

The impact of Gilles de la Tourette in adolescent life: an interview study.

Master Thesis proposed to achieve
the degree of master in medicine by

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COVER LETTER

Estimated Editor,

We would like to submit this original article entitled “The impact of Gilles de la Tourette in adolescent life: an interview study.” for publication.

In this qualitative interview study, we investigated the experience of 14 to 18 years old adolescents with a diagnosis of Gilles de la Tourette (GTS). We investigated this question by means of qualitative in-depth interviews, in this paper we will discuss our findings on this topic. How do adolescents experience their diagnosis?

The manifestation of tics can vary drastically between and within individuals over time. This makes it a difficult disorder. Given these findings, one of the best ways to understand the disorder is to gather personal accounts of those who live with the condition.

We will focus specifically on young adolescents with a diagnosis of GTS. Adolescence is viewed as a period in time where individuals construct and challenge their own individuality. It is also a time where exclusionary practices become more prominent. In addition, in this stage of life individuals experience their symptoms as most challenging.

To our knowledge, this is the first qualitative interview study on this topic in this age category.

The aim of this study is to gain insight into the personal impact for adolescents on their daily life.

Thank you for considering this study for publication.

Yours sincerely,

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ABSTRACT

Background and objectives: Gilles de la Tourette Syndrome (GTS) is a neurodevelopmental disorder included in the group of tic disorders according to the DSM-5 (1). Onset of GTS usually occurs during childhood with a peak incidence around 7 (4). Tic severity spikes around 10-12 years and symptoms usually decrease with age (5). However, for 20% of diagnosed patients, symptoms persist. Manifestation of symptoms can vary drastically between individuals and within the same individual over time (14). The aim of this study is to gain insight into the personal impact for adolescents on their daily life. What do adolescents think about GTS? Are there consequences of GTS on a day-to-day basis? In short, how do adolescents experience their diagnosis?

Methods: We recruited and selected 10 participants through UZ Leuven/ UPC KU Leuven. All patients either had been diagnosed or treated within this care setting. To establish a baseline of communicative skills exclusion criteria consisted of an IQ below 80 and/or the presence of a language disorder. We then conducted 6 semi structured interviews using an interview guide. We anonymized all collected data before we uploaded it to NVivo 12. We used this qualitative analysis software to manage and analyze the data via thematic analysis. After initial coding, we restructured and discussed personal findings within the research group.

Results: Multiple themes became visible during interview-taking and after encoding the data. Despite the small sample, different points of view arose, as well as similarities. Control over tics and the importance of social context seemed to be the most important topics. These often interfere, as social settings often lead to a higher wish for control and need for suppression. Attributed causes for the onset of GTS or triggers for tics vary from stress to social stimuli, such as speaking in public. Tic presentation also varies greatly between individuals. The participants distinguish between simple tics (vocal and physical), complex tics and tic attacks. Participants mention preliminary sensations, although not all of them. Tics impact daily life in different ways and on different levels, ranging from physical influence to communication and interaction with others. When it comes down to the general knowledge of surrounding peers on the topic, all participants agreed on a significant gap. The adolescents hope and anticipate that the broader society soon will display a learning curve on how to address and how not to address people with GTS.

Discussion: The importance of general knowledge in society, and especially the lack thereof, came forward multiple times in this research. Embedding existing research into the education of medical students, starting with the education of general medicine, could therefore make a difference. Current studies often focus on pathophysiology, clinical presentation or diagnostic tools. However, the personal experiences of adolescents seem underexposed. Even though they could lead to a better understanding of the disorder as well. In this study we did not take comorbidities into account, this could serve as a subject of future research.

ABSTRACT (DUTCH)

Achtergrond en doelstellingen: Gilles de la Tourette-syndroom (GTS) is een neurologische ontwikkelingsstoornis die volgens de DSM-5 wordt gerekend tot de groep van ticstoornissen (1). Het begin van GTS treedt meestal op tijdens de kindertijd met een piekincidentie rond 7 (4). De ernst van de tics neemt toe tot ongeveer 10-12 jaar en de symptomen nemen gewoonlijk af met de leeftijd (5). Bij 20% van de gediagnosticeerde patiënten blijven de symptomen echter bestaan. De manifestatie van symptomen kan in de loop van de tijd drastisch variëren tussen individuen en binnen hetzelfde individu (14). Het doel van dit onderzoek is om inzicht te krijgen in de persoonlijke impact op het dagelijks leven van adolescenten. Wat vinden jongeren van GTS? Zijn er gevolgen van GTS op het dagelijks leven? Kortom, hoe ervaren jongeren hun diagnose?

Methodes: We rekruteerden en selecteerden 10 deelnemers via UZ Leuven/UPC KU Leuven. Alle patiënten waren ofwel gediagnosticeerd binnen deze zorgsetting ofwel behandeld binnen dit kader. Om een minimum van communicatieve vaardigheden te verzekeren, bestonden de uitsluitingscriteria uit een IQ onder de 80 en/of de aanwezigheid van een taalstoornis. Vervolgens hebben we 6 semi-gestructureerde interviews afgenomen met behulp van een interviewgids. Alle verzamelde gegevens werden geanonimiseerd voordat ze werden geüpload naar NVivo 12. We gebruikten deze kwalitatieve analysesoftware om de gegevens te beheren en te analyseren via thematische analyse. Na de initiële codering werden persoonlijke bevindingen geherstructureerd en besproken binnen de onderzoeksgroep.

Resultaten: Meerdere thema's kwamen naar voor tijdens het afnemen van interviews en na het coderen van de data. Ondanks de kleine steekproef kwamen er verschillende standpunten naar voren, maar ook overeenkomsten. Controle en sociale context leken de belangrijkste onderwerpen. Deze interfereren vaak, omdat sociale instellingen vaak leiden tot een grotere wens tot controle en behoefte aan onderdrukking. Toegeschreven oorzaken voor het ontstaan van GTS of triggers voor tics variëren van stress tot sociale stimuli, zoals spreken in het openbaar. Tic presentatie varieert ook sterk tussen individuen. De deelnemers maakten onderscheid tussen eenvoudige tics (vocaal en fysiek), complexe tics en tic-aanvallen. Voorafgaande sensaties werden door sommigen genoemd, hoewel niet door allemaal. Tics beïnvloeden het dagelijks leven op verschillende manieren en op verschillende niveaus, variërend van fysieke invloed tot communicatie en interactie met anderen. Als het ging om de algemene kennis van de omringende collega's over het onderwerp, waren alle deelnemers het eens over een aanzienlijke leemte. De adolescenten hopen en anticiperen op een leercurve in de maatschappij over het wel en niet aanspreken van mensen met GTS.

Discussie: Het belang van een basiskennis in de maatschappij, en vooral het gebrek eraan, kwam verschillende keren terug in dit onderzoek. Het beter implementeren van huidige literatuur tijdens de basisopleiding geneeskunde zou al een verschil kunnen maken. Huidige studies focussen vaak op pathofysiologie, klinische presentatie en diagnostische tools. De persoonlijke ervaringen van de adolescenten lijkt vaak onderbelicht, desondanks dat deze ook zouden kunnen leiden tot een beter begrip van de stoornis. In deze studie werd er geen rekening gehouden met comorbiditeiten, dit zou als onderwerp kunnen dienen voor verder onderzoek.

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1. INTRODUCTION

According to the DSM-5, Gilles de la Tourette Syndrome (GTS) is a neurodevelopmental disorder. It is included as one of the motor disorders and is further included in the group of tic disorders (1). To be diagnosed with GTS one must have: (i) both multiple motor tics and at least one vocal tic, (ii) they have to be present for at least one year, but may wax and wane in frequency and (iii) the tics must have begun before the age of 18 years. (iv) Symptoms are not due to taking medicine or other drugs or due to having another medical condition (e.g. Huntington's Disease, dystonia or post-viral encephalitis). When there are only vocal or physical tics, the term 'persistent vocal or motor tic disorder' is used. If they have been present for less than a year, we speak of provisional tic disorder.

Tics are defined as sudden, rapid, recurrent and nonrhythmic motor movements or vocalizations (2). Severity varies widely between individuals. With GTS the first presentation of tics is usually located in the head and face area, where blinking of the eyes is a common example (3). Vocal tics range from simple tics such as throat clearing or sniffing, to more complex ones such as animal sounds like barking. A common misconception is the classification of coprolalia as a pathognomonic feature for GTS as it is only present in around 20 to 30% of GTS clinic populations (3).

Onset of GTS typically occurs during childhood between the age of 2 and 18 years with a peak incidence around 7 (4). The global prevalence is suggested between 0,4 and 3,8% between the age of 5 and the age of 18 with a male:female ratio of 3-4:1 (3). Tic severity spikes around 10 to 12 years and symptoms usually decrease with age. Less than one in four diagnosed patients report tic symptoms in adulthood (5). However, for 20% of diagnosed patients, symptoms persist or can even worsen over time.

There is increasing evidence that tics are preceded by so-called 'premonitory sensations' (PMS) (3). Sometimes these movements or vocal outbursts can be the result of a voluntary capitulation to a demanding urge accompanied by an exceptionally subtle sensation that provokes this urge (6). The resulting movement or vocal outburst will provide the final release of the sensation and tension build-up prior to the tic. Current scientific research agrees that tics are not completely involuntary. They can be deliberately suppressed, at least temporarily. As such, they may only seem involuntary because of the instant capitulation to the sensory stimulus. For example, some patients tic less or do not tic at all when concentrating on other tasks (6).

According to the review of Robertson and Eapen, around 10%, with GTS purely have tics (3). The majority have other psychiatric comorbid symptoms. These typically include attention deficit disorder (ADHD), autism spectrum disorders (ASD) and obsessive-compulsive behavior/disorder (OCB/OCD). Co-existent psychopathologies such as depression or anxiety are also very common. However, controversy persists regarding repetitive behaviors, such as touching, counting and symmetry searching. (7). Worbe et al. state that these are frequent in patients with GTS, on one hand corresponding to complex tics, but on the other hand can also be a manifestation of OCD. Thus, this distinction between simple tics, complex tics and manifestations of comorbidities should not be overlooked. These comorbid or co-existent psychopathologies can result in decreased quality of life (QoL), functional impairment and social difficulties.

As stated earlier, GTS is considered to be a movement disorder. It is characterized by a lack of inhibitory control, although this is a contentious issue (8). Increasing evidence from experimental, electrophysiological and imaging studies points to a disorder within fronto-striatal pathways. Specifically, structural and functional anomalies in cortico-striato-thalamo-cortical circuits have been found in relation to tic generation. In post-mortem neuropathological studies

of GTS patients, anomalies in the dopaminergic system were shown in frontal, primary motor and premotor cortical areas (9).

Twin studies suggest a substantive factor of heritability (10). Concordance rates are significantly higher in monozygotic (77%) than in dizygotic twins (23%), making it one of the most heritable, non-Mendelian neuropsychiatric disorders (11). However, no particular high-risk gene has been identified for GTS specifically. Polygenic multifactorial inheritance has been postulated (12). But identifying causative genes has been challenging. Structural and copy-number variations in susceptibility genes have only been identified in very few individuals and may thus be rare instances of causative genetic factors. A large proportion of disease heritability may be attributable to common risk variants that are distributed across the genome (13). There is some discordance between monozygotic twins, which is why prenatal and perinatal environmental factors are proposed to play a role in the development of GTS via epigenetic mechanisms.

The manifestation of tics can vary drastically between individuals and within the same individual over time. This makes it a difficult disorder to understand (14). Given these findings, one of the best ways to understand the disorder is to gather personal accounts of those who live with the condition. This study aims to gain insight into the personal impact for adolescents on their daily life. We investigated the perception and experience of the diagnosis of GTS.

In this study, we will focus specifically on young adolescents with a diagnosis of GTS. Adolescence is viewed as a period in time when individuals construct and challenge their own identity and individuality. It is also a time when exclusionary practices become more prominent. In addition, in this stage of life individuals experience their symptoms as most challenging (4).

We investigated this question using qualitative in-depth interviews. To our knowledge, this is the first qualitative interview study on this topic in this age category. In this paper we will discuss our findings on this topic. What do adolescents think about GTS? How do they presume that other people view their behavior and tics? Is there a main consequence or cause for their tic disorder? Whether the diagnosis impacts their future and if so, how? These questions all circle back to the main research question for this paper: how do adolescents experience their diagnosis?

2. METHODS

2.1. Recruitment of participants

We recruited 23 participants through UZ Leuven/ UPC KU Leuven. All of the selected patients/participants either had been diagnosed or treated within the same care setting and by the associated multidisciplinary teams specialized in tic disorders/ GTS.

The selected adolescents were aged between 14 and 18 years and were formally diagnosed with GTS, as defined by the DSM-5 (1). Exclusion criteria consisted of an IQ below 80 and/or the presence of a language disorder. This way we tried to establish a baseline of communicative skills with which the adolescents could express their thoughts and beliefs during interviews. We then screened the list of patients, taking the inclusion and exclusion criteria into consideration. This resulted in a total of 11 suitable candidates. Subsequently, we contacted 10 adolescents from this list in random order. We were unable to find any contact details for one potential participant. Six of them responded and were interested to participate. We provided contact details and further information when asked for. After receiving formal confirmation of participation, we scheduled a concrete appointment in terms of place and time.

2.2. Data collection

We (A.M. and S.V.) conducted semi structured interviews using an interview guide (appendix I), when useful or necessary we digressed from the interview guide, e.g. when the participants came with relevant themes not comprised in our interview. Two supervising researchers (Kristien Hens, Jean Steyaert) with experience in qualitative research trained and guided us before, during and after interview-taking. We gave the participants the opportunity to express their preferences regarding the interview format. We offered the possibility to choose between a face-to-face interview, a chat conversation, an email conversation and an online interview via Microsoft Teams. All 6 interviews took place at different locations. Three participants chose an online interview, one interview took place at the participant's home and two preferred to do it at the hospital as it was a familiar environment for them. The interviews lasted between 28 and 84 minutes. We recorded each interview and transcribed it afterward.

2.3. Data analysis

We anonymized all collected data before we uploaded it to NVivo 12. This qualitative analysis software was used to manage and analyze the data. We used the methodology of thematic analysis. We read the interview transcripts repeatedly, simultaneously listening to participants' voices while writing down the interviews on paper. We conducted inductive labeling of the interview fragments with codes and annotations separately to avoid influencing each other before discussing and matching our personal findings. After this initial coding process these codes and annotations were restructured and discussed within the research group. This resulted in greater, summarizing themes and subthemes. During the writing of the results, we reread the interviews frequently to make sure we did not miss important themes or particular nuances.

2.4. Ethical considerations

The ethical approval for this study was obtained from the Ethics Committee Research UZ/KU Leuven and UPC KU Leuven with study number S65583.

Participants and their legal guardian signed informed consent after receiving extensive written and verbal information regarding the means and purpose of the study. Collected data was anonymized after conducting the interviews and no identifying data was logged.

3. RESULTS

3.1. Description of participants

We interviewed a total of six participants, three male and three female. Ages ranged from 14 to 18 years. These adolescents had been diagnosed with GTS between the ages of 10 and 16. Each of the participants was diagnosed at UZ Leuven/ UPC Leuven. We use encoded names in the results (Table 1). We conducted the interviews in Dutch, some nuances may be lost in translation. We identified six overarching themes: 'Conceptualisation', 'Presentation of GTS and tics, evolution in life', 'Control over tics: provoking and suppressing factors', 'Impact of tics', 'Social context' and 'Future'.

Interview	Age (years)	Gender	Age at time of diagnosis	Code name
1	16	Female	15	Caroline
2	16	Male	10-11	Louis
3	16	Female	16	Chloe
4	17	Male	12-13	Tom
5	14	Male	14	Kevin
6	16	Female	16	Elisabeth

Table 1: Description of participants

3.2. Results

3.2.1. Conceptualisation

Terminology

We opened the interview by exploring the terms and nomenclature the adolescents are familiar with. This gave us a notion of the participants' knowledge of GTS, but also made it easier to decide which terms we would use for the remainder of the interview.

Most of the participants refer to GTS as 'tics' as well as 'Tourette's'. Two participants know the term Tourette's, but only use the former. One participant distinguishes between different tic disorders. Her categorization partly resembles the differences between the three defined tic disorders (GTS, provisional tic disorder and persistent, also called chronic, motor or vocal tic disorder) as described in the DSM-5. She talks about the chronic and non-chronic forms, with which she refers to GTS and provisional tic disorder.

Prior knowledge of and interest in GTS

The adolescents' knowledge concerning GTS prior to receiving their diagnosis, varies greatly. Certain participants were well informed about the definition of GTS beforehand. They gave several possible explanations in the interviews. The father of Caroline had been diagnosed with tic disorder at a young age and had tics in this period of time. Therefore, when Caroline's tics started, the diagnosis of GTS did not come as a surprise. Elisabeth remembers watching a documentary, most likely out of interest, about tic disorders at the age of 8, long before receiving the diagnosis and long before the onset of her own tics. Additionally, she became more aware of GTS through social media (cf. *infra*). She expresses a great interest in behavioral sciences as a whole, with the subject of tic disorders included:

*"When people talk about it or when an article is published, I'll definitely read it because I find it interesting."*¹

Others found the diagnosis less of a given. Kevin had never heard of the term GTS when receiving the diagnosis. Alongside his mother and family, he explored the meaning and significance of it through a children's book. Chloe indicates she had never heard of GTS in elementary school. However, she did know of tics in general. When her tics became more prominent to her and her close environment, she did look up an article online about tics once. Afterward, she had no remaining questions and she did not make any further search inquiries. She phrases it as follows:

¹ "Als mensen erover praten of als er een artikel over is, ga ik dat sowieso lezen want ik vind het interessant."

*"At the time I was like, 'oh well, I also have tics', but I didn't go into more detail."*²

Louis and Kevin both state that at the time of diagnosis they were not yet in possession of a mobile device to look things up with. They also are the two participants who were diagnosed the youngest (at the age of 10). Louis remembers he was more occupied with gaming, than with searching for information about GTS. Even without taking this context into consideration, their interest in the condition did not seem to grow after receiving the diagnosis. Kevin even adds that he prefers people not asking questions out of fear he would not be able to explain everything thoroughly. Later on in the interview he articulates this as follows:

*"I just say I have tics, because that's the only thing of Tourette's I have."*³

This way he seems to be implying that GTS also consists of other things aside from tics. Tom reports doubting his own knowledge on the subject. He says he knows GTS consists of physical and phonic tics, but also raises the question whether there are other symptoms or traits that should be added to its definition.

3.2.2. Presentation of GTS and tics, evolution in life

Onset of GTS and becoming aware of tics

The participants were diagnosed between the age of 10 to 16 years. This correlates to current scientific evidence, where it is mentioned that tic severity spikes around 10 to 12 years of age (3). Remarkable is how much the notion of the onset of these tics varies among the adolescents. What do they remember about this period? How much do they remember? Half of them recall this vividly. For example, Caroline noticed a few months before being diagnosed, that 'something' was 'wrong'. She recalls the doctor stating at the beginning of the diagnostic path that GTS was one of the possible outcomes. However, she also contemplates the idea that tics had been a part of her daily life for a longer period of time, even though it was unnoticed. Elisabeth can even point out the exact date her tics started. She thereafter nuances this statement, adding that other elements or expressions emerged before this date. She defines these peculiarities as tics in retrospect. Others can't define tic-onset equally well as the cases described above. We found more than one rationale. Louis states that he does not remember much before the age of 12 in general, due to it not being the most favorable period in his life. Tom and Kevin point out that they did not fully understand the meaning of this diagnosis when receiving it. The onset of tics or the moment of diagnosis did not seem to have a lasting impression on them. For this reason, Tom says that he is unsure of the exact moment tics started:

*"It is possible I had it earlier, but even if so, I don't realize nor remember it."*⁴

Possible cause for the onset of tics and GTS

Three participants thoroughly contemplate the question of what exactly lies beneath their tics, what caused them. Caroline links this to a personal experience in her past. She was also diagnosed with Post Traumatic Stress Disorder (PTSD) and believes this is why she began to develop tics. She explains:

² "Dan was ik zo van 'ah ja ik heb ook tics', maar ik ben er dan niet verder op ingegaan."

³ "Ik zeg gewoon dat ik tics heb omdat dat het enige is van Tourette dat ik heb."

⁴ "Het kan dat ik dat al vroeger had, maar dat besef ik niet."

*"I probably had so much tension build up over the past couple of years... that's why it's all coming together at this age, during puberty. That's the reason I got Tourette's and why I cannot control my muscle spasms etc."*⁵

Additionally, she considers a genetic influence given the fact that her father also had tics growing up. Louis states something similar. He had, as previously mentioned, not yet considered his tics extensively. Moreover, he no longer has any tics at the moment of the interview. They died out a couple of years ago. The days prior to the interview he reflected on the subject and concluded that his tics had stopped rather suddenly. This halt came around the time he did not have to go to his father anymore. He elaborates that at the time, these visits caused him a lot of stress. He believes that tics are related to stress and suggests the following question:

*"I wonder if it's something that originates in your head or if it can also arise from external factors."*⁶

He believes there is a multifactorial cause behind a diagnosis like GTS. Where Louis is very conscious about this possible cause, other participants are not. They state that they could not even in the slightest explain why their own personal tics would have begun. For Elisabeth, the question remains unanswered. She differentiates between her current 'severe' tics and earlier 'mild' tics. The onset of the former is precisely defined in time, while she finds the latter more difficult to match with a certain cause. She then addresses a possible link between levels of stress and the more severe tics. An additional argument for stress being an underlying cause for a broader symptomatic presentation is the fact that panic attacks also appeared when feeling stressed. She recalls the doctor explaining to her the tics could be a reaction to stress or fear.

Presentation of GTS, differences within and across individuals regarding the course of tic expression

When mapping out the personal tics of the adolescents, it quickly becomes clear how much this varies within and between individuals. Four out of six interviewed participants had or still have both physical and vocal tics. For some of them, physical tics are more prominent, others describe vocal tics as more present. Next to this distinction between physical and vocal tics, half of the adolescents also describe tic-attacks. For these three participants, these 'tic-attacks' are mainly a rapid and intense succession of different tics. After discussing their personal tics, we then continue uncovering the specific phases of a tic. We wanted to know what general experience was associated with a tic first. This will be further discussed within the next theme. Chronologically, sensing a tic coming on, is the first thing we will describe. Three out of six participants describe this very explicitly. Louis says it as follows:

*"It's as if you have an itch and you need to scratch something."*⁷

Caroline subdivides this preceding sensation into two elements. Firstly, she mentions a sensation that takes place right before the tic. Secondly, she also mentions an even earlier increased sense of awareness for the possibility of the occurrence of a tic. This increased awareness is mainly triggered by a heightened sense of tension.

⁵ "Ik heb waarschijnlijk zoveel stress jaaren ingehouden en daarom is het op deze leeftijd in mijn puberteit allemaal een beetje ontploft. Daarom heb ik Tourette gekregen en ben ik niet meer in controle van spasmes enzo."

⁶ "Ik vraag me een beetje af of het iets is in je hoofd of ook gewoon kan komen door factoren van buitenaf eigenlijk."

⁷ "Het is alsof je jeuk hebt zeg maar en móet ergens aan krabben."

*"You know, when you start to become increasingly nervous. Then I'm already thinking 'Ow, my tics.'"*⁸

Elisabeth notices a difference between vocal tics and physical tics. She clarifies that vocal tics usually go hand in hand with a more distinct preliminary sensation. Moreover, she often knows beforehand which tic specifically she is going to have. Next, she is the only one who speaks of a dissociative state. By this, she means a physically fixed posture, with a total loss of orientation in time and space, and where no contact can be made with her. She also can sense this coming:

*"Often I sense my tics repeating more rapidly and lasting longer and longer, this can lead to it getting 'stuck'. I often start dissociating when the spasm lasts for a very long time."*⁹

The experiences of these 3 participants are strongly contrasted by the experience of Kevin. He categorically answers no to the question if he senses his tics coming. He adds that he often is not even aware of making tics. It's only when a lot of brief tics would come up shortly after one another that he grows aware of them. The other two participants answer the question rather hesitantly. They sometimes sense their tics coming, even though not always. They do not succeed in finding a certain pattern or regularity in their tics. Tom clarifies:

*"I think it's always something that's going on in the back of my mind. But when there's one moment when I think: now I'm going to need to do a lot of tics, then I will try to suppress them."*¹⁰

Five of the adolescents do not speak spontaneously of a sense of relief when talking about the 'stages' of a tic. Except for the ones who make a difference between simple tics and tic attacks. They state that these attacks are sometimes associated with a postponement of relief, but they do not further specify this.

3.2.3. Control over tics: provoking and suppressing factors

When we explore a potential suppression of tics and possible triggers for tics, parallels between can be found. Participants share that when they're concentrated on something other than their tics, e.g. focusing on breathing or on computer games, they do not occur as much. Analogously when they are more focused on the tics, e.g., when talking about it or when they see others tic, this causes them to tic as well.

Caroline on suppressing tics: *"So yeah, when I feel them coming, I move my fingers for example and then I focus on that movement instead of focusing on what exactly is going on in my head. Or I try to occupy myself with something else."*¹¹

Chloe on triggering tics: *"I came across a lot of people [on TIKTOK] who talked about the subject, but I do not follow them. Because often when they discuss this subject, I start ticking myself."*¹²

⁸ "Ja, je weet wel, wanneer je echt nerveuzer begint te worden. Dan weet ik al wel van 'oei mijn tics'."

⁹ "Ja, vaak wel, dan merk ik dat mijn tics dan steeds vaker komen en steeds langer duurt, dat dat dan zo vast blijft. Vaak begin ik te dissociëren als de verkramping heel lang duurt."

¹⁰ "Ik denk dat het wel altijd ergens in mijn hoofd zit dat ik weet dat ik het aan het doen ben. Maar als er dan zo 1 moment is waarop ik denk: nu ga ik het veel moeten doen, dan ga ik het wel echt proberen inhouden."

¹¹ "Dus ja, als ik die voel opkomen, dan beweeg ik bv. met mijn vingers en dan focus ik op die beweging i.p.v. op wat er juist in mijn hoofd omgaat ofzo. Of dan probeer ik bezig te zijn met iets anders."

¹² "Ik ben veel mensen tegengekomen die erover praten maar ik volg het zelf niet echt. Want vaak als die daarover beginnen, begin ik zelf ook te ticcen. Als ik dat 1 keer ga bekijken ga ik dat nog niet overnemen."

Caroline and Elisabeth mention more detailed triggers. Caroline sometimes experiences that when others use words or sounds that sound similar to one of her tics, this tic is then triggered. This is an interesting contradiction to what Elisabeth says about the soothing effect when people repeat her tics to her.

The social aspect, which we will discuss further in greater detail, also has an impact on the presentation of tics. They both talk about the fact that unpleasant or exhausting social interactions are usually a trigger too.

Caroline: *"When I have a day where my social battery has truly died, I am way way more troubled by my tics on top of it."*¹³

Elisabeth: *"In school, when I have class from a teacher with whom I don't feel as comfortable, and where I'm more stressed, in those moments I have tics."*¹⁴

Nervousness is a recurring theme when we investigate what influences tics and their presentation. More than half of the adolescents use the words stress or commotion. This can be viewed as an increase of tension within themselves that arises, for example, when they have to give a presentation, meet deadlines, start in a new school... Chloe explains this as follows:

*"Especially concerning school-related stuff. I am often that stressed that I get a lot of tic attacks. /.../ There are a lot of factors actually. When I have to be social, but also when I have to start in a new school after summer holidays. There's always the same stress. With presentations too for example..."*¹⁵

Even though every one of the participants can give us a concrete example or presumption of a trigger, they all ask supplementary questions. Tom elaborates that there are times when people call him out on having more tics and follow up with questioning if there is a reason for it. In contrast, he himself often is not even aware of having more tics, let alone a possible explanation or cause. Kevin talks about a different kind of uncertainty. He anticipated more tics during stressful periods, e.g. during exams. Yet, tics did not spike as expected during these times. For him, there are no distinct clues to what may or may not be triggering. He explains this as follows:

*"It's not entirely clear to me. For example, two years ago, during exams, my mother, father and I thought I would have a lot of tics, but the opposite turned out to be right. I almost had nothing. And then, other moments, for example when I'm just chilling at home, or when I'm on holiday, I do have them exponentially. And possibly other times during exams they do come up. So it's more of a coming and going."*¹⁶

This lack of clarity for Kevin also is reflected when he talks about suppressing his tics. The peculiarity of not being completely aware of his tics also plays an important role. As he is often unaware of his tics and when they occur, he rarely asks himself the question if he would want to suppress them. During the interview he thinks out loud:

¹³ "Als ik een dag heb dat mijn sociale batterij echt op is, dan heb ik erna ook echt wel heel veel last van mijn tics."

¹⁴ "Op school heb ik vaak, als ik les heb van een leerkracht waar ik me niet zo goed bij voel, waar ik dan stress van krijg, op die momenten tics."

¹⁵ "Vooral bij dingen van school. Dan ben ik vaak zo gestrest dat ik heel veel ticaanvallen krijg./.../ Al die dingen eigenlijk een beetje. Als je sociaal moet zijn, maar ook als je opnieuw naar school moet bv na de zomer. Dat is altijd opnieuw stress, ook presentaties bv"

¹⁶ "Dat (= hoe zijn tics getriggerd worden) snap ik helemaal niet. Bv. 2 jaar geleden in mijn examenperiode, dachten mama en papa dat ik kei veel tics zou hebben, maar toen had ik echt bijna niks. En dan op andere momenten, bv. als ik gewoon rustig thuis ben, of op vakantie dan opeens wel fel. En dan in andere examenperiodes ineens wel fel. Dus dat is eigenlijk met komen en gaan."

"Most of the time I don't even realize I have them. /.../ I can, for example, hold my hands together all the time, or clench my teeth. But if I were to get distracted, even for a split second, my jaw would automatically start making those movements [the tic]." ¹⁷

Suppressing tics often costs all the adolescents a lot of energy. This sometimes can be disproportionate to the consequences of expressing the tic. Still, most of the time they prefer suppressing a tic rather than expressing it. Elisabeth elaborates on this by explaining the different impact between one of her vocal and one of her physical tics:

"When it comes to words, I can often hear what I am going to say. That can come in handy, because some things would be extremely embarrassing if I would say them. Last year I had a tic in class where I said 'fuck off' to everyone. When you raise your hand to answer a question and the teacher picks you, you prefer to hold that one in, so that's kind of helpful." ¹⁸

"The one with my neck I do very often sense coming, but I can't really suppress that one. If I were to try it, it would hurt even more and make matters even worse. And that's not nice." ¹⁹

The adolescents do clarify that suppression of tics does not necessarily mean eliminating tics. It can also mean weakening. Suppressed tics often come back later on, sometimes even with greater intensity or higher frequency.

Elisabeth on softening tics: *"I notice with words in class, when I'm around a lot of people, that for example the 'wow' is only whispered. It's as if it has become automaticity to do that with all my words, before that was not the case." ²⁰*

Caroline on rebound phenomenon of tics: *"You can't stop Tourette itself. You can hold them [the tics] in. But you can't really say 'and now I'm going to [permanently] stop'." ²¹*

Tom also mentions the use of medication and the assistance of it in regulating his tics. Important to note he does not attribute all suppression or stabilization to this medication:

"Whether you take medication or not... Yes, it does affect your tics, but in the end, your head decides everything, right? If you tried flipping that switch off not doing it, maybe eventually you would succeed." ²²

When we consider the influence of the environment even more extensively, and examine if and how an atmosphere affects these adolescents and their tics, findings are similar. Five out of six participants address the impact of public areas, social challenges, commotion, turmoil etc. as triggering factors. These are also characteristic of moments and places where they prefer suppressing their tics. This is an interesting contradiction. These participants seem to experience an elevated arousal and a lower tic-threshold in situations where they would, in contrast, prefer to tic less.

¹⁷ "Het grootste deel van de tijd heb ik niet eens door dat ik er doe. /.../ Ik kan bv. de hele tijd mijn handen samenhouden, of mijn tanden op elkaar houden. Maar als ik dan bv. afgeleid ben, doe ik dat niet meer. Mijn kaak gaat dan bijna automatisch terug die beweging maken."

¹⁸ "Vooral woordjes kan ik vaak horen wat ik ga zeggen, allee zo precies weten wat ik ga zeggen. Dat is handig, want sommige dingen zouden enorm gênant zijn als ik die zou zeggen. Vorig jaar had ik in de les een tic waarbij ik 'fuck off' zei tegen iedereen. En als je dan je hand in de lucht steekt en die leerkracht duid je aan en je voelt dat komen, dan houd je dat liefst in, dus dat is wel handig."

¹⁹ "Die met mijn nek voel ik wel heel vaak komen, maar die kan ik echt niet onderdrukken. Want als ik dat wel doe, doet het heel veel pijn en is het veel erger. En dat is niet fijn."

²⁰ "Ik merk bij woordjes ook dat ik in de klas, als ik dus tussen heel veel mensen ben, dat ik bv. die 'wauw' [= een tic] gewoon fluisterend is. Dat is precies een automatisme met al mijn woordjes, dat was daarvoor niet."

²¹ "Maar Tourette zelf kun je op die momenten zelf niet echt stoppen. Je kunt het wel inhouden, maar niet echt zeggen van 'nu stop ik'."

²² "Maar of je nu medicatie neemt of niet... Allee ja, dat heeft wel invloed op je tics, maar je hoeft beslist alles, hé. Als je probeert die klik te maken van het niet te doen, dan zou dat misschien wel lukken."

3.2.4. Impact of tics

Consequences of tics

Words like 'odd' or 'annoying' are used by the adolescents while describing their tics. These are broad terms, open for interpretation. We thus asked them to further specify them. Two mention the physical aspect of a tic first. Four out of six participants have tics that strain their muscles, sometimes resulting in pain and/or cramps. Additionally, Tom suggests two things within this physical connotation, one is the fact that through GTS he has become more aware of his body, another is the interference of tics in sports.

Elisabeth on the physical aspect: *"The one with my neck is the most unpleasant. That one is highly painful, on top of it is usually accompanied by another tic. /.../ I also have this tic where I start hitting myself in class. It hurts a great deal."*²³

Tom: *"Even when running; those movements cost me so much air and energy... You run out of breath very easily. I can try to hold it in, okay, but then I'm constantly thinking in my head: 'now I need to do this and that.' It can get very tiring. After a while it's just no fun anymore."*²⁴

Four out of six participants brought another aspect into light: the impact on concentration and functioning at school. For Louis, this mostly translates to meeting deadlines and the stress that comes with it. This is the same for Caroline, she adds that she sometimes even is not able to physically complete her projects. She does nuance this after her train of thoughts.

Caroline: *"Sometimes with photography, when I have to take pictures for example in the classroom, I'm sometimes not even capable of doing that just because my hands shake too much. So yeah, it does have an effect on it. It's still not overpowering me, or as distracting that it really bothers me. But it is still there."*²⁵

Tom: *"Well, sometimes it is a little annoying. E.g. when I want to concentrate. For example, studying. When I'm constantly tapping my fingers or doing something with my jaw, it can become a little distracting."*²⁶

The consequences for communication and interaction with others are also a strongly discussed theme. Chloe struggles the most with the eye-catching nature of some tics. This results in an anxious attitude towards meeting new people and self-doubt for social interactions in general. Elisabeth too talks about the expressive nature of tics. She describes some of her tics as 'embarrassing', others she finds disruptive, especially when conversing. She gives us the following example:

*"I find my vocal tics often disturbing, for example when I'm in class or in a group or just with someone. Because I can't have a normal conversation. Sometimes you have to stop in the middle of a sentence because a tic is coming. That is annoying, especially when you're having a serious talk with someone and such a stupid tic interferes."*²⁷

²³ "Die met mijn nek is voor mij echt het vervelendste. Die is zo heel pijnlijk, daar komt vaak nog een tic bij... /.../ Ik heb ook een tic waarbij ik mezelf in de les begin te slaan. Dat doet veel pijn."

²⁴ "Gewoon bij lopen; die bewegingen, dat kost zoveel lucht en energie. Je gaat zo snel buiten adem. Als ik het inhoud oké, maar dan denk ik in mijn hoofd: nu moet ik dat en dat en dat doen. Je wordt er moe van. Na een tijdje is het gewoon niet meer leuk."

²⁵ "Of soms ook met fotografie dat ik bv. foto's moet nemen in de klas en dat ik echt niet in staat ben om te doen omdat bv. mijn handen heel veel trillen. Dus ja, dat heeft wel een effect daarop. Maar in principe ook niet zoveel dat het echt storend is. Maar ja, het is er wel."

²⁶ "Jua, soms is dat wel een beetje irritant, bv. als ik me wil concentreren. Bv. op het studeren. Want als ik dan de hele tijd met mijn vingers iets doe of met mijn kaak, dan leidt me dat zowat af."

²⁷ "Ja. Mijn vocale tics vind ik vaak enorm storend, als ik bv. in de klas zit of in een groep zit of gewoon bij iemand ben. Omdat ik dan niet normaal een gesprek kan voeren. Soms moet je middenin je zin stoppen omdat er een tic komt. Dat is vooral heel vervelend als je serieuze gesprekken aan het voeren bent dat er dan soms zo een dómme tic tussenkomt."

Putting into perspective: impact on quality of daily life

Something that stands out in this theme compared to other themes are the nuances rapidly given by the participants. They say to have grown used to the tics, try to give it less time a day or try to relativize it in a bigger picture. Kevin even says that in his own experience GTS or tics do not influence his life that much.

Tom: *"It's just no fun to have it. But then again... You should be happy you're able to live. You should be happy you have the opportunity to live. /.../ If you have tics or something of the sort, it doesn't matter that much. /.../ Not everyone is perfect."*²⁸

Kevin: *"I just do the things I want to do. Almost all the people that are close to me know of it. And if someone who I do not yet know asks me "what is that with your jaw?", I'll just tell them "ah, that's my tic". It doesn't really stop me from doing the things I want to do."*²⁹

Caroline and Elisabeth also describe it this way. They acknowledge GTS as an entity that, among others, may distinguish them from others. But they also stress that this should not be seen as a pernicious element. It is not a given that GTS should come with a manual or a lot of impact on one's daily life.

Caroline: *"And for me, it really wasn't that big of a deal. I mean, I knew something was off, but then again, yeah... It didn't trouble me as much."*³⁰

Elisabeth: *"It is a part of me, but it's not as important that it should define my whole day. /.../ I find it important that it always stays this way for me and I don't let it have too much impact on my doing etc. Okay, it does change some things. For example, I went dancing once. There it was sometimes annoying that I had to be separated from the group for fifteen minutes because I just couldn't succeed. Those are the moments where it does have an impact. But in my daily life, I try not to let it have too much impact because I don't want it, you know?"*³¹

Elisabeth: *"Since I have tics, I often have times where I think: "oh then I had plenty of tics, and it hurt so much." It does change the way I look at my day. A few weeks ago, I needed to write day by day if I had a lot of tics. I do look at my day in a different way then: 'this was a bad day when it comes to tics.'"*³²

Impact on identity

Both Caroline and Chloe spontaneously describe GTS as a part of themselves, an element that contributes to their identity. This often is in alignment with how they perceive their diagnosis itself. They do not see it as an unbearable label or inevitable difficulty. They see it as a part of themselves, no more, no less. Chloe stresses that people should not make a big deal out of it, not make it bigger than it actually is. Elisabeth also agrees that it should not be a core element of the personality others perceive.

²⁸ "Het is gewoon niet leuk om dat te hebben. Maar ja... Je mag ook blij zijn dat je nog kunt leven ofzo. Je mag al blij zijn je kunt leven. /.../ Als je tics ofzo hebt, dat maakt niet heel veel uit. /.../ Niet iedereen is perfect."

²⁹ "Ik doe gewoon alles wat ik wil. De mensen die dicht bij mij staan, die weten dat bijna allemaal. En als iemand die ik nog niet ken vraagt: 'Wat is dat met je mond?', dan zeg ik: 'aah dat is mijn tic'. Dat stopt me eigenlijk niet met te doen wat ik wil doen."

³⁰ "En voor mij was dat eigenlijk niet zo'n probleem. Alleen, ik wist dat er wel iets mis was, maar, ja... ik had er niet zoveel last mee."

³¹ "Het is een deel van mij, maar dat is geen belangrijk deel dat mijn ding (dag routine?) moet bepalen. /.../ Ik vind dat heel belangrijk dat dat voor mij ook altijd zo gaat blijven en dat ik dat niet te veel invloed ga laten hebben op wat ik doe enzo. Oké, het verandert wel dingen. Ik was bv. gaan dansen. Het was vervelend dat ik apart moest gaan zitten een kwartier omdat het gewoon niet lukte. Dan heeft dat wel invloed. Maar op mijn dagdagelijkse leven probeer ik dat niet te veel invloed te laten hebben omdat ik niet wil dat, ja, snap je?"

³² "Nu ik tics heb, is dat vaak zo: oh toen had ik zoveel tics, en dat deed zoveel pijn. Het verandert wel de manier waarop ik kijk naar mijn dag. Een paar weken moest ik dag per dag opschrijven of ik veel of weinig tics gehad had. Ik kijk er dan wel naar als: dit was nu een erge dag qua tics."

Chloe: *"I don't struggle with it. It's not as if I'm thinking 'oh that's a problem to me'. It is a 'side' of me."*³³

Elisabeth: *"It isn't the same as describing someone using their skin color or something. If someone were to have blue hair for example, one might say 'that's the person that has blue hair', that's okay for me. But to say 'ah yes, X is the person who has Tourette's' is totally different."*³⁴

Kevin suggests that GTS also might have shaped his identity, whether it be subconsciously. In doing so, he mostly emphasizes the initial predisposition of character traits he might have had at birth, and how these were strengthened or weakened because of GTS. He explains:

*"I think that who I am... in a way it might be because of Tourette's. Maybe it made me someone who didn't stand out, and I took that with me. And maybe that's why now, I'm not someone who likes too much attention."*³⁵

For Chloe, we found similar nuances. She was simultaneously diagnosed with an anxiety disorder while being diagnosed with GTS. This diagnosis is of greater importance to her than GTS. She explains that the two affect each other, and that if she would understand one more, this would result in a boost in self-confidence regarding the other. Tom, while thinking out loud, does say that GTS does not particularly change who he is, but without it, his life might have turned out different. He even takes this a step further and asks himself the question if others' perception of his identity would change. He clarifies:

*"But who knows, maybe if I didn't have it, I would have done something completely different. Maybe I would've never lived here. Everything might have changed. But I do think, if it were to disappear, I'd stay the same. /.../ I also wonder if others would say: 'heh, you're so different?'"*³⁶

Additionally, we asked the participants if they saw GTS as a disability or a disease. All of them are clear on the fact that they do not at all see it as a disease. This word is seen as a completely false description or nomenclature for the diagnosis they received. The participants who do consider the word 'disability' still are steadfast that the terminology 'disease' should never be used. They also consider this definition from a broader perspective. They prefer calling it an obstacle or something that's always playing in the back of your head. Something they're prone to dealing with, the same way others deal with their own stuff. Here too the portrayal of GTS as 'a part of them' shows through. Elisabeth describes this beautifully:

"In my case it definitely is a 'problem' in many situations, and that is what makes it super annoying. It's also very aggravating, especially in the very beginning and now still, learning to accept it and learning to cope. So when you see it that way... yes then I find it a problem. A disability in some regards too. But a disease, definitely not. GTS is not a disease. Tic Disorders are not diseases. It's an impairment... it's actually just that, a problem you have. For some people it's worse than for others. I think that if you learn to deal with it and accept it little by little, you certainly will not see it as a disease. I can't

³³ "Ik heb er inderdaad nu niet echt een probleem mee. Het is niet dat ik echt zoiets heb van 'oh dat is een probleem voor mij'. Het is een 'kantje'."

³⁴ "Dat is zo niet hetzelfde als iemand beschrijven adhv zijn haar of huidskleur ofzo. Wel als die persoon zo blauw haar ofzo heeft, zoals ik een maand hiervoor. Dan zegt men ook: 'die persoon met dat blauw haar', dat vind ik oké. Maar om nu te zeggen: 'Ah ja XXX is die persoon met die Tourette.'"

³⁵ "Ik denk wie ik ben, misschien ook wel een beetje van Tourette. Misschien dat het mij in het begin al als iemand niet opvallend gemaakt heeft, en dat ik dat een beetje heb meegenomen, en dat ik daarom nu zo iemand ben die niet te veel aandacht wil."

³⁶ "Maar wie weet, als ik dat niet zou gehad hebben, zou ik misschien iets helemaal anders gedaan hebben. Zou ik misschien nooit hier gezeten hebben. Alles zou misschien kunnen veranderd hebben. Maar ik denk als ik dat nu niet meer zou hebben, ik zou gewoon hetzelfde blijven doen. /.../ Maar ik vraag me af of de mensen die ik ken dan gaan zeggen: 'huh' je bent zo anders."

*really explain why, but disease is not a fitting word to describe Tourette's. It just really isn't appropriate."*³⁷

3.2.5. Social context

Prejudice, ideas and assumed impressions of others

The adolescents are more often than not thinking about how others see their tics. Louis expresses that if the tics would return, he doubts if others would believe him. Caroline also thinks of it this way, she tells us:

*"Sometimes I have this small fear that they would think it's not real. That they don't really believe me. That's something that goes on in my mind. Oh well, you learn to deal with it. You stop thinking 'what would they think'. I've learned to focus on myself."*³⁸

Half of the participants do have an underlying fear that their diagnosis would not be acknowledged by others. Therefore, Chloe finds it very frustrating that some people would fake GTS, e.g. on TikTok. She speculates that this could result in a disbelief towards people who do have GTS. Even further, she is afraid that outsiders would grow to think that tics are a way of seeking attention. On the other hand, the adolescents do state that they are learning or have learned to care less about the opinion of others. Two words stand out when asking how GTS affects their social status and interactions: 'different' and 'weird'. Five out of six of the adolescents use one or both of these words when describing their tics, how others perceive them or how it affects their social presence. Moreover, four out of six have considered the risk of people avoiding them because of their tics. However, all four of these participants immediately add that this has never actually happened to them. Kevin concludes that he is reassured that his entourage is growing older as well and would not jump to (the wrong) conclusions too quickly anymore.

Kevin: *"I think they might have thought in the beginning 'What is he doing?' or 'What a weirdo is that?' Possibly new people still think like that, but less since we're older."*³⁹

Louis: *"People are always quick to judge. For example, people with ADHD are thought to be aggressive, people with GTS will be weird. That's the only thing I fear."*⁴⁰

The adolescents continue some thoughts and beliefs about social impact into a wider perspective. They consider what certain topics mean for society in general and sometimes even what it means for the world. This is also the case when it comes to (unfair) judgment. The adolescents point to a causative relationship between the lack of general knowledge about GTS and the setback in terms of prejudice and stereotypes. For some this leads to an anxiety that strangers might misjudge them. What if others can only see them in a biased light? What if they already made up their minds based on a fixed first impression that these adolescents are in fact 'weird' or 'different'.

³⁷ "In mijn geval is dat zeker een 'probleem' in veel situaties, en dat is heel vervelend. Het is ook heel ambetant om in het begin, nu nog steeds dus eigenlijk, mee om te gaan en een beetje te accepteren dat je dat hebt. Dus op die manier... ja, ik vind dat sowieso wel echt een probleem. En een beperking op sommige manieren ook. Maar een ziekte niet. Tourette is geen ziekte. Ticstoornissen is geen ziekte. Dat is een beperking... ja dat is eigenlijk gewoon een beperking die je hebt, een probleem dat je hebt. Bij sommige mensen is dat erger en bij andere mensen is dat minder erg. Volgens mij, als je ermee leert omgaan en dat een beetje accepteert, dan ga je het zeker niet als een ziekte zien. Ik weet ook niet waarom, maar ik vind ziekte geen juist woord om Tourette te beschrijven. Ik kan moeilijk uitleggen waarom, maar dat is echt niet het juiste woord."

³⁸ "Soms heb ik dan wel een beetje schrik dat ze denken dat dat niet echt is, dat ze dat niet echt geloven. Dat zit zeker wel ergens in mijn hoofd. Maar ja, je leert daar ook wel mee omgaan, dat je niet echt denkt van 'oh wat denken die'. Ik heb me echt een beetje leren proberen focussen op mezelf."

³⁹ "Ik denk dat ze in het begin misschien wel gedacht hebben: wat doet die nu? Of: wat een rare is dat? Ik denk nieuwe mensen nu misschien ook nog een beetje maar nu ze ouder zijn minder."

⁴⁰ "Er wordt altijd heel snel geoordeeld door mensen als je zoiets hebt. Bv. mensen met ADHD die zullen altijd wel agressief zijn enzo, zij met Gilles de la Tourette zullen wel raar zijn. Daar was ik een beetje bang voor."

Louis: *"I used to think that others just thought: 'They are weird people.' That's why I wanted nobody to know [I had Tourette's]."*⁴¹

Kevin: *"People might think it's only the cuss-part. I think a lot of people see Tourette's that way, and less the tics themselves. I think compulsive disorders also are part of it /.../ I think the world only knows what they see most. For example: every time they see a stereotype on TV: 'aah, so that's someone with Tourette's'. If the world would get to see that normal tics are also Tourette's, they would automatically know better."*⁴²

Even though tics might be noticed by others or perceived as weird, this does not mean that all interviewed adolescents fear this observation. Kevin for example worries very little about possible negative opinions or reactions of others concerning his tics or himself altogether. He has a very rational point of view on the subject and states that if he himself would not have had GTS, he too might have found it weird for someone else to make a tic. Thus, his answer is twofold. On one hand, he does not care too much about the preconceptions of others. On the other, he does understand their logic.

*"It doesn't really matter to me what other people think. But I also know others who say 'he looked at me like that, what would they think of me?'. I think people with that kind of character are more likely to be offended. Maybe they would feel ashamed more easily. Or even be more scared that people would want to hurt them."*⁴³

Lastly, another thought that plays in the minds of these adolescents is that the assumptions made by others might be based on very little knowledge about GTS and tics. As a result, first impressions and their following reactions towards the interviewees are largely influenced by this limited education. Tom clarifies:

*"They might think: What are you doing? What is that?"*⁴⁴

Others also address this gap. Their direct environment, often being the people in their classroom, is poorly educated on the topic of GTS. This unawareness and minimal knowledge reach further for the adolescents. They mention an absence of knowledge on the subject, not only in their classmates or close friends, but also in the general population. However, this is not necessarily a purely negative thing. The adolescents seem to leave a lot of space for improvement. An increase in knowledge could, for example, give an opportunity for people to adapt their attitudes towards GTS in a more instinctive fashion. For the average person knowing how one should or should not (inter)act with a person who has GTS, might already make a great difference. But professionals as well can still improve. Elisabeth explains this as follows:

"There are só little specialists in this field! We couldn't find any person who was specifically trained for patients with Tourette's. Not even psychiatrists, who do know something about it. But in general... people don't know what to do at all, they simply don't know enough about it. It's annoying. So, I do think that when you study something in the medical field... yeah, people need to be taught more. Because it's also

⁴¹ "Vroeger dacht ik ook dat mensen gewoon dachten: dat zijn rare mensen. Daarom ook dat ik wou dat niemand dat wist"

⁴² "Dat ze denken dat dat ene scheldding is. Ik denk dat veel mensen dat als Tourette ziet, en minder die tics. Ook dwangstoornissen denk ik dat daar ook bij hoort/.../ Ik denk dat de wereld weet wat ze vaak te horen krijgen. Bv. telkens op tv stereotypen zien van: 'aah dat is iemand met Tourette'. Als de wereld zou weten dat gewone tics ook Tourette zijn, dat ze het dan ook gewoon normaal zouden weten."

⁴³ "Mij maakt het niet echt veel uit wat mensen over mij denken, maar ik ken ook mensen die zeggen: 'die keek al zo naar mij, wat zou die vinden van mij?', ik denk dat mensen met zo een karakter, die zich snel beledigd voelen, dat die misschien zich wel sneller zouden schamen als die het zouden hebben. Of sneller schrik zouden hebben dat mensen iets zouden doen tegen hen."

⁴⁴ "Dat ze denken: wat doe jij nu? Wat voor iets is dat?"

something, my psychiatrist told me this, more and more people have tics or something that has to do with tics.”⁴⁵

Reactions of others and how to cope

Tics are sometimes expressed differently depending on the setting. How do peers react to their tics? How does this affect our adolescents? Caroline splendidly describes what other participants seem to experience when having tics in a social setting:

“You see other students watching you etc., but they don’t come to you at all. They are well aware of what is happening, but don’t approach you, except true friends. It seems as if their attitude is like ‘okay, well then, we’ll let her be’.”⁴⁶

Hereby she addresses that others, mostly people who do not know her that well, try to stay out of the situation as much as possible. There seems to be an underlying suspicion that others do not really know how to react: they do look and they do spot what’s happening, but do not act further upon it. Elisabeth shares a similar belief. This being said, it does not always seem to be a problem that people nearby avoid an individual whilst she or he is having tics. Three participants express that they appreciate people not responding to it at all. Aside from strangers, some close friends do not react to it either. When Chloe told her friends about GTS and the fact that she had it, they on their end revealed they had already realized it a long time ago, but chose not to mention it. This came as a surprise for Chloe, seeing as she thought she hid it well. But she did appreciate their chosen response of ignoring it until she herself came forward with it. When meeting someone for the first time, two participants notice a negative first impression of others, something they describe as unpleasant. It seems as though people are startled in a way when seeing tics.

Chloe: *“There is always that split second when they stare at you strangely. And then they realize: “ah, she must have tics”. I don’t like that first look, when they’re wondering why I have tics.”⁴⁷*

Elisabeth: *“They were like: “Oh okay, she does that”. After a while you could see the puzzled look fading. This way you do get that it takes a while for people to process what it actually is.”⁴⁸*

Another particular happening, largely occurring at a young age, is people copying tics. Chloe says the following:

“There was a boy in my class who didn’t know and when I started shaking my head, he copied this. In hindsight, he was like ‘Oh no, she might have tics. I should not have done that.’”⁴⁹

She adds that this event took place in elementary school and thinks that the boy in question acted out of ignorance. These issues did not seem to repeat themselves at the current age

⁴⁵ “Er zijn zó weinig specialisten daarin! Er was nergens iemand die er specifiek was voor patiënten met Tourette. Zelfs psychiaters die er wel een beetje over weten. /.../ die weten daar wel wat over, maar die weten totaal niet wat ze moeten doen, die weten daar gewoon niet genoeg over. Ik vind dat vervelend. Dus ik vind wel dat als je iets medisch gaat studeren... ja, daar moet gewoon meer over aangeleerd worden. Omdat het ook iets is, mijn psychiater heeft dat ook gezegd, dat er meer en meer mensen zijn met iets met tics of iets dat met tics te maken heeft.”

⁴⁶ “Dan zie je dat leerlingen kijken enzo, maar zelf helemaal niet naar je toekomen. Ze zien wat er gebeurt maar komen niet, behalve dan echte vrienden. Ze zijn precies zo van ‘okeeje dan, we laten ze doen’”

⁴⁷ “Er is dan altijd zo even die seconde dat ze zo vreemd naar je kijken. En dan zo beseffen: aah die heeft tics. Maar ik vind die eerste blik niet leuk, dat ze zich zo afvragen waarom ik tics heb.”

⁴⁸ “Zij waren zo van: aah Ja, die doet dat. Een tijdje later zag je dan dat die rare blik weg ging. Daar zag je wel dat dat echt wel tijd neemt voor mensen om te verwerken wat dat nu eigenlijk is.”

⁴⁹ “Er was ook eens een jongen in mijn klas die het niet wist en toen ik dan met mijn hoofd begon te schudden, deed die dat na. Achteraf was die dan van ‘oei die heeft misschien tics’. Dat hij het misschien niet had mogen doen.”

and stage of life. Other participants also mention people copying their tics, they too put things into perspective. Kevin even seems to find it funny:

*"Sometimes somebody copied my tic as a joke, but that was it."*⁵⁰

As explained in greater detail above, adolescents do have a fear of possible negative reactions or assumptions, for some bigger than for others. However, they all have had experiences that showed them the opposite and are empowered by them. Elisabeth summarizes this as follows:

*"Up until now, not many people have reacted too strangely. And I'm talking about name-calling etc. They never really did anything like that, I've never experienced that. "Yeah... everyone is rather respectful about it, they say: "None of it matters, just let it happen, we will help you when needed". That feels nice."*⁵¹

The participants also notice that people tend to react by asking questions. This again shows the lack of common knowledge on the subject. Caroline views it as follows:

*"Teenagers in my class also ask me a large number of questions. They are not really aware of what Tourette's actually is. That's when I realize it's not as well-known as I sometimes think it is."*⁵²

On one hand, there seems to be a negative connotation to this constatation. Namely, it seems as if they would have hoped people had more extensive inherent knowledge regarding GTS. On the other hand, the adolescents all say that they see the effort the people in their direct environment want to put in to learn. Caroline words this as follows:

*"The question that is the most present is 'How can I help you?'"*⁵³

Positive reactions also occur from time to time. Kevin gives us a concrete example on this topic:

*"For example, I once was with the hairdresser and she asked "what is it you do with your head and jaw?" and then I explained it together with my mother: "I have tics, I have Tourette". To which she responded: "Oh! Too cool! That is so unique."*⁵⁴

He continues that he has been handling GTS in a playful way ever since. At home they often joke about the tics and his mother even made a T-shirt out of it with a quote 'Tic-Tac-Boom'. The others also state that their close environment handles it quite well.

Explaining tics and talking about GTS

All the participants express talking freely about the subject with their family and close friends, with no limits regarding timing, place or contents. Outside these circles, it is not a topic they would elect to elaborate on. Chloe even expresses not liking the feeling of being the center of attention. Kevin, although slightly more nuanced, agrees with this opinion:

⁵⁰ "Soms bv. deed iemand om te lachen mijn tics eens na. Maar dat was het dan."

⁵¹ "Tot nu toe zijn er niet veel mensen die daar echt heel vreemd op gereageerd hebben. Dan bedoel ik rare namen ofzo noemen. Dat hebben ze echt nog nooit gedaan, nog nooit meegemaakt. Ja... iedereen is wel respectvol, ze zeggen: 'dat maakt allemaal niet uit, doe maar gewoon, we zullen wel helpen als het nodig is'. Dat is wel leuk."

⁵² "Maar bv. ook kinderen in mijn klas stellen nog enorm veel vragen. Die zijn er zo nog niet echt van op de hoogte van wat dat juist is. Dan heb ik ook wel een beetje door van het is toch niet zo bekend als dat ik zelf zou denken."

⁵³ "De vraag die het meest voorkomt, is toch wel 'hoe kan ik je helpen?'"

⁵⁴ "Ik was bv. eens bij de kapper en die vroeg: 'wat doe je met je hoofd en kaak?' en dan hadden mama en ik uitgelegd: 'ik heb tics, ik heb Tourette'. En dan zei die: 'aah keicool, dat is bijzonder.'"

*"A lot of attention, people observing me constantly, I just don't like that very much. It feels like I'm being examined too closely. I'm fine with it within my close friend group, but if everybody would suddenly approach me and would start asking questions like "what is that?" I wouldn't feel comfortable."*⁵⁵

For Caroline and Elisabeth however, sharing intel and experiences with others is beneficial. This also reflects in the help that they both appreciate and expect from their environment. They find it necessary that the environment is informed beforehand. This way peers can comprehend what is going on when they tic. Caroline tells us how she explained it at the beginning of the school year and how this gave her a good feeling:

*"I talked to my headteacher and care coordinator. We decided to explain it together during PE, the class of my headteacher. It was a brief group discussion where we all sat down and had a small conversation. My classmates were able to ask me questions as well. It felt quite natural that way, it didn't feel forced. It was also nice that it took place during PE, this made it more casual."*⁵⁶

Although both participants prefer talking things through ahead of time, they also voice the understanding that others would prefer another approach, such as not talking about it at all. Caroline does specify that she too, could sometimes find it tiring to explain herself over and over again.

*"Every time I meet someone new, I need to talk it over again. Sometimes that's not so fun. Some people already have some kind of idea about Tourette's, but it is always different when it's about another individual. So you always have to explain what your tics specifically are and what the impact is. It does bother me sometimes."*⁵⁷

When canceling out an active role played by the adolescents where they themselves need to explain GTS, it seems as if they all agree that the theme should be exposed more. Media might play an important role. Caroline, Louis and Elisabeth give us the example of TV shows or movie productions where a certain character has GTS or where an actor with GTS is cast. The influence of social media is also undeniable, now often via TikTok. Caroline and Tom elaborate on TikTok:

Caroline: *"I like that! That it's brought more into light that way, especially for teenagers. That way they see others who have it. Teens can ask their questions and creators can answer them and teach them more about what it actually is. So yeah, I don't mind it at all."*⁵⁸

Tom: *"I don't think everybody knows what tics are, so if it were to go viral more often, more and more people would know. People would learn how to deal with it, I think."*⁵⁹

For the adolescents, covering the entirety of GTS via these channels is just as important as featuring it more frequently. Kevin notes that social media sometimes reinforces the higher

⁵⁵ "Super veel aandacht en dat mensen mij de hele tijd aankijken, dat vind ik gewoon echt niet superleuk. Dan voel ik me te hard bekeken. Bij mijn vriendengroep vind ik het oké, maar als bv. ineens iedereen naar mij zou komen: 'wat is dat?', dan zou ik dat niet echt leuk vinden."

⁵⁶ "Dan heb ik echt goed gesproken met de titularis en zorgcoördinator en dan hebben we dat samen uitgelegd bij LO, het vak dat mijn titularis geeft. Even een groeps gesprek, even allemaal gaan zitten, en dan hebben we gewoon even gebabbeld. De klasgenoten konden dan ook vragen stellen. Dat voelde vrij natuurlijk aan, het was niet geforceerd. Ook leuk dat het gewoon bij LO was, dat is zowat losser."

⁵⁷ "Elke keer als ik iemand nieuw ontmoet ofzo moet ik dat weer uitleggen. Dat is dan wel zo een beetje minder. Sommige mensen weten dan al wel wat het is, maar het is altijd anders voor een persoon, dus dan moet je toch ook weer uitleggen wat mijn tics juist zijn en welk effect dat heeft op mij. Ik kan me er wel aan storen."

⁵⁸ "Ik vind dat wel leuk! Dat het zowat meer in het licht wordt gebracht, vooral bij tieners. Dat je zo ziet dat er echt mensen zijn die dat hebben. En dan kunnen kinderen hen vragen stellen en dan kunnen die creators ook zeggen wat dat juist is. Dus ja, ik vind dat helemaal niet slecht."

⁵⁹ "Ik denk niet dat iedereen wat tics zijn, dus als het zowat meer normaal zou gaan, zouden meer en meer mensen dat weten. Mensen zouden er dan ook mee kunnen omgaan, denk ik."

mentioned stereotypes instead of dismantling them. Chloe tells us about a recent hype around GTS on social media where peers often faked tics. This also had a counterproductive effect on the growing awareness in the world. This led to an increase in anxiety seeing that others might think she would be faking it as well. When we further inquire what exactly people need to know, Caroline spontaneously answers this question very simple and yet all-inclusive:

“Just that some people deal with it, what exactly it is, which tics people can have or what it can mean for someone.”⁶⁰

We could say that the knowledge concerning GTS itself, should consist of both factual elements and personal significance. For the adolescents the interindividual difference seems to be just as important as the similarities that possibly bind them.

Guidance of others and how others can help

Half participants express clearly that they do not need specific help from others while having tics. Chloe even says she wants as little attention as possible when she's having her tics. When we ask what the best possible attitude of others is, she says this:

“To not pay any attention to it.”⁶¹

When she has her tics, she prefers others to let her be over undertaking any specific actions. The guys also do not feel the need for extra help from others. This might also be explained by the limited impact they experience while having tics. As we will discuss further, these participants also do not feel the need to explain GTS to other peers, e.g. in the classroom. With the same reasoning of not wanting to draw too much attention to the topic. Thus, they do not expect anything from their direct environment. In contrast, Tom does acknowledge the heartening feeling that is accompanied by the possible concern of others, he appreciates that 'people are there for him', without specifying this further. He seems to imply that must there arise any problems concerning his tics, he would have people to rely on. He phrases it as follows:

“I don't really enjoy talking about it myself, but if they can help me, I do appreciate it. I know who I can fall back on when needed. /.../ handle it in a good way. You don't need to laugh at people for it. A disability, that's what I call it. That you learn how to help the person. For example, by going in for a chat. I myself don't like that very much, but I do think there are others who would find it nice if they had someone to talk to. I am sure of it.”⁶²

For a minority of the interviewees, the demand for help does come up. This is mostly the case for participants who view their tics as more severe or interfering. For example, Elisabeth who talks about tic attacks, does wish for specific assistance from others. She attributes a supporting role to possible bystanders, friends or family. This assistance could be in the form of a permit to leave the classroom when the tics become too much to handle, but also in the form of physical help. Then again, this is not a black and white situation, and sometimes no help is more beneficial and these participants too want to be left alone. The participants give the following explanations:

⁶⁰ “Gewoon dat er mensen last van hebben, wat het juist is, welke tics mensen juist kunnen hebben of wat dat kan betekenen voor iemand.”

⁶¹ “Om er geen aandacht aan te besteden.”

⁶² “Zelf babbelen ik er niet heel graag over, maar als ze me kunnen helpen, waardeer ik dat wel. Ik weet dat ik hier terecht kan wel. /.../ Je moet daarvoor niet lachen met mensen. Een beperking, zo noem ik dat toch. Dat je die persoon ook ermee kunt helpen. Door bv. eens met die persoon te babbelen. Zelf doe ik dat bv. niet graag, maar ik denk dat er mensen zijn die het wel leuk zouden vinden om erover te kunnen babbelen. Ik weet dat zeker.”

Caroline: *"I can leave the classroom if I want, that was arranged by my teacher. I can leave the classroom and go to the bathroom to let out the tics and to settle down."*⁶³

Caroline: *"It's just talking to me for a moment, trying to distract my thoughts with other stuff. Sometimes you just have to hold me. Especially when I have my physical tics, you just need to grab my hands and make sure I can't hurt myself. But sometimes you just have to let me tic until they stop. I prefer this for my vocal tics, not so much for my physical tics seeing that I can actually hurt myself."*⁶⁴

Elisabeth: *"When I have multiple vocal tics, but it's not yet a tic attack, my tics mostly calm down when people talk back to me. For example, when I have my 'hello'-tic and people reply back with 'hey', it seems as if my head flips a switch and thinks 'it's okay'. Then it usually only continues for a little while. When people react in this way, it usually quiets down. In a way, it also relieves the tension around it. That's why I always tell people that they can respond to my tics, up until I express otherwise during a tic, because it really helps me."*⁶⁵

Others with GTS

The interviewed adolescents all say knowing at least one other person with GTS in their direct environment. This also seems to affect the personal experience of their diagnosis. Almost all the adolescents state that due to knowing these people, they no longer feel alone or are alone with their tics. Tom tells us:

*"I know other people in my school who have it. I'm actually quite happy to see other people that have it, this way I'm not alone. That there are others. We are, in a sense, connected to each other."*⁶⁶

Kevin and Elisabeth among others join Tom in this experience. The latter adds the following:

*"I think it's a good thing. It makes it more comfortable, because now I am not the one weird kid that makes weird noises at school. People/ outsiders can try to learn what Tourette's means, but they'll never fully understand it."*⁶⁷

Additionally, the adolescents seem to realize, because of knowing these peers, that the diagnosis is very heterogeneous. They acknowledge similarities but also emphasize the many differences. Two participants also suggest a downside to peers with tics in their close environment. Chloe talks about the risk of adopting the tics of others (. She also seems to feel guilty when others adopt her tics:

⁶³ "Dus ik kan ook wel uit de klas stappen, dat heeft mijn titularis geregeld. Ik kan uit de klas stappen en naar de wc gaan en daar even tics uit laten en tot rust komen."

⁶⁴ "Dat is gewoon even tegen mij babbelen, mij proberen te laten denken aan andere dingen. Soms is dat ook gewoon dat je mij vast moet houden. Dat is dan bij mijn fysieke tics, dan moet je mijn handen vastpakken en gewoon zorgen dat ik mezelf geen pijn meer kan doen. Maar soms is het ook net dat je mij moet laten 'uitticcen', maar dat heb ik dan liever met mijn vocale tics i.p.v. met mijn fysieke tics, omdat ik mezelf wel echt serieus pijn kan doen."

⁶⁵ "Als ik zo veel vocale tics heb, en het is geen erge ticaanval, dan kalmeren mijn tics een beetje als ik merk dat mensen terug praten. Als ik die 'hallo'-tic heb, en mensen zeggen 'hey' terug, dan is het precies alsof dat in mijn hoofd een klikje maakt van: 'Het is oké.' Dan gaat dat zo nog eefjes verder. Maar als mensen daarop reageren, kalmeert dat precies bij mij. Dat haalt die spanning erond precies een beetje weg ofzo. Dat is echt iets dat ik dan voel. Daarom dat ik ook tegen mensen zeg, tot ik zeg dat het niet meer oké is, dat ze mogen reageren op mijn tics, omdat dat mij ook helpt."

⁶⁶ "Ik heb wel mensen op mijn school die het ook hebben. Ik ben eigenlijk blij om mensen te zien die dat ook hebben, omdat ik dan weet dat ik niet alleen ben. Dat er nog mensen zijn. Wij zijn zo ja... verbonden met elkaar."

⁶⁷ "Ik vind dat wel goed. Dat maakt het meer comfortabel omdat ik dan niet meer dat ene rare kind ben dat op de speelplaats of in de klas rare geluidjes staat te maken. Mensen kunnen dat wel begrijpen maar uiteindelijk snappen die dat niet helemaal."

*"I did find it unfortunate that a classmate of mine adopted my tics, she already had many more for which she frequently needed to leave the classroom. And then I make it even worse by adding another..."*⁶⁸

Elisabeth seems to have the same troubles. Moreover, she sometimes finds it difficult that because of this, relations with people with GTS were lost, even though they might be the ones who could understand her the best.

*"That's what I find annoying when it comes to others with tic disorders. On one hand, we can all relate, we all have similar issues and would normally be able to discuss these things very well. But on the other hand, because of the impact of each other's tics, you can't even have a proper conversation most of the time. When you try, you just get more and more tics and you trigger each other. That is super annoying."*⁶⁹

3.2.6. Future

To conclude the interview, we asked the adolescents how they see their future. As young adolescents, they are finding their own voice and paving their own path in the world. They are getting to know themselves, with or without obstacles along the way. We wondered where and if GTS would fit into this bigger picture. Half of them do not even mention GTS in their answers. They speak of getting their degree, which career paths they envision and how they picture their independence altogether. They mention the challenges, doubts or insecurities they struggle with, and how they want to overcome them in the (near) future. For the other half of the participants, the ones who do mention GTS in their future, tics can be, but are not always the main focus. They hope these tics will diminish or even disappear. Elisabeth also talks about learning to accept the tics in case they would not go away. Here too, the impact of GTS varies. Caroline starts her answer by talking about her tics, they play a central role in her future. Kevin also spontaneously explains how he sees the evolution of his GTS for himself. However, when his parent inquires if he would give the same response to a question regarding his future, had it not been raised by us as interviewers, he is less convinced. They say the following:

Caroline: *"So yeah, when I think of my future, I immediately think of Tourette's."*⁷⁰

Kevin's mom: *"If you were to sum up 10 traits characteristic for yourself, would you include Tourette's?"*

Kevin: *"I might... maybe. I'm not sure though."*⁷¹

4. DISCUSSION

4.1. Summary of main results

Not many of the adolescents have prior knowledge about GTS when receiving the diagnosis. Exceptions are adolescents with a relative with the same diagnosis, which in our sample was the case for three participants. This is no surprise as genetic factors play a role in GTS (12). Another exception to this limited knowledge was due to interest in behavioral sciences as a whole. After receiving the diagnosis, interest in the subject naturally grows for four of the

⁶⁸ "Ik vond dat eigenlijk wel heel erg dat ze die tics aan het overnemen was, want ze heeft er al super veel waarbij ze zelfs uit de klas moet gaan omdat het zo erg wordt. En dan zorg ik er zelfs voor dat er nog 1 bijkomt..."

⁶⁹ "Dat vind ik vervelend aan anderen met ticstoornissen; wij kunnen allemaal 'relaten', wij hebben allemaal een gelijkaardig probleem en zouden daar normaal gezien heel goed over moeten kunnen praten. Maar omdat dat zoveel effect heeft op elkaar, kan je bijna geen normaal gesprek voeren met elkaar. Je staat dan samen en krijgt gewoon constant tics. Dat is kei vervelend."

⁷⁰ "Dus ja, als ik aan mijn toekomst denk, denk ik wel vrij direct aan Tourette"

⁷¹ Ouder Kevin: "Als je 10 dingen van jezelf zou moeten opsommen, zou je Tourette er dan bij vermelden?"

Kevin: "Misschien wel dan... (twijfelend), ik ben niet zeker"

participants, however still not for them all. The main focus of these interests also varies. For some, the differences or similarities with peers are deemed more important, for others the pathophysiology prevails.

Causes for onset can be very specific for some, three participants in our sample, e.g. stressful or negative experiences. For others what, when or how GTS was caused is less evident. We can suggest many reasons. Diagnoses may have already happened at a young age, as such memories were no longer as vivid. Tics may not influence life as much as one would think. Or maybe they are just not interested in finding this out and did no further research.

Tic presentation also varies greatly between individuals as well as there are many changes within individuals over the course of time. Both vocal and physical tics were present in the sample of interviewed adolescents. Half of them also spoke of 'tic-attacks'. The incidence of comorbidities also frequently came to light. However, we did not discuss this in this paper. As described in other articles that focused on tic progression, the adolescents also mention a preliminary sensation in this study (3). However, this preliminary sensation was not always as clear, as prominent, or even there at all. One participant subdivided this into the preliminary sensation itself and an even earlier elevated sense of awareness that a tic might happen, due to stress for example. Other participants mentioned a different preliminary sensation for vocal and physical tics.

Control and its nuances were an important matter for the adolescents. This meant the ability and possible need for suppression of tics, but also had implications regarding triggers for tics. The most important triggers for our adolescents were commotion, nervousness, socially stressful situations and the subject of GTS or others with GTS. For those who talked about suppressing their tics, this need often arose in conditions that also triggered tics. Suppressing these tics costs a lot of energy for the adolescents and could be tiring. It was often not a permanent solution, since tics would come through more frequently or intensively later on during the day. Although two participants mention medication, the attributed role in regulating GTS was more of an assisting nature than it was something that would determine the entire course, presentation or experience of tics.

Tics impacted daily life in different ways and on different levels. This could be a physical influence, an impact on concentration, function in school or have an impact on communication and interaction with others. All described their tics as annoying or intrusive. However, they all communicated the importance of nuancing possible negative influences. GTS and its influence in life should be nuanced. It should not be used as a *pars pro toto*, where one's life is to be determined by this one element or diagnosis. Four out of six participants described GTS as 'a part of them' and not something that should define their day-to-day living or entire life course. For all the adolescents GTS should never be seen as a disease, not even an impairment but rather a disability.

Another important and recurring theme was the impact of GTS in a social setting. The adolescents often had a certain anxiety towards a misjudging of their character by others solely based on tics. The reasoning behind this was the frequently observed use of stereotypes in media and sometimes even by bystanders. This use of stereotypes was partially attributed to the lack of knowledge in the general population on the subject of GTS, but also contributed to this ignorance and limited education. The adolescents also mention this when talking about the reactions of others. Half of the adolescents worried, each in their own way, for negative reactions, although none of them truly experienced harmful or lasting damaging situations. The reactions that were more prevalent were those of not knowing what to do. Bystanders, friends or strangers rarely knew how to handle or what to do when the participants started to tic. For some this was not a problem, others did mention that it would feel as a comforting safety net must others know, even the basics, what they should do best in that kind of situation. Five of the participants also received positive reactions and comforting reactions.

Many of the participants spontaneously talk about knowing others with GTS, this leads us to think it's an important theme for them. Still, this is twofold. On one hand, they often find recognition and comfort in each other. Discussing the subject with them offers new insight but also confirms some of their own struggles. On the other hand, it can sometimes bring new frustrations. An example that came forward in this paper was the adoption of each other's tics as well as triggering tics by watching someone else tic, thus sometimes resulting in a worsening cascade. Among others, this impacted the potential beneficial communication.

When it comes down to the future, the answers were evenly divided. The adolescents mention typical subjects for a life in full development, but also the expected or desired evolution of GTS. For the latter, the role of GTS still varied, for half of them it was merely a part that should be included, for the other half it played a more central role.

4.2. Implications for clinical practice

Research about the portrayal of GTS shows a gap between what patients themselves think about GTS and what exactly the rest of the world knows and thinks about it. Often an incorrect image of GTS is painted (15). Capturing the experiences and opinions of adolescents with GTS can offer a better understanding of how youth perceive and cope with the stigma surrounding GTS. For example, in the present study, many adolescents highlighted the need to emphasize to others (e.g., peers, teachers, family) the lack of control over tics or the approval to let the tics happen.

On the other hand, we see the importance of embedding the existing research into clinical practice, and last but not least, into the education of medical students. During medical studies, focus often lies on knowledge about diagnosing pathologies and finding a fitting cure. However, the experience of patients with GTS seems at least as important, if not more. To give a concrete example, participants resist seeing GTS as a disorder as is mostly done, but prefer seeing it as a disability.

4.3. Strengths and limitations of the study

Due to the oral nature of the interview with the young people, it was possible to deviate from the exact questions from the interview guide drawn up in advance. We obtained a unique conversation with each adolescent. In this way there was a lot of space to reflect on each separate individual. No two interviews were the same. Because the young people could choose in advance how they wanted to conduct the interview, we made them as comfortable as possible.

As already mentioned, the perception of the GTS diagnosis is a very individual concept. By working with qualitative semi-structured interviews, we have tried accentuating the individual experience of young people with GTS. Because we worked with only six adolescents, it is more difficult to give a realistic image and make statements that apply on a larger scale. Possibly, the same individual variation persists in a larger group of adolescents and again few strict conclusions can be drawn, perhaps even new elements emerge that have not yet been discussed in this paper.

Another limitation is that since we interviewed the participants 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.

In qualitative research, on the other hand, it is a strength to work with a small number of young people, this way individual experience can be explored even more thoroughly. This is

interesting in clinical practice as the caregiver-patient relationship is different for each individual.

An additional consideration is that we could have forwarded the results of this study to the participants in order to check whether they would see certain things differently than how we interpreted them.

Finally, we have touched on a lot of topics, but have therefore not questioned and elaborated on all of them in depth. It could be interesting to research these themes separately in further interviews. Additional nuances could potentially be mapped out even better.

4.4. Future research

Current research still raises a number of questions. In this study, (for example,) the participants clearly indicate that few people know about GTS what they think they should know. We think it would be interesting to embed current research and all similar studies more in clinical practice. The more this topic is read and talked about during healthcare provider training, the more a trustworthy relationship between individual patients and corresponding clinicians can be formed.

Changing the sample criteria to adolescents with a below-average intelligence might also show new or additional results.

The influence of the comorbidities on the perception of GTS is something that we did not address in this study. This could be the subject of future research. How do people with a diagnosis of autism or ADHD experience GTS's diagnosis, for example? Which diagnosis do they consider to be worse?

The participants themselves also propose a theme for future research. Although all of them see TikTok as a positive tool for raising awareness and creating self-acceptance, they also mention a possible risk. They express the fear of not being believed to have GTS anymore, given the reaction both on social media and in academic publications that the people on TikTok do not really have GTS, but would rather be attention-seekers (17). They fear this would also discredit their own tics as, potentially, fake. More study is needed on TikTok and GTS, specifically concerning those who have GTS, as other academics suggest that, in line with our interviewees' remarks, this phenomenon can shed light on a number of open issues in the literature (18).

5. REFERENCES

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (5th ed.). American Psychiatric Association (APA). Washington, DC; 2013.
2. Singer, H. Tics and Tourette Syndrome. Continuum (Minneapolis Minn). 2019; 936-958.
3. Robertson, M., Eapen, V. Tourette's: Syndrome, disorder or spectrum? Classificatory challenges and an appraisal of the DSM criteria. Asian Journal of Psychiatry. 2014; 106-113.
4. Malli, M., Forrester-Jones, R. *"I'm not being rude, I'd want somebody normal"*: Adolescents' Perception of their Peers with Tourette's Syndrome: An Exploratory Study. J Dev Phys Disabil. 2017; 29(2):279-305.
5. Bloch, M., Peterson, B., Scahill, L., Otko, J., Katsoyich, L., Zhang, H., and Leckman, J. Adulthood outcome of tic and obsessive-compulsive symptom severity in children with Tourette syndrome. Archives of pediatrics & adolescent medicine. 2006; 160(1), 65–69.
6. Bliss, J. Sensory Experiences of Gilles de la Tourette Syndrome. Arch gen Psychiatry. 1980; 37:1343-1347.
7. Worbe, Y., Mallet, L., Golmard, J. L., Béhar, C., Durif, F., Jalenques, I., Damier, P., Derkinderen, P., Pollak, P., Anheim, M., Broussolle, E., Xie, J., Mesnage, V., Mondon, K., Viallet, F., Jedynak, P., Ben Djebara, M., Schüpbach, M., Pelissolo, A., Vidailhet, M., Hartmann, A. Repetitive behaviours in patients with Gilles de la Tourette syndrome: tics, compulsions, or both? PloS one. 2010; 5(9).
8. Beste, C, Munchau, A. Tics and Tourette Syndrome — Surplus of Actions Rather Than Disorder? Mov Disord. 2018; 33: 238-241.
9. Cheng, B., Braass, H., Ganos, et al. Altered intrahemispheric structural connectivity in Gilles de la Tourette syndrome. NeuroImage. Clinical. 2013; 4, 174–181.
10. Gagné, J. The psychology of Tourette disorder: Revisiting the past and moving toward a cognitively-oriented future. Clinical Psychology Review. 2019; 11-21.
11. Pedersen, J. H., Skytthe, A., Bybjerg-Grauholm, J., Kucukyildiz, A. S., Skov, L., Debes, N. M., & Tümer, Z. Concordance and comorbidities among monozygotic twins with tic disorders. Journal of Psychiatric Research. 2021.
12. Dehning, S., Müller, N., Matz, J., Bender, A., Kerle, I., Benninghoff, J., Musil, R., Spellmann, I., Bondy, B., Möller, H., Riedel, M., and Zill, P. A genetic variant of HTR2C may play a role in the manifestation of Tourette syndrome. Psychiatric genetics. 2010; 20(1), 35–38.
13. Robertson, M., Eapen, V., Singer, H. et al. Gilles de la Tourette syndrome. Nat Rev Dis Primers. 2017; 3, 16097.
14. Edwards, K., Mendlowitz, S., Jackson, E., Champigny, C., Specht, M., Arnold, P., Gorman, D., and Dimitropoulos, G. A Qualitative Exploration of the Experiences of Children and Adolescents with Tourette Syndrome. J Can Acad Child Adolesc Psychiatry. 2017; 26(1): 39-44.
15. Calder-Sprackman, S., Sutherland, S., Doja, A. The Portrayal of Tourette Syndrome in Film and Television. Canadian Journal of Neurological Sciences / Journal Canadien des Sciences Neurologiques. 2014; 41, 226 - 232.

16. Hull, M., Parnes, M. Tics and TikTok: Functional Tics Spread Through Social Media. *Movement disorders clinical practice*. 2021; 8(8), 1248–1252.
17. Müller-Vahl, K., Pisarenko, A., Jakubovski, E., Fremer, C. Stop that! It's not Tourette's but a new type of mass sociogenic illness, *Brain*. 2021.
18. Conelea, C., Bervoets, J., Davies, B., Varner, K., Malli, M., Jones, D., Capriotti, M. It's Time to Stop Telling Patients to "Stop It": Response to Müller-Vahl et al.'s "Stop That! It's not Tourette's but a New Type of Mass Sociogenic Illness". 2021.

6. APPENDIX

I. Interviewgids

I.I. Thema's

Deel 1: beleving van de adolescent

1. Terminologie en conceptualisatie
2. Klinisch beeld: kenmerken en ervaringen tics
3. Impact op functioneren en dagelijks leven
4. Sociale impact

Deel 2: beleving in een sociaal kader

5. Terminologie en conceptualisatie
6. Klinisch beeld: kenmerken en ervaringen tics
7. Perspectief van de omgeving

Deel 3: toekomstperspectief

I.II. Ingekorte versie

Deel 1: Beleving adolescent

1) Terminologie en conceptualisatie

- Wanneer is de diagnose van Gilles de la Tourette bij jou gesteld? Wat dacht je toen men dit jou vertelde?
- Hoe zijn de tics bij jou ontstaan? Wat voel je nu?

2) Klinisch beeld: kenmerken en ervaringen tics

- Hoe zien jouw tics eruit
- Voel je je tics aankomen? Kan je ze onderdrukken?

3) Impact op functioneren en dagelijks leven

- Zie je jezelf als iemand met een beperking of een ziekte? Of zie je dit helemaal niet zo?
- Op welke manier heeft Gilles de la Tourette een impact in je leven? Heeft dit ook een invloed op hoe je je voelt van dag tot dag?

4) Sociale impact

- Voel je dat je Gilles de la Tourette soms een invloed heeft op je omgeving en sociale interacties?
- Denk je dat sommige jongeren liever niet met jou omgaan owv je tics/Gilles de la Tourette?

Deel 3: Beleving in een sociaal kader

1) Terminologie en conceptualisatie

- Vertel je anderen over Gilles de la Tourette?
- Leg je hen uit hoe de tics kunnen ontstaan?

2) Klinisch beeld: kenmerken en ervaring tics

- Hoe denk je dat anderen jouw tics ervaren of zien?
- Maakt de reactie van anderen jouw eigen ervaring anders?
- Passen de tics zich aan aan de omgeving? Pas jij je aan aan de omgeving?

3) Perspectief van de omgeving

- Hoe denk je dat **de wereld** kijkt naar Gilles de la Tourette?
- Heeft deze kijk een invloed op jou?

Deel 3: toekomstperspectief

- Hoe zie je jouw toekomst?

I.III. Uitgebreide versie
Deel 1: beleving van de adolescent

Nr.	Hoofdvragen	Follow-up vragen	Doel/parameters
V1	Terminologie en conceptualisatie		
1	Wanneer is de diagnose van Gilles de la Tourette bij jou gesteld? Wat dacht je toen men dit jou vertelde?	<i>Ken je hier nog andere namen voor? Hoe noem je het zelf?</i>	Vaststellen terminologie Terminologie waarmee de jongeren vertrouwd zijn. Terminologie die meest aanwezig is in de praktijk. Eerste indrukken over diagnose <ul style="list-style-type: none"> - Emoties - Gedachten
2	Voor dat die diagnose bij jou gesteld werd... Hoe zijn de tics bij jou ontstaan? Wat voel je nu?	Wanneer werd je je ervan bewust dat je tics maakte? Of was dit misschien iemand uit de omgeving die dit eerst opmerkte?	WANNEER HOE AANLEIDING?
V2	Klinisch beeld: kenmerken en ervaringen tics		
3	Hoe zien jouw tics eruit?	<i>/ welke tics heb je?</i>	Parameters Duur Simpel vs complex Motorisch vs fonetisch Ernst (intensiteit, frequentie, interferentie met functioneren, merkbaar voor anderen, onderdrukbaar, exacerbatie bij stress/vermoeidheid/andere dingen, fysieke verwondingen) andere vormen: copropraxia, echopraxia, palilalia, echolalia, coprolalia
4	Voel je je tics aankomen? Kan je ze onderdrukken?	<i>Kan je beschrijven hoe een tic verloopt? Zijn er dingen die je tics uitlokken?</i>	Parameters Urge ? JA/NEE/ bij elke tic? Opluchting na tic ja nee?
V3	Impact op functioneren en dagelijks leven		

5	Zie je jezelf als iemand met een beperking of een ziekte? Of zie je dit helemaal niet zo?		
6	Op welke manier heeft Gilles de la Tourette een impact in je leven? Heeft dit ook een invloed op hoe je je voelt van dag tot dag?	<i>Denk je dat je een ander persoon zou zijn zonder GTS? Kan je inbeelden hoe je leven zou zijn zonder GTS? Heeft dit je sterker gemaakt of hindert dit je juist meer?</i>	
V4 Sociale impact			
7	Voel je dat je Gilles de la Tourette soms een invloed heeft op je omgeving en sociale interacties?	Kan dit zowel positief als negatief zijn? Wat is die invloed dan?	
8	Denk je dat je omgeving, zoals vrienden, familie, maar ook mensen die je niet kent, je anders zouden zien als je geen GTS had?	<i>Waarom denk je dat? Heb je dit al eens meegemaakt? Hoe ga je hiermee om?</i>	

Deel 2: Beleving in een sociaal kader

Nr.	Hoofdvragen	Follow-up vragen	Doel/parameters
V1 Terminologie en conceptualisatie			
1	Vertel je anderen over Gilles de la Tourette?	Leg je hierbij specifieke nadrukken? <i>(bv. Wat je zelf ervaart, wat je zelf dacht toen je de diagnose kreeg...)</i> Beschrijf je dit anders afhankelijk van bij wie je bent? <i>(bv. Ouders, vrienden, vreemden...)</i>	Bepaalde nadrukken?
2	Leg je hen uit hoe de tics kunnen ontstaan?	<i>Zeg je dat er iets gebeurt in je hersenen? Of is er bv. Een stemmetje dat je zegt om dit te doen?</i>	Bepaalde processen? Analoog met wetenschap?
V2 Klinisch beeld: kenmerken en ervaringen tics			
3	Hoe denk je dat anderen jouw tics ervaren of zien?	Welke context/ wie <i>Op school: lkr, ltg Thuis: ouders, siblings Breder: vreemden, 'de maatschappij'</i>	WIE WAAR HOE
4	Maakt de reactie van anderen jouw eigen ervaring anders?	Wat doet zo een reactie met jou? Hoe reageer jij op zo een reactie/situatie?	Invloed op de omgeving op de adolescent

5	Passen de tics zich aan aan de omgeving? Pas jij je aan aan de omgeving?	<i>Evt in terugkoppeling met vorige vraag.</i>	Invloed van omgeving op adolescent
V3	Impact op functioneren en dagelijks leven		
6	Hoe denk je dat de wereld kijkt naar Gilles de la Tourette?	<i>Wat denk je dat anderen van jou vinden?</i>	EIGEN idee over invulling omgeving
7	Heeft deze kijk een invloed op jou?		IMPACT van omgeving

Deel 3: Toekomstperspectief

Nr.	Hoofdvragen	Follow-up vragen	Doel/parameters
V1	Toekomstperspectief		
1	Hoe zie je jouw toekomst?		-

7. CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

8. FINANCIAL DISCLOSURE

None.

9. FUNDING

None.

10. APPROVAL RESEARCH ETHICS COMMITTEE

UPC
Z.ORG KU LEUVEN

Kortenberg 6 september 2021

Geachte,

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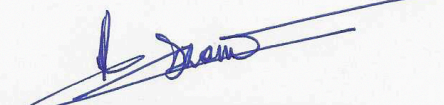
De beleving van de met Tourette gediagnosticeerde adolescent: een interview studie
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Het ethisch comité van UPC KU Leuven, partner van Z.Org.be heeft deze studie nauwkeurig en met zorg bekeken. In het bijzonder de punten 4°, 6°, 7° van paragraaf 4 van artikel 11 van de wet van 7 mei 2004.

1. De adequaatheid en volledigheid van het IFC: Gunstig advies.
2. De geschiktheid van de centrumfaciliteiten: geen bemerkingen: Gunstig advies.
3. De bekwaamheid van de onderzoeker en zijn medewerkers: Gunstig advies.

In de hoop U hiermee van dienst te kunnen zijn, groeten wij U



Ria Dhaeze, secretaris ethisch comité

i.o. Prof. Dr D.De Wachter, voorzitter ethisch comité