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An interpretative phenomenological analysis of eating behaviors and mealtimes experiences of young people with Tourette syndrome

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ABSTRACT

Little is known about how young people with Tourette Syndrome (TS) perceive their own eating behaviors and subsequent effects on their mealtimes. Six adolescents aged 12–14 years with a self-reported clinical diagnosis of TS took part in semi-structured interviews. Interpretative Phenomenological Analysis of the transcribed interviews revealed central experiences of mealtime challenges in relation to their tics. Tics were described as creating functional mealtime challenges, often interrupting their ability to eat, drink and be seated. While sensory-based food preferences were noted, including the need for food to be plated a certain way, these preferences were not viewed as being problematic. Adolescents taking Aripiprazole reported dissatisfaction with the appetite stimulating side effects and subsequent weight gain. Eating out-of-home was found to be especially challenging, with some of the young people reporting feeling self-conscious and stigmatized when eating out-of-home, including at friends' houses. There is a need for clinical guidance around eating and mealtimes, to meet the specific need of young people with TS and their families. Support from clinicians could entail monitoring changes in eating patterns resulting from tics and/or from side effects of medication, as well as in helping young people to manage any discomfort associated with eating out.

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Mealtimes; Tourette syndrome; sensory sensitivity; eating behavior; youth

Introduction

Tourette syndrome (TS) is a neurodevelopmental disorder characterized by both vocal and motor tics, that often emerge during early childhood (Bloch and Leckman 2009; Cavanna et al. 2017). TS differs from Chronic Motor or Vocal Tic Disorder (CTD) and Provisional Tic Disorder (PTD) by the type and persistence of the tics. For a CTD diagnosis, an individual only needs to have the presence of a vocal or motor, whereas for PTD, like TS, both types of tics are present but have yet to reach the

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minimum duration of a year (American Psychiatric Association 2013). Tics are described as involuntary stereotyped repetitive movements or vocalizations that can be simple or complex. For example, while simple vocal tics tend to be brief and meaningless sounds or noises (e.g., barking or coughing), more complex vocal tics tend to combine meaningful words or phrases (e.g., repeating words or use of obscene language). Moreover, simple motor tics may include brief, repetitive movements limited to a small muscle group (e.g., eye blinking or a shoulder shrug), which contrasts with complex motor tics involving coordinated patterns of movement and several muscle groups. Other symptoms associated with TS can also include self-injurious behaviors (e.g., self-hitting), obsessive-compulsive behaviors (e.g., repetitive tapping) and non-obscene socially inappropriate behaviors (e.g., insulting others) (Cavanna and Rickards 2013).

Tics usually begin in early childhood and peak in severity between the ages of ten and 12 years, with many adolescents with TS experiencing a decline in tic severity by early adulthood (Bloch and Leckman 2009). However, it is during childhood and adolescence when tics are reported to be most impairing (Cutler et al. 2009). For example, studies addressing the personal accounts of young people, indicate that TS symptoms can be distressing (e.g., cause pain, fatigue, peer victimization) and adversely affect quality of life (Cuenca et al. 2015; Rivera-Navarro, Cubo, and Almazán 2014; Taylor, Anderson, and Davies 2022; Wadman, Tischler, and Jackson 2013).

Tics play a crucial role in shaping young people experiences, perceptions and interactions with others and their environment (Cutler et al. 2009), and are reported to have a profound effect on their social life and their social relationships (Eapen, Cavanna, and Robertson 2016; Eddy et al. 2011). Moreover, tics can be particularly challenging during adolescence, where visible differences threaten acceptance by their peers. For example, a qualitative study by Malli and Forrester-Jones (2017) explored peer perception and found that young people with TS were overly aware of their tics, and consequent fear of stigma-by-association. Unfortunately, many young people with TS are found to experience stigmatization (Malli, Forrester-Jones, and Murphy 2016), interpersonal relationship challenges (O'Hare et al. 2015) and low self-concept and self-esteem (Lee et al. 2016; Silvestri et al. 2018).

Considering young people with TS experiences of stigma and self-consciousness, mealtimes as a social context are speculated to be pressurized environments that may exacerbate tics. For example, individuals with TS will often struggle to conform to societal norms (Cox et al. 2019; Lee et al. 2019) and mealtimes are steeped in norms surrounding behaviors, such as table etiquette (Packer 2014). Therefore, mealtimes may not be an affirmative social experience and may instead highlight characteristics that sets them apart from the group, heightening social isolation. However, very little research has specifically explored mealtime behaviors of young people with TS.

Anecdotal reports suggest that both eating behaviors and mealtimes are considerable concerns for young people with TS (Ludlow and Rogers 2018), with reports from online forums providing everyday examples of tic-related feeding challenges, including inhibiting an individuals' capability to eat (Ludlow, Brown, and Schulz 2016). This was recently affirmed by mother's accounts of mealtimes whereby they referred to an assortment of their child's explosive and disruptive tics, including hitting, throwing, and kicking, which impacted their child's ability to eat, be seated and stay seated, as well as having a negative

effect on other family members' mealtime experiences. Moreover, outside of the family home, tics were seen as drawing unwanted attention to the family, with many avoiding dining-out rather than having to navigate what they perceived to be a hostile environment (Bamigbade et al. 2022).

In addition to the tics themselves, mothers of adolescents with tics disorders have also noted that their children's eating behaviors, namely selective eating and food refusal, to be a particular source of mealtime stress (Bamigbade et al. 2022). Selective eating, also referred to as "food selectivity," denotes a more extreme and maladaptive form of picky eating (Johnson, Moding, and Bellows 2018). Alongside food refusal, selective eating may include high-frequency intake of a single food type or food group (e.g carbohydrates). Previous research has established that children and adults with TS show selective eating difficulties outside of the normal developmental trajectory; levels of selective eating were akin to that found in children with other neurodevelopmental disorders including autism and attention deficit hyperactivity disorder (ADHD), even when controlling for co-occurring diagnoses (B. L. Smith, Gutierrez, and Ludlow 2022; B. Smith et al. 2020).

As with most eating behavior research, findings are rooted in the parental perspective, which is usually less accurate for adolescents who begin to engage in more activities outside of the home, thus, making it harder for parents to report their child's food preferences and eating behaviors accurately (Bartholdy et al. 2017). Arguably, one of the best ways to understand the young person's perspective is to gather personal accounts. Therefore, the aim of the current study was to capture young people with TS accounts of their own eating and mealtime experiences.

Material and methods

Participants and procedure

Six young people age between 12 and 14 years with TS took part in the study. All participants except one, who was awaiting sensory processing disorder and ASD diagnoses, had at least one comorbid disorder. Co-occurring disorders included: obsessive compulsive disorder ($n = 4$), anxiety disorder ($n = 4$), ADHD ($n = 3$), learning disability ($n = 2$), sensory processing disorder ($n = 2$), and sleep disorder ($n = 1$). Participants were all white British, equally split between gender (50% female) and medication status (50% taking medication).

Young people were recruited through Tourette's Action and Tourette's Hero who helped disseminate information about the study among their networks of people with TS. All communication surrounding a young person's involvement was mediated through their mothers. Mothers were sent an information sheet that detailed the study's aims and objectives and how data would be used and protected. Two mothers sat in the interviews based on a young person's wishes. Ahead of the interview, mothers were sent an overview of the interview schedule so they and their children could know what type of questions to expect. All participants and their mothers provided informed written and verbal consent and were assured of their anonymity and right to withdraw.

Empirical literature and anecdotal evidence guided the creation of the interview schedule in agreement with the research team. The first part of the schedule captured contextual information about participants and their families, including diagnoses,

parental occupation, and work patterns. The second part of the schedule focused more specifically on mealtimes and including the following:

- (1) When was the last time you sat down to eat a meal with your family? Can you describe that mealtime for me?
- (2) What are your favorite and least favorite things about mealtimes?
- (3) When was the last time you ate out as a family? Can you describe it to me?
- (4) When was the last time you ate out with, or at, your friends? Can you describe it to me?
- (5) How, if at all, does your TS/tics influence your mealtimes?

Mealtimes are an integral and inescapable part of our daily lives. Thus, IPA allows for exploration of the meaning attached to these experiences and the cumulative effect, if any, on one's life. IPA is bound by a commitment to the voice of participants, ensuring that they have an opportunity to "to think, speak and be heard" (Reid, Flowers, and Larkin 2005, 22). There is also an interpretative necessity to contextualize participants' experiences and make sense of their accounts (Larkin, Watts, and Clifton 2006; J. A. Smith and Osborn 2003). All interviews were conducted virtually, using platforms such as Skype and Zoom. One interview was held face-to-face at the participant's home at their request (before the COVID-19 pandemic). Interviews ranged from 25 to 89 minutes. Interviews were conducted by the lead researcher between October 2018 and August 2020. All interviews were audio-recorded and were transcribed verbatim by the first author. All participants provided written and verbal consent and were assured of their anonymity and right to withdraw at any stage. Participants also provided consent for their interview to be recorded for transcription purposes. All participants were given pseudonyms. Ethical approval for this research was obtained from the University Ethical Advisory Committee Protocol Number: aHSK/PGT/UH/03340(5) and the research was performed in accordance with the Declaration of Helsinki.

Data analysis

IPA guidelines by Smith et al. (2009) were used to analyze transcripts. NVivo 12 software was used to code and organize themes. The researcher used line-by-line open coding to create initial codes and capture key experiences, concepts and meaning. A total of 88 codes were created. After each transcript was coded, initial observations were noted allowing for patterns within a particular case to materialize. These observations were documented and bracketed in the form of analytical memos before moving onto the next case. Bracketing refers to a process of documenting presuppositions, biases, and assumptions so they do not interfere with the phenomenological investigation (Tufford and Newman 2010). The final superordinate and subordinate themes presented in the results arose through abstraction (the combining of similar codes and themes) and subsumption (deriving superordinate themes). Rigor relates to methodological competence, how data is collected and the scope of analysis (breadth and depth) (Yardley, 2000). However, without confirming that the findings are plausible to others, reliability claims remain

Table 1. Participant characteristic, interview type, comorbidities and medication.

Pseudonym	Age (Yrs)	Gender	Interview	Comorbidities ^a	Medication ^b	Tics causing mealtime challenges
Annabelle	13	F	joint interview	6 diagnoses	Antipsychotics	Coprolalia and throwing tics
Ivy	14	F	alone	2 diagnoses 2 pending	None	Coprolalia, throwing and spitting
Talia	13	F	mother present	2 diagnoses	None	Coprolalia and spillages
Thomas	14	M	joint with mother	3 diagnoses	Antipsychotic Antidepression	Coprolalia and spitting
Warren	12	M	mother present	4 diagnoses	Antidepression Melatonin	Inhalation (tics)
Zack	14	M	alone	2 traits	None	None

Please note that the specific diagnoses of participants and list of medications that they take have not been detailed within the table in order to preserve confidentiality. Instead, aggregated information is presented.

^aAll participants were diagnosed with TS. Additional diagnoses included OCD ($n=4$) anxiety disorder ($n=4$), ADHD ($n=3$), learning disability ($n=2$) sensory processing disorder ($n=2$) and sleep disorder ($n=1$).

^bMedications: Aripiprazole ($n=2$), Sertraline ($n=2$), Melatonin ($n=1$) and Phenergan ($n=1$).

Table 2. Theme structure for young people with TS.

Superordinate themes	Subthemes
How tics shape mealtime experiences	Disruptive tics Anxiety and self-consciousness when eating out of home
How sensory sensitivity and rigidity shape eating behaviors	Food choices Plating preferences and specific eating practices
How medication affects appetite and weight	Appetite stimulation Socio-emotional effect of weight gain and weight management attempts

unsubstantiated. Therefore, the research team along with an independent researcher, carried out “independent audits” to corroborate interpretations, ensuring that they were plausible and credible.

Results

Analysis of six semi-structured interviews resulted in six subthemes which were grouped under three superordinate themes: (1) how tics shape mealtime experiences, (2) how sensory sensitivity and rigidity shape eating behaviors, and (3) how medication affects appetite and weight, see Table 2. These themes captured young peoples’ thoughts surrounding, and the meaning they attributed to, their eating behaviors and mealtime experiences. Some of the words young people with TS used to describe mealtimes were *stressful*, *embarrassing*, *inappropriate*, *anxious*, *awkward*, *enjoyable* and *fussy*. Each theme articulates these descriptors more fully while situating them within the context of distinct behaviors and characteristics associated with TS and comorbidities.

How tics shape mealtime experiences

Tics were noted to have two main effects on mealtimes; each effect is discussed in a subtheme: (1) disruptive tics and (2) anxiety and self-consciousness when eating out of home.

Disruptive tics

Annabelle and Ivy both experienced throwing tics, which resulted in drinks being spilt and cups being smashed. As Ivy illustrates: “I had a bad tic day a couple of days ago [...] I threw a cup and it smashed.” While momentarily disruptive, both girls described this as a minor inconvenience that only happened on occasion and did not impact their overall mealtime experience. What was more challenging was throwing tics aimed at specific people or when tics would “destroy” food. Furthermore, despite being unintentional, the tics appeared to follow directions at an unconscious level. For example, Annabelle explained that her tics often destroyed the things she disliked, “*when I don’t like something my tics obviously don’t approve, and they try and destroy it . . . in any way possible. Which is a problem.*” When asked to clarify what her tics did to destroy things, she detailed the following:

Throwing it, hitting it, trying to hit my head on the plate [...] Hit the food on my face, throwing it at the dog and the dog eats it and stuff like that. (Annabelle)

Annabelle explained that her mother and sister were often a “target” for her throwing tics which “annoyed” her sister. Annabelle was able to empathize with what it must be like to have things frequently thrown at you. To help make mealtimes less disruptive, her family opted for separate meals in the day during the national lockdown, limiting family meals with all members present to once a day.

Another disruptive tic noted was spitting tics. For example, Ivy and Thomas experienced spitting tics whilst drinking. Understandably, this tic disrupted their ability to drink as they would expel rather than swallow. It also had a socio-emotional effect, with Ivy describing the experience as “embarrassing” and Thomas dubbing it as “disgusting.” It is thought that the negative sociocultural associations with spitting may have played a role in shaping how they felt about this tic and why they felt more shame-based emotions than mere frustration.

Warren reluctantly discussed a choking tic, fearful it would resurface by talking about it. When asked how the tic impacted him, Warren said: “*I worry sometimes [...] that I might . . . die*”, highlighting the fear the experience evoked for him. He continued, stating “*It makes me worry uh it scares me sometimes . . . it feels blocked, and so I can’t breathe sometimes. I don’t know, what to say really.*” The experience was understandably frightening for Warren as he felt unable to breathe. The emotional and physical impact of these tics was so strong that Warren sometimes avoided eating or limited how much he ate.

Anxiety and self-consciousness when eating out of home

Many of the young people noted their anxiety surrounding eating out of home, specifically at a restaurant and/or eating at a friend’s house. Annabelle and Ivy highlighted that being seated near families was particularly challenging as they were acutely aware of their use of obscene language and how they might impact other families’ mealtime experience.

Another thing I struggle with is when families sit down next to us as families with young children <kill the child> my tics says things like that constantly at them. And you can see them getting more and more annoyed. And where my tics are inappropriate, you can see them getting more and more worried, because they’ve got young children or children that don’t really know this stuff. (Annabelle)

Annabelle's repetition of "*more and more*" highlights her hypervigilance as she fixates on the family with young children, monitoring their response to her tics. Both Annabelle and Ivy expressed anxiety about being confronted by fellow diners which effected their ability to fully enjoy their dining experience. Annabelle described people in restaurants as not being "*very impressed*" by her tics and that on occasion, people responded with hostility, "*screaming 'shut the F up'.*"

Annabelle also described eating out as challenging because "*everyone is sitting down to be quiet*". This awareness of an expectation of quietness and her inability to conform, alongside her obscene language use, made Annabelle feel self-conscious. Unfortunately, the more self-conscious she felt, the worse her tics were. This left her feeling caught in a cycle.

And the public situation where there's people looking at you to see what you're doing and making comments, whispering and I really struggle with that because then that makes me even more anxious which then/It all kind of goes in a circle making it worse, and worse and worse. (Annabelle)

Annabelle had created a routine around eating out that eased some of the discomfort associated with eating out and the public gaze.

Mum has to ring up in advance, book the table ask to ok, so I have to know in advance, so I can mentally prepare myself, and I have to wear a lanyard with it on, and I have to wear badges (Annabelle)

An additional safety behavior for Annabelle included requesting corner tables, Annabelle explained that it limits the surrounding tables and the number of people who might stare when they hear her tics. Annabelle also opted for louder venues to help her tics blend into the background so "*you can't really hear it [tics] across the other side of the restaurant.*" This highlights just how uncomfortable she felt about being heard and presumably judged by onlookers. Considering all these steps Annabelle and her mother had to take to eat out as a family, it was understandable that they reserved eating out for birthdays.

While Annabelle felt that her mother's presence aided her mealtimes in restaurants, Ivy explained that her friends made her "*really confident*" as such, she "*wouldn't go out without*" them.

When I don't have my friends, they assume that I'm the only one that's sort of making noises, swearing. I think everyone is just staring at me, and I feel like I can't do anything, and I feel quite suffocated I guess . . . , and when I'm with my friends I feel happier and more confident, I guess. (Ivy)

Ivy felt that there was less of a spotlight on her when she was with her friends as onlookers would be unable to single her out as the source of the noises or swearing. This lessened her anxiety and self-consciousness, allowing her to have a pleasurable experience. While Ivy and Annabelle could find ways to manage eating at restaurants, Thomas avoided it altogether as he had "*bad experiences*" with strangers' reactions to his vocal tics.

God. If, if I didn't have any bad experiences outside of just home in general then I probably would like to go out and have a meal, but I've had so many, not assaults but so many . . . situations I've been put in. Like for example, a guy threatened to smash my face in and break

my legs once. A guy took me by the neck and threw me into a beer stall in the Co-op in [UK Town]. Like people just threaten me every single day like when I'm outside so I don't know why I'd like to go into a posh restaurant where they probably have no idea what Tourettes is and they won't understand it. I don't want to get kicked out with my family or anything like that . . . (Thomas)

It is important to note that dining out was not always a challenging experience. For example, Zack explained that it was “*normally quite a good experience*,” agreeing that it can be “*really enjoyable*,” while Talia and Warren did not mention any challenges. It appeared that those with coprolalia tended to be more anxious and self-conscious when eating at restaurants, often worrying about how others perceived and react to them. Notably, while Talia also experienced coprolalia, she explained that this was not an issue as they were inaudible to fellow diners, stating “*my vocal tic will come out like really quietly that only I can hear them and only people sitting next to me can hear them*.” This only became a challenge for her when eating at friends' houses. Annabelle and Talia worried about how their friends' family or other friends would perceive them and react to their tics. Their anxiety and self-consciousness were usually most prominent during the first encounter.

Sometimes I'll get a bit nervous like if I'm going to a friend's house to go for lunch or for dinner, somewhere that I've never really been before with people that I don't really know. Sometimes I'll be a bit nervous about how their family or other friends that they have may react because I know that not everybody like knows me like my mum does or how my friends do. And they might not be comfortable with some of the things I come out with. (Talia)

Both Talia and Annabelle noted that they tended to avoid eating at new friends' houses, preferring to either eat before they visit or dine out with their friends to avoid perceived judgment from their friend's family. Talia mentioned that she feared being laughed at during these encounters, unsure whether people would laugh because they found her tics funny or laugh at her.

I was a little bit nervous seeing whether my friend Lianne's little sister would be laughing at me or laughing like at my tics. Would she find them . . . funny? Would she find them . . . awkward? I didn't really know how her dad or how her mum would find them. But that would make my motor tics worse. (Talia)

Talia explained that anticipating their response usually increased the severity of her tics and emphasized how others would respond to the things she says. Annabelle focused more broadly on her behavior and motor tics. For example, Annabelle described feeling more comfortable when eating with a family with toddlers and younger children as she feels “*they can understand Tourettes better*” as Annabelle likened her behavior to that of a toddler.

When you go to other people's houses like where all the children are grown up, they kind of forget. I don't know, it's like when you meet someone with toddlers, it's almost like I described Tourettes as having an uncontrollable toddler trapped inside of me constantly (Annabelle)

Annabelle explained that she feels the weight of expectations more as an adolescent than when she was younger, as there is more of a discrepancy between her age and behavior.

Likening herself to a toddler and feeling more accepted by people who were used to toddlers, suggests that Annabelle struggled to conform to expectations she believed people placed on her based on her age.

Sensory behaviours shape eating behaviours

This superordinate theme consists of two subthemes: (1) food choices and (2) plating preferences and specific eating practices.

Food choices

Food choices had a sensory basis, with young people describing the sensory properties of food they liked or disliked, with texture appearing to be the most common reason for disliking foods. For example, Annabelle stated *"I don't like things that have a weird texture or don't have enough flavour like lettuce just to me tastes like water with texture, and it's weird."* And Warren said he does not like sandwich meat because of the *"texture and floppiness and umm the taste sometimes."*

Texture also influenced preferences for food preparation. For example, Talia described herself as being *"really fussy"* about how her potatoes were cooked – explaining that they needed to be *"buttery but not too buttery. It would be smooth and soft, not thick and lumpy, but it wouldn't be like runny. Like not pureed"*. She explained that the texture of her potatoes was particularly important as potatoes that did not meet her requirements would trigger a disgust response that would increase in severity until it became intolerable.

Kind of, kind of fills me with disgust, kind of like you have an annoying itch or something on your body. [...] And you're not allowed to itch it. Eventually, it would get like ... the feeling would get too much for you, and you have to itch it. (Talia)

Talia was also particular about which foods were cooked, having some notions about what was, and was not, acceptable. Talia explained that she felt that fruits and vegetables should remain raw as cooking *"changes taste and texture"* in an unpleasant way, making it *"horrible," "mushy,"* and *"strange."* This was also noted by Zack when discussing carrots as he felt they were *"too gooey"* when cooked.

Plating preferences and specific eating practices

Mealtime rigidity appeared in two main ways: plating preferences and engaging in specific eating practices. For example, Annabelle, Talia and Ivy disliked when each component of the meal touched in a way that changed the components' texture. For example, something dry becoming soggy because it was plated next to something wet.

I can't have any wet things ... touching dry things. Like having beans touching bacon or anything like that. (Talia)

Usually if I have a sauce with it, I don't like it touching the food. (Ivy)

Meals that consisted of multiple and mixed components such as a stir fry or cereal with milk were deemed acceptable, both texture-wise and being served with all elements

touching – meals with components cooked separately needed to be plated in a way that allowed components to remain separate. As Talia explained “So, *things that are meant to be touching, like I’m fine with ‘cause you can’t really separate like cereal from milk.*” An emphasis was placed on keeping wet and dry components separate to avoid an undesirable change of texture that could not be undone.

If there were things, wet touching anything dry, I would push like the wet ones to the side, scrape it off and eat the dry ones. If it was chips touching something wet, I wouldn’t eat those chips. (Talia)

When dry components touched on the plate, Annabelle, Talia, and Ivy separated them before eating, which minimized their discomfort. Annabelle noted that despite separating items that were served touching, the fact it was touching would put her off, and she would not be able to eat as much as she would have if it were served separately.

I can still eat it, just it will put me off, and I won’t eat as much of it [. . .] I’ll kind of sit there and just stare at it for a bit and try and separate it myself. (Annabelle)

Annabelle, Talia and Ivy also engaged in specific eating practices, preferring to eat each component of the meal separately. Thus, there appeared to be a relationship between their plating preference and specific eating practices as both focused on food separation; being plated separately and eaten separately. Annabelle explained that she liked food plated “*in a certain way,*” with each component not touching, so she could “*eat it bit by bit.*” Ivy and Talia also ate their food one component at a time, although they also ate in a particular order. Talia worked her way from the “*most amount of numbers to the least. Even if that does mean cold fish*”. Talia’s use of “*even if*” suggests that components getting cold, and presumably less appealing, was an acceptable drawback of the eating ritual. Moreover, Ivy ate in a circular pattern, starting with whatever was directly in front of her and rotating her plate clockwise until she finished her meal, saying “*[it] depends on what way/what part is facing towards me first. [. . .] I usually go umm to my right and turn it to my right.*”

Medication and impact on appetite and weight

This section is split into two subthemes noting both the direct effect of medication and indirect effect: (1) appetite stimulation, and (2) socio-emotional effect of weight gain and weight management attempts.

Appetite stimulation

Warren had only recently begun noticing an increase in his appetite after starting melatonin, although there was uncertainty whether it was related to this medication. Annabelle and Thomas were both on Aripiprazole, an antipsychotic medication known to increase appetite, and both felt that their appetite increase was a result of their medication. With Annabelle saying “*I think that was the main reason for the struggle with my appetite*”. Thomas described his appetite as insatiable:

I come home and have something to eat straight away, and then I go upstairs, and about an hour later I feel really hungry again. Go downstairs, have something to eat and then go back upstairs. About an hour late (laughs) come down, get something to eat and go back

upstairs: process same, same, same, the whole entire night. Then I have dinner, and then I feel hungry like I just did then like I feel hungry after dinner because there's like something wrong with me at the moment. (Thomas)

Thomas portrayed his inability to satisfy his hunger in a way that sounded relentless. He felt a constant need to eat until he was able to fall asleep. He also mentioned that he would typically spend all his lunch money during mid-morning break, leaving him unable to eat until he gets home.

I go to school and can feel really hungry. I wait until break and buy about £3 worth of food (laughs) like a bap, like for example like pancakes and chocolate sauce or whatever and a drink and then I won't have enough for lunch because I've just spent all of it on break. (Thomas)

Missing lunch partly contributed to how much he ate the rest of the day, although Thomas was not regularly attending school at the time of the interview (unrelated to the pandemic closing schools). As a result of an increased appetite, Annabelle and Thomas' eating behaviors changed, which resulted in weight gain and led them to attempt to manage their weight.

Socio-emotional effect of weight gain and weight management attempts

Both Annabelle and Thomas were upset about the weight they had gained because of their antipsychotics medications (Aripiprazole) and subsequently desired to control their eating behaviors to either mitigate against any further weight gain or lose weight. For Thomas, there was a sense of helplessness associated with his eating behaviors as he felt he could not successfully manage his appetite, which meant he was unable to manage his weight.

I eat, I eat so much, don't I? Cause I eat so much; obviously, I'm going to put on weight, but I can't help eating so much 'cause that's just my appetite at this point. (Thomas)

Annabelle mentioned an old friend making a negative comment about her eating habits which *"really upset"* her. Annabelle and her mother explained that she would take a variety of options to school, so she could eat what she fancied. Other students, and this friend, commented on the number of options she had, calling it a *"buffet."* As a result of such comments, Annabelle felt judged by her peers; she felt they viewed her as greedy, eating more than what they deemed appropriate for one person.

I had a friend who we don't talk about anymore, who every time I sat down with my food made a comment about how I had a whole buffet to myself. And that umm if I didn't eat less, then I'd get fat. I had comments like that from them all the time. (Annabelle)

Discussion

Mealtime experiences of young people with TS highlighted the negative role tics played in their mealtime experiences, disrupting mealtimes to varying degrees and being a source of anxiety and self-consciousness when eating out of the home. While sensory sensitivity and rigidity influenced food preferences, including the preparation and presentation of food, these preferences were not viewed as a mealtime challenge for young people with

TS. However, mothers of TS have been shown to have a different perspective with selective eating and mealtime rigidity cited as being a major source of stress (Bamigbade et al. 2022) and highlights the importance of research addressing multi-perspectives (Walton et al. 2017). Notably, the young people identified eating out of home as being particularly challenging and stressful.

Mirroring both the mother's accounts (Bamigbade et al. 2022) and anecdotal reports from online forums, young people with TS noted several tics that were disruptive to their mealtime experiences, and their ability to eat and drink including those that led to throwing, spitting, and spilling food and drink. Tics have previously been shown to affect the conviviality of family mealtimes through their impact on the ability of others at the table to relax and enjoy their meal, as well as self-consciousness when dining-out (Malli, Forrester-Jones, and Murphy 2016). Furthermore, families have also been found to change the timing of meals to accommodate their children's tics, often opting for earlier mealtimes to prevent tiredness exacerbating their tics (Ludlow, Brown, and Schulz 2016).

Mealtimes are complex multi-sensory experiences involving various senses including textures, tastes, smells (Nadon et al. 2011). Sensory experiences associated with mealtimes have been suggested to particularly challenging for neurodivergent young people (e.g., autism, ADHD and TS), who can experience differences in sensory modulation resulting in avoidance and/or preference for particular foods or textures (Cermak, Curtin, and Bandini 2010; Nadon et al. 2011; Page et al. 2022; B. Smith et al. 2020). For example, mothers of children with tic disorders have indeed indicated their children to show "problematic" selective eating, which they considered to be in part sensory orientated (Bamigbade et al. 2022). However, synonymous with the research carried out with older neurotypical and neurodiverse populations, sensory sensitivity was deemed less of a concern for the young people in the current study, suggesting sensory challenges may attenuate over time as people desensitize to their environments (Dovey, Kumari, and Blissett 2019; Zickgraf et al. 2020).

While sensory-based food preferences were noted including the need for food to be plated a certain way, the young people with TS did not perceive these sensory based preferences to be problematic or impacting on their diet, contradicting previous research suggesting children with TS to be increasingly likely to have restricted diets and more dependent on nutritional supplements (Smith & Ludlow, 2021; Kompoliti, Fan, and Leurgans 2009). Therefore, the need to understand eating patterns of young people with TS is important, as restrictive, and selective food intake has been associated with increased levels of stress and frustration for the child and their families, alongside difficulty eating in social environments (Jansen et al., 2017; Bamigbade et al. 2022). More importantly, irrespective of weight concerns, healthy eating practices are essential to reducing children's risk of immediate and long-term health problems, which can range from stunted growth, iron-deficiency anemia, and chronic diseases such as obesity, heart disease, type 2 diabetes and osteoporosis (Awuchi et al. 2020).

Previous research has also highlighted that young people with TS who are taking antipsychotics to be at increased risk of weight gain (Degrauw, Li, and Gilbert 2009; Pringsheim et al. 2017), with a review by Deng (2013) suggesting that behavioral changes because of increased appetite (i.e., increased food intake) alongside metabolic changes (e.g., delayed satiety signaling) account for antipsychotic-related weight gain. In the

current study, some of the young people who were taking an antipsychotic medication, raised weight concerns and subsequent impact on their own eating patterns.

Notably, some of the young peoples' accounts highlighted the challenges of eating outside of the home environment, restricting social eating opportunities for other families members (Bamigbade et al. 2022). Young people with TS found eating out particularly challenging due to their concerns about how others perceived them and whether they would be confronted (Davis, Davis, and Dowler 2004; Malli, Forrester-Jones, and Murphy 2016). For example, young people with TS frequently report high levels of victimization by peers (Storch et al. 2007), with Thomas physically and verbally assaulted by members of the public because of his tics, and Annabelle experiencing verbal hostility.

Eating out of home appeared to heighten the looking-glass self (a process where individuals base their sense of self on how they imagine others view them), with young people actively engaging in self-observation as they monitored their external image and whether they adequately met social norms (Lee et al. 2016). As they begin to tic, they become more self-conscious which further increases anxiety and intensifies tics (Coffey et al. 2000; Conelea and Woods 2008). Forceful, visible, or socially unacceptable tics have previously been reported to be particularly provoking of rejection or questions from others (Smith et al., 2015), and this was reiterated in the accounts of Thomas and Annabelle.

Young people themselves have highlighted the effortful and endless adjustments they make to control their tics, including suppressing and/or displacement strategies where they create intervals of solitude to express tics (Edwards et al. 2017). Such strategies were addressed in the current study whereby young people described multiple techniques they adopted to deal with their tics when eating outside of their home, to avoid negative attention for fearing negative reactions and perceptions. For example, some avoided dining out altogether (e.g., Thomas) or took steps to mitigate the discomfort associated with the public gaze and pressurized environment (e.g., Ivy relied on the social support of her friends and Annabelle relied on her mother and informing staff and fellow diners about TS). The long-term effects of these experiences on young people's quality of life and relationships with TS is unclear. Although, it is thought that avoidance of eating out of home may weaken social ties due to the pivotal role that mealtimes play in shaping adolescents' social lives and relationships (Neely, Walton, and Stephens 2014).

Despite notable strengths of the study, including capturing the young person's understanding of their own eating behaviors as opposed to descriptions provided by caregivers or a third-party, there are several limitations to note. For example, the small sample size makes the ability to generalize the findings to TS more difficult, the contexts and meaning attributed to their experiences will vary. Even within the small pool of young people in the current study, there were significant variations in experiences with some young people (e.g Zack) not reporting any challenges with eating out. Future studies need to address how eating mealtimes and differ depending based on the type, severity, and intensity of tics. Moreover, as is common in TS, all participants except one had a formal diagnosis of at least one clinical disorder (Cavanna and Rickards 2013; Hirschtritt et al. 2015). For example, almost all the young people who took part in the interviews had OCD or traits of OCD as part of their TS symptomology. It is possible that obsessive-compulsions and/or neurodiverse symptoms may account for some of the mealtime

rigidity. For example, common selective eating characteristics reported in individuals with OCD have included rejecting food others have touched or that had been mixed, food that touched a plate, and texture-based food refusal (Bozzini et al. 2018). Therefore, a larger study addressing eating and mealtime challenges in TS in relation to co-occurring diagnoses is warranted.

Limitations aside, this is first study that has captured the perceptions, experiences, and feelings of young people with TS concerning their eating behaviors and mealtime experiences. Akin to the mothers' accounts, selective food choices and specific needs for how food was plated were also reported by the young people. There exists a clear need for clinical guidance around eating and mealtimes to meet the specific need of individuals with TS and their families, as well as monitoring changes in eating patterns following the prescription of medication. Moreover, the stress associated with eating out of home also needs to be addressed due to the potential effect on a young persons' self-concept, quality of life and social relationships. Educating and raising awareness about TS could combat TS discrimination and prejudice (Malli, Forrester-Jones, and Triantafyllopoulou 2019), alongside enhanced social skills training to empower youth with TS with peers (Zinner et al. 2012)

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