

## RESEARCH ARTICLE

# A Qualitative Exploration of the Experiences of Children and Adolescents with Tourette Syndrome

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### Abstract

**Objective:** The purpose of this qualitative study was to explore the experiences of youth with Tourette Syndrome (TS). **Method:** Thirteen participants with TS were recruited from a large tertiary care hospital to complete semi-structured interviews and two questionnaires pertaining to demographic information and tic severity. Thematic analysis was utilized to systematically analyze the data. **Results:** Three main themes were identified: 1) beliefs about TS; 2) TS related distress and impairment; and, 3) coping with TS. **Conclusion:** The findings from this study suggest that most participants were aware of their tics but unaware of the cause of tics/TS. The interviews also highlighted that, for most participants, TS caused emotional, social, physical, and/or occupational impairment. Despite their distress, participants provided several suggestions for coping with TS and for supporting those who are diagnosed with this condition.

**Key Words:** *Tourette Syndrome, children and adolescents, coping, qualitative research*

### Résumé

**Objectif:** Cette étude qualitative visait à explorer les expériences des adolescents souffrant du syndrome de Gilles de La Tourette (SGT). **Méthode:** Treize participants souffrant du SGT ont été recrutés dans un grand hôpital de soins tertiaires pour répondre à des entrevues semi-structurées et à deux questionnaires portant sur les données démographiques et la gravité des tics. Une analyse thématique a servi à analyser systématiquement les données. **Résultats:** Trois thèmes principaux se sont dégagés: 1) les croyances sur le SGT; 2) la détresse et la déficience liées au SGT, 3) l'adaptation au SGT. **Conclusion:** Les résultats de cette étude suggèrent que la plupart des participants étaient conscients de leurs tics mais pas de la cause des tics et du SGT. Les entrevues ont aussi révélé que pour la plupart des participants, le SGT causait une déficience émotionnelle, sociale, physique, et/ou professionnelle. Malgré leur détresse, les participants ont fourni plusieurs suggestions pour s'adapter au SGT et soutenir ceux qui reçoivent un diagnostic de cette affection.

**Mots clés:** *syndrome de Gilles de La Tourette, enfants et adolescents, adaptation, recherche qualitative*

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## Introduction

Tourette Syndrome (TS) is a neurodevelopmental disorder characterized by the presence of multiple motor tics and at least one vocal tic that have persisted for a minimum of one year (American Psychiatric Association, 2013). Studies estimate that TS affects 1% of the general population and between 0.4% and 3.8% of young people aged five to 18 years (Abi-Jaoude et al., 2009; Knight et al., 2012; Robertson, 2008). TS commonly co-occurs with other psychiatric conditions and behavioural problems, such as Attention-Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), and learning disabilities (Storch et al., 2007). The presence of tics and these co-occurring conditions has been found to be associated with poorer psychosocial functioning and quality of life in young people with TS (Eapen, Cavanna, & Robertson, 2016; Storch et al., 2007).

Tics usually begin in early childhood and peak in severity between the ages of ten and 12 years, but the majority of adolescents with TS experience a decline in tic severity by early adulthood (Bloch & Leckman, 2009). Therefore, it is important that studies exploring the experiences of individuals with TS involve young people, as it is during childhood and adolescence when the disorder is typically most distressing and impairing (Cutler, Murphy, Gilmour, & Heyman, 2009).

TS is a difficult disorder to understand because the manifestation of tics can vary drastically between individuals and within the same individual over time (Grace & Russell, 2005). As a result, arguably, one of the best ways to understand the disorder is to gather personal accounts of those who live with the condition every day. A review of the literature revealed six qualitative studies that have specifically focused on exploring the experiences of young people with TS (Cuenca et al., 2015; Cutler et al., 2009; Grace & Russell, 2005; Rivera-Navarro, Cubo, & Almazan, 2009; 2014; Wadman, Tischler & Jackson, 2013). Overall, themes across the studies indicate that TS symptoms can be distressing (e.g., cause pain, fatigue, peer victimization) and adversely affect quality of life. However, half of these studies used focus groups, which can be subject to group dynamics, thereby hindering participants from sharing perspectives that differ from the most dominant members (e.g., Wadman et al., 2013). Furthermore, all but one study recruited participants from local TS advocacy organizations. Findings from these participants may not generalize to all young people with TS since membership in these groups may reflect proactive populations with similar views on treatment (Cuenca et al., 2015). Given that TS is associated with considerable health economic burden (Dodel et al., 2010), the experiences of young people, engaged in hospital clinics, might be most useful to consider when informing, designing, and improving the utilization of specialized TS services. Young people seen in a tertiary care setting

may also be more likely to present with severe symptoms compared with a community sample, and therefore, a better understanding of their perspectives is needed.

The aims of the present study were to explore how young people with TS understand their symptoms and are impacted by their condition. In addition, given the relevance of this information to clinical care, it was of interest to investigate what young people perceived as the most useful advice they have received from health care professionals regarding TS, and what advice they would share with newly diagnosed peers.

## Methods

### Participants

Thirteen participants were recruited from the outpatient psychiatry clinic at a large tertiary pediatric hospital in Toronto, Canada, during a ten-month period (April 2015-January 2016). Inclusion criteria were a diagnosis of TS made or confirmed by a psychiatrist or psychologist on the clinic team, average intelligence (as determined by a regular school placement), and age between six and 17 years. Exclusion criteria were unstable medical condition, current diagnosis of substance use or dependence, and lifetime diagnosis of mania and/or psychosis.

The average age of children in the sample was 10.2 years, with a range from six to 17 years. Ten participants were male (77%) and three were female. This ratio is reflective of the 3-4:1 ratio documented in the general population of individuals with TS (Abi-Jaoude et al., 2009). **Table 1** provides further details of the participants.

### Materials and Procedure

Following informed written consent (and assent, when applicable), participants engaged in a semi-structured interview which lasted approximately 30 minutes. The interview was facilitated by one of the authors (K.E., who is also a registered psychologist). An interview guide consisting of open-ended interview questions was used to elicit the participants' perceptions about their experience living with tics. Examples of questions include: "How do you explain what *tics* are to other people?" and "What is life like for you living with *chronic tics*?" The underlined word(s) were replaced with vocabulary that the participant used to describe his or her tics (e.g., "habits").

While their child was being interviewed, parents completed the *Parent Questionnaire* (PQ), developed for the present study, to obtain demographic information about their child's ethnicity, age, and psychiatric diagnoses.

Parents also completed the *Yale Global Tic Severity Scale* (YGTSS; Leckman et al., 1989) to assess various dimensions of their child's tic severity. Of note, the YGTSS is intended to be clinician administered but for practical reasons,

Table 1. Characteristics of the study participants								
	Demographics			Diagnoses		YGTSS Scores		
	Gender	Ethnicity	Age (years)	OCD	ADHD	Score on the YGTSS	Total Tic Severity	Tic Impairment
1	M	White	12	Yes	Yes	64	34	30
2	M	Canadian-Columbian	17	No	Yes	20	20	0
3	M	White	8	No	No	43	23	20
4	M	White	10	Yes	No	6	6	0
5	M	East Asian	9	Yes	Yes	38	28	10
6	M	East Asian	13	Yes	Yes	60	40	20
7	F	East Asian	8	No	No	43	23	20
8	F	White	6	No	No	*	*	*
9	M	White	7	No	No	15	5	10
10	M	White	12	No	Yes	46	26	20
11	M	White	8	No	No	28	8	20
12	M	Filipino	12	No	No	49	19	30
13	F	White	10	Yes	No	32	12	20

Note: \* indicates that the participant did not provide responses to the items constituting these scales.

this measure was used as parent-report (consistent with how the measure is used in various clinical settings). Total tic severity and tic impairment scores each range between 0 and 50. Thus, total YGTSS scores, which are the sum of the tic severity and impairment scores, range between 0 and 100.

The study received approval from the Research Ethics Board of The Hospital for Sick Children.

### Data Analysis

All qualitative interviews were audio-recorded and transcribed verbatim. An inductive, analytical approach was employed to allow for significant themes to emerge. The following stages of thematic analysis by Braun and Clarke (2013) were used by the research team: (1) Two coders independently reviewed each transcript multiple times for familiarisation with the data. (2) Next, the coders generated labels (codes) for important elements of the data. Bi-weekly meetings occurred with one of the authors, G. D. (an expert in qualitative data analysis supervising the coders). In these meetings the codes independently identified by each coder were discussed and inter-coder agreement was reviewed. (3) Codes were collated and grouped into broader codes (sub-categories) and (4) eventually into themes. Disagreements among grouping of codes and themes were resolved through a discussion until consensus was achieved. (5) Distinct themes were developed, defined, named, and reported.

## Results

The analysis of the qualitative interviews resulted in three main themes and a number of sub-themes. The text below provides a summary of the content of themes accompanied by illustrative quotes.

### Theme 1: Beliefs about TS

Three sub-themes emerged to capture how young people with TS understand tics and their awareness of tics and urges, as well as causes of tics.

**A. Tic Conceptualization.** Participants used a variety of terms to talk about repetitive movements and sounds, including “tics,” “habits,” “behaviours,” and “TS.” Some participants described how the labels changed as their understanding of tics increased. For example, an 8-year-old male shared, “We used to call it habits. But one of our people in our school said that it might be Tourette’s.” (P14). In terms of conceptualizations of tics, seven participants emphasized the lack of perceived control over tics. For example, a ten-year-old described tics as “something that is not your fault and....it’s really hard to get to go away” (P7, male). Younger participants appeared to have more difficulty describing the concept of tics, perhaps due to less sophisticated language and/or less awareness of symptoms. For example, one youth shared, “I actually really don’t know how to explain it [tics].” (P8, male, age nine).

**B. Awareness of Urges and Tics.** Most participants stated that they usually realize when they are doing a tic. However, some youth expressed that they rarely notice their tics, particularly when distracted (e.g., “when I’m watching TV sometimes and when I’m having lots of fun” [P7, male, age 10]). Most participants reported feeling some sensation (i.e., premonitory urge) prior to their tics. Terms such as “tingle” (P4, P13), “itch” (P5), “pressure” (P4, P7), “squirm” (P12), and most commonly “a weird feeling” (P10, P14, P16) emerged during interviews. A 13-year-old male described one of his urges as “Something stuck in your throat. If you don’t get it out, it bugs you a lot.” (P9, male).

**C. Causes of Tics.** Participants’ statements generally reflected a poor or limited understanding of the causes of tics and TS. Causes endorsed by participants included allergies, anxiety, stress, and the brain. One participant (P8, male, age nine) stated he was born with tics and another explained, “It just happens” (P13, male, age 12). Participants appeared to have better insight into the factors that may affect the severity and frequency of their tics (in comparison to the causes of tics). Locations (e.g., school, home), situations (e.g., giving a school presentation), and strong emotions (e.g., anxiety) were frequently discussed as factors that may exacerbate or reduce tics.

## **Theme 2: TS-related impairment and distress**

Our sub-themes emerged to reflect how participants perceive the impact of TS on their life. These sub-themes include impairment and distress in: (1) emotional; (2) social; (3) occupational; and, (4) physical functioning.

**A. Emotional impact.** Embarrassment, worry, and irritation were prominent emotions reported by participants when discussing their experiences living with TS. The following were salient quotations highlighting the emotional impact of tics on youth: “I’m just worried that people will think I’m really weird” (P5, male, age 17); “I feel nervous because I think it’s just gonna come over and over again” (P12, male, age eight); and “It’s tiring, because you have to do it all the time. Can you imagine?” (P10, female, age eight). On the other hand, a few participants noted that they do not find their tics overly bothersome. For example, a nine-year-old participant stated, “It’s alright with me, having tics, actually. [...] It’s fine, it doesn’t bother me.” (P8, male).

**B. Social impact.** Participants described a range of reactions from others in response to their tics. These reactions included acceptance: “[My parents] understand that most of them [tics], basically all of them, I can’t help. They don’t punish me or anything.” (P9, male, age 13); curiosity from peers: “[I get asked] What is that? Why do you always do that?” (P13, male, age 12); being noticed: “I used to make like humming noises ...out loud and my grandma said ‘Stop it, you sound like an old lady.’” (P16, female, age ten); and bullying: “They [classmates] don’t want to hang around me because I’m weird. Like I know that there are inside jokes

about my Tourette’s at school and ADHD” (P4, male, age 12). Of note, a few participants were unsure if others knew they had tics. For example, one youth reported, “People at school might have noticed [my tics] but they don’t tell me” (P7, male, age ten).

**C. Occupational (Daily Living) Impact.** Many participants provided examples of how tics are distracting and disruptive during school, sports, and/or leisure activities. A 13-year-old participant explained, “They [my tics] are really repetitive so I can barely write” (P9, male, age 13). Another participant stated, “It [tics] makes it hard for me to play sports because it distracts me from what I’m trying to focus on” (P15, male, age 12). Attempts to manage tics (e.g., through suppression) were also experienced as disruptive by some participants.

**D. Physical impact.** Physical consequences of tics, described by participants, included fatigue, pain, and muscle aches. For example, one participant explained, “The snorting and sniffing sometimes makes me have nose bleeds [...] and [...] if I do it [clearing my throat] too much, then the throat aches after” (P7, male, age ten).

## **Theme 3: Coping with TS**

Many participants discussed ways to help them cope well with TS. For information about helpful advice participants received about TS and would share with newly diagnosed peers, please see Table 2. Participants described a variety of techniques to control symptoms including ignoring, suppressing, or disguising tics. For example, one participant shared that he draws in order to distract himself from his tics (P9, male, age 13). In terms of suppression, a 15-year-old male described how he suppresses his tics at school until the classroom is loud enough that he can “Just do it [tics] because no one will notice” (P15). One youth shared that when in public, he tries to hold in his tics “Because I don’t want people around to think I’m weird” (P9, male, age 13). With respect to disguising tics, one participant explained that she pretends to sniff while completing her lip movement tic in order to divert people’s attention away from her tic (P16, female, age ten). Participants varied in their reports of how helpful they found these management strategies and how much effort was involved in implementing them. Furthermore, most participants highlighted that they used management strategies considerably more when in public. Conversely, participants often described their home as a safe place in which they could “let everything out” (P4, male, age 12).

## **Discussion**

The findings from in-depth qualitative interviews revealed three prominent themes pertaining to how youth with TS understand, are impacted by, and cope with their condition. Each theme is discussed in more detail below by comparing

**Table 2. Helpful advice participants have received about TS and/or would share with peers who have tics**

There's a lot of people who have it, you're not the only one. (P14)
They're [other children with tics] not the only one. (P16)
If they just got diagnosed, I'd tell them, like, you need to find a way of controlling it... What I do, I concentrate on something else ... [To peers who don't have TS, I would share] I wanna stop but I can't (P4)
Try to be normal ... Try not to stress out too much. (P5)
I think it'd be helpful for them [newly diagnosed peers] to know that if you work on a tic... if you do your homework and do your Tic Busters [competing response in habit reversal therapy] a lot, it'll go away eventually. (P7)
Tics are fine. It may feel weird, but you'll get used to it. (P8)
Try your best to ignore it [tics] ... There isn't really anything to worry about. Everyone's different in their different ways. I've been trying to cope with it for a long time and it's been working out well. There's no reason to give up on life or give up what you do. (P9)
It's not really bothering. I have tics too, you know. (P10)
I would say don't really pay too much attention to them and then you won't notice them as much and you'll feel like someone who doesn't have them, almost. Like if you're doing something that you like ... they'll probably go away for a while.... [Also] My mom always talks to my teacher in the first week or so of it [school] so they [classmates] don't keep telling me to stop (P15)

and contrasting the results with other research conducted with this population.

### **Theme 1: Beliefs about TS**

The results showed that youth use a variety of terms to talk about tics (e.g., “*habits*,” “*behaviours*”). Fortunately, none of the children described their symptoms using negative labels (e.g., “*bad habits*”). The results also indicated that while most youth reported some awareness about the factors that mitigate or exacerbate their tics, very few youth understood the cause of TS. It is difficult to compare and contrast these findings to other studies because previous research tends to focus on the beliefs of others (i.e., non TS patients) about tics (e.g., Smith, Fox, & Trayner, 2015) at the expense of exploring how youth conceptualize and describe their own condition (e.g., symptoms, etiology). This type of research is important to assess whether youth understand their condition accurately. Previous studies have shown that youth want to receive useful information about their own disorder, but that many perceive a lack of knowledge about TS by health care professionals (Cuenca et al., 2015; Rivera-Navarro et al., 2009). In the present study, all youth received assessments within a specialist clinic, so their lack of understanding about the cause of TS may reflect the fact that the exact cause of TS is poorly understood in the scientific literature (Abi-Jaoude et al., 2009). Alternatively, the youth may not have been provided with this type of information from their health care professionals. Educating youth and their families about the factors that are thought to be implicated in the etiology of TS may be important in reducing potential self-stigma.

### **Theme 2: TS-related impairment and distress**

Youth in our study spoke about embarrassment, fatigue, and anxiety caused by knowing that tics could emerge at any moment. In addition to impairment caused by tics, young

people referenced distress related to other disorders/symptoms such as ADHD and compulsions. These findings are in keeping with what has been previously described in the literature (e.g., Cutler et al., 2015; Rivera-Navarro et al., 2014; Wadman et al., 2013). For example, a young person with TS may report physical consequences associated with tics such as pain and discomfort, anxiety about having tics in front of peers, depression from difficulties at school, frustration from lack of response to treatment, or challenges associated with comorbidities (e.g., distractibility limiting academic progress; Eapen et al., 2016). Studies have found that these social and emotional sequelae can negatively affect quality of life (e.g., Cutler et al., 2009; Eapen et al., 2016; Storch et al., 2007). Of note, consistent with past research (e.g., Smith et al., 2015), not all youth in our sample reported impairment and distress associated with TS. This was particularly true for youth who appeared to experience less severe TS (in which symptoms may not even be recognizable by peers), and for youth who perceived families and peers to be understanding and supportive.

### **Theme 3: Coping with TS**

Many youth in our study described the importance of explaining the involuntary nature of TS symptoms to peers. Youth also discussed “holding in” their tics in public places, and some shared that they then “let everything out” at home. These findings are consistent with previous results in which youth frequently describe the need to control or suppress tics in order to fit in with others (e.g., Cuenca et al., 2015; Cutler et al., 2009).

One unique aspect of the present study involved exploring the type of advice that youth have found most useful and/or would share with others with TS. As seen in **Table 2**, most commonly discussed was the idea “they’re [patients with TS] not the only one.” This feedback suggests that health care professionals working with youth with TS should make

a concerted effort to convey the idea that TS is a far more prevalent disorder than was once thought (Robertson 2008).

## Limitations and strengths

**Limitations.** The study results are based on interviews with a small group of participants recruited from a specialist outpatient clinic. Therefore, results may not be generalizable to youth with TS treated in less specialized settings. There was also considerable variability in the ages of participants. Another limitation is that since participants were interviewed at one point in time, it is unknown whether their perspectives may shift over time. Future research using longitudinal qualitative designs could provide valuable data about the experiences of young people with TS as they age.

**Strengths.** We conducted individual interviews with children and adolescents who were assessed in a highly specialized treatment setting for TS. The interviews were analyzed by research volunteers without any specific knowledge of TS, ensuring that their analyses were not influenced by such knowledge. This was also the first study to ask youth about the most helpful advice received from a health care professional about TS, and the most helpful advice that they would share with newly diagnosed peers.

## Implications

Capturing the experiences and opinions of youth with TS can offer a deeper understanding of how youth perceive and cope with the stigma surrounding TS. For example, in the present study, many youth highlighted the need to emphasize to others (e.g., peers, teachers, family) the lack of control over tics. Many participants also reported engaging in strategies in an attempt to control or disguise their tics so that their peers do not think they are “weird.” From a policy perspective, these findings suggest that there is still considerable work to be done around increasing awareness and understanding of TS as well as its impact on quality of life.

We also learned that few youth understand the cause of TS, many were unclear about how to describe tics or explain their symptoms to others, and most found it very helpful to learn about the prevalence of TS (since it enabled them to feel that they were not alone in having TS symptoms). These topics could be potential targets of intervention.

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The authors have no financial relationships to disclose.

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