean=3.59), responses for Item 3 ranged from 3-4 (mean=3.59), responses for Item 4 ranged from 2-4 (mean=3.82), responses for Item 5 ranged from 2-4 (mean=3.41), responses for Item 6 ranged from 2-4 (mean=3.71), responses for Item 7 ranged from 2-4 (mean=3.88), responses for Item 8 ranged from 2-4 (mean=3.88). At follow-up, responses for Item 1 ranged from 3-4 (mean=3.89); responses for Item 2 ranged from 3-4 (mean=3.78); responses for Item 3 ranged from 3-4 (mean=3.44); responses for Item 4 were all 4 (mean=4.00); responses for Item 7 were all 4 (mean=4.00); responses for item 8 were all
4 (mean=4.00). These mean changes indicate high satisfaction on a 1-4 scale and increased endorsement of positive experiences at follow-up versus post.

At post, the free text items included: “What do you expect might change for you following your experience at the 2016 Academy?” and “Any additional comments or feedback?” At the 9-month follow up, the equivalents of these items were: What has changed for you about the way you feel or think about your TS (if anything) since attending the 2016 Academy? and the last item was repeated (“Any additional comments or feedback?”) In response to the items “What do you expect might change…?” and “What has changed…?” five responses were coded as socialization, five responses were coded as knowledge, eight responses were coded as empowerment, seven responses were coded as resilience, and two responses were coded as academic success at post. At follow-up, three responses were coded as socialization, one response was coded as knowledge, five responses were coded as empowerment, five responses were coded as resilience, and zero responses were coded as academic success.

At post, in response to the item “Any additional comments or feedback?”, 10 out of 11 total responses generally indicated positive experiences at THLA while one respondent indicated a negative experience. Three responses specifically indicated plans to attend THLA again in the future, one response explicitly stated the feeling of safety and acceptance at THLA, and three responses indicated that they gained knowledge at THLA. At Follow-Up, there were four responses to this item (out of ten total respondents at Follow-Up). Two of these responses specifically indicated plans to attend THLA again in the future and one response explicitly stated the feeling of safety and acceptance at THLA.
Answering the Research Questions

1. In what way, if any, did THLA attendance alter the participants’ attitudes toward tics?
   a. Answer: Participants’ attitudes trended toward being more positive (based on means from paired samples t-tests) after attending THLA. However, due to a lack of responses this test was underpowered and results should be interpreted with caution. This finding is consistent with the consensus in the literature which suggests that programs focused on the quality of life for youth with TS have the potential to improve attitudes toward symptoms and overall self-esteem. In the qualitative measures of self-esteem, results indicate that participants shifted from providing general psychoeducation to others about tics/TS to providing more individualized psychoeducation at the 9-month follow-up time point. In addition, participants changed their behavior from not telling other people ahead of time that they have tics, to endorsing that they do tell people ahead of time that they have tics, after attending THLA. These changes in behavior may suggest higher self-confidence and less negative attitudes toward tics.

2. Did participants gain knowledge and/or better understanding of their conditions after attending THLA?
   a. Answer: Based on the means from the paired samples t-test of perceived knowledge items, the majority of participants experienced a perceived increase in how much they know about their TS as a neurobiological condition. Based on the means from the paired samples t-test, participants’
perceived understanding of their TS and how it affects them increased overall, although when examined at the individual response level some participants’ responses stayed the same across time. It is also noteworthy that five participants stopped responding from pre to post, therefore those participants’ potential changes in endorsed scores were not included in the overall perceived increase in knowledge. Qualitative responses indicated a perceived increase in knowledge but there was no evidence that this perceived increase in knowledge was maintained at the 9-month follow-up. The participants’ perceived knowledge of their condition is directly relevant to Christner & Dieker’s (2008) findings that increasing self- and other-knowledge of TS has the potential to reduce social stigma and victimization that occurs as a result of tics/TS. Additionally, this is relevant to Packer’s (1997) findings that self-advocacy is the key to obtaining educational support and enhancing academic success in those with TS.

3. Were participants satisfied with their experiences at the THLA and why?

a. Answer: Based on means from gradient scale responses to consumer satisfaction items, changes across time points indicated high satisfaction and an increased endorsement of positive experiences at follow-up versus post. However, the increase in means at follow-up have been affected by the lack of responses at follow-up and this result should be interpreted with caution. When given the opportunity to provide additional feedback at the end of the survey, ten out of eleven participants responded with
positive feedback regarding their experiences at THLA, specifically noting plans to attend again and feelings of safety during the program. This information is relevant to the developers of THLA who are motivated to maximize participants’ satisfaction with the program.

Limitations

The findings of the present study cannot be generalized to the general population of adolescents with TS. The limitations include small sample size, limited demographic diversity, and a self-selecting bias of participation.

One concern in the design of the original study was that participants may have felt pressure to respond in a desirable way (i.e. provide positive feedback about the Academy). However, this threat to internal validity was limited by administering questionnaires through secure online software and emphasizing to participants that all data, as well as their decision to participate, would be sent directly to the research team and that this information would not be shared with NJCTS, the program developers.

Due to potential bias (as a result of a self-selecting reduction in responses at follow-up), much of the results were limited to pre- and post- comparisons (paired samples t-test analyses for pre and post). The results of the CATIS-Tics t-test were underpowered (due to missing data), therefore any pattern in these results should be interpreted with caution. This is both due to the lack of power and potential self-selecting bias in responses at follow-up (N=10). It may have been beneficial to conduct the post survey at two months following the conclusion of THLA programming, rather than conducting both an immediately post and a 9-month follow up survey. In retrospect, it is evident that this may have been a flaw in the research design due to the apparent lack of responses at
follow-up. Additionally, because participants had a four week window in which to respond to each of the three questionnaires, there may have been some participants who responded immediately post-THLA (e.g. the day after the program ended) and others who responded just shy of four weeks following the end of THLA. In this way, findings could have varied based on time spent interacting in systems outside of THLA (e.g. in the home, school, community).

Findings cannot be generalized to the general population of adolescents with TS. There may be something unique about adolescents who decided to apply to THLA and who were accepted, compared to the general population of adolescents with TS. The purpose of this research is to provide preliminary support for the effectiveness of the NJCTS THLA program so threats to external validity were tolerable.

In the future, the use of a control group in a study of the THLA would provide increased internal validity. The present study has low statistical power due to N=18 at post-THLA. Future studies should aim to study larger treatment groups, if feasible. In addition, the use of other-report data (e.g. for observable domains of functioning such as academic success as evidenced by report card grades and parent/teacher reports) would allow for increased internal validity but would make for a different kind of study, perhaps interested in looking at changes in behavior or symptoms after attending THLA or a similar program. Future studies may consider including a control group (e.g. adolescents involved in NJCTS not attending the THLA). This would allow for findings to be compared to a group who has not attended THLA, increasing the significance of findings attributable to the effect of THLA alone.
Regarding qualitative analyses, the writer chose to utilize a subjective judgment method in order to interpret free-text responses from the survey. This analysis could have been done in a number of ways and different meaning could have been made from the analysis depending upon the method. For instance, if a computer program were used to code frequency of vocabulary words used, the study’s results may have taken a different form and the interpretation would follow. This is not necessarily a limitation but a noteworthy aspect of the methodology used.

Regarding quantitative analyses, it would have been ideal to have both a larger sample size and consistent responses across the time points. This would have allowed for a repeated measures ANOVA to look at pre, post, and follow-up. The small sample size and the reduction in responses at follow-up limits the ability for the writer to interpret the results of the follow-up responses. This points to a flaw in the design of the survey as well as a limitation of the results of the present study.

Regarding the plan for data analysis, the writer was interested in items that queried about perceived knowledge, acceptance and self-esteem, and satisfaction with the program. This means that a category of changes in symptoms was left out of the present study. This is an area that remains to be explored.

Finally, this research was conducted without the use of any psychometrically validated, sound measure to assess the psychosocial aspects of living with TS due to no such measure having been created. This leads to some suggested directions for future research.

**Concluding Comments and Directions for Future Research**

One of the major limitations to the research design is the lack of psychometrically sound measures for adolescents with TS. The questionnaire used in the present study was
created subjectively by the original researcher from the TS Program. Similarly, this writer used subjective methods to isolate items and to group them in order to answer research questions related to the variables of interest. Data reported on participants’ perceptions and experiences which are useful information to inform administrators at NJCTTS about the successes of their program. The subjective nature of the data itself, the methods for data collection, and the analyses indicate a need for the field of TS research and clinical practice to create a validated measure to examine the psychosocial impact of having tics/TS. Such a measure would allow for more standardized data collection at a range of group programs. This data could inform future THLA programming, potentially allowing for improved efficacy of existing programs.

For this particular population, it is evident that treatments like HRT and THLA programming combined would have potential to produce best outcomes (McGuire et al., 2015). However, there are few programs that focus on evaluating or improving quality of life for adolescents with TS (Storch et al., 2007). The practical implications of the findings of this study include enhancing the existing THLA programming; informing other group treatment options for adolescents with TS; reducing the resource burden on families by providing an intensive group treatment option; and information that can be applied to the formation and adaptation of outcomes measures to include quality of life factors related to TS diagnosis.

In addition, the study emphasizes the need for school staff education (e.g. in-service trainings), peer education (e.g. self-advocacy by individuals with TS), and community education regarding TS and its comorbidities. Peer and educator misperceptions about tics can lead to judgment and mistreatment of adolescents with tics (Eapen et al., 2016).
OUTREACH INTERVENTIONS OF THESE KINDS HAVE THE ABILITY TO REDUCE THE NEGATIVE IMPACT OF TS ON ADOLESCENTS’ QUALITY OF LIFE (RIVERA-NAVARRO, 2014).

Further research is needed on whether there is a relationship between self-advocacy training (e.g. anticipatory guidance, bullying education, etc.) and decreased peer victimization and/or social stigma. Self-advocacy is thought to be an important factor in quality of life for youth with TS, however research in this area is limited.

Youth with TS have been shown to have uniquely impacted functional impairment across five main domains: physical, social, familial, academic, and psychological (Conolea, et al., 2011). Future THLA research should focus on collecting data on self-perceptions of each of these domains. It would be interesting to compare self-perceptions of changes in familial impact due to TS, and the family’s report of changes (by asking the same survey questions across reporters).

In future THLA research, it would be helpful to follow up with participants of THLA to directly query about their perceived abilities and actions as self-advocates, as developing this capability was one of the main goals of the program. Data from the THLA program should continue to be collected, assessed, and adapted accordingly based on outcomes and consumer satisfaction. The present study provided a starting point for the enhancement of the existing program and for the development of similar programs in other regions.

In summary, the data collected at the 2016 Tim Howard Academy indicate that participants exhibited more positive attitudes toward tics after attending THLA (as evidenced by the results of the paired samples t-test analyses of “attitudes toward tics (CATIS-Tics)” which was consistent with the predicted trend. Participants exhibited
increased perceived knowledge of their condition after attending THLA, as evidenced by the results of the paired samples t-test analyses of “knowledge” items. The qualitative analyses concluded that participants reported overall consumer satisfaction with THLA programming, highlighting many factors that contributed to a positive consumer experience. Further research is needed to duplicate the findings of this study, to inform future THLA programming and similar outside programming, and to potentially provide alternatives to the resource-intensive individual therapies (e.g. HRT) that are currently the gold standard interventions for TS+.
Appendix A

*Entire Qualtrics Survey (2016)*:

*Bolded items are selected questions for the present study.*

**Baseline survey:**

How much do you know about Tourette Syndrome (TS) as a neurobiological condition?

How well do you understand your TS and how it affects you?

Do you have Attention Deficit Hyperactivity Disorder (ADHD)?

How well do you understand your Attention Deficit Hyperactivity Disorder (ADHD)?

Do you have Obsessive Compulsive Disorder (OCD)?

How well do you understand your Obsessive Compulsive Disorder (OCD)?

Do you have Anxiety?

How well do you understand your Anxiety?

Do you have Depression?

How well do you understand your Depression?

Do you have Executive Functioning Difficulties?

How well do you understand your Executive Functioning Difficulties?

Do you have any other related difficulty not listed above? If yes, please write what type of other related difficulty you have in the text field below If no, please leave this text field blank

How well do you understand the other related difficulty that you wrote in the previous question?

How accepting do you feel toward your tics/TS?

How accepting do you feel about the related conditions that you indicated above (if any)?

How comfortable do you feel explaining TS in your own words to other teens?
How confident are you that you can be successful socially (with friends, peers in school, peers in your activities) with your TS and related conditions?

How confident are you that you can be successful academically (in school) with your TS and related conditions?

How confident are you that you can be successful with your TS and related conditions overall in the future?

How much do you feel your TS and related conditions interfere with goals that you set for yourself in your life?

How much do you feel your TS and related conditions interfere the things you enjoy in your life?

How much do you view yourself as a leader?

How much do you consider yourself to be resilient (able to get back up after getting knocked down, able to overcome difficulties)?

How much do you advocate for yourself?

How much do you view yourself as an advocate for others with TS?

How good or bad do you feel it is that you have tics/TS?

How fair is it that you have tics/TS?

How happy or sad is it for you to have tics/TS?

How bad or good do you feel it is to have tics/TS?

How often do you feel that your tics/TS is your fault?

How often do you feel that your tics/TS keeps you from doing things you like to do?

How often do you feel that you will always be unhealthy because of your tics/TS?

How often do you feel that your tics/TS keeps you from starting new things?

How often do you feel different from others because of your tics/TS?

How often do you feel bad because you have tics/TS?

How often do you feel sad about having tics/TS?
How often do you feel happy even though you have tics/TS?

How often do you feel just as good as other people your age even though you have tics/TS?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way -

- doing fun things by yourself (playing alone, reading for fun, watching TV, playing video games, or collecting things)?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way -

- doing fun things with other people (hanging out with friends, going shopping, or going out places)?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way -

- making new friends or getting closer to friends that you already have (like making “best friends”)?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way -

- having close relationships or getting along with people who are in your family?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way -

- doing things you have to do around the house, like chores or cleaning your room?

Think about one month when your tics were at their worst in the past year (since this time last year) Drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - How much do you think tics interfere with school or your school work?

Is it harder for you to do well in your classes because of your tics?
Do your tics make it hard for you to study?

Do you have a job?

Think about one month when your tics were at their worst in the past year (since this time last year) Drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - How much do you think your tics get in the way of doing the things you have to do for your job?

**Do you feel different or abnormal because of your tics?**

**Do you feel special (in a good way) because of your tics?**

**Do you joke with others about your tics?**

**Do you tell other people ahead of time that you have tics?**

**Why?**

**What do you tell them?**

As you are about to begin the 2016 NJCTS Tim Howard Leadership Academy, think about three goals you want to set for yourself about what you want to get out of the experience. Identify 3 personal goals that you hope to accomplish by attending the 2016 NJCTS Tim Howard Leadership Academy:

- **Goal 1**

- **Goal 2**

- **Goal 3**

**Post Survey:**

**How much do you know about Tourette Syndrome (TS) as a neurobiological condition?**

**How well do you understand your TS and how it affects you?**

Do you have Attention Deficit Hyperactivity Disorder (ADHD)?
How well do you understand your Attention Deficit Hyperactivity Disorder (ADHD)?

Do you have Obsessive Compulsive Disorder (OCD)?

How well do you understand your Obsessive Compulsive Disorder (OCD)?

Do you have Anxiety?

How well do you understand your Anxiety?

Do you have Depression?

How well do you understand your Depression?

Do you have Executive Functioning Difficulties?

How well do you understand your Executive Functioning Difficulties?

Do you have any other related difficulty not listed above? If yes, please write what type of other related difficulty you have in the text field below If no, please leave this text field blank

How well do you understand the other related difficulty that you wrote in the previous question?

**How accepting do you feel toward your tics/TS?**

How accepting do you feel about the related conditions that you indicated above (if any)?

**How comfortable do you feel explaining TS in your own words to other teens?**

**How confident are you that you can be successful socially (with friends, peers in school, peers in your activities) with your TS and related conditions?**

**How confident are you that you can be successful academically (in school) with your TS and related conditions?**

**How confident are you that you can be successful with your TS and related conditions overall in the future?**

How much do you feel your TS and related conditions interfere with goals that you set for yourself in your life?

How much do you feel your TS and related conditions interfere the things you enjoy in your life?
How much do you view yourself as a leader?

How much do you consider yourself to be resilient (able to get back up after getting knocked down, able to overcome difficulties)?

How much do you advocate for yourself?

How much do you view yourself as an advocate for others with TS?

**How much has your experience at the Academy increased your overall confidence?**

**How much has your experience at the Academy helped you to better understand your strengths and skills?**

**How much has your experience at the Academy helped you to better understand your challenges and needs?**

**How much did you feel the climate of the Academy was respectful and accepting?**

**How much did you feel that the Academy presentations were relevant and helpful?**

**How much did you feel that the Academy activities were relevant and helpful?**

**How much did you feel that your coach demonstrated leadership and resilience?**

**How much did you feel understood and supported by your coach?**

How much do you plan to stay in touch with other Academy participants?

Of the following methods of communication, rate how likely you would be to utilize each of these ways of staying in touch... - Text

Of the following methods of communication, rate how likely you would be to utilize each of these ways of staying in touch... - Phone Call

Of the following methods of communication, rate how likely you would be to utilize each of these ways of staying in touch... - Facetime/Video Call

Of the following methods of communication, rate how likely you would be to utilize each of these ways of staying in touch... – Email

Of the following methods of communication, rate how likely you would be to utilize each of these ways of staying in touch... - Social Media (Facebook, Instagram, Snapchat, etc)
CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

Of the following methods of communication, rate how likely you would be to utilize each of these ways of staying in touch... - Hanging Out in Person

Of the following methods of communication, rate how likely you would be to utilize each of these ways of staying in touch... - Attending other TS Organization Events

**How good or bad do you feel it is that you have tics/TS?**

**How fair is it that you have tics/TS?**

**How happy or sad is it for you to have tics/TS?**

**How bad or good do you feel it is to have tics/TS?**

**How often do you feel that your tics/TS is your fault?**

**How often do you feel that your tics/TS keeps you from doing things you like to do?**

**How often do you feel that you will always be unhealthy because of your tics/TS?**

**How often do you feel that your tics/TS keeps you from starting new things?**

**How often do you feel different from others because of your tics/TS?**

**How often do you feel bad because you have tics/TS?**

**How often do you feel sad about having tics/TS?**

**How often do you feel happy even though you have tics/TS?**

**How often do you feel just as good as other people your age even though you have tics/TS?**

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - doing fun things by yourself (playing alone, reading for fun, watching TV, playing video games, or collecting things)?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - doing fun things with other people (hanging out with friends, going shopping, or going out places)?
Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - making new friends or getting closer to friends that you already have (like making “best friends”)?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - having close relationships or getting along with people who are in your family?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - doing things you have to do around the house, like chores or cleaning your room?

Think about one month when your tics were at their worst in the past year (since this time last year) Drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - How much do you think tics interfere with school or your school work?

Is it harder for you to do well in your classes because of your tics?

Do your tics make it hard for you to study?

Do you have a job?

Think about one month when your tics were at their worst in the past year (since this time last year) Drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - How much do you think your tics get in the way of doing the things you have to do for your job?

Do you feel different or abnormal because of your tics?

Do you feel special (in a good way) because of your tics?

Do you joke with others about your tics?

Do you tell other people ahead of time that you have tics?
CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

Why?

What do you tell them?

Now that you have participated in the Academy, rate how much you feel that you accomplished the goals you set for yourself at the beginning of the Academy:

What do you expect might change for you following your experience at the 2016 Academy?

Identify any new personal goals you want to set for yourself following your experience at the 2016 Academy:

Any additional comments or feedback?

Follow-Up Survey:

How much do you know about Tourette Syndrome (TS) as a neurobiological condition?

How well do you understand your TS and how it affects you?

Do you have Attention Deficit Hyperactivity Disorder (ADHD)?

How well do you understand your Attention Deficit Hyperactivity Disorder (ADHD)?

Do you have Obsessive Compulsive Disorder (OCD)?

How well do you understand your Obsessive Compulsive Disorder (OCD)?

Do you have Anxiety?

How well do you understand your Anxiety?

Do you have Depression?

How well do you understand your Depression?

Do you have Executive Functioning Difficulties?

How well do you understand your Executive Functioning Difficulties?

Do you have any other related difficulty not listed above? If yes, please write what type of other related difficulty you have in the text field below. If no, please leave this text field blank.
How well do you understand the other related difficulty that you wrote in the previous question?

**How accepting do you feel toward your tics/TS?**

How accepting do you feel about the related conditions that you indicated above (if any)?

**How comfortable do you feel explaining TS in your own words to other teens?**

**How confident are you that you can be successful socially (with friends, peers in school, peers in your activities) with your TS and related conditions?**

**How confident are you that you can be successful academically (in school) with your TS and related conditions?**

**How confident are you that you can be successful with your TS and related conditions overall in the future?**

How much do you feel your TS and related conditions interfere with goals that you set for yourself in your life?

How much do you feel your TS and related conditions interfere the things you enjoy in your life?

How much do you view yourself as a leader?

How much do you consider yourself to be resilient (able to get back up after getting knocked down, able to overcome difficulties)?

How much do you advocate for yourself?

How much do you view yourself as an advocate for others with TS?

How much has the Academy increased your overall confidence?

How much has the Academy helped you to better understand your strengths and skills?

How much has the Academy helped you to better understand your challenges and needs?

How much did you feel the climate of the Academy was respectful and accepting?

How much did you feel that your coach demonstrated leadership and resilience?

How much did you feel understood and supported by your coach?
CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

How much have you stayed in touch with other Academy participants?

Of the following methods of communication, rate how much you have utilized each of these ways of staying in touch... – Text

Of the following methods of communication, rate how much you have utilized each of these ways of staying in touch... - Phone Call

Of the following methods of communication, rate how much you have utilized each of these ways of staying in touch... - Facetime/Video Call

Of the following methods of communication, rate how much you have utilized each of these ways of staying in touch... – Email

Of the following methods of communication, rate how much you have utilized each of these ways of staying in touch... - Social Media (Facebook, Instagram, Snapchat, etc)

Of the following methods of communication, rate how much you have utilized each of these ways of staying in touch... - Hanging Out in Person

Of the following methods of communication, rate how much you have utilized each of these ways of staying in touch... - Attending other TS Organization Events

How good or bad do you feel it is that you have tics/TS?

How fair is it that you have tics/TS?

How happy or sad is it for you to have tics/TS?

How bad or good do you feel it is to have tics/TS?

How often do you feel that your tics/TS is your fault?

How often do you feel that your tics/TS keeps you from doing things you like to do?

How often do you feel that you will always be unhealthy because of your tics/TS?

How often do you feel that your tics/TS keeps you from starting new things?

How often do you feel different from others because of your tics/TS?

How often do you feel bad because you have tics/TS?

How often do you feel sad about having tics/TS?

How often do you feel happy even though you have tics/TS?
How often do you feel just as good as other people your age even though you have tics/TS?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - doing fun things by yourself (playing alone, reading for fun, watching TV, playing video games, or collecting things)?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - doing fun things with other people (hanging out with friends, going shopping, or going out places)?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - making new friends or getting closer to friends that you already have (like making “best friends”)?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - having close relationships or getting along with people who are in your family?

Think about one month when your tics were at their worst in the past year (since this time last year). For each question, drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - doing things you have to do around the house, like chores or cleaning your room?

Think about one month when your tics were at their worst in the past year (since this time last year) Drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - How much do you think tics interfere with school or your school work?

Is it harder for you to do well in your classes because of your tics?

Do your tics make it hard for you to study?
Do you have a job?

Think about one month when your tics were at their worst in the past year (since this time last year) Drag the dial to a number between 1 and 9 to rate how much you think your tics get in the way of the following things... 1-3 = tics “mildly” get in the way 4-6 = tics “moderately” get in the way 7-9 = tics “severely” get in the way - How much do you think your tics get in the way of doing the things you have to do for your job?

Do you feel different or abnormal because of your tics?

Do you feel special (in a good way) because of your tics?

Do you joke with others about your tics?

Do you tell other people ahead of time that you have tics?

Why?

What do you tell them?

Now that you have participated in the Academy, rate how much you feel that you accomplished the goals you set for yourself at the beginning of the Academy:

What has changed for you about the way you feel or think about your TS (if anything) since attending the 2016 Academy?

Identify any new personal goals you want to set for yourself going forward related to your TS

Any additional comments or feedback?
Appendix B

Information Regarding the Original Qualtrics Survey

Given that few measures developed for individuals with TS exist beyond symptom inventories (i.e., YGTSS; Leckman et al., 1989), the researchers created a self-report questionnaire in collaboration with NJCTS THLA program developers. This questionnaire assesses psychological variables emphasized by the NJCTS THLA program content (self-leadership, self-empowerment, resilience, and grit). The questionnaire was designed to be administered at three time-points, with the post and follow-up versions including some additional items about the participants’ experiences at the NJCTS THLA.

Information Regarding the Tic Impact Survey

The Tic Impact Survey (TIS) was adapted using select items from the Tourette Syndrome Impact Survey (TSIS). The TSIS was initially modeled after previously-developed internet surveys such as a survey created to gauge the impact of Trichotillomania. The full TSIS includes popular tic questionnaires, measures related to anxiety, measures of Attention Deficit Hyperactivity Disorder (ADHD), and questions about family functioning and a client’s overall quality of life. The TSIS also includes ten items that assess tic interference across several areas of functioning. The questions relate to physical functioning, social functioning, tic-related academic issues, and tic-related avoidance. Responses for each of these questions were rated by the clients using a 10-point gradient scale (options were 0–9), with 0 indicating no impact (Conolea et al., 2011).
Appendix C

CATIS-Tics:

1. How good or bad do you feel it is that you have tics/TS?
2. How fair is it that you have tics/TS?
3. How happy or sad is it for you to have tics/TS?
4. How bad or good do you feel it is to have tics/TS?
5. How often do you feel that your tics/TS is your fault?
6. How often do you feel that your tics/TS keeps you from doing things you like to do?
7. How often do you feel that you will always be unhealthy because of your tics/TS?
8. How often do you feel that your tics/TS keeps you from starting new things?
9. How often do you feel different from others because of your tics/TS?
10. How often do you feel bad because you have tics/TS?
11. How often do you feel sad about having tics/TS?
12. How often do you feel happy even though you have tics/TS?
13. How often do you feel just as good as other people your age even though you have tics/TS?
## Descriptive Statistics

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CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA
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<td>How much did you feel the climate of the Academy was respectful and accepting?</td>
<td>9</td>
<td>4</td>
<td>4</td>
<td>4.00</td>
<td>.000</td>
</tr>
<tr>
<td>How much did you feel that your coach demonstrated leadership and resilience?</td>
<td>9</td>
<td>4</td>
<td>3</td>
<td>4.00</td>
<td>.000</td>
</tr>
<tr>
<td>How much did you feel understood and supported by your coach?</td>
<td>9</td>
<td>2</td>
<td>4</td>
<td>2.33</td>
<td>.500</td>
</tr>
<tr>
<td>How good or bad do you feel it is that you have tics/TS?</td>
<td>9</td>
<td>1</td>
<td>3</td>
<td>2.44</td>
<td>1.014</td>
</tr>
<tr>
<td>How fair is it that you have tics/TS?</td>
<td>9</td>
<td>1</td>
<td>4</td>
<td>2.33</td>
<td>.707</td>
</tr>
<tr>
<td>How happy or sad is it for you to have tics/TS?</td>
<td>9</td>
<td>1</td>
<td>4</td>
<td>2.56</td>
<td>.882</td>
</tr>
<tr>
<td>How bad or good do you feel it is that you have tics/TS?</td>
<td>9</td>
<td>1</td>
<td>2</td>
<td>1.22</td>
<td>.441</td>
</tr>
<tr>
<td>How often do you feel that your tics/TS is your fault?</td>
<td>9</td>
<td>1</td>
<td>3</td>
<td>2.00</td>
<td>.866</td>
</tr>
<tr>
<td>How often do you feel that your tics/TS keeps you from doing things you like to do?</td>
<td>9</td>
<td>1</td>
<td>2</td>
<td>1.33</td>
<td>.500</td>
</tr>
</tbody>
</table>
CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>You will always be unhealthy because of your tics?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often do you feel that your tics/TS keeps you from starting new things?</td>
<td>1.33</td>
<td>.500</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often do you feel different from others because of your tics/TS?</td>
<td>2.78</td>
<td>1.093</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often do you feel bad because you have tics/TS?</td>
<td>1.67</td>
<td>.707</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often do you feel sad about having tics/TS?</td>
<td>1.78</td>
<td>.667</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often do you feel happy even though you have tics/TS?</td>
<td>4.33</td>
<td>.707</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often do you feel just as good as other people your age even though you have tics/TS?</td>
<td>4.67</td>
<td>.707</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel different or abnormal because of your tics?</td>
<td>.56</td>
<td>.527</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel special (in a good way) because of your tics?</td>
<td>.44</td>
<td>.527</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Do you joke with others about your tics? | 9 | 0 | 1 | .22 | .441
Do you tell other people ahead of time that you have tics? | 9 | 0 | 1 | .44 | .527

**Paired Samples T-Tests**

1. Knowledge Gained

<table>
<thead>
<tr>
<th>Paired Differences</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
<th>95% CI of the Difference - Lower</th>
<th>95% CI of the Difference - Upper</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you know about TS as a neurobiological condition? (Pre- and Post-)</td>
<td>-.333</td>
<td>.485</td>
<td>.114</td>
<td>-.575</td>
<td>-.092</td>
<td>-2.915</td>
<td>17</td>
<td>.010</td>
</tr>
<tr>
<td>How well do you understand your TS and how it affects you (Pre- and Post-)</td>
<td>-.111</td>
<td>.471</td>
<td>.111</td>
<td>-.346</td>
<td>.123</td>
<td>-1.000</td>
<td>17</td>
<td>.331</td>
</tr>
</tbody>
</table>

2. Attitudes Toward Tics (CATIS Total)
### Changes After Adolescents with TS Attend THLA

<table>
<thead>
<tr>
<th>Pair</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
<th>95% CI of the Difference - Lower</th>
<th>95% CI of the Difference - Upper</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-CATIS and Post-CATIS</td>
<td>.22596</td>
<td>.52509</td>
<td>.13127</td>
<td>-.05384</td>
<td>.50576</td>
<td>1.721</td>
<td>15</td>
<td>.106</td>
</tr>
</tbody>
</table>

#### 3a. Self-Esteem (Pre and Post)

<table>
<thead>
<tr>
<th>Pair</th>
<th>Paired Differences</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
<th>95% CI of the Difference - Lower</th>
<th>95% CI of the Difference - Upper</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre self-esteem and Post self-esteem</td>
<td>-.24706</td>
<td>.37769</td>
<td>.09160</td>
<td>-.44125</td>
<td>-.05287</td>
<td>-2.697</td>
<td>16</td>
<td>.016</td>
<td></td>
</tr>
</tbody>
</table>

#### 3b. Self-Esteem (Post and Follow-Up)

<table>
<thead>
<tr>
<th>Pair</th>
<th>Paired Differences</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
<th>95% CI of the Difference - Lower</th>
<th>95% CI of the Difference - Upper</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post self-esteem and Follow-Up self-esteem</td>
<td>.04000</td>
<td>.33731</td>
<td>.10667</td>
<td>-.20130</td>
<td>.28130</td>
<td>.375</td>
<td>9</td>
<td>.716</td>
<td></td>
</tr>
</tbody>
</table>
**Paired Samples Correlations (T-tests)**

1. **Knowledge Gained (Pre and Post)**

<table>
<thead>
<tr>
<th>Pair</th>
<th>N</th>
<th>Correlation</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you know about TS as a neurobiological condition? (Pre and Post)</td>
<td>18</td>
<td>.658</td>
<td>.003</td>
</tr>
<tr>
<td>How well do you understand your TS and how it affects you? (Pre and Post)</td>
<td>18</td>
<td>.624</td>
<td>.006</td>
</tr>
</tbody>
</table>

2. **Attitudes Toward Tics (CATIS Total, Pre and Post)**

<table>
<thead>
<tr>
<th>Pair</th>
<th>N</th>
<th>Correlation</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre CATIS and Post CATIS</td>
<td>16</td>
<td>.465</td>
<td>.069</td>
</tr>
</tbody>
</table>

3a. **Self-Esteem (Pre and Post)**

<table>
<thead>
<tr>
<th>Pair</th>
<th>N</th>
<th>Correlation</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre self-esteem and Post self-esteem</td>
<td>17</td>
<td>.248</td>
<td>.338</td>
</tr>
</tbody>
</table>

3b. **Self-Esteem (Post and Follow-Up)**

<table>
<thead>
<tr>
<th>Pair</th>
<th>N</th>
<th>Correlation</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post self-esteem and Follow-Up self-esteem</td>
<td>10</td>
<td>.327</td>
<td>.356</td>
</tr>
</tbody>
</table>
### Paired Samples Statistics (T-tests)

1. **Knowledge Gained (Pre and Post)**

<table>
<thead>
<tr>
<th>Pair</th>
<th>Mean</th>
<th>N</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you know about TS as a neurobiological condition? (Pre)</td>
<td>3.44</td>
<td>18</td>
<td>.616</td>
<td>.145</td>
</tr>
<tr>
<td>How much do you know about TS as a neurobiological condition? (Post)</td>
<td>3.78</td>
<td>18</td>
<td>.548</td>
<td>.129</td>
</tr>
<tr>
<td>How well do you understand your TS and how it affects you (Pre)</td>
<td>3.61</td>
<td>18</td>
<td>.502</td>
<td>.118</td>
</tr>
<tr>
<td>How well do you understand your TS and how it affects you (Post)</td>
<td>3.72</td>
<td>18</td>
<td>.575</td>
<td>.135</td>
</tr>
</tbody>
</table>

2. **Attitudes Toward Tics (CATIS Total, Pre and Post)**

<table>
<thead>
<tr>
<th>Pair</th>
<th>Mean</th>
<th>N</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre CATIS</td>
<td>2.6394</td>
<td>16</td>
<td>.58226</td>
<td>.14557</td>
</tr>
<tr>
<td>Post CATIS</td>
<td>2.4135</td>
<td>16</td>
<td>.37144</td>
<td>.09286</td>
</tr>
</tbody>
</table>

3a. **Self-Esteem (Pre and Post)**

<table>
<thead>
<tr>
<th>Pair</th>
<th>Mean</th>
<th>N</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre self-esteem</td>
<td>3.5412</td>
<td>17</td>
<td>.35189</td>
<td>.08534</td>
</tr>
<tr>
<td>Post self-esteem</td>
<td>3.7882</td>
<td>17</td>
<td>.24971</td>
<td>.06056</td>
</tr>
</tbody>
</table>
3b. Self-Esteem (Post and Follow-Up)

<table>
<thead>
<tr>
<th>Pair</th>
<th>Mean</th>
<th>N</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post self-esteem</td>
<td>3.760</td>
<td>10</td>
<td>.27968</td>
<td>.08844</td>
</tr>
<tr>
<td>Follow-Up self-esteem</td>
<td>3.720</td>
<td>10</td>
<td>.30111</td>
<td>.09522</td>
</tr>
</tbody>
</table>
Appendix E

INFORMED CONSENT (FOR ADULT PARTICIPANTS AGE 18+)

Title of the Project: Evaluation of the New Jersey Center for Tourette Syndrome Tim Howard Leadership Academy for Adolescents with Tourette Syndrome

Primary Investigator:
Daniela Colognori, Psy.D.
Clinical Director
Tourette Syndrome Clinic, Psychological Services Clinic
Graduate School of Applied and Professional Psychology, Rutgers University

Telephone: (848) 445-3896
Email: colognor@rci.rutgers.edu

Project Co-Investigators: Barbara Chabner, Maddie Pucciarello, Sam Nayman, Amanda Ferriola, Bracha Schnaidman

Purpose of the Study:
You are invited to participate in a research study conducted by Daniela Colognori, Psy.D., who is the Clinical Director of the Tourette Syndrome Program in the Psychological Services Clinic of the Graduate School of Applied and Professional Psychology at Rutgers University. The goal of the study is to investigate the impact of the New Jersey Center for Tourette Syndrome (NJCTS) Tim Howard Leadership Academy. The decision to participate in this study is up to you. This consent form includes information about this study to help you decide whether you would like to be included.

Participant Selection:
You are being asked to participate in this study because you will be participating as an attendee (age of 18+) or a coach in the 2017 NJCTS Tim Howard Leadership Academy. We are interested in learning about your experience with TS and whether you have benefitted from participating in the Academy. The target enrollment for participation in the study is approximately 30 adolescent attendees (ranging from 14-18 years old) and 15 adult coaches.

Procedure:
If you consent to participate in the study, we ask you to provide an email address below, to which you would like future correspondence about this study to be sent. Participation in this study would mean that you would be asked to complete a survey delivered via email at three time-points. Surveys will be administered using Qualtrics, a secure software using SSL Technology to encrypt responses. Completion of the survey is expected to take approximately twenty to thirty minutes each time. The first survey will be sent in June-July 2017 before the Academy and participants will be given one month to complete the online survey. A second survey will be sent in August 2017-immediately following the Academy and participants will again be asked to complete it within one month. The final survey will be sent nine months after the completion of the Academy in April 2018 to be completed within one month. At each time point, an automated reminder will be emailed via Qualtrics up to two times prior to completion of the survey.

Voluntary Participation and Withdrawal:
If you decide not to take part in this study, it will not affect any other benefit to which you are otherwise entitled. Declining to participate will not harm your relationship with the NJCTS, or eligibility to participate in any other programs offered by the NJCTS. All correspondence will be with the research team at Rutgers University, and therefore NJCTS will not be aware of your decision to participate in the study. Similarly, if you decide to take part in the study, you may withdraw at any time without loss of benefit to which you would otherwise be entitled.
Confidentiality:  
This research is confidential. Confidential means that the research records will include some information about you. Please note that we will keep this information confidential by limiting individual's access to the research data and keeping it in a secure location. Participant information (e.g., names, email addresses, signed consent form) will be kept in a locked file cabinet in the office of the primary investigator at Rutgers University. Survey data will be de-identified by Qualtrics, meaning that the software will separate the survey responses from each participant’s email and IP address prior to delivery to the research team. Electronic data from Qualtrics will be stored in a password-protected file on the password protected computer in her Primary Investigator’s office at Rutgers University. If a report of this study is published, or the results are presented at a professional conference, individual responses will not be reported. Any data will be reported in aggregate form only. Five years after the completion of this study, all informed consent documents will be shredded and electronic files will be deleted.

Potential Risks and Discomfort:  
Participation in this study carries minimal risk. You may experience some psychological discomfort associated with answering questions about your attitudes toward tics and the impact of tics on you daily life. However, these questions are similar to those posed by the Academy application and the content that will be discussed at the Academy. The final screen of the online survey will provide resources that you may contact if you become distressed while completing the survey. In addition, participation in this study is voluntary. You may choose not to participate, and you may withdraw from participating at any time during the study activities without any penalty. In addition, you may choose not to answer any questions with which you are not comfortable.

Potential Benefits:  
It is possible that you will not experience any direct benefit from participating in this study evaluating the Academy. However, your participation will contribute to researchers’ knowledge about the effectiveness of the Academy to inform future programming and to make similar programs available to individuals with TS.

Questions:  
If you have any questions about the study or study procedures, you may contact me at:  
Daniela Colognori, Psy.D.,  
Tourette Syndrome Clinic, Psychological Services Clinic  
Graduate School of Applied and Professional Psychology, Rutgers University  
Telephone: (848) 445-3896  
Email: colognor@rci.rutgers.edu  
If you have any questions about your rights as a research subject, you may contact the Institutional Review Board (a committee that reviews research studies in order to protect those who participate). Please contact an IRB Administrator at the Rutgers University, Arts and Sciences IRB:  
Institutional Review Board  
Rutgers University, the State University of New Jersey  
Liberty Plaza / Suite 3200  
335 George Street, 3rd Floor  
New Brunswick, NJ 08901  
Phone: 732-235-9806  
Email: humansubjects@orsp.rutgers.edu
CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

Please return one copy of this consent form with your signature and email specified below. Retain the additional copy of this consent form for your records.

Sign below if you agree to participate in this research study:

Subject (Print) _____________________________________________

Subject Signature ___________________________________________ Date ________________

Principal Investigator Signature _______________________________ Date ________________

--------------------------------------------------------------------------------------

Please CHECK one of the following:

[  ] I will be an ATTENDEE at the 2016 Academy

[  ] I will be an COACH for the 2016 Academy

PLEASE PROVIDE AN EMAIL ADDRESS THAT YOU WOULD LIKE THE SURVEY TO BE SENT.

PLEASE WRITE LEGIBLY, as the research team will have no other means to contact you.

Email: -
Appendix F

PARENTAL INFORMED CONSENT (FOR ADOLESCENTS 17 AND UNDER)

Title of the Project: Evaluation of the New Jersey Center for Tourette Syndrome Tim Howard Leadership Academy for Adolescents with Tourette Syndrome

Primary Investigator:
Daniela Colognori, Psy.D.
Clinical Director
Tourette Syndrome Clinic, Psychological Services Clinic
Graduate School of Applied and Professional Psychology, Rutgers University

Telephone: (848) 445-3896
Email: colognor@rci.rutgers.edu

Project Co-Investigators: Barbara Chabner, Maddie Pucciarello, Sam Nayman, Amanda Ferriola, Bracha Schnaidman

Purpose of the Study:
Your child is invited to participate in a research study conducted by Daniela Colognori, Psy.D., who is the Clinical Director of the Tourette Syndrome Program in the Psychological Services Clinic of the Graduate School of Applied and Professional Psychology at Rutgers University. The goal of the study is to investigate the impact of the New Jersey Center for Tourette Syndrome (NJCTS) Tim Howard Leadership Academy. The decision to have your child participate in this study is up to you and your child. This consent form includes information about this study to help you decide whether your child would like to be included.

Participant Selection:
Your child is being asked to participate in this study because he or she will be an attendee of the 2017 NJCTS Tim Howard Leadership Academy. We are interested in learning about your child’s experience with TS and whether your child has benefited from participating in the Academy. The target enrollment for participation in the study is approximately 30 adolescent attendees (ranging from 14-18 years old) and 15 adult coaches.

Procedure:
If you consent to your child’s participation in the study, we ask you to provide an email address below, to which you would like future correspondence about this study to be sent. Participation in this study would mean that your child would be asked to complete a survey delivered via email at three time-points. Surveys will be administered using Qualtrics, a secure software using SSL Technology to encrypt responses. Completion of the survey is expected to take approximately twenty to thirty minutes each time. The first survey will be sent in June-July 2017 before the Academy and participants will be given one month to complete the online survey. A second survey will be sent in August 2017 immediately following the Academy and participants will again be asked to complete it within one month. The final surveys will be sent nine months after the completion of the Academy in April 2018 to be completed within one month. At each time point, an automated reminder will be emailed via Qualtrics up to two times prior to participants completing the survey.

Voluntary Participation and Withdrawal:
If you decide not to take part in this study, it will not affect any other benefit to which you or your child are otherwise entitled. Declining to participate will not harm your relationship with the NJCTS, or eligibility to participate in any other programs offered by the NJCTS. All correspondence will be with the research team at Rutgers University, and therefore NJCTS will not be aware of your decision to participate in the study. Similarly, if you decide to take part in the study, you may withdraw at any time without loss of benefit to which you would otherwise be entitled.
Confidentiality:
This research is confidential. Confidential means that the research records will include some information about your child. Please note that we will keep this information confidential by limiting individual's access to the research data and keeping it in a secure location. Participant information (e.g., names, email addresses, signed consent form) will be kept in a locked file cabinet in the office of the primary investigator at Rutgers University. Survey data will be de-identified by Qualtrics, meaning that the software will separate the survey responses from each participant’s email and IP address prior to delivery to the research team. Electronic data from Qualtrics will be stored in a password-protected file on the password protected computer in her Primary Investigator’s office at Rutgers University. If a report of this study is published, or the results are presented at a professional conference, individual responses will not be reported. Any data will be reported in aggregate form only. Five years after the completion of this study, all informed consent documents will be shredded and electronic files will be deleted.

Potential Risks and Discomfort:
Participation in this study carries minimal risk. Your child may experience some psychological discomfort associated with answering questions about their attitudes toward tics and the impact of tics on their daily lives. However, these questions are similar to those posed by the Academy application and the content that will be discussed at the Academy. The final screen of the online survey will provide resources that your child may contact if they become distressed while completing the survey. In addition, participation in this study is voluntary. You may choose for your child not to participate, and you may withdraw your child from participating at any time during the study activities without any penalty to your child. In addition, you/your child may choose not to answer any questions with which your child is not comfortable.

Potential Benefits:
It is possible that your child will not experience any direct benefit from participating in this study evaluating the Academy. However, your child’s participation will contribute to researchers’ knowledge about the effectiveness of the Academy to inform future programming and to make similar programs available to individuals with TS.

Questions:
If you or your child have any questions about the study or study procedures, you may contact me at:
Daniela Colognori, Psy.D.,
Tourette Syndrome Clinic, Psychological Services Clinic
Graduate School of Applied and Professional Psychology, Rutgers University

Telephone: (848) 445-3896
Email: colognor@rci.rutgers.edu

If you or your child have any questions about your rights as a research subject, you may contact the Institutional Review Board (a committee that reviews research studies in order to protect those who participate). Please contact an IRB Administrator at the Rutgers University, Arts and Sciences IRB:
Institutional Review Board
Rutgers University, the State University of New Jersey
Liberty Plaza / Suite 3200
335 George Street, 3rd Floor
New Brunswick, NJ 08901
Phone: 732-235-9806
Email: humansubjects@orsp.rutgers.edu

Your child will also be asked if they wish to participate in this study on the introductory screen of the online survey. Please return one copy of this consent form with your signature and email specified below. Retain the additional copy of this consent form for your records.

Sign below if you agree to allow your child to participate in this research study:

Name of Child (Print) _____________________________ ___________
CHANGES AFTER ADOLESCENTS WITH TS ATTEND THLA

Name of Parent/Legal Guardian (Print) ____________________________

Parent/Legal Guardian’s Signature ___________________ Date _________________

Principal Investigator Signature _____________________ Date _________________

---------------------------------------------------------------------------------------------------------------------------------

PLEASE PROVIDE AN EMAIL ADDRESS THAT YOU WOULD LIKE THE SURVEY TO BE SENT.

PLEASE WRITE LEGIBLY, as the research team will have no other means to contact you.

Email: -
Appendix G

ADOLESCENT ASSENT FORM

**Title of the Project:** Evaluation of the New Jersey Center for Tourette Syndrome Tim Howard Leadership Academy for Adolescents with Tourette Syndrome

**Primary Investigator:**
Daniela Colognori, Psy.D.
Clinical Director
Tourette Syndrome Clinic, Psychological Services Clinic
Graduate School of Applied and Professional Psychology, Rutgers University

Telephone: (848) 445-3896
Email: colognor@rci.rutgers.edu

**Project Co-Investigators:** Barbara Chabner, Maddie Pucciarello, Sam Nayman, Amanda Ferriola, Bracha Schnaidman

**What is the study about?**
You are invited to participate in a research study run by Daniela, Colognori, PsyD., who is the Clinical Director of the Tourette Syndrome Program in the Psychological Services Clinic of the Graduate School of Applied and Professional Psychology at Rutgers University. The goal of the study is to investigate the impact of the New Jersey Center for Tourette Syndrome (NJCTS) Tim Howard Leadership Academy. The decision to participate in this study is up to you and your parent(s). This assent form includes information about this study to help you decide whether you would like to be included.

**Why me?**
You are being asked to participate in this study because you are attending the 2016 Tim Howard Leadership Academy. We want to know about your experience participating in the Academy.

**What will I be asked to do?**
If you decide to participate in the study, you will go to the next screen to fill out a survey with questions about your experience having TS and about the Academy. We think this survey will take you about 20-30 minutes to complete. You will be asked to complete this survey today and two more times: once in the month after the Academy (August 2016) and again nine months after the Academy (April-May 2017). You will get email reminders to fill out the survey each time and will have one month to complete it from when the first email is sent to you.

**Can I decide to stop being in the study?**
You can decide to stop being in the study at any time. You might decide not to take part in the study today, and that is ok. If you decide not to be in the study, it will not affect your relationship with NJCTS and nobody will be mad at you for not participating. Only the research team at Rutgers, not NJCTS, will know who has decided to participate.

You might also decide now to participate in the study, but change your mind later on and decide that you do not want to keep doing it. This is ok and you can change your mind at any time. If you decide that you do not want to keep being in the study later on, this will also not affect your relationship with NJCTS and nobody will be mad at you.

**How will my information be kept private?**
Everything that you answer on the surveys is private. This means that only the researchers will see the answers that you give, and your responses will be separated from your email by the Qualtrics software program. The consent form that your parents mailed to us with your name on it will be kept in locked cabinets in the office of the person in charge of the study, at Rutgers University. If the researcher decides to share
information from the study in meetings or conferences later on, they will not give out your name or personal information, so other people will not know that the answers are yours.

**What are some possible risks (negatives) about being in the study?**
One possible negative of being in this study is that you might feel uncomfortable answering some of the questions we ask you about your tics and about how they affect your life. It is important to remember that if you begin to feel uncomfortable and do not want to continue answering the questions, you do not have to continue. You can stop answering questions at any time and you can also decide that you do not want to answer any questions you are not comfortable answering. Also, you can choose to stop being a part of the study at any time.

**What are some possible benefits (positives) about being in the study?**
It is possible that you might like participating in the study and giving feedback about the Academy. Your participation will also help us learn more about what teens with tics think about the program and how to improve it in the future or make it available to more adolescents with TS.

**Questions:**
If you have any questions about the study, you or your parent may contact me at:

Daniela Colognori, Psy.D.,  
Tourette Syndrome Clinic, Psychological Services Clinic  
Graduate School of Applied and Professional Psychology, Rutgers University

Telephone: (848) 445-3896  
Email: colognor@rci.rutgers.edu

If you or your parents have any questions about your rights about participating in the study, you may contact the Institutional Review Board (a group of people that reviews research studies in order to protect people that take part in studies). You may contact an IRB Administrator at the Rutgers University, Arts and Sciences IRB:

Institutional Review Board  
Rutgers University, the State University of New Jersey  
Liberty Plaza / Suite 3200  
335 George Street, 3rd Floor  
New Brunswick, NJ 08901  
Phone: 732-235-9806  
Email: humansubjects@orsp.rutgers.edu

**Agreement to participate:**
My parent/guardian knows about this study and wants me to be in the study if I want to. I want to be in the study, and I know that I can stop being in the study at any time. I know that the people doing the study can talk to other people in charge of the study about my answers, but will not talk to anyone else that is not working on the study.

Sign below if you agree to participate in this research study:

Name of child (Print) ____________________________ Date: ________________

Signature of child ____________________________ Date: ________________

Principal Investigator Signature ____________________________ Date: ________________
Letter from NJCTS to Potential Participants

Dear Academy [Parent/Participant],

The NJCTS is excited to announce that we are partnering with the Rutgers University TS Clinic research team to conduct an evaluation of our annual NJCTS Tim Howard Leadership Academy. We hope to gain knowledge about participants’ and coaches’ experience at the Academy and whether the program effectively accomplishes its goals.

You are receiving this letter because your child is participating in the Academy. You will find a detailed consent form enclosed that reviews the research study and describes what participation would entail. We hope that you will read the following document carefully and consider providing consent for your child to participate. If you have any questions about the research study or what participation would entail, please do not hesitate to contact Dr. Colognori at 848-445-3896. Dr. Colognori is the Clinical Director of the TS Clinic at Rutgers University, a close partner of NJCTS. She has worked with families of individuals with TS for many years and is also very familiar with the Academy, as she attended last year’s program. Dr. Colognori would be happy to answer any questions you may have.

If you choose to participate in this research study, please return one copy of the enclosed form with your signature to Dr. Colognori’s staff at Rutgers by FRIDAY, JULY 14th. Please use the enclosed self-addressed, stamped envelope. In addition, you must provide the email address to which you would like correspondence related to the research study sent. Email correspondence will include instructions and reminders to complete the survey, in addition to the surveys themselves. Please print the email address LEGIBLY, as this will be the only method by which Dr. Colognori’s staff will be able to contact you. Keep the second, blank copy of the consent form for your records.

We would very much appreciate your participation, however please understand that if you choose not to participate in this research study, it will not impact your standing with the Academy or NJCTS in any way. In fact, NJCTS will not receive information about who chose to participate in the study.

Thank you for your consideration. Please review the attached form carefully and do not hesitate to contact Dr. Colognori with any questions or concerns (848-445-3896).

Sincerely,

Faith Rice
References


New Jersey Center for Tourette Syndrome and Associated Disorders Website: [https://njcts.org/academy/the-mission/](https://njcts.org/academy/the-mission/)


